

Global perspectives on assistive technology

Proceedings of the GReAT Consultation 2019

Volume A – Day 1

22 and 23 August 2019,
WHO Headquarters, Geneva, Switzerland

Editors: Natasha Layton and Johan Borg

Global perspectives on assistive technology: proceedings of the GReAT Consultation 2019

ISBN 978-92-4-151685-3

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Suggested citation. Layton N, Borg J [ed.]. Global perspectives on assistive technology: proceedings of the GReAT Consultation 2019. Geneva: World Health Organization; 2019. Licence: CC BY-NC-SA 3.0 IGO.

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Global perspectives on assistive technology

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Volume A – Day 1

Foreword

The World Health Assembly recognizes the need for improving the access to assistive technology across the world and, through its resolution 71.8, has commissioned the World Health Organization to prepare a global report on effective access to assistive technology by 2021. The development of the Global Report on Assistive Technology (GReAT) is led by a Steering Committee with representatives from the WHO Secretariat, the Global Cooperation on Assistive Technology (GATE) and UNICEF, and an Ad-hoc Advisory Group of Experts on Assistive Technology. The work is carried out in collaboration with international experts and stakeholders in assistive technology.

As a first step to inform the development of the Global Report, WHO Headquarters in Geneva hosted the GReAT Consultation on 22-23 August, 2019. Over 260 participants from 60 countries representing academia, civil society, users of assistive technology, global assistive technology stakeholders, States and UN agencies participated in this global consultation.

There was an overwhelming response to the call for contributions addressing the objectives of the Global Report, which are to highlight the current need, demand and supply of assistive technology, as well as to outline good practices for innovation and recommendations to improve access. More than 130 abstracts were submitted, and following a review process considering the relevance, quality and geographic representation, over 80 manuscripts or illustrative contributions were subsequently invited to be developed into full manuscripts for presentation at the GReAT Consultation.

Contributions were sought to illuminate the range and breadth of assistive technology and to recognise the diversity of stakeholders within the complex system of assistive technology. An encompassing view of evidence ensured that evidence-based practice, practice-based evidence, and situated knowledges were recognised and considered. Submitted manuscripts were reviewed from academic, technical and accessibility perspectives. These Proceedings represent the first foundation for the Global Report. Its 76 sections comprise 72 manuscripts and four abstracts, and are presented across eight themes:

1. Needs and supply
2. Access
3. Outcomes
4. Policies and programmes
5. Procurement and service provision
6. Capacity building
7. Innovations
8. Enabling the sector

Many sections are authored by international groups of authors, and a substantial proportion were received from author teams who had not previously published. All authors are to be congratulated on sharing their knowledge and perspectives. The sections present a 'state of the science' for the assistive technology sector in 2019 at a time of great need and great opportunity.

Work will now continue to identify and fill knowledge gaps, collect data and listen to unheard voices to further inform the development of the Global Report. Our sincere wish is that the spirit of the GReAT Consultation – great things happen when great people meet – will inspire us to continuous concerted efforts to improve the access to assistive technology worldwide.

Natasha Layton and Johan Borg
Editors

Acknowledgements

We would like to thank all authors whose rich and diverse contributions have made these proceedings into a valuable resource for years to come. Recognition is also due to the Co-Chairs of the GReAT Consultation, Mac Maclachlan of Maynooth University and Rosangela Berman Bieler of UNICEF, and the GReAT Consultation moderators Arne Eide, Desleigh DeJonge, Lynn Gitlow, James Rwampigi Aniyamuzaala, Claude Tardif, David Constantine, Catherine Holloway and Patanjali Nayar. Across sessions and throughout the two days, their skill and commitment wove a coherent narrative from the diversity of presentations.

Ultimately, tribute must be paid to Chapal Khasnabis for guiding the programme development and for an encompassing approach to contributions. His visionary leadership over many years has led to this pivotal moment for assistive technology access globally.

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Needs and supply

Rapid Assistive Technology Assessment: Survey on the use and demand for assistive products in Pakistan

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Abstract

In Pakistan, first regional meeting of WHO's EMRO region on improving access to assistive technology was held on 8 May 2018 in Islamabad. In another meeting of governments of ESCAP (South Asia and Pacific) including Pakistan, was held in the Republic of Korea in November 2012 agreed on The Incheon Strategy. Pakistan showed resolve in keeping a track on progress towards improving quality of life of people with disabilities. The Pakistan DHS 2017-18, questions included 6 functional domains, hearing, seeing, self-care, cognition, communication and walking and basic information on disability was taken from 67,586 respondents. Nine percent of women and 7% of men age 15 and older had a lot of difficulty or cannot function at all in at least one domain. The word disability in most surveys of Pakistan limited the scope of individuals with special needs and undermined requirement and needs of concerned people as disability has social stigma attached with it. In order to determine the need of assistive technology in Pakistan, a nation-wide survey was undertaken through the support of WHO HQ Geneva. It covered all the four provinces and three regions of Pakistan. All the persons in randomly selected households of 16 selected districts were interviewed and examined for any need for assistive technology. The districts included both urban and rural areas, and survey tried to capture the national level estimates. A letter from the DG Health was issued to all the district administration and incharge of the district health department of the relevant district. It was copied to the provincial health departments. A copy of signed letter was given to each enumerator so they can show it to any relevant official in case of need. It also helped in gaining confidence of the security agencies and also seeking their help in case needed. Data collection in 16 districts started at same time as each district had their own data collection team. Within each district there were two teams of data collection; each comprised of both female and male enumerator. Data collection was done using android mobile phones, with prior installation and testing of software of rATA tools from Survey 123 app. Data was uploaded on real-time basis. In case of internet connectivity issues, the team collected data on hard copy and then data was entered on software. In addition to mobile app, each team member was provided with optimal size folded banner for displaying list and pictures of assistive products for convenience of respondents. Each member was given a power bank to ensure

functionality of mobile battery. In addition to this, they were issued prepaid internet cards so they may not lack internet access due to insufficient funds for mobile data in the field. A WhatsApp group was created for monitoring as well as interaction of group members in case anyone needs an update or have any query in the field. All enumerators, supervisors, national team leader, WHO focal person in Geneva and Islamabad were included in WhatsApp group, so the survey management was able to track activity of each district and province. In addition to WhatsApp group, a call system was also used to monitor where teams were called randomly on the day to ask about their progress and work done so far. Some randomly selected respondents were called individually by team leader to verify the data filled by enumerators. A field visit was done by the survey manager and national team leader to see the data collection activities. Two stage sampling methodology was used in the survey. At first phase, 16 districts were randomly selected from four provinces and the regions of Pakistan. At second stage 20 Clusters were randomly selected from each of the district. Within each cluster, 30 households are selected based on systematic random sampling. Average number of members in household in Pakistan has been estimated be around 7, which varied from district to district and household to household. Approximately, in 16 districts, with 600 households in each district and 7 members in each household we expected a respondent number of 67,200. However, the total sample completed the forms was around 63000.

Assistive product use and demand: The Model Disability Survey survey with Gallup in Tajikistan, India and the Lao People’s Democratic Republic

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Abstract

The world is facing important trends associated with an increase of disability in populations, especially due to a rise in non-communicable diseases (NCDs) and the rapid ageing of the world population. The level of disability in countries and regions is influenced also by physical, human-built, attitudinal and socio-political barriers, including a critical lack of access to assistive products. High-quality and comprehensive disability data are essential to address these trends and challenges. Policy development and planning of public health actions and services require a precise understanding of disability, including detailed information on needs for assistive products, inequalities, and barriers faced by persons experiencing different levels of disability. To address this need for high-quality disability data, the WHO Brief Model Disability Survey (MDS) was integrated into the Gallup World Poll questionnaire and administered in face-to-face household interviews in India, the Lao People’s Democratic Republic and Tajikistan in 2018. The questionnaire included a module dedicated to the use and need of assistive products. The results show that the need for assistive products increases as the level of disability increases. In the Lao People’s Democratic Republic and Tajikistan, approximately 30% of people with severe disability report not having assistive products but needing them. The corresponding figure for India is 18%. The assistive product most frequently reported as needed for all three countries is spectacles/glasses. Various reasons are reported for why respondents do not have the assistive products they need. Among the most frequently cited reasons for all three countries is “could not afford the cost.” Overall the data indicate that the need for assistive products is high, and the problems that people currently face to obtain and use their products are varied and complex. More high-quality data is needed to analyze these issues globally. The final report describing all the results from the Brief MDS with the Gallup World Poll will be publicly available soon.

A rapid assessment on access to assistive technology in the World Health Organization's European Region

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Abstract

Background: Access to appropriate, quality assistive technology (AT) at an affordable price enhances individual functioning and independence, while facilitating participation and integration in society. The WHA resolution (WHA71.8) calls upon Member States and WHO to improve effective access to AT by 2030. Accordingly, in Q2 2019, the WHO European Region initiated an assessment of the capacity of a few countries within the region to procure and provide AT. This study was coordinated by the Health Technologies and Pharmaceuticals Unit, Division of Health Systems and Public Health at WHO Regional Office for Europe in collaboration with the GATE initiative in WHO Headquarters. **Methods:** The primary objective of the study was to obtain a high-level estimate of the prevalence of mobility, hearing, and visual impairments and map the need of assistive products (AP) that could potentially benefit the people with identified functional limitations. The secondary objective was to qualitatively assess a country's capacity to procure and provide the AP that could support the functional limitations identified in the primary goal. The study was conducted in four selected countries in the region: Denmark, Spain, Armenia and Ukraine. **Results:** Prevalence of upper and lower limb amputations, vision and hearing impairments with different severity levels are extracted from the 2017 Global Burden of Disease database. Data on procuring and providing 15 priority AP within a country was collected using the rapid AT capacity assessment tool through email and in person meetings with identified respondents. Prevalence of vision and hearing impairment, as well as upper and lower limb amputations increases with age across the 4 countries. Across all 4 countries, the high prevalence of mild hearing loss amongst 65-79 age group transitioning into high prevalence of moderate and moderately severe hearing loss amongst people of 80+ further indicates that potential need for AT increases substantially with age. Differentially, the prevalence of presbyopia across all age groups was at least 50% higher in Armenia and Ukraine when compared to Spain, and almost 90% higher in Armenia and Ukraine when compared to Denmark. This suggests a higher need to access reading glasses in Armenia and Ukraine than Denmark and Spain. Lower limb amputations are significantly higher than

other mobility impairments, with the largest prevalence estimated in Ukraine followed by Armenia, Denmark and Spain, except in the 80+ age group, where the prevalence for lower limb amputations in Denmark is higher than Armenia. Based on the rapid AT capacity assessment results, all 4 countries are able to provide the 15 priority AP should an AT user access the appropriate services. However, there are gaps in regulating AP sold by the private sector, and availability of follow up after the initial AP prescription and provision.

Conclusion: The trends identified in the estimated prevalence of hearing, visual, and mobility impairments indicate that the burden of functional limitations increase with age in both severity and magnitude. Assessment of the prevalence of functional limitations and country capacity to meet AT needs can help quantify the gap between AP procurement, provision, and population need for AT. All 4 countries appear to have the capacity to distribute the 15 priority AP should an AT user access the appropriate services. There is a need to ensure comprehensive service provision of quality AP that is regulated by adequate standards for products procured both in the public and private sectors for all, irrespective of the registered status as a person with a disability.

Keywords

Assistive products, procurement, quality, regulation, functional limitation and disability, health systems, situational analysis, WHO European Region

Introduction

It is estimated that 1 billion people need assistive technology (AT) globally today, but only 1 in 10 have access. Need for AT is estimated to double globally by 2050, primarily due to population ageing and rise in non-communicable diseases (NCDs) (1). To address this challenge, WHA resolution (WHA71.8) calls upon Member States and WHO to improve access to AT as a part of universal health coverage (UHC) (2). This is particularly relevant to WHO European Region given the rapid population ageing trends (3). Countries are facing many challenges in meeting population need for AT due to insufficient procurement and provision of appropriate, affordable, quality AT alongside limited information systems that provide accurate estimate of the population need for AT and a country's capacity to meet such needs. The lack of structured and harmonized data for quantifying the need for AT leads to an inaccurate estimation of AT provision and procurement requirements.

Therefore, it is critical to understand a country's capacity to meet population need for AT in order to raise awareness and develop strategic action plans as a first step to improving access to AT. The primary objective of the study was to estimate the prevalence of hearing, visual, and mobility impairments and map the assistive products (AP) that could potentially benefit people with functional limitations to the estimated impairment prevalence in 4 selected countries in the region: Denmark, Spain, Armenia and Ukraine. The secondary objective was to qualitatively assess each country's capacity to procure and provide AP that could support the functional limitations identified in the primary goal. This study explores and identifies potential trends, challenges and links between AT system across the 4

selected countries and the functional limitations based on the demographic and geopolitical context. Finally, this study recommends potential next steps to improving current understandings of AT need. This study was coordinated by the Health Technologies and Pharmaceuticals Unit, Division of Health Systems and Public Health at WHO Regional Office for Europe (WHO EURO) in collaboration with the GATE initiative at WHO Headquarters.

Methodology

This study was a joint effort conducted between WHO Headquarters and WHO EURO, where WHO Headquarters led the estimation of prevalence of functional limitations across all 4 countries and mapping potential AP of benefit and WHO EURO led the implementation and follow up of the rapid AT capacity assessment. Functional limitation is defined as the impairments, activity limitations, or participation restrictions that interfere with an individual’s ability to interact with others and his/her physical and social environment (4). Throughout this paper, functional limitation and functional impairments will be used synonymously as the hearing, vision, and mobility functional limitations considered within this study are categorized under the 9 functional impairments of the 2017 Global Burden of Disease Database (5). The following describes the methodology to estimate the prevalence of functional limitations in hearing, vision, and mobility across all 4 countries, the potential AP of benefit for such functional limitations, and how the rapid AT capacity assessment was implemented.

Selected database for functional limitations analysis

To obtain the prevalence of mobility, hearing, and visual impairments, the Global Burden of Disease (GBD) database was used. The Global Burden of Diseases, Injuries, and Risk Factors Study 2017 includes a comprehensive assessment of incidence, prevalence, and years lived with disability (YLDs) for 354 causes in 195 countries and territories from 1990 to 2017 (6). Previous GBD studies have shown how the decline in mortality rates from 1990 to 2016 has led to an increase in life expectancy, an ageing global population, and an expansion of the non– fatal burden of disease and injury (6). These studies have also shown how a substantial portion of the world’s population experiences non– fatal health loss with considerable heterogeneity among different causes, locations, ages, and sexes (6). Through the use of the GBD database, we can obtain consistent and comparable information about the four countries for hearing, visual, and mobility impairments. Table 1 depicts the data extraction protocol conducted using the GBD database to gather prevalence data of aforementioned impairments across the 4 countries in 2017.

Table 1. Search criteria within the Global Burden of Disease 2017 database for prevalence of hearing, visual, and mobility impairments

Criteria	Selection made
Location	Armenia, or Ukraine, or Spain, or Denmark
Year	2017
Context	Impairment

	Hearing loss					
	<input checked="" type="checkbox"/> Mild hearing loss	<input checked="" type="checkbox"/> Moderate hearing loss	<input checked="" type="checkbox"/> Moderately severe hearing loss	<input checked="" type="checkbox"/> Severe hearing loss	<input checked="" type="checkbox"/> Profound hearing loss	<input checked="" type="checkbox"/> Complete hearing loss
	Blindness and vision impairment					
	<input checked="" type="checkbox"/> Mild vision loss	<input checked="" type="checkbox"/> Moderate vision loss	<input checked="" type="checkbox"/> Severe vision loss	<input checked="" type="checkbox"/> Blindness	<input checked="" type="checkbox"/> Presbyopia	
	Injury					
	Amputations					
	<input checked="" type="checkbox"/> Upper limb amputations, unilateral		<input checked="" type="checkbox"/> Upper limb amputation, bilateral	<input checked="" type="checkbox"/> Lower limb amputation, unilateral	<input checked="" type="checkbox"/> Lower limb amputation, bilateral	
	Spinal injuries					
	<input checked="" type="checkbox"/> Spinal cord lesion at neck level			<input checked="" type="checkbox"/> Spinal cord lesion below neck level		
Age	Under 15, and 15 to 49, and 50 to 64, and 65 to 79, and 80 plus					
Sex	Female, and male, and both					

For a representative sample, prevalence was considered to be the number of people in the sample with the characteristic of interest, divided by the total number of people in the sample as presented in the following equation (Equation 1). Hearing, visual, and mobility impairment prevalence for each country was calculated by extracting the total number of individuals with a certain impairment (e.g. spinal cord lesion at neck level) and divided by the total population of each respective country (Equation 1). The prevalence was calculated for each functional impairment as listed in Table 1 and for Armenia, Denmark, Spain, and Ukraine respectively.

Equation 1: Formula used to estimate prevalence of mobility, hearing, and visual impairment

$$Prevalence(\%) = \frac{\text{\# of people in sample with characteristic}}{\text{Total \# of people in sample}} \times 100$$

To calculate the prevalence of our interest, population estimates in 2017, for Denmark, Spain, Ukraine, and Armenia were used (6).

Mapping need for assistive products

When determining which AP could support or improve certain functional limitations or impairments, widespread need and impact on a person's life was taken into consideration. Fifteen AP that were deemed most relevant in the European region were selected based on

a recently prioritized AP process conducted in Tajikistan which targeted 4 main functional domains and used within the rapid AT capacity assessment (7). These 15 AP were categorized according to intended function in addressing hearing, visual, and mobility impairments, and further classified by their respective ISO 9999 codes listed below in Table 2. A literature search was conducted to map the 50 priority products identified in the APL, including the 15 AP used in the rapid AT capacity assessment, to the relevant functional impairments it supports or improves. Hearing aids, communication products, and signaling products were considered for all types of hearing impairments (8-14). Spectacles and magnifying devices were considered for presbyopia and moderate vision loss (15-18). Tactile sticks, communication devices, products for reading and writing, and talking devices were additionally considered for severe vision loss (12,19-25). Upper limb prostheses and communication devices were mapped to upper limb amputations, while crutches, walkers, walking sticks and canes, wheelchairs and accessories, lower limb prosthesis, personal care products, and bedding accessories were mapped to lower limb amputations (12, 26-34). For spinal cord injuries, wheelchairs and accessories, spinal orthoses, personal care products, and bedding accessories were considered (12, 27, 31-37). Table 2 summarizes the types of functional impairments considered for each of the 15 priority AP assessed in the rapid AT capacity assessment.

Implementing the rapid AT capacity assessment

Armenia, Denmark, Spain, and Ukraine were selected from the WHO European Region based on the following criteria: commitment to share knowledge on access to AP, willingness to complete the assessment and understanding of English (the assessment was only available in English).

The rapid AT capacity assessment aimed to gather information on each country's capacity to procure and provide 15 priority AP. The rapid AT capacity assessment questions were developed and adapted from a longer AT capacity assessment, which is currently being validated by WHO Headquarters by implementing the capacity assessment in countries. The adapted rapid AT capacity assessment aimed to collect preliminary information on the entities who provide the 15 priority AP, the types, number, and cost of products provided annually, while assessing product availability through various procurement and supply mechanisms. Product quality assurance is assessed by collecting information on national/regional standards, use of adequate technical specifications, and registration with government authorities or similar.

Table 2. Mapping 15 priority AP assessed within rapid AT capacity assessment to relevant functional limitations and ISO codes

Name of product by functional limitation	ISO code	Functional limitations that could benefit from use
Mobility		
Canes/sticks	12.03.03/12.03.16	Lower limb amputation
Crutches, axillary/elbow	12.03.12/12.03.06	Lower limb amputation
Orthoses, lower limb	06.12.06/06.12.09/06.12.12	Spinal cord injuries
Prostheses, lower limb	06.24.09/06.24.15	Lower limb amputation
Therapeutic footwear: neuropathic/diabetic/orthopedic	06.33.30	Unmapped due to study scope ¹
Walking frames/walkers	12.06.06/12.06.03	Lower limb amputation
Wheelchairs, manual for active use	12.22.03	Lower limb amputation Spinal cord injuries
Vision		
Braille writing equipment/braille	22.12.12	Severe vision loss Blindness
Spectacles	22.03.06	Presbyopia Moderate vision loss Severe vision loss Blindness
White canes	12.39.03	Severe vision loss Blindness
Hearing		
Hearing aids	22.06.06/22.06.12/22.06.15	Mild hearing loss Moderate hearing loss Moderately severe hearing loss Severe hearing loss Profound hearing loss Complete hearing loss
Cognition		
Fall detectors		Unmapped due to study scope ²
Environment and Personal Care		
Bath/shower/toilet chairs	09.33.03	Lower limb amputation Spinal cord injuries
Incontinence products (absorbent)		Spinal cord injuries
Pressure relief mattresses	04.33.06	Lower limb amputation Spinal cord injuries

¹ Therapeutic footwear (neuropathic, diabetic, orthopedic) were not mapped as the types of mobility impairments considered were not relevant for the use of therapeutic footwear.

² Fall detectors were not mapped as the types of mobility and cognitive impairments considered were not relevant for the use of fall detectors.

Rapid AT capacity assessment respondents were selected from a list of participants who attended the European Assistive Technology Information Network meeting (Geneva, 7 and 8 February 2019). The respondents from Denmark, Spain and Ukraine were from the governmental sector (Ministry of Social Policies for Ukraine, Ministry of Social Affairs, Center for Disability and Mental Vulnerability for Denmark, *El Centro de Referencia Estatal de Autonomía Personal y Ayudas Técnicas* in Spain). The respondent from Armenia is from an UN Agency (UNDP) and has been collaborating with the Ministry of Health and Ministry of Labour and Social Affairs to complete the rapid AT capacity assessment. The rapid AT capacity assessment was sent by email on the 27th of March 2019 to the identified respondents. A period of 2.5 weeks was given to respond to the assessment. Afterwards, in person meetings and phone calls were organized to clarify the responses received. The information received from the rapid AT capacity assessment and the follow-up meetings were summarized into a framework containing the sections; provision, budget, regulation, procurement, supply and distribution of AP.

Results

Mapping AP need according to prevalence of functional limitation

Across all four countries, approximately 30-40% of individuals aged 65 and over experience some form of mild hearing loss, while 20-30% of individuals will experience moderate hearing loss when they are 80 years of age and older (Figure 2). Similarly, prevalence of presbyopia is as high as 39.72% and 50.75% amongst the 65-79 and 80+ age groups respectively (Figure 3). Consistently across all four countries, lower limb amputation has the highest prevalence amongst all mobility impairments considered, which gradually increases with age from 0.1% of the under 15 age group to as high as 3.19% amongst the 80+ age group (Figure 4). Unanimously, the burden of functional limitations increases substantially with age. The primary results for mapping AP are shown in Figures 2-4 for each functional limitation; vision, hearing and mobility respectively.

Prevalence of vision loss with different severities and causes increases with age across the four countries and the four types of vision loss; presbyopia, moderate vision loss, severe vision loss and blindness, as shown in Figure 2. Vision loss prevalence decreases as the severity of vision loss increases for all four types (Figure 2). Most notably, the highest estimated prevalence across all age groups, across all four countries, is presbyopia (Figure 3). The prevalence of presbyopia increases with age across all four countries and could be as prevalent as one in every two older persons experiencing some form of presbyopia (see Armenia, in Figure 3). Individuals 80+ of age experience the highest prevalence of all types of vision loss, while individuals 65-79 of age experience the second highest prevalence of all types of vision loss. Armenia has the highest prevalence of vision loss, followed by Ukraine. Differentially, prevalence of all types of vision loss in Spain and Denmark is approximately 10-50% of the estimated prevalence for all types of vision loss in Armenia and Ukraine. The

AP, which are necessary to support and/or improve the indicated types of vision loss could be spectacles, white canes and braille writing equipment.

Similarly, prevalence of hearing loss with different severities increases with age across the four countries and hearing loss with different severities; mild hearing loss, moderate hearing loss, moderately severe hearing loss, severe hearing loss, profound hearing loss, and complete hearing loss (Figure 3). Mild and moderate hearing loss is more prevalent than moderately severe, severe, profound, and complete hearing loss (Figure 3). The 65-70 age group experiences the highest prevalence of mild hearing loss across all four countries, which declines substantially as the severity of hearing loss increases to moderate hearing loss (Figure 3). The prevalence of mild hearing loss is highest in Ukraine followed closely by Armenia, Denmark, and Spain respectively. In parallel, the 80+ age group experiences the highest prevalence of moderate and moderately severe hearing loss across all four countries (Figure 3). Denmark experiences the highest prevalence for moderate hearing loss followed by Spain. Different types of hearing aids can be used to improve hearing loss, as indicated in Figure 3. For more severe hearing loss conditions, cochlear implants could be of additional benefit, also indicated in Figure 3.

A very similar trend is shown in Figure 4, where the prevalence of lower and upper limb amputations increases with age across the four countries. Lower limb amputations are significantly higher than other mobility impairments, with the highest prevalence located in Ukraine followed by Armenia, Denmark and Spain, except in the age of 80+, where the prevalence for lower limb amputations in Denmark is higher than Armenia. Prevalence for spinal cord lesion below neck level and at neck level remains consistent across all age groups for all four countries. The AP that can improve these mobility impairments are crutches, walkers, lower limb prostheses, canes, wheelchairs, lower limb orthoses, as noted in Figure 4.

Summary of rapid AT capacity assessment results across Armenia, Denmark, Spain, and Ukraine

Armenia

Armenia has a centralized AT procurement and provision system, where the priority AP are all available at primary health care level. The Ministry of Labor and Social Affairs (MLSA) are responsible for the regulatory bodies for AT provision. The Ministry of Health (MoH) and Ministry of Education (MoE) also play a role in regulating the provision of AT, where the latter focuses on providing AP for educational purposes. MLSA is the decision-making body for AT legal framework, needs assessment and development of technical criteria to ensure well-functioning, quality products, repair and maintenance facilities, AT provision planning, as well as AT budgeting.

AP regulation for provision is limited and only required in public sector. Products must comply with regional standards, such as the national standards of the Russian Federation and CIS countries (GOST) (38). If the AP is procured by the private sector, there are no

guarantees that it is registered or is complying with any international quality standards. Furthermore, no registration with government authorities are required.

AP are mostly procured by a public tender contract and is based on individual need and mainly takes place annually. The primary suppliers for mobility AP are mainly from international manufacturers with local distributors or authorized representatives, while canes/stick, orthoses and therapeutic footwear are also manufactured locally. No policy for recycling AP currently exists in Armenia.

Denmark

Denmark has a decentralized system for AP provision and procurement. Denmark is divided into 5 regions and 98 municipalities. The municipalities are considered as local authorities and operate under the Services Act (39). The selected priority AP are all available at primary health care level.

All citizens living in Denmark are given the opportunity to live a dignified life despite their disabilities (39). AP are provided without regard to age, income or property-owning status. According to government policies (e.g. Social Service Act), a person with disabilities must receive compensation for his/her disability in order to equally participate in community life (39). The general population shares this responsibility through taxes to ensure that older and persons with disabilities receive the necessary AP, free of charge, as well as its related services.

Each local authority has their own stock of AP. Each local authority will have its own budget and will procure its own AP, and ensure appropriate maintenance and re-use of AP. As a result, the country does not have a national information system collecting data on AP expenses, types of AP and numbers of AP provided across each local authority by product type.

AP used in Denmark must meet the European safety, health and environmental protection requirements and must therefore have a *Conformité Européenne* marking. The Danish manufacturers and suppliers selling the AP must be registered with the Danish Medicines Agency database, where the classification of the AP as well as the technical specifications are publicly available.

Within such decentralized system, the local authorities conduct procurement separately or jointly with other local authorities. In practice, many of the local authorities cooperate in joint procurements. The local authority holds a variety of AP on stock that meet about 80% of the populations' AT needs. AP are delivered from the municipal AP warehouse to the health centers. It can be a new device or a second-hand device in good condition or previously repaired. The local authority is obliged to ensure that the AP is assembled correctly, repaired if necessary and provide instructions (and sometimes training) on how to use the AP. This obligation may be transferred to the supplier, but the local authority still holds the responsibility. Individuals who need AT have the right to choose a different product than what the local authority provides. The individual will be granted an amount of

money which covers the cost of the AT pre-approved by the local authority. If the alternative product exceeds this amount, the person will need to pay the excess him/herself. The right to choose a different product is very complicated to administer, and in practice, few persons use different products than those provided by the local authority,

Spain

Spain has a decentralized provision and procurement system for AP, consisting of 17 local authorities and two autonomous cities, Ceuta and Melilla, which are managed by the Central Government through the National Health Management Institute (who conducts centralized procurement). Local authorities have their own health services, which is the administrative and management body responsible for health centers, services and facilities in its region, administration and town councils and any other intra-community administration. As a result, each local authority has their own provision system where different procedures and products are offered. The 15 priority AP are all available at primary health care level.

All AP must be marked with European Conformity (CE marking). However, products do not need to be registered with government authorities. According to the focal person, this is likely going to change in 2020 as the National Health System (NHS) is asking the suppliers to register their product to comply with price requirements, amongst many other requirements.

The NHS and the Ministry of Defense (ISFAS) developed two catalogues for AP procurement. The NHS is coordinated by the Ministry of Health, Social Services and Equality. However, the local authorities are not restricted to the catalogues and can procure other AP. Only Ceuta and Melilla are required to procure AP from the catalogues. AP can also be purchased by users in private shops. An individual can purchase an AP at his/her own discretion and be partially or fully reimbursed by NHS or ISFAS. The AP is then temporarily owned by the AP user. AP users can choose to return the AP to the NHS to be reused. In some local authorities returning the AP to the NHS is compulsory, however, the AP user can choose to be reimbursed for the cost of the AP if the AP is in good condition. AP that are not funded by the NHS, are funded by the social services sector within the Ministry of Health, Social Services and Equality. The amount refunded to the patient/family depends on the income level. The national budget used to procure AP is collected through tax.

Supply and service facilities are available for repair and maintenance. However, since the source of AP has changed from local manufacturing to importation, it is more difficult to repair or get spare parts quickly. Recycling policies are few but are increasing and differs across each local authority. Most of the market consist of international manufacturers of whole product with local distributors or authorized representatives, as well as international manufacturers of product parts with local assembly.

Ukraine

Ukraine has a centralized AP provision system where the 15 priority AP are available in the country. However, the 15 priority AP are only accessible by people registered with disabilities. The Ministry of Social Policy (MoSP) and the Ministry of Health (MoH) work together to procure and provide AP to registered people with disabilities. The Medical and Social Expert Commission (MSEC), subordinated to MoH, assesses patients for disabilities. MSECs includes physicians with various medical specialties. Physicians are responsible for providing a document which includes the rehabilitation needs of individuals with disabilities and recommendations for a personalized rehabilitation programmes, where the necessary and appropriate AP is indicated. The person independently chooses the vendor, informs the regional social service and applies to the vendor for the AP with a referral provided by the social service. The regional social service then pays the vendor after the person has received the AP.

AT is financed through the public budget. The national budget allocates approximately 44 million USD per year towards AT, which is sufficient to distribute the 15 priority AP listed in the assessment for registered people with disabilities. However, the available national budget is not sufficient to cover the required service provision and training facilities.

AP procurement in Ukraine occurs in a decentralized manner on an ad-hoc basis. Public procurement for AP is regulated through self-declaration from the supplier or manufacturer. The AP offered by the state-budget must have a certificate of conformity from the qualification commission under the MSEC. Manufacturers and suppliers that want to provide AP to people from the national budget must have an approval by a qualification commission. The commission assesses the availability and accessibility of the workplace on the conditions of equipment availability and the number of educated staff with sufficient and relevant AT expertise. Over the last 3-5 years, no manufacturer or supplier has been declined a certificate from the qualification commission. Ukraine currently does not have a policy on recycling AP.

Discussion

This study aims to map 15 priority AP that has the potential to alleviate and/or support persons with hearing, visual, and mobility impairments, and assess Armenia, Denmark, Spain, and Ukraine's capacity to meet the estimated need for AT. The following discusses the key findings of the study's primary and secondary objectives and its implications for policymakers.

The trends identified in the estimated prevalence of hearing, visual, and mobility impairments indicate that the burden of functional limitations increase with age in both severity and magnitude. The severity of hearing loss and prevalence of presbyopia, vision loss, upper and lower limb amputations increase with age across the four countries. In Armenia and Ukraine, the proportion of people above 65 years old is 11.33% and 16%, respectively, whereas 17.98% and 19.23% of the population is above 65 years of age in

Spain and Denmark respectively (40). It implies that the higher prevalence of moderate hearing loss could potentially be associated with the higher proportion of older people in Denmark and Spain compared to Ukraine and Armenia (39). Overall, there is an increased need for AT to support hearing, vision, and mobility needs in ageing populations.

Distinctively, prevalence of presbyopia, moderate, and severe vision loss is highest in Armenia and Ukraine compared to Spain and Denmark, with the most substantial difference in prevalence observed for presbyopia and moderate vision loss (Figure 2). As it is unclear whether the GBD estimates the prevalence of all types of vision loss considering the use of visual aids, differences in ability to provide AP that support and/or compensate types of vision loss such as presbyopia could be an influential factor that explains the observed difference in prevalence.

The trends identified in the rapid AT capacity assessment demonstrate that the 15 priority AP are available in the 4 selected countries. All 4 countries appear to have the capacity to distribute the 15 priority AP should an AT user access the appropriate services. However, gaps exist in understanding the comprehensiveness of service provision, which includes follow-up, maintenance, and repair services after the initial prescription, as well as access to the 15 priority AP irrespective of registered status as a person with a disability. A centralized provision and procurement system do not exist in Denmark and Spain, which results in very limited information at the subnational level. As such, it was not possible to obtain information on the national budget spent to procure AP in Denmark, Armenia, and Spain. Only Ukraine provided a quantitative number on the national budget allocated towards AT per year. However, 44 million USD per year was insufficient to cover the maintenance and repair facilities. In Armenia and Ukraine, AP regulation is mandatory for AP procured with public funds, whereas the regulation in the private sector is very limited. More specifically, in Armenia, sustainable access to AP is not coordinated nor sufficiently developed. Overall, there is a need to ensure comprehensive service provision of quality AP that is regulated by adequate standards for products procured both in the public and private sectors for all, irrespective of the registered status as a person with a disability.

Limitations

One significant challenge faced when using the GBD database is the ambiguity in considering visual and hearing aids when reporting prevalence for vision and hearing loss. As it is difficult to understand how the GBD database in 2017 considers the use of visual and hearing aids when illustrating prevalence of all types of vision and hearing loss, the prevalence data we were able to extract may not represent the true prevalence of vision and hearing loss without taking into account any use of visual or hearing aids. As such, we can speculate that the true prevalence and therefore the true burden of vision and hearing loss in each country may be higher than stated.

When gathering information using the rapid AT capacity assessment, very limited information could be gathered on the amount of AP procured and provided across all four countries. Further information gathered from the clarification meetings were also

insufficient. Indeed, some questions focus on regulation, some on price, some on procurement, which required a multi-disciplinary team to respond. There were significant challenges faced in collecting systematic information in Armenia and Ukraine on AT needs in population, which potentially could be due to a lack of developing, planning, and implementing initiatives that improve access to AT. For Denmark and Spain, the limited information gathered from the assessment tool and clarification meetings could potentially be due to limited time, which restricted the ability to engage more stakeholders.

Potential next steps

Estimating the prevalence of functional limitations is a proxy for estimating AT need in a country. By mapping the identified functional limitations to the appropriate AT is a key step in providing a reasonable estimate for AT need. Assessing a country's capacity to meet AT needs can help quantify the gap between AT procurement, provision, and population need. Quantification of this gap will support key decision making at both the sub-national and national level for policymakers, planners, programme managers, and all relevant stakeholders. Increasing understanding of population need for AT and a country's capacity to procure and provide appropriate, affordable, quality AT is foundational to informing key decision making that aim to improve access to life-changing AT.

In order to improve understanding of population need for AT and a country's capacity to provide such AT, data collection can be strengthened by creating AT information systems where all AP and related interventions are registered and monitored. In order to ensure appropriate and high-quality AP, strengthening regulatory mechanisms, particularly in the private sector is key. Use of adequate, relevant technical specifications in tendering processes, which should be harmonized with international quality standards and best procurement practices can further ensure the procurement and provision of quality AP. Establishing maintenance and repair facilities and investing in follow up after the initial AT prescription and provision can improve the appropriateness of AT in addressing individual functional needs. The development of the AP sector should go hand in hand with development of interventions aimed to reduce barriers to using AP, in order to maximize the benefits for both users and society.

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Appendix

Figure 2 - Prevalence of presbyopia, moderate and severe vision loss, blindness across Armenia, Denmark, Spain, and Ukraine in 2017 amongst under 15, 50-49, 50-64, 65-79, and 80+ age groups and potential assistive products of benefit.

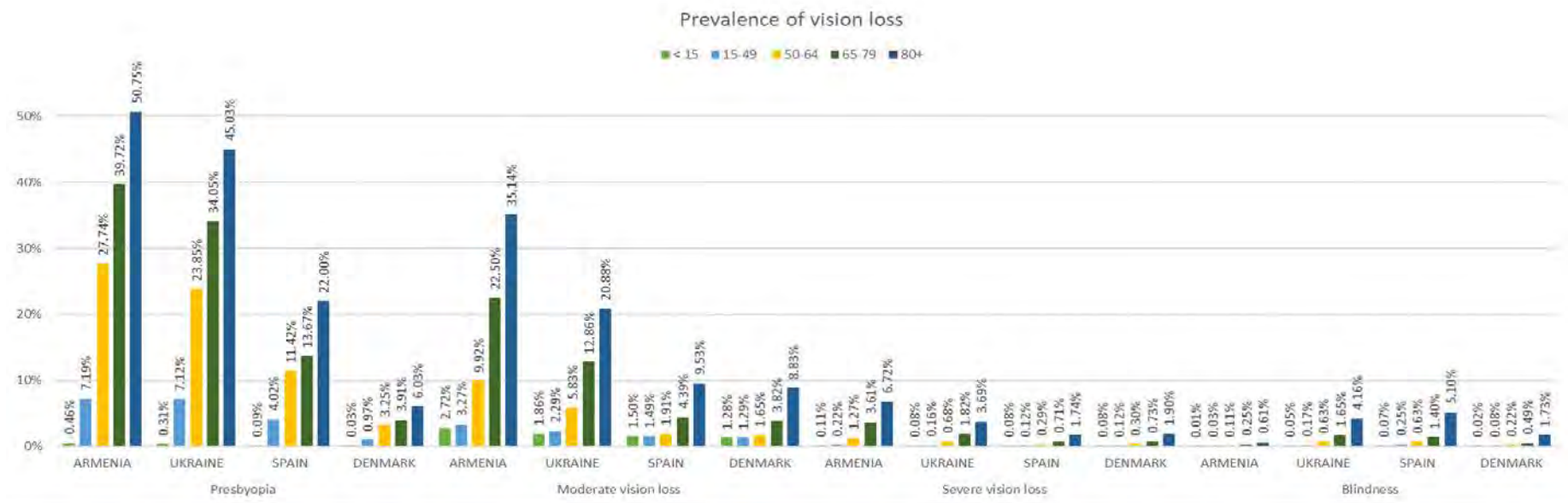


Figure 3 - Prevalence of mild, moderate, moderately severe, severe, profound, and complete hearing loss across Armenia, Denmark, Spain, and Ukraine in 2017 amongst under 15, 15-49, 50-64, 65-79, and 80+ age groups and potential assistive products of benefit.

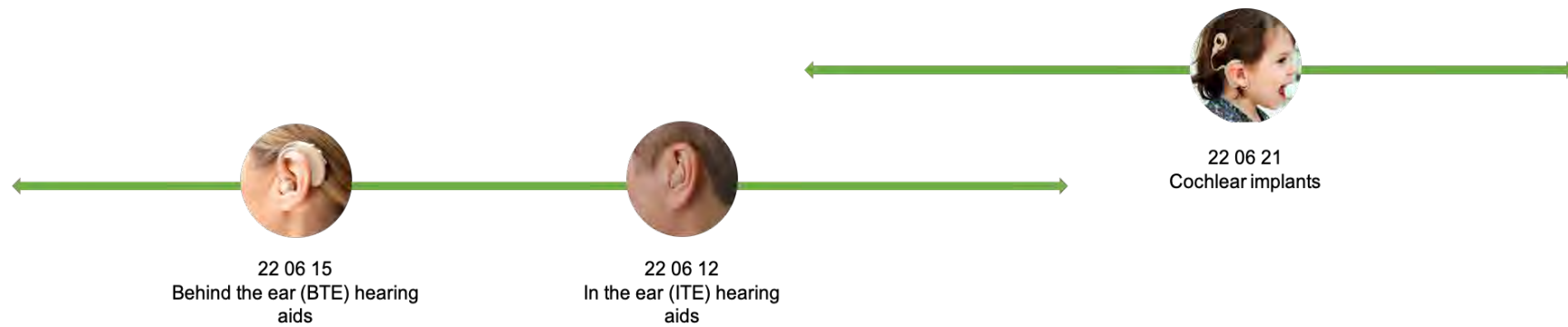
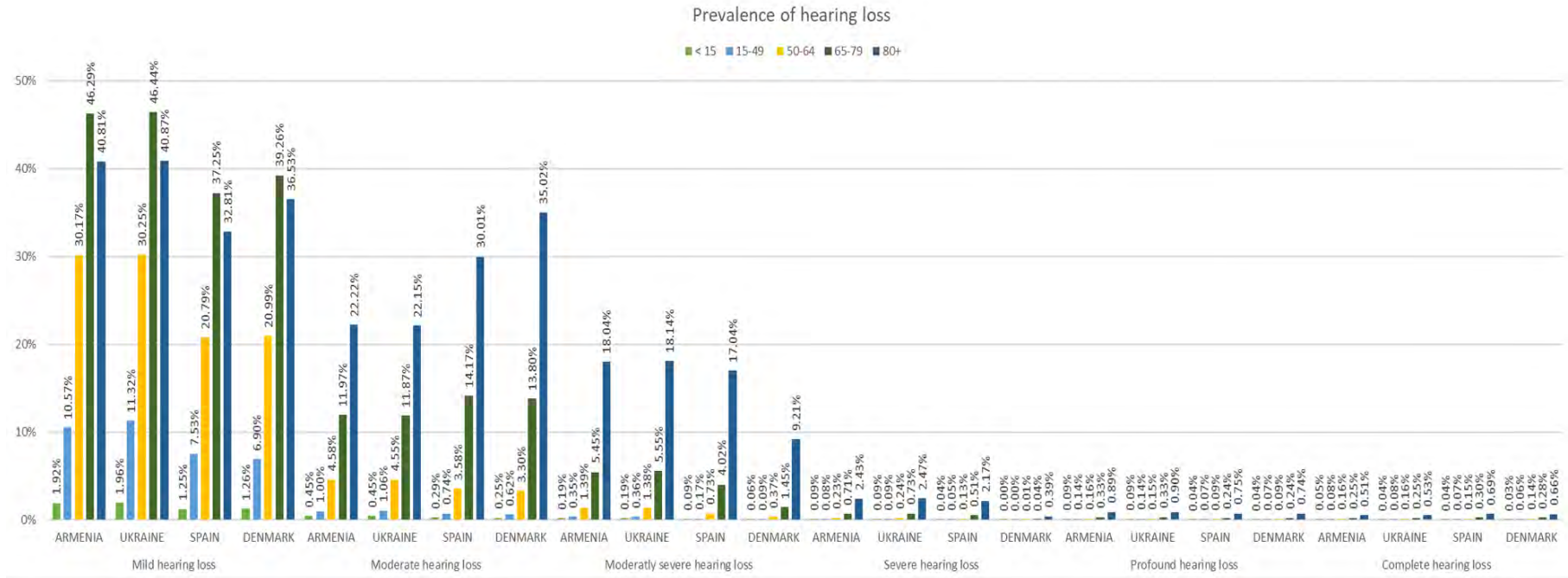
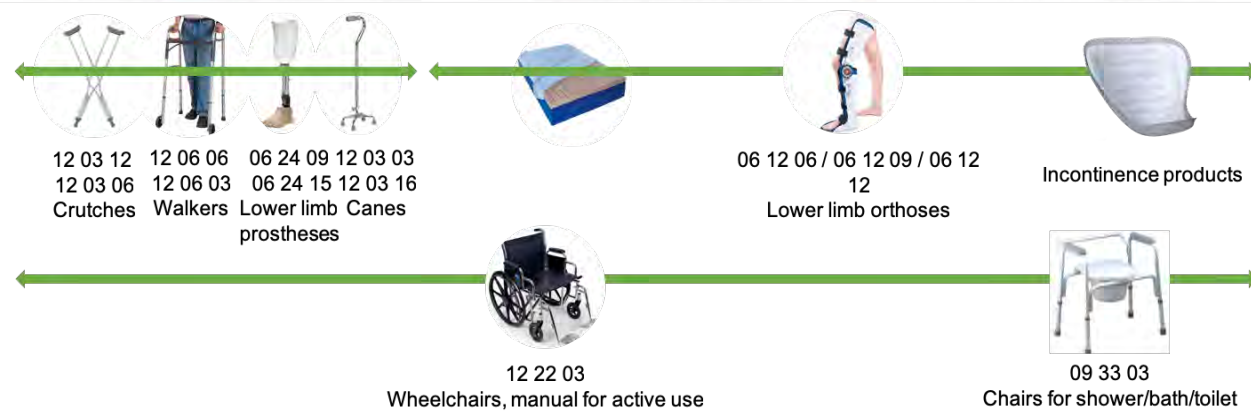
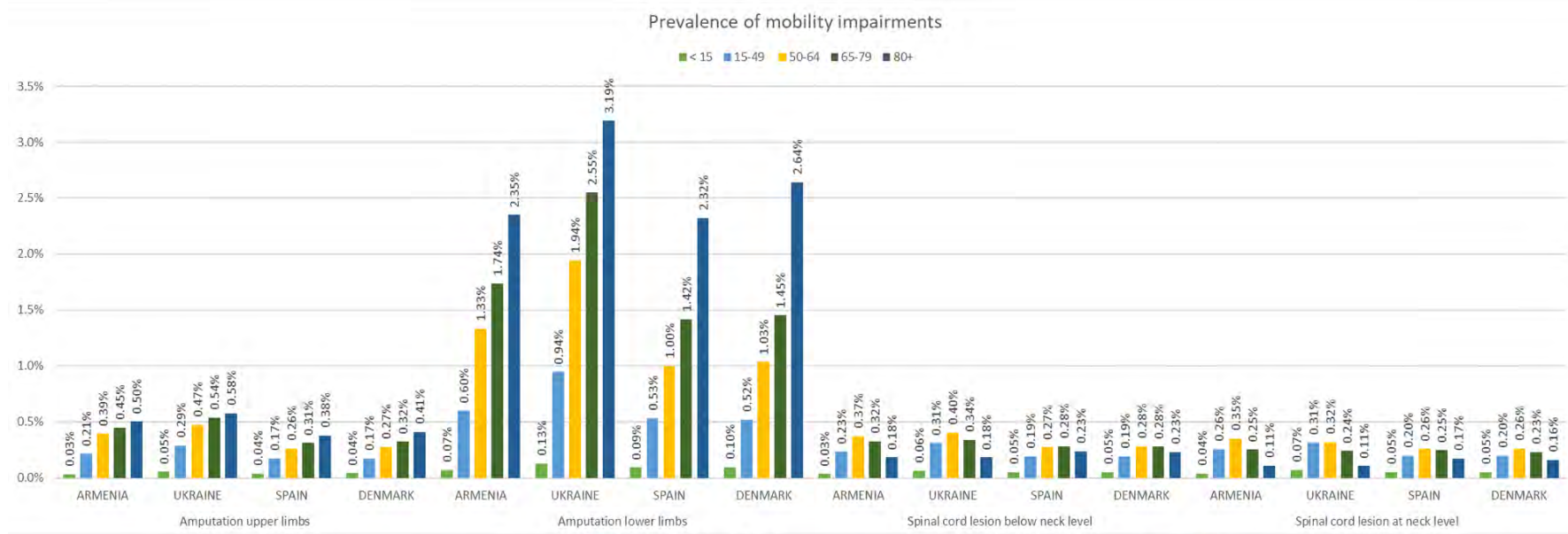


Figure 4 - Prevalence of upper and lower limb amputations, below neck level and at neck level spinal cord lesions across Armenia, Denmark, Spain, and Ukraine in 2017 amongst under 15, 15-49, 50-64, 65-79, and 80+ age groups and potential assistive products of benefit.



Measuring met and unmet assistive technology needs at the national level: Comparing national database collection tools across eight case countries

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Abstract

The development and implementation of assistive technology policy that meets the needs of citizens is dependent on accurate data collection and reporting of assistive technology use and unmet needs on a national level. This study reviews the methodology from instruments intended to capture national statistics on assistive technology use across eight case countries from varying regions and income levels. Recommendations are provided, which highlight the need for mandatory, census level data collection according to international standards for data collection in the areas of disability and assistive technology.

Keywords

Assistive technology, epidemiology, database, census, data collection

Introduction

The World Health Organization (WHO) estimates there are approximately 1 billion individuals worldwide who require the use of assistive technology (AT) (1). However, meeting individual needs is challenging given the diversity of contexts and commitment to AT provision (2). Furthermore, AT provision is complex and the products prioritized in different settings will vary (3). For example, some countries may experience a higher rate of

certain diseases which require specific AT (i.e. high rates of multiple sclerosis in the northern hemisphere) where other regions may be challenged to provide basic mobility equipment to address the needs of their citizens (i.e. high need for prosthetics and wheelchairs in conflict zones). In order to address these disparate needs on a global scale, it is important to have a full understanding of the current use and need for AT both on a national and a global level.

Accurate, comprehensive, and current data is required on both AT use and unmet need to justify systems investment in AT policy, programs, and spending (2). Understanding prevalence of use, as well as prevalence of need, helps direct funds where they are most needed, and inform program decisions at a national level. Without reliable data on AT use, and unmet and projected needs, planning for and investing in appropriate and sustainable provision is compromised. Furthermore, it may be difficult to develop systematic and context specific policies, guidelines, and standards with consideration for a systems thinking approach (2,4). This may leave national governments vulnerable to the delivery of inefficient and ineffective services, resulting in poor quality and unaffordable AT. Improving available national statistics provides indicators for context specific planning, evidence for advocacy groups (5), and opportunities to promote cost-effective national procurement methods through bulk purchasing for items of the greatest need (3). These data may therefore enhance equitable access to AT required by all people with disabilities regardless of gender, age, race, or ethnic characteristics (6). Regular data collection also promotes monitoring and reporting on progress of existing or new policies and programs by providing baseline and follow up data to complement additional evaluative measures (4).

The use of data captured on a national level also helps to inform the understanding of regional and global trends. Understanding regional needs may help to promote the use of economies of scale, breadth in procurement programs, and deliver tailored education to the individuals who deliver services to enhance access to AT (3,7). It is therefore necessary to explore some examples of national level AT data collection, to identify the strengths and limitations of existing methodologies, and make recommendations for the future.

Objectives

1. To compare national data collection tools and methods for understanding prevalence of AT use and unmet need statistics across eight case countries from varied regions and income levels.
2. To identify strengths and challenges in the collection of AT data based on the experiences across each of the case countries reviewed.
3. To provide recommendations on national data collection for AT use and unmet need statistics.

Methods

This methodological review compared methods used across eight case countries who have embarked on national data collection of AT use and unmet need statistics through a national census or health and disability database. Representatives who are familiar with

national datasets for each country reviewed and summarized the methodology used for data collection, availability of data, and commented on relevancy for the local population. They were also asked to identify strengths and limitations of the methodology used. Table 1 provides an overview of the topic areas addressed for each national dataset.

Table 1. Topic Areas for Data Collection

Sample Selection	Level (population vs. sample) of data collection. Voluntary or mandatory response. Respondent recruitment/selection. Inclusion of vulnerable groups.
Data Collection	Methodology used. Strengths and limitations for country context. Demographic and socio-economic indicators collected.
Assistive Technology Analyses	Level of analysis for specific assistive products. Relevance of assistive products to in-country requirements. Data collected on assistive product use and unmet need, including reasons for use or unmet need, and barriers to obtaining AT.
Availability of Data	Researcher access to data and process to obtain. Data available to the public and process to obtain.
Strengths and Limitations	Strengths of the methodology. Limitations of the methodology specific to in-country requirements.

Analyses

Country representatives were provided with a set of questions corresponding to the topic areas outlined above and asked to provide information on each of the topic areas. Where multiple datasets were identified, a single primary dataset was identified which was national in scope, with preference given to population level datasets. In the case where no national survey was identified, a dataset of individuals with disabilities was used in lieu. Additional datasets, including other national databases, are identified in the results. Relevant methodological data were collated and reviewed for common and differing approaches, strengths, and limitations. Narrative data provided were reviewed and summarized, providing national examples to illustrate common strengths and limitations. Results are presented by topic area.

Results

Representatives of eight case countries reviewed and provided information on their national datasets. Table 2 provides an overview of the datasets reviewed for this paper, including the name of the data collection tool, agency, population, and AT use and unmet need data. In many cases, additional tools or datasets were identified which are not reported in the table; preference for analyses was given to national datasets which included assistive products in the analyses, or datasets which would provide more robust national data. Additional details regarding the results are presented by topic area. To illustrate key themes or concepts in the results, case countries may be used as examples.

Sample Selection

The majority of datasets report on a sample of the population, with approximately half reporting voluntary responses. Samples were largely selected geographically by household or dwelling. In Canada, the sample was selected based on those who identified an activity limitation in a national census (8). In Argentina, the sample was selected only from households in urban areas of 5000 or more (9). Data from Ireland is presented from an opt-in database of individuals with disabilities (10).

Data Collection

In all cases, methodology included in person (door to door or telephone) interviews guided by a questionnaire or computer assisted data collection tool. In countries where results were not linked to a national census which includes demographic indicators, basic demographic data was captured including gender, age, and education. Varying levels of information were collected regarding disability status or activity limitation; in Colombia, Brazil, and Zimbabwe these data were guided by the Washington Group on Disability Statistics short set of questions, while the Telangana Disability Study in India (16) (not reported in Table 2) used the Washington Group extended set (17). The Disability Certification database which is currently being implemented in Colombia (not reported in Table 2) bases activity limitation questions on the International Classification on Disability, Functioning, and Health (18), while the Assistive Technology Bank database, also in Colombia uses the ISO9999:2016 classification (6).

Assistive Technology Analyses

The level of analyses for AT related data varies widely, from no data collected at all regarding the use of AT (Argentina) to over 70 named assistive products across areas of activity limitation (Canada). In general, the categories of AT reflected are broad, without specific mention of individual products, or limited in scope with only a few products mentioned. Reasons for use are identified in the majority of data collection tools which identify AT use. Of those datasets reviewed, very few addresses unmet need for AT, or the reasons for unmet need. Table 2 provides additional details.

Table 2: National Data Collection Tools

Country	Name of Tool* (Date)	Agency Responsible*	Population/Sample; Mandatory/Voluntary; Description (n)**	AT Use Data Collected	AT Unmet Need Data Collected
Argentina	National Study of Profiles of Persons with Disabilities (9) (2018)	National Institute of Statistics and Census	Sample; Voluntary; Individuals living in homes in urban areas with over 5000 inhabitants (n=4100)	No.	No.
Australia	Survey on Disability, Ageing, and Carers (11) (2015)	Australian Bureau of Statistics	Sample; Mandatory; Individuals living in private dwellings, cared accommodations (n=25 555 households, 1 009 caring establishments)	Type of aid used and reason for use for: hearing aids, mobility aids (specific), guide dogs, orthoses and orthotics, lifts, apps, and communication aids (computer and non-computer based).	Partial: Broad questions on reasons for unmet need, not linked to specific AT.
Brazil	National Health Survey (12) (2013)	Brazilian Ministry of Health and Brazilian Institute of Geography and Statistics	Sample; Voluntary; All households (n=63 000 households responding)	Whether AT used for mobility (canes, crutches, wheelchairs, walkers, other), hearing (hearing aids), or vision (glasses, lenses etc.). No specific AT named. Linked to perceived difficulties and activity limitations requiring use.	Partial: Difficulties when using/not using AT.
Canada	Canadian Survey on Disability (8) (2017)	Statistics Canada	Sample; Voluntary; Individuals self-identifying with activity limitation in National Household Survey (Census) (n=50 000)	Type of AT used: Over 70 specific AT named in areas of hearing, seeing, moving/bending/reaching/fine motor, learning difficulties, and other. Reasons for use linked to activity limitation.	Yes: AT “need but not have” and reasons recorded.
Colombia	National Population	National Statistics	Population; Mandatory; All individuals (n= unavailable)	Use of specific types of AT: glasses, lenses, magnifiers, canes,	No.

Country	Name of Tool* (Date)	Agency Responsible*	Population/Sample; Mandatory/Voluntary; Description (n)**	AT Use Data Collected	AT Unmet Need Data Collected
	Census (13) (2018)	Administrative Department		wheelchairs, cochlear implants, other. AT not linked to specific activity limitation.	
India	Survey of Persons with Disabilities (14) (National Sample Survey 76 th Round Schedule 26; 2018)	National Sample Survey Organization, Ministry of Statistics	Sample; Voluntary; Stratified sampling identifying villages, urban blocks, and households (n=Approximately 384 000)	Partial: Whether AT was advised/prescribed, type of aid, current use. Reasons for use: locomotor, visual, hearing, speech and language, intellectual disability, mental illness, other. List of AT not comprehensive.	Partial: Whether indicated aids acquired.
Ireland	National Physical and Sensory Disability Database (10) (2017)	Health Research Board	Population; voluntary; Opt-in database based on service use/need (n=20 676)	Partial: AT used which is funded by the government is coded. Privately funded AT is not captured.	Partial: Needs captured for funded AT only.
Zimbabwe	Living Conditions Among People with Disability in Zimbabwe (15) (2013)	Ministry of Health and Child Care and Zimbabwe Statistical Agency	Sample; voluntary; Stratified cluster sampling in private households (n= 64 300)	Use and working condition of assistive devices, how device was obtained, training and maintenance, device satisfaction.	Partial: Access needs to AT related social services

Notes: *Names of data collection tools and agencies translated into English where necessary. **Sample sizes may be approximate, based on publicly available data.

Availability of Data

Data is available (or is anticipated) for researchers to access in all countries reviewed. In those countries where data is currently available to researchers, the majority must apply for access to the microdata for analyses through a partnership with a university or a national statistics organization. General data is made available to the population as high-level analyses, as published by the organization who has collected the data. Generally, AT specific data are not included in these high-level analyses.

Strengths and Limitations

The national scope of datasets was identified as the primary strength. When comparing all tools, we identified the lack of consistency of data collection, as a key limitation. Other limitations identified included inadequate sampling and the use of voluntary samples, self-identification of disability status, and inadequate specificity on AT use and unmet needs, including barriers to obtaining AT. We expect substantial variation in data collection methods and available data on AT use and unmet need statistics.

Discussion

In this report, we have compared eight national data collection tools for AT across varying income levels and regions. Overall, we found survey tools to be largely sample driven in lieu of population based approaches. This may lead to sampling frames which are inadequate for specific vulnerable groups, with a higher potential for the resulting dataset to present an incomplete picture of the population. For example, the use of sampling frames often excludes individuals living in group living environments including residential care facilities, where potential AT users, including individuals with disabilities or older adults may be living. Systematically excluding these individuals from data analyses may result in underestimating the prevalence of AT use. This is the case in Canada, where the sampling frame only includes those living in private dwellings. This excludes the estimated 270 000 individuals living in residential care or alternative levels of care, who may be more likely to use assistive technologies associated with functional limitations due to ageing or severe disability (19). Given the increase in use of assistive products with ageing (20,21), excluding these populations likely results in underreporting of AT use. Other surveyed countries, including Colombia, specifically include these groups in the National Census.

In addition to the use of sampling frames which exclude groups based on type of residence, we also found evidence of sampling frames which exclude individuals living in rural or remote areas. For example, the National Study of Profiles of Persons with Disabilities in Argentina included only those living in communities of 5000 individuals or more (9). In some cases, this has been addressed through the use of regional surveys, which may be better suited to capturing the needs in rural and remote areas. In India, the Kerala State Disability Survey was a mandatory census of an entire region, specifically addressing disability and associated needs, both for individuals living in private dwellings, and for those in institutions (22). Regional surveys which capture the entire population may be better suited to

understanding specific needs of the population where a larger national sample is more difficult to obtain.

Sampling frames may also be problematic if they exclude certain vulnerable groups. For example, Australia excludes individuals living in distinct Indigenous or Torres Strait Islander communities. This is concerning as recent statistics suggest nearly half of the individuals in these communities (45.1%) experience a disability and require assistance with activities of daily living (23). Canada also excludes indigenous populations living in reservations. Previous research has found indigenous people in Canada may experience disability at twice the rate as non-Indigenous Canadians (24). Excluding these individuals results in a lack of understanding of the needs of individuals in these areas and may impact service delivery to these vulnerable communities.

We also found samples were largely voluntary throughout the majority of our data collection tools or required self-identification of disability status in order to trigger inclusion in the sample. There is evidence that voluntary samples exclude individuals in marginalized communities, and certain vulnerable groups. To illustrate this, we might consider the evidence that voluntary samples have been demonstrated to underreport data from individuals with lower socio-economic status (25,26). Further, individuals who have poorer health status have been shown to be underrepresented in voluntary health surveys (25). Given the likelihood that individuals who require the use of assistive technologies experience poorer health status than the general population (27,28), and the evidence demonstrating income inequality for individuals with disabilities (29), it is reasonable to assume that the use of voluntary surveys may systematically underrepresent this population.

Registries or databases may provide opportunities for ongoing monitoring and data collection, where national surveys do not meet the need. In Colombia, several databases exist which record and classify individuals with disabilities, and those who have received AT services (30,31). These allow for an ongoing record of individuals who are using or need assistive products and may be a more reliable source of data from groups who might otherwise be excluded from national samples. The same is true in Ireland, where the National Physical and Sensory Disability Database maintains data on individuals who are identified as experiencing a disability (10). However, there are limitations to these databases. First, individuals must have been identified as requiring or seeking services related to their disability. Second, this does not include those individuals who may benefit from the use of assistive products however do not meet the stringent criteria for disability classification. Furthermore, these databases often include only those products which are procured through national insurance schemes, and do not include those products purchased or created by the individual privately.

When considering the AT content in the cases we reviewed, we found a varying level of specificity to identify the types of AT used. In many cases, there were either limited lists of potential AT products, or the categories were so broad as to not provide enough detail to

inform future research or policy. In Zimbabwe, data were collected using open questions across 7 device categories including availability, utilisation, training, maintenance, and satisfaction. This appears to be among the most complex analyses of AT and related services among the countries reviewed. However, very few of the tools addressed details regarding unmet needs and the reasons for unmet need. These are critical components to understand when developing policy and implementation plans, and for advocates in the community.

Finally, we found an effort to use standardized terms and agreements in a number of the tools, including the Washington Group on Disability Statistics questions (17), however there was no universal use of a single framework. As a result, there is little ability to compare data from one country to the next, and in some cases, from one survey to the next, when the frameworks are not used universally across all tools, or in each subsequent survey. The use of a single framework would enhance comparability of the data on a national, regional, and global level.

Limitations

This study was not intended to provide an exhaustive review of all data collection tools used globally to assess use and unmet need for AT. Rather, we used a sample of countries representing varying income levels, government systems, and regions to highlight some of the challenges and successes in national AT statistic collection. We acknowledge the limitations of a sample in this case.

We may also have neglected to include relevant sources of data, including surveys which did not specifically address health and assistive technologies, and information from the military or veterans' organizations which may have differing health coverage.

Recommendations

Based on our analysis, there are several recommendations which we would propose to enhance the collection of national statistics in the area of AT:

1. Data is ideally collected at the population level, within or secondary to a mandatory national census. If secondary to a national census, it is important the data can be linked to demographic and socio-economic indicators collected during the census. Population level statistics are inclusive of all members of society and would acknowledge the use of AT as a universal experience for all individuals at all ages.
2. Where sampling frames are used in lieu of population level data, sampling should not rely on self-identification as a person with a disability and should apply methods or tools which are representative of the population as a whole. Sampling frames must also carefully consider the potential for underrepresentation of marginalized and vulnerable groups and take steps to ensure these groups are accurately represented.
3. Global alignment with a minimum set of questions, including a single classification system for assistive products, would enhance comparability of data. Alignment with the Washington Group on Disability Statistics should be considered, with modifications to the AT related questions to align with the WHO Global Cooperation on Assistive

Technology (GATE) initiative list of the 50 priority assistive products (1). Specifically, an amended set of questions in the Washington Group Expanded Question Set should reflect the variety of AT used across all impairment categories, with notable changes in the areas of communication and cognition.

4. Where possible, researchers should endeavour to gain access to the microdata which does exist in order to publish the data on AT use and unmet need, and clearly identify strengths and limitations within the dataset in their published material. Analysis of microdata allows researchers to identify inequities in the AT provision process, contributing to rationale for adjustment of policies regulating funding and provision models.

Conclusions

National level AT use and unmet need information is not adequately captured by existing data collection tools in the case countries we reviewed. Addressing sampling strategies to ensure the inclusion of vulnerable or marginalized groups and adhering to an international standard for disability and AT related questions will improve our national, regional, and global understanding of the current use and unmet needs for AT. Researchers should also endeavour to make use of the data which does currently exist, by requesting access to microdata to identify trends and inequities in service provision, and ensure this data is available to advocates and policy makers. Increased understanding will contribute to more robust and sustainable policy making and implementation.

Acknowledgements

We would like to thank the following individuals for their contributions to our data collection efforts: Anne Doyle, Research Officer, National Health Information Systems, Ireland; Aleida Fernández Moreno and Katherine Lorena Blanco Munevar, Universidad Nacional de Colombia; Solángel García Ruiz and Adriana Patricia Torres Agudelo, Secretaría Distrital de Salud de Bogotá.

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Need for, access to and quality of assistive technology in low- and middle-income countries

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Abstract

Reliable data is necessary in order to develop policy, interventions and services to fill the gap between need for and supply of assistive devices in low- and middle-income countries (LMICs). The aim of this paper is to present results on use and quality of assistive devices and services from a unique data base that has been accumulated over 15 years. The data is based on a series of nationally representative household surveys on living conditions among persons with disabilities in nine countries in southern Africa and Nepal. The data reveals that availability of assistive devices is strongly dominated by devices for personal mobility and for information purposes (sensory impairments); there are large needs-gaps across all studies; use of assistive devices among persons with disabilities is comparatively low; use of assistive devices is higher in urban areas, among men and among persons who have accessed formal education; assistive device services is limited; most users of assistive devices are either content or very content with their devices, and; the supply system varies considerably between countries. The findings indicate large shortfalls in supply of assistive devices in the study countries. In order to fulfil the obligations of governments according to the UN Convention on the Rights of Persons with Disabilities (CRPD), it is necessary for the actors on this arena, including national service systems, national and international organisations to join forces to develop comprehensive models of assistive device service delivery that is adapted to each country context.

Introduction

Access to assistive devices and services of good quality is critical for many persons with disabilities to participate in the community and in society at large (1). Provision of assistive products is highly relevant and important in order to obtain inclusion of persons with disabilities (2) and through this instrumental in achieving the Sustainable Development Goals (SDGs) (3) and to ensure that "no-one is left behind". Although data is weak and limited, it suffices to say that in Low- and middle-Income Countries (LMICs), there are substantial gaps between supply and needs (4). International policy has thus targeted the huge shortfall of assistive devices over three decades, from the *UN Standard Rules for*

Equalization of Opportunities for People with Disabilities (5) to the *United Nations Convention on the Rights of Persons with Disabilities (CRPD) (6)*, the WHO Resolution *Improving access to assistive technology* adopted at the seventy first World Health Assembly (7), and the Charter for Change adopted at the Global Disability Summit 2018 (8). Article 26, Habilitation and Rehabilitation, of the CRPD calls for countries to organise supply of assistive devices and technologies. In the aftermath of the first Global Research, Innovation and Education on Assistive Technology (GREAT) in 2017, several authors have brought the attention to the need for more comprehensive, systematic and systemic approaches to remove the gap between supply of and needs for assistive technology, in particular in LMICs (9-11).

Tebbutt et al. (12) argue that in order to develop policy, intervention and services aiming at filling the gap between demand for and supply of assistive devices globally, it is necessary to have reliable information about the need and barriers to access. The World Report on Disability (4) states that research is a key ingredient in developing rehabilitation services including assistive devices In Low-Income Countries (LMICs). The recent WHA resolution (WHO 2018) consequently include explicit requirement of collecting population-based data to obtain knowledge about the needs. According to Borg et al. (1), research on assistive technology in LMICs is limited and largely concentrating on design and production of mobility products. A recent scoping review (13) found limited quantity of available research, in particular in LMICs, and further that quality of existing research is problematic.

The aim of this chapter is to present results from a unique data base that has been accumulated over 15 years from eight countries in sub-Saharan Africa, and from Nepal. Such a comparison can be used to better understand country variations, in Africa and beyond. A series of nationally representative studies on living conditions among persons with disabilities has been carried out in collaboration between researchers and the disability movement in the specific countries¹.

Methods

The twelve studies on living conditions among persons with disabilities carried out by SINTEF and partners in the period 2003 – 2018 (year of reporting) (14-25) basically use the same sampling procedure and set of research instruments (questionnaires) capturing a broad range of indicators on level of living and a large number of specific disability-related information. All studies applied a two-stage cluster sampling strategy, using the National sampling frame developed by the National Statistical Office in the respective countries and a disability screening procedure ensuring a representative sample of households with and without disabled members and individuals with and without disabilities. The studies thus form a unique regional data base (+ Nepal) that allows for comparison within and between countries. However, experiences over the years, development of new disability and

¹ Most of the studies have been funded by Atlas Alliance on behalf of NORAD, while two studies were funded by UNICEF.

screening measures, and thorough adaptation processes in each context, have all led to several small and a few major changes in the design. Of these, the six disability screening questions developed by the Washington Group Short Set in 2004 (25) and the UNICEF/Washington Group Child Module in 2016 (26) are clearly the most important developments influencing directly on the identification of persons with disabilities and in practice leading to the inclusion of different populations of persons with disabilities in the earlier studies as compared to those who were carried out after 2004, and likewise with the Child Module being applied in the last two studies in Malawi and Zambia (14, 25). The studies in Zimbabwe 2003, Namibia 2003, Malawi 2004 and Zambia 2006 all used screening questions developed prior to the Washington Group Short set, which was used for all the later studies. The screening questions used in the four earlier studies were: i) Does anyone in this household ever have any difficulty in doing day to day activities because of a physical, mental or emotional (or other health) condition which has lasted or is expected to last for six months or more? (Response categories: yes, no), ii) Does anyone in this household need assistance in participating in any of the following activities? (walking, seeing, speaking, hearing, breathing, mental coping, learning/comprehending) (Response categories: yes, no). Confirming both (yes to both) was required for qualifying as a person with disabilities. For the remaining (later) studies, the Short Set was used and a wide definition of qualifying as a person with disability when reporting at least some difficulty on one of the six items. In the latest studies in Zambia and Malawi, the Washington Group/UNICEF Child Module was used for screening children (< 18 years). Disability severity was operationalized by dividing the additive scales, i.e. the 47 items, WG Short Set and the Child Module respectively, into three equally large categories (mild, moderate and severe disability).

It needs to be acknowledged that the studies have undergone a comprehensive adaptation to context in each country, involving a large number of stakeholders that influenced several aspects of the design including the content and understanding of the survey instruments. The roles of the disability movement, in-country research groups and other key partners have varied between the countries, including in this different duration and content of training as well as ability and/or motivation to stick to agreed procedures. All these and other aspects contribute to influence comparability and should be taken into consideration when assessing the results. It is thus advised to pay more attention to patterns in the results rather than comparing exact figures.

Table 1 shows the number of households and persons with disabilities included in the different national studies.

Table 1. Number of households and persons with disabilities by country

Country	Year of the study	Number of Households surveyed (Disabled)	Number of Households surveyed (Non-Disabled)	Number of Persons with disabilities
Namibia	2003 ²	2286	1356	2537
Zimbabwe	2003	1943	1958	2071
Malawi	2004	1521	1537	1579
Zambia	2006	2885	2866	2898
Mozambique	2009	622	1737	666
Lesotho	2010	589	631	639
Eswatini	2011	812	823	876
Botswana	2015 ³	944	993	995
Zimbabwe	2015	7505	7477	7944
Nepal	2016	2000	2000	2123
Zambia	2018	2912	7078	2377
Malawi	2018	4071	2384	4439

Results

In the following, some key results from analysing the different data sets are presented. Number of studies that are included in the different analyses vary due to problems with comparability.

Table 2 presents the distribution of different types of devices, which is useful for understanding the other descriptive statistics in this text. There is a pronounced domination of assistive devices for personal mobility with two exceptions where information devices are more common (Nepal and Zambia 2018). In the majority of the studies, information devices are a clear number two. Communication devices are in most of the countries the third most common. Variation between the country data is another feature of the results in Table 2. Devices in the remaining categories seem to be very limited in the countries represented in this study.

² Year of report.

³ Used a different threshold for disability on the Washington Group Short Set than all other studies after 2006

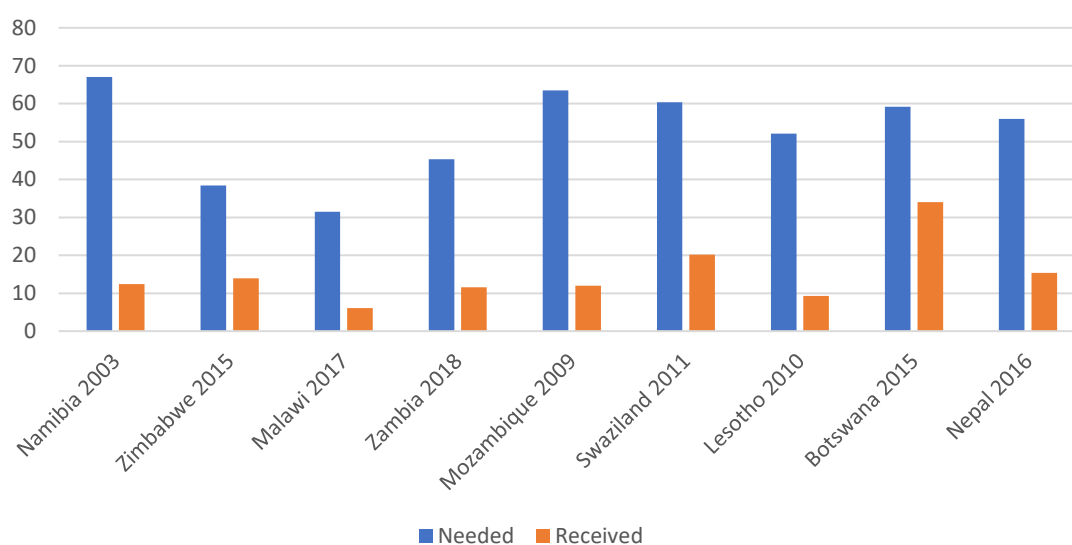
Table 2. Distribution of types of assistive devices among persons with disabilities by country

Device	Namibia 2003	Zimbabwe 2003	Malawi 2004	Zambia 2006	Lesotho 2010	Eswatini 2011	Botswana 2015	Zimbabwe 2015	Nepal 2016	Malawi 2018	Zambia 2018
N	436	543	350	369	98	350	414	1104	259	265	529
Information – eye glasses/hearing aids/braille, etc.	11.5	15.8	16.3	27.1	15.3	16.3	7.2	34.5	53.7	34.7	56.9
Communication – sign language/ interpreter/portable writer/computer, etc.	2.1	1.7	9.4	7.9	1.0	9.4	2.4	0.1	0.4	2.6	2.7
Personal mobility – wheel chair/crutches, etc.	79.8	75.1	61.1	59.3	68.4	61.1	77.1	57.9	33.2	51.3	28.4
Household items – flashing light on door bell, etc.	0.0	0.0	0.9	1.1	3.1	0.1	0.5	0.1	0.0	1.5	1.1
Personal care and protection – special fasteners/bath and shower seats, etc.	0.7	2.0	2.9	0.8	3.1	2.9	1.7	0.2	2.3	2.6	1.1
For handling products and goods – gripping thongs/aids for opening containers, etc.	0.0	0.7	1.4	0.5	2.0	0.1	0.7	0.1	0.0	1.5	1.3
Computer assistive technology – keyboard for the blind, etc. interpreter	0.0	0.0	1.1	0.5	1.0	0.1	11.4	0.0	0.4	0.8	0.2
Other	9.3	4.7	6.9	2.7	3.1	6.9	1.5	3.4	9.3	4.9	8.1

Gap in assistive device services

Respondents with disabilities were asked if they needed assistive device services and whether they had received/accessed such services. The proportion who stated that they needed assistive device service varied from 31.5% to 67% with Malawi recording the lowest and Namibia the highest percentage. The proportion who had received an assistive device varied from 6.1% (Malawi) to 34% (Botswana). The gap in services is the difference in percentage between the blue (needed) and the orange (received) column by country. The largest gap in assistive device services is found for Eswatini (54.6 percentage points) and the lowest for Zimbabwe (24.5 percentage points) and Botswana (25.2 percentage points).

Figure 1. Gap in assistive device services by country

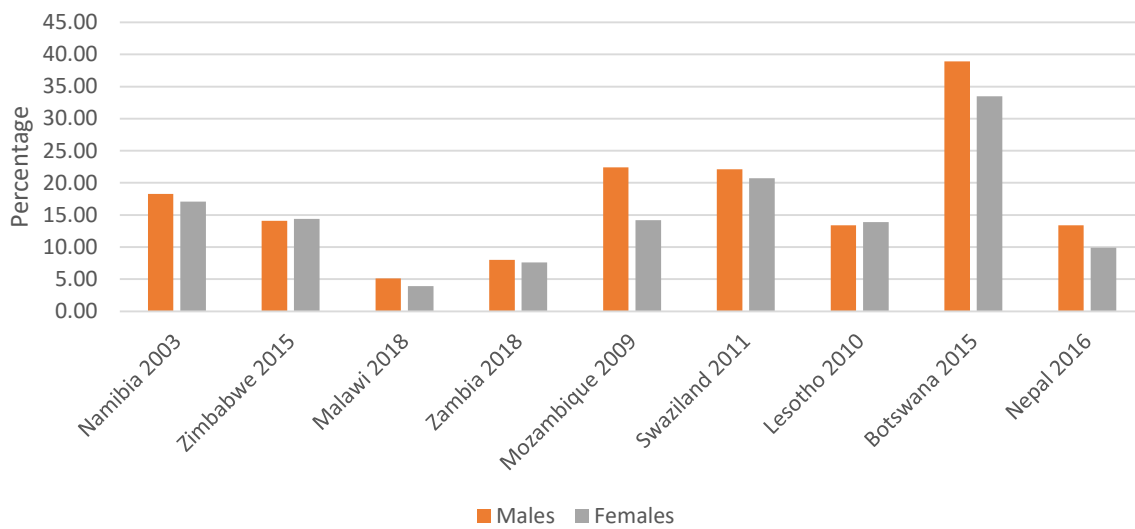


Use of assistive devices

Figure 2 confirms the substantial variation between countries as shown in Figure 1 and further shows that more males than females use an assistive device¹ in all countries except Lesotho and Zimbabwe. Gender differences are however mostly relatively small and only statistically significant in four of the studies. The proportion using a device varies across countries with Botswana reporting the highest figure (38.9% among males) and Malawi reporting the lowest (3.9% among females). The largest male-female difference was found in Lesotho (11.4%).

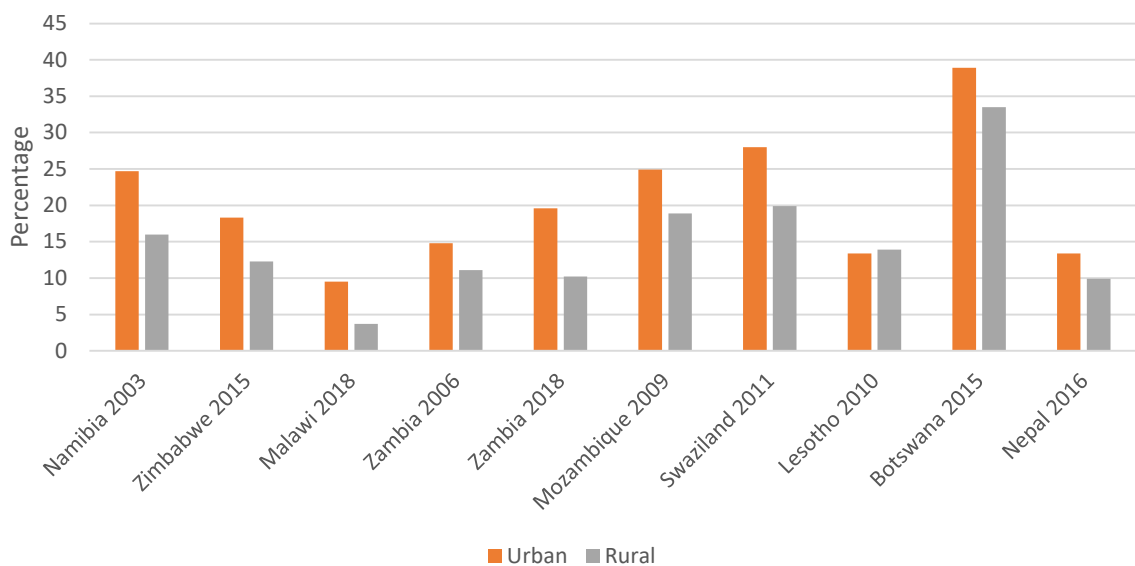
¹ Table 1 shows assistive device services, while Table 2 shows the proportion who uses an assistive device. The measures in Table 1 and 2 are thus not the same.

Figure 2. Use of assistive device by gender and country



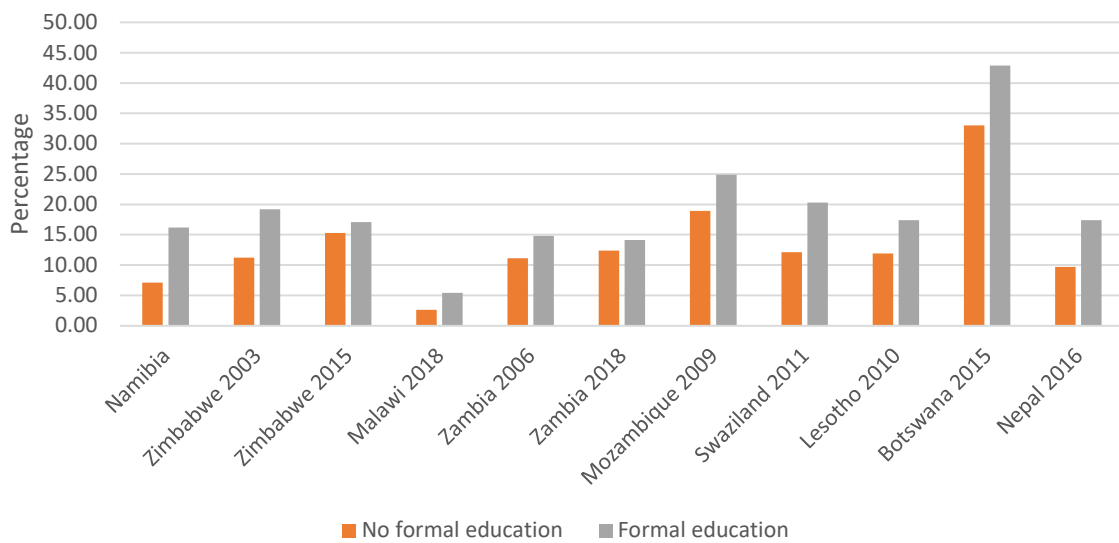
Use of assistive device is with one exception (Lesotho) more often reported among respondents living in urban areas. The largest urban/rural difference is found in Eswatini (9.1%).

Figure 3. Use of assistive device by location



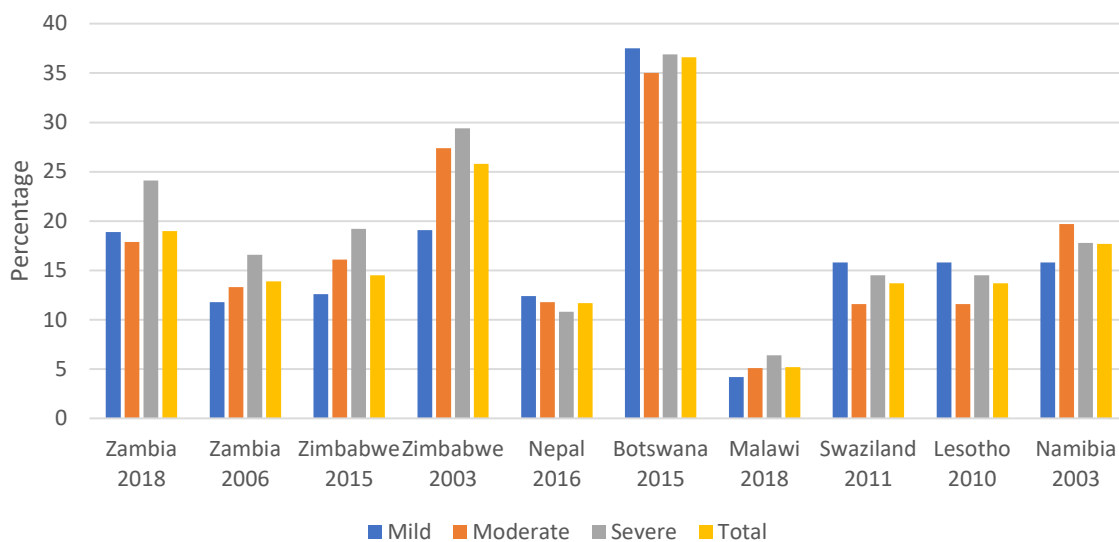
As shown in Figure 4, more individuals with disability who reported to have accessed formal primary education stated that they used an assistive device. The difference varies from approximately 2 to 10 percentage points with the largest difference found in Botswana (9.9 percentage points).

Figure 4. Use of assistive device by accessed formal primary education



A positive association is found between disability severity and use of assistive device in five of the ten studies included in Figure 5 (Zambia 2018 and 2006, Zimbabwe 2017 and 2003, Malawi 2018). In Nepal, the association is reversed while no association was found in the remaining four studies. In Botswana, Eswatini and Lesotho, Figure 5 shows that more persons with mild disabilities use an assistive device.

Figure 5. Use of assistive device by disability severity



Quality indicators

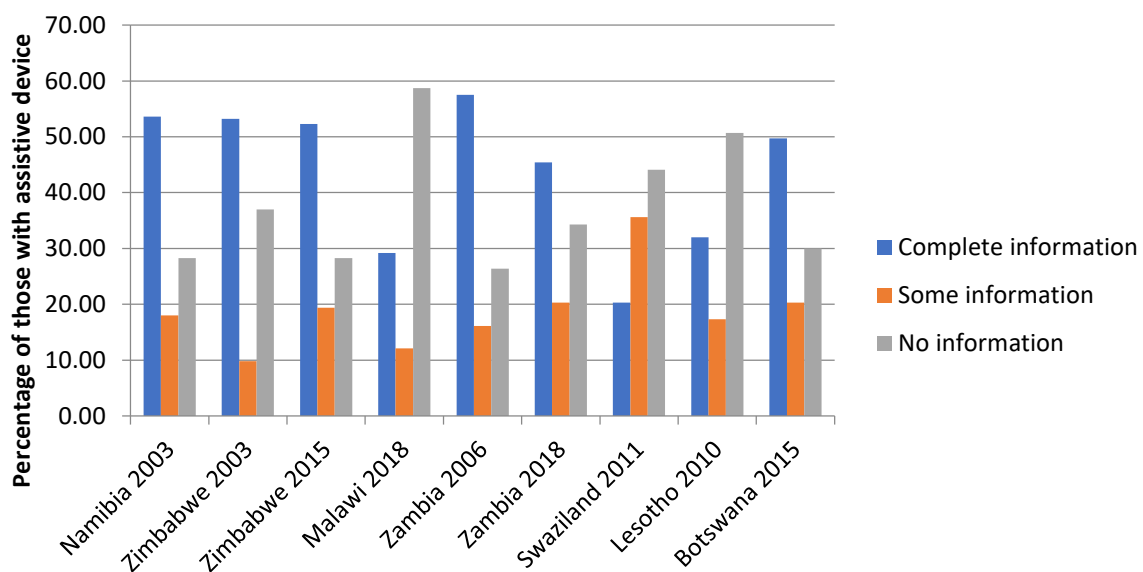
Quality of assistive device services were assessed by means of the following four indicators:

- Were you given any information or help on how to use your device(s)? (1 = complete/full, 2 = some, 3 = none).
- Is the assistive device(s) mentioned above in good working condition/order? (yes = 1, no = 2).

- Who, if any, maintains or repairs your assistive device(s)? (self = 1, government = 2, family = 3, employer = 4, ngo = 5, other = 6, not maintained = 7, cannot afford to maintain = 8=).
- Think of the MAIN assistive device you are using – on a scale from 1 (not content) to 4 (very content) – How would you describe your level of content/satisfaction with the device that it meets your needs? (not content = 1, less content = 2, content = 3, very content = 4).

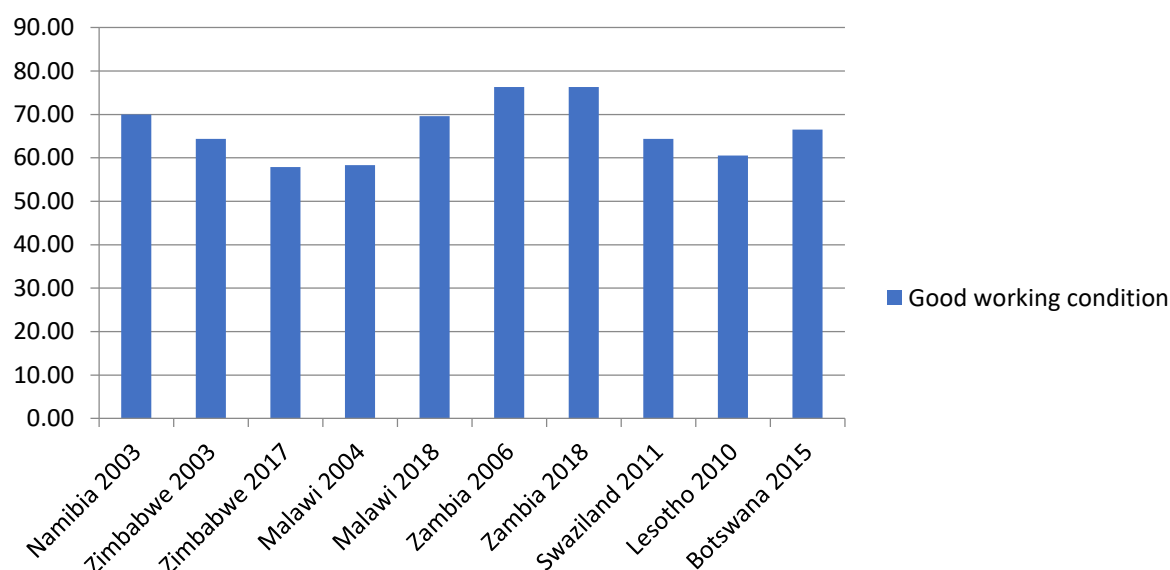
Information or help on how to use the assistive device is important for proper use, maximising the impact of the device and reducing risk of wrong use with potential damaging consequences. The proportion of respondents who report that they have received complete information/help on how to use the assistive device varies from 57.5% in the first study in Zambia to 20.3% in Eswatini. On the other hand, the proportion saying that they had not received any information or help varied from 58.7% in Malawi 2017 to 26.4% in the first study in Zambia. There is some variation between the countries, with Malawi 2017, Eswatini and Lesotho coming out with the most negative figures.

Figure 6. Information/training given on use of assistive device



In all countries included in Figure 7, more than half of the respondents stated that their assistive device is in good working condition, varying from 57.9% in Zimbabwe 2017 to 76.3% in Zambia. We can further observe that the data indicates a drop-in proportion of devices being in good working condition in Zimbabwe, an increase in Malawi and no difference in Zambia over a period of approximately 10 years.

Figure 7. Proportion of assistive devices assessed by their users to be in good working condition



A majority of the respondents in eight of the eleven studies presented in Table 3 reported that they maintain and/or repair the assistive device themselves or they are helped by someone in the family. Lowest on self-maintenance is Lesotho with 28.4% and the highest is Zambia with 67.5% and 65.2%. The second most common response is that the device is not maintained at all, ranging from 17.5% in Namibia to 42.6% in Botswana. Government, which largely means public health services, is reported by 35.3% in Namibia, which is highest and by 0.3% in Zambia 2006 which is lowest. Relatively few stated that an NGO does the maintenance and repair, with Malawi 2004 being the highest with 5.8%.

Table 3. Maintenance/repair of assistive device by country/study (%)

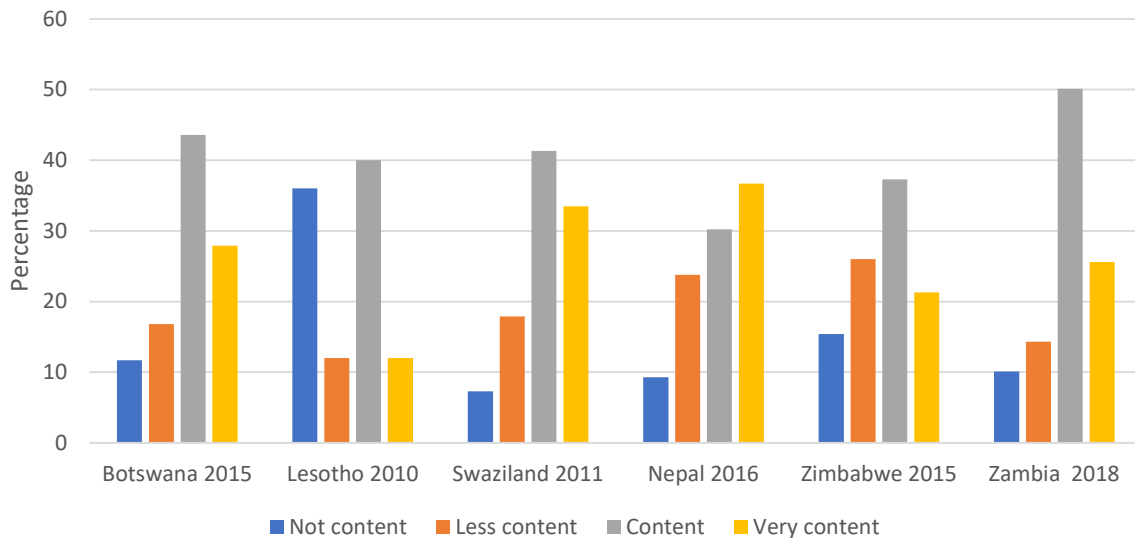
Country	Year of the study	Self / family	Government	NGO	Other	Not maintained ¹
Namibia	2003	44.6	35.3	0.4	2.1	17.5
Zimbabwe	2003	57.2	13.9	4.2	5.8	19.0
Zimbabwe	2015	58.2	8.1	1.7	4.3	27.7
Malawi	2004	38.6	6.5	5.8	10.8	38.3
Malawi	2018	53.4	8.4	2.6	3.8	31.8
Zambia	2006	65.2	0.3	4.6	5.2	21.9
Zambia	2018	67.5	4.5	0.0	6.8	23.0
Eswatini	2011	52.6	5.1	4.1	3.7	32.3
Lesotho	2010	52.0	12.0	4.0	4.0	28.0
Botswana	2015	28.4	23.1	1.9	3.9	42.6
Nepal	2016	51.8	1.2	2.7	2.3	17.9

Note: *Includes a small number of don't know responses.

In six of the studies, respondents were asked to rate their level of satisfaction with the assistive device. In five of the countries, the rank order of the different answer categories is

similar. I.e., most respondents stated that they are content, followed by very content, then less content and fewest say that they are not content. The proportion of respondents reporting that they are either content or very content ranges from 58.6% (Zimbabwe 2017) to 75.7% (Zambia 2018), and the proportion reporting either less content or not content ranges from 24.7% (Zambia 2018) to 41.4% (Zimbabwe 2017). Results for Lesotho deviates from the other countries with very high level of dissatisfaction. However, N for Lesotho was very low on this particular question, thus yielding more insecure statistics.

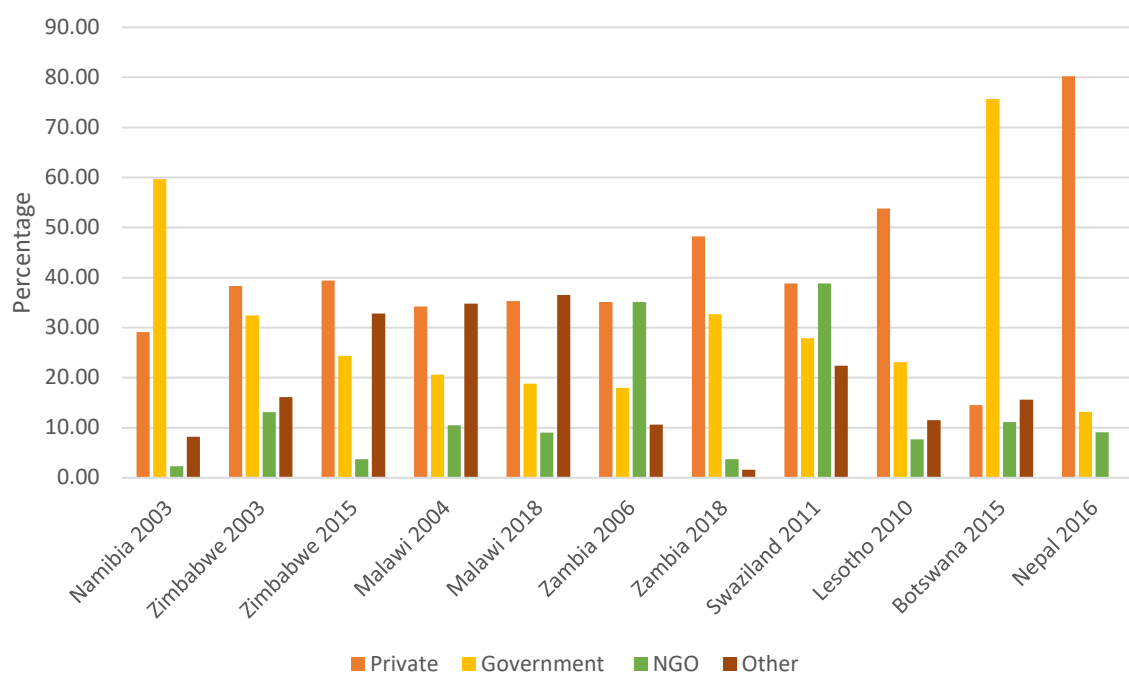
Figure 8. Satisfaction with assistive device



Acquisition

The studies also asked respondents from where/whom they had received the assistive device. Figure 9 reveals considerable variation between the different countries. Private acquisition (includes bought self, provided by family, other individual connections) dominates in particular in Nepal and Lesotho, is also quite high with nearly 50% in Zambia 2018 and generally an important source in most countries. Government (primarily Government health services but also other sectors) is the main source in Botswana and Namibia to the extent that in Botswana private sources are the lowest among all countries. NGOs as source of assistive devices are particularly important in Eswatini and Zambia 2006 but is generally less important than Government and private sources. The studies do not indicate what the "other" category comprises but is assumed to reflect that the respondents not necessarily know through which channel their device was acquired.

Figure 9. Source of assistive devices



Discussion

The studies presented in this chapter are rather unique in providing a range of individual indicators on assistive technology in eight countries in southern Africa and Nepal. Bearing in mind the limitations mentioned above, the data from these studies allow for a description of the situation within each country and for comparison across the different countries. The main findings are as follows:

- Availability of assistive devices are strongly dominated by devices for personal mobility and for information (sensory)
- There are large needs-gaps across all the studies, varying from above 50 to around 25 percentage points
- Use of assistive devices are mostly between 10 % – 20 % of persons with disabilities and particularly low in some countries
- Urban dwellers more than rural, males more than females, and persons with formal education more than persons without formal education report to be using an assistive device
- Around half of the assistive device users report that they have not received complete information and guidance on how to use their device, while between one fourth and half have received no information and guidance on use whatsoever
- Most assistive devices are in good working condition – still, around 20 % – 25 % are not
- The large majority of assistive device users either maintain/repair their device themselves, with help from the family or not at all – in most countries public services are an option for very few

- The majority of assistive device users are content/very content with their device – still, around 25 % - 40 % are either not content or less content
- Source of assistive devices varies considerably between the countries and show that Government is the major source only in two countries.

Access to assistive devices is limited in the countries included in the study and the distribution varies with some key demographic factors (sex, urban/rural, SES/access to formal education) as expected. Some of the variation between countries may reflect the general socio-economic differences at country level including resource-input into services for persons with disabilities. However, some of the variation shown in the results section is also due to methodological differences as explained further up. The study nevertheless shows that the share of persons with disabilities who actually use an assistive device for the most part is low and consequently that many more could have benefitted if services and supply were able to meet the needs in these populations.

The pronounced variation in source of assistive devices indicates that much of the acquisition is left to the individuals and families, which is also confirmed by the high level of self- or no-maintenance. Governments are supplying devices to persons with disabilities, but the results indicate very low capacity and dependence on several other types of sources. It is likely that the source of assistive devices is somewhat blurred to many respondents for instance when donations from international NGOs or as a result of bilateral relations are channelled through government service structures. It may thus be that the level of Government involvement as shown in Figure 9 is overestimated. The results clearly demonstrate that variation in the supply chain between countries is a factor that needs to be counted in when addressing assistive device supply and services in LMICs.

Use of assistive devices is about much more than the supply itself – without a service system that can provide information and guidance, maintenance and repair, and ensure the quality of devices that are distributed, the impact of the devices may be negatively affected and even negative. The study results clearly indicate that the service system by and large is rudimentary and do not cater for the needs of persons with disabilities. The high proportion of assistive devices being in good working condition is of course a positive result, as is also the level of satisfaction with the devices. It is however likely that questions on level of satisfaction in particular tend to produce positive responses and further that many devices, such as for instance crutches and canes, are relatively simple and may not need much of either guidance or maintenance.

Conclusion

The findings presented in this chapter indicates large shortfalls and skewed supply of assistive devices, considerable quality problems, and that government structures do not take full responsibility for service delivery in this area. In order to fulfil the obligations of the governments according to the CRPD, it is necessary for the actors on this arena, including national service systems, national and international organisation to build on the outcomes

of the GREAT Summit 2017 (9-11) to develop comprehensive models of assistive device service delivery systems that are adapted to each country context but with the common aim of reaching everyone in need.

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Estimating assistive technology need through population-based surveys: An analysis of data from Cameroon and India

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Abstract

Background: Assistive technology (AT) is an umbrella term covering the systems and services related to the delivery of assistive products (AP). The World Health Organization estimates that there are at least 1 billion people in the world today in need of AT, and this figure is set to double by 2030. However, global population-level estimates for AT needs vary, are inconsistent and use different approaches (e.g. self-report, clinical assessment). There is a need for the development of a standard population-based survey methodology to generate reliable and comparable AT data in low-and middle-income countries (LMICs). This information is needed to support the development of national policies, planning, and services to increase the availability of, and access to, AT. **Methods:** We conducted a secondary analysis of data from district level population-based disability surveys in Cameroon and India to i) estimate the use, unmet need and coverage for three ATScale priority APs (distance glasses, hearing aids, wheelchairs), and ii) explore the relationship between the data on AP need captured through clinical assessment and through self-report to inform the development of AP survey methodology. **Results:** In total it was estimated that 6.5% and 1.9% of the population needed (defined as use plus unmet need) at least one of the three priority APs in India and Cameroon respectively based on impairments of moderate or worse severity. This estimated need increased in India to 9.3% if mild vision impairment was included. For each AP, the total need was highest for distance glasses in India at 3.7%, while notably lower in Cameroon 0.8%, and the total need for hearing aids was 3% and 1.2% of total population in India and Cameroon respectively. The prevalence of need increased significantly with age in older adults (60+years) for distance glasses (8.2% and 4.4%) and hearing aids (20.7% and 7.7%) in India and Cameroon respectively but not significantly by gender. The total need was lowest for wheelchairs in both settings (0.1%) and additional analyses were limited due to low numbers. Coverage for each AP was less than 40%, except 87% distance glasses (moderate visual impairment) in India. Amongst those who needed each AP according to clinical impairment assessment, there was low recognition of need through self-report for distance glasses (60% and 40% reported they did

not need distance glasses) and hearing aids (24% and 26% reported they did not need hearing aids) in India and Cameroon respectively. **Conclusions and recommendations:** There is a need to close the AT data gap by building up the evidence base. Further research is required to develop improved approaches and tools compatible with the international classification of functioning, disability and health that can estimate the all-age population-level AT need and be used systematically to enhance comparability between settings and over time to improve AT advocacy and planning.

Keywords

Assistive technology; data; surveys; population; need




Introduction

Background

The World Health Organization (WHO) has estimated that there are at least 1 billion people in the world in need of assistive technology (AT) and this figure is set to double by 2030 (1). AT is an umbrella term covering the *systems* and *services* related to the delivery of *assistive products* (AP). People who might benefit from AT include older people, people with disabilities, and people living with non-communicable diseases, communicable diseases, and chronic conditions (2). Access to AT can positively impact inclusion and participation in education, work, family and community life, and is a human right, well supported in United Nations' (UN) frameworks and Conventions such as the Sustainable Development Goals (SDGs) and the UN Convention on the Rights of Persons with Disabilities (CRPD) (1-6).

However, to date, there is very limited data on the need for AT globally (7, 8). Table 1 presents examples of population-level estimated need, unmet need and low coverage AP estimates in low-and middle-income countries (LMICs) in the domains of vision, hearing and mobility; however, these WHO estimates are based on extrapolations from sparse data and cannot be considered reliable. Measuring the population-level AT need, unmet need and coverage is critical for evidence-based advocacy and planning policies and services aimed at improving availability and access to AT for all people, including people with disabilities and older people.

Table 1. Examples of the estimated AP need and unmet need in vision, hearing and mobility domains (9)

Domain	Assistive product	Need	Unmet need
VISION	 Glasses	970 million people	Over 200 million people do not have access to spectacles or other low-vision devices.
HEARING	 Hearing aids	466 million people	Product productions meets only 10% of global need and 3% of the need in low-income countries.
MOBILITY	 Wheelchair	75 million people	Only 5–15% of the population has access to one.

Numerous disability and mainstream initiatives have supported improving access to AT over the past ten years. Notably, the WHO Global Cooperation on Assistive Technology (GATE) initiative aims to ensure that everyone, everywhere has access to affordable and high-quality Aps (9). More recently, in 2018, ATscale launched as a broad global cross-sector partnership aiming to reach 500 million people with AT by 2030 and is supported by AT2030 programme which aims to build the evidence base for AT (10, 11). ATscale selected the following five priority products to focus on: glasses, hearing aids, wheelchairs, prosthetics, and smart personal digital assistants (PDAs) and tablets with accessible software/applications.

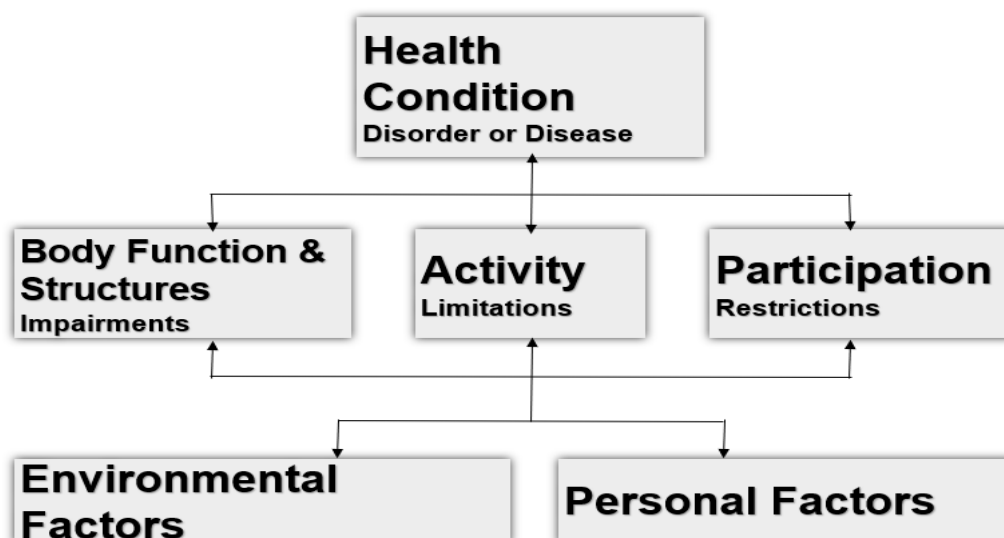
Population-level AT need and the ICF

AT assessment is complex. There are different approaches to measuring AT need in population-level surveys, and this partly depends on the way that impairments, functioning and AT are defined, conceptualised, screened and measured.

The International Classification of Functioning, Disability and Health (ICF) is the prevailing WHO framework for measuring health and disability at both individual and population levels (Figure 1) and provides clear definitions of impairments, functioning, activity, participation, and environmental and personal factors as highlighted in Box 1 (12, 13). For example, in this framework, a health condition (e.g. diabetes) may lead to an abnormality in body structure or function (i.e. impairment e.g. mobility), which can consequently cause activity limitations (e.g. difficulty walking) and participation restriction (e.g. exclusion from employment). This pathway will not be the same for all people but influenced by the presence of personal factors (e.g. education) and environmental factors (e.g. terrain).

AT is typically considered an ICF environmental factor. However, in order to determine the need for AT, information about each ICF element is critical given pathways are influenced by all of the ICF elements. This paper will use an ICF lens to review population-based measurement approaches to assess AT need.

Figure 1: International Classification of Functioning, Health and Disability



Box 1: International Classification of Functioning, Health and Disability (ICF) definitions

Definitions for the ICF terms that are used throughout this paper are provided below as defined in WHO and World Bank's *World Report on Disability*.

ICF term	Definition
Disability	An umbrella term for impairments, activity limitations, and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (13)
Functioning	An umbrella term in the ICF for body functions, body structures, activities, and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (13)
Impairment	Loss or abnormality in body structure or physiological function (including mental functions), where abnormality means significant variation from established statistical norms (13)
Activity	The execution of a task or action by an individual. It represents the individual perspective of functioning (13)
Participation	A person's involvement in a life situation, representing the societal perspective of functioning (13)
Environmental factors	A component of contextual factors within the ICF, referring to the physical, social, and attitudinal environment in which people live and conduct their lives – for example, products and technology, the natural environment, support and relationships, attitudes, and services, systems, and policies (13)
Personal factors	A component of contextual factors within the ICF that relate to the individual – for example, age, gender, social status, and life experiences (13)

Existing approaches to measuring population-based AT need

There are four main approaches for estimating AT need within population surveys: single question, self-report, clinical impairment assessment and indirect method. Table 2 presents these approaches describing the advantages and disadvantages of each of the tools and methods, and Box 2 provides specific examples of self-report and clinical impairment assessment approaches.

Table 2. Measuring population-based AT: description of four approaches with methodology advantages and disadvantages (14, 15)

Method	Description	Advantages	Disadvantages
Single question	Relies on a single question only, i.e. 'Do you think that services/APs, like hearing aids or walking sticks, would be helpful for you?'	Rapid. Beneficial if limited survey space.	Response is non-specific. Risk of underestimate due to poor awareness of AT. Risk of overestimate due to perceived benefits of responding positively.
Self-report	Relies on participants self-report of i) functional limitations and ii) associated need for AT amongst people who report functional difficulties. <i>Examples:</i> WHO Model Disability Survey (MDS) (16, 17) and WHO Assistive Technology Assessment (ATA)-need tool, now called rapid ATA or 'rATA' (18, 19). See Box 2 for details.	Simple and rapid. Fewer cost and resources to administer. Doesn't require clinical expertise or equipment. Based on participants' reported need in their own environment. Gathers information on participants' experience and impact.	Risk of underestimate due to low awareness of APs (e.g. hearing frequency modulation system). Risk of overestimate due to poor awareness of underlying cause (e.g. people reporting functional limitations with vision due to cataracts which can be treated by a simple operation) (20, 21). Limited reliability for use planning services and interventions.
Clinical impairment assessment	Relies on standardised population-based methods for examining for presence of impairment and clinician's assessment of certain AT needs based on impairment measurement findings for type, cause and severity. <i>Example:</i> Rapid Assessment of Avoidable Blindness (RAAB) (22, 23). See Box 2 for details.	Impairment type, severity and causality assessed (e.g. assessing the need for cataract surgery or wax impaction for hearing). Reliable impairment estimates.	Costly. Time and resource intensive, often requiring presence of clinician. Only focuses on one ICF component, providing a more limited medical view of disability. Lacks broader functioning assessment with consideration of personal or environmental factors.
Indirect source, i.e. prevalence or incidence of related pathologies or conditions	Relies on using data from the prevalence or incidence of related pathologies or conditions that were most strongly correlated with use of AP (e.g. lower limb amputations) and/or international AT data. <i>Example:</i> Tajikistan AT study led by WHO regional office (18).	Timely using data available. Some conditions or pathologies strongly associated with specific APs (e.g. presbyopia and the need for reading glasses).	Impractical for some APs to base estimates on correlations with pathologies or medical conditions.

Box 2: Examples of self-report and clinical impairment assessment approaches to measuring population-based AT need

Self-report approaches

The WHO Model Disability Survey (MDS) aims to collect globally comprehensive and comparable disability data by asking people what they do, or do not do, in their daily lives focusing on functioning in multiple domains well-aligned with the ICF (16).

Alongside functioning questions, the MDS asks a series of questions regarding domain-specific and participation-specific AT use, need and barriers through self-reported questions using show cards as AT picture prompts (see Figure 2) (17).

WHO GATE has also developed a series of population-level AT-specific tools, the Assistive Technology Assessment (ATA) tools, which include an AT systems situational analysis survey (ATA-S) and a self-reported AT needs survey (ATA-N). The ATA-N measures AP need and unmet need using adapted WG Short Set as initial screening and AT images alongside each question (see Figure 2) (18,19). The ATA-N tool, now called rapid ATA or 'rATA,' is presently undergoing piloting (19).






Figure 2a. Model Disability Survey (MDS)





Figure 2b. GATE Assistive technology assessment needs (ATA-N) or rATA

7. Which of the following assistive products do you think you need that you do not already have?

These are products that help with seeing:

	Name of product	Image	Yes	No		Name of product	Image	Yes	No
1	Spectacles		<input type="radio"/>	<input type="radio"/>	4	White cane		<input type="radio"/>	<input type="radio"/>
2	Talking or touching watch		<input type="radio"/>	<input type="radio"/>	5	Braille equipment		<input type="radio"/>	<input type="radio"/>
3	Magnifier or telescope		<input type="radio"/>	<input type="radio"/>				<input type="radio"/>	<input type="radio"/>

These are products that help with hearing:

SN	Name of product	Image	Yes	No	SN	Name of product	Image	Yes	No
6	Alarm signaler with light or vibration		<input type="radio"/>	<input type="radio"/>	8	Personal sound amplifier		<input type="radio"/>	<input type="radio"/>
7	Hearing aid		<input type="radio"/>	<input type="radio"/>				<input type="radio"/>	<input type="radio"/>

These are products that help with moving from place to place:

SN	Name of product	Image	Yes	No	SN	Name of product	Image	Yes	No
9	Crutches, axillary or elbow		<input type="radio"/>	<input type="radio"/>	15	Portable ramp		<input type="radio"/>	<input type="radio"/>
10	Stick or cane		<input type="radio"/>	<input type="radio"/>	16	Grab bar		<input type="radio"/>	<input type="radio"/>
11	Walking frame or rollator		<input type="radio"/>	<input type="radio"/>	17	Therapeutic footwear		<input type="radio"/>	<input type="radio"/>
12	Orthosis or brace (for the foot, leg, hand, arm or spine)		<input type="radio"/>	<input type="radio"/>	18	Wheelchair		<input type="radio"/>	<input type="radio"/>
13	Prosthesis (artificial leg)		<input type="radio"/>	<input type="radio"/>				<input type="radio"/>	<input type="radio"/>

Box 2: Examples of self-report and clinical impairment assessment approaches to measuring population-based AT need (continued)

Clinical impairment assessment approaches

There are standardised population-based methods for examining for presence of impairment, such as visual acuity (VA) assessment for vision, pure tone audiometry assessment for hearing, comprehensive clinical examination assessment for mobility. Clinicians assess certain AT needs based on impairment measurement findings for type, cause and severity. The AT assessment might be simple, such as refractive error to determine need for glasses, or more complex, such as upper and lower limb assessments to determine walking device needs. Various tested impairment measurement tools exist and are now increasingly available on mobile applications making the assessment faster and not reliant on the presence of clinicians. For example, the Rapid Assessment of Avoidable Blindness (RAAB) is designed to objectively measure distance visual impairment (VI) and now integrates Peek acuity, which assesses VA by a non-specialist using a smartphone (22,23).

Objectives of this paper

Two population-based disability surveys conducted in one district each of Cameroon and India were completed in 2013-14 and investigated the relationship between self-reported functional limitations and objectively-screened clinical impairment (14, 15).

In this paper, we aim to conduct secondary analysis of district level disability surveys in India and Cameroon to:

1. Estimate the population need, use and unmet need for three of the five ATScale priority APs (distance glasses, hearing aids and wheelchairs) in each setting.
2. Explore the relationship between data on AP need that are captured through clinical impairment assessment and self-report.

Based upon our findings, we provide recommendations for improved survey methodology to generate much-needed data on population-based AT need.

Methods

Data collection, screening and clinical impairment assessment

The detailed methodology for these surveys has been published elsewhere (14, 15, 24-29).

Sampling

Approximately 4,000 people were selected using two stage cluster-sampling. Firstly, 51 clusters were selected from population-based sampling frames using probability proportionate to size sampling. Secondly, households within clusters were selected using compact segment sampling, whereby each cluster was divided into equal segments of approximately 80 people. One segment was chosen at random and all selected households

were enumerated and invited to attend a central place over the next two days. Any eligible participants who did not attend were visited in their homes by the survey team.

Self-reported functional limitations

All participants were screened for self-reported functional limitations using the Washington Group (WG) extended set (ES) of questions for ages >17 years, and the Child Functioning Module (CFM) for ages 2-17 (30-34).

Clinical impairment assessment

- All participants also underwent clinical assessment for vision, hearing and musculoskeletal impairment. Anyone identified as having vision, hearing or musculoskeletal impairment were examined by relevant clinicians to determine cause and associated referral/AT needs, which included determining use and need for three of the five ATScale priority APs: distance glasses, hearing aids and wheelchairs. This clinical assessment process is summarised for each impairment below:
- Visual acuity (VA) was assessed using a tumbling E-chart. Pinhole vision was assessed for people with vision impairment (VI) to identify uncorrected refractive error (URE) and therefore need for distance glasses. In India, VI was defined as those with VA<6/12 ('mild' VI) in either eye, while in Cameroon, it was defined as VA<6/18 ('moderate' VI) in either eye. Participants with vision loss not due to URE underwent examination with an ophthalmoscope by an ophthalmologist/ophthalmic nurse to determine the cause.
- For hearing, all participants were screened using Otoacoustic Emissions Testing. Participants ages ≥ 4 years old who failed this underwent Pure Tone Audiometry at 0.5, 1, 2, and 4 kHz to assess for presence and severity of hearing loss (HL). Participants with disabling HL (using WHO's definition of disabling hearing impairment (HI) >31dB HL for children 4 to 17 years of age and >41dB HL for adults ≥ 18 years of age) in the better ear underwent examination by ENT specialist using an otoscope to assess cause and service/intervention needs, including hearing aids.
- For musculoskeletal impairment (MSI), participants were asked six validated screening questions from the Rapid Assessment of MSI (RAM) (35). Anyone who screened positive underwent a standardized examination by a physiotherapist using the RAM to assess presence, cause, diagnosis and need for services and APs, including wheelchairs.

Self-reported AT need

For the purposes of this study, people who were identified as having a moderate or worse impairment and/or reported "a lot of difficulty" or more with core domains of the WG questions were defined as having a disability. They were interviewed about their self-reported need for and use of different APs including glasses and hearing aids.

