



Disability Activism on Social Media: Sociotechnical Challenges in the Pursuit of Visibility

Shruti Sannon
sannon@umich.edu
University of Michigan
Ann Arbor, MI, USA

Erica Shusas
ejr93@drexel.edu
Drexel University
Philadelphia, PA, USA

Jordyn Young
jby28@drexel.edu
Drexel University
Philadelphia, PA, USA

Andrea Forte
aforte@drexel.edu
Drexel University
Philadelphia, PA, USA

ABSTRACT

Activism efforts have played a central role in advancing the rights of disabled people in the United States. Social media offers new opportunities for people with disabilities to engage in activism while bypassing the accessibility issues involved in traditional activism. At the same time, disabled people face various forms of social and technical exclusion that may also complicate their use of social media for disability activism. To understand how disabled activists advocate for social change online, we interviewed 20 disabled content creators about their goals, strategies, and challenges around posting activism content on social media. We find that visibility is essential for successful online activism, but that the pursuit of visibility requires disabled content creators to navigate additional challenges including social stigma, algorithmic suppression, accessibility issues, and a heightened risk of harassment. We identify three main types of disability-related harassment faced by disabled activists, along with six ways in which they respond to such harassment. We examine the sociotechnical nature of the strategies disabled activists use to gain visibility, and identify key trade-offs involved in mitigating harassment while engaging in activism on social media.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in collaborative and social computing**; **Accessibility**; • **Social and professional topics** → **People with disabilities**.

KEYWORDS

activism, disability, visibility, algorithms, accessibility, harassment, risk, stigma, marginalization

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1 INTRODUCTION

“You may not achieve everything in a few years to get people with disabilities where they need to be on the equality scale, but you can be a piece of that, that moves it forward bit by bit. [...] And it slowly became my goal to use [social media] as something that could lift people up in a very positive way.” — P11, Study Participant

Activism has played a central role in advancing the rights of people with disabilities. Yet, there is still far to go for disabled people to achieve equality and inclusion in mainstream life. As the quote above by a popular online activist who is also a wheelchair user illustrates, social media is one way for people to contribute and organize toward incremental social change.

Social media can be particularly well suited as an avenue for disabled people to participate in activism, given that it bypasses some of the accessibility issues involved in traditional activism, such as the lack of accessible transportation to a protest or the functional limitations posed by chronic pain. Some notable disability activism efforts online have leveraged hashtags on social media platforms for policy reform, such as #HandsOffMyADA, #CriptheVote, and #DisabilityMarch. Social media users also engage in advocacy work by posting content that raises awareness about their disabilities and debunks myths about disability [15]. While social media activism has sometimes been negatively characterized as “slacktivism” that carries little cost and cannot bring about real social change [22], researchers have demonstrated that social media serves as a public venue for disabled people to engage in collective action and organize for change [38]. Online advocacy highlights that activism does not require physical spaces [42] and that social media is a legitimate site for activism [38].

At the same time, people with disabilities also face challenges on social media that may be further amplified for those who engage in highly visible activism work. Posting about disability on social media can lead to harassment and the invalidation of people’s disabilities [28, 53]. Disabled content creators may also face technical

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suppression from the platforms themselves: In 2020, the popular video-sharing platform TikTok admitted that it had been suppressing the content of disabled users [31, 32], which likely had a drastic impact on the efficacy of disability activism on the platform. How do disabled content creators engage in social media activism in light of such social and technical challenges?

In this study, we conducted semi-structured interviews with 20 disabled social media activists in the United States to understand how they engage in highly visible activism work online, the risks and challenges they face, and how they navigate these challenges in the contemporary social media landscape.

We make three main contributions. First, our analysis reveals three key dimensions of visibility that shape social media activists' experiences: (1) **needing** visibility, (2) **gaining** visibility, and (3) **counteracting the costs** of visibility. We show how each of these three dimensions presents challenges that are magnified or additionally complex for disabled content creators. Second, we build on research that identifies challenges faced by social media activists by highlighting the sociotechnical nature of these challenges—a combination of algorithmic and accessibility challenges as well as audience-imposed considerations. We show how activists must draw on a holistic understanding of both the social and technical aspects of online activism in order to circumvent these challenges and to successfully gain and manage visibility. Third, we identify three main types of disability-related harassment that social media activists must contend with, and six ways in which they respond to such harassment. Contrary to characterizations of social media advocacy as “low cost” [22], we show how activists must navigate problematic trade-offs between seeking out visibility and protecting themselves from harm in order to further their advocacy.

2 RELATED WORK

We begin by providing a brief overview of disability activism. Then, we explore what is presently known about disability activism on social media, and also draw on related literature in HCI on online activism. Finally, we identify the research gaps this study seeks to address and describe our approach for doing so.

2.1 Disability Activism in the U.S.

The disability rights movement has a long, rich history of fighting for equal rights and opportunities for disabled people, and has been fueled by the slogan “Nothing about us without us,” first invoked by South African disability activists in the 1990s [7]. Building on disability rights, the disability justice movement has shone a light on the many intersectional challenges disabled people can face when they hold multiple marginalized identities, such as along the lines of race, gender, and sexual orientation [57]. In the context of technology, disabled scholars and activists have called for the centering of disabled people as “knowers and makers” who have long engaged in designing tools and remaking the material world to fit their needs [27, p.7].

Activism has yielded major strides for disability rights. In the United States—the context for this study—the fight for disability rights brought about the Americans with Disabilities Act (ADA) in 1990. Activists played a notable role in the passage of the ADA, culminating in the “Capitol Crawl”, a historic protest where many

activists left their wheelchairs and mobility aids and crawled up the 365 stairs of the Capitol building in Washington D.C. to rally against the stalling of the Act in Congress [21]. The ADA is landmark legislation that prohibits discrimination on the basis of disability in multiple contexts and aims to provide disabled people with equal opportunities and access to mainstream life.

However, such legislative efforts have not been a panacea. Disabled people still face barriers, both in the U.S. and across the globe. Some of these challenges center around social attitudes and discrimination. For example, in the workplace, disabled people face prejudicial hiring decisions [13, 65], lower wages than able-bodied people [2], and a lack of career advancement opportunities [13]. Navigating the stigma around disability also impacts people's psychological well-being [47] and physical health outcomes [50]. Other challenges stem from disabled people's needs being systematically excluded from consideration, such as through inaccessible systems and a lack of accommodations [54] in everyday life domains.

More recent research shows that these deeply entrenched social and technical challenges extend to modern technologies; for example, disabled people face stigma and harassment on social media [53], and many technologies are inaccessible to a range of disabilities [34, 63], creating economic, social, and personal costs [24]. It is clear that true inclusion and equity for disabled people remains an unmet goal.

2.2 The Use of Social Media for Disability Activism

Social media campaigns are important tools for activists because they can reach and engage people who would otherwise be removed from, or even disinterested in, a particular cause [40]. Research has demonstrated that online activism supplements and promotes traditional activism, such as donating, volunteering, and planning events [36]. People exposed to online activism were found to be twice as likely to volunteer their time or take part in an event, three times more likely to ask others to donate to a social cause, and five times more likely to recruit others to sign petitions [64].

In the context of disability, online activism can be a way for people with disability-related needs and constraints to participate in furthering social causes. Having multiple ways to participate in social movements is particularly important for people who may be excluded from traditional activism due to environmental, social, and physical accessibility challenges [38, 46]. For example, environmental barriers like the lack of accessible transportation combined with physical barriers like chronic pain may prevent disabled activists from participating in an in-person protest. In contrast, online activism challenges the idea that social movements need embodiment (as the term ‘movement’ may imply [42]), and promotes greater inclusion.

