

(In)Visibility in Disability and Assistive Technology

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In this article, we present a meta-analysis of research examining visibility of disability. In interrogating the issue of visibility and invisibility in the design of assistive technologies, we open a discussion about how perceptions surrounding disability can be probed through an examination of visibility and how these tensions do, and perhaps should, influence assistive technology design and research.

CCS Concepts: • **Human-Centered Computing** → **Accessibility** → **Accessibility Design and Evaluation of Methods**;

Additional Key Words and Phrases: Assistive technology design, assistive technology evaluation, invisible disability, hidden disability, stigma, social interactions, identity

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1 INTRODUCTION

Disability is universal and “the one identity category that all people will embody if they live long enough” [8, 26]. The social construction surrounding the lived physical and cognitive experiences of people with disabilities are in flux, meaning that everyone will experience disability at some point and almost no one will experience it in the same way. Assistive technology researchers have considered this kind of variability in multiple contexts. One notable example of explorations into the flux of disability in recent research can be found in the movement to support “independent living” [12] and “aging in place” [54]. Additionally, there has been a recent but growing trend in design and research communities emphasizing the need to understand populations with differing abilities as part of cultures [13]. This concept emphasizes the need to consider cultural contexts of disabilities, given that how disabilities are perceived, performed, and acted on are all distinctly and indelibly linked to their surrounding historical and social contexts. However, one area of flux that has not been discussed at length within the community is the spectrum of visibility of a disability.

This visibility spectrum can be thought of most easily in terms of its two extremes and how those with disabilities might lay somewhere between them; those with disabilities that are highly visible, or immediately apparent to the outside observer, lie on one end of the spectrum and those with disabilities that might be called “invisible” or “hidden” occupy the other. The former case is more commonly considered by the general public; those with paralysis of a major extremity or individuals who have had an amputation, for example, are immediately recognizable as disabled

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Fig. 1. Woman with heart condition wearing a chest-worn heart monitoring device. The device protrudes from the chest and is visible through most clothing.

individuals and thus are said to be *visibly* disabled. However, people with chronic illness, such as severe migraines, heart conditions, autism, or chronic fatigue, may be substantially impacted by their symptoms, at times to the point of incapacitation, but in ways that others cannot easily observe or recognize. The public, family and friends of the disabled individual [7], and even physicians [3, 7, 49] may not be cognizant of their plight. This lack of awareness and legibility to others leads to the label of *invisible* disabilities for those with these or similar conditions. Such disabilities encompass a large variety of conditions including psychosocial disabilities, internal conditions (e.g., heart conditions), chronic pain, deafness, visual impairment, developmental disorders, and mobility disorders that are not apparent to others.

Assistive technology has its own spectrum of visibility with nearly invisible hearing aids at one end of that spectrum and the wheelchair at the other. At times, it is the visibility of the assistive device that a disabled individual uses that betrays their condition and makes visible an invisible disability. A heart condition, for example, is often not visible but may be made so when the person with the heart condition uses a chest-worn heart monitor (Figure 1).

For this reason, assistive technologies have an important role to play not only in augmenting human abilities, but also in hiding and showing disabilities. In an attempt to examine the complicated interplay among these roles, we examine the varying mechanisms and capabilities of making legible disabilities to others with an explicit eye towards the ways in which vast and varied technological artifacts play into these experiences. In other words, what does it mean for the experience of disability when the visibility of the disability and its supports are in conflict? What do the concepts of variability, visibility, disability, and disclosure have in common and in what ways are they in tension? How might designers and assistive technology researchers better engage these concepts in their work?

In this article, we present a meta-analysis of research conducted in our lab as well as across the extant literature to explore how the fluctuating and inevitable nature of disability might—and perhaps should—influence assistive technology design. In particular, we interrogate the issue of (in)visibility in the design of assistive technologies. By considering the case of invisible conditions and the strategies used by individuals to navigate this complex space, we open a discussion within the assistive tech design and research community about the work current assistive technology designs accomplish and what challenges remain.

2 METHODS

In this analysis, we build on 10 years of our own research on assistive technologies and an examination of the published literature. Specifically, we conducted a meta-analysis of data collected from

three studies in our lab. These studies were chosen because they all include people whose disabilities are variable and frequently invisible. Additionally, they represent both children and adults and both people with lifetime disabilities and those brought on by chronic illness. To fill in gaps left by the analysis of our own work, we additionally conducted a structured review of the existing research literature. In this section, we describe the three original studies and the data we extracted from them as well as our approach to meta-analysis of published work of other researchers.

2.1 Empirical Sample

The sample for this study includes empirical data from three research projects, covering a variety of challenges related to disability and assistive technology. For this analysis, we first collected data from these three extant datasets. In this section, we describe briefly the methods used to collect the original data as well as characterize the existing data.

Data from our previous studies included in this article span more than 10 years of assistive technology research. These works include participants with multiple disabilities and chronic illnesses and were intentionally chosen from a larger body of work to cross a variety of spaces of visibility—both in terms of disability experiences and assistive technology design. These studies were not conducted initially with this review in mind. Rather, these studies were selected for analysis because, while these studies were initially conducted for very different purposes and using differing methods, a similar theme surrounding issues of visibility in assistive technology arose from each of them. In this section, we describe these studies and how these data were collected from and about them.

2.1.1 Autcraft Users. Autcraft is a semi-private server on Minecraft that was created for children with autism and their allies [55]. Autcraft currently has more than 7000 white-listed members with a daily average of approximately 50 players in-world at peak hours of the day.

