# Slacktivists or Activists?: Identity Work in the Virtual Disability March

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# ABSTRACT

Protests are important social forms of activism, but can be inaccessible to people with disabilities. Online activism, like the 2017 Disability March, has provided alternative venues for involvement in accessible protesting and social movements. In this study, we use identity theory as a lens to understand why and how disabled activists engaged in an online movement, and its impact on their self-concepts. We interviewed 18 disabled activists about their experiences with online protesting during the Disability March. Respondents' identities (as both disabled individuals and as activists) led them to organize or join the March, evolved alongside the group's actions, and were reprioritized or strained as a result of their involvement. Our findings describe the values and limitations of this activism to our respondents, highlight the tensions they perceived about their activist identities, and present opportunities to support further accessibility and identity changes by integrating technology into their activist experiences.

### **Author Keywords**

Social media; activism; accessibility; identity theory.

### **ACM Classification Keywords**

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

### INTRODUCTION

The freedom to participate in protests or public activism is one of the fundamental components of being heard in a democratic society. Public assembly holds a unique significance as a collective performance that supports a particular cause [9]. Many rights have been gained through activism in democratic societies like the United States, such as the right for women to vote and the creation of new civil rights legislation to prohibit racial discrimination. In 1977, sit-ins by disability activists directly led to the passing of Section 504 of the Rehabilitation Act, which prevents

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Figure 1: A poster held at an in-person march recognizing people with disabilities who could not attend. Posted on Facebook; used with permission.

discrimination against people with disabilities when they apply for or use federal services.

However, in-person activism remains inaccessible for many people with disabilities. Activities such as marches, rallies, and town hall meetings often introduce environmental, social, or physical accessibility barriers that people with disabilities must navigate. These events may have multiple accessibility barriers that impact different populations – for example, a crowded protest may be hard for a blind person to navigate with only their cane, and overwhelming to someone with social anxiety disorder.

While the disability rights movement of the 1960s in the US achieved great progress in improving the accessibility of public services like buildings, voting booths, and governmental websites, people with disabilities remain discouraged from participating in public engagement by the perception that their collective voice is not being heard [22]. Involving people with disabilities in public activism is of utmost importance to include this population in public voices that affect policymaking.

Technology has enabled new digital forms of activism, such as participating in online social movements or signing epetitions. Performing these actions in lieu of physical protesting may eliminate accessibility barriers for people with disabilities. Unfortunately, many of these actions are viewed as 'slacktivism' – low-effort and low-impact alternatives to meaningful engagement with a cause [27]. Activist rhetoric often refers to 'putting your body on the line' or 'being in the streets' [35], which not all disabled activists <sup>1</sup> can do. There remains a tension around the legitimacy and efficacy of online forms of participation.

To explore how this tension impacts disabled activists, we conducted a study of activists who participated in the Disability March, a virtual satellite march of the 2017 Women's March on DC. This virtual march primarily took place on a website <sup>2</sup> and across multiple social media platforms. The march invited people with disabilities to share personal stories to raise awareness of disability rights and called for collective actions (*e.g.* calling lawmakers) to influence policymaking. This march demonstrates a technologically-mediated opportunity for people with disabilities to engage with activism and provides a unique opportunity to study technology's advantages and limitations in facilitating disabled activism.

We interviewed 18 respondents with disabilities who participated in the Disability March. We first reported a variety of accessibility barriers that our respondents experienced while practicing activism in general and highlight technology's role in working around such barriers. To better understand participants' motivation and involvement with the Disability March, we adopted identity theory to turn our attention to why and how people participated in this event. Specifically, we considered the ways in which participants organized or joined the march because of their existing identities, collectively made meaning of their group identity, and expanded their activist involvement after the march. We argue that participants of this march are not slacktivists who sought for feeling good on the internet, but activists who took a variety of actions to achieve specific changes.

Our study's contribution is two-fold. The first is empirical: we situated identity theory in an activist event online, providing evidence supporting identity theory's implication in social movement studies. We highlight the mutually reinforcing relationship between disabled activists' identities and their social movement participation. Thus we argue that the march participants are intrinsically motivated to be online activists, instead of slacktivists. Our second contribution is providing practical implications for technology design of online activism. HCI studies around collective action and activism have focused on multiple social movements [12,13]. Our study extends this work by revealing the need to make online activism accessible from the perspective of people with disabilities. We examined disabled activists' experiences and practices, and proposed opportunities for technology to further support disabled activism through extending disabled activists' presence to offline events and environments.

### **RELATED WORK**

Activism involves actions taken by people to make social, political, economic, or environmental changes in society. Activists work on social issues and causes in a variety of domains, including environmental conservation, social justice, and human rights. Activism can be meaningful for multiple reasons – besides addressing these societal problems, participating in activism is also beneficial to the activists' psychological well-being [26].