Disabled activists have leveraged social media in several ways to raise awareness and effect change. Hashtag campaigns [1, 29, 51] have been used to advocate for policy reform; for example, #CripTheVote was a Twitter campaign to engage disabled voters and encourage discussions about disability in the U.S. Presidential election [20, 42]. Similarly, #HandsOffMyADA encouraged important discussions and mobilized the disability community around

a specific legal bill [1]. Recent research finds that social media activists are also using videos on TikTok for advocacy [35], such as by sharing lighthearted and creative content to raise awareness about disability issues [15].

At the same time, disability activism on social media can also be challenging. An interview study with activists with concealable disabilities found that their decision to engage in social media activism was influenced by their perception of potential risks [3]. While research has yet to uncover the range of risks and harms faced by disabled social media activists, research conducted on social media activism in marginalized contexts beyond disability can serve as a helpful reference point. Researchers have identified several challenges faced by activists from marginalized groups that likely extend to disabled social media activists. For example, posting advocacy content can raise privacy risks for marginalized groups, such as those in the LGBTQ+ community [4]. Further, by being highly visible on social media, activists can also run the risk of being retaliated against and punished, as in the case of political dissidents [48]. Marginalized groups have developed a range of strategies to mitigate harm from engaging in online activism, though these strategies can be costly and difficult. For example, transgender activists protect themselves against threats (like blackmail and doxxing) by using strategies like preemptive disclosure and cryptographic defenses; however, these require emotional investment and technical expertise [37]. It is likely that disabled activists, as another marginalized group, also experience many of these risks and harms, thus motivating us to explore these issues in the context of disability.

2.3 Our Focus and Approach

The research described above demonstrates how online activism can be an effective means of generating awareness and driving social change. In the context of disability, social media can provide disabled people with a way to engage in activism while bypassing offline accessibility challenges. However, we also know that disabled people face several challenges on social media, including ableism and harassment [28, 53], inaccessible platforms [23], and content suppression [31]. These challenges likely extend to disability activism on social media.

While researchers have examined the experiences of disabled content creators broadly, we know less about the experiences of disabled content creators who are *also* social media activists. Engaging in social media activism involves being hyper-visible to a broad audience, but this hyper-visibility may raise unique challenges and risks for people who are already marginalized based on disability. Research on disability activism on social media largely examines the content of online advocacy—such as tweets [42] and videos [15]. We build on prior interview studies that center the experience of disabled social media activists; these studies have examined specific activism campaigns (the #DisabilityMarch in [38]) and people with specific disabilities (concealable disabilities in [3]). In this study, we take a holistic view of the experiences of disabled activists across a range of social media platforms and disabilities. Further, while prior interview studies reveal valuable insights about the tensions between public and private performances of activism on social media [3] and the role played by social media in the construction of

disabled identities [38], we extend this prior work by focusing on the range of sociotechnical challenges disabled activists encounter on social media and the strategies they use to navigate them.

Our research efforts were guided by a few broad research questions: *How and why do disabled content creators engage in social media activism? What are the challenges they face, and how do they navigate these challenges? How does pursuing high visibility on social media as a marginalized group impact the experience of disabled content creators?*

Our approach to exploring these questions is informed by disabled activists and scholars in a few key ways. First, we center the expertise and voices of disabled people hamraie2019crip in understanding how they experience social media activism and the strategies they use to navigate challenges online. Second, disability is not a monolith, but dynamic and changing, with wide variation in experience [56]. As such, we interviewed people who self-identified as having a wide range of disabilities rather than imposing pre-set criteria for participation.

Finally, we take a disability studies approach [41] by recognizing that the experience of disability is shaped by complex social, cultural, economic, political, and technical dynamics. For example, the needs of disabled people are often overlooked (e.g., when designing technologies), which can obstruct or exclude them from participating in daily life. Thus, we privilege disabled individuals' experiences while also focusing on how sociotechnical structures perpetuate exclusion and exploring how these structures can be improved to be more inclusive and equitable.

3 METHODS

To understand disabled content creators' experiences engaging in social media activism, we used methods informed by interpretivist views of knowledge. Our approach embraces the idea that knowledge about social phenomena requires knowledge of participants' own understanding of their experiences. Toward this end, we designed semi-structured interview protocols and used inductive methods of analysis common in interpretivist approaches to grounded theory [8] as described below.

3.1 Recruitment and Procedure

To recruit participants, we searched Twitter, Instagram, and TikTok to find people involved in disability-related activism using the hashtags #disability, #disabilityadvocacy, and #disabilityactivism. We directly contacted self-identified disabled activists who used these hashtags and invited them to participate in the study; messages included a link to the online consent form with study information. Despite the diversity of hashtags used in the disability community, this approach allowed us to interview 20 participants with wide-ranging disabilities and identities. We provided multiple ways to participate (e.g., through both text-based and audio interviews) to accommodate accessibility-related needs. Participation was restricted to people over 18 years of age located in the United States.

All interviews except one took place by audio call and began with a verbal informed consent process, which included obtaining permission to record the interview. One interview took place over email to accommodate a participant's disability. Interviews focused on participants' experiences engaging in online disability-related

activism. First, we asked participants to tell us about themselves broadly (including their age, location, and employment status) and their personal experience with disability. Then, we asked participants to tell us about their experiences using social media for disability activism through several open-ended questions about their goals, the benefits they perceived, the challenges they encountered, and the strategies they used to mitigate these challenges. We also asked focused follow-up questions about specific concepts, such as asking them to reflect on the role of algorithms in their online activism work.

Interviews lasted approximately an hour, and participants were provided \$25 USD in the form of an Amazon gift card or a Venmo cash transfer, based on their preference. All interviews took place between June and December 2021, with approval from Drexel University's IRB.

3.2 Analysis

We conducted an inductive, qualitative analysis, drawing on principles from grounded theory [9]. This approach allowed us to focus on participants' own interpretations of their experiences rather than imposing a priori framings from existing theoretical or empirical work, in line with grounded theory approaches [5]. Data collection and analysis occurred simultaneously and each process informed the other. We wrote extensive memos after each interview to identify important concepts that were salient to our broad research questions. Throughout data collection and analysis, all authors met regularly to discuss codes and themes in the data.

We followed the constant comparison method in our analysis of interviews and memos by continuously comparing codes, concepts, and categories to identify similarities and differences in the data [8]. We began the coding process while interviews were still in progress. First, three authors independently applied open codes to interview transcripts to identify concepts in the data. Then, we conducted axial coding [9] by exploring connections between open codes and grouping them into higher-level categories. For example, we identified the category "types of harassment" by grouping several open codes in the data (e.g., hate, sexual harassment, and coordinated attacks).

Our analysis also concurrently influenced our data collection; we used theoretical sampling [8] to seek out participants who varied along key dimensions that were deemed important in the analysis, such as content creators with visible versus invisible disabilities, and those with relatively small or large follower counts. Similarly, the coding processes during our analysis influenced our interview guide as we honed in on important concepts. For example, early into our interviews, we discovered that some participants felt strongly about the role of algorithms in their online activism, and we added questions that explore this concept to the interview guide. We ended data collection once we reached theoretical saturation—that is, once interviews no longer surfaced new concepts.

The final step in our analysis was selective coding, where we sought to identify a core category that links the categories identified through axial coding [9]. Through discussion, we identified 'visibility' as the core uniting concept across our data and used this concept to orient our thinking about the themes in our data and, eventually, to organize our Findings section. With the core category

identified, we jointly developed a codebook that two authors used to re-code the dataset. In keeping with best practices outlined in McDonald et al. [44], we used regular, iterative discussions between all four coauthors to achieve consensus, instead of quantitative metrics such as inter-rater reliability. To provide a further check on the trustworthiness of the findings, the codes and findings were validated by two other authors who were familiar with the dataset, as suggested by Denzin [10].