Ringland collected approximately 150 hours of immersive in-game observations, including participating in activities on the server, recording chat-based dialogue, and field notes on everyday practices and events as they occurred in the virtual world over a 2-year period. This work employed methods established by other studies of virtual world communities [4]. As Autcraft is a semi-private server, we gained access to Autcraft via permission of the server’s creator for the purposes of this study. The researcher’s presence and purpose was made clear to the community through both the Autcraft web-based forum as well as in the in-game chat. In addition, focus groups were created informally on the forums through forum posts prompts, wherein the community was asked open-ended questions. A variety of digital artifacts were collected from the various platforms used by the community. Data collected include approximately 5,000 forum threads and 150 blog posts created by players, parents, and administrators [34, 35, 36]. In this meta-analysis, we examined chat logs, forum posts, and interview transcripts.

2.1.2 Secondary Stakeholders of Recording Technologies. To study how people might react to a device that automatically records still images on a frequent basis—the SenseCam [29]—Hayes worked with a large research team to collect empirical evidence of preferences and concerns. This study used the paratyping method, which is a combination of event-contingent experience sampling and in-depth interviews [16, 29]. A paratype is “a simulation of interaction with a technology, which is evaluated alongside real-world experiences” [16].

In this study, 19 individuals in four countries acted as proxy users of the SenseCam, creating the experiences with the technology on which feedback was desired. The proxies first described SenseCam and the research by following a short pre-defined script. They then handed the participants written information about the study attached to an anonymous survey form to be completed privately. The proxies completed short questionnaires about the encounters, also in private.

Rather than focus on SenseCam for any one purpose, survey recipients were asked to react to the specific person handing them the survey in the current situation. The research team then conducted in-depth follow-up interviews with a subset of survey respondents ($n = 15$, 9 women).

While this study was not conducted with the intent of focusing on the topic of disability, participants in the study brought this topic up during the interviews. In this meta-analysis, we examined the interview transcripts and have included those discussions surrounding disability which emerged during these interviews.

2.1.3 Chronic Cancer Patients and Their Caregivers. To understand the specific needs of *chronic* cancer patients, as opposed to acute, Hayes led an exploratory, qualitative research study that used participant and direct observation [15], collected artifacts related to cancer, and in-depth interviews over a period of 18 weeks.

Twenty-one people participated in interviews either in person ($n = 14$) or by phone ($n = 7$). The interviews lasted 1 to 2 hours each. Participants included seven patients and survivors, four medical professionals, four social workers, one hospital health data manager, one home health manager, and four family members. All patients and survivors had been diagnosed with cancer at least 2 years before the interview, and some as long as 7 years.

When in person, interviews were conducted at a place of the participant's choosing, usually homes or offices. One patient asked that the interview take place during her chemotherapy treatment. The interviews were open ended and conversational in nature by design to uncover those issues most significant to the participants. They typically occurred as one-on-one sessions, but in one case, two social workers and the director of hospice care participated as a small group. Only the interview transcripts were available for this meta-analysis, the other data having been destroyed.

2.2 Literature Sample

To supplement our meta-analysis and provide additional insight, we conducted a structured literature review. We began with collecting articles from various fields examining the roles of assistive technologies from venues including the Conference on Human Factors in Computing Systems (CHI), the Conference on Computer-Supported Cooperative work and Social Computing (CSCW), the International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp), the ACM Transactions on Accessible Computing (TACCESS), and the ACM SIGACCESS Conference on Computers and Accessibility (ASSETS). We collected research from these venues spanning from 2012 to 2016, giving a picture of assistive technology research in the past 5 years. This time span was selected in an effort to both examine and identify recent trends in this field while maintaining a reasonable scope. The selected articles were included in our analysis if the title, abstract, or keywords indicated that the article would be examining issues of disability or chronic illnesses as they relate to assistive technologies. Because authors may use a wide range of ways to refer to these topics, we did not use an automated method for selection. Instead, the first and second authors read the abstract, title, and keywords of each article to determine if they fit the criteria (apparently related to disability/AT). With this, we identified 374 articles that fit our criteria, with 136 from ASSETS, 132 from CHI, 32 from CSCW, 29 from UbiComp, and 45 from TACCESS. We then read each article and analyzed each alongside each other and with our own data to identify patterns and summarize key findings as presented in this article.

2.3 Analysis

Given the themes that emerged from our three empirical studies regarding visibility of disability and/or assistive technology, we paid particular attention to how these themes were discussed in this sample. We used an immersion-crystallization approach to analyze data, meaning that we approached data without *a priori* hypotheses in mind but rather with the aim of identifying emergent

findings [6] with a general topic lens of visibility and how it emerges, impacts, and is discussed in assistive technology research. Again, given that authors do not always use words like “visibility” or related terms like “stigma” explicitly, this analysis was done by the authors without any automated processes. As each study was unique and not conducted with the goal of a combined analysis, we engaged in this process for each case as well as collectively. We started by analyzing the documents and information we had about each study to identify how visible the disabilities addressed in the work are and how visible the related assistive technology was. Each of these was analyzed in light of the context of the time in which the study was conducted, because visibility of particular technologies has changed over time since these works were completed. We conducted a cross-case comparison to identify patterns and variations across the studies included in this analysis. While not all works included discuss visibility specifically, they often still included participants with disabilities of different visibilities. As such, these works were considered in the analysis though their content may not be explicitly included. In this work, we discuss the themes that emerged from this analysis with an eye toward the role and impact of visibility in disability and assistive technology research.