Data entry and analysis

Data were analysed using STATA 15.0. The 'svy' command was used to derive proportion estimates accounting for cluster sampling, and descriptive and bivariate analyses were used. For each AP (distance glasses, hearing aid and wheelchair) we calculated:

- Use: the proportion of the study population who were using the AP.
- Unmet need: the proportion identified as needing, but not using, AP.
- Total need: the proportion identified as using or needing the AP.
- Coverage: the proportion of people who actually use the AP by the total number of people who need the AP, calculated as 'use' divided by 'total need'.

Estimates of 'total need' for distance glasses and hearing aids were also stratified by age and sex, but this was not possible for wheelchairs because of the low numbers.

To explore the relationship between self-report and clinical impairment assessment for estimating AP need we calculated:

1. The proportion of people identified as needing an AP through clinical impairment assessment (e.g. distance glasses) who reported 'no difficulty' with functioning using the WG questions in the corresponding domain (e.g. vision). This was to assess how many people who could benefit from an AP would be captured through using self-report of functional difficulty alone (i.e. no clinical assessment).
2. The proportion of people identified as needing distance glasses or hearing aids through clinical impairment assessment who also self-reported a need for the corresponding AP.
3. Among people who self-reported needing distance glasses, the distribution of the causes of vision loss identified through clinical impairment assessment.

Findings

Estimated population AP need, unmet need and coverage in India and Cameroon

Table 3 shows estimated use, unmet need, total need and coverage of each AP using data from disability surveys in India and Cameroon according to clinical impairment assessment. All estimates are based on AT need for people with moderate or worse vision, hearing and musculoskeletal impairments, according to the survey methodology. The exception is in India, where need for distance glasses for people with mild or worse VI was also assessed.

Distance glasses

A total of 114 people in India [3.2% (95% CI 2.4-4.2)] were identified as using distance glasses. This figure was considerably lower in Cameroon where only 10 people wore distance glasses [0.3% (95% CI 0.2-0.5)]. The prevalence of unmet need based on moderate vision impairment was similar in each country, with 0.5% (n=17) of the population in each setting identified as having URE [India 0.5% (95% CI 0.3-1.0); Cameroon 0.5% (95% CI 0.3-0.8)]. Unmet need for people with mild vision loss or worse in India was 4.1% (95% CI 3.2-5.1). Based on vision loss of moderate or worse, coverage with glasses was relatively high in

India (87%) but was only 37% in Cameroon. Coverage for glasses, including people with mild vision loss in India, was 44%.

Hearing aids

Hearing aid use was low across both countries, with only 5 people in India [0.1% (95% CI 0.1-0.3)] and 3 in Cameroon [0.1% (95% CI 0.03-0.3)] reported using hearing aids. In India, a total of 107 people were identified as having an unmet need for hearing aids [3.0% (95% CI 2.2-4.0)] which was higher than in Cameroon [n=40, 1.12% (95% CI 0.8-1.5)]. Coverage was low in both settings: 4% in India and 7% in Cameroon.

Wheelchairs

The overall numbers for wheelchair use and need were low. Only one participant in India and none in Cameroon used a wheelchair. Two participants in India [0.1% (95% CI 0.01-0.2)] and four participants in Cameroon [0.1% (95% CI 0.04-0.3)] were identified as needing a wheelchair. Coverage was therefore 33% in India and 19% in Cameroon.

Need across the three APs

Combining the three APs; a total of 119 people [3.3% (95% CI 2.5- 4.3)] were identified as using at least one device in India and 13 [0.4% (95% CI 0.2-0.6)] in Cameroon. Restricting to VA<6/18, the number of people with unmet need for at least one device was 124 [3.5% (95% CI 2.7-4.5)] in India and 57 [1.6% (95% CI 1.2-2.1)] in Cameroon. If we include unmet need for glasses at VA<6/12 in India, this increases to 224 [6.3% (95% CI 5.1-7.7)]. Overall coverage of at least one AP was low: 51% in India, decreasing to 36% if VA<6/12, and 19% in Cameroon.

Total need for distance glasses and hearing aids by age and gender

As shown in Table 4 prevalence of need for distance glasses and hearing aids increased significantly with age ($p<0.001$). Among adults over 60 years, an estimated 8.2% and 4.4% needed glasses and 20.7% and 7.7% needed hearing aids in India and Cameroon respectively. There were no significant differences in estimates for men and women in either setting.

Table 3. Three ATScale assistive product use, unmet need, total need and coverage estimates in India and Cameroon

Assistive Products	India				Cameroon			
	Uses N [% (95% ci)]	Unmet need N [% (95% ci)]	Total need N [% (95% ci)]	Coverage (uses/Total need) %	Uses N % (95% ci)	Unmet need N % (95% ci)	Total need N % (95% ci)	Coverage (uses/Total need) %
Glasses <6/12 (mild VI)	114* [3.2 (2.4-4.2)]	145** [4.1 (3.2-5.1)]	259 [7.2 (6.2-8.5)]	44%				
Glasses <6/18 (moderate VI)	114* [3.2 (2.4-4.2)]	17** [0.5 (0.3-1.0)]	131 [3.7 (2.8-4.7)]	87%	10* [0.3 (0.2-0.5)]	17** [0.5 (0.3-0.8)]	27 [0.8 (0.5-1.1)]	37%
Hearing aids	5 [0.1 (0.1-0.3)]	107 [3.0 (2.2-4)]	112 [3.1 (2.4-4.1)]	4%	3 [0.1 (0.03-0.3)]	40 [1.1 (0.8-1.5)]	43 [1.2 (.9-1.6)]	7%
Wheelchairs	1 [0.03 (0.004-0.2)]	2 [0.1 (0.01-0.2)]	3 [0.1 (0.03-0.3)]	33%	0 [0]	4 [0.1 (0.04-0.3)]	4 [0.1 (0.04-0.3)]	0%
TOTAL 3 APs (moderate VI)	119 [3.3 (2.5-4.3)]	124 [3.5 (2.7-4.5)]	234 [6.5 (5.4-7.9)]	51%	13 [0.4 (0.2-0.6)]	57 [1.6 (1.2-2.1)]	69 [1.9 (1.5-2.4)]	19%
TOTAL 3 APs (mild VI)	119 [3.3 (2.5-4.3)]	224 [6.3 (5.1-7.7)]	334 [9.3 (8.0-10.9)]	36%				

Abbreviations: VI=vision impairment, CI=confidence interval; * Reports wearing glasses (and no refractive error); ** Uncorrected refractive error is case definition for the unmet need for glasses.

Table 4. Distance glasses <6/18 (moderate VI) and hearing aids total need stratification by age and gender in India and Cameroon

Stratification Categories	Distance Glasses		Hearing Aids	
	India N % (95% ci)	Cameroon N % (95% ci)	India N % (95% ci)	Cameroon N % (95% ci)
TOTAL	131 3.7 (2.8-4.7)	27 0.8 (0.5-1.1)	112* 3.1 (2.4-4.1)	43 1.2 (0.9-1.6)
Gender				
Male	44 2.6 (1.8-3.7)	13 0.9 (0.5-1.5)	47 2.8 (2.0-3.8)	22 1.4 (0.9-2.1)
Female	87 4.7 (3.5-6.2)	14 0.7 (0.4-1.1)	60 3.2 (2.4-4.3)	21 1.0 (0.6-1.5)
P-value	<0.01	0.4	0.3	0.2
Age groups				
0 to 17 years	12 1.0 (0.4-2.2)	2 0.1 (0.03-0.4)	2 0.2 (.04-0.7)	2 0.1 (0.02-0.4)
18 to <60 years	90 4.5 (3.4-5.6)	6 0.5 (0.2-1.1)	32 1.6 (1.0-2.6)	8 0.6 (0.3-1.3)
60+ years	29 8.2 (5.7-11.7)	19 4.4 (2.8-6.8)	73 20.7 (15.9-26.6)	33 7.7 (5.5-10.7)
P-value	<0.001	<0.001	<0.001	<0.001

Abbreviations: VI=vision impairment, CI=confidence interval. *5 are missing data.

Relationship between AP need data captured through self-report and clinical impairment assessment

The findings on the relationship between clinical impairment assessment need for distance glasses, hearing aid and wheelchairs and self-reported functional difficulty in corresponding domains are shown in Table 5.

Comparing WG reported difficulties and clinical impairment assessment

Out of the 17 people identified as having moderate URE (VA<6/18) in both settings, 4 (24%) in India and 7 (41%) in Cameroon self-reported having 'no difficulty' with seeing. In India, out of the 145 people identified as having mild URE (VA<6/12), 35 (24%) did not report any difficulty.

In India, out of the 107 people identified as needing a hearing aid, 21 (20%) self-reported having 'no difficulty' with hearing. In Cameroon, out of the 40 people identified as needing a hearing aid, 12 (30%) of those identified as needing a hearing aid reported having 'no difficulty' with hearing.

In India, out of the 2 people identified as needing a wheelchair, 1 (50%) reported 'no difficulty' with mobility and 1 (50%) reported WG 'a lot of difficulty' or worse. In Cameroon, out of the 4 people identified as needing a wheelchair, 4 (100%) reported 'no difficulty' with mobility.

For all categories, if the screening used WG 'a lot of difficulty' or worse category then the vast majority of those needing an AP would be missed.

Table 5. Comparing Washington Group reported responses with clinical impairment measurement of assistive product need for distance glasses, hearing aids and wheelchairs for both India and Cameroon

Clinical impairment measurement of AP need	Washington group reported responses			
	Report no difficulty	Report some difficulty or worse	Report a lot of difficulty or worse	Missed if only used WG (a lot+)
India				
Need glasses - <6/18 (n=17)	4 (24%)	13 (76%)	5 (29%)	12 (71%)
Need glasses - <6/12 (n=145)	35 (24%)	110 (76%)	7 (5%)	138 (95%)
Need hearing aids (n=107)	21 (20%)	86 (80%)	55 (51%)	52 (49%)
Need wheelchair (n=2)	1 (50%)	1 (50%)	1 (50%)	1 (50%)
Cameroon				
Need glasses – <6/18 (n=17)	7 (41%)	10 (59%)	5 (29%)	12 (71%)
Need hearing aids (n=40)	12 (30%)	28 (70%)	8 (20%)	32 (80%)
Need wheelchair (n=4)	0 (0%)	4 (100%)	0 (0%)	4 (100%)

Self-reported need for distance glasses among people with URE (VA<6/18)

In India, of the 10 people with URE and who had data on reported AP need, 6 (60%) reported not needing distance glasses (see Figure 3A1). In Cameroon, of the 15 people with URE, 3 (20%) use glasses, 6 (40%) reported needing distance glasses and 6 (40%) reported not needing distance glasses (see Figure 3A2).

All people identified as having a disability in the study were asked about self-reported need for glasses. In India, of the 60 people who reported needing distance glasses, 25% actually needed distance glasses based on clinical impairment assessment, while 47% needed cataract surgery and 28% didn't have a VI (see Figure 3B1). In Cameroon, of the 69 people who self-reported needing distance glasses, 9% actually needed distance glasses based on clinical assessment, 20% needed cataract surgery, 20% had other eye conditions (e.g. posterior segment disease) and 51% didn't have VI. (see Figure 3B2).

Self-reported need for hearing aids among people who were clinically assessed

In India, of the 102 people who were clinically assessed to need hearing aids and who had data on reported AP need, 4 (4%) use one, 62 (61%) reported needing one, 26 (26%) reported not needing one and 10 (10%) reported not knowing what it was (see Figure 4A1). In Cameroon, of the 38 people who were clinically assessed to need hearing aids and who had data on reported AP need, 18 (47%) reported needing one, 9 (24%) reported not needing one and 11 (29%) reported not knowing what it was (see Figure 4A2).

All people identified as having a disability in the study were asked about self-reported need for hearing aid. In India, of the 90 people who self-reported needing hearing aids, 69% actually needed hearing aids based on clinical assessment and 31% did not (see Figure 4B1). In Cameroon, of the 54 people who self-reported needing hearing aids, 33% actually needed hearing aids based on clinical assessment and 66% did not (see Figure 4B2).

Figure 3.A.1. Cases (moderate vision impairment) who need distance glasses (n=10) in India

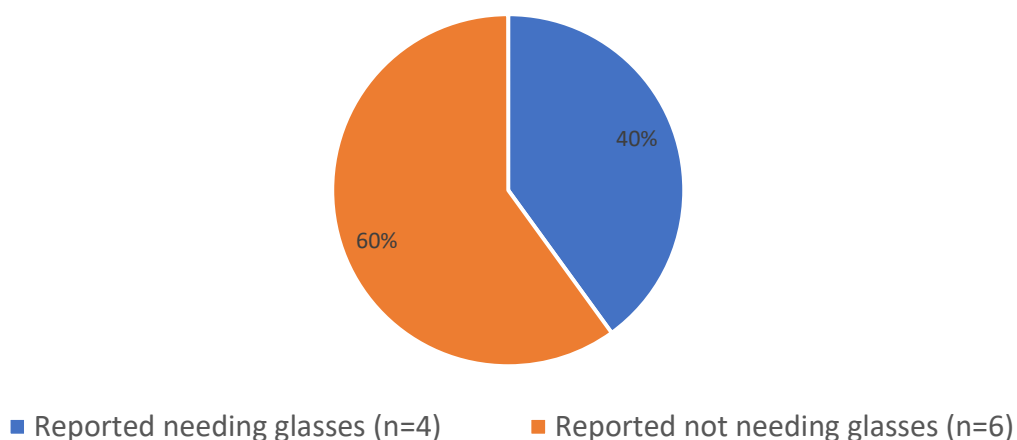


Figure 3.A.2. Cases (moderate vision impairment) who need distance glasses (n=15) in Cameroon

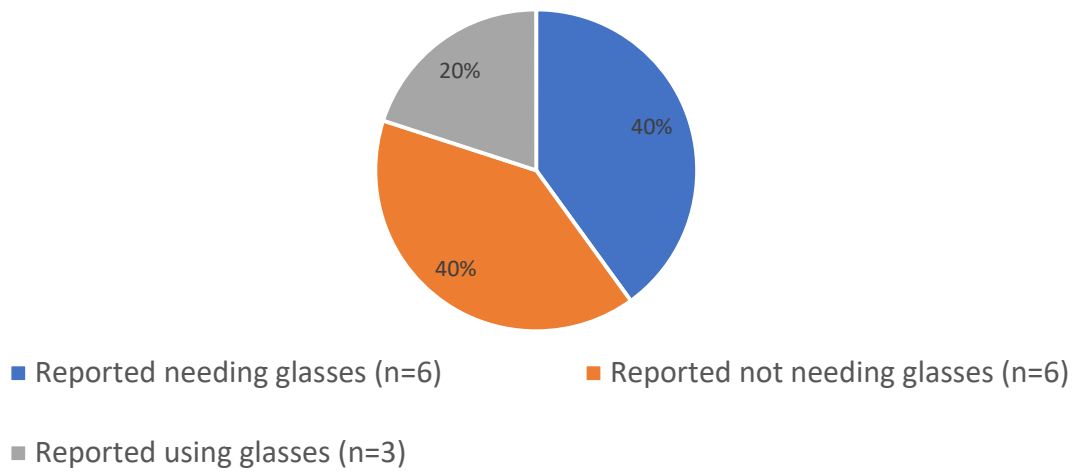


Figure 3.B.1 Cases (moderate vision impairment) who reported needing distance glasses (n=60) in India

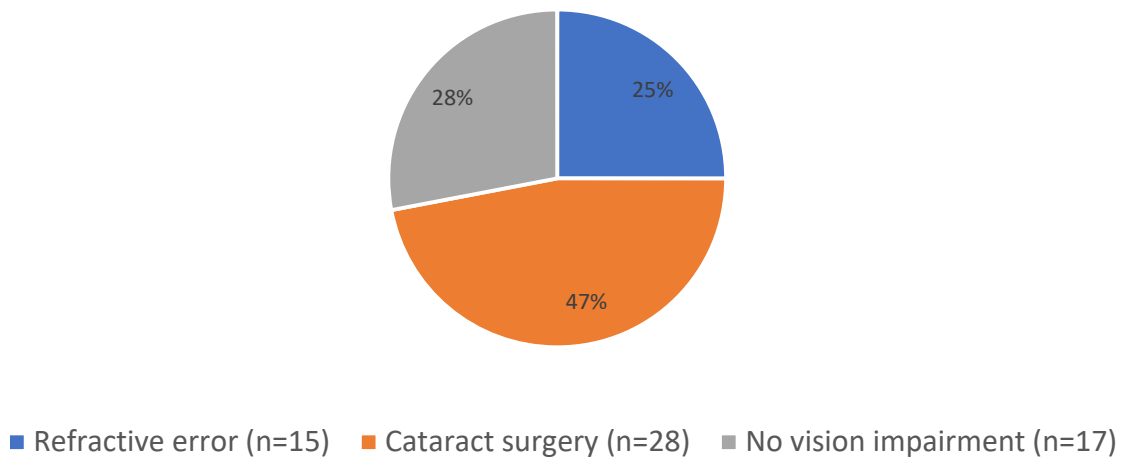


Figure 3.B.2. Cases (moderate vision impairment) who reported needing distance glasses (n=69) in Cameroon

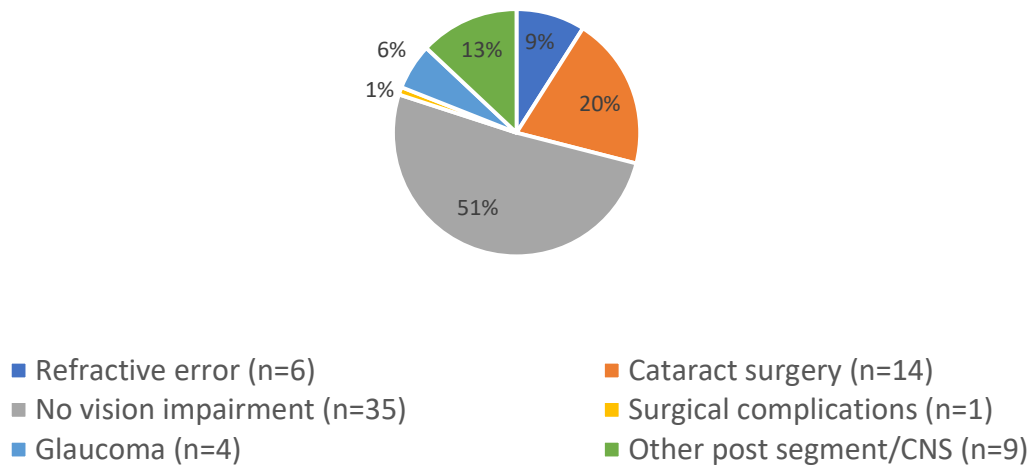


Figure 4.A.1. Cases with hearing impairment who need hearing aids (n=102) in India

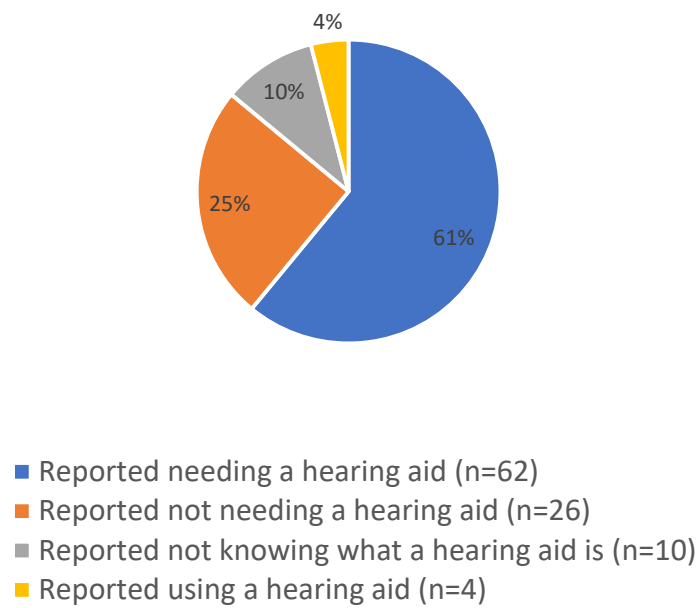


Figure 4.A.2. Cases with hearing impairment who need hearing aids (n=38) in Cameroon

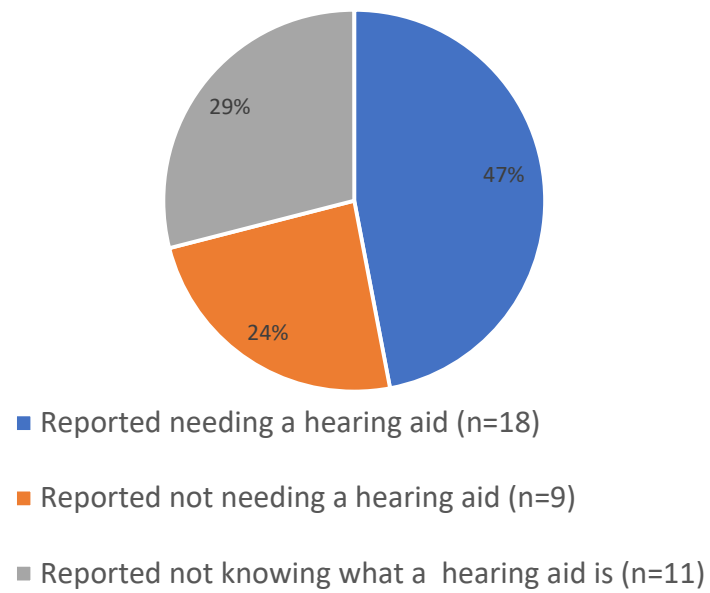


Figure 4.B.1. Cases who reported needing a hearing aid (n=90) in India

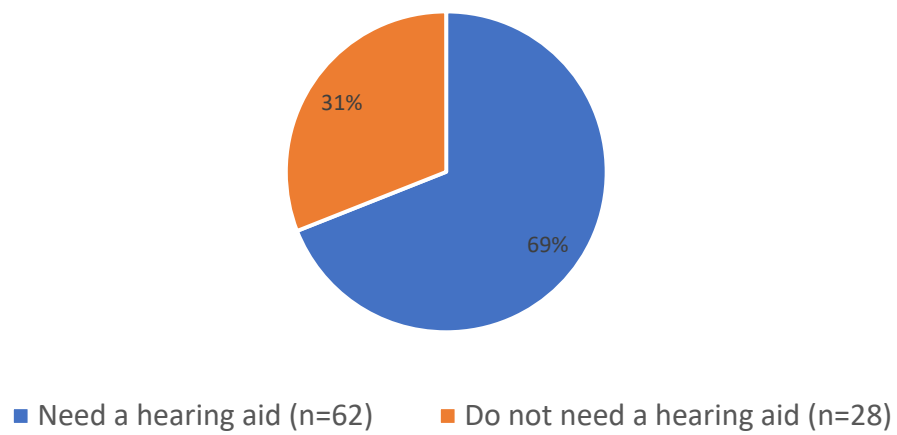
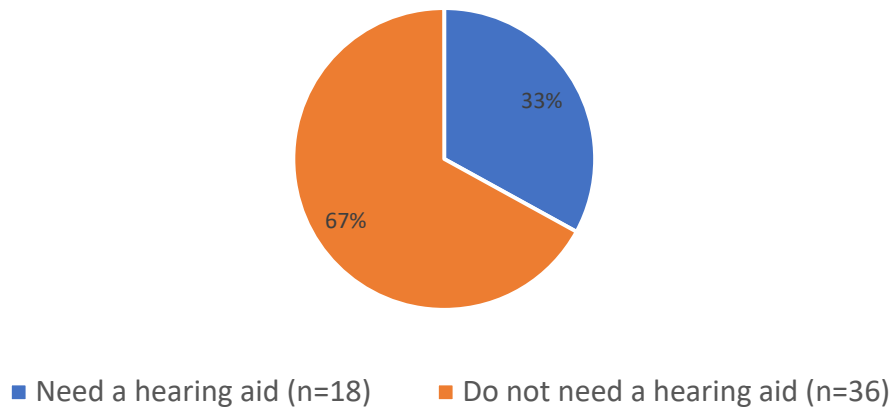


Figure 4.B.2. Cases who reported needing a hearing aid (n=54) in Cameroon



Discussion

Estimated population AP need, unmet need and coverage in India and Cameroon

This paper provides population-based estimates of total AP need for distance glasses, hearing aids and wheelchairs in two settings based upon clinical impairment assessment. In total it was estimated that 6.5% and 1.9% of the population needed (defined as use plus unmet need) at least one of the three priority APs in India and Cameroon respectively based on impairments of moderate or worse severity and clinician assessed need for AT. This prevalence increased in India to 9.3% if mild VI was included.

The total need was highest for distance glasses and hearing aids and much lower for wheelchairs. Need increased rapidly with age but did not differ between males and females.

The total need was low for wheelchairs at in both settings (0.1%). It will be important to ensure the sample size is powered to gain better wheelchair and other broader mobility AP estimates of need. Additionally, this highlights the complexity of mobility impairment assessment, which is less standardised compared to hearing and vision, and that this needs to be further developed. For example, It is noted that the study district in Cameroon was rural and hilly with uneven terrain so other mobility devices, rather than wheelchairs, might have been more appropriate (26). Therefore, the environment and availability of services might influence clinicians' perceived need of wheelchairs and other AP.

The relatively low AP coverage confirms previous assertions that many people in need of AP in LMICs do not have access to them. Fewer than 40% of people who needed distance glasses, hearing aids or wheelchairs for moderate or worse impairments actually used them. The exception was distance glasses in India where coverage was high (87%).

There are limited studies for comparison further emphasising the AT data gap. Many population-based clinical impairment studies provide estimates of impairment type, cause and severity but not specific AP need (36). Further, studies that typically provide AP need estimates are either individual-level studies or solely use self-reported AP methodology. For

example, an adapted version of rATA was used in a study in two districts Bangladesh where an estimated 7.1% of the studied population reported any AP use and, of all people with any functional difficulty, 71% self-reported an unmet need for AP (19).

As well as providing population estimates and highlighting low coverage, this analysis also identified methodological limitations. Firstly, the WHO APL included 50 priority APs, but this study only captured data on three of these (2). Considering this, population-based need including additional APs in broader categories across multiple functional domains will be higher. Further work is needed to identify what APs should be included in population surveys and the best methods to assess them. For example, in the vision APL domain alone, the APL includes three additional glasses categories in addition to long-distance glasses- low vision glasses, short-distance glasses and filters and protection glasses- as well as eight¹ other APs for VI (2). Secondly, AP need was estimated only for people with moderate or worse impairments (with the exception of vision for India) and based on bilateral (not unilateral) vision and hearing loss which may result in underestimates of need. This was illustrated through the India data by comparing unmet need for the two vision clinical assessment categories – 4.1% for mild VI (VA <6/12) and 0.5% for moderate VI (VA <6/18). Given that people with mild vision, hearing and mobility and other domain impairments *may* also benefit from APs, further research is recommended to determine the cut-off impairment levels for determining AP need, and this finding further indicates that it is important to recognise that people who might benefit from AP includes, but is not limited to, people with disabilities (14).

Comparison of AP measurement approaches

Through the analysis of two approaches for measuring AP need, unmet need, total need and coverage, this paper identified both benefits and challenges of using reported need and clinical impairment assessment approaches, as well as the use of the WG questions as screening questions alongside this approach.

Reported AP approach

Collecting data through self-report has several advantages, such as rapidity, less cost and resources and based on person's functioning in own environment. However, our findings suggest self-report is an inaccurate measure of AP need. For example, among people self-reporting need for distance glasses in India, nearly half (47%) actually needed cataract surgery and just over a quarter (28%) did not have a VI. Similarly, in Cameroon, of those reporting needing glasses, 20% needed cataract surgery, 20% had other conditions not benefitting from glasses (e.g. posterior segment disease) and just over half (51%) did not have a VI. Further, of those who reported needing a hearing aid, 31% of participants in India

¹ Vision APL domain includes the following APs: Audioplayers with DAISY capability; Braille displays (note takers); 3. Braille writing equipment/brailers; Magnifiers, digital hand-held; Magnifiers, optical; Screen readers; Spectacles; low vision, short distance, long distance, filters and protection; Watches talking/touching; White canes

and 67% of participants in Cameroon did not need one. In Cameroon, as noted by Ferrite et al, some participants' self-reported needing a hearing aid due to wax impaction which does not require one (29). This data suggests that self-report alone could result in significant overestimates of AP need.

At the same time, self-reported AP may under-estimate the numbers of people who could potentially benefit from an AP due to low awareness of having an impairment and/or of APs available. For example, of those identified as needing distance glasses for moderate VI ($VA < 6/18$), 60% in India and 40% in Cameroon reported not needing glasses, which could be reflective of environmental factors. Low awareness was also an issue, particularly in Cameroon, where 29% reported being unaware of what a hearing aid is. Awareness is likely to be even lower for other less common devices (e.g. Hearing loops/Frequency Modulated systems) that are included in the WHO 50 priority APL.

Clinical impairment assessment approach

In this study, the clinical impairment assessment approach was used as the 'gold standard' method of assessment for AP against which self-reported AP need was compared. However, it is important to note that the clinical impairment measurement approach also has limitations.

There is a need for surveys to use a standardised approach to clinical reasoning (e.g. unilateral versus bilateral impairments and assessment of each AP). Future research therefore could explore definitions used and ensure capturing clinicians' clinical reasoning, such as through clinical decision analysis using decision trees (37).

Moreover, clinical impairment measurement approach is essentially based only on the presence of 'impairment' and doesn't consider participants' activities, participation and personal and environmental factors. People with the same impairment may not have the same AT need. Therefore, understanding participants' activities, participation and personal and environmental factors is also important for identifying their AT need, which was highlighted by qualitative research completed alongside the these two surveys (38).

Comprehensive clinical functional assessments can be completed to provide holistic picture of individuals' abilities and daily living skills. This approach usually includes physical, cognition, mood, and carer related matters (12, 39). Functional assessment can use a variety of approaches, including indirect, observational, and experimental/functional analysis procedures, and is frequently used by rehabilitation professionals, such as occupational therapists, physiotherapists and speech therapists, to assess participants' functioning and to determine treatment plans, follow up services and AT need (39, 40). However, existing functional assessments primarily measure individual-level functioning, and few exist for population-level measurement. Of the population-based assessments, most only measure disability and do not assess AT need. For example, the WHO Disability Assessment Schedule 2.0 (WHODAS 2) is a general reported measure of functioning and disability to determine severity of difficulty covering six life domains (cognition, mobility, self-care, getting along,

life activities and participation), but it does not assess related AT need (41). The WHO MDS asks functioning questions across multiple domains at population-level alongside AP need; however, this functional assessment only uses a self-reported approach which has limitations as highlighted in this paper (16).

There is therefore a gap in multi-domain clinical functional assessment methodology for use in population-based surveys. This should be a focus of future research to develop standardised clinical reasoning approaches incorporating the broad ICF framework to determine service and AP need, as well as testing the validity and assessing the feasibility of this approach within the context of population-based surveys (38).

Use of WG questions

The findings suggest that the use of the WG questions to screen for reported functional difficulties must be examined when the aim is to determine AP need. Firstly, given the aim of using the WG questions for AT surveys is to screen for the presence of functional difficulties *without* the use of APs, future research should consider asking participants about reported functional difficulties *without* APs for those that use them (28). Additionally, though our findings are congruent with *Mactaggart et al's* recommendation to use a WG cut-off of 'some difficulty' as first stage screening followed by clinical impairment assessment (14), our analysis also suggests that up to 50 % of people needing at least one APs would have been missed through use of this screening cut-off. This therefore needs further consideration in the development of methodology to assess AT need. Finally, in the two surveys, the WG questions only asked about wearing glasses and using mobility devices in general. Future research may consider modifying these questions to ask about specific types of APs.

Further gaps in the AP measurement approaches

Analyses of the data highlighted additional data collection gaps that could be improved for future AP measurement approaches. All-age AP estimates were low especially in the younger children population in the India and Cameroon data using both AP measurement approaches, and it is noted that the WG CFM is only for children aged 2-17 (31). Early identification, especially for children ages 0-3, is critical for ensuring appropriate referral and access to related services and APs so measurement tools for younger age groups could be reviewed. Additionally, clearer AP definitions alongside use of visual aids could be provided to ensure measurement is more consistent and accurate within and across settings and in line with WHO guidelines and training packages (2, 42, 43). Finally, though this paper analysed available data for three APs, APs must be accompanied by appropriate services, such as rehabilitation, so it is recommended that future research review reported and clinical assessment approaches for services as well.

Survey limitations and strengths

The analyses of AP need from the India and Cameroon population surveys had several strengths. The survey included all ages and was population-based. Clinical measurement of

impairment was conducted by trained interviewers using standardised procedures and measured by clinicians who determined cause of impairment. The inclusion of AP reported measures allowed us to make important comparisons between two different approaches for select APs.

However, limitations did exist. Firstly, the surveys were not initially designed or powered statistically to assess AP need and to compare AP measurement approaches. Though we were able to analyse the AP need for three select products using the two approaches, gaps existed as highlighted above and future research is required with improved survey tools. Secondly, aside from India's VA category, the study did not allow for in-county or cross-country AP need comparisons between severity categories in the three domains so this could be addressed in future research. More, when comparing the self-report and the clinical impairment assessment specifically for vision, participants might have been reporting difficulty with near vision, contrast sensitivity or other low vision impairments which were not assessed by VA assessment only. Further work is required to determine if additional clinical vision assessments specific for additional referral services and AP need would be beneficial to include.

Challenges and opportunities for measurement of AP need

There are many challenges to measuring population-level AT need, unmet need, total need and coverage given variability in AT scope, definitions, and measurement approaches as highlighted above. However, there are also opportunities to improve this measurement and develop tools to better estimate this gap. It is recommended that future research investigate clinical impairment assessment cut-off levels for determining AT need and explore using an all-age two-stage screening process utilising reported functional limitations and AT use, then clinical impairment assessment, and then followed by clinical functional assessment to gather essential data in the other ICF domains about participants' activities, participation and personal and environmental contexts to ultimately determine service and AP need. This assimilation of data would need to capture this clinical reasoning, perhaps through use of decision trees following an algorithm.

Conclusions and recommendations

There is a need to close the AT data gap by building up the evidence base. This requires the development of tools compatible with the ICF that can estimate the all-age population-level AT need, unmet need and coverage and be used systematically to enhance comparability between settings and over time.

As part of AT2030 under the ATScale mandate and working closely with WHO and Global Disability Innovation Hub, London School of Hygiene & Tropical Medicine will develop all-age methodology building upon previous study approaches and recommendations by combining a hybrid model of self-report and clinical impairment and functional assessment to estimate AT needs for functional impairments across six domains – vision, hearing, mobility, communication, cognition and self-care. The review of different survey

approaches, and this secondary data analysis is important for informing the development of this survey tool.

It is anticipated that the development of survey tools in the SDG era to assess AP need, unmet need and coverage will play a key role in data collection and data monitoring progress towards 2030. Further, this data on estimated AP in two countries allows for evidence-based policy making and planning of appropriate services, including human resources and procurement, as well as provide a baseline upon which to test the effectiveness of intervention elements of AT2030. Increased availability of AP need data will assist in monitoring the SDGs, global access to AP, and allow for evidence-based policy making and planning of appropriate services, including human resources and procurement.

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A rapid needs analysis for North East Syria: Key findings on age, disability and technology

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Abstract

The purpose of this study is to better understand the story of older people in crisis and ensure their voices are better listened to. The data collected and analysed from this Rapid Needs Analysis (RNA) is intended to inform humanitarian actors and wider audiences to design more inclusive responses at organisational, programme and technical levels and inform and guide advocacy at UN and national level. The RNA assessment was conducted in January 2019 by the Syrian Expatriate Medical Association and Al-Ameen, a Syrian emergency relief and rehabilitation organisation, with support from HelpAge International. A total of 614 older returnees, internally displaced people and people (344 women and 270 men) living in host communities in ten districts of Al-Hasekeh, Ar-Raqqa, and Deir-ez-Zor were contacted, using a purposive sampling approach. The data has created a picture of the complexity in older people's lives in north west Syria during this 7-year protracted crisis. The data moves away from looking at numbers of older people to recognising their levels of dependency and isolation, their levels of difficulty in accessing services focusing on their health conditions related to non-communicable diseases and their level and number of disabilities and their use of and access to assistive products in this setting. Half of older people surveyed have some type of impairment. Twice as many older women as men report a lot of difficulty walking and leaving their home. More older women than men are living with multiple disabilities and the rate and number of types of disability increases with age. Among the respondents, 90% depended on their family or friends to enable them to meet their basic needs, and 77% cared for others, including children, other older people, or people with disabilities. The most commonly used assistive products are mobility products (51%), including crutches, walking sticks, walking frames and wheelchairs, and eyeglasses (28%). Over half of older people say the assistive products they have do not work.

Keywords

Older people, older people, disability, dependency, isolation, assistive products, non-communicable diseases, multiple disabilities

Introduction

UN data (1,2) puts the prevalence of disability in lower income countries among men and women aged 60 years above at 43%, compared with just under 30% in higher income countries. With rates of disability increasing due to population ageing and rising numbers of people with chronic health conditions, among other causes, older men and women with disability need to be better included in the ageing and disability agenda in humanitarian and development activities. It is also recognised that older people may not self-identify as having a disability, despite having significant difficulties in functioning, because they consider their level of functioning appropriate for their age.

In humanitarian action, there has been limited data to understand the story of older people in crisis and ensure their voices are better listened to and understood in shaping an appropriate response to meet people's diverse needs over their life course. The direct aim of the Rapid Needs Analysis (RNA) is to support organisations in north-east Syria to develop programmes that include older people, and to support advocacy for older people's rights to be upheld. The intention of this is to inform humanitarian actors to design more inclusive responses at organisational, programme and technical levels to leave no one behind, where older people actively participate in the design and implementation of a humanitarian response as an essential step in respecting the humanitarian principles of humanity, neutrality, impartiality and independence. Syria is a location where these principles have been challenged over a protracted period and this assessment has provided a set of information to trigger more in depth assessment and consideration.

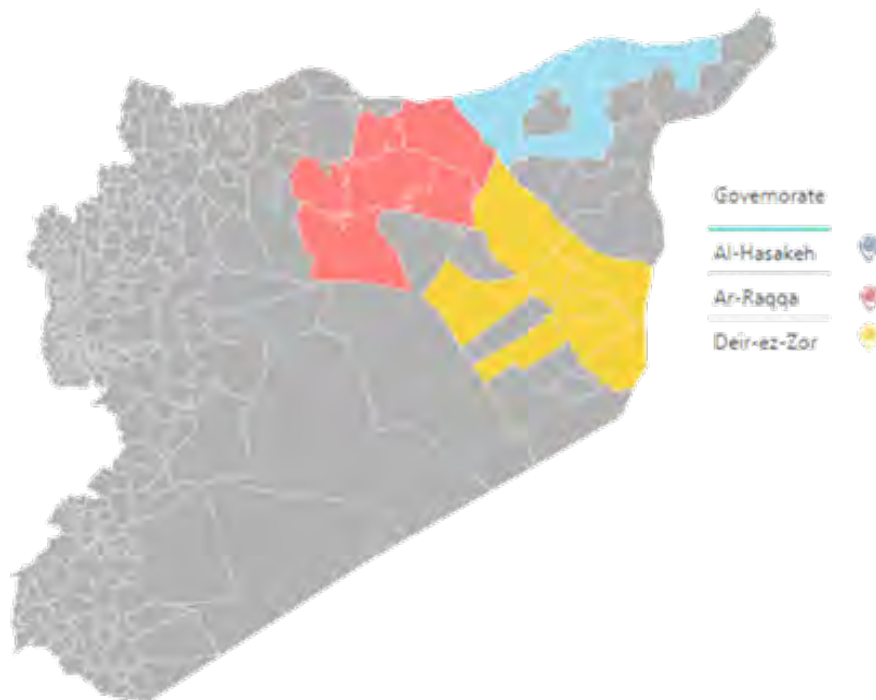
Context

As part of the Syrian conflict that started in 2011, the so called Islamic State of Iraq and the Levant (ISIS) was formed out of other militant Islamic movements and began seizing territory. By 2014, the group was occupying 88,000 square kilometres of land in north-west Syria and northern Iraq.¹ People living in these areas were subjected to the group's interpretation of Islam, which involved repressing women and minority groups. While an international coalition of forces pushed ISIS out of their stronghold of Mosul in Iraq, mainly Syrian Kurdish forces were driving the group out of north-west Syria.

In the resulting conflict, hundreds of thousands of people were cut off from humanitarian services and displaced from their homes, with the number of civilian casualties impossible to estimate. Despite the defeat of ISIS, uncertainty in the region remains, particularly close to the Turkish border where tensions exist between Kurds in Syria and the Turks.

¹. 'IS "caliphate" defeated but jihadist group remains a threat' according to the BBC (3)

Figure 1. Areas of north east Syria where data were collected.



Humanitarian needs remain extremely high. Figure 1 shows the three governorates included in this Rapid Needs Assessment (RNA) have a total of 1.65 million people in need of humanitarian assistance, with 900,000 people considered acutely in need of humanitarian assistance (4). Furthermore, given that ISIS has now lost control of much of north-west Syria, people displaced by the conflict have been returning to their home areas. Between January and August 2018, Deir Az Zor and Ar-Raqqa governorates experienced high levels of returns, with 295,000 returnees in Deir Az Zor alone (4). Basic services remain highly disrupted, with infrastructure now destroyed or unstaffed due to lack of qualified workers.

One of the key areas of investigation is to better understand the story of the older people in this region and to design a package of humanitarian support which is targeted more to meet the older people's needs in their community rather than the traditional humanitarian tailored response of providing basic needs without recognising the diversity of older age and their layers of complexity in this protected humanitarian context.

Selected findings look at understanding of the older community in this area – the older people's levels of independence, isolation, their individual complexities in older age such as health, disability and access to assistive products and the interrelationship and gaps.

In HelpAge experience, provision of appropriate mobility products and other assistive products was found to have a phenomenal impact of removing the physical and psychological barriers faced by older people with disabilities, with better inclusion in their communities and access to humanitarian and other protection services. In this report, there is a focus on understanding the older community and their challenges and bringing more

attention to the lack of focus on provision of appropriate assistive products to promote independence and autonomy in later life. For the purpose of this report we will focus on these areas.

Methods

The RNA was conducted in January 2019 by the Syrian Expatriate Medical Association (SEMA) and Al-Ameen, a Syrian emergency relief and rehabilitation organisation, with support from HelpAge International. Permission from local councils to conduct the RNA was given in 2 days.

Enumerators were trained for 2 days and they collected data for 5 days. This was followed by 4 days of analysis and production of initial findings.

A daily risk assessment reviewed the security situation in the areas to ensure the safety of the enumerators visiting the areas and ensuring informants' information was not be visible to public.

Data collection

The rapid needs assessment of older people and older people with disability targeted information gathering in humanitarian settings with over 80 questions addressing: Protection and inclusion concerns, Levels of difficulty and disability, Priority needs in a protracted crisis, Health, food and income, Shelter, water, sanitation and hygiene, and Accountability and participation. Data collection field team consisted of 21 enumerators (7 for each province) from both genders led by a field coordinator for each province.

This was carried out using purposive sampling approach to survey women and men aged 50 and over. Consideration in applying gender and age quotas were discussed but it was decided not to do this, as they might contradict the purposive sampling approach. In addition, to increase the diversity of the sample, we asked participants to recommend other people aged 50 and over who might be difficult to reach.

Informed consent was sought at the outset of the assessment process. ensuring that all information remains confidential.

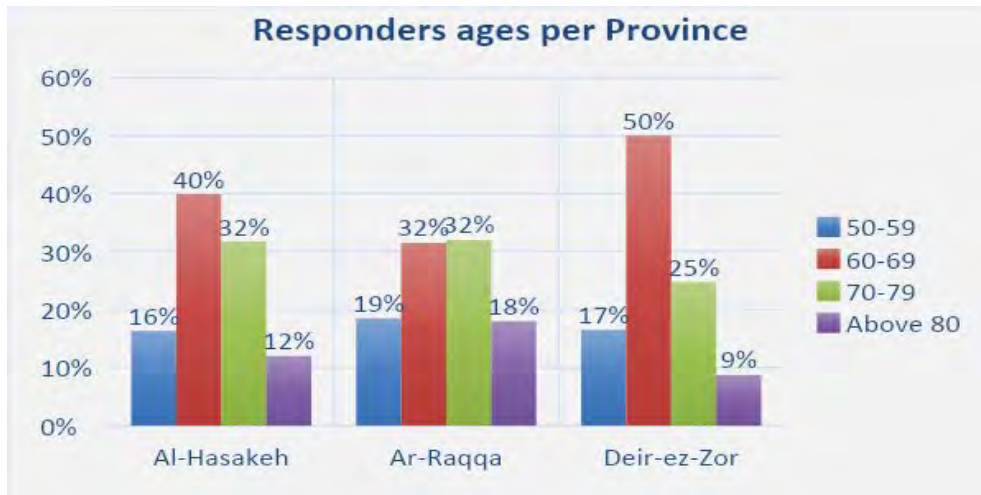
Data collected was through face to face interviews in the visited assigned communities. The team was divided into 3 groups and conducted the interviews in parallel. Each enumerator carried out 6 individual interviews per day as an average, within 6 working hours. They uploaded all the data daily using the Kobo toolkit. The Information Management unit set the data aggregation method and analysed the data with visualized trends and charts, which support the key findings and indicators of the results.

Participants

A total of 614 older returnees, internally displaced people and people living in host communities in ten districts of Al-Hasekeh, Ar-Raqqa, and Deir-ez-Zor (344 (56%) women and 270 (44%) men) were interviewed. Figure 2 shows that of the participants, 17% were

aged 50-59, 43 % aged 60-69, 28 % aged 70-79 and 12% aged 80-plus. This group participated in a structured questionnaire exceeding the minimum sample size to allow for analysis of sub-samples, for example, women aged over 80 with dependants.

Figure 2. Participants' age ratio by province.

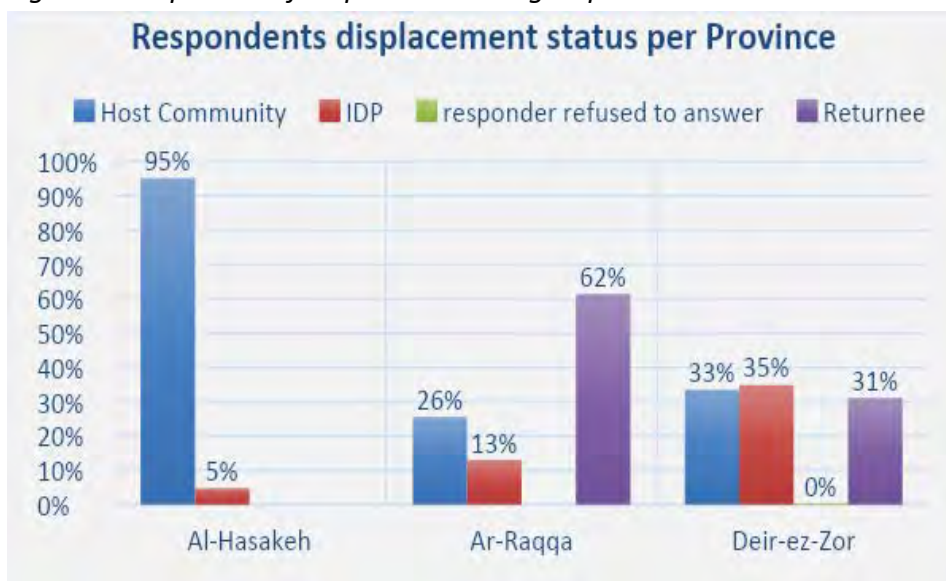


Findings

Displacement status

Regarding the responders interviewed displacement status, figure 3 shows the proportion of the targeted groups per province; from the samples of older people interviewed, in Al-Hasakeh the highest percentage were the host communities with 95%, whereas in Ar-Raqqa 62% of responders are returnees. The interest was to see if there were trends and differences from the 3 distinct communities. The internally displaced people (IDP) have the largest ratio in Deir-ez-Zor with 35%.

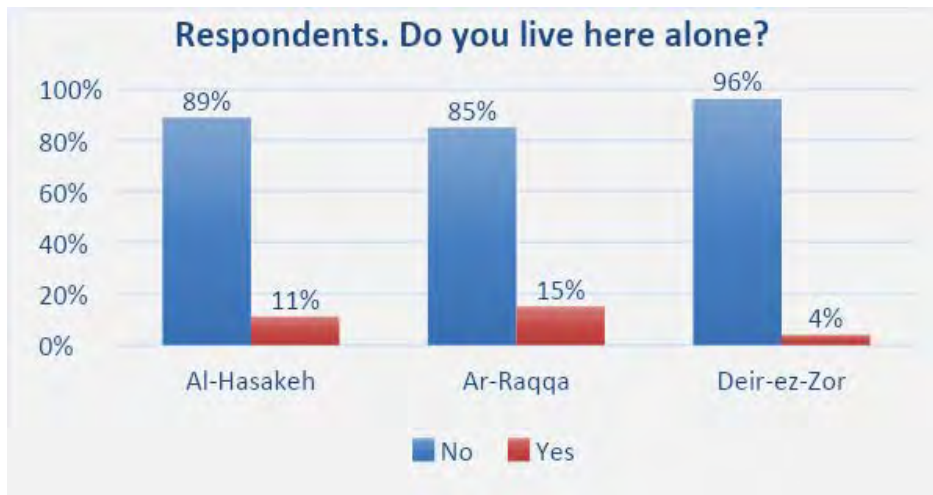
Figure 3. Proportion of respondents being displaced.



Isolation and Inclusion

Responders were asked if the older people were living alone or not. Figure 4 illustrates that most of the respondents were older people living with others. In Ar-Raqqa 15%, and 4% in Deir-ez-Zor, where-as in Al-Hasakeh 11% of older people are living alone. In Figure 4, although it appears a small figure, it identifies where more IDP's live alone and raises the question how this group can access humanitarian aid.

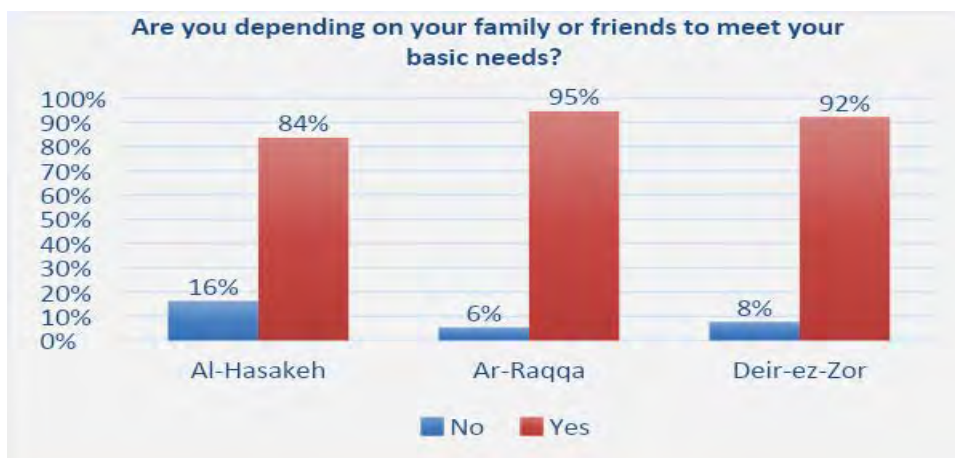
Figure 4. Proportion of respondents living alone.



Dependency

When older people were asked if they depend on their family or friends to meet their basic needs, 84 % in Al-Hasakeh, 95 % in Ar-Raqqa and 92 % in Deir-ez-Zor confirmed this was the case, see figure 5. This suggests that family and community supports are in place, however there are a small, yet significant number who do not have this support and this again raises the question how this group can access humanitarian aid.

Figure 5. Proportion of respondents reporting dependency.



Caring is a key aspect of older people’s lives. The 90% of respondents said they depended on their family or friends to enable them to meet their basic needs. At the same time, 77% are caring for others, including children, other older people, or people with disabilities. Of these, 39% are aged 70 or over. Three quarters of older people depending on others are also caring for people themselves. This raises questions on providing appropriate home-based support that moves away from traditional distribution.

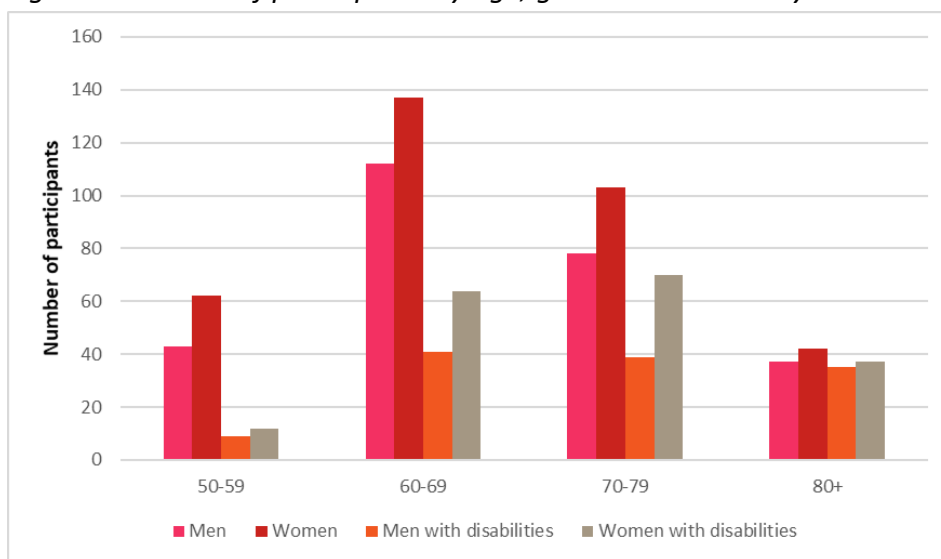
Ten per cent of respondents said they were living alone. Older people including older people with disability identified medicine, cash, fuel, water and food as their top five priorities.

Many older people with disabilities have difficulty reaching aid distribution points and health services without support. Over 40% of older people with disabilities either pay for someone to bring relief items to them or pay for transport to services.

Age and gender

Figure 6 shows the age, gender and disability distribution of the sample. Rates of disability increase significantly with age, as do the number of disabilities older people are living with. Half of older people surveyed have some type of disability.

Figure 6. Number of participants by age, gender and disability status.



Disability

The most common types of disability are difficulties with walking (74%), difficulty leaving the home or shelter (47%) and seeing (43%), see Table 1. Twice as many older women as men report a lot of difficulty walking and difficulties leaving their home. More older women than men depend on others for self-care. More older women than men are living with multiple disabilities. The data showed that the rate of disability and number of types of disability increases with age.

Table 1. Types of disability reported by older people with disabilities

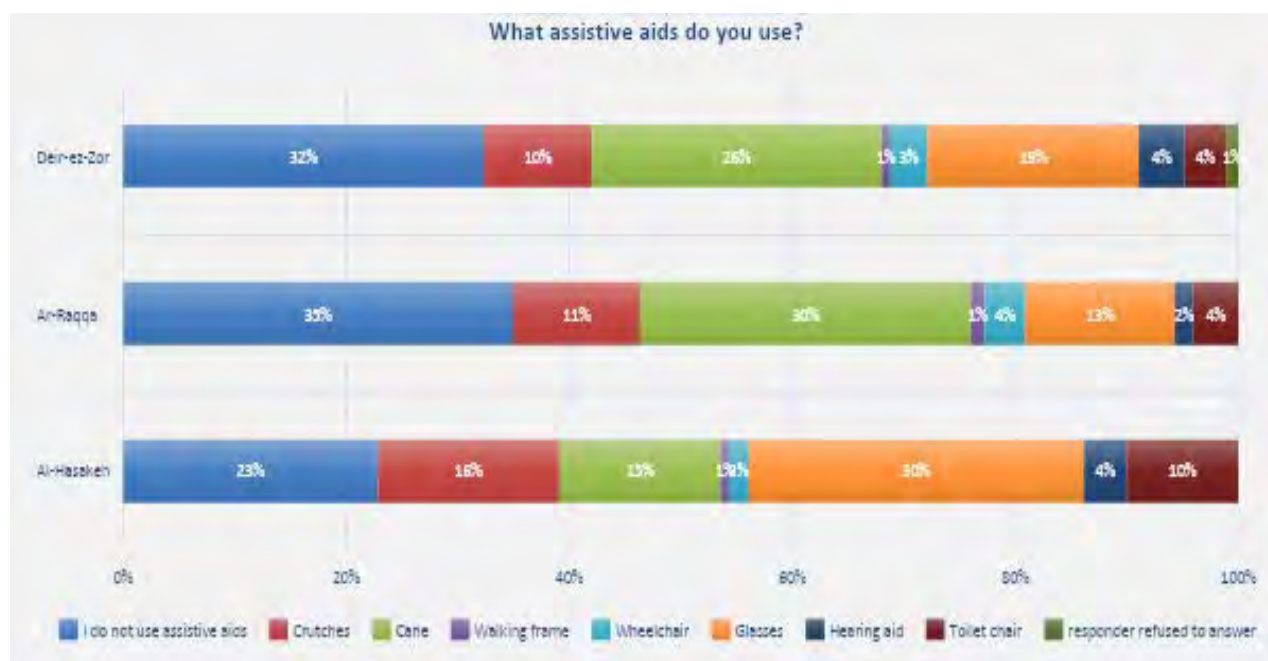
Disability type	Older people	Older women	Older men
Getting out of living space	47%	53%	39%
Seeing	43%	46%	39%
Walking or climbing stairs	74%	80%	66%
Communication	11%	13%	9%
Self-care	41%	43%	38%
Remembering or concentrating	25%	25%	24%
Hearing	30%	28%	33%

The high number of people having a lot of difficulty with self-care, hearing and remembering and concentrating flags up a concern for follow up to ensure the appropriate support is put in place. The danger of looking at the highest percentage can mislead the use of the data and looking in more detail at the findings as shown below has highlighted a more detailed set of concerns.

Assistive products

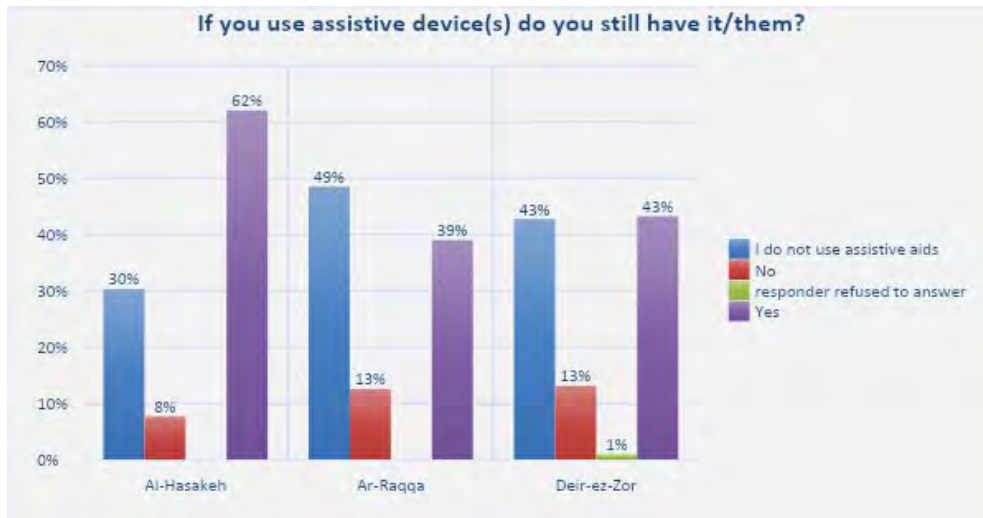
Figure 7 shows that the most commonly used assistive products are mobility products (51%), including crutches, walking sticks, walking frames and wheelchairs, and eyeglasses (28%). A smaller percentage of older people use toilet chairs and hearing products to help them maintain their independence.

Figure 7. Proportion of respondents using various types of assistive products covered by the RNA



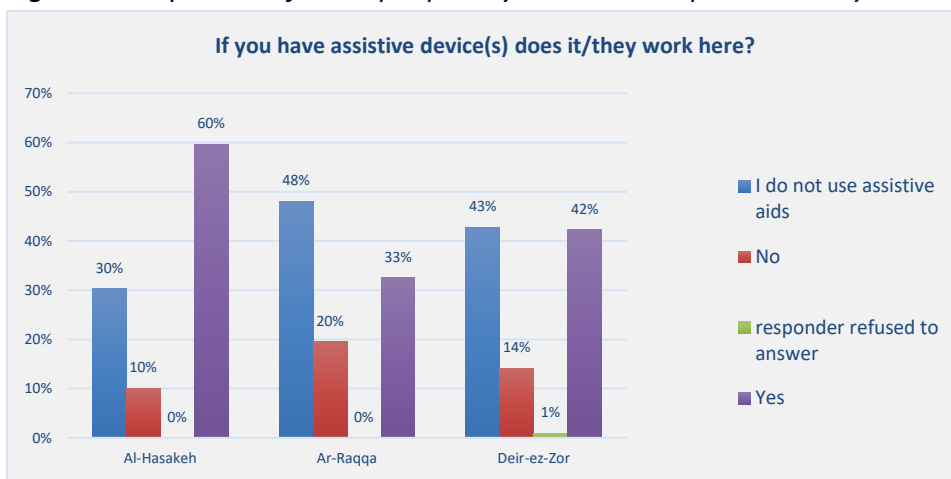
When asked if they still have their assistive products, the response was high, whereas 13% of older people in Ar-Raqqa and Deir-ez-Zor and 8% in Al-Hasakeh did not have them, see Figure 8.

Figure 8. Proportion of users of assistive products still having them



Whereas Figure 9 shows that around a third of older people say the assistive products they have do not work.

Figure 9. Proportion of older people say the assistive products they have do not work



When asked if the assistive product is functioning and usable, the responses show that 20% of older people in Ar-Raqqa, 14% in Deir-ez-Zor and 10% Al-Hasakeh report that their assistive products do not work and not usable. Whereas, 60% of older people in Al-Hasakeh, 42% in Deir ez-Zor and 33% in Ar-Raqqa stated that their assistive products are in use and work properly,

Understanding older people in this community

Following the initial findings, a set of more in-depth analyses was carried out to better understand the older people with disabilities' health and functioning and looking at the links between chronic diseases and multiple disabilities.

On average, older people with disability reported 2.5 non-communicable diseases (NCD); the more detailed data shows this breakdown by gender where the percentages are fairly similar, see Table 2.

Table 2. Proportion of older people with disability with NCD

Number of chronic diseases per person	Older people with disability 60+ with chronic diseases	Older women with disability 70+	Older men with disability 70 +
4	10.4%	11.2%	14.9%
3	33.6%	41.1%	32.4%
2	34.9%	30.8%	33.8%
1	18.2%	13.1%	17.6%
0	2.9%	3.7%	1.4%

The health data collected in this RNA looked at the finding for four specific chronic diseases, common in older age; hypertension and arthritis share higher levels of incidence as compared to diabetes and respiratory conditions, see Table 3. The data analysis looked at the relationship between non-communicable diseases and disability to better understand the relationships between the chronic health conditions and any related disability, such a hypertension and stroke and arthritis and loss of mobility and walking, diabetes and cataracts and amputation and respiratory conditions and loss of mobility and walking. This information can impact on the need for more preventative health or multidisciplinary health, rehabilitation and care approaches in designing an appropriate model of health care.

This data is building up a complex picture for the older men and women in this survey having multiple layers of chronic health and serious layers of difficulties/disabilities in daily life and levels of independence and autonomy, which impacts on their access to services. This also highlights the need to identifying where assistive products can support and reduce the levels of function and dependency respectively that come with the multiple levels of ill health and disability.

Table 3. Proportion of older people with disability living with specific NCD

Chronic condition	Older people with disability with chronic diseases	Older women with disability	Older men with disability
Respiratory Conditions	36.2%	36.1%	36.3%
Hypertension	70.4%	76.0%	62.1%
Diabetes	47.2%	50.8%	41.9%
Arthritis (painful joints)	76.5%	78.1%	74.2%

Table 4 presents the level of difficulties (as defined by the Washington group questions +1 question on Cannot get out of the home) for older people and highlights how multiple disabilities get more complex with age – often assumed but rarely analysed to inform and guide a response.

Table 4. Proportion of reported levels of difficulties across age group of older people

Levels of difficulties (from 1 to 7, with 7 being the highest)	Older people with disability	Older people with disability 70 +
5, 6 and 7	17%	24.3%
3 and 4	30.3%	32%
1 and 2	52.8%	43.7%

The data does tell its own story in that there are many older people who have some form of difficulty, which may need further assessment and support and, in some cases, an assistive product or more. Among those who do not have assistive products, Table 5 shows the proportion of older people' requesting support related to their disability.

Table 5. Proportion of older people with disability who do not have any form of assistive products related to their disability requesting support

Type of difficulty and need support /assessment	Older women with disability requesting support	Older men with disability requesting support
Sight	57%	32%
Hearing	89%	77%
Walking	44%	34%
Mobility	87%	85%
Selfcare	85%	77%

Discussion

The aim of this RNA was carried out to identifying the older community, who are not always included in rapid needs assessments and collect basic information on the age, gender and disability to inform the design of humanitarian support to ensure equal access to services; however it led to looking at the complexity of being an older women or man in this protracted crisis whether living in the host community, or being an IDP or a returnee; with this more in-depth picture of the older community identifying their high levels of dependency and multiple health and mobility, sensory, communication and cognitive needs, the importance in addressing access to appropriate assistive products becomes a priority for many of the older people involved in this RNA and possibly in the wider community.

The questions on who has access to assistive products, whether they are being used or lost may seem un-important. However, it was considered a starting point to know more about what is available, useable and fit for purpose in this setting. The selection of assistive products was based on the traditional assistive products seen in many humanitarian

contexts and this in itself is limiting the useful information on more age-related issues on remembering and concentrating and communication. As there are older people reported with communication and remembering difficulties this can be followed up in the next steps.

The findings on assistive products in this survey are leading towards more in-depth assessment on access, quality, design and availability of providers and relevant assistive products, affordability to the end user. There is also a need to recognize that the lack of access to assistive products is due to a number of factors including high costs, limited availability, and lack of governance and inadequate financing in many settings, as well as a widespread lack of awareness and suitably trained personnel (5).

The information from the RNA identifies that over 50% of older people are living with 1-7 types of difficulties/disabilities and 2-3 non-communicable diseases, which supports the recommendations for more appropriate in-depth assessment to provide and prioritise the provision of appropriate assistive products to meet these complex needs.

The World Health Organisation estimates that over one billion people, the majority of whom are people with disabilities and older people, need one or more assistive products (6).

The number in need of assistive products is projected to increase to beyond two billion by 2050 as a result of rises in non-communicable diseases and the aging global population (7). However, evidence indicates that an estimated 90% of people who would benefit from assistive technologies do not have access to them and there is a huge unmet need for such products.

Older, disabled and injured refugees face specific challenges that contribute to their vulnerability. In a report by HelpAge International and Handicap International on the hidden victims of the Syrian crisis, Calvot (8) states that studies of humanitarian programming show that older, disabled and injured refugees are often neglected in the assessment, data collection, design and delivery of responses. More than 34,500 IDPs and 100 refugees were assisted through primary health clinics and community centres with medical assistive products such as crutches, wheelchairs, and medical glasses for their temporary or permanent disability (9). What we don't know is how many reached older people, if the minimum standards of assessment, training in use and maintenance was covered and what was not available in Syria.

The intention with developing the RNA tool is to make it useful tool for gathering information and to mainstream it into more advanced assessment tools. It is work in progress and open for ideas and suggestions to improve the tool and look towards answering the many questions raised from carrying out this exercise.

Key findings and implications

1. The RNA tool has provided a starting point to understand the community. However, there is a need to review the questionnaire to ensure the information is accessible to all.

2. Older people with disabilities have complex health care needs. Therefore, there are needs to carry out more health and rehabilitation focused assessments, and to ensure there are outreach and community services in place with well trained staff.
3. Many carers are older people with disabilities, and many have more than one non-communicable disease. Thus, there is a need to ensure a carer support programme is put in place to provide training in psychological support to carers of all ages.
4. Older people with disability have limited access to assistive products and in most cases they are not useable. This leads to a need for doing follow up assessments to assess availability, access, affordability, and acceptability of assistive products.

Acknowledgements

A strong thankyou to all involved in the data collection, analysis and reporting from Syria, Jordan and UK, including the following agencies:

Help Age International (www.helpage.org): a global network of organisations promoting the rights of all older people to lead dignified, healthy and secure lives;

The Syrian Expatriate Medical Association (www.sema-sy.org): an independent humanitarian, medical relief, non-profit, national organisation providing high-quality healthcare to conflict-affected communities in Syria;

Al-Ameen (www.alameen.org): a Syrian non-profit organisation providing emergency relief and rehabilitation to conflict-affected communities in Syria;

The author also acknowledges the compilers of the RNA Syria Report 2019 (<https://reliefweb.int/report/syrian-arab-republic/rapid-needs-assessment-report-older-people-rna-op-north-east-syria>)

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Access

Challenges in access to appropriate assistive technology in less-resourced settings: Argentina's case

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Abstract

Access to appropriate and affordable assistive technology is a human right, a public health, and a development priority. In developing countries like Argentina most people with disability who would benefit from Assistive Technology (AT) do not have access to a service delivery and the means to pay for the products. In less resourced settings, it is imperative to develop AT provision as a policy to ensure the appropriate AT service. I will describe an experience in Chaco Salteño, Argentina, that illustrates the various opportunities and barriers to achieving appropriate access to AT. A pilot project, involving the health agents and following principles of community-based rehabilitation, was conducted to explore the possibility of introducing an AT service provision system. Based on the World Health Organization (WHO) paradigm of the 5 Ps related to assistive technology: the interlocking ideas of people, personnel, policy, products and provision. Always promoting the importance of achieving the Sustainable Development Goals (SDGs) in an equitable and inclusive manner, leaving no one behind.

Keywords

Assistive technology, access, policy, service provision, less-resourced settings

Introduction

The WHO e *International Classification of Functioning, Disability, and Health* (2001) considers that the spectrum between functioning and disability is the result of a complex interaction between an individual with a health condition and his/her context that may result in activity limitations and participation restrictions (1). Assistive technology (AT) is an umbrella term for products and related services used by persons with disability to enable and enhance their inclusion in all domains of participation (2). AT promotes independence in people with disabilities across their lifespan (3). According to the WHO, more than 1 billion people globally require assistive products and in many low and middle-income countries only 5 - 15 percent who need such products have appropriate access to them. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (4) provided worldwide legal framework for rights, including those relating to access to AT. The CRPD

was ratified by Argentina in 2008, therefore recognizes access to appropriate and affordable AT as a human right (5). The Sustainable Development Goals calls for inclusive actions to leave no one behind and design poverty alleviation and development programs as mandatory to people with disabilities (6).

Access is a complex concept that involves availability, physical accessibility, adequate supply, affordability, and acceptability (7). Although AT products are essential, successful access depends on integrated efforts related to end users ('people'), provision, products, personnel, and policy, considered the five 'P's by the World Health Organization's Global Cooperation on Assistive Technology (WHO- GATE) (8). These 5Ps are unique to each context (9).

Are there opportunities in improving access to appropriate AT and service provision if the 5 Ps are not considered in less-resourced settings, like in Chaco Salteño? We know that a multi-disciplinary workforce in a health system is required to meet AT needs. The recent WHO publication Rehabilitation in Health Systems suggests that multi-disciplinary rehabilitation can be effective in managing chronic, complex, or severe conditions. Based on the high level of evidence, they recommend that a multi-disciplinary workforce should be available, 'as different rehabilitation disciplines require specific skills'. Planning provision and service impact requires understanding of the context, people, speed, and policy required to build a sustainable community of practice, utilizing sustainability indicators based on follow-up, measure, and respond to the AT provision process (10, 6).

Argentina is an emerging-frontier country, similar to some countries in the Latin American region and shares corruption scandals that make poverty and violence evident. Currently, 27.3% of its population live in poverty (11) and disability is prevalent in 12.6% of the population (12). Since 2001, the Ministry of Health manages the unified national disability registry which provides the disability certificate that includes the cause, level, and rehabilitation services (13). This law allows for the provision of AT products, but most remote and poor places lack appropriate processes to guarantee the rights of people with disabilities.

What challenges in assistive technology do we have in Argentina? Resulting from the 5 Ps proposed by the WHO to analyze AT situation, these are the main demanding tasks I found in the most vulnerable areas of my country, Argentina:

- Lack of "Person-Center Approach", that means intended to support care and service delivery focused on meeting the persons need, values or preferences (14). For maximizing the impact of AT in enabling participation, requires an individualized understanding of the value and meaning of AT for the individual, taking a universal model perspective, focusing on the person, in the context and considering the condition and /or technology. *People (user)*
- Lack of policy implementation: In Argentina, the law that provides AT in people with disability is accurate, the problem is the implementation and the fairness. *Policy*

- Lack of awareness: both users, practitioners and community people are unaware that with some appropriate technology they can enable their lives. They just accept the exclusion and isolation. *Policy*
- Lack of services related to the appropriate AT provision: The current focus is on the absence of product access, but the real problem is that there are no trained professionals to evaluate the need of the user, select the product from the available, prepare it, make the adjustment, train the users and organize the follow-up. As we know AT products are necessary but not sufficient to guarantee the right to appropriate AT (15) *Provision-Personnel-Products*
- Lack of maintenance of products: noticed in the number of abandoned products, it is necessary to teach people how to use them and how to repair. *Products - Personal*

The objective is to present an experiment design program in order to improve the quality and efficiency of opportunities in improving access to appropriate AT and service provision. This study intends to achieve feasibility of some crucial components: the process, the resources and the management, considering the 5 Ps and hoping to find a progression towards making AT available for more people in less- resourced settings in Argentina.

Method

We took an example of a vulnerable group in Argentina, the indigenous group *Wichi*, that lives in the Chaco Salteño. This region accounts for a higher rate of childhood malnourishment and poverty, than the national average (16).

A health community strengthening program led by social workers identified several cases of children with mobility impairments laying on the floor all day due to lack of appropriate AT. To promote the rights of these children, by providing access to appropriate AT (4), a pilot project based on the WHO Community-Based Rehabilitation (17) (CBR) and 5 Ps plus the 8-steps-Wheelchair provision (18), started in 2016.

A team of 3 AT experts composed by 1 physical therapist and 2 social workers defined the 7 phases needed to build up an adapted program on AT provision to ensure the inclusion of the WHO paradigm on the 5 Ps and the WHO's 8 steps of wheelchair provision, as outlined in *Guidelines on the Provision of Manual Wheelchairs* (2008) and expand inclusion programming. The training program was delivered by the non-local experts and was paid by private donations from higher income places. These are the phases we planned in order to achieve our goals:

Phase1: Advocating for *Provision- Policy*. Involve the local government – Salta ministry of health, with a special program for the early childhood called *Ministerio de Primera Infancia*. They have a program for nutrition and schooling for children under 16 years old. No specific work in disability was addressed in the mention area, no money to pay rehabilitation and assistive technology products. With their network, we planned together to train the health agents and teachers prior to obtain donated wheelchairs

Phase 2: *Personnel* involved in the community system. Community-based rehabilitation training, provided by non-local experts

Phase 3: Awareness - Identify the need in *People*. Referral list of children in need of Assistive Technology. (step 1 WHO guidelines) There were many children with functional limitations that were not identified as needing resources and help.

Phase 4: Training of two local leaders. *Personnel* trained in product preparation, fitting and maintenance (step 5-6-8 WHO guidelines) We knew that if we were introducing At Products, like wheelchairs, it is urgent to have some local personnel able to maintain, repair and fit the person with the product

Phase 5: Assessment and prescription conducted by expert PT. *Provision*. (step 2-3 WHO guidelines) In this pilot project we still have non-local expert doing the steps of assessment and prescription

Phase 6: Funding, we accepted donations of *Products* from higher income settings. (step 4 WHO guidelines) Donations we both of used and refurbish products and purchase for the purpose. All of them we carried from higher income settings (Buenos Aires city of Argentina)

Phase 7: Provision- *Personnel*. Follow up conducted every three months by local leaders, sending to the project coordinators pictures and questions. (step 8 WHO guidelines). We took interviews to obtain results concerning mobility increase and inclusion.

Findings

The Program has been functioning with very good results during the last two years (2017-2018). Main findings:

- Coordinated efforts to advance policy, provision, products, and personnel based on understanding the population's needs are urgent in the emerging countries.
- We fitted 21 children with an appropriate wheelchair and trained on how to use it. They have a process in the provision that includes training and follow up.
- Awareness increase is shown in the number of cases (6 to 21 in 8 months) of children requiring wheelchairs. This may indicate that there were families having children at home without any community involvement.
- We trained 140 health agents in community-based rehabilitation with emphasis in AT
- We instructed 2 local leaders in product preparation, fitting and maintenance.
- Access to appropriate AT, led to increased community participation that resulted in more inclusion. The follow up process included monitoring how they can access to different school and community programs. The children were left at home without the mobility product. All of the families could describe a situation where the child increase participation: going to school, community activities, family gatherings
- Sustain Program for AT provision, diminish the abandon products. All of the 21 children got a wheelchair before we introduce our program, most were abandoned, and some were used although not with good support. The pilot program has a follow up phase

and every three months they send a photo of the user in the wheelchair, this allows us to mend or improve any need and benefits the reduction of neglecting products.

Discussion

In less-resourced settings like Chaco Salteño, Argentina there is an urgent requirement to understand the deep needs and limitations of the community, and to take charge of the opportunities to ensure access to AT by observing the 5 Ps: their people, policy, personnel, products and provision. The actual system is based in delivery, this means to bring in any wheelchair technology not considering the needs, the context, the safeness and durability. We hope to move the system to an appropriate wheelchair provision. To understand the efficiency of AT equipment and services, it is important to not only consider the cost but the subsequent benefits they provide for AT users. Profound understanding of details, characteristics of each context are necessary to progress.

In our experience in Latin America, it is mandatory to have the government involved in the Service with adequate policies. The above-mentioned Program is just a pathway that is ensuring appropriate AT products and service provision for the community. The benefits of AT and appropriate service provision should be known by the different stakeholders involved with such disabled people throughout their lifespan.

Future perspectives

- Monitoring and evaluation plans to be created and followed up in order to build and strengthen the evidence of the cost and benefits of AT.
- Training Service AT providers to contribute to reduce disparities. Building capacity goes hand in hand with the integration of these services into existing healthcare programs for ensuring equitable access to appropriate AT (19)
- The government to offer more training opportunities in CBR that promote inclusion.
- Sustainability of the program: the government to be more involved in provision, specially training experts for assessment / prescription and for purchasing the products.
- The Program discussed here can be replicate in less resource settings in Latin America.

The aim of the pilot project research is to figure out if we can improve the results in inclusion and mobility with wheelchair provision as a process in accordance to the WHO's paradigm. The main challenge we encountered was that there were no health professionals, only agents so we needed to increase educational programs. From the present situation of *wheelchair deliver* (obtaining donated wheelchairs not meeting the needs of the users and context), we present opportunities in improving service provision considering the 5 Ps and hoping to find a progression towards making access to appropriate AT for more people in Argentina.

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Challenges in access to assistive technology in Hungary

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Abstract

Background Hungary is a high-income country in Central-Eastern Europe. About 5% of the population is disabled, while 15% of the citizens has difficulties in everyday activities due to their health conditions. This paper deals with the accessibility of assistive technology. The aim is to illustrate the provision system of assistive devices with a specific focus on the role of the state: what kind of devices and related services the Hungarian state provides and what is the process of accessing a state-subsidised product. Methods Besides literature review, comprehensive legislation analysis, a focus group and sociological interviews were made with users (n=20) and assistive technology (AT)-related experts (n=13). Findings Based on the policy analysis and the interviews, four main challenges can be identified in access to AT in Hungary: the provision system is obsolete, follows the medical model of disability, and inequitable, furthermore, most actors in the process lack information. The greatest losers of the obsolete system and inequity are people with communication disorders and severe disabilities - especially children.

Keywords

AT provision, AT national policy, accessibility of assistive technology, Hungary

Introduction

The provision systems for AT are very diverse across Europe and dependent on the different welfare models. The post-communist welfare regimes' development differs considerably, but generally, primary health and social services are provided by the state with crucial role from families and civil organisations in the field of care – including the provision of assistive devices (1,2). This paper concludes the partial results of a social policy PhD research that sought to explore the provision of AT in Hungary, with a specific focus on the role of the state.

In the following sections, it is argued why Hungary needs an assistive technology programme ensuring AT to be accessible and affordable, and then we briefly present the AT-related state functions (legislation, financing and service provision) to describe the current policy framework. Subsequently, the paper deals with the system from the users' point of

view: what kind of devices are available with a state subsidy, and what is the process of accessing them?

Methods

Besides the literature review, comprehensive legislation analysis and sociological interviews were made. The interviews included both individual user interviews (n=12), a focus-group interview (with 8 participants), and professional interviews (n=13) with disability and health policy experts, physiotherapists, nongovernmental organisations, suppliers, and manufacturers. Four subjects were both experts and users. The users were interviewed about the process of accessing assistive devices while the experts were asked to describe how they participate in the provision. These interviews do not represent every AT users' opinion; this qualitative method aims to have an overview of the provision system from users' point of view, in complementarity with the policy framework analysis. Each subject participated voluntarily with informed consent obtained; the study respects the anonymity of the respondents. The study also included participatory observation in one of the rehabilitation clinics in Hungary, where nine of the professional interviews were made. Furthermore, the available state-subsidised assistive devices were analysed, also in comparison with the Priority Assistive Products List by the WHO (3), to review the needs (not) covered.

The research is a policy analysis, which means it has its limitations. The interviews aim to identify the challenges and difficulties the users and experts face because of the current process of accessing AT. Many subjects reported day-to-day practical problems regarding, e.g. some specific products. These inconveniences are severe and relevant, although they might not all be concluded in the Findings of this paper.

Need for assistive technology (programme) in Hungary

There is no available statistical data or estimation regarding the number of people in need of assistive technology in Hungary, and the same is true for the number of AT users. According to the Hungarian Central Statistical Office (2011), there are almost 500,000 people with disabilities in Hungary, 4.9% of the population, more than 35,000 of whom are under the age of 19. More than 90% of the disabled population have difficulties in everyday activities, most frequently in participating in family life, self-care, community activities, communication, and collecting information (4). Disability is sensitive data, which means the statistics mentioned above represent the persons who reported themselves disabled. We may assume that more people need at least one assistive device.

In 2016 a representative sample was asked whether they feel impaired in instrumental activities of daily living due to their health conditions. 1.5 million people reported that they experience difficulties - regardless of disability -, which is more than three times the number of people who consider themselves disabled, 15% of the Hungarian population. A quarter of people who have difficulties experience disadvantages in participating in family life, 35% of people who have difficulties face disadvantages in community participation, 35%

of people who have difficulties have disadvantages when using (public) services (5). According to Eurostat, the share of persons aged 16 and over with self-reported long-standing limitations in usual activities due to health problems in Hungary is higher than the EU-28 average, 26.8% of the population has some or severe limitations (6).

The number of people in need of AT is increasing as the population ages. Older people are overrepresented among people with disabilities and among people with daily difficulties, too. 60% of people who feel impaired is older than 60 years, which is twice the proportion of persons over 60 years in the Hungarian population (4,5).

In 2016 the employment rate of people with disabilities was 16%. According to the statistics of the European Commission (2011), Hungary has the most significant gap between the employment rate of people who feel impaired and those who do not. The difference is 37 percentage points while the employment rate of people who do not have any difficulties due to their health status is only 6 percent lower than the EU average (5,7).

The economic activity and employment rate have a negative impact on the income situation of people with disabilities and their families. Families which include at least one person with disabilities earn 15% less on average than a family without a disabled member. The risk of social exclusion and poverty is 22% higher among people with disabilities than in the non-disabled population, 17 out of 100 disabled persons live below the poverty line (8). The poverty risk and disability mutually reinforcing each other. Studies show that raising a child with a severe disability goes hand in hand with poverty in Hungary (9-11).

Using assistive technology can have a positive impact on the lives of people with disabilities and their families; the effects are far more beyond the individual benefits. Technology not only supports the activities of daily living but enables people to live dignified, independent lives, participate in the community and the labour market. With the help of assistive technology social exclusion can be overcome (12) which is a significant barrier in the lives of people with functional limitations in Hungary: the statistics mentioned above represent the need for accessible and affordable assistive devices in Hungary. It is evident that assistive devices can be purchased from the market. As the statistics showed, the Hungarian potential AT-users' low purchasing power makes it financially challenging to buy the products out-of-pocket. What kind of state support can Hungarian people have in case they need AT?

Findings

Policy framework

There is no assistive technology programme in Hungary yet, although there exists a national list of 'medical devices' (MD) with State subsidies. The translation of the term 'assistive technology' – as it can be found in the Hungarian translation of the Convention on the Rights of Persons with Disabilities (CRPD) (13) which was ratified in 2007 - is not used in the legislation, neither by the interviewed users or experts. According to the relevant legislation,

medical devices (*gyógyászati segédeszközök*) are 'those medical technology products or care-related technology products which are directly used by people with permanent/temporary impairments or people with disabilities; the use of which does not require the persistent presence of a medical professional.' (14,15) [Translated by the author]

The definition of medical devices is more restrictive than the definitions of assistive technology (16,17) and lacks the mention of related services (see section VI.3. for details). The XXVI. Act of 1998 about the rights and equal opportunities of people with disabilities contains another name and definition: "4. § e) *aid*: a device that serves to partially or fully make up for the partial or full lack of physical or sensory capacity in a person living with disabilities" (18,19) 11. § states that people with disabilities must be provided with the appropriate medical devices based on their needs resulting from their disabilities.

The provision of medical devices is under the responsibility of the health care system (15,20). The Hungarian health care system is a comprehensive, compulsory, employment-based insurance scheme (21). The health insurance is financed by employers' and employee's contributions together with central budgetary contributions (the latter one was approx. 20% of the overall revenues in 2017). The National Health Insurance Fund Management of Hungary (NHIFM) is a central agency supervised by the Hungarian Government and the Ministry of Human Resources, that is the main allocator of the health-related cash benefits and benefits in kind - just like medical devices (22).

NHIFM is responsible for, among others, maintaining the national list of devices and for negotiating with the distributors and manufacturers. The distributors, who want their product to be granted by the insurance system, can make applications, then the NHIFM decides if it can be added on the list. The negotiation with the NHIFM is mostly about the economic advantages and disadvantages the product could cause, and the aspects of cost-effectiveness, regardless of the long-term benefits for the users. This might be the reason why there have been only small changes in the list for the last decade.

There are 3433 products on the national list of subsidised medical devices¹ (23). If an MD is needed, the users need a prescription from a doctor, just like in case of medicaments. The list contains the ISO:9999 code, the name of the products, the amount of subsidy and the name of the contracted distributors each. The state provides social insurance subsidies, which are 0, 50, 70, 80, 90, or 98% of the price (including repair) that means co-payment from the user is required. The price of the products on the list are not their market price but are determined by the NHIFM – this is the amount of money the Fund pays to the MD distributors in case a prescription was turned over to them.

There is a way of accessing subsidised MDs other than through insurance. The so-called 'public health care cards' (*közgyógy igazolvány*) are given to socially disadvantaged persons who need financial support in order to maintain or improve their health status. The card can be given to the citizens by right of birth (regardless of the financial status of the family, such

¹ Based on the data available on the website of the NHIF, July 2019.

as people who are entitled to invalidity annuity, who are considered unable to work; and families raising a disabled child) or by right of normative (means-tested, where the household income per capita is less than approx. 89 euro a month, or 135 euro in case of people living on their own) (24). 73% of the devices on the list can be granted with public health cards; the amount of subsidy is 100%.

There is a possibility to subsidise a device which is not on the list in case a doctor can justify the need with the so-called 'equity subsidisation of individuals' (*egyedi méltányossági kérelem*). The persons who need this kind of cost reduction must fulfil an application, with a medical history not older than three months, which justifies that the need for a particular device is inevitable. The applicants must enclose a price offer from a manufacturer or distributor and a prescription from a doctor. The name of 'equity subsidisation' suggests that social factors are considered in the decision-making, though the NHIFM committee must take into consideration '1. the medical history, 2. the severity of illnesses, 3. if the usage of the device has medical reasonableness, 4. the costs and cost-effectiveness, 5. why the need cannot be satisfied with a complementary subsidised device, 6. the opinion of a medical professional invited by the NHIFM, and 7. the expected health profits' (25,26).

The experts added that the amount of money for individual applications runs out until the end of the year; furthermore, the committee responsible for deciding the requests would never meet the applicants in person. Still, they can second-guess the decisions of the therapists or doctors who prescribed the device.

In 2017 the NHFIM spent 64356.8 million HUF (approx. 197 million EUR) on the social insurance subsidies of medical devices, it is one-fifth of the expenses on medicaments. 18% of the expenses were spent on public health care subsidies; only 1.8% of the expenses were spent on equity subsidisation of individuals (27).

After a brief introduction to the policy framework of MD provision, with the results of the professional and the user interviews, we can reconstruct the process of applying for a state-subsidised medical device. It presents how the policy works in progress and let us identify the challenges regarding the current system.

In practice: the process of accessing a subsidised device from the users' point of view

If a Hungarian person needs an assistive device, they can purchase one from the market, any retailer or manufacturer. The problem is that people in need – mainly those with disabilities or with poor health conditions – have a far less favourable social-economic status than the average (see section III.). There is a significant difference in the process of accessing a subsidised device and buying an AT out-of-pocket. Figure 1 in the Appendix is made to illustrate the steps in both cases. The grey rectangles show who is responsible for deciding on each step.

If a person needs a subsidy, they must see an appropriately qualified medical specialist, who is contracted to the NHFIM. Each product on the list has an indication which defines the criteria of different kinds of health condition which make the users eligible. The doctors are

responsible for: 1) addressing the need, deciding whether the user's health condition requires the use of a device 2) choosing the appropriate product from the list, 3) making a prescription, and 4) informing the user (about the products, the co-payments and the alternatives). The process of accessing the subsidised devices seems to follow the medical model of disability (28) which suggests that disability is an individual deficit which makes it difficult for disabled people to make decisions about their own life; they need professionals to look after them and to make the decisions instead of them.

According to the interviews, the lack of information is the first obstacle the users face. They do not always know what kind of technical support they might have for the satisfaction of their individual needs; where they can get support; and where they can find professionals who might help them with information. Both the users and experts mentioned that general practitioner family doctors are not well informed. Furthermore, in Hungary, there exist an inequality between the regions – the smallest villages are in the most disadvantaged areas. There is a connection between the size of the local administrative area and access to public services in general (29). We may assume that people with disabilities and elderly who live in the countryside have fewer opportunities regarding the available assistive devices and related services, and more so, regarding the available information. NGOs and civil organisations play an essential role, and users have most of the information from the internet (where accessible) and each other.

After the users had found a doctor and got a prescription, they must decide if they can afford to pay the co-payment (except they have a public health care card). It still can be financially challenging to pay the co-payment of 50, 30, 20 per cent of the price; in particular, if an expensive product is needed. There is an indirect financial difficulty as well, the VAT in Hungary is 27%.

The user does not have an opportunity to argue the doctor's decision or initiate a change request unless they lose the subsidy. The doctors are obliged to prescribe the cheapest appropriate product from the national list except there are professionally based arguments in favour of a costlier device.

Only one product can be prescribed from each ISO class. It means that if a person needs an active wheelchair to be used outside, and a manual wheelchair inside their home, they can have only one of these with state-subsidy. Every product on the list has a 'time limit'- a certain amount of each product can be prescribed for a certain amount of time. E.g. in case of a wheelchair, this time is eight years, meaning that every person can have one wheelchair in eight years. In other words, if a wheelchair becomes unusable earlier than the eighth year of usage, the user cannot ask for another with social insurance subsidy.

The prescriptions can be used only in medical device shops or at retailers who are also contracted to the NHIFM. The doctors decide about the type of devices but, in principle, the prescription can be turned over to any distributor whose product is on the national list with the prescribed ISO code.

This process takes a considerable amount of time and tends to be overruled. According to the interview subjects, it happens many times that the users prefer to buy the products second-hand. Especially in cases when there are no appropriate devices available with state-subsidies.

The national list of medical devices with subsidies

The research showed that there are people whose needs are unmet because the national list does not contain the necessary devices. The professional interviews confirmed that the more specific the need, the fewer opportunities the end-users have in case they need a price subsidy.

The list of products with a subsidy, based on ISO class and sub-class, with the amount of subsidies, are collected in Figure 2, in the Appendix.

The device groups have not been updated since 2009; the products are listed based on the ISO 9999:2003 standard. None of the interviewed experts could explain why the standard is obsolete. Using the 2003 version is an indirect impediment of providing specific types of devices, namely products for education and for training skills, products for controlling carrying, moving and handling objects, products intended to control or modify specific elements of the physical environment or to measure the conditions and components of the natural or physical environment, products for recreation and leisure and also, there is not a code for devices for work activities and participation in employment. Hungary participated in World War I. and II. when the first medical devices – mostly prothesis – were provided to the injured soldiers. Disability insurance was introduced in 1928 when the basis of the current medical device provision system was created. The changes in the provision process did not follow the technological and the market developments nor the paradigm shift in the approach to disability.

The Hungarian list still contains bandages with the ISO code 02, with 375 products. The ISO 21 code is called 'Devices for communication, informing and signalling' but if we take a more in-depth look into the products' list, there are no communication boards, no communication software, no Braille devices, no alarming devices. There are more than 860 products in this group, but it is limited to spectacles and contact lenses, voice prothesis, digital speech aids, hearing aids, alarm clocks and equipment for these. (See Figure 2 in the Appendix.) In 2017 the Commissioner for Fundamental Rights (ombudsman) stated in his report, that the lack of available communication devices with social insurance subsidies is against the principle of equal opportunities and equal treatment, improving accessibility was essential for human right reasons (30).

The subsidised devices had been compared with the WHO Priority Assistive Products List (3), the results are in Figure 3 in the Appendix. The need for an update is evident: the state provides less than half of the 50 priority products in Hungary.

There are only a few products which are made for, or available in the size of children. This problem mainly arises in case of children with severe disabilities considering their needs for

more devices and their need for adaptation of the available devices at the same time – the cost of adaptation is not covered in the subsidies.

AT-related services

Assistive technology means not only devices but related services and systems. The definition of medical devices in section IV.1. seemed to suggest that the related services are missing from the legislation. In practice, the provision of medical devices does not contain the costs of related services like adaptation, training, or accessibility of the living environment; furthermore, the Hungarian care system lacks occupational therapy (2). The CRPD states that governments are responsible for the users to be trained to use AT, too. All the user interview subjects mentioned this as a severe deficiency because often they cannot use the devices properly or they find them uncomfortable because no one helped them learn how to adjust the products. It also meant that some devices are provided but remain unused.

The interviewed users reported that in case they need adaptation or additional tools (e.g. a tablet stabilising for a wheelchair) they must pay for these or try to solve the minor changes themselves. Almost all the interview subjects mentioned that they deal with situations like this with the help of family and friends, or they rely on the favour of the manufacturers and suppliers. The state-subsidies include the cost of repair and maintenance of the products. These services need to be prescribed by a doctor, too. In case the user made a change in the device themselves, and it breaks down, the cost of repair might not be covered any more.

The state does not provide any opportunities in case the user does not need the device anymore, even if it was subsidised. These products remain unused, become unsorted waste or enter the secondary market.

Discussion

Examining the AT- or disability-related legislation, it can be considered that access to assistive technology is not a universal right. It appears that a well-defined and well-designed AT delivery programme is missing, which should contain the provision of the AT-related services, too. Based on the policy analysis and the interviews, four main challenges can be identified in access to AT in Hungary, in 2019: the provision system is obsolete, follows the medical model of disability, and inequitable; furthermore, most actors in the process lack information.

The system is not up-to-date, and there appears to be a considerable obstacle to modernise it: the financial-economic aspects have precedence in policy-making over professional and user-orientated considerations. There is only financial-economical and some health-related factors to consider before any update of the national list. Figure 2 and 3 suggest that the granted devices support biological needs more than any other, less than the independent living of people with disabilities.

It was found that there are massive inequalities between Hungarian people who can afford a product themselves and the ones who need financial support to do so (see Figure 1). One

of the essential human rights is ignored depending on the financial status of the user: freedom of choice. If a person does not have enough money to buy the products and pay for the related services as well, many decisions are made instead for them (it suggests the medical approach of disability): the doctor decides if the need is essential (based on the indicators defined by the NHIFM), and he decides which product he prescribes (the least expensive appropriate); then the user should buy the product in a contracted shop. The family has no opportunity to choose another product or ask for any changes (from additional tools to changing the colour) unless they lose the subsidy.

Paying for the 10, 20, 30 or 50% for the devices as a co-payment is also financially difficult for the users. In principle, the public health care cards for the most disadvantaged, and equity subsidisation of individuals for specific cases are the possibilities of getting subsidy based on equity. In practice, only a small portion of the whole social insurance expenditures are spent on these kinds of subventions. The decision-making process of the individual equity applications is rather about the financial-economic aspects of the NHIFM than about the status and actual need of the users.

The greatest losers of the obsolete system and inequity are people with communication disorders and severe disabilities as well as people with mental health conditions -, especially children. They are the ones whose needs are often unmet because of their specific needs, particularly disadvantaged social-economic status, the lack of available subsidised devices.

Awareness should be raised about assistive technology not only among people with disabilities or functional limitations but among doctors and in the whole society.

Opportunities

There is a need for re-imagining the delivery system of assistive products, regarding the legislation, policy and the available state-subsidised devices, too.

Some experts suggest that specific subsidised devices should be lent to the user contrary to the current process where the users are owners and have difficulties what to do with the products after they do not need them anymore (see, e.g. Denmark (31)). There are NGOs which provide lending opportunities for devices which are not available with state-subsidies, e.g. augmentative and alternative communication products, toys, household articles. The longstanding state systems, like social insurance, are hard to reform. Good international practices can be examples, taking into account the country-specific characteristics and welfare schemes.

The political will and engagement in rethinking the current provision system are essential, in collaboration with civic organisations. The Hungarian civil society has a significant influence on the lives of people with disabilities, and their advocacy activities have had significant impacts. In 2018, eight organisations submitted a proposal to the Ministry of Human Resources in order to reregulate the current provision system (31). The civic organisations have suggestions, regarding the renewal of the whole legislation, the need for a responsible person from the Ministry, and adding devices (e.g. AAC technology) on the list (32). In 2019

the Ministry started to organise a working group meeting, by the end of August. It is a significant opportunity to rethink the current system and start working on making it more accessible, affordable, and equitable – involving the users themselves.

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Appendix

Figure 1. Process of accessing assistive technology in Hungary. The user's point of view

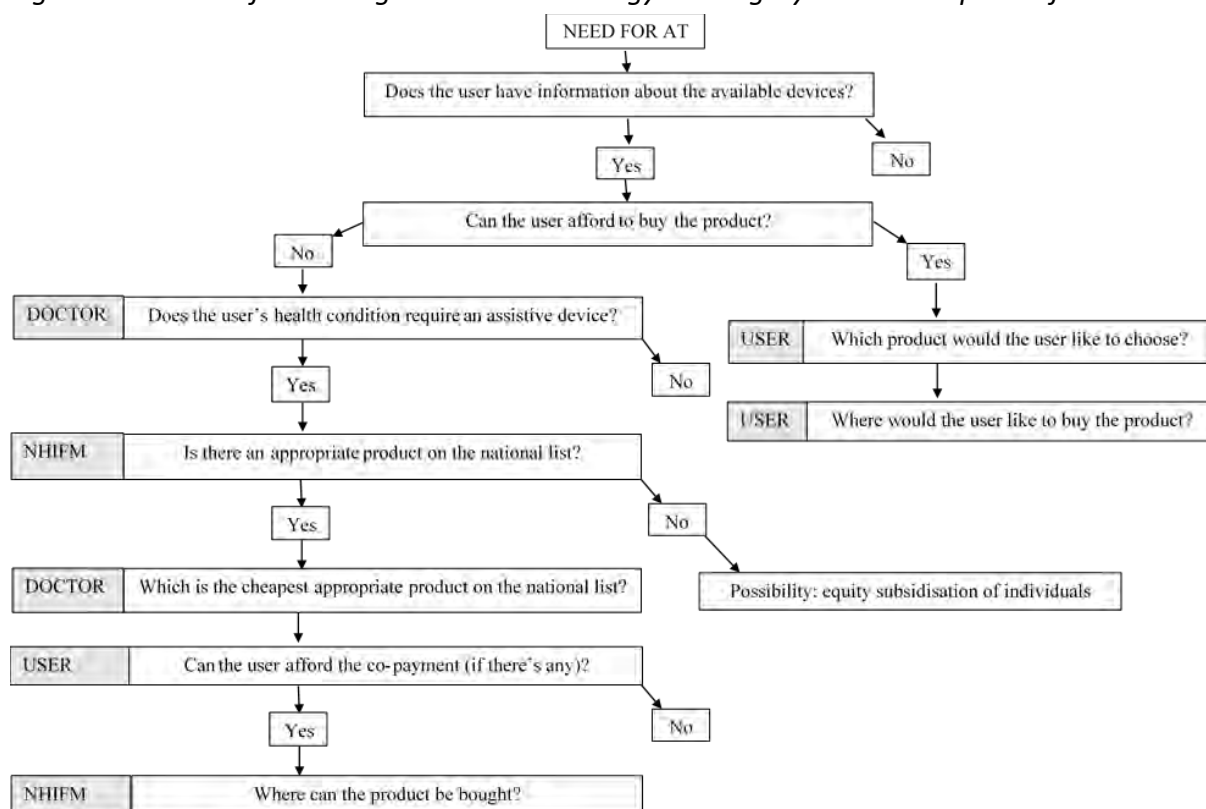


Figure 2: Groups of devices on the Hungarian national list, number of products (piece), amount of social insurance price subsidy (%) based on ISO classes and sub-classes

ISO	Device group (name)	Piece	Subsidy (%)
02	Bandages	375	80*
04	Personal treatment devices	424	50, 70, 80*
04 03	Devices for respiration	84	50, 80*
04 06	Devices for circulation therapy	158	80*
04 12	Devices for ventral hernia	86	70*
04 16	Devices for taking medicine	42	80*
04 24	Physical, physiological and biochemical test equipment and materials	18	50, 80*
04 27	Muscle stimulators	11	50, 80*
04 39	Blindfolds	10	80*
04 45	Devices for spinal traction	0	-
04 48	Equipment for movement, strength and balance training	15	70
06	Orthoses and prostheses	597	50, 70, 80, 90, 98*
06 03	Spinal and cranial orthoses	103	50, 70, 80*
06 06	Upper limb orthoses	69	70, 80*
06 12	Lower limb orthoses	200	50, 70, 80, 90, 98*
06 18	Upper limb prostheses	18	98

ISO	Device group (name)	Piece	Subsidy (%)
06 24	Lower limb prostheses	59	70, 98
06 30	Prostheses other than limb prostheses	130	50, 80*
06 33	Orthotic shoes	18	50, 80, 90
09	Devices of personal care and protection	957	50, 70, 80, 98*
09 03	Clothes and shoes	49	70*
09 06	Body-worn products for body protection	17	98
09 12	Products for toileting	25	80*
09 15	Products for tracheostomy care	43	98
09 18	Products for ostomy care	527	50, 98*
09 24	Urine diverters	54	80*
09 27	Products for collecting urine	13	80*
09 30	Products for absorbing urine	217	50, 80*
09 33	Products for washing, bathing and showering	12	80*
12	Devices of personal motion	141	50, 80, 90, 98*
12 03	Products for walking, manipulated by one arm	39	80*
12 06	Products for walking, manipulated by both arms	26	80*
12 16	Mopeds and motorcycles	8	80
12 21	Wheelchairs	55	80, 90*
12 24	Wheelchair accessories	6	50
12 39	Products for orientation	7	98
15	Products for domestic activities	10	98*
15 09	Products for eating and drinking	10	98*
18	Furniture and flat alteration	67	80*
18 09	Sitting furniture	32	80*
18 12	Beds	19	80*
18 18	Supporting handrails and grab bars	16	80*
21	Devices for communication, informing and signalling	862	50, 70, 90, 98*
21 03	Optical aids	401	50, 70 90*
21 42	Products for face-to-face communication	6	98
21 45	Hearing aids	455	50, 70*

Notes: * Amount of subsidy is not a certain percentage of the price but a predefined (net) amount of money which will lower the price the users have to co-pay.

Figure 3: Devices on the Hungarian national list (Yes or No) compared to the WHO Priority list

ID	Lists in the WHO Priority List	Y/N
1	Alarm signallers with light/sound/vibration	No
2	Audioplayers with DAISY capability	No
3	Braille displays (note takers)	No
4	Braille writing equipment/brailers	No
5	Canes/sticks	Yes
6	Chairs for shower/ bath/toilet	Yes

ID	Lists in the WHO Priority List	Y/N
7	Closed captioning displays	No
8	Club foot braces	Yes
9	Communication boards/books/cards	No
10	Communication software	No
11	Crutches, axillary/ elbow	Yes
12	Deafblind communicators	No
13	Fall detectors	No
14	Gesture to voice technology	No
15	Global positioning system (GPS) locators	No
16	Hand rails/grab bars	Yes
17	Hearing aids (digital) and batteries	Yes
18	Hearing loops/FM systems	No
19	Incontinence products, absorbent	Yes
20	Keyboard and mouse emulation software	No
21	Magnifiers, digital hand-held	No
22	Magnifiers, optical	No
23	Orthoses, lower limb	Yes
24	Orthoses, spinal	Yes
25	Orthoses, upper limb	Yes
26	Personal digital assistant (PDA)	No
27	Personal emergency alarm systems	No
28	Pill organizers	No
29	Pressure relief cushions	Yes
30	Pressure relief mattresses	Yes
31	Prostheses, lower limb	Yes
32	Ramps, portable	No
33	Recorders	No
34	Rollators	Yes
35	Screen readers	No
36	Simplified mobile phones	No
37	Spectacles; low vision, short distance, long distance, filters and protection	Yes
38	Standing frames, adjustable	Yes
39	Therapeutic footwear; diabetic, neuropathic, orthopaedic	Yes
40	Time management products	No
41	Travel aids, portable	No
42	Tricycles	No
43	Video communication devices	No
44	Walking frames/ walkers	Yes
45	Watches, talking/ touching	No

ID	Lists in the WHO Priority List	Y/N
46	Wheelchairs, manual for active use	Yes
47	Wheelchairs, manual assistant-controlled	Yes
48	Wheelchairs, manual with postural support	Yes
49	Wheelchairs, electrically powered	Yes
50	White canes	Yes

Colonization, climate, and critical analysis: Examining access to assistive technology in Northern Canada using the World Health Organization's Global Cooperation on Assistive Technology initiative

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Abstract

Introduction: Northern Canada embodies a unique intersection of socio-political and physical features that influence AT access and fit, including a vast geographic area on the ancestral lands of Inuit, Métis and First Nations Peoples; an ongoing legacy of colonization, oppression and racism; a cold climate; limited accessible infrastructure, health, and financial resources; and a high cost of living. As insufficient attention has been drawn to severe inequities that can exist within developed countries and how factors such as colonization and cold climate intersect with AT access and fit, we are interested to explore if the World Health Organization's (WHO) Global Cooperation on Assistive Technology (GATE) can support access to AT for residents of Northern Canada. We seek to achieve two objectives in this paper: 1. outline unique AT access challenges in Northern Canada and 2. critically investigate GATE's conceptual potential to support advocacy to address these challenges

Approach: To inform and structure analysis of this paper's two objectives, we drew on the Indigenous Intersectionality-Based Policy Analysis (IIBPA) framework, GATE's literature about colonization and Indigenous worldviews in Northern Canada, and reflections of Indigenous and non-Indigenous health-care providers with Northern practice experience.

Findings: AT access challenges in Northern Canada are described using GATE's 6 Ps of key topics influencing AT access (people, place, products, provision, personnel and policy). The broad inclusive values of GATE have potential to support improved AT access for residents of Northern Canada. However, many of GATE's proposed solutions to improving AT access are not directly relevant in Northern Canada and would require critical and reflexive application to adequately address Northern contexts, in association with locally generated solutions that respect Indigenous ways of knowing. GATE's overarching human rights and social justice values can be undermined by solutions informed by neoliberal ideology.

Discussion: We recommend that the uptake of GATE in Northern Canada attend to the legacy of colonization and context-specific AT needs, along with their associated impacts on equitable access to AT. GATE would benefit from greater attention to socio-political and physical features impacting inequitable access to AT within developed countries and supports to address these.

Keywords

GATE, Northern Canada, colonization, equity, assistive technology

Introduction

Assistive technology (AT) has the potential to equalize opportunities for individuals living with disabilities and older adults through maximizing everyday functioning, independence and inclusion (1-3). AT needs are context dependent, as solutions work best when they match the needs of people in the place where they are, at the time they are required (4). This paper explores the unique context and AT requirements of Northern Canada, and the fit of the World Health Organization's (WHO) Global Cooperation on Assistive Technology (GATE) to support advocacy for AT solutions in this region.

Although Canada's population has better access to AT than the global average, the current Canadian AT system is described as underfunded (5); highly fragmented, restricted and difficult to navigate (5, 6); unresponsive to the needs of people it is intended to benefit (5-7); and lacking central engagement of its users (5, 7). Canada does not have federal legislation that stipulates universal access to AT, and the responsibilities for AT fall primarily to the provinces and territories, resulting in a complex web of programs offering a patchwork of devices and services (6, 7). This results in inequity of access to AT across the country.

We focus in this paper on access to AT within Canada's Northern regions. These areas embody a unique intersection of socio-political and physical features that influence AT access and fit, including a vast geographic area on the ancestral lands of Inuit, Métis and First Nations Peoples; an ongoing legacy of colonization, oppression and racism; a cold climate; limited accessible infrastructure, health, and financial resources; and a high cost of living. And although, it has been suggested by government bodies that AT is readily available and fully funded for most Northern residents, access to appropriate assistive products (AP) and services remains a challenge in practice. For example, wheelchairs funded to fit individuals' needs for home use are not suitable for community access over snow-covered roads, preventing individuals from being able to safely or independently leave their homes. Further, without accessible housing, a wheelchair may be of limited benefit for meeting the objectives of individuals (8-10).

Acknowledging that Canada's federal, provincial and territorial governments have much work to do in carrying out their obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (11) by making AT accessible and available to all across the country, and recognizing AT as a human right and a necessary facilitator in the achievement of the United Nations' Sustainable Development Goals (SDGs) (12), we are a group of Indigenous and non-Indigenous occupational therapists and physiotherapists with Northern and Southern Canadian and global health experience who are concerned with equitable access to AT in Northern Canada. In this paper, we:

- a. Explore unique AT access challenges that are present in Northern Canada.
- b. Critically analyze GATE's potential to lend support for improved access to AT in Northern Canada

This exploration is important because insufficient attention has been drawn to severe inequities that can exist within developed countries and the unique impacts that socio-political and physical factors such as colonization and cold climate can have on AT access and fit.

Approach

Exploring unique AT access challenges that are present in Northern Canada

To address the first objective, the authors utilized literature about colonization and Indigenous worldviews in Northern Canada and critical reflection by Indigenous and non-Indigenous health-care providers with Northern practice experience. GATE's "6P" priority topics relating to AT access (4) provided a structure for organizing results. The 6P priority topics consist of six interlinked areas: people, policy, products, provision, personnel and place. These areas were identified by the GATE community as strategic priorities for ensuring 'everyone, everywhere can access assistive products' (4). The GATE community advises that these six elements can be organized in different ways, but that all six must be in place for an AT solution to be effective. We apply GATE 6P priority topics to organize and elicit AT access challenges of Northern Canada.

Critical investigation of GATE's conceptual potential to support AT access in Northern Canada

To address the second objective, we critically analyze the potential for GATE to support AT access in Northern Canada by drawing on the Indigenous Intersectionality-Based Policy Analysis (IIBPA) framework (13); literature about colonization and Indigenous worldviews in Northern Canada; and, reflections of Indigenous and non-Indigenous health-care providers with Northern practice experience.

The IIBPA facilitates a multi-level examination of policy and programming processes in terms of their implications for equity and social justice within complex societies while foregrounding Indigenous sovereignty, Indigenous worldviews, and the need to confront colonial power (13, 14). The IIBPA is grounded in intersectionality theory, which focuses on a variety of multi-level interacting social locations, forces, factors and power structures that shape and influence one's well-being (15). Intersectionality postulates that the multiple processes of oppressions (for example, heterosexism, colonization) that have been historically embedded within systems intersect with people's social contexts and identities to create interlocking experiences of inequity at both micro and macro levels (16-18). It further suggests that access to healthcare and social services is highly dependent upon one's lived context and intersecting positions of privilege and disadvantage within the social hierarchy of power (19, 20). The IIBPA can enhance the capacity for analysis and decision

making among a range of stakeholders by capturing the multi-level interacting social locations, forces, factors and power structures that shape one's well-being while contextualizing the ongoing history of colonization (13). As such, IIBPA provides a well-suited and novel method for addressing health and social inequities in Northern Canada.

We performed our critical analysis by applying the IIBPA's guiding principles to a hypothetical application of GATE to the Northern Canada context. Specifically, we asked: How relevant is GATE's approach for enabling AT access in the context of Northern Canada? Does GATE enable access to AT to "everyone, everywhere" when applied to Northern Canada? Through a careful review of available GATE publications, we extracted what we perceived to be GATE's values and foundational characteristics, as well as its proposed solutions. Using the IIBPA, and literature and knowledge about Northern Canada, we considered the relevance and applicability of these to the Northern Canadian context. We drew values, foundational characteristics and requirements of AT solutions for Northern Canada from literature and experiential knowledge from working in Northern Canada.

Findings

Exploring unique AT access challenges that are present in Northern Canada

The context of Northern Canada, including place, people and policy, is unique within Canada. Features of the population, history, geography, climate, culture, infrastructure and access to resources produce needs and issues when it comes to AP, provision and personnel that are different from those of Southern and urban regions of Canada. In this section, we describe issues with AT access in Northern Canada in terms of GATE's 6 P's.

Place

What we describe as Northern Canada includes the traditional territories of Inuit, some Métis and several groups of First Nations Peoples. In terms of settler-defined¹ jurisdictional boundaries, this region includes Canada's three territories (Nunavut, Northwest Territories and Yukon) and the northern regions of most of Canada's provinces. Refer to Figure 1 for a map of Canada².

The climate of Northern Canada has temperatures much lower than Southern Canada. Its high latitude means the days are longer in the summer and shorter in the winter. Daylight and temperature create unique AT needs in terms of accessibility and AP durability.

¹ Canada's establishment as a nation was created through colonization of lands and peoples by groups of European settlers over the last few centuries. Recognizing that readers are most likely to be familiar with place names defined by the state, we use these names but qualify them as "settler-defined" to draw attention to their creation by settler populations.

² Readers will note that we don't draw a firm line to enclose boundaries of what we are calling Northern Canada. We have left this intentionally vague because not all issues discussed will apply evenly across all its areas.

Figure 1. Map of Canada.



Northern Canadian communities are often at great distances from one another and urban centres. Transportation to urban centres, where additional material and health-care resources can be accessed, is typically expensive and may be only possible by airplane. For example, a return flight to Nunavut communities from Ottawa (the city from which these communities access specialized resources) ranges in cost from approximately \$1,000 to \$8,000 USD³. Accordingly, shipping to Northern communities is expensive and slow and may only be possible when waterways are free of ice.

People

The residents of Northern Canada include both Indigenous Peoples and people of settler ancestry. As a result of colonization, significant inequities exist between many northern residents. For example, the median annual income before tax for Inuit is \$ 17,839 USD \$51,000 USD less than that of non-Indigenous people in the same region (21). Inequities also exist between residents of northern and southern parts of Canada. For example, residents of parts of Northern Canada have a shorter life expectancy than other Canadians (22).

³ All conversions from Canadian dollars to United States dollars (USD) were completed on July 29, 2019. Amounts are communicated in USD for ease of communication to a global readership.

Northern regions are less densely populated than Southern regions of Canada. For example, while they make up more than a third of Canada's land mass, the three Northern territories (Yukon, Northwest Territories and Nunavut) make up 0.3% of the country's population with just over 113,000 people at the last census (23).

Indigenous Peoples in Northern Canada may subscribe to worldviews that are distinct from Western worldviews, which dominate in Western nations. Indigenous worldviews are comprised of values, beliefs, knowledge, and ways of being and doing that have evolved over centuries on their ancestral lands. As such, the Indigenous Peoples of Northern Canada know these regions best. They have been innovating and responding to challenges in this environment for millennia. This is a key resource that would support appropriate AT for the context.

Policy

In Northern Canada, consideration of policy must include both current and historic policies, as they both impact current lived experience in Northern Canada. Colonization in Northern Canada, as in the rest of the country, included colonial policies and tools such as residential schools, forced relocations and high rates of child apprehension, designed to eliminate Indigenous Peoples through assimilation or genocide (24, 25). A direct line of causation can be drawn between colonization and the health, education and income inequities between Indigenous and non-Indigenous Peoples in Canada today. Government policy responses, historically and at present, have been slow, ineffective and often inappropriate. Indigenous peoples in Canada report experiencing systemic racism and services that do not align with their worldviews during encounters with health-care services (26). Indigenous populations in Northern Canada experience severe rates of food insecurity, crowded housing, unemployment and infant mortality (22, 27). Access to health care services in the north, including AT experts, is significantly less than in other parts of Canada (21).

National reports (24, 25, 28) call for increased equity in access to services, resources and basic rights, of which AT can be considered a part. These documents call for change to occur in a manner that respects and is guided by Indigenous worldviews.

AT funding access differs according to province or territory, with some northern regions providing greater funding access than others to cover the cost of AT. Indigenous peoples across Canada have access to a supplementary funding source, called Non-Insured Health Benefits, to pay for health-related goods and services, including much AT. Given limited local access to specialized equipment and services, Northern Canadian residents may be restricted by travel policy that limits transportation and lodging funding, and therefore access to AP and training.

Products

AT for Northern Indigenous residents must fit with their worldview and culture, including language, values, knowledge, relationships and community activities. We know of no

evidence that Indigenous Peoples in Northern Canada have ever been consulted in the design of commercial AP.

Cold temperatures and snow-covered or dirt roads may impact AP that are used or transported outside. Public and accessible transportation and accessibility infrastructure (e.g., paved sidewalks, ramps) is scarce, creating both barriers to AT and increased opportunities for AT breakage. Many people travel across land and water by boat or snowmobile and sled to reach camps or hunting grounds, and as such may spend significant time outside and away from electricity required to charge AT devices. Further, cellular phone coverage and internet bandwidth are generally reduced, which impacts the usability of AT devices that require these technologies.

Experience using mainstream AP in Northern environments has shown us that many AP are designed with the assumption of an urban, temperature controlled, accessible environment. Devices designed for areas with less accessible infrastructure (e.g., tricycles) are not necessarily applicable in Northern Canada as they are often designed for use in settings without snow.

Personnel

Professionals who would prescribe, fit and provide training on AT, do not live in many Northern communities. Rather, they often visit communities periodically and/or follow clients using telehealth. These professionals tend to be generalists, which limits specialization in particular AT. Most therapists are non-Indigenous and, although they may live in the North, they may not understand Indigenous worldviews and their relevance for AT, leading to a culturally unsafe service. Canadian health professions regulatory organizations require any delegation of services to unskilled care providers to be closely monitored and performed under specific conditions. Although these standards are set to ensure client safety, this also results in some level of gatekeeping and reduced access to assistive technology if Northern residents must wait for a therapist to be available.

Generally, across the north, residents requiring specialized services, including some AT prescription, must travel to Southern urban centres. Professionals prescribing specialized AT in Southern urban centres have often never traveled to Northern Canada and are not familiar with AT needs specific to this context. This lack of insight can result in prescription of inappropriate devices, ineffective training on AT usage (e.g., how to use a wheelchair in snow or dark conditions), inappropriate usage of scarce funding resources and significant delays.