3.3 Ethical Considerations

Throughout the research process, we considered the ethical implications of the work and took steps to respect participants' privacy and dignity. Considering positionality is particularly vital when conducting research with marginalized groups [39]; at least one author has lived experience of disability, which guided the research process from conceptualization through completion and influenced methodological choices to mitigate potential harm, as follows.

We sought to be inclusive in our sampling; thus, we interviewed people who self-identified as having a disability rather than constraining recruitment based on preconceived criteria about what constitutes disability. We also asked participants about any accommodations they needed to ensure the interview process was accessible.

Discussions of disability require careful consideration of language to prevent exclusion or othering. Preferred terminology varies among people; for example, some prefer individual-first language (e.g., "person with a disability") whereas others view such language as implying that disability is inherently negative, and instead prefer disability-first language (e.g., "disabled person") [33]. We follow recent conventions in critical disability studies [56] and HCI by using either disability-first language or both based on how participants described their disabilities.

Because the people we interviewed were highly visible on social media (or in pursuit of such visibility), they could risk being identified by information about their age, gender, race, disability, and social media platform use. Therefore, in Table 1 and Section 3.4, we present aggregate participant demographics and minimal details about individual participants to protect their privacy.

3.4 Participant Demographics

We interviewed 20 participants whose ages ranged from 19 to 54 (mean = 30 years). In terms of gender, participants self-identified as women (11), men (4), non-binary (4), and two-spirit (1). Racial and ethnic identities included White (13), Latinx (2), Asian (1), Black (1), and mixed race (3). In terms of education level, most participants had obtained a bachelor's degree or higher; participants reported having an associate's degree (1), some college (4), a bachelor's degree (9), some graduate school (2), and advanced graduate degrees (4). More than half of the participants were employed full-time (11), and others indicated that they were employed part-time (1), self-employed (5), unemployed (1), or a student (1). One participant did not provide information about their employment status.

Participants self-identified as having a range of disabilities, including mobility impairments, mental health conditions, and chronic illnesses. An overview of participants' disabilities is summarized in

Disability Category	Participants
Mobility impairment (e.g., limb paralysis)	10
Neurodivergence (e.g., autism)	6
Mental health condition (e.g., bipolar disorder)	4
Amputee (including congenital or post-illness)	3
Chronic illness (e.g., fibromyalgia)	3
Deaf or hard-of-hearing	1
Achondroplasia	1
Visual impairment	1

Table 1: Participants’ self-reported disabilities; several participants reported multiple disabilities

Table 1. Disabilities sum to more than $n=20$ because some participants (6/20) had multiple disabilities.

Participants reported using multiple social media platforms for disability activism, with TikTok (14) and Twitter (12) being the most popular. Other platforms used were Instagram (11), Facebook (8), YouTube (6), LinkedIn (2), Twitch (1), and Tumblr (1). Almost all participants (19/20) used more than one social media platform, and some used up to 6 different platforms for their activism.

4 FINDINGS

We organize our findings according to three main aspects of visibility that cut across our participants’ experiences: (1) **needing visibility** to be a successful online activist, (2) sociotechnical challenges around **gaining visibility**, and (3) **counteracting the costs of visibility**—particularly harassment—as a marginalized group. For an overview of the themes, see Figure 1.

4.1 Needing Visibility: A Way to Achieve Activism Goals

Participants’ reasoning for using social media as a site for activism centered on accessibility, ease, and reach. Echoing prior work [38], social media was often a more accessible way to engage in disability advocacy compared to offline activism. For example, P12 had a mobility impairment and said: “I can’t be like, ‘I’m going to go to Congress and hold up a sign.’ I physically can’t do that type of advocacy.”

Social media also enabled participants to broaden their reach beyond their own physical locations so that their activism could have wider social impact. For example, P11 said:

“Every time I have a video that does really well, or a picture that does really well, and I get those comments of people saying, ‘This really helped me.’ I was just this little girl in [mid-sized U.S. city] who had no idea what she was doing. And now I’m getting to help give advice to people all around the world.”

The disabled content creators we spoke with had two main goals for their social media activism. The first goal was directed toward the general public: to raise awareness and advocate for change. The second was focused toward the disability community: to establish community bonds and share informational and emotional support.

Both of these goals required achieving high visibility online, and we discuss each in turn.

4.1.1 Raising Awareness and Advocating for Change Among the General Public. Creators wanted their content to be widely visible to shed light on the marginalization faced by disabled people and to address the under-representation of disability in public discourse. P7 spoke about the importance of using her platform to raise awareness about disability and fuel a broader social movement, saying:

“For disability rights to advance to disability justice, we need to be public on [social media] with not only what we are protesting for on a specific day, but also the obstacles and issues and discrimination and ableism we experience from the day-to-day as well [...] And I don’t think that people often have the opportunity to learn about ableism and discrimination unless it’s put in their feed.”

Similarly, P10 felt that his content normalized disability as a topic of content and conversation: “I know my normal is not everyone’s normal, but if I keep doing it, then it becomes normal.”

Achieving visibility can be particularly important for people with multiple, intersectional marginalized identities in addition to disability. For example, a Black, non-binary content creator said, “if you’re representing a group that is more marginalized or where there isn’t as much visibility or as much dialogue, I think the visibility part is important. It makes it real” (P5).

For many creators, raising awareness involved making their own disabilities more visible on social media so as to de-stigmatize them. P14, an amputee, described this goal by saying, “At the end of the day, there is that purpose of people getting to see someone look different online and being okay with that.”

In addition to spurring change on an individual level by changing people’s perceptions and awareness about disability, participants also sought structural level changes. For example, P6 said:

“One of my biggest, biggest goals in my life is to get constitutional protection for the disabled. That’s my biggest mission because...we aren’t protected by the Constitution like everyone. And the ADA doesn’t do enough either. And so, I use social media and make videos and make art to educate the masses on that.”

4.1.2 Supporting the Disability Community. Creators also posted content to support the disability community, particularly through increased representation. For example, P15 said, “Representation matters. And having an adult to look up to would have impacted me as a child. Especially one that uses a power chair like me.”

Such representation involved not only highlighting their disabilities and the challenges they’ve faced, but also their overall journeys. For example, P13 felt it was important to share his trajectory with disability:

“You could go back to March of 2021 and see that it took me 15 minutes to vacuum my kitchen and now here I am on a world tour...That’s what I wanted. I wanted that story of somebody that showcased the entire journey without knowing it was possible.”

Many activists spoke of the positive impact of providing not only representation but also emotional and informational support

Findings: Aspects of Visibility

Why It's Needed section 4.1	How to Get It section 4.2	Managing Its Costs section 4.3
Raising awareness & advocacy outside disability community Supporting individuals within the disability community	Social Strategies <ul style="list-style-type: none"> - authenticity vs positivity - showing disability and being vulnerable - being a whole person (one account) Algorithm Strategies <ul style="list-style-type: none"> - altering content - gaming/censoring hashtags Managing Accessibility	Types of Harassment <ul style="list-style-type: none"> - invalidation/hate - fetishization - technical/coordinated Responses to Harassment <ul style="list-style-type: none"> - education/awareness - alter content strategy - alter algorithm strategy - control comments - control audience - no action

Figure 1: Three aspects of visibility that surfaced in our findings: needing, gaining, and managing the costs of visibility.

within the disability community. P17 explained the benefits of doing online activism in terms of *“how many lives I get to change from either somebody who was disabled and felt alone or was at a low point in their life and found my posts and felt accepted for the first time”* and went on to note that the impact of her activism included informational support as well:

“Their lives have literally changed by my advocacy. They learned what they needed to say in order to get a custom fit wheelchair...like a hospital wheelchair which is a literal game changer for them.”