3 RESULTS

Across the assistive technology design and research space, topics of visibility often focus on stigma created by the use of assistive devices, strategies used by those facing such stigmas, and implications for design given this knowledge. Of our dataset, 62 articles, or ~17%, mention the word “stigma” directly. In these cases, stigma is thought to stem directly from the visible qualities of assistive devices. This focus is in contrast to the themes of work that focus on invisible disability that bring up issues of misperception [3, 22, 44] and lack of awareness [22, 41, 44, 46] that stem from disabilities being invisible. Throughout these sections, we explore these differences and the complex interplay surrounding (in)visibility and unpack the potential consequences of showing and hiding disabilities and assistive devices. Finally, we engage in a discussion of how and why devices both can and should be explicitly designed with this interplay in mind.

3.1 Stigma

How visible one’s disability is to others may depend on multiple factors. For some, such as in the case of amputation, their disability may always be apparent to others. In some cases, a disability may be more apparent because the disabled individual is experiencing visible symptoms at that time, such as a child experiencing an asthma attack. However, one aspect of visibility of disability that has been of particular interest to assistive technology researchers and designers is how visible assistive technologies impact how apparent the disability is to others and what the form and function of the devices conveys about the user to the outside world.

Just as clothing may influence how an individual is perceived [24], so, too, can observable assistive technologies. As Shinohara and Wobbrock write, “There persists a notion that ‘you are who you are perceived to be’ and that perception can be influenced by what you use” [41]. Apparent assistive technologies can communicate a myriad of messages to outside observers, and these messages may be interpreted multiple ways. For example, in their recent work examining the perceptions of visible assistive technologies in public and social spaces and in working with student designers creating such assistive technologies, Shinohara et al. found that non-disabled observers and designers often “othered” those with disabilities. This “otheredness” manifested in multiple ways, most notably in those without disabilities either pitying those with disabilities and being unsure of how to interact. Often observers without disabilities were unsure of what a device’s function was and how it worked, leading them to ask questions about the device. These questions, while sometimes welcomed, have been described several times through the literature as being a factor of informant fatigue, in which the disabled individual feels as though the focus of the conversation

is always on their devices rather than on them as a person [41]. For example, in our work with SenseCam [29], some participants noted that devices used “for a medical condition” are not subject to polite questioning, “because maybe they don’t want to talk about [their disability].” While this participant felt it would be inappropriate to ask questions of someone using an assistive technology, research indicates that this kind of exposure as a form of disclosure is not unheard of. As Davis writes: “Those whose disabilities are invisible may be pressed to reveal the sort of details about their personal medical history that most of us regard as private, and as humiliating to expose. [7]”

Assistive technology stigma can threaten one’s livelihood, because those with invisible conditions may fear losing their jobs from exposure through their use of assistive devices or face job barriers that able-bodied applicants may not face [7, 25, 39, 40]. This may be of great-enough concern to the disabled individual that they may abandon health and assistive technologies that carry stigma and/or unwanted attention. This technology abandonment may also occur when the assistive technology threatens how the users view themselves [7, 21, 41, 48]. Toscos et al., for example, found that negative associations with health care technologies may be made by those with Type I diabetes (an invisible condition) and that these negative associations may lead to abandonment of these technologies [48]. Similar findings have been reported in designs and evaluations of technologies for individuals with other invisible conditions. For example, in their 2011 study, Shinohara and Wobbrock found that those in their study who had invisible conditions prominently grappled with choices between self-consciousness and utility, concluding that assistive devices should “strive to be designed for social acceptability” [40].

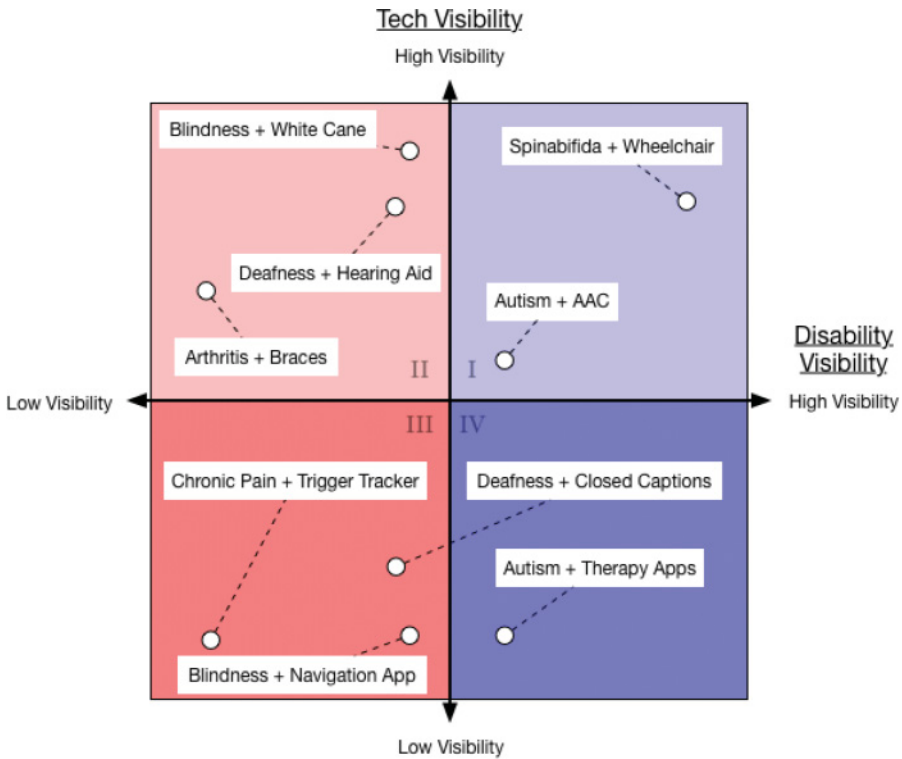
These negative perceptions of what it means to be disabled or ill can be both internal and external and deal with the complex issue of identity preservation around disability. Externally imposed disability identities may stigmatize those with disabilities as being incapable, or even stereotypically unkempt, and unfashionable [8, 27, 38, 47]. Assistive technologies that then serve as markers for disability or reinforce stereotypes through unfashionable and out-of-date designs, may then expose the disabled or ill person to a stigmatized identity that they do not identify with. Importantly, when an assistive technology draws negative attention to a disability or illness through its visibility, the technology is abandoned [7, 21, 40, 41].