Provision

While the Canadian government maintains basic publicly funded health facilities and services in Northern communities, AP suppliers are entirely private enterprises. Communities with small populations do not typically provide a large enough market for AT vendors and technicians to be based locally, and so they may visit periodically or conduct their work via videoconferencing, email, phone and shipping. As such, people may not be

able to trial equipment before placing an order. On delivery, AP assembly and training may be provided by someone locally with limited knowledge of the product. When AP need repair, people may choose between going without the item for long periods of time while damaged parts are shipped away for repair, wait for a professional to come to town, purchase a new item if they can afford it, continue to use the item in bad repair (with safety risks) or employ local expertise that may or may not be appropriate.

Taken together, the factors described above according to the six P's, when compared with equivalent factors in Southern or urban Canada, present patterns of disparity, including: decreased or slower access to AT, increased risks for personal injury, potential for inappropriate AT fit, concern for equipment breakage and, overall, less than optimal participation in meaningful activities. In the following section, we explore how GATE might support increased access to AT in Northern Canada.

Critical investigation of GATE's conceptual potential to support AT access in Northern Canada

The findings from our first objective (above) identify AT access issues in Northern Canada. Considering these through the framework of the IIBPA and in the context of literature and our experiential knowledge, we have assessed GATE's fit and opportunity for supporting increased access to AT in Northern Canada.

We found that the broad inclusive values of GATE have potential to support improved AT access for residents of Northern Canada and Canada's SDG commitments by arming stakeholders with tools, education and a philosophy for AT access (see Table 1). However, many of GATE's proposed solutions to improving AT access are not directly relevant in Northern Canada and would require critical and reflexive application to adequately address Northern contexts, in association with locally generated solutions that respect Indigenous ways of knowing (see Table 2). GATE's overarching human rights and social justice values can be undermined by solutions that are underpinned by neoliberal ideology⁴. For example, the AT industry would not be expected to profit from designing affordable arctic-ready wheelchairs to meet the needs of the small population that require them. Further, solutions targeting individuals can miss opportunities for community-level interventions that may have broader impact, such as obtaining wheelchair accessible public transportation when individual mobility devices capable of traversing snow-covered roads do not exist. Finally, GATE would benefit from greater acknowledgement of the socio-political complexities impacting inequitable access to AT within developed countries and supports to address these.

⁴ Neoliberalism refers to an economic model that privileges private over public control, and which promotes specific values, including individualism, efficiency and productivity (29).

Table 1. Considering the values and foundational characteristics of GATE in terms of the Northern Canadian context.

Values and foundational characteristics expressed in GATE	Values and foundational characteristics of shared relevance	Values and foundational characteristics relevant to Northern Canada
<ul style="list-style-type: none"> • Focus on global solutions • AT enables “independent and dignified lives” • Western, neoliberal underpinnings evident in some sections • Focus on individuals 	<ul style="list-style-type: none"> • Social justice and equity • Social participation and function • Redressing of power differentials between service users and providers • Universal access to AT and context-specific AT design • Diverse knowledges • Research and innovation • Supports attainment of Sustainable Development Goals • For “everyone, everywhere” • Draws attention to current inequities • Recognizes limitations of current AP, developed primarily for needs of high-income settings • Responds to the United Nations Convention on the Rights of Persons with Disabilities • Recognizes insufficiency of existing AT funding in most countries. 	<ul style="list-style-type: none"> • Indigenous worldview • Consideration of colonization and ongoing legacies of oppression and racism • Understanding of remote arctic communities • Focus on individuals and the collective

Table 2. Considering solutions proposed by GATE in terms of the Northern Canadian context.

Solutions proposed by GATE	Solutions of shared relevance	Solutions relevant to Northern Canada
<ul style="list-style-type: none"> • Have many neoliberal underpinnings <ul style="list-style-type: none"> ○ Focus on individual needs ○ Suggest markets can be counted on to support increased access to AT (by pooling AT needs of currently underserved users, the AT industry stands to profit) ○ Standardization. E.g., a) assuming priority equipment for a country can be pre-determined in one list doesn't account for intra-country differences, b) a central agency overseeing all distribution becomes de facto gatekeeper. • Determined through voting and consensus among broad groups of AT users • AT recommendations for community mobility presume a hot climate or urban environment (e.g., a tricycle wheelchair is appropriate in equatorial countries, and a power wheelchair is appropriate in urban high-income countries with paved sidewalks and accessible public transportation, but no products are proposed that are effective in remote, low-resource, cold climates). 	<ul style="list-style-type: none"> • Draw attention to some "priority" equipment not currently funded through Canadian funding systems • Address intersecting categories of access to resources, disability, age and socioeconomic status. • Recommend including AT users in all stages of research and policy development • Support advocacy for devices suited to the Northern climate 	<ul style="list-style-type: none"> • Must respond to all intersecting social locations of Northern residents with disabilities <ul style="list-style-type: none"> ○ Must be developed with and by Indigenous peoples, specifically valuing Indigenous knowledge ○ Must meet the resource and geographic features of rural and remote arctic communities • Require reflexivity to meet individual and community needs • Allow room for resistance by Indigenous peoples to standards applied to the broad Canadian population • Have flexibility to adapt to needs of specific individuals and communities, which are expected to change over time and space • Support advocacy for community-level needs, including infrastructure, public transportation, funding systems, etc.

Discussion

Based on our exploration and analysis, we recommend that the uptake of GATE in Northern Canada:

- a. Represent a reflexive process resulting in flexible dynamic solutions that involve collaboration with Indigenous peoples and other Northern residents, and that support advocacy for individual and community-level solutions and infrastructure.
- b. Centre local values, priorities, knowledge, language and partnerships in the development of the local AT access solutions. For example, GATE proposes country-wide Priority Assistive Products Lists (APL) but for a country as diverse as Canada, a country-wide APL may not be appropriate as needs in Canada's cities will differ significantly from regions such as Northern Canada.
- c. Consider focusing on the *activities and meaning of these activities to the local population* rather than listing specific devices (e.g., "community mobility" rather than "tricycle") to promote fit adaptable to context and to consider community-level infrastructure in addition to AT devices for individuals.
- d. Understand and mitigate barriers posed by systemic and structural factors (e.g., AT funding and provision structures, systemic racism within healthcare)
- e. Support advocacy to government for reduction of inequity in access to AT
- f. Understand and mitigate the legacy of colonization and its impact on equitable access to AT. Guidance from the Truth and Reconciliation Commission of Canada, National Inquiry into Missing and Murdered Indigenous Women and Girls, and United Nations Declaration on the Rights of Indigenous Peoples may inform GATE's application within Indigenous communities in Canada.
- g. Support the self-determination of Indigenous peoples by ensuring opportunity and resources to self-define AT needs and apply Indigenous worldviews.
- h. Include development of a communication network among circumpolar arctic countries to exchange knowledge.

Through exploration and analysis, we have identified key insights that may hold significance for the uptake of GATE more broadly, in addition to in Northern Canada specifically. These relate firstly to the need for recognition of and space and respect for Indigenous knowledge. It is important to remember that the way in which this knowledge is employed will not necessarily follow Western norms and is crucial for ensuring that the needs of Indigenous populations are met. Employing a global strategy such as GATE unquestioningly in a place such as Northern Canada could risk replicating colonial forces. AT providers are challenged to reflect on how they are implicated within colonial structures impacting AT provision, policy and products. Facilitating local rather than country-wide application of GATE solutions can also help to ensure contextual relevance. Further, colonialism's legacy in an area creates challenges to AT access that are not easily captured within GATE's 6Ps. The IIBPA guides users to foreground colonization as a key factor impacting the lives of Indigenous Peoples. Beyond this, we recognize that around the world, stigma and oppression impact people with

many identities beyond Indigeneity, including age, ability, religion, gender, etc. As such, we suggest that a 7th P, power, be considered to draw specific attention to the ways that oppressive social forces can impact access to AT. Attending to power through an intersectional lens enables understandings of the many ways that multiple identities and social locations can impact an individual's access to AT.

Another key lesson relates to the global norm of operating on a capitalist economic model. Neoliberal solutions, so "normal" to so many of us that they hide behind good intentions, will, by their own design, leave some people behind and reproduce inequitable access to AT. Research and development of AT to meet the needs of relatively small populations, such as those in arctic regions is expected to be expensive as arctic models of AT devices and service delivery cannot be applied to a wide range of settings, thus preventing manufacturers from financially benefiting from mass production. While market-based solutions may be of benefit in some regions, putting an emphasis on solutions that emphasize the meeting of rights above all can help to ensure that those who belong to population groups that would not support market-based solutions are not left behind. Accountability in access to AT is needed and should be the purview of governments rather than private enterprises.

Through the analysis presented in this paper, we have found overall that there is much opportunity for GATE to support the AT access needs of Northern Canadian residents if applied in a reflective and contextually relevant manner. Further, there is opportunity for the lessons found here to contribute to ongoing conversations about GATE's evolution on a wider scale.

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Improving access to incontinence assistive technology in developing and resource-constrained countries

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Abstract

Incontinence, as opposed to other disabilities in need of AT, is hidden, silent and much more shameful. Recent research in Canada has documented just how under-reported and managed both urinary and fecal incontinence remains exerting huge social and economic pressures on the affected individuals, their families and society as a whole. Almost 9% of the world's population suffers from incontinence making it, if it were a country, the third largest in the world. Reported prevalence may differ by country, population or region but incontinence is a global health issue. The barriers to access to incontinence AT has been documented for developed countries and the barriers to access to healthcare generally has been documented for low-income countries but access to AT for incontinence in low- and middle-income countries has not been examined to date. This paper attempts to close this gap in knowledge as yet another piece in the AT puzzle being assembled by the GReAT Consultation. This paper also calculates the economic benefit of incontinence being properly managed in developing and resource-constrained countries.

Keywords

Assistive technology, Barriers to access, Continence, Developing countries, Incontinence.

Introduction

Incontinence is not a single disorder but a symptom of a family of related conditions with different etiologies; it is chronic and carries an enormous stigma. Despite what many think, incontinence is not a normal part of the aging process; incontinence is usually a result of a combination of pathologic, physiologic and pharmacologic factors. In few medical areas is so much known, so much misunderstood, so little spoken, and so little done. To improve continence care anywhere does not require investigative or developmental prowess but a simple, concentrated effort to diffuse existing knowledge to close the knowledge gaps, both at the healthcare provider and patient level, in simplified layperson's language.

Incontinence, as opposed to other disabilities in need of AT, is hidden, silent and much more shameful. Recent research in Canada documented just how misunderstood, under-reported and unmanaged both urinary and fecal incontinence remains exerting huge social and

economic pressures on the affected individuals, their families and society as a whole (1). Incontinence has a negative impact on quality of life and often leads to disturbed sleep, loneliness, stress, isolation and exclusion from mainstream economic and social activities including education and employment. Co-morbidities often include skin irritation and breakdown with related infections, asthma, diabetes, high blood pressure, bladder or prostate cancer, depression, and neurological conditions (2).

Almost 9% of the world's population suffers from incontinence making it, if it were a country, the third largest in the world yet it is almost totally ignored by healthcare providers, leaders and investigators leaving patients to suffer in silence and embarrassment preventing them from fully realizing their potential. There is no evidence to suggest that the prevalence differs by arbitrary country boundaries, populations or regions – only by gender and age with incontinence being more prevalent amongst women (14%) than men, and more amongst seniors over the age of 65 (12%) (3). Although many individual country statistics are not available, and those that are available are debatable because of inconsistent definitions and methodologies used, for some developing countries the prevalence of incontinence may need to be adjusted downwards to account for lower life expectancies, or upwards because of gender ratios.

The Commission on Intellectual Property Rights, Innovation and Public Health has declared that all governments have failed in addressing poverty and health in developing countries. According to the World Bank the real threat to developing countries today is not environmental degradation – although very real – but poverty. Open markets, economic growth and education (especially female literacy) go hand in hand but the 10% of the developing world's population suffering silently with incontinence need not wait for this generational shift to better manage their symptoms.

The barriers to access to incontinence AT have been documented for developed countries (4) and the barriers to access to healthcare generally has been documented for low-income countries (5) but access to AT for incontinence in low- and middle-income countries has not been examined to date. This gap in knowledge is another piece in the AT puzzles being assembled by the GReAT Consultation. Evidence from developed nations as well as evidence from developing countries has shown that centralized government bureaucracies are also not the answer but decentralized systems wherein competition is allowed. The provision of incontinence AT is a case where public-private partnerships will probably have the greatest results (13). Industry members in collaboration with NGOs, such as the World Federation of Incontinence Patients, and a third-party funding agency would be an example.

This paper's objectives were to (i) extrapolate from the literature a framework of barriers to access to incontinence AT in low- to middle-income countries; (ii) quantify the social and economic benefit from addressing those barriers; and (iii) recommend action steps by which those barriers to access may be overcome and patients receive the AT they need.

Methods

With an extensive network of colleagues world-wide the authors have over the years researched and written extensively - both qualitatively and empirically - about the barriers to access to incontinence AT. They have successfully influenced healthcare curricula, industry practices and government policies although much remains to be done. One of the studies published in *Public Health Research* won the 2019 award for best contribution to public health knowledge.

The barriers to healthcare products in low-income countries has also been researched and documented by the collaborator and his research colleagues. Cost, education, and supply chain security and management are all key along with infrastructure issues such as potable water and lavatories for hydration and hygiene.

Previously the authors conducted a full literature review of incontinence the results of which were reported in 2018 (3). Using the key words for this article as search parameters of the literature since 2018 as cited in PubMed, MEDLINE and Google Scholar, 264 articles met the parameters. However, when these were screened for the theme under which this paper has been written – challenges in access to AT – there remained only clinical papers calling for the need of the sort of research being conducted by the GReAT Consultation. It was an unproductive iterative loop conditionally validating our claim that incontinence is a hidden, under-studied condition affecting 1 in 10 people worldwide the moderate and severe sufferers of which can benefit greatly from AT. Based upon this the authors qualitatively extrapolated a framework of access issues regarding AT and incontinence in low- and middle-income countries. This, in turn, was used to develop solutions and an action plan. The original economic analysis was conducted by the authors to quantify and monetize the benefits of taking action. The economic benefit calculation was presented as an increase to GDP as a result of increased participation by incontinence sufferers in their economies as a result of improved access to AT based upon previous modelling.

Findings

Continence care in developed countries: patient needs, barriers to access to AT, and solutions

In developed countries there are often gaps in healthcare funding, and continence is one of the conditions that often fall into those gaps. In Canada, for instance, 38% of Canadians have no group insurance health coverage, and in 2015 over 180,000 Canadian households mortgaged their homes to cover unaffordable healthcare costs (6). To use a term that has been often used in the USA, there is a “doughnut hole” in health insurance and government assistance – a segment of the population left without coverage or support. For the incontinent population with scarce personal resources this includes:

- individuals/families with high out-of-pocket expenses relative to their income (especially seniors living at home with an average combination of government pensions);

- people not covered with private health, medical or disability insurance and/or whose insurance does not cover continence products;
- those who work seasonally, part-time or are self-employed;
- individuals/families who may not be eligible for private or supplemental insurance;
- people with high drug costs in addition to other product costs such as continence products;
- those with a significant loss of salary due to their irresolvable incontinence.

In Canada, incontinence costs Canadian employers over 11.5 million person-days of lost work and over CAD2billion in lost productivity. On a yearly basis incontinence adds CAD3.8 billion to health care costs nationally. In total, incontinence costs Canadians nearly CAD8.5 billion annually (7).

In Ontario alone – Canada’s largest province by population with just over 14 million people - the funding shortfall was nearly CAD1 billion with about one-third of that borne by individuals living at home and two-thirds living in long-term care facilities. The average senior suffering from incontinence living at home in Ontario pays out-of-pocket CAD1500-2250 on continence supplies – up to 10% of their income (8)¹.

Healthcare in developing/resource-constrained countries: patient needs, barriers to access, and solutions

The heterogeneity and non-standardized nature of the small number of epidemiological studies of incontinence in the developing world does not provide a reliable estimate of the prevalence of incontinence. For example, in single studies the prevalence of just urinary incontinence (UI) ranged from being 2.8 in Nigeria (9) to 57.7 in the Islamic Republic of Iran (10). Different definitions of UI, under-reporting in some cases due to the stigmatization of those suffering from incontinence, and inconsistent stratification and representation of populations studied confound these findings. Despite these study flaws, however, it cannot be denied that incontinence is as much of a problem for people living in developing countries and countries that are resource-constrained as it is in the developing world.

In recognition of this, in 2016, WHO launched its Priority Assistive Products List (APL). In the discussion leading up to the approval of the APL it was recognized that incontinence can be as disabling as not being able to walk; for many suffering from incontinence without AT, they cannot leave the house. Incontinence is also a major contributor to the increased risk of falls amongst the elderly. Incontinence has been considered by WHO as a mobility issue. For this reason the APL includes absorbent incontinence products and pads².

¹ 2014 cost data accessed and inflated at the cumulative inflation rate of 7.07% for 2014-2018 as per the Canadian inflation calculator, available from <http://www.in2013dollars.com/2014-CAD-in-2018>

² A survey conducted by the WHO’s Global Co-operation on Assistive Technology of its member AT organizations showed that all members wanted incontinence AT included as part of emergency supplies sent to disaster zones.

However, 90% of those in need of these AT products cannot access or afford them (11). Amongst the developing countries of the world the average GDP per capita is approximately USD1200, literacy rate is 74% (lower for women than men) and life expectancy is 63 years. For the 50 least developed countries comparable figures are USD300, 52% and 50 years respectively. But poverty is not the only barrier to access of AT. In many of these countries there is little or no rule of law, human rights are violated, corruption is rampant, infrastructure is minimal and healthcare nominally or not at all state financed. NGOs and third-party programs often fail to deliver healthcare because their supplies never leave the ports, are stolen and sold on the black market locally and globally, and/or health human resources and supply chain planning are inadequate/non-existent on the ground (5,12,13).

There is no scientific evidence that patents or prices are major barriers to market access, or causatively associated with worse health outcomes, in developing and resource-constrained markets. Almost all drugs deemed to be “essential medicines” by the World Health Organization are off-patent and available as generics yet one-third of the world’s population does not have access to essential medicines. The real barriers to access in these countries are money, power, politics, and ideologies, which manifest themselves in market failure, corruption, and the lack of political will to create stable, ethical, and law-abiding government administrations that will ensure products arrive where they are destined without delay, diversion, theft, or unnecessary tariffs. There is a need for infrastructure, roads, communications, health human resources, provider compliance, patient adherence, political stability, and professional regulatory structures and protections. Enhanced state capacity to serve indigenous populations and the rule of law are integral to promoting global health and healthcare, in which AT plays a vital role (5).

As a result, there are over 150 public-private partnerships to improve access to medicines in the least developed countries; 90% having been industry-led. Together they have treated a billion patients with ten billion doses of medicine and trained 350,000 health personnel in primary healthcare.

Notwithstanding all this, incontinence is seldom, if ever, a topic at the health and development table because it is invisible, greatly stigmatized, and is not directly life-threatening. However, lessons can be learned from the drug industry’s experience in developing countries. Provision of AT products at low or no cost is important but so are training in assessment, fitting, user adherence and follow-up. Industry assistance in this regard, working with nurses and basic health service providers at the community level, could expedite these elements, simplify procedures, and build capacity. Good practice guidelines already exist and need only be modified to recognize cultural, social and religious needs.

Continence care in developing/resource-constrained countries: costs and benefits

There are many treatment and management options for urinary and fecal incontinence including surgery, medication, exercises, prompted voiding and lifestyle/environmental

changes but the first line of management is the availability and use of appropriate pads – a simple, relatively inexpensive AT option which is not readily available to most patients in resource-constrained countries. When appropriate absorbent continence AT is used 95% of patients report improvement in their quality of life; when AT is appropriately chosen and fitted 38% of users experience less leakage; and 47% have a reduction in skin irritation and infection (14). With over 300 million people living on less than USD1 per day patients suffering from incontinence in the poorest of countries cannot afford even this AT.

This situation is further complicated by decision-taking around the supply and use of disposable versus reusable absorbant products. Disposable products are cheaper per item – which is good for the populations under discussion - but would require a continuous supply chain (most difficult under the above circumstances) as well as garbage collection and disposal the likes of which many in developed countries take for granted but which is all but non-existent in the poorest of countries. On the other hand, reusable products are more expensive for good quality but require adundant supplies of clean water for laundry and associated hygiene.

In a public-private partnership industry can provide financial aid, products and expertise to humanitarian, government and public health providers. Through industry-provided education, training and awareness programs and technical support health system infrastructure can be reinforced and capacity built. Potable water is also necessary for proper hydration (a key factor in continence) and proper hygiene to reduce infection. Ideally, a user-centred approach can be collaboratively developed to ensure that patient needs are recognized and products not just made physically accessible and affordable but culturally appropriate³.

A major problem in the distribution of essential medicines in developing regions of the world, especially by the public sector to patients who cannot afford their medicines themselves, is the determination of a fair and affordable price. If it is accepted that the total cost of essential AT for moderate-to-severe incontinence patients in the most resource-constrained countries should be less than the value of the benefits gained then the price(s) should reflect this desired outcome, as in the provision of essential medicines.

The individual and system benefits can be calculated at a principal economic level (see Figure 1). Using the 50 least developed countries (15) as a sample, which has been used in past research (12), with a combined population of 700 million people and Gross Domestic Product (GDP) of USD196 billion, the average GDP/capita for these 50 countries can be calculated as approximately USD280. Assumptions made in this Figure were based upon the data provided above: a lower incontinence prevalence rate of 5% given the lower life expectancies amongst these countries yielding 35 million people affected; that 90% of the incontinent population cannot afford AT yielding 31.5 million people to be benefitted; and

³ For example, Muslims cannot pray without having washed - thus any form of incontinence after the last cleansing and before prayer would be problematic, especially if in a mosque and not at home.

that those with incontinence and without AT are, on average, only 30% active in their economy and therefore their share of GDP/capita would be just USD84 producing a loss to the individual of USD196. With absorbent continence AT being nominally supplied by a public health system, with the assistance of industry, financial aid, and healthcare-providing NGOs, these 31.5 million people could fully participate in society at the average rate of USD280. Incomes of individuals now able to manage their incontinence will rise along with all the health and social benefits accrued along with higher incomes.

In 2018 it was calculated that the average out-of-pocket cost for a Canadian experiencing incontinence was USD1425⁴, far in excess of the reach of those living with incontinence in the 50 least developed countries. For the 50 least developed countries taken as a whole this would translate into an increase in their collective GDP of USD6.3 billion or 3.2%. Therefore, for these health benefits and economic gains to be realized amongst a population unable to afford incontinence AT ideally the “fair and affordable” price for this AT would yield a cost less than USD196 per person. If the incontinent populations of developing countries are to participate fully in their societies then the price for AT to the patient must be close to zero requiring a fully collaborative partnership of suppliers, third-party funders and patients.

Table 1. Potential economic benefit of the provision of free incontinence AT in the 50 least developed countries

Total population (2004) of the 50 least developed countries (15)	700 million ppl
Total GDP (2004) of the 50 least developed countries (15)	USD 196 billion
Average per capita GDP of the 50 least developed countries (total population/total GDP)	USD 280
5% prevalence rate for incontinence in the total population of the 50 least developed countries	35 million ppl
90% of those with incontinence who cannot afford AT	31.5 million ppl
GDP/capita for those with incontinence at 30% participation rate (30% of USD280)	USD 84
GDP per capita lost due to incontinence (USD280 – USD84)	USD 196
Total GDP for the 50 least developed countries regained by full participation of people with incontinence accessing AT (31.5M ppl x USD196 rounded to nearest DP)	USD 6.2 billion
% increase in GDP with full participation of those with incontinence (USD6.2B/USD196B rounded to nearest DP)	3.2%

⁴ 2014 cost data [<http://www.canadiancontinence.ca/pdfs/en-incontinence-a-canadian-perspective-2014.pdf>] inflated at the cumulative inflation rate of 7.07% for 2014-2018 as per the Canadian inflation calculator [<http://www.in2013dollars.com/2014-CAD-in-2018>]; US-Canada exchange rate as of November 16, 2018 was 0.76 [<https://www.xe.com/currencytables/?from=USD&date=2018-11-16>].

Recommendations

Continence care for 10% of the world's population is integral to supporting the human right to live an independent life, the right to universal healthcare, and the right to fully participate in a sustainable world.

Much of the work remains to be done to place incontinence alongside other disabilities managed by AT. A standardized multinational population study would be ideal for high-level continence AT policy development across the developing world. But that is an academic desire; there are very real, practical considerations that can and must be addressed immediately.

For both disposable and reusable incontinence AT, the barriers identified and the means by which to overcome them are similar to that encountered by other widespread disability-AT pairings in resource-constrained countries.

The findings above should be incorporated into a wider system of universal public health to address needs that apply to large affected populations around the world as opposed to the more targeted programming required in other circumstances.

The greatest barriers of awareness and education, while never simply overcome, have been shown to be surmountable if key opinion leaders are given the right information and shown how to act on the problem. The stigma attached to incontinence, often reinforced by strong historical, cultural, religious and gender traditions and stereotypes, and the subsequent unwillingness to-date of authorities almost everywhere to recognize the problem and deal with incontinence can be overcome.

De-stigmatizing incontinence with the facts and educating healthcare providers as well as patients and their families on how best to manage incontinence without embarrassment will allow affected individuals to become productive and fulfilled members of their societies.

The AT required is theoretically readily available to all and, although expensive for the individual, is comparatively quite affordable at the system level on a continuum of low cost to high cost AT. Strategies from the biopharmaceutical industry where public-private collaboration is used can play a role in making AT affordable and accessible to all in need as a part of essential and universal healthcare.

Minimal cost of absorbent continence AT, education, and supply chain security and management along with infrastructure issues such as potable water for and lavatories for personal hygiene are all instrumental to improving quality-of-life and economic participation for those suffering silently with incontinence.

A world where everyone with incontinence has access to quality, affordable assistive products to lead a healthy, productive and dignified life is attainable. Whether in developed or developing countries, where surgery or medication is not indicated, there is a low-tech solution to a problem plaguing hundreds of millions of women as well as men. The opportunity to have a positive impact on a large scale is inherent in making AT accessible

and affordable to almost 10% of the populations of low- and middle-income countries. The improvement of the health, economic and social well-being of large numbers by a single programme is exciting.

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Closing the gap on access to vision-related assistive technology

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Abstract

There is huge unmet need in access to vision-related assistive technology. The impact on people and the scale of the challenge make this a major concern. Over 250 million people have distance vision impairment and over 1 billion people are affected by presbyopia (near vision impairment) alone globally. With a business-as-usual approach, projections point to an explosion in prevalence with (distance) vision impairment tripling and half the world's population experiencing myopia by 2050. Vision-related assistive technology is indispensable for effective treatment and rehabilitation of people with vision or eye health conditions and as such to promoting a person's well-being, social and economic development and equity. Yet – there are major challenges and blockages in ensuring access to glasses and other low vision devices and support for appropriate and safe use. There are a range of market and health system barriers to accessing vision-related assistive technology, whether low vision devices such as white canes and magnifiers or glasses particularly in low income settings. Procurement and financing decisions must be taken to ensure these products are affordable for all people, and appropriate to the setting. Maintenance and training or upskilling of the workforce are important factors for successful delivery, and access to vision-related assistive technology must be better integrated within health systems including efforts to advance on universal health coverage. This paper 'ensuring access to vision related technology' will share learning from available research and some case examples. It will cover setting up of the low vision centre Hong Kong Society for the Blind a leader in its field, and experiences from vision centres distributing glasses and other important initiatives. It will take in selection of devices, and addressing global demand, experiences of ensuring access in low resource settings and in remote areas. It will share learning from the establishing of the low vision essential list which covers primary to tertiary levels of care, and the IAPB's Standard List procurement platform. The Standard List contains information on tried and tested products, but also identifies the new and innovative. Drawing from these and other examples it will set out some principles and recommendations to promote access to vision-related assistive technology and the appropriate enabling policy and financing environments.

Introduction

There is huge unmet need in access to vision-related assistive technology. It is estimated that over a billion adults and children are impacted by the lack of accessible vision services. No country or demographic is immune, no person is exempt. With a business-as-usual-approach, projections point to an explosion in prevalence with distance vision impairment tripling and half the world's population experiencing myopia by 2050 (1).

This paper has been prepared by the International Agency for the Prevention of Blindness (IAPB) together with the IAPB's work groups on refractive error, school eye health and low vision. As such the focus is on low vision assistive devices and glasses in particular.

The objective of the paper is to share learning from research and cases studies involving IAPB and members and make recommendations based on experience to close the gap on access to vision-related assistive technology. The paper takes in production of devices, addressing global demand via integration in health systems and schools, and experiences of ensuring access in low resource settings.

Vision-related assistive technology is indispensable for the effective treatment and rehabilitation of people with vision loss. It promotes personal well-being, social, educational, and economic development and equity (2). Yet – there are major challenges and blockages in ensuring access to glasses and low vision devices and support for their appropriate and continued safe use (3,4).

There are a range of market and health system barriers to accessing vision-related assistive technology, low vision devices such as white canes and magnifiers, or glasses particularly in low income settings. Costs and remoteness of facilities amongst other barriers, make it difficult for marginalised communities and sectors of society including minority groups and persons with disabilities to have access to vision-related assistive technology. Negative stereotyping and peer pressure are among key barriers for people with sight loss or low vision to fully benefit from assistive technology (3). Another constraint is lack of training for the client and their families in the proper use of assistive technology, and non- accessibility, poor ergonomic and environment further exacerbate the situation.

Procurement and financing decisions must be taken to ensure these products are affordable for all people, appropriate to the setting. Maintenance and training or upskilling of the workforce are important factors in providing access to, and the successful delivery of, vision-related assistive technology (5). It is essential that vision and other assistive technology is better integrated within health systems and efforts to advance universal health coverage. It must also be adequately integrated within education systems (5). Governments have a duty to ensure access to vision-related assistive devices for people who need them, as set out in the vision of “Universal Eye Health: The Global Action Plan” (6) and in keeping with the Convention on the Rights of Persons with Disabilities (7).

Low vision and functioning

People with low vision are affected differently. They may suffer from some or all of the following: severely reduced visual acuity; blurred vision; visual field loss: central or peripheral; loss of contrast sensitivity; increased light sensitivity (4). The impact of low vision on functioning is dependent on the type or cause of sight loss and can have a major impact on vision-related tasks i.e. face recognition, mobility, reading and copying from the blackboard. Children with low vision do not get the optimal help and support required to improve their functional ability and sometimes end up in schools for blind children when they could attend mainstream schools with support.

“Individuals who can only see light or movement of large objects will need rehabilitation that focuses on non-visual strategies for learning and daily tasks. However, there are many people who have slightly better vision, but are still classified as blind, who have the potential to use their sight. These people could benefit from low vision care, which may include refraction, provision of magnifiers, and/or environmental modifications” (8).

Low vision unmet need and impact of services

Low vision rehabilitation services are not available in 36% of countries (9), and where they are available they often exist without appropriate support. Further, only 5 to 10% of people who need low vision rehabilitation services are estimated to access them (9). Challenges include sparse geographical distribution of services, cost of the devices and services, lack of effective referral systems and unintegrated services. There is a major shortage of people trained to provide low vision rehabilitation services. Usually services are limited to secondary or even tertiary hospitals.

Yet, access to assistive devices and accompanying support can be life-changing. Successful programs have been developed in diverse countries. For example, in Australia the majority of children attend mainstream schools in their local areas where they are trained by teachers in the devices they access from specialist low vision services or eye care providers. Pakistan is a global leader in promoting access to assistive technology.

Evidence available demonstrates the major impact low vision assistive technology can have on people’s lives. Patient quality of life surveys have been used to assess low-vision rehabilitation programmes in Victoria, Australia. Research on the impact of a multi-disciplinary approach for adults attending low-vision rehabilitation for the first time demonstrated considerable benefits. At an average of just over 80 years old, the majority of those surveyed had Age-Related Macular Degeneration and were moderately to severely vision-impaired (2). With access to tailored services such as occupational therapists, low-vision devices, and talking books, the researchers found significant improvements in overall Quality of Life (QoL), with the highest impact on emotional well-being (2).

Strengthen the low vision workforce

As with other areas of (re)habilitation there is a huge lack of availability of appropriately trained workforce to support access to the assistive technologies. Investment in pre-service training is essential across the globe and particularly in Africa. Existing teams need to be encouraged to adopt a pragmatic approach in order to help reduce the gap.

Rehabilitation workers, ophthalmologists, mid-level eye care workers, optometrists/refractionists, and special education teachers, may not have a working knowledge on low vision. It is recognised that eye health providers must look beyond providing care that is restricted to their specialty, to link with other providers including on disability. To support the training of ophthalmologists, optometrists, refractionists, teachers and rehabilitation workers the IAPB Low Vision work group has produced guidance on low vision curricula. These can be used to inform both pre-service training and continuing education (10).

Additionally, tasks can be delegated to non-specialist health workers where possible. Instead of the optometrist doing the refraction and basic low vision care, a trained vision technician can do these. In settings where there are no ophthalmologists or optometrists, the cadres of refractionists, ophthalmic nurses, opticians and teachers can be trained to take on additional low vision tasks appropriate to their skills and experience to support the provision of assistive devices (5).

Case study: Capacity building of low vision practitioners in Sub-Saharan Africa

Assistive technology and low vision services comprise a vital component of comprehensive eye health services addressing needs across a range of age groups and sectors including children, working people and the elderly, transcending promotion, preventive, curative and rehabilitative services. The current capacity to address this wide range of needs in Africa remains limited with only one lower level training programme available in Kenya.

The Sub-Saharan Africa Capacity Building Programme was set up to develop two centres of excellence for the training of Low Vision Practitioners in Nigeria and South Africa. It was then expanded to incorporate Kenya and Uganda with possible extension to other countries.

The African Council of Optometry (AFCO) is the continental apex optometry professional association and is affiliated to the World Council of Optometry. It has developed a strategic framework for optometry in Africa. The development of subspecialties, including low vision, have been identified in the strategic framework. Given the variations that exist across the countries in the certification and accreditation of sub-speciality training programs, AFCO will be responsible for accreditation of the Low Vision training programme and to advocate for this accreditation to be recognised in all countries through its members.

In phase one (2017-2018) one optometrist per the 4 countries was trained to be faculty staff on low vision. The Low Vision Training Programme included participation in an online “Education Design for Learning Course” run by Brien Holden Vision Institute. After initial face-to-face low vision coursework, the four faculty members went to the LV Prasad Eye

Institute in India for three months' intensive low vision practice and education at the tertiary centre. Low vision services, which included use of assistive technology, were observed in primary and secondary care locations. All are now back at their universities charged with integrating LV services as part of the LV Training Program. They are each required to undertake a research project on the LV needs and services in their countries. Later in 2019, they will further consolidate their learning in an outreach low vision trip together with an experienced low vision educator.

To ensure the sustainability of the new Low Vision training centres, memorandum of understandings (MoUs) will be drawn up between BHVI and the host institutions confirming the commitment of the host institution to sustain the training programmes once donor funding from the Standard Chartered Bank's See is Believing funding comes to an end in 2020. A complete assessment low vision kit along with seed inventory is provided to each university to start the tertiary low vision service. This will help improve the training but also access for patients with low vision to quality assessment and provision of low vision devices.

The training of new Low Vision Practitioners in Kenya, Uganda, Nigeria and South Africa will cascade the benefits of this intervention into LV programmes in tertiary hospitals for more complex cases, disability agencies and schools of the blind and vision impaired, potentially benefitting thousands of people increasing access to the essential assistive devices and other supports that they need.

Integration of low vision assistive technology across the health care system

Governments have a responsibility to ensure that their populations have access to health care including rehabilitation services and assistive devices. This needs to occur in a manner that ensures individuals and their families do not face financial hardship. As resources are not finite the health systems need to adjust and be people-centred. Progress on universal health coverage requires an efficient health system reaching the entire population, including the poorest and marginalised, with access to good quality services, medicines and assistive technologies. Cost is one of the three highest barriers to the use of eye health services in most low- and middle-income countries so affordable access must be factored in. Assistive technology needs to be treated as a key component in reaching universal health coverage, such as in Australia where assistive devices are part of the National Disability Insurance Scheme.

A Global Public Health Perspective: "Facilitating Access to Assistive Technology" describes what is needed – "Good-quality, affordable AT, which is appropriate and acceptable to the user, would ideally be provided by competent personnel, working in multi-disciplinary teams, offering comprehensive, person-centred services, including rehabilitation, fully integrated into the various levels of the health system". This paper very usefully sets out the importance of integration and how this can best be done. Horizontally to 'promote holistic care and improve access to comprehensive services' such as through training to use assistive technology, providing support, facilitating referrals, and access to education, rehabilitation,

livelihood, social participation, empowerment, and health elements of community-based rehabilitation’. It highlights the need for vertical integration to ‘promote continuity of care and access to integrated LVRS’. In countries where there are few services it proposes starting at secondary level integration in existing eye health services as a pragmatic meantime approach (11).

Case study: Vision 2020 Low Vision Resource Centre, Hong Kong Society for the Blind

The last few decades have seen significant advancements in the surgical and medical management of eye diseases including Cataract, Glaucoma, Diabetic Retinopathy, and Age-related Macular Degeneration. People who previously ended up with blindness are retaining and regaining useful or full vision. However, there are still some eye diseases for which there is no medical or surgical cure at present although studies are under way to identify cures and treatments. These include Albinism, Macular Dystrophy, Optic Atrophies etc. The only option to gain useful vision in such instances is through the use of low vision services. There are approximately 65 million people in the world who have irreversible low vision and require low vision care. Most of those affected are older people and the numbers could double over the next 20 years because of the ageing population. Whilst the number of children with low vision is relatively small, the burden in life years with disability is significant.

The World Health Organisation (WHO) has identified the development of low vision services as a priority area and the last 30 years have seen a concerted effort to integrate low vision services into comprehensive eye care.

The Vision 2020 Low Vision Resource Centre (LVRC) was established in 2003 as a recommendation of the Asia-Pacific Regional Low Vision Workshop. The workshop was hosted by the Hong Kong Society for the Blind (HKSB) and sponsored by the International Agency for the Prevention of Blindness (IAPB) and the WHO. The LVRC was established under the guidance of the IAPB Low Vision Work Group. It received its start-up funding from the CBM, Dark and Light Blind Care, Sightsavers and HKSB – it is non-profit with all income reinvested.

The LVRC aims to expedite the establishment of low vision services and stimulate accessibility of low vision care by offering high-quality equipment, assessment materials and low vision devices at a lower cost to developing countries. Strict quality control is implemented to ensure that persons with low vision actually benefit from these products.

In addition to supplying equipment and devices to low vision clinics in the developing countries, the LVRC, together with the Low Vision Clinic of HKSB, provides exchange and training programmes for eye health personnel in low vision. Training covers clinical and functional skills in low vision, management of a low vision resource centre, quality assurance, and systemic inventory management.

The LVRC works closely with ministries of health, education, social welfare and rehabilitation; national and international non-governmental organisations; and

blind/disabled persons' organisations to provide them with products to improve the quality of life of men, women and children with low vision.

The LVRC recognised the need, explored the untapped market and proved that by developing a supply chain of the products for low vision services in developing countries, it was possible to play a vital role in increasing access. The LVRC has supplied over 384,000 pieces of vision assessment equipment and enhancement devices to almost 100 countries to improve the education and employment opportunities for hundreds of thousands of persons with vision impairment.

Low vision services across the world, particularly in developing countries, still remain far from adequate. Coverage in most cases is still less than 10% of the need. The impact of the LVRC supplements the basic principles of universal health coverage that all people should enjoy access to quality eye health, and out-of-pocket payments should not impede access or cause difficulties. The LVRC has redefined low vision services by setting new standards in technical features, mass production, capacity-building and access especially in the context of developing countries. The blue-print of this model can be replicated to develop regional low vision resource centres to further improve the cost-effectiveness, efficiency and scale up of low vision services.

Procurement and IAPB's Standard List

A major factor in ensuring access to assistive devices is the cost of procurement and practicalities of sourcing the right products accounting for the context. There is significant waste in terms of health and rehabilitation expenditure globally and better approaches to procurement can improve access to quality products at manageable prices. The International Agency for the Prevention of Blindness (IAPB) Standard List and Essential List for Low Vision Services is an important facility to help with this. The list includes the Global Co-operation on Assistive Technology products as part of a broad range of optical and assistive products, screening and diagnostic equipment and instruments that are recommended by the IAPB's Low Vision Work Group. The list is based on a three-tier model of care: at primary, secondary and tertiary levels. Eye health providers from low- and middle-income countries can use it to assist them to source and compare eye health products from dependable suppliers and guide their procurement decisions so that they obtain the most cost-effective and appropriate equipment, devices, and consumables (12).

What is needed to significantly increase access to low vision devices and accompanying services?

Need for a multi-disciplinary and integrated person-centred approach:

- Provision of the device/s alone is insufficient as it must be backed up with the right counselling and support services and follow-up systems to ensure effective use and compliance

- There must be inclusion of low vision services and assistive devices within eye health strategies and eye health systems, with appropriate referral systems in place
- There must be integration of low vision services into the roles of the wider health care team and existing health facilities and inclusion across universal health coverage
- To ensure inclusive education, there must be integration of low vision within the school system so that children are effectively screened and provided with the assistive technology that they need, with low vision training included in special education teacher training
- Access to low vision assistive technology needs to be included in relevant budgets for health, education, rehabilitation and others at national and district level
- The huge gap in human resources needed must be tackled, where necessary taking a competencies-based approach to shorten entry and exit, incorporating low vision in all ophthalmic and optometric training and for rehabilitation workers, and building on skills of the available staff
- Outreach services are necessary to ensure people are aware of services, for detection and also then for follow-up to ensure devices are used properly
- Improve collaboration and co-ordination across government, non-governmental organisations and private stakeholders

The scale of uncorrected refractive error and impact of no glasses

Refractive errors (myopia, hypermetropia, astigmatism, presbyopia) result in an unfocussed image falling on the retina. Uncorrected refractive errors which can affect persons of all ages and ethnic groups, are the main cause of vision impairment. They may result in lost education and employment opportunities, lower productivity and impaired quality of life (13). People may not access glasses for a range of reasons including poverty, isolation, poor availability, poor access to eye health facilities and lack of awareness (14).

There is mounting evidence on the impact of corrected vision impairment on people's lives, their well-being, education and employment. A randomised controlled trial in India found that workers' productivity rose by 22% (and up to 32% for over 50s) when their poor vision was corrected with a pair of glasses (15). The global burden of uncorrected Presbyopia, in lost productivity, is estimated to be over US\$11 billion annually (15). Presbyopia can be corrected with reading glasses, but more than half of those requiring near-vision spectacles globally cannot access them" (15).

Myopia is a leading cause of blindness and vision impairment worldwide. It is a global issue, rising to epidemic proportions, with 50% of the world's population predicted to have myopia by 2050 (16). It commonly onsets in childhood and is due to a mismatch between the eyeball length and its optical power, resulting in light focussing in front of the retina and thus causing blurred distance vision. Myopia is commonly corrected with glasses or contact lenses, and increased time spent outdoors serves as a protective measure for children (17). For millions of children with myopia, if their myopia progression is not controlled, they could

develop high myopia in adulthood, which could result in significant complications leading to blindness. Myopia can influence the economic success of individuals, create a burden for families and communities, and add significant cost to the health system.

The pressing problem of the lack of services and growing rates of myopia, in many countries, will be solved by strengthening:

1. policy and program frameworks,
2. health and education systems,
3. a collective health workforce,
4. a response where all stakeholders align strategies to prioritise child eye health.

Tackling refractive error within health systems and universal health coverage

The task of meeting the needs of all of those with uncorrected refractive error is monumental. Traditionally refractive error has been tackled separately from the health system but now diagnosis and treatment (with glasses) must be addressed in the most effective way to meet need. This means integrating access within health systems, accounting for and ensuring appropriate regulation of the private sector and ensuring glasses and eye health are factored into employment, road safety and other relevant strategies and policies.

The report from the International Council of Ophthalmology (ICO): “Learnings from the ICO Task Force on uncorrected refractive errors and school eye health” evaluated a number of refractive error and school eye health projects (including the one in Uganda below). The point made very clearly is that there is a need to avoid continued separation of eye health: “Segregation of eye health from general health is disadvantageous to raising awareness and improving prioritisation of eye health policies and strategies, which can subsequently interfere with providing adequate funding for eye health programs” (18).

This report also states that integration of eye health within national health systems is essential to ensure that cadres providing refraction services are properly recognised by the ministries, staff and clinic times are given priority, and that health administrators assume ownership of the programs for providing health services that include refraction services. “It has been demonstrated in both Uganda and Pakistan to be important that refraction services are identified as part of the ministry of health (MoH) to allow appropriate prioritisation of training, funding and services” (19).

Screening and provision of glasses within school eye health

Poor vision can significantly impact a child’s education and social development. Millions of children and young people are blind or vision impaired because they cannot access eye care or a pair of glasses. As a result, they are often denied education, isolated from their peers and at a significant disadvantage later in life when their employment prospects are limited.

The uptake and effective implementation of eye health within school health programmes, is crucial to increase access to glasses as well as other eye health care. Early detection and

referral of children with eye problems is key to timely and cost-effective interventions such as glasses.

To understand the factors that affect children's access to eye care services within schools in lower and middle-income countries, a systematic review of interventions in school eye health was carried out by the Brien Holden Vision Institute, supported by the World Bank Group and Global Partnership for Education (19). There are a number of valuable findings in this review. Amongst them, the authors noted the importance of communication with the schools and the schools' commitments, as well as the parents as factors for success. They highlight the need for provision of glasses and also simple referral pathways between education and health systems, and clear processes that support follow-up, and continuity of care. The cost of the glasses was an important factor (20).

In order to develop a normative framework in terms of best practice approaches to school eye health, the IAPB School Eye Health Workgroup has released the "Standard school eye health guidelines for low and middle-income countries". The document should help deliver standardised comprehensive eye health services to the more than 700 million children attending schools around the world (21).

Cost as a barrier for uptake of glasses

The cost of glasses for children has been identified as a significant barrier and cause of inequity. Factors associated with a higher willingness to pay for spectacles were previous/current ownership of spectacles, regular spectacle wear, a recognised need for spectacles, or an understanding that vision improves with spectacles (22).

Countries taking steps to provide access to glasses for free or at a heavily subsidised price for the most marginalised must be applauded. In Rwanda, a country which spends a massive proportion of its overall budget on health, low-cost Presbyopia glasses are made available to the public at a fixed price of US\$2 equivalent, and free for the poorest (23).

With innovations there are possibilities to save costs as appropriate to context. The IAPB's Refractive Error work group has produced guidelines on recycled glasses, self-refracting adjustable glasses and ready-made glasses to inform best practice.

Case study: The National Intervention on Uncorrected Refractive Error (NIURE) in Uganda (with support from Light for the World and Brien Holden Vision Institute)

The focus of the successful NIURE project was on training ophthalmic clinical officers in refraction, provision of refraction equipment, and setting up a national optical workshop using courier services to all trained Ophthalmic Clinical Officers (OCOs), Refractionists based throughout the country. The approach was to ensure good quality training including practicals over six weeks and that the project could be useful for learning for other countries. The programme also included school eye health activities in 8 pilot districts, and the programme helped set up the 4-year bachelor's degree in optometry at Makerere University.

The founding NGO staff met with the national eye health co-ordinator and formulated a strategic development plan according to identified needs. Refractive error wasn't in the national action plan on eye health at the time but was then incorporated into the next one. They formulated a five-year plan and then a second one, and then planned for handover. It has been key right from the beginning to put Government in the driving seat regarding major decision- taking.

They worked with the Ministry of Health and the regional ophthalmologists to identify the right OCOs to get the training. Eight students were trained to begin with and by the end of the programme 74 OCOs were trained.

To bridge the gap due to the lack of optometrists, an optometry education programme was established at Makerere University. In January 2019, the first 5 students graduated in optometry. From 2017, the new intake was 20 students per year. Ten of those students now get stipends on an annual basis from the government so do not pay fees.

There was a realisation that sourcing the glasses was going to be a problem. A national optical workshop was established to address this. The courier service meant that people could access the glasses within 3 days which has proven quite effective. The OCOs have 16 sample frames so patients can decide their preference, based on what best suits them. They are subsidised to approximately 12 USD equivalent for all powers.

From 2012-2013 the plan was extended to tackle school eye health. They rolled out vision corridors, pamphlets for teachers etc.

For three years the glasses were free at schools and via the OCOs. Then the project would withdraw with a district MOU. After that the cost is again approx. 12USD equivalent paid by the individual patient. The government needed to cover some of the revolving costs, e.g. employing trained staff such as spectacle technicians. For most families this price is manageable, but it is still costly for the poorest and most marginalised. Compliance is very good.

An important factor in the success of the project was clear community messages that raise awareness of conditions and their management helping to ensure timely intervention. Evidence from the national refractive error screening programme in Uganda demonstrated significant improvements in performance and attendance of children at school after receiving glasses (23).

Going forward there are a number of areas that would help to improve provision of glasses. This would include getting screening as a module in the pre-service training of teachers, regulation of optometry, and influencing the appliances policy to reduce the cost of the glasses so subsidised glasses can be treated as medical devices.

What is needed to significantly increase access to glasses to tackle the crisis?

- Refractive error needs to be addressed in planning and development of national health plans and budgets
- Systems need to be in place to ensure access to the poorest so that glasses provided within these schemes are treated as medical devices to reduce taxation and out-of-pocket payments
- Refractive error and access to glasses must be prioritised within education with screening at 5 years and either leaving primary or entering secondary school, with appropriate referral systems in place
- There needs to be significant investment in the optometry profession accounting for minimum standards
- There is a need for regulation of private spectacle shops in settings where this is not already the case, and ensuring effective referral systems where secondary or tertiary care is required
- To increase spectacle compliance there is a need to reduce misconceptions and stigma about spectacles with strong community messages
- Increase the evidence base on integration within UHC and health systems
- Improve collaboration and coordination across government, non-governmental organisations, and private stakeholders

Acknowledgements

Thank you to the contributors of the case studies:

‘Capacity building of low vision practitioners in Sub-Saharan Africa’ - authored by May Ho and Hasan Minto, Brien Holden Vision Institute Foundation, and Jonathan Jackson, Royal Groups of Hospitals

Case study on ‘Vision 2020 Low Vision Resource Centre, Hong Kong Society for the Blind’- authored by Sumrana Yasmin, Brien Holden Vision Institute Foundation

Case study on The National Intervention on Uncorrected Refractive Error (NIURE) in Uganda - authored by Zoe Gray in interview with Wolfgang Gindorfer, Light for the World.

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Including the views and experiences of people with intellectual disabilities to improve access to assistive technology: Perspectives from India.

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Abstract

Background: People with intellectual disabilities (ID) are a group deeply affected by health inequity, which is also reflected in their access and use of assistive technology (AT). While people with ID could greatly benefit from AT, availability, access and the use of AT for people with ID is still a neglected area in research and practice. **Objective:** Including the perspectives of adults with ID and their caregivers, together with the views of local health professionals, suppliers of AT and policy makers, this paper aims to provide an overview of factors influencing access and use of AT for people with ID in the Bangalore region, India. **Approach:** Face-to-face Interviews with 15 adults with a mild to profound ID and their caregivers, and 16 providers of AT were conducted to gain insight into current use, needs, knowledge, awareness, access, customization, funding, follow-up, social inclusion, stigma and policies around AT and ID. **Findings:** Examples which facilitated access were community fieldworkers and services to reach out and identify people with ID. Important barriers were stigma, and lack of knowledge and awareness among parents. Factors related to continued use were the substantial dependence on the care system to use AT and the importance of AT training and instructions of the user and the care system. **Recommendations:** The barriers and facilitators for people with ID related to AT differ from other populations in need. The findings of this study can be used to inform and adjust country policies and frameworks whose aim is to improve access to AT and enhance participation of people with ID within their communities.

Keywords

Intellectual Disability, Assistive Technology, Assistive Products, Health inequity, Access.

Introduction

The Seventy-first session of the World Health Assembly (WHA) in 2018 stipulated the need for improving access to assistive technology (AT) worldwide. Following the United Nations Convention on the Rights of Persons with disabilities (UNCRPD) and the Sustainable Development Goals (SDG's), especially SDG 3, it is shown that equitable and affordable access to AT needs to be an integral part of universal health coverage (1). However, there is a current gap in research and practice regarding the need, demand and supply of AT, as well as evidence of good practices for innovation and recommendations to improve access (1). The WHO Global Cooperation on Assistive Technology (GATE) programme was initiated to identify those contributions which provide scientific and/or practical input to improve the current situation of AT policy, products, provision, personnel and users (people).

A specific group of people that should not be excluded from AT initiatives and contributions are people with intellectual disabilities (ID). People with ID are deeply affected by health inequity, still regarded as a stigmatised and devalued group and often marginalised from healthcare services (2, 3). This is also reflected in their access and use of AT services (4). ID is defined by the American Association on Intellectual and Developmental Disabilities (AAIDD), the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) and the International Classifications of Diseases (ICD-10, mental retardation) as an IQ below 70, manifested during the developmental period (onset before 18 years of age), with impairments in adaptive functioning, such as communication skills, social skills, personal independence, school or work functioning (5-7). It has been found that people with ID use fewer AT compared to other people in need (2, 8-10), despite the fact that people with ID could greatly benefit from AT (2, 11-14). These benefits relate to AT that (1) could be used to support cognitive limitations in order to enhance independence and inclusion, (2) could facilitate better management of chronic health conditions and comorbidities which people with ID experience more often compared to the general population, such as sensory impairments, speech and language impairments, and dementia (2, 15), and (3) could support those with early onset of functional decline (12, 16). People with ID follow the same ageing trend as the general population, and their demand for AT increases as they get older.

Although the UNCRPD and the SDGs stipulate the importance of access to AT for anyone in need, access to AT, and AT use, for people with ID is still a significant neglected area in research and practice (2, 17). It is unknown how many people with ID actually have access to AT globally, and which factors influence their access. Difficulties in accessing services and unmet healthcare needs for people with ID is more prevalent in low and middle-income countries but is also a significant inequity in high-income countries.

In collaboration with the GATE programme, Boot et al. started an international research project called GATE-ID which aimed to identify the current barriers and potential facilitators for people with ID to access and continuously use AT in differently resourced settings. One of the countries included in the GATE-ID programme was India. India is classified as a lower middle income country according to the World Bank data (18). India includes a variety of

social-economic classes, healthcare systems and cultures. Healthcare resources and facilities are unevenly distributed and in general, services are concentrated in urban areas. The prevalence of people with ID in India is estimated at 2-3% (19), but most individuals with ID in India have not been formally identified. The prevalence is higher in rural compared to urban areas. It is estimated that 26 million people have ID in India, out of which more than 15 million are under the age of 10 years (19). According to the national sample survey, the main causes of ID in India are illness during childhood (42%), head injury during childhood (10%), and pregnancy or birth related impairments (3%) (19). The majority of individuals live at home, supported by family caregivers (20). India ratified the UNCRPD in 2007, which led to the adaptation of the Rights of Persons with Disabilities Act in 2016. To monitor and achieve the SDGs and associated targets, a National Indicator Framework (NIF) has been developed which serves as a key tool for policy making, implementation strategies, and allocation of resources, researchers and other stakeholders (21).

An important aspect of this research project was to include the views and experiences of people with ID themselves and their families. Including the perspectives of people with ID and their family members is key to better understand which barriers they currently encounter regarding effective access to and continued use of AT. Together with the views of local health professionals, suppliers of assistive products and policy makers, this paper aims to provide an overview of factors influencing access and use of AT for people with ID in the Bangalore region, India. A phenomenological approach was used to answer the following research questions: Which barriers and facilitators are currently present in India to provide the essential assistive products for people with ID? And, how can we realise the improved provision of AT aspired to by GATE specifically for people with ID?

Methods

This study is part of the larger cross-sectional GATE-ID research project. The methods described below are similar to the methods of the GATE-ID research project conducted in South Africa and Ireland (22). A full description of the development of the interview guides, the interviewing method, and analysis has been published elsewhere (22).

Study Design

This study consisted of a qualitative research design using semi structured face-to-face interviews with a phenomenological approach. Relatively few people with ID are able to read, write and fill in written questionnaires. Therefore, interviewing is the most appropriate method to gain personal views from people with ID. Participant interviews took place in July 2018. Ethical approval for this study was granted by the Bangalore Baptist Hospital Institutional Review Board. Ethical approval for the overall GATE-ID research project was obtained from the Health Policy & Management/Centre for Global Health Research Ethics Committee, Trinity College Dublin, Ireland (04/2017/01) and Maynooth University Research Ethics Committee, Ireland (SRESC-2017-053). The study adhered to the Declaration of Helsinki for research involving human subjects.

Participants

The participants were divided in two main groups; 1) *adults with ID*, and 2) *providers of AT*. Purposive sampling was used to recruit participants. Participants of group 1) *adults with ID* were approached through an Indian rehabilitation centre in Bangalore. The manager of the rehabilitation centre and the community fieldworkers were informed about the study and asked to recommend adults with ID who might be willing to participate in an interview, either as users or non-users of AT. The information leaflet and consent form were adjusted to the cognitive level of the participants (i.e. easy to read, larger font size, few words per row and the use of symbols) and were translated into the three main local languages of the Bangalore region; Kanada, Tamil and Urdu. If the participant was not able to give informed consent, his or her legal representative (family member) gave informed consent. Participants of group 2) *Providers of AT* consisted of health professionals, community field workers, suppliers or retailers of AT, and governmental commissioners. Participants for group 2 were approached through the network of the rehabilitation centre in Bangalore and snowball sampling was used.

Interviews

The semi structured interview guide focused on AT current use, needs, knowledge, awareness, access, customisation, funding, follow-up, social inclusion, stigma, and policies. At the start of each interview, AT were defined using a booklet containing images of different AT to highlight the variety of AT. AT included any low- or high-tech product to maintain or improve a person's functioning in the domains of vision, hearing, mobility, communication, cognition, environment and personal care. The questions were adjusted to the level of ID and the family members aided participants in understanding questions they found challenging.

Analysis

The recorded interview data were first transcribed verbatim. The technique of constant comparison analysis, as described by Elliott and Timulak (23), was used to analyse the data. Accordingly, the data were divided into meaning units – units by which the analysis was conducted. Meaning units are segments of the data that even if interpreted out of context would provide adequate information to the reader. For organising participants' responses, the meaning units were sorted into three themes: 1) stigma, 2) access to AT, and 3) continued use of AT. The meaning units were subsequently organised per theme into broad headings, or domains, to provide a conceptual framework for each theme. Next, the meaning units were coded into categories within each of the domains to categorise the meaning units. The categories emerged from the meanings in the meaning units.

Findings

The findings represent the perceived perspectives of the participants of both groups, shown as an overview of factors (both facilitators and barriers) related to stigma, access to AT and continued use of AT for people with ID.

Participants Characteristics

In total 31 participants were interviewed. Tables 1a and 1b presents the participants' characteristic of group 1) Adults with ID (n=15) and group 2) Providers of AT (n=16). Three participants of group 1) were professionally assessed for their intellectual functioning prior to the interview. The level of ID of the other 12 participants was estimated by the researcher at the time of the interview, based on the researcher's experience as a specialist ID physician, and categorised into either mild-moderate or severe-profound ID. All adults with ID were accompanied by their caregiver (family member or carer) during the interview to support them where needed. Often parents were taking the lead in answering the questions for their child with ID. Six adults were non-verbal and/or had a severe-profound ID in which case the caregiver answered all the questions for them.

Assistive Technology in use

Table 2 shows the current AT which participants were using. On average, participants from group 1) *Adults with ID* used two products per person, ranging from 0-3 with one participant using nine products. The products most commonly used were in the domains of communication (mobile phones) and environment or self-care (shower stools or chairs).

Qualitative analysis

The results of the qualitative analysis are presented below with the themes and domains as headings and subheadings respectively. Domains and categories per theme are illustrated schematically in Figure 1-3; these domains are not ordered in terms of importance, nor do they imply any hierarchy.

Table 1a. Participants characteristics (people with ID)

Characteristics	People with ID (n=15)
Age (mean)	31 years
Female gender	8
Mild-Moderate ID level	11
Severe-Profound ID level	4
Aetiology: Pre or perinatal infection	2
Aetiology: Down Syndrome	1
Aetiology: Meningitis/encephalitis	1
Aetiology: Rhesus disease	1
Aetiology: Asphyxia	1
Aetiology Unknown	9
Care setting: Centralised setting	5
Care setting: with family	10
Semi-urban setting	6
Urban setting	9

Table 1b. Participants characteristics (providers)

Characteristics	Providers (n=16)
Age (mean)	50
Female gender	4
Speech and language therapist	1
Audiologist	1
Ophthalmologist	1
Physiotherapist	1
Social worker	1
Special educator	1
Community fieldworker	2
Supplier of AT	2
Care facility manager	1
Policy maker	5
Urban setting	16

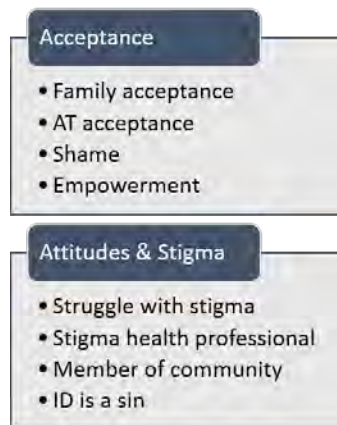
Table 2. Current AT in use by participants of group 1) adults with ID

Participants code	Total no. of AT in use	Hearing	Vision	Communication	Mobility	Cognition	Environment and self-care
INT_ID_IND_001	1	0	0	1	0	0	0
INT_ID_IND_002	0	0	0	0	0	0	0
INT_ID_IND_003	9	0	5	1	1	0	2
INT_ID_IND_004	0	0	0	0	0	0	0
INT_ID_IND_005	2	0	0	1	0	0	1
INT_ID_IND_006	1	0	0	1	0	0	0
INT_ID_IND_007	2	0	0	2	0	0	0
INT_ID_IND_008	3	0	0	1	0	0	1
INT_ID_IND_009	2	1	0	1	0	0	1
INT_ID_IND_010	3	0	0	1	1	0	1
INT_ID_IND_011	2	0	0	0	1	0	1
INT_ID_IND_012	2	0	0	1	1	0	0
INT_ID_IND_013	3	0	1	0	0	0	2
INT_ID_IND_014	2	1	1	0	0	0	0
INT_ID_IND_015	1	0	0	0	1	0	0
Total	33	2	7	10	5	0	9
Average	2	0	0	1	0	0	1

Theme 1. Stigma

Data analysis resulted into two domains for stigma: Acceptance; and Attitudes & Stigma. The meaning units were coded into four categories for both domains see Figure 1.

Figure 1. Domains and categories for stigma



Acceptance

Family acceptance and shame played an important role in AT provision for people with ID. Participants could clearly explain how shame influenced isolation of both the person with ID as their family members. For example, one mother explained she did not accept her child having ID which made her keep her child indoors all the time. As a result, she had never had her child assessed for any AT support. One participant clearly described the importance of family acceptance as a first step before AT can be realized: “*P: The family gives up on them, thinking that he is no good for nothing, then he becomes a burden in the family and that makes them feel even lower all the time....they are made to believe they are not wanted.... These are all necessary [pointing at AT]. But this is even secondary. Make them believe that they come out, and work and succeed.*” (INT_PRO_IND_004). Acceptance of AT also played a role and was influenced by modern mainstream AT developments: “*P: But in India people will have that feeling, nobody should notice I am wearing a hearing aid. R: Do you think it is more stigma then as well? P: It’s a bit, but now it has changed, because now everyone goes with the headphones.*” (INT_PRO_IND_008).

Attitudes & Stigma

Worldwide people with ID still have to face stigma which negatively influences access and use of AT services. In many regions of India and within many beliefs, ID is still seen as a sin, for example: “*P: It is still considered as something linked to your karma and all those things and a lot of superstitious beliefs and other things. And in some places that some of those people have been sacrificed in the name of this or that.*” (INT_PRO_IND_002). Some parents struggled with negative attitudes from other family members towards their child with ID. Others shared their experience of positive attitudes from neighbours and local community. However, in general the community did not see people with ID as productive members of

society. These attitudes were more present in urban compared to rural areas, which was explained by lower expectations within rural areas and the type of work people with ID could do there. In addition, stigma from health professionals was also very much present. Participants with ID explained that health professionals did not include them during consultation and would mainly focus on the parents: *“R: And could you choose the glasses, choose yourself which glasses you want? P: My parents selected.” (INT_ID_IND_003)*. Health professionals also misled parents, providing incorrect information on ID: *“P: some of them are also misled by doctors. Professional doctors where they go for a treatment. They say your child will become alright after ten years, they want to escape from the parents asking questions. So, they say something and send them out. So, these parents are in the impression that my child will become alright one day.” (INT_PRO_IND_015)*.

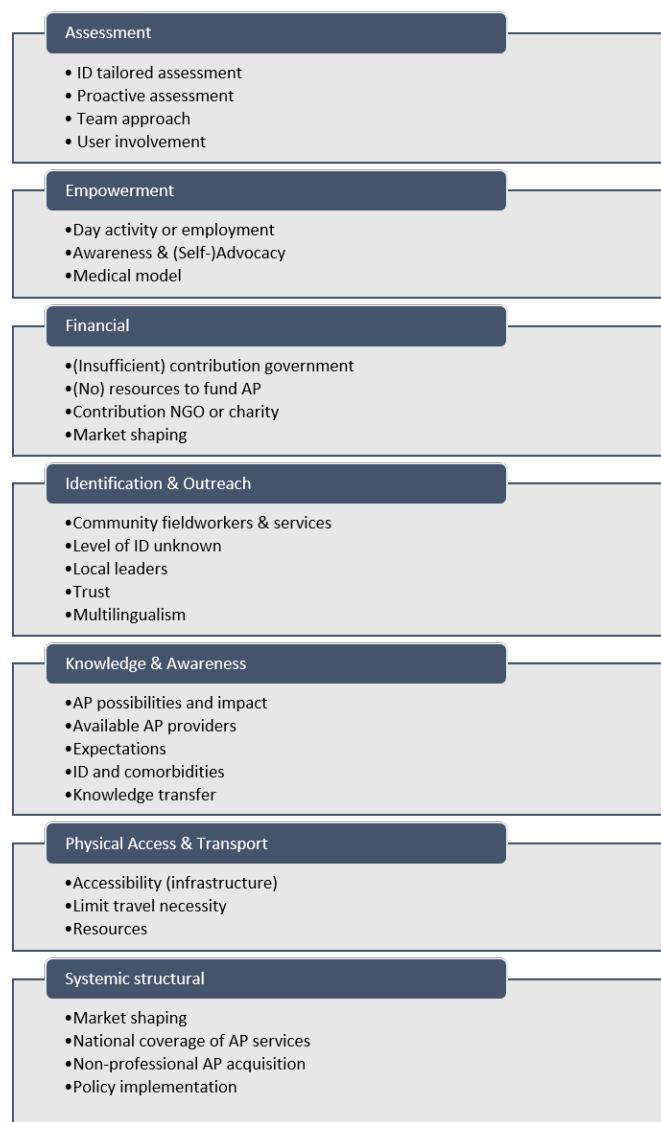
Theme 2. Access to AT

Data coding developed into seven domains for access to AT: Assessment; Empowerment; Financial; Identification & Outreach; Knowledge & Awareness; Physical access & Transport; and Systemic structural (e.g. policies, resources and the organisation of AT services), see Figure 2. The meaning units were coded into 3-5 categories per domain.

Assessment

Pro-active and ID tailored assessments were rare. The majority of participants from group 1 were never tested for hearing, vision, or communication and did not go to the dentist. Participants from group 2 explained the difficulties to assess a person with ID: *“R: Can you test every person with ID and low vision? P: It is difficult for me to assess ID child’s vision. Assessment is very, very difficult. Because they do not have language skills, they do not have understanding of objects. So, difficult.” (INT_PRO_IND_015)*. Providers of AT did mention they were aware of the importance of including the user with ID, during AT assessment. An important facilitator for access to AT, highlighted by participants from group 2, was network and collaboration to ensure assessments for different health needs. For example, the local rehabilitation centre worked closely together with other professionals to provide those AT which the rehabilitation centre could not provide. Networking was mentioned as a substantial aspect of the work of the community fieldworkers.

Figure 2. Domains and categories for access



Empowerment

It is expected that empowerment of people with ID will lead to greater access to AT. It was mentioned, that after liberalisation took place in India people became more aware and demanding of their rights. However, various answers were given related to this topic. On the one hand participants stated a lack of advocacy: “P: Persons with mental illness and ID, they are not able to voice their needs... We don’t have such an association who speak for them.” (INT_PRO_IND_010). On the other hand, participants believed that people with ID were well able to advocate for themselves. During the interviews it became clear that the medical model of disability was very much still in place, for example: “R: Are there any AT that she doesn’t have but she thinks she could use it? Participant A: She not require any assistive device according to her [mother] when she [mother] is with her.” (INT_ID_IND_001). And the voice of the person with ID was often neglected: “R: Do persons or their parents, do they always know what they need? P: ...Sometimes the children do express that need. But parents could deny that need. Thinking that this person is not capable enough to express such needs.

P: The needs expressed by the person and the caregivers is totally different. So many times, we professionals go with the caregivers, neglecting the person with ID.” (INT_PRO_IND_010). Perhaps as a reflection of the medical model, it was observed during the interviews, that parents were often taking the lead in answering the questions for their child with ID, even though the person with ID would have been capable of answering questions themselves. Related to empowerment is having a day activity or employment, which can also function as an access point to AT (22). However, the majority of the participants did not have a day activity or employment.

Financial

The government in India provides identity cards (Aadhar), below poverty level cards, and disability certificates, which assist in entitlement for a monthly pension for people with ID, travel concession passes and funding for certain AT (24, 25). The introduction of disability certificates has resulted in carers taking their family members outside the home, instead of hiding them, in order to visit the health professionals and qualify for funding. The type and quality of AT funded by the government was limited to certain basic AT. For example, communication devices were not eligible for government funding. In addition, the implementation of funding policies weren't always happening according to some participants: *“P: They [the government] have formulated 10 schemes and they said that these schemes will be implemented now... Now after two years the whole thing is in a state of collapse. These 10 schemes are now put in cold storage. Why, they have no money. They don't release the funds for that.” (INT_PRO_IND_014).* People with ID or their family weren't always in the position to afford AT themselves, or afford the correct AT that would suit the person's need. NGO's and charities were available in the Bangalore region to raise some funds to support the costs for AT. Participants did notice a change in the AT market, making AT more affordable. However, specific AT with a low demand remained very expensive.

Identification and Outreach

Community fieldworkers played an important role in identifying people with ID and linking them to AT providers: *“P: With these people we can definitely access the person who is in the far remote area of the village. We can identify the person with disability in a particular village and find out what are all his needs and bring him to the district level hospital and see that all the needs are fulfilled.” (INT_PRO_IND_011).* Community fieldworkers required the help of local leaders, such as ward counsellors, who would know their area and are in touch with the community members. Yet it wasn't always known which community members ID and ID assessments had rarely took place. The multilingualism in India was also mentioned as a big challenge to reach out to people with ID and their families.

Knowledge and Awareness

Lack of knowledge and awareness regarding ID and AT, and the possibilities for AT to effectively address impairments were often mentioned by the participants as a barrier to acquiring AT: *“P: The receiver does not know what to ask for. The service provider also does*

not know what to offer. So, there is a gap.” (INT_PRO_IND_002). Some participants explained they were not thinking about AT possibilities for people with ID due to their main focus on the intellectual disability aspect of the person. Parents often thought that AT would have a negative impact on their child’s development and were convinced the child did not need any AT, for example with communication AT: “P: This is not going to make the child speak, so why are we doing this?” (INT_PRO_IND_009). Participants were not aware of the higher prevalence of comorbidities within people with ID, and officials misunderstood the definition of ID: “P: According to them ID means that they should have a mongoloid face, there should be liquid coming out from their mouth, and also they should be doing some seizure moments. If all of these are absent, according to them the child does not have ID” (INT_PRO_IND_015). The importance of training and education was clearly stated: “P: First we have to educate the people, then only whatever changes will come, we benefit. Otherwise it won’t work.” (INT_PRO_IND_013). Opportunities noted for knowledge transfer and raising awareness, included online training initiatives and peer learning activities organised by community fieldworkers or local leaders. The participants with ID all mentioned they would ask their family member if they needed information on AT.

Physical access and Transport

The lack of accessibility was often mentioned as a barrier to access AT services: “P: The road... Any hospitals... Slowly it’s developing, but not everywhere. Only high-level hospitals. Normal hospitals don’t have. If I go to any hospital or the dentist we have to carry him.” (INT_ID_IND_010). To be physically able to travel is one thing, but people with ID often need cognitive support to be able to travel and to understand the information provided by the health professional: “R: And how do you get to [X], if you need to go there? P: Father will drop me.” (INT_ID_IND_003). Instead of letting the user travel to different professionals, some professionals collaborated over the phone or online to discuss AT needs or customisation for a specific user. Sometimes on-site visits were organised to limit the travel necessity of people with ID who found it difficult to travel or simply didn’t have the money to do so.

Systemic Structural

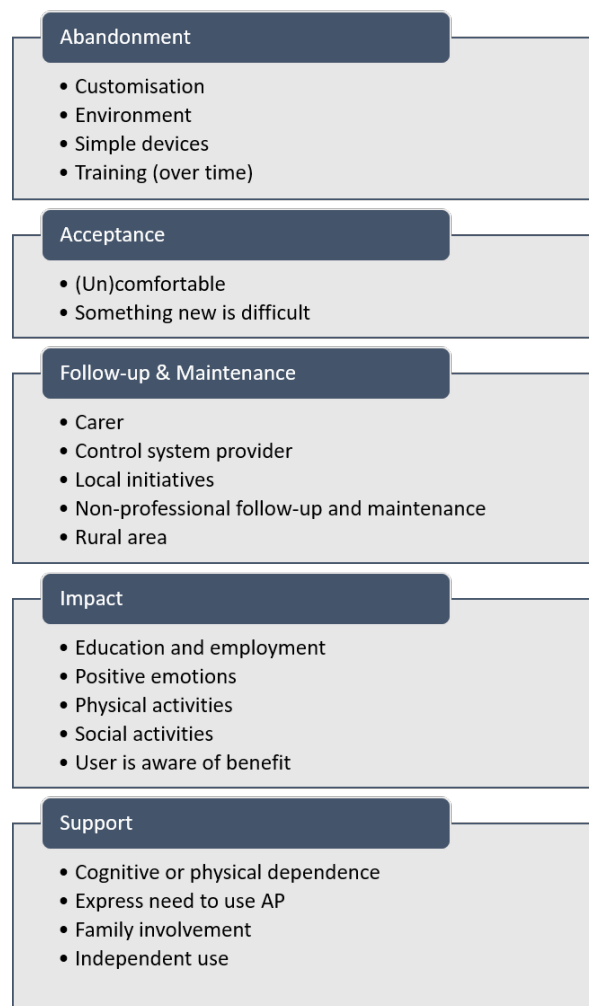
Lack of AT resources (services and professionals) especially in the rural areas was often mentioned by participants: “P: We do design, we do plan the programmes in such a way to reach the services and to reach the population, but due to lack of man power, lack of qualified persons availability in the rural areas, it tend to be a difficult task. (INT_PRO_IND_011). Available AT services often did not provide professional acquisition. Participants mentioned that people in India often buy AT in the so called ‘surgical-pharmacy shop’ without any professional assessment or advice and buy AT according to availability in the shop: “P: they usually don’t go to the rehabilitation centre, because they are not aware. So straight they will to the surgical shop. With brake, without brake, whatever, they will just buy it.” (INT_ID_IND_010). Lack of policy implementation was stated as a systemic barrier to access AT: “P: The government has lots of schemes and grants for various kinds of assistive devices. But to access these grants is so difficult. There are so many channels, and so many

things....to get the file moved from here to that ministry of Delhi, it becomes a nightmare.” (INT_PRO_IND_002). The implementation of the disability act (2016) was limited: “P: The act is very clear, which is on paper. It doesn’t happen in reality.” (INT_PRO_IND_015). The need for an AT policy adapted to the India context was often supported.

Theme 3. Continued Use

Data coding developed into five domains for continued use of AT: Abandonment; Acceptance; Follow-up & Maintenance; Impact; and Support, see Figure 3. The meaning units were coded into 2-5 categories per domain.

Figure 3. Domains and categories for continued use



Abandonment

The importance of customisation to prevent abandonment and ensure continued use of AT was stated by all professionals. Parents and users were not aware of the advantages of customisation or the possibilities on offer. Those who acquired AT without assessment of a (health) professional did not receive customised AT. In addition, AT acquired and funded through the government often did not involve a health professional and did not include customised AP: “P: With the tender only a few fabricated assistive devices is available, for

example walker, crutches, wheelchair; one design for everyone. People are receiving the product that is not suiting them. Because government is free of cost, so they go and collect it. By the end of the day the collector tries to use it, they are not able to use it effectively. It's not useful to them. So they keep the devices somewhere in stored places.” (INT_PRO_IND_001). Logistical barriers also resulted in AT abandonment, such as the size of the AT to transport from one place to another or the inaccessible infrastructure of India. It was stated that with the development of new technologies, AT did become easier to use for people with ID and resulted in less abandonment. Training was needed for people to understand how to use the AT which was provided. Training was essential for the users themselves and their carers to prevent abandonment. But also for people involved within their day activity or employment: *“P: I go to the workplace, where we explain the employee this is what the person's problem is, this is how he does work. This is what he needs to work. And this is what we're providing him. And you should collect it from him everyday evening, send him home without that, when he comes back next morning, give it to him to use for during the work.” (INT_PRO_IND_015).*

Acceptance

If the person with ID felt comfortable using AT, the product was easily accepted. If there was any discomfort, the users did not want to use the AT: *“P: She is not willing to use that shoe. She used to cry. When she used to wear that shoe, she would start crying, screaming, I don't want this, like that. R: Do you think she also felt ashamed that she had to use it? Participant A: No not like that. She was not feeling comfortable, so she is screaming.” (INT_ID_IND_002).* Participants stated that for people with ID acceptance of new AT can be difficult and it takes time for them to get used to new AT.

Follow-up & Maintenance

Users indicated they did not know themselves how often they would have to go for follow-up, they depended on their carers to indicate the need and arrange the follow-up. They also indicated that if their AT broke they would go to a family member to ensure repair: *“R: How often do you have to go back to the shop, to check if the glasses are still ok? P: My brother came and took me.” (INT_ID_IND_013).* Frequent follow-up according to international standards was not organised by the majority of providers. Some families were very punctual regarding follow-up, but the majority would only go for follow-up if the AT had broken down: *“P: Maybe after 6 months, we ask for 3 months, but maybe after 6 months they come, because at that time the belt might be broken or they want it to repair it. So not according to our instructions, but according to their need they may come, that way.” (INT_PRO_IND_001).*

Some providers organised an alternative for parents to contact them for follow-up if visiting the professional was not an easy option. For example, there was the possibility to phone the provider or send photos by email. According to these photos the provider could send the parts for the AT which were needed. Living in rural areas was definitely seen as a barrier to ensure follow-up. The equipment needed to repair AT would not be available in rural areas

and people would not be able to travel to urban areas. This led to non-use of AT in some cases: *Participant A: prescribed hearing aid, it expired after some time, but repair was not possible there. So we dropped it for some years.*" (INT_ID_IND_014). Local initiatives where professionals would make on site visits for follow-up were seen as a good method to ensure continued contact with users. If individuals with ID live long-distance from the provider, they would be allocated an option for follow-up and maintenance at a local centre. The importance of community fieldworkers and self-help groups were mentioned as important facilitators to ensure follow-up when resources of professionals were scarce. Providers indicated the importance of follow-up and maintenance by a professional and not by people who are not trained or not equipped to do so. However, most parents did not see any issues by going to a non-professional shop. AT provided through the government did not receive any follow-up: *"P: That's a good question actually. No, we don't have any follow-up.... We distribute to the people. Following up is not there."* (INT_PRO_IND_005).

Impact

The impact or benefit AT has for a user or their carer can be seen as a very important facilitator to use AT in daily life. Some participants were well able to describe the benefit of the AT they were using: *"R: And how will the crutches help you? P: With the crutches I have a support and I'm able to slowly walk. R: Can you walk without the crutch? P: No."* (INT_ID_IND_003). Another participant attended adult classes where he used a recorder: *"P: Sometimes volunteers won't be available to explain to him [in classes]. Another thing, classes will be noted, so many classes he will miss, that time he uses recording."* (INT_ID_IND_003). One aspect of impact included the emotions generated by using the AT which influenced their continued use: *"R: And how does it make you feel to use the iPad, does it make you happy or sad? Participant A: Happy, satisfied."* (INT_ID_IND_007). Using AT also enabled some users to increase social interaction: *"R: Does it make her feel more included in society? P: Yes... All her difficulties e.g. school issues, she expresses [over the phone]."* (INT_ID_IND_004).

Support

Frequently users needed their carer to help them use the AT on a daily basis, either because they did not understand how to use a specific AT or they were physically not able to use it. For example, a lot of adults with ID and motor disabilities enjoyed using the mobile phone to call friends or family, but they would need their parent to dial the number and hold the phone to their ear. Some users would forget using their AT and depended on their carer to remind them: *"R: Do you remember yourself to use the glasses? P: I know. [Mother does not agree, laughing] Mother: for anything I need to remind him 10 times."* (INT_ID_IND_003). To ensure continued use of AT it helped if the user could indicate and express when they wanted to use their AT: *"R: And it's the phone of father? P: yes, fathers... She can express that she wants to talk, then he [father] gets the phone."* (INT_ID_IND_004). Providers indicated the importance to involve parents when new AT was acquired. If the family did not support the AT, the person with ID was not using it: *"P: If we work with the whole family the*

rehabilitation will happen. If you only do it for the person with disability [it does not work]... and if we withdraw, the family will take care.” (INT_PRO_IND_003). If the person with ID could use the AT independently, without any support, continued use was guaranteed more often. Some providers indicated the importance of working with them individually, to encourage independent use: “R: Can you remember to get the crutch and use it or does somebody helps to remind you? P: I take it.” (INT_ID_IND_012).

Discussion

This study presented the views and experiences of people with ID, their carers, local AT providers, health professionals and government officials in the Bangalore region of India regarding access and continued use of AT for people with ID. The findings showed that stigma and negative attitudes towards ID were still present as an important barrier for this group of people to have access to AT. Empowerment and self-advocacy were mentioned as opportunities to break this. However, the strong medical model approach to disability seen within India, may present a challenge to individual AT user empowerment. The medical model of disability may create low expectations for some individuals with ID and may lead to individuals actively reducing independence, choice and control of their own lives. People with ID are seen as persons who need carers and professionals to make decisions for them. People with ID want to be empowered to individually choose and use AT, but they cannot do this in an environment that is not supportive of such choices (26). While in Indian policy documents there has been a shift from a charity model to a rights based model, in daily practice this shift remains limited for people with ID (27).

Another important barrier to people with ID having access to AT was a lack of knowledge and awareness on the impact and possibilities of AT for people with ID. Firstly, possibilities of AT to support people with ID in their limitations of cognitive functioning were unknown; none of the participants were using any type of AT which supported cognition. Second, AT which could be used to support any co-existing impairments or health problems the person with ID might have, was often not assessed; it was found that it was difficult for carers, or others involved, to look beyond the intellectual disability of the person. Parents also had difficulties in accepting their child with ID, having expectations for typical development; which in turn led to a non-acceptance of supporting AT, e.g. communication AT. This expectation of a typical development was on occasion fed by health professionals providing parents with incorrect information on ID, including the changes to be expected over an individual’s life-course. Increasing knowledge and providing education on ID and AT for both professionals and carers was mentioned as a facilitator to increase access to AT. Methods of knowledge transfer and education around AT mentioned by participants were via interactions with community fieldworkers and by accessing information online. E-learning is often defined as the use of online information technology to enhance or support learning. E-learning is becoming more frequently used as a method of delivering education and training in isolated and rural areas, and it has been suggested that E-learning is a potential sustainable option for capacity building in low- and medium-resource countries (28). Indeed,

E-learning through mobile devices could be applicable, as smartphones are becoming more affordable worldwide. However, it will remain a challenge to ensure E-learning is accessible and adjusted to the specific needs of people with ID.

Abandonment was found to be an important barrier which negatively influenced continued use of AT for people with ID. Factors which lead to abandonment were a lack of customised AT, unsuitable environments to use AT, and a lack of training over time. As this study also showed, people with ID often need daily support from their care system to use (or be reminded to use) their AT. For a person with ID to be capable of using their AT independently, training adjusted to the level of ID is needed during the introduction of AT. In addition, recurrent training is required to remind the person with ID how to use their AT over time. Training methods also have to be adjusted to the communication method preferred by persons with ID (e.g. use of visuals and gestures) (29).

Recommendations

The findings of this study can be used to inform and adjust AT implementation programmes of countries whose aim is to improve access to AT to people with ID. The barriers and facilitators for people with ID related to AT are different from other vulnerable populations and should be taken into account in country specific policies and frameworks. AT can have a huge impact on the quality of life and inclusion for people with ID. Training programmes on AT selection and use should be implemented to support community based initiatives to identify people with ID and refer them to the appropriate services.

Challenges and opportunities

The health needs of people with ID are often unrecognized and unmet (2). This is also reflected in a lack of assessments and underdiagnoses of health problems, which could be better managed with AT, such as hearing and vision loss. People with ID have twice as many health problems as the general population (29). Outreach and identification of people with ID, and if possible their cause, need to be prioritized in order to proactively screen for health problems in people with ID. ID assessments are needed, to know which members of the community actually have ID. People with mild ID, who often go unrecognized, may be particularly important to identify. The government in India has shown commitment to improve information on epidemiology, support systems and services for people with ID in India, but there is still a long way to go (30). Our results also indicate the importance of aiming to address the five strategic Ps of policy, products, personnel, provision and people; whilst also taking into account the five contextual Ps of procurement, promotion, pace, partnership and place; which strongly influence the extent to which the strategic Ps can be addressed, and may suggest alternative ways of doing this, though a systems-thinking approach (31).

The findings of this study provide opportunities to support implementation of the UNCRPD through AT and to advance population health realising basic human rights for people with ID. Countries such as India who have ratified the UNCRPD and who have also agreed to

work towards the achievement of the SDG's will need to take action to realise these commitments, so that every person with ID in need of AT should have access to quality affordable products.

Funding

This research was supported by funding from the charity RESPECT and the People Programme (Marie Curie Actions) of the European Union's Seventh Framework Programme (FP7/2007-2013) under REA grant agreement no. PCOFUND-GA-2013-608728'.

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Global challenges to access appropriate wheelchairs

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Abstract

Introduction: Appropriate wheelchair and seating assistive technology is often essential for the health and wellbeing of people with mobility impairments, to enhance fundamental freedoms and equality of opportunity. To date, provision has mainly focused on just delivering the wheelchair product instead of following an evidence-based wheelchair service-delivery process. In addition, many governments have not committed to national wheelchair provision policy, which need to be strengthened through policies, trained personnel and a range of appropriate wheelchairs. **Approach:** Utilising systemic development model concepts, supported by the frameworks of sustainable human security, a mixed-method approach was employed which aimed to explore the global challenges to access appropriate wheelchairs. **Findings:** *Capturing perspectives across the life course* illustrates the multitude of variables affecting the smooth transition to wheelchair use, whether slow or sudden, for children, families, adults and older people. Indicators note the meaning and essentiality of the wheelchair as a lifeline and the consequences of poor provision systems on quality of life affecting health and wellbeing. *Wheelchair service delivery and education and training* encountered can be perceived as a matter of luck, with navigation of services generating stress and burden for both people accessing services and personnel providing services. Building capacity and delivering adequate education and training for all is key to developing wheelchair provision systems. *Wheelchair product quality* is generally poor and there is a need to strengthen performance quality standard measures and processes which lead to best practices for design, testing and procurement. *Wheelchair funding* is either through government or charity, with systems varied across jurisdictions. Restricted access to wheelchairs creates a cycle of poverty and disability.

Governments need to invest in infrastructure to enable universal health coverage, and where possible, transition to local manufacturing of wheelchairs to produce sustainable, long-term services which support wheelchair users to take part in all aspects of life. *Wheelchair provision policy* is limited and based on the evidence found the overall recommendations lead to a call for government commitment to develop and implement national strategies. **Conclusion:** To address the global challenges, understanding in-country perspectives and inclusive solutions, which connects with the priorities of national governments, is important. The vision is to take positive action to develop appropriate and sustainable wheelchair and seating provision infrastructures globally, for me, for you, for us.

Keywords

Appropriate wheelchairs, People, Human Security, Context, Economics, Education, Product, Policy, Provision, Sustainable Development

Introduction

Assistive products, such as wheelchairs, are an *'essential component for inclusive sustainable development'* (1). Appropriate wheelchair and seating assistive technology (WSAT) is often essential for the health and wellbeing of people with mobility impairments to enhance fundamental freedoms and equality of opportunity. Every aspect of the wheelchair provision process, whether waiting for an assessment, the type of assessment conducted, the quality and fitting of the product or the follow up supports available will affect a person's life positively or negatively depending on the experience. In 2008, the World Health Organization (WHO) published Guidelines of the provision of Manual Wheelchairs in Less Resourced Settings (LRS), which emphasized the need for appropriate wheelchairs, with a provision system addressing design, production, supply and service-delivery processes (2). Although the guidelines were directed toward LRS, they are relevant globally (3). Some progress has been made; however, evidence suggests that despite the WHO's guidelines on wheelchair provision training packages and other resources, getting *'the right wheelchair'* (manual or electric-powered), in *'the right way'* (4), and learning how to use the device properly remains a global challenge. Provision has been focused around just delivering the product, instead of following an evidence-based service-delivery process. In addition, many governments have not committed to national wheelchair provision policies.

Several authorities employ ad hoc, unsustainable systems instead of providing accessible person-centred services, skilled personnel, quality products, training, maintenance, follow up and management. To this end, universal wheelchair provision appears piecemeal, with tenuous links among stakeholders, such as wheelchair service users and families, therapists, service providers, manufacturers, regulators and policy makers. This creates systems that continue to be untenable, leaving people vulnerable to human insecurity (5-7). Countries fail to provide appropriate and sustainable wheelchairs service delivery systems. These concerns were further reiterated in January 2018, when United States Agency for

International Development (USAID), World Learning and the International Society of Wheelchair Professionals (ISWP) facilitated a wheelchair stakeholders meeting hosted in Bangalore, by Mobility India. Bringing together fifty-six sector leaders to share perspectives and consider future developments, the goal was to establish key priorities for the next five years to strengthen wheelchair services through policies, trained personnel and a range of appropriate wheelchairs. To achieve this goal, ten priority actions were identified to effect change towards sustainable development. These actions include building awareness, conducting research, establishing global service standards, establishing product standards, fostering innovation, improving wheelchair supply, promoting policy, stimulating collaboration, supporting competency development and supporting good practice (8).

Sustainable Human Security Perspective

Building sustainable wheelchair provision communities of practice (5,7,9), working collaboratively toward a common goal which is in keeping with the Sustainable Development Goals (SDGs) (10) and the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is key for a sustainable future (11). Taking a sustainable human security perspective enables an evaluation of the potential threats that inappropriate wheelchair provision has on protecting the health and welling being of individuals, families and communities. Human security is multifaceted and is defined in the General Assembly resolution 66/290 as *'...an approach to assist Member States in identifying and addressing widespread and cross-cutting challenges to the survival, livelihood and dignity of their people'* (12). Unstable wheelchair provision infrastructure can lead to human security threats which may include poverty, unemployment, lack of basic healthcare and education, resources and access to appropriate products, personal and community inclusion and participation. Limited political will to create policy and deliver services with respect and accountability confounds these security issues. Moving beyond basic survival when requiring a wheelchair, an integrated approach is needed, generating empowerment and accountability processes that are, according to the United Nations, *'people-centred, comprehensive, context-specific and prevention-oriented responses that strengthen the protection and empowerment of all people'* (12).

Approach

Applying the frameworks for sustainable human security, which promotes fundamental human rights and freedoms from fear, want, shame and vulnerability, the World Engagement Institute (WEI) proposes a systemic development model (SDM) founded on the sustainable human security paradigm to support multifaceted methods. Four interlinked pillars for sustainability are included in the SDM to understand personal, organisational and institutional capacity: natural (health), social (culture), economic (technology) and political (law) (13).

Utilising the SDM concepts, supported by the frameworks of sustainable human security, this position paper aims to better understand the global challenges to accessing appropriate wheelchairs, by achieving the following objectives:

1. To build awareness as to the importance of appropriate wheelchairs to enhance the health, wellbeing and fundamental freedoms of people who require wheelchair services across the life course.
2. To establish an overview of context specific wheelchair service delivery systems and situations.
3. To understand the economic landscape when providing products and services and the viability of provision.
4. To review the product production environment to access quality wheelchair and seating assistive technology.
5. To generate political governance priorities to access appropriate wheelchairs

A mixed-method approach was employed to prepare this position paper. The authors, wheelchair service providers and researchers were engaged to formulate findings and discussion. This was based on authors' knowledge and expertise regarding people, personnel, product, procurement, provision and policy development to provide appropriate wheelchairs. Authors were engaged to develop core subject themes, supported by scientific and grey literature, to provide an overview of existing literature since 2008, identifying main concepts and discussion on wheelchair provision and impact on children, adults and older people. In addition, in-country case studies were supported by the authors' experiences were included to highlight context specific examples. All authors reviewed the paper for accuracy of concepts and conclusions.

Findings

Perspectives on wheelchair provision across the life course

Human beings generally strive to achieve a sense of well-being, meaning and positive purpose even in the face of adversity. Flourishing in daily living is influenced by life experiences, the ability to set goals, take risks and navigate the context in which we live (14). Wheelchair use does not discriminate; any person could need a wheelchair in their lifetime. The meaning of the wheelchair for people, children, adults and older people who require one is well documented, noting its essentiality as a lifeline and freedom to personal mobility and daily living across the life course (15-17). Bray et al (18) report young children and parent's perspectives on mobility related quality of life are linked to '*participation and positive experiences; self-worth and feeling fulfilled; and health and functioning*', and noted by Labbé et al (19) as a dynamic process.

However, people and families face many challenges to negotiate life's journey to promote health and prevent illness as wheelchair service users (20). Acquiring an appropriate wheelchair is uniquely complex to meet individual needs depending on personal narratives, reason for wheelchair use, diagnosis, life stage, secondary complications, and living

conditions across the globe (21, 22). Capturing perspectives across the life course illustrates the multitude of variables requiring consideration when seeking to develop sustainable wheelchair provision infrastructures.

Children and their families transitioning to wheelchair use should enable participation in play, school and community engagement and as Casey et al note “*reduce stress and burden*” (Casey et al, 2016). A child’s transition to wheelchair use affects the whole family, with wheelchair provision processes influencing the health and wellbeing outcomes for the child and the caregivers (18, 23-26). Evidence suggests that while parents value the benefits of the wheelchair, mixed emotions are expressed given the service provision experience, having to continuously advocate for correct wheelchair prescription and follow up services (23), alongside the challenges of accepting disability within the family and wider community. Anticipatory approaches with continuous re-examining for a child’s growth and developmental needs, provided in a family centred way and in tune with the emotional sensitivities experienced by caregivers, is recommended (24). In addition, twenty-four-hour postural management should complement wheelchair education and training skills throughout life (27-29).

In adulthood, becoming a wheelchair user resulting from sudden and traumatic onset such as spinal cord injury, brain injury and stroke or a progressive neurological condition such as multiple sclerosis or motor neuron disease, successful adjustment to a new lifestyle is influenced by the wheelchair provision experience (30, 31). People with spinal cord injury, as one example, are vulnerable to pressure injuries and numerous other secondary health complications which have significant treatment and management costs (32). For instance, it is estimated that the NHS in the United Kingdom spends between as much as £2.6billion on the treatment and management of pressure injuries each year (33).

Evidence suggests that poorly prescribed and inappropriate provision has irreversible long-term effects causing incapacity to participate and vulnerability to early death (34). In addition, untimely follow up, maintenance and repair services, particularly when the wheelchair breaks down, has a negative impact on equality of opportunity to access education and employment (35,36), increasing the risk of poverty and ill health. Becoming a parent as a wheelchair user, people experience social prejudice, personal and environmental obstacles. Notwithstanding challenges with personal health, finance and support networks, easy access to assistive technology was also noted as influencing the practicalities of parenting (37).

As people age, decline in independent mobility for wheelchair users is reported, with many influencing factors such as health conditions and overall long-term physical endurance (38). For older people, maintaining life at home and in the community is challenging and appropriate choice of mobility device requires consideration (39). Acceptance of wheelchair use for personal mobility is difficult and further confounded by caregiver burden assisting with the wheelchair (40). With aging populations, old age /nursing home accommodation is on the rise, with approximately eighty percent (41), of residents requiring wheelchairs,

many needing customised seating. Access to appropriate wheelchair assessment and provision services are limited in many cases, further challenged by the complexity of the setting and high numbers of staff turnover (42). This results in limited postural support, inadequate pressure care management, and poorly fitted/maintained wheelchairs (41), with individuals at the advanced stages of dementia care being particularly vulnerable to pressure injury and postural deformity (43,44).

Wheelchair service delivery, capacity building, education and skills training

Receiving the right wheelchair in a timely manner is noted as a matter of luck and gratitude, dependent on the services in place and the attitude and skill set of prescribing personnel (5, 45). Wheelchair provision personnel face many obstacles given poor service delivery infrastructure, limited resources, attitudes of wheelchair users and organisations, education and training (46, 6). Research highlights the effects that the wheelchair service delivery ecological system has on wellbeing for both wheelchair service users and practitioners. Wheelchair service users' relationships with wheelchair service personnel reflects both positive and negative experiences (45). There are notable concerns about a disconnection from person-centred practice affecting core philosophies, principles and ethical standards of practice, leaving wheelchair users feeling vulnerable and reluctant to complain about inappropriate provision and personnel susceptible to moral distress and burnout (45, 47).

A key issue with how wheelchair services are provided is that across both low and high-income settings there are few countries that recognize a specific professional related to wheelchair service provision (6), likely impacting both the training that is provided and existing capacity. Several recent studies (48-50) have identified that there are disparities related to providers' or students' current knowledge of appropriate wheelchair service provision and the amount of wheelchair service provision training provided around the world. That adequate training is not included in health and social care training programs is reflective of the lack of specificity related to wheelchair education in most professional rehabilitation bodies' educational standards (e.g. 51-54) Fung et al (48) identified across several contexts (e.g., region, income-level, and type of training program) the amount of wheelchair training is highly variable, with programs citing anywhere from 2-40 hours in a global survey. In a follow-up study, Fung et al. (49) suggested several barriers including: limited funding; limited expertise; awareness of and training for instructors; limited physical resources (wheelchairs, related equipment, access to local clinics); and physical space limitations. As a result, student (and likely future provider) knowledge on the wheelchair service provision process is lacking. For example, Toro-Hernández (50) investigated over 100 undergraduate physiotherapy students' wheelchair service provision knowledge. This study identified that none of the students were able to demonstrate the minimum required knowledge based on performance on the ISWP basic knowledge test (55), a test which mirrors the eight steps of wheelchair service provision as identified by the World Health Organization Guidelines (2). These findings related to insufficient knowledge and capacity

may suggest a commonality across other lower income settings where training is often limited (6).

Novel training methods such as hybrid (i.e., part in-person, part online) methodology may help to offer adaptable and less costly alternatives to training at the basic level (56). In a recent study, both in-person and hybrid learning methodologies had a statistically significant effect on increasing wheelchair service knowledge with overall high levels of satisfaction with the in-person group reported overall larger effects when compared with the hybrid methodology (57). Organizations may improve hybrid learning interventions based on best-practices as recommended by Caulfield (58) to enhance participants' learning experiences and reduce potential barriers and limitations (57). Further, the use of open source resources (e.g., WHO Wheelchair Service Training Package, Wheelchair Skills Program and platforms designed to share wheelchair education information, i.e., the Seating & Mobility Academic Resource Toolkit (SMART)) (59-61) may help to advance the training provided to future wheelchair service providers. Promotion of these resources through professional organizations' communication channels (e.g., WFOT Bulletin, ISWP Hub Newsletter), facilitation of dialogue amongst professionals via online forums (e.g., WFOT's Occupational Therapy International Online Network and ISWP's Wheelchair International Network) and continued work by groups dedicated to improving wheelchair education (e.g., ISWP's Integration Committee, ISPO's Wheelchair Advisory Group) may also serve to enhance wheelchair education and capacity building of adequately educated professionals. In addition, national ministries globally could stipulate mandatory education qualifications in the wheelchair and seating product prescription and delivery. This is demonstrated by New Zealand's national training for wheeled mobility and postural management credential responding to the accreditation framework 2010, to ensure proper assessment of ministry of health funded products (62, 63).

Wheelchair product quality development, performance and procurement standards

WHO's consensus definition of an appropriate wheelchair is '*a wheelchair that meets the user's needs and environmental conditions; provides proper fit and postural support; is safe and durable; is available in the country; and can be obtained and maintained and services sustained in the country at the most economical and affordable price*' (2). This underlies both the reason and the importance of developing and utilizing reliable manufacturing and performance standards and procurement procedures to maximize the likelihood that users have access to appropriate wheelchairs, and that over-time the supply of inappropriate wheelchairs is eliminated.

Unfortunately, there is convincing evidence that wheelchair product quality is generally poor and not improving over time, highlighting the importance of strengthening performance measures and procurement processes. Evidence for instance that poor quality, inappropriate wheelchairs were being widely distributed in less resourced countries (2, 64-66) can be combined with recent systematic research in higher resourced environments (67-69) that more than half of all wheelchair users experience a breakdown every six months.

Evaluating the performance of wheelchairs through standardized testing methods is important during the design process, as well as once a wheelchair is in production. Standardized tests have been developed to measure wheelchair quality, and include the tests listed in the Table 1.

Table 1. Standardized Tests

Name	Scope
ISO 7176 https://www.iso.org/committee/53792/x/catalogue/	Covers testing for manual and power wheelchairs and is used as a reference for most national standards
Whirlwind ISO+ https://whirlwindwheelchair.org/simplified-strength-testing-of-manual-wheelchairs/	Low-cost approach to ISO 7176, with additional tests focused on conditions in LREs
ISO 16480 https://www.iso.org/committee/53792/x/catalogue/	Test for Wheelchair Seating Systems
WC 19	Wheelchair Crash Testing
ISWP Wheelchair Standards	Caster, rolling resistance, corrosion, and whole-wheelchair testing

Product procurement is the process of selecting and purchasing products. This could occur at several scales. For instance, a wheelchair service may procure products to provide choice to their clients. At a larger scale, procurement can happen at a national or provincial level. This paper recommends large-scale purchasing similar to national or provincial level, and that the same principles apply on procuring for a smaller scale level. A critical aspect of procurement is that products purchased are appropriate for the client population, namely; are readily available, are low-cost, repairable locally with access to spare parts and meet the user's needs in their environment.

Assuring products are appropriate requires expertise in contracting, clinical service provision and the technical aspects of wheelchairs. As a single person rarely has all of these skills, purchasing committees are often established to support procurement.

Recommended steps for appropriate procurement include:

1. Performing a situational analysis to determine the range and quality of products that will be needed;
2. Developing a tender that includes key performance requirements such as independent standardized test results;
3. Opening and marketing the tender to attract a large number of suppliers to respond, and

4. Performing a thorough unbiased technical product review carried out by a broad range of personnel with a range of both technical and clinical experience.

Readers are referred to *'Design Considerations for Wheelchairs Used in Adverse Conditions'* an expansive document describing best practices for design, testing and procurement, which was developed through a team of technical experts coordinated by the International Society of Wheelchair professionals (70).

Understanding the economic landscape when providing wheelchairs

The cost of even basic wheelchairs can be beyond the means of many individuals, particularly in low and middle-income countries. Without government or charity support many people with impaired mobility are simply going without essential mobility aids. For instance, *'lack of economic means'* is a key factor in restricted access to assistive technology in low-income countries such as Bangladesh (71). Even in high-income countries wheelchair users are forced to purchase equipment privately; it is estimated that in the United Kingdom parents are regularly having to self-fund 85% of the cost of powered wheelchairs for their children due to a lack of NHS coverage (72). The situation is not helped by high import duties and informal charges levied on medical appliances in many low-income countries, such as Ghana (73).

Restricted access to wheelchairs creates a cycle of poverty and disability - *the disability causes poverty, and the poverty increases their disability'* (74). Microfinancing can help individuals to afford wheelchairs through personal loans. Daher et al. (74) found that this was a favourable approach for individuals with impaired mobility in Syria, but this still places the financial burden on the individual. Universal coverage of wheelchair provision should therefore be a goal for all nations, to enable people to live with dignity and to escape the cycle of poverty.

WHO succinctly identifies three models of wheelchair product provision (75):

1. Importation of complete wheelchairs
2. Importation of wheelchair components for local assembly
3. Local manufacturing of wheelchairs

Wheelchair provision in low-income countries has historically been based on either donation or importation of complete wheelchairs, with price as the key selection criteria. This often leads to issues with service efficiency and wheelchair quality. For instance, in Tajikistan wheelchairs are typically of low quality and inconsistent with international quality standards, leading to wheelchairs lasting little more than a year of regular use (75). The low quantity of importation (around 800 wheelchairs per year) in Tajikistan causes long waiting lists for government provided wheelchairs. Furthermore, limited resources to support essential services associated with wheelchair provision, such as maintenance and repair, has further compounded the issues of inefficient and unreliable wheelchair provision. In line with WHO guidelines (2), Tajikistan is now moving towards a service-provision model of wheelchair distribution, with an aim to provide universal coverage of wheelchairs by 2023.

Significant government commitment is required to ensure that large-scale contracts and national procurement strategies are in place to support universal coverage of wheelchairs. Low-income countries, such as Tajikistan, need to first increase capacity to assemble wheelchairs locally, and in the long-term develop infrastructure to manufacture wheelchairs locally, using locally sourced materials. Significant net benefits can be achieved by moving towards local production of wheelchairs, including increased employment and manufacturing skills (75). One approach to reducing the cost of wheelchair provision is to promote sustainable practices through refurbishment and recycling. It is estimated that 50% of all wheelchairs supplied by the NHS are refurbished (76), cost savings of between 9% and 14% are achieved through this approach (77). At present many wheelchair users pay for their own repair and maintenance, particularly in low-income countries, which impacts quality standards and affordability.

In order to appropriately allocate government resources to wheelchair provision, it is essential that the full spectrum of costs associated with wheelchair provision are identified. A number of financial factors must be taken into account, including the capital cost of equipment, customisation and environmental adaptation; staff costs; service overheads; repair and maintenance costs; and training. Lack of economic evidence is still a major hurdle in improving wheelchair provision; thus, future research must focus on developing a better understanding of what approaches to wheelchair procurement and provision work in different contexts.

Lead from a human rights perspective, UNCRPD states that assistive technology is essential to enable people to be independent, to participate in all aspects of life and to exercise their personal rights (78). Furthermore, the UNCRPD emphasises the importance of personal mobility and equal access to assistive technology to facilitate the highest degree of independence for each individual. Without adequate wheelchair provision many people are caught in a cycle of poverty and deprivation, and consequently have reduced access to education, work and social facilities (2). People with disabilities are more likely to be unemployed compared to non-disabled peers, and when employed tend to earn less (79). These issues also have national economic impacts due to loss of productivity and health service resource use (World Health Organization, 2011). Therefore, universal health coverage for wheelchair provision is needed to promote equal access to wheelchairs. However, across the world most people who require a wheelchair do not have access to one (2, 79). This is a consequence of limited availability of wheelchairs, high cost of equipment, lack of awareness and a paucity of trained professionals to facilitate provision, particularly in low income countries. Governments need to invest in infrastructure to enable universal health coverage, and where possible transition to local manufacture of wheelchairs to produce sustainable, long-term services which support wheelchair users to take part in all aspects of life.

Policy in Context

A significant amount of research across the globe has been conducted, evaluating wheelchair service delivery systems and evidence suggests that while there is some funding, albeit limited, for wheelchair products, getting the right wheelchair is challenging. In many cases the overall efficiency of wheelchair provision processes is poor (5, 7,80-83), despite the availability of guidelines for good practice (2, 84, 85). While the Norwegian service delivery system appears to be the most visible exemplar for appropriate assistive technology provision, specifically related model wheelchair service delivery systems are not easily identified (86,87). Based on the evidence found, the overall recommendations lead to a call for government commitment to develop and implement national strategies, yet specific government legislation and policy as to the appropriate provision of wheelchairs and ongoing support to enhance the health and wellbeing for people requiring wheelchair services is not visible or easily accessible. In addition, there is little or no evidence that evaluates good practice to provide a blue print or template for countries to follow to support sustainable development of wheelchair service infrastructure (88-90).

Research conducting situational analyses captures context specific conditions for wheelchair provision (for example, Ireland, Romania, Philippines and Tajikistan (5,7,74)), with the view of developing and implementing strategic plans by engaging with key stakeholders, including governments, in conversation for change and long-term commitment to sustainable service provision. Contexts reviewed are evidently divergent, with distinct geographic, demographic and socio-political governance dimensions and require individualized strategic planning. Contextual diversity reflects the type of wheelchair services available across countries from low to high income. Nonetheless, many of the key issues affecting appropriate provision are similar, to assume responsibility for oversight of the provision system. Common components include the need for advocacy, wheelchair service infrastructure, product and procurement standards, capacity building, education, training and further research. The starting point to address key issues within each country differs, with graded supports require careful consideration within individual contexts to engage government in meaningful exchange to achieve the best outcomes.

Discussion

Universal consciousness and commitment to see real world change in wheelchair service provision that meets peoples' needs now and in the future is the key. Evidence presented indicates the importance of understanding across the life course experiences as essential to lifelong access to appropriate wheelchair services. There are many key aspects which need to be addressed relating to access to services, assessment, procurement and delivery process, follow up, repair and management and ongoing education for all involved, alongside research for development.

There are many examples of countries striving for better wheelchair services to enable people to engage in daily societal activities, while faced with country-specific practices that

either enhance or inhibit participation. However, to strengthen wheelchair provision globally, there is a need for effective context-specific market shaping, engaging in-country stakeholders in conversation to collectively achieve consensus, which reflects sustainability action to build infrastructure enabling good practice, standards, processes and capacity building. Understanding specific in-country wheelchair service development is key when working towards strategy development and longer-term government commitment. Through a global collaboration and coordination, major progress has been made toward implementing the WHO's guidelines. However, progress has been slow, and clarity of the message being portrayed to society and governments requires a refreshed approach, which connects with a human eligibility to human rights and security knowing that getting the right wheelchair is primary to living and cannot be lived without.

Given this, a collective voice as to the importance of appropriate wheelchair provision as a basic human right is required to open the debate on key issues highlighted in this paper. Personnel involved in providing service require additional supports to develop and deliver services with recognised education and training to strengthen their role, wellbeing and increase and maintain capacity in the field. An international consortium is required to come together to prepare an advocacy strategy which includes situation analysis, stakeholder engagement and strategic planning within context with in-country government support. Working, as a collective should awaken a universal consciousness and commitment to see real world change in wheelchair service provision, leaving no one behind.

Best Practice to Recommend

In order to take action, triumphs and challenges experienced globally need to be reviewed and reflected upon, informing the wheelchair sector on next steps to strengthen evidence-based, adequately-resourced, integrated wheelchair services supported by policies, competent personnel, and a range of appropriate products. There is a need to build self-sustaining networks and best practice in wheelchair service provision around the world, to bridge the gap to access appropriate wheelchairs for all at all ages from a sustainable human security perspective.

Opportunities to address these challenges are materializing in several ways. For instance, international collaborations, such as those developed through ISWP, WHO/GATE, ATScale help to codify best-practices, drive policy changes, and guide funding to improve access. These developments provide opportunity to collate evidence, propose recommendations, publish and disseminate in a meaningful way to build greater awareness of the issues, negotiate and generate committed in and across country partnerships towards sustainability action and change.

Conclusion

Demand, need, availability and supply of appropriate wheelchairs is complex. Studies in the field highlight a lack of consistency in how services are prioritised and regulated, with a dearth of appropriately trained personnel, resulting in poorly delivered services affecting

peoples' lives. In addition, funding and the lack of policies that guide (and require) appropriate wheelchair provision are the primary challenges that restrict access. Therefore, to convey the complexity of wheelchair provision in context to meet peoples' health and wellbeing needs across the life course is challenging. Understanding in-country perspectives and inclusive solutions, reflecting specific personal, social, economic, environmental, historical and political nuances, which connects with the priorities of national governments is important. The vision is to take positive action to develop appropriate and sustainable wheelchair and seating provision infrastructures globally, for me, for you, for us.

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Outcomes

Committing to assistive technology outcomes and synthesizing practice, research and policy

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Abstract

Decades of outcomes research has occurred in widely disparate fields, using diverse measures and methodologies, and from the vantage point of very different stakeholders. Many tools have been developed to measure assistive technology (AT) outcomes, but in most settings AT outcomes data are not routinely collected or published, adversely affecting the evaluation and development of policy and practice in the field. The five P's of people, policy, provision, personnel and products represent the complex and multiple AT systems and stakeholders. A strategy is required to evaluate and to develop shared understandings of outcomes across each of the P's. This paper summarizes existing knowledge and approaches to AT outcomes and identify gaps, mapping these across the five P's. We identify and present contemporary outcome constructs for critical review and discussion regarding their application in diverse contexts. Our aim is to provide a foundation to frame and evaluate the results or effects of actions taken to improve access to AT. We recommend a method to work towards a shared global outcomes commitment, and a range of strategies to improve the state of assistive technology outcomes today.

Keywords

Outcomes, measurement, impact

The Mandate for Assistive Technology (AT) Outcomes: Needs and Opportunities

Our Approach

This paper is informed by the research expertise of the contributors and their global networks of collaborators with diverse experiences designing and implementing AT outcomes. We deliver on point one of a proposed three-point method for systematic global AT outcome practice:

Key authors reviewed the state of the science in AT outcomes, incorporating peer reviewed literature, grey literature, and non-traditional research outputs. The review captured

practice-based outcome activities, providing a holistic view of AT outcomes beyond academia and research. Findings are synthesized and presented as a commentary that links the state of the science to the five P's.

This overview builds key perspectives on a historical foundation and creating the basis for critical and timely future visioning about the potentials of AT outcomes systems recommending to WHO that we tap a more extensive international set of AT outcomes experts by convening a conference specific to AT outcomes and using a Delphi Technique to clarify gaps in knowledge, categorize opportunities for collaboration, and prioritize actions for development.

Feedback from successive rounds of this future Delphi Technique assessment would target the creation of a consensus of opinions to guide future actions and collaboration.

Historical view of assistive technology outcomes: A new science and practice

Every assistive technology consumer, their practitioner, and the researchers, product developers, policy makers and other stakeholders within the constellation of the AT system, want to see outcomes achieved. What these outcomes look like, who defines them, and how they are measured, is the question.

The global community is diverse and yet the phases of AT provision, and the human outcome domains sought, are shared. Rather than summarize the stage of development of outcomes thinking across the globe, we commence with an in-depth view of outcomes work in one developed region, North America. North America, among high income countries, has a substantial and coordinated body of outcomes work and this is provided as a casting off point for discussion.

Assistive technology outcomes measurement received a significant degree of attention in North America in the late 1990s and early 2000s. In 1998, as the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) was developing its assistive technology professional certification, as a part of its review of the field, RESNA published a seminal three volume set of monographs as a resource guide for assistive technology outcomes. The first volume was on "Measurement Tools" (1), the second on "Assessment Instruments, Tools, & Checklists from the Field", and the third on "Developing Domains of Need and Criteria of Services" (2,3). These included early bibliographies, and early listings of the tools. These were published by RESNA before the internet was adopted and these monographs remain among the domain of gray literature and thus, are not easy to locate. Volume I of this series, included papers entitled 1. Concepts and Rationale for Accountability in Assistive Technology (4), 2. Accountability in Assistive Technology Interventions: Measuring Outcome (5), Program Evaluation (6), Characteristics of a Meaningful Outcome Assessment (7), Where Are We Headed with Assistive Technology Outcomes? (8), and Annotated Bibliography (9). These papers scoped primarily North American activities although attempts were made at the time to incorporate and cite global findings, such as the CERTAIN Project (Cost Effective Rehabilitation Technology through Appropriate

Indicators) that orchestrated by the Technology Initiative for Disabled and Elderly (TIDE) as a program of European Union (10).

Also, during this era the National Institute on Disability and Rehabilitation Research (NIDIRR - now the NIDILRR, the National Institute on Disability Independent Living and Rehabilitation Research) funded two major projects specific to assistive technology outcomes measurement. These two projects called the ATOMS Project (11) and CATOR (12) ran for most of a decade contributing major field reviews, research projects, and publications related to assistive technology outcomes. One of the field scans run by the ATOMS Project was published as a technical report and included a graphical chronology and a list of references related to 30 years of assistive technology outcome measurement events from the years 1973 to 2003 (13).

This work was U.S. centric, but did depict major foci of activity during these early years of AT outcomes measurement. It was also during this time that many assistive technology outcomes and research instruments were developed, validated, and revised such as those depicted in Table 1: Sample Outcomes Instruments. In other countries, such as Italy, outcomes were directed at the program level. For example, The SCAI instrument was developed in Italy to help clinicians estimate the economic aspects of the provision of assistive technology (AT) solutions to individual users. In 2002, the journal *Technology and Disability* featured a special issue on “The Assessment of Assistive Technology Outcomes, Effects and Costs”. A look at the table of contents shows the emphases of many of the measures available at that time internationally (14-23). It was also during this time the many assistive technology outcomes and research instruments were developed, validated, and revised such of those depicted in Table 1. Most of the current work on AT outcomes measures consists of derivatives, translations and cultural adaptations, and validation studies. Measures frequently cited are listed.

Key concepts in the literature reflected by these instruments included, the importance of not only examining functional performance outcomes, but also identifying underlying and proxy factors of outcomes that influenced the use of AT such as reluctance to use due to perceived aesthetics, complexity of devices, lack of training. The trilogy of “matching person and technology” books by Scherer (24-26) included consumer perspectives of AT products used, avoided, or discarded and these perspectives were used to create influences on use and non-use that became items in the set of MPT measures. The set of measures address specifications of goals, history of support use and prior use. The Assistive Technology Device Predisposition Assessment (ATD PA) in particular has separately validated scales measuring (a) subjective functioning, (b) subjective well-being linked to activities and participation, (c) personal Factors (including mood, social support, therapist and program trust) and (d) device match ranking and comparison (non-use reasons at follow-up). These instruments were used in investigations to identify technology adoption, continuing use, longevity of use, and critically, the role of the users’ subjective perception of the technology. Moreover,

early use of instruments like these demonstrated the need for repeated measurement for comparative analysis. Without comparisons, outcomes assessment was not possible.

These instruments and others also identified a conundrum among measurement instrument use that remains perplexing today. Some instruments are excellent for examining factors that lead to outcomes. These are particularly beneficial for identifying ways to improve technologies and services in AT systems. These instruments are research oriented. Other instruments are more likely to produce data that do not explain outcomes but may be more clearly identify changes in functional performance, well-being, or quality of life. One might summarize these two types of instruments as ones that measure factors of AT outcomes versus those that measure effects of AT use.

Forward Thinking for Higher Income Nations

We foresee there to be significant interest among the high-income nations surrounding assistive technology and accompanying outcome documentation over the next decade. Given that, today, high income nations currently focus on service delivery and implementation with little mandate or commitment toward documentation and data collection, we do not anticipate that this will automatically occur. Even though higher income nations have been promoting outcomes concepts for decades, policy systems have not mandated or funded efforts toward collecting outcomes data. Thus, high income nations have an inertia toward stagnation around outcomes acquisition. They may have the financial ability and opportunity, but little internal mandate.

Within this pessimism resides optimism. As an example, in the United States, a new community and home-based funding model is being implemented for acute-care medicine. We anticipate we will see more interest in helping people stay at home and in the community as acute-care medicine will emphasize lowering recidivism rates back into the hospital system (27).