In addition to representing specific disabilities and supporting individuals, many participants also felt the need to support the disability community at large. Almost all of our participants had received messages from people with a wide range of disabilities thanking them, sharing similar experiences, and asking for advice. P16 explained this by discussing the commonalities that bring the disability community together, saying *“Even though so many disabilities are so different, the experience can be, especially with dealing with other people in society, more similar than you may think.”*

Across the board, participants spoke about having an intrinsic motivation to further their advocacy goals, and disavowed seeking visibility for the sake of being “influencers.” Some participants were able to monetize their content due to their online popularity, such as through brand deals with sponsors or by joining the Creator Fund on TikTok.¹ However, creators felt strongly about not letting monetization compromise their integrity or their advocacy. They were vocal about not being “influencers” who were “shilling” themselves (P13), and emphasized that they prioritized their advocacy goals over money. This stance was succinctly summarized by P12, who said, *“If I can make ethical money, cool. If I can’t make ethical money, then I’m not going to make money.”*

¹TikTok creators who reach a certain level of popularity on the platform (at the time of writing, those who have at least 10k followers and over 100k video views in the last 30 days) are able to join the Creator Fund, which makes them eligible to earn money on the platform.

4.2 Gaining Visibility: Sociotechnical Challenges and Strategies

Gaining visibility on social media involves negotiating complex, opaque sociotechnical systems. Our participants’ strategies for doing so can be grouped into two major types: 1) strategies that consider the social aspects of online activism, such as the preferences of one’s audience, and 2) strategies that consider and respond to the impact of technical platform features on activism. Realistically, these two sets of strategies dovetail and inform each other as participants test and observe the results of different strategies for gaining visibility.

4.2.1 Social Challenges and Strategies: Understanding Audience. Strategies for gaining visibility that highlight social factors are constructed on disability activists’ desired audience and the type of content that they believe will be appealing. Participants described a variety of strategies and guidelines for creating the right tone and framing for disability activism content.

Several strategies hinged on striking the right balance between being honest about their experiences with disability while also being sufficiently positive to keep their audience engaged. Specific strategies differed, but the perceived importance of making disabilities more visible through content creation was universal. P17 noted that an honest portrayal of disability was not only an ideological goal but a pragmatic one:

“The more somebody owns their disability, the better it is. If they kind of shy away from their disability, they don’t get as many views... just owning your disability, it kind of normalizes it and so it intrigues more people in a way.”

P9 explained why vulnerability was an important feature of their online presence by saying, *“The more vulnerable I’m getting in my posts, the better feedback, the more likes and things I’m getting.”* Although participants viewed authentic portrayals of disability as an important feature of making engaging content, they also highlighted the need for temperance. P13 emphasized the need for activist content to be enjoyable: *“I want it to be entertaining and fun so people find this interesting, but then I want to interlace that with some of that medical journey.”* When discussing their

mental health advocacy, P2 asserted that realism was not a practical visibility strategy for all disability activism: *“I know for a fact that if I start talking publicly about psychosis, or about suicidal thoughts, and things like that, that’s when people are going to stop following and slowly back away scared, basically.”* P9 suggested a different approach to sensitive content; rather than avoid it completely, they used ephemeral content sharing like Instagram stories if they felt it was important to share content that might trigger their audience. All of the above narratives highlight content decisions that are based on insights and inferences about audience responses.

Other participants called attention to meta-features of content decisions, like whether or not to maintain distinct accounts for personal versus activist content. P12 explained:

“I wanted people that may not follow or engage with disability-related content to be forced into seeing it, but I can’t tell you how many times somebody that followed me for the other type of content has said, ‘I have inadvertently learned so much because I’ve seen your other posts as well.’”

Similarly, P3 received feedback from followers that their personal content humanized their activism, and so they concluded: *“I just want to present as the most real version of myself on any of the platforms.”* Maintaining one account also furthered the goal of normalizing disabilities and gaining broad visibility for their advocacy.

4.2.2 Technical Challenges and Strategies: Understanding Algorithms.

Strategies for gaining visibility that highlight technical factors are constructed mainly on disability activists’ understandings of the algorithms that mediate the distribution of content. Participants described their theories of technical systems’ features, the labor involved in testing and refining those theories, and how this in turn influenced their strategies to gain visibility.

Disabled content creators experienced what was described by P12 as *“a very weird form of censorship,”* where disability-related content would be inaccurately flagged as violating terms of service and consequently would be taken down, despite being benign or even prosocial content. P12 recalled a TikTok video she had posted about movie casting, saying: *“I had one video that I posted where I literally just said [a character] should be cast by a Black disabled woman. And that was literally all I said, and then TikTok took the video down for bullying and harassment.”*

P15 expanded on the problem to explain that the harm went beyond the initial takedown of content, because there was no way to correct the situation:

“So our content is getting banned. And I feel like that is one of the biggest problems, because there’s no way for us to fight it. Because TikTok’s system of fixing getting banned from live[stream] or your videos is just automated. So nobody’s actually watching them.”

The urgency of circumnavigating barriers posed by automated restrictions caused creators to theorize and test assumptions about the underlying algorithms. Strategic efforts to try and understand how the algorithms work came from a combination of external sources and personal experiences. After reading about the TikTok

algorithm, P12 found that her personal data analytics also suggested that her disability content performed differently to her other content:

“It’s like, ‘I have 44,000 followers. How does this [video] have 300 views?’ It’s always the chronic illness and disability ones. I think it plays a role and TikTok admitted in the very beginning that it did suppress disabled creators.”

When visibility statistics deviate from established trends, as P12 described, creators see the platforms as treating disability like a taboo topic. *“I don’t have any proof, but... sometimes the topics regarding disability can be controversial, and so the algorithm will sometimes suppress that I believe”* (P17).

Based on observing and testing what content is picked up by the algorithm, creators were able to take some steps to mitigate the impact of suppression—although the options open to them were limited. Prior work has found that using multiple hashtags is a common strategy to get one’s content served to a wide audience, and participants used the same strategy for their activism content, as with P18: *“I use an overwhelming amount of hashtags. Literally I’m so desperate with them. I’m just like, please reach whoever.”* At the same time, creators discovered that using certain disability-related hashtags seemed associated with content suppression. Despite feeling the need to use a lot of hashtags, P18 had developed theories about which hashtags worked and which may be suppressed on TikTok: *“If I post a video about #insulin4all, it definitely gets suppressed. Absolutely. It never reaches people.”* In response to this issue, participants including P18 felt compelled to censor their hashtags and captions to avoid suppression, such as by typing ‘d1s@bility’ instead of ‘disability’: *“Whenever I spell disability or diabetes or something, I don’t actually spell it. I use the numbers and stuff [...] I’ve been very careful about what I include in my captions.”*²

Together, these experiences echo prior findings that platforms can incorrectly censor content from marginalized groups [25], and that such censorship suppressed marginalized identities [30], as also voiced by P1:

“Facebook loves to say, ‘Oh, it’s just our algorithm. We’re sorry. You were a victim of our algorithm.’ Over the years, I’ve watched a definite pattern, where it’s always the more marginalized person that gets harmed by this.”

Such technical challenges can dissuade people from using a social media platform altogether. P7 had used several platforms for their personal activism and in a professional capacity with a disability-focused non-profit organization. She and her organization decided to leave TikTok after experiencing discrimination on the platform:

“For a while, we were good with TikTok, but TikTok has been rather discriminatory against disabled people and disabled content creators. So we made the decision to not continue with TikTok for that specific reason, because we don’t want to contribute to a platform that is discriminatory towards the creative, disabled people.”