Shinohara finds that these negative experiences arise when there is a breakdown associated with the device (meaning the device did not function as intended, or it functioned properly, but its mere presence was distracting, inappropriate, or embarrassing such that it highlighted inequalities). Participants were very cognizant of how their device’s appearance, in particular when their devices looked “weird” and “awkward” to those not familiar with assistive technologies [40, 41]. Stigma is a common result of such breakdowns. This demonstrates that stigma does not always manifest from the disability itself. This indicates that dual roles of stigma exist: disability stigma, and assistive technology stigma (Figure 2). Because disability is dynamic, so, too, is assistive technology use, thus impacting how visible disability is. How stigma impacts those with disabilities will vary greatly depending on where in the visibility spectrum (Figure 2) they land at any given time.

These risks are most often discussed in assistive technology literature as arguments for making devices as invisible as possible. However, as we discuss in the following sections, by examining the literature surrounding invisible conditions we find that the same technologies that are seen as *stigmatizing* to some may be seen as *functionally empowering* and *socially empowering* to others.

3.2 The Work of Visibility for Assistive Devices

Because assistive technologies are often visible, they may be the only means an observer would have to know whether a person is disabled. Use of a wheelchair for someone with rheumatoid arthritis who may walk at other times acts as a visual indicator that the individual has a disability. Similarly, use of electronic devices for augmentative and alternative communication can serve as



Quadrant	
I	Tech + disability stigma, credibility, awareness
II	Tech stigma, credibility, awareness
III	No stigma, lack credibility, low awareness
IV	Disability stigma, high disability credibility, low tech credibility

Fig. 2. Tech/Disability Visibility chart and its effects. This chart is simply meant to act as a way of thinking about how tech visibility and disability visibility at any given time. Individuals could move along these spectrums.

an indicator that a person is in need of that assistance. By using, hiding, or discontinuing the use of these technologies, an individual can make their disability more or less visible. Because invisible conditions are not readily apparent, many with such conditions struggle with issues of disbelief, minimization, denial, and illegitimacy [22, 38, 41, 44, 46, 49]. Apparent assistive devices that communicate one’s disability status may then be a source of legitimacy to those who otherwise may have no outward evidence of their condition. As Felipe et al. [9] write in *Roles for Personal Informatics in Chronic Pain*:

[Chronic Pain] is an invisible condition and the distress caused by it may not be obvious to even close ones... Some participants felt that their condition is disbelieved or minimized, even by healthcare professionals who they turn to for help... In these cases,

[Personal Informatics Systems] could be used to gather and provide physical evidence of pain, so others would be more understanding. This desire for trust and support also extended to general others (in addition to family, friends and healthcare providers) to address situations such as having to ask for a seat on a train when pain increased

Similarly, MacLeod et al. [22] write that this can be compounded when the condition is rare, with one participant reporting,

There's nothing to see. Nobody's ever heard of [my disorder]. I mean, if I said I had Multiple Sclerosis everybody would know what I was talking about and they would know what to expect... It's not obvious that there is anything wrong with me at all. So I think that some people think that maybe I'm putting them on a bit.

Because challenges with disbelief, minimization, denial, and legitimacy arise when a disability is invisible, assistive devices may be used as a means of mitigating these effects. Samules, for example, described how people might use visible devices, such as a cane, to “empower” themselves to get the accommodations they need when their needs might otherwise not be visible [38]. The visibility of the assistive technology affords credibility, allowing the user to communicate their needs without words.

This visibility might not only serve to legitimize a person’s condition but also legitimize the use of the device itself. For example, in our study of a photo-based memory aid for people with cognitive disabilities [29], one participant noted that she would agree to use of the data if she knew it were “for a memory issue” but without such confirmation would be “weirded out” and would not “automatically” attribute the device to a health-related use. Another participant described wanting to hide the device to avoid “provok[ing] anybody.” Yet another participant in this same study went so far as to suggest that the device should have “a little handicap sign, like the little chair or maybe there should be a universal handicap sign for mental [sic]... There has to be some kind of sign that is universal.” This suggestion of having a visible sign on the device that is was being used for assistive purposes was given as a suggestion to make the technology’s use and the disability of the user more visible, thus legitimizing the use of an otherwise controversial piece of technology as an assistive, and therefore necessary, device. More recently, in this regard, Profita et al. found that when onlookers perceived users of otherwise controversial technologies (e.g., Google Glass) to have disabilities, they were more accepting of these devices. They termed this phenomenon, the “AT [Assistive Technology] Effect” [29]. Although designers have by and large not spent significant time considering the potential uses for such an effect, people with disabilities themselves are well aware of this challenge. Additionally, this work echoes what is seen in the literature around chronic pain, with participants describing the need to signal to others that they have a legitimate disability [3, 10, 49].