### **Disability Rights Movement**

In the United States, the disability rights movement started in the 1960s, following a series of other movements for racial and gender equality. The following decades witnessed the impact of disability rights movements on more accessible public policies, education, and public facilities, as well as increased funding and social awareness [5]. Influential examples include the ADAPT Bus Blockade for wheelchair-accessible buses in Denver in 1978 and the Capitol Crawl for the Americans with Disabilities Act's delay in Washington D.C. in 1990. However, people with disabilities continued to be marginalized from public policymaking and political engagement [43].

Increasing participation of people with disabilities in public engagement is crucial to prevent further exclusion of this population. It also helps to create self-efficacy, promote social integration and develop personal interests for the disability community [4]. Existing studies have engaged advocacy groups and nonprofit organizations to examine how to increase public engagement of people with disabilities through advocacy and technology [16,22]. Accessibility advocates have used social media to promote accessibility in physical environments [31]. In our study, we uncover how experienced disabled activists' presence further manifests online through the modern virtual Disability March. We present technology's role, opportunities, and limitations in increasing involvement of people with disabilities in activism.

# Accessibility Barriers in Public Spaces

Public activist events may be inaccessible to people with disabilities, due to accessibility barriers in public spaces and transportation. These inaccessible situations can result from three types of accessibility barriers: *environmental, social* and *physical* accessibility barriers [40].

*Environmental accessibility barriers* are most common and include any architectural or structural features which make it harder for people with disabilities to interact in a space. Missing ramps or elevators and noise or air pollution are all common examples of environmental barriers that might

<sup>&</sup>lt;sup>1</sup> We have learned the conflicting opinions about using person-first language (*people with disabilities*) or identity-first language (*disabled person*). We join disability groups, such as the American Deaf community and autistic communities, in using identity-first language, i.e. *disabled activists*, to reflect disability as an inseparable part of their identities [57]. However, we would also like to acknowledge there are cases when our respondents strongly identify as activists, rather than "disabled person" (P14).

<sup>&</sup>lt;sup>2</sup> http://disabilitymarch.com

impact people with disabilities. These barriers contribute to an overall sense among people with disabilities that public spaces are not welcoming to them [21].

Social accessibility barriers occur due to other peoples' misunderstanding of disability. People with disabilities are often avoided or treated as incapable [17]. Visible disabilities and assistive technology use can result in unwanted public attention or other kinds of stigmatization [44]. These experiences discourage people from attending events in public or make their experiences negative.

Finally, *physical accessibility barriers* are inherent to the individual, including symptoms such as chronic pain or an inability to leave the home. While some of these barriers can be solved by careful attention to accommodations in public, others require the availability of accessible alternatives that are custom-designed for each individual.

Because of these accessibility issues, traditional forms of activism, like protests, volunteering for organizations, or attending government meetings, may be more difficult for people with disabilities to participate in. Temporary events, like protests, are uniquely difficult to make accessible because of their short length and the unknown range of disabilities that attendees may have [56]. There are low participation rates by people with disabilities in other forms of in-person engagement, like volunteering [3,41], attending town council meetings [24], and voting [42], due to transportation problems and accessibility barriers. Finding accessible ways to facilitate engagement of people with disabilities in these activities is critical to creating representative activism [4,5].

## Activism in the Digital Age

The internet provides new opportunities for activism by facilitating durable campaigns, connecting organizations, and communicating messages broadly [6]. Land's networked activism model illustrates that technology helps to address the tension between mobilization and participation, *i.e.* broadly mobilizing public efforts and encouraging in-depth engagement at the same time [28].

Common online activist actions include high-effort activities, like drafting proposed legislation, and low-effort activities like sharing and signing online petitions, clicking "like" to show support of an interest, getting engaged with conversations about social causes, publishing or propagating opinions, or simply change one's profile picture as a response to activist events. There have been many examples of using social media in activism, especially related to politics and policy, which have further resulted in political uprisings and social protests [7,12,33].

The role of social platforms like Facebook and Twitter in communicating, disseminating, and organizing movements is evident [51,55], especially for public advocates and organizations [32,52]. However, from organizers' perspectives, the ubiquity of these platforms introduces new problems in controlling action, decision-making and

collective identity [6]. Thus, activism-focused technologies have been specifically built to facilitate collective engagement, such as Hollaback!, a digital story-telling platform to end street harassment [13].

On the other hand, online activism has been heavily criticized as an approach to merely make participants feel good about themselves, rather than to directly achieve concrete goals [27,30,58]. The term 'slacktivism' has been used to disparage these actions as subpar replacements to in-person activism. While literature around 'slacktivism' has shown that it may be an initial step to further involvement in a cause [10,30] and is positively correlated with offline activism [37], there are still negative perceptions of certain forms of online activism. Because performing a good deed may be an excuse to not perform further actions [34,36], critics of slacktivism state that acting online may actually pose a negative impact on future engagement.