P7’s response takes a strong stand for disabled people by choosing not to participate on a platform that they perceive as being

² Although participants reported creating variants of hashtags to avoid suppression, all creators we spoke with used our recruitment hashtags at least some of the time, despite concerns that these hashtags were being suppressed.

discriminatory. At the same time, it also results in the reduced representation of disabled people on the platform.

4.2.3 Technical Challenges and Strategies: Navigating Accessibility. While participants' stories about technical challenges primarily focused on navigating algorithms, some participants also had to contend with two types of challenges around accessibility: navigating social media platforms that they found personally inaccessible, and ensuring that the content they produced was accessible to their audience.

Participants had to work around a range of accessibility challenges when using social media. Some platforms require fine motor skills to create and edit content, which could be challenging for participants with certain disabilities. For example, P14 is an amputee who found it difficult to make the *"incredibly small, painstaking thumb movement[s]"* that are required to create videos on TikTok, particularly since his phone also did not interact well with his prosthetic hand. As a result, such participants had to invest more time and effort than other users in producing content, as P4 attested: *"It takes a lot of physical dexterity to make even the most simple of the videos. [...] Those take 20 to 30 minutes to edit."* P4 was also hard-of-hearing, and thus experienced difficulty interacting with audio-only content when captions were unavailable, mentioning that they *"have to turn the hearing volume up some... pause it... watch it multiple times. It's often not worth the trouble."* For participants who experienced high levels of fatigue, posting on social media could be especially draining, as with P13: *"Every little thing takes a lot of energy and it can be hard to talk or tell the story or whatever."*

Experiencing such accessibility challenges could at times influence participants' choice of platform; for example, P19 eschewed platforms that were cognitively inaccessible, saying *"I prefer Facebook mostly due to the fact that Twitter and TikTok are cognitively inaccessible for me. [...] [On] Twitter, the way comments and conversations are stacked and move quickly is just really, really difficult for me to follow in a way that makes sense."*

In conjunction with navigating accessibility issues themselves, participants were also concerned about making their content accessible for disabled audiences and frustrated by the difficulties they encountered in doing so: *"It's tough because while you're trying to get your message out there, you know that your message is not fully accessible to the people that you may want to reach"* (P18). For example, creators were concerned that the lack of auto captioning on some platforms excluded Deaf audiences, and that comment sections could be inaccessible to people with visual impairments.

Overall, P7 summarized the need for greater accessibility of content on social media, saying:

"Even us in the disability community, we really could do a lot better at [...] understanding how to make things accessible to everyone, like using plain language so that everyone can understand what's happening, using images, describing those images, but also having visual contrast in those images so that people with low vision are able to see them, or [ensuring that] people who have seizures [are not exposed to] a bright triggering image."

These challenges around making accessible content were not only frustrating for participants but also impacted who could access

their content, and thus ran counter to their activism goals of greater inclusion and representation.

4.3 Counteracting the Costs of Visibility: Harassment Risks and Responses

Visibility comes with consequences, especially for people who belong to a marginalized group. Engaging in activism on social media requires creators—along with their content—to be highly visible to a broad audience, which can open them up to a wide range of risks and harms. Most of our participants had experienced harassment and other negative interactions that they perceived as going hand-in-hand with online activism. As their popularity among viewers increased, negative interactions increased as well, as explained by P11: *"If you have a platform that brings in viewers outside of your follower base on a larger level... it's a numbers game of getting more negativity."*

Harassment took a toll on participants' well-being. When talking about doing activism work on social media, P1 said, *"It has changed me a lot. It's very stressful. At one point, I actually was put in the hospital because of the stress over being attacked like this by a lot of people."* Despite the enormous stress from these attacks, creators feel it is important to continue their work. As P6 said, *"If people [...] want to try and ruin my activism work, then if I stopped doing my activism work, that's going to give them what they want. And I can't do that."*

As a result, many creators faced a tension between needing to be visible to spread their message and shielding themselves from harassment. In this section, we discuss the types of harassment and related risks faced by disabled creators and how they respond to these risks.

4.3.1 Types of harassment and negative interactions. While many individuals—both marginalized and not—experience online harassment, participants experienced a few types of harassment that specifically centered on disability. These involved (1) invalidating, ignorant, and hateful messages about disability, (2) sexual harassment and fetishization of disability, and (3) the use of targeted attacks to suppress disability content.

1) Invalidating, Ignorance, and Hate. Participants received a slew of negative messages from their audience that invalidated their disabilities and contained ignorance and hate—a phenomenon that some attributed to *"the toxic atmosphere of social media"* (P2).

While disabled people often receive messages that invalidate their disabilities on social media [53], the fact that disabled activists put in additional effort to make their disabilities highly visible to a broad audience could also be used against them to further invalidate their disabilities and to question their motivations. For example, P8 talked about some of the messages they had received:

"They say that I'm faking it for the likes, for the follows. I've had people tell me, 'You're faking your disability,' 'You're only doing it for followers,' 'You're only doing it for likes.'"

Participants also received extremely hateful messages, including death threats. Harassment was so common among disabled creators that P18 pointed out how normalized it had become, saying, *"Do you*

remember a time when it was a big deal to get a death threat? That was not a normal thing. And now I feel like it's just so normalized."

2) *Sexual Harassment and the Fetishization of Disability.* Disabled creators also have to contend with sexual harassment, including the fetishization of disability. Several participants spoke about their experiences with "devotees"—people who fetishize disabled people and seek them out online.

This disability-focused sexual harassment took two main forms. In many cases, participants received explicit content in direct messages or comments. For example, P9 described the lengths to which people go to sexually harass creators, saying *"I get more creepy DMs from people I don't know, so those are just ... Yeah, people are weird. People are really weird...I got...a voice DM of [someone] basically jacking off."* Others had discovered that their content had been reposted on accounts dedicated to the fetishization of specific disabilities, as with P13: *"Acrotomophilia, which is sexualizing amputees... I see my stuff appear in profiles of amputee models [and] it's just like, is this for awareness and advocacy or is this for sexualizing things?"*

Participants had to take extra care to avoid such interactions or mitigate these risks. Sexual harassment could come under several guises and was thus hard to avoid. For example, P11 described having an innocuous conversation with a follower that unexpectedly turned negative: *"I've actually been totally catfished by somebody like that who was talking to me and I thought they were normal and it turns out they were just disability obsessed [with] the wheelchair."*

3) *Technical or Coordinated Attacks Targeting Disability.* In addition to harassment in the form of direct messages and comments on their content, participants also had to contend with technical or coordinated attacks.

Individual users could suppress disabled creators by reporting their accounts to shut them down. In this way, bad actors were able to leverage platforms' own features in order to enact a chilling effect on disabled creators, as in the case of P19:

"I have been Facebook banned for asking someone to stop repeating racist comments. That individual claimed I was harassing them by saying their comments were racist—which they were—and I was banned for three days from Facebook while the racist commenter was able to use the service."

In addition to receiving account bans, participants also reported having their content removed for inaccurate reasons, as with P12: *"There was a video where I was talking about ableist experiences and they took it down for harassment."*

Disabled creators also experienced coordinated attacks where people banded together to suppress disability-related content online. For example, P15 described a community on Reddit that is organized around suppressing disabled creators on TikTok and other platforms, saying:

"They're from Reddit. They find a creator, they put their name in, and then they go over and they spam report their accounts until they get banned. They're specifically targeting disabled creators, and mass reporting us."