Additionally, visible devices may serve as a reminder that an individual has a condition for those who may have been informed of the condition but are not cognizant of it without the presence of a visible indicator of the illness or condition. Awareness of an illness or disability can wane with time when that condition is not visible. Without knowing it, people surrounding someone with a chronic illness may not be sensitive to the ongoing physical and emotional pain the disabled or ill individual may feel. For example, in our study of chronic cancer patients [15], a stable metastatic breast and bone cancer survivor explained to us that people around her often do not understand why she struggles to celebrate her “stable” prognosis noting that “*You never really beat it. It's always sort of hovering over your head once you've got it, but people don't see it that way.*” Similarly, a cancer survivor who had been 3 years with no evidence of disease (as close to “cured” as oncologists will say in most cases) noted that, “*Once you have it, the age of innocence is over. You*

feel vulnerable the rest of your life...” With this kind of anxiety, every bump or bruise raises fears that the cancer will recur. However, without visible indicators of cancer (e.g., hair and weight loss) acting as reminders, the support network built up during an acute phase may slip away. Similarly, those close to someone with a chronic illness may have unreasonable expectations for them when their health or disability status has been forgotten [3, 15, 22, 38]. For example, working with stroke victims, Stone described how people, even loved ones, might need continual reminders of a stroke patient’s disabilities because her disabilities were not visible and were therefore often forgotten [43]. When users wish to ensure their invisible disabilities are visible, pervasive health technologies can serve as a means of making the disability or illness visible and, as a result, less forgettable. That is to say, for the outside observer, the visibility of the device removes much of the responsibility for recalling a person’s health status. In this way, visibility of a disability may serve as a kind of protective reminder for those around the disabled individual.

As previously discussed, the ability to remain discreet can allow some people to feel secure in their daily lives, because the revelation that they are disabled comes with the fear of losing a job or facing barriers to employment that an able-bodied person may not have to face. On the other hand, however, people with invisible disabilities who choose not to disclose through visibility must live with the risk of the moral judgment of others who perceive them to be taking benefits they are not due. For example, Faucett was once scolded and called lazy by another person for using the disability access button to open a heavy door because her recent shoulder dislocation injury was not visible. A more extreme version of this is detailed by Davis as the “handicapped parking space challenge,” in which an individual with an invisible disability is questioned by “vigilante” citizens assuming the invisibly disabled person is “cheating” as they appear to be able-bodied, despite their need being made clear by use of a handicapped placard [7].

In *Fantasies of Identification*, Samuels describes a website through which people could report those who they thought were taking advantage of services for disabled people. Evidence used to support claims of misrepresentation included the supposed “frauds” being too young, healthy looking, attractive, athletic, or fashionable to be disabled [38]. Some even wrote about those using services for disabled people holding babies and toddlers raised their suspicions as to whether they were in need of such services or disabled at all. Samuels writes that this reflects “widespread assumptions about the ability of disabled people to bare or care for children” [38]. There is a wide array of perceptions of disability identity, many of which envision those with disabilities as a vulnerable or incapable population in need of protection [27, 38, 47]. Such perceptions of disability identity can lead well-meaning individuals to thinking that those with physical disabilities are then incapable of living active lives.

Similar reactions can occur when an assistive device is used in an unexpected way [31]. For instance, when the first author, who has a mobility disability and at times requires a wheelchair, once stood and walked after using a wheelchair, a nearby observer accused her of faking her disability and joked that her standing was “a miracle,” implying a perception of wheelchair users as being incapable of standing. Benjamin *et al.* explains further that this may lead to withdrawal from social interactions for fear of being labeled a malingerer [3]. Here, the individual may decide that the risk of exposure to others’ judgement is too great and, as a result, opt out of using the parking spot or other resource that is lawfully theirs to use [3, 7, 38]. It is the lack of obvious and visible indicators that the individual is disabled, injured, or sick that leads to a breakdown in communication here. The risk of being “outed” as disabled is in direct battle with the risk of being judged—and perhaps acted against—for perceived morally reprehensible behavior. In some cases, having an illness or disability that is highly visible can be advantageous or even necessary. Thus, people sometimes must actively strategize to make a condition visible to others. Certainly, people with disabilities weigh the “cost and benefit associated with sharing, revealing, or transmitting

information” using their assistive devices [3, 38, 40]. There is a “utilitarian” view of device use that encourages anyone with a disability to use the devices to be “efficient” while working towards an acceptable level of public “notice.” However, this is no standard cost-benefit analysis but rather a series of considerations fraught with moral judgment by and of people with disabilities.

3.3 Strategies for Visibility Management

The risk of being visible or invisible changes continually based on a variety of contextual concerns. The relatively static nature of the visibility of assistive technologies (they can be seen or not seen and/or used or not used) and the relatively dynamic nature of visibility and its surrounding social phenomena makes for a challenging situation for users. This effect is so pronounced that individuals may frequently sacrifice their own personal health and well-being at times when the risks to their self-perception and livelihood [7, 21, 45] become too great.