Forward Thinking for Middle- and Lower-Income Nations

The fact that WHO and GATE have activated assistive technology program implementation worldwide we are seeing anticipate substantial growth and attention and assistive technology distribution with the development of services. While historically, little or no funding has accompanied the commencement of new assistive technology programs specifically to support outcomes documentation, we think this is actually the perfect opportunity for assistive technology outcomes documentation to be infused into assistive technology provision programs as they're developed. There is no historical precedent that we see stagnating high income nations to prevent low- and middle-income nations from implementing assistive technology programs with active outcomes assessment.

Table 1. Measuring Individual Outcomes: Examples of available and validated technology-focused instruments

Outcome	Measure	Focus	Related constructs
Intention to use	UTAUT, TAM (28,29)	Perceived usefulness and ease of use	Task worthiness
Expectations of benefit from use	MPT measures/ATD PA initial (30,31)	Motivation, readiness, subjective need, personal factors	Prior use, familiarity with technology
Goal attainment	IPPA (32)	Goal identification and attainment	But may not benefit or like using
Satisfaction with Product and Service delivery	QUEST (33)	Device features, service delivery, usability	But may not benefit
Realization of benefit from use	ATD PA follow-up (34)	Performance Use worthiness	Goal achievement, enhanced well-being, subjective functional gain
Psychosocial Impact	PIADS (17)	Competence, adaptability, self-esteem	
Functional Performance	OTFACT (35)	Function with and without the use of assistive technology	Other functional area specific measures assessing function with and without technology

Notes: ATD PA = Assistive Technology Device Predisposition Assessment; IPPA = Individually Prioritized Problem Assessment; MPT = Matching Person and Technology; OTFACT = OT Functional Assessment Compilation Tool; PIADS = Psychosocial Impact of Assistive Devices Scale; QUEST = Quebec User Evaluation of Satisfaction with Assistive Technology; TAM = Technology Acceptance Model; UTAUT = The unified theory of acceptance and use of technology.

Moreover, with the advent of information technology worldwide where the prevalence of mobile technology is high, even higher than in high income nations, the lower income nations may be even more poised and ready to develop and implement assistive technology outcomes data collection via mobile devices than the higher income communities (36). We need to encourage low- and middle-income nations to lead the globe in this area. The WHO also encourages international collaborations that further increase the potential for assistive technology outcomes to cross borders, continents, cultures, and other population parameters. This can enable assistive technology outcomes to demonstrate outcomes research possibilities as an example for other intercultural technology and service provision

programs outside of AT. New AT initiatives can serve as fresh examples that demonstrate innovative and successful outcomes measurement.

Evidenced-based Practice

In 1993 the Journal of the American Medical Association, one of the most prominent medical and health journals in the world, began a series of articles on evidence-based medicine. This series continued regularly finishing in the year 2000 with its 25th installment (37,38).

This increased exposure of the concept of evidence-based practice worldwide and in many fields extending well beyond medicine. Evidence-based medicine became evidence-based practice and evidence-based education and more broadly evidence-based interventions. Interestingly, there was the negative side as well. In the area of assistive technology, evidence-based medicine began to implement “evidence-based funding” (36). Consumers needing assistive technology devices and services we're being denied funding and third-party reimbursement in the United States because insufficient randomized controlled trials existed to document the effectiveness of assistive technology devices and services.

Thus, this has elevated the importance of creating, implementing and proliferating assistive technology outcomes systemic models. Evidence documentation is becoming a survival need to demonstrate the continuing effectiveness of the assistive technology solutions. We predict that globally, this concept of evidence-based funding will broaden and challenge AT programs everywhere. Thus, collecting evidence through assistive technology outcomes documentation will become essential to all populations of people who require assistive technology devices and services as well as to the providers of those services. It seems increasingly clear that the implementation of assistive technology outcomes measurement systems must be incorporated during the development of assistive technology programs.

Definitions of outcomes

An outcome is the result or effect of an action, so efforts to capture Assistive Technology outcomes are relevant to every chapter theme, but particularly Theme 9 as outcomes are central to understanding effectiveness. At a global level, WHO member states resolved to “develop, implement and strengthen policies and programs, as appropriate, to improve access to AT” (39). Any assessment of the effectiveness of actions taken to realize this resolution is dependent on a definition of AT and method to identify and measure access and change over time.

Unfortunately, the definition of outcomes is complex. Even the concept of outcomes is perplexing. One reason for confusion in AT outcomes discussions is the difficulty in knowing what outcomes to measure and what specific interventions are being examined. Identifying the specific "InGo" variables have been noted as difficult as identifying the "Outcomes" (40). Assistive technology systems include many factors of the person, of the environment, and are highly contextual and situationally dependent. Thus, where randomized controlled trials may work as outcomes research strategies for pharmaceutical interventions, assistive

technology interventions often require personalized and individualized approaches. Successful outcomes methodologies in assistive technology respect personalized and highly diverse population distributions (41). These challenges defining a generic intervention as is done in RCTs where outcomes can be easily measured. Plus, assistive technology devices and services are rarely used in isolation so to examine the outcomes of assistive technology systems special attention must be given to examine the relationships of other concurrent interventions. The ATOMS Project highlighted this concurrent and parallel intervention complexity in its IMPACT2 Model (42).

Moreover, outcomes are highly variable depending on the stakeholders' perspectives. The WHO GATE five Ps of people, product, provision, personnel, and policy define an important set of stakeholders in the assistive technology field; all which are highly relevant to assistive technology outcomes. In fact, over the years the literature has identified the highly diverse perspectives of the stakeholders (4,43,44).

An example of how much these perspectives differ on the concept of AT outcomes was revealed in focus groups created specifically to identify what consumers thought were important as AT outcomes (45). Consumers of AT devices and services were even confused on what the term "outcomes" meant. This revealed to the research team that the term "outcomes" was esoteric language to a consumer. It was a research or policy term, not one of a patient, client or technology consumer.

Next, this paper examines AT outcomes from the perspective of each of the 5 Ps in more detail.

The Stakeholders of Assistive Technology Outcomes: 5 Ps Differential Desires for Outcomes

Table 2 (Examples of Influences on Outcomes of the System) portrays the varied outcomes perspectives of each stakeholder. For example, People (consumers of AT interventions) look at how the technology works for their particular circumstances and uses, not as generic features. Plus, the interventions are much broader than receiving the product. The "outcomes" for a consumer depend on all of the other outcomes of the other stakeholders, but how they apply to the individual person. How do the service program (provision), the policies, the personnel, and the product all deliver to improve the well-being of the person to comprise the outcome?

People

Users care about realizing benefit from the use of a product. It has to do what the user wants and be useworthy. Useworthiness (46) means that a product is worth the effort and time it takes to set it up, use it, maintain it, etc. If it is too much of a hassle to use, it will not be used or not used as much as may be desired. It does not have to be great looking and a pleasure to use, but it cannot be stigmatizing and overpower the user. Nor should it be uncomfortable to use or cause fatigue. Thus, there is no single AT outcome that will satisfy the needs of the variety of stakeholders along the continuum of AT selection and provision. Importantly, this domain of outcomes includes subjective user perspective and the changes

in functional performance from the AT intervention. The functional performance outcomes depend on the collection data with and without the AT intervention, usually documented as baseline (before AT) and at least a second data collection period during or after the intervention. Often this occurs across time or as comparative groups. As will be emphasized in Provision, this outcome highly depends on repeated services as a follow-up or follow-along, not typical in AT product provision.

Policy

Policy outcomes examine and document the legislative, regulatory, structural, environmental context of the other Ps. The existence of laws, codes, and funding sources, for example, are key outcomes related to policy. On the other hand, as stakeholders, policymakers have primary interests of comparative costs and benefits of AT interventions.

Provision

AT program provision is an administrative outcome that typically examines the process of service delivery and may typically include surveys of the sufficiency of the services or the user satisfaction of the services. The nature of services such as processes, timelines, efficiency, costs, and often consumer feedback are typical administrative outcomes. Additionally, key to AT outcomes, as mentioned earlier, is that outcomes depend on data collection by the services. The minimum of baseline data is required. Plus, to obtain informative outcomes, data must also be collected after the intervention as follow-up or follow-along. Thus, Provision is challenged to create these phases of documentation. Provision characteristics may include team and interprofessional data. Data need to identify the nature of the AT team and how are they integrated into the services.

Personnel

Professionals such as occupational, physical and speech therapists, nurses, teachers, counselors, suppliers, advocates as well as para and non-professionals, such as family members are who provide products. They may have received special training and credentials to help people/users select, obtain and implement the best product to achieve the goal of functional gain without causing undue strain or discomfort. The effectiveness of personnel depends on their individual experiences, perspectives, and pre- and post-service training. Key outcomes include the sufficiency of personnel, best documented with quantitative and qualitative data. The interest of personnel for outcomes includes their success in delivering best AT interventions.

Products

Product outcomes are basically the technical and comparative characteristics of the product. Product designers, manufacturers and suppliers are primary stakeholders of products. While product designers do attend to a product's appearance, they are more highly concerned about costs, safety, usability and the inner workings of a device. (e.g., how much battery power does it use). Products have no inherent need for outcomes but

acquiring the right product and service system fundamentally requires implicit if not explicit knowledge of product features and characteristics as “InGo” to the product component of the intervention. Obviously, these “InGo” directly lead to the outcomes.

The key message from the 5 Ps is that all are stakeholders’ positions with unique contributions and interests pertaining to AT outcomes. Some Ps may have common interests between them, but often they are disparate. Consequently, considering all 5 Ps is a necessary step in designing, creating, and implementing an AT outcomes system that ultimately successfully measures the impact of AT interventions.

Table 2. Examples of Influences on Outcomes of the System

Examples of Influences on Outcomes of the System	Outcome Documentation Examples
People (the User)	
<p><i>Partnership</i></p> <ul style="list-style-type: none"> • What are the expectations of what will be gained from use of the device compared to what is currently being done or used? • What are the characteristics of others in the environments of use? Supportive, resistant, stigmatizing? • Are there cultural mores or beliefs that disavow use of the technology? • Has the need for additional supports and assistance been considered and are they available if needed? 	<p>Documentation of personal and contextual characteristics (functional needs, subjective needs, social and material support, personal preferences and priorities, well-being)</p> <p>Identified expectations of benefit and documentation of the realization of benefit follow-up</p>
Policy	
<p><i>Place</i></p> <ul style="list-style-type: none"> • Are all of the necessary architectural supports in place? • Is there an adequate infrastructure for use? • Sufficient electricity, accessibility? • If assistance is required for student training and use of the technology, is it available? • Do classroom settings need to be reorganized? • Is there access to ancillary facilities? For example, classroom environments for training and learning. 	<p>Sufficient availability of facilities, equipment, accessibility, supplies, materials and other resources</p>
<p><i>Legislative/Political/Regulatory</i></p> <ul style="list-style-type: none"> • Are there mandated services? Licensure of providers? • Are relevant community resources needed and are they available? 	<p>Sufficient law, regulation and codes</p> <p>Legal and regulatory compliance</p> <p>Products meet regulatory standards</p> <p>Products have been safety-tested</p> <p>Documented guidelines for exceeding minimal requirements</p>

Examples of Influences on Outcomes of the System	Outcome Documentation Examples
<p><i>Economic</i></p> <ul style="list-style-type: none"> • What are the service provision costs? Training costs? Costs for repairs, maintenance? • Funding for products and of services? • Can products be reused, recycled? 	<p>Funding available for program and facilities Funding available for products Funding available for services Documentation that the program is economically viable</p>
Provision	
<p><i>Selecting the technology or other support</i></p> <ul style="list-style-type: none"> • Has a comprehensive assessment been done to select what will best suit the person's needs and preferences? A technology? Additional personal assistance? A combination? • Has the technology has been assembled correctly? • Have options been prioritized and has it been documented why one product or feature is preferable to another? • Has trial use occurred in the settings of use? 	<p>A process to guide AT selection and decision-making is used Documentation that a comprehensive assessment was done Documentation of the results of consumer trials and locations of trials Directories exist of local facilities and resources Products meet regulatory standards Products have been safety-tested There is a satisfactory balance sheet There is a satisfactory safety record Partnerships exist with manufacturers, suppliers, and vendors</p>
Personnel	
<ul style="list-style-type: none"> • Have providers received adequate training? • Are regular training opportunities provided to provide new and updated information? • Do providers have the essential certification or licensure? • Do providers have the resources and support they need? 	<p>Providers meet all qualifications to practice Satisfactory provider performance Provider satisfaction</p>
Products	
<p><i>Performance</i></p> <ul style="list-style-type: none"> • Is the product reliable? • Is the product stigmatizing, fatiguing, painful to use? • Is the product compatible with use of other supports, durable, portable, easily serviceable? • Does the technology require customizing or other adaptations? 	<p>Is the product reliable? Appropriate products are available</p>
<p><i>Procurement</i></p> <ul style="list-style-type: none"> • Can products be purchased, fabricated, leased? 	<p>Products available in a timely fashion Services available in a timely fashion Product updates and innovation are available in a timely fashion</p>

Examples of Influences on Outcomes of the System	Outcome Documentation Examples
<p><i>Pace</i></p> <ul style="list-style-type: none"> • Can they be obtained in a timely fashion? • How easily and quickly can servicing and repairs be done? • For those with rapid developmental changes, how easily and quickly can upgrades be obtained? 	<p>Products are publicly accepted</p>
<p><i>Promotion</i></p> <ul style="list-style-type: none"> • Are positive promotional materials available? 	<p>Products have high customer satisfaction ratings Specifications and manuals easily accessible and understandable Operations manuals complete and understandable, available in accessible formats</p>

The Measurement of Assistive Technology Outcomes

Assistive technology outcomes cross over many domains of variables from functional performance to mechanical properties of the devices/products. We naturally think of quantitative rating scales, physiological or physical measures as best evidence. This is not true, as the subjective preferences and opinions of consumers who live the 24/7 experience of the disability and technology use are of extraordinary value. Qualitative data can be of extreme value, particularly if the source is from the user of the technology.

Satisfaction is sometimes considered an outcome variable, but usually it is not a factor that is important to Person/People. Satisfaction often measures the processes surrounding AT implementation that can be of primary importance to providers, but satisfaction should not be confused as an outcome that reflects “realization of benefit” (44). Although satisfaction has sometimes been used as a proxy to user outcomes, generally, its value pertaining to outcomes relates more to marketing and other elements of service provision.

Regarding functional performance, domains of interest vary substantially in outcomes measurement as they touch on almost every element in the WHO International Classification of Functioning (ICF) (47). Outcomes measures used to assess functional gains from assistive technologies can range from global functional assessments to specialized ones. For example, the 6-Minute Walk Test may be used to assess walking speed before and after receiving an AT.

Some intervention programs value focal areas of function, such as a rate improvement in typing words per minute. Other programs may be concerned with broad outcomes such as the ability for a person to succeed in competitive employment or whether an assistive technology related law was passed.

The literature often defends the use of a wide variety of measurement instruments and the domains of outcomes they examine. Of critical importance is that measures are audience and stakeholder specific. Thus, selecting the best set of outcomes instruments should be based on the variables of interest based on understanding the purpose of the outcomes assessment.

The Methodologies for Documenting Assistive Technology Outcomes

Assistive Technology outcomes documentation methodologies are also varied. We highlighted earlier that the RCT (randomized controlled trial) works well for pharmaceutical outcomes assessment. However, the personalization and individualization of assistive technology interventions requires different types of methodologies. This has challenged the field for many years and continues to challenge the field (41,48). The British Medical Journal many years ago published a parody on RCTs using the parachute as an example (49). The technology of the parachute has no RCTs defending its functionality and outcomes. In many situations assistive technology interventions are similar to the parachute. Sometimes the outcomes and benefits of assistive technology interventions are obvious, and thus do not require outcomes data. However, more often than not, these outcomes may be obvious to the people who use the technologies and the providers of services but are not so obvious to concerned policymakers or funders. Consequently, assistive technology outcomes measurement and documentation is necessary to communicate the effectiveness of the interventions.

One of the exciting methodologies that has been adopted by many areas of outcomes research such as in special education, is the single subject experimental design. Sometimes this is called the single case design or sometimes the N=1 study. In the area of assistive technology outcomes, the N=1 study has been highlighted as a viable methodology many years ago (50). Thus, we would be amiss to neglect recognizing the N=1 RCT as effective and powerful outcomes methodology. In fact, in the medical and health literature, the N=1 RCT rose to the top level as a method in evidence-based medicine as explained in the 25th issue of the evidence-based medicine series in JAMA (37).

Epidemiological research methodology is known for its population-based research as opposed to the use of classical experimental design. Epidemiology is attuned to the use of registries that have been found in the medical sciences as being important outcomes methodologies (41,51). Currently "big data" and "data intensive science" are *en vogue* as the computer science field has been identifying how they can better mine big data to make social, societal, and outcomes predictions. Assistive technology outcomes systems can benefit from this new attention to this outcomes methodology.

The timing for advancing assistive technology outcomes is also prime. The recent sophistication of the "cloud" and its associated social networking and crowd sourcing technologies opens many methodologies that are just now being conceptualized and designed. Mobile technologies are pervasive in most nations regardless of income enabling

opportunities for creating, administering, and reporting state-of-the-science assistive technology outcomes. This is one place where low- and middle-income nations may actually have advanced capabilities for administering new science where high income nations are more challenged due to their size and commitments to already embedded systems. This, in fact, has the potential for low- and middle-income nations to take a lead over the higher income nations.

We need to launch new methods for AT outcomes data collection and analysis for documentation and discovery. The WHO GATE initiative may be the perfect place for the perfect realignment of both related and disparate techniques. A recent AT Outcomes Summit supported by the U.S. National Science Foundation and RESNA articulated the possibilities for nationwide systems (52). Perhaps this can be extended into global thinking.

The Challenges and Opportunities for Securing Assistive Technology Outcomes

Challenges that have been identified include the lack of consistent terminology and concepts across the entire field of AT. This highlights the imposed barriers on effective collaboration and knowledge translation between the various fields involved.

A further challenge is that of inertia, where existing structures may hinder innovation, or where action is stifled by debate about responsibility for leading change. A substantive opportunity addressing both these challenges is the agreement on priorities as expressed in multiple international agendas such as the Sustainable Development Goals, the Convention on the Rights of Persons with Disabilities, and Rehabilitation 2030 (53). These should be leveraged to secure the political commitments and funding necessary for action on improving access to AT.

The challenge of creating the infrastructure for an assistive technology outcome system deserves particular attention. Infrastructure development is not a standard process for practitioners or researchers. Tasks include setting up data collection systems, setting up processes, training and educating data collectors, identifying assistive technology outcome instruments, creating reports, and creating a sustainability plan. These are essential administrative tasks for the implementation of new assistive technology programs and for updating existing services, research and development processes and is relevant for all assistive technology system stakeholders.

Years ago, we documented the interest in desirability of assistive technology outcomes systems from technology developers (54), consumers (45), policy makers (55). Most recently this was confirmed at the assistive technology Outcomes Summit in Washington DC by various stakeholders (52).

But there are challenges. Besides understanding that this is setting up an infrastructure, assistive technology services typically only collect baseline data and do not pursue data after assistive technology has been implemented in follow-along services. A new model of services needs to be considered at the time new assistive technology programs are developed and implemented. This is an opportunity for WHO and GATE to consider how

assistive technology outcomes and systems can be realized at this exact time when new programs are being conceptualized, invented, developed, and implemented.

To help new programs think about how to implement AT outcomes systems we have developed a checklist for AT outcomes implementation. Table 3 (AT Outcomes Measurement System Development Steps & Checklist lists) important steps to be considered in the development of an AT outcome system. Many of the concepts discussed in this chapter are listed in a practical format in this checklist as we take this enormous step towards global collaborative assistive technology outcomes documentation.

Recommendations: The Vision for the Future of the Global Implementation of Assistive Technology Outcomes

Finding an assistive technology outcome measurement instrument can be a challenge. The ATOMS Project supports a website that lists various assistive technology assessments (11). Many of these assessments were created years ago when assistive technology outcomes measurement was actively supported in North America. More recently, other instruments have been conceptualized or are being adapted from existing validated instruments and are being tested in other parts of the world and are showing promise (56,57). An updated field search of validated assistive technology instruments is needed to update and/or replace the historical instrument inventories described in this paper.

Table 3. AT Outcome Measurement System Development Steps & Checklist

<p>1. COMMIT TO CREATE THE AT OUTCOMES SYSTEM AND ARTICULATE PURPOSE</p> <ul style="list-style-type: none"> <input type="checkbox"/> Draft and revise purpose <input type="checkbox"/> Document audience(s) for reports generated by the system <p>2. IDENTIFY INGO(S) (what is to be measured and contexts)</p> <ul style="list-style-type: none"> <input type="checkbox"/> Specify Target Population(s) of Users <input type="checkbox"/> Specify target population of secondary users and other affected persons (e.g., co-workers, employer) <input type="checkbox"/> Specify Target Products of Interest <input type="checkbox"/> Specify Exact Target Product Features of Interest <input type="checkbox"/> Specify Target Product Performance Areas of Interest <input type="checkbox"/> Specify Target Situations and Environments <p>3. IDENTIFY OUTCOME(S) of INTEREST</p> <ul style="list-style-type: none"> <input type="checkbox"/> Specify P's of Interest <input type="checkbox"/> Specify Measurement Domains within each P of Interest <p>People, e.g.</p> <ul style="list-style-type: none"> ● Functional areas of interest (quantitative or qualitative change) ● Well-being (quantitative or qualitative change) ● Expected and realized benefit ● Goal attainment <p>Product, e.g.</p>

- Durability
- Reliability
- Cost
- Safety
- Comfort
- Complexity of device use
- Delivery time
- Set-up time
- Need for Maintenance and repairs

Policy, e.g.

- Regulatory requirements met
- Compliance to voluntary standards
- Available discretionary funding for purchase by end-users or by third party funders

Provision, e.g.

- Waiting list, turn-around time
- Essential specialties available
- Essential assessments available
- Partnerships forged (e.g., voc rehab, external evaluators, driving assessors)

Personnel, e.g.

- Qualifications
- Caseload, available time
- Resources
- Continuing Education

4. REVIEW AND IDENTIFY OUTCOMES MEASUREMENT INSTRUMENTS

- Locate Existing Measurement Instruments that Measure the Outcomes within Relevant Ps

If no Instruments are available or found consult experts to consider:

- Using non-AT specific instruments as a
 - Pre/Post AT intervention or
 - With/Without AT intervention
- Development of a new instrument
- Select Outcomes Measurement Instrument(s)

5. DECIDE ON DATA COLLECTION MECHANISM

- Decide who collects and how you will find them
- Identify or create incentives for data collectors
- Determine what privacy and data security protocols are needed
- Determine if human subjects review is needed
- Select technology or technologies for data collection (e.g. mobile phones, paper and pencil)

6. DECIDE ON DATA COLLECTION FREQUENCY (MINIMUM)

Baseline (before or without AT product use)

Result of Intervention (After or without AT intervention)
Ongoing data collection (follow-along)

7. CREATE DATABASE INFRASTRUCTURE

- Select where the data will be housed
- Determine how the data will be compiled, cleaned, managed and maintained

8. DESIGN REPORTS for OUTCOMES DATA

- Specify audience(s) for reports
- Specify content of reports
- Select frequency of reports
- Select outcomes report media and methods of distribution and audience

9. CREATE SUSTAINABILITY PLAN FOR OUTCOMES ASSESSMENT

- Identify ongoing funding for outcomes measurement system

The Mandate for Assistive Technology Outcomes: Needs and Opportunities

The perspectives presented here draw together the diverse literature on AT outcomes, and expert knowledge from the practice sector, such as organizations in the international AT Alliance (<https://aaate2019.eu/iaato/>).

Mapping the science of AT outcomes across the 5 P's has brought four decades of research into the current global political context and demonstrated the urgency of not only acting to improve access to AT but assessing the results or effects of those actions.

The Vision for the Future of the Global Implementation of Assistive Technology Outcomes

We propose a range of focal and broader recommendations to embed good AT outcome practice in our sector for the next decades. These include:

- EBP (evidence-based practice) and PBE (practice-based evidence): to fully address the complex system that is assistive technology, outcomes must be viewed holistically, from both evidence-based practice and practice-based evidence perspectives.
- Fit for purpose: explicit consideration of high, middle, and low-income settings.
- Adoption of standard terminology related to AT and the five P's.
- Conceptualized data fields for outcomes across each P.
- Conceptualized data fields for inputs across each P.
- Building of outcome measurement into actions around each P.
- Commitment to 'progressively realizing' a stronger outcome-base.
- Potential strategies for implementing useable and scalable outcome measures across each P.
- Promotion of mentorship from and collaboration between networks e.g. International Alliance, universities, DPO's, NGO's in building outcome measurement capability.

- Outcomes thinking at every level: Considering the outcome must be an essential thread in every AT event, large or small, globally. The task of the global AT community is to support outcomes-thinking and knowledge translation so that individuals and groups, in diverse settings, are able to effectively comprehend, measure and report on “that which matters”.
- Global Collaboration: The potential global collaborations are unlimited today.
- Building event opportunities: Envisioning the future, a global AT summit with a focus on AT outcomes would enable the systematic updating of our assessment inventories, our methodologies, and our possibilities. Creating plans where we can tackle the evidenced based documentation of assistive technology interventions on a global level when high, middle, and lower income nations are in relative parity may truly reside at a unique juncture in history. The potential of this common interest and motivation for assistive technology outcomes is poised for a major impact at this time.

Conclusion

This paper is a summary of the historical and state of science in AT outcomes, as systematically mapped for the first time against the five P’s. To fully address the complex system that is assistive technology, outcomes must be viewed holistically, from both evidence-based practice and practice-based evidence perspectives. This paper is also a starting point and a call to enact a knowledge translation process which will bring together the global community for collaborative action. The five Ps has staged a superb conceptual foundation for launching such an initiative. All of the correct factors are coalescing in 2020 for an opportunity around assistive technology, disability, and related health issues that may never reside with the same potential again.

Acknowledgments

We gratefully acknowledge the technical support of Qussai Mohammed Obiedat, University of Wisconsin-Milwaukee and the content contributions of Emily Steel, The University of Southern Queensland.

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Technology acceptance: A key process for an effective access to assistive technology

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Abstract

Assistive technologies may support older adults in their aging process. Obviously, AT have to be at an affordable cost, accessible and usable to be useful. Moreover, technology acceptance is essential to leading to real system use. In other words, effective access to AT implies user AT acceptance. Technology acceptance models are tools for: - predicting user's reception of AT, - analysing technology appropriation, - determining whether the effects of AT use on the collective activity system are acceptable. However, existing technology acceptance models are not well adapted into the gerontological context. Analysis of literature shows that significant factors are not included in the models. They probably neglect aging-specific acceptance factors. Furthermore, gerontechnology acceptance studies are principally carried in the context of pathological aging. Accordingly, there is a lack of knowledge related to normal aging. This literature provides a solid grounding for conceptual extensions on technology acceptance models. The aim of this study is therefore to understand the technology acceptance process by the older people. We develop an inductive and empirical approach for conceptualizing the acceptance dimensions related to the biopsychosocial experience of aging. We use an adaptation of the Grounded Theory (GT) methodology to investigate older participants' experience during the participatory design of an AT (an interactive calendar intended for use as an external memory aid). This international design project involved two universities (Sherbrooke University, Canada; University of Southern Brittany, France) from 2014 to 2018. The elderly co- designers lived in residential homes in both countries. At design stage, a total of 34 elderly worked on the AT interface, features and interaction modalities. Focus groups and collective workshops were organized. The functional AT was then tested in four participants' home for 12 weeks. The methodology was based on training of the participants in the use of technology, usability tests, in-depth interviews (e.g. explicitation interview). Data were primarily qualitative (e.g., verbatim transcripts, audiovisual records, workshop's groups production). We collected them in both collective and individual setting. Using a variety of research methods from participatory design, ergonomics, psychology and ethnography we developed the AT, evaluated his accessibility, and learned about acceptance or rejection of technology throughout the entire design process. Understanding user experience represents the

empirical basis of a grounded theorisation. Systematic analysis of the data highlight « time » as the core category of the technology acceptance process among the elderly. Three conceptual dimensions appear regarding time: 1) chronological, 2) adaptive, 3) axiological. The gerontological context gives precise meaning to those dimensions. Study findings suggest that technology acceptance by the elderly especially depends on 1) specific moments, 2) adjustment process regarding aging changes, 3) time value. The first dimension refers to time as a life-long succession of experiences. The moment to learn how to use the device seems to be a determining factor in technology acceptance by the elderly. They have to deal with cognitive, physical and sociological challenges due to the aging process. Accordingly, we particularly recommend that learning materials should be developed at the early design stages with a strong consideration for implications of aging on the learning capacities and processes and delivered with the assistive technology through several possible methods (eg.; multimedia tools, classroom teaching, peer support). In this view, simple and universal instructions for use are not sufficient to address learning issues. We argue for combining pedagogical engineering and gerontology. The second dimension shows time as a biopsychosocial change process. People develop strategies and resources in order to address those changes. Acceptable technology supports strategies for ageing well, adapts to changes, help users to keep control on their life. It should be mentioned that control (or sense of control) has a beneficial effect on older people's quality of life and successful aging. Thus, one of our recommendations is that AT usability be systematically tested in scientific conditions. Moreover, AT have to be enough customizable and adaptable to evolve with the user and its strategies. Lastly, the axiological perspective means time has symbolic and subjective values. The way people think about time is connected to the way they think about their lifetime. As they grow older their time perspective shifts. It impacts well-being, attitudes and behaviour. Technology acceptance depends therefore in part on the axiological time dimension. It is difficult to know subjective representations. This kind of information cannot be defined a priori, without gathering information among end-users. Hence the need to assess time perspective in a collective (eg. with participatory design methods) or individual (eg. assessment by a psychologist) ways. To conclude, underlining the importance of time in technology acceptance by the elderly provides directions for assistive technology access. The findings favour interdependence of academic, technical and experiential knowledges. It would therefore be interesting to promote means and places allowing the intersection of those knowledges, like third-age universities or living labs. As a limitation, we specify that the findings of a grounded theorisation and the sociocultural setting are intrinsically linked. In this respect, results cannot be generalized to all contexts.

Keywords

Technology acceptance, biopsychosocial aging, time, grounded theorisation

Introduction

Assistive technologies (AT) may support older adults in their aging process. Obviously, AT have to be affordable, accessible and usable to be useful. Moreover, technology acceptance is essential to lead to the real system use. In other words, effective access to AT requires the acceptance of AT by users. Nevertheless, criticism of technology acceptance models applied to assistive technology for the elderly occur in literature. Accordingly, the aim of this study is to understand better the technology acceptance process by older adults. We used an adaptation of the Grounded Theory (GT) methodology to investigate older participants' experience during the participatory design of an AT, and thus conceptualize the acceptance dimensions related to the experience of aging.

What is « technology acceptance »?

Technology acceptance is the process whereby a person develops the intention to use, starts, then keeps on using a technology, or rejects it.

Technology acceptance models are tools for:

- Predicting the user's reception of AT, referred to as « social acceptability »
- Analyzing technology appropriation, referred to as « practical acceptability »
- Determining whether the effects of AT use on the collective activity system are acceptable, referred to as « situated acceptance ».

Social acceptability approaches aim at evaluating the user behavioral intention. It refers to a person's willingness to employ technology. One of the most commonly referenced and used model is the Unified Theory of Acceptance and Use of Technology (1). In this model, performance expectancy, effort expectancy, social influence and facilitating conditions are the four core determinants of intention and usage (with four moderators which are: gender, age, previous technology experience and voluntariness of use). The TAM¹ (2) is another model widely used. According to TAM, the two most important attitudinal factors in explaining acceptability of a technology are perceived usefulness (PU) and perceived ease of use (PEOU). Thus, accessibility of assistive technology may be partly determined by behavioural intentions. But, as a limitation, social acceptability models cannot sufficiently predict the effective acceptance.

The practical acceptability of a technology mainly depends on its utility and usability (3). In this cognitive ergonomics approach, an acceptable device allows the user to complete a task in an efficient and effective way with a high level of satisfaction. Interestingly, the International Organization for Standardization (ISO) has developed a usability standard (ISO 9241-11:2018). This standard may be crucial for product design and launch. For instance, medical devices certification includes the requirement to significantly limit the amount of

¹ Technology Acceptance Model

user errors. The role of practical ergonomics in the effective access to assistive technology is therefore undeniable.

However, usefulness does not guarantee device acceptance. The situated acceptance approach argues that the effects of the technology use have to be accepted also. Using an assistive technology may have effects on both individual and collective activities. At an individual level, users develop cognitive and behavioural patterns that guide their actions, they may also feel emotions and experience an increased (or decreased) workload. At a collective level, using technologies may reconfigure interpersonal relationships, social roles or certain ways of communicating and acting collectively. These evolutions may or may not be acceptable, and as a consequence, the technology could be accepted or rejected (4).

To sum up, an accessible AT is also an acceptable one. This includes social and practical acceptability as well as the acceptance of individual and collective effects over time of using the AT. Nevertheless, the technology acceptance models mentioned above may not to be totally adapted for gerontological and aging issues.

About gerontechnology acceptance

Based on the analysis of five literature reviews studying technology acceptance by the elderly (tab.1), limitations in technology acceptance models appear. The main criticism is that they fail to take the biopsychological experience of aging into account. More precisely, there is first a lack of acceptance factors including aging dimensions and concerns. Secondly, the acceptance assessment methods are questioned.

Literature reviews description

The existence of many studies on technology acceptance by the elderly has enabled the release/publication/issue of several literature reviews. Table 1 presents the five reviews selected on the basis of the following criteria:

- Research aimed at reviewing factors that influence the intention to use or the actual use of technology,
- Participants are adults aged 55 years or older
- Full text written in English or in French
- Published between 2010 to 2019.

Reviews selected were published between 2014 and 2019. The concept of « technology acceptance » is not clearly defined in Atoyebi et al. (5), Fletcher et al. (6) and Nikou (7) but linked with the concepts of attitude, adoption, use and acceptability. In Astell et al. (8), technology acceptance is described as a complex process underlying the decision to adopt or abandon any given technology. Only one review specifies that “technology acceptance in this study is defined as the intention to use a technology or the actual use of a technology” (Peek & al. (9), p.237).

Table 1. Reviews Description

Reference	Type of literature review	Technology	Acceptance issue	Inclusion criteria concerning the population
Astell et al. (8)	Scoping review	Any assistive technology	Understanding how older adults' identity influences their adoption of assistive technology	55 years and older (rather than 60 years and older to include people with disabilities who may often experience accelerated ageing)
Atoyebi et al. (5)	Literature review	Any assistive technology for fall detection and prevention within homes and clinical settings	Identifying factors influencing the adoption of technology for fall detection and prevention	65 years and older
Fletcher et al. (6)	Literature review	Mobile Health technology used to monitor health and chronic diseases, to provide information and support	Identifying barriers to the use of mobile phones for health purposes	65 years and older
Nikou (7)	Systematic literature review	Mobile apps used to promote healthy behaviours and to enhance well-being	Studying existing knowledge of the « young elderly » adoption of mobile health apps. Identifying factors involved in technology adoption	60-75 years (called « the young elderly » by the authors)
Peek et al. (9)	Systematic literature review	Any already existing assistive technology for ageing	Mapping of assistive technology acceptance factors	60 years and plus

Criticism of technology acceptance models applied to assistive technology for the elderly

Acceptance factors

The literature reviews gather various factors concerning the process of technology acceptance by the elderly. Such results are particularly well documented in the review conducted by Peek and his colleagues. They counted twenty-seven factors, identified in pre-

implantation and post-implantation acceptance. This data is based on qualitative, quantitative and mixed-methods research. The authors organized them into seven categories (ie. concerns regarding technologies, benefits expected, need for technology, alternatives to technology, social influence, characteristics of older adults).

The overall study of the five reviews suggests more than twenty age-specific factors, which we classify into the following categories: chronological, cognitive, sensory and motor, psychological, social aging, residential experience, and, theoretical and technical knowledge regarding the connection between technology and aging (Table 2).

Table 2. Acceptance factors

Categories	Age-related acceptance factors	References
Chronological aging	Socio-demographic determinants: age	(9)
Cognitive aging	Risk of losing or forgetting the device	(9)
	Variety and quantity of device functions which might increase cognitive load imposed on the user	(5,7)
	Sufficient training with a qualified instructor	(5,6)
	Degree of learning and use difficulties	(6,7)
	Age-related cognitive decline	(6,7)
Sensory and motor aging	Age-related sensory and motor decline	(6,7)
	Degree of learning and use difficulties	(6,7)
Psychological aging	Resisting the ageist stereotypes (ie. frailty or dependence); risking stigmatisation or discrimination	(5,7-9)
	«Technology anxiety» (The degree to which the usage or idea of using the technology in question arouses negative feelings and fear.)	(7)
	Possibility to maintain meaningful activities through technology use (goal of successful ageing)	(8)
	Congruence with their perception of their capabilities or their subjective health status	(7-9)
Social aging	False alarms	(9)
	Burdening family, friends, or society more generally	(8,9)
	Facilitating social and emotional ties	(5,6)
	Possibility to be helped by a relative	(9)
	Influence of family, friends, professional caregivers, peers	(7,9)
Residential experience	Access to services and help where they live	(9)
	Desire to age in place	(9)
	Socio-demographic determinants: housing type, rural/urban environment	(9)
Theoretical and technical knowledge	Device designed according to needs, capabilities and desires of the elderly.	(6-8)
	Evidence that demonstrates the technology quality and efficiency for the elderly.	(5)

Results highlight that only a few of these factors appear in technology acceptance models, but they are not age-specific enough. For instance, the age-related factors « sufficient training with qualified instructor » and « degree of learning and use difficulties » seem consistent with the factor « ease of learning » (models of practical acceptability). The question asked when ease of learning is measured is « How fast can a user who has never seen the device before learn to use it? ». However, literature reviews specify learning issues for older users. Normal or pathological aging actually implies new learning challenges beyond a question of speed. For example, results emphasize that training and education should consider the age-related changes in the learning, memorizing and recalling processes.

Methods

The second limitation concerns the methods used for technology acceptance study in a gerontological context. Three major criticisms are noted. Firstly, there are few studies that actually rely on technology acceptance models. We hypothesized that the lack of age-related dimensions might explain this observation. Secondly, studies are mainly conducted in the pre-implantation stage before the real use of the technology by the elderly. Thus, data are collected without any experience of the device. This limitation is also documented by other researchers on technology acceptance by the elderly. Chen and Chan (10) wrote “longitudinal studies are needed since users acceptance may change when they become more familiar with a technology”. Lastly, gerontechnology acceptance studies are mainly carried out in the context of pathological aging.

To conclude, existing technology acceptance models are not well adapted to the gerontological context. Literature review shows that significant factors are not included in existing models. They probably neglect aging-specific acceptance factors. In particular, there is a lack of knowledge related to normal aging. The studied literature provides a solid grounding for conceptual extensions on technology acceptance models. Accordingly, the aim of this study is therefore to understand better the technology acceptance process by older adults, from the pre-implantation phase to assistive technology use.

Objective: a grounded theorisation of technology acceptance by the elderly

We develop an inductive and empirical approach to conceptualise the acceptance dimensions related to the biopsychosocial experience of aging. We use an adaptation of the Grounded Theory (GT) methodology to investigate older participants’ experience during the participatory design of an AT (an interactive calendar intended for use as an external memory aid).

Method

Data collection

This international design project involved two universities (Sherbrooke University, Canada; University of southern Brittany, France) from 2014 to 2018 (11,12). The elderly co-designers lived in residential homes in both countries.

As a first step, we carried out an analysis of their activity at home based on field observations. The main goals were to understand how the participants already use assistive technologies and how they use external memory aids.

Then, during the design time, a total of 34 elderly (aged from 60 to 92) worked on the AT characteristics: interface, features and interaction modalities (including tactile interface and voice interaction with a virtual agent). We conducted one focus group and three collective workshops in each country.

The functional AT was then tested in four participants' home during 12 weeks. We recruited volunteers who lived alone, were aged 70 or over, had obtained the highest MoCA scores¹ (13), had no sensory-motor troubles which might prevent them to use the AT and used at least one external-memory aid (ie. calendar, reminder or notebooks). Participants (one man, three women) ranged in age from 76 to 84 and obtained MoCA scores from 22 to 28. During the home study phase, the methodology was based on training the participants to use technology, usability tests, in-depth interviews (e.g. explicitation interview) and user interaction logging.

Data were primarily qualitative (e.g., verbatim transcripts, audiovisual records). We collected them in both collective and individual settings. Participants were involved from the assistive technology design to its final use. They could first express their perceptions *a priori*, and then, their lived experience. Using a variety of research methods from participatory design, ergonomics, psychology and ethnography, we addressed two kinds of objectives:

- Developing the AT and evaluating its accessibility, which were actually operational objectives,
- Understanding the ongoing process of technology acceptance or rejection throughout the entire elderly participants' experience, in order to proceed with the grounded theorisation.

Data analysis

Grounded theory (GT) was originally developed by Glaser and Strauss (14) to promote qualitative research and inductive analysis in social sciences. We used an adaptation of their

¹ The Montreal Cognitive Assessment (MoCA) is a brief measure of global cognitive function originally developed to detect mild cognitive impairment. That requires approximately 10 minutes to administer. A 30-point screening tool evaluates aspects of attention, orientation, language, verbal memory, visuospatial, and executive function. The suggested normal range for the MoCA is 26-30 points.

method proposed by Paillé and Mucchielli (15). This author defined GT as a continuous process through which an extensive conceptualization of a phenomenon is developed. This conceptualization is strongly grounded in the empirical data collected by the researcher. GT follows an empirico-inductive approach. Analysis move from specific observations of human experience to the emergence of more general concepts qualifying this experience. Emerging concepts represent the core of the theorisation. As a limitation, a conclusion drawn on the basis of a GT cannot be totally generalized as a formal theory. Nevertheless, GT may bring new meanings that might not be discovered by a hypothetico-deductive approach based on existing theoretical models.

The GT process involves several phases, which may be iterative (15). The process starts with a phenomenological approach anchoring the analysis. Concepts emerge as of the second stage (called “conceptual categorization”²). Then the theorisation can be refined by linking concepts, and finally a theoretical and comprehensive model of the phenomenon studied is developed. GT results are presented either in a model or in a narrative report.

Results

Systematic analysis of the data highlight « time » as the core category of the technology acceptance process among the elderly. Three conceptual dimensions appear regarding time: (a) chronological, (b) adaptive, (c) axiological. The gerontological context gives precise meaning to those dimensions. Study findings suggest that technology acceptance by the elderly especially depends on (a) specific moments, (b) the adjustment process regarding aging changes, (c) time value. In this regard, key concepts for AT accessibility can be highlighted.

Chronology

The first dimension refers to *time* as a life-long succession of experiences. Technology acceptance process evolves over time. Our results suggest that learning represents a pivotal moment of this process.

Chronology and technology acceptance

Learning how to use the device seems to be a determining factor in technology acceptance by the elderly. They have to deal with cognitive, physical and sociological challenges due to

² A « conceptual category » (CC) is defined as a “brief textual production which names a phenomenon identified by analytical reading of the data” (p.316, (15), our translation). CC is a concept developed until it no longer evolves despite the collection of new empirical data. CC comprises the name of the phenomenon qualified, its definition and specific characteristics. For instance, the CC named “informatics like a foreign language” (name) means that learning how to use and talk about technology may represent the same as learning a new language for the elderly experiencing a material, cultural, psychological or linguistic gap (definition). We can identify this phenomenon through at least four characteristics which are: (1) difficulties of mutual understanding between a novice learner and an expert; (2) explicit desire to communicate, especially orally, on technology; (3) feeling of lack of expert knowledge and words; (4) difficulty translating objectives into concrete actions with / on the electronic device.

the ageing process. In these conditions, training needs and expectations may be age-specific.

Learning is a challenge comparable to learning a foreign language. A material, cultural, linguistic or psychological distance separates some of the elders from technology. Older learners may find difficulties translating objectives into actions with the device or lack in words to express their needs or interact with experts. This hinders an optimal use of the system, but also, it limits the possibility of being assisted for use. Indeed, without speaking exactly the same language, misunderstandings occur between novice and expert users.

Age-related changes in biological, sociological and psychological functions can also be obstacles for learning. These can be emotional (eg. self-perception), environmental (eg. the spouse repeatedly refusing to equip the housing with technologies), material (eg. no internet connection in residential care), or cognitive (eg. difficulties in building mental models).

Given age-specific learning characteristics, elderly express the need to be trained rather than learning on their own or following instruction in a user guide. Three pedagogical aspects emerge. First, the pedagogical structure must provide sufficient training time. Indeed, training appears as a necessary condition for consolidating learning. In addition to adjusting the pace and duration of the training, it is important that the pedagogy be structured. In particular, it must allow step-by-step guidance with learning materials whose content is explicit. Thirdly, pedagogy has an emotional aspect that should not be neglected. The older learner should have a positive experience.

Key concepts for AT accessibility

The concept of “Informatics like a foreign language” highlights the challenge that elderly learners have to face. Identifying “barriers to the learning process” informs about the multiple factors involved in this process (eg. biopsychosocial, environmental, material). Results also highlight that the pedagogical organization must be specifically thought through according to the three following concepts: “temporal extension of training”, “structured pedagogy”, “emotion-based pedagogy”.

Adaptation

The second dimension shows *time* as a biopsychosocial change process. The elderly develop strategies and resources in order to address those changes and maintain control over their lives and aging. To be accepted, the technology has to become such a resource.

Biopsychosocial adaptation and technology acceptance

Elderly create complex and dynamic systems of resources aimed at supporting strategies that allow them to exercise control over their own lives. These systems evolve over time.

If the technology is associated in this system without deregulation, it may be judged acceptable. This implies that the introduction of a technological resource allows the person

to cope with age-related changes in order to maintain or restore balance in daily life. An acceptable technology supply means to support the user's abilities to think, act and control. For that purpose, the technology must be reliable, in line with expectations, adaptable and fully developed. The user will be finally able to appropriate the device by shaping it at his convenience.

The question then arises of the acceptability of assistive technology recommended, and sometimes imposed, by relatives, carers or even by our society. For instance, in some countries, social injunction requires the use of the internet to complete administrative tasks or accepting a remote alarm device may be mandatory in some retirement residences. One paradox stands out: on the one hand, technology is expected to bring people control, autonomy and the possibility to exercise their own choice; while on the other hand, technology is imposed.

Key concepts for AT accessibility

The concept of "support abilities to control" suggests that an acceptable technology supports strategies for ageing well, adapts to changes and helps users maintain control on their life; with no risk on the adaptive system comprised of resources and strategies. The concept of "stable and mature technology" refers to a crucial condition for technology acceptance. Lastly, it is also important to understand that some older people are restrained when they face "paradoxical injunctions related to the use of technologies".

Axiology

The axiological perspective means *time* has symbolic and subjective values. The way people think about time is connected to the way they think about their lifetime. As they grow older their time perspective shifts, which can impact both attitude and behaviour. Technology acceptance depends therefore in part on the axiological time dimension.

Time value and perception impact technology acceptance

A technology is all the more acceptable as it corresponds to the values of the user. The value of time appears as a strong concept in our grounded theorisation. As people get older, the time of life before you is limited. This affirmation applies to all ages of life, nonetheless perception of time by the elderly seems to take on a particular meaning. Elders express two different ways of thinking about restricting their temporal perspective. On the one hand, this temporal perspective reminds them of their own finiteness and the fact that they will undergo age-related changes, mainly interpreted as losses. The point is that there is an « ultimatum on life ». On the other hand, the future may bring the opportunity to grow personally in order to age well. The elderly thus express the idea of an « urgency to live ».

In the « ultimatum on life » perspective, people reduce their activities to those that require the least commitments and changes. Thus, daily life is mainly based on a few routines and its organization is partly delegated to a third party (eg. carers). In this time perspective,

technology is unacceptable if it produces uncertainties and demands forward-looking commitments.

In the « urgency to live » perspective, people express their desire to develop their skill, to participate in society and to be part of the changing world. In this dynamic, seniors tend to accept technologies that represent an opportunity for active aging. By contrast, they refuse stigmatizing technologies that show ageist stereotypes.

Key concepts for AT accessibility

To conclude, the way of apprehending time varies from one individual to another. According to the dominant time perspective, a technology can be judged more or less acceptable. The « ultimatum on life » and « urgency to live » are dimensions worth remembering.

Recommendations on effective access to assistive technology

Technology acceptance is an essential process involved in assistive technology accessibility. We identified three temporal dimensions of this process which may be crucial in technology acceptance by the elderly: learning (chronology), keeping control on his own life and ageing over time (adaptation), and ensuring consistency with personal value of time (axioloxy). We therefore propose recommendations on these points in order to promote a better access to assistive technology.

Learning

We recommend first that learning materials should be developed at the early stages of design. This material must be delivered with the AT. It could be a user manual on paper-type or digital media, but the important point is usability. We argue that usability of user guide should be systematically tested, as usability of AT is itself tested.

Actually, we can deliver user guidance through several methods like multimedia tools, classroom teaching or peer support. Their quality can be evaluated on the basis of the three criteria identified with the GT which are: “temporal extension of training”, “structured pedagogy”, “emotion-based pedagogy”.

We also need trainers. We suggest that carers could play this role, in particular those who provide home support in daily activities. More than housekeeping, they often provide social and emotional support, or administrative assistance. The status of this occupational category is low. Career development opportunities are limited and working conditions are difficult. The profession is thus not appealing. This is both a social and ethical issue. Accordingly, we consider that such carers could be valorised by being in charge of AT training.

Whatever the method, it should be organized with a strong consideration for implications of aging on the learning capacities and processes. In view of this, simple and universal instructions for use are not sufficient to address learning issues. We therefore argue for combining pedagogical engineering and gerontology.

Control

The overall idea is that control on AT allows elder users to maintain control on their own life and adapt on age-related changes. It should be mentioned that control (or sense of control) has a beneficial effect on older people's quality of life and successful aging (16).

We make two recommendations about AT control. Firstly, we recommend that AT usability be systematically tested in scientific conditions. Moreover, AT has to be customizable and adaptable enough to evolve with the user and his adaptive strategies. Secondly, the AT should not stigmatize older adults, hence the need for participatory design which aims at "more human, creative, and effective relationship between those involved in technology's design and its use, and in that way between technology and the human activities that provide technological systems with their reason for being" (17).

Results highlight how important it is for the elderly to keep control and adapt to age-related changes. We thus recommend ensuring that a new assistive technology becomes part of the user adaptive resources and strategies. The question arises of how and to which extent AT can enrich this adaptive system without deregulation. We suggest that ergotherapists carry out systematic diagnosis to answer this question before AT implantation. That implies dedicated organizational and financial resources.

Time value and perspective

We make two recommendations regarding time value and perspective, the first refers to AT design and the second refers to AT pre-implantation stage.

Time value and time perspective are subjective representations. This kind of information cannot be defined *a priori*, without gathering information among end-users. Once again, we recommend participatory design. We emphasize that ergonomic methods are essential to supplement design approaches. Indeed, ergonomics is an applied science which aims to adapt products and the process to biopsychosocial characteristics of humans.

Time perspective can be assessed to determine the most likely acceptable AT. For instance, an AT which requires the most learning effort could be suggested to the elderly who have a longer time perspective ("urgency to live"). Different tools have been developed to assess time perspective (eg. Zimbardo Time Perspective Inventory, developed by Zimbardo and Boyd, in 1999; quoted by Droit-Volet (18)) and time value (eg. Meaning in Life Questionnaire from Steger, Frazier, Oishi and Kaler, quoted by Bernaud (19)). Each tool should first be tested for its relevance and applicability. Psychologists seem to be the most qualified professionals to conduct this kind of assessment.

Conclusion

To conclude, underlining the importance of time in technology acceptance by the elderly provides directions for assistive technology access. Our recommendations focus on: design of AT and all other supports aimed at facilitating AT appropriation, evolution of carers

practices and roles in AT accessibility, and organisational and financial needs to carry out aforementioned advices. These conclusions favour interdependence of academic, technical and experiential knowledge. It would, therefore, be interesting to promote means and places allowing the intersection of these knowledges, like third-age universities or living labs. As a limitation, we specify that the findings of a grounded theorisation and the sociocultural setting are intrinsically linked. In this respect, results cannot be generalized to all contexts.

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Improving assistive technology services through outcome measures and global knowledge sharing in order to make the best match of person and technology

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Abstract

Assistive Technologies are resources to promote autonomy and to empower people with disabilities in their participation and performance of their preferred activities. But unfortunately, access to these devices is not equal and a lot of people with special needs (especially in low- and middle-income countries) cannot get the ATs they need and want. The WHO General Assembly in May 2018 passed a resolution on the importance of assistive technology devices and services globally (including assessment) and supported the position papers that emerged from the 2017 GREAT Summit. In 2018 the UN issued the UN Flagship Report on Disability and Development on the “Realization of the Sustainable Development Goals by, for and with persons with disabilities”. Concretely, the SDG10 addresses the importance of *“reducing inequality for persons with disabilities. In addition to accessibility, assistive products need to meet the preferences and expectations of a user to be effective (p. 245).”* Other factors that can negatively influence the perceived effectiveness of assistive technology include the lack of information or training, high cost, the complexity of devices, lack of funding or the lack of AT suppliers, as they often result in the real needs of the person with disability not being met. With this in mind, it is relevant to consider the importance of applying tools to assess the match (at selection) or acceptance and realized benefit (as an outcome) between the user and AT. The incorporation of outcome measures into the process of prescribing and providing AT will help ensure the efficiency, effectiveness and quality of the services. Matching Person and Technology (MPT) is a model based on Person, Milieu, and Technology factors and it considers important aspects of these domains in the assessment through a process divided into several steps in a User-Focused AT Assessment. MPT domains are important factors to consider for anybody waiting to receive any assistive device. So, the implementation of models like MPT will contribute to improving the quality of AT services. The MPT tool is a set of questionnaires developed to identify the assistive technology that best suits a given person, taking into account their capabilities,

needs, personal preferences and lifestyle as well as characteristics of the environments of use and of the technologies themselves. The Matching Person and Technology (MPT) model and its questionnaires were translated into Spanish and adapted to use in that country Spain through research done with university students (57 of them without disabilities 98 with disabilities). The obtained results indicate the adequacy of the construct validity of the Survey of Technology Use (SOTU) questionnaire as well as a certain predictive value of one of its sections (consumer's experiences with current technologies). Results from other MPT questionnaires showed that students with and without disabilities have a positive predisposition to online learning. In the future, more information is sought on the validity of the instruments through other evaluation methods (e.g., criterion-related concurrent validity) that can offer information of interest on the translated version adapted to the Spanish version of the MPT. Researchers have developed a manual to manage the administration of the MPT model (and assessment tools) adapted to Spanish healthcare services. That document is complemented by a training program that will help professionals to implement the model in their interventions, therefore improving their AT services and delivery. The AT selection and outcome measures are tools that when incorporated in the process of prescription of AT can improve health and social services and optimize the utilization of all key and relevant resources (e.g., personnel, finances). Taking into account that the protocol and assessment tools have already been validated, there is no doubt that the results obtained in specific research studies of outcome measures can be useful to apply in different contexts and countries. The present communication will be focused on the process of validation and adaptation of the MPT model, as an outcome measure, and its use in Spain in order to illustrate a model that can be implemented in other countries. This piece of work will generate a set of challenges and opportunities. Tangible ways forward include: i) Funded outcome global projects to get an international profile of AT practices. ii) Mentorship / linkages to build knowledge and capacity between low- and middle-income countries and developed regions. iii) Incorporation of research results into national catalogs of AT and take the results into account in the process of delivery of AT devices. In the future, more information is sought on the validity of the instruments through other evaluation methods (e.g., criterion-related, concurrent validity) that can offer information of interest on the translated version of the MPT adapted to the Spanish culture.

Keywords

Outcome measures, Assistive Technology Services, Matching Person & Technology, Equality.

Assistive technology as a facilitating factor

Assistive Technology (AT) is an umbrella concept that refers to devices with different levels of technological complexity that are designed to improve functional capacities in different areas of the person's life, such as eating (for example, adapted cutlery, dishes with flange), mobility (for example, electronic wheelchairs, walkers, canes), communication (for example, augmentative and alternative communication systems), computer access (for example,

screen readers, adaptations to keyboards, push buttons, computer systems, switches, etc.) or in other areas of life such as housing, transport, leisure or sports (1).

That is to say, AT are devices and products that facilitate and allow engagement and participation in the activities chosen by a person with a disability.

But, despite clear benefits, the use of assistive devices by people with disabilities has also been associated with some problems, which can be grouped into several categories: lack of information about available AT, economic factors such as affordability related to the high price of products, forms of access to support products, as well as factors related to the warranty and maintenance of the devices (2-4).

One of the most frequent and important factors influencing the process of prescription and subsequent use of the device is the lack of matching between the person and the recommended technology (5,6). This can lead, in the worst case, to the abandonment or non-use of the AT. The non-use of devices has clear causes and obvious consequences not only on the quality of life and the autonomy of the person with disability, but also cost-benefit effects (7).

Outcome measures in assistive technology

It is essential to apply evaluation tools that improve decision making to the use of assistive technologies in order to achieve an increase in the successful use of assistive technology and, therefore, a reduction in the probability of it being abandoned or not fulfilling its desired purpose.

An outcome measure is defined as "the evaluation process in the provision service that is designed to quantify and establish a baseline on something that works (its effectiveness), the group on which it works and what level of economic efficiency it provides" (8). So, professionals prescribing AT have to take into account the need for applying outcome measures to improve their intervention and use a process that is evidence-based.

According to Sackett (1998), 4 types of evaluation are identified that should be considered in terms of results. Each of these aspects can be addressed by different issues and with different evaluation instruments (9):

- Effectiveness: Does it work? It is measured in terms of the impact of AT on life and the needs of the user.
- Efficiency: Can it work? It is the ability to produce the desired result or effect.
- Availability: Does it reach those who need it? It refers to the possibilities that the user has to acquire the product.
- Efficiency: Is it worth doing? It refers to the relative importance of the service provided in relation to other products that could be purchased with the same resources.

The WHO General Assembly in May 2018 passed a resolution on the importance of assistive technology devices and services globally (including assessment) and supported the position

papers that emerged from the 2017 GREAT Summit. The main considerations that need to be taken into account by governments in the provision of assistive technology to all citizens are related to Personnel, Products, Provision, Policy and characteristics of the Person/People (10).

So, to give support to the professionals, to improve the services of assistive technology and to benefit the final users of those devices, several theories and models have emerged.

Fuhrer et al. proposed a framework to consider all important factors that have been contemplated in models of outcomes measures (11):

- The functional problems that AT intends to solve.
- The characteristics of the device that are responsible for its intervention.
- The characteristics of individuals that are candidates to be final users.
- The elements and contingencies of the causal chain, connecting the device's provision with the possible results.
- The expected changes in the state of the user and its context, that are the results, both short and long term.

So, that framework establishes a good way to implement theories based on outcomes measures in AT, considering a temporal process, with the following steps (11):

- Provision of the devices.
- Introductory use: Period during the training of AT use. That includes professional and final user.
- Short-term results: These are derived directly from introductory use. That results can lead to discontinuous/abandoned or continuous use. And if the device is abandoned, the process has to start again from the stage of AT's provision.

From all assistive technology's outcome measures, the Matching Person & Technology (MPT) Model stands out. It was developed from research projects conducted by Marcia Scherer and collaborators over many years which aligns with the assessment of the effect of AT on the user's quality of life/subjective well-being (12).

The Matching Person & Technology model

The MPT model serves to guide decisions and factor to consider during the selection process about achieving the most appropriate AT for the person. The application of the MPT is an aid to identify devices that fit not only the capabilities, needs and personal preferences, but also the lifestyle of the user. In addition, it considers the level of motivation and the potential predisposition towards the use of assistive technologies, as well as the expectations of benefits from the use of the device.

For that, the model takes into account the specific characteristics of the person, his/her preferences and activities, the context in which the user lives and key personal and environmental factors that can affect the use or non-use of AT.

From that, a conceptual model emerges (Figure 1), pointing to several factors to consider during the prescription and selection of AT, based on three main components (13–15):

- The Person: Consider personality, temperament, preferences and needs of the final user. It includes psychosocial factors such as age, gender, mood state, prior support use, functional capacity, lifestyle, motivation, cooperation, optimism, self-discipline, positive life experiences, as well as the perception between the desired situation and the current situation.
- Technology: Includes the desirable functions and characteristics of the device itself. It includes specific factors of the product, such as its availability, ability to be used without discomfort or stress, compatibility with other technology, the cost, the credibility of the device, ease of use in the present and future, and its portability.
- Millieu (Environments): Determines the characteristics of the environments where technology is used (cultural, political, economic, attitudinal and physical) and the associated social factors (family, peers, bosses). It also includes the possibilities of adaptations or adjustments that benefit the use of the device and reduce the external requirement.

Figure 1. Fundamentals of Matching Person and Technology Model



The MPT model focuses on the match between the person and the assistive technology, so if there is an incompatibility between the two, it is necessary to detect it early, to try to avoid inappropriate use of the technology and the possible disappointment that it can generate in the user as a result.

The MPT Tool: Instruments and forms of MPT

The MPT tool is a set of questionnaires developed to identify the assistive technology that best matches a given person, taking into account their skills, needs, and the user's preferences and lifestyle. The process allows for organizing the many influences which impact on the use of assistive, educational, workplace, and healthcare technologies,

including personal and social factors. Additionally, the potential device user's motivation and readiness for technology use, as well as expectations of use, are identified (14).

The Matching Person and Technology Model and accompanying assessments have been found to have very good psychometric properties and they have been validated by a number of studies. They have been translated into eight languages. Several derivative measures have been developed (12).

The MPT assessment process can:

- provide a report of what the person thinks and feels.
- help consolidate information to use in planning the person's training.
- encourage client participation in the process of developing and setting goals
- help clients better understand their own needs and interests
- be useful when the client is a "complex" case, good tool for assessing a client's "story" with AT
- help avoid the "one size fits all" mentality;
- be useful as case documentation
- reduce the worry that I'm omitting something; it forces one to be thorough
- let the client be the person who makes the final decision
- help organize thoughts while focusing on the entire picture
- provide a good framework in which to build the counselor-client relationship
- allow me to get insight that I would not have otherwise from my agency's traditional assessment process
- be useful in gauging clients' motivation and willingness to move forward, overall attitude and views of themselves (14).

After the person has received the most appropriate technology for his or her use, the MPT forms can be administered after technology acquisition to assess changes in perceived capabilities, subjective quality of life, and psychosocial factors such as self-esteem, mood, self-determination, and social participation (14,15). Expectations of benefit can be compared to the realization of benefit.

The set of instruments take a personal, collaborative (user and provider) approach to assessing the potential technology need; choosing the most appropriate technology given the user's needs and goals, the technology features, and environmental support. The forms that comprise the MPT tool are:

1. **Initial Worksheet for the MPT** is used to determine initial goals that the professional and the consumer have established. Potential interventions supportive of these goals and technologies needed to support the attainment of the goals are recorded.
2. **History of Support Use** is used to identify supports used in the past, satisfaction with those supports, and those which are desired and needed but not yet available to the consumer.

3. **Specific technology matching:** The consumer is asked to complete his or her version of the appropriate form depending on the type of technology under consideration:
 - a. The Survey of Technology Use (SOTU) examines the following influences that impact most on the consumer's use or non-use of technology in general:
 - i. The technologies frequently used by the consumer (for example, computer, TV, smartphone)
 - ii. The consumer's experiences with current technologies
 - iii. The consumer's perspectives on new technologies
 - iv. Typical activities of the consumer
 - v. Personal/social characteristics of the consumer
 - b. **The Assistive Technology Device Predisposition Assessment (ATD PA):** is designed for rehabilitation professionals who help individuals select new and/or additional assistive technologies and who want to ensure the match is optimal. The consumer form of the Assistive Technology Device Predisposition Assessment (ATD PA) consists of two checklist forms:
 - i. Person Form items inquire into consumers' subjective satisfaction with current achievements in a variety of functional areas (9 items), asks consumers to prioritize aspects of their lives where they desire the most positive change (12 items), profiles consumers' psychosocial characteristics (33 items), and asks for consumers' views of their opinions regarding their expectations regarding the use of a particular type of assistive device. Subscales include the view of capabilities, subjective quality of life/well-being, self-determination, mood and self-esteem, motivation for technology use, and program/therapist reliance.
 - ii. Device Form inquiries into consumer ratings of up to three competing devices in a category. Its items ask for the consumer's views of competing choices.
 - c. **Educational Technology Device Predisposition Assessment (ET PA):** The ET PA is a 43-item self-report checklist developed to assist professionals and teachers in compiling comprehensive pre-learning and post-learning profiles of the individual that they are planning to equip with educational technology so that the use of the technology will result in an enhanced educational experience. The use or non-use of educational technology is the outcome of a complex constellation of contributing factors, and the ET PA will give insights into those factors that contribute to (or detract from) its use. With such insights, the teacher can diagnose and intervene in potential or existing problem areas and, thus, better ensure that the use of the technology will enhance a student's educational experience.
 - d. **Workplace Technology Device Predisposition Assessment (WT PA):** The WT PA is designed to assist employers in identifying factors that might inhibit the acceptance or use of new technology in the workplace so that appropriate employee training can be planned, modifications made to the technology, and employees' skills enhanced. The set consists of two forms: The WT PA-Employee Form, and the WT PA-Employer Form.

- e. **Health Care Technology Predisposition Assessment (HCT PA):** has been developed to assist health care professionals in identifying factors that might inhibit the acceptance or appropriate use of health care technologies.

The instruments to assess specific technology matching each have two forms: one for the person and another one for the perspective of professional (except the HCT PA).

Specific instruments can be completed in approximately 15 minutes; a more comprehensive battery in approximately 45 minutes. Thus, time does need to be allocated to the process, but it should be thought of as an investment rather than an expenditure of resources as outcomes will be better.

The instruments have been created and tested in multiple research studies with different populations and technology use situations.

Spanish version of MPT: translation and adaptation

The Matching Person & Technology Model and tool was considered for its adaptation to the Spanish population because it is one of the few models that include, in a holistic way, the complete process of prescription and use of a support product:

- Includes several evaluation instruments that, in themselves, form a battery.
- Its evaluation tools cover the whole process, from the moment before the recommendation to the evaluation of the results and follow-up.
- The MPT allows assessing the variable of predisposition towards assistive technology, both in the personal environment, as well as in work or educational activities.
- Expectations of benefit at selection can be compared to the realization of benefit at follow-up.

The model is both a personal assessment, as a collaboration (the user and the professional) and the record sheets can be used as an interview script.

The MPT model has been translated and adapted by a research group of the Institute of Integration in the Community (INICO, University of Salamanca). The process was carried out with a sample of 155 university students (57 of them without disabilities 98 with disabilities).

To carry out the translation and adaptation of the assessment instruments of the MPT (Matching Person & Technology), the methodology followed the guidelines for the adaptation of tests of the International Test Commission (ITC) was followed (16).

The process contemplated the following four areas which, normally, are the source of the primary errors when adapting a test from one culture to another.

1. **The Context:** It is the socio-cultural environment in which the people to whom the test will be administered are immersed. In the adaptation of the MPT assessment instrument, work has been done to ensure that the different influential factors that must be taken into account when selecting the support device are appropriate to the

Spanish context. To do this, the different items that compose the MPT questionnaires have been analyzed carefully, one by one, to guarantee their meaning and meaning within our culture.

2. **Construction and adaptation of the test:** The technique applied to translate the MPT was the reverse translation. During the process of adaptation of MPT tools into Spanish culture several guidelines were taken into account:
 - a. Consideration of cultural differences.
 - b. Guaranteeing that the terminology and language employed along the instructions, items and manual are adequate to the population for which it has been adapted.
 - c. Use of familiar language to the population to whom it is directed.
3. **Application:** The way in which a test application influences its psychometric properties, reliability and validity, from the relation of the examiner to the person evaluated, the way of giving the instructions, etc. To avoid these effects on the psychometric properties, the questionnaires of the MPT assessment instrument have been administered by psychologists with aptitudes and experience in the application of evaluation tests, and therefore aware of the importance of following a protocol of action to the time to administer the test. In this way, the questionnaires under study have been administered to 98 students with disabilities and 57 students without disabilities.
4. **Interpretation of scores:** The interpretation of the scores must be carried out by professional specialists who have the appropriate psychometric training.

The process of adaptation was done with a sample of 155 university students (57 without disabilities and 98 with disabilities), selected through a non-probabilistic convenience sampling. Participants were from 10 different regions of Spain. Specifically, the sample of students with disability consisted of 58 women and 40 men, with an average age of 28.8. With respect to kind of disability, 49% have a physical disability, 21,4% have a visual impairment, 14,3% have a hearing disability, and the remaining groups were those with chronic diseases (10,2%) and mental health conditions (4,1%).

The forms translated and adapted to Spanish were:

- Initial Worksheet for the MPT
- History of Support Use
- The Survey of Technology Use (SOTU)
- The Assistive Technology Device Predisposition Assessment (ATD PA)
- Educational Technology Device Predisposition Assessment (ET PA)

The forms of specific technology matching (SOTU, ATD PA, ET PA) were the focus. The ET PA, in particular, was applied based on the performance of a specific task of virtual learning: to take a course or subject through an online learning platform.

The main preliminary psychometric properties obtained with this research were:

- **Reliability:** The internal consistency of SOTU was moderately acceptable, and the removal of a few items of its components improved its consistency. The questionnaires

ATD PA and ET PA also show a moderate internal consistency, and some items (for example, the educational environment of ET PA) caused clear problems.

- **Validity:** The results of the analysis done to get information about validity, indicate that SOTU form has construct validity, as well as predictive value of one of the sections of SOTU (consumer's experiences with current technologies). Nevertheless, that predictive value is only applicable in order to predict the use of assistive technologies.

It is necessary to implement more research applying the MPT forms translated into Spanish in order to get more information about criterion validity and concurrent validity and offering information about the translated version of MPT.

That the research was done with university students allowed getting interesting data regarding their technology needs, adaptations, and support services for students with disabilities. The main technologies desired by this population were also the technologies that could benefit the rest of students (for example, the computer, mobile phone, or TV). That is congruent with the principles of universal design for learning, that minimizes the need for adaptations.

The analysis of the predisposition to technology, in general, shows the low frequency of use of specific technology devices for people with disability, but a high frequency of use of general technologies. There are no differences with regard to the factors that could determine the predispositions to technology, and all participants showed a favorable positive predisposition to technology.

Other experiences employing MPT in Spain:

Apart from this main study to adapt the MPT model to Spanish two other research projects were done in Spain with a different population.

The thesis by Pousada (17) was done with a population of people with neuromuscular diseases (NMD) using a wheelchair and circumscribed to the Galicia region. In that research, SOTU and ATD PA forms were applied to identify participants' predisposition to the technology and the psychosocial characteristics, environmental factors and matching with a wheelchair, that could lead to use, low use and satisfaction with that device. Among other important results, are the following conclusions (7,17-18):

- The wheelchair becomes an additional part of the person affected by NMD. Consideration is given to a fundamental, environmental factor, according to the International Classification of Functioning (19), to maintain independence in activities as basic as mobility.
- A wheelchair has a positive social impact in terms of the perceived quality of life in persons with NMD. Among the different types of assistive tools, the electronic wheelchair offers improved competency and adaptability in users.
- During the process of prescribing a wheelchair, the professional health care provider should consider not only the user but also his/her needs in terms of goals, the fulfillment

of activities, and degree of participation, as well as his/her interaction with the environment.

- The wheelchair and the user with NMD are matched correctly.
- As the degree of user-device matching is increasingly optimized, the degree of the psychosocial impact associated with the use of device becomes greater and with a higher positive value.
- The presence of caregiver’s burden is related to the perceived effect on the state of health of the care-provider, his/her changes in mood, and the reduced opportunity for social interaction.

The other one is the thesis of Jiménez (20), done with people with hearing impairment. The sample was formed by 291 participants, 115 men and 176 women. The mean age was 56.12. One hundred forty-six persons used the oral language as a means of communication, versus 39 that used signed language, and 106 persons used both (20). The assistive technology for hearing impairment included cochlear implant (n= 30), retro-type headset (n= 89), intra-channel (n= 36), deep insertion (n=5), hearing glasses (n=2), mobile phone (n=26), Oovoo (n=17), Skype (n=15), and video intermediation systems (n=74).

The Survey of Technology Use was applied to all participants. In Table 1, the mean score of positive, neutral and negative answer from participants are showed

Table 1. Mean score of each section of SOTU

	Positive	Negative	Neutral
Total	16,3 (7,3)	7,25 (6,03)	6,39 (5,1)
The consumer's experiences with current technologies	3,1 (2)	0,37 (0,82)	1,5 (1,86)
The consumer's perspectives on new technologies	3,59 (2,3)	2,6 (1,96)	1,8 (1,9)
Typical activities of the consumer	2,1 (1,3)	0,7 (1)	1,2 (1,3)
Personal/social characteristics of the consumer	7,6 (3,7)	3,1 (3,4)	2,3 (2,7)

That it is noted that the users of hearing glasses, mobile phone, retro-type headset and Skype obtained a higher number of positive answers. On the contrary, the users of the intra-channel type hearing aid had higher negative score in SOTU. On the other hand, users of smartphones obtained the worst score in the section of “consumer's experiences with current technologies” versus other participants. Nevertheless, those persons had a more positive score in the section of “personal/social characteristics of the consumer”.

Certain differences about consumer’s experiences with technologies were found through SOTU questionnaire. A relationship between positive experiences with technologies and the use of video intermediation systems (known by the acronym VRS-video relay services) exists. That result indicates that the users of this technology have, both historical and

positive perspectives with technologies. Overhead, the score of SOTU, it can be deduced that personal / social factors are not linked to the use of these technologies (21).

The questionnaires SOTU and ATD-PA have demonstrated to be a good tool for assessing and to prescribing AT for people with deaf or hearing impairment (22). But the novelty of the Spanish study was the fact that participants were deaf people from the Deaf Community and not only people with a type of postlocutive loss.

Previous studies have pointed out the importance of using assistive devices and technologies to mitigate the effects of hearing loss in communication (23,24). There are many types of new technologies very, and the number of those is getting higher, so it is necessary to know the technological profile, as well as previous experience in the use of technologies. From this perspective, it is noted the importance of that assessment tools, especially when the users are deaf people that thanks to AT their social participation increases (25).

Providing support to apply MPT in the Spanish context: Manual and Training

Apart from this research implementing the MPT model, the expertise and use of outcome measures and models in Spain are really low. Actually, the prescription of assistive technology in our country isn't guided by a protocol or guidelines, and in the majority of regions, the provision of AT is circumscribed to devices for mobility. Rehabilitation professionals don't consider the psychosocial characteristics of the person, nor his/her activities in lifestyle neither environmental factors or contexts. They are limited to the consideration of the anthropometric characteristics and the economic aspects so that the person can receive wheelchair funding by the health system.

In order to improve that situation, it is necessary to implement models and to spread the use of outcome instruments in assistive technology.

So, the Spanish workgroup in this research line has edited and published the Matching Person & Technology's Instruction Manual and its questionnaires into the Spanish language. The purpose is to spread it among the community of rehabilitation professionals and to demonstrate the interesting contribution of this model, in order to get more efficiency and efficacy of the AT provision system in the country.

With this in mind, several training courses to apply the MPT model will be planned to be implemented in a few regions of Spain. The manual and forms will be presented and study cases with different populations will be described.

There have been other cultural adaptations and validations of the Matching Person and Technology Model and tools conducted in other countries as well, such as Brazil, Germany, Greece, Ireland, Italy, and the Republic of Korea. Citations to the translations and research findings can be obtained from the website of the Institute for Matching Person & Technology at <http://matchingpersonandtechnology.com>. Use of the MPT Model and tools has consistently resulted in improved device selection and realization of benefit by users.

Obstacles to use of the MPT Model and tools include appropriate training of rehabilitation professionals and the allocation of time to the assessment process.

The set of challenges and opportunities is in front of us. And taking into account the statements fixed by the Global Priority Agenda (10), tangible ways forward include:

- Funded outcome global projects to get an international profile of AT practices.
- Mentorship / linkages to build knowledge and capacity between low- and middle-income countries and developed regions.
- Incorporation of research results into national catalogs of AT and take the results into account in the process of delivery of AT devices.

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Evaluating the economics of assistive technology provision

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Abstract

This paper defines an approach to calculating the economic impact assessment of public investment in assistive products. In addition to directly attributable financial costs and benefits, it incorporates qualitative measures of personal and social impacts of assistive technology (AT) provision. The role of economics as the efficient allocation of resources, enacted through policies and programmes, generating variable impacts. Our objectives therefore are to provide a measurable and comparative impact analysis of programme or policy efficiency. Currently policy decisions are commonly based upon social and political objectives, driven by an agenda for inclusion. To date, outcomes delivered against these objectives have been difficult to measure, or the impact has been simplified to the elements of direct costs and returns that can be identified and measured monetarily. This is in part due to a lack of a clear, well-established methodology of how to measure and assess total economic impact, including both financial and non-financial changes. Based on the available data, we propose and illustrate an approach and share the methodology so that others may apply it to broader and more detailed datasets, testing it across a range of regional and economically diverse contexts to progress the concepts. With use and further consideration and practical understanding of how the methodology could be applied both in high as well as low-income countries, for the public as well as private funding, we hope to progress the maturity and completeness of economic analysis of assistive technology provision. This in turn should increase the net positive impact of provision for individuals, communities, economies or societies as relevant to the goals of the policy or programme being developed or assessed. The authors have drawn on their combined expertise in the fields of assistive technology provision and service delivery as well as inclusive research and market value analysis, across a range of very varied locations, to jointly derive a methodology that is both sufficient and flexible to be further tested and applied in a range of contexts. By sharing the methodology rather than a specific research outcome in a specific context at this point, we seek to provide an approach for implementation in a range of funding decisions and in economies of differing means, opportunities and constraints. We welcome researchers to

test and progress the approach with data at their disposition and considerations of their regions.

Keywords

Economics, impact, outcomes, person, downstream, mixed methods

Background

Assistive Technology

Assistive technology is a key facilitator to enable full participation in society. Yet, barriers prevent its full deployment and cause global unmet and under met needs, fueling digital, consumer, education, employment and social exclusion or restriction (1). A clearer economic case, better understanding the net impact of provision is one strategy identified in global policy to address this (2). To date, microeconomic costing and forecasting research has had a relatively low profile in contrast to other assistive technology outcome dimensions.

Assistive technology users and their assistive technology practitioners have had few tools available to capture data at an individual, service delivery level. In part because to date, there has not been a robust, well-accepted or tested economic model that outlines the measures of value (costs and impacts) and how they can be used to assess the overall outcome, individually or programmatically.

Identifying the costs and outcomes of interventions is becoming a priority in the context of individualised funding approaches and assessment of comparative programme or policy impacts.

Understanding the challenge

During the past decade many governments have committed to encouraging an inclusive society that recognizes the needs of people with a disability. Both in signing and ratifying the United Nations Convention on the Rights of Persons with Disabilities (CRPD), or in public commitments at events such as the Global Disability Summit in London, 2018; politicians have sought to address access and inclusion of people with a disability.

However, in many national contexts and regional settings, the scale of investment required seems daunting. Approaches to provision of services, including assistive technologies, that have been established in the USA and Europe do not necessarily transfer easily to other national contexts. In addition, both products and services are subject to considerable innovation that is disrupting existing provision systems and requiring new approaches to address needs efficiently. Such disruptive technologies, particularly those marketed as mainstream solutions to a very broad target base, but which also have assistive or adaptive capabilities, may be available for a fraction of the cost of traditional products.

While dedicated technologies are increasingly being replaced by software and technologies established on consumer devices, an expert model of matching needs to solutions is also

being augmented by self-determination of options based on data available openly online. The AT ecosystem is therefore undergoing significant change as a result of shifting economics, solutions, business models, demographics and increased expectations.

Governments are faced with the challenge of creating access to products and services that have a positive net social and economic impact. Currently most lack coherent and cohesive local data and a robust analysis approach to make decisions on the efficient allocation of resources on an economic costs and benefits basis. This gap inhibits efficient investment consideration and decisions that will improve inclusion. There is a need to address this gap with systematic tools and analysis upon which reliable decisions can be based.

Background on health economics

As contributors to the economies we live in, and with many competing spending priorities, stakeholders generally agree that government spend on our social safety net should provide value for money. We look for expenditure in social and health schemes that are,

- **beneficial** - to recipients and society
- **effective** - in achieving outcomes relative to other alternatives, and provide a
- **good return on investment** - spent such that future costs are avoided, and benefits optimised

In order to assess economic impact, we need to be able to effectively measure total costs and outcomes and assess these relative to other alternatives.

Within the discipline of economics, health economics is a relevant field for considering assistive technology provision. The economics of health acknowledges both 'fiscal' or 'financial' impacts, which are able to be measured and costed monetarily, as well as 'non-fiscal' or 'non-financial' aspects, such as quality of life or social cohesion. Overall economic impact combines the change in both financial and non-financial costs and outcomes (3). It is optimised at the lowest costs for any desired outcome/s, or best outcome/s for any programme of similar costs. Improvements are made when costs fall relative to outcomes, or outcomes improve relative to costs. This requires the ability to attribute, measure and assess full costs and outcomes in a robust, comparable way.

Prevailing methods for reviewing health economics currently include cost analysis (comparing costs) and cost-effectiveness analysis (comparing costs with health outcomes, measured in a standardized way) and budget impact analysis (comparing costs and impacts on a specific budget such as the agency providing the AT).

Each of these quantitative methods has been critiqued for their inability to reflect important variable outcomes of interventions such as emotional health, social and broader economic impacts on the individual and their direct community (such as employment status, family and carer support) (4). See the Appendix for a description critique of these approaches.

Despite the importance of economic evaluation to support financially and socially efficient funding of interventions in the health sphere, including assistive technology, there has not

been a strong, widely used economic evaluation tool or methodology available, offering robust analysis of all costs and outcomes. This is true both for single programmes and also for understanding relative net impacts across programmes, practices or policies. The prevailing approaches used, lack a balanced, person-centred standpoint, which is critical to uncover and assess all costs and outcomes (5). This requires both quantitative and qualitative, financial and non-financial data to be captured, understood and assessed.

This gap in economic impact assessments, and implications on health economics and related areas such as social welfare economics has been increasingly recognised. Other, more “balanced scorecard” approaches have been tried and are being increasingly adopted by regional, national and international organisations. These identify areas for evaluation and then bring together a scorecard of quantitative and qualitative data, financial and non-financial measures that can be assessed over time and policy changes ¹. There appears to be little evidence of the use of these to date in the economic assessment of Assistive Technology provision.

Economics applied to assistive technology

Assistive technologies have been a key intervention in health, disability and ageing for many years, addressing the negative impact of impairment on functional capacity. Benefits include increased independence, physical and mental health and wellbeing, economic and social interactions and reduced demands on a person’s network and local community (6). These outcomes are well understood by many providers and practitioners with ongoing relationships with their patients to perceive impact of provision on the individual and their community. Benefits are also felt and understood personally by recipients.

With increasing proliferation of AT solutions (including leveraging mainstream and consumer technologies), cost and impact variance is growing in range and complexity. The benefits of reliable “data, evidence and knowledge” to AT policy and programmes is growing (2). Intuition, even of experienced practitioners is increasingly unlikely to be accurate, presenting challenges to the development of appropriate policy responses to attract public funding.

Economic evaluation models need to effectively recognise the impact of AT interventions and implementation. This requires data capture and an assessment approach, including incremental costs, and outcomes achieved, across each time period. From this we can assess the efficiency of the intervention, and the relative efficiency of one intervention in comparison to another. Good quality and sufficiently complete cost and outcome datasets are critical to improving economic rationale.

¹ See for example OECD How’s Life index, The Global Youth Wellbeing Index, New Zealand’s Living Standards Framework, Australia’s AIHW Children’s Headline Indicators, including Family Social Network, Social and emotional wellbeing, Family economic situation and the Victorian Government’s Public Health and Wellbeing Outcomes Framework are all useful examples of data approaches which identify key categories of focus for evaluation and then determine the relevant specific quantitative and qualitative, financial or non-financial indicators for each.

A strong economic evaluation methodology is rarely applied to assistive technology interventions (7). This is in part because costs can be spread across a range of providers and over long periods of time; before, during and after the provision of the AT, including both direct and indirect cost elements. Outcomes measurement is also challenging as a number of common benefits of AT provision are very difficult to convert in a robust way to a financial impact basis or objective quantitative measures. Equally in many cases, intervention for a person with a disability will include, but is not limited to, assistive technology. Therefore, disaggregating the impact data related to the AT from the impacts of other changes can be challenging.

These factors may limit the allocation of resources to AT relative to other potential competing approaches that may have more easily demonstrated economic returns.

We propose that there are two changes that could significantly improve the economic evaluation of AT. These are,

1. Better quality longitudinal data capture and allocation across the full pathway to usage and possibly to eventual replacement or abandonment, and
2. The use of a mixed-methodology approach, incorporating and assessing a broader range of outcomes, including a balanced scorecard of financial, other objective quantitative data along with subjective qualitative data

Combined, these changes would increase the reliability of analysis and effective use of economic evaluation models.

These recommendations recognise and build on a number of assessment methods that have started to emerge and have promising potential for improving the evaluation of assistive technology.

- Health technology assessments: most frequently supporting decision-making for medical devices in hospital contexts. Includes a systematic evaluation of the product's properties and effects, as well as direct and intended effects of this technology, and indirect and unintended consequences. It attracts critiques for its lack of consideration of contextual information and stakeholder perspectives (8).
- Social Cost Analysis Inventory: stems from rehabilitation research in Italy. Captured costs are quite comprehensive including purchase (discounted if reusable/ recyclable), delivery support, maintenance and impacts on personal assistance (costed individually for differing skill /requirements levels). They are also split by funding/ services provider (9). This has been important in empowering practitioners and AT users to identify costs from their own perspective. Andrich et al identify a range of dimensions which require further research in order to strengthen this approach, including, '*standard parameters for the valuation of assistance as well as for the technical duration of different AT devices, so as to help make consistent estimates and improve inter-rater reliability*' (p99)
- Social return on investment (SRoI) (10) and Valuation of Social Outcomes (11) are principles-based methods for measuring extra-financial value, including the

environmental and social value not currently reflected in conventional accounts, SRoI calculates a value for non-tangible 'social returns' by looking at the measurable effect, providing a financial proxy, discounting the effect for other contributors to the change and for any future drop off. This was found to be a useful tool to assess the overall impact of assistive technologies for vehicle modifications in South Australia in 2018 (12). It enabled a payback period (the period of time by which the benefits would exceed the value of the initial investment) to be generated. The challenges of SRoI are: the proxy required to convert the social impact to a financial measure can be challenging and differing, reasonable priorities and weightings can drive quite variable outcomes.

- Mixed-method evaluation combines qualitative data sources along with quantitative data without trying to convert the qualitative outcomes into quantitative data. This means outcome results are denoted in multiple measures that cannot be added to a single result. A range of sequence options have been outlined (qualitative then quantitative, quantitative then qualitative, or simultaneous capture) along with a range of functional options (use qualitative data to converge, complement, expand or develop on quantitative solutions or generate a research sample) for combining these data sources effectively (13).
- Economic pathway analysis provides insights into upstream/ downstream costs, such as how costs can be avoided or reduced at a later date through 'early intervention'. This is essentially a time-based cost analysis, incorporating variable outcomes by embedding them into future costs avoided. This improves resource allocation decision support relative to data that is limited to direct costs of provision. It captures total costs of provision across the full "pathway" from those involved from recognition of need through provision to post-implementation assessment, maintenance and management (14). It assesses richer than usual cost data from across the delivery and usage "pathway", captured longitudinally across time on an individual basis, including direct and indirect time, along with costs of the product itself, setup, shipping, parts/ add ons, training and maintenance.

Each of these approaches offers a distinct perspective on economic modelling and assessment in different ways, either through better capture or inclusion of costs and/or the social or financial outcomes. Our approach recommends a combination of both of these – capturing broader-based costs in combination with mixed-methodology outcome analysis, combining quantitative and qualitative data sources.

Approach

The literature review summarizes and synthesizes current research on the business case for the provision of assistive and accessible technologies and products, with specific reference to the 50 priority products defined by the WHO. This provides a base of current leading practices, both as methodologies and applied research.

Further research then seeks to define those elements that comprise the total cost of provision from need awareness to users having gained the competence and competence required for efficient usage. This includes categories that are currently often not captured, assessed or built into overall economic efficiency analysis. Such an approach recognizes the breadth of infrastructure that is required to effectively implement assistive technologies. Such breadth is reflected in the 5 “P’s” described by the WHO, and in greater depth in relation to Market Shaping (15) or as an AT ecosystem for digital assistive technologies (16).

We then consider how the economic outcomes of the provision of AT, at both policy and programme level, may be assessed through capture and assessment of a broadly-based combination of measures. These combine the financial measures that predominate current analysis, with qualitative behavioural and attitudinal data. Currently available data can illustrate relative economic impact assessment, and the tools outlined offer an approach to analyzing further data. The usage of such qualitative measures across locations, settings and organisations for other policy and social impact assessment needs is growing. This combined approach, integrating quantitative and qualitative measures for a complete economic assessment, is being tested and applied in related policy fields (for specific examples please see Footnote 2).

Method

Enhancing cost data capture and analysis

Enable Ireland² offer relevant cost data in the provision of assistive technology from 2011 to 2018. We use this to describe ways in which direct and indirect costs can be captured throughout the pathway from referral and assessment to usage to identify trends.

The current available dataset does not offer aligned data related to personal outcomes, but it does highlight interesting variable cost trends. As social and financial outcomes vary significantly across individuals, costs in isolation cannot be used as a measure of economic efficiency. Outcome attribution based on individuals’ age, setting and assistive technology solution could generate an approximate impact assessment for each person. Such analysis would need to be based on an average across demographic groups, technologies and settings from prior experience, rather than actual impact on these individuals. Future economic analysis would benefit from an aligned set of individuals’ cost and impact data for a statistically significant cohort of assessment interest.

The data sample

145 individuals are included in our dataset, of which 91 (63%) were male and 54 (37%) were female. In terms of age profile, ages ranged from 2 to 73 years old. Most however were children in prime educational years, with 83% below 20 years old, 16% working age and 1% over 65 years old. 20 individuals (14%) received assessment and advice only, with the remaining 125 (86%) being provided with the assistive technology also.

² <https://www.enableireland.ie/>

Costs were captured covering direct health professionals time spent with and for the specific individual, along with an indirect flat allocation of administrative costs based on averages over time. Direct time included hours for travel, AT assessment, technical support, managerial support and training. Indirectly allocated hours included administration time. Hourly salaries allocated to each reflect a real average cost for that category of staff at Enable Ireland.

Besides demographics (gender and age at referral and assessment), time taken for the assessment and related costs of provision; two other elements were captured. Firstly, the different primary settings for the use of the AT such as education, employment, home or community. Secondly, technology categories such as smartphone, augmentative and alternative communication (AAC), environmental controls etc.

The analysis

Even without capture of post-implementation outcomes, this set of cost data offered interesting insights. It suggests a range of research questions, which could be addressed with access to aligned individual outcomes, to establish the actual patterns of economic efficiency.

From the cost data (Tables 1a-c) we can observe the average costs per provision across all categories, genders and usage contexts, the components of costs, as well as the variance for each.

Table 1a. Time spent on provision

Time spent on provision	Travel (hrs)	Admin (hrs)	AT Assessor (hrs)	Technical (hrs)	Manager (hrs)	AT Training (hrs)	Total time (hrs)
Average	0.78	0.50	4.98	2.30	0.29	2.88	11.73
Median	0.00	0.50	5.00	0.00	0.25	2.00	8.75
High	8.00	0.50	17.00	37.00	4.00	14.00	68.00
Low	0.00	0.50	0.00	0.00	0.25	0.00	0.75
Sum of all participants	113.00	72.50	721.50	334.00	41.75	417.50	1700.25
% of hours	7%	4%	42%	20%	2%	25%	100%

Table 1b. Converted cost of time

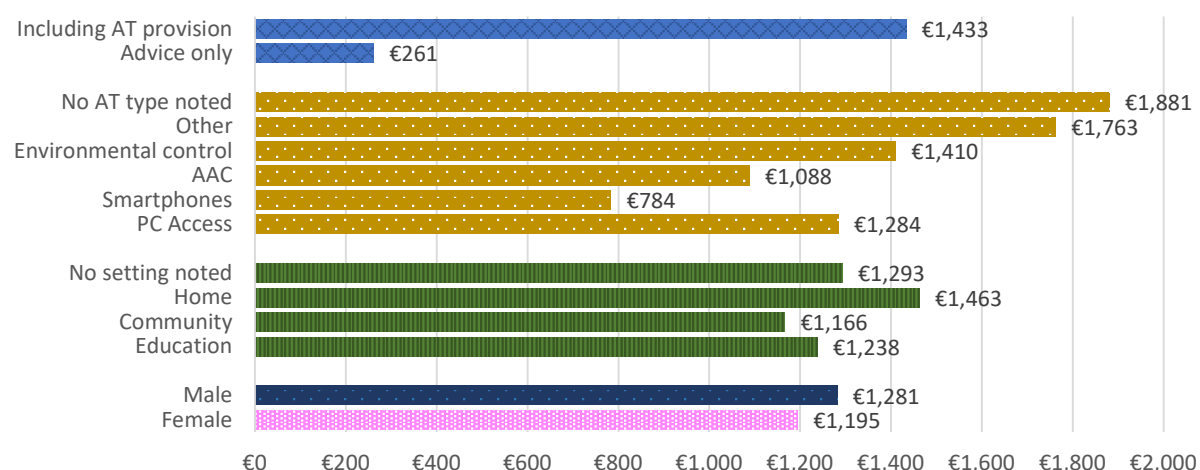
Converted cost of time	Travel (€)	Admin (€)	AT Assessor (€)	Technica (€)	Manager (€)	AT Training (€)	Total time (€)
Average	24.16	11.00	154.25	64.50	14.40	115.17	383.48
Median	0.00	11.00	155.00	0.00	12.50	80.00	298.50
High	248.00	11.00	527.00	1,036.00	200.00	560.00	2,131.00
Low	0.00	11.00	0.00	0.00	12.50	0.00	23.50
Sum of all participants	3,503	1,595	22,366	9,352	2,087	16,700	55,604
% of cost of hours	6%	3%	40%	17%	4%	30%	100%

Table 1c. Total captured costs

Total captured costs	Hours	Equipment	Total Cost
Average	€ 383.48	€ 1,032.02	€ 1,273.14
Median	€ 298.50	€ 985.00	€ 1,258.50
High	€ 2,131.00	€5,100.00	€ 5,916.50
Low	€ 23.50	€ 30.00	€ 23.50
Sum of all participants	€ 55,604	€ 129,002	€ 184,606
% of cost of hours	30%	70%	100%

When we compare different average total costs across other dimensions further questions emerge such as gender spend gaps and PC vs Smartphone digital AT differences. Figure 1 shows the genders, AT categories, usage contexts, and whether the costs included the provision of the AT itself or not.

Figure 1. Average cost of assessment and provision by AT by sub-categories



This cost data highlights trends, even without associated outcome data. To illustrate the value of rich provision pathway cost analysis, we explore one analysis category, related to gender.

Significantly more euros are spent in total on men (€118,318, 64%) than women (€66,293, 36%) in this cohort. This is due to two factors, fewer women are in the group (54, 37%) vs men (91, 63%) and an observed 6% lower average spend on women relative to men. When this is analysed at the sub-category level, there are some interesting gender differences between AT provided for the same user context, e.g. women on average receive AT that costs €1,260 for in the home, relative to €1,960 for men. In this context, on average 36% more is spent per male relative to female recipient. Given this sample is heavily skewed towards students from 2 – 20 years, this is unlikely to reflect different requirements such as traditional adult gender roles in the home. Further analysis might explore why more males

are assessed, and of those assessed, why they are getting more costly solutions. Research analysis might question whether the outcomes bear out the difference. Are males benefiting more from AT than the females in this cohort, or are females less supported for other, less economically valid reasons, limiting the overall efficiency of the provision?

Table 2a. Analysis of average and total provision costs (overall, all AT)

Overall – All AT	Male average	Female average	Difference F:M	Male total	Female total	Difference F:M
Total cost	€ 1,300	€ 1,228	-6%	€ 118,313	€ 66,293	-44%
Cost of time	€ 379	€ 391	3%	€ 34,508	€ 21,096	-39%
Cost of AT provision	€ 921	€ 837	-9%	€ 83,805	€ 45,197	-46%

Table 2b. Analysis of average and total provision costs (usage context)

Usage context	Male average	Female average	Difference F:M	Male total	Female total	Difference F:M
Education	€ 1,237	€ 1,304	5%	€ 77,946	€ 43,017	-45%
Community	€ 1,303	€ 920	-29%	€ 26,066	€ 9,204	-65%
Home	€ 1,960	€ 1,260	-36%	€ 11,761	€ 12,601	7%
Other	€ 0	€ 0	N/A	€ 0	€ 0	N/A
None noted	€ 1,271	€ 1,472	16%	€ 2,541	€ 1,472	-42%

Table 2c. Analysis of average and total provision costs (AT category)

AT category	Male average	Female average	Difference F:M	Male total	Female total	Difference F:M
PC Access	€ 1,328	€ 1,248	-6%	€ 90,288	€ 38,676	-57%
Smartphones	€ 784	€ 0	N/A	€ 1,567	€ 0	N/A
AAC	€ 1,070	€ 1,184	11%	€ 14,982	€ 23,688	58%
Environmental control	€ 1,483	€ 1,229	-17%	€ 7,413	€ 2,459	-67%
Other	€ 1,763	€ 0	N/A	€ 1,763	€ 0	N/A
None noted	€ 2,301	€ 1,472	-36%	€ 2,301	€ 1,472	-36%

It would also be worth noting that an additional, very useful category for analysis may be adoption vs abandonment 3- and 12-months after provision. With quite high average abandonment rates of assistive technology solutions (17) this would add a valuable outcome layer further down in the provision “pathway”.

In summary, rich cost data, including direct and indirect costs, incurred across the full pathway to provision and use of AT, can provide interesting insights and questions that would warrant further investigation. However, without an understanding of the impact on

the individuals, their community and society, this enhancement in cost capture and understanding, is insufficient to provide a robust economic analysis.

Outcomes of AT

Once the costs of options are well captured and understood, the next requirement is a need to better capture and understand relative outcomes.

Outcomes from AT interventions include a wide range of personal, community and social impacts. Some of these can be quite appropriately captured, attributed and robustly converted to a financial basis, for example reduced hours of personal care required translate to an hourly rate * hours saved. Other outcomes can be measured in an objective, statistically conclusive way, such as number of years of education attained. Other changes are more subjective or interpretive, such as an individual's perspective of their wellbeing, personal efficacy or social confidence. The Psychosocial Impact of Assistive Devices Scales (18) provides an example of a validated tool that measures the impact of assistive technology on the individual's functional independence, well-being, and quality of life. Such impacts have been referred to as the "qualitative residual" or "thick description" of outcomes (13).

Without an effective way to measure and incorporate these elements into current economic models, financially ascribable or more quantitatively measurable changes are likely to be deemed more important; as they can be evaluated directly and comparatively. Qualitative changes are likely to be ignored or discounted as currently they are not easily reliably measured or incorporated into decision support models. If on average, qualitatively measurable changes are positive following an intervention, as would generally be expected and experienced practitioners attest to, then quantitatively measured benefits of AT provision will under-represent the total actual economic returns achieved. This would likely lead to chronic under-investment in AT relative to actual realised, but uncaptured or represented, returns.

AT outcomes, particularly those related to personal independence, social interaction and integration, mental health and wellbeing are difficult to measure as objective quantitative data, or converted to financial value, as required for many current economic evaluation methods. There is a need to capture and integrate qualitative measures that removes the current dependence on converting data to a single financial measure.

In order to do this in practice, our proposed mixed-methodology model adds qualitative assessments including interviews or questionnaires with recipients of the intervention, on a modified attitudinal Likert scale where 0 reflects no change, 1 being some perceivable positive change and 5 represents transformational change. This would allow for a consistent scaling of change across varied categories. Should an unintended negative net impact occur from the AT implementation, a negative score could be applied on the same basis, 0 to -5.

A consistent numerical output of qualitative outcomes allows comparison across categories, programmes and time. Each category is not necessarily equivalent in the assessment to

another. Differing social values or initial programme priorities could numerically or non-numerically weigh one outcome as more or less valuable than another. This incorporates some of the concepts of Social ROI and Valuation of Social Outcomes methodologies, as well as the intended / unintended consequences used in health technology assessments.

Where practical, altitudinal results could be supported by behavioural qualitative input from teachers, parents, carers or other health care professionals with deep knowledge of the impact of the intervention on the individual. This combined approach has been used successfully in Australia for assessments of children’s wellbeing where teachers and parents are asked to provide an assessment, in addition to the children’s self-assessment³.

Many other factors may impact these measures beyond the provision and use of AT, particularly given that the period of intervention and assessment may be quite long. This could be managed in a number of ways. Some effectiveness studies could be done with a control group that doesn’t receive the intervention, such as that used in a study in Canada of AT interventions for older individuals living with dementia (19). Alternatively, for qualitative surveys or interviews, questions could be phrased in a way that directs participants to assess their perspective of what has changed specifically as a result of the access to, and usage of the AT.

Outcomes measures should try to take into consideration impacts on,

- the individual recipient
- their immediate family and direct community, including carers and friends
- broader society, where change may increase available social capital through more cohesion, resilience, awareness / understanding of varying needs, and less loss of human capability

Table 3 identifies a range of measures that we feel may be worth considering when creating a “balanced outcomes scorecard”, to assess different AT programmes and policies before and after the intervention. Such an approach would measure the net change and add the missing qualitative data back into the overall benefits assessment. Outcomes that are financially convertible could be captured where appropriate for each category also and noted alongside the qualitative change.

This is not a definitive or complete list. Should such a methodology become widespread in use, it would be advantageous to use a consistent set of categories and scales which would facilitate comparisons between programmes, regions or approaches.

³ Australian Institute of Health and Welfare. (2018). Childrens Headline Indicators. Canberra: AIHW. <https://www.aihw.gov.au/reports/children-youth/childrens-headline-indicators/contents/18-social-emotional-wellbeing>

Table 3. Measures of value

Category	What could be measured	Data source format
Personal independence, autonomy and choice	Selection of personal capabilities desired (set by the practitioner, as determined by the recipient prior to intervention). As not all changes are equivalent to recipients, these could be weighted by the importance to the recipient ⁴	Interviews or survey completed by participants (attitudinal) Interviews or survey completed by others who have a significant opportunity to observe the recipient (behavioural)
	Change to number of hours of formal or informal support required for a standard week	Quantitative, financial measure for change in professional care. For unpaid care – valued through the change in hours spent * either opportunity or replacement cost value (20) (pp 21)
	Change in housing or living situation due to increased autonomy <ul style="list-style-type: none"> - Impact on quality of life - Impact on costs (personal or borne by public funding) 	Interviews or survey completed by participants (attitudinal) Interviews or survey completed by others who have a significant opportunity to observe the recipient (behavioural) Financial measure for change in funding required or personal financial situation
Educational outcomes	Time in education (e.g. additional year of schooling completed)	Age at the highest level of education attained. Change since the intervention. E.g. if one additional year attained, the outcome is +1
	Personal efficacy in the educational environment	Qualitative survey or interview with the perception of change captured on a 0 to 5 scale from the participant and where possible also from their teacher
	Additional skills attained. Changes to results from reports or changes to specific measurable skills like literacy, numeracy or digital literacy	Change in results such as from school reports, converted to a 0 to 5 scale. Any change in literacy, numeracy or other skills (such as digital literacy)

⁴ For example, if getting bathed and dressed independently is the most important element to the recipient, any change to this capability could be weighted more heavily than being able to access digital information independently where that is less important to the individual. In practice this could work in a consistent way, as a discount rate to changes that are deemed less important. If at inception possible/expected changes were rated by the recipient on a High, Med, Low importance scale (to the recipient) then any changes to a High item could be reflected fully, whereas changes to a Med or Low item would be discounted to different levels when incorporated to an overall rating for the category. Changes that are highly beneficial to the community or society could be weighted more highly and adjusted also.

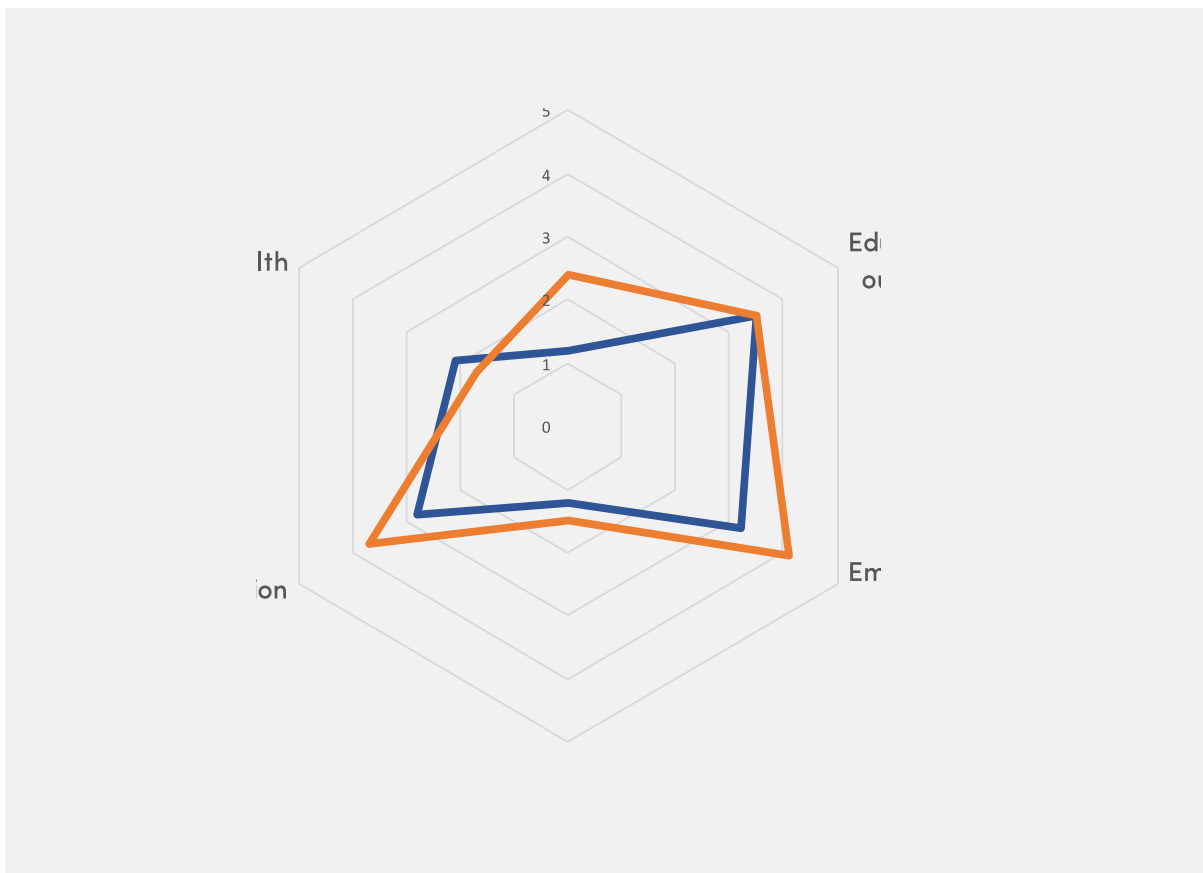
Category	What could be measured	Data source format
Employment and meaningful work	Any change in employment status or hours worked	Specific objective data – Employment status, FT, PT, casual. Hours worked
	Change in income from various sources, salary, social security, other as a result of the intervention. This flows further to: changes in income earned and mix of sources; change in taxes paid; and changes in social benefits received	Measurable objective financial data in addition to subjective assessment - the proportion of change due to AT intervention
	Job strain or uncertainty variation following the AT intervention	Qualitative survey or interview with the perception of change captured on a 0 to 5 scale from the participant
Mental health / wellbeing	Changes to overall mental health. This is a very large area, so sufficiency would be key to not creating a very complex to administer and/or costly data requirement. There are many well-tested assessment approaches available such as (21)	Self-administered qualitative survey capturing changes in the occurrence of poor mental health such as suicide attempts, symptoms of depression, anxiety, phobias, and other mental health conditions. This could be supported by a health professional, parent or carers assessment also
	Any changes to mental wellbeing: personal confidence, optimism about the future and general life satisfaction. Beyond the lack of poor mental health, this qualitatively looks to assess changes to personal confidence and life satisfaction – mental wellbeing	Self-administered qualitative survey capturing changes in mental wellbeing using a validated approach such as the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) (22)
Community and social participation and connection	Political, economic, civic, spiritual, family or other social participation elements. This is highly context-specific but could include more objective measures such as number of proactive social engagements, and more subjective measures such as perceptions of connectedness to family and community	Self-administered survey capturing changes in the community and social participation and connection, possibly supported with some objective measures such as the number of proactive and total social engagements over a period
Physical health	As appropriate relevant to the AT intervention. e.g. if the older person and providing in-home skin hydration monitoring it could be reduced problems with dehydration. If mobility support, it may be reduction in falls / injuries	This could be measured to be highly specific to the intervention and expected changes to physical health or a more general assessment of physical health

Selecting appropriate sampling size and depth of assessments will be critical to ensure that the assessment of outcomes provides relatively accurate estimations of the net impact, but the costs of generating it are manageable. Each programme should be designed for sufficiency and efficiency. The balance between these will remain an ongoing challenge for research design.

As an example, a recipient survey could be provided before the intervention and after it at two different time intervals with the difference being generated by the change between each. Alternatively, more efficiently, recipients could be asked to complete just one survey at one period after the receipt of the AT and questions designed to look for perceived change in each outcome category. This is less accurate, but much lower cost.

Personal or programme average results would generate something like Figure 2, below. This particular results summary identifies the outcomes of one intervention programme relative to another. In this illustration, Intervention 2 has a higher overall positive impact on average across categories, however it is slightly lower than Intervention 1 in terms of Physical Health Outcomes. If the primary goal of these interventions was purely Physical Health, despite benefits to other areas, Intervention 1 may be preferred. If the goal was an overall improvement in quality of life outcomes, then Intervention 2 would be preferred on the basis of this research.

Figure 2. Relative assessed change example from two alternate interventions

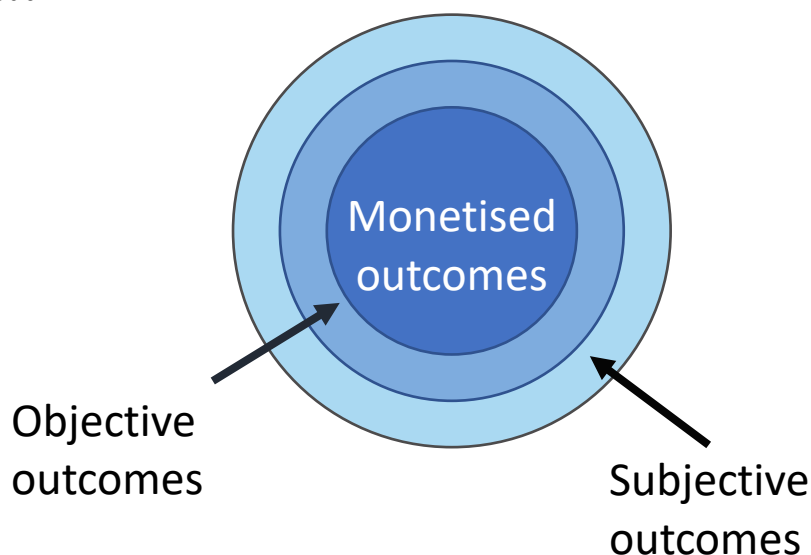


These results are the summary of the overall change to personal outcomes from the “qualitative residual” that to date has tended to be undefined, unmeasured or undervalued. However, just like financial measures, used in isolation, this data is insufficient for economic analysis and efficiency measurement. To generate a robust economic analysis, all costs and all outcomes need to be compared. As they are not all denominated in a single currency that provides one mathematical ROI result, the multi-dimensional output provides multiple layers requiring an approach for generating an integrated assessment.

There are three main ways that mixed-methodology data can be combined for assessment. Sequentially, either quantitative then qualitative first or concurrently (5).

Despite the ability to capture and assess alternate data, financially measurable outcomes remain the easiest to integrate into current economic models. You can easily compare financial outcomes to costs or alternative programmes, as well as adjust them for varying time and risk. Therefore, these should remain the assessment priority, wherever possible to do so relatively accurately. However as noted in this paper, there are significant benefits from the provision of AT that are not suited to conversion on a financial basis, or in doing so, require assumptions that are not robust and can be easily challenged. These outcomes are still very valid and should form part of the overall economic assessment of the policy or programme. Following capture of all financial outcomes, we recommend a layered approach, incorporating objective measures as the next most preferred source of outcome data. It doesn't include risks of subjective bias. Finally, subjective attitudinal and behavioral insights can complete the outcomes where financial results or objective data are not available. See Figure 3.

Figure 3. The circle of outcome measures, starting with priority at the centre and working out



In summary, in order to integrate all relevant outcomes into the economic assessment of intervention programmes or policy, outcomes need to be captured and considered from three sources, financially measurable data, other objectively measurable data and

subjectively measurable data with priority starting by trying to generate direct monetizable outcomes and then flowing outward through objective to subjective data.

Findings

The economic impact of assistive products must be considered within each of the 5 “P’s” identified by the WHO (i.e: People, Policy, Products, Provision and Personnel). To date, research has not fully investigated, consistently captured data or incorporated the complete costs and benefits/impacts of relative assistive technology policies and approaches. Approaches have been constrained by using either predominantly financial analysis for economic validation or social impact assumptions and values that have not been comparatively measured or integrated with the financial analysis. Both these approaches are likely to lead to systematic underinvestment in Assistive Technology provision and use. Relying solely on measures that can be converted to a financial basis has sometimes also led to less than robust assumptions, causing misalignment between actual impact and attributed financial effect.

A systematic, economically valid approach capturing a more complete set of both costs and outcomes is essential in seeking to address the likely widespread underinvestment in AT products, and optimise the net return on investment across all contexts. This is particularly acute in nations and regions where resources are more constrained such as in low- and medium-income countries, as well as financially stretched local government authorities in nations or regions that generally have more abundant resources. Even within such resource-rich settings, the increasing demand as a result of demographic trends demands that much greater analysis of costs and impact of various assistive technologies and models of delivery will be essential if sufficient resource is to be made available.

Conclusion

We would recommend that in implementing or evaluating an AT programme or policy that those charged with implementation should:

1. Capture a broad base of costs incurred in the provision of the AT including all direct and indirect elements along the provision pathway.
2. For impact assessment, start wherever possible with direct measures or those based on robust assumptions to identify the financial effect of AT provision. For example, this could be a change in earnings generated or costs avoided.
3. Recognise that not all qualitative measures need to be translated to costs and revenues if it is difficult robustly do so. It is the direction and scale of change from the baseline that is important.
4. Where financial costs are no longer available or robust, use qualitative measures of social or individual wellbeing to extend impact assessment beyond the financially measurable change.

5. Where there is sufficient observation for valid behavioural assessment of individuals, (such as in a school setting or supported living environment) these offer an effective balance to attitudinal qualitative measures from the AT recipient. This balances the perspectives of change that people perceive and note of themselves (personal attitudes) against what others see (observed behaviours).
6. We recommend drawing measures as relevant for each programme or policy from a relatively consistent set of qualitative measures of social and individual wellbeing - across time, policy areas and programme types.
7. Ensure that a good baseline is captured from which change can be measured, whether financial, behavioural or attitudinal.
 - a. If there is a natural opportunity to assess two otherwise parallel environments – one with and one without the change implemented (A/B test) – this can be a strong test of the impact of the change. Unrelated change that moves consistently in both environments will be easily disaggregated from the change generated as a result of the AT provision programme or policy
 - b. For assessment where an A/B test is not practical, the baseline will need to be measured in the changing environment prior to implementation. The net change may need to be assessed and adjusted for any impacts over the period that are identifiable and not due to the AT programme / policy such as rising overall incomes, wellbeing or a broader trend of reducing social cohesion.

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Appendix

Cost analysis requires identifying, capturing and adding together the total costs of provision. It will naturally lead providers to the lowest cost solution. The benefits are that it is relatively easy and low cost to assess. However, this approach is only effective where outcomes are, like commodities, unvarying across all alternatives. Where outcomes are variable, and lower-cost outcomes may be inferior to higher-cost ones. In most cases, a more sophisticated model would be advisable as there is not enough information captured through cost analysis to determine which option provides the greater total economic benefit.

Cost-effectiveness analysis can be calculated through cost-benefit or cost-utility analysis. Cost-benefit analysis is a 'dollar for dollar' comparison where the benefits of the intervention are 'monetised' by converting all outcomes to a financial basis (23). The limitation of cost-benefit analysis is that there may be data that is excluded where it cannot be easily attributed to the intervention, captured, and then converted to monetary values (13).

Cost-utility analysis generally uses standardized outcome measures such as QALY or DALY. Both are measures that are based on age at impact (positive or negative) relative to average age life expectancy. QALY, or the Quality Adjusted Life Year has been used since the 1970s to measure the positive change of interventions on years lived, weighted by health outcomes. Whereas DALY, or Disability Adjusted Life Year emerged in the 1990s as a measure of the burden of disease. It weighs years from the negative impacts relative to life expectancy by severity and then age- and time-adjusted to reflect social values (24). The

benefit of these is that they are standardised internationally recognised measures that can incorporate less monetizable aspects of impact in a consistent way across different interventions. However, the way in which the years (QALY or DALY) are calculated largely ignores varying distributions across impact groups, is based on values of personal utility gained or lost that are difficult to assess, and treats all years as having equal social value.

Budget impact analysis is limited as it only captures and looks to understand the impacts on a single defined budget, not the broader effects of the intervention on additional budgets (public or private) or any non-financial impacts. Offset costs (costs that impact other budgets such as elsewhere in the health system) are ignored and impacts that are difficult to convert to a direct financial measure are also left out of this assessment approach.

Using a standard procedure to assess assistive technology service delivery outcomes: A proposal from the Italian Network of Independent Assistive Technology Centres

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Abstract

Introduction: Standards or evidence-based practices are only sporadically and unevenly used in daily practice by assistive technology (AT) professionals to measure the outcomes of their service delivery practices. In order to assure a standard approach to AT service delivery outcome assessment, the Italian Network of Independent AT Centres (GLIC Network) has recently developed and tested a core set of internationally validated outcome measurements tools to be used by AT professionals working in all the active independent AT specialist referral Centres in Italy ($n = 30$). **Objective:** The present contribution reports on the methodology used to select the set of measurements and to assess their feasibility in AT practice. **Methods:** To identify and test the measurements we followed a 3-step approach. In the first step, three AT professionals performed a review of the measurements used to assess AT outcomes in peer-reviewed journal articles. Relevant articles were analyzed in depth and the data describing the related study and the instruments were extracted and coded. In the second step, results from the review were presented and discussed with a group of AT professionals from 10 Centres from the GLIC Network. In the third step, 10 AT Centres pilot-tested the selected measurements over a period of 12-months with the aim to collect information on their feasibility and usability in busy clinical settings. Semi-structured interviews were used to collect feedback from AT professionals involved in the pilot test. **Findings:** Three measurements were included in the final AT assessment battery: IPPA, to evaluate perceived effectiveness of AT intervention; QUEST 2.0, to evaluate user's

satisfaction with the AT device and the AT-related services; and KWAZO, to assess user's satisfaction with the whole AT service delivery process. These measurements are currently used in several countries and are thus internationally recognized. Further, the identified measurements are applicable to AT interventions targeting both children and adults. In the pilot test, the three measurements were administered to a total of 71 AT users recruited from 10 AT services. From the preliminary analysis of the feedback from AT professionals, the three measurements resulted feasible and well accepted by AT professionals. They were further deemed informative of the overall impact of the AT intervention from a user perspective. **Conclusions:** Variability in AT service delivery systems may prevent the diffusion of standard practices for AT outcome assessment. Moreover, both AT professionals and managers still hardly appreciate the importance of AT outcome measurement. This study aimed at contributing to the development of good-practice examples around the topic of AT service delivery outcome evaluation that can be used by a global community of AT and rehabilitation professionals with a very short training.