4.3.2 *Responses to Harassment and Associated Costs.* Our interviews revealed that disabled content creators respond to harassment

in a variety of ways, and that while these responses may help mitigate harassment, they also had costs. In this section, we discuss six main responses to harassment, and the costs they incurred to creators' visibility, content, and well-being.

1) *Educate and Spread Awareness.* Some creators used the harassment they received as an opportunity to educate people about the prejudice and ignorance faced by disabled people. In many cases, this strategy meant participants would choose to not delete the negative comments they received in order to make ableism and hate more visible, as explained by P11:

"I want people to see those comments. I want people to see when somebody says something that isn't kind. And it's not because I want them to believe it, but it's because I want them to know it's there. And I don't want people to think that we're in a world where [...] everyone is accepting people with disabilities because we're not. And the only way we move forward is by creating awareness and creating education."

Some participants also addressed their harassers directly to educate them. Doing such educational work in the face of harassment often required participants to put aside their personal feelings; for example, P12 said, *"The biggest thing I struggle with is how to respond because there's a part of me that is like, 'I want to demolish you. I want to rip you to shreds.'" However, she continued by explaining why she would set aside these feelings to further her advocacy:*

"We already in society do such a terrible job educating kids on disability. And for some kids, maybe seeing one of my videos is genuinely the first time they've heard about invisible illness or ambulatory wheelchair users. And if they ask a question that has good intentions but is poorly worded, and [I reply] back and shit on them, then they're not going to have a very nice attitude towards people with disabilities."

Many participants also wanted the focus to remain on educating people about disability issues rather than protecting themselves. It was common for participants' followers to defend them on social media, and participants took steps to ensure their followers would not attack the harassers, as explained by P17:

"If I reply to [a harassing comment], sometimes my followers will go to that person's page and harass them or bully them. So I always say 'don't send any hate to this person', or I'll try to block out their username so they can't go to that person and do the same things that they were doing to me because that doesn't solve anything. I share what the comment is to show, 'Yes, this is something that I actually get, but also I want to remind you guys this is an educational moment.'"

2) *Alter content strategy.* Participants also combated harassment by altering their content—either by including content that would deter harassment, or by excluding content that would be more likely to receive harassment.

Participants found that they could deter harassment if they included specific types of content. For example, since people with invisible disabilities often receive comments that question their disabilities, finding ways to make disabilities more visible could help

avoid harassment. This tactic could also be employed by people with visible disabilities that may not be visible in their content. For example, P15 was a wheelchair user, and would often choose angles that would show her wheelchair in her TikTok videos, saying *“I get more invalidation when they can’t see my wheelchair.”*

Alternatively, creators also excluded content that seemed more likely to receive harassment—for example, they chose to not talk about controversial topics. Several participants were selective about the content they shared online more broadly to avoid negative interactions: *“I self-censor a lot. I take a lot of care about what I post, out of fear of what people will think and say, basically”* (P2).

3) *Alter algorithm strategy.* Participants also drew a connection between the harassment they faced and the algorithms underlying social media platforms. This was particularly true in the case of TikTok, which makes hyper-personalized content recommendations to users based on inferences about their preferences [58]. Participants theorized that they received more harassment when the algorithm served their content to a broad audience that may not be receptive to marginalized identities, including those along the lines of disability, race, and sexual orientation. In these cases, creators would attempt to get back to the “right side of TikTok”—i.e., to a more receptive audience. Based on the theory that the algorithm would direct their content toward people who are more likely to engage with it, participants would post video appeals to ask pro-disability people to engage with their content through likes or comments in order to redirect the algorithm. After experiencing a lot of harassment from a viral video, P4 described their attempt to get back to the “right side of TikTok”—in their case, users who are either members or allies of multiple marginalized communities—saying:

“That was the video that had gotten on the wrong side of TikTok. And I had seen so many other people making ‘I got on the wrong side of TikTok, please help’ videos that I figured that well, can’t hurt. Lo and behold, I put that up and I got back on to the right side of queer TikTok, and [specific disability] TikTok, and [religious] TikTok within like 24 hours. [...] Yes, it’s effective. I don’t know why, but it is.”

Based on the theory that the TikTok algorithm boosts content that receives a lot of engagement, some participants talked about a ‘silver lining’—that negative comments could contribute to their content going viral, even if for the wrong reasons. These creators used humor to deal with harassment; for example, P8 described with a touch of irony how she responded to people harassing her:

“My comments back to them are like, ‘Thanks for the engagement. It’s only giving me more views, it’s only giving me more numbers, so hey. Thank you.’”

In addition to having their content boosted through such engagement, some creators also found that they could receive more money from the platform from higher engagement:

“I’ve noticed when people comment a lot, it sometimes will give you more money. I don’t know if that’s true, but I noticed that one day, because I had a video where a lot of people were commenting and getting into these fights with each other. And I was like, ‘Oh whoa, this is a lot of money. This is insane.’ I was like, ‘I didn’t know

that my haters would really be financing me like this. But thank you.” (P18)

However, responding to the algorithm’s role in harassment was a costly endeavor. Even if participants gained additional visibility through harassment, they had to experience extremely unpleasant interactions, which took a toll on their well-being. Attempting to get on the ‘right’ side of TikTok also required additional labor on top of managing the existing challenges in gaining visibility as detailed in Section 4.2.

4) *Control comments and feedback.* Participants also mitigated harassment by controlling people’s feedback on their content. They did this in a variety of ways, including using automatic filters, manual filters, deleting comments, or turning off comments entirely; each of these strategies also had associated costs.

On many platforms, people can use filters to avoid harassment before it occurs, though this strategy requires effort in terms of developing a list of potential bullying keywords to filter, along with their many variations. On TikTok, a way of managing comments is to manually approve each comment before it is visible to the public—however, this is even more time-intensive, and does not prevent the creator from experiencing the harassment in the first place. P4 described how they chose which strategy to employ:

“I have my comments set to filter all comments. So nothing goes up without me approving it. I’m still having to see them. It’s not the best solution, but it’s the only solution TikTok currently gives us. Some people use comment, keyword filters and that just filters out comments with a specific keyword in it but I found that was much more work than just filtering all comments.”

However, deleting or turning off comments had an additional consequence—creators theorized that these strategies were penalized by the algorithm, and ultimately lowered their visibility. P15 explained this theory by discussing the analytics on a TikTok video where she had turned off the comments:

“I’ve only gotten 388 likes on that video, and I was getting thousands per hour. Thousands. So I can already tell you by turning those comments off today, it’s already impacted [the number of likes].”

This algorithmic penalty for self-protection could impact creators in one of two ways. Some creators decide to delete or turn off comments despite the cost to their visibility by prioritizing their well-being. When we asked P15 to explain her rationale for turning off her comments despite the cost to visibility she described in the quote above, she said:

“One of the reasons why I turned off my comments, and started deleting and getting rid of them, [was] because somebody was just like, ‘it’s not reaching the people you want to reach anyways.’ [...] At this point my sanity is way more important than how many views I get.”

Alternatively, some creators choose to not delete or filter their comments to avoid being penalized with lowered visibility. While this decision prioritizes their activism, it also harms their well-being and leaves them vulnerable to further harassment.

5) *Control audience: blocking, restrictions, private mode.* In addition to controlling comments, content creators can also control their audience by limiting who can see their content. Participants reported blocking accounts, restricting specific accounts, and using private mode to limit their visibility more broadly.