Managing levels of visibility, often in service of a particular sense of identity, can be complex in social settings, even in the relative comfort and safety of one’s own home [3]. For example, people might hide visible indicators of illness (e.g., medications, assistive devices) to “avoid patient status” [7, 38, 48]. Avoiding patient status through hiding visible technological indicators of illness may then act as not only a way to make a condition invisible to those around them but also to the individual themselves. For example, people might misuse or avoid use of blood glucose monitoring technologies that make them feel badly about themselves or remind them of their diabetes [48].

The ability to conceal devices, medications, and so on enables individuals to control disclosure of their disability in an attempt to maintain their confidentiality and maintain their social and internal identities. However, concealment does not necessarily mean literally hidden from view. Assistive technologies, in particular, may be hidden in plain sight through the use of off-the-shelf technologies that have a variety of uses. Indeed, researchers have suggested making devices attractive to draw attention in a positive way or “mainstream” to blend in with the general population [2, 5, 14, 17, 20, 23, 28, 31, 33, 37, 41, 45, 50, 51, 53]. For example, Cochrane and Schiphorst suggest that due to the social stigmas associated with mental health that “it is important to design health technology that is unobtrusive, invisible, fashionable, and comfortable” [5]. Likewise, Shinohara and Wobbrock note that in an empirical study of assistive technology use in social interactions, assistive technologies were often seen as solely for disabled users, and mainstream devices, in contrast, as not necessarily being assistive [40, 41]. This idea is pervasive. In fact, the British Standards Institute [18] defines what they call Inclusive Design as

“the design of mainstream products and/or services that are accessible to, and usable by, people with the widest range of abilities within the widest range of situations without the need for special adaptation or design.”

Although the authors and designers whose work we have evaluated in this study do not go quite this far in their reasoning, this kind of attribution could ultimately lend a sort of stigma to a device itself even if it were to be useful to a variety of people, with and without disabilities. For example, in our study of Minecraft, a widely popular computer game, we found that this mainstream game is being used in assistive ways [34, 35, 36]. While on the surface, children with autism are simply engaging in play on Minecraft as a leisure activity, parents of the Autcraft community are modifying both the technology itself to be supportive and assistive, as well as how the children engage in the play. This combined effort of social intervention along with modifying a mainstream video game to be assistive technology allows the children playing in Autcraft to participate in social play—an important part of childhood development. Due to the nature of mainstream video games, many parents and teachers may at first disregard the assistive aspects of Minecraft, instead just seeing it simply as a video game with little redeeming qualities beyond its entertainment value [52].

However, work in Autcraft shows that this community has found value in appropriating this mainstream technology as an assistive platform for their socialization and sensory needs. This reaction to seeing mainstream devices as non-assistive can have broad-reaching impacts. In *Giving Voice: Mobile Communication, Disability, and Inequality*, for example, Alper writes that insurance companies are resistant to funding augmentative and alternative communication devices for children with speech disabilities when they use a mainstream device such as a tablet [1]. Alper continues, noting that Medicare's stated explanation for denial of funding such devices is that tablets "... 'are useful in the absence of an illness or injury' ... and thus cannot be classified as durable medical equipment" [1]. This is of major concern to the research community. In the event that we should see our research leave the "research" stage and be implemented in actuality, it is important to note the potential consequences of mainstreaming. While one motivation of mainstreaming may be to mitigate costs, those costs may be passed on to the user in other ways, such as having to pay for the device and application out of pocket when a claim is denied for being on a mainstream device.

Mainstreaming is also seen as a potential solution to stigma as a means of making the device less visible and, it is thought, less potentially stigmatizing. However, those with invisible disabilities may opt to make their disabilities more visible to make their needs more obvious or to be seen as legitimately disabled by playing into people's expectations about what disability "looks like." People perform their disabilities through what Siebers calls "masquerades," which can draw attention to their challenges, impairments, and diagnoses by conforming to stereotypical expectations of what it means to be disabled, such as exaggerating a limp or carrying assistive devices they may not need at the moment [42] or in the case above by keeping detailed records of past experiences. Without such documentation, others have encouraged people when applying for benefits or services to adhere to stereotypical expectations of disability, as eloquently described in the memoir of a woman with a hearing impairment:

I dressed in the drabest clothes I could dig out of my closet... I didn't gel my hair up but let it adhere, naturally, flatly to my skull. I left my contacts in their case, my funky glasses by the bedside, and dug up the ghost of three prescriptions past—a hoot-owl-shaped pair with finger-thick lenses I didn't bother to clean, thinking the scratches and smudges would add to the overall effect... I did feel a residual bit of shame. But I needed those hearing aids. That's how I thought I needed to act to get them. And that's how I got them

—Terry Galloway [11] as quoted in Samuels [38].

Assistive devices, then, are also a way in which those who need them communicate with the world. In the example above, Terry Galloway performs her disability in such a way that makes it not only more visible but also more acceptable by meeting perceived expectations. She discloses her disability through this performance to gain access to the assistive devices she needs. In this case, as with many others, disclosure of one's disability is desired and even necessary. In some cases, the visibility of the device itself is the only means an individual has to gain access to the assistance they need.