This concern remains among activist communities, and the value of physical presence at marches and protests is still venerated [35]. Even among disabled activists, the rhetoric of 'putting your body on the line' is used to describe high-impact, meaningful activism, like the die-ins held by ADAPT members in senator offices to protest proposed cuts to healthcare [59]. The tension around physical presence may lead disabled activists who are unable to be 'in the streets' to feel ineffective or question their role as activists.

## Identity Theory in Social Movements

Identity theory explains social behaviors which result from the interplay between society and self-conception. It suggests that social interaction and actions are shaped by meanings people attribute to themselves, *i.e.* selfconceptions, which is developed based on societal situations [47]. It is argued as the key to address the differences in social movement participation [48]. Recent work about the "Black Lives Matter" movement found evidence showing different levels of engagement in movement participation [12]. Using identity theory as a theoretical lens, we explore how individuals became part of the Disability March differently.

Another advantage of using identity theory in social movement research is understanding changes in identities as a process of co-creation during social movement participation [25]. Although self-change among participants is a side-effect of social movements, it could have a significant impact on individuals' future activities [39]. However, it has not been thoroughly investigated how participation in social movements affected people's self-concept, *i.e.* identity and personality traits, and how this could provide implications for future movements to sustain participation and bring positive changes to society.

### BACKGROUND: THE DISABILITY MARCH

The Disability March that inspired this research is a virtual march. It occurred as a digital contingent of the 2017 Women's March on Washington DC, happening at the same time offline. It was led by a small ad-hoc group of people with disabilities and initially started as a website<sup>1</sup> where disabled marchers submitted their pictures along with reasons for marching (as shown in Figure 2). The organizers also started a Facebook group a month before the march for communication among march participants. At the time of writing, there are 1891 members in the Disability March Facebook group.

This virtual march unfolded on multiple social media platforms including Facebook, Twitter, Instagram, and Tumblr. Participants of this virtual march used the hashtag #DisabilityMarch along with other hashtags related to the Women's March on these social media platforms. They shared their stories, selfies, posters, slogans, and opinions online, either instead of or in addition to attending the Women's March in person. Not only did this march manage to have a large number of participants, but it also gained attention from traditional media outlets before and after the event [14,54,60]. This unique form of digital activism motivated us to conduct this exploratory study to better understand the current activist practices of people with disabilities and identify potential opportunities for designing technology to support these practices.

### DATA COLLECTION

We interviewed disabled activists who had participated in the event. We reached out to the Disability March participants through social media platforms including Facebook, Twitter, and Instagram. On Facebook, we sent our recruitment call through direct messages to Facebook users who posted about the Disability March publicly using #DisabilityMarch, or in Facebook's Disability March group. One respondent also posted our study recruitment call to the group, helping us to get in touch with more respondents. On Twitter and Instagram, we found tweets tagged #DisabilityMarch, and contacted the posters through comments or direct messages. In total, twenty participants responded to our recruitment call, and we conducted semistructured phone interviews with these respondents. Respondents were compensated with a \$20 digital gift card. This study was approved by our institution's IRB.

Respondents were primarily female due to the gendered nature of the Women's March. Four respondents attended their local Women's March in addition to the virtual Disability March. We removed 2 participants from our sample who did not participate in the Disability March directly (*i.e.* who were aware of the Disability March but did not post about the march on any social media platform), leaving data from 18 participants. Respondents' disabilities varied greatly, including physical disabilities, invisible disabilities, chronic health problems, and mental illness. Respondents' demographic information can be found in Table 1.

Our interview questions focused on four major topics: 1) intrinsic and extrinsic motivations for participating in the Disability March; 2) respondents' experiences with the march; 3) the march's aftereffect in their daily life; 4) any other forms of activism that they have taken previously. Interviews lasted 45 minutes on average and were later transcribed for further analysis.

# CURRENT PRACTICES OF DISABLED ACTIVISM

To contextualize the Disability March, we did an initial round of inductive coding to understand respondents' experiences with activism in general. Below we present the initial coding process and our findings of disabled activists' current practices of activism.

### Methods

Two researchers each coded and created memos for half of the transcripts, and met regularly to discuss code definitions for three weeks. This analysis led to two dominant themes: accessibility barriers with subthemes about 1) environmental, social, physical and barriers; 2) workarounds to activism with subthemes about online, offline, and hybrid activism. There were a variety of accessibility barriers which made it difficult for people with disabilities to participate in traditional in-person marches, rallies, protests, town hall meetings, and so on. As a result, they have developed creative online and offline workarounds to voice their opinions publicly and become engaged with activism.

## Accessibility Barriers in Offline Activism

Respondents identified a variety of actions as ways to be an activist. Actions that happened in offline settings included forms of collective public assembly (*e.g.*, going to protests, marches, or town hall meetings) and in-person activities (*e.g.*, volunteering for nonprofit organizations; attending support meetings). Offline activism also included individual activities (*e.g.*, raising awareness of causes with friends and family through conversation; making phone calls or sending letters to lawmakers). Many of these forms of activism remained inaccessible to our respondents.