When participants blocked accounts that harassed them, they found that harassers could circumvent this strategy by opening a new account. P17 explained how an Instagram feature that restricts rather than blocks users was helpful in avoiding harassment, though this feature did not exist on other platforms they used:

"Instagram has a restrict feature [so] I just don't have to see their comments. Nobody has to see their comments, but they think that everybody can see their comments. The restrict feature is really great because it used to be if you would block them, somebody could just create a new account and go continue to harass somebody. But with the restrict feature, they think they still have full control, but you've taken the control away."

Some social media platforms allow content creators to set their accounts to private mode so that only their approved followers can view their content; however, this also comes at the cost of their visibility. The decision to stay private or public was a complicated one, as explained by P9:

"The debate I have is if I make myself private, then I'm not going to get as many followers. I used to be private until I really started saying, 'You know what, I'm going to do this.' Then I made myself public again, so I kind of go back and forth, mainly to avoid the creeps."

In addition to taking steps within their control to limit their audience—such as blocking and restricting accounts—creators can also report accounts so that the social media platforms can take action and penalize harassers. However, reporting as a strategy is not always successful; P12 described the frustrations around reporting accounts, saying:

"There's an account [...] that has been harassing me and other chronically ill folks on TikTok for like weeks now and I can't tell you how many people have reported them and they're still there. They're still there."

6) *Take no action.* A subset of participants took no action to mitigate or avoid harassment, even if they were bothered by it. Despite harassment having had an extreme emotional toll on her, P1 said, *"My way of dealing with it is just to ignore it."* Some participants viewed harassment as an inevitable consequence of engaging in activism, and others thought that pleasing everyone with one's content was an impractical goal, as stated by P10: *"I can't cater to everyone and it's exhausting. So I just do me and I know how to do me, best."*

5 DISCUSSION

This study explored how disabled content creators engage in online activism and navigate challenges. Visibility surfaced as a recurrent theme that motivated creators and influenced their actions, but also engendered challenges, underscoring McCosker's observation that "Visibility is the scarce and highly contested currency upon which new modes of digital activism or civic participation depend" [43,

p.1]. Treem et al.'s [60] contention that visibility is central to all computer-mediated communication suggests that understanding activities related to visibility must be a foundation for any scholarship that aims to understand online activism. Many scholars have also highlighted the political nature of visibility; Brighenti [6] reflects on how visibility can disadvantage minoritized groups, for example, when representations of immigrants as criminals are made highly visible. Bitman's work on disability activism depicts an effort to retake control of the public narrative around disability [3]. Our findings similarly reflect a desire for control over visibility—the online activists we interviewed not only pursued visibility, but pursued control over the narrative that visibility creates.

5.1 The Double-Edged Goal of Visibility

Many of the disability activists we interviewed wanted to make disability visible to people both within and outside of the disability community, and they were drawn to social media in part because of its ability to reach a broad audience. The use of social media to document disability and ableism echoes efforts around disability activism in traditional physical spaces. For example, by casting their wheelchairs aside and climbing up the U.S. Capitol stairs to protest for their rights, disabled activists made the inaccessibility they face in daily life hyper-visible to the public through media coverage of the "Capitol Crawl" [21]. Similarly, on social media, disability activists are able to shine a light on the ableism they face in daily life and render it hyper-visible to a broad audience in a bid to raise awareness and effect social change.

Yet, visibility on social media in the context of disability is complex and comes with both opportunities and costs. Faucett et al. [19] describe the complex relationship between visibility and disability in their examination of assistive devices, such as heart monitors, canes, and wheelchairs. The stigma around assistive devices can lead people to eschew using them; at the same time, such devices can also be invaluable in bringing visibility—and thus legitimacy—to disability [19]. This can be particularly important in the case of invisible disabilities that are questioned and invalidated in society [53]. As a result, Faucett et al. [19] caution that visibility in this context is a nuanced concept, and that making assistive devices socially invisible may not be desirable, and may actually create challenges for some users. Importantly, the performative nature of social media creates a context within which disabled content creators have *choices* about when and how their disabilities are made visible. Yet the visibility of disability (and assistive devices) on social media remains complex and fraught with challenges: being hyper-visible on social media helps expand the reach of disability activism, but visibility is also a key driver in the harassment of disabled content creators. Further, our findings show that certain strategic kinds of visibility can also mitigate this harassment by conferring legitimacy and generating social support for disabled content creators, and that even bringing visibility to *negative* online incidents—notably ableism and harassment—can in some cases be beneficial and help disabled activists further their activism goals of education and awareness.

5.2 Navigating Sociotechnical Challenges as a Disabled Social Media Activist

We observed how activists' strategies for gaining and controlling visibility and managing risks and costs can involve thinking about novel technologies like algorithms that filter and rank content, but remain deeply sociotechnical and contingent on creators' understandings of both social and technical aspects of their activism.

Prior work has examined new forms of discrimination and bias that emerge as social interactions are increasingly mediated by algorithms. For example, research finds that users on TikTok believe the platform algorithmically suppresses marginalized identities [30], and that marginalized users are compelled to find ways to circumvent being rendered "algorithmically invisible" [14]. Similarly, we found that beliefs about how platforms filter and rank content pervaded activists' strategies to gain and manage visibility, but we also observed that these strategies were *sociotechnical* in nature. Like DeVito's participants from the LGBTQ+ community who developed theories of algorithms to inform the careful work of self-presentation online [11], our participants developed and tested theories about how to create effective content and modified their practices accordingly. Importantly, they explained successes and failures of creating well-received content in terms of how people reacted (if they believed the content felt good to their audience), how people responded within the system (if their audience commented or liked), and how the system used those responses as input. Reaching a desired goal—whether trying to raise the visibility of posts, cultivate a specific audience, or eliminate a problematic segment of their audience in response to harassment—involved sociotechnical reasoning that unites theories of people with theories of technology.

Understanding how people navigate an online world in which their social lives are mediated not only by norms and expectations but also by unseen but deliberate, human-designed systems has become an object of interest for human-computer interaction as a field. Whereas discussions about designing explainable systems have centered on decision support in high-stakes industries like finance, law, or healthcare [62], the impact of inscrutable systems on social interaction has been largely addressed through research on how people respond, through questions such as: What theories do people hold about these systems [12, 17]? How might such theories impact online activity [11]? When it comes to social media platforms, there has been relatively little discussion of how explainable systems might better facilitate self-presentation, advocacy, support seeking, and other features of online social interaction. The HCI community has an opportunity to problematize explainable systems for social interaction. Explainable AI is often cast as a challenge related to decision support systems. In the context of social media, it may be more apt to set a goal of designing systems that are amenable to theorizing.

Finally, navigating sociotechnical challenges in their many complexities requires a great deal of invisible labor [59]. By needing to cater to their audience as well as navigate the opaque algorithms and accessibility challenges on social media, disabled activists are faced with an "invisible cost of disability" [16]. Catering to these sociotechnical demands is a complicated and stressful task, and it may also have an acute impact on disabled content creators who already face major life stressors.

5.3 Mitigating Harassment while Maintaining Visibility

Many social media activists aim to achieve high visibility online in order to create change, and this visibility makes them more susceptible to harassment. Our interviews revealed that disabled online activists face multiple types of harassment, including invalidation, ignorance, hate, sexual harassment, fetishization, technical attacks, and coordinated attacks.

Further, visibility impacts various subgroups differently. The disability justice movement has called attention to the fact that people with multiple marginalized identities face compounding challenges [57], and similarly, we found that our participants experienced harassment differently based on other marginalized attributes in addition to disability; this was true of participants of color, LGBTQ+ participants, and women. This is in line with prior work that finds that some disabled groups can be at higher risk of being harassed than others based on race, gender, and age [55], and shows that these findings extend to social media.