For example, in fieldwork with families coping with autism, one mother kept nearly 100 large binders of paperwork to demonstrate that her child, who no longer tested as though he had autism, still needed services and had in fact had several diagnoses and recommendations for services over the years [19]. Policies and norms around use of health supports can make this kind of discursive practice challenging. For example, in our prior work with families coping with asthma, we found that school policies prohibiting students from carrying their own medication can make self-care and alerting people to the condition challenging. Thus, parents would have lengthy discussions with school staff regarding their children's needs. For example, one mother

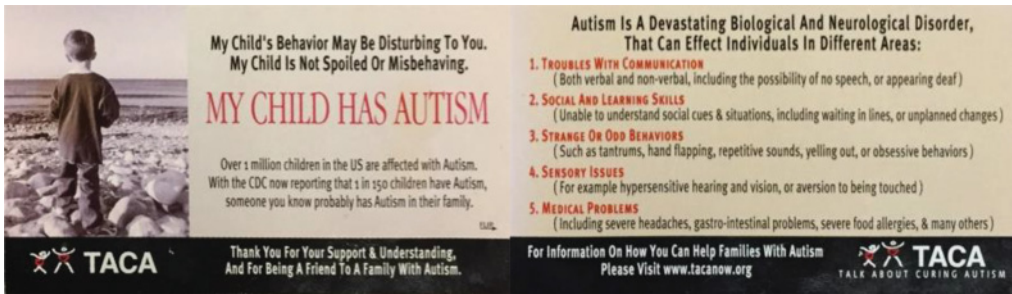


Fig. 3. Business cards parents of children with autism would hand out to explain their child's behaviors to others.

described talking regularly with her child's sports team coach to ensure that the coach would "sit him to the side" if his breathing was affected.

Not all families actively communicate about these issues with the schools, however. Solomon, for example found that children with autism in "regular education" classrooms whose families told not only school staff but also fellow students about the disability had the best experiences with their inclusion in mainstream education. Surfacing the otherwise invisible condition enabled those interacting with the children with autism to make sense of and empathize with their action [30]. Similarly, some parents of children with autism carry business cards with them (see, for example, Figure 3) to hand out if a severe behavioral incident occurs in public and passersby question, stare, or try to intervene. Whereas a mother lifting a child into a wheelchair or helping her child interact with a service dog is giving off clear signals about the health status of her child, the mother of a child with autism has few such signals to provide. These cards are one solution to the kind of communication needed surrounding this particular invisible disability.

Finally, individuals with disabilities may practice visibility as a means or self-expression or identity assertion. In their work exploring the act of decorating hearing aids, Profita et al. found that "customization practices are not entirely a response to ugly consumer devices, but rather that the act of customization itself provides the wearer with some intrinsic value" [32]. Participants in the study reported that they felt they could wear their devices with pride and empowerment after customizing, where before they may have felt self-conscious to the point of not using the device. This may be, in part, because others who interact with the individual with a disability may "impose, intentionally or not, a specific disability or non-disability identity on a person" through the practical actions they take [27, 38, 42, 47]. For example, a participant with cerebral palsy in one study said that her technologies allowed those around them to "see I can communicate like any other person" [40], suggesting that one perception of those who cannot speak, or have impaired speech, is that they cannot communicate. Similarly, in our own work with children with autism, we found that while there exists a pervading assumption that children with autism are not social, they were in fact socializing in alternative ways [36]. The pervading assumption about individuals with autism is that they are unable or uninterested in being social with others, largely due to challenges they face in face-to-face interactions. For the children with autism who participate in the Autcraft community, interactions via social media, text-based chat, and avatar movement within the virtual world all allow for and support sociality. As one parent wrote, the Autcraft virtual world "allows people with autism the opportunity to play around with social interaction without the pressure of worrying about getting it wrong." Contrary to what one might observe in a face-to-face interaction, the children on Autcraft work in teams to build new structures in world, play games such as hide-and-seek together, and engage in fantastical, pretend play in groups. Here, it is the

context (environment and supportive assistive technology) in which these children are engaging with others that changes the perceived interest and ability to socialize. It is through the use and expression of their assistive technologies that these individuals find empowerment and challenge assumptions about their disabilities and, by extension, themselves.

4 DISCUSSION

Rather than a mere technological concern, visibility is embedded in the social and cultural contexts of larger discourses around health and disability. A focus on the practice of visibility, then, encourages us to consider the ways visibility is not simply a thing that can be turned on or off. Rather, it is an ongoing, emergent accomplishment of the individual, the device, or both. Some such practices of visibility are the practices and techniques surrounding issues of disclosure. Disclosures, and their lack, can be intentional and even performative. They are also complex and require enormous effort to manage.

It can be tempting to focus solely on the negative aspects of visibility given how strong and pervasive they may be. However, we must not forget the positive and practical applications visibility lends as well. Visibility is a complex and nuanced concept, and from that nuance comes both opportunities and challenges. In some ways, it is simple to consider how visible an assistive technology is, whether through a literal question of whether it can be seen with the eyes or through the slightly larger question of whether it can be detected by an outside observer through other means. However, this view relegates design of assistive technologies then to mere technical challenges. How visible a device is becomes a feature to be considered. However, we suggest here that visibility—of technology and associated need for and use of it—is more complex than that initial, straightforward, question.