Public assemblies were often planned and organized without consideration of people with disabilities at the onset. This tendency towards interventionary accessibility fixes, rather than preventative consideration of accessibility, is especially troublesome for members of the disability community [8]. Respondents elaborated on the details of problems caused by lack of consideration of accessibility, including environmental, social, and physical barriers.

Many activist events require participants to be in an unfamiliar environment, and thus introduce environmental barriers to people with disabilities, preventing them from being engaged in these events and communities. Examples of this include lack of accessible restrooms and sensory rooms, inaccessible parking, and no seating areas. Our

ID	Age	Gender	Disabilities	Activities for Activism	
P1	27	Female	Neuropathy, anxiety	Marched virtually, signed e-petitions	
P2	27	Female	Autism	Marched virtually, signed e-petitions, Twitter bombing	
P3	26	Female	EDS Type 3, fibromyalgia, & PTSD	Marched virtually, advocated on social media, owned a Facebook page, joined the Invisible Disability Project	
P4	38	Female	Bipolar-1, limited mobility	Marched virtually, advocated on social media	
P5	38	Female	Autoimmune disease, Colitis	Marched virtually and in-person, signed e-petitions, advocated on social media, had a Facebook page	
P6	45	Female	Chronic pain, connective tissue disease	Marched virtually, volunteered for organizing the virtual Disability March, joined several activist Facebook groups, advocated on social media	
P7	52	Queer	Mobility impairment	Organized the virtual Disability March, moderated several disability- related activist Facebook groups, marched and protested in-person	
P8	45	Male	Lupus	Marched virtually and in-person, advocated on social media	
P9	30	Female	PTSD, chronic migraines	Marched virtually and in-person, advocacy writer	
P10	57	Female	Functionally blind. No central vision.	Marched in-person, called lawmakers, advocated on social media	
P11	51	Female	Chemical sensitivities, chronic migraines, fibromyalgia	Marched virtually, joined several chronic illness Facebook groups.	
P12	46	Female	Chronic illness, Rheumatoid disease, Hashimoto's Thyroiditis	Organized the virtual Disability March, marched virtually and in- person, advocacy writer	
P13	20	Female	Chronic illness, immune deficiency	Marched virtually, called and wrote to lawmakers, advocated on social media, joined several Facebook groups and The Mighty community	
P14	50	Female	Myalgic Encephalomyelitis, cognitive difficulties	Marched virtually, joined several political activist Facebook groups, called and wrote to lawmakers, attended community meetings.	
P15	64	Female	Triple amputee since infancy	Marched virtually, in-person campaigns, social worker	
P16	34	Female	Chronic illness, spine injury	Marched virtually, signed e-petitions	
P17	65	Male	Polio, hard of hearing	Marched virtually, signed e-petitions, social advocate	
P18	24	Female	Rare genetic disorder, digestive problems	Marched virtually, disability advocate	

Table 1: Respondent demographics and experience participating in activism

respondents with autism, PTSD, chemical sensitivities, or immune deficiencies emphasized the risks of being part of a crowd could trigger health symptoms for them.

Our respondents also faced social barriers interactioning with other people at events, such as being asked invasive questions about their personal medical conditions, or encountering non-consensual physical contact in an attempt to "help" the individual. One respondent explicitly expressed her discomfort and anger when her arm was grabbed by strangers who tried to help her. Thus, she had to go to the march with her neighbor who acted as her "guardian".

"People do things to blind people that they don't do to others, like grabbing. It is hard to tolerate...I feel like they are petting me. The more upset I got, the more people do. So I need a guardian." – P10

Such social barriers support the fact that accessibility problems do not always result from 'impairment' [15], and require a better social construction of disability in the general public through educating and advocating.

Finally, physical barriers often varied from person to person depending on their individual disability. Many activist events took places in public spaces, which required participants to be mobile enough and have sufficient energy to travel outside their home environments and walk for a period of time. Individual activities, such as calling senators or writing a letter, required communication skills and were difficult for people with cognitive impairments.

Respondents additionally expressed a need for accessibility information to be made public before events, allowing them to make an informed decision about whether they can participate in in-person activism and what accommodations they may need. Knowing about the environment in advance was necessary for making transportation arrangements and getting themselves prepared. However, this information is not always available in satisfactory detail – marching paths may not be marked or described in the event literature, and amenities like benches or bathrooms are rarely marked. Without this information, disabled activists must chance to put their health at risk to be a part of activist events.

Our respondents' experiences with these barriers caused them to seek alternative, online venues for activism.

## Workarounds to Activism

Despite various accessibility barriers existing in traditional forms of offline activism, our respondents shared multiple approaches they used to work around these barriers and remain involved in activist causes. Some of these approaches introduced socio-technical systems as a means to engage with in-person events' participants remotely; others involve solely online actions, such as signing epetitions or advocating on social media.