Participants described several strategies for counteracting harassment (the primary cost of visibility) with the aim of mitigating harassment while maintaining visibility. Heung et al. report two main ways in which disabled social media users respond to ableist microaggressions online—(1) deleting, blocking, and reporting content, and (2) changing social media use [28]. We build on this work by presenting an in-depth look at six responses used by disabled social media activists in the face of ableist harassment and how their responses are influenced by their commitment to disability activism and the need for visibility.

Further, our analysis of these responses to harassment revealed a set of key trade-offs based on an inverse relationship between self-protection and visibility. If participants chose to respond to harassment in a way that protected themselves from harm, it decreased their visibility, and vice versa. As a consequence, disabled content creators are faced with three key trade-offs—prioritizing visibility at the cost of self-protection, trading visibility for self-protection, and choosing self-protection at the cost of self-expression. These trade-offs are summarized in Table 2, and we discuss them in greater detail next.

5.3.1 Visibility at the cost of self-protection. Disability has historically been rendered invisible in society through the exclusion of disabled people, including in mainstream media. The unique context and history of disabilities and disability activism motivate people to be extremely visible despite high costs like harassment. Social media is an accessible way to represent disabled individuals and describe disabilities; the resulting increased visibility is critical for continued impact. This causes many disabled activists on social media to choose to respond to harassment in ways that prioritize visibility despite increased vulnerability. Through purposeful in-action as well as using their own harassment as opportunities to educate others, disabled activists preserve (and boost) visibility at the personal cost of decreased self-protection.

Many activists we interviewed chose to educate their audience about harassment by letting the harassment stay visible to their audience. While activists hoped that this would help combat harassment in the long term, it also increased their own immediate vulnerability. Research finds that marginalized groups can often take

Harassment Response	Trade-off
Educate and spread awareness (e.g., draw attention to ableist harassment)	Visibility at the cost of self-protection
Take no action (e.g., be resigned to receiving harassment)	Visibility at the cost of self-protection
Alter content strategy (e.g., self-censor sensitive content)	Self-protection at the cost of self-expression
Alter algorithm strategy (e.g., get on the “right side of TikTok”)	Self-protection at the cost of visibility
Control comments (e.g., filter or delete comments)	Self-protection at the cost of visibility
Control audience (e.g., block or restrict viewers)	Self-protection at the cost of visibility

Table 2: Disabled Content Creators’ Responses to Harassment and their Trade-offs

on a complex and collective responsibility, as in the case of LGBTQ+ parents [4]; many disabled activists we spoke with voiced similar feelings of responsibility that prioritized the long-term safety and inclusion of the disability community over individual needs.

5.3.2 Self-protection at the cost of visibility. Disabled activists may at times prioritize self-protection over educating people about ableism, and in these cases, they often pay a penalty in the form of lowered visibility. For example, if activists respond to harassment by deleting ableist comments or turning their comments off, systems that are built to identify and elevate “interesting” posts (e.g., posts that receive many comments) will effectively punish them for doing so. A few activists we interviewed had felt compelled to leave some platforms entirely; when disabled creators are forced off platforms in this way it reduces not only the visibility of specific disability-related content but disability representation on social media overall.

Privacy controls allow social media users to control their audience online, and thus, improving privacy controls and settings is a common recommendation to reduce harassment, particularly in the case of marginalized groups [52]. However, for activists whose goals depend on visibility, regulating audience engagement can have the detrimental effect of reducing visibility. As we pointed out in the opening paragraphs of this paper, it has been postulated that social change necessitates social risk. We suggest conversely that social media can and should be designed to reduce risk and, in doing so, enhance opportunities to effect change. If social media are to be effective sites of activism and places where real social change is precipitated, such sites cannot be places where marginalized voices are threatened and in response, made even less visible. Privacy controls can protect people without limiting the reach of their messages, but this requires designers to recognize that visibility and privacy need not be at odds. For example, one might imagine privacy controls that allow social media users to choose enhanced protections to help eliminate personal identifiers like geographic tells in posted content or potential links to outside identifiers that can protect the poster without curtailing their audience. Another design goal could be algorithms that recognize and compensate for efforts to block or limit the influence of harassers, so as not to reduce the visibility of the target.

5.3.3 Self-protection at the cost of self-expression. Whereas the prior two sections discussed trade-offs between self-protection and visibility, in this section we examine how self-protection sometimes comes at the cost of saying what one wants to say. Being truly authentic online requires sharing sensitive and negative content and thus can involve risks and harm, particularly for marginalized

groups. Participants spoke about the need to produce authentic content in order to be effective activists, but also perceived constraints on how authentic they could be about disability without losing their audience or generating negative comments. This is in line with the online authenticity paradox that describes how true online authenticity can be out of reach for many people, particularly those who are marginalized, because it requires sharing negative or sensitive content with a large audience [26].

When marginalized populations are harassed and trolled, they may respond by becoming silent or changing the nature of the content they create; in this way, harassment brings about the silencing of marginalized voices in the digital public sphere, thereby changing its character [45]. Further, concealing one’s disability may protect creators from external threats, but it can negatively impact their own psychological well-being [61].

Self-expression is affected whenever someone changes what they want to say in order to protect themselves. Many disabled people have historically felt compelled to limit or strategically manage disclosures about disability to avoid stigma, harassment, and discrimination in settings including the workplace [18], social media [53], and dating [49]. Similarly, we found that disabled social media activists sometimes altered their self-expression in order to stay safe online. This self-expression was influenced by considerations of stigma and harassment, as well as by theories about how to effectively gain visibility in light of sociotechnical suppression. For example, one participant made sure her wheelchair was visible in her posts to avoid receiving invalidating comments; assistive devices can often be used in this way to increase the visibility of disability in social settings, which in turn can legitimize disability and mitigate harassment [19]. In purposefully posting content that showed her wheelchair, this participant tweaked her content not because showing a visible wheelchair was important to her self-expression, but because she felt it protected her from harmful responses. When disabled content creators are compelled to change the stories they tell to protect themselves from the actions of harassers and trolls, they do so at the cost of authentic self-expression.

5.4 Limitations and Future Work

Like all interview work, our findings are bounded by the experiences of the people we talked to. We sent messages to online activists to recruit participants, and we cannot know the biases introduced by non-response. All our interviews were with individuals in the United States; other regions likely have different disability-related norms, laws, and popular platforms that should be explored in future research. We only recruited participants from TikTok, Instagram, and Twitter; while several participants also discussed their

use of other platforms, we did not systematically collect comparative data on platform features. Future studies should systematically examine how specific features of different social media platform designs support or do not support disabled content creators. We also found that some creators tweak hashtags to avoid algorithmic suppression; future researchers in this space should be cognizant of this practice and use a variety of original and amended hashtags when recruiting participants.

6 CONCLUSION

This study centered the experiences of disabled content creators, and sought to understand how they navigate activism on social media. Our findings highlight the centrality of visibility in social media activism—that visibility is a necessary component of disability activism online, that disabled activists face several roadblocks in gaining visibility, and that high visibility also presents several challenges that disabled activists must counteract. We explain the sociotechnical nature of strategies that activists use to gain and manage visibility by leveraging and testing personal theories about algorithms together with theories about audiences.

We also identify three main forms of disability-related harassment faced by disabled activists, and six ways in which they respond to such harassment. Based on our analysis of these responses, we show how disabled content creators are faced with a set of key trade-offs between furthering their activism goals and protecting themselves from harm.

Contrary to some assertions that online activism is low risk [22], our findings paint a picture of disability activists on social media taking real risks and creating real change in the world. Our discussion raises questions about how social media can be designed better to facilitate real change with lower risk, and to help people engage in sociotechnical theorizing about how to best leverage social media toward this end.

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