Introduction

The assistive technology (AT) service delivery process can be considered only when there is *evidence* of a 'satisfactory match between the person and the provided solution' (1; p.21). The process by which AT and rehabilitation professionals can gather information on the effects of any AT intervention is termed "outcome assessment" and is generally defined as 'a systematic investigation aimed at identifying the changes that are produced by AT in the lives of users and their environments' (2; p.1244).

Measuring outcomes of AT service delivery is a crucial aspect of any AT intervention and may fulfil a number of purposes at individual, service and system levels. At individual level, it allows AT and rehabilitation professionals to constantly monitor their interventions and make corrective actions when necessary. At service level, it facilitates assessment and monitoring of the overall functioning of a specific service delivery process over time. At system level, outcome assessment allows the identification of the differences in service delivery practices and processes, programs and policies, as well as the consequences associated with these differences.

Despite its importance for AT practice and research, however, evaluating the outcomes of AT service delivery is still perceived as a challenging task by AT and rehabilitation professionals, mainly because the AT field is chronically lacking evidence-based procedures to reliably evaluate outcomes of AT service delivery (3). As a consequence, little evidence is available concerning the effectiveness of AT service delivery systems (4).

Following the recent recommendation from the *GREAT Summit 2017 Report* that 'effective outcome measurements should also be included in the [assistive technology (AT)] service provision system' (5; p.18), in order to assure a standard approach to AT service delivery outcome assessment, the Italian Network of Independent AT Centres (GLIC Network) has

recently identified, selected and tested a set of internationally validated outcome measurements to be used by AT professionals working in the AT Referral Centres in Italy.

The aim of the study was to identify a core set of outcome measurements that AT professionals in Italy could consider as the minimum agreed set of outcomes to be reported in any AT interventions. The present contribution reports on the methodology used to select a set of measurements and to assess their feasibility in AT practice. Our aim is to contribute to the development of good-practice examples around the topic of AT service delivery outcome evaluation that can be used by the global community of AT and rehabilitation professionals.

Method

Definitions

Outcome is here broadly defined as what is being measured on AT users to examine the effect of the AT intervention. This latter concept, *AT intervention*, refers in turn to the whole process that leads from the user's need identification to the provision and the usage of the related assistive solution. This process can be ideally broken down into distinct sequential steps, most of which are valid in any AT system: Access to service provider (Initiative); Assessment of the user's and stakeholders' needs and resources (Assessment); Identification and selection of the most adequate assistive solution, adaptation, modification and fitting of the product to the user (Selection); Access to public funding to obtain the recommended assistive solution (Authorization); Implementation of the technology in the user's context(s), including the training of the user (Implementation); and, Follow-up, maintenance and repair of the AT solution (Management and Follow-up). Within this framework, we considered that the most appropriate time to assess outcomes of AT interventions is at Follow-up, after significant time of usage in daily life context (no less than three months).

Study context

Italy has a tax-funded national health service (*Servizio Sanitario Nazionale, SSN*) that guarantees the universal provision of comprehensive care throughout the country. The responsibility for the organization and delivery of services, including AT provision, lies with its 20 Regional Authorities. The provision of AT is regulated by the 'Tariffs Nomenclature' (*Nomenclatore Tariffario*): a law by the Italian state (Ministerial Decree 332/1999, and DPCM 12/1/2017) establishing the norms and tariffs for assistive products provided within the SSN. Roughly described, the decree includes a list of AT (organized by category, code and tariff) that can be financed by the SSN.

The growing availability of solutions implies that in-depth knowledge of the AT devices on the market, including the most recent and sophisticated technologies, is necessary for the selection and customization of several solutions. For this reason, health professionals may take advantage of the expertise of professionals working in specialized AT Centres. The

acronym GLIC refers to the Italian association of independent AT Centres, which gathers the centres specializing in AT for people with disabilities. The GLIC network was founded in 1997 and now includes almost all the active independent AT Centres in Italy (30 at present). From GLIC perspective, an AT Centre is an organization that has the following characteristics: (1) it has no commercial interest; (2) it provides information, evaluation, assessment, support, training and research; (3) it draws on a multi-disciplinary team of highly specialized professionals; (4) it avails a comprehensive range of AT products for trials. These Centres represent a reference resource for professional and for people with disabilities. They offer a variety of AT-related services, in collaboration with professionals from the respective local health authority, social services and, in the case of children, the school system. The AT Centres are managed at a local and regional level, with the objective of helping the users and the professionals to identify the most suitable AT solutions. Usually, AT Centres belong to a more complex network of public or private services, and are part of the rehabilitation, education and assistance pathways which are addressed to the person with disabilities and which include the involvement of different, but mutually integrated, professional profiles.

Procedure and data analysis

The selection of the core set of outcome measurements followed a 3-step approach. The following is a synthesis of the whole process. When available, sources reporting supplementary methodological information are indicated.

Step 1: Literature review. In the first step, three researchers with extended expertise in the field of AT provision performed a review of the measurements used to assess AT outcomes in peer-reviewed journal articles. Given the limited space available to describe the study, we created an open access repository (6) in which we provided a detailed description of the methodology used for the literature search. In brief, the researchers identified a list of journals whose field of interest included AT. The articles published between January 2003 and December 2016 (overall, 1284 issues) were considered by the review work. The journals issues were randomly split into 3 groups and assigned to the three researchers. Each researcher extracted from the assigned group all articles responding to the search terms "OUTCOME" or "MEASURE" or "EFFECTS" or "TOOL", as appearing in their title, keywords, abstract or in the body of their text. Relevant articles were analyzed in depth and the data describing the related study and the instruments were extracted and coded.

Step 2: Measurements selection. In the second step, results from the review were presented and discussed with a panel of AT professionals from 10 Centres from the GLIC Network. The panel first met face-to-face to discuss the results of the review and to achieve consensus on a preliminary set of AT outcome measurements that were applicable to a broad range of assistive products and services. Two co-chairs (LD, CS) guided the discussion during the meeting. Participating AT experts were invited to provide a summary of their personal experience in AT service delivery outcome assessment and illustrate the main challenges faced. Afterward, they were asked to define whether each of the measure identified in the review would be useful or not in the assessment process. For each measure, a group

agreement was reached on a preliminary set of outcome measurements during the meeting and summarized in a first note, which was circulated among the meeting participants for critical discussion and revision. Eventually, the measurements selected by the panel were presented in a second meeting to representatives of the whole GLIC network, feedback was collected, and a definitive set of measurements was identified.

Step 3: Pilot test. In the third step, seven AT Centres pilot-tested the selected measurements over a period of 12-months with the aim to collect information on their feasibility and usability in busy clinical and AT services. Participating Centres were involved in the pilot test on a voluntary basis. The aim of the pilot test was to allow AT professionals working in the participating Centres to familiarize with the selected measurements over a period of time long enough to cover the whole AT service delivery process. Each Centre was required to pilot the set of measurements with at least 10 users. By the end of February 2019, a total of 71 AT users was involved. Characteristics of the users recruited are shown in Table 1. At the end of the pilot-tests, a purposely developed questionnaire based on open-ended questions was administered to collect feedback from AT professionals who pilot-tested the set of measurements in their services. The questionnaire addressed barriers and facilitators to the use and implementation of the outcome measurements in daily AT practice.

Table 1. Characteristics of the users involved in the pilot test (n = 71)

Variable	Value
Mean Age [SD]	40.04 [23.26]
N Gender [%]	
<i>Male</i>	37 [52%]
<i>Female</i>	34 [48%]
Mean WHODAS (total score) [SD]	61.8 [19.9]
N of AT interventions (ICF-based) [%]	77*
<i>Learning and Applying Knowledge (d1)</i>	8 [10%]
<i>General tasks and demands (d2)</i>	1 [1%]
<i>Communication (d3)</i>	37 [48%]
<i>Mobility (d4)</i>	20 [26%]
<i>Self-care (d5)</i>	5 [6%]
<i>Domestic life (d6)</i>	4 [5%]
<i>Interpersonal interactions and Relationships (d7)</i>	2 [2%]

Notes: The sum of the AT interventions is greater than the size of the total sample as some AT users were recommended with more than one device.

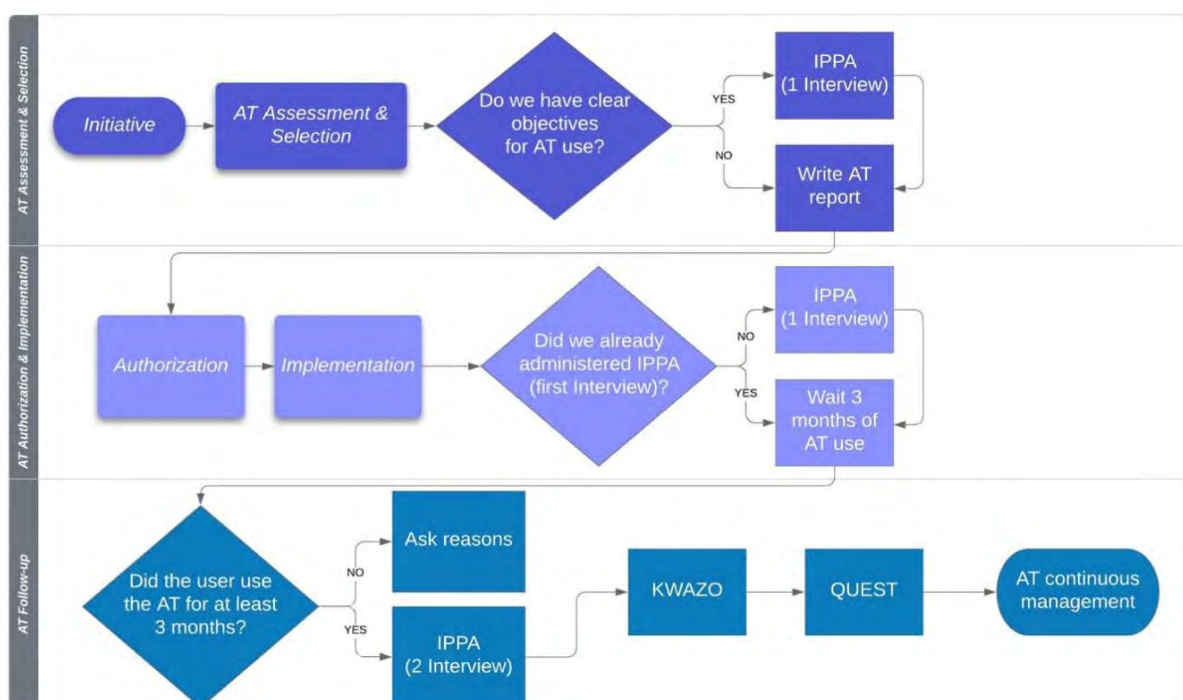
The ultimate goal of this study was to explore whether the selected outcome measurements matched the AT professional's understanding of the effects of the whole AT intervention and service delivery process. Accordingly, answers to the questionnaires were grouped according to two main themes: (a) the perceived clinical applicability of each measure in AT service delivery contexts (Clinical applicability); and (b) possible recommendations to

effectively administer each measure in daily practice (Recommendations). Concerning the analysis of the clinical applicability, respondents' answers to the questionnaire were further analyzed using a modified version of the feasibility dimensions of the the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) initiative (7), these being: *Usability* (i.e. the degree to which the measure is easy to administer by the AT professional and the clinician as well as understandable for the respondent); *Perceived usefulness* (i.e. the extent to which the instrument is likely to capture real change if it occurs; user's satisfaction); *Sustainability* (i.e. length of the outcome measurement instrument; implementation in routine clinical practice).

Follow-up process

Before the beginning of the study, all AT Centres agreed on a structured procedure of measurements administration in order to collect comparable feedback across AT professionals (see Figure 1). In brief, after the selection of the AT solution that best matched the AT user needs, AT professionals were required to administer the first Individually Prioritised Problem Assessment (IPPA) interview (for details see Appendix). They, however, could wait until the AT solution were provided before administering the IPPA, if they felt that only at that time the user could provide more detailed responses. After three months of presumed use of the AT solution, AT professionals contacted again the users to complete the second part of the IPPA interview, along with the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST 2.0) and the "Kwaliteit van Zorg" (KWAZO) questionnaire; in case, at that time, they had not actually used yet the AT solution, the users were asked the reasons for non-usage.

Figure 1. Flowchart illustrating the follow-up process used in this study



Results

Step 1. Literature review

The review yielded a total of 1312 candidate articles of which 53 were considered relevant by all the three researchers (for further details see the open access document by Salatino et al. (6)). Relevant articles included 86 AT-specific measurements of which only 5 were found to be outcome measurements that are actually applicable to a broad range of assistive products (see Appendix). In addition, three further measurements were found that, although unable to fully capture the AT outcome if used alone, can add useful information on the quality of the AT intervention: KWAZO (8), SATS (9) and ATD-PA (individual predisposition to AT use) (10).

Step 2. Measurements selection

The identified measurements were discussed both within the first panel of AT experts and the wider GLIC group. Discussions helped in the selection of the measurements to be included in the final AT assessment battery, these being: IPPA (11), to evaluate perceived effectiveness of AT intervention; QUEST 2.0 (12), to evaluate user's satisfaction with the AT device and the AT-related services; KWAZO, to assess user's satisfaction with the whole AT service delivery process. These measurements are currently used in several countries and are thus internationally recognized. Further, the identified measurements are ideally applicable to AT users with any health conditions and to AT interventions targeting both children and adults.

Step 3. Pilot test and clinical applicability evaluation

Table 2 illustrates a summary of strengths (+) and weaknesses or critical aspects (-) reported by the AT professionals involved in the study. The table also includes their suggestions to increase the reliability and the informativeness of the selected measurements. Overall, from the analysis of the feedback, the three measurements resulted feasible and well accepted by AT professionals. They were further deemed informative of the overall impact of the AT intervention from a user perspective. Notably, IPPA seemed to be useful not only to assess effects of the AT intervention but also as way to establish a solid relationship between the AT user and the rehabilitation/AT professional. As such, this tool can be used to improve the quality of both AT assessment and follow-up processes.

Difficulties in using the measurements are mainly related to the heterogeneity of the AT users (e.g. degenerative conditions) and the devices (e.g. low-tech or high-tech). Again, IPPA resulted the tool that may be perceived as the most challenging in terms of usability due to its low inter-individual reliability. For this reason, it is fundamental that professionals receive specific training by organizing, for example, role-playing activities before implementing it in routine clinical practice. The QUEST 2.0 resulted difficult in some cases, as for example when users had to rate their satisfaction with the "comfort" experienced with their eye-tracker. Difficulties in term of comprehensibility were also found for the KWAZO questionnaire, as the wording seemed to be not immediately clear to some users and professionals. Providing

a glossary with short definitions of key concepts included in the questionnaires may increase comprehensibility and encourage the use of these tools also as self-administered measurements. Importantly, scores from both the QUEST 2.0 and KWAZO further seemed to be flawed by high rates of high-satisfaction ratings. This aspect is a well-known issue when using measures of satisfaction in health services research, for which high satisfaction rates does not necessarily imply that the user will be compliant with professionals' recommendations (13) (for instance, AT adoption and use). For this reason, our proposal was to combine satisfaction assessment with a measure of AT effectiveness, i.e. the IPPA interview.

A final consideration (not included in the summary table) concerns the need to create more accessible versions of all instruments (e.g. by using symbols) in order to allow those with cognitive or communication disabilities to actively participate to the evaluation process. However, in the most severe cases or complex situations (e.g. people not able to understand; very young children), professionals should be trained for proper administration to their reference caregivers and/or be able to set/complete themselves the main items to avoid, at least, clinical complications (in case of IPPA first interview). It might be further useful to adapt some of the items of the QUEST 2.0 to the characteristics of ICT-based AT solutions.

Table 2. Summary of feedback from at professionals on clinical applicability of the selected outcome measurements. Plus (+) indicates strengths; minus (-) indicates critical aspects.

Tool	Usefulness	Usability	Sustainability	Recommendations
IPPA	<ul style="list-style-type: none"> + Helps establishing clear AT objectives and priorities; + Facilitates establishing a strong AT user-AT professional relationship; + Allows evaluation of effects of any AT; + User-centred; users are free to express themselves; + Qualitative & quantitative approach. - Not suitable for users with degenerative conditions (e.g. ALS). 	<ul style="list-style-type: none"> - Users may find it too difficult to express themselves or formulate clear objectives; - It needs specific training; - High inter-individual variability when administered by different professionals; - Not a self-administered tool. 	<ul style="list-style-type: none"> - Time consuming; - Qualitative data are difficult to elaborate. 	<ul style="list-style-type: none"> • Beginning the interview talking about daily routines may facilitate the emergence of AT needs from the user perspective; • It is important to specify problems that can be easily monitored over time (e.g. initiating conversations) instead of reporting only general issues (e.g. communication); • It is important that each professional using the IPPA develops its own list of user-reported problems that can serve as examples to facilitate the interviews; • Role-playing is essential to learn how to administer the IPPA. It may be useful if AT professionals from different settings and services share their interview modalities and “styles”; • If, for whatever reason, the user is not able to directly answer, IPPA can be administered to the primary caregiver. In that case, professionals should make it clear that the respondent has to make the list of the objectives as close as possible to the will of the user; • In any case, at the end the user-reported list of problems, professionals must complete the list of user goals with any objectives not emerged but essential from a clinical point of view (e.g. avoid pressure sores with a cushion for tissue integrity) • In the case of very severe health conditions, for which the use of the AT is mostly carried out by the caregiver, it might be important to add the goals of the caregiver (e.g. be able to lift and transport the user with a simple hoist system).

QUEST	<ul style="list-style-type: none"> + Covers important aspects of satisfaction; + Qualitative & quantitative approach. - Not suitable for AT devices; - Not always possible to answer to "Service" sub-scale. 	<ul style="list-style-type: none"> + Easy to administer (self-administration allowed); - In certain cases, some concepts are not immediately comprehensible (e.g. "comfortable"; "service delivery")*. 	<ul style="list-style-type: none"> + Short administration time; + Quantitative data easy to collect and elaborate; - Blank spaces for comments are not always used; - Open comments increase administration time. 	<ul style="list-style-type: none"> • Administer only after the user used the AT properly fitted to her/his needs for at least 3 months; • Possibly avoid the presence of the AT professional when the user is compiling the questionnaire to reduce the response bias towards high-satisfaction scores; • Before administering the questionnaire, explain to user the meaning of the target concept or provide a user-friendly glossary;
KWAZO	<ul style="list-style-type: none"> + Covers important aspects of satisfaction; 	<ul style="list-style-type: none"> + Easy to administer (self-administration allowed); - Wording is sometimes challenging (e.g. cooperation and communication among the different service delivery professionals?) 	<ul style="list-style-type: none"> + Short administration time; + Quantitative data easy to collect and elaborate; 	

Notes: * Referred to Italian translation only (i.e. comodità; servizio di fornitura).

Discussion

Variability in AT service delivery systems may prevent the diffusion of standard practices for AT outcome assessment. The measurements here proposed can be used by a wide variety of professionals with a very short training. This could help the introduction of user-centred and internationally validated measurements in a number of AT centers. In addition, the measurements proposed can be considered useful for both the assessment of individual interventions as perceived by AT users and epidemiological studies, and do not exclude the concomitant use of other more device-specific measurement tools.

It must be recognized, however, that outcomes of all AT interventions may be influenced not only by specific processes related to AT service delivery (which seem to be well captured by the measurements we selected), but also by several factors that are independent of such processes, such as the user's type and severity of disability, socio-economic status, family structure and well-being. AT professionals should thus be aware that, at the level of the individual intervention, the current set of outcome measurements may not be fully able to capture the *true AT effects*, but may provide important indications about how the AT intervention is progressing and, if needed, take corrective actions.

We further recognize some limitations of this study that may hinder the generalizability of our results to other contexts. First, the study is based on the experience of professionals working in a specific AT context with rather consolidated AT provision practices, service delivery systems and regulations. As such, our results may not fully reflect the perspectives and needs of AT professionals and AT users working and living in different cultures. Second, we took exclusively into consideration the perspectives of the AT professionals involved in the AT service delivery process. Despite evidence is available reporting on the acceptability of the identified outcomes measurements also from a user and caregivers' perspectives (14), literature on this topic is rather scant and does not properly address the wide variability of the users' characteristics and views. Third, the strategy used to identify the outcome measurements is not fully compliant with current recommendations suggesting to achieve consensus first on a minimum set of outcomes (or constructs) that should be measured (e.g. user satisfaction; levels of participation), and then on how these outcomes should be measured, i.e. which outcome measurement instruments should be selected.

This study, however, can be considered a first attempt – at least within the Italian context – to stimulate the discussion on the need to align AT practices with recommendations from evidence-based healthcare approaches (15). Its methodology may further serve as a reference for AT professionals working in other contexts to agree on a core set of outcome measurements. More in general, all the above-mentioned limitations may be overcome by replicating the current study at a larger scale, using a more solid and reliable protocol (e.g. see <https://www.cosmin.nl/>), and involving AT professionals and AT users from different contexts, settings and cultures.

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Appendix

Description of outcomes measurements identified in the literature review

Name	Acronym	Times cited	Description
Family Impact of Assistive Technology Scale	FIATS	3	Evaluates the changes in family functioning resulting from the adoption of an assistive product. It includes 89 items clustered round 9 subscales (autonomy, caregiver relief, contentment, daily activities, effort, family and social interactions, caregiver supervision and safety, technology acceptance). Each item is scored on a 7-point scale to measure the level of agreement ("strongly agree" to "strongly disagree")
Individually Prioritised Problem Assessment	IPPA	2	Evaluates the perceived effectiveness of an AT intervention. In the first interview (baseline) - to be administered before the user starts to actually use the AT solution in daily life - the user is asked to express some "problems" (up to seven problematic activities he/she expects to solve thanks to the AT solution) and rate each of them on a 5-point scale in relation to its importance and the difficulties it brings about in daily life. In a follow-up interview, the user is asked to rate again the difficulty encountered now (i.e. with the assistive solution in use) with each problem. In this way, a baseline and a follow-up score are calculated. The difference between the follow-up and the baseline scores provides the IPPA indicator of perceived effectiveness.
Quebec User Evaluation of Satisfaction with assistive Technology	QUEST 2.0	10	Asks for the individual's satisfaction with the AT equipment he or she is using. It contains 12 questions, eight of them focusing on the device and four on the associated services. The respondent is asked to rate the satisfaction with the assistive device and the related services on a 1 to 5 scale, with 1 representing 'not satisfied at all' and 5 'very satisfied'. In addition to this, the user is requested to choose the three most important items related to that specific assistive device. It is worth mentioning that not all QUEST 2.0 items are applicable to software AT.
Psychosocial Impact of Assistive Technology Scale	PIADS	11	Asks the respondents for their judgments on how their life has been affected by the AT equipment they are using. It is a 26 items self-rating scale that uses a 7-point Likert scale ranging from -3 to +3, depending on whether and to what extent the adoption of the assistive device increased or decreased – in the user's perception – the personal characteristic described by such items. The items fall within three sub-scales, namely Competence, Adaptability, and Self-esteem.
SIVA Cost Analysis Instrument	SCAI	3	Estimates the social costs involved in an individual AT intervention. Social cost is defined as the sum of the costs incurred by all actors involved in a given situation, including technology investment, maintenance, human assistance, and associate services. The social cost is measured over a pre-defined period of time, according to the estimated clinical duration of the AT solution.

Name	Acronym	Times cited	Description
Kwaliteit van Zorg	KWAZO	4	Developed in the Netherlands, the KWAZO is composed of seven questions, each covering the HEART-related quality indicators of the ATSD process (Accessibility, Information, Coordination, Know-how, Competence, Efficiency, Participation, Instruction). Here the Italian version of the KWAZO was used, which has been validated through a series of studies. The responder is requested to rate his/her degree of satisfaction with each indicator on a 5-point Likert scale (1 = insufficient, 2 = modest, 3 = sufficient, 4 = good, 5 = very good) and to write a comment to justify any rating below score 5.
Satisfaction with Assistive Technology Service	SATS	1	SATS is very similar to KWAZO. It consists of nine items: Accessibility, Knowledge, Information, Coordination, Efficiency (waiting times), User participation, Instruction, Follow-up services, Overall satisfaction. The questions are rated on a 5-point scale (1 = very dissatisfied to 5= very satisfied) plus a “don't know” option.
Assistive Technology Device Predisposition Assessment	ATD-PA	1	ATD-PA is part of the MPT model (Scherer, 1998); it involves a clinician-client collaborative process to evaluate the individual's predisposition to AT and facilitate user-device matching by taking into account the user' skills, task priorities, device preferences, and environmental support systems. The ATD-PA consists of two forms: the Person Form (54 items across three domains) and the Device Form (12 items).

The impact of assistive technology on the educational performance of students with hearing impairment: A rapid review of the research

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Abstract

This rapid review examined the research literature during the period 1998 to 2018 (20 years) on the impact of the assistive technology that is used by students with hearing impairment in the post-school sector. The authors located and reviewed 477 articles for evidence-based research on assistive technology that had an impact on educational performance and reported on these practices. Of the 20 studies that met all the inclusion criteria, only 7 provided promising evidence-based practices on the impact of assistive hearing technology.

Key words

Assistive (hearing) technology, hearing impairment, post-school, effectiveness, educational performance

Introduction and Background

According to the World Health Organization (1), assistive technology (AT) is used as an umbrella term which includes the systems and services related to the delivery of assistive products and services. The main goal for the use of an assistive product is to maintain or improve an individual's functioning and independence, and in this way, promoting their well-being and therefore their quality of life. Assistive technology 'enables people to live healthy, productive, independent and dignified lives, participating in education, the labour market and social life' (2) yet most people who need them are currently unable to access them. Examples of assistive products related to hearing loss would include hearing aids (including batteries), cochlear implants, assistive listening systems e.g. FM (frequency modulation) systems and induction loop systems, visual alerting devices etc.

The WHO reports that globally more than 1 billion people need 1 or more assistive products, with only 1 in 10 people in need having access. There is thus a huge unmet global need, for example, 466 million people globally (1) experience hearing loss but hearing aid production currently meets less than 10% of this global need. This has an impact on health, well-being

and socioeconomic benefits (3), for example, with the provision and proper use of hearing aids by young children, it leads to improved language skills, without which severely limits their opportunities for education and employment, and hence independence, and the ability to lead a quality, happy and fulfilled life. Hearing loss is the fourth highest cause of disability globally. Disabling hearing loss can be defined as a loss greater than 40 dB¹ in adults and 30 dB in children. Hearing loss is on the rise with WHO estimating that by 2050 more than 900 million people globally will have a hearing loss (4). A recent scoping review (5) explored the current evidence base on AT in resource limited settings and reported that over 80% of the available literature focuses on the types of AT that address mobility (45.2%) and vision (35.5%) needs, with the evidence on AT that addresses hearing, communication and cognition needs being the most underrepresented. There is also a paucity of evidence on AT provision in low- and middle-income countries (6).

Great progress has been made over the past twenty-five years with the enrolment numbers of students with a hearing impairment in postsecondary education increasing significantly. One American (7) reports significant progress for deaf and hard of hearing students, citing an increase in overall enrolments in postsecondary education from 50% to 73% between 1990 and 2005. This trend has continued in the USA and is globally relevant, however, the success of these students, in terms of graduation rates, is concerning. One study reported a 35% graduation rate in 2002 (8), and more recently a 53% graduation rate was reported with students earning a diploma or certificate from a 2- or 4-year college (7).

For centuries, technology has been used to provide persons with hearing impairments (that is, deaf or hard of hearing) enhanced opportunities in life. Over the past 50 years, assistive (hearing) technology for students with hearing impairment has seen great advancements, moving from body aids and large, analogue, linear hearing aids to digital superpower hearing aids and cochlear implants (9). These radical advancements have allowed some deaf children sufficient auditory access to acquire function spoken language, contributing to laying the groundwork for successful literacy and academic development, including post-school education (9). Fundamentally, assistive (hearing) technology has the potential to be the “great equalizer” for persons with disabilities (10) as it has the ability to reduce many of the barriers faced by persons with a hearing impairment. Two of the most significant barriers for students with hearing impairment is access to information and communication which are essential for success in education, as well as employment and life.

Existing literature in the primary school setting suggests that the acoustic environment of a classroom is an important variable in the psychoeducational and psychosocial development of children, indicating that inappropriate levels of classroom reverberation and/or noise can negatively affect speech perception, reading/spelling ability and academic achievement (11) – there is thus a need to provide an adequate and appropriate listening environment for all

¹ A unit used to measure the intensity of a sound or the power level of an electrical signal by comparing it with a given level on a logarithmic scale

students, even at college or university. The use of assistive hearing technology can help to mitigate these 'risks' and improve access to communication and information.

In this study, two broad questions were investigated and are presented below:

- What is the knowledge base regarding AT and the education of persons with a hearing impairment?
- To what extent has the field determined, through rigorous, scientific-based methods, the use and/or impact of AT for individuals with a hearing impairment?

Method

In the current study, a modified definition of AT was developed using the WHO definition previously presented. Furthermore, services rendered regarding selection and acquisition of AT has been excluded, with the primary focus of the study being the impact of AT in a post school education environment on performance. Therefore, the definition of AT used in this study pertains exclusively to the use of devices and does not include the services rendered in the use of assistive devices. Furthermore, the definition AT research was broadly regarded as studies examining the application and impact of AT in a 'class-room' (lecture-room) based educational setting.

Multiple means were used to search the literature for relevant research. Initially, a systematic search of four electronic databases were conducted using Boolean search methodology for literature pertaining to the use of AT by hearing impaired individuals from January 1998 to December 2018. Databases searched included EBSCO Academic Search Premier, ERIC, PsycArticles and ProQuest Education. In accordance with Boolean search methods the 'and operator was used to combine AT terms with hearing impairment terms. The specific search terms that were used in the electronic database search were *deaf, deafness, hearing impaired, hearing impairment, partial hearing, hard of hearing, hearing disorders, hearing disabilities and hearing loss* each **paired** with the terms *assistive technology, assistive hearing technology, assistive device, assistive product, hearing aids, cochlear implant/s, note taker, CART, CAN, real-time speech to text, induction loop system*.

In addition, a manual search was conducted for articles relating to assistive technology and hearing impairment in Google Scholar using the same search terms as above. Lastly, the reference list of articles meeting the inclusion criteria of the study were examined to identify any additional relevant articles. All articles were filtered according the indicated 20-year time span. The criterion was set to exclude out-dated, and irrelevant studies not pertaining to AT in hearing impaired individuals.

All studies were imported into the Covidence Systematic Review Manager (www.covidence.org), wherein a comprehensive review process was undertaken by the authors. Initial reviews were conducted based on the title and abstract of studies and required both reviewers to anonymously include or reject the study according to relevance with conflicts being resolved by mutual agreement. Subsequently, included articles were

reviewed in full text, according to the inclusion and exclusion criteria. See Table 1 for inclusion and exclusion criteria. Included studies then underwent data extraction and categorisation to present relevant data in a thematic manner.

Table 1. Inclusion and exclusion criteria

Inclusion	Exclusion
January 1998 – December 2018	Outside of specified time span of 20 years
Post-School education (college, university)	Primary and high school education; ABET
Exclusively hearing impaired/deaf/hard-of-hearing (using verbal communication)	Additional disability or Deaf (using sign language)
Assistive hearing technology e.g. hearing aid, assistive listening device, visual alerting device etc.	No mention of assistive hearing technology
Evidence based research	Non-empirical studies
Scientifically based research (peer-reviewed English journal articles)	Books, book chapters, non-peer-reviewed articles, grey literature

Results

The articles identified by this analysis covered 20 years of research pertaining to assistive hearing technology used by students with a hearing impairment in the post-school sector, without any additional disabilities. Of the articles located (n=477), 4 were removed due to duplication and 259 studies were found to be irrelevant. The remaining studies (n=214) were reviewed, with 28 studies being removed as they did not meet the inclusion criteria as described in Table 1.

The American psychologist Urie Bronfenbrenner, formulated the Ecological Systems Theory to explain how the inherent qualities of ‘children’ (people) and their environments interact to influence how they develop, in all aspects of their lives (12). The authors elected to characterize the remaining literature (n=186) according to a modified version of Bronfenbrenner’s ecological systems model, whereby, the individual and their environment is classified into the microsystem, mesosystem, and macrosystem. In this rapid review the micro-, meso- and macrosystems refer to the individual, the environment that they interact with and the environment external to their control respectively. See Table 2 for the thematic characterisation of the literature.

Table 2. Literature characterisation

Microsystem (n=93)	Mesosystem (n=74)	Macrosystem (n=19)
Language skills (n=39)	Post-school education (n=20)	Education and developmental facilitators (n=12)
Audiometric and clinical studies (n=27)	Parental and or Broader family (n=18)	Policy and practice (n=5)
Rehabilitation studies (n=10)	Interpersonal communication (n=15)	Curriculum development (n=2)
Literacy skills (n=9)	AT Installation and testing (n=9)	
Deaf Identity (n=3)	High school education (n=7)	
Musicality (n=2)	Primary school education (n=4)	
College and workplace readiness (n=2)	Participation in research (n=1)	
Knowledge acquisition (n=1)		

Of the 186 articles, 20 articles met the inclusion criteria. On further analysis, 13 of these were again excluded for one or more of the following reasons, as depicted in Table 3 below.

The articles listed in Table 3 above met all of the set inclusion criteria, but the full text analysis revealed a lack of focus on the ‘impact of assistive (hearing) technology on educational performance’ and were thus excluded. The reasons for the exclusion are also provided in the table.

The following 7 studies as listed in Table 4 below remained which met all of the inclusion criteria, and focused on the ‘impact of assistive (hearing) technology on educational performance’ and were thus included and thematically analysed.

These studies reveal how the limited current body of knowledge depicts the impact of hearing AT on the educational performance of students with a hearing impairment in the post-school sector.

Table 3. Articles that met the initial inclusion criteria, but were ultimately excluded

Authors	Year	Country	Title	Reason
Stinson, McKee & Elliot	2000	USA	Development and implementation of the C-Print Speech-to-Text Support Service	Narrative – technology development
DiSarno, Schowalter & Grassa	2002	USA	Classroom amplification to enhance student performance	School setting
Elliot, Foster & Stinson	2002	USA	Student study habits using notes from a Speech-to-Text support service	Use of printed notes from the speech-to-text technology
Marshark, Leigh, Sapere & Burnham	2006	USA	Benefits of Sign Language interpreting and text alternatives for Deaf students' classroom learning	Deaf (not oral) students
Wald	2006	UK	An exploration of the potential of Automatic Speech Recognition to assist and enable receptive communication in higher education	No empirical evidence
Kuzu	2011	Turkey	The factors that motivate and hinder students with hearing impairment to use mobile technology	Motivating and hindering factors re use of PDA (not impact)
Archbold & Mayer	2012	Global (Literature Review)	Deaf Education: the impact of cochlear implantation	School setting
Rekkendal	2012	Norway	Assistive hearing technologies among students with hearing impairment: factors that promote satisfaction	Children (not students) as participants
Cawthon & Leppo	2013	USA	Accommodations quality for students who are D/deaf or hard of hearing	Focus on effective accommodations use
Maiorana-Basas & Pagliano	2014	USA	Technology use among adults who are deaf and hard of hearing: a national survey	Focus on the needs, preferences, and accessibility of current Internet- and mobile-based technologies through a national survey
Cawthon, Leppo, Ge & Bond	2015	USA	Accommodations use patterns in high school and postsecondary settings for students who are D/deaf or hard of hearing	Use of accommodations e.g. extra time (not AT)
Ismail & Ibrahimi	2016	Morocco	Mobile learning as alternative to AT devices for special needs students	Comparison of smartphone apps
Griffin	2015	United Kingdom	Who uses closed captions? Not just deaf or hard of hearing.	Non-empirical study

Table 4. List of 7 studies that met all inclusion criteria

Authors	Country	Title	Objectives
(13)	USA	The benefit of real-time captioning and a mainstream classroom as measured by working memory	The goal of this study was to determine if real-time captions benefit both students with normal hearing and students who are deaf or hard of hearing, and if the format of the display affects working memory. Working memory was measured with an established test that has been shown to be sensitive to perception difficulty.
(14)	USA	College students' perceptions of the C-Print Speech-to-Text transcription System	To evaluate the C-Print system to determine its educational effectiveness and also limitations
(15)	USA	Higher education for deaf students: research priorities in the new millennium	Summarises relevant research and suggests directions for educational researchers interested in enhancing academic success and the retention of deaf students in higher education programs
(16)	Canada	Students with disabilities in distance education: characteristics, course enrolment and completion, and support services.	To describe the characteristics, enrolment, and completion rates of students with disabilities and the support services they received over a 3-year period (1998 and 2001)
(17)	USA	Predicting academic success among deaf college students	Aimed at determining predictors of the performance of DHH students in mainstream college classrooms.
(18)	USA	Deaf and hard-of-hearing students' memory of lectures with speech-to-text and interpreting/note taking services	<ol style="list-style-type: none"> 1. To determine whether students retained more information using speech-to-text or interpreter/notes support. 2. To determine whether students' review of text or notes for a lecture increased retention relative to only viewing the lecture. 3. To determine if retention with speech-to-text and interpreter support was related to whether sentence-completion or multiple-choice items were used 4. To determine the relative benefit of speech-to-text and interpreting support for high school and college students.
(19)	Global (literature review)	Technology intervention research with deaf and hard of hearing learners: levels of evidence	Authors evaluated the research base relative to technology use with DHH students, examining 29 peer-reviewed studies published 2000 to 2013 that used technology-based intervention (multimedia instructional applications/software) and investigating its effects on academic variables (academic skills used in instructional settings).

Discussion

Our review determined that only a limited number of articles have been published pertaining to the impact of assistive (hearing) technology, being used for class-room based educational intervention, for students who have a hearing impairment (without any additional disabilities) and who are studying in post-school programs at colleges and/or universities. It is important that specific assistive technologies that are used by students with a hearing impairment must provide clear benefits (such as a personal amplification device provides access to communication and information) or there must be scientific evidence that it will have a positive impact on student's learning and therefore their educational attainment. There were 9 articles that reported evaluations or reviews of products which were excluded. Many other studies focused on Deaf students that make use of sign language to communicate or were in a primary or secondary schooling setting. Furthermore, the existing broader knowledge base tends to focus on eight main areas related to deaf students: language skills ($n=39$), audiometric and clinical studies ($n=27$), parental and/or broader family issues ($n=18$), interpersonal communication ($n=18$), education and developmental facilitators perspectives ($n=12$), rehabilitative studies ($n=10$) and the installation/testing of assistive technology & literacy skills ($n=9$ each). Many of the studies also only provided anecdotal evidence, and although evidence that is developed through practice is important, it does not provide sufficient scientifically based evidence.

Some of the research designs of the articles listed in Tables 3 and 4 were limited to case or exploratory studies and did not provide sufficient data to determine the actual impact of the use of a particular assistive (hearing) technology. Most (58.3%) of the studies listed in Table 2 were based in the USA. One key reason for this could be that academics working at the Rochester Institute of Technology (RIT), in the USA, which has a college for deaf students publish regularly in the field of AT related to hearing loss.

Thematic analysis was used to synthesize the information related to a particular topic or data domain within the 12 included articles. There were 9 articles that reported evaluations or reviews of products which were excluded. The following two main themes emerged:

Academic Achievement

The review of research on deaf students in higher education by Lang (15) reports that a significant body of knowledge exists concerning the barriers that deaf students face in gaining access to information in the classroom, with much less been known about potential solutions. In this article findings indicate that there is a gap in the literature concerning the effectiveness of support services such as real-time captioning, especially related to the impact on academic achievement.

The study by Moisey (16) described the characteristics, enrolment and completion rates of students with disabilities and the support services that they received over a three-year period at Athabasca University in Canada, with 3% of the students included in the study having a hearing impairment. The services received included students receiving information

as well as assessments for AT. Common types of AT included the use of speech-to-text software. Overall the study found that students with disabilities, generally, who received more services had more success in terms of course completion i.e. accommodations (including the provision of AT) appeared to have a positive (but nonsignificant) effect on course completion. Of the 18 students with hearing disabilities, 12 (66.7%) completed one or more courses in which they were enrolled, and in this group, students received a higher than average number of support services. However, in an experimental study by Convertino, Marshark, Sapere, Sarchet & Zupan (17) which aimed at determining predictors of the performance of deaf and hard-of-hearing (DHH) students in mainstream college classrooms, they found that similar to the evidence described by Marschark, Rhoten and Fabich in 2007 (20) with regards to cochlear implants and academic achievement suggested that although implants clearly support early literacy and academic achievement for deaf children, the case for high school and college students has not been made. Furthermore, in this study, the locus of the consistent negative relation between hearing aid use and academic success also remains inconclusive.

Technology Interventions

In the past two decades the use and development of speech-to-text services as a support for deaf and hard-of-hearing students has steadily grown. This technology works as follows: an intermediary operator, who could be in the classroom or remotely located, produces text as it is spoken by a lecturer/teacher either using a stenographic machine, with automatic speech recognition, or with a QWERTY keyboard (18).

C-Print is one such example of a real time speech-to-text transcription system used as a support service with deaf students in mainstream classes. In a 2001 study (14) regarding college students' perceptions of this technology, it was found that (i) the software enhanced their educational experience, (ii) they were more confident about learning, and (iii) the study contributes to the emerging body of knowledge that software such as C-Print is an effective way of increasing accessibility to information. Students also reported that they used the notes from C-Print more frequently than handwritten notes from notetakers. Similarly, in a study by Steinfeld (13) findings indicate that real-time captioning produced improved performance for both hearing and non-hearing students, with a recommendation being made for the provision of four lines of captioning text to enhance academic performance. Griffin (21) also argues that captions benefit many at risk groups, including, for example, students who are deaf or hard of hearing. In contrast, however, in an investigation, conducted by Stinson, Elliot, Kelly & Liu in 2009 (18) with one objective being 'to determine the relative benefit of speech-to-text support for high school and college learners', the results pertaining to relative performance with the two approaches are consistent with previous research that indicates that real-time speech-to-text transcription and saved text, C-Print in particular, benefit deaf/hard-of-hearing students equally as much as note taker support. Moreover, Stinson and Walter (22) identified three social issues that

need to be addressed for students who are deaf to adjust effectively to higher education, one of which is 'acquiring independence' – the use of AT can serve an important role in this.

A 2014 literature review study (19) which examined the use of technology-based intervention and investigated its effects on academic variables such as academic skills, found that only a few studies satisfied the proposed quality indicators. This study argues for the need to increase the rigor and replication of effective and efficient intervention studies, particularly related to the use of AT, to increase positive academic outcomes for students who are deaf or hard of hearing.

Limitations

As with any type research, this study also had some innate limitations that should be mentioned. First, it was primarily a rapid (brief) review of the body of literature over a 20-year period. Its only purpose was to provide a snapshot of the evidence related to the impact of AT in the post-school sector. Second, the criteria that were established produced some limitations, such as not sufficiently guiding the thematic characterisation of the literature from the onset and requiring the researchers to recharacterize the literature according to an existing model. Thirdly, we selected studies focused on the post-school sector (college/university) thus excluding a wide range of research focussed on school-going age children. Also, the review included only peer-reviewed journals that are in English and that focused on oral students with a hearing loss in the post-school sector which gave rise to a smaller set of results.

Conclusion

The research that we identified is useful and valid. This limited body of literature speaks to the positive impact of the use of AT on educational outcomes for students studying at college or university. This brief review also highlights the great need to develop a body of scientifically based research in this field and hopefully will inspire current and future researchers. As pointed out by Harry Lang (15), 'it is especially important that researchers work toward finding solutions that lead to increased participation of deaf learners in the higher education classroom. Studies are needed that examine the relationship between academic achievement of participation by deaf learners and the use of assistive technology', such as developing a more comprehensive understanding of the benefits and limitations of educational technologies such as C-Print.

For students with a hearing impairment to be able to receive high-quality AT that will enhance their educational success, more concrete research on the impact (or effectiveness) of hearing AT needs to be conducted, especially as newer technologies emerge in this technological era. It was hoped that a more significant body of knowledge would exist that would make the case for access to quality, suitable assistive hearing technology, and that would serve to draw attention concerning the need for and benefit of assistive hearing technology, especially the return on investment, but due to the paucity in the research, this

was not possible. What is key, is that this important topic warrants much more investigation to provide evidence-based results to inform future policy and practice.

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The wheelchair user's voice: Preliminary results related to unmet need for assistive technology in Indonesia and El Salvador

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Abstract

Objective: To describe demographics across two LMIC countries and report outcomes related with mobility assistive technology received: health-related with wheelchair use, social integration, life satisfaction, quality of life, wheelchair skills, wheelchair use, as well as caregiver burden associated. **Design:** Report of baseline data collected in two studies in two LMICs. **Setting:** Three not-for-profit and two governmental organizations (one under the Ministry of Health and the other under the Ministry of Social Affairs) in Indonesia and El Salvador. **Participants:** A sample of manual wheelchair users with unmet need for mobility assistive technology, recruited from not-for-profit and governmental organizations in Indonesia and El Salvador. **Interventions:** Not applicable. **Main outcome measures:** Poverty Probability Index (PPI) for Indonesia and El Salvador, Social Integration subscale of the Craig Handicap Assessment and Reporting Technique (CHART), Life Satisfaction Questionnaire (LiSAT-11), abbreviated version of the WHO-QOL (Quality of Life) assessment tool (WHO-QOLBREF), Wheelchair Breakdown and Adverse Consequences Questionnaire (BAC-Q), wheelchair-related health (MIT-Health), Wheelchair Skills Test Questionnaire (WST-Q), self-reported wheelchair use, objective measures of speed and distance traveled, and measures of caregiver burden (Zarit Burden Interview). **Results:** Education attainment, employment, and poverty rates were poorer for participants in comparison to the general population in Indonesia and El Salvador (education attainment rate: 25%-58% vs 83% in Indonesia, and 18%-29% vs 60%-81% in El Salvador; employment rate: 17%-61% vs 66% in Indonesia, and 28% vs 61% in El Salvador; poverty rate: 10% vs 1.9% in El Salvador.) Other outcomes were similarly lower for participants in comparison to wheelchair users in resourced countries: Wheelchair skills (WST-Q-Capacity score, Means: 45%-66% vs 83%-88%), daily distance travelled (Means: 55-427 meters vs 1878-2457 meters), average speed (Means: 0.21-0.33 vs 0.79 meters per second), social integration (CHART, Means: 40-70 vs 93-95); life satisfaction (LiSAT-11, % that rated 4 or more: 63%-70% vs 87%-88%); and WHO-QOLBREF physical, psychological and environmental health domains in El Salvador (Means: 44 vs 67, 56 vs 70, and 44 vs 80, respectively). **Conclusions:** Wheelchair users in LMICs are more disadvantaged than the general population within their countries and then other wheelchair users living in

resourced countries. It is recommended that governments and not-for-profits follow international recommendations when providing wheelchairs as they have the potential to improve health and socioeconomic outcomes for wheelchair users in their regions. There is a need for more evidence about the benefits of providing wheelchairs following the WHO 8-Steps approach.

Keywords

Mobility assistive technology, outcome measures, low- and middle-income countries.

Introduction

Personal mobility refers to the ability to move around in a manner and at the time of one's choosing and is essential to the fulfillment of other human rights. Personal mobility increases access to education, work, family life, and healthcare, promoting health, social and economic inclusion – in sum – enriching people's lives (1).

A wheelchair is one of the most common Assistive Products (AP) used to increase personal mobility. Yet, according to the World Health Organization (WHO), only between 5 and 15% of the world population in need, have access to one, and very few have access to one that meets their unique needs (1). When the need for a wheelchair is not met, people with mobility limitations can become isolated and are left behind without access to opportunities their community members enjoy (1). In addition, the lack of access to wheelchairs increases the dependence on others, impacting individuals and family members (2, 3).

An appropriate wheelchair not only increases mobility levels and independence; when appropriately fitted, a wheelchair also promotes the user's overall health. Importantly, an appropriate wheelchair with seat cushion, fitted to the user's unique needs, can prevent the development of secondary medical conditions, such as pressure sores (4). Pressure sore prevention reduces health expenses, and the risk of premature death (5). In pediatric populations, the postural support provided by an appropriately fitted wheelchair can prevent orthopedic deformities and contractures, improve respiratory and digestive functions, and maximize head, trunk and arm control (6,7). The promotion of health and independence provided by an appropriate wheelchair has socioeconomic implications to the users and their families. When a person remains healthy and functional in a wheelchair, chances to access educational opportunities and paid employment increases, thereby promoting economic inclusion and social mobility (2).

To ensure that governments, private-entities, and not-for-profits distribute appropriate wheelchairs that lead to the desired impacts, WHO led the development of guidelines related to the design, production, supply and service delivery of manual wheelchairs (1), and standardized training packages to build wheelchair service capacity (WHO-WSTP) (3,4,7). According to these guidelines, in order to be effective and provide maximum benefits, a wheelchair should be 'appropriate'. This means it meets the user's physical, medical, and environmental needs and life style. It also means the wheelchair provides good postural

support and skin protection, is safe, durable, locally maintainable, and repairable (1). The 8-Steps associated with wheelchair service delivery include appointment and referral, assessment, prescription (selection), funding and ordering, wheelchair preparation, fitting, user training, maintenance/repair and follow-up (4,7).

Despite efforts to promote wheelchair service delivery through the 8-Steps process, the lack of outcomes evidence of this approach has led to a weak investment case and poor incentives for organizations to provide wheelchairs that would be considered 'appropriate' (8) through a service delivery approach that include the WHO recommended 8-Steps (1,4,7). Mixed evidence about the added value of using the 8-Steps approach versus a less intensive and less costly standard-of-care (no or unregulated service and product) suggest that wheelchairs have a positive impact on the quality of life, independence, mobility characteristics, employment status, and health of wheelchair users (9 -11); and that the degree to which services are provided increases that impact (12-14). However, due to limitations in the previous studies associated with the study design, such as the lack of control groups, cross-sectional methodology, or weakly validated measures, there is still a significant gap in evidence related to the impact of the 8-Steps service provision approach, versus the standard of care. This needed evidence is increasingly important to drive policy changes related to rehabilitation services and AT purchasing decisions.

For this reason, United Cerebral Palsy, Wheels for Humanity (UCPW) decided to carry out a study to investigate the short-term outcomes of wheelchair services and products that follow international standards as compared with the standard of care. The baseline demographics, health, social integration, life satisfaction, quality of life (QOL), wheelchair skills and mobility characteristics information presented in this manuscript, are part of this larger original research which is funded by the Google Foundation, grant #322068, designed by the Comprehensive Initiative on Technology Evaluation (CITE) from the Massachusetts Institute of Technology (MIT) and the University of Pittsburgh (U-Pitt), and managed by UCPW.

Methods

Pilot phase

A quasi-experimental pilot phase implemented in 2017, evaluated the impact of wheelchair service provision from two wheelchair providers in Indonesia: Puspadi Bali Foundation (PBF) and the Department of Social Affairs (DSA). PBF provided six different models of ISO-certified wheelchairs using the 8-Steps service provision model described in the WHO guidelines (1), whereas the DSA used the standard-of-care where they distributed hospital-style wheelchairs to those who requested them without associated services recommended in the WHO 8-Steps.

The Comprehensive Initiative on Technology Evaluation, at MIT designed the pilot study and supported in-country data collection, and the Center for Health Policy and Management

(CHPM), Gadjah Mada University (UGM), led the data collection efforts in Indonesia. Both secured ethical approval.

150 persons 16 years or older with ability to interact and communicate independently, who had unmet mobility needs were identified from PBF and DSA waitlists, and recruited. Unmet need was defined as those in need of a wheelchair because they did not have one, or because the wheelchair owned was not appropriate. The sample size was limited by the size of the waitlist, budget and logistical constraints.

Data was collected from the subjects through in-person interviews at baseline and again 3 months after having received a wheelchair. The interview protocol included a set of seven adapted standardized questionnaires and open-ended questions about the impact of wheelchair use on health, Quality of Life (QOL), independence, and social and economic status. Standardized questionnaires included the International Society of Wheelchair Professionals (ISWP) Minimum Uniform Data Set (MUD) (15), Wheelchair Skills Test Questionnaire (WST-Q) (16), Poverty Probability Index (PPI) for Indonesia (17), Craig Handicap Assessment and Reporting Technique (CHART) (18), Life Satisfaction Questionnaire (LiSAT-11) (19), Wheelchair Breakdown and Adverse Consequences Questionnaire (BAC-Q) (20), and a wheelchair-related health questionnaire developed for this study by the MIT (MIT-Health). All questions were translated to Bahasa and revised for cultural appropriateness by CHPM-UGM team.

A device to measure, log, and transmit wheelchair use data developed by Sensen Inc. was adapted to collect daily distance traveled and speed, and modified for installation on the spokes of each new wheelchair provided (see Figure 1).

Figure 1. Numerator installing and configuring data-logger in participant's wheelchair.



Full-study phase

The full study, still underway at the time of writing, in El Salvador will conclude in November 2019 and employs a within-subjects longitudinal study design. In El Salvador a control group was not ethically feasible. Three wheelchair providers participated, the Asociación Pro-Rehabilitación Teleton (FUNTER), the Salvadorian Institute of Social Security (ISSS), and the UCPW field office in El Salvador (UCP-ES). Three models of ISO-certified wheelchairs were provided following the WHO 8-Steps approach.

The University of El Salvador (UES) led in-country data collection, both UES and U-Pitt secured ethical approval.

In El Salvador, as in Indonesia, individuals with unmet mobility needs were identified, however, only users 18 years or older were recruited, and the use of a proxy to answer the interview questions was allowed. The target sample size was 300 wheelchair users based on power analysis.

Data was collected at four timepoints: at the time of assessment (baseline), at the time of wheelchair delivery (2 months after assessment), 3 months after delivery, and 6 months after delivery. The interview protocol included the ISWP-MUD, WST-Q, PPI for El Salvador, CHART-Social Integration domain, BAC-Q, MIT-Health, and the abbreviated version of the WHO-QOL assessment tool (WHO-QOLBREF) (21). Measures of caregiver burden (Zarit Burden Interview) (22) and Activities of Daily Living (ADL) performance (12), as reported by caregivers, were also included. Objective measures of speed and distance traveled were measured using the same Sensen data-loggers.

Data Analysis

Descriptive statistics are used to report demographics and questionnaire results for study participants at baseline alone. A comparative evaluation of outcomes obtained after providing a wheelchair following WHO guidelines will be published in a forthcoming manuscript.

For continuous variables, measures of central tendency and variability are reported in terms of Mean (\pm Standard Deviation) or Median (Interquartile Range, Range). For categorical variables, the frequency and percentages of the total sample will be reported.

Data from Indonesian participants is presented by group of wheelchair provider (PBF or DSA), whereas data from Salvadorian participants is presented combining all wheelchair providers in a single group.

Scores and sub scores of standardized questionnaires were computed as indicated in the scoring procedures for each of the questionnaires. For instance, to calculate likelihood for living below National and USAID "Extreme" Poverty Lines for the group of households interviewed, the individual PPI score for each participant was obtained and transformed to likelihood rate using the PPI lookup tables, then the average likelihood rate was computed for all households' poverty. WHO-QOLBREF domain raw scores were converted to a range

between 4-20. LiSAT-11 did not included the question about satisfaction with sexual life as it was considered culturally inappropriate. Therefore, only 10 questions were asked and the score was computed for these 10 questions alone. ADL performance with bathing, dressing, toileting, and eating was analyzed as in (12).

Where individual standardized questionnaires missed more than 20% of data, the individual assessment was discarded.

Descriptive statistics were performed using SPSS software version 25 (SPSS, Inc., Chicago, IL, USA).

Results

In the Indonesia pilot study, a total of 142 participants were included in the data analysis. 118 participants came from PBF and 24 from the DSA. In El Salvador (ES), a total of 235 participants were included in data analysis.

Demographics

Table 1. Participants demographics.

Categories	PBF (Indonesia) N=118	DSA (Indonesia) N=24	ES (El Salvador) N=235
Age, years mean (\pm SD)	40.1 (\pm 12.6)	58.3 (\pm 15.1)	55.1 (\pm 19.5)
Female, % (n)	30.5% (n=36)	16.7% (n=4)	37.0% (n=87)
Marital status, % (n)			
Married	44.1% (n=52)	66.7% (n=16)	45.5% (n=107) ^a
Unmarried or divorced	52.5% (n=62)	8.4% (n=2)	
Widow	3.4% (n=4)	25.0% (n=6)	
Education level, % (n)			
None	20.3% (n=24)	16.7% (n=4)	17.9% (n=42)
Some Primary School	8.5% (n=10)	41.7% (n=10)	28.5% (n=67) ^b
Complete Primary School	27.1% (n=32)	16.7% (n=4)	--
Some Secondary School	--	8.3% (n=2)	18.3% (n=43) ^c
Complete Secondary School	17.8% (n=21)	8.3% (n=2)	--
Some High School	1.7% (n=2)	--	2.1% (n=5)
Complete High School	17.8% (n=21)	8.3% (n=2)	17.9% (n=42)
Completed beyond High School	5.9% (n=7)	--	11.9% (n=36)
Completed technical education	0.8% (n=1)	--	3.0% (n=7)
Employment status, % (n)			
Employed (include all: employee, self-employed, part-time and full time)	61.0% (n=72)	16.7% (n=4)	27.7% (n=65)
Unemployed	--	--	56.6% (n=133)
Homemakers of full-time parents	--	--	13.2% (n=31)
Students	--	--	2.6% (n=6)

Categories	PBF (Indonesia) N=118	DSA (Indonesia) N=24	ES (El Salvador) N=235
Employed part-time (either self-employed or employed)	--	--	9.0% (n=21)
Employed full-time (either self-employed or employed)	--	--	18.7% (n=44)
% of households living below the National Poverty Line (average PPI transformed scores)	5.8%	10.3%	27.4%
% of households living below the USAID "Extreme" Poverty Line (average PPI transformed scores)	1.9%	4.0%	10.0%
Conditions that caused the need for mobility AT, % (n)			
Polio	51.7% (n=61)	--	3.4% (n=8)
Spinal cord injury	18.6% (n=22)	16.7% (n=4)	24.7% (n=58)
Cerebral palsy	4.2% (n=5)	--	2.6% (n=6)
Stroke	0.8% (n=1)	37.5% (n=9)	5.1% (n=12)
Muscular dystrophy	2.5% (n=3)	4.2% (n=1)	0.4% (n=1)
Osteogenesis imperfecta	2.5% (n=3)	4.2% (n=1)	0.4% (n=1)
Amputation	1.7% (n=2)	--	25.5% (n=60)
Aging process or weakness	--	--	7.7% (n=18)
Injury	--	--	6.4% (n=15)
Brain injury	0.8% (n=1)	--	4.7% (n=11)
Rheumatoid arthritis	--	--	3.8% (n=9)
Other conditions (spina bifida, multiple sclerosis, etc.)	17.8% (n=21)	37.5% (n=9)	15.3% (n=36)

Notes: ^a Reported living with spouse or significant other. ^b Includes participants that completed between first and sixth grade. ^c Includes participants that completed between seventh and ninth grade. -- No answers were reported, or question not included in the interview protocol. SD= Standard deviation, AT= Assistive Technology

Mobility assistive technology

Table 2. Characteristics of mobility assistive technology owned by participants before the study.

Characteristics	PBF (Indonesia) (N=118)	DSA (Indonesia) (N=24)	ES (El Salvador) (N=235)
Mobility products owned at baseline, % (n)			
Manual wheelchair	87.3% (n=103) ^a	33.3% (n=8) ^b	71.4% (n=168) ^c
Hospital-style	--	--	54.2% (n=91)
Standard	--	--	29.2% (n=49)
Active (rigid or folding)	--	--	7.1% (n=12)
Power wheelchair	7.6% (n=9)	--	2.1% (n=5)
Homemade device	2.5% (n=3)	--	0.8% (n=2)
Walking aid	25.4% (n=30)	41.7% (n=10)	37.4% (n=88)
No mobility aid	2.5% (n=3)	33.3% (n=8)	9.7% (n=23)
No seat cushion	--	--	49.4% (n=83)
Pillow or other homemade	--	--	18.5% (n=31)
Foam cushion	--	--	18.5% (n=31)
Pressure relief cushion	--	--	13.7% (n=23)
Discussed wheelchair options with wheelchair provider in the past and received training on how to use it, % (n)	50.0% (n=59)	25.0% (n=2)	12.5% (n=21) ^d
Satisfaction with wheelchair, % (n)			
“Very dissatisfied” or “Dissatisfied”	7.8% (n=8)	0.0% (n=0)	27.4% (n=46)
“Neither satisfied nor dissatisfied”	16.5% (n=17)	37.5% (n=3)	33.9% (n=57)
“Satisfied” or “Very satisfied”	75.7% (n=78)	62.5% (n=5)	38.7% (n=65)
Does not fit their body well, % (n)	18.4% (n=19)	37.5% (n=3)	45.8% (n=77)
Does not support them to sit up, % (n)	--	--	25.6% (n=43)
How did the wheelchair was obtained?, % (n)			
From a friend or acquaintance	--	--	41.1% (n=69)
From a charitable or religious organization	--	--	16.0% (n=27)
Bought it at a drug store or medical supply storage	--	--	18.5% (n=31)
From a hospital or clinic	--	--	16.6% (n=28)
Had a wheelchair in the past if not currently have one, % (n)	60.0% (n=9) ^e	0.0% (n=16)	--

Notes: ^a 69.0% (n=71) had owned it for more than 4 years. ^b 50.0% (n=4) had owned it for more than 4 years. ^c Had owned their wheelchairs for around 4.8 (4.0, 30.0) years. ^d Of these participants, 42.9% (n=9) received the wheelchair from a charitable organization, 28.6% (n=6) from a hospital or clinic, and 19.0% (n=4) from the government. ^e Had been without a wheelchair between 8 months to 26 years; -- No answers were reported, or question not included in the interview protocol.

Life satisfaction, quality of life and social integration

Table 3. Life satisfaction, Quality of life (QOL) and Social integration of study participants

Categories	PBF (Indonesia)	DSA (Indonesia)	ES (El Salvador)
LiSAT-11, median (IQR, R) ^{a,*}	4.5 (0.9, 3.2), (n=95), (missing=23)	4.6 (1.5, 2.6), (n=16), (missing=8)	--, (n=224) (missing=11)
WHO-QOLBREF			
"How do you rate your quality of life", mean (\pm SD), median (IQR, R) ^{b,*}	--	--	2.8 (\pm 1.1), 3.0 (1.0, 4.0)
"Very poor" or "Poor", % (n)	--	--	44.6% (n=99)
"Neither poor nor good", % (n)	--	--	31.1% (n=69)
"Good" or "Very good", % (n)	--	--	24.3% (n=54)
"How satisfied are you with your health?", median (IQR, R) ^{b,*}	--	--	2.8 (\pm 1.1) 3.0 (2.0, 4.0)
"Very dissatisfied" or "Dissatisfied", % (n)	--	--	41.5% (n=93)
"Neither satisfied nor dissatisfied", % (n)	--	--	32.1% (n=72)
"Satisfied" or "Very satisfied", % (n)	--	--	26.4% (n=59)
QOL Domains ^{c,*}			
Physical health, mean (\pm SD), median (IQR, R)	--	--	11.7 (\pm 3.3), 11.4 (4.6, 15.3)
Psychological, mean (\pm SD), median (IQR, R)	--	--	13.3 (\pm 3.1), 13.3 (4.7, 14.7)
Social relationships, mean (\pm SD), median (IQR, R)	--	--	14.7 (\pm 3.7), 16.0 (6.0, 16.0)
Environment, mean (\pm SD), median (IQR, R)	--	--	11.8 (\pm 2.6), 11.8 (2.9, 12.6)
CHART - Social integration mean (\pm SD), median (IQR, R) ^{d,*}	69.6 (\pm 28.4), 75.0 (49.3, 100.0), (N=118)	39.8 (\pm 25.7), 37.5 (36.3, 100.0), (N=24)	69.8 (\pm 32.7), 83.0 (57.0, 100.0), (N=235)

Notes: * Higher score more favorable. ^a Score range: 1 to 6. Sex life question removed. ^b Score range: 1 to 5. ^c Score range: 4 to 20. ^d Score range: 0 to 100. ^e Just asked to those who reported having a wheelchair at baseline. ^f In the previous year. ^g In the previous 3 months. -- No answers were reported, or question not included in the interview protocol. SD= Standard deviation, IQR= Interquartile Range, R= Range.

Wheelchair use, skills and mobility characteristics

Table 4. Self-reported wheelchair use

Categories	PBF (Indonesia) (n=103)	DSA (Indonesia) (n=8)	ES (El Salvador) (n=168)
Days per week			
Less than 1, % (n)	2.9% (n=3)	12.5% (n=1)	--
1 – 3 days, % (n)	8.7% (n=9)	--	--
4 – 6 days, % (n)	2.9% (n=3)	12.5% (n=1)	--
7 days, % (n)	85.4% (n=88)	75.0% (n=6)	--
Hours per day			
Less than 1 hours, % (n)	3.9% (n=4)	25.0% (n=2)	--
1 – 3 hours, % (n)	27.2% (n=28)	--	--
4 – 6 hours, % (n)	12.6% (n=13)	37.5% (n=3)	--
7 – 8 hours, % (n)	3.9% (n=4)	12.5% (n=1)	--
More than 8 hours, % (n)	52.4% (n=54)	25.0% (n=2)	--
Daily distance travel			
Less than 100 meters, % (n)	38.8% (n=40)	75.0% (n=6)	--
Between 100 and 500 meters, % (n)	35.0% (n=36)	12.5% (n=1)	--
Between 501 m and 1 km, % (n)	15.5% (n=16)	12.5% (n=1)	62.5% (n=105) ^a
Between 1 and 5 km, % (n)	8.7% (n=9)	--	32.1% (n=54)
More than 5 km, % (n)	1.0% (n=2)	--	5.4% (n=9)
Locations of wheelchair use			
Home, % (n)	90.3% (n=93)	87.5% (n=7)	92.3% (n=155)
School, % (n)	9.7% (n=10)	--	2.9% (n=5) ^b
Work, % (n)	33.0% (n=34)	12.5% (n=1)	25.0% (n=42) ^c
Other public places, % (n)	66.0% (n=68)	37.5% (n=3)	94.6% (n=159)
Outdoors in rough surfaces, % (n)	51.5% (n=53)	37.5% (n=3)	--
Sports, % (n)	20.4% (n=21)	25.0% (n=2)	--
Leisure, % (n)	38.8% (n=40)	37.5% (n=3)	--
Transportation, % (n)	13.6% (n=14)	12.5% (n=1)	--
To move from place to place, % (n)	--	--	95.8% (n=161)

Notes: ^a Reported traveled less than 1 km. ^b Includes only 6 participants attending school who had a wheelchair. ^c Includes only 53 participants working who had a wheelchair. -- No answers were reported, or question not included in the interview protocol.

Table 5. Self-reported wheelchair skills

WST-Q Categories	PBF (Indonesia) (n=100) (missing=3)	DSA (Indonesia) (n=6) (missing=2)	ES (El Salvador) (n=165) (missing=3)
Total Capacity Score, % mean (\pm SD)	66.1 (\pm 17.9)	48.0 (\pm 36.9)	44.7 (\pm 27.4)
Total Capacity Score, % median (IQR, R) ^a	67.5 (21.8, 78.0)	66.0 (73.5, 81.0)	46.9 (40.7, 100.0)
Number of basic skills performed, of 10 ^b	9 (2, 6)	9 (10, 10)	8 (6, 10)
Number of intermediate skills performed, of 12 ^b	10 (5, 10)	11 (11, 12)	4 (7, 12)
Number of advanced skills performed, of 10 ^b	1 (3, 9)	1 (3, 5)	0 (1, 10)

Notes: ^aScore range: 0% to 100%. ^bIncludes skills reported as “Yes” in the WST-Q, median (IQR, R). SD= Standard deviation, IQR= Interquartile Range, R= Range.

Participants with no wheelchair at the beginning of the study or less than 7 days of data logging with sensors were not included.

Table 6. Mobility characteristics measures with Data-loggers

Characteristics	PBF (Indonesia) ^a (n=76)	DSA (Indonesia) ^a (n=20)	ES (El Salvador) ^b (n=101)
Days of data recorded, mean (\pm SD)	51.8 (\pm 42.3)	49.7 (\pm 20.4)	26.8 (\pm 10.3)
Days of data recorded, median (IQR, R)	39.4 (32.3, 180.5)	46.4 (32.7, 69.7)	27.1 (16.4, 45.0)
Average daily distance (in meters), mean (\pm SD)	426.6 (\pm 615.6)	54.5 (\pm 84.0)	328.5 (\pm 516.7)
Average daily distance (in meters), median (IQR, R)	208.2 (510.5, 3705.5)	15.1(52.5, 284)	165.7 (362.4, 3609.0)
Average Speed (in m/s) mean (\pm SD)	0.29 (\pm 0.14)	0.21 (\pm 0.11)	0.33 (\pm 0.22)
Average Speed (in m/s) median (IQR, R)	0.27 (0.21, 0.57)	0.19 (0.10, 0.46)	0.27 (0.29, 1.01)

Notes: ^a DLs were attached to new study wheelchairs in the delivery day. PBF group received a wheelchair through WHO 8-Steps service whereas DSA group received wheelchair through standard-of-care. ^b DLs were attached to the previously owned wheelchairs in the assessment day. SD= Standard deviation, IQR= Interquartile Range, R= Range.

Health related with wheelchair use

Table 7. Wheelchair-related injuries

Injuries in the past 3 months	PBF (Indonesia) (n=103)	DSA (Indonesia) (n=8)	ES (El Salvador) (n=168)
Pressure sores			
Have had pressure sores, % (n)	11.7% (n=12)	12.5% (n=1)	11.9% (n=28)
In the buttocks, % (n)	58.3% (n=7)	--	75.0% (n=21)
Had consequences, % (n)	66.7% (n=8)	0.0% (n=0)	39.3% (n=11)
Sought medical care for this issue, % (n)	33.3% (n=4)	--	71.4% (n=20)
Falls during transfers			
Have fallen during transfers, % (n)	16.5% (n=17)	0.0% (n=0)	54.0 (32.1%)
Had consequences, % (n)	29.4% (n=5)	--	100.0% (n=54)
Sought medical care for this issue, % (n)	5.6% (n=1)	--	13.0% (n=7)
Falls during wheelchair riding			
Have fallen during wheelchair riding, % (n)	15.5% (n=16)	12.5% (n=1)	20.8% (n=35)
Had consequences, % (n)	25.0% (n=4)	0.0% (n=0)	100.0% (n=54)
Sought medical care for this issue, % (n)	12.5% (n=2)	--	17.0% (n=6)
Upper extremities injuries or pain			
Have had upper extremities injuries or pain, % (n)	40.8% (n=42)	12.5% (n=1)	23.8% (n=40)
Had consequences, % (n)	19.0% (n=8)	0.0% (n=0)	11.0 (27.5%)
Sought medical care for this issue, % (n)	9.5% (n=4)	--	17.0 (42.5%)
Hand wounds			
Have had hand wounds on the brakes or spokes, % (n)	9.7% (n=10)	0.0% (n=0)	22.6% (n=38)
Sought medical care for this issue, % (n)	10.0% (n=1)	--	5.3% (n=2)
Back pain			
Have had back pain, % (n)	48.5% (n=50)	25.0% (n=8)	57.1% (n=96)
Sought medical care for this issue, % (n)	14.0% (n=7)	0.0% (n=0)	45.8% (n=44)

Notes: -- No answers were reported, or question not included in the interview protocol.

Consequences of pressure sores among participants included being stranded in bed, missing work or school, having an infection, or having surgery because of the pressure sore.

Commonly reported causes of falls during transfers were carelessness or accident, loss of balance, malfunction of the wheelchair, inappropriate transfer technique, weakness or dizziness, other cause such as inaccessible bathroom. Most common consequences of these

falls were mild to severe pain and bruises. Only a few reported broken bones and being stranded at home. Types and consequences of falls during wheelchair riding were similar of those caused by falls during transfers.

Pain in the upper extremities, followed by bruising, swelling, fatigue, and muscle strain were the most cited problems reported.

On the other hand, of those participants with back pain, many indicated that pain began one year or less after wheelchair use. Primary causes of back pain identified by participants include sitting too long in the wheelchair, their body position in the wheelchair, their medical condition, the wheelchair it-self, and the cushion and the backrest.

Table 8. Healthcare utilization and related cost

Categories	PBF (Indonesia) (N=118)	DSA (Indonesia) (N=24)	ES (El Salvador) (N=235)
Doctor visits			
Between 1 and 12 times per year, % (n)	52.5% (n=62)	50.0% (n=12)	--
More than 12 times per year, % (n)	4.2% (n=5)	16.7% (n=4)	--
Once a month, % (n)	--	--	23.8% (n=56)
Once or twice per month, % (n)	--	--	29.4% (n=69)
More than once a month, % (n)	--	--	23.4% (n=55)
None, % (n)	43.2% (n=51)	33.3% (n=8)	23.4% (n=55)
Reported health expenditure in the last year			
Less than 19 USD, % (n)	33.9% (n=40)	12.5% (n=3)	--
Between 19 and 75 USD, % (n)	15.2% (n=18)	16.7% (n=4)	--
More than 75 USD, % (n)	6.8% (n=8)	12.5% (n=3)	--
Less than 500 USD, % (n)	--	--	52.3% (n=123)
Between 501 and 1,000 USD, % (n)	--	--	9.4% (n=22)
More than 1,000 USD, % (n)	--	--	7.9% (n=19)
None, % (n)	44.1% (n=52)	58.3% (n=14)	29.8% (n=70)

Notes: -- No answers were reported, or question not included in the interview protocol.

Assistance and independence

Table 9. Levels of required assistance from others

Levels	PBF (Indonesia) (N=118)	DSA (Indonesia) (N=24)	ES (El Salvador) (N=235)
Independence			
Have someone helping while indoors, % (n)	56.8% (n=67)	95.8% (n=23)	77.9% (n=183)
Have someone helping while outdoors, % (n)	72.9% (n=86)	75.0% (n=18)	83.0% (n=195)
Difficulty moving short distance such as 100 m			
No difficulty, % (n)	--	--	1.3% (n=3)
Some difficulty, % (n)	--	--	3.4% (n=8)
A lot of difficulty, % (n)	--	--	32.8% (n=77)
Severe difficulty, % (n)	--	--	62.6% (n=147)
Difficulty moving long distance such as 1km			
None, % (n)	27.1% (n=32)	--	--
Mild to moderate, % (n)	27.9% (n=33)	33.3% (n=8)	--
Severe to extreme, % (n)	33.0% (n=39)	58.3% (n=14)	--
Can enter or exit home without assistance, % (n)	60.2% (n=71)	29.2% (n=7)	--
Hours of assistance for ADLs in a typical day, median (IQR,R)	0.0 (1.0, 30.0)	1.0 (3.0, 10.0)	--
Hours of assistance for Instrumental ADLs in a typical month ^a , median (IQR,R)	1.0 (30.0, 360)	2.0 (12.5, 151.0)	--

Notes: ^a Include grocery shopping, laundry, housekeeping, managing medicines, etc. IQR= Interquartile Range, R= Range. -- No answers were reported, or question not included in the interview protocol.

Caregiver burden (Zarit Burden Interview)

94 caregivers were included in the study of which only two (2.1%) received care-taking payment. 56.4% (n=53) of the caregivers were unemployed, students or homemakers, 24.4% (n=23) were part-time employees, and 19.1% (n=18) were employed full time. 4.3% (n=4) reported less than 10 hours of care provided per week, 5.3% (n=5) between 10 and 20, 13.8% (n=13) between 20 and 40, 16% (n=15) between 40 and 60, 12.8% (n=12) between 60 and 80, and 46.8% (n=44) reported to provide more than 80 hours of care per week.

In terms of caregiver burden, only 92 (96.8%) of the participants were included in the analysis due to missing data.

Table 10. Zarit Burden Interview (ZBI) global and domain scores for ES group.

ZBI global and domain scores	ES (El Salvador) (n=92)
ZBI global score mean (\pm SD)	27.8 (\pm 13.2)
ZBI global score median (IQR, R) ^a	25.5 (17.9, 60.7)
Burden in the relationship” domain ^b mean (\pm SD)	9.3 (\pm 4.2)
Burden in the relationship” domain ^b median (IQR, R)	9.0 (6.8, 19.9)
“Emotional well-being” domain ^c mean (\pm SD)	6.8 (\pm 4.7)
“Emotional well-being” domain ^c median (IQR, R)	6.0 (5.0, 23.0)
“Social and family life” domain ^d mean (\pm SD)	2.7 (\pm 3.2)
“Social and family life” domain ^d median (IQR, R)	2.0 (5.0, 14.0)
“Finances” domain ^e mean (\pm SD)	2.8 (\pm 1.4)
“Finances” domain ^e median (IQR, R)	3.0 (2.0, 4.9)
“Loss of control over one’s life” domain ^f mean (\pm SD)	5.9 (\pm 2.9)
“Loss of control over one’s life” domain ^f median (IQR, R)	6.0 (3.9, 13.2)

Notes: ^a Tool range is 0 to 88, lower score more favorable. ^b Domain range:0-24. ^c Domain range is 0-28. ^d Domain range is 0-16. ^e Domain range is 0-4. ^f Domain range is 0-16. SD= Standard deviation, IQR= Interquartile Range, R= Range.

Assistance with Activities of Daily Living (ADLs) in El Salvador group

The following table shows the number and percentage of participants that required none, some or complete assistance with ADLs (bathing, dressing, toileting, and eating). Only participants who reported having a caregiver at the beginning of the study were included in the analysis (n=94).

Table 11. Frequency of assistance for ADLs for ES participants (n=94)

ADL	No assistance (n; %)	Some assistance (n; %)	Complete assistance (n; %)	Total that required any assistance (n; %)
Bathing	36; 38.3%	27; 28.7%	31; 33.0%	58; 61.7%
Dressing	42; 44.7%	26; 27.7%	26; 27.7%	52; 55.4%
Toileting	34; 36.2%	35; 37.2%	25; 26.6%	60; 63.8%
Eating	80; 85.1%	4; 4.3%	10; 10.6%	14; 14.9%

35 (37.2%) caregivers reported providing assistance for one or less ADLs (high ADL performance by the participant), whereas 59 (52.8%) reported providing assistance for two or more ADLs (low ADL performance by the participant.)

Limitations

During the implementation of this two-phase study, different factors may have impacted the results presented. Firstly, in Indonesia, individuals from the PBF and the DSA groups were significantly different in age ($p=0.001$), which limited comparison between the two groups.

Second, the use of standardized questionnaires that had not been previously validated in Indonesian languages. Although many efforts were made to accurately translate the questionnaires into Bahasa, these were neither back-translated to English nor validated in Bahasa. In addition, there were some participants who spoke Balinese and therefore, the data collectors had to directly translate the Bahasa questions to them, potentially affecting the quality of the data. Unlike in Indonesia, in El Salvador, many of the standardized questionnaires used had been previously validated in Spanish or extensively used in other studies. To mitigate the above limitations, local research teams in Indonesia and El Salvador led data collection. Data collectors revised all questions before the study to clarify confusing questions and answer options. Study staff received training on research design, data collection tools, good practices in human studies research and ethical considerations. Ongoing confusion regarding questions was addressed in weekly meetings.

Socioeconomic aspects of disability are complex and difficult to measure, not only due to a lack of validated outcome measures, but because of prevailing stereotypes. Data collector biases and lack of familiarity with mobility limitation and poverty led to their discomfort asking participants and caregivers personal questions about emotional health, quality of life, or socioeconomic status. We conclude that within research there exists a significant need for training on cultural competency focused on the experience of living with a disability in poverty. The participation of people with disabilities as members of the research team is highly recommended to interview study participants to bridge this divide and support data accuracy.

Wheelchair provision is still considered an act of kindness from the government or not-for-profit organizations, rather than a right entitled by people with disabilities. This operating principle may have inhibited study participants from expressing their thoughts and satisfaction with the products and services received as complaining could be considered inconsiderate. This highlights the importance of empowering wheelchair users to know their rights, in order to drive demand for improved products and services.

Discussion

Social and economic indicators of people with mobility limitation as compared with the general population

People with mobility limitations in LMICs face formidable barriers to accessing appropriate wheelchairs. This may contribute to poor outcomes in function, independence, and participation, resulting in lower socioeconomic status. Socioeconomic factors in turn prevent people with mobility limitations from accessing an appropriate AP. For example, households with a member with disability have lower monthly incomes and thus a shortage of personal finances to afford a wheelchair (23). People with disabilities also tend to have less access to public services such as medical and rehabilitation services, education, and public transportation (11).

Although not directly linked with mobility limitation, as the age of disability onset was not recorded, educational attainment of study participants from Indonesia was lower than that of people without disabilities in the same country. According to the Indonesian National Social and Economic Survey (Susenas) 2012, about 83.0% of people without a disability between 5- and 17-years old attended school in Indonesia (24). In this study, only 35.6% to 58.4% completed some or all primary education, and 24.9% to 37.3% completed between secondary and high school (similar to the national prevalence of people with disabilities attending school) (24). In the same year, 38.0% of people with disabilities and 66.0% of people without disabilities in Indonesia participated in the labor market (24). The PBF group had greater employment rate (61.0%) than the DSA group (16.7%) probably due to differences in the severity of disability and age. In addition, according to the World Bank, in 2017, 10.6% and 5.7% of the population in Indonesia lived below the national and the international poverty lines, respectively (25). In this study, PBF participants had lower poverty rates than the general population (5.8% and 1.9%, respectively), probably due to the high employment rate reported by PBF participants in this study.

According to UNESCO, 81% of children in El Salvador were enrolled in primary education, 60% in secondary education, and only about 29% advanced to tertiary education in 2017 (26). Participants from ES group had attained lower levels of education than the general Salvadorian population: 29% completed some primary education, 18% some secondary education, and 20% some or complete high school. Unlike Indonesia, the unemployment rate for the ES group was lower than that of the general population. Only 28% reported participating in the labor market in contrast with the 61% of the rest of the country (27). Furthermore, 27% and 10% of the ES households interviewed were living below the national and international poverty lines respectively, in comparison with the 29% and 2% of the general population for the same poverty indicators (28), which may be related to low employment rates reported by this group.

Access to Assistive Technology

As both the pilot and full studies specifically recruited participants with unmet mobility assistive technology needs, the prevalence of participants without a manual wheelchair at baseline were high (87%, 33%, and 71%). Research funded by the Australian government for the improvement of evidence-based economic policy in Indonesia (24), reported an unmet need for wheelchairs between 11% and 25% depending on the medical condition. Between 40% to 100% of Indonesian participants without a wheelchair in our study had never had a wheelchair before. Of those who had a wheelchair previously, only 25% to 50% discussed wheelchair options with, or received training from, the provider. For ES group, 81% did not receive support from a wheelchair provider, 54% had a hospital style (which is not appropriate for long term use), 49% had no skin protection at all, and 19% had a pillow as a seat cushion. All these factors may have a relation with the high rates of improper fitting and body support, and the low mobility skills, ADL performance, and wheelchair use (discussed below) reported by the participants and supported by literature that wheelchair

users who are provided a wheelchair and training from an expert therapist, use their wheelchair more and are more functional than those who do not (12, 29).

Life satisfaction, quality of life and social integration

Most of the PBF participants were to some degree satisfied with life in general (70% rated 4 or more) but dissatisfied with their financial situation (45%). Overall satisfaction with life for the PBF group was lower than that of individuals with post-polio from a resourced country (88% rated 4 or more) (30), where satisfaction with physical health decreased with significantly higher degrees of impairment. DSA participants reported similar overall levels of life satisfaction (63% rated 4 or more), but were to some degree dissatisfied with their vocational and financial situation (37%) and to some degree dissatisfied with their physical health and leisure (31%). DSA group satisfaction with life was similar that reported by patients with chronic stroke in a resourced country (87% rated 4 or more) (31).

Overall, ES participants rated their QOL as “neither poor nor good” and were “neither satisfied not dissatisfied” with their health, 45% rated QOL as “poor” or “very poor” and 42% said they were “dissatisfied” or “very dissatisfied” with their health. The physical health and environment domains had the lowest scores, and the social relationship domain rated the highest (Transformed Means: 44, 44, and 69, respectively). Overall QOL of ES group was lower to that reported by individuals with spinal cord injury (SCI) with significant chronic pain in the United States (Means: 2.8 vs 3.5, respectively) (32). The physical health, psychological (Transformed mean: 56), and environment domains were also lower for ES participants than for persons with SCI in other European countries (Means: 67.0, 70.0, and 80.0, respectively) (33). The social relationship domain was higher for ES group than for the European population (Mean: 64.0) (33). There are many factors that can lead to low QOL among wheelchair users such as pain, low psychosocial functioning, restricted occupational and social participation, among others (32). Factors that impact QOL of wheelchair users in LMICs needs to be further investigated with special focus on those that can be ameliorated with the provision of appropriate mobility assistive technology, such as distance travelled, social integration and participation, as they can have a mediating effect on QOL (32,34).

Social integration, as measured by CHART, was lower for participants from DSA group than from PBF and ES groups (Means: 39.8 vs 69.6 and 69.8, respectively); which at the same time, were lower than that of other wheelchair user populations in resourced countries (Mean: 93.0) (34). According to Oyster et al. (35), time propelling a wheelchair is associated with more extensive social integration. Participants from DSA group used their wheelchair mainly at home, reported the shortest time of wheelchair use per day, and had significantly less daily distance traveled than PBF and ES groups which, in combination with age, may explain the low scores in social integration. Although, ES participants reported the longest distances traveled, as they used their wheelchairs mainly for going to public places, and had the highest rates of social integration in this study, these were still lower than those reported by other wheelchair users in resourced countries (Mean daily distance travelled:

1,877.6 meters) who at the same time reported higher social integration levels (Mean: 94.6) (35).

Wheelchair use, skills and mobility characteristics

Overall wheelchair mobility characteristics of participants were largely different from those of wheelchair users living in resourced countries. Whereas a study from Tolerico et al. (36) found that participants in their study traveled a Mean of 2,457.0 meters daily at a Mean speed of 0.79 meters per second while using their primary wheelchair in the home environment, our study found significantly lower distances and speeds (Means: 54.5 to 426.6 meters, and 0.21 to 0.33 meters per second, respectively). Although, some participants were able to reach longer distances and faster speeds, the vast majority of participants did not. The distance and speed at which one is able to move with a wheelchair has been associated with both, employment and participation after SCI (34,36). Mobility characteristics of participants in this study may reflect not only their occupational and social participation levels but may be also indicative of the accessibility of their environment and their wheelchair skills (34) which may be improved with the provision of a well-fitted wheelchair and training (12).

The total scores for wheelchair skills capacity were low overall for the three groups (Means: 44.7% to 66.1%), but mainly lower for the ES group. DSA group had a greater spread in wheelchair skills ranging from 0% to 81%. Age and medical condition may have an influence. DSA group was comprised mainly by older individuals with stroke and SCI, whereas PBF had the youngest individuals with effects of polio. ES group had participants with diverse ages, and diverse medical conditions. Overall wheelchair skills scores obtained in this study were lower than the scores of other wheelchair user populations in resourced countries (83% and 88%) (37,38) and also lower than the scores obtained in another study with similar population in Indonesia (71% and 78%) (10), which may be related with the lack of expert advice and training when selecting and providing the wheelchair. The evidence shows that when a wheelchair user receives a wheelchair prescribed by an expert provider and is trained in wheelchair skills, daily wheelchair use increases (12,34).

Health related with wheelchair use

Pressure sores are a frequent secondary health condition among wheelchair users affecting health, function and QOL (39). Those users who require a wheelchair for their indoor and outdoor mobility have a long-term risk of developing pressure ulcers (40). Pressure sores are more prevalent in LMICs (41) increasing the risk for premature death (5). The prevalence of pressure sores during the 3 months period before the pilot and full study phases were around 12% for all groups. This prevalence is below the prevalence range reported for people with SCI in LMICs (27–46%) (41) and high-income countries (29%) (42), which may be due to the diversity of medical conditions that affected each group (persons with effects of polio and stroke have better sensation than people with SCI who are at greater risk of pressure ulcers.)

Wheelchair-related injuries among study participants were common in both PBF and ES groups. ES wheelchair users fell more (21-54%) than PBF users (16-17%). Prevalence of falls for ES participants is comparable to that of full-time wheelchair users living with a variety of disabilities in home environments in high-income countries over a year period (38-57%) (43, 44). Main causes of falls in this study can be categorized in the same way as those reported in the literature (45) and which encompasses extrinsic factors related to the conditions of the wheelchair (ex. malfunction) and to the capacity of the user to perform a safe transfer (ex. improper transfer techniques).

Independence, assistance and caregiver burden

The majority of participants in this study reported requiring significant assistance. About 40% of Salvadorian participants reported to have somebody assisting them. Moreover, as per caregivers' report, only 37.2% of the ES participants were able to perform three or more ADLs without assistance from their caregivers which is lower than the percentage reported in another study of wheelchair users in Kenya and the Philippines (12). Of the caregivers interviewed, more than half reported more than 60 hours of care provided per week with a mean burden score (ZBI) of 27.8 which is considered low (only 8% reported burden scores above 47) (46). The only high scoring burden domain among caregivers was the "Finances" domain. In general, these results were more favorable than those found in the literature. A study carried out in Spain had caregivers reporting 18.7 hours of care per day and burden scores higher than 47 for 72% of them (46). Burden experienced by caregivers in our study may have been influenced by cultural context. For instance, a study carried out in another Latin-American country, caregivers of wheelchair users reported similar levels of burden than in our study (88% had burden scores lower than 40 and 13% had scores between 41 and 60) (47).

Conclusions

Wheelchair users in Indonesia and El Salvador are more disadvantaged than the general population within their countries (based on educational, labor participation, and economic measures), and they are more disadvantaged than wheelchair users in resourced environments (based on wheelchair skills, distance travelled and speed, social integration, life satisfaction, and other QOL measures like physical, psychological and environmental health). It is recommended that governments, private-entities, and not-for-profits follow guidelines related to manual wheelchair provision, especially those with potential to increase function and wheelchair mobility, as this is related to education and labor market inclusion. More studies evaluating the impact of the 8-Steps approach versus the standard-of-care are needed in order to make the case for wheelchairs to be provided following standardized processes. In turn, this has the promise to drive evidence-based policy related to mobility assistive technology.

Acknowledgements

Research reported in this publication was supported through a contract with UCP Wheels for Humanity, Agreement No. WFH-2017-049-Google, under Prime Award Agreement Number 322068 with Google.org. The publication is the result of work funded by Google.org under the Google Impact Challenge 2015: Disabilities. The contents of this publication are solely the responsibility of the authors and do not represent the views of UCPW or Google.org. The authors would like to thank the personnel of UCPW, CHPM-UGM, PBF, DSA, CITE-MIT, UES, FUNTER, ISSS, and UCP-ES.

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Footwear as a means of offloading for the prevention and management of foot ulcer in people with diabetes in low resource settings.

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Abstract

Background: Among the complications of diabetes foot problems not only cause suffering of people with diabetes but also inflict economic burden. The yearly incidence of foot ulcer is 2-4% in developed countries and even higher (11%) in developing countries. Adopting the preventive strategies is most cost-effective way of coping with the enormous burden of diabetic foot, particularly in the low resource countries. Therapeutic footwear has been successfully used as an assistive technology to prevent foot ulcers. However, most people with diabetes in Low and Middle-Income Countries do not have access to protective footwear. **Objective:** The main objective of this initiative is to provide standardized, low cost, durable and acceptable footwear to people with diabetes in a low resource country and to use footwear as an assistive technology to prevent and manage the foot ulcers and resultant amputations. **Methodology:** “Footwear for Every Diabetic” is a joint venture of World Diabetes Foundation and Baqai Institute of Diabetology and Endocrinology, Karachi. The concept is adopted from FLIRT (Footwear in low income regions all together) project of D-Foot International. It is a three-year project carried out from November 2016 to October 2019. Ten project centers were established across Pakistan. At each of the center “Risk Assessment Clinics” were established, where the people with diabetes were examined and the risk for developing foot ulcer was categorized from Risk Category 0 to Risk Category 3 according to IWGDF Guidelines 2015. Therapeutic footwear was manufactured and provided according to the specific risk category. The planter pressure is assessed by using a baropodograph platform. Development of first ulcer or recurrent ulcer was noted. People with diabetes having foot ulcers classified according to University of Texas wound classification (UT classification) were also provided the therapeutic footwear and were followed for wound healing. **Results:** A total of 14,564 pairs of footwear have been manufactured at all centers, and of them 10,001 pairs were for those at risk of developing foot ulcer. Among the users of these footwear, 1.65% people developed first foot ulcer or recurrent ulcer. The remaining 4,563 pairs of footwear were for those with active foot ulcers. Among those who used footwear for most of the time they were engaged in activities, ulcers of 76.0% people healed completely. In people who did not use footwear,

ulcers of 44% people healed completely. **Conclusion:** In low resource countries like Pakistan, the outcome of the project at completion of two years has shown that therapeutic footwear is an effective means of offloading in the prevention of first and recurrent ulcer, and also in the complete healing of existent foot ulcers in people with diabetes. Given these outcomes, it appears promising to initiate similar projects in low and middle-income countries keeping in view local circumstances.

Introduction

It is estimated that there will be nearly 629 million people with diabetes in the world by the year 2045, among these 80% will be in developing countries (1). According to the National Diabetes Survey 2016-2017, the prevalence of type 2 diabetes in Pakistan is as high as 26.3% (2). This means currently there are 27.4 million people with diabetes in this country. To further aggravate the situation, there are another 14.47% of the population over the age of 20 years who are pre-diabetic (2).

Among the complications of diabetes, foot problems are the most common and not only cause significant suffering but also inflict an enormous socio-economic burden (3).

The yearly incidence of foot ulcers is 2-4% in developed countries (3) and even higher (11%) (4) in developing countries. A huge burden of diabetic foot prevails in Pakistan. It is estimated that currently there are 1.9 million people with foot ulcer in Pakistan (5).

Among the foot ulcers, two-thirds heal completely (6,7) and nearly 28% end up in amputation (8). Approximately one million people with diabetes every year lose a part of their lower limb as a result of diabetes. Every 20 seconds a leg is lost due to diabetes somewhere in the world (3).

Foot problems also affect the family and inflict financial burden on the healthcare system. In resource-constrained societies, the treatment cost of a non-healing ulcer can be equivalent to 5.7 years of yearly income (9). Adopting preventive strategies is the most cost-effective way of coping with the enormous burden of diabetic foot, particularly in low resource countries (10,11). Appropriate footwear is one of the most effective methods of preventing foot ulcer (12). The widespread use of inappropriate footwear is one of the major reasons for the lack of progress in reducing ulceration and amputation rates in people with diabetes (13).

There is a long clinical tradition in the use of footwear and offloading techniques in the prevention and healing of plantar ulcers in people with diabetes. The landmark article by Bauman, Girling and Brand which provided insight into the role of plantar offloading for diabetic foot was published almost 50 years ago in the "Journal of Bone & Joint Surgery". The pivotal role of appropriate footwear in reducing ulcer rates was recognized by both the American Diabetes Association and the International Consensus Group on the Diabetic Foot (13). Uccoli et al have demonstrated that ulcer recurrence rate was reduced to 28% in those receiving therapeutic footwear, compared with 58% in those wearing their own shoes (14).

Our published study (15) concluded that “Footwear is the most cost-effective offloading technique having healing rate comparable to other techniques, in this part of the world.

Considering that the resource constraint and poor socioeconomic conditions are the major limitations to the prevention and management of diabetic foot ulcer in the developing countries. A number of studies have furnished the evidence of efficacy of footwear in the prevention of recurrence of ulcer in people with diabetes (16) and there are a few studies which show the efficacy of footwear in prevention of first ulcer (14).

We revisited the role of low-cost therapeutic footwear in the prevention & management of diabetic foot in the developing world and designed this project on that basis.

However, most people with diabetes in low and middle-income countries do not have access to protective footwear. “Footwear in Low Income Regions all Together (FLIRT)” (17) is a project of D-Foot International, that works with academics and experts to develop footwear that can be made locally according to the local environmental, climatic, social and cultural conditions. The goal is to provide standardized, low cost, durable and acceptable footwear to all people with diabetes (for Everyone, Everywhere) and prevention of foot ulcers and amputations.

This concept was adopted from the FLIRT project of D-Foot International. We – the authors, as the diabetic foot care team at Baqai Institute of Diabetology and Endocrinology, Karachi-Pakistan translated the FLIRT -BIRD concept into implementation through the initiative “Footwear for Every Diabetic” (FED). The financial support is provided by World Diabetes Foundation. It is the first ever project of its kind in Pakistan. The three years nationwide initiative is being carried out from November 2016 to October 2019. The primary objective of the FED project is the manufacture and provision of low cost, standardized, durable and acceptable footwear to every diabetic in the prevention and management of foot ulcer.

Materials and methods

The project “Footwear for Every Diabetic” was initiated in different cities of three major provinces of Pakistan. It is a joint venture of World Diabetes Foundation as the financing partner and Baqai Institute of Diabetology and Endocrinology (BIDE), Karachi- Pakistan as the implementation partner. The three-year project is being carried out from November 2016 to October 2019. Ten project centers were established across Pakistan. Ethical approval was obtained from Institutional Review Board of BIDE via approval reference no BIDE/IRB/zmiyan-FED/04/1/16.

Establishment of Project Centers

Ten diabetic foot centers in the major cities of the country were identified for the project implementation.

The project Team

The project is headed by the Project Director. The Project Manager is responsible for the execution of project activities. The Project Coordinator takes the responsibility of communication and coordination between the centers. The Finance Manager looks after the financial affairs of the project. There is an in-charge and a coordinator at each of the project centers. A health care professional at each center conducts the risk assessment clinic. Moreover, a team of a Foot Care Assistant and two Footwear Technicians (cobblers) are responsible for taking appropriate measurements, booking the orders and manufacturing of therapeutic footwear.

Train the Trainers Program

A standardized training manual in accordance with the international recommendations in footwear manufacturing was developed by the master trainer Mr. Bent R. Nielsen from Gentofte University Hospital, Copenhagen, Denmark (18). The training manual describes the step by step manufacturing process of therapeutic footwear for prevention and management of foot ulcer in people with diabetes (Figure 1) (Table 1).

Figure 1. Training Manual



Table 1. Contents of Training Manual

Training modules	Contents
Diabetes and foot complications	<ul style="list-style-type: none">• Diabetic foot;• Ulcer;• Diabetic foot ulcers (DFU); and,• Neuropathy.
Foot Deformities	<ul style="list-style-type: none">• Hammer toe;• Claw toe;• Flat feet/fallen arches;• High arched feet;• Metatarsalgia;• Bunion Foot; and,• Charcot Foot.

Training modules	Contents
Anatomy of foot and ankle	<ul style="list-style-type: none"> • Basic foot anatomy; • Basic ankle anatomy; and, • Biomechanics of the foot.
Gait	<ul style="list-style-type: none"> • Definition of gait.
Risks assessment and recommendations of footwear	<ul style="list-style-type: none"> • Knowledge and importance of footwear; and, • Important shoe features for people with diabetes.
Equipment and tools	<ul style="list-style-type: none"> • Grinding machine; • Oven; • Heating blower; • Measuring instrument; and, • Tools.
Grinding techniques	
Materials	<ul style="list-style-type: none"> • Characteristics of materials required; and, • List of Materials.
How to take the measurement of the foot	
Manufacturing of footwear for risk category 0	<ul style="list-style-type: none"> • Manufacturing Process • Insoles (Patava) • Upper Part (Cow/Buffalo) Leather
Manufacturing of footwear for risk category 1	<ul style="list-style-type: none"> • Custom-made temporary footwear for management of foot ulcer
Manufacturing of footwear for risk category 2	<ul style="list-style-type: none"> • Therapeutic Footwear for Foot Deformity; • Outer Sole; • Insoles (Patava); • Top Cover; and, • Upper Part (Cow/Buffalo) Leather.
Manufacturing of footwear for risk category 3	<ul style="list-style-type: none"> • Therapeutic Footwear for people with history of ulcer & amputation; • Outer Sole; • Internal Bottom or Insole (Patava); • Top Cover; and, • Upper Part & Heel Counter (Cow / Buffalo) Leather.
Support and off loading	<ul style="list-style-type: none"> • Forefoot Support; • Medial & Lateral Support; • Medial Support; • Manufacturing Process; • Lateral Support; and, • Heel Pad.

A team of diabetic foot care assistants and cobblers underwent focused training in risk assessment and therapeutic footwear manufacturing for the pre-ulcer, ulcer and post-ulcer phases.

Training in Risk Assessment: The foot care assistants were trained in foot care education, taking short history (particularly history of previous ulcer/amputation), complete foot examination to assess Peripheral Neuropathy, Peripheral Arterial Disease, foot deformities and subsequently categorizing the risk of developing foot ulcer in people with diabetes and also entering the data in the specific software and referring to the footwear section (Table 2).

Table 2. IWGDF Risk Classification and Recommendations for Footwear (19)

Category	Characteristics	Frequency	Recommendation
0 (low risk)	No peripheral neuropathy	Once a year	Off-the-shelf, properly fitting footwear
1 (medium risk)	Peripheral neuropathy	Once every 6 months	Properly fitting footwear and custom-made insoles
2 (high risk)	Peripheral neuropathy with peripheral artery disease and/or a foot deformity	Once every 3 to 6 months	Therapeutic footwear, shoes, custom-made insoles, or toe orthoses
3 (very high risk)	Peripheral neuropathy and a history of foot ulcer or lower-extremity amputation	Once every 1 to 3 months	Therapeutic (custom-made orthopedic) footwear or custom-made insole: has demonstrated 30% plantar pressure relieving effect at high risk areas on previous ulcer location

Training in footwear manufacturing: The team was trained in manufacturing therapeutic footwear in accordance with the risk category and for the management of foot ulcer.

Equipment for footwear manufacturing: Flat-bed Stitching Machine, Post-Bed Stitching Machine, Grinding Machine, Oven, Heating Blower (heat gun), Measuring Instrument, tools such as Hammer, Punch Pliers and Pliers for pressing materials.

Materials for Footwear Manufacturing: the recommended material for manufacturing of footwear is listed in Table 3.

Table 3. Recommended material for manufacturing of footwear

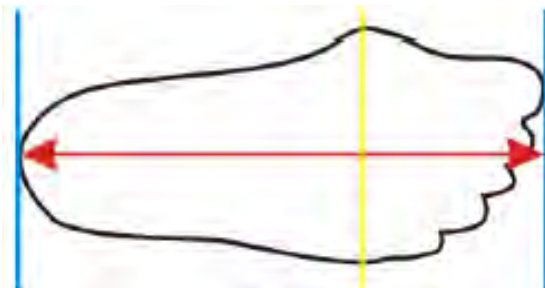
Parts of Footwear	Types of material used internationally	Types of material locally available in Pakistan
Outer Sole Sheet	Nora Lunasoft	Sheet (6 mm)
Bottom Sheet	Lunasoft SLW	Rubber Sheet (20 mm)
Outer Soles (PU)	-	Polyurethane (PU) Soles
Insoles	Lunairflex Sheet - 12 mm	Rubber Sheet (12 mm, 8mm)
Top Cover for Insoles	-	polyurethane
Material for Support	PPT 6 mm	Rubber Sheet (6 mm)
	Airlastic 9 mm	Rubber Sheet (6 mm)
Upper Part	-	Cow / Buffalo Leather
Internal Lining	-	Fabric
-	-	Foam

Measurement for Footwear: The size and shape of the foot is measured when the subject is standing with full load. The foot is placed on a paper, a sketch is drawn, a margin of a thumb width between the end of the longest toe and the end of the shoe is given (Figure 2) (4). To measure the length, the subject stands on a measuring tape and the measurement is taken from the tip of the subject's longest toe to the center back of heel (Figure 3).

Figure 2. Drawing the sketch of the foot



Figure 3. Measuring the length of the foot



To measure the width, the widest part of the foot is measured. This will be circumference of the foot (Figure 4). To measure the instep, measurement is taken over the bone which can be felt at the top of the foot (Figure 5).

Figure 4. Measuring the width of the foot

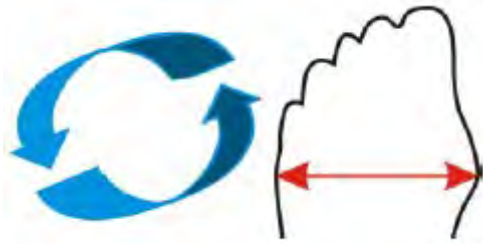
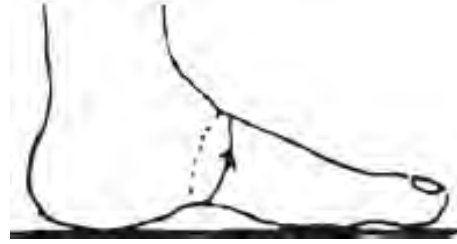


Figure 5. Measuring the instep



Marking on the sketch for different deformities: Marking for ulcer/callus/corn etc. is made on the sketch.

Manufacturing of footwear for Risk Category 0: The Outer Sole of the footwear is made of PU (Polyurethane) and is easily available.

Manufacturing of footwear for Risk Category 1: Has the same steps. In the upper part, a back strap is added to give support to the foot. The strap prevents the footwear from slipping out of the foot.

Manufacturing of footwear for Risk Category 2 & 3: Different sheets are used for outer sole, bottom and insole which are heat moldable and have shock absorbing qualities.

The insole is designed to adopt the shape of the foot, providing cushioning and redistribution of plantar pressure. Nearly 36-39% reductions of plantar pressures can be achieved in the central and medial forefoot regions through application of a metatarsal dome and/or an arch support or an extra arch support (20) (Figure 6).

Figure 6. Insole



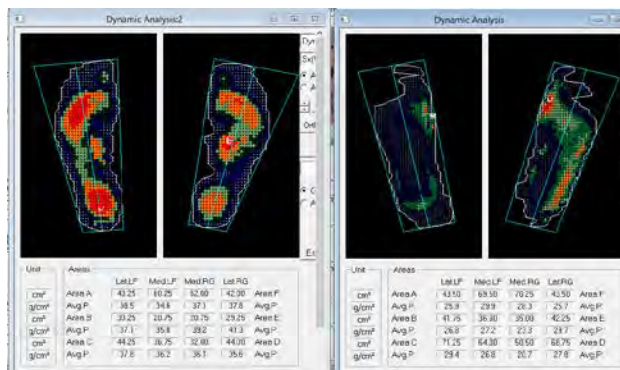
Rocker bottom soles are used to transfer weight, reduce plantar pressure and limit motion. Rocker bottom shoes move the foot forward to move from heel strike to toe off in one quick sweep. Shoes with a rocker bottom principle reduced pressure 35-65% underneath the heel and the central metatarsal heads (21) (Figure 7).

Figure 7. Features of therapeutic footwear



Foot Pressure Assessment: Baropodograph use as an objective measure to assess the plantar pressure with bare foot and therapeutic footwear. (Figure 8)

Figure 8. Pressure assessment by baropodograph platform



Manufacturing of Footwear for Diabetic Foot Ulcer: The manufacturing process of footwear for Diabetic Foot Ulcer has the same steps as that of the manufacturing process in for Risk Category 2 & 3, though there are a few modifications to accommodate foot deformity and relieve pressure over the ulcer site (22) (Figure 9).

A “Negative Cast” is made from plaster of paris which imitates the shape of the foot as may be required. Changes in the insole were made according to the ulcer site to offload the ulcer.

Figure 9. Custom-made temporary footwear for management of foot ulcer



Training of teams from other project centers

The training manual was translated into Urdu - the national language of Pakistan, for easy understanding of the trainees. A team of a diabetic foot care assistant and a footwear technician (cobbler) from each of the project centers was trained.

Foot care and Footwear Education

Education on foot care and footwear carried out at each of the project center. A concise educational booklet in Urdu- national language designed, compiled, published and distributed to people with diabetes. Education was also focused on regular use of the footwear and the compliance was assessed by regular phone calls and every follow up visit.

Footwear manufacturing

The footwear manufacturing is being continued at all project centers

Project Outcome

The duration of the project is 3 years. We are presenting the outcome at the completion of the first two years.

A total of 88,098 people with diabetes were examined. Among these 77,959 (88.5%) were at increased risk of developing foot ulceration (male 54% and Female 46%) (IWGDF risk classification 2015) and 10,139 (11.5%) had active foot ulcers (male 68% and female 32%). A total of 14,564 pairs of footwear have been manufactured at all centers. Among these 10,001 (68.7%) were for those at risk of ulceration and 4,563 (31.3%) were for those with active foot ulcers (Table 4).

Table 4. People with at risk of foot ulcer and active foot ulcer

	People at risk of foot ulcer (%)	People with active foot ulcer (%)
Total No. of people examined (n= 88,098)	77,959 (88.49%)	10,139 (11.51%)
Pairs of footwear manufactured (n=14,564)	10,001 (68.67%)	4,563 (31.33%)

In those at risk of ulceration, 4,912 people were followed who used the footwear for most of the time they were engaged in activity. A total of 81 people (1.65%) developed first foot ulcer or recurrent ulcer, of those 16 (0.32%) in category C-0, 26 (0.53%) in category C-1, 36 (0.74%) in category C-2 and 3 (0.06%) in category C-3 (Table 5).

Table 5. Outcome of People at risk of foot ulcer

Total number of people followed	4,912
Number of people who developed first or recurrent foot ulcer (%)	81 (1.65%)
C-0 (low risk) (%)	16 (0.32%)
C-1 (medium risk) (%)	26 (0.53%)
C-2 (high risk) (%)	36 (0.74%)
C-3 (very high risk)	3 (0.06%)

In the foot ulcer group of 3,145 people, 1,184 used the footwear for most of the time they were engaged in activity, and 76.0% (n=900) of these healed completely. Amongst the 1,961 people who did not used the footwear, 44% (863) people healed completely (Table 6).

Table 6. Outcome of subjects with active foot ulcer

No. of people with foot ulcer (n=3,145)	Used therapeutic footwear	Used own foot wear
No. of people followed (%)	1,184 (37.6%)	1,961 (62.4%)
No. of people who healed completely (%)	900 (76%)	863 (44%)
UT Grade & Stage		
I A	290 (24.5%)	421 (21.5%)
I B	255 (21.5%)	537 (27.4%)
II A	507 (42.8%)	692 (35.3%)
II B	132 (11.1%)	311 (15.8%)

Discussion

Footwear for Every Diabetic (FED) is a ‘first of its kind’ project. It was a pilot project adopted from FLIRT project of D-FOOT International and by the Pakistan team, translated into daily quality clinical practice.

The most important outcome is that only a small proportion of the “at risk patients” developed first or recurrent ulcer at two years’ period with the use of the therapeutic

footwear manufactured in this project. There are only few reports regarding the prevention of first foot ulcer in the literature (14) although many studies favor the use of therapeutic footwear in the prevention of recurrent ulcer (16).

In people with foot ulcer who used footwear for most of the time they were engaged in activity the healing is significantly better than in those people who did not use the footwear.

As increased plantar pressures due to peripheral neuropathy in people with diabetes is the main cause of foot ulcers on the plantar surface of the foot (23), we achieved a 20 - 40% reduction in the plantar pressure as assessed by baropodograph platform with the therapeutic footwear manufactured by this project, as recommended by IWGDF Guidance document 2015 (24,25). This pressure measurement taken as a tool of efficacy of therapeutic footwear which is also shown by Pham et.al (26).

One of the most important aspect of this project is the “cost” of the footwear. It is particularly significant that these outcomes were achieved by low cost footwear. We have been able to keep the cost low by using approved, locally available material and utilizing the services of the locally trained team. The footwear under this project costs USD 15-30 as compared to USD 100-200 for commercially available customized footwear. More importantly, the cost is even lower than regular and traditional footwear.

Therapeutic footwear for people with diabetes is an entirely new concept in this country, particularly, for people, health care professionals and for health care institutions. We encountered many constraints and the barriers in implementation of this project.

- **Awareness:** The project is regularly conducting educational and counselling sessions. However, the desired awareness level has not yet been achieved. A significant element of unawareness regarding the benefits and necessity of therapeutic footwear, still persists. A considerable number of people with diabetes, still do not wear the therapeutic footwear.
- **Affordability issues:** Although the cost of the footwear is minimal, yet there are number of people who cannot afford even this minimal price.
- Social barriers and emotional hesitations towards wearing therapeutic footwear still persist to a certain extent.
- **Non -Adherence to wearing of therapeutic footwear:** A number of people still do not wear the therapeutic footwear for most of their activity time as advised by the footwear team.

The objectives and the achieved outcome of this project are in accordance with the five priority themes identified in the Global Priority Research Agenda produced by GATE:

- The cost of this assistive technology (Therapeutic Footwear) has been kept to minimum possible which makes it affordable for most of the people with diabetes. It not only has a beneficial preventive and therapeutic effect but by preventing foot ulcers and

amputations, it greatly contributed in reducing the huge economic burden of diabetic foot.

- It forms a practical service provision model.
- Along with being a quality product, it ensures affordability of people with diabetes for preventive and therapeutic care of diabetic foot.
- The production and provision of this assistive technology involves appropriate, trained human resources.
- Standards have been set and methodologies evolved for the assessment and justification of the need of this assistive technology and how far this need yet remains unmet.

Although most developed countries have the facilities and provision of footwear for people with diabetes, many LMIC are lacking in this regard. Given these outcomes, it appears promising to initiate similar projects according to local circumstances.

Further exploration is recommended to see if this project can be integrated in other fields, where therapeutic shoe wear is needed.

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Barriers to using mobility devices in rural homes in low resource settings: Development of a practical assessment tool for local fieldworkers

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Abstract

The usefulness of mobility devices can be totally undermined by an inaccessible environment. In low and middle-income countries home modification is not addressed while providing mobility devices. Especially in rural areas existing assessment tools are not suitable as these are designed for settings that are completely different from conditions in the rural settings. In order to improve the situation, in this study we developed a basic tool to systematically assess barriers in the environments in which persons with mobility impairments will be using their individual mobility devices, with an aim to recommend solutions for increasing their mobility. The tool was designed based on review of existing standards and relevant literature, it was improved based on field visits to see whether the tool adequately addressed all areas and sub areas in rural houses and the draft tool was shared with experts for their feedback. It is an easy to use tool for non-technical CBR and other fieldworkers who are working in these rural areas.

Keywords

Evaluation-tool, Rural-area, Fieldworkers, mobility devices, home modification

Introduction

For effective home mobility, in addition to a suitable mobility device, the physical environment in which these would be used, is equally important for making the user more mobile and independent (1, 2). Most often it is the non-availability of one of the two that poses a barrier to mobility. In high income countries where mobility devices and physical infrastructure are more standardized, there are also better-established systems that look at mobility devices along with home modifications required to use these devices comfortably. Moreover, some countries have also started looking at the issue from the point of universal design where all homes are designed to be accessible to all users irrespective of the type of mobility devices they use (3, 4).

Such systems, however, are not yet applied to the context of rural areas in the low and middle-income countries. The key challenge in making personal mobility within rural home environments for persons with mobility impairments seamless stems from the environmental structure and internal design of the home not matching the requirements for using the specific mobility devices. There are several reasons for this mismatch for instance, first, the accessibility design standards in these countries often address only public areas (5) and guidance used for accessible housing are largely based on western homes that are very different from homes in rural areas in the global south countries, as a result there are no accessible design specification for homes in rural areas.

Second, the mobility devices that are available to disabled people are mostly not designed to address the requirements in the context of their environments. The design standards for these devices are again based on western research that addresses the requirements for western environments and population that may not always be best suited for rural environments and to the lifestyle of indigenous people that live in rural areas. Third, most efforts to address accessibility have been focused on urban public environments with also the ISO document focusing on accessibility of urban public areas (6) creating a dearth of standards and guidance on rural accessibility. Fourth, is the lack of awareness about home modifications and accessibility of home environments amongst field workers who are unable to always identify barriers and suggest simple solutions to users of mobility devices. However, considering that majority of the global disabled population live in rural parts of the global south countries (7) and that they are disproportionately impacted by the lack mobility devices and home environments that complement each other (8, 9), there is an urgent need to undertake further research to see how the mobility devices and the environments they are used in can be better attuned to ensure better home mobility for persons with disabilities living in less-resourced settings.

This research considers the physical home environment of persons with mobility impairments in rural areas in relation to the mobility devices that are available for them. The objective of this project is to design an easy to use tool for non-technical Community-Based Rehabilitation (CBR) and other fieldworkers to systematically assess barriers in the environments based on the mobility devices being used. The tool is intended to be used primarily in rural areas of low and middle-income countries where physical accessibility of homes is not considered as an important criterion associated to the use of the mobility devices.

Methodology for developing the draft tool

There were three steps undertaken to prepare the tool that included: 1. Designing the tool; 2. Field visits to ensure all areas and sub areas of rural homes were adequately addressed in the tool; and, 3. Seeking expert feedback on the tool.

Designing the tool

In order to design the tool, literature search was undertaken in two areas. We started by exploring the various types of mobility devices that were commonly available to persons with disabilities. With regards to mobility devices we searched through the online database such as Able Data, the Global Assistive Technology Information Network (EASTIN) catalogue that put forward a wide range of mobility devices, we also looked at the list assistive devices and technology available to the person with disabilities through government Scheme for assistive devices (ADIP) in India (10). Since there was a large disparity in the range of assistive devices shared in the online databases and what is actually available through government schemes, we decided to use the WHO Priority Assistive Products list (APL) (11) The APL is a model proposed by the WHO for countries to adopt while looking at their own national assistive products list on and thus the APL has the maximum reach and global acceptance .

With regard to assessing environments we began by searching scientific research catalogues using keywords 'rural', 'accessibility' 'tool' 'physical accessibility' 'India' 'home modification', 'WASH' in different combinations. However, we did not get adequate literature through scientific research search platforms and therefore did an open web search of resource documents generated by development organizations, UN organizations and international donor organizations on their work related to disability (12-14). We also looked at the international standards organizations (ISO) standards on physical accessibility (6) and we gathered some literature on accessibility in rural areas through these sources.

Analyzing the information literature, we designed a tool which combined two sides. On the one hand we categorised the mobility devices; on the other we categorized the common spaces in the home. The categories of common spaces were further elaborated by breaking them into sub-areas with descriptions specific to these areas. These common areas and the accessibility solutions for them were related to the different mobility devices that users could potentially use and this indicated the design of the environment specific to the mobility device. The mobility devices were listed in the 'x' axis and since different kind of physical environment was required to enable easy movement these accessibility solutions were listed in the 'y' axis. Therefore, the tool elaborates on the accessibility requirements in different areas of the home in relation to the three categories of mobility devices and gave suggestions on how to make adjustments to the environment to use device more effectively. The tool is described in more detail in the next section and tool itself is presented in the appendix.

Field-visit to check adequacy of the tool

To check the adequacy of the draft tool prepared on the existing literature, field-visits were undertaken in fourteen homes of persons with mobility impairments in three villages in the Ananthapur District of Andhra Pradesh in India. The participants for the field visit were identified with the support of the Rural Development Trust (RDT), a development

organisation working to improve the quality of life of the rural poor in the district, they also run a CBR programme focusing on persons with disabilities. Before visiting their homes, the participants were provided with information on the nature and purpose of the visit. Before proceeding with the home visit, a consent – including the permission to take photographs of different areas of their homes and audio recording of our conversation was taken from each participant. They were informed that anonymity would be maintained and that they had a choice of what they wanted to share. RDT workers - who are already working in and have the support of the local community - gained prior permission and meeting time suitability from the participants and their families.

The basic criteria for selecting these participants was that they were all adults with disabilities who had a mobility impairment and required a mobility device to move around. The different mobility aids these persons were using included wheelchairs, lower limb prostheses, lower limb orthoses, leg braces; sticks; crutches and walker. During these visits the list was verified in relation to the main areas and the sub areas in a typical rural home and additional barriers, sub areas and descriptions that were seen were added to the tool. Photographs were taken to document the situation and all the 14 persons with disabilities visited who were asked to describe their mobility within their homes, thus elaborating on the barriers they faced and the solutions they had developed or hoped to develop to remove these barriers.

The homes visited helped not only validating the adequacy of the areas and sub-areas of a typical rural home in the tool, but it also highlighted the inadequacy of a wheelchair to be used in rural homes because of their small size. Therefore, to address individual mobility of persons who were not using ambulatory devices, further literature search of mobility devices was undertaken. The mobility boards in ISO category 12.27.15 from the EASTIN catalogue was considered suitable. Thus, an additional category of persons using floor boards was included to the tool.