### Offline Activism

In some cases, respondents participated in offline activism through proxies. One type of proxy was a physical artifact which represented them in offline spaces, independent of being engaged online. In particular, some respondents who participated in the Disability March reported that they also had a friend holding a sign for them, had their names in friends' shoes, or had their names on a sign that is held by someone at the Women's March.

Another type of proxy for offline activism was an ablebodied individual being a proxy representative for a person with a disability and performing activist tasks on their behalf. One respondent, who wrote emails to her senator regularly, mentioned she also has a friend deliver her letters to the senator's office in person.

## Hybrid Activism

Many respondents' activism combined in-person activities with socio-technical systems, creating a form of *hybrid* activism. Below we describe how some respondents participated in online and offline activism simultaneously.

Respondents who were able to go to in-person marches or protests were often very active online at the same time, using social media platforms to share documentation about the event. Similar to findings of previous work [37], online and offline activism were mutually beneficial for people with disabilities:

"It (the march) is wonderful. I saw this woman holding a big sign, 'to those who cannot be there, your voice matters'. I took a pic and posted to the disability march group." -P5

Another form of hybrid activism described was attending via telepresence or watching video streams of the protest. These synchronous connections to offline events are likely to be more immersive than other online activities. One respondent mentioned she enjoyed watching the live stream on Facebook and interacting with other audiences online at the same time; another respondent who watched the march on TV, however, did not feel the group energy that she believed would be felt at the march itself. This supports the importance of interactivity for making events engaging [20], and suggests activism-related technology should facilitate offline-online interactions for remote attendees.

## Online Activism

Finally, all respondents reported using a variety of platforms to practice online activism, including participating in collective actions organized by hashtags, conducting social networking or e-petitioning, and taking individual actions such as consuming and interacting with online information. Information and communication technologies played an important role in connecting activist communities.

Our findings further support Land's networked activism model [28], showing that online community is helpful for activists to reach out to a larger community and form collective actions. By joining online activist groups, respondents were able to expand their networks, share political news, and discuss what actions to take.

# "I joined a disability group... Through this group, I joined a more regional and progressive group. I have these connected social activism." – P6, organizer

Besides engaging in discussions about political issues and actions within cause-focused groups, respondents also use social media as a way to publicly broadcast advocacy for social causes. Respondents had created Facebook pages, Twitter accounts, and blogs to further spread information about the causes they supported. Other grassroots actions include the use of activism-related hashtags within their personal networks, such as #cripthevote to promote more accessible voting, and #disabledandcute, and #stillsexy to combat disability stigma.

Though technology has played a major role in supporting or substituting traditional offline activism, social network sites are still not accessible to everyone [38,53]. People with certain disabilities may be unable to keep up with technological advances if new assistive technologies or inclusive accessible practices are not developed in parallel with mainstream devices. Respondents faced additional barriers while participating in online activism due to web accessibility failures. For example, pictures and screenshots of marches shared online are not accessible for people with visual impairments who use screen readers and were often not given alternative text captions by the sighted activists who posted them. While Instagram was one venue for the Disability March, two respondents reported that they did not use this platform because the images were not accessible; another stopped using Instagram because the auto-playing videos could cause her to experience migraine and dizziness.

## IDENTITY WORK THROUGH THE DISABILITY MARCH

In the second phase of our study, we focused on interpreting our data through the lens of identity theory for two reasons. Firstly, after the initial coding, we noticed a major role of social movement participation on the identity of our respondents and how respondents' existing identities as disabled activists furthered their participation in the march. Secondly, prior studies show that technology use is closely associated with people's identities [18], which motivated us to examine online activism by disabled activists through this lens.

We thus applied Snow et al.'s identity theory framework as it addresses the nexus between identity theory and social movements [45], specifically, the mutually reinforcing relationships between participation in the march and disabled/activist identities. We provide further evidence to describe social movement participants' identity work as the Disability March unfolded.

### Methods

For the aforementioned reasons, we re-coded the data specifically to find further instances of respondents' discussing their identity as disabled people or activists in relation to the Disability March. Our codebook was developed based on identity theory literature [42], which has been used in HCI work about older adults use of technology against ageism [29]. Three members of our research team independently coded one interview to identify relevant concepts from identity theory. Then, we collectively created and structured a codebook from three chronological phases: introduction, identity construction, and identity self-change. In this process, we relied on additional literature to clarify code definitions: 1) the introduction phase describes the change of people's identity hierarchy in response to external factors [46,47]; 2) for the identity construction phase, we referred to the definition proposed by [45], *i.e.* the process through which personal and collective identities are aligned; 3) we also examined the different types of *self-changes* categorized by [25] meaning change and hierarchy change. After establishing the codebook, the researchers coded the remainder of the interviews independently, meeting to reach consensus. The codebook the team agreed upon is in Table 2 below. We will further unpack codes' meanings in the following results.