Diagnostic criteria, service attainment processes, and even assistive technology procurement tend to be slow, regimented processes that require a static, defined disability category. The reality, however, is much more fluid and dynamic. Age, illness, strain, time, and changes in the environment can all cause movements across the disability spectrum. Assistive devices do not necessarily have to adhere to the same regimented categories as the processes that lead to their attainment. To date, however, we as a community have not tended to embrace the full scope of dynamic change we might expect or wish. This is not to say that fluidity is an entirely absent concept in assistive technology design and research. Indeed, a wide variety of research and commercial products support personalization and customization. These approaches take an important first step towards truly dynamic assistance, but they are limited. In this article, we have explored just one of the many ways in which disability statuses and experiences are dynamic: the level of visibility of the disability. This, in turn, leads to a consideration of the visibility of assistive devices that builds on and expands discussions of stigma that have recently emerged in the assistive technology research community.

Expectations of what it means to be disabled often rely on the visible. What a disabled person looks like and whether and how they are using assistive devices are all acts of disclosure of disability status. Indeed, many people with disabilities inherently disclose their status—and any changes in their status—on a near continual basis. For others, however, these indicators are absent or much subtler, removing both the stigma and support they might receive from such disclosure. As assistive technologies shrink and become less obtrusive, we must be mindful of the dual role visibility plays *both* as a form of “othering” the disabled person and as a form of signaling need and even legitimizing or empowering. As designers, we are left with the question of how we might embrace, leverage, or overcome this dual nature of visibility in our devices.

One proposed solution to mitigate negative perceptions of assistive technology has been mainstreaming said technologies. While this is an admirable goal, many of these mainstream devices

come with their own conventions and expectations for use that often do not include specialized uses for disability. Consider, for example, hearing aids designed to look like headphones. Headphones come with their own conventions and expectations, such as wearing headphones when you wish to appear busy to co-workers as to limit conversation. What social signals, then, do hearing aids designed to look like headphones send? An outsider may interpret this as being rude, or when attempting to communicate, think they must speak very loudly over the sound they expect the user to be hearing through what are apparently headphones. Similarly, an iPad being used as an assistive device by a child with autism using may be mistaken for a toy or other form of entertainment. By making the devices *socially invisible*, we may introduce the challenges those with invisible disabilities currently face with believability, conveyance of needs, and access to assistive services. By considering the discursive practices surrounding the disclosure of health conditions, we can begin to recognize the communicative work that assistive and pervasive health technologies can do, indeed in many cases already are doing. Thoughtful design can enable the kinds of discursive work that people do now to be accomplished more easily or more clearly. However, design that ignores this work may actually further burden a person experiencing severe health issues, chronic health concerns, and disabilities. A secondary reason for mainstreaming is that it is apparently cheaper. However, this assessment does not consider potential costs to the user should our designs leave the research phase and enter the general market. Because mainstream devices are not seen as being medical devices, it is the individual with the disability or their caregiver who will take on this cost when their medical insurance denies the claim for the mainstream device on the basis that it is not medical. With all of these things considered, it becomes apparent that *mainstreaming is far from simple*.

Finally, what is stigmatizing to some people in some time and some place under some set of circumstances is legitimizing, too, and we simply must develop new approaches that accommodate this reality. Visibility of assistive devices is an incredibly nuanced subject with broad implications for both assistive technology design and research. By focusing on stigma, we see only one side of the story, and prescribe solutions based on a limited view. In designing assistive technologies, we must not only consider the functionality of the device, and how that might vary with circumstance as the user's needs change, but also consider the nuanced social implications their designs might elicit through their (in)visibility. In selecting participants, we might explicitly ask about their experiences with their disability, how it changes, and how others perceive it. Particular attention should be paid to potential unintended consequences of the (in)visibility of the design. Additionally, designers might consider way their technologies might be more dynamic to be able to accommodate the user wherever they may lay on the spectrum. Future work must examine this interplay further, probing on both the challenges and the opportunities afforded through different designs and the nuanced experiences of people with disabilities both visible and invisible.

5 CONCLUSION

In this article, we have explored, through both our own research and a literature review of the community, the complex, nuanced experiences of individuals with invisible disabilities and their use of assistive technologies. Disability is not a static experience, with some individuals experiencing both visible and invisible disability, visible and invisible assistive technology, and the desire or not to be visible to others. Visibility is not a simple binary presentation but is rather a dynamic and continuous process negotiated individuals and devices. In addition, visibility is a complex and nuanced process that presents both opportunities and challenges for individuals and devices. The complexity of visibility absolutely comes to bear on assistive technology, especially given the slow and regimented ways in which disability is often conceived. The interactions of perceived level of visibility and disability, and the slow rate at which a spectrum of disability is being recognized,

necessitates further discussion of stigma in relation to assistive technology. One response to this stigma has been to advocate for mainstreaming, but by making assistive tech devices we may inadvertently create more challenges for those who want or even need their disability to be visible. In addition, visibility is a complex and nuanced process that presents both opportunities and challenges for individuals and devices. The complexity of visibility absolutely comes to bear on assistive technology, especially given the slow and regimented ways in which disability is often conceived. The interactions of perceived level of visibility and disability, and the slow rate at which a spectrum of disability is being recognized, necessitates further discussion of stigma in relation to assistive technology. One response to this stigma has been to advocate for mainstreaming, but by making assistive tech devices we may inadvertently create more challenges for those who want or even need their disability to be visible. As researchers and designers, we must look beyond stigma to recognize the variety of nuance in the human experience. Universal design, or one-size-fits-all, will not always work when taking into consideration the different dynamic experiences found even in one individual. We must begin to understand the complexity of our endeavor and work to create assistive technology that meets users half-way—whether they experience invisible or visible disability.

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