Seeking expert feedback on the tool

The draft tool was shared with eight experts from three different domains: assistive technology, accessibility and Community-Based Rehabilitation (CBR) with experience of working in low resourced setting. The draft tool was shared with them with a background and objective of the project via email. They were asked to share their thoughts on the tool and specifically the adequacy of the tool while addressing mobility devices in the three categories and the areas in the typical rural homes. Feedback was received from 4 experts and amongst them they represented each of the three domain experts we had originally identified. Their feedback was related to the structure of the draft tool and applicability of the tool. The feedback received was carefully considered and adjustments were made accordingly.

Results

In developing the tool, we decided to cluster the different assistive devices that were identified from the APL and the EASTIN catalogue, into three different groups of potential users that included -- wheelchair users, floor board user and the ambulatory devices users. A table indicating the different device categorization can be found as Table 1 below.

Table 1. Categorization of mobility devices

Source of AT	Users moving in chair sitting position	Users moving in floor sitting position	Users able to walk a little
WHO Priority Assistive Products list	Manual wheelchair for active use; Manual wheelchair, assistant controlled; Manual wheelchair with postural support; Tricycle; Wheelchair, electric powered; Handrails / grab bars; Portable ramp	Handrails / grab bars; Portable ramp	Club foot brace; Canes; Sticks; Axillary/elbow crutches; Lower limb orthoses; Lower limb prostheses; Rollators; Walking frames / walker; Therapeutic footwear; Handrails / grab bars
EASTIN catalogue ISO category 12.27.15		Floor boards	

The reason for categorizing them in these three clusters was related to the differences in the basic physical accessibility requirements for persons with mobility impairments as gathered from literature that included aspects like:

1. the minimum dimensions of a given space;
2. height of operating elements in the environment;
3. change in levels;
4. minimum width of spaces to pass through;
5. floor finish.

The key findings gathered were that the minimum dimensions of the space required for maneuvering a wheelchair was much larger as compared to the other devices. And since this minimum space was not usually available in rural homes people were crawling to move within the house or had to be carried. Thus, a floor board was seen as an alternative that could enable them to have better mobility without having to make major changes to their homes and floor boards also enabled floor level activities that was the common way of life.

The height of the operating elements in the environment varied for persons performing the activity from floor level as compared to those who performed sitting on a chair or those who did it standing and therefore these had to be addressed differently for the three mobility device categories.

For the change in level, persons who use ambulatory devices may not find the ramp as their most preferred option instead they may prefer steps unlike the other two categories for whom ramp was mandatory to negotiate level differences.

The minimum width required to pass through areas such as the door was different for different devices. While a minimum width was a mandatory requirement for wheelchair users it was not as rigid for the other two categories.

A firm, cement and non-swampy and slippery floor finish was a requirement for all the three categories.

The basic idea of the tool is to provide accessibility requirements for each of the basic areas in a typical rural home that most often was on the ground floor and had a very simple layout comprising of five main areas: the courtyard, the living room, kitchen and the toilet and bathing room. Each of these areas had sub areas that comprised of different spaces within them. These accessibility requirements are defined for the three categories of assistive devices users based on the understanding presented above. The tool itself, which has a tabular format, can be found as Table 2 in the appendix. Below is elaboration on the aspects of accessibility in the areas that the tool addresses. The presentation of information below has been made by separating the aspects of the environment that were common to all mobility devices and aspects that were specific to certain devices.

Access route and Courtyard

Common aspects for all mobility users

All different mobility device users required an access route leading to the house that was levelled, cemented, dry and without any obstacles like open drain in the route.

Mobility device specific aspects

First, the access route to the courtyard had to be levelled from the road and in case it was not levelled, a ramp may be provided for persons using wheelchairs or floor boards. However, steps may be preferred for ambulatory devices users. Second, the access route may have resting benches for persons using ambulatory devices to rest.

Courtyard

Common aspects for all mobility users

The courtyard required to be cemented and non-swampy for all mobility devices users.

Mobility device specific aspects

First, the minimum dimension of the courtyard is important for wheelchair access while it is not as important for other device users. Second, a bench in the courtyard may be useful for an ambulatory device user.

Living room

Common aspects for all mobility users

First, the thresholds at the entrance door may be avoided for all mobility device users. While this is a requirement, the tool recognizes the cultural and religious importance of the threshold and offers way of addressing the threshold at the entrance. Second, ensuring that internal doors are minimized and are without a threshold for all mobility device users.

Mobility device specific aspects

First, the minimum internal dimensions of the living room for a wheelchair were important, however this wasn't so for the other devices. Second, the height of the storage shelves, switches were dependent on the mobility devices used as that dictated the reach of the user. Third the entrance door at times had a level difference from the courtyard where a ramp was required for wheelchair and floor board users but not necessarily for an ambulatory device user.

Kitchen

Common aspects for all mobility users

First, the lack of plumbing made water storage in the kitchen for cooking and washing important for all different mobility devices users and the water storage needed to be close to the cooking slab and to the utensil washing area.

Mobility device specific aspects

First, the height of the stoves used for cooking required to be adjusted differently for different mobility device users. Second, accommodating a wheelchair user in the kitchen required larger internal dimension while this was not so for the other device users. Third, for cleaning utensils the height of the areas where this activity was undertaken was important, for instance a washbasin height was better for wheelchair users and ambulatory devices users while for a mobility boards user ground level was required.

Toilet and bathing area

Common aspects for all mobility users

First the lack of plumbing in the toilet or the bathing areas was a barrier identified that impacted the way the toilet and bathing areas were used by all mobility device users. Not having plumbing in the toilet and bathing area required having a water storage preferably within the toilet or shower area as carrying water with a mobility device is challenging. Second, the location of the toilet and the bathing area was identified as an important aspect in the tool that was important for all mobility devices users. Third, well drained cemented floor was important for all users.

Mobility device specific aspects

First, the internal dimensions of the toilet and shower room and the width of the door that were important only for the wheelchair users. Second, the type of toilet seat used was based on cultural preference and an Indian style toilet was used as a given in these villages. Indian seats were useable by persons using mobility boards, however for persons using a wheelchair or ambulatory device required a higher seat that could be made available by replacing the Indian seat with a western style seat or placing a bench or a stool over the Indian seat. The bathing area required similar considerations with a need for an additional stool or a bench to sit while bathing for ambulatory devices users or wheelchair users. Third, the useable height of clothes hook, toiletry shelf, or the door lock, placement of grab rails were different for different device users.

In the tool we systematically present aspects of physical accessibility of rural homes in relation to the mobility devices in a tabulated form in a way that is very simple and can be used by CBR and other community workers without having prior training on aspects of accessibility

Discussion

The aim of this paper was to develop a tool that attunes the mobility devices used by persons with disabilities with the physical home environments in rural areas where they live. Based on a literature review, a pretest in rural India and an expert consultation we conclude that it is relevant to distinguish the mobile devices into three categories based on the way the users of these mobility devices interact with the environmental. Each of these devices require different conditions in the internal environment to make it possible to use their devices and the environment efficiently. For different spaces in rural homes in rural India, we identified five common areas and defined the physical accessibility requirements for these areas in relation to the three categories of mobility devices.

This is a first attempt and although we think it is potentially useful for other rural areas in low and middle-income countries. There may be a need to make it more context specific through testing and further developing it depending on the location, for instance, Ananthapur is a dry area with ground that does not retain water. Therefore, it does not have issues related to water stagnation and loose mud that may not be in some other villages. We also feel that there may be a need to adjust it for specific conditions such as disaster especially because there was nothing found in literature and the field area that was used for checking the adequacy of the tool was not a disaster-prone area, therefore, this aspect has not been addressed in this tool.

Although further development is needed, the tool demonstrates already that there is a need for such an instrument adjusted to rural areas in low and middle-income settings. It deviates from existing tools for instance in taking into consideration the fact that people in rural India, culturally all perform home activities such as eating, sleeping, sitting cooking in many cases at the floor level (15). Therefore, the floor board as a device for indoor mobility is

suggested as being most suitable. Thus, even if the house is made to suit a wheelchair, the user may not be most comfortable being on the chair and may prefer being on the floor while at home. While using a floor board may not be considered as the most dignified way of mobility by urban or western standards, but from the life style of persons with disabilities living in rural areas and the rural homes, it seemed the only option for not crawling or being carried every time by someone else. It is therefore also recommended that floor mobility devices such as a mobility board may be added as a part of the APL (11) to influence the national governments to include these in their assistive devices programmes as an additional device for home or indoor mobility.

Some of the experts consulted mentioned that it may be of relevance to make use of universal design principles. Although we do think that these principles are what we must strive for, we also think that realizing these principles in rural India is not easy and will take years if not decennia to achieve their application. However, until we progress to achieving full realization of personal mobility and home accessibility in rural areas (16) we think it is important to begin working towards making personal home mobility possible in a more urgent manner by taking a more reasonable and achievable approach that can be implemented more easily, such as using such a tool that supports attuning the existing physical environment with the mobility device in a simple manner to enable better indoor mobility for persons with disabilities in rural areas. In the future we intend to translate the tool in local language and work with the CBR workers to see what change it can bring in the lives of persons with disabilities living in rural areas.

Conclusion

Not having a suitable mobility device significantly lowered the mobility and independence to undertake activities at home of persons with mobility impairments living in rural homes. Especially in rural areas in low income setting this is a big problem as often persons with disabilities are unable to use the mobility device within their homes as a result of inaccessibility of homes or cultural preferences to be at floor level. The existing tools for evaluating physical accessibility are not adjusted to these rural settings and neither do they address differences in personal homes spaces based on the mobility device used by individuals. The tool we have designed and presented here will contribute to a better assessment of the environment in rural settings and better attune the environment with the mobility devices people use, contributing to making people more mobile.

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Appendix

Table 2. Tool for attuning home environments to the mobility devices

Areas	Sub-areas	Description	For wheelchair users	For floor mobility device users	For walking aids users
Access route	Surface finish	Step free	OK	OK	OK
		With steps	Ramp with gradient less than 1:12	Ramp with gradient less than 1:12 and handrails on both sides of ramp	Handrails on both sides of the steps
		Cemented	OK	OK	OK
		Covered drains	OK	OK	OK
		Remains dry without stagnated water	Cross slope less than 1:50	OK	OK
	Minimum width	NA	Minimum 0.9 m for wheelchair & 1.2 m for tricycle	--	--
	Resting spaces	NA	--	--	After every 50 m
Illuminated	Well illuminated at night	OK	OK	OK	
Courtyard	Entrance	Step free	OK	OK	OK
		With steps	Ramp with gradient less than 1:12	Ramp with gradient less than 1:12 and handrails on both sides of ramp	Handrails on both sides of the steps
	Entrance Gate	NA	Minimum 0.9 m for wheelchair & 1.2 m for tricycle	--	--
	Floor surface	Levelled and cemented	OK	OK	OK
	Size of courtyard	NA	Minimum 1.5 m X 1.5m for wheelchair & 2 m x 2m for tricycle	OK. To allow to park and transfer to ground mobility device	--

Areas	Sub-areas	Description	For wheelchair users	For floor mobility device users	For walking aids users
	Bench	NA	--	--	A seat or parcel shelf may be provided for rest opportunities
In Door	House entrance	Step free	OK	OK	OK
		With steps	Ramp with gradient less than 1:12	Ramp with gradient less than 1:12 and handrails on both sides of ramp	Handrails on both sides of the steps
		Door width	Minimum 0.8 m	--	--
		Threshold absent	OK	OK	OK
		If threshold present	Lower than 35mm	OK	OK
			Portable ramp on both sides of gradient 1:8 with a connected landing of 0.28 m Alternatively, a threshold that slides out be provided	OK	OK
	Inside the house	Dimension	Internal dimension of living room to all wheelchair manouvering space	--	--
		Internal mobility	Doors absent where privacy is not required. No thresholds on internal doors	OK	OK
		Storage	Storage shelves reachable while sitting on chair	Storage shelves reachable while sitting on floor device	Storage shelves reachable by a standing height
		Switches and sockets	Installed at a height 600 – 1100 mm and not in the corner	Installed not higher than 0.8 m	--
Kitchen	Cooking slab	Height	At height that allows the vision of the contents in the pan in a sitting position	At height that allows the vision of the contents in the pan while sitting at floor height	At a height that allows the vision of the contents in the pan in a sitting position

Areas	Sub-areas	Description	For wheelchair users	For floor mobility device users	For walking aids users
			--	--	A chair/stool available to sit next to the slab.
	Access to water	While cooking	Close to cooking at a height reachable from chair sitting position	Close to cooking areas at a height reachable from floor sitting position	Close cooking area at a height reachable without moving chair
		While washing utensils	Washbasin with at a height of 750-800 mm with space for wheelchair access and water storage close at hand	Lower level platforms or seats for washing utensils on floor with water storage close at hand	Washbasin with at a height of 750-800 mm with space to keep a chair/stool and water storage at close hand
	Internal Dimension		Internal dimension of room to all wheelchair manouvering space	--	--
Toilet & Bath	Location	Close to home	OK	OK	OK
	Access route	Step free	OK	OK	OK
		With steps	Ramp with gradient less than 1:12	Ramp with gradient less than 1:12 and handrails on both sides of ramp	Handrails on both sides of the steps
		Cemented	OK	OK	OK
		Covered drains	OK	OK	OK
		Minimum width of pathway		Minimum 0.9 m for wheelchair & 1.2 m for tricycle	--
	Toilet room	Internal Dimension	Internal dimension of room to all wheelchair manouvering space	--	--
		Door width	Minimum 0.8 m	--	--
		opening outwards	OK	OK	OK

Areas	Sub-areas	Description	For wheelchair users	For floor mobility device users	For walking aids users
		Door handle and lock	Reachable from chair sitting height. D-shaped handle preferred.	Reachable from floor sitting height. D-shaped handle preferred.	Reachable from standing height. D-shaped handle preferred.
		Threshold absent	OK	OK	OK
		If threshold present not higher than 0.15m and bevelled	OK	OK	OK
		Floor finish	Cemented	OK	OK
			Well drained	OK	OK
			Non-slip	OK	OK
		Indian style toilet seat	Provide a bench or chair with a hole	OK	Provide a bench or chair with a hole
		Western style toilet seat	OK	--	OK
		Location of seat	Located against the wall diagonal from the entry door with center line of toilet 450 to 500mm from the wall	--	Located against the wall diagonal from the entry door with center line of toilet 450 to 500mm from the wall
		Grabrails to support in transferring or standing	Grabrails 200mm above toilet seat	Grabrail 200 mm above floor height	Vertical grabrail fixed on wall next to the seat to help in standing from sitting position
	Water storage at arms distance from seat	OK	OK	OK	
	Shower seat/bench	Shower seat/bench height	Height 0.45- 0.50 m	At floor height	Height 0.45- 0.50 m
		Clothes hook and toiletry shelf	Reachable while sitting on bench	Reachable from floor height	Reachable while sitting on bench

Policies and programmes

Assistive technology content in United Nations Convention on the Rights of Persons with Disabilities reports by states parties

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Abstract

The UNCRPD lays out specific reporting guidelines for States Parties which describe progress made towards the commitments, which may be used to understand the global level of reporting on issues related to disability. The objective of this research is to assess the degree of engagement by countries who are signatories to the UNCRPD in development and implementation of policies related to assistive technology to promote participation for their citizens. To complete this research, we conducted a keyword analysis of a sample of UNCRPD Reports by States Parties and compared reporting across countries at different UN Human Development Index levels in each of the six WHO regions. The majority of reviewed reports demonstrate evidence of a systematic approach to assistive technology, without evidence of evaluation or engagement of persons with disabilities in policy development or evaluation. Different approaches to the provision of assistive technology are apparent throughout States Parties reports, however without evidence of evaluation, it is difficult to ascertain if these policies are effective at achieving their aims. Future reporting should focus on specific policies and activities undertaken to promote access to assistive technology for all citizens, using systematic reporting methodologies.

Keywords

UNCRPD, reporting, assistive technology, monitoring and evaluation

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) came into force in 2008, as the first international human rights treaty to address the rights of persons with disabilities (PWD) (1). The UNCRPD goes beyond the rights and freedoms stated in the UN Declaration on Human Rights (1948) to explicitly spell out how these rights and freedoms should be realized for all individuals with disabilities. Furthermore, the UNCRPD attempts to place the narrative within a social and human rights model of

disability, recognizing the role of society in creating or dismantling disabling environments (2).

The Articles of the UNCRPD recognized the intersectionality of disability, and the necessity for States Parties to address the challenges associated with disability across a variety of sectors. The articles notably include content related to the experience of women and children with disabilities, who are historically marginalized, and addresses topics as broad as transportation, access to justice, and participation in social and political life. Each of these Articles represents key areas which must be addressed to realize the full rights of persons with disabilities, requiring States Parties to take appropriate assistive technology measures to ensure the enjoyment of these rights (3). Particularly relevant to this paper, Article 32 (International Cooperation) outlines the requirement for States Parties to provide “as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies” (1). To respond to this call, the World Health Organization (WHO) formed the Global Cooperation on Assistive Technology (GATE), to mobilize global resources to advance and meet the assistive technology needs of persons with disabilities (4). This initiative is now underway, prompting a need to consider evaluation of the initiative on a global scale.

The UNCRPD lays out mandated reporting schedules, with each State Party required to report on progress made towards achieving the objectives of the Convention, two years after bringing the convention into force, and subsequently every four years following (1). This reporting requirement provides a window into global progress towards achieving comprehensive rights for persons with disabilities in each of the 177 states who are signatories to the Convention. Reports by States Parties represent the standard reporting methods for countries on their obligations to the UNCRPD as signatories (5). As such, they are an excellent source of data on a state’s progress towards meeting their obligations, including those relevant to assistive technology.

Understanding the current situation of reporting on assistive technology by States Parties will provide an opportunity to highlight those who are meeting their obligations in this area very well, and to provide incentive and guidance to those who may be struggling to do so. Providing guidance to States Parties for future reporting may also inspire opportunities to enhance access to assistive technology for their citizens and allow identification of those countries or regions who may be struggling to meet their obligations. This may promote projects which can be initiated through regional or international partnerships to meet these obligations, and ultimately result in greater access to assistive technology on a global scale. Therefore, the objective of this research is to assess the degree of engagement by countries who are signatories to the UNCRPD in development and implementation of policies related to assistive technology to promote participation for their citizens.

Methods

We conducted a content analysis and rating of a selection of UNCRPD Reports by States Parties, using keyword analysis. Countries who have ratified the UNCRPD and completed reporting were listed in order of UN Human Development Index (HDI) ranking (6) for each of the six WHO regions. To select a sample for analysis, every third state (as listed in the HDI) in each region was included for analysis, beginning with the state ranked highest in that region and proceeding through the list. If a States Party's initial report was not available in English, we used the next state on the list for analysis. Table 1 lists all States Parties included in the analyses by WHO Region.

Table 1. States Parties included for Analyses

WHO Region	States Parties Reports Analysed
Africa	Seychelles, Gabon, Kenya, Mauritania, Senegal, Ethiopia, Niger
Americas	Canada, Uruguay, Cuba, Brazil, Colombia, Paraguay, Guatemala
Eastern Mediterranean	United Arab Emirates, Oman, Iran (Islamic Republic of), Iraq, Djibouti
Europe	Norway, Sweden, United Kingdom of Britain and Northern Ireland, Luxembourg, Slovenia, Italy, Greece, Lithuania, Latvia, Croatia, Bulgaria, Turkey, Georgia, North Macedonia, Turkmenistan
South East Asia	Thailand, India, Nepal
Western Pacific	Australia, Japan, China, Viet Nam, Lao People's Democratic Republic

Each report was searched for keywords including assist*, techn*, device*, equipment, prosthe*, aid*, enable*, product*, wheelchair*, mobility, and communication. We also conducted a manual search of articles 1-4 (General Provisions), 19 (Living Independently and Being Included in the Community), 20 (Personal Mobility), 24 (Education), 25 (Health), 26 (Habilitation and Rehabilitation), 27 (Work and Employment), 29 (Participation in Political and Public Life), 30 (Participation in Cultural Life, Recreation, Leisure, and Sport) and 32 (International Cooperation) for mentions of assistive products or relevant policies. These articles were selected by the research team as the most likely locations for assistive product mentions.

Based on the keyword and article search, we then assigned a rating (with reliability assessed between two raters) according to a six-point rating scale ranging from 0 to 5. Details of each rating is provided in Table 2. Once ratings were assigned, we conducted descriptive statistical analyses (percentages, median, mode) to describe the current state of reporting in each region, and overall. We also assessed the relationship between HDI value and reporting rating using a Spearman's correlation and graphical analysis.

Table 2. Description of Ratings

Rating	Description
0	No mention of assistive technology services or products in any article.

Rating	Description
1	Mention of specific assistive technology in isolation (i.e. mention of prostheses but no other assistive technology)
2	Several mentions of assistive technology across a variety of articles, but no systemic approach or inclusion
3	Assistive technology related policy or systematic inclusion of a range of assistive technology, across a variety of sectors, with limited or no evidence of evaluation of policy or provision.
4	As in 3, with evidence of evaluation of assistive technology policy or provision
5	As in 3, with evidence of user engagement in assistive technology policy development, implementation, evaluation, and provision.

Results

Reports by States Parties were reviewed from a total of 42 countries across the six WHO regions. Two countries (Bahrain and Andorra) were not reviewed as their Initial Reports were not available in English. In each case, the subsequent state on the list was used in lieu.

Reporting Status

Of the 177 countries or states which have ratified the UNCRPD, 68.0% have completed reporting. Rates of reporting range by region from 62.5% in the Western Pacific, to 88.9% in South East Asia. Table 2 provides additional details regarding ratification and reporting.

AT Content Ratings

Ratings across the 42 countries which were analyzed ranged from 1 to 5. No countries reported a policy unique to assistive technology, and no countries were entirely without mention of assistive technology in their reports. Nearly half (n=20; 47.6%) of the countries reviewed were rated as a 3, with 26.2% (n=11) rated as a 2. The median and mode ratings across all countries were 3. Further details are available in Table 3 regarding ratings by region. Table 4 provides sample language from case countries at each of the 5 rating levels (1-5). Figure 1 provides a visual representation of reporting ranking by UN HDI Value and Region. There was a small positive correlation between HDI Value and Rating (0.148; i.e. as HDI Value increases, assistive technology reporting rating increases) however it is not statistically significant (p=0.349).

Table 3. Ratification and Rating Data by Region

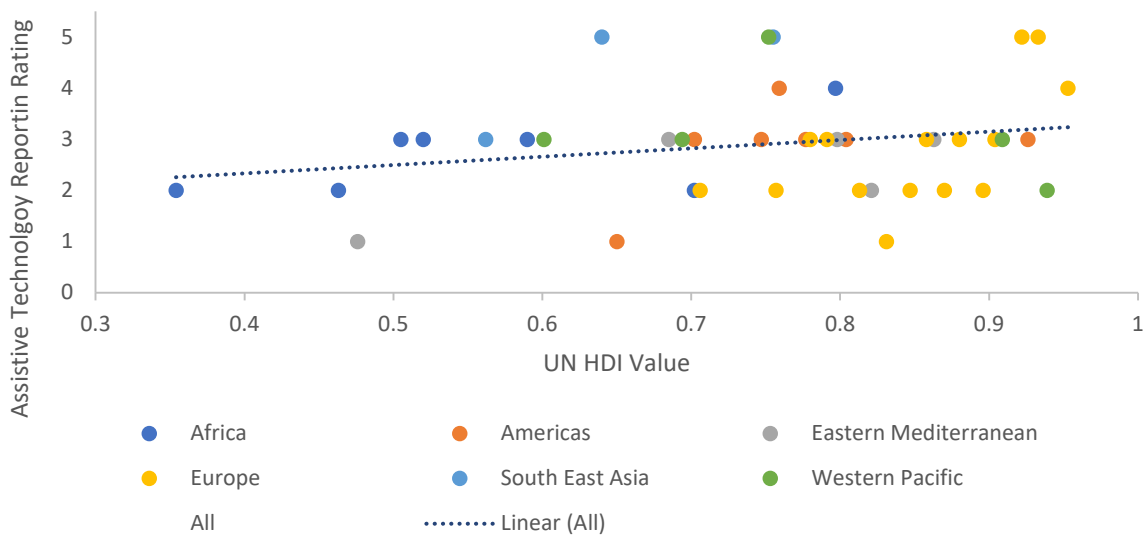
Region	# Ratified	# Reporting (%)	Rating (median)	Rating (mode)	Rating (range)
Africa	42	19 (45.2)	3	2	2-4
Americas	32	21 (65.6)	3	3	1-4
Eastern Mediterranean	19	13 (68.4)	2.5	3	1-3
Europe	52	45 (86.5)	3	2	1-5
South East Asia	9	8 (88.9)	5	5	3-5
Western Pacific	24	15 (62.5)	3	3	2-5
All	178	121 (68.0)	3	3	1-5

Table 4. Sample Reporting Language by Rating Level

Rating	Criteria	Sample Reporting Language (Country)
1	Mention of specific assistive technology in isolation	“To address the issue of mobility of persons with disabilities, two centres produce prostheses and orthoses to improve mobility for persons with disabilities.” (Guatemala)
2	Several mentions without systematic approach	(In residential care homes) “...Persons with disabilities and elderly persons with special needs are provided with hearing aids, eyeglasses, prosthetic and orthopaedic appliances, as well as unpowered mobility devices such as wheelchairs, walking sticks and crutches (Article 28); “...children with disabilities under 16 years old are provided with medicines, dental prosthetic, treatment, orthopaedic and other such appliances, patient-care equipment and wheelchairs free of charge” (Article 7) (Turkmenistan)
3	Assistive technology policy or systematic approach with no evidence of evaluation	“Assistive devices (e.g. walking frames, wheelchairs, special beds, adapted vehicles) and home alterations (e.g. walk-in showers, lifts, concrete ramps) have been made available to persons with disabilities with a view to maintaining or increasing their level of independence. The maximum amount that can be claimed stands at €26,000.” (Article 19) “The dependency insurance scheme provides persons with any assistive devices they need, including wheelchairs and walking frames. Assistive devices are available free of charge to persons with disabilities.” (Article 20) “The aim of the Accessory Equipment Service is to improve the quality of life of persons with reduced mobility and enable them to remain at home. It offers advisory and information services and lends equipment and accessories, as well as technical aids.” (Article 26) (Luxembourg)

Rating	Criteria	Sample Reporting Language (Country)
4	Assistive technology policy or systematic approach with evidence of evaluation	<p>“Within the framework of the National Plan on the Rights of Persons with Disabilities launched in November 2011, the SUS rehabilitation network will be expanded and qualified, in partnership with national institutions, and 45 Rehabilitation Reference Centers (Centros de Referência em Reabilitação) ... implementation of 6 orthotic workshops and 13 traveling orthotics workshops, ... qualification of professionals engaged in the 60 existing orthotics workshops...allocation of SUS resources to adapt and maintain wheel chairs...20% expansion of orthotics, prosthetics, and mobility aid supplies...” (Article 26)</p> <p>“... The survey focuses on questions previously by the Ministry of Health, namely, the need for greater decentralization of specialized rehabilitation services and greater flexibility in care delivery and the supply of adaptive technologies, in particular to the poorest population segments.” (Article 26)</p> <p>(Brazil)</p>
5	Assistive technology policy or systematic approach with user engagement in development and evaluation	<p>“Scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances (ADIP) Scheme: The main objective of this Scheme is to assist the needy PwDs in procuring durable, sophisticated and scientifically manufactured, modern, standard aids and appliances with ISI specifications that can promote their physical, social and psychological rehabilitation, by reducing the effects of disabilities and enhance their economic potential.” (Article 20)</p> <p>“The Central Coordination which is headed by the Minister of Social Justice and Empowerment, members “five persons, as far as practicable, being PwDs to represent NGO’s or associations which are concerned with PwDs” ...This Committee has been envisaged “to serve as the national focal point on disability matters and is required to facilitate the continuous evaluation of a comprehensive policy towards solving the problems faced by PwDs”...Monitor and evaluate the impact of policies and programmes designed for achieving equality and full participation of persons with disabilities...” (Article 33)</p> <p>(India)</p>

Figure 1. Reporting Rating by HDI Rank and Region



Reporting by Article

Reporting differed substantially by Article of the UNCRPD. There was no reporting of any assistive technology related content in 10 of the articles. Article 20 (Personal Mobility) had the most frequent assistive technology related reporting, with 71.4% of countries reviewed having content in that area. This was followed by articles 26 (Habilitation and Rehabilitation; 66.7%), Article 25 (Health; 42.9%), Article 24 (Education; 40.5%), and Article 19 (Living Independently and Being Included in the Community; 31.0%). The remaining articles had 10 or fewer countries reporting in the area.

Discussion

Reporting status differed substantially across regions, suggesting capability to complete reporting according to the prescribed schedule may be challenging in some areas. Across all states, roughly two thirds had completed reporting at least once between ratification and the time of writing. Considering the reporting mandate of two years following ratification, and every subsequent four years, this has not been complied with in most, if not all, cases. However, non-reporting, or delayed reporting, is not uncommon in other international treaties (7) and the sometimes lengthy turn-around time of treaty bodies may contribute to this. Furthermore, without meaningful penalties which can be assigned to non-reporting states, there is little incentive to complete reports on the prescribed schedule. Further research may review reporting status across international treaties to identify facilitating factors and barriers to reporting.

Among those States Parties reviewed, the majority demonstrated some systematic approach to assistive technology, or the presence of assistive technology content, across a range of articles or sectors. However, more than half did not demonstrate any evidence of evaluation of those policies in their reports. While it is possible this reflects on poor

reporting of existing evaluation procedures, it is equally likely that there is little policy evaluation or monitoring occurring. It has been suggested this may be due to a lack of analytical capacity and expertise within governments, leading to poorly developed policies which are not evidence informed (8). However, policy evaluation is critical for monitoring and understanding the impact of policies, to help craft effective and meaningful future policy (9). Both the process of policy development and evaluation (10), and the content of policy (2,11), should be equitable, allocating the necessary resources to provide different sections of the population – including people with disabilities – with opportunities to achieve similar outcomes. Given the limited reporting on evaluation in this study, this consequently means the majority did not describe evidence of inclusion of assistive technology users or individuals with disabilities in crafting or evaluating their policies. This is contrary to the recommendation of a co-construction approach, engaging persons with disabilities in the policy development process (12). Engaging individuals with disabilities in the development and evaluation of policy democratizes these process, and leads to more meaningful and effective policy (13).

While a State Party report may indicate a relevant policy exists, or where there are mentions of assistive technology in other policies, we are neither able to ascertain the quality of the policy, nor the likelihood of implementation. This is similar to the challenge of user engagement in policy development or evaluation. In five cases, countries reported user engagement in policy development or evaluation in their States Parties Reports, however it is impossible to speculate on the quality of the engagement. For example, in India user engagement is reported through the engagement of a committee, where a minimum of five individuals with disabilities sit on the committee, each of whom represents a different disability. Whether this is meaningful engagement or tokenism is worthy of consideration. Arnstein's ladder of citizen participation suggests consultation in the policy evaluation process may represent a form of tokenism, which should not be mistaken for true engagement or involvement (14). Instead, individuals impacted by the policy, in this case assistive technology users, should be an integral part of both policy development and evaluation (15).

The possibility of inadequate reporting should also be considered. Simply because something is lacking in a report is not an indication that it does not exist. However, there is an expectation of ongoing reporting on relevant policies, strategies, and programs which pertain to individuals with disabilities, and therefore, assistive technologies. Should those policies and programs exist, we expect they would be reported on in this format, but this may also point to the potential value of more explicitly reporting guidelines regarding assistive technology.

It was interesting to note the varying rates of reporting depending on the specific Article of the UNCRPD. While there was some expectation that there would be higher rates of reporting relevant to assistive technology in Articles 20 (Personal Mobility), 24 (Education), 25 (Health), and 26 (Habilitation and Rehabilitation), others were notably absent. For

example, there was a very low rate of relevant reporting in Article 32 (International Cooperation) despite the explicit involvement of assistive technology in the text of the article (1). While there is recent interest on international co-operation in assistive technology, in the form of the AT2030 project supported by the British Department for International Development (DFID), for instance, this is a ground-breaking initiative and certainly not the norm among government donor agencies (16).

We encountered some challenges specific to the rating scale which should be addressed. For example, states which are federated (e.g., Canada) or who are made up of constituent countries (e.g., the United Kingdom) were more difficult to assess due to varying policies across their various jurisdictions. With responsibility for many of the facets of the UNCRPD lying with each jurisdiction, this may be reported in a disjointed manner. In the case of Canada, the report was difficult to read, and showed a national system which is not well coordinated, with provincial variation in access to services. In the absence of coordinated access to assistive technologies, there is inequity in access across provinces and territories (17). The lack of an overarching policy which is relevant to all jurisdictions is a notable deficit in this case, which is difficult to capture with the current rating system.

Furthermore, in countries with well-established national insurance schemes, there may not be specific mention of assistive technologies as they are understood to be covered. In these cases, it would have been necessary to review additional documents in detail to make an informed decision. However, certain assumptions were made based on additional information provided for each of the relevant articles. Given the recognition of the value of a systems-thinking approach to assistive technology (18), we believe it would be important to encourage a more systematic approach to how state parties report on assistive technology in their country. For instance, the extent of the “Assistive Technology System Gap” could be probed by reporting on the known or estimated need for assistive technology, and the populations awareness of it, its availability, affordability, accessibility, adaptability, acceptability, quality and use; which may be conceptualized as a funneling process, and one which can easily create barriers to access if not systemically addressed (15). Similarly the human resources ‘gearing’ of a country, in terms of its readiness to supply the necessary assistive technology to scale – the distribution of the available skill mix (19) – could be reported in ways that would allow for easier comparison between countries, affording greater opportunities of learn form each other.

Recommendations

1. We recommend that a General Comment on Assistive Technology be developed and adopted in addition to the UNCRPD (15). This would facilitate more specific and guided reporting on assistive technology related activities and contribute to more effective assessment of States Parties’ initiatives to improve access to assistive technology.
2. When reporting on assistive technology related policies and activities, the use of standardized language would promote greater understanding and monitoring of

relevant activities. We recommend the use of language used by the GATE initiative, including the term 'assistive products' to refer to the specific products used to promote independence at home or within the community (20).

3. In UNCRPD reporting, States Parties should endeavour to identify how access to assistive technologies may be relevant across a variety of articles, and report on those activities to promote access to assistive technologies for their citizens.
4. When presenting relevant policies, States Parties should endeavour to include details on the inclusion of persons with disability in policy development, implementation and evaluation.
5. Where there are no relevant policies in place or activities to report, States Parties should endeavour to comment on any plans or efforts made towards the provision of assistive technology for their citizens.
6. We recommend that social protection policies that include social cash transfer programs for the elderly, children, and persons with disabilities in developing country context that are increasingly assessing general population to ascertain disability status consider offering assistive technology. This would allow for procurement at scale and potentially competitive prices.

Conclusions

Different approaches to the provision of assistive technology are apparent throughout States Parties reports, however without evidence of evaluation, it is difficult to ascertain if these policies are effective at achieving their aims. Future reporting should focus on specific policies and activities undertaken to promote access to assistive technology for all citizens. To achieve this, a systematic reporting methodology may be facilitated by the development of a General Comment on Assistive Technology reporting for the CRPD. This approach should also feature within the forthcoming Global Report on Assistive Technology.

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Innovation in sustainable assistive technology services using social enterprise as a basis for collaboration between non-governmental organizations and government

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Abstract

To understand the innovation in collaboration and funding in South and South East Asia, it will be necessary to recap the 26 years history of the efforts to build sustainable Prosthetic Orthotic PO services in the region. The context is important, in order to understand the level of collaboration, investment and understand successes and failures (1). This paper will be focusing on South and South East Asia, one of the fastest growing economic regions of the world in this discussion on Assistive Technology AT in particular PO services, starting with Cambodia. We will attempt to tap into the considerable body of knowledge that exists among the stakeholder, much of it in internal reports and amassed through the experience of the authors (2). We also draw on reflections with academic partners researching user, industry, government relationships. The story is important in terms of best practice and lessons learned. During the time period from the end of conflict and through the genocidal and civil war periods of Cambodian history, new PO technologies emerged, new NGOs were formed, many still playing an important role in PO services. The paper will report on how lessons learned have informed a pilot project developed with the Royal Government of Cambodia to attempt to understand the market for PO devices and test models for financial sustainability. Results from pre-project evaluation and interim results of the market testing are presented.

Keywords

Social Enterprise. Physical Rehabilitation. Cambodia. South East Asia. Sustainability. Prosthetics Orthotics

Prosthetic Orthotic development.

Education, infrastructure, technology, investment

Cambodia is a focal point for PO innovation in the region and leads the way in training of PO professionals. With a major investment from Japan's Nippon Foundation, (3) working with Exceed, the country became the focal point for the dissemination of PO education across

the region. Cambodia, burdened by high number of amputees from Explosive Remnants of Warfare ERW, and high numbers of person with Post-Polio syndrome, received a high level of investment from the international community in both infrastructure and capacity building. The high level of investment in Cambodia reflected the amount of public interest in the traumatic history of the country, but also the focus of the Ban the Landmine Campaign and the Nobel Peace Prize 1997.

In the early 1990s, a high level of collaboration between NGOs, INGOs and the Ministry of Social Affairs, Veterans and Youth Rehabilitation MoSVY (4) created the basis of a symbiotic national PO system, establishing 15 Physical Rehab Centres PRCs across the country. The PO sub-committee of MoSVY established a very high level of collaboration that addressed component and raw material supply chains, unified technology, infrastructure, financial support and PO professional training. The key players were:

- The International Committee for the Red Cross, ICRC, who manufactured PO components for the country, and supported one PRC
- Handicap International HI, supported 5 provincial PRCs
- Veterans International VI, supported the National Rehab Centre Phnom Penh and two provincial PRCs.
- American Red Cross, supported 1 PRC
- The Cambodia Trust (Now Exceed) PO professional Education and three PRCs (5-7).

N.B. Physical Rehabilitation of mobility impaired persons was the purvey of a Social Affairs Ministry and NOT the Health Ministry. It can be speculated that the “Social Model” of disability, as a philosophy, was much more to the fore. However, recent reports indicate a worrying disconnect between Hospitals and PRCs (8).

Bulk purchasing, quality assurance and delivery processes were put in place for both locally manufactured and imported materials and components, the PRCs shared data bases and managed workflow from the component factory.

Funding was available through donors for the building and equipping of new PRCs, usually on Government owned land, close to Hospitals or on their grounds. Most PRCs achieved client accessibility via outreach teams and free or subsidized transportation.

The Cambodian School of Prosthetics and Orthotics CSPO, established by Cambodia Trust (now EW) 1994 is now the Department of PO (DPO) of the National Institute of Social Affairs (NISA) founded in early 1994, delivered accredited international standard PO professional training. This amounted to three years of study, at Category II (WHO/ISPO guidelines) (9) level, in classes of up to 12 students annually. Having achieved ISPO standards of recognition in the 1997 audit, the CSPO had achieved its target of delivering 100 trained POs to the PRCs by 2002.

Throughout the years 2000-2012, programs consolidated and strengthened their structures. EW accredited (ISO 9002) and managerial tasks were progressively passed from foreign

experts to local staff. In late 2010 the NGOs began to prepare for “handover” to government, however, the handover planning process was not participatory, i.e. NGOs and Government did not have a consensus plan. In addition, the government ability to fund and maintain the projects was limited. In effect, the first attempt to handover failed.

In response to the UN convention on the rights of PWD, the Disability Action Council DAC was established as an independent oversight body, but soon was absorbed into the Government system, rather than remain a quasi-autonomous body to check and challenge.

In response to dwindling levels of international support, the government established in 2011-13 a “Persons with Disability Foundation” PWDF, which was funded by a levy on Cambodia’s commercial sector linked to employment of persons with disability (or not). In 2019, the Disability Rights Administration Office was established to develop further the levy initiative.

Since its formation, the PWDF has taken over full responsibility for six PRCs, as NGOs have pulled out, while six others remain with support from NGOs or INGOs. Three have been downgraded to repair centres. The PWDF also provides support for the centres still supported by the international community and provides salaries for key staff and material support. The PWDF also manages the Orthopaedic Component Factory OCF since 2015, but now charges the NGOs for components.

While there is some “lack of clarity” about the overlapping roles of the three oversight bodies, Department of Disability Welfare in MoSVY, DAC and PWDF. There has been progress towards sustainable service delivery. However, it is clear that during the transition, services have declined as staff have resigned and supply the chain has become less robust, bringing some cause for concern. What is clear is that Cambodia is some way off from total funding of all free PO services at this time.

CSPO/DPO and sustainability

In July 1993, Exceed (then the Cambodia Trust) took up the role of “educator”. It was accepted that the new PO school should conform with the guidelines (9) of the International Society for Prosthetic Orthotics ISPO and The World Health Organisation. Accreditation audit was complete in 1997-98.

By 2002-2003, the target figure of 80-100 Cambodian graduates was within sight, and following consultation with the partners, it was decided that the school should remain in place in Cambodia but offer its services to fee paying students from abroad, while maintaining a small number of Cambodian graduates to sustain the workforce. From the 2000 intake until the present day, fee paying students (from 25 countries) and bursaries have provided up to 70% of the cost of the school and its training clinic and sustained an important strategic asset within the country (7).

In 2000- 2001, with the support of The Nippon Foundation, Japan, and Exceed Worldwide carried out a two-year process of regional strategic planning (10) for PO in the region was

carried out and a document outlining the needs and offering solutions for Sri Lanka, Indonesia, Philippines and Myanmar was developed. Over the next 12 years, Exceed Worldwide rolled out the CSPO model across the region, using the curriculum, management processes, teaching methods, teaching manuals and utilizing Cambodian teaching staff and resources to seed the modern PO service in each country.

In Sri Lanka and Indonesia, following ten years of investment, training of trainers and institutional development, the training school SLSPo and Jakarta School JSPO were fully handed over to the local Government within the MoH education departments, and are fully sustained by them.

Philippines school is embedded in a “Not for Profit” private university and is due to be handed over in 2021, Myanmar is also due for handover 2024 to the Ministry of Health Education system, within the University of Medical Technology.

The investment by The Nippon Foundation, in all six schools over a twenty-year period, will top out at around \$55 million, if we include Thailand, where investment was also made in Mahidol University Bangkok. Objectives set in the plan have been achieved and the investment has been successful (8), and graduates who are seeking jobs are able to find jobs, however a recent ISPO evaluation voiced disappointment that the Health care systems in all six countries had not fully integrated the professional PO into the systems and had not invested enough in infrastructure. Some 800 graduates or students currently are to be found in the region, with the probability of an output of 100-120 per annum going forward. (ISPO accredited)

It is therefore likely that the upper target figure of 2-4,000 PO practitioners for the region is not fully achievable given the capacity of the education system and given that within the next 5-10 years, the earliest graduates from the mid 1990’s will be starting to retire.

Questions therefore arise

1. Absorptive capacity: Is there enough infrastructure and funding in place to employ 2-4,000 practitioners in the region?
2. Is there the will to invest from within the countries?
3. Is there a willingness for high school graduates to enter a profession that is not well established?
4. Is the training capacity in the right places to match populations?
5. Is there going to be money in the service delivery system to drive demand and create a market?
6. Where does financial sustainability for service provision come from?

For the present moment, there is not enough committed funding from regional governments to absorb graduates into a government funded health or social system. Recruitment of new students is becoming more difficult as graduates face employment challenges.

Training capacity per country is not yet balanced. Cambodia with a population of 12 million and Indonesia with 250 million both have just one PO school (accredited). Thailand, Myanmar and Sri Lanka are reasonably well balanced. The Philippines with almost 100 million people could easily absorb a second school.

While each of the target countries, stimulated by the availability of trained PO professionals, has invested in PO infrastructure and supply chain, the investment is often opportunistic rather than planned, and often resource limited. Broadly, we can claim that creating a work force has stimulated investment. However, the absorptive capacity and political will to create more jobs and hence better services remains questionable.

What does “financial sustainability” mean in this context?

- Balancing the books
- Maintaining core activities and outputs
- Most importantly, it was seizing opportunities, creating opportunities and taking responsibility for one’s own fate.

It was concluded by experienced and pragmatic Cambodian staff that financial sustainability would be a blend of Government money, donations, fees and sales, a dynamic balance that would change year by year. With infrastructure, trained staff and equipment in place, the missing element is financial. In many ways, this definition mirrored the attributes of any small to medium enterprise SME

Historic Models of Funding PO development and services

CSPO/DPO and Exceed supported services and regional development partners have experienced:

1. Government support for staff salaries and some overheads
2. Donor support for service provision
3. Engagement and donations from High Net Worth Individuals
4. Grants from other Governments for education and services
5. Fee paying students coming from 25 separate countries
6. Bursaries for students from abroad and at home.
7. Institutional development grants from The Nippon Foundation over 20 years.
8. Large and small grants for buildings and infrastructure.

All of these funding systems are transient and while they are highly valuable at the development stage, they are not reliable for long term financial sustainability.

What model can provide that level of financial sustainability in the region

Funding from Government Health Systems.

In countries with public health care infrastructure, income from the taxation pots will be used to sustain services but of course, PO services must compete with acute services, public health programs, emergency medicine and other demands. Experience shows that PO

services are rarely seen as a priority in LMICs, except in post conflict situations where government want to support veterans.

Funding from Private Medical Insurance.

Medical insurance or workers compensation plans are often used for PO services, but often they don't cover PO at all. Universal coverage often does not understand the life-long commitment to PO care demanded by each client.

Charitable donations.

While there is a place for donation led services, it is hard to maintain continuity of funding for generations. It can also be argued that persons requiring a PO device should not be seen as "charity cases". The "charity model" can lock PWD into a culture of dependency and victimhood.

Profitable Business.

In the SE Asian region, we are seeing growing interest from large PO service provider "for profit" companies, who target the super wealthy patients. The companies are employing PO graduates of the regional schools (without having to invest in a workforce) and profits return to the company.

Social Enterprise

A profitable business, if well managed, is truly sustainable. Social Enterprise, is a more viable and equitable alternative to "for profit".

"A social enterprise is a commercial organization that has specific social objectives that serve its primary purpose. Social enterprises seek to maximize profits while maximizing benefits to society and the environment. Their profits are principally used to fund social programs (11).

Funding is obtained primarily by selling goods and services to consumers, (payment can be via the customer or through a Third Party Payer) although some funding is obtained through grants. Because profit-maximization is not the primary goal, a social enterprise operates differently than a standard company".

Embracing the social enterprise model in PO services

In 2013 (12), Exceed dropped any expectation that Government funding would be able to fully sustain PO services and looked at more innovative ways to generate sustainable income. It therefore established a private limited company called Exceed Social Enterprise ESE.

This company is entirely owned by Exceed Worldwide (the NGO) and is registered in the United Kingdom. The company was capitalized by a legacy donation, a grant from The Australian Government and a grant from an international oil trading company foundation (Vitol). Three subsidiary companies were set up and registered in the Philippines, Sri Lanka

and Cambodia. Clinic space and workshops were established (through 2016) and graduate POs employed along with managers, technicians and salespeople.

The purpose of the company is to generate profit to sustain PO services and education.

Exceed Social Enterprise identified four specific areas where profits might be generated.

- High net worth clients who might travel abroad
- Middle-income clients or those with third party payer arrangements who wanted a differentiated service at a reasonable cost.
- Organisations and other service providers who needed a reliable and diverse supply chain.
- Individuals or small groups of PO graduates seeking to set up small private clinics (a rudimentary franchise)

Two separate divisions of the company were formed. Exceed Clinical Services and Exceed Supply and Distribution. One operates directly with PO service users while the other deals with suppliers and local service providers.

Local and regional products

With the emerging supply chains coming from China and other countries (e.g. Turkey, India) which are compliant with ISO standards, the marketplace is changing rapidly and medium to high tech products are now affordable. Exceed Social Enterprise is now acting as distributor for a growing variety of high end and medium level component manufacturers.

Clearly the market is changing, bringing generic components to the table. The impact of cheaper, high-quality products will be significant in the future and will be an important factor in PO service development.

It may be assumed that the new low-cost components will shift the market from the “exclusive, high end boutique” model and more towards the “Wal-Mart” low cost, high volume model. This can only be positive for consumers and third-party payers especially in LMICs.

Clinical services

Two ESE private clinics are now running, one in Sri Lanka and another in Philippines. Both seek referrals and support from the private sector medical system, and both work closely with clients and referring hospitals. Both have been established for three or more years and both are providing income to the core activities of the NGO Exceed.

Supply and Distribution

Exceed Supply and Distribution is working well and has a good trading relationship with a broad range of material and component suppliers and is profitable.

Social Enterprise as a model for sustainability in Cambodia.

A third clinic in Cambodia operates in close collaboration with the government through the PWDF and MoSVY. The original stand-alone clinic, which was completely outside the government sphere of influence, was not successful.

Exceed held detailed discussions with the Minister, The CEO of the PWDF and other stake holders which created ideas and innovations. To achieve these objectives a pilot project was designed and established.

The following are the overarching project objectives.

1. To establish if there is a market for “paid for,” differentiated PO services in Cambodia.
2. to provide evidence that might be used by Government to promote a change in legislation that might unpin the MoSVY from a “free services” constitution
3. To provide a road map for potential services in cost recovery or high-end services at other PRCs

Financial sustainability of the Physical Rehabilitation sector.

Adapting the Social Enterprise model to The Royal Kingdom of Cambodia.

A Pilot Project. December 2018 – December 2020

In discussions with the Royal Government of Cambodia, MoSVY (The Minister), it became apparent that Cambodia needed a new idea and a joint approach to sustainability and in particular, to financial sustainability. With a growing private sector, and many Public Private Partnerships across the nation, the Minister expressed a desire to tailor PO services to the needs and abilities of the population of persons with disability. He was willing to discuss a blended approach, with some clients paying (all of or partial costs) and free services being maintained for less resourced families. However, the MoSVY basic founding legislation, set in place decades ago, mandated free services for all. Basic founding legislation for the MoH has already been changed to allow cost recovery and fee paying in MoH hospitals, based on a means test.

In order to change the legislation, MoSVY needed evidence of a desire for differentiated services, evidence of an ability to pay for services, and an accurate methodology for assessing levels of poverty.

This Pilot Project is funded by EW as part of its general support to the Physical Rehab Sector, Cambodia and the education of Prosthetist Orthotists (PO) at DPO. It is carried out with support of academic partners.

The Thesis

Exceed believes that sustainability of services to people with disability through the PRCs, will come through a blended PPP approach, where Government, Not-for-profit (NFP) and Business enterprises will work together.

Testing the hypothesis.

Working with research institution partners Exceed aims to develop and test, PO services to persons with physical disability, offering a range of differentiated services, at a variety of “price points”. The pre-project scoping data, and information gathered over the two-year period would inform MoSVY of the willingness and capacity of clients to contribute to the cost of devices or seek higher levels of technology.

- Free simple Physical Rehab services at the point of delivery to those with low income.
- Simple Rehab devices, on a cost recovery basis for Physical Rehab services to those who have sufficient income.
- Fully private services to those who wish to pay for a differentiated and high-tech service.

Methodology

Pre-project market testing.

Before starting, client poverty assessments were made by senior staff comparing two separate poverty assessment tools, commonly used in Cambodia. Pre-approval by Government of the tools was an important factor. Over a period of one month, clients were assessed using both tools.

- MoSVY tool was developed several years ago with NGO Veterans International
- MoH tool was developed by MoH and is use in the National Pediatric Hospital NRH.

Results of 89 interviews were collated and compared.

NB. A new national assessment of poverty is being rolled out in the ex-years which will provide an identity card that will guarantee those in poverty will be identifiable (ID Poor)

Describing the service choices

Three services models are available on site at the clinic. All three are integrated in the DPO and is a teaching clinic for the students of the three-year training course.

The free service will continue, as before, with intern students, mentored and supervised by experienced POs, providing standard, high quality but simple technology devices to persons with disability with low income.

The same students will provide a similar service to clients who have demonstrable means, who can pay a modest fee to cover costs of materials and manufacture of devices.

In addition, there has been established, on the same premises, a Modern Services Clinic (MSC), providing appropriate but imported technology, as part of the teaching and internship experience for students and giving access to clients who wish to avail themselves of a higher level of service. Devices will be charged at a price that reflects the cost of components and the labour/overheads incurred. Very senior staff of DPO, those who have been well trained and have robust international experience will supervise the clinic. This service will be run on a “Social Enterprise” basis.

Income/profits from both the “cost recovery model and the MSC, will be monitored by the partners, and will fully comply with Cambodian Tax regulations. Profits will be used to offset costs of the free services of the DPO.

In addition to the clinic pilot project ESE will

- Support the other PRCs through supply chain management for the materials and components that need to be imported. ESE will enter the market as a competitive bidder for supplies.
- Promote the Cambodian Component Factory as an international supplier. ESE is the exporting agent for the factory (owned by the PWDF). This provides valuable income for the factory and helps assure its sustainability
- ESE will act as the importer and component supplier for the MSC at DPO, providing a sustainable supply chain.
- ESE will act as mentor and support to the research activity.

Project implementation.

The project has been integrated within the DPO BSc and Diploma level courses and is being managed from within existing resources.

Project management

The project will be managed on a day-to-day basis by the Senior Management Team of DPO and Exceed Worldwide.

Financial Management

Fees collected for the cost recovery model, or from those clients who avail of the MSC services, will be logged in a separate report on the electronic accounting system. This will be backed up with written pro forma invoices, charge slips and receipts, as per Exceed’s externally audited financial system. Supply items imported or used from stock will be recorded as costs to the project and suppliers paid in a timely fashion. The process of financial management of this income will be managed in accordance with our ISO 9002 accreditation.

Financial oversight will take place on a monthly basis and if the project is proving to be a financial loss-making event, its closure will be considered.

Project oversight

As a pilot project, which might provide strong guidance in the development of PO sustainable services, it is important that all lessons learned are properly understood and disseminated. An oversight committee has been proposed by the Minister. This committee will receive monthly updates and financial reports and will meet quarterly to review the progress and eventually, write the report. The initial project period should be two years: December 18 – February 2 2020.

Outcomes

Pre-project testing

Participants

Clients who came to receive services from DPO, whether they are first time clients or existing clients, were subject to the assessment. A parent or guardian of a child client who are under 18 years old was interviewed. There were 89 participants interviewed.

Method

An Exceed Community Development Team interviewed all clients by using the questionnaire which was adapted from a tool used previously by VI (MoSVY).

The questionnaire from the National Pediatric Hospital (NPH) (MoH) was also studied by the team to see differences. The contents of the questionnaires VI and NPH are similar. The different area is score-determining for categories. NPH produces 3 categories: (0-10 = very poor; 11-18 = poor; greater than 19 = not poor). VI produces 5 categories: (0-9 = very poor; 10-18 = poor; 19-27 = below medium poor; 28-37 = medium poor; 38-46 not poor). Exceed produces 3 categories: (0-19 = poor; 20-39 = medium; 40-56 = above medium to wealthy).

Figure 1. Outcomes using MoH poverty assessment tool

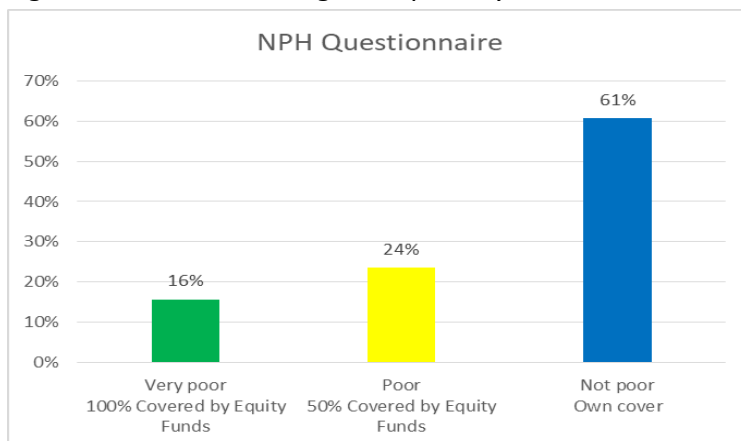
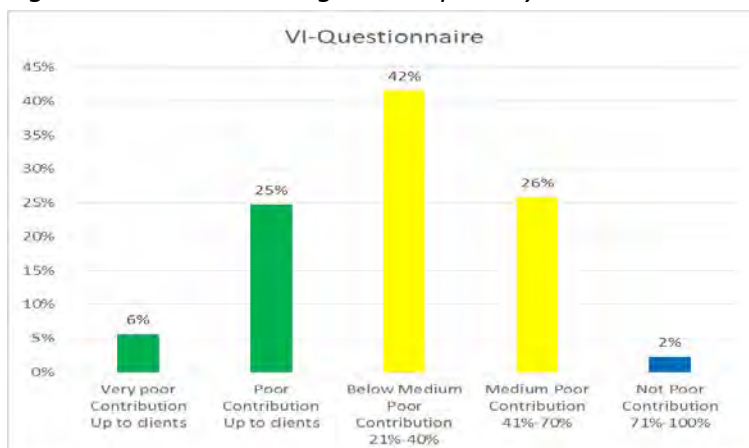


Figure 2. Outcomes using MoSVY poverty assessment tool



Results of pre-project testing

For NPH, only the client obtaining scores from 0 to 18 will be eligible to full finance coverage by Equity Funds.

For VI, the client falls in any category will not be eligible to free-of-charge services. No matter they are defined as very poor or poor. The client will be asked to pay contribution according.

For DPO, only the client defined as being very poor or poor by either MoSVY tool or carrying an ID poor card will be offered free-of-charge services. Those who fall in other categories will be requested to pay a cost recovery fee for devices they need.

Results

Based on the category setting from NPH, (MoH) there are 54 clients (61%) of 89 will not be eligible to free-of-charge services.

For VI, (MoSVY) there are 42% (37 clients) will be asked to pay between 21%-40% of total device cost of the device and 26% (23 clients) is eligible to the contribution of 41%-70% of the total cost of the device. Only 2% (2 clients) are defined as “not poor” and is supposed to pay between 71% - 100% of the total cost.

Decision

The MoSVY tool (VI) was adopted for the pilot project

Outstanding issues

Some clients know that Exceed is going to ask them to pay or make contribution for their devices. Therefore, they were trying not to tell the interviewer the truth particularly the questions related to their incomes.

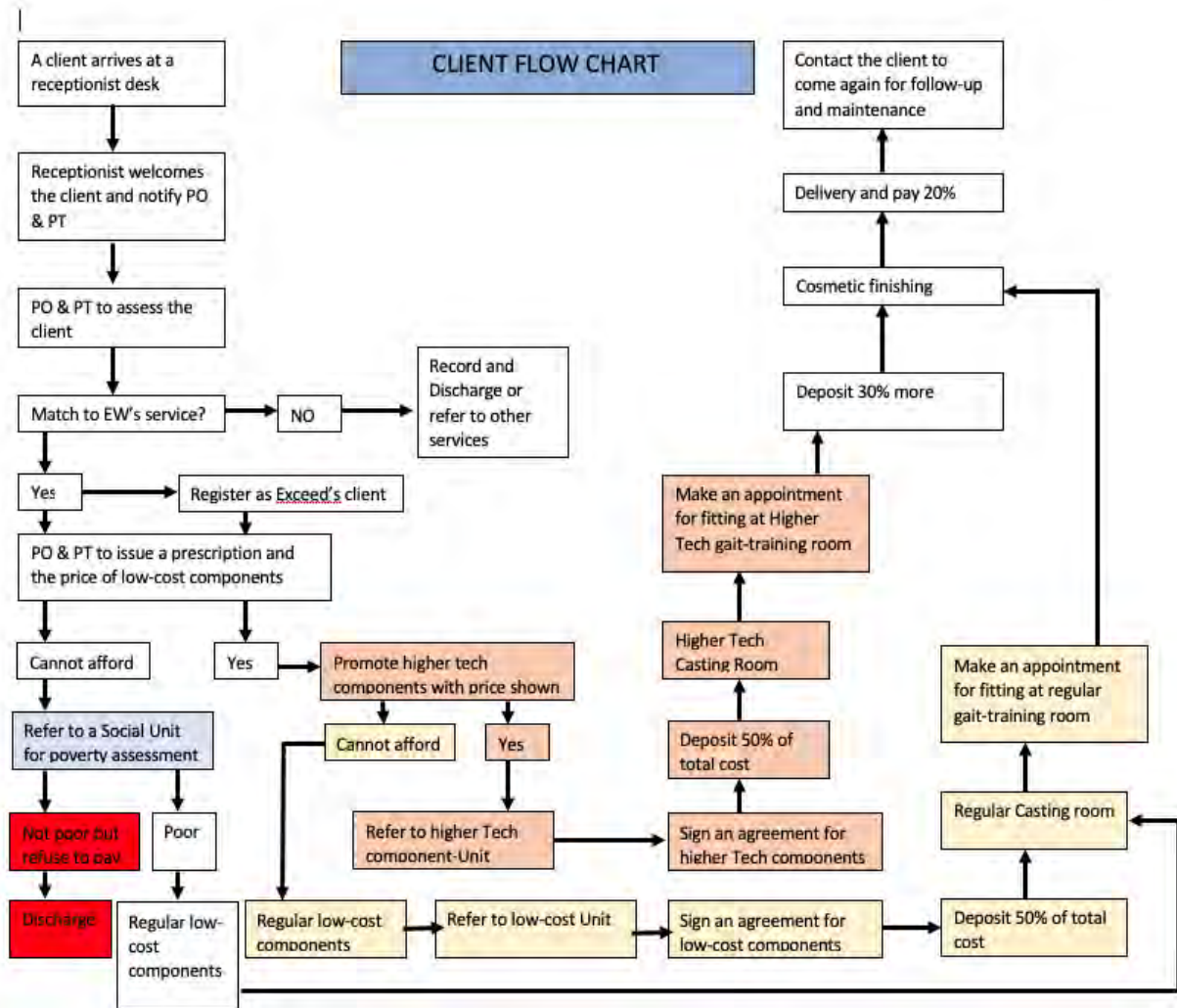
Indicators for scoring look ambiguous to the team, so it was difficult for the team to decide which scores should be given to the clients. The team needs better training on interview technique. Sample size is small.

The Pilot Project. Implementation phase.

In mid-December 2018, the building modifications were completed and the Modern Services Clinic MSC was opened. Agreements with MoSVY were signed and client information posted clearly announcing the new regime. It was made clear to all clients that this was a pilot project and no one would be coerced into paying.

Clients are assessed according to the following regime.

Figure 3. Client management system



Outcomes

Using the means test tool developed by MoSVY and Veterans International VI, clients were assessed and directed to the “free service” of the “cost recovery basic service”. Clients were also informed of the Modern Services Clinic MSC and allowed to choose to pay the full price or not.

Over a seven months period, 947 clients have attended the clinic.

- 96 have chosen to pay for high tech devices
- 272 have contributed to the cost of their devices
- 579 have enjoyed free services

Table 1. Client numbers attending.

Month	No of clients attending the clinic	No of clients cost recovery	No of clients choosing high-tech solution
December 18	157		8
January 19	181	26	19
February 19	114	50	15
March 19	168	56	8
April 19	105	42	13
May 19	100	38	15
June 19	122	60	18
Total	947	272	96

Value of services

Over the initial trial period:

- Cost recover has brought a figure of \$5,485
- The MSC has generated a turnover of \$68,958.

Preliminary results

From our initial small sample research, carried out before the initiation of the pilot project we would have expected to find.

- 43% of clients would qualify for free devices
- 55% of clients should pay some small Cost Recovery charges
- 2% of clients would seek high cost high tech devices

Initial activity figures in the first seven months of the project suggest that

- 61% of clients qualify for free services
- 29% of clients are paying for cost recovery
- 10% of clients are opting to pay for devices of higher technical value

Conclusions

1. Five times more clients than estimated are paying for modern high tech devices. This demonstrates a demand that should be addressed
2. Only 29% of clients are contributing a small amount (cost recovery), we had expected a higher figure.
3. Clients qualifying for free services are higher than expected

Early indications

Three years of work with a “paid for service” model has clearly demonstrated that there is a demand among clients for a differentiated model, and that a standard, monolithic service provision is no longer acceptable. This precedent has been firmly established in mainstream medicine, ophthalmic surgery, optician services, hearing aid provision and wheelchairs.

Exceed believe “Social Enterprise” as opposed to “For Profit” is a viable way to deliver a range of services, create profit and return that profit for the advantage of “stakeholders” and not “shareholders”

The generic component market, now being led by companies from China, (in the majority) adds impetus to the model and brings high technology closer to the means of a larger number of users.

Above all, Exceed remains committed to the service of those for whom mobility disability and the costs of rehabilitation is a burden too heavy to carry. If we are to retain a motivated professional workforce, maintain aspirations for improvements in quality of life linked with access to improved technology, we must address financial sustainability. At this stage, we envisage positive outcomes if an efficient business creates profits from those with resources and return it to those excluded financially

Financial sustainability should evolve through multiple routes. Self-paid, insurance paid, government subsidised, donor paid. Social enterprise, in partnership with Government holds much promise.

Future issues

This paper represents a starting point, but also triggers aspirations to know more about the issues. Exceed Research Network, ERN working with a broad range of academic and research organisations are seeking to better understand technology, social structure, funding and payment, impact on lives and communities and above all. Above all ERN is working towards understanding client aspirations and needs (13).

Recommendations

1. Social Enterprise if carefully matched to the needs of the country, can seed the private sector while supporting education and the public sector.
2. Providing capital for social enterprises in PO will be a worthwhile strategy to engage High Net Worth Individuals or corporation seeking CSR engagement
3. Considerable work needs to be done to raise awareness about PO services and their benefits
4. Third party payers and universal coverage schemes will need to adapt to become accessible in private sector/social enterprise service delivery.

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The key importance of including faith-based health providers in a strategy for the development of appropriate assistive technology services around the globe

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Abstract

Faith-based health providers (FBHP) are major players in health care provision around the world. A 2015 series of articles in that premier British medical journal, Lancet, shone a highlight on the scope of these organizations which provide 20 to 70 percent of medical care in Africa South of the Sahara. Evidence indicates that care is provided without prejudice to people of all faiths. FBHP are well regarded by the populations they serve and often have provided quality medical care through several changes of government. FBHP whenever possible have transitioned to local ownership and leadership. In fact, there is a strong commitment to local education resulting in nursing schools and pan-African medical internships. Working with FBHP has enhanced the global response to HIV, malaria, neonatal health and Ebola. In many countries, there is a constant struggle with corruption resulting in funds not being used as intended by granters. FBHPs have received public recognition from local governments for their effective use of funds. They maintain a focus on serving the poor and have established ways to subsidize services for those unable to pay. At FBHPs, assistive technology (AT) services would be provided as part of a broader hospital system that can respond to other medical needs. Many have longstanding relationships with populations of over one million people and have community health programs which could identify and follow up with those needing AT services. FBHP have historically focused on acute care a transition toward more holistic care including rehabilitation is underway. However, many FBHP may lack knowledge of resources and training for appropriate assistive technology provision. This may be overcome through directed dissemination of information. FBHP are numerous and independent, making them potentially difficult to engage as a group. However, information could be shared through umbrella organizations which engage with many FBHP. An example of what is possible when a FBHP engages in assistive technology provision is the initiative by BethanyKids in Kenya. BethayKids grew out of the large FBHP hub at Kijabe and has a focus on surgical and rehabilitative care of children. They recently have broadened their focus to build capacity for appropriate wheelchair services. This was initiated through their rehabilitation facility at a boarding

school for children with disabilities. Staff and leadership received WHO wheelchair provision training. They built capacity through the Accelerating Core Competencies for Effective Wheelchair Service and Support initiative. They are now in the process of initiated wheelchair services through their Kijabe location and through the mobile clinic which visits 17 locations around Kenya. Their largest hinderance to appropriate wheelchair provision is the lack of a diverse and appropriate wheelchair supply. Including FBHP in planning and providing them with opportunities for training, education and AT supplies would have significant country-wide impact in each of the countries where FBHPs are working. Any plans to develop appropriate AT services in country where FBHP are working should intentionally include collaboration and coordination with FBHP.

Keywords

Health providers, Assistive technology, Wheelchair, Provision, Community.

Introduction

The importance of FBHP is evident around the world and is obvious even in developed countries where the names of many well-known hospitals and medical schools reflect their origin in faith-based initiatives (1). A series of articles in Lancet, the premier British medical journal focused on the scope of FBHP in Africa south of the Sahara. That group is also be the focus of this paper (2-4). In those countries, faith-based health providers (FBHP) were the initiators of modern health provision, and in spite of major changes in the health care situation, they have remained major players (2-4). At the turn of the last century when there were few local resources, FBHP were run almost entirely by expatriate volunteers who committed many years to the people they served. Very early in their history, many recognized that some of the acute illnesses they were seeing could be ameliorated by prevention programs through public health and began programs in the surrounding communities (5,6). They also began local medical training initiatives. As locally trained medical and administrative staff became available, more staff were hired from local populations, and FBHP moved to local ownership (2). As FBHP moved toward locally sustainable funding, government funding has become key to their ongoing success (2-4).

In short, these faith-based initiatives have provided parallel health care systems, working with local government initiatives (2-5). Although it is difficult to estimate exactly how much of local health care is provided through FBHP in Africa South of the Sahara, it is clearly a significant amount. Across the African continent estimates range between 20 – 70% of services (2). Evidence indicates that clients seem to view the health care provision by FBHP to be of better quality than that available at other centers (2). A series of articles in Lancet has recently reviewed the impact of FBHP and has recommended methods by which public and faith sectors might collaborate more effectively (2-4). Evidence indicates that working with FBHP enhances the global response to a health challenge. Partnership with international health initiatives has successfully included FBHP on several fronts. For

example, they are currently significant partners in the global response to AIDS, malaria, neonatal health and Ebola (6-8).

FBHP have often been very involved in local medical education. Many of the larger hospitals are part of the Pan African Academy of Christian Surgeons (PAACS), training African physicians as surgeons through internships. In addition, many host nursing schools. Continuing education for medical personnel is also a focus, and expatriate long-term volunteers are recruited who have the medical and academic training to teach (2).

Although FBHP are a large presence, they have sometimes been overlooked in strategies for appropriate AT provision. In countries with fragile infrastructure, challenges in delivering effective national health care abound, and the proportion of health care provided by FBHP is high (2-4). In many countries, FBHP may be the most effective possible partners for global initiatives to improve AT provision. This is especially the case because there is often a constant struggle with corruption. There is always a danger that funds may go in directions not intended by granters (8). In contrast, FBHPs have received recognition for their effective use of limited funds. Research publications have suggested that effective use of limited funds, and commitment to service by FBHPs may be enhanced by a shared intrinsic motivation through the shared faith-based organizational ethos (2). This sometimes results in local government recognition. For example, at the opening of an eye clinic by Tenwek, a large FBHP in Kenya, President Kenyatta was quoted in the Daily Nation as saying *"I have learned several lessons here. You will not be able to blind me again. I continue to warn officers who think they are in office to squander public money. We have seen the development here (at Tenwek), and it is clear that the money has been well spent"* (9).

In the past there may have been apprehension that treatment and care came with a requirement to agree with the FBHPs spiritual world view, however research has indicated no evidence for this; instead, findings indicate that care is provided equally to all comers (2). There has also been hesitance since it is sometime thought that these institutions are not nationally owned and managed; however, as mentioned above, evidence indicates that over the past 60 there has been a transition to national ownership and leadership (2).

Approach

Strategies for appropriate AT services should include FBHP who have the capacity to scale-up significantly due to their long history of working effectively in country, commitment to medical excellence and extensive local networks. Significant and stable country-wide impacts could result. However, there are barriers. Historically, many FBHPs have often focused primarily on acute care responses to conditions which were immediate threats to survival. Resources are spent responding to water born illnesses, malaria, trauma, surgical interventions and so on. Although most FBHPs have rehabilitation staff, because of the focus on acute care, rehabilitation staff and medical directors may not be aware of resources that have become available over the last ten years. For example, they may not know of the guidelines or training and resources now available through the World Health

Organization's GATE initiative and wheelchair training programs. Very often both salaried and volunteer personnel are working long hours on limited pay. Commencing a new initiative is challenging. Wheelchair supply has also been a big barrier, and FBHP have often been limited to occasional donations of wheelchairs of uneven quality.

Because of their wide impact, and because FBHP have learned sustainable methods to provide health care in country, many will be able to scale up very significantly when they engage. It is essential to have understanding and buy-in from top leadership. The World Health Organization stakeholder training is addressing this requirement and could be utilized (10). Unless leadership is engaged and fully understand the benefit of appropriate AT provision, it is very difficult for a program to go forward. Leadership of FBHP are often very aware that staff and budgets are stretched. The option of starting small and building to capacity in a stepwise manner is much more likely to be seen as possible. External funds for start-up costs would open doors.

Each FBHP has over time developed long-term ways of paying for staffing and services for their existing programs. These often include essential links to any local government health funding. Once up and running, AT program could become part of the fabric of services provided. However, because of the relatively high cost of wheelchairs, some sort of sustainable funding for a diverse source of appropriate high-quality wheelchairs would be necessary. Paying for the full cost of the wheelchairs and the shipping is simply not affordable to FBHP or their clients. If funds to cover wheelchair costs were available, and startup costs were available, many FBHP would be able to go forward to provide excellent local long-term care.

A benefit of linking AT provision to FBHPs is that it would then be part of an integrated hospital and community health system. The presence of multiple medical specialties is common at many FBHPs. This means, for example, that wheelchair users would not only have their AT needs met but would also become clients of a medical organization which could provide necessary surgical interventions and medical care. Community health programs in place at many FBHP could identify and follow up with those needing AT services. With some training, public health personnel and volunteers could teach life skills programs linked to the initiation of family groups dealing with disability. For example, children with cerebral palsy are often much more disabled than they would have needed to be if parents had been taught to do simple therapy as part of activities of daily life. Training programs are available which could be disseminated through rehabilitation and community health personnel and parent groups (10-13). Roots in the community are especially important because those who need AT may be hidden by families (14-16). This occurs partly because many cultures see disability as evidence of a curse or as the result of some shameful behavior by the person with a disability or their family. Community level change is necessary. FBHPs are in a unique position to facilitate that change with their long-lasting relationships to local populations. In addition, in many cultures the root cause of disability is thought to be spiritual, and much of the social isolation cannot be addressed by the

simple provision of a device. Modern medicine recognizes that health has social and spiritual aspects as well as physical aspects; these need to be addressed at the cultural level (17,18). In Africa south of the Sahara, in many countries, the key social groups are religious. Because of their links with religious communities, FBHP are in a position to be agents of change with the ability to encourage inclusion in local spiritual communities.

Because FBHP are locally owned and managed, many now run on local funding with some supplementation from international donations. Levels of supplementation and methods to provide long-term sustainable health services differ at different locations. For surgical and medical services, local government funding is a key part of the picture in all countries where such funding is available. The intentional inclusion of FBHP in governmental and international plans for appropriate AT provision would very likely increase effectiveness.

Findings

The initiative by BethanyKids (BK) in Kenya is an example of what is possible when FBHPs engage in appropriate AT provision. BethanyKids is a compassionate Christian organization which focuses on transforming the lives of children with congenital conditions in need of surgery and children with disabilities. They are registered as a not-for-profit in Kenya, and their programs in Kenya are directed by Kenyan executives who lead their extensive Kenyan program and staff. BK headquarters in Kenya is at Kijabe and is part of the extensive FBHP center there. That center includes schools and training initiatives such as PAACS membership and a nursing school and has been a major player in the response to HIV/AIDS in Kenya. Clients come from all over Kenya and from neighboring countries.

Initially, BethanyKids was primarily concerned with surgical care. They have moved toward more holistic care, and now focus on improving long-term quality of life, health, and functioning in the community. For example, initially BethanyKids had provided surgical care to some children at a boarding school for children with disabilities. Several years ago, BK also arranged to provide rehabilitation, and assistive technology to the students at that school. There were over 150 students in need of appropriate wheelchairs. As part of that initiative, BK partnered with a research project on the comparative effectiveness of wheelchairs intended for use in low and middle-income countries. BK began to search for sources diverse and appropriate wheelchairs (19-22). Several rehabilitation personnel were sent for formal training in appropriate wheelchair provision.

A key step, central to the growth of the program, was the inclusion of BK top administration in the World Health Organization wheelchair provision stake holder training. BK leadership began to see appropriate wheelchair and AT provision as essential long-term care for the pediatric population they serve. They found that AT provision also facilitates long term contact and referral back to BK medical services for ongoing issues that require medical and surgical care. This broad long-term view of care includes other aspects of care. BK has enabled the teaching of Clean Intermittent Catheterization (CIC) a procedure which allows those with spina bifida and spinal cord injuries to be continent. They initiated CIC

independently, but now have tied into the Spina-bifida and Hydrocephalus Association of Kenya, a group connected with the International Federation for Spina Bifida (IF). IF now supplies CIC kits through BK and helps to fund some of BK care of children with spina-bifida. BK also hired a mentor who was herself disabled as part of the chaplaincy program to encourage spiritual and social inclusion and wellbeing.

When it became available, they applied to be part of the Accelerating Core Competencies for Effective Wheelchair Service and Support (ACCESS) grant through World Vision. During the duration of the grant, more staff were trained, and BK wheelchair services increased significantly. ACCESS had a limited time frame, and the end of that time frame left BK without a source of appropriate wheelchairs. It was clear that complete dependency on one large grant was not sustainable. A diverse and integrated plan was needed. BK leadership sat down with consultants to put in place a three-year plan to proactively develop a wheelchair provision program. Initial funds for hiring staff and establishing a wheelchair provision facility in Thika were obtained through small grants. BK wanted a local sustainable way to pay their wheelchair provision staff, and they are in the process of addressing that challenge in a creative way. They have found that affordable buy-in on the part of families encourages ownership and value for their child and for the wheelchairs. Local families are expected to pay an affordable cost for wheelchair services. This is less than 10% of the total cost of the wheelchair, however, it enables a stable sustainable source of funds to pay the salary of a wheelchair provision team. Because some families are unable to pay even this small amount, a benevolence fund is being put into place to which families can apply for funding for the portion of this small cost they are unable to pay. This enables steady reliable local funding from each wheelchair provision to be available for paying the wheelchair provision team. Although the plan is still in the early stages of full implementation, last year BK provided over 1000 wheelchairs.

In addition to wheelchair services at their initial wheelchair provision facility in Thika, BK is in the process of initiating wheelchair services at two other venues: their mobile clinic which visits 17 locations around Kenya, and the large FBHP hub at Kijabe where BK has become the go-to organization for wheelchair services. For the facility at Kijabe, separate fundraising and grant applications are in process to enable the development of a larger rehabilitation wing which includes a wheelchair provision and wheelchair skills training area.

Since the ACCESS grant ended, BK has struggled to find a sustainable appropriate and diverse wheelchair supply. Complex duty requirements make bringing AT through customs into Kenya difficult. Although there is one type of locally made pediatric supportive wheelchair, these are too expensive for many families, and have very significant and dangerous quality control issues (19,20). Chinese made folding hospital transport chairs are also widely available for purchase in Kenya. However, these are also expensive, and not appropriate for long-term use (21). A supply of diverse and appropriate wheelchairs could be ordered from the Consolidating Logistics for Assistive Technology Supply Project (CLASP). However, the wheelchairs would need to be paid for, as would shipping costs and duty on

imported wheelchairs. BK has found this prohibitively expensive. Free Wheelchair Mission (FWM) provides wheelchairs free to port, making FWM chairs an affordable option, but the selection of wheelchair types is extremely limited. Two containers of Gen 2 and Gen 3 wheelchairs from FWM have been ordered and received. Research indicates that these FWM chairs work adequately for those with good upper body function (22). However, BK also serves a pediatric population that includes children with complex seating needs. Using locally available materials, they have begun adapting some FWM Gen 2 frames by creating seat inserts for those with more complex seating needs. They have also been able to bring in smaller donations of other types of wheelchairs including some HoneyBee adaptive pediatric chairs from BeeLine; but the small numbers of these chairs are far from adequate for the population BK serves. An affordable, diverse and sustainable source of appropriate wheelchairs is very badly needed and is the largest barrier to effective wheelchair provision through BK.

Discussion

Although each situation will be unique, providing well thought through support to FBHP like BethanyKids could result in effective, stable and significant growth in appropriate AT provision. Any initiative to enhance appropriate technology services around the globe is incomplete without the inclusion of FBHP. Each organization will be somewhat different, but most FBHP will share a long-term commitment to excellent local service. Collaboration with leaders of FBHP at the local and global level is essential.

FBHP are numerous, making them potentially difficult to engage as a group. However, there are centralized organizations which are in contact with many of them. Interacting with these more centralized organizations may be very effective and result in a trickle-down effect. There are umbrella organizations such as the Christian Connections for International Health with 5000 facilities which are members. The World Medical Mission branch of Samaritans Purse with its strong relationship to over 40 faith-based hospitals; SIM with representatives working in more than 70 countries; the Christian Medical and Dental Association with members working in FBHP and secular health providers around the globe. Even at the clinic level, those advocating for change in AT services have found that stakeholder training is essential (20). Once a strategy is put into place, it could be disseminated through these larger organizations. Strategies to encourage appropriate AT provision at FBHP hospitals could include information targeted specifically to FBHP leadership.

Well thought through initiatives aimed specifically at opening doors for FBHP to initiate or improve their services are of key importance. Collaborative planning for training opportunities and financial resources for the initial start-up of AT provision programs would open many doors. The lack of a sustainable and diverse source of appropriate wheelchairs is a significant barrier which must be addressed. It would be prohibitively difficult for each FBHP to pay for and ship containers of wheelchairs. Small in-country wheelchair

manufacturers are very often limited by poor economics of scale and poor-quality control making local supplies sporadic and often low quality. Without access to appropriate and affordable wheelchairs, appropriate wheelchair provision is simply impossible. Initiatives to improve wheelchair services should also include strategies which make it simpler to import wheelchairs and other AT supplies. Even higher resource countries import AT and wheelchair parts and supplies, so import laws that make this very complicated are counterproductive to the well-being of citizens of any country. Careful consideration of the scope of FBHP in the planning of any government or international funding initiatives for AT provision is of key importance. In fact, it would be effective if the FBHP were included in the planning of strategies. The implementation of these strategies could enable effective use of limited funds and would harness the capacities of FBHP. Their long history of working effectively in country and their extensive local networks could result in significant and stable country-wide impact.

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The Colombian assistive technology sector: National policies and experiences from the National Disability System representatives

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Abstract

Colombia is a democratic country with advanced rights for disabled people evidenced through various laws including the 1991 constitution, the 2007 National Disability System (NDS) and the enactment of The United Nations Convention on the Rights of Persons with Disabilities. In practice, people with disabilities continue to have poorer outcomes compared to those without disabilities such as limited access to health, education and employment, among others. Our goal was to identify the systemic aspects of the 10Ps (people, policy, provision, personnel, products, place, partnerships, pace, promotion, procurement) related to the right to access assistive products which have been included in the national legislation since 1997. More than 240 legislation documents were reviewed, our main findings include an overall lack of systemic approach with most of the legislation relating to assistive products in health. We found few legislations demonstrating progress towards a more comprehensive understanding of what appropriate assistive product provision through trained personnel for hearing aids, prosthetics and orthotics products. National software licenses for screen readers and magnifiers, the Military Forces AP guidelines, and Bogota's assistive product bank guidelines. Commentaries from three of its municipal disability-representatives reflect that currently there is a general lack of: awareness about assistive products, pathways to access, qualified professionals, and affordable products. There is little reflection of the policies' implementation in reality. It is vital to emphasize the immense potential of the NDS to foster the systemic approach to build the country's capacity to secure access to appropriate assistive products throughout the national territory.

Keywords

Policy, assistive technology, local access, National Disability System.

Introduction

Colombia is an upper-middle-income country in South-America. The 45.5 million population are divided between municipalities (77.8%), rural areas (15.1%), and populated centers (7.1%) (1). Over 25% live in poverty (2). A democracy with a bi-chamber congress (3), the official languages are Spanish (4) and Colombian Sign Language (5) with additional 66 native languages (6). 94.74% of the population is covered by a mandatory health plan (7). The Military Forces have a special health system. The internet subscription, including mobile, was 35% at the end of 2018 (8). 60 years of armed conflict have left over 8 million victims (9), 7.9 million displaced people, and 11,000 landmine victims (10,11).

The Constitution (1991) binds the state to promote conditions of equality for all citizens (4). The National Disability System (NDS) was established in 2007 (12), and since 2015, discrimination against people with disabilities (PWD) is penalized (13). Colombia ratified international conventions to eliminate discrimination and guarantee the participation of PWD (14), including the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (15). However, the effective enjoyment of all human rights, including access to assistive products (AP), for PWD is not a reality (16-18). This is why international organizations provide access to AP locally (19-21).

The objective of this work was two-fold:

1. Describe the current state of national policies related to AP, relating the findings with NDS civil society representatives' experiences in municipalities through commentaries.
2. Identify opportunities for action to advance effective access to AP.

Methods

This work was developed in two phases:

First a review of national policies related to PWDs from 1997 to June 2019, 1997 saw the enactment of the first law to promote the rights of PWD (22). These were identified from the Ministries of Health (MoH) (23) and Interior (24) policies compilation; the UNCRPD regulatory process balance (25), the NDS (26), the private healthcare observatory (27), and the coauthors' experience. Each identified policy was reviewed searching for the keywords (in Spanish): disability, aid, product, assistive, technology, apparatus, orthopedic, prosthetic, implement, device, accommodation, reasonable, other elements, materials, training, professional, personnel. The identified information was grouped in the corresponding "Ps" from the system's thinking approach to access to AP (28): People, policies, provision, personnel, products, procurement, partnership, promotion, pace, and place. Secondly each NDS representative co-author commentated, reflecting on the policies identified and their experiences as disability community leaders.

Results

Over 240 policy documents were identified and reviewed. Only the AP-related findings are presented.

People

The 2018 national census indicates that 7.2% of the country's population are PWDs (1). One census question related to AP use (1). The voluntary National Disability Registry reported a disability prevalence of 2.6% (18). The Registry has three questions related to AP: prescribed, currently used, and persistent AP need (29). The Registry must be up-to-date and integrated to the other national information systems (30). Some of the data is available in the National Disability Observatory (31) or through the MoH, like the national registry of people with short stature (32).

In 2018, the procedure to obtain the individual disability certificate was regulated, based on the International Classification of Functioning, Disability, and Health (33-35) classifying disability in physical, hearing, visual, deaf-blindness, intellectual, psychosocial, and multiple (33). The first three are described as benefitting from AP to achieve personal independence (33). There are two AP-related questions: use and training received (33). Health facilities will implement the certificate and are responsible for adding this information into the aforementioned Disability Registry (33). The government will create the National Observatory of Social and Productive Inclusion of PWD (articulating the previous information systems) (36,37). Only the Military Forces policies have stated the need to comprehend AP demand to better plan for the needed local services, including maintenance and AP replacement (38).

Policy

The first law aimed at PWDs (1997) mandated that the government had improved comprehensive rehabilitation services so individuals could access the devices needed (22).

In 2007, the NDS was created to coordinate the policies, resources, and services related to persons with disabilities at all government levels (12), working with committees formed by representatives from each governmental division and disability representatives (12), democratically elected by the disability community (12). The UNCRPD was enacted in the Disability Law in 2013 (30,39) and captured in the National Disability Policy (40). Policies mandate necessary measures guaranteeing independence for people with visual, hearing, deafblind (5,41); children and adolescents (42-47); persons with psychosocial disabilities (48,49); conflict victims with disabilities (50-52); persons with epilepsy (53); persons with intellectual or multiple disabilities (41), and persons with short stature (32). These policies are unspecific to APs and only explicitly mention prosthetics and orthotics for landmine victims (54) and visual/auditory signals and braille (45-47). The following subsections elaborate on the AP-related policies identified as they relate to specific rights.

Public transportation and infrastructure

Public transportation and spaces, including social housing, must meet accessibility requirements (55-60) as indicated in the National Technical Norms (NTC) that include recommendations for handrails and tactile signs (61) and transportation requirements for people with mobility impairments (62-67). Assistance dogs are allowed on public transportation (68). As per personal driving, the assessments toward the driver's license must allow the use of the orthopedic instruments or mechanical aids needed by the license's applicant (69). Under the current government, every infrastructure and transportation system development publicly co-financed must be accessible (36). The Ministry of Transportation will incentivize the implementation of Smart traffic lights (36).

Employment

Public employment must prioritize candidates with disabilities (70) there is a mandatory quota of employees with disabilities (71). The public employer entity is responsible for any needed reasonable accommodation (71). As per private employment, policies aimed at facilitating access to employment for PWDs tackle discrimination (43), promote telework (72,73), and tax discounts (74,75). A newly formed Disability Inclusion Council has been mandated to coordinate inclusive employment actions (76). Colombia has implemented a *Unified work capacity loss* (77). It classifies the restrictions in employment role, AP use is one of the evaluation criteria (77). This classification is unrelated to the Disability Registry and Disability Certificate mentioned in the "People" section above.

Education

Free public education from kindergarten until the eleventh grade (78). To achieve inclusive education, implementation of strategies such as special communication systems used by persons who are deafblind are needed, among others (52,79-83). Guaranteed access to education for PWDs an objective of the former and current decade national education plans (84,85), education technology mentioned with APs omitted (84,85). The Disability Law mandates that local governments promote the availability and use of ICT, mobility aids, technical devices, and AP for PWD's education (30).

For primary and secondary public education, each student with a disability will have an individual reasonable accommodations plan that may include technological support (86). The territorial education entity will provide additional financial resources to the public schools proportional to the number of students with disabilities registered (86). The National Learning Service (SENA), public postsecondary technical center, must guarantee sign language interpreters, technological aids for people with visual disabilities, and the specific supports needed by people with intellectual disabilities (30,87) for teaching, assessment, and certification (87). It is unspecified which or how (30,87). Similarly, the Ministry of Education (MoE) guarantees these supports, in addition to pedagogical, therapeutic, and infrastructure resources (88).

Health

Health is a human right for all Colombians (4,89,90); including rehabilitation services and technologies (89), mental health (49), and sexual and reproductive health (91-93). To accomplish the right to health for PWDs, the MoH must ensure that health-related plans at all levels include APs for rehabilitation (88,94) and the provision entities define intersectoral and interdisciplinary processes that guarantee the best care (89).

The current national health policy creates the National Commission on Medicines and Medical Devices Costs (95), a unique classification of health procedures (96), and a unified reimbursement fee for each individual affiliated in the mandatory health plan (97). Citizens may actively participate in national health system decisions (89), including mandatory health plan services, procedures, medicines, and devices exclusions (98). The decision-making process includes an evidence-based analysis by the Health Technology Evaluation Institute (IETS) and commentaries from both professional and patients' organizations (98). Several types of AP are excluded from the health finances such as closed-circuit TV for people who are legally blind (99) and from the unified reimbursement fee, orthopedic footwear, shoe insoles, and wheelchairs (100). AP that is not included in health financing will be covered either by the territorial entities or by the Social Security Resource Administration, depending on the individual's income (101).

Sports

PWD have the right to enjoy appropriate sports facilities, without specifications of what reasonable accommodations should be made (102). Entities at the departmental level should finance and implement guidelines to promote and develop the inclusion of PWD in physical education, recreation, physical activity, and sports (103). These indicate that all sports facilities in the country will have evacuation plans to support PWD, including AP users. Health Secretaries can access funds to support sports implementation and access to sports and recreation from the MOE and AP on a national level (103). None of the legislation related to sports explicitly talks about AP access.

Culture

The National cultural policy must take PWDs into account; although it does not dictate how and AP or reasonable accommodations are not mentioned (104,105).

Communication

Access to information is a fundamental right (106,107). News television programs at all levels are mandated to provide sign language interpretation, closed-caption, or open-caption in a limited capacity (106-109). Websites of public and private entities that provide public services must comply with accessibility standards; however, the NTC is not explicitly stated (110,111). Public information must be on accessible formats, both in electronic and physical media (112,113). The MoICT guarantees access to information, communications, and knowledge for persons with visual disabilities (111), mandated to provide access to

screen reader and magnifying software ICT (111). Public entities are responsible for the implementation of public centers and user training (111).

Military Forces Special Regime

The health care policy mandates timely provision to AP meeting the individual's needs through functional rehabilitation process (38,114,115). Its disability policy establishes the provision of AP to support the inclusion processes of PWDs (116). There are two protocols including AP provision: otorhinolaryngology (117) and the prescription, monitoring, and control of health-care AP (118).

Provision

Health care coverage has increased from 29.2% (1995) to 94.7% (2019) (119), coverage does not guarantee access, many have to travel extensively and/or to petition for access (120). Telemedicine has been proposed for neglected regions, including rural areas (121). Health services must be accredited by meeting infrastructure, personnel, and processes requirements (122,123). Comprehensive care routes must contain information on interventions for prevention, diagnosis, treatment, rehabilitation of disability, and palliation (124,125). The manual of standards for rehabilitation services (2006) expresses that the rehabilitation plan must be developed with the user, his family, and an interdisciplinary team, considering AP (126). The user and his family receive information and training in the use and maintenance of AP (126). Rehabilitation services are in coordination with other institutions and sectors to ensure comprehensive care, including AP (126). The certification of places involved with the provision and manufacture of prostheses, orthoses, and hearing aids is regulated (127,128). Specific to the victims of landmines, the regulations mention adaptation of prostheses and orthoses and their replacement when necessary (54).

Rehabilitation services are recognized within the list of health procedures: optometry, audiology, speech, physical and occupational therapy, psychology and physical medicine and rehabilitation (129). The list includes evaluation and adaptation of prostheses and hearing aids and design, monitoring, adaptation, and training on AP use for: orthoses, prostheses, mobility devices, and AP to use at home, school or work (129). MoH guidelines for Community-Based Rehabilitation promote coordination between the Ministry and community agents to facilitate access and maintenance to AP (130). Regarding health coverage, PWD are exempt from co-payment (131). Prosthetic adaptation and training in the use of prosthetics, crutches, walkers, and canes are covered (100,132). For those APs not covered in the health plan or individuals without coverage, a mechanism exists to request access either through health or territorial funds (100,133-136). Wheelchairs, orthopedic footwear, and footwear insoles are not covered in the health plan (100). Municipalities and departments are mandated to establish AP banks to guarantee access to products through appropriate service (137). To comply with this, the district of Bogotá developed implementation guidelines of the Assistive Products Bank that include:

assessment, prescription, product preparation, fitting, user training, and follow-up at one-month, 1-year, and 2-years after the AP delivery (137).

The Direction of the Inclusive Rehabilitation Center executes the Comprehensive Rehabilitation Model for the Military Forces (138). It has a financing mechanism for AP (38). The Otolaryngology Protocol describes the assessment and prescription of hearing aids (117). The Protocol for the prescription, monitoring, and control of AP establishes that professionals should be involved in prescription, training, and follow-up, also including maintenance and warranty times, the Central Board of Rehabilitation grants high-end Aps (118).

Personnel

Several policies mandate training professionals, and community workers to provide appropriate, inclusive PWD health services (49,89,92), rehabilitation (126), education (49,86), social welfare (30), employment (37,139), and transportation (59). The government recognizes the lack of trained personnel and access to technology are two factors hindering the realization of inclusive education (37). Similarly, lack of implementation of reasonable accommodations for employment is a factor preventing PWDs employability (37).

Specific to AP, the policy mandates that technical personnel involved in the provision of prostheses and orthoses must have at least a certificate of competence in orthopedic technology, the profession is defined (127). As for hearing aids services, must be indicated by an otolaryngologist, the user assessed and the device prescribed and fitted by an audiology specialized speech therapist, the product preparation by a technologist or electronic engineer, and/or qualified technicians (117,128).

The Guidelines for AP provision in Bogotá indicate AP prescription is by a rehabilitation professional, a specialist doctor or the appropriate professional required according to the device (137). APs for people with visual impairment must be prescribed by a low-vision expert or a therapist (137). A physical, occupational or speech therapist, with one-year experience in community activities, public health and/or AP (137) must be responsible for coordinating the AP project. Support professionals require the same profile, 6 months of experience (minimum) or a training certification on prescription and development of AP (137).

In the Military Forces, the importance of an interdisciplinary approach is highlighted in the rehabilitation service, including APs and access to a peer-support program (38). The information about interdisciplinary teams are also in the protocols of the military forces and in the document that regulates the establishments involved with prostheses and orthoses (117,118,127).

Products

The NTC-ISO 9999 defined AP based on ISO 9999:1992 (140). Nonetheless, there is a lack of unified language in the policies to refer to AP. The following terms were identified to be

used interchangeably: technical aids (30,39,59,77,86,94,100,126,127), technical and technological aids (30,87), special aids (22), assistive devices (92,126), assistive technology (39,94), assistive products (46,94), technical devices (39), orthopedic apparatus (22,132,141), orthopedic instruments (69), mechanical aids (69), assistive additaments (129), rehabilitation technology (129), gait and mobility artifacts (129), devices for personal assistance (137), and assistive devices (92). In some policies the term is defined (59,77,132,137,141) and in others, it refers to the NTC (137). One policy defines prosthetics and orthotics as a separate category and not as a type of AP (127).

Regarding product regulation, IETS provides evidence-based guidance to the inclusion/exclusion of procedures and devices in the health-care plan (90). The National Food and Drug Surveillance Institute (INVIMA) guarantees the quality, safety, and efficacy of drugs and medical devices that are commercialized in the country according to international quality standards (90). These types of standards are adopted in the NTCs which are available for: wheelchairs (142-146); desks for wheelchair users (147); structural tests for lower limb prostheses (148-155); hearing aids (156,157); lenses (158,159); and crutches (160). To the authors understanding, the compliance with these quality norms is not mentioned as an explicit requirement in the provision of these APs (128). Since the ratification of the UNCRPD, the INVIMA established best practice procedures for fabrication and/or assembly of hearing aids (128) and orthopedic technology (127), both covered in the health plan. Wheelchairs, orthopedic footwear, and insoles are excluded from the health plan coverage (100) and closed TV circuit and desk magnifier for people legally blind are excluded from any health-financing (99).

To illustrate the type of APs explicitly mentioned in the policies reviewed, Table 1 presents them classified based on ISO 9999:2016 (161).

Table 1: type of AP explicitly mentioned in the Colombian policy and grouped based on ISO 9999:2016.

AP classification	Product mentioned in the policy
For measuring, supporting, training or replacing body functions	Talking tensiometer, pillbox, glucometer, thermometer (137)
For education and for training in skills	Didactic cards, texture mat, embossed books, adapted toys (137)
Attached to the body for supporting neuromusculoskeletal or movement related functions (orthoses) and replacing anatomical structures (prostheses)	Orthopedic footwear, insoles (1,30,100,132) Prosthetics, orthotics (29,33,38,45,50,54,77,118,127,129,132,135)
For self-care activities and participation in self care	Gradient socks, girdle (30) Hospital bed, lift (118,137) Positioning cushion, customized cushion, bath chair, mattress, dressing hooks, toilet elevator, sponge, tooth brush, utensils (137)
For activities and participation relating to personal mobility and transportation	Wheelchairs (manual and power)* (1,30,33,38,45,55,58,100,118,132,137,141) Strollers (137) Cane*, crutch*, Walker* (1,33,45,55,58,100,118,132) White cane (33,45,137) Public vehicles (59,62,64,67,162-164) Special vehicles (65) Train, tram (66) Guide system for mobility (55) Stander, transfer board, hand-bike (137)
For domestic activities and participation in domestic life	Food scale, jar opener, oil measurer, lighter, alarm (137)
Furnishings, fixtures and other AP for supporting activities in indoor and outdoor human-made environments	Hand rail and bar (58,61,137,165) Desk for wheelchair, rope stair, portable ramps (137)
For communication and information management	Hearing aids* (1,5,33,45,92,100,117,129) Visual alarms*, closed-caption*, adapted public phone (5,33,45,92) Cochlear implants (1,45,92,117,129) Tactile signs (46,166) Trumpets (33) Spectacles* (1), telescope, binoculars (33)

AP classification	Product mentioned in the policy
	Guide or communication system (55,58) Screen reader software* (38,92,111) Screen magnifier, electronic magnifier, autonomous reader (92) FM System* (92,129,137) Lenses*, magnifiers* (1,45) Low-vision aids (129) Augmentative and Alternative Communication System (92,137) Web accessibility (166) Public information accessibility (112) Accessible traffic light, auditory/visual/tactile signals (46,59) Sign language and communication systems, graphic symbols (46,92) Braille, large Font, audiobook, pictograms (92) ICommunicators for people who are blind and people who are deaf (137) Relay call, online sign language interpretation (137,167) Decision-making supports (92) Accessible ICTs* (37)
For controlling, carrying, moving, and handling objects and devices	Switches, handles, holders, pointers, reachers, suction cups, magnets (137)
For controlling, adapting or measuring elements of physical environments	Not found
For work activities and participation in employment	Keyboard adaptation, talking calculator, geometry kit (137)
For recreation and leisure	Scented lottery, textured signed, adapted chess, sound soccer ball, positive/negative drawing board, tactile/braille board game (137)

Note: *Included in WHO's Assistive Products Priority List (168).

Procurement

Only the MoICT has a national procurement strategy for screen-reader and magnifier software, resulting in individual licenses at no-cost to end-users and in some cities provided training in its use (169). The National Institute for the Blind is responsible for the production, provision, and distribution of teaching materials in Braille, tactile, and specialized AP needed by individuals with visual disabilities and deafblindness to exercise their right to education (86). The Electronic Public Procurement System allows national or territorial public entities to obtain AP through public tenders (170).

Partnership

The NDS is conceived as an exemplary coordination body articulating civil society and all levels of government (12). The former national development plan mandated that the Administrative Department of the Presidency assumed the coordination of all programs offered for PWD and to create "Intersectoral Care Path" (171). This pathway is not known to have been published (172). The current national government mandates intersectoral actions for the employment for PWD (36,37) and to strengthen the NDS for coordination, implementation, and monitoring of public policies (36).

Promotion

Disability Law mandates that the government must promote PWD rights awareness campaigns (30). The current government mandates that the office of the disability counselor to the Colombian President implements these campaigns (36). There is no specific mention of awareness-raising on the right to AP.

Pace

Congress issues national laws (28), to be implemented, the entity (e.g. Ministry, specialized units) indicated in the law has to regulate it by issuing a decree, agreement, resolution, regulation, or circular (28). The following step comprises the communication of the regulation to the territories (municipalities and departments), which must immediately implement it (28).

The Disability Law indicated that it should be regulated in two years (25,30). The latest official implementation report indicated 0% of regulation pending, the report counted all the regulation projects (yet to be enacted) (25). To date, there are unregulated aspects of the law, including AP-related issues.

Place

A culturally and geographically diverse country, with significant inequalities, and systematic abandonment of rural areas. Since the ratification of the UNCRPD, the rights of PWDs are increasingly more present in the national development agenda, the current National Development Plan has an entire chapter devoted to PWDs, for the first time in the country's history (36).

Commentaries

Representative of families of persons with disabilities

Families lack information about AP and the related policies in place. Families have to deal with many situations, AP is just one aspect of them. Without appropriate information, families cannot access APs needed to promote the independence of their children. Only if the family meets an appropriately informed professional, is access to quality AP likely. Unfortunately, there are few professionals with this knowledge, and few provide user-centered services. Even when the families access this professional, they may face three additional barriers. First, the health-care coverage denies financing, resulting in a legal appeal. Second, an inappropriate AP is delivered (e.g. poor quality, wrong size). Third, families seldom receive training on how to use and maintain the AP.

The situation in the territory varies depending on disability type and AP. Specific to mobility impairments, families commonly use baby strollers and only self-refer to inquire about other supports when their children outgrow them. With white canes, although there is health care coverage, families on professional's advice, buy out-of-pocket, through a cumbersome healthcare process with poor quality APs. Access to communication APs is near null, hindering their rights to communicate and participate actively in their education and community. One of the most neglected groups are people with intellectual and multiple disabilities.

The National Institute for the Blind has specific obligations related to APs that are unmet. Families don't demand these obligations are followed.

The Municipal Disability Committee (MDC) in Medellin has stated that access to APs is out of their scope of work since it only pertains to health care coverage.

Representative of persons with visual disabilities

PWD are unaware of existing AP-policies, hindering their ability to request them. Commonly, organizations and professionals providing services to PWD also lack knowledge on AP and therefore are unable to refer PWD to possibly beneficial AP-services. In some instances, it appears that even entities managing health care coverage and public regulatory bodies lack appropriate knowledge as they provide conflicting information to PWDs on whose responsibility it is to finance APs.

Often, PWDs rely on AP donations and out-of-pocket purchases instead of through health-care coverage. Commonly, AP products are inappropriate and hinder individual autonomy and health (e.g. wheelchairs not matching rough terrains and distances), professionals indicate that the wheelchair is not transportation means and withstanding these adverse conditions is beyond the APs possibilities. Progress has been made, it's now more common to see individual body measurements taken during the evaluation to inform an appropriate AP prescription. Nonetheless, frequently, professionals lack the knowledge to provide AP use training.

Exemplary cases:

1. The low-vision program at a local hospital providing a user-centered service including prescription, provision, and training in the user's context with the new AP.
2. The disability community in Envigado supporting the implementation of built-environment accessibility policies by partnering with the local government to validate the accessibility of current public infrastructure developments.

Representative of persons with physical disabilities

Significant policy progress has been made in Colombia to guarantee the rights of PWDs. However, the AP-related policies identified in this work do not match the reality on the ground. PWD access AP-related information through word-of-mouth by other PWD or their families who are current AP users. PWDs rely on the luck of meeting an appropriately informed professional that can refer the person to the AP services. Untrained professionals are a risk factor to reduced PWD independence. Technical committees deciding AP products prescription and coverage must be appropriately trained. Professional and continued education are imperative to solving this issue.

Lack of knowledge by all stakeholders (PWD, families, professionals, organizations, decision-makers) result in a lack of established access or care pathway, financing wheelchairs is confusing. As mentioned in the policy findings, they are neither covered through health care nor excluded from health financing. Meaning doctors should be able to use the information system designed to prescribe devices excluded health care coverage, to prescribe wheelchairs. In reality, doctors are unable to prescribe wheelchairs through the system, adding barriers to access AP.

Commonly, PWD are of low-income, many living outside of major cities, increasing their vulnerability. Stronger partnerships between government-academia-disability community are needed to increase awareness of current policies and promote effective access to AP.

The National Disability Registry should be used to inform the actions that the municipalities must take to provide AP based on identified users' needs. Political will could achieve this change. Specific to Envigado, the MDC has discussed access to APs through the Secretary of Health. The Secretary lacks a technical committee to advise on the appropriate procurement, prescription, and fitting of AP which will likely result in the provision of inappropriate APs (i.e. waste of public financing). On receiving a new AP, he/she must receive training in the use and maintenance. Some MDC members are advising the Secretary to bring trained personnel to coordinate this AP project. Another example on how the MDC positively impacts public actions is through the accessibility validation of newly built public infrastructure.

Discussion

The purpose of this work was to understand the national policies and explore their implementation from the perspectives of three disability leaders. To the authors'

knowledge, this is the first effort to analyze the national policies that respond to the fulfillment of the UNCRPD concerning the right to AP from a systemic perspective.

Main lessons learned on the key strategic drivers of systems-level change (31):

- People: the met and unmet need for AP is unknown and a policy that directs its measurement is yet to be developed. User-centered services are indicated in the policies but the commentaries from the NDS representatives suggest that in practice, this is not the case. Policy discourse as it related to AP focuses on PWDs, potentially excluding others that do not identify in this group but may benefit from APs.
- Policy: significant policy developments have been achieved, especially since the ratification of the UNCRPD (25). AP is a subsection of many different policies, resulting in a lack of a unified national vision on AP access. The high number of fragmented policies results in a lack of clarity on what public entity is responsible for what task (28,173). The former national government aimed at developing the Intersectoral Care Route for PWDs, a promise to solve the lack of coordination (171). Unfortunately, this task was not accomplished (172) nor is it part of the current government (36,37). Prosthetics, orthoses, and hearing aids are the most advanced AP in terms of regulation with a systemic approach since it has specific technical and sanitary criteria for its provision, personnel, and product (25,127,128). The military forces and Bogota's AP Banks also have policies more alike to the systems thinking approach. Policies lack of explicit feedback loops that inform their revisions (174).
- Provision: the policies reviewed do not indicate intersectoral nor level coordination. Most AP provision services that are explicit in the policies relate to health services (138,175). Only the AP Bank guideline covers provision for a broad range of AP; beyond health (118,137). Coordination among these AP provision is not indicated. An exemplary provision service for AP for people with visual impairment was identified by a disability leader, calling to a need to identify and scale-up, in a coordinated fashion, local successful initiatives.
- Personnel: several professionals are listed as responsible for the provision of AP. Building the task force capacity is recognized in the policies but not the strategy to achieve this mandate. Disability leaders identify appropriate personnel as key drivers of AP access.
- Products: Most of the mentioned types of AP correspond to products for mobility, prostheses and orthoses, and for ICTs. There are gaps in augmentative and alternative communication, products for the support of people with intellectual disabilities, for the control of the environment, AP for emergencies, and those necessary for people who are deafblind. There is no mention of the WHO AP priority list (168). There are fragmented national product standards and product regulating bodies that need to be implemented in a coordinated manner.

Main lessons learned of the key situational factors that influence systems-level change (28):

- Procurement: only one national procurement policy was identified for screen reader and screen magnifier software. The existing general public procurement system may facilitate implementation of public AP procurement. The Military forces and Bogota's AP bank procurement strategies are not explicit in the policies reviewed. Further understanding of these may inform local or national strategies. Experiences from the disability community indicate that local procurement teams do not have appropriate AP knowledge.
- Partnership: the intersectoral and coordinated nature of the NDS pose an important opportunity to foster the political engagement (176) and partnerships needed to drive change among the stakeholders public-private-academia-civil society (98).
- Promotion: AP awareness-raising policies were not identified. The need for promotion is evident to use unified language (177), accessible information systems (178), and coordination. The limited mention on the right to access AP in the first CRPD reports to the UN by the government (179) and civil society (16,17) suggests a lack of awareness of access to AP as mediators and moderators of the rights of Colombians with disabilities (180). In response, the UN did not have any observations specific to AP (181).
- Pace: after the ratification of the UNCRPD, policies have been enacted at a faster, and fragmented, pace. Policy implementation pace is yet to be investigated.
- Place: policies recognize the complexities of the country including conflict zones, those more prone to natural disasters, and indigenous communities. However, little specificity on how to impact these contexts is given in the policies.

A limitation of this work is that it does not cover the experiences of all representatives of organizations of PWD, the military forces systems, or regulatory experts. This study was not intended to provide an exhaustive review of all the policies (from national to municipal). Rather we used the national legislation to highlight some of the challenges and successes in the steps towards access to AP.

Recommendations and future work

- Expand this work by engaging other stakeholders such as policy experts (182), other disability leaders, professional organizations (178) and those are promoting AP (183).
- Draft a tentative national AP access route based on the policy findings, share it and revise it with the NDS.
- Communicate the results with the National Disability Council with a call to appoint a task force to lead an overarching National AP plan that promote interoperability, cross-sectoral, and inter-organizational activities that avoid continued fragmentation of services (174).
- GATE could collaborate the CRPD committee to assess countries reports with AP lens.

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“Equipping, empowering, enabling”: Centre-staging assistive technologies in disability and rehabilitation policy discourse in India

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Abstract

A growing body of evidence suggests that owing to global demographic and epidemiological transition NCDs, ageing and injuries will continue to show an upward trend. Following the trail, will be a manifold rise in disabilities and functional impairments. WHO points out that 90% of the Persons with Disabilities (PWDs) have no access to ATs. Assistive technology ‘enables people to live healthy, productive, independent and dignified lives, promoting participation in education, the labour market and social life’. Whereas the inability to afford or maintain assistive devices and technology can result in people experiencing exclusion, poverty, and increasing their support needs from their families and society. Despite the emergence of new policies and strategies to address the issues of reach, access, affordability, quality, maintenance of ATs, factors such as social and economic discrimination; inaccessible built environments; and expensive, socially isolating, and often counterproductive disability policies and institutions, together with insufficient information, inadequate data and limited coordination of disability policies, strategies and activities, continue to result in an ineffective system of disjointed and often contradictory approaches to disability. The current review aims to understand the evolution of the global and national mandates for improving access to assistive technologies and make these affordable by identifying and addressing the current challenges and making the health service system respond to these needs. ICMR is aligning its research priorities in accordance with the international conventions and WHO recommendations to equip enable and empower Persons with Disabilities (PWDs) in India.

Keywords

India, policy, assistive technology, access, disability

Introduction

Disability is a complex, dynamic and multidimensional experience and is variously understood -- from an individual and medical viewpoint (in early years) to structural and social elements (contemporary). The Convention on the Rights of Persons with Disabilities (1) recognized that disability is an “evolving concept” and emphasized that it “results from

the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others". Defining disability as an interaction means that "disability" is not an attribute of the person (1). The WHO Commission on Social Determinants of Health underscored that inequality is a major cause of poor health, and hence of disability (1).

Rehabilitation is defined as "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments". Rehabilitation should help empower a person with a disability and her/his family; it is essential to being able to participate in education, employment and civic life. It is a cross-sectoral functional process and may be carried out by health professionals in conjunction with specialists in education, employment, social welfare and other fields. In resource-poor contexts it may involve non-specialist and community-based workers in addition to family, friends and community groups. The effectiveness of early intervention is particularly marked for children with, (or at risk of) developmental delay, and has been proven to increase educational and developmental gains.

Global data on the need for rehabilitation services, type and quality of measures provided, and estimates of unmet need do not exist; the data is often incomplete and fragmented. The priority is to ensure access to appropriate, timely, affordable and high-quality rehabilitation interventions consistent with the CRPD. The approach in LMICs is on introducing and gradually expanding rehabilitation services and prioritizing cost-effective approaches.

An assistive technology (AT) device is defined as "any item, piece of equipment, or product, whether it is acquired commercially, modified, or customized, that is used to increase, maintain or improve the functional capabilities of individuals with disabilities" (2) and includes wheelchairs, hearing aids, walking frames, spectacles, pill organizers, as well as assistive information and communication technology such as memory aids, specialized computer hardware and software, augmentative communication, and customized telephones.

ATs contribute significantly in rehabilitation by increasing independence and improving participation when those are accessible, affordable and custom made as per the individual, and geographical needs (specifications for an urban 8-year-old female child will be quite different from that of a woman residing in a village whose surrounding infrastructure is more challenging). People with disabilities and older people without ATs are often excluded, isolated and locked into poverty and the burden of morbidity and disability increases.

We make a critical analysis of the current policy environment to equip and empower the disabled and functionally impaired persons in India in the context of Assistive Technologies and Products.

Review Process

Key national and international documents including policy documents, legal documents, academic articles and advocacy pieces as well as several key national and international data sets were reviewed. Of particular significance are recent legal and policy initiatives under the thematic areas such as Global Vision for Agenda Setting, Third report of committee, recommendations of 71st World Health Assembly, 10th and 11th meeting; Technical briefing for Member States of the South-East Asia Region on subjects to be discussed at the 71st Session of the World Health Assembly, 143rd Session of the executive Board and 28th Meeting of PBAC; World Report on Ageing and Health, 2015; Health system and associated issues for AT reach and use: New Delhi: 8–9 May, 2018; Improving Access to Assistive Technology, Report by the Director-General, 15th March, 2018; Rehabilitation in health systems, WHO, 2017; WHO Assistive Products List; World Report on Disability 2011; Legal discourse for PWDs: United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), The Rights of Persons With Disabilities Act (India), 2016; National burden of disabilities and country specific initiatives: Disabled Persons in India: A Statistical Profile 2016, Social Statistics Division, Ministry of Statistics and Programme Implementation, Government of India; Annual Report 2017-18, Department of Social Justice and Empowerment, Ministry of Social Justice and Empowerment, Government of India; Evaluation Study on “The Scheme of Assistance to Differently Abled Persons for Purchase/Fitting of Aids/Appliances (ADIP)”, Planning Commission Programme Evaluation Organization, Government of India, New Delhi, December 2013.

Magnitude of the Problem

The proportion of people who experience disability of any severity has increased globally in consonance with chronic health conditions. As populations continue to age exponentially, low and middle-income countries (LMICs) will have to deal with ageing associated disabilities (prevention and management). A substantial proportion of young population also experience disabilities of varying severity. The GBD childhood disability (0-14 years) estimates were 95 million (5.1%) children, of whom 13 million (0.7%) have ‘severe disability’. Of particular significance among those disabled are the ones who have ‘severe disability’ (such as quadriplegia, severe depression or blindness) – 2.2% of the global population (110 million as per World Health Survey) and 3.8% (190 million as per GBD).

WHO has estimated that the proportion of the world's population over 60 years will nearly double from 12% to 22% 2015 and 2050 (3). The aging populations will surpass the children under 5 years, with most of the elderly living in the LMICs. This has major implications for health and social care systems because human function tends inevitably to deteriorate with age (4). The greatest burden of disability will be contributed in the 60 years age group by sensory impairments (particularly in low- and lower middle-income countries), back and neck pain, chronic obstructive pulmonary disease (particularly in low- and lower-middle-

income countries), depressive disorders, falls, diabetes, dementia (particularly in high-income countries) and osteoarthritis (5).

The World Report on Disability cautions that disabled people are more susceptible to developing chronic conditions because of the influence of behavioral risk factors such as lack of exercise and smoking, as well as higher rates of overweight, obesity and premature ageing (6). The contribution of road traffic injury, occupational injury, violence, and humanitarian crises has grown manifold yet data on the magnitude of their contribution are very limited. Armed conflicts generate injuries and trauma that can result in disabilities. For those incurring such injuries, the situation is often exacerbated by delays in obtaining emergency health care and longer-term rehabilitation. Also, the PWDs in areas of conflict or disabled migrants are the vulnerable and groups which need special focus. Reducing vulnerability of persons with disabilities through proper planning, needs assessment and follow up services is a health system imperative.

The South-East Asia (SEAR) has the second highest prevalence rate of moderate disability (16%) and the third highest prevalence rate of severe disability (12.9%) (6). The 2011 Indian census put the national estimate of the disabled at 2.21% of the total population (26.8 million persons) including persons with visual, hearing, speech, locomotor and mental disabilities with the majority in 19-59 years which is in consonance with the GBD global estimates. The rural populace has a higher percentage of disabled (75%) with only 49% being literate and less than half (34%) employed. The data for quality of employment opportunities available for the persons with disabilities (PWDs) *vis-à-vis* their educational qualifications is largely unknown. The Indian situation is marked by a high percentage decadal change in disabled population (22.4%) during 2001-11 as compared to that for the total population (17.7%).

Inequities in access to Assistive Technology (AT)

The WHO estimates that over a billion people need one or more assistive devices and two billion by 2050; yet only 5-15% of AT needs are currently met. Lack of access to assistive devices is due to high costs, limited availability, lack of awareness, lack of suitably trained personnel, lack of governance, and inadequate financing of assistive technologies (6). The *within* inequities are along predictable categories: economic conditions, persons with different impairments, genders, ages, languages and cultures. There is a lack of awareness among service providers and users about the range of available assistive devices and their benefits (7).

The MDG report highlighted that children with disabilities have limited opportunities and also suffer marginalization in education. The Ministerial Declaration of July 2010 recognized disability as a cross-cutting issue essential for the attainment of the MDGs, emphasizing the need to ensure that women and girls with disabilities are not subject to multiple or aggravated forms of discrimination, or excluded from participation in the implementation of the MDGs. The United Nations General Assembly has emphasized the invisibility of persons

with disabilities in official statistics. The General Assembly concluded its High-Level Meeting on the MDGs in September 2010 by adopting the resolution “Keeping the promise: united to achieve the Millennium Development Goals,” recognizing that “policies and actions must also focus on persons with disabilities, so that they benefit from progress towards achieving the MDGs”.

The 71st World Health Assembly noted that ATs enable and promote inclusion, participation and engagement of persons with disabilities and the fact that 90% (of those requiring it) do not have access to ATs have significant adverse impact on their education, livelihood, health and well-being. It also recalled that the 2030 Agenda for Sustainable Development should be true to its motto of “leaving no one behind” rendering the Sustainable Development Goals (SDG) for Universal Health Coverage (UHC) relevant for all health provisioning needs including those for the disabled (8). The WHO estimated that less than 10% of the persons with disabilities (PwDs) get any of support from the government or other systems. Analysis of the World Health Survey (2002–2004) showed that, compared with people without disability, men and women with disabilities were twice as likely to find that health care facilities and provider skills were inadequate, three times more likely to be denied health care and four times more likely to be treated badly in the health care system.