#### **Identity-Introduced Participation**

In identity theory, identities are ordered into a salience hierarchy, which means those ranking higher are more likely to be salient in certain situations. *Identity salience* is defined as the probability for someone to act out one of their many identities in a given situation, depending on how the situation relates to that identity [49]. Many respondents described identity salience as an influence for them to be part of the Disability March, and their identities as disabled people, activists, or both were highly salient.

Respondents who had already acquired identities as activists felt an internal motivation to continue performing and expanding their activist work. These respondents saw the Women's March and Disability March as events that could further these intersectional social causes and develop unity among oppressed communities. This can be seen among our respondents who were already involved with social work, political parties, or advocacy. Their prior experiences with disability rights and activist networking help them relate their prior identities to the Disability March.

"I belong to a variety of illness groups and writer groups. I am marching not as [a] disabled person. I want to participate in something huge. It was for broader issues." -P14

The majority of our respondents learned about the march through networks of other disabled people on social networks. Joining the march reinforced their identities as members of these disability-centered communities. Even

Phase	Code	Mentions
Introduction	Identity salience	18
	Identity pervasiveness	8
Identity	Identity amplification	12
construction	Identity extension	4
	Identity transformation	5
	Identity management	7
Self-change	Meaning change	13
	Hierarchy change	10

Table 2: Codebook used for interview transcripts, and thenumber of participants who described experiencing that code.organizers joined the group through online socialnetworking after seeing posts about the March from otherdisabled friends.

Our respondents' disabled and activist identities are not exclusive of each other; instead, they are intertwined. Some respondents expressed their identities as people with disabilities and their disabled life experiences gave them a sense of responsibility to advocate for disability rights and help other people with disabilities.

"My experiences and world are shaped by my disability. I feel so repelled. I am visible as a blind person... People need to march. [It is] not because I read about the platform and article, it is I need a venue." -P10

Overall, respondents adopted their marcher identities because their existing identities as people with disabilities, activists, or both became salient.

Identities can vary not only in salience regarding a situation but also in the range of situations to which they are relevant [45]. Basic and general identities, such as people with disabilities, in this case, are relevant to a number of situations [11]. In social movements, people's existing identities become pervasive to this context and lead to participation, i.e. their identity pervasiveness is affected [45].

In the march, the political uncertainties prompted the Women's March and made respondents concerned about their health care and rights as disabled individuals. The elected administration was hostile to healthcare legislation which prohibited insurance discrimination on the basis of pre-existing health conditions. These regulations were extremely beneficial for people with disabilities, and the administration's challenges to these policies was seen as an attack on these vital provisions [1]. The perceived threat made their disabled identity more salient, and respondents resonated deeply with this aspect of the activism:

"I would die if there is no treatment. I need my congress people to understand that. But it is difficult to go to a town hall meeting and stand in front of them." -P13

These respondents may identify more strongly as disabled people than as activists, and they were driven to participate in activism as a performance of their disabled identity.

### **Identity Construction and Evolution**

The meaning of being a participant in the Disability March evolved over time as individuals joined the march and aligned their individual identities with the group. This process of identity alignment and merging was described as *identity construction* in [45].

### Emergence of a Shared Marcher Identity

The emergence of a shared 'marcher' identity began with a group of 20 volunteers who wanted to attend the Women's March but could not due to accessibility barriers.

"I'm connected with other writers with similar health conditions, who couldn't go to the march either, so I reached out. I thought I would make a space for people to post stories." -P12, organizer

These volunteers recognized their shared experiences and identities as disabled activists and formalized a new identity and group around it, which we coded as *identity amplification*, i.e. a phase when social movement participants relate their existing identity congruent to a movement's agenda [45]. The idea of the Disability March was further refined within the volunteer group through internal discussion.

"We [the volunteer group organizing the Disability March] wanted people to post pictures [for the March]. Because I think people with disabilities are invisible. People who participated said they never went to march before. We discussed what people should include in their stories." – P12, organizer

Organizers diffused this idea by appropriating their existing social networks on Facebook and Twitter. As the march proceeded, organizers started to call for more collective actions from participants and spent efforts to keep people continuously engaged over the course of the March.

"We put out call to actions whenever an appeal or bill happens, like Medicaid related. We advocate, asking the people to contact their representatives, senators, governors etc." – P7, organizer

As the march unfolded, both organizers and participants started to integrate this march identity into more social and personal contexts. The organizers decided to reach out to the in-person Women's March, making the Disability March a formal contingent of that event. While marching online, participants also helped to advocate for the movement in their non-movement related interactions with others, *e.g.* sharing and talking about the March on their Facebook pages and in disability-centered support groups. We coded this phase as *identity extension*, a phase in which personal and movement collective identity become closely integrated [45].

# Collective Meaning-making of Marcher Identities

However, the evolving identity of the group left some respondents confused about the marcher identity, especially when the event was integrated with other social causes. "I don't think a lot of people got it. A lot of people didn't understand the difference between the disability march and the women's march. If it was talked about, it was grouped as the same issue and not like a solidarity with the women's march." -P2

During the identity construction process, some of our respondents reflected on how their marcher identities were challenged during their interactions with non-marchers, a process that participants gain different perspectives of their marcher identity, i.e. *identity transformation* [45]. The meaning of online marching was questioned when respondents shared and described the march to others, and respondents expressed a desire to extend their online marching to physical settings to gain more legitimacy.

"People asked me - what is that [the Disability March]? There is huge need to extend our presence to the street. Somehow to connect who we are, what we are to what is going on the street. It is becoming important. Because we are being visible, active, and fighting for certain causes." – P11

While supporting disability rights through the march, participants and organizers had to dedicate efforts to *identity management* to avoid hostile comments or cyberbullying. Respondents shared various strategies: limiting their opinions to a politics-centered community, being transparent with personal experiences with disabilities, and verifying the content before posting.

Organizers also played a role in mediating the Disability March's identity as a whole. As moderators of the Disability March group, they monitored the content generated by participants, mediated interactions between group members, made announcements to clarify the purpose of the march, and "muted" certain members when the conversations became uncomfortable for other members. These actions allowed the organizers to exert some control over the evolution of the group's shared marcher identity.

### **Identity Self-Change**

Finally, respondents elaborated how participating in the march affected their future activism and their perception of self. Drawing from theories of identity and self-concept, we examine what changes occurred in their identities and how. Self change is not the main purpose of most social movements but has been reported in civil rights and lesbian feminist movements as a by-product [39]. Similarly, participants in the Disability March experienced self-concept change at various levels over the course of their involvement.

### Identity Meaning Changes

The majority of our respondents gained further insights into what can and cannot be accomplished through their identities as disabled activists, i.e. what is the *meaning* of this identity [25]. Despite our respondents' active engagement with the group and widespread attention to the march, the question of whether their collective actions resulted in positive social and political change remains unanswered, causing them to doubt the efficacy of being a disabled activist online.

"I counted myself [as part of the larger movement] online. But I don't know if the number makes an impact... I am concerned about whether the politicians hear us." -P13

Aside from the efficacy issue, many respondents also reported feeling burnt out after the march. The gap between respondents' goals of social equality or political change and the current state of the world leads to negative psychological feelings and burnout. One respondent compared her feelings during and after the march:

"In a rally, I felt more empowered. Now I'm back to life, I noticed I'm not part of 'we'. I got more depressed. I don't think our civil rights are accomplished." – P10

However, doubts around marching and negative feelings did not lead to negative impressions of the marcher identity; instead, they motivated people to reflect on the effectiveness of online activism and learn how to better support activism.

"Overwhelming it is. So I take a break and gather my thoughts around what might be coming ahead, how things are going to proceed." -P17

Respondents also reported how their participation changed their own representation of identities as people with disabilities. Having to cope with accessibility barriers was an important societal issue for our respondents, and they reported that joining the march and connecting with people who shared similar experiences helped them to deal with that situation.

"[The] Disability March taking place online and having conversations with friends built a lot for me. I know a lot of people in solidarity recognized the barriers and know it is ok to be that way." -P4

Furthermore, respondents stated that they felt more empowered and uplifted through participating in the march, recognizing positive characteristics of their identities.

"This virtual thing, it makes you feel good as it's emotionally all good, and it helps confirm your identity as a disabled person. You still have a voice, you still have an opinion, you are important, coming together virtually with all the other people." -P18

### Identity Hierarchy Changes

Respondents reported various *hierarchy changes* after the march, which mean a person's identities are re-ranked in terms of salience [25,49]. Two of the organizers adopted new roles respectively: one saw people's need for policy analysis and became an admin for a policy-focused Facebook group; the other got connected with a larger civil group and became a member of the group to continue to facilitate future online contingents of movements for people with disabilities, including the campaign for prisoner rights.

The majority of respondents did not report gaining new identities but stated that activist has become a more important identity for them. Respondents reported feeling a stronger sense of responsibility to raise awareness of disability rights, promote policy change, and be more vocal and active in future activism. An example of this is respondents feeling supported through interactions with other online marchers and deciding to participate in the offline Women's March. More respondents stated that through joining the Disability March, they were able to expand their activist connections and be more vocal in awareness raising.

"I have enormous respect for people in the Disability March. It was enormous what they did. I am now very vocal about my disability." -P18

Overall, we saw identity changes in both meaning and hierarchy. Online marching activities made participants to reaffirm and restructure their identities as disabled activists.

### DISCUSSION

This paper presents how an online social movement unfolded and influenced participants' identities as disabled activists. People with disabilities must overcome multiple accessibility barriers to be involved with traditional protests and activism. These barriers were described as the main reason for the successful growth of this online movement by our respondents. Using identity theory as a theoretical lens, we have highlighted how marchers conducted identity work during the movement and experienced self-change.