Affordability of health services and transportation are two main reasons why people with disabilities do not receive needed health care in low-income countries - 32-33% of non-disabled people are unable to afford health care compared to 51-53% of people with disabilities. In India, the awareness level about assistive products and technology continues to be a neglected area.

Recent Global Initiatives

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) viewed disability as an evolving concept, which is influenced by the attitudinal and environmental barriers hindering the effective participation of PwDs in the society on an equal basis with others.

It further states that: “persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Article 1); it does not explicitly refer to NCD in the definition of disability though. However, states are required to recognize that where persons with NCDs (asymptomatic or symptomatic) have impairments which, in interaction with the environment, limit their participation, they can fall under the protection of the Convention.

The 50 articles of the Convention highlighted and discussed issues spanning across diverse dimensions of rehabilitation and ATs including provision of AT as per the choice of the person and acceptable cost, adequate training to the PwDs and specialized staff for mobility skills, encouraging production of mobility aids, promoting research and development of universally designed goods, services, equipment and facilities require the minimum possible

adaptation and the least cost to meet the specific needs of a person with disabilities and to promote universal design in the development of standards and guidelines.

The estimates for the global unmet need for assistive products are neither available nor documented; however, it is true that many people have little or no access to basic assistive products, even in some high-income countries. Few countries have national policies or programs on ATs and therefore grossly limited access. People from poorer strata of society frequently rely on donations or charitable services that may provide substandard or used products that are often not appropriate for the user or the context (and may result in secondary complications or premature death). Similar scenarios are common in emergency response programs where the need for APs is high but often neglected.

The recommendations of the WHO Rehabilitation in health systems, 2017 report again have highlighted very strongly that the quality of evidence for integration of rehabilitation services into the health systems, availability of rehabilitation coordination mechanisms at each level of health care, allocation of financial resources to implement and sustain service delivery of rehabilitation services, affordability of rehabilitation services and insurance coverage, is very low and poor globally (9)

Affordable and appropriate access requires government commitment to adequate and sustained financing, including efficient procurement of appropriate assistive products and delivery systems (10). The WHO undertook an exercise to develop an assistive products list (APL, 2016) with consensus and representation from every WHO region and fifty priority assistive products were finalized. The APL list has defined the users of the assistive technology such as older people, people with disability, people with noncommunicable diseases, people with mental health conditions including dementia and autism and people with gradual functional decline. The aim of the list was to provide Member States with a model from which to develop a national priority assistive products list according to national need and available resources. Like the WHO Model List of Essential Medicines, the APL can also be used to develop product development, production, service delivery, market shaping, procurement, and reimbursement policies (including insurance coverage).

In response to the request, of the High-level Meeting of the General Assembly on the WHO on Disability and Development (New York, 23 September 2013), following a consultative meeting (Geneva, 3 and 4 July 2014), the WHO Secretariat established the Global Cooperation on Assistive Technology in partnership with international organizations, donor agencies, professional organizations, academia and user groups with the goal of improving access to high-quality and affordable APs globally. It also urged Member States to develop policy, financing mechanisms and standards in order to increase access to assistive technology (10). This leads to the resolution to develop a draft outlining the steps to implement the WHO's priority assistive products list.

In January 2018, the Executive Board at its 142nd session considered an earlier version of this report; the Board then adopted resolution EB142.R6. The WHO secretariat provided

technical expertise to shape the focus of the Global Cooperation on Assistive Technology initiative on four interlinked components within the framework of universal health coverage (UHC): policy, product, personnel and provision.

An AT policy framework is being prepared by the WHO, to include an AT assessment toolkit and financing models, such as health and welfare insurance programs, to ensure the sustainability of service provision and universal access. It will also include guidance on implementation of the priority assistive products list, minimum standards, appropriate training and service provision. The priority assistive products list was launched at the Sixty-ninth World Health Assembly in 2016. The aim was to provide a model which each member state can improve upon as per national demands and resources. Other initiatives included developing a procurement manual for ATs to provide guidance, support for strengthening the regulatory framework, product selection and procurement and possibilities for local and/or regional manufacture. Building capacity of the healthcare workforce (those working in rehabilitation, nurses and community health workers) has been marked as a priority to expand their skill set in order to provide a range of basic assistive products at the primary health care or community level that will enable early intervention and universal access.

The WHO's Third Committee Report (71st World Health Assembly, 26 May 2018) pointed to global demographic and epidemiologic transitions (which will double in 2050 as compared with the current estimates of 1 billion PWDs) with consequent implications for demand of ATs. The report also pointed out that 90% of PWDs continue to have no access to ATs. In order to step closer towards the individual country's target of SDG's relating to UHC inclusive and equitable quality education, inclusive and sustainable economic growth, full and productive employment, each country needs to include ATs into the existing health systems (9).

In the UN Convention on the Rights of PWDs (2006), 175 member states committed *inter alia* to ensure access to quality assistive technology at an affordable cost and to foster international cooperation in support of national efforts for realization of purpose and objectives of convention. The committee also emphasized the need for a comprehensive, sustainable and multi sectoral approach to improve access to assistive technology (10).

Since 2013 onwards, the WHAs have called upon member states to improve access to ATs for elderly, PWDS, people with hearing and vision loss. The points of focus as recommended by regional committee were to develop, implement and strengthen policies and programs which improve access to ATs within UHC and/or social services coverage, trained human resources at all levels of health system for provision and maintenance of ATs, and ensure that AT users and their care givers can access and safely use ATs effectively to develop a national list of priority assistive products that are affordable and cost effective but with no compromise on quality and safety (11).

The WHO Action Plan 2014-21 highlighted the lack of research and data on needs, unmet needs, type and quality of services provided, costs, and benefits also constrains the

development of effective rehabilitation and habilitation services. It advocated research to generate policy-relevant data on functioning and disability and urges need for data to strengthen health care systems include: number of people and health status of people with disability; social and environmental barriers, including discrimination; responsiveness of health care systems to persons with disabilities; use of health care services by people with disability; and the extent of the need, both met and unmet, for care (12).

Priority areas for research include: identification of barriers to health care, rehabilitation, habilitation and assistive technology provision and strategies for overcoming them; success factors for health promotion interventions for people with disability; prevention of secondary conditions; early detection and referral of health problems through primary health care; the link between rehabilitation and habilitation needs, receipt of services, health outcomes (functioning and quality of life), and costs; models of service provision, approaches to human resource development and financing modalities; and cost-effectiveness of rehabilitation measures.

It is imperative that research on disability be inclusive of persons with disabilities, ageing populations and disabilities and functional impairments resulting from NCDs, injuries and mental health conditions and the research agendas should be drafted with the active participation of persons with disabilities or their representative organizations

Recent Indian Initiatives

Indian RPWD Act 2016

In the Indian context, the earlier Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 defined disability as several specific conditions including blindness, low vision, leprosy-cured, hearing impairment, locomotor disability, mental retardation and mental illness. The Parliament of India enacted The Rights of Persons with Disabilities Act - 2016" (RPWDA 2016) on December 16, 2016, replacing the earlier PWDA 1995. It defined disability as an evolving and dynamic concept and increased the types of from existing 7 to 21 conditions namely physical disability (including a wide range of locomotor disabilities such as dwarfism, muscular dystrophy and acid attack victims); visual disabilities; hearing impairments; speech and language disabilities; intellectual disability; mental behavior; disabilities caused due to chronic neurological conditions; blood disorders; and, multiple disabilities (13).

Section 2 (w) defined rehabilitation as "a process aimed at enabling PwDs to reach and maintain their optimal physical, sensory, intellectual, psychiatric or social functional levels" and Section 66 -1 required that "the appropriate governments and the local authorities shall within the limits of their economic capacity and development undertake or cause to be undertaken rehabilitation of all persons with disabilities" (13). It also called for developing technology, assistive devices and equipment to facilitate access and inclusion for persons with disabilities. Governments and local authorities were tasked with provision of aids and appliances, medicine and diagnostic services and corrective surgery free of cost to persons

with disabilities. Provisions were made in the Act for designing insurance schemes and creating National and State Funds for persons with disabilities.

Roles of Ministries Health and Social Justice & Empowerment

The Ministry of Health and Family Welfare is responsible for current public health programs such as the National Programme for Control of Blindness and the National Programme for Prevention and Control of Deafness.

The Ministry of Social Justice & Empowerment has the overarching vision of an inclusive society and to empower its target groups through programs of educational, economic and social development, and rehabilitation wherever necessary (10). Under the Rashtriya Vayoshri Yojana (RVY) that aims to cover half a million senior citizens (below the poverty line) beneficiaries in 260 districts, aids and assistive devices will be provided for age related disabilities such as low vision, hearing impairment, loss of teeth and loco-motor disabilities. The Scheme is being implemented by Artificial Limbs Manufacturing Corporation of India (under the Ministry of Social Justice and Empowerment) which manufactures and supplies a wide range of AT for social welfare programs.

The Department of Empowerment of Persons with Disabilities was carved out of the Ministry of Social Justice and Empowerment in May 2012 as Department of Disability Affairs. In 2016 the Department has been renamed as Department for the Empowerment of persons with Disabilities (DIVYANGJAN). The Statutory bodies, institutes and organizations under the department: (i) Rehabilitation Council of India (ii) Chief Commissioner for Persons with Disabilities (iii) National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities.

Agenda Setting for India

The AT industry as well as the policies regarding its provisioning is evolving in India. The demand for ATs vis-a-vis the functionally impaired and disabled persons need better estimates. Disabilities or functional impairments need to be treated as distinct epidemiological entities, for which assistive technology (ATs) and devices constitute the core intervention (for appropriate rehabilitation). The WHO recommends a distinct program for ATs that need to take account of demand, manufacturing, standards, availability, affordability, reach, maintenance, and sustainable use. The approach is not just about making available some devices or technologies, but about comprehending the complex lived experience of the disabled and the functionally impaired across age and socio-economic groups and shaping a flexible and sustainable system that is equitable to this vastly disadvantaged group.

The current RPWD (2016) Act was introduced to bring into effect the UNCRPD (2006). It addresses a wide range of issues including rights, entitlements, education, skill development, employment social security, health, rehabilitation and recreation; however, it falls short of addressing issues of disability on account of NCDs and elderly, a public health

approach to disability rehabilitation, the complexities of the AT industry and its provisioning and research (including implementation research).

An essential step to bridge the gap in policy and practice is to develop a comprehensive national policy for people with disabilities and functional impairments (NPPDFI) to appropriately channelize available resources as compared to the current fragmented efforts and merge the current siloed programs such as those for blindness, deafness, or provision of artificial limbs. This public health response needs to have a comprehensive package for disabilities and FIs attributed to ageing, NCDs mental health disorders, and injuries.

National and programmatic priorities for ATs ought to address both service provisioning as well as research and should include setting up a disability registry (to generate national and sub-national estimates of burden of disabilities), identify specific barriers, provide rehabilitation and assistive technology, undertake health promotion interventions, prevent secondary conditions and sequelae. There is a need to establish linkages across primary, secondary and tertiary levels of care and foster linkages with related national health programs for access to ATs. Development of human resource, financing mechanisms, understanding of socio-cultural dimensions and cost-effectiveness of rehabilitation measures are other imperatives.

The Indian Council of Medical Research (ICMR) plans to align its research priorities as per the international conventions and WHO recommendations. It has already begun the initiatives that can soon be a part of the above-mentioned program in near future. The program will address rehabilitative interventions to equip, enable and empower the disabled and functionally impaired persons with respect to access to assistive technologies.

The proposal for National Disability and Rehabilitation Research Network (NDRRN) has been developed with key four key domains (4-Ps): policy, products, provision and personnel. A Directory of AT Manufacturers (ATM), National Association of AT Manufacturers (ATM) and ATM Co-op Society will be created for the ease of access to affordable and latest certified ATs. The AT industry is a highly unregulated sector; there is lack of design standards and collaboration is being forged with the Department of Science and Technology (DST) for research and development of new assistive technologies and supporting the industry with technical expertise Health financing mechanisms, including research, is critical for addressing issues of both the industry as well as the users. All these require multi-sectoral efforts and collaboration across ministries and agencies.

The issue of implementing the WHO APL list will be addressed through National List of Essential List of Assistive Technologies (NLEAT). Work on Disability Insurance Scheme has been initiated which will be merged with Ayushman Bharat (National Health Protection Scheme). The proposal for implementation of the National Programme for Prevention and Control of Deafness (NPPCD) has been developed and is being implemented in state of Punjab using four technologies – Sohum (newborn hearing screening device, developed under Department of Biotechnology (DBT), Ministry of Science and Technology;

Government of India supported School of International Biodesign (SIB), Shruti (screening and diagnosis kit to detect and diagnose ear infections for use in), Tarang (an amalgamation of diverse design technologies such as Digital Signal Processing (DSP), algorithm and tightly-coupled firmware development, ASIC and analog circuit design and power management, along with the physics of audiology, the anatomy of the human ear, and precision mechanicals using fine-geometry components) and Cochlear Implant. The need of spreading awareness and information regarding various disabilities and FIs is being prepared through the SERVE (Strengthening Education and Research via Entertainment) strategy. There is a need to address diverse specialists including psychiatrists, pediatricians, neurologists, careers, geneticists, psychologists, social workers and NGOs. The 2030 agenda for Sustainable Development and its fundamental aim of “leaving no one behind” can be realized when the vulnerable groups such as persons with disabilities and functional impairment including those with co-morbidities and disabilities (with special attention to children and women) are empowered and provided timely support in terms of equitable access to ATs so that they can realize their full potential.

Challenges and opportunities

- It is imperative that research on disability be inclusive of persons with disabilities, ageing populations and disabilities and functional impairments resulting from NCDs, injuries and mental health conditions and the research agendas should be drafted with the active participation of persons with disabilities or their representative organizations
- Lack of research associated with ATs needs, provision, economic sustainability of ATs
- Awareness of need, availability, use of ATs is very poor amongst users and thus poor IEC is one of the biggest hindrances
- Poor health system infrastructure and responsiveness
- Poor trained and lack of adequately trained health care work force
- Social and environmental barriers, including discrimination; of health care systems to persons with disabilities
- Vulnerable groups such as women, children, disabled persons in war zones, disaster risk management for disabled

Recommended best practices

- Global and national AT research agenda needs to focus on generating good quality of data on the need for rehabilitation services, estimates of unmet need do not exist;
- To prioritize research associated with health-economic evaluation and cost-effective approaches in LMICs for ATs;
- An essential step to bridge the gap in policy and practice is to develop a comprehensive national policy for people with disabilities and functional impairments (NPPDFI) to appropriately channelize available resources as compared to the current fragmented efforts and merge the current siloed programs such

- National and programmatic priorities for ATs ought to address both service provisioning as well as research
- To establish linkages across primary, secondary and tertiary levels of care and foster linkages with related national health programs for access to ATs;
- The Indian Council of Medical Research (ICMR) plans to align its research priorities as per the international conventions and WHO recommendations

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Integrating a new prosthetics and orthotics workforce: Lessons from an evaluation of the Nippon Foundation's investments in South East Asia

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Abstract

Background: Integration of new services is a poorly researched but critical element of efforts to strengthen access to assistive products (AP). A large philanthropic investment in prosthetics and orthotics (P&O) provided a unique opportunity to generate new knowledge in AP implementation. Aims: We aimed to describe how new P&O services have been integrated into existing systems in South Asia, using findings from an evaluation of a large international philanthropic investment. Methods: Using key informant interviews and focus groups, we interviewed more than 100 stakeholders in 6 countries. Document analysis and secondary analysis of available datasets were used to complement testimony. Data analysis was guided by a program logic and sought to develop illustrative and generalisable theories of how services might be integrated into existing systems. Results: A program of leadership development, clinical services, formalised training, mentoring and related advocacy resulted in strengthened, professional P&O workforces. The sector in South East Asia has been transformed, and since 1991, estimated half a million clinical sessions have been provided by program graduates supported by the investment. Positive signs for integration include locally managed training program, emerging policy reform including regulation, and improving relationships and formal links with other health services. Challenges remain for adequate financing of services, workforce retention, and integrated clinical services such as coordinated care pathways and interdisciplinary practice. Conclusion and main implications: Integrating P&O services through foundation training, model services, and advocating for policy reform is possible with long term, multi-stakeholder commitment and financing. Lessons for integrated professional AP services include proposed theories to introduce alternate financing models, address slow policy reform, strengthen coordination of services, and mitigate threats to workforce retention.

Keywords

Provision, personnel, policy, integration, implementation, training

Background

Orthoses and prostheses are essential assistive products for many people with musculoskeletal conditions or limb loss. Accurate information about the needs and unmet needs for orthotics and other assistive products is scarce (1-3) but current estimates suggest poor access to assistive products (AP) that is likely to worsen. People are living longer, and disease patterns are shifting from premature death to years lived with disability (4, 5) - and from communicable disease to non-communicable disease and injuries. Services for rehabilitation and AP often lag other services in the development of health policy and are rarely included in basic health packages. Where services exist, resource and capacity issues threaten quality (1).

International philanthropic assistance and Official Development Assistance (ODA) have been the dominant source of financing and expertise for health-related rehabilitation and prosthetics and orthotics (P&O) services in conflict-affected or low and middle-income countries (LMICs), often driven by the needs and rights of survivors of landmines and unexploded ordnance (UXO). As local economies have changed, and services matured, foreign support has been withdrawn, leaving important but mostly unanswered questions about how those investments can have durable impacts.

Recently, there have been calls to examine and strengthen the systems in which AP service are provided (6-8). The Global Cooperation on Assistive Technology (GATE) proposed that *'integration of assistive products service provision into the health system'* is fundamental to strengthening provision of AP (9). Currently, rehabilitation services are often separate from other healthcare, (1, 10-14), and poorly understood in the community (14, 15). Limited financial and human resources (16-18) are among the most likely barriers to scale and integration, and likely to be threatened by declining foreign support.

Despite new consensus about the importance of integrating AP services, there is little research or guidance concerning effective strategies to improve coordination, or how the broad concept of integration might be defined, operationalised and monitored.

Broadly defined, integration refers to how components of health (and related) services are linked and related to one another. Heyeres and colleagues (2016) described four broad approaches to strengthening integration; integration of care for specific health issues, care pathways, collaboration between related services, and integrating new services into existing systems (19). This provides a useful basis for critically examining the integration of AP services.

The Nippon Foundation's investment

Recognising the neglect of adequate services to respond to conflict survivors and other people in the community with skeletomuscular impairments, the Nippon Foundation has

contributed more than USD\$55 million dollars (until end 2017, inflation adjusted) to foundational training programs and clinical services in Cambodia, Indonesia, Myanmar, The Philippines, Sri Lanka, and Thailand, with additional contributions in at least 4 other countries not part of this analysis. Starting in Cambodia in 1991, the investment was largely implemented by a UK-Charity known as Exceed Worldwide, formerly known as The Cambodia Trust (CT). In short, the key characteristics of the overall investment design were a combination of foundational training in partnership with national training providers, introducing clinical services in a mix of state and non-state sectors, and policy development including basic standards of practice and training. This design aimed to stimulate national uptake of P&O services and integration of a new workforce (20). Integration was broadly understood to mean adequate financing of services and Human Resources (HR), operational links to other healthcare services, and recognition of P&O services in policies.

To provide robust analysis of the program and synthesise lessons from a large and complex intervention, the Nippon Foundation commissioned a whole of program evaluation. The researchers (Nossal Institute) explored i) a descriptive overview of the total outputs of graduates of training programs, and clinical services provided, ii) the experience of and impacts for P&O service users, and iii) integration of a new P&O workforce into national services, which is the focus of this paper.

Aims

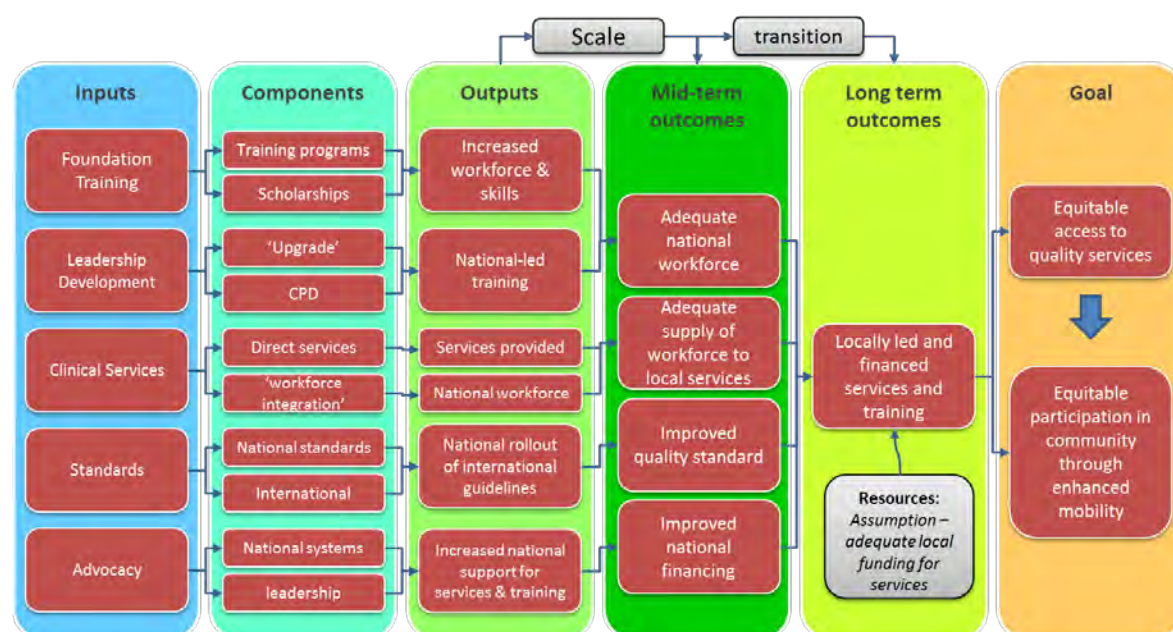
This paper aims to provide new information about effective measures to integrate a new profession and its workforce into health systems.

We sought to answer the questions “how has a program of technical support and foreign aid changed the P&O workforce”, “to what extent are new P&Os integrated into existing health systems?”, “what is the experience of the new workforce?” and “were measures to nurture new graduates effective?”

Methods

We conducted a mixed method, whole-of-program evaluation drawing on realist methods for health systems analysis. A consolidated program theory was developed based on the initial strategic plan and country project designs (figure 1), before refinement in consultation with the Nippon Foundation and Exceed management.

Figure 1. Investment logic used to inform the evaluation



Study context

The study was designed to examine the impact of Nippon Foundation’s investment in Cambodia, Indonesia, Myanmar, the Philippines and Thailand, where training programs have been supported. The investment also supported other countries, through support for training in the United Republic of Tanzania and Australia. Activities included establishing the facilities and curriculum in all study countries, except for Thailand, Australia and the United Republic of Tanzania, where the program comprised scholarships for baccalaureate training for regional professionals.

Table 1. Financial contribution, key characteristics and summary outputs of the 6 main countries evaluated

Characteristic	Cambodia	Indonesia	Myanmar	Philippines	Sri Lanka	Thailand
Total financial support ^a	\$9.4M	\$12.5M	\$5.7M	\$6.2M	\$9.1M	\$12.4M
Period of support	1991 - ongoing	2008 - 2018	2014 - ongoing	2012 - ongoing	2005 - 2018	2001- 2014
International recognition of program	1999	2012	2016	2015	2006	2008
Number of graduates	219 ^b	63	19	38	70	152 ^c
Current students	36	70	35	46	70	26
Estimated/known graduates still working ^d	169	63	34 ^e	37	65	-
Estimated episodes of care provided by graduates	211,000	41,000	18,000	18,000	79,000	118,000

Notes: a: USD, inflation adjusted (until 2018); b: Includes 104 international graduates; c: Excludes domestic, Thai graduates who received no direct financial support; d: At end 2017; e: Includes 17 Myanmar graduates from the Cambodian program

Study participants

Graduates and stakeholders from each country were purposively sampled based on year of graduation, gender, and working context. Potential participants were invited to participate by representatives from training centres in each country and provided information about the study and an invitation to be followed up for interview, at which time, they provided informed, written consent. Other participants identified during in-country visits were invited directly by the researchers. Clients were randomly sampled from waiting rooms in participating clinics and gave either written or verbal consent.

In-country interviews were conducted between June 2017 and August 2018. Follow up telephone interviews were conducted until January 2019. We interviewed more than 120 stakeholders; 98 individual key informant interviews (41 female:57 male) and the remainder in 10 small groups. More than 35 graduates of supported programs, 10 other health professionals including referrers and employers, and 9 representatives of government agencies and disabled persons organisations, were interviewed. We interviewed 3 persons identified as having an unmet need for P&O services.

Program management, and Nippon Foundation representatives were interviewed to develop and refine the program logic used to guide development of question guides and interpretive frameworks. Question guides for key informant interviews drew from the program logic, models of health service integration (19, 21), professional identify formation (22), challenges for rehabilitation in LMICs (16, 18) and current standards for P&O service delivery. Interviews were recorded by audio file, hand typed notes by a 2nd researcher, or both.

Data analysis

Analysis first involved assigning interview transcripts and other raw data such as program documentation to pre-defined themes based on the refined program logic and initial frameworks. In that process, new themes relevant to the topic emerged. Findings from earlier countries were used to refine question guides for subsequent data collection.

Data were coded separately by one of two researchers, with around 1 in 4 transcripts coded by 2 researchers. Code hierarchies and structures were discussed and refined throughout the coding, analysis and interpretation. Direct quotations are deidentified other than country, gender and professional group, or by general description of the respondent type.

Additional documents, including alumni destination surveys, graduate information, policies, and program documents were used to complement and triangulate primary data.

Overall Ethics approval was granted by the University of Melbourne Health Sciences Human Ethics Subcommittee (approval 1748606.1), and by relevant institutional review boards in each of the countries visited.

Results

How has the investment changed the P&O workforce?

Among all students who had enrolled across all the programs and countries we studied, including related enrolments in the United Republic of Tanzania and Australia, 576 had passed and 173 did not finish, which represents a crude 69.5% overall pass rate. At the end of 2017, 213 students were enrolled.

Existing alumni surveys conducted by all the programs except Thailand showed that about three quarters of students who passed were still working. A further 22 were participating in internship programs or about to start them. Forty-nine (14.2%) had left the profession, 6 men had passed away, 3 had gone abroad, 1 retired, and the status of the remaining 16 (and all Thai graduates) were unknown.

Table 2, below, summarises estimated professionals working in the main CT/Exceed supported countries. The per capita ratio of P&O professionals based on the data available range between 0.035/100,000 in Myanmar (1 practitioner per ~2.9 million people), to 0.64/100,000 in Cambodia (1 practitioner per ~155,000).

Table 2. Estimated recognised P&O professionals working in studied countries.

Country (Pop M)	Cat I (n)	Cat I (per 100,000 population)	Cat II (n)	Cat II (per 100,000 population)	Total (n)	Total (per 100,000 population)
Cambodia (14.4)	17	0.12	76	0.53	93	0.64
Indonesia (231.6)	54	0.02	54	0.02	108	0.05
Myanmar (48.8)	--	0.00	17	0.04	17	0.04
Philippines (88)	37	0.04	8	0.01	45	0.05
Sri Lanka (19.3)	24	0.14	65	0.58	89	1.03
Thailand (69.4)	99	0.14	100	0.14	199	0.29

Notes: For simplicity, this table estimates 80% of all graduates were currently working at the 2017 cut-off date, which was based on data for whom the working status was available. Future estimates will need to account for mean 'separation' rate, or the estimated time for a graduate to leave the workforce.

Effective measures to support and integrate a new workforce

Using a broad definition of integration, there were several important drivers of or potential barriers to integrating a new P&O workforce. We present these findings as generalisable theories linking the program inputs with observed changes. The theories are intended to be

specific enough to be supported by the present findings but generally enough to be useful in other settings. We report explanatory or illustrative findings including potential barriers to integration, missed opportunities, design limitations or unanticipated consequences that constrain program integration.

New influence: Investing in future leaders promotes integration through nationalised training

The investment sought to build leadership in the new workforce through supporting for further international qualifications and to assume senior teaching positions in the schools. Respondents provided testimony of a positive impact on the esteem of the profession, nationalising the teaching staff, and thus integrating training into national schools. Scholarships for upgrade training in Thailand (and earlier in Australia) created healthy competition among graduates, but fewer opportunities for scholarships and leaderships as programs have matured have diminished the role of competition.

Linked to advocacy, support to professional association formation, and continuing professional education, leadership development was a strategy to influence integration of services;

“To get good clinical services, you need to have people employed. That affects awareness (of P&O), and leads to policy, through new decision-makers and influence.” – Graduate, Female (F), Cambodia

Direct services address critical gaps and model good practice, but rural areas are de-prioritised

Providing direct services to address unmet needs was central to the design, but had the additional purposes of modelling good practice and developing infrastructure and processes. Informants suggested that this approach led to improved coverage but described persistent barriers outside of major cities, and in linking P&O care to other health services.

While outreach and satellite services were part of the design, services were deliberately targeted in major cities. Choices about the distribution of services intersect with poor knowledge about P&O and perceived service quality and range, causing clients to circumvent appropriate nearby services;

“You know the new centres open in Nichina, Janyo, Mandalay. But most they come here (to Yangon) because they don’t know about the information for the new centres. If they knew they would come. The new centres, they cannot provide for all. Some centres are doing for prosthesis only and don’t have the knowledge for some patients.” – Sector key informant, Male (M), Myanmar

Well supported, but worried: Mentoring and other support to new graduates is valuable, but workforce issues threaten ongoing service integration

Several program interventions had the effect of supporting and nurturing new professionals as they entered their careers in existing health services. Results were highly context specific, varying with the conditions where graduates were employed. Formal methods included clinical mentoring, continual professional education opportunities, and strategies to continue links between graduates and P&O schools. Often the links were informal, arising from strong, trusted relationships with the training staff. These measures had the impact of staff feeling supported and having knowledge and expertise available to them.

Mostly arising from uncertain financing and nationalisation of services after foreign financial support is withdrawn, graduates reported concerns about career growth, salary, relationships with other staff, and links with other health professionals.

Issues concerning opportunities for work affect the availability of services and integration of the workforce directly and indirectly. Direct effects include delays in establishing new job posts, and limited options for work in regional health services. Indirect mechanisms include demotivation of existing professionals and prospective students. One graduate describes how slow processes affected him, but how he was able to be employed based on previous qualifications;

“(recruitment processes started) 8 months before coming here, the govt had to wait for ordering positions transfer form - so that was why I had to go back as nurse and wait for that procedure.” – Graduate (M), Philippines

Other graduates reflected on how poor support of their employers and job insecurity limited their confidence, and thus threatens ongoing service;

“No (I would not recommend this profession) – because the government is not welcoming of PO and there will not be many jobs for graduates” – Graduate (F) Indonesia

“The profession in Cambodia it is hard to get in. Every centre have enough staff to work. So maybe after graduate they may not get job. So, they might not apply because of this.” – Graduate (M), Cambodia

While limited job opportunities are unfortunate, they were not unexpected. Agreements with partner organisations and relevant state actors have been pursued, and formed the basis of assessments of feasibility of new training programs;

“Before all this I went to government and requested whether there was a P&O with degree, would they be hired. The govt agreed that this should be recognised, but it wasn't until some 7 years later that it happened.” – Respondent (M), associated with early design of investment

Recognition of prosthetics and orthotics in national governance has delayed service implementation and uptake of new graduates

Central to the program logic was that within a planned 10-year project cycle, enough national opportunities for employment and financing of services would arise. While in all countries, policy recognition has strengthened during the time of this investment, translating policies into real financial and other support has been slow. One scenario concerning services outside of major cities in the Philippines is illustrative. Especially but not only in the Philippines, there are mechanisms for regional health services to implement P&O services. Occasionally, professionals are sought and appointed, but there are delays in establishing the service.

“They could have prepared ahead some of the hospitals where we can apply afterwards. Create proper job positions so they are prepared before we graduate. In my batch most people are not working in the field anymore. It’s a waste of their knowledge and skills. It would have been better if hospitals were prepared for employment.” – Graduate (F), Philippines

Elsewhere, most international students were supported by a national agency, increasing the likelihood that there would be a service to work in on their return. But this was not the case for all.

“It was difficult to invest in the assets and all. For one year after graduation, I was dependent on my family. The premises are in the hospital, I have to pay the rent, 5000 USD per year. One BW salary 200USD, and for PO 350 dollars.” – Graduate of SSPO from non-NF/Exceed supported country

“Hospitals don’t want to hire PO – because there is no workshop in the hospital; if they do make a workshop it is just for accreditation, but they don’t use it.” – Graduate (F) Indonesia

One alternative was for graduates to establish services themselves, in nationally financed hospitals. But, several graduates reflected on challenges in doing so;

“Hospitals don’t provide the proper machine, it is more struggle. It is difficult to ask the hospital to get the machine and the material. The hospitals don’t know yet about the PO profession.” – Graduate (F), Indonesia

In countries where formal recognition or licensure of other health professionals is required for practice (at least in the state system), adding a new discipline takes time. The implications of slow recognition on the realities of employment was prominent in the Philippines, Cambodia and Myanmar.

“You see the first intake, the 4 PO working here. Their designation is PT because that is the same and that is why the government gives the PT label, but they work as PO.” – Graduate/Employer (M), Myanmar

“They forget us and the profession and importance of providing mobility for persons with disability, so we are not included in national planning.” – Respondent, Cambodia

Many respondents, especially graduates, reflected on negative issues associated with poor formal recognition of P&O. In Cambodia, P&O is overseen by the Ministry of Social affairs, Veterans and Youth Rehabilitation (MosVY); this was interpreted as a barrier to cooperation by one respondent;

“The challenge is not just the money but also system recognition. We are isolated from other health system and services. The MoH does not prioritise PO in the strategic plan. When I want to cooperate with them they say, ‘it’s not my job’.” – Graduate (F) Cambodia

Regulation is mostly a semi-formal arrangement. Qualifications, employer choice of graduates and ISPO recognition of the programs act as forms of ‘proxy’ regulation.

In the Philippines, pursuing a licencing and regulation arrangement through the national commission has higher stakes, because of national insurance financing. However, one account suggests there is administrative block to regulation of a new professional group;

“(Here we) have a professional regulation commission, (there are) boards for OT/PT – but we need three schools to establish a board for P&O.” – Sector respondent, Philippines

Elsewhere, new graduates, better services and better relationships have led to better knowledge of P&O among government actors.

“First the government has recognised the PO and has brought high level awareness to the ministry level and to the rehabilitation doctors.” – Sector informant, Myanmar

Know us, work with us: Care pathways, referrals and interdisciplinary practice are constrained by interpersonal and interprofessional issues and consumer behavior.

Interdisciplinary practice is central to the understanding of service integration. Collaboration between healthcare professionals and client-centred models of practice are prominent in the curricula of all the training programs. One respondent reflects on the benefit of cooperation between P&O and other disciplines to strengthen referrals, but constraints in doing so;

“...(but) – PT (physiotherapist/s) and PO not working well together. (There is) training for PT and PO – we recommend that the students have some classes together, this will impact on their respect and knowledge of each other when they are working... but nothing is happening.” – Employer

Challenges working across disciplines probably arise from entrenched practices, but also because there are insufficient rehab professionals overall;

“We have to train the patients we need a lot of PT here too, but we don’t have them. So, we need PTs but in PT department, they said there are not enough PT here. We need at least one.” – Graduate (F), Myanmar

This highlights a concern about emphasis on support for P&O compared with other disciplines.

“There is not a lot of training here, but they have done for example training in other countries like Thailand and Japan on OT (Occupational Therapy) and speech (therapy), so PTs are doing that. So, they have to go abroad.” – Physiotherapist, Myanmar

While uncommon, respondents described situations where other disciplines were actively unhelpful, rather than simply disconnected, from P&O;

“The (physiotherapists) say patient just need Physio. They care about their profession and making money, so they say brace won’t work with stroke patient but really they worry they won’t need their profession anymore.” – Graduate (M), Cambodia

Concerning referrals and consumer knowledge, many clients reported that they learned about the P&O services through word of mouth rather than through any formal referral or information mechanism. For example, they learned about services from village leaders, neighbours, friends, colleagues or extended family who had received services themselves or knew someone who had.

“When she was 6 they lived in a province area. A group of people from her village (neighbours) told her to go to the centre and she would receive braces, wheelchairs and so on.” – Client (F), Cambodia

“I (service user) tell my friends about this place sometimes. Very seldom people know about this place.” – Client (F), Philippines

In Thailand, there was evidence of service design changes that promoted ongoing follow up and referral of amputee clients.

“We have a system to follow up patient month by month and create system to make patient receive the prosthesis, in the hospital if the patient amputate, the patient will have prosthesis months after, like that.” – Graduate (M), Thailand

Finding ways to pay: Without broader health systems reform, national financing of specific P&O services has been challenging and slow to evolve

Overall, the financial contribution of international and national NGOs has been fundamental to the delivery of even the most basic services. Prominent exceptions are Thailand and the Philippines.

In Thailand, through national health services, a modest but useful reimbursement is paid to hospitals.

“Because I have Government insurance, 30 Baht scheme. If they refer here, they have to pay from Sibichai hospital through that scheme.” – Client (M), Thailand

“But prosthetic is based on money that the Government is going to pay. Consumers can buy their own fancy product and get the 220 (dollars) from government. They can only get basic component with that.” – Graduate (M), Thailand

In the Philippines, some prosthetics services are included in national health insurance mechanisms, even if there are uncertainties about the uptake and effectiveness of that program.

“Philhealth will now pay for PO including therapy. (A) basic package (was only) transtibial and expanded to other conditions.”

And while there are current limitations, insurance-based financing offers the potential for purchasing arrangements with P&Os;

“Private P&Os could be subcontracted to a public hospital and claim Philhealth reimbursements.” – Employer, Philippines

In Indonesia, there are some mechanisms for workplace injuries to be financed through a work insurance mechanism, but awareness and uptake is low, and clients are likely to need to travel to major centres.

“Some prosthetics are covered by insurance – e.g. work insurance, but if usual insurance they are not covered.” – Graduate (F), Indonesia

By contrast, respondents in Myanmar, where international support is ongoing, noted the current emphasis on donor support, and the threat of transition to national financing. One respondent described;

“...so for import (of components and materials), its (international support) 50000 (US) dollar for one year, so after Exceed there will be some difficulty. Before Exceed was around - around 2013 - we had problems to get devices to clients. But during the Exceed supported years, we had no problems, free of charges and patients are happy” – Sector informant, Myanmar

User-pays systems have the effect of reducing choice, restricting access, or burdening individuals and families with potentially catastrophic costs of self-financing (23). Graduates provided testimony of some impacts of current financing arrangements;

“In hospitals, in Government hospitals salaries are funded but the patients pay for the devices. It is only affordable for the middle and high-income people.” – Graduate (F), Indonesia

“You can start a private business if you target the right people. Like rich people, people with insurance. But not people in the provinces.” – Graduate (F), Philippines

Discussion

The large, long-term investment in P&O services analysed here has had a transformative impact on P&O services. Internationally recognised training, model clinical services, advocacy, professional development and long-term support of emerging professionals and leaders has delivered nationally-run training programs and created conditions for new services that are unlikely to have evolved otherwise. However, our analysis revealed important differences between contexts and lessons about how new professionals might be better integrated. We focus here on major implications for integrating new AP services, and situate our analysis within current reforms to the AP sector and existing literature on AP provision.

First, investing in future leaders promotes integration through nationalised training, leading to better recognition of the profession and a means to sustain training programs. Opportunities to provide clinical leadership outside of formal training programs were less prominent and may have demotivated ambitious graduates who did not work in training programs. Investing in clinical and teaching leadership should be emphasised in future AP investments.

Second, the centralisation of P&O services is usually explained as the result of the need for specialised equipment and targeting scarce services where the need is greatest. Nonetheless, access at all levels of the health system is a goal of health services planning overall, and of P&O standards specifically (24). Barriers to services at the primary level included challenges with finding start-up capital, and reluctance of graduates to work in regional settings, which is consistent with findings in other healthcare settings (25), but there is little published work on the motivation of rehabilitation professionals to work in rural or regional areas. Emerging technologies, innovative service models, and attention to motivating staff to work in regional areas emerge as necessary conditions to improve coverage.

Third, while the rehabilitation workforce is poorly understood in health systems (26), most conclude that it is insufficient to meet demand (27, 28). Here, we find that even for a growing profession like P&O, there is sluggish uptake of new graduates, often linked to access to finances and appropriate workplace infrastructure, despite new policies. Poor financial support is related to a combination of awareness of rehabilitation and P&O services in health service decision-makers, prioritisation of rehabilitation, AP and P&O specifically in health planning, weak or limited policies for rehabilitation, or limited accountability for the delivery of commitments under existing policies. Collectively, these challenges threaten the ongoing employment of new graduates, especially in the lower income countries. This is consistent with how normative frameworks for services (29) and action planning for rehabilitation are slow to implement (16-18). Findings underscore the critical importance of coordinated service planning and development, linking new professionals with new services and policies.

Fourth, links with other rehabilitation specialties such as physiotherapy, occupational therapy and speech pathology, and services for the provision of other AP for mobility or self-care, are essential (30, 31), and a clear component of integration. Despite some emphasis on multidisciplinary services in foundation training, P&O professionals reported working in isolation, and clients report inharmonious transitions between services. While training programs often share basic science subjects, there is little opportunity for health-condition specific co-training. Addressing barriers to collaboration through investment in other disciplines and in care pathways is an important design consideration. Equally, P&O services are a logical place to emphasise expanded mobility AP services, but wheelchairs and other mobility products are not integrated into P&O services.

Fifth and finally, without broader health systems reform, national financing of specific P&O services has been challenging and slow to evolve. By committing to long-term plan of scale up and transition, backed by regionalisation and other strategies, this long-term, multi-stakeholder collaboration has created good conditions for national buy-in and transition to national financing of P&O services. However, results have been mixed. All countries have strengthened financial commitment to P&O in the time since the investments begun in respective countries. However, especially in countries with established programs, scale, quality and choice of services are constrained by access to finances, and consumers are mostly (but not always) unable to self-fund. Innovative financing options, other than Exceed's own Social Enterprise model, were not prominent in the countries we researched. Both government and private health expenditures are increasing as a proportion of GDP in South East Asia (32), but given the pressures on health systems, it is likely that the experiences reported by P&Os are similar to other health professionals, and potentially that other health professionals have not enjoyed similar financial support. Given consistent financial barriers to scale, and the potential to negatively impact how a new profession emerges, renewed focus on contemporary health financing options will be timely and important for P&O.

This analysis has drawn on knowledge and expertise of more than 100 people in 6 countries of implementation. It drew on relevant frameworks and used appropriate, robust methods to address the aims. Nonetheless, there are important limitations of the work.

Time and resource pressures meant that limited time was available for field work in each country. Even though we used careful methods to purposively sample a representative group of stakeholders including clients and graduates, there is a risk of bias associated with working with programs to identify relevant sector experts. This risk was mitigated by cross referencing potential informant lists with multiple country stakeholders, and by using snowball sampling wherein stakeholders were asked to identify other people who might have complementary or alternate views about the local situation.

A crucial limitation of this study was that clients interviewed were mostly those who could access services. We could only access a few people who might benefit from services but had

not accessed them; our study does not adequately reflect views of clients who chose not to, or could not, access services.

Conclusions

A large, long term investment in prosthetics and orthotics has strengthened the profession and provided much needed services. Integration of a new workforce has been supported by leadership development, establishing new services, and policy reform, but ongoing financial constraints threaten the longevity of services. The findings raise challenging questions about long-term integration of new professionals working in AP.

Authorship contribution statement

WP designed and managed the project and led manuscript preparation. WP and FS conducted analysis, field data collection, and project monitoring. WP, WP and CH developed and refined the analytical framework, based on program logic originally developed by CH (with others). FK contributed to manuscript preparation, project monitoring, and interpretation of findings.

Acknowledgements

This work was funded the Nippon Foundation who contracted the International Society for Prosthetics & Orthotics to engage external consultants to conduct an independent evaluation. The Nossal Institute and ISPO gratefully acknowledge the financial support of the Nippon Foundation. The authors acknowledge the contribution of the staff of country programs, collaborating partners, and the clients and graduates who participated in the research.

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Assistive products' international trade and tariffs

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Abstract

International trade is an important component of assistive technology sustainability at a global level, and directly relates to the supply and availability of assistive products (AP) in many countries. Aiming at (i) presenting how AP can be identified, grouped and tracked using Harmonized System (HS) codes; (ii) identifying the global export/import flows of AP, as well as market concentration for supplying and importing countries; and, (iii) identifying bound tariffs, most favored nation (MFN) tariffs, and non-MFN (preferential) tariffs effectively applied to AP; this manuscript presents the findings of an initial exploratory quantitative study on international trade flows and tariffs of AP using open access databases pertaining to the World Trade Organization (WTO), the World Customs Organization (WCO) and the United Nations International Trade Statistics Database (UN Comtrade). Relying on a set of WCO Harmonized System (HS) codes, data for this analysis comes from the International Trade Centre's (ITC) Trade Map. Data on applicable tariffs were collected using the WTO Tariff Download Facility and uses the latest available reports from all WTO member countries that reported their bound, MFN and preferential tariffs. In 2017, the total trade value of AP reached almost USD 144.4 billion. A valuable and global market as it is, Herfindahl indices show that it is also a concentrated market for both supplying and importing countries, and that the share of low- and middle-income countries (LMIC) in this market is limited. Data shows that orthotics and prosthetics devices accounted for more than 40% of the total trade value in 2017, followed by glasses, lenses, frames and spectacles (30.1%). AP are also subject to a number of different tariffs. Data shows that approximately 25% of all reporting countries have bound their tariffs on AP at 0%. Notwithstanding their bound tariffs, countries often choose to apply lower tariffs to their trade partners. Data from 150 countries that reported on their MFN tariffs shows that many apply a 0% tariff on many AP as well. Apart from MFN tariffs, AP are also subject to be included in preferential agreements between trade partners that contribute to lower tariff levels. Additionally, the existence of many tariff lines for the same products highlight a need to further improve Harmonized System codes with respect to AP.

Keywords

Supply, Availability, Market Concentration

Introduction

International trade is an important component of assistive technology sustainability at global level, and directly relates to supply and availability of assistive products (AP) in many countries. Many of the papers resulting from the first Global Research, Innovation, and Education in Assistive Technology (GREAT) Summit, held by the World Health Organization (WHO) in 2017, have highlighted that.

MacLachlan and Scherer (1) identified a two-way road between different aspects of supply and a number of topics around systems thinking in assistive technology, such as procurement, policy, products, and provision, but also promotion and partnerships. De Witte and others (2) highlighted (i) the impact that the lack of an economy of scale has for many AP; (ii) the level of fragmentation of the existing AP market; (iii) the lack of participation of low- and middle-income countries (LMIC) in the global AP market; and (iv) the importance of establishing effective supply and delivery chains to improve provision around the world. Moreover, MacLachlan and others (3) stressed that market shaping could be an efficient tool to promote effective market supply and a favorable market environment that might collaborate to bridge the gap between the met and unmet needs for AP.

Although market shaping and other tools are not directly mentioned in the “Global priority research agenda for improving access to high-quality affordable assistive technology” (4), published by WHO in 2017, it is clear that exploring demand and supply is crucial to addressing many of its thematic areas and to deliver on the market potential and great opportunities that the agenda presents for the industries and populations worldwide.

Hence, aiming at (i) presenting how AP can be identified, grouped and tracked using the World Customs Organization (WCO) Harmonized System (HS) codes; (ii) identifying global export/import flows of AP, as well as market concentration for supplying and importing countries; and, (iii) identifying bound tariffs, most-favored-nation (MFN) applied tariffs and non-MFN (preferential) applied tariffs; this manuscript presents the findings of an initial exploratory quantitative study on international trade flows and tariffs of AP using open access databases pertaining to the World Trade Organization (WTO), the WCO and the United Nations International Trade Statistics Database (UN Comtrade).

With regard to market concentration, the Herfindahl index is an indicator calculated by squaring the share of each country in the selected market and by summing the resulting numbers. Antitrust authorities such as the USA Federal Trade Commission use the Herfindahl index as a screening tool to identify harmful market concentration. They consider Herfindahl indices between 0.1 and 0.18 to be moderately concentrated and indices above 0.18 to be concentrated (5).

With reference to different types of tariffs, bound rates are specific commitments made by individual WTO member states, acting as a ceiling rate for any applied tariff. MFN tariffs are what countries promise to impose on imports from other members of the WTO, unless the country is part of a preferential trade agreement, in which case a mutually agreed non-MFN (preferential) rate applies (6).

Approach

Tracking international trade data depends on search strategies that use WCO HS codes in order to identify products of interest. At an international level, products can only be identified, and data collated at the 6-digits level or lower (2 and 4-digits). The current version of the HS was adopted by the WCO in 2017 and has product categories that cover many AP. Unfortunately, not all codes and products descriptions are strictly related to AP, as is the case with 902190.

Relying on this set of HS codes, data for this initial analysis comes from the International Trade Centre's (ITC) Trade Map, an application that uses the UN Comtrade Database and provides both raw data on import and exports and trade indicators. ITC is a joint agency of the WTO and the UN (5).

Data on applicable tariffs were collected using the WTO Tariff Download Facility (7), and uses the latest available reports from all WTO member countries that reported their bound tariffs, MFN tariffs, and preferential tariffs effectively applied to AP.

Considering this is an initial exploration of the data, the analysis only uses descriptive statistics to provide insights on the objectives set forth for the study.

Findings

Table 1 presents the HS codes used in order to identify, group and track AP of interest. All the data and analysis presented and discussed in this manuscript is based either on these codes or on reporting countries and territories.

Table 2 presents exported and imported values, as well as the share of each product group in total trade values of AP. In 2017, the sum of total imported and exported values for AP in the world reached almost USD 144.4 billion.

A valuable and global market as it is, a first glance at Herfindahl indices shows that it is also a concentrated market for both supplying and importing countries for many product codes. Table 3 shows the Herfindal Index for each product code included in the analysis.

Table 1. Harmonized System codes and descriptions organized in product groups

Product Groups	HS 17 Codes	Product Descriptions
Wheelchairs	871310	Carriages for disabled persons, not mechanically propelled
Wheelchairs	871390	Carriages for disabled persons, motorized or otherwise mechanically propelled (excluding specially designed motor vehicles and bicycles)
Wheelchairs	871420	Parts and accessories for carriages for disabled persons, n.e.s
Orthotics and Prosthetics	902110	Orthopedic or fracture appliances
Orthotics and Prosthetics	902131	Artificial joints for orthopedic purposes
Orthotics and Prosthetics	902139	Artificial parts of the body (excluding artificial teeth and dental fittings and artificial joints)
Glasses, Lenses, Frames and Spectacles	701510	Glasses for corrective spectacles, curved, bent, hollowed or the like, but not optically worked (excluding flat glass for such purposes)
Glasses, Lenses, Frames and Spectacles	900130	Contact lenses
Glasses, Lenses, Frames and Spectacles	900140	Spectacle lenses of glass
Glasses, Lenses, Frames and Spectacles	900150	Spectacle lenses of materials other than glass
Glasses, Lenses, Frames and Spectacles	900311	Frames and mountings for spectacles, goggles or the like, of plastics
Glasses, Lenses, Frames and Spectacles	900319	Frames and mountings for spectacles, goggles or the like (excluding of plastics)
Glasses, Lenses, Frames and Spectacles	900390	Parts of frames and mountings for spectacles, goggles or the like, n.e.s
Glasses, Lenses, Frames and Spectacles	900490	Spectacles, goggles and the like, corrective, protective or other (excluding spectacles for testing eyesight, sunglasses, contact lenses, spectacle lenses, and frames and mountings for spectacles)
Hearing Aids	902140	Hearing aids (excluding parts and accessories)
Others	902190	Articles and appliances, which are worn or carried, or implanted in the body, to compensate for a defect or disability (excluding artificial parts of the body, complete hearing aids and complete pacemakers for stimulating heart muscles)

Table 2. Exported and imported values, and share in total trade values for each product group in 2017 (presented in US Dollar thousands)

Product Groups	Exported Value	Imported Value	Share in Total AP Trade
Wheelchairs	2,417,174	2,452,624	3.4%
Orthotics and Prosthetics	29,539,125	31,812,913	42.5%
Glasses, Lenses, Frames and Spectacles	21,688,149	21,845,722	30.1%
Hearing Aids	3,538,291	4,321,260	5.4%
Others	13,732,098	13,062,565	18.6%
Total	70,914,837	73,495,084	100%

Table 3. Herfindal indices of supplying and importing countries for each product code in 2017

Product Code	Concentration of supplying countries	Concentration of importing countries
871310	0.25	0.08
871390	0.17	0.09
871420	0.12	0.11
902110	0.15	0.08
902131	0.15	0.09
902139	0.16	0.06
701510	0.24	0.14
900130	0.12	0.08
900140	0.12	0.08
900150	0.1	0.06
900311	0.33	0.08
900319	0.32	0.07
900390	0.26	0.1
900490	0.26	0.08
902140	0.1	0.1
902190	0.13	0.08

A closer look on imported and exported values by countries and territories highlight the lack of participation of LMIC. Tables 4 and 5 show the major exporters and importers ranked according to their import and export values in 2017, respectively.

Table 4. Major exporting countries and territories ranked according to exported value in 2017 (presented in US Dollar thousands)

Exporter	Exported value	Share in total exports
United States of America	10,497,571	14.8%
China	8,905,582	12.6%
Mainland China	5,713,157	8.1%
Hong Kong SAR	2,088,060	2.9%
Taiwan, China	1,104,365	1.6%
Netherlands	7,733,641	10.9%
Germany	6,225,504	8.8%
Ireland	6,004,714	8.5%
Switzerland	4,847,436	6.8%
Belgium	3,718,467	5.2%
France	2,674,293	3.8%
United Kingdom	2,540,250	3.6%
Singapore	2,273,490	3.2%
Italy	2,077,181	2.9%
Mexico	1,463,593	2.1%
Poland	1,197,663	1.7%
Thailand	1,103,844	1.6%
Denmark	1,006,292	1.4%
World exports	70,914,830	100.0%

Table 5. Major importing countries and territories ranked according to imported value in 2017 (presented in US Dollar thousands)

Importer	Imported value	Share in total imports
United States of America	14,921,707	20.3%
Germany	6,213,614	8.5%
China	5,342,174	7.3%
Mainland China	3,833,374	5.2%
Hong Kong SAR	1,508,800	2.1%
Netherlands	5,327,972	7.2%
Japan	4,353,164	5.9%
France	4,063,763	5.5%
United Kingdom	3,388,099	4.6%
Belgium	2,876,648	3.9%
Italy	2,449,175	3.3%
Switzerland	1,996,661	2.7%
Canada	1,854,662	2.5%
Australia	1,731,271	2.4%
Spain	1,431,800	1.9%
Singapore	1,084,337	1.5%
Korea, Republic of	960,731	1.3%
Russian Federation	835,244	1.1%
World imports	73,495,050	100.0%

Apart from data on international trade flows, the study also intends to explore data on tariffs, the customs duties that usually take the form of ad valorem tariffs, which are calculated as a percentage (rate) of the value of the product (6).

Table 6 presents several aspects related to bound tariffs. Among the 136 reporting countries, it presents the percentage of countries that chose to bound, unbound or partially bound their tariffs for each product code. Partially bounding their tariffs means that countries hold more than one tariff line for that product code, and that only a part of them are bounded. By bounding their tariffs, countries establish ceiling which they commit to apply to imported products. As such, the binding coverage for each product reflects the predictability of the market.

Besides showing the percentage of tariffs bounded at 0%, it also shows the median tariff and the tariff range for those tariffs that are not bounded at 0%.

Table 6. Percentage of countries with bound, unbound and partially bound tariffs, as well as the percentage of tariffs bounded at zero, and median tariff and tariff range for rates not bounded at zero, for each product code in 2017 (all rates presented in %)

Product Code	Countries with Bound Tariffs	Countries with Unbound Tariffs	Countries with Partially Bound Tariffs	Tariffs Bounded at 0%	Median Bound Tariff	Bound Tariffs Range
871310	72.1	27.9	0.0	32.7	35	5-100
871390	72.1	27.9	0.0	32.7	35	4-100
871420	73.5	25.7	0.7	28.7	35	5-100
902110	77.2	22.8	0.0	29.5	35	4-110
902131	77.2	22.8	0.0	31.4	35	4-110
902139	77.2	22.8	0.0	31.4	35	4-110
701510	74.3	25.7	0.0	5.9	30	1-100
900130	74.3	25.7	0.0	9.9	30	1-100
900140	75.7	24.3	0.0	4.9	25	1-100
900150	75.0	25.0	0.0	5.9	27.5	1-100
900311	74.3	25.7	0.0	2.0	30	2.2-100
900319	72.8	27.2	0.0	4.0	30	2.2-100
900390	73.5	26.5	0.0	3.0	30	1-100
900490	72.8	25.7	1.5	3.0	30	2.5-100
902140	77.2	22.8	0.0	31.4	35	4-110
902190	78.7	21.3	0.0	33.6	35	2.1-110

Table 7 shows the percentage of countries, among the 150 reporting countries, which chose to set their MFN tariffs at 0%, as well as the median rates and tariff range for those countries that did not zeroed the import tariffs applied to their trade partners, for each product code. The largest the tariff range and the difference between the bound and applied MFN rates, the most unpredictable trade policies are (6).

Table 7. Percentage of countries with MFN tariffs set at zero, and median tariff and tariff range for rates not set at zero, for each product code in 2017 (all rates presented in %)

Product Code	MFN Tariffs at 0%	Median MFN Tariff	MFN Tariffs Range
871310	74.0	5	2-26
871390	74.0	5	2-26
871420	72.0	5	2-26
902110	62.0	5	1-26
902131	64.7	5	1-26
902139	64.7	5	1-26
701510	43.3	5	1-26
900130	37.3	5	1-26
900140	37.3	7.5	0.7-32
900150	38.0	7.5	0.7-32
900311	24.7	10	1.3-35
900319	25.3	10	2-35
900390	25.3	5	1-35
900490	18.0	7.5	2-30
902140	68.0	5	1-26
902190	62.7	5	0.5-26

As countries might agree on preferential tariffs to be applied for free trade areas or customs unions, for example, for each product code, Table 8 presents the number of reporting countries, the number of reported preferential tariffs and the percentage of preferential tariffs zeroed, as well as the median tariff and tariff range for those rates that were not zeroed.

Although international agencies like the WTO and WCO can only use information up to the 6-digits level to collate and compare data across countries, these are free to create additional tariff lines for each product code. Tables 9 and 10 show the percentage of reporting countries that chose to apply one, two to four, or more than five tariff lines to each product code for their MFN and preferential tariffs, respectively. Additional national tariff lines can be used to further refine tariffs as well as for statistical purposes.

Table 8. Information on reporting countries and reported preferential tariffs for each product code in 2017.

Product Code	Reporting Countries	Reported Preferential Tariffs	Preferential Tariffs at 0%	Median Preferential Tariff	Preferential Tariff Range
871310	20	54	83%	4.5%	1-40%
871390	20	54	87%	2%	1-15%
871420	20	59	86%	4.75%	1-60%
902110	30	135	82%	4.4%	0.1-55%
902131	27	107	79%	4.4%	0.4-55%
902139	27	106	77%	4.4%	0.4-40%
701510	52	292	89%	7.6%	1-40%
900130	56	335	94%	2.75%	2-40%
900140	53	357	95%	4%	0.5-40%
900150	54	360	94%	4.25%	0.55-40%
900311	70	411	92%	5%	1-50%
900319	70	374	91%	5%	1-50%
900390	74	429	90%	4.4%	1-50%
900490	76	451	89%	8.9%	0.33-40%
902140	27	109	80%	4.4%	0.4-35%
902190	30	122	82%	8.2%	0.4-35%

Table 9. Number of reporting countries and percentage of countries applying 1, 2 to 4 or 5 or more MFN tariff lines to each product code in 2017.

Product Code	Number of reporting countries	1 Tariff Line	2-4 Tariff Lines	5+ Tariff Lines
871310	150	97.3%	2.7%	0.0%
871390	150	96.7%	3.3%	0.0%
871420	150	91.3%	8.7%	0.0%
902110	150	66.0%	27.3%	6.7%
902131	150	96.0%	3.3%	0.7%
902139	150	66.7%	27.3%	6.0%
701510	150	94.0%	6.0%	0.0%
900130	150	96.0%	4.0%	0.0%
900140	150	62.0%	38.0%	0.0%
900150	150	60.7%	39.3%	0.0%
900311	150	95.3%	4.7%	0.0%
900319	150	68.7%	29.3%	2.0%
900390	150	88.0%	11.3%	0.7%
900490	130	33.8%	61.5%	4.6%
902140	150	99.3%	0.7%	0.0%
902190	150	65.3%	29.3%	5.3%

Table 10. Number of reporting countries and percentage of countries applying 1, 2 to 4 or 5 or more preferential tariff lines to each product code in 2017.

Product Code	Number of reporting countries	1 Tariff Line	2-4 Tariff Lines	5+ Tariff Lines
871310	54	98,1	1,9	0,0
871390	54	98,1	1,9	0,0
871420	59	59,3	40,7	0,0
902110	135	30,4	40,0	29,6
902131	107	99,1	0,9	0,0
902139	106	40,6	58,5	0,9
701510	292	92,8	7,2	0,0
900130	335	89,0	11,0	0,0
900140	357	50,4	49,6	0,0
900150	360	48,3	51,7	0,0
900311	411	93,7	6,3	0,0
900319	374	74,6	24,3	1,1
900390	429	92,1	7,2	0,7
900490	451	28,4	64,3	7,3
902140	109	100,0	0,0	0,0
902190	122	41,0	36,1	23,0

Discussion

Regarding the appropriateness of the HS codes to adequately identify AP, wheelchairs and hearing aids, as well as glasses, are in a much better position than orthotics, prosthetics and others, which would certainly benefit from improvements in their coding. Both the description and the significance of 902190 (Articles and appliances, which are worn or carried, or implanted in the body, to compensate for a defect or disability) in terms of its share of the total trade values (above 18%), adds a striking note on the need for its refinement. Nevertheless, by looking at the number of countries that create additional national tariff lines for the codes used in this study, we see that spectacles lenses, spectacles and orthotics and prosthetics score even higher. On the other hand, wheelchairs and hearing aids seem to have more appropriate codes, despite the high number of additional tariff lines for wheelchairs parts and accessories between preferential trade partners.

Despite the effect caused by the unprecise description of 902190, it is possible to see that orthotics and prosthetics (42.5%) and spectacles and its parts (30.1%) concentrate a significant share of the market. They are only distantly followed by hearing aids (5.4%) and wheelchairs (3.4%). Once we have only used export and import aggregated values, it is not possible to say if this is caused by differences in trade volumes or prices.

Apart from the product groups that concentrate trade flows, data also shows high market concentration levels for many product codes. Data on global imports indicates that Herfindahl indices for all AP are above 0.1, which indicates some level of market

concentration of supplying countries. As a matter of fact, six out of the 16 product categories show indices above the 0.18 threshold, indicating concentrated markets. On the other hand, data on global exports demonstrate that only four products in the list have Herfindahl indices of 0.1 or higher, indicating a lower concentration of importing countries.

Additionally, although data from 2017 shows that 223 countries imported AP, only 17 countries accounted for more than 80% of world imports, all of them either High-Income or Upper-Middle-Income Economies, as per World Bank classification. Figures for exporters are not much different. Although there were 188 exporting countries in 2017, only 17 countries exported more than USD 1 billion, totaling more than 87% of world exports. Again, all of them scored high in World Bank classifications. Hence, despite the significant size of their markets and regional or global industrial potential, only China, Mexico, Thailand, and the Russian Federation are among the major world exporters and importers. Despite not being evident in this manuscript, other LMIC, like Brazil, Viet Nam, the Dominican Republic, and Algeria have some level of participation in specific markets, such as for spectacles and its parts.

Essential to explore international trade, diving into customs tariffs is important as they inform about the predictability of the market and assist us in identifying areas for international orchestrated action and negotiation in order to reduce barriers to trade and facilitate and improve the supply and availability of imported products.

As such, AP are subject to several different types of tariffs (bound, MFN, and non-MFN preferential tariffs, as previously mentioned). By committing to bound their “ceiling” tariffs, countries increase the binding coverage, hence improving market predictability (6). Data demonstrates that 70-80% of all 136 reporting countries bound their tariffs on AP, with “9021” products scoring higher, above 75%. Moreover, it shows that approximately a third of these countries chose to bound their tariffs at 0%. As such, almost 20% of all reporting countries have bound their tariffs on AP at 0%, although wheelchairs, hearing aids and orthotics and prosthetics have much higher level of tariffs bounded at 0% (around 30%) than spectacles and its parts (below 10%). For the remaining reporting countries that did not bound their tariffs on AP at 0%, the median tariff was around 30-35%, although actual tariffs still ranged from 1% to 110%. Hence, the tariffs binding status, despite its relevance to diminish possible variations, has a limited effect for those countries that did not zero their tariffs on AP.

Notwithstanding their bound tariffs, countries often choose to apply lower tariffs to their trade partners. Data from 150 countries that reported on their MFN tariffs shows that many apply a 0% tariff on many AP, as well (above 60% of the reporting countries for all product groups, except spectacles and its parts). For the remaining countries, the median applied MFN tariff was around 5 to 10%, with tariff levels ranging from 1 to 35%. Thus, in practice, no country applies a tariff (whether bound or unbound) higher than 35% to any AP, though the gap between the bound and applied MFN rates (tariff overhang) is still substantial, demonstrating some level of market unpredictability.

Apart from MFN tariffs, AP are also subject to be included in preferential agreements between trade partners that contribute to lower tariff levels. In many such cases, reporting countries have also chosen to zero their tariffs on AP (circa 80% of applied non-MFN tariffs on orthotics, prosthetics and hearing aids, above 83% on wheelchairs, and approximately 90% for glasses, lenses, frames and spectacles). As with MFN tariffs, the median non-MFN preferential tariffs that were not zeroed is below 10%.

Conclusions

Exploring data on international trade and tariffs depends on HS coding, hence our efforts to use product categories that relate with AP. However, HS codes might not be directly applicable to many AP. For those categories that exist, countries still create several tariff lines for the same HS subheadings that are not comparable, demonstrating a need for further detail in products classifications. The international community would certainly benefit if these could be aligned with other references such as ISO 9999:2016 (Assistive products for persons with disability) (8), which establishes a widely accepted classification and terminology of assistive products, increasing the level of data comparability internationally.

Additionally, as countries can report the quantities of exported and imported goods in terms of both individual units and overall weight, data is not readily comparable across all countries. Creating and consolidating search and analysis strategies is fundamental to exploring AP trade and tariffs at a global level.

The data presented and analyzed demonstrates that the market is concentrated around some groups of products and countries, with limited participation of LMIC. Additionally, despite the significant binding coverage established by WTO member countries, the binding overhang is still considerable. Information on preferential trade agreements that include customs duties on AP demonstrate that there is an opportunity for negotiation at international level, and that the international community would benefit from diminishing the barriers to the international trade of AP.

Further studies on this topic would be able to provide additional information about trends in AP trade over time, as well as providing more detailed data on importers and exporters. Further efforts could also serve to explore possible relations between countries level of income, unit prices, countries' share in the world market, markets concentration and applied tariffs to shed a light on high level determinants of products quality, affordability and availability at local level in many countries.

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Understanding and advancing Canadian policies for equitable access to assistive technology

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Abstract

While assistive technology (AT) can support self-management of health and social needs and promote social inclusion and participation, many Canadians experience unmet AT needs. We present insights from a comprehensive Canadian research initiative to enhance equitable AT access. The initiative applies an integrated knowledge mobilization approach and fosters transdisciplinary and multi-sector partnerships to create maximum impact. Citizens (including seniors, persons with disability, caregivers); policymakers; professional, service provider, advocacy, and industry organization stakeholders; and researchers are involved. Methods applied to understand system challenges and identify options for policy action include a scoping review, a jurisdictional scan, evidence syntheses, interviews, citizen panels, a stakeholder dialogue, a citizen survey, and a policy symposium. Findings show that the Canadian system for AT access lacks national leadership; has variable legislation, policies, and programs across jurisdictions; lacks system integration between main providers; and offers poor access to funding. There is also a universal lack of awareness and knowledge regarding AT and how to access AT. These are understood as underlying causes of experiences of inequitable AT access, disparities for certain groups, system navigation issues, and unmet AT needs. Principles identified make clear the necessity for rights-based, person-centred, and co-creation approaches. We are acting on the recommendation to create a policy vision which includes short- and long-term policy priorities and guiding principles to underpin action. Through our initiative we are co-creating a national vision

document and action plans that provide guidance to drive policy action and system transformation.

Keywords

Access, equity, policy, aging, federation

Context

Canadian population

Canada is experiencing population aging along with a growing number of persons living with disability. In 2018, the proportion of Canadians aged 65 years and older was 17.2% or 6.4 million people (1). This proportion is anticipated to reach 20% or 7.9 million people by 2024. The 2017 Canadian Survey on Disability reported that an estimated 22.3% of Canadians aged 15 years and over, or 6.2 million people, were living with disability that restricts daily activity performance (2). Disability prevalence increases with 13.1% of people between ages 15-24 with a disability as compared to 37.8% aged 65 years and older. Of those with disabilities, over 40% identified as having severe to very severe disability.

Many Canadians also have unmet assistive technology (AT) needs. In a 2012 survey, 81% of Canadians with a disability were reported to use at least one aid or device to support participation (3). In a more recent survey, 26% of those with a disability aged 15 years old and older identified unmet needs for at least one disability support which included aids, devices, and medications (2). For those with disabilities aged 15 years and older, 1.5 million people identified an unmet need for an aid or device, of which approximately 1 million people cited cost as the reason.

Health and social systems in Canada

Most of the government programs offering AT funding and services in Canada are through health and social systems. Health systems are largely the responsibility of provinces and territories with the federal government playing a financing and regulatory role. The Canada Health Act provides “criteria and conditions related to insured health services and extended health care services that the provinces and territories must fulfill to receive the full federal cash contribution under the Canada Health Transfer” (4, 5). The Act outlines five key conditions for health care, namely public administration, comprehensiveness, universality, portability, and accessibility. Under these conditions, care provided in hospitals or by physicians in the provincial or territorial health systems is free to eligible individuals at the point of use, but there is no similar provision for funding prescription drugs or other supports including homecare and AT (6). Consequently, the nature and extent of public funding for these products and services varies across the country. Social systems, which offer publicly-funded social services for families, seniors, persons with disabilities, and others, are not addressed broadly in federal legislation and do not have national agreed upon principles or standards like health systems (7). Jurisdictions receive some funding through the Canada Social Transfer, but each jurisdiction is responsible for the majority of

the funding and for allocating funding to necessary services (8). Services may include programs offering AT funding or services, e.g. for those seeking employment or considered low income. How social services interface with health services is determined by each province or territory through its legislation, policies, and programs.

Policy context for disability and assistive technology

A recent disability policy scan noted a high level of complexity in legislation and programs that were multi-level and -sector (involving different government levels, ministries or departments) (9). Thirty-eight federal statutes were found that included content relevant to disability, ranging from broad legislation such as the *Canadian Charter of Rights and Freedoms* and *Canadian Human Rights Act* to sector specific legislation such as transportation, housing, education, employment, and others (10, 11). Other legislation, while not mentioning disability, was noted to potentially impact persons with disability. Beyond federal legislation, provincial and territorial jurisdictions have their own legislation and specific programs.

The *Accessible Canada Act*, Canada's first overarching legislation specific to persons with disabilities, came into force in July 2019, with the aim of creating a barrier-free nation (12). The Act seeks to proactively address barriers to societal participation for persons with disabilities, by identifying, removing, and preventing barriers that are "physical, architectural, technological, or attitudinal", "based on information or communications", or "the result of a policy or practice". The Act pertains to areas such as banking, telecommunications, transportation, and the Canadian government, which are under federal jurisdiction. Where accessibility legislation exists in provinces such as Ontario (2005), Manitoba (2013), and Nova Scotia (2018), these also apply.

Canada does not have federal legislation or any other overarching policy that stipulates universal access to AT. Some subsets of the population (e.g., First Nations and Inuit peoples, veterans, refugees) have federal-level legislation, though provisions for each group vary. Considering the governance of health and social systems, there is great variability within and between provinces and territories regarding provisions for AT.

United Nations Convention on the Rights of Persons with Disabilities

In 2010, Canada ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and in 2018, Canada acceded to the Optional Protocol (12, 13). A preliminary report from the UN Special Rapporteur on the rights of persons with disabilities concluded that Canada has not put plans into place to address or fully enact many of its obligations under the CRPD (14). While passage of the *Accessible Canada Act* is an advance, Canada does not have comprehensive legislation or a policy framework to facilitate implementation of the CRPD. Further, espousing a human rights-based approach, rather than the current social-assistance approach where services vary based on jurisdiction, was recommended as critical to realizing the obligations under the CRPD and creating system change to fulfill the rights of persons with disabilities.

AGE-WELL

Our work described in this manuscript is funded by AGE-WELL, Canada's technology and aging network. AGE-WELL is a pan-Canadian network that brings together researchers, older adults, caregivers, partner organizations, and future leaders to accelerate the delivery of technology-based solutions that make a meaningful difference in the lives of Canadians. AGE-WELL was launched in 2015 through the federally-funded Networks of Centres of Excellence program.

Objectives

In this manuscript, we present insights from our Canadian research initiative to support equitable access to AT, focusing on systemic and policy challenges particular to federated countries providing universal health coverage. This manuscript will:

1. Describe findings from a comprehensive study of AT access and multi-level and -sector challenges described by citizens, policymakers, and stakeholders within federal and 13 provincial and territorial jurisdictions;
2. Demonstrate Canada's need to shift approaches regarding equitable AT access considering an aging population and societal values that emphasize community-based solutions that promote aging-in-place;
3. Discuss the necessity of rights-based, person-centered, and co-creation approaches with those affected by the issues, as well as policymakers and stakeholders to advance equitable access; and
4. Highlight opportunities for enhancing equitable AT access from perspectives of a social model of disability which underpins the UN CRPD.

We also outline our initiative's ongoing activities, working with citizens, policymakers, and stakeholders to identify short- and long-term priorities and guiding principles for Canadian policy action, which can be adapted to inform efforts to improve equitable AT access in countries facing similar challenges.

Overview of approach

The approach undertaken in this initiative is based on practices for policy innovation developed and applied by our researchers, networks, and partnering organizations and centered on enhancing collaboration and knowledge mobilization across disciplines, sectors, organizations, and jurisdictions. All aspects of the approach are based on integrated knowledge mobilization, which prioritizes meaningful engagement of citizens, policymakers, stakeholders, and researchers in guiding all phases of our initiative (15). This has involved engaging partners who work collaboratively throughout all aspects of the initiative, as well as conducting meaningful engagement with the above groups on specific projects (e.g., as steering committee members and/or participants). Table 1 provides a summary of our core partners, including the focus of their work and their roles and contributions. Table 2 details the projects developed and implemented in our initiative.

Table 1. Summary of partners

Partner	Organizational focus	Role and contributions
AGE-WELL	<ul style="list-style-type: none"> • Vision and mission: Canada’s leadership in technology and aging benefits the world; to develop community of researchers, older adults, caregivers, partners, and future leaders that accelerates delivery of technology-based solutions that make meaningful differences in lives of Canadians • Produces technologies, services, policies, and practices that improve quality of life for older adults and caregivers, and generate social and economic benefits for Canada • Trains next generation of leaders in field (700+ trainees already engaged) • Fosters active involvement of older adults and caregivers (4,700+ already engaged) who ensure products practical and useful 	<ul style="list-style-type: none"> • Main funder of research initiative • Offers network and expertise of over 250 funded and affiliated researchers from 42 universities and research centres across Canada, over 400 industry, government, and non-profit partners • Pioneering transdisciplinary approach to research that breaks down silos between disciplines and sectors
AGE-WELL National Innovation Hub Advancing Policies and Practices in Technology and Aging	<ul style="list-style-type: none"> • Vision of driving policy innovation to improve future of aging in Canada • Mobilizes power of research, collaboration, and innovation to support Canadian federal, provincial, and territorial governments in generating policy options that address complex challenges of aging population • Centers approach for problem-solving on principle of connectivity of policy partners, as Canada’s health and social care systems are diverse, and often disconnected 	<ul style="list-style-type: none"> • Offers network of engaged policy stakeholders from across Canada • Creates opportunities for meaningful exchange between policy stakeholders, by bringing government representatives together to share ideas and work collectively on policy solutions (e.g. roundtable meetings, targeted practice communities, private online portal) • In-kind supporter of initiative
March of Dimes Canada	<ul style="list-style-type: none"> • Canada's largest community service organization for people with physical disabilities, offering wide array of programs and services to Canadians with disabilities, their families, and communities • Service delivery organization and advocacy charity since 1951 	<ul style="list-style-type: none"> • Reflects lived experiences of service users and providers • Provides extensive knowledge and expertise in disability, aging, AT sector • Offers network of stakeholder and advocacy connections and knowledge dissemination channels to inform initiative and ensure direct uptake of research findings to inform policy and practice

Partner	Organizational focus	Role and contributions
	<ul style="list-style-type: none"> E.g. Assistive Devices Program in Ontario assists people in financial need to purchase assistive devices that increase their mobility and independence 	<ul style="list-style-type: none"> In-kind supporter of initiative
McMaster Health Forum (WHO Collaborating Centre for Evidence-Informed Policy)	<ul style="list-style-type: none"> Goal of forum to generate action on pressing health-system issues, based on best available research evidence and systematically elicited citizen values and stakeholder insights Aims to strengthen health systems – locally, nationally, and internationally – and get the right programs, services, and drugs to people who need them Through Forum+, has expanded its work to include social systems 	<ul style="list-style-type: none"> Initiative co-lead through M. Wilson, providing scientific and knowledge mobilization leadership
University of Toronto - Intelligent Assistive Technology and Systems Lab (IATSL)	<ul style="list-style-type: none"> Interdisciplinary group of researchers in engineering, computer science, occupational therapy, and others with collective goal of developing technologies that are adaptive, flexible, and intelligent to enable older adults to participate fully in their daily lives 	<ul style="list-style-type: none"> Initiative co-lead through R. Wang, providing scientific and knowledge mobilization leadership

Table 2. Projects in research initiative

Project	Aims	Status/Outputs
Scoping review	To identify and map literature on ethical challenges related to AT access to inform policy development	<ul style="list-style-type: none"> Protocol paper (16) Manuscript in preparation
Policymaker and stakeholder interviews	To examine policymaker and stakeholder views on ethical, social, and policy issues related to AT adoption and access, and solicit suggestions on how to address equity of access and service gaps	<ul style="list-style-type: none"> Interviews complete Manuscript in preparation
Jurisdictional scan	To survey current AT funding and service programs offered by government and charity organizations in Canada	<ul style="list-style-type: none"> Jurisdictional scan report (17) Paper (18) Additional manuscript in preparation
Citizen Panels	To convene citizens to identify values and preferences for enhancing equitable access to AT in Canada to guide efforts of policymakers, managers and professional leaders who make health system decisions	<ul style="list-style-type: none"> Citizen brief (19) Panel summary (20) Paper (21)

Project	Aims	Status/Outputs
Stakeholder dialogue	To convene policymakers, stakeholders, and researchers who are in positions to champion system change to deliberate about the problem, options for addressing it, implementation considerations, and next steps that need to be taken to enhance equitable access to AT in Canada	<ul style="list-style-type: none"> • Evidence brief (22) • Dialogue summary (23) • Paper (21)
Policymaker, stakeholder, and researcher interviews	To interview key informants to explore views and experiences about building and implementing vision for enhancing equitable AT access, to identify: principles that should underpin any policy actions taken and policy priorities that should be addressed in short and long term for enhancing equitable AT access	<ul style="list-style-type: none"> • Interviews complete • Principles and priorities for citizen survey defined • Report and manuscripts in preparation
National citizen survey	To survey citizens (seniors, persons with disability, caregivers) to identify relative importance of principles to guide policy actions and short- and long-term priorities for enhancing equitable AT access	<ul style="list-style-type: none"> • Survey deployed • Draft policy vision to inform deliberations at the AT policy symposium (in preparation)
AT policy symposium	To convene policymakers, stakeholders (including representatives from citizens' groups), and researchers to deliberate about what steps can and should be taken to address short- and long-term priorities for enhancing equitable access to AT	<ul style="list-style-type: none"> • In preparation for Oct 2019 • Vision and action plan report pending
Web-based database for AT programs across Canada	To support system navigation by creating and deploying searchable database on programs providing AT funding or services	<ul style="list-style-type: none"> • In development

Summary of Pertinent Findings

Jurisdictional scan

AT funding and service programs are offered by a mix of federal, provincial, and territorial governments; legislated or private insurance; or charitable organizations. We completed the first comprehensive pan-Canadian scan of government and charitable programs providing AT funding and services (17). The scan found 86 government and 134 charitable organization AT programs in 14 jurisdictions (federal/national, 13 provincial/territorial). Overall, programs are fragmented, overlapping, complex, and uncoordinated, creating access barriers and system navigation issues. Programs are highly variable in eligibility criteria (e.g., based on age, income, type of residence, disability type), funding (e.g., co-payments, deductibles), and service delivery mechanisms (e.g., requirements for health care providers, authorizers, vendors), resulting in inequitable access. Disparities exist in funding for issues addressed by different AT. Most programs offer funding for physical mobility concerns; communication, vision, and hearing funding across jurisdictions is inconsistent, ranging from full funding to none at all; and little to no funding is offered for cognitive or mental health concerns. The scan also found that charitable organizations play numerous important roles in the AT system, in some cases providing funding for devices or partnering with governments in service delivery.

Policymaker and stakeholder interviews

We completed 24 interviews with 32 participants that illustrated the perspectives of diverse policymakers, stakeholders, and researchers from 11 jurisdictions in Canada (national, seven provinces, three territories, manuscript in preparation). Participants represented government, charity, non-profit, for-profit, and academic sectors, and included persons with lived experience of disability. An analysis to explore challenges and potential solutions to AT access revealed a system of policies and programs operating in silos that do not view users in a client-centred and holistic way. Unmet needs and service gaps existed for several segments of the population with a host of access barriers including funding, system navigation, among others. Lack of awareness regarding AT, how to access AT, and AT benefits were commonly identified across groups. Along with specific targeted system improvements, several recommendations were proposed for AT system advancement, including adopting a human-rights based perspective, incorporating a user-centred approach, viewing users holistically as individuals through a social rather than a medical model, and applying a holistic and integrated approach to streamline service delivery.

Citizen panels

Citizen panels, with 37 citizens, conducted in three cities across Canada uncovered values to underpin policy action for enhancing equitable access to AT (19-21). Citizens were selected according to diverse ethnocultural and socio-economic backgrounds, and many had lived with experience with disability/AT use or were caregivers of persons with disability. Themes pertaining to policy action focused on enhancing collaboration and ensuring equity and

accountability. Citizens underscored the need for reliable information to support informed choices, ensuring equity of access regardless of ability to pay, and collaboration and coordination across and among users, providers, and organizations within health systems and across sectors.

Stakeholder dialogue

We convened a national stakeholder dialogue with 22 federal and provincial policymakers; representatives from citizen, professional, and industry organizations; and researchers in positions to champion system change (21-23). Participants identified needs for supporting informed decisions, getting the most out of public programs, and enhancing access to AT not publicly covered. The imperative to create a policy vision which includes short- and long-term policy priorities and guiding principles to underpin action was identified. Key principles identified include: 1) applying a client-driven and -centred approach; 2) achieving consensus on a definition of AT; 3) ensuring universal access to AT for basic and instrumental activities of daily living; 4) developing a simplified method to AT access that is flexible for individual needs; 5) advancing from a medical to a social or rights-based approach ; 6) promoting leadership and collaboration; and 7) supporting innovation in approaches for policy development and implementation.

Developing a policy vision

We are currently undertaking a set of three projects to act on the recommendations from the stakeholder dialogue to create a policy vision which includes short- and long-term policy priorities and guiding principles to underpin action. These projects include interviews with policymakers, stakeholders, and researchers; a national survey of citizens (seniors, persons with disability, caregivers); and a policy symposium. For the first stage, we conducted 27 interviews, which focused on refining the priorities and principles that we initially identified through the citizen panels and stakeholder dialogues.

From the interviews we identified eight short-term priorities that were identified as important to address within the next one to two years and six long-term priorities for the next five or more years. The short-term priorities focus on:

1. adopting a common language for AT;
2. building awareness and knowledge about AT (e.g., about its possible benefits and the range of AT available);
3. enhancing access to individualized assessments for AT;
4. ensuring the needs of those who can benefit from AT are reflected in programs provided;
5. making it easier to navigate programs that support access to AT;
6. minimizing coverage gaps and financial burden for individuals;
7. building national leadership for enhancing equitable access to AT; and
8. fostering partnerships with industry to achieve common goals.

The long-term priorities identified, include:

1. designing government programs to enhance access to AT that supports basic independence;
2. designing government programs to focus on access to AT for anyone who requires support with instrumental activities of daily living;
3. making access more equitable for those facing the biggest challenges to AT access;
4. ensuring timely decisions about what new technologies can enter the market;
5. ensuring that universally designed environments are consistently supported through public policy; and
6. improving the knowledge and skills of professionals assessing need for and providing ATs.

To complement these priorities, nine principles to underpin policy actions were derived and refined, which include:

1. using a rights-based perspective;
2. applying a social model of disability;
3. using a person-centred and co-creation approach to policy;
4. supporting autonomy and informed decision-making among those in need of AT and their caregivers;
5. ensuring anyone in need of AT has access to them;
6. ensuring collaboration and coordination among all those involved in accessing AT;
7. using simple, flexible, and adaptable approaches to accessing AT;
8. fostering innovation for new technologies and policy approaches; and
9. ensuring accountability to keep pricing affordable.

The national survey of citizens is underway, which asks participants to rank the priorities and principles in order of importance. Findings from the interviews and survey will be integrated into a briefing document to inform a half-day policy symposium in October 2019. The symposium will convene 30-35 policymakers, stakeholders (including representatives from citizens' groups), and researchers to identify specific next steps that should be taken to address the priorities.

Discussion

In this manuscript we present Canada's health and social systems and policy context and our comprehensive research initiative that aims to enhance equitable access to AT. The initiative applies an integrated knowledge mobilization approach, and is grounded in the approaches developed and advanced by AGE-WELL, the APPTA Hub, March of Dimes Canada, the McMaster Health Forum, and the IATSL, that together foster transdisciplinary and multi-sector partnerships to create maximum impact. These approaches, focusing on system and policy challenges particular to federated countries providing universal health coverage, illustrate Canadian initiatives emerging as leading practices in fostering policy change within complex systems.

The research initiative is comprehensive as it applies several research methods to complement and corroborate findings: a scoping review, a jurisdictional scan of publicly available program data, evidence syntheses in citizen and evidence briefs, interviews, citizen panels, a stakeholder dialogue, a survey, and a policy symposium. Individuals participating in the initiative as researchers, partners, steering committee members, and study participants cover all jurisdictions in Canada and represent diverse groups impacted by the issue of equitable AT access: citizens (including seniors, persons with disability, caregivers); policymakers; professional, service provider, advocacy, or industry organization representatives; and researchers.

While our initiative is ongoing and positioned to be completed in March 2020 the research thus far has demonstrated Canada's need to shift its current approaches regarding equitable access to AT. The pressure to shift approaches stems from the need to better address current unmet AT needs and more broadly to respond to increased AT demand that can support self-management of health and social needs owing to an aging Canadian population and concomitant increase in the number of people living with chronic health conditions. Further, AT supports goals for community-based living as it "enables and promotes the inclusion, participation and engagement of persons with disabilities, aging populations and people with co-morbidities in the family, community and all areas of society, including the political, economic and social spheres" (24) and can address shifting societal values that emphasize community-based solutions that promote aging-in-place.

We found that the Canadian system providing AT is characterized by issues of lack of national leadership or minimum standards; legislation, policy, and program variations across jurisdictions; lack of system integration and coordination between the main providers; poor access to funding; and lack of awareness and knowledge regarding AT and how to access them among citizens, policymakers, and others. These are understood as some of the underlying causes of Canadians' experiences of inequitable AT access, disparities for certain groups, system navigation issues, and unmet AT needs. The AT system is embedded in broader complex systems involving multiple levels and sectors of government and other sectors, and significant leadership and collaboration are needed to drive policy action. A vision document with a clear set of short- and long-term priorities, principles to underpin policy actions, and action plans is needed to guide AT system transformation.

Principles identified make clear the necessity for rights-based, person-centred, and co-creation approaches (with those affected by the issues and with policymakers and stakeholders) to address challenges reported by system users and what underlies the systemic challenges. Policies and practices relevant to AT access are often based in a medical model where service users' rights and autonomy are restricted, and users are not viewed holistically and as individuals. This approach has translated into restrictive program eligibility criteria centred on programs' or funders' requirements rather than users' needs and rights to access and use AT that addresses their needs, and into system navigation issues owing to highly complex systems and access procedures. While right-based, person-

centred, and co-creation approaches have been discussed at length by seniors and disability advocates and in the academic literature, embracing these approaches has not been realized and requires substantial commitment and collaboration to shift historically entrenched power balances and transform policies and practices through co-creation. Again, a co-created vision document with clear principles to underpin policy actions can provide needed guidance.

The findings from this initiative have highlighted several opportunities for enhancing equitable AT access from a rights-based approach and from the perspective of a social model of disability which underpin the CRPD. The Convention's purpose is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities" (13). Further, the Convention asserts that persons with disabilities are bearers of human rights, able to make decisions about their lives and futures, and contributors to society, and should have mechanisms to defend their rights. In taking the perspective of a social model of disability, the interplay between barriers in the environment and individuals' attributes result in restrictions to full societal participation. The necessity of AT is underscored in several articles in the Convention, and it is a right to have access to and use AT and access to and use of AT helps persons with disabilities to exercise their rights. As a ratifying state of the CRPD, Canada has a legal obligation to make AT available and affordable, and to support AT use that promotes and protects the human rights and freedoms of persons with disabilities. Future policy action related to enhancing equitable AT access can have better alignment with the CRPD by embracing a rights-based approach and a social model of disability.

There are other opportunities to support greater access to quality and affordable AT for Canadians. Considering the momentum created by the *UN's 2030 Agenda for Sustainable Development* (an agenda that Canada has adopted), the WHO's report *Rehabilitation 2030: A Call for Action*, and the WHO's GATE Initiative, we see significant opportunities to leverage these drivers to find champions in policymakers and advocates in various sectors to enhance awareness of the significance of AT, to create strategic opportunities for policy action, and to support market strategies for lowering the cost and increasing the availability of AT. Within Canada, there may be opportunities to link AT access needs to the *Accessible Canada Act* as AT can be complementary to creating a barrier-free environment. Further, as the national pharmacare program is developed there may be opportunities to link to AT access to or to learn from the development and implementation processes.

Implications

Our research initiative is still a work in progress, with several projects pending, including the analysis of the national citizen survey, development of the draft national vision document, and convening an AT policy symposium with policymakers, stakeholders, and researchers in Canada. Our hope is that through this initiative that a national vision for Canadian policy action for equitable AT access is created and can be broadly endorsed. It is also hoped that

convening system champions who can spark change within their jurisdictions may serve to enhance equitable AT access. Some of the system-level issues identified in the Canadian AT system are similar to those identified in other countries and regions, particularly of federated countries. The approaches and methods applied and the findings from this initiative may be adapted to inform efforts to improve equitable AT access in countries facing similar challenges.

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Global indicators of assistive technology use amongst occupational therapists: Report from the World Federation of Occupational Therapists' Global Survey

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Abstract

An online survey was conducted in 2017 with individual occupational therapy practitioners and the national occupational therapy associations that serve as members of the World Federation of Occupational Therapists. The survey was undertaken to map provision of priority assistive products across the occupational therapy workforce in order to identify barriers and facilitators to assistive technology access. Respondents indicated that occupational therapists are the health professionals most frequently involved in the provision of assistive technology, often in collaboration with other professionals. While occupational therapists assist with user access to all identified priority products, assistive technology was most often provided to address environmental accessibility and mobility needs. Users most frequently received assistance for recommendations and prescription of devices, assessing assistive technology for suitability, and obtaining product training. Variable scores of satisfaction with assistive technology provision were reported by respondents, with few low or middle income countries indicating that access was well provided. Findings identified a number of considerations impacting assistive technology access including human resource capacity, affordability of products and acceptability of devices for the user. Despite an over-representation of respondents from high income countries in this study, the findings are consistent with previous research investigating assistive technology access. Results of the study will therefore be used to inform initiatives of WFOT relating to access to assistive technology.

Introduction

Occupational therapists promote equitable access to assistive technology as a means to enable independence and support the participation and well-being of persons with disabilities and their communities (1). Moreover, occupational therapists recognise the critical role of assistive technology as a mechanism by which people can enact their human rights (2).

Today, one billion people around the world are estimated to need at least one type of assistive technology, yet only one in ten people have that need met (3). Barriers to assistive technology use have been identified in relation to: skilled personnel that can support provision; affordability, availability and quality of products; and policy that facilitates supply and access³. These barriers reach a critical level in low- and middle-income countries (4). In an effort to improve assistive technology access, the World Health Organization (WHO) developed the Global Cooperation on Assistive Technology (GATE) programme to harness the experience, resources, knowledge, and expertise of the international community to overcome such barriers across the globe. Initiatives of the GATE programme include the launch of the Priority Assistive Product List (APL), a compilation of 50 priority products to assist nations in developing models for the provision of critical assistive technology for their citizens. While not intended to be restrictive, the aim of the list is to serve as a catalyst for urgent action to improve assistive technology use across WHO Member States (5). As such, the experiences of people with disabilities around the world who do not have access to appropriate assistive technology, and the vision launched by the APL initiative represent a call to action to all stakeholders, including occupational therapists.

As the international representative of the occupational therapy profession, the World Federation of Occupational Therapists (WFOT) advocates for evidence-informed contextually relevant occupational therapy practice worldwide. The occupational therapy profession is growing worldwide and currently estimated at 550,000 occupational therapists (6). WFOT recognises the vital role of occupational therapy for realising the WHO vision to increase equitable access to assistive technologies around the globe (3). WFOT is committed to understanding barriers limiting global access to assistive technology and developing collaborations to address these challenges.

One approach to overcoming the barriers of access to assistive technology includes understanding how it is framed within current national policies and strategies, as well as the specific use patterns and obstacles that impede access in practice. Occupational therapists around the world are among the primary skilled personnel at the front line of assistive technology provision and advocacy efforts. The diverse experiences and perceptions of occupational therapists can therefore provide unique insight regarding assistive technology access and use across the world.

This report outlines the findings and recommendations of surveys conducted within the occupational therapy profession by WFOT relating to assistive technology. The purpose of the surveys included: 1) mapping the status of access and use of the 50 assistive technology priority products compiled by GATE across the occupational therapy workforce; and 2) identifying barriers and facilitators to assistive technology access in local and global contexts.

Methods

Separate surveys were designed and circulated to obtain data from two groups of participants. A practitioner survey sought feedback from individuals whose work in occupational therapy involved the provision of assistive technology within the previous 12 months. A second survey targeted national occupational therapy professional associations that serve as member organisations of WFOT. Both surveys were conducted online using the SurveyMonkey webtool.

Individuals were recruited to participate in the practitioner survey between September and November 2017 through invitations posted on the WFOT website. Invitations were also circulated to individual occupational therapy practitioners using the WFOT e-newsletter, social media and member organisation email lists. The survey used multiple choice questions to obtain information about respondent experiences with provision of priority products, as well as perceived facilitators and barriers to assistive technology access in their own context.

An email was sent to representatives of WFOT member organizations in October 2017 to request completion of the organization survey. Multiple choice questions on the survey requested input from one representative of each member organization regarding the status of assistive technology provision within the country, as well as policy, resources, guidelines and activities which had national implications for assistive technology provision.

Findings

Respondents

A total of 1020 individuals responded to the practitioner survey. Of the individual respondents, 96% (n=975) were qualified occupational therapists. The remaining practitioners reported to be occupational therapy assistants (1%, n=14) or others such as occupational therapy lecturers and scientists (3%, n=31). Among the qualified occupational therapists, 86% (n=839) graduated from a WFOT approved education programme and 65% (n=659) had been practicing for ten years or more. Most practitioners (60%, n=687) were employed in the public sector. The majority either worked in community services (31%, n=317) or health facilities such as rehabilitation centres, hospitals and nursing and residential care homes (30%, n=308). Other practitioners worked in universities, education and research (13%, n=131); schools and education facilities (9%, n=87); and other services such as charitable organizations, public health, occupational health, government ministries and corrections (17%, n=171). The practice of almost all practitioners included assistive technology at the time of the survey (97%, n=991), with 45% reporting that most or all of their time working with people involved the provision of assistive technology. Most individuals (87% n=885) practiced in high-income countries, according to the World Bank Classification.

A representative from each of the 52 of the 85 WFOT member organisations completed the organisation survey (61% response rate). Again, responses were most frequently received from high-income countries (61.5%, n= 32). Given the limited response rate and over-representation of high-income countries for both surveys, findings must be interpreted with caution.

Professionals involved in assistive device provision

When asked to report the professionals in their country that facilitate access to assistive technology, 96% of member organisations identified occupational therapists as the top health profession to provide assistive products. Other health professionals reported to frequently be involved in assistive technology provision included: physiotherapists (88% of member organisations, n=46); speech and language therapists (71%, n=370); prosthetists (69%, n=36); and wheelchair service providers (69%, n=36).

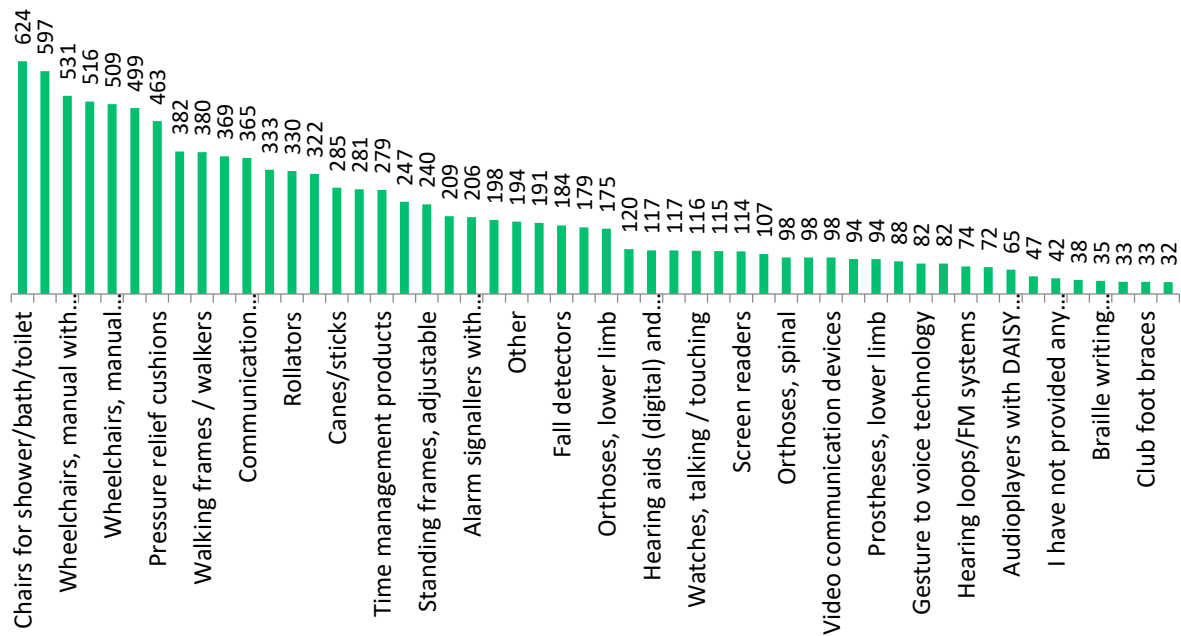
Practitioners indicated that occupational therapists often work with other health professionals in the provision of assistive technology. While practitioners worked with a broad range of 25 professions to provide assistive products, most often the respondents worked with physiotherapists (reported by 71% of practitioners, n=692); other occupational therapists (68%, n=666); wheelchair service providers (49%, n=475); doctors (42%, n=409); and speech and language therapists (38%, n=370).

Assistive technology products

Practitioners reported that occupational therapists are involved in the provision of all products included on the Priority Assistive Product List (Figure 1). The most commonly provided products included: chairs for the shower/bath/toilet (61%), manual wheelchairs for active use (59%), manual wheelchairs with postural support (52%) and grab bars (51%). Other frequently prescribed products included assistant-controlled wheelchairs (50%); electrically powered wheelchairs (49%); and pressure relief cushions (45%).

When assistive products were grouped according to function, practitioners were most likely to provide technology related to environmental accessibility needs, including bathing/toilet chairs, grab rails and ramps (average of 50% practitioners, n=501). Mobility products were the second most commonly provided items, including wheelchairs, pressure relief cushions and other devices (average of 40%, n=408). An average of 23% of practitioners provided assistive technology relating to communication and cognition needs, including communication boards, communication hardware and software, time management products, hearing aids and low vision products (n=233). Products classified as orthoses and prosthetics were provided by an average of 21% of practitioners (n=211). Items grouped under other products were provided by an average of 17% of practitioners (n=172); such devices included pill organizers, incontinence products and therapeutic footwear.

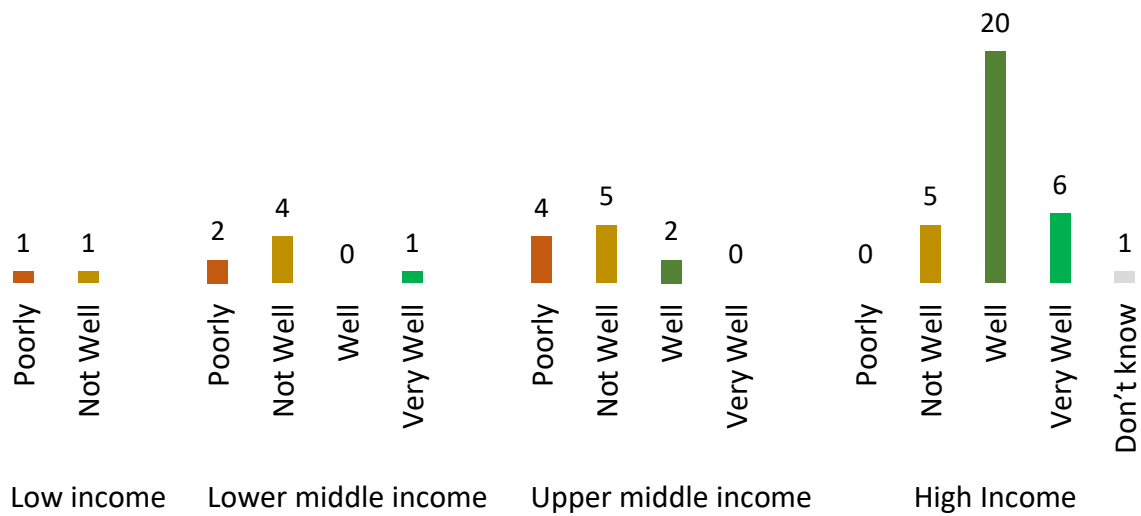
Figure 1. Assistive technology products provided by practitioners in the past 12 months (n=1020)



Practitioners indicated that assistive technology is usually purchased or received from a supplier such as a manufacturer, producer, government or charity (88% of respondents, n=856). Only 12% (n=122) of practitioners reported that assistive technology is custom built or modified using locally available materials.

Representatives of member organisations rated the provision of assistive products in their country for meeting population needs using a four-point Likert scale. Only 55% of respondents (n=29) reported population needs for assistive technology were met well or very well. When responses were grouped by the World Bank income categories, 15% (n=3) of member country representatives in low income nations reported access to assistive technology for population needs was met well or very well, in contrast to 84% (n=26) of respondents from high income countries (Figure 2). Statistical significance of differences in ratings between countries was not sought, due to the small size of the subgroups in the survey population.

Figure 2. Comparison of responses from WFOT Member Organisations, grouped by the World Bank income categories, of how the provision of Assistive Technology meets the needs of the population (n=52)



Services provided to users

Services provided to assistive technology users were analysed according to the process necessary for them to obtain and use assistive products. Practitioners most frequently provided support with the selection of assistive technology, including assessing products for suitability, prescribing devices and making recommendations to the person and providers (average of 62% of practitioners, n=610). Common, but less frequent involvement was reported for roles relating to facilitating access to the assistive technology product, such as supporting people to apply for devices, making referrals to other professionals and assisting with fund raising (average of 39% of practitioners, n=385). Fifty-three percent of practitioners were involved in roles associated with managing use of the assistive technology, including providing product training, delivering instructions to other health professionals, managing risks relating to use, assembling products, ensuring follow up maintenance and removal of products when not required (n=519).

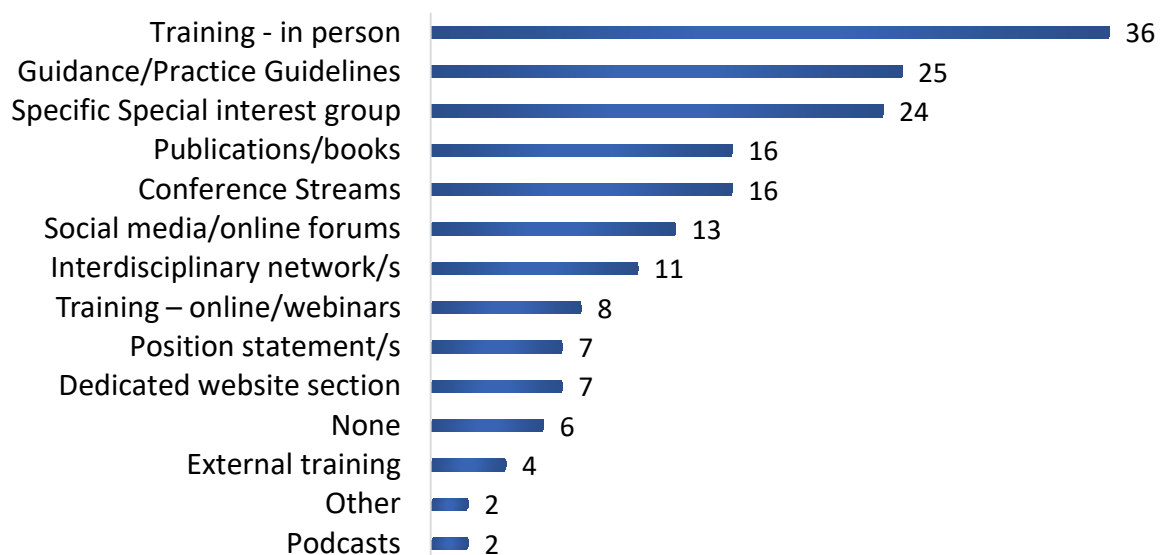
Facilitators

Occupational therapists were reported by 90% (n=47) of member organisations to be required to obtain a licence, certification or registration to practice occupational therapy in their country. Most respondents indicated that their national professional association provided resources for occupational therapists to supplement the entry-level skills and knowledge of occupational therapists to facilitate assistive device technology provision and learning. Most frequently, member organisations provided in-person training regarding assistive technology (69%, n=36), practice guidance or guidelines (48%, n=25) or special interest groups (46%, n=24) (Figure 3).

Ninety-one percent of practitioners (n=663) indicated that they had participated in specific training for the assistive products they provided. Post-professional training was most frequently received through peer-to-peer demonstration (73%, n=712), continuing education courses (49%, n=479) or online webinars/e-modules (25%, n=257).

Sixty-three percent of member organisation representatives (n=33) stated that specific legislation and regulation was in place in their countries for assistive technology provision. Specialist training for occupational therapists was reported to be necessary for the provision of some assistive technology products by 40% of all member organisation respondents (n= 21). Another 4% of member organisations stated specialist training was required for all assistive products (n=2). Specific legislation and regulation to monitor quality of assistive technology was reported by only 40% of member organisation representatives (n=21).

Figure 3. Resources provided by WFOT Member Organisations to facilitate Assistive Technology provision and learning (n=52)



Barriers

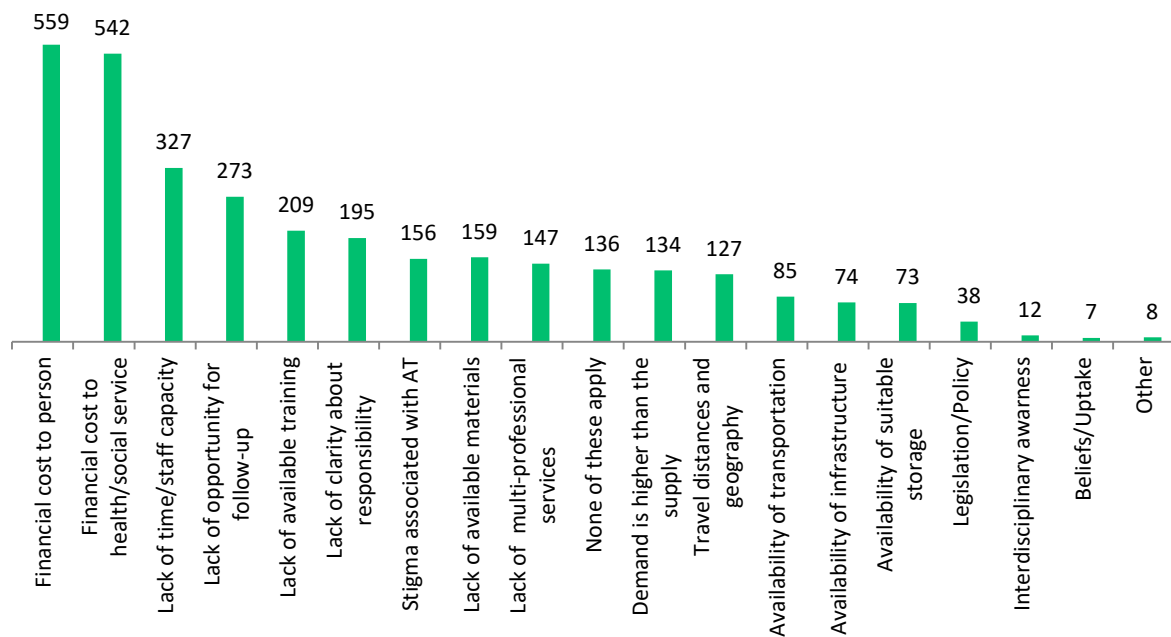
Barriers to the provision of assistive technology were identified by practitioners relating to affordability and availability of devices, human resources capacity to support access and stigma regarding use (Figure 4). Practitioners reported that affordability of assistive products was the top problem, either for the individual person (55% of practitioners) or the health/social service as a whole (53%). Assistive technology was reported by 57% of practitioners to be provided free-of-charge as result of health/social government support (n=553), with another 6% indicating the products were donated (n=62). Alternatively, assistive products were purchased (20%, n=196), borrowed (5%, n=47) or rented (3%, n=28) by the user.

Common human resource concerns identified by practitioners included lack of time for assistive device provision (32%) and follow up (27%), poor availability of appropriate training

(20%) and organisational issues such as unclear roles and responsibilities, reduced interdisciplinary awareness and a lack of multi-professional support (15%).

Stigma was considered a barrier to assistive technology for 15% of respondents. Issues were also identified that impact availability of products, such as a lack of materials (16%) and high demand (13%).

Figure 4. Barriers to the provision of assistive technology as reported by practitioners (n=978)



Discussion

Accessibility to assistive technology

The provision of assistive technology is often the integral first step towards allowing people with disabilities to take care of themselves, gain mobility and engage with their community³. The APL initiative launched by the GATE programme represents a significant step forward in the recognition of the need for action to improve global access to priority assistive products. Such products promote independence and quality of life by facilitating optimal participation in daily living. Economic benefits arise from appropriate access and use of assistive technology through improved health, better education and employment outcomes and higher productivity (7).

Results of this study support the need for APL initiative. Large variations were found with satisfaction with access to assistive technology, with very few low and middle-income countries reporting that user needs are well met. Although all products identified by the APL initiative were provided to users, assistive technology was most frequently provided by occupational therapy practitioners related to environmental accessibility and mobility needs, including shower chairs, grab rails, wheelchairs and pressure-relief cushions.

Human resources capacity

Access to priority products alone cannot attain the WHO vision for equitable access to assistive technology. The influence of assistive technology to promote participation in daily life activities can be realised only if it is provided in a way that is meaningful and valued by the user. Competent provision of assistive products must uphold the autonomy of the user, and the user's central role in all stages of assistive technology design, development, access and implementation (2,8). Health professionals therefore require specialized knowledge and skills for providing access to assistive technology (9). Competence is required not only regarding the availability and use of individual products, but also to assess the needs and wants of users and determine how assistive technology can interact with other physical, social and cultural elements of the user's environment (2,9).

In this study, a number of health professional groups with specialised knowledge in assistive technology were reported by member organisations to be involved in providing access to products, including occupational therapists, physiotherapists, speech language therapists, prosthetists or wheelchair providers. Practitioners indicated that they work with a range of other professions, suggesting that a team-based approach is often used to provide assistive technology. This approach allows team members with complementary skills and knowledge to work collaboratively to address user needs. While team members may share some competencies, different perspectives or skills are also provided to assist with the provision, fit and use of assistive products. Occupational therapists bring a unique perspective grounded in occupation in their approach to prescribing assistive products. Assistive technology is a core competency within occupational therapy practice for optimising the fit between a person's ability and desire to engage in occupations, the characteristics of the occupation, and the environment (2).

Study results indicate that users obtain support from health professionals for many services related to the provision of assistive technology, including assistance for product selection, access and use. Given the knowledge and skills of occupational therapists, the most frequently required roles involve assessment, prescription and recommendations for assistive technology products. Other common roles reported by practitioners related to managing use, including providing education and instructions to users, carers and other health professionals regarding assistive technology.

Member organisations and individual practitioners participating in this study acknowledged the importance of training for professionals involved in the provision of assistive devices. Because technological developments are continuous and often occur rapidly, ongoing professional development regarding assistive products is required for effective practice. The majority of member organisations participating in the study offered education resources to assist occupational therapists with assistive technology provision. Most practitioners engaged in professional development regarding assistive technology, with peer-to-peer teaching models as the most frequently used training method. Such involvement in professional development may be partially driven by regulation and legislation; 44% of

member organizations reported that some specialist training was required to provide assistive technology in their country.

Practitioners reported that access to occupational therapists to assist with provision of assistive technology is often impeded by a lack of staff time to provide the required services. These findings are consistent with previous reports of shortages of trained personnel able to provide basic assistive products (3,9).

Data from the 2018 WFOT Human Resources Project indicate shortages of occupational therapists exist in 41% of countries that serve as member organisations (10). The shortages were reported in countries across all the income levels defined by the World Bank Classification. A large growth in the occupational therapy profession is responding to the identified shortages. Between 2006 and 2018, the number of occupational therapists worldwide increased by 96%, from 267,124 to 527,977 (11) while WFOT approved occupational therapy education programmes grew by 68%. To supplement this growth, WFOT is actively supporting 30 countries across the globe to establish the profession in their jurisdiction (11).

Affordability of assistive technology products

Practitioners in this study indicated that most assistive technology provided to users was obtained from a supplier, rather than custom built or modified using local materials. The supplier market for assistive technology has been characterised as small, involving few companies, with the result that products are expensive or very expensive (12). Consistent with such reports, affordability of technology was identified by occupational therapists as the top barrier for users to accessing assistive products.

Although the public provision of assistive technology has been widely advocated (7), occupational therapists reported large gaps in external funding for products. Only 57% of practitioners stated that assistive technology was available free-of-charge to users as result of health/social/government funding coverage, with an additional 6% reporting assistance for access to products through donation. The increasing availability of technology such as customisable and personalisable smartphones offers some hope for improved affordability of assistive products for people with disabilities, although the cost is expected to remain out-of-reach for populations in lower income countries (12).

Acceptability of assistive technology

Acceptability of assistive technology is of paramount concern as such products can facilitate participation in daily activities only if they are used by people who receive them. Quality of an assistive product may highly impact acceptability and utilization of the technology, particularly if the device is unreliable, difficult to use or costly to maintain. Problems reported by practitioners regarding high demand for products and lack of availability of materials compound difficulties with access to assistive technology that is appropriate and acceptable for the user. While this emphasises the importance of knowledgeable health professionals to assist users with selection and utilisation of products, it also raises

questions regarding the need for regulation to ensure quality and safety of assistive technology. Many assistive devices identified by GATE as priority products carry risk of harm if the technology malfunctions or is of insufficient quality to meet user needs.

Results of this study suggest that regulation of assistive technology is inconsistent across the world. Only 40% of member organisations surveyed indicated knowledge of specific legislation or regulation regarding the quality of assistive technology products provided in their country.

Occupational therapists in this study reported that acceptability of assistive technology is also influenced by stigma. Fifteen percent of practitioners stated that stigma served as a barrier to the provision of assistive technology.

Assistive devices have an important role to play in augmenting abilities, but also may often result in making a user's disability appear more visible. The impact may be so pronounced that potential users may sacrifice their own personal health and well-being because of risks to their self-perception and social acceptability. Mainstreaming is one proposed solution to mitigate negative perceptions of assistive technologies (13). Such efforts seek to make devices less "socially visible", for example through improved design or by increasing common usage of specific products. The APL initiative advanced by the GATE programme presents a promising opportunity to use such a mainstreaming strategy to increase use and acceptance of assistive technology.

Recommendations

This study advances understanding the current assistive technology landscape of occupational therapy practice, particularly in respect to the priority assistive products identified by the APL initiative. The findings raise important considerations regarding human resource capacity for assistive technology provision, as well as the affordability and acceptability of priority products. Despite an over-representation of respondents from high income countries in this study, the findings are consistent with previous research investigating assistive technology access, allowing results to inform efforts at the local, national and international level to improve technology access. As such, with awareness of the study limitations, the data presented in this report will be utilised by WFOT to direct collective efforts in three primary directions:

1. WFOT will advocate for access to assistive technology as a fundamental right of people with disabilities worldwide and will participate in international networks and initiatives that address the barriers to access.
2. WFOT will advocate for the role of occupational therapists in the assistive technology process and their need for training and contextually relevant strategies and supports.
3. WFOT will develop collaborative initiatives to understand and address the needs of Member Organisations pertaining to assistive technology development, prescription, procurement, and implementation processes that are contextually relevant and culturally safe.

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Access to assistive technology: A descriptive review and application of systems-thinking approach in the conceptualization of the assistive technology passport

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Abstract

Background: Facilitation of universal access to Assistive Technology (AT) is an entitlement enshrined in the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD). Access to an appropriate, effective and timely delivery of AT, has been identified as a key driver to the realization of the United Nation's (UN) Sustainable Development Goals (SDG) and an essential right for empowering and supporting the needs of the population. To promote effective access to AT, an AT passport was proposed as a tool aimed at promoting access to AT products and services. This paper presents a review of literature of the concept 'passport' as a user led-system in use within the health and social care setting. The findings from the review are aimed at informing the conceptualization of the AT passport and recommendations for further research and development. **Approach:** The paper utilised a scoping literature search of the health passport concept followed by a descriptive review of data presented in a matrix table. The matrix table presented data from 29 identified sources under the following headings; source of document, the title, population and type of document, the main concept/purpose of the passport, the format/mode of the passport and its attributes, reported and/or anticipated outcomes and the implication of the individually reviewed document on the AT passport conceptualization. Emergent recurring themes across the reviewed documents were thematically identified. **Findings:** Eight themes emerged from the review articles that are of relevance to AT passport conceptualization. These were enhancing communication, participatory service development process, transition management, within and between agencies; promotion of continuity of care; self-advocacy and personal empowerment; person-centred, contextual and personal social needs; user-led systems operating within existing wider system and effective and timely access to Services. **Conclusion:** The application of the systems thinking approach to the themes emerging from the review offers an important and pragmatic conceptualisation of the AT passport, rooted in a framework of user ownership and empowerment. The idea of an AT passport should to be researched and developed for application within what are likely

to be changing and diverse community contexts, supported by national policy and that also reflects global AT policy recommendations.

Keywords

Access, Assistive Technology, Passport, Systems thinking, User-systems, UNCRPD, SDG.6

Introduction

The purpose of this paper is to report on a literature review of how the idea of a ‘passport’, which is user led, has been applied within other health and social care settings. This review is an initial stage in establishing a practical framework for further conceptualization, research and establishment of an Assistive Technology (AT) passport. The concept of an AT passport was originally proposed in a 2016 report by Enable Ireland and Disability Federation of Ireland (DFI), as an effective user focused process for service provision (1). Additionally, the report contained a number of other recommendations including the establishment of a central coordinating agency with the responsibility of coordinating a comprehensive AT service delivery and promoting innovation. Figure 1 illustrates the Enable Ireland and Disability Federation of Ireland’s conceptualization of the AT passport, as it operates within a wider AT eco-system of supports; while Fig 2 shows the AT passport specifically as a tool for facilitation of service provision.

To build on the original concept of the AT passport, this review explored other extant passport concepts within the health and social care settings to inform the development of a user led-system tool that offers the potential for interaction between the individual AT user, and the system required to effectively support that use. The use of an AT passport in other sectors, such as education or employment, is beyond the scope of this paper (but will be described elsewhere).

Figure 1. Ecosystem of support

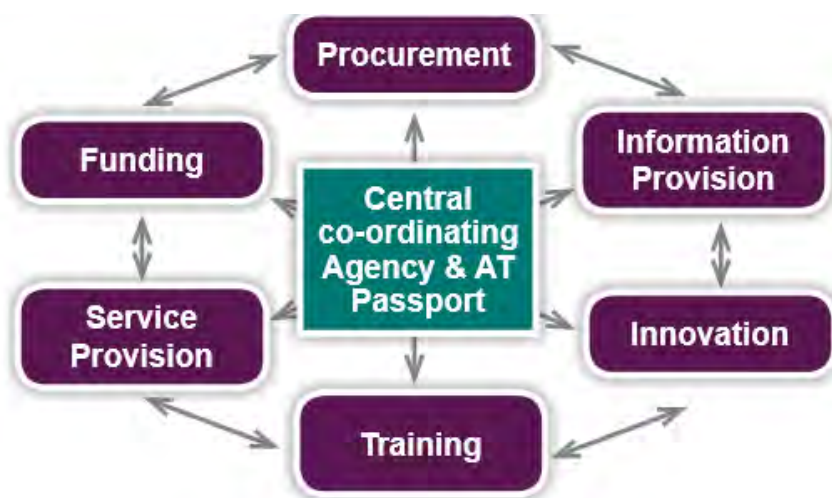
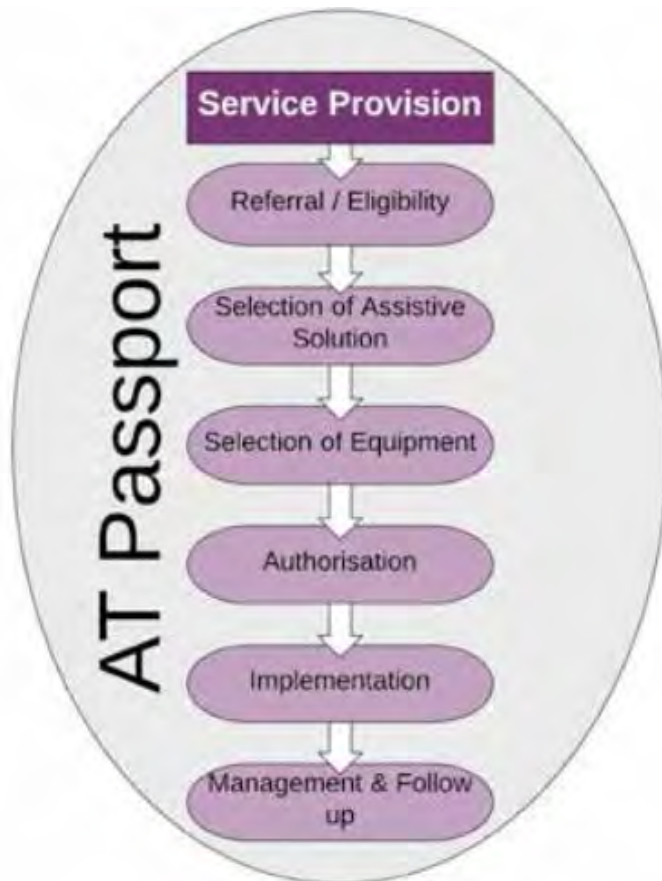


Figure 2. Service provision Model



Review Background and Rationale

The definition of AT and Assistive product

An assistive product is “any product (including devices, equipment, instruments, and software), either specially designed and produced or generally available, whose primary purpose is to maintain or improve an individual’s functioning and independence and thereby promote their wellbeing (2). Assistive technology systems refer to “the development and application of organized knowledge, skills, procedures, and policies relevant to the provision, use, and assessment of assistive products” (2).

Assistive products provide functional supports to diverse population groups and includes products for; mobility, communication, environment controls, educational, sensory functioning and self-care independence. AT solutions may range from lo-tech such as walking sticks, prosthetics, wheelchairs, screen magnifiers or white canes, cochlear implants, symbol pictures and calendar pill boxes (2). Complex hi-tech AT may include sensing and computer technologies and intelligent user-interfaces such as the eye-gaze computer interfaces and home automation systems (3).

The purpose of AT is to enable user participation in activities that they want and need to do, in order to considerably impact an individual’s personal independence and access to educational, productivity and leisurely pursuit (4). Access to an effective and appropriate AT

solution is dependent on much more than the specific technology in question, it is dependent on an optimum service delivery process. This process is inclusive of multiple essential elements such as availability and affordability of quality AT solutions, professional competencies, training, product maintenance infrastructure and appropriate policies and procedures for funding, and eligibility assessments (5). These varied components of AT service provision function as complexities that are further compounded by rapid technological advances that constantly shifts the settings, design and implementation of AT solutions (3). The complexities within AT service provisions influenced by the effects of the wider system (health, education, social welfare, employment) and further impacted by the faster pace of technological advances, warrants a re-thinking of AT service delivery pathways to incorporate the new actors/elements and their interactions and emerging patterns within a system. Innovation and change in AT and the environments in which it may operate, is a constant and so the AT systems must be able to continually develop and adapt.

Based on WHO figures a considerable gap exists globally between the need for and access to AT (6, 7). The current estimates suggest that 10% of the one billion people in need actually have access to AT. The number in need of AT is predicted to increase to over two billion by the year 2050 (7). Conversely, the lack of access to AT pushes individuals with a disability or impairment, with chronic illnesses and older people, to the fringes of society by encouraging marginalization, dependency on basic self-care needs, exclusion from education, a lack of personal productivity and a lack of engagement in leisure activity (4). Subsequently, the lack of contribution to the community both socially and economically encourages exclusion and stigmatization of people with disability (8).

Global policy framework

Facilitation of universal access to AT is an entitlement enshrined in the UN's Convention on the Rights of Persons with Disabilities (UNCRPD) and its Optional Protocol adopted in 2006 by the international community (9). The realisation of this right has been slow and partial, with only around 10% of the world's population, from mainly highly resourced regions have access to appropriate AT (7). As such, to enable adequate, timely and appropriate delivery of AT, the United Nation's (UN) Sustainable Development Goals (SDG) have been identified as the key to the realisation of AT as an essential right for empowering and supporting the needs of the population (10). Similarly, the World Health Assembly Resolution (2018) called upon member countries to improve access to AT within universal health and social coverage through the development, implementation and strengthening of programmes and policies (7). The resolution, among other things, calls upon the member states to engage in research and development relevant to improving access to AT, globally.

Global Assistive Technology Initiatives

In an effort to close the gap between the need for and access to AT, the Global Cooperation on the Assistive Health Technology (GATE) initiative was established by the World Health

Organization (WHO) in 2014 (2). The aim of the GATE initiative is to support the international community's strategies such as the UNCRPD and the SDG, by identifying measures that would assist member states improve access to AT for everyone in need (2). The GATE initiative identified five priority themes to influence the research agenda aimed at improving access to high quality and affordable AT. One of the priority areas identified is the theme on 'Policies, systems, service provision models and best practices' (11). These research areas complement five strategic Ps identified by GATE: Person, Policy, Products, Personnel and Provision (5P) (11). The Person (AT User) is the central player in the interconnection between the AT product & services, the required personnel that offer services, and the importance and impact of policy and provision systems across all sectors (11). Additionally five contextual Ps help to think through how the first five strategic Ps are to be applied in particular circumstances (for instance, community, region or country) and these are Promotion, Place, Pace, Procurement and Partnership (12).

Systems Thinking Approach

A system is a combination of various interacting, interconnected, interrelated and interdependent components that makes up a complex whole (13). Multiple components interact constantly while adapting and changing; changes that may occur in one area of a system may directly or indirectly influence other components within the system (14). Systems thinking has been defined as "a set of synergistic analytic skills used to improve the capability of identifying and understanding systems, predicting their behaviours, and devising modifications to them in order to produce desired effects" (13).

Systems thinking encompasses quite diverse features, including dynamic thinking (behaviours within a system occur in patterns that may constantly change), forest thinking (focus on the whole forest while appreciating the interconnection between the trees), and loop thinking (occurrence of continuous circular loop may explain the relationship between cause and effect where each may have an influence on the other) (15). Additionally, systems-as-cause-thinking; here a component in a system, or a newly introduced element, may have an effect on the whole system, or on another component, without them necessarily being in direct contact. These phenomena cannot be explained through models or approaches that are more concerned on understanding cause and effect from a linear perspective (16).

When seen as a system, AT includes stakeholders; such as AT users and their families, health-care practitioners, policy makers and suppliers, as well as organization specific characteristics (from government, private sector, civil society), policy and legislative frameworks. The phenomenon of AT can therefore be considered a complex or "wicked" problem, as it cannot be viewed simplistically by employing partial or siloed perspective, but rather requires a coordinated, adaptive and concerted effort to address (17) and one that is likely also changing. Similarly, the complexities within AT are non-linear; there are multiple and diverse characteristics of AT users, varied range of assistive products available and there is person-specific need for transitions and transfers within organisations and between

multiple sectors (health, education, employment). Likewise, there is a need to conform to country specific legislative frameworks; to operate AT service within existing systems that may or may not be adequately prepared; and the rapid pace of technological advancements, all calls for a system thinking approach to plan and deliver effective access to AT.

One example of a systems-based model in use within AT area that highlights an individualized approach to the identification of appropriate AT solutions is the; Human, Activity, Assistive, Technology (HAAT) model (18). The HAAT model is strong on emphasizing the interactions between the person, the activity to be performed and the appropriate choice of the AT solution. However, it is less well developed in terms of other systems issues, such as procurement, pace of change within the existing system, the place in terms of the build environment, or the need to counter stigma and promote positive views of AT users.

The systems thinking approach provides policy makers and key stakeholders the opportunity to plan and execute broadly based solutions to AT problems, by shifting from narrow linear pathways, to a complex multi-faceted approach (16). The systems thinking approach has been gaining momentum in public health projects such as in tuberculosis, obesity and tobacco control (19-21) and is increasingly recommended as a viable approach to tackle public sector challenges (16). MacLachlan and Scherer provide examples of system-thinking and non-systems thinking for each of the 10 Ps (5 strategic Ps and five contextual Ps) (18).

Health passports

Health passports are mainly owned and held by a user with the purpose of improving health-care service delivery. They are designed to empower the user, improve access to services, facilitate continuity of care and enhance communication between the user, carer, family and health care personnel. The use of the passports have been reported across health care; for instance, diabetes management (22-24), mental health (25-27) cancer care (28-30), intellectual disability (31, 32), medication management (33, 34) and care of older people (35).

While this paper focuses on health passports, it is important to acknowledge that the concept of 'passport' as a user owned tool, is also found within the education and employment sectors (30, 36, 37). In respect of the current review our concern was how the passport concept is applied and used, and not on evaluating the effectiveness of its use as such. This is therefore a descriptive, not an evaluative review.

Review Objectives

This review seeks to answer three important questions:

1. How are health and social care passports used?
2. How relevant are the uses of health and social care passports to a systems thinking approach?

3. How can the review findings be applied to conceptualization and application of an AT passport, which promotes ownership, access to, and effective use of, appropriate AT solutions?

Approach

The key terms used for the search included; Health passport, Patient passport, Personal hand-held record and Hospital hand-held records. All types of literature ranging from grey literature to randomized control trial documents covering the 'passport' concept were included. The exclusion criteria employed include; passport ideas in non-health and social care settings and documents published before the year 2009. The search process utilized both a systematic searching approach and snowballing, by initially scoping the literature to identify the number of documents returning. Furthermore, in collaboration with a Maynooth University librarian a more specific search strategy was employed to identify documents in databases relevant to health, disability, rehabilitation and nursing including and not limited to the following; PubMed, WHOLIS, Embase, PsycINFO, SCIE, CiINAHL and Scopus. The identified articles were initially reviewed on the title, then abstract and finally full text to ascertain appropriateness for inclusion into the review.

Data Extraction and Synthesis

All the articles included in the review were descriptively presented in a data extraction template under the following headings; source of document, the title, population and type of document, the main concept/purpose of the passport, the format/mode of the passport and its attributes, reported and/or anticipated outcomes and the implication of the individually reviewed document on the AT passport conceptualization was synthesised. The descriptively generated data were thematically explored (using a constant comparison analysis approach) to identify and synthesize frequently emerging patterns.

Findings

A total of 29 articles and documents were identified. The extracted descriptive data are presented in Table 1. The presented data identified a variety of population groups utilizing the health passport by presenting each articles purpose, type article, forms/content of passport and reported/or anticipated outcomes. Table 2 provides a summary of the populations included in this review, itemizing the number and type of articles per the population group.

Emerging Themes

The descriptive data were analysed through the process of constant comparison analysis which identified eight recurring themes. These themes will be further deliberated upon in the discussion sections of this paper.

1. Enhancing communication
2. Participatory service development process

3. Transition management; within and between agencies
4. Promotion of continuity of care
5. Self-advocacy and personal empowerment
6. Person-centred: contextual and personal social needs
7. User-led systems operating within an existing wider system
8. Effective and timely access to service

Table 1. Summary of the descriptive data derived from the reviewed literature

ID	Source	Document title	Area/Type of document	Concept/Main Idea	Passport format	Reported/Anticipated findings	Implication for 'AT' passport
1	(22)	Determining the impact of an intervention to increase problem-solving skills in diabetes self-management: the diabetes problem-solving passport pilot study	Diabetes / RCT	Clinic-based designed to improve diabetes self-management behaviours', efficacy, and blood-glucose levels.	A list of questions to promote service user's self-management	Low retention, however, passport use has the potential to enhance diabetes self-management behaviours.	This passport is clinic based and does not fully align with the user-led system
2	(24)	Diabetes passport	Diabetes management / Multi-stakeholder Passport Development project	User held Diabetes Passport aimed to enhance communication to empower and inform the user on self-management	Booklet: personal details, assessment results, medication etc.	The audit indicates poor utilization of the passport particularly within secondary care. Case reports from patients indicate satisfaction with the self-management information	Enhancing communication and user empowerment
3	(38)	A Qualitative study to explore the use of the RCPCH epilepsy passport	Epilepsy / Qualitative study	To improve communication and reduce morbidity and mortality associated with epilepsy		Anticipated: Improve communication and reduce morbidity and mortality associated with epilepsy	Communication
4	(39)	Children's epilepsy passport set to improve emergency care	Epilepsy / News Report	Aimed to improve the sharing of information in the event of an emergency	Booklet contents: Medications, seizure type clinician's contact details for	Bridges the communication gap	Enhancing communication and reduces duplication of work

ID	Source	Document title	Area/Type of document	Concept/Main Idea	Passport format	Reported/Anticipated findings	Implication for 'AT' passport
					the clinicians, a user profile		
5	(40)	A patient-centred checklist, the Asthma Passport, for improving asthma self-assessment (Asthma Control Test, ACT) and self-management (Asthma Action Plan, AAP) utilization in clinic	Asthma / A randomized, interventional quality-improvement project	Aimed at improving asthma self-assessment (Asthma Control Test, ACT) and self-management (Asthma Action Plan, AAP) utilization in clinic	A patient-centred checklist: Questionnaire	Reported improvement in Asthma self-management	Not user owned; an intervention-based passport.
6	(41)	Patient-held medical records for patients with chronic disease: a systematic review	Chronic Patients / Systematic Review	Investigating whether patient-held medical record (PHR), compared to usual care, improves clinical care, patient outcomes or satisfaction.	Paper-based patient held records	No clear benefit of implementing a PHR. More high-quality studies are needed	AT passport information should target specific relevant information and not a duplicate record held in institutions.
7	(42)	Severe asthma: emergency care patient-driven solutions	Asthma Emergency care / Systems thinking approach	To improve confidence in communication during the emergency department visit	Paper based on the user's medical and personal profile.	Envisioned to decrease (from 12 to 5 steps) the number of steps patients had to do to achieve care.	AT Passport to provide ready information to reduce repetitions and promote effective access.
8	(28)						

ID	Source	Document title	Area/Type of document	Concept/Main Idea	Passport format	Reported/Anticipated findings	Implication for 'AT' passport
		Radiation passport: an iPhone and iPod touch application to track radiation dose and estimate associated cancer risks	Childhood cancer / Description of an intervention	An APP aimed to track radiation dose and estimate associated cancer risks	The application contains; clinical history, together with personalised follow-up and screening recommendations	Offers potential for follow up and empowerment to reduce risk	Potential for a Mobile phone application as part of diverse platforms for the AT passport.
9	(43)	Development of a Multidisciplinary Brain Tumour Patient Passport	Brain Tumour / Project development	Enhances the management of tumour and promote inter-disciplinary communication	Book format;	User feedback: useful and would enhance self-management	Importance of Multi-stakeholder involvement in the AT passport development process; Person-system interaction.
10	(30)	A School Passport as Part of a Protocol to Assist Educational Reintegration After Medulloblastoma Treatment in Childhood	Childhood cancer / Qualitative study	To enhance school reintegration for children and communication (health and education) post Medulloblastoma.	The standardised protocol of information in the booklet	Enables timely and useful sharing of information	Potential for the AT passport to be incorporated into a multi-agency communication and transition management system
11	(44)	Implementation and evaluation of health passport communication tools in emergency departments	Intellectual Disability / Mixed methods study (questionnaire and interview)	Communication tool used by people with IDD in psychiatric and general emergency departments	Contains; medical history, medication, and required supports.	Enhances communication between health and education.	Emphasises the need for customising the contents and use of the AT passport in relation to the personal and local settings.

ID	Source	Document title	Area/Type of document	Concept/Main Idea	Passport format	Reported/Anticipated findings	Implication for 'AT' passport
12	(45)	Patient healthcare passports in community specialist palliative care: a mixed methods study	Cancer; Palliative Care / Mixed methods, prospective, longitudinal cohort study	Patient held record	Patient held record	Patient held records are unlikely to be used by palliative care patients	Consider user's medical and social needs as well as motivation when designing the AT passport.
13	(46)	The evaluation of a healthcare passport to improve quality of care and communication for people living with dementia (EQuIP): a protocol paper for a qualitative, longitudinal study	Dementia care / Protocol paper	Communication tools for sharing information on the healthcare needs of people living with dementia.	An expandable document containing personal, clinical and social care information is recorded	Promotes communication and user dignity	The AT passport should envision to enhance communication while simultaneously maintaining the user's dignity.
14	(35)	Geriatric My-Health Passport: A Pilot Study of a Portable Health Summary in an Elderly Population	Geriatrics / Pilot study survey based	An online generated portable health summary to be used with the older population	Printable wallet sized; includes service user's medical information.	Users report ease of receiving care	Individualized format for AT passport
15	(47)	One-page patient passport for people with learning disabilities	Learning Disability / Pilot study	A reference by health personnel and administrative staffs	A one-page passport containing service user profile	Supports communication locational context	Consideration for user's dynamic needs such as learning, sensory and physical disability needs
16	(48)						

ID	Source	Document title	Area/Type of document	Concept/Main Idea	Passport format	Reported/Anticipated findings	Implication for 'AT' passport
		Hand-held health records (HHHR) for individuals with intellectual disability: a systematic review	Intellectual Disability / Systematic review	Empower individuals to increase access, continuity and quality of health care. Improve communication	A structured record of the information held by the service user	Widely acceptable no clear short-term benefits found indicating further long-term research	The AT project to consider the heterogeneous population of AT users and consider the best measure of benefit when evaluating it.
17	(32)	Hospital passports, patient safety and person-centred care: A review of documents currently used for people with intellectual disabilities in the UK	Intellectual Disability /Qualitative content analysis	Designed to alleviate communication barriers experienced by people with intellectual disabilities when accessing healthcare	Paper booklets contain key user information and other support networks	Documents reviewed contained several varied information, formats and terms of references	AT passport design, terminology and format should consider some uniformity while simultaneously considering the user's contextual diversities.
18	(49)	Evaluation of My Medication Passport: a patient-completed aide-memoire designed by patients, for patients, to help towards medicines optimisation	Older people: / Qualitative study; Telephone interviews	Designed by patients to record own	A passport-sized booklet, An App for smartphones is under development	My Medication Passport aids to increase information sharing and discussions regarding medicines with family, carers	AT passport should enhance information sharing between the user and other significant entities
19	(25)	Preventing chronic disease in people with mental health	Chronic conditions / Semi-qualitative questionnaire with	A tool to help patients make lifestyle changes to	Pocket-sized, the patient held the record	The HEALTH Passport could almost halve the proportion of	Design to own behaviour change

ID	Source	Document title	Area/Type of document	Concept/Main Idea	Passport format	Reported/Anticipated findings	Implication for 'AT' passport
		problems: The HEALTH Passport approach	the results subsequently compared with those of 100 controls	reduce the future burden of chronic disease.		psychiatric patients at high risk of chronic disease.	
20	(26)	Physical health passports for patients with severe and enduring mental illness	Severe and enduring mental illness / Description of the passport	The Passport provides one location for the medical history for patients with severe mental illness in addition to information on how to manage their physical health through the provision of lifestyle advice and easy to understand assessments	Passport-style document.	The passport provided access to physical health assessments, resulting in almost half of the patients showing a risk for cardiovascular disease	Access to information may have an immense influence on the early identification of risk factors and timely interventions where necessary.
21	(27)	Development and Introduction of "Communication Passport" in an Adult Inpatient Psychiatric Unit for Persons with Intellectual Disabilities: A Brief Report from Singapore	Inpatient Psychiatry-Intellectual disability / Qualitative study	A person-centred accessible document of presenting important and complex patient information	Consisted of a 12-page document encompassing multiple aspects including communication and behavioural profile	Provides a framework for developing communication passports	AT passport should be an accessible communication tool for all.

ID	Source	Document title	Area/Type of document	Concept/Main Idea	Passport format	Reported/Anticipated findings	Implication for 'AT' passport
22	(50)	A qualitative study exploring the value of a catheter passport	Acute in-patient / Qualitative study	Aimed at providing accessible information to improve self-care	A patient-held document, with information and a record of catheter care.	The catheter passport has the potential to promote self-care in conjunction with specialist support	AT Passport alone may not offer all the solutions if not completed by specialists supports wherever relevant.
23	(51)	The use and usefulness of My-Health Passport: An online tool for the creation of a portable health summary	Paediatrics / Book chapter	Provides education information and enhances communication	Printable, online created	Key anticipated elements: enjoyment, education, communication/navigation, ease of use	Opportunity to create and customize the AT passport online with a printable option and any other accessible platforms that are user-centric.
24	(33)	Use of a My medication passport (MMP) in a disabled child seen across many care settings	Paediatrics / Case presentation	Aimed to help children and young people, parents and carers to manage medicines more effectively	Pocket-sized booklet and as a smartphone app.	Has the potential to monitor medication, promote a sense of ownership and user empowerment	Service user empowerment, communication enhancement and promotion of ownership and independence
25	(48)	The Patient Passport Program: An Intervention to Improve Patient-Provider Communication for Hospitalized Minority	Paediatrics / Qualitative study	A patient-provider communication program, the 'Patient Passport'.	Passport-type document	Enhances the quality of communication among minority families of hospitalized children	Varied communication methods and platforms to facilitate diverse populations

ID	Source	Document title	Area/Type of document	Concept/Main Idea	Passport format	Reported/Anticipated findings	Implication for 'AT' passport
		Children and Their Families					
26	(52)	Improving paediatric pain management: introducing the 'Pain Passport'	Paediatrics / Qualitative study	Promotes prompt analgesia provision in children, empowers and encourages a re-evaluation of pain	leaflet carried by the patient which records serial pain scores.	Passport use was associated with an improvement in standards of pain management	User/parent/guardian/caregiver empowerment
27	(53)	Hospital Passport for Patients with a Communication Difficulty	Acute care, Learning disability, Care of Older Person / Practice development document	The purpose of this passport is to support persons during secondary health services visit	The passport is in a traffic light format.	Provides clear and concise communication promotes safety and travels with the user always	Communication and access simple precise and clear language.
28	(54)	My Personal Health Passport for Paediatric Patients	Paediatrics / Service development project	Provides a snapshot of information about a child when attending hospital appointment, A&E, community services, therapy and respite.	A4 sized folder with colour-coded signposts	Promotes person-centred care, reduces the repetition of information, allows the child's voice to be heard, useful at times of transition and avoids repetition.	Promote person-centred care, transition management, user empowerment
29	(55)	A Participatory Action Research Project into the Implementation and Evaluation of My Healthcare Passport	M.Sc. Dissertation / Participatory action research report	My Healthcare Passport - owned by the service user to facilitate a person-centred, safe and	Available in two forms: 1) An A5 booklet; 2) An online generated printable document	Supports communication and choice making and coordination of services for people	All stakeholders participatory approach effective in the research and development of the AT Passport

ID	Source	Document title	Area/Type of document	Concept/Main Idea	Passport format	Reported/Anticipated findings	Implication for 'AT' passport
				effective care by the HCP.		with a learning disability	

Table 2. Summary of the populations included in this review, itemizing the number and type of articles per the population group

Population	No. of Articles/Documents	Types of Article/Documents
Diabetes	2	RCT; Project Development
Epilepsy	2	Qualitative Study; News article
Asthma	2	RCT; Project Development
Chronic Patients (General)	2	Systematic review; Qualitative study
Cancer Care (Adults)	2	Project Development; Mixed Methods longitudinal study
Childhood Cancer	2	Descriptive Report; Qualitative study

Discussion and Recommendations

This paper utilized a descriptive review of the literature to identify how the user-system concept of ‘passport’ is used in health and social care settings, in order to inform further conceptualization of an AT passport (56). The themes emerging from the review are now discussed and then their implications for the 10 strategic and contextual Ps are reviewed (2, 57).

Before highlighting our recommendations however, we note two important omissions from the literature. First, there is a notable gap in the reviewed literature in the use of a systems-thinking approach adopted alongside the use of the passport development and utilization (except in one case, concerning Asthma service). This passport used a systems-thinking approach through soft systems methodology to examine the reluctance of people who experience asthma attacks in attending the emergency department. This process culminated in a recommendation to develop an ‘Asthma Passport’ as system-wide solution to facilitate people with asthma attacks to access emergency care (43). A second gap identified in the literature is the lack of description of how the data in the passports interface with the broader system, especially in relation to data protection, data storage and confidentiality issues.

The AT passport development ought to consider the complexities of the AT system, especially user characteristics, preferences, privacy and their relationship with the wider system. Here we consider each of the 8 themes emerging from the review followed, up with their application to the 10P's based upon a systems-thinking approach.

Emerging Themes

Enhanced communication

Enhancing communication between service user and their families with the health/care professionals for facilitation of effective healthcare has extensively featured in the reviewed 'passports' (32, 39, 43, 44, 48, 49). Although, the role of the passport to enhance communication is widely accepted in the review, factors such as non-involvement of users, seeking consent, and the perception and trust of the health care professionals regarding the quality of information included in the passport, are some of the challenges for adoption (31, 47).

A participatory process for tool development

To ensure the research, design and development of the AT passport conforms to the overall aim of enhancing appropriate and effective access to AT (2), user participation and ownership of the process is of utmost importance (9). Lack of user participation in the process of AT research, design and development will render the tool less user-focused and may encourage abandonment (56).

Transition management; within and between agencies

Passports may enhanced a smooth process of transfer of care within a specific organization and/or across sectors, for example, between primary and secondary care services within the healthcare sector (54, 55) and between health and education institutions (30).

Promotion of continuity of Care

Passport utilization has been identified as a means of promoting continuity of accessing care; this was achieved through effective communication attributes especially in emergency care (42). Additionally, improved user knowledge, self-management behaviours and person-centred approach to the design and development of the tool ensures access to appropriate supports (26, 33, 39, 40, 44).

Self-advocacy and personal empowerment

Passports have consistently been referred to us a tool that empowers users and the relationship between patient/user and carer (24, 47). Additionally, patient empowerment is reported to be promoted through self-management attributes inherent in passports, especially for chronic care (24, 25, 58). During emergency care, the passport potentially promotes greater self-advocacy by sharing pertinent and useful information with less or minimal reliance on carers (39, 42, 44, 59).

Person-centred: contextual and personal social needs

User centred care entails the placement of an individual’s needs within a specific context at the forefront of care and support. Passports can be designed and developed based on a person centred holistic approach, by encompassing user need, likes and dislikes, presented in an accessible style (27, 32, 44). The format and attributes of the passport are designed according to the user’s level of communication, utilizing modes such as colour coding information, use of pictures and symbols to communicate emotions and traffic light systems to indicate delivery of care perception or perception of the level of pain scale (32, 52, 55).

User-led systems operating within an existing wider system

Passports initiatives are not stand alone but operate within an institution and/or local settings. Reasonable accommodation legislation has been quoted as a basis for establishing passports, embedded within the hospital and community care systems, especially for people with intellectual disability (47). While passports were mostly user owned, their acceptance was usually established within the hospital care pathway (22, 24, 54, 55). There were higher rates of passport use in the healthcare system by the healthcare personnel, if the passport was developed through stakeholder consultation and entrenched into the care pathways (47).

Effective and timely access to services

Passport use was identified as a tool that enhances timely and effective access to services through better communication, minimization of duplication, and user empowerment, resulting in speedier access to care and supports (28, 30, 32, 39, 42).

The implications of our findings, translated into a systems-thinking format, as described by the 10Ps outlined by MacLachlan and Scherer, are illustrated by some examples in Table 3.

Table 3. Some examples drawn from the literature review of how an AT passport can contribute to a systems’ thinking approach

People	The AT passport should place the user as the driver of what type of communication needs to be enhanced through the AT Passport. The goal of enhancing communication is to enable the user effectively access services. The AT passport concept building should be a participatory approach that includes all the relevant stakeholders, but driven by the AT user’s needs
Product	The AT passport’s design and function should promote swift transfers of assistive products during transitions, for example; from primary to secondary care, consequently facilitating an uninterrupted system of supports. The AT passport will be utilized across multiple contexts and user group, as such design and development should ensure conformity with the existing system to ensure its adoption and achieve the eventual purpose of accessing AT supports and services
Personnel	Communication of relevant and targeted information to health-care personnel rests on the user’s preference and need at each point and time.

	The AT passport through user consent should offer a platform where relevant personnel can selectively access relevant data to aid in the assessment and service provision
Provision	The AT passport should be the primary interface between the user's product needs and experiences, and the ability of service providers to meet these needs. It should also act as the central store for monitoring, follow-up and evaluation of technologies and services, as well as potentially user's experiences of individual staff members
Policy	Policy should provide procedures for consent, data storage and protection measures, as well as framework for validating the information contained in the passport. The policy formulation, if not yet in place, should ensure alignment to international standard for the right to AT
Partnership	AT Passport should offer a framework for enhancing communication not only between the user and the local services and supports, but to establish a common network of communication between the relevant players in the wider system
Place	The AT passport should consider the influence of physical, societal, psychosocial, cultural and social-political infrastructure when designing the attributes of the passport and how it can be used to promote appropriate and effective communication
Pace	Given the rapid pace of technological advancement, the AT passport should be a flexible, adaptable and resilient tool that can withstand systemic changes. However, it also has to take account of the absorptive capacity for the system to change in a way that can support the introduction of the AT passport
Promotion	The AT passport should itself communicate its value in the promotion of access to AT; for instance, in being able to provide information on user experience and satisfaction at all levels of government, civil society and private institutions
Procurement	The AT passport should be able to feed back to national procurers the types of AT in use, how long they are functional for, how often they may need to be replaced, to where they need to be distributed, and so on; and as such make an important contribution to market shaping (59)

Conclusion

This paper aimed to present recommendations for further conceptualization of the AT passport as a user-led system tool that offers the potential for interaction between the individual AT user, and the system required to effectively support that use. A descriptive review of the concept of user-systems "passport", as applied in other areas of health and social care services, was presented and analysed to identify emerging themes.

AT is not just a piece of technology, or the user of the technology, but encompasses the broader ecosystem on which both of these are dependent. The systems thinking approach encourages us to identify relevant components within this ecosystem, but not to assume they must all work the same way in different contexts; but rather to be flexible and

imaginative in how these components are addressed, and crucially, how they interact. We believe that the concept of an AT passport has much promise in achieving this goal, while keeping the AT user centre-stage. In adopting a systems thinking approach, this review recognises the complexities inherent within AT systems requires in-depth understanding of interlinks and connections that are characteristically present within complex systems. This has an implication for enabling the meaningful placement of the AT user at the centre of supports, innovations and services especially in the current environment of rapid technological changes.

Three broadly based conclusions emerged from this review relevant to the design and development of the AT passport as a driver for the promotion of effective appropriate and affordable access to quality assistive products:

1. AT user involvement, participation and ownership resulting in enhanced design, development, piloting, uptake, evaluation and scalability.
2. National and international alignment across policy, systems, IT infrastructure and data management resulting in standardised implementation, procedures, protections and legal frameworks to improve continuity of care.
3. To promote an impactful, comprehensive and inclusive access to AT, the application of systems-thinking approach can offer the potential for understanding the interconnections in the at system.

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Orthotic service provision in the United Kingdom: Does everyone get the same service?

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Abstract

In the United Kingdom orthotic services are provided by the National Health Service (NHS), and this service has previously been described as a “Cinderella service” which is poorly understood and low in any list of priorities. Coding issues and poor recording have resulted in a lack of accurate data on orthotic service provision in the United Kingdom. Several reports from both the NHS and other organisations have highlighted issues within Orthotic Service provision in the United Kingdom, and the potential benefits of improving these services which include clinical benefits for patients, financial benefits for the NHS and economic benefits for the wider economy. The aim of this work is to gain an understanding of current orthotic service provision in the United Kingdom, and to establish the current state of regional differences in provision. In January 2017 identical Freedom of Information requests were sent to all Trusts in England and Northern Ireland and Health Boards (HBs) in Wales and Scotland; this request consisted of a survey designed to gather information on orthotic service provision. Responses were received from 61% of the contacted Trusts/HBs with results providing information on the number of patients accessing orthotic services and showing large variances in appointment waiting times and orthotic device lead times across the different United Kingdom regions. Additional research and service evaluations of orthotic service provision in the United Kingdom are needed in order to develop and implement strategies to improve service provision.

Keywords

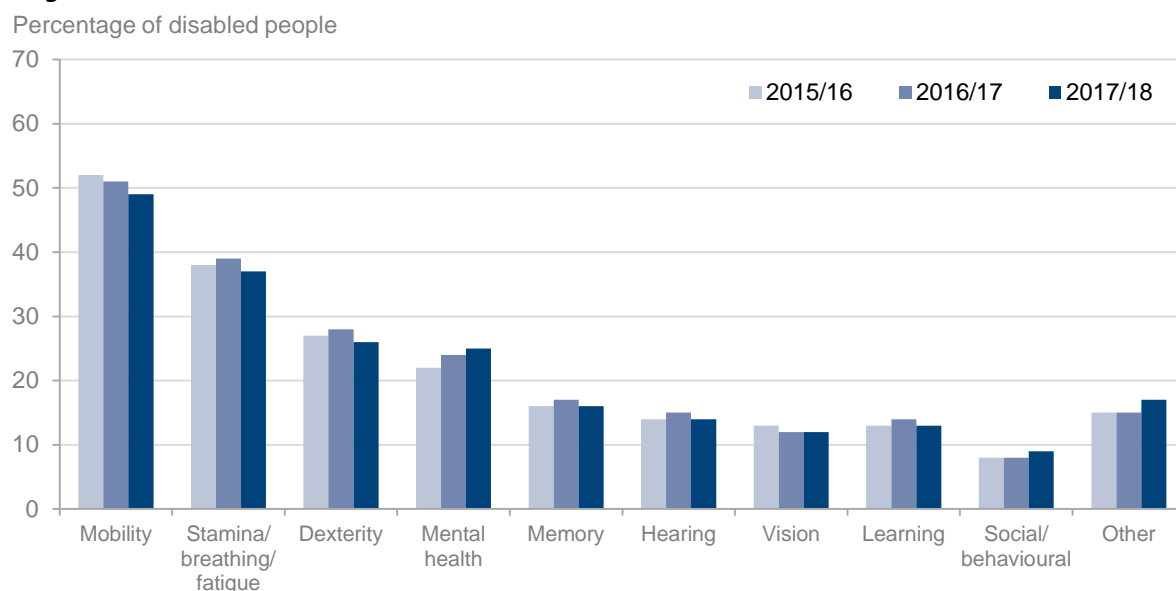
Orthotic Devices; Outcome Measures; National Health Services; Health Care Survey

Introduction

There are 6.5 million people with a mobility impairment in the United Kingdom; accounting for the largest percentage of disabled people at 49% (see Figure 1) (1). Pension age adults with a mobility impairment account for the largest percentage of disabled people at 67%, with 41% of working age adults and 19% of children reporting a mobility impairment (1).

Within the United Kingdom National Health Service (NHS) orthotic services provide mobility assistive devices; with these services provided by orthotists and other allied healthcare professionals (e.g. podiatrists, physiotherapists, and occupational therapists).

Figure 1. Impairments reported by disabled people, 2015/16, 2016/17 and 2017/18, United Kingdom



Source: Family Resources Survey 2017-18 (1)

Orthotic service provision within the NHS is not well understood, with many reports from both the NHS and other organisations highlighting the issues within service provision, and the significant potential benefit if service provision was improved (2–11). Improvements in service provision are particularly important considering that with the projected population growth and aging population there will be a global increase in the demand for orthotic services (12). Due to the lack of data available in regard to NHS orthotics services (5) accurate figures on the number of orthotic users in the United Kingdom do not exist; reports from organisations in 2007 (13) and 2011 (14) have approximated the number of users at 1.2 million and 2 million, respectively.

The aim of this work is to gain an understanding of current orthotic service provision in the United Kingdom; (1) establishing the number of patients attending orthotic services, (2) the waiting times for appointments and provision of mobility assistive devices, and (3) to explore if regional differences in service provision exist.

Methods

A freedom of information (FOI) request was made to all Trusts who provide orthotic services in England and Northern Ireland and Health Boards (HBs) in Wales and Scotland in January 2017. Trusts and Health Boards are organisations within the NHS generally serving either a geographical area or a specialised function. The request consisted of a survey of 30

questions designed to gather information on the service provision; with this work focusing on the questions related to volume of orthotic users, appointment waiting times and lower limb mobility assistive device lead times. The survey questions related to these topics were as follows:

- Please provide manufacturer lead times for the last 12 months (2015-16):
 - Stock paediatric Footwear
 - Modular adult Orthotic Footwear
 - Bespoke Orthotic Footwear
 - Orthotic Footwear repairs
 - Moulded EVA Insoles
 - Plastic Heel cups
 - Carbon Fibre Insoles
 - Bespoke AFOs
- How many patients were seen in your entire orthotics service in 2015-16?
- What is your average waiting time from referral to assessment for a routine adult appointment?
- What is your average waiting time from referral to assessment for an urgent adult appointment?
- What is your average waiting time from referral to assessment for a routine paediatric appointment?
- What is your average waiting time from referral to assessment for an urgent paediatric appointment?
- What is your average waiting time from assessment to supply of paediatric AFOs?

The results were analysed using descriptive statistics with comparisons made between United Kingdom regions. There was a total of twelve regions; Northern Ireland, Scotland, Wales and nine regions within England. An ethics disclaimer form for this study was submitted to the Staffordshire University ethics committee prior to the start of the study.

Findings

A total of 196 Trusts/HBs were sent the FOI request. Responses were received from 119 (61%), 20 (10%) declined to reply and 57 (29%) did not respond. A breakdown of the total number of responses and those included in the analysis are provided in Table 1. Of the included responses, there were varied response rates to individual questions within the survey.

Table 1. Number of Responses to the FOI request by country. HB = Health Boards

Country	Number of contacted Trusts/HBs	Number of Trusts/HBs who provided response	Number of responses included in analysis
England	170	98	90 [#]
Scotland	14	12	12
Wales	7	6	5 [*]
Northern Ireland	5	3	3

Notes: #Ten Trusts were excluded from analysis as they stated that their service was run within another service and their survey response provided limited information, leaving 88 Trusts. However, one trust provided separate responses for adult and paediatric services, and one trust sent two individual replies for different areas within their Trust resulting in a total of 90 surveys. *One Health Board was excluded from analysis as they stated that their service was run within another service and their survey response provided limited information.

Number of patients attending orthotic services

The total number of patients attending orthotic services for the year 2015-16 was 459,212 (response rate 81% (89/110 Trusts/HBs responded) (Table 2). The highest number of patients, at 67,140, were seen in England – North West; with the lowest number, at 17,136 seen in Northern Ireland. The number of patients attending orthotic services was compared to the estimated population with a mobility impairment in each United Kingdom region, the total number of patients equates to 6.6% of the United Kingdom population with a mobility impairment.

Table 2. Number of patients attending orthotic service in 2015-2016.

Locations	Response rate % (No. of Trusts/HBs)	Number of patients	Population with a mobility impairment [§]	% of population with a mobility impairment who attended an orthotic service
England - East	86% (6/7)	22262	624000	3.6
England - East Midlands	75% (3/4)	17812	520000	3.4
England - London	77% (10/13)	36652	624000	5.9
England - North East	100% (6/6)	38216	312000	12.2
England - North West	75% (12/16)	67140	936000	7.2
England - South East	92% (12/13)	54017	884000	6.1
England - South West	89% (8/9)	24469	676000	3.6
England - West Midlands	77% (10/13)	66334	624000	10.6
England - Yorkshire and Humber	89% (8/9)	51248	572000	9
Northern Ireland	100% (3/3)	17136	208000	8.2
Scotland	58% (7/12)	41021	572000	7.2
Wales	80% (4/5)	22905	416000	5.5
Total	81% (89/110)	459212	6968000	6.6%

Notes: § Calculated from data provided in the Family Resources Survey 2015/16 (15).

The total number of paediatric patients attending orthotic services for the year 2015-16 was 87,798 (response rate 67% (75/110 Trusts/HBs responded) (Table 3). The highest number of patients, at 20,062, were seen in England - West Midlands; with the lowest number, at 945 seen in Northern Ireland. The number of paediatric patients attending orthotic services was compared to the estimated population with a mobility impairment in each United Kingdom region, the total number of patients equates to 3.1% of the United Kingdom paediatric population with a mobility impairment.

Table 3. Number of paediatric patients attending orthotic service in 2015-16.

Locations	Response rate % (No. of Trusts/HBs)	Number of paediatric patients	Paediatric population with a mobility impairment [§]	% of population with a mobility impairment who attended an orthotic service
England - East	86% (6/7)	4429	252000	1.8
England - East Midlands	75% (3/4)	5731	210000	2.7
England - London	69% (9/13)	5131	252000	2
England - North East	83% (5/6)	7138	126000	5.7
England - North West	69% (11/16)	14206	378000	3.8
England - South East	69% (9/13)	11625	357000	3.3
England - South West	78% (7/9)	6431	273000	2.4
England - West Midlands	77% (10/13)	20062	252000	8
England - Yorkshire and Humber	44% (4/9)	3473	231000	1.5
Northern Ireland	67% (2/3)	945	84000	1.1
Scotland	42% (5/12)	4505	231000	2
Wales	80% (4/5)	4122	168000	2.5
Total	68% (75/110)	87798	2814000	3.1%

Notes: § Calculated from data provided in the Family Resources Survey 2015/16 (15).

Appointment waiting times

The median adult appointment waiting times in January 2017 are presented in Figure 2. While median waiting times across regions, for the majority, was reasonably consistent there were large variances across all regions of the United Kingdom. Wales had the longest median waiting time for a routine appointment at 10 weeks. The longest waiting times were seen within the English regions; with individual Trusts within London, the North West, the South West and the West Midlands reporting waiting times for routine appointments of 17.2, 34, 19 and 23 weeks, respectively.

The median paediatric appointment waiting times and time from assessment to supply of paediatric AFOs are presented in Figure 3. None of the Northern Ireland Trusts provided information on appointment waiting times, and only one provided a response on the time from assessment to supply of paediatric AFOs. The longest waiting times for routine appointments were seen within the English regions; with individual Trusts in the North West

and the South West reporting waiting times of 20 and 19 weeks, respectively. Some paediatric patients had to wait up to 8 weeks for an urgent appointment.

Lead times for provision of mobility assistive devices

Lead time for footwear and lower limb orthoses in January 2017 are provided in Tables 4 and 5, respectively. While for most of the mobility assistive devices there was some consistency in the median lead times there were large variances across all Trust/HBs across all regions of the United Kingdom. The longest lead times for footwear were seen in Northern Ireland with 14.6 weeks for modular adult orthotic footwear and 20 weeks for bespoke orthotic footwear. The longest lead time for molded EVA insoles was 17.07 weeks in England – West Midlands, with a wait for 11 weeks for plastic heel cups in England – North East. A Trust in England – West Midlands reported a lead time of over 34.65 weeks for a bespoke AFO, the maximum reported by any other Trust/HB was 6.2 weeks.

Figure 2. Median adult appointment waiting times in January 2017. Error bars represent the minimum and maximum waiting times. No information was provided by any of the Northern Ireland Trusts.

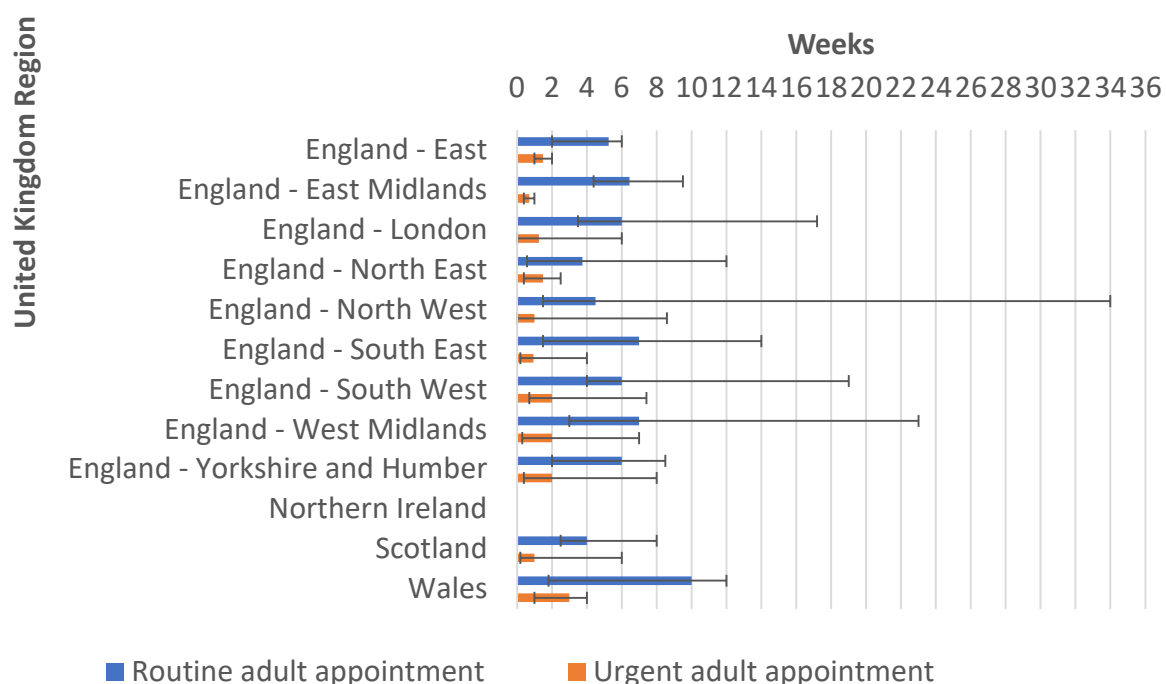
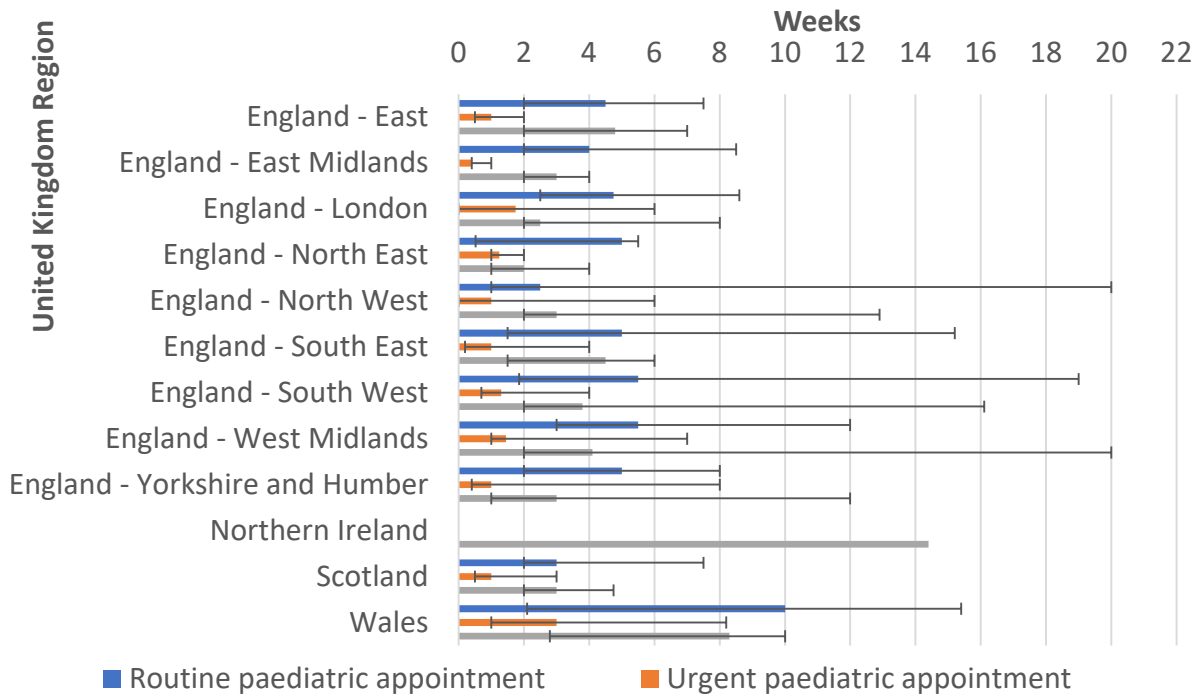


Figure 3. Median paediatric appointment waiting times and time from assessment to supply of paediatric AFOs in January 2017. Error bars represent the minimum and maximum times. Only one Northern Ireland Trust provided the average time from assessment to supply of paediatric AFOs, with no information provided for appointment waiting times.



Discussion

This work aimed to gain an understanding of current orthotic service provision in the United Kingdom and to explore regional differences in service provision. As accurate figures on the number of orthotic users in the United Kingdom does not exist (5) the findings of this study provide new insight into the volume of patients accessing orthotic services in the United Kingdom. The current surveys adds to the limited body of knowledge on orthotic service provision; a previous FOI survey conducted by the Medway NHS Foundation Trust in 2014 analysed responses from 38 Trusts (5).

In 2015/16 there were 7 million people with a mobility impairment in the United Kingdom, 52% of disabled people; pension age adults with a mobility impairment at 68%, with 44% of working age adults and 21% of children reporting a mobility impairment (15). The findings on patients accessing orthotic services from this survey were compared to these reported numbers from the Family Resources Survey 2015-5 (15) to establish how many people with a mobility impairment access orthotic services across the different United Kingdom regions; the total number of patients equated to 6.6% of this populations, with this figure ranging from 3.4 – 12.2% across the different United Kingdom regions. It should be noted that the figures reported in the Family Resources Survey are for all mobility impairments, so these figures would include people who may require other mobility assistive devices e.g. wheelchairs and prosthetics, not only orthotic devices.

The appointment waiting times and orthotic device lead times across regions showed that there are large variances in service provision across the United Kingdom. The longest appointment waiting times and lead times for mobility assistive devices in regions were within England. The recommended maximum reasonable timescales in the United Kingdom (16) (10 working days for an AFO, 25 working days for bespoke footwear and 15 working days or stock footwear) were not achieved by the majority of the Trusts/HBs.

Structured service evaluation and further research are needed to understand why these differences are seen across Trusts/HBs; this information is required in order to develop and implement strategies to improve service provision. Work is ongoing by the authors exploring the findings from all the questions within the FOI survey (17), which will provide additional insight into orthotic service provision in the United Kingdom.

While this study provides valuable information on orthotic service provision it is limited by the low response rate (61%) to the survey. As Trusts/HBs are all different sizes it is not possible to accurately extrapolate the results for those Trusts which did not reply to the FOI request. There is a requirement for processes to be put in place within the NHS to accurately capture data on orthotic service provision.

It could be argued that as a developed country it is unacceptable that the United Kingdom has such limited information available on its orthotic service provision. Findings from the present survey show that the service patients receive is very much dependent on where they live as large variances are seen across Trusts/HBs; this is unacceptable as all patients should receive a high level of service with short waiting times and access to mobility assistive devices when they need them.

Table 4. Lead times for footwear in January 2017 (Median (Minimum – Maximum))

Locations	Stock paediatric footwear	Modular adult orthotic footwear	Bespoke orthotic footwear	Orthotic footwear repairs
England - East	3.5 (0.4 - 6)	4.5 (3 - 7)	6 (4 - 7)	2 (2 - 2)
England - East Midlands	3 (2 - 4)	4 (4 - 5)	5 (4 - 5)	1.5 (0.8 - 3)
England - London	2.9 (2 - 4)	6.5 (2.6 - 11.9)	7 (5 - 15)	3 (1 - 4)
England - North East	2.8 (2.7 - 3)	2.35 (2 - 7)	3.5 (3 - 11)	2.1 (2 - 4.2)
England - North West	2.05 (1 - 5)	4 (2.5 - 9.6)	4.4 (2.5 - 13.2)	1.5 (2 - 2.8)
England - South East	2 (1 - 6)	4.5 (2 - 7)	5.5 (3.4 - 15.4)	2 (1 - 4)
England - South West	3.9 (1 - 9)	5 (4 - 9.4)	6 (5 - 11.4)	2.4 (1 - 3)
England - West Midlands	2 (1 - 3.6)	3 (1.42 - 10)	4 (1.56 - 11)	1.75 (0.6 - 4.5)
England - Yorkshire and Humber	2 (0.2 - 6)	4 (3 - 7.2)	5 (2 - 10)	1 (1 - 10)
Northern Ireland	2*	10.3 (6 - 14.6)	13.5 (7 - 20)	1.5*
Scotland	3.5 (2 - 7.4)	4.6 (2 - 6)	5.67 (3 - 12.8)	1.5 (1 - 2.8)
Wales	3.5 (2 - 4)	6 (3.5 - 8)	6 (3.5 - 8)	2 (2 - 2)

*Notes: *Response from one trust only*

Table 5. Lead times for lower limb orthoses in January 2017 (Median (Minimum – Maximum))

Locations	Molded EVA insoles	Plastic heel cups	Carbon fibre insoles	Bespoke AFOs
England - East	2 (2 - 4)	3 (2 - 4)	2 (2 - 4)	2.5 (2 - 4)
England - East Midlands	3 (2 - 3)	3 (2 - 3)	2 (2 - 2)	3 (2 - 3)
England - London	4 (2 - 7)	3 (0.2 - 7)	3 (2 - 6)	3.5 (1 - 6)
England - North East	2.8 (1 - 6.2)	6.55 (2.1 - 11)	1 (1 - 1)	2.75 (2.5 - 3)
England - North West	2 (1 - 2)	2 (1.5 - 3)	2 (2 - 2.5)	2.75 (2 - 4.2)
England - South East	2.8 (1 - 7.8)	2.8 (0.14 - 6)	2 (1 - 4)	2.5 (1 - 6.2)
England - South West	3.25 (2 - 6)	4.2 (1.6 - 6)	4.4 (3 - 6)	3 (2.3 - 6)
England - West Midlands	2 (1 - 17.07)	2 (0.2 - 8.92)	2 (1 - 5.76)	2 (2 - 34.65)
England - Yorkshire and Humber	2 (1 - 5)	2 (0.2 - 3)	2.5 (2 - 5)	2 (1 - 3)
Northern Ireland	3.85 (2.5 - 5.2)	4.45 (3.5 - 5.4)	4.95 (3.5 - 6.4)	4.75 (3.5 - 6)
Scotland	3.1 (1 - 6.4)	3 (2 - 6.41)	2 (1.29 - 5)	4.1 (1.45 - 6)
Wales	3.15 (2.8 - 3.5)	2.8 (2.8 - 2.8)	3.5 (3.5 - 3.5)	2.75 (2 - 3.5)

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Provision of assistive devices for people with diabetes at risk of mobility impairment

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Abstract

Whilst diabetes is a growing global health problem, diabetic foot disease is one of the most expensive complications of diabetes leading to significant morbidity and mortality in the adult population. Previous research has clearly highlighted the limitations of currently available diabetic foot screening guidelines; which aim to identify patients at risk of foot complications, such as ulcerations and amputations, and who therefore may require mobility assistive devices. Also, there are differences between screening guideline recommendations at the national level and this contributes to the differences in national diabetic foot disease outcomes and associated burden. There is also a lack of high quality evidence on which these guidelines are based which is responsible for the current gaps between guidelines, standard clinical practice, and development of complications. Whilst indicating that diabetes is associated with a clear increase in the risk of physical disability, studies have called for efforts to promote healthy ageing and strategies for mitigating this risk through prevention and management. In addition, reports showcase that diabetes related lower extremity complications are one of the leading causative factors in the global burden of disability. This study focussed on publicly available datasets to retrieve relevant information relating to physical disability as a result of diabetes. It also examined the national guidelines for screening and their relationship to global guidelines. Whilst publicly available datasets highlight and host up to date information on the global burden of the diabetes, it has little or no information relating to the complications resulting from diabetes and in particular no data on amputations or mobility related assistive devices. There is a clear need for collecting structured data during screening at a primary care level. This, in addition to helping to reduce the complications of the disease will help to understand the assistive technology needs of these patients.

Keywords

Orthoses; Assistive Devices; Diabetic Foot

Introduction

The worldwide diabetic population is expected to grow from 171 million to 381 million by 2030 posing a serious international challenge. Reports highlight that there has been a clear increase in the age standardised diabetes prevalence in adults since 1980. When this is coupled with the growth in population and the effects of ageing, the number of adults with diabetes has nearly quadrupled. In addition, the reported data suggests that this growth has increased faster in low-income and middle-income countries than in high-income countries (1).

Diabetic foot disease is one of the most expensive complications of diabetes and leads to significant morbidity and mortality in the adult population with a prevalence of 9.7%. The lifetime risk of diabetic foot ulcers (DFUs) is 15% to 25%. 15% of these DFUs result in amputation, which amounts to 85% of all lower-limb amputations (2). Following a first amputation, the likelihood of the need for a subsequent amputation for people with diabetes is twice as likely as people without diabetes. After a diabetic foot ulceration or amputation mortality rates are high; within 5 years of having an amputation up to 70% of people will die and within 5 years of developing a DFU around 50% will die (3). As the incidence of diabetes and the resulting complications are on the increase, we need a step change in all aspects of prognosis, diagnosis and prevention. In addition, more sustained efforts are needed to understand not only the progression of the disease but also the resulting complications. Whilst assistive technology, in the form of orthoses, footwear, is pivotal in the clinical management of people with diabetic foot disease, there is a clear paucity of structured information and research evidence to inform the clinical management of this population (4). Assistive technology to aid mobility are vital to prevent and treat DFUs. They combat the exclusion of people with disabilities from the workplace, enabling them to participate in education, work and social activities. Without them, people can be isolated increasing the impact of disease on them, their families, and society (5).

Whilst general healthcare support for people with diabetes is still not uniform both within and between countries, it is particularly evident for diabetic foot disease and its complications. Previous research (6,7) has clearly highlighted the limitations of currently available diabetic foot screening guidelines; which aim to identify patients at risk of foot complications, such as ulcerations and amputations, and who therefore may require mobility assistive devices. Also, there are differences between screening guideline recommendations at the national level and this contributes to the differences in national diabetic foot disease outcomes and associated burden. There is also a lack of high quality evidence on which these guidelines are based which is responsible for the current gaps between guidelines, standard clinical practice, and development of complications (6). Even in the countries who have established guidelines, our previous work (8) identified 3 key themes highlighting barriers to the implementation of diabetes foot screening guidelines. Although this data was local to Malta, the results might be applicable to other countries.

Our findings clearly highlight the need for change in current practices if effective diabetic foot screening is to be offered and ultimately, to reduce the mortality rates.

As a first step to tackle some of the issues, there is a need for structured epidemiological data on lower limb amputations related to diabetes and its complications. One of the recent reports (9), whilst showing that a significant variation exists in the incidence of lower extremity amputations, clearly highlights the variation in reporting methods and calls for standardised reporting methods. Although ethnicity and social deprivation might play a significant role in these amputations, the role of diabetes and its complications cannot be ignored and based on existing data, it is most profound. Diabetes and its complications are associated with a clear increase in the risk of physical disability and studies have called for efforts to promote healthy ageing and strategies for mitigating this risk through prevention and management (10). In addition, reports (11) showcase that diabetes related lower extremity complications are one of the leading causative factors in the global burden of disability.

Despite improvements in morbidity and mortality levels, general health inequalities remain. This is particularly prevalent in the management of chronic conditions such as diabetes and its complications. It is important to develop a version of Global Quality and Outcomes Framework (QOF) on trends in diabetes management and inequalities in care with a focus on musculoskeletal and mobility issues. The Quality and Outcomes Framework is a system designed within the National Health Service (NHS) in the United Kingdom, to encourage high quality care and cost-effective management of medical condition, using an evidenced based checklist (12). This scheme was established by NICE in the United Kingdom and research has shown this system has been associated with improved care in multiple conditions, including diabetes (13). Whilst indicating that the QOF led to modest improvements in diabetes care within the NHS, this report concluded that the healthcare providers should look at other alternatives (13).

In the context of this paper, the QOF is used as a reference point to highlight the need for a structured screening, reporting and management system rather than a system for financial compensation. Given that there is a pledge to achieve universal health coverage by 2030, and that the healthcare organisations and departments are currently negatively subjected to various resource implications, the quality of services can only be improved by structured recording and analysis of appropriate information. Whilst commitment from the politicians and policy makers to provide universal health coverage is a step in the correct direction, one of the previous papers (14) have synthesized the lessons learnt from the NHS that provides a universal health coverage, free at the point of care for over 70 years. This report identified that: 1) the development of a coherent strategy to improve quality, 2) to boost public health as a measure to reduce disease burden, 3) to adopt evidence-based priority setting methods that ensure efficient spending of financial resources, 4) to introduce an independent way of inspecting and regulating providers, and finally, 5) to allow for task-shifting, specifically in regions where staff retention is low as main factors to consider.

The overall experiences of Thailand, where QOF similar to the United Kingdom was adopted in 2013 with an objective of strengthening the quality of primary health care by introducing financial incentives and quality indicators for measuring health care service performances have been positive. Evaluations and research reports of the initial pilot show that some of the main barriers for the QOF program include budgetary constraints, lack of evidence-based quality indicators, lack of involvement from key stakeholders and the incompatibility of policies between the ministries of public health and the health service provision. This meant an increase in burden for health workers in the primary care sector and poor communication between various stakeholders. Based on these findings a new set of indicators were developed, implemented and evaluated. Although long term effects are yet to be reported, the initial indicators show that the QOF in Thailand is a promising intervention despite its many challenges (15–17).

It is generally accepted that the development of quality indicators using a specific screening and guideline-based approach is a useful way of generating evidence to support the effective implementation of a health policy program. There have been some research reports which provides a framework for insurance and cost implications in improving health care quality in low resource settings. This framework bridges the gap in literature between strategic designs for system improvement and narrower discussions of the technical methods to influence the quality by the organisations and departments which make the payments (18).

The main purpose of this work is to explore the available data on the global burden of diabetic foot disease and to review the research and clinical literature to explore what information is needed to develop a structured framework. This should give us an understanding of the level of health inequalities in the provision of assistive devices for people with diabetes at risk of mobility impairment and to establish a protocol for basic requirements to mitigate the risk of further physical disabilities.

Methods

In addition to a thorough literature search relating to diabetic foot screening guidelines(6,8), publicly available datasets (19–22) were explored in a systematic way to retrieve any relevant information relating to physical disability as a result of diabetes. We also examined the national guidelines for screening and their relationship to global guidelines.

In terms of the quantitative data, as we wanted to focus on developing and under developed regions of the world, the dataset from the Demographics and Health Services (DHS) program was first explored to see how many surveys included questions on diabetes. The next step was to synthesize the data available from the World Bank. A particular focus was given to the prevalence rate of diabetes. The third step was to look at individual country profiles on diabetes and related data published by the World Health Organisation (WHO). Finally, we approached the International Diabetes Federation (IDF) for any available data.

Results

Within the DHS out of the reports from multiple years (2002-2018), 21 full country reports were available which consisted of survey answers based on questions on diabetes. These questions related to the general prevalence of diabetes and did not have any specific data related to causative factors or complications resulting from diabetes.

The data from the World Bank showcased the prevalence of diabetes (% of population ages 20 to 79). This dataset showed a weighted average data of people who have type 1 or type 2 diabetes. This data indicates that diabetes is an important cause of ill health and a risk factor for other diseases in developed countries and is spreading rapidly in developing countries. Although it is highest among the elderly, the prevalence rates are rising among younger populations in developing and under-developed regions of the world. Data on a total of 217 countries and territories has been reported and the diabetes prevalence ranges between 0.99-30.53%. Out of these 72 countries reported a prevalence rate between 10.08-30.53%. The data were also grouped by the following regions: East-Asia & Pacific, Europe and Central-Asia, Latin America & Caribbean, Middle-East & North-Africa, North-America, South-Asia, Sub-Saharan Africa and by the following income groups: low, lower-middle, upper-middle, high.

In terms of the dataset from the WHO, country profile reports published in 2016 were scrutinised to understand the data relating to the complications resulting from diabetes. In addition to the prevalence data, the profile includes data on: 1) mortality, 2) risk factors, 3) the country's plans and policies on: 1) monitoring and surveillance; 2) primary prevention, 3) treatment and availability of medicines and, 4) basic technologies and procedures. Out of the 72 countries identified with diabetes prevalence of over 10% from the World Bank data, 34 countries had profiles within the WHO dataset. Although the IDF has data on prevalence, they do not collect data on amputations and specific data related to the complications of diabetes.

In summary, although the publicly available datasets highlight and have up to date information on the global burden of the diabetes, it has little or no information relating to the complications resulting from diabetes and in particular no data on amputations or mobility related assistive devices. In addition, there is little information within the scientific literature on the potential clinically viable outcome measures for documenting and assessing physical disability in people with diabetes. A critical evaluation of available foot screening guidelines highlights the need for culturally competent, nationally relevant guidelines.

Discussion

The purpose of looking at publicly accessible datasets is to make sure that this data could be used by local policy makers who might not have access to specific research datasets. In addition, although one could argue that these large surveys normally provide superficial

data and not individual, highly scientific and quantifiable data, it gives a global trend and provides pointers to scientists and policy makers on the direction to follow.

The results and the synthesis of available reports highlight that availability of health data is limited. It is not only a major constraint in the assessment of any health indicators in the developing and underdeveloped regions of the world but also impedes the development of policies and procedures to alleviate the issues relating to any particular non-communicable disease. Whilst this report focused on diabetes, its complications and assistive technology, the analyses of data sets show that there is a paucity of data relating to important public health issues. In addition to this, the reports also highlight the fact that some of the estimates relating to disease incidence and prevalence are either incomplete or unreliable.

Recognising the global burden, in 2016 the WHO released the first global report on diabetes along with a series of country profiles to highlight the status of diabetes prevention and control in each member state. These profiles provide a comprehensive information which could support further focused work. Although the data presented within these profiles were derived from a variety of sources, the mortality and risk factor data were estimated using standard methods to maximize cross-country comparability. Whilst these may not represent true values and official statistics of member states, it provides a clear picture of the growing burden in various parts of the world.

A report (1) on the global burden which used the data from 751 studies (4372000 adults) showed that global age-standardised diabetes prevalence increased from 4.3% in 1980 to 9.0% in 2014 in men, and from 5.0% to 7.9% in women. This means that the approximate total number of adults with diabetes across the world increased from 108 million in 1980 to 422 million in 2014. Other reports (23) highlight that the burden of musculoskeletal (MSK) diseases also increased significantly between 2000 and 2015. It is universally accepted that foot screening is important in diabetic patients as it is recognised as the basis to save a high-risk foot. For this screening to be effective it must be performed correctly. The skills required to complete this screening is complicated and needs appropriate training. Our research within the reported literature show that a range of healthcare sector workers from a variety of specialities perform this screening with little training. This possibly needs to change if the screening has to be effective in saving limbs (8). Our previous work highlights the need for appropriate assessment of ABPI (24,25), the need for structured screening within the primary care (26,27) and accurate evaluation of footwear (28). In addition our work on the critical analysis of the current foot screening guidelines developed by various organisations and policy makers (6) shows a clear disparity and inconsistencies in areas with regards to tools and methods for effective screening and the diagnosis patients at an early stage of their disease. Based on 10 complete diabetes foot screening guidelines (out of which 6 of them included the full-process guidelines recommended by the IDF) our analysis showed that most of the recommendations within many of these guidelines are either poorly evidenced or based solely on an 'expert opinion'. There is a clear need to create a network of clinical practitioners and health policy experts who would look at these

guidelines in a clear and structured fashion taking into consideration the technological developments for clinical assessment and cultural differences across the world, to develop appropriate screening tools which are fit for purpose. This will no doubt have a substantial impact not only in reducing ulcerations and amputations but also in improving the quality of life of people with diabetic foot disease.

Previous research conducted in a primary care setting in Malta where the prevalence rate is high, showcases the importance of structured observation coupled with strengthening of existing screening protocols and introducing clinical guidelines with regards to biomechanical assessment of the feet in a primary care setting. This report concluded that this has the potential to reduce the incidence of diabetes foot complications (29). Although various scientific and clinical publications indicate that peripheral vascular disease (PVD) is strongly associated with type 2 diabetes, the assessment and diagnosis of PVD are often neglected within primary care. Another report on the same population showed that a significant proportion of these patients with type 2 diabetes who visit primary care have vascular insufficiency. The paper called for the use of Ankle Brachial Pulse Index as an added measurement in order to facilitate early detection and treatment and reduce the burden of PVD in this high-risk population (26). Finally, the demographics within this population showed that, whilst metabolic outcomes such as hypertension and dyslipidaemia were present in most subjects, peripheral vascular disease, peripheral sensory neuropathy and foot deformities were also common. The report indicated that 26 per cent of the participants had to be referred for further vascular assessment following this screening program due to their critical vascular status (30).

Based on some of these findings, it is important that structured screening is carried out at a primary care level. The WHO country profiles do provide some insight into the technologies available at the primary care. These technologies and the facilities could be strengthened to include some of the quantitative outcome measures to facilitate structured screening. In terms of the profiles themselves, out of the 34 countries which were looked at in detail, only 4 were from the low-income countries and the rest were from middle or high-income countries. One could easily attribute this to change in socio-cultural and dietary habits. Only 18 of these countries report to have a diabetes registry. Given that this situation is there to stay some urgent measures are needed to tackle the situation.

Inequalities to access healthcare are preventable and have a huge socio-economic impact because they result in people who are disadvantaged having poorer health and quality of life. This is amplified in people living with chronic health conditions such as diabetes. The complications of diabetes result in physical disabilities. To improve health outcomes and to help with mobility issues relating to diabetic complications appropriate actions, strategies and interventions are required.

These include not only the development of clinical protocols but also the development of appropriate technology. United Nations Sustainable Development Goals (SDG) (31) clearly outline the need for effective, innovative, and affordable medical devices. This is a critical

component of any effective healthcare intervention and to achieve the WHO goal of 3 billion lives saved as stated in the 13th General Programme of Work. It is clear that lack of access to quality, affordable medical devices is most apparent in low – and middle – income countries and contributes to global health inequalities.

Whilst the WHO statistics series (32) provides an annual snapshot of the state of the world's health and contains data for 36 health-related SDG indicators, there is a gap in knowledge in terms of complications resulting from diabetes. To address this gap and as a first step, there is a need to design and employ measures to collect data in a structured way across the world on diabetes and more importantly on its complications. Our exploratory work clearly highlights that there is no global data on amputations and the level of amputations relating to diabetes. Also, there is a clear paucity of information on the assistive technology needs for this population. This data is essential to policy makers, healthcare providers and commercial organisations to develop a quality provision of AT to people with diabetes.

Various reports clearly highlight that inequalities in access to healthcare exist across different socio-demographic groups across the world both for financial and non-financial reasons. To ensure universal access to care, an effective screening program followed by evidenced based clinical management is paramount. Reports (11) analysing the global burden of disability highlight the need for policymakers to prioritise the development of policies that will improve evidence-based care for people with diabetes complications. This will no doubt influence the reduction of the largest cause of lower limb amputations and the global burden of disease.

Limitations of currently available guidelines and lack of evidence on which the guidelines are based are responsible for the current gaps between guidelines, standard clinical practice, and development of complications. For the development of standard recommendations and everyday clinical practice, it will be necessary to pay more attention to both the limitations of guidelines and the underlying evidence. In addition to this, one needs to consider the fact the AT needs of a patient with diabetes will be different to a patient with other MSK conditions and other disease complications. Collecting structured data during screening at a primary care level can lead not only to reduce the complications of the disease but also to understanding the AT needs of these patients. The results of these findings will also help the policymakers to prioritise policies that will improve evidence based screening and clinical management of people with diabetes and mobility impairment. This might also help us develop a QOF which will help not only in improving the standards for the provision of care but also structured data to identify investment needs for the government and non-governmental agencies.

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Enabling assistive technology-usage through a holistic support process

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Abstract

The current process of AT research, development and procurement in visual impairment related areas is sometimes characterized through a quite lopsided approach. While engineers and developers strive to incorporate as many options as possible, most persons with or without impairment are regularly overwhelmed by the sheer amount of usage options that in the end only serve to increase complexity but not usability. Furthermore, this situation extends to vendors and funding agencies, as they too have problems with providing the best fitting solutions to persons with disabilities. Taking stock of the existing process by virtue of long-term data gathered from the members and business partners of the Austrian Association in support of the blind and visually impaired, we deduced the main goals and shortcomings of the different stakeholder groups involved in the provision process of assistive technology (AT) in Austria. We then provide solutions on how to incorporate the different groups in a holistic process. Eventually we derive some enabling factors that help facilitate a smooth and successful development and deployment of AT.

Keywords

AT deployment, collaboration, case study

Introduction

The effective use of AT hinges on many variables that need to interact in a sound and functional way in order to allow persons with disabilities to fully utilize current developments and technological advancements. Although there is benefit for the persons concerned the underlying goal is much rather satisfying the technical curiosities of scientists and engineers. Here they can show off what is possible with current technologies and can integrate ever more functionalities and options into ever smaller packages. This often results in what is known as the engineer's fallacy hereby stating, "More functions are always better". One of the main opportunities to influence the success of newly developed solutions is the integration of persons with disabilities right from the start of the development process (1). Despite good examples (2) this is often neglected, as contact to and interaction with the target audience is hard to establish for technical development

teams and further there is often no common language or understanding between the parties involved (3-5). Another major factor for non-usage of current technology is the simple fact that many persons with disabilities are not aware of the opportunities they already have (6-8). This not only limits the possibilities of the target audience but also severely impacts the business case for the technology providers thus reducing revenue and making further development of AT less lucrative (9). A third main issue with not using AT is the insecurity on part of persons with disabilities whether the support will be available for longer time and whether there will be proficient technical support and training (10,11). Especially in the fast-changing world of Internet of Things (IoT) and Smart Home Solutions this fear of losing employed beneficial solutions (12,13) due to incompatibility might be frightening to persons with disabilities (14).

Besides newly developed technology also the adoption of existing solutions and services is sometimes quite limited. This holds particularly true in rural areas where there may be less regular contact to specialists or solution developers than in densely populated areas (15). Here the adoption of assistive technology may strongly hinge on the knowledge of family members and friends or on the local medical practitioners who have a general medical training but no disability specific add-on education. Thus, persons with disabilities living in dispersed or rural settings even in the well-connected parts of Europe often have to refer to stock technologies or quite elderly models of assistive solutions.

A key reason for the previously mentioned shortcomings can be found in the non-connectedness of the various stakeholders included in the process of providing assistive technologies to persons utilizing them (16). This is not only due to the different parties not being aware of each other but also due to different goals and approaches in conducting business or research that makes interaction between them hard (17). Following established business principles in cases of diverging targets and interests there needs to be a moderating third party to provide neutral moderation and connection facilities (18,19).

Provision process of assistive technologies

In Austria, the Austrian association in support of the blind and visually impaired 'Hilfsgemeinschaft der Blinden und Sehschwachen Österreichs' (HG) has established a holistic approach to providing assistive technologies to our beneficiaries. As an advocacy for blind and visually impaired persons the main goal is to improve their daily living conditions. Thus, we conducted intensive research in the needs and requirements of our members in order to establish a baseline for how to best support them.

Method

The survey was and is still conducted in a mixed method approach as can be found in Johnson et al. (20) or Greene (21). Initially pulling data on HG's members was done with qualitative questions that were answered during consultations between visually impaired or blind members and employees. This process actually started in the 1980s but was not

institutionalized and taken further until the early 2000s, although it has to be stated, that the change was a gradual process that ended up in the current structure. Over the last ten years, we also intensified the cooperation with universities in order to base our data on sound scientific methods.

As a result of this cooperation, there have been several quantitative questionnaires to various topics run by scientific organizations concerning different fields of the lives of HG's members. These range from mobility related issues over household activities to financial and supportive situations. Many of these questionnaires are run during funded research projects or by students completing their bachelor or master thesis. As we are not a scientific organization ourselves, the publication of these survey results rests mostly with our scientific partners, while we integrate the gained knowledge in our internal structure. All the time, the qualitative assessment of the needs and requirements has still been ongoing, and the results are incorporated in HG's internal knowledge database.

The data base for the results found below is just a fraction of the 4,600 persons belonging to HG as regular members (visually impaired or blind), but through constant contact and ongoing consultations there is now a very large knowledge pool that these findings as well as the resulting recommendations are based upon.

Furthermore, there is the option for HG's members but also other parts of the society (be that companies, politicians or citizens) to raise topics with the organization and trigger actions to resolve identified issues. This is also fostered by our management board and our supervisory board, which both, by statute, have to consist of at least 50% persons with visual impairment or blindness.

Results

It turned out that there were several issues that were problematic for them, among which was the provision of AT that might help them in coping with everyday problematic situations at home, at work or while about. The problems referenced by our clients were mainly focused on currently available technology, however also the knowledge about new or upcoming developments was deemed to be rather poor. While clients in metropolitan areas often stated the latter problem, for rural areas the former topic along with funding issues was more important. This was the onset for HG to widen our reach which was formerly more focused on providing social consultation.

The first step in generating the holistic process was to identify all the stakeholders responsible for a sustainable provision of assistive technology in Austria. Here we found a couple of stakeholders being key players and some others having minor or supporting roles. As the centrally important partners the solution developers and the vendors for them were identified. This was due to persons with disabilities often voicing the concern that there are no appropriate solutions for their problems or that they are unable to purchase any solutions. Another major factor for our members was the investment necessary, which meant that funding agencies also play a vital role in the provision process. In metropolitan

and densely populated areas most persons with disabilities know, where to get information on assistive technology, which is not the case in rural areas. Thus, medical practitioners in small cities or towns also have big impact on a successful provision process for assistive technologies.

With the background of knowing that our members required better and more focused solutions we established contact or used existing contacts to national and international development teams of assistive technologies. This process started in the early 2000s with several publicly funded research projects on national and European level and has by now developed to cooperation with universities, Start-Ups and technological development companies. To model the interactions, we adopted the PUSH-PULL-Concept found in logistics research (22,23). There it is designed in two different types, one in which the development of ATs is initiated through the communication of unfulfilled needs (PULL-process) and one where the development teams initiate the research and then require persons testing their proposed solutions (PUSH-process). Especially with Start-Ups the PUSH-process is quite often employed, as they often have ideas or first prototypes already developed but lack the access to a user base to further refine their solutions. Established research and development organizations used to work in a similar way but since establishing a constant exchange and interaction now often follow the other route and rely on problem descriptions made by persons with disabilities. This two-way approach has proven to be quite effective as it utilizes the creativity, tech-savviness and risk-taking of Start-Up entrepreneurs for disruptive innovations and allows the larger organizations to invest their resources in incremental innovations that require more resources but also pose a lower risk of total failure. However, the development side is only one part of the whole provision process for ATs.

The next step was to integrate the vending parties in the loop. While the suppliers and resellers of AT were quite eager to join with HG and development teams, which they saw as a good opportunity to sell existing products, particularly the resellers were less than optimistic when asked to join development projects as they dreaded the administrative expenditures and generally could not imagine their input to such activities. Through intensive support and by being led through the process of supporting development projects suppliers and resellers started to interact more often and closer with the other partners in the process and eventually enough trust and capabilities were built so that they felt comfortable with an ongoing inclusion in the enhanced provision process. By now, vendors of AT have become an integral part especially with regards to support and providing long-term availability for persons with disabilities.

Once the development and the sales side were integrated with our client base, there still was the funding problem to be solved. As many ATs require quite expensive upfront investments and the financial situation of persons with disabilities is most often quite restricted there was a significant gap that needed to be addressed in order to smooth out the provision process. In Austria, the respective organisation for funding ATs is the Federal

Ministry for Social Affairs, which has its own subsidiary that provides financial support for persons with disabilities to acquire assistive technologies. Through our social counseling activities, we had longstanding and well-established channels to this party, however they were not formalized in any way and especially with regards to AT they were quite underdeveloped. Through intensive negotiations and many working meetings, we could establish that the main problem for the ministry was the evaluation of assistive technologies regarding the usefulness and acceptance of certain solutions within the target groups. A consensus was eventually reached that HG as an advocacy could provide that information through its close ties to its members. Another key point was, that HG employs ophthalmological-qualified personnel that is allowed to conduct official assessments. This process however took more than five years until 2015 and there is still ongoing negotiation regarding its continuation.

The current provision process now includes the whole product lifecycle starting with the development of AT solutions, through to the sales and financing activities and eventually also training and support for the end users. This holistic approach enables blind and visually impaired persons in Austria to access assistive technologies much more easily, and to be more secure about it as they know that there is an established network of partners that can support them in many different ways. Especially regarding the use of assistive technologies, we found that thanks to the tight integration of research organizations and vendors we were able to improve the training for persons with visual impairments drastically. This now allows persons with disabilities to more effectively select the assistive technologies that really help them with their tasks and to more efficiently utilize the solutions they are employing. Eventually this leads to an overall increase in the usage of AT which also improves the familiarization with these tools thus starting a positive feedback loop.

To solve the problem of getting knowledge about available assistive technologies to rural and areas with dispersed populations, we established a novel regional dissemination project in 2017. Here our employees (two dedicated persons) travel to regional centers that provide the infrastructure for consultations while persons with disabilities and their families and relatives are made aware of this opportunity by local medical practitioners and social insurance organisations well in advance so that they can plan ahead. In the pilot phase that is ending by 2020 the regional scope was limited to Lower Austria. This approach proved to be more efficient than educating all local stakeholders, as the landscape of assistive technology is constantly changing, and it is just impossible for someone not engaged on a daily basis to keep up with all the latest developments. As there have been very positive responses by public authorities and citizens, we will continue the project in Lower Austria and are currently working on extending the reach to the whole of Austria.

Key enabling factors

The process described is the result of an ongoing effort from many sides to establish and maintain a well-working and functional structure that allows persons with disabilities

optimal access to as focused as possible solutions to their requirements. Before this could be done however there were several hurdles and problems that needed to be overcome. These will be presented in the following:

- **Common understanding of capabilities of persons with disabilities:** In our work with development teams, it soon became clear, that not only were many of the developers unaware of the actual situation persons with visual impairments and blind persons are in, but also that they did not make any distinctions between the different groups and therefore thought that solutions provided for blind persons would also work for visually impaired ones. This was not due to neglect on their behalf but more to not having been made aware of specific needs and competencies of persons with different disabilities during their education and training. This situation also brought another partner in the process that has not been formally integrated yet, the educational system, specifically secondary technical schools and technical universities/university programmes.
- **Common language:** As has been often proven in business literature, especially Human Resource (HR)-related work, the jargon and language between different disciplines can vary dramatically. This was also something we faced when first approaching the development teams and again when trying to integrate the vendors in the whole process. While most persons on our side had a sociological or social-sciences background, the development teams predominantly originated from technical backgrounds, thus the employed language was strongly different and also the meaning of certain terms or the acceptability of phrases had to be established. This happened again, when the vendors with their business background joined the process. However, this time it was easier, as the basic principal of realizing that there were different languages and that a common ground needed to be established was already present.
- **Financial support is important for all:** Although the financial support is now more or less integrated in the provision process in Austria, this subsystem is still not as closely connected to all the other partners as the development or the sales part. Furthermore, time has shown that financial support in the provision process needs not only be provided to persons with disabilities to acquire ATs but also to all members of the process as especially destructive innovations carry high risk and high investments that the involved parties cannot stem on their own. Thus, integrating research promotion funding agencies be they publicly or privately funded is a vital part in ensuring long term viability of a holistic AT provision process.
- **Enable end users to speak up:** Especially with regards to the development process, solutions that were developed through a PULL-process showed much more acceptance in the target audience. Thus one main learning was that advocates for persons with disabilities need to maintain close relations with their members and constantly investigate their current needs and requirements and specifically their "pains" (referring to the needs of a customer; (24,25)) in order to provide accurate and sophisticated information to solution developers. In contrast to that, disruptive innovations are shown

to originate from PUSH-processes way more often, which is also in line with current literature on innovation.

- **Play to the strengths of the partners:** As has been outlined above, the provision and usage of assistive technology hinges on all partners contributing their share. While established companies often can bring existing resources, know-how and networks to bear, including Start-Ups especially in the development and initial deployment phase often allows for more flexibility and quicker cycle times thus it is important to always have an open communication structure allowing new partners to connect.

Conclusion

With the establishing of a joint process along the whole product lifecycle of assistive technology solutions, we can now provide persons with disabilities in Austria with better and more focused support than ever before. Through integration of development partners, problem arising in the use of existing technologies or one that have not been solved yet can be tackled. The business partners provide availability of solutions and provide information on newly introduced products from other markets or countries. Thanks to the expert assessments and recommendations, public bodies now know, which solutions should be funded and what the appropriate costs for providing supporting measures are. With the novel regional dissemination process, we also enable persons in rural areas to keep up-to-date with current developments and provide access to state-of-the-art assistive technologies. Furthermore, thanks to our constant interaction with developers and vendors, we can provide more sophisticated training and education to our members and thus ensure that the assistive technologies are not only bought but also utilized.

The general process is designed in a way to be easily transferable to other advocacy agencies for persons with different impairments and to other countries. However, the specific systems of the respective country have to be taken into account, as especially funding is regulated quite differently throughout even the EU. With clearer and more sophisticated regulations on accessibility and the provision of assistive technology through private companies especially in the EU, the transfer of this process will also be supported and a harmonisation at least in the EU will take place.

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Improving access to assistive technologies for persons with disabilities in China: Practice, opportunities and challenges

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Abstract

China has witnessed the development of assistive technology (AT) from scratch to a significant level of activity. This paper reviews the growth in AT by considering it through four stages and we show some key data relating to these stages of growth. The current situation of China's assistive technology is also described from regulation & policy, service network, personnel, product and international exchange. Moreover, China's practice in accelerating its assistive technology growth is described in three respects: concept evolution, government's leading role and resource integration. By briefly describing opportunities and challenges for China's assistive technology, the essay shows China's firm determination in improving access to assistive technology for persons with disabilities.

Keywords

Assistive Technology, Practice

Introduction

By the end of 2018, mainland China has a population of more than 1.39 billion (1), and nearly 200 million of them are in need of assistive technology according to the criteria used by WHO in its estimation on global assistive technology demand. A survey on basic service conditions and needs, conducted by China Disabled Persons' Federation (CDPF) in 2015, showed that, more than one-third of China's 85 million persons with disabilities (2) (data of 2010) were badly in need of assistive technology. Among the older population of 249 million, aged 60 and older (1), roughly over 40 million are disabled or semi-disabled, and they also need assistive technology to improve their functions. It is reported that, the annual visits the Chinese citizens made to medical institutions have reached 8.42 billion person-times in 2018 (1), a certain proportion of these population called for assistive technology for rehabilitation. In brief, it is the huge population that indicates there's a big demand for assistive technology in China.

In the past 30 years, with the deepening of China's reform and opening up and the development of economy and society, assistive technology for disabled people in China has substantially progressed. More disabled people can go out of their homes, enjoy education

and employment, integrate into the community, and become active and contributing members of the society, with equal rights to non-disabled people (3).

In this paper, based on literature review and case studies, we describe the development of assistive technology in China, and share China's practice and experience with other countries. At the same time, we are very willing to learn more from others, so as to continuously develop China's assistive technology, and effectively improve people's access to assistive technology.

History Review

China has witnessed a rapid development of assistive technology since the founding of China Disabled Person's Federation (CDPF) in 1988, starting from scratch and becoming stronger and stronger. The development could be roughly divided into the following four stages:

1. During stage one (1949-1992), the provision of assistive products relied on the scattered supply by social and charitable organizations.
2. During stage two (1992-2007), people mainly obtained assistive products from government services and the quantity of assistive products delivered depended on the governments' functioning. Several milestones were recorded during this period: The Law of the People's Republic of China on the Protection of Persons with Disabilities was promulgated and implemented; China Assistive Devices and Technology Center for Persons with Disabilities (CADTC) was established in 1994 and centers at provincial and city levels were set up. Some projects, like the Cheung Kong New Milestone Plan on Prosthetic and Orthotic, were implemented.
3. During stage three (2007-2015), the development and provision of assistive service was driven by the promotion of people-centered values. Several important events happened: China signed and ratified the UN Convention on the Rights of Persons with Disabilities; the State Council of the People's Republic of China issued its Directives on Promoting the Cause of Persons with Disabilities; The Law of the People's Republic of China on the Protection of Persons with Disabilities was amended; the work of "establishing assistive service system" was included into the overall plan for national economic and social development.
4. During stage four (2015-present), the development and provision of assistive technology has been moving forward systematically. This period has seen China host the Global Conference on Assistive Technology Industry and the implementation of the Directives of the State Council on Accelerating the Development of Assistive Technology Industry.

Table 1. Key data shows the development of assistive technology in China (4)

	1991	2007	2017
Service Institutions	Few, 30-40	Around 1,900	Around 3,000
Manufacturers	Few, About 20	500+	1300+
Type of Assistive Products	100-200	500	10,000
Personnel for AT services	Less than 1,000	About 5,000	30,000
Proportion of persons with disabilities receiving AT services	Few	4.1%	Around 20%
Quantity of Assistive Products Delivered	Random	Planned by Governments	Based on the Needs People Applied

Current Situation

Policies related to assistive technology have been improving steadily.

Considering assistive technology's crucial role in realizing the Convention on the Rights of Persons with Disabilities (5) and the 17 global goals for sustainable development of the 2030 Agenda for Sustainable Development (6), the Chinese government has already incorporated the development of assistive technology and the provision and services of assistive technology into the national development strategies, policies, regulations, and action plans as an important part.

The Law on the Protection of Persons with Disabilities, which was issued in 1991 and amended in 2008, offers legal support to people's access to assistive technology services and China's assistive technology development. The Law prescribes that "Government departments concerned shall organize and support the research, production, supply and maintenance of rehabilitation equipment and supplementary appliances." (Article 20) and "People's governments at various levels shall provide relief and subsidy according to regulations for the basic medical care, rehabilitation services and installment and replacement of necessary assistive devices." (Article 48) (7).

Since 1996, China has been treating the provision of assistive technology for persons with disabilities as a subsector in the formulation of its each five-year plan for the development of the cause of persons with disabilities with separate development plan for assistive technology and corresponding financial arrangement.

According to incomplete statistics, some twenty documents referring to assistive technology were issued by ministries and higher-level authorities during 2016-2019. To ensure the provision of assistive devices and related services, the Chinese government issued Directives of the State Council on Accelerating the Development of Assistive Technology Industry, and the 13th Five-Year Action Plan on Promoting Assistive Products and Services. The Action Plan puts forward that by the end of 2020, 80% of people with disability certificates that need assistive technology should have access to AT. Governments also offer subsidies for poor disabled people through many projects (the central government allocates 400 million Yuan

each year) (8). Aiming at promoting the development of assistive technology, the Directives of the State Council will promote the assistive technology industry, in order to meet people's demand for assistive products (9).

Service network expands constantly to provide accessible AT services

With up to 3,000 organizations being capable of offering services, an assistive service network covering central, provincial, prefectural, county and community level has been set up by CDPF and CADTC. There are also some 2,400 AT service vans and more than 30,000 employees ready to provide services. Thanks to this network, it is possible for most people with disabilities and older people in need, including those in remote areas, to conveniently enjoy assistive technology services, such as fitting, repair and replacement, etc. The network also carries out some assistive technology service projects, like Lottery Fund for Assistive Technology, Early Rehabilitation of Children with Disabilities, Cheung Kong New Milestone Plan and Fukang Program, having benefited some 15 million disabled persons with over 30 million products fitted since 1996.

Several ways to enrich the supply of assistive products

Developing products catalogs

The Guidance Price Catalog of Basis Assistive Products of China issued in 2009, containing 318 products/services, helped to improve the market for assistive products (10). In the following year, the Basic Assistive Products List for Persons with Disabilities was published, expecting to accelerate assistive services to be integrated into social security system (11). Encouraged by the list, some local governments formulated local assistive products subsidy rules. The Assistive Products List for Work-Related Injuries published in 2012, containing 70 products, and was used to regulate the AT service for people with work-related injury (12).

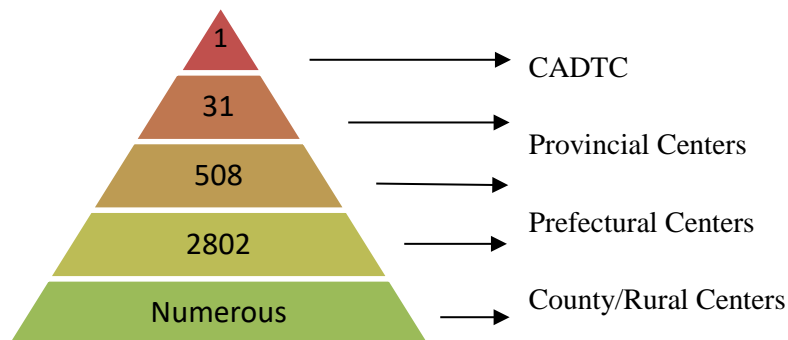
Strengthening products: Research, Development and Innovation

Ministry of Science and Technology of China launched a key program named Active Health and Scientific/Technological Response to Aging, with 7 areas of assistive technology R&D which were supported (13). CADTC leads the "Study and Pilots of Assistive Products' Assessment and Fitting System for Persons with Disabilities and Elderly People with Entire or Partial Physical Functions Decline", which calls for a total investment of 60 million Yuan. This study is expected to build a service system covering assessment, fitting and follow-up. Pilots will be set to test the outcomes and act as models. Meanwhile, attention is also paid to basic assistive products. CDPF and companies jointly conduct programs to accelerate technology transformation and popularization. 3.3 million Yuan was invested in 2018 to promote 17 products, and 4-5 million Yuan will be used for 25 products this year. Some provinces also organize R&D activities to spark innovation in the field of assistive technology. In addition, to urge enterprises, colleges, research institutions and other stakeholders to focus on innovation, CADTC has established a National Strategic Alliance on

Assistive Technology Research and Innovation. Now the Alliance has attracted as many as 22 members.

Box 1. Assistive Technology Service Network in China

Figure 1. Numbers of service institutions



Responsibilities of centers at all levels:

National center:

- Push for the formulation and implementation of national policies, regulations and action plans in terms of assistive technology;
- Organize R&D activities and promote their application;
- Disseminate assistive technology knowledge;
- Provide professional trainings;
- Test and monitor product quality;
- Conduct assistive technology service projects;
- Offer guidance to provincial centers;
- Serve persons with disabilities in its administrative regions.

Provincial centers:

- Formulate and implement policies, regulations and action plans regarding assistive technology in provinces (autonomous regions, municipalities directly under the central government);
- Carry out assistive technology services projects in provinces;
- Open assistive technology dissemination to cities in its administrative regions;
- Offer professional training;
- Mentor to city-levels centers;
- Organize R&D of basic assistive products and promote them at a large scope;
- Serve local persons with disabilities with relatively high skills.

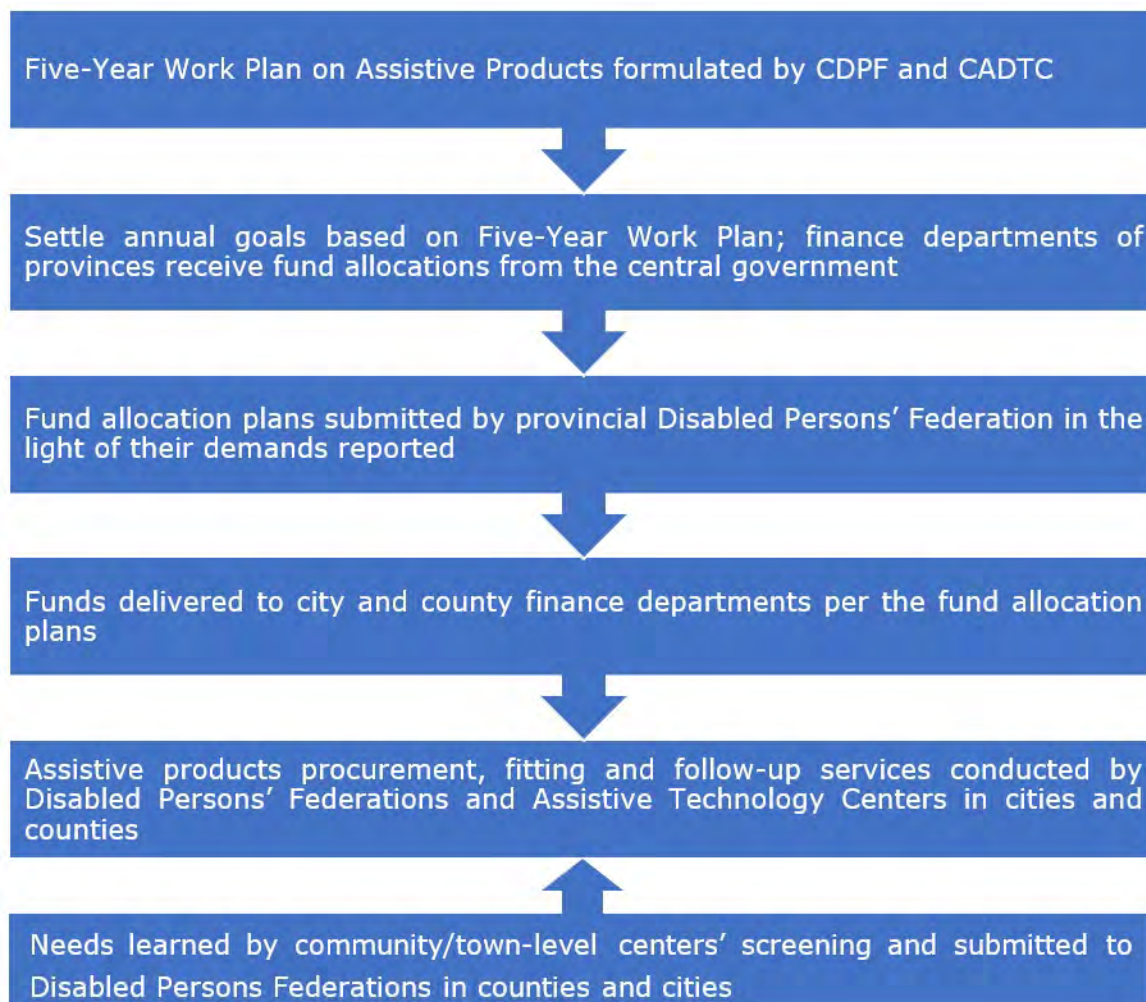
Prefectural and county/rural level centers:

- Foster the implementation of national and provincial policies, action plans, etc.;
- Provide information about policies and knowledge;
- Upgrade local workforces' knowledge and skills;
- Procure assistive products and offer fitting services for local people;
- Provide referral pathways when it is needed.

Community level centers:

- Identify needs for assistive technology services in community;
- Link the demand and supply sides;
- Offer basic repair and products lending services.

Figure 2. The operation of the system: an assistive product's journey

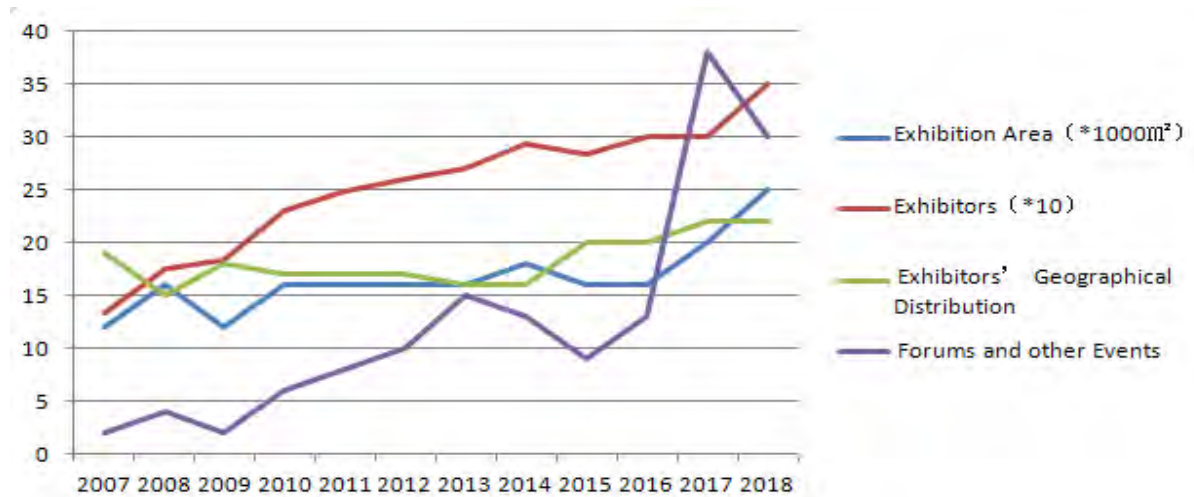


Note: This chart only describes the general procedure of assistive technology service delivery, which is a simplified version of how it often works in practice. The service process also varies depending on areas.

Promoting assistive products by holding Expo and other activities.

The Care & Rehabilitation Expo China, a yearly event hosted by CDPF, has been organized for 12 consecutive years. Last year, 350 companies with tens of thousands of products appeared at the Expo, including companies and products from abroad. It now has evolved to a high-quality demonstration and communication platform where governments, corporations, colleges, research organizations and user groups can assemble and policy, production, academic, innovation, and application can be integrated.

Figure 3. Key Data about Expo from 2007 to 2018



The capability of the service team has been continuously improved

Offering professional training for the workforce

To ensure at least one professional service personnel is available at each service unit, CADTC organizes national-level training courses for different categories of personnel, with over 2000 person-times attending these annually. Provinces and prefectures also organize their own training according to their own scope of responsibility. To popularize the advanced assistive technology concept and stimulate the workforce to update their knowledge and practical skills, CADTC also hosts professional competitions each year.

Adhere to "people-oriented" and strive to improve the AT Service quality.

The center follows the "people-oriented" service concept, formulates the assistive products fitting service flow (including primary screening, evaluation, fitting, use guidance, maintenance), and promotes it throughout the country, which effectively reduces the abandonment rate of assistive products.

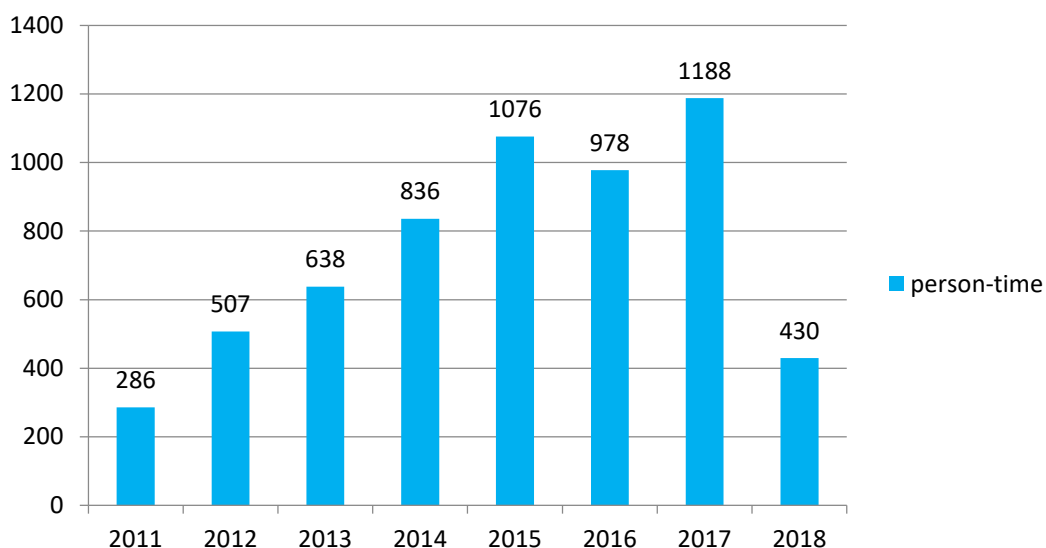
Carrying out academic education.

According to incomplete statistics, at present, there are 145 colleges and universities in China with undergraduate majors in biomedicine engineering, 5 colleges and universities with undergraduate major in prosthetic orthotic engineering, and 365 related specialties in assistive technology in higher vocational colleges and over 28,000 students enrolled in 2017. The continuous improvement of academic education will continue to transport talents for the development of assistive technologies.

Box 2. Post Capacity Building Program for workforces

To make training courses more effective, CADTC has launched Post Capacity Building Program, since 2011, aligned to trainees' professions and competence. The training is set for three levels: namely Primary level, Intermediate level and Advanced level, spanning mobility, hearing, vision, and accessible home environment transformation fields. Each level of each category has the corresponding criteria and training courses to ensure that students can master the corresponding skills through training.

Figure 4. Workforce Accepting Training Courses in Post Capacity Building Program during 2011-2018



Feedback from a trainee of Shanghai: The Post Capacity Building Program highlights three Basics: basic principle, basic assistive products and basic skills for AT fitting, which is in line with the work practice at grass-roots level. The practice part, which is designed as the core of the course, enables trainees to obtain skills for practical work. Shanghai has opened the course to community doctors and now has achieved good results.

International Exchange Increases

China has been an active promoter and a benefiter of international assistive technology communication; CDPF organized the Global Conference on Assistive Technology Industry in 2015 and 2017 respectively, creating opportunities for global dialogues. CADTC engaged in work related to the Priority Assistive Products List (APL) initialed by World Health Organization, through organizing its workforce in the CADTC system to take part in the List's global survey; through attending the consensus meeting during which the APL was finalized; and by carrying out a awareness survey of APL products throughout the country to spread the APL in China; and through trying to work out some APL product standards together with stakeholders from Germany, Sweden, the Republic of Korea and Japan. CADTC also

cooperates with neighboring countries on the upgrading of assistive technology through the implementation of the “Belt and Road” project.

These international exchanges have brought in some advanced concepts and cutting-edge technology for staff occupied in this field and for users in China. The communication has also opened up global trade to China’s products and consolidated friendships with other nations.

Some practices to share

Focusing on concept evolution and developing the legal system

Along with the understanding of the Convention of the Rights of Persons with Disabilities, the World Report on Disability, Community-Based Rehabilitation Guidelines, the 2030 Agenda for Sustainable Development and the practice in assistive technology work, China’s contribution to this field has continually upgraded in quality. This progress also gives impetus to the development of China’s assistive technology via improved laws and regulations. For example, when recognizing assistive technology’s public-good nature, efforts were made to push government to realize that it is the government’s obligation to support assistive technology services financially. As a result, the government carried out some public welfare projects and a local subsidy system was made accessible in some places. When we recognize the need for professionalism in assistive technology services, we have formulated relevant service regulations and set up standardized training courses to ensure the service meets the necessary standards. At the same time, we also actively promote academic education related to assistive technology. When it came to its systemic nature, the government published the Directives of the State Council on Accelerating the Development of Assistive Technology Industry, and the 13th Five-Year Action Plan on Promoting Assistive Products and Services, expecting to get a comprehensive enhancement in assistive technology, by dint of upgrading manufacturing and services (8, 9).

Box 3. Our systemic thinking about assistive technology (14)

Figure 5. Systemic thinking about assistive technology

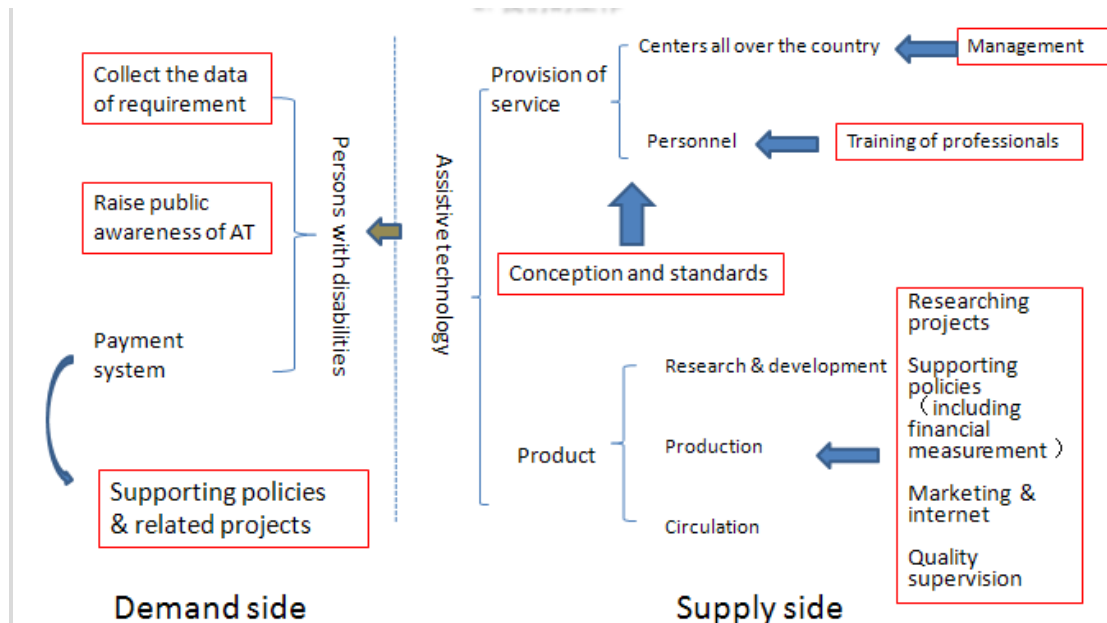


Figure 5 shows that assistive technology is an umbrella term that covers production, services delivery, polices, operational system, personnel training, R&D, financial support, data collection, etc. Therefore, to promote assistive technology, systemic thinking is required.

Considering assistive technology's systemic nature, all stakeholders should be involved when promoting assistive technology. Functions of all stakeholders should be seen in the progress:

- Government resources (policies, finance and infrastructure construction) should give guidance to other parts;
- Institutions should offer better services;
- Health organizations should gradually get involved in assistive technology sector;
- Companies, research institutes and colleges should be encouraged to take part in R&D and promotion of assistive technology;
- Assistive technology related courses should be set in colleges so as to cultivate professional workforce;
- Social sectors should be guided to take part in assistive technology service field, including offering financial support and technology transformation.

Highlighting government's leading role and stimulating social forces' participation

The government plays a crucial role in the assistive technology field:

- Formulates and implements policies, laws, regulations and action plans;

- Offer support to workforce, finance and other resources (particularly at the initial stage of establishing the service network);
- Constructs a platform for assistive technology development;
- Supports basic assistive technology services.

Disabled Persons' Federations and Assistive Technology Centers at all levels spare no efforts to make assistive technology work to be included in government work plans, giving great power to its development. For instance,, "Opinions on Promoting the Cause of Persons with Disabilities" jointly published by the Central Committee of the Communist Party of China and the State Council, boosts government investment in assistive technology programs and the number of people obtaining services has climbed (Figures 6 and 7). In addition to government initiatives, other social initiatives cannot be neglected: the Cheung Kong New Milestone Plan, sponsored by Mr. Li Ka-shing, has attracted government allocations and fitted prosthetics for 170 thousand people. It also played a significant role in establishing national service networks.

Figure 6. Projects investment from 2006 to 2015

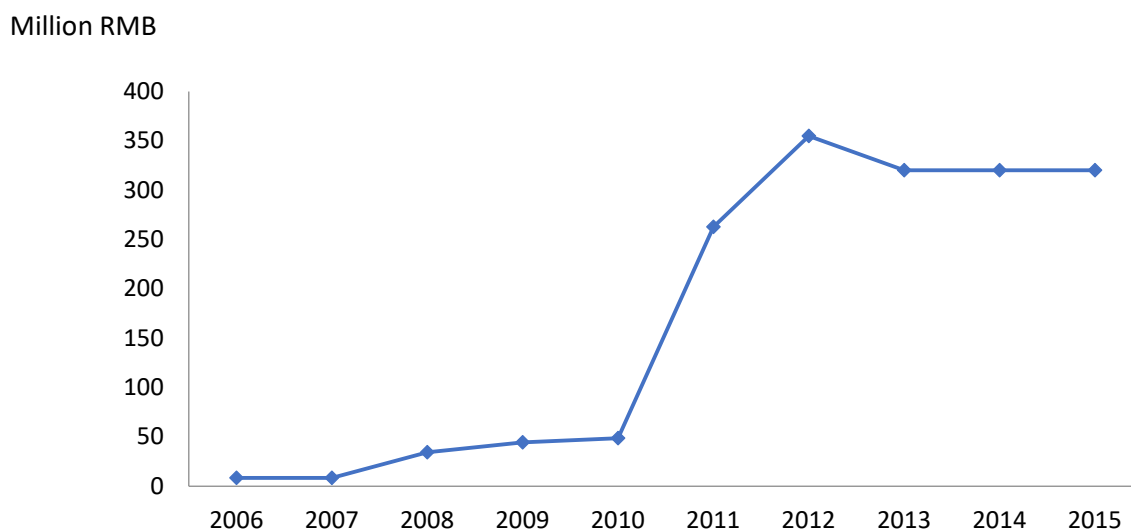
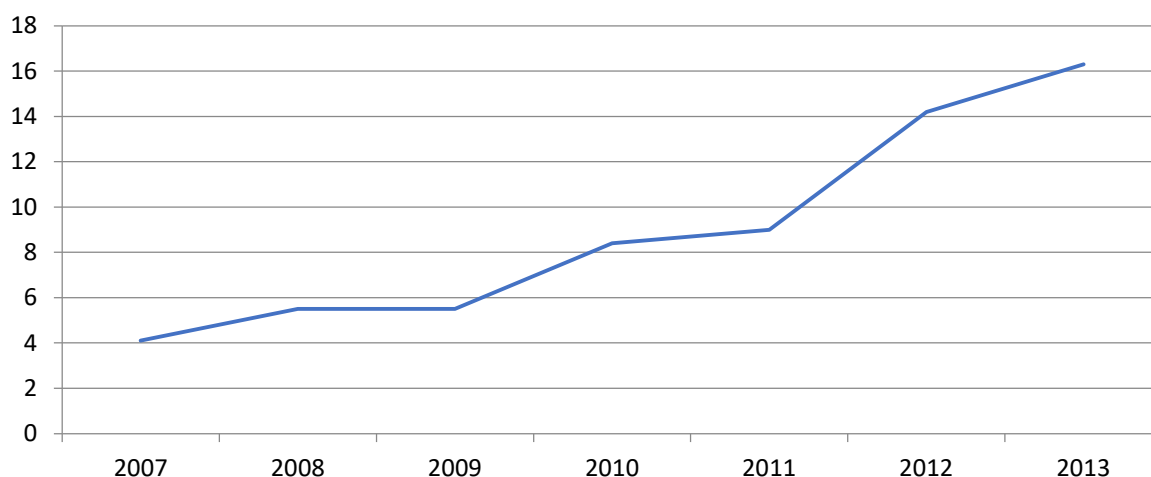


Figure 7. Changes in Fitting Rate during 2007-2013 (%)



Matching resources and implementing programs

To keep the assistive technology system operating healthily, assistive technology centers at all levels should gather and match resources from every aspect: government resources should be matched to that of the market; service resources should be linked with services demanders. In addition, a platform should be created to provide opportunities to resource integration. Taking the assistive technology Expo as an example, it is a good place to display products and to trade; as communication and outcome sharing are synchronized. As time goes by, government-owned organizations' roles will change. A state-owned institution may be a service provider when local assistive technology is still in its early stage, and it may transform into more of an administrative one, with more non-state service suppliers emerging.

Designing and adopting projects is an efficient way to match resources. Programs vary at different periods depending on people's needs and development trends. For example, assistive technology institutes have obtained equipment through projects for capacity building of organizations; workforces' quality has been upgraded via personnel training programs; institutions have performed their responsibilities and technicians have practiced their skills continuously, by carrying out assistive technology service projects for poorer disabled persons with disabilities. In view of the limited reach of some service organizations, we have also implemented mobile vans as an important part of service configuration, so that the disabled in remote areas can have access to assistive services.

Challenges, Opportunities and Moving Forward

Challenges that China is encountering

Low social awareness and participation: To learn about people's awareness about APL products, CADTC conducted a survey in China. It showed that nearly 300 persons among the total 1200 participants did not have a clear understanding of the use of crutches.

Immature insurance system: most disabled persons are in poor economic conditions and cannot afford assistive products. The fact that national subsidy system is still to be developed hinders people's access to assistive products to some degree.

Service network should reach out to community: there were 34,652 community health service centers in China by the end of 2017. It is a big task for both CDPF and CADTC to have assistive technology service included in these centers.

Slow development in standardization of products and services: It is undeniable that there is still a way to go before realizing standard management in service qualification, service evaluation and training systems. The slow pace of this progress has affected the development of the whole industry, as well as persons with disabilities' satisfaction.

Three Opportunities

Opportunity from China's growth: a mature payment system is under way along with the establishment of national security protection system. And the assistive service network is moving forward due to the Health China Action plan (2019-2030).

Opportunity from technology innovation: the enriching types and better quality of assistive products, due to the application of new materials and technology, will enable needs to be met more effectively; the interaction between assistive technology and big data, Internet plus and the Internet of Things, will contribute to the delivery of products and services.

Opportunity from international exchanges: the GATE Initiative gives impetus to global communications covering concepts, technology and other areas that will improve access to assistive technology. China takes parts in it and will learn from it.

Outlook

CADTC will continuously upgrade its work, concepts and integrate resources to advocate for progress in assistive technology, to ultimately meet the needs of people with disability in China; based on the 9 requirements that are stated in the "Resolution on Improving access to assistive technology" (15). At the same time, the world will also recognize China's contribution to improving access to assistive technology globally, as well as to realizing the goals of 2030 Sustainable Development and Universal Health Coverage.

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The **GATE** Initiative