However, the marchers still questioned the legitimacy of their actions and activist identities. Based on our findings, we believe the legitimacy of virtual activism must be reconsidered by able-bodied activists. We propose ways to support participation of disabled people in online activism.

### Slacktivism or Activism?

Slacktivism is criticized for not contributing to democracy and civics, and even posing negative impacts on activism. Similarly, individual respondents felt that the legitimacy of online activism was not clear. Some respondents voiced concerns about whether the number of marchers would be meaningful for the policy-making process, and whether their voices were heard by the general public or by politicians who could impact government. This echoes the tension between slackvitism and activism.

However, we also found online activism was a catalyst to the Disability Marchers' further engagement and identity changes. This result echoes with a prior study on e-petition website, change.org, showing that online activism helps foster lightweight activist actions [23]. In our study, over the course of the march, participants developed identities that led to other forms of actions, *e.g.* going to an in-person march or advocating for disability awareness.

Our study results did not support the perception that people participate in online activism because of the easiness to act online. In fact, the inaccessible situations in traditional activism, which is often seen as real 'activism', drove our respondents to balance their options and take actions online in the end. Given the accessibility barriers to in-person activism, online activism may be the most accessible approach for people who cannot participate in activism through traditional approaches.

Prior research compared online and offline feminist communities, and discovered differences in meaning and actions among the groups [2]. However, we did not observe such phenomena in our study. Although respondents who participated in the in-person march reported that the inperson event was more uplifting, there were no differences from the perspective of engagement and self-change. Furthermore, respondents supported the idea of having virtual alternatives to future activism events.

### Supporting Disabled Activism

Through interacting with other social media users through the march, many respondents reported to have gained more connections in the disability community and joined more interest- or cause-based groups on Facebook. Respondents experienced energy, power, and self-change through interacting with other marchers during the march. However, current socio-technical systems have not yet met people's expectations to feel inclusive of offline activist events and activities. Connecting offline and online activism could increase the visibility of disabled activists, thus increase the importance of remote activism and challenging its perception as 'slacktivism'. Bringing disabled participants' presence into an in-person march will be a step toward addressing the legitimacy issue of online activism, as well as educating the public about disabled activism. With the availability of mobile and social technologies, we envision two approaches to achieve this goal.

First, video-streaming and virtual reality technologies could allow online participants to view the events remotely and interact with in-person participants. It could also enable inperson participants to know who is with them from afar, increasing their sense of community. Through increasing the interactivity of remote activism, we foresee that disabled participants will be able to manifest their presence to offline events and feel empowered to work toward their goal. Second, respondents reported a variety of accessibility barriers and sometimes had to rely on their caregivers and friends to navigate through offline activism events. Technology could provide a communicational channel for participants with disabilities to communicate with event planners about their accessibility needs. It is also possible to connect people who have offline activism needs with volunteers to increase offline representations of people with disabilities.

# **Design Caution**

Social media became an important space for disabled activists' involvement in activism. We caution that designing for this population requires a substantial understanding of privacy in this context. The virtual

Disability March invited participants to share their personal stories as a way to raise awareness of this population's rights; respondents were very transparent with their medical histories, experiences, and opinions when they interacted with others online. They speculated that such actions made people more aware of disability rights and less suspicious of their identities. However, as prior work suggests, requiring authenticity on Facebook may exclude certain users' engagement [19]; thus, as powerful as personal stories are, some potential participants may not be comfortable with the form of marching and have decided not to be part of the march. Furthermore, sharing personal stories exposes potential risks to this population, as respondents shared their concerns with cyberstalking, cyberbullying, and trolling. As implementation of security and privacy measures is needed for such activist technology use [50], we caution that designing for activists requires a consideration of balancing transparency and trustiness at the first place.

### Limitations and Future Work

This virtual march was event-based, created as an alternative to an offline march, and heavily skewed female because of the connection to the Women's March. Thus, respondents' marching experiences may be unique from other purely online or offline social movements. However, we believe this study is a step further toward understanding disabled activism.

Several design and research opportunities for future technology to facilitate activism emerged from our study. The variety of activism practices utilized by our participants suggest that future research in this realm should select specific activism practices to support, rather than trying to employ a universal approach. We plan to conceptualize and design socio-technical systems to test how technology can facilitate activism in particular disability communities.

Further understanding how online activism propagates would enable future technology to organize activism and improve its efficacy. In ongoing work, we will identify key tasks and functionalities performed by activists which helped them structure and disseminate their actions online. Future work must strongly incorporate features to legitimize online activism and measure its impact.

# CONCLUSION

Our interview study sheds light on identity work and activism practices through studying the Disability March that unfolded online. We found that participants joined this movement because of their prior identities as disabled people or as activists. Participants expanded their identities during the march, resulting in new forms of activist practices and changes in their identity hierarchies and meaning. We argue that online activism, which is provoked by the inaccessibility of traditional activism, is valuable and legitimate. We further highlight design considerations for technology to facilitate future disabled activism.

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