

Understanding and Amplifying Labor among Content Creators with Disabilities

Katya Borgos-Rodriguez
kborgos@u.northwestern.edu
Northwestern University
Evanston, Illinois, USA

ABSTRACT

My research combines field observations, interview, and design exploration methods to understand content creation practices involving disabled creators and, at times, their caregivers and collaborators. This analysis investigates the varying ways in which disabled creators approach their labor across different creative modalities and spaces. Further, it reveals how their practices might be shaped by broader social issues around disability such as ableism and marginalization from traditional workplaces. In doing so, I uncover the ways technology can both support and hinder the goals of these creators. Insights from this work can inform future directions and opportunities for research that supports and recognizes the contributions of disabled creators.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in accessibility**.

KEYWORDS

accessibility, content creation, creative work, monetization, online marketplaces

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1 INTRODUCTION

Accessibility has garnered increasing attention from Human-Computer Interaction (HCI) scholars in recent years [18]. However, much accessibility research continues to be driven by a “deficit” narrative, where technologies are designed to “fill gaps left by disability.” [15, 24, 26]. Technology design often centers independence as the end-goal, neglecting the rich social interactions that shape access [3]. In many cases, designers also position themselves as “experts,” while people with disabilities are assumed non-experts or non-designers. As a result, technological “solutions” might not only lack input from disabled people, but may also erase their efforts as makers and innovators creating accessible interactions in a world that

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does not prioritize access [14]. Scholars have called out the ableist¹ roots in these approaches to technology design, which are harmful to disabled people as they question their identities and challenge individual capacities [26]. As such, there is much that accessibility researchers in computing can do to realign our existing practices and better value the contributions of disabled creators.

In my PhD research, I move beyond the need to “fix problems” and instead highlight the ways in which disabled individuals create access, educate broader audiences and express themselves through their creative work. I also study how their non-disabled collaborators approach content creation as a way of understanding how others are involved in the process of creation [8, 9]. To achieve this, my work engages with disabled creators and their collaborators through field observations, interview, and design exploration methods to understand their varying creative processes, goals, and the role of technologies in their work. I define disabled creators as individuals who engage with creative work and identify as disabled, whether publicly or privately. Similarly, I define content creation broadly, referring to both digital and physical creative work including, but not limited to, writing, painting, weaving, and video production. To date, I have studied two contexts involving disabled experiences and content creation. First, I analyzed YouTube content uploaded by parents about their children with disabilities. Second, I studied creative work among a community of blind weavers and their sighted collaborators. Through these studies, I analyze the ways in which content creation encourages creative expression and fosters community among individuals with shared life experiences. My work also highlights content creation as a medium where both disabled creators and collaborators share the labor of educating audiences on disability-related issues, and gain financial support from their work. At the same time, there is room to unpack tensions between monetizing content related to disability, how disabled creators manage their identities with respect to their work, and how their practices might intersect with broader social issues around disability. These insights are crucial in the collective effort to design technologies that support disabled creators’ goals, while also respecting the expectations and boundaries they have set around technology use.

2 RESEARCH APPROACH AND QUESTIONS

Throughout my work, I engage with literature in Computer-Supported Collaborative Work (CSCW), HCI, assistive technologies and disability studies. I draw from prior work in these spaces, which has

¹Ableism is defined as “a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human.” [6]

studied how individuals from marginalized backgrounds find support within communal spaces [1, 10, 21], express their identities through art and play [11, 17, 20], and designed technologies that center creativity (e.g., [23]). I extend this body of literature by studying how disabled creators and collaborators promote their work across various platforms to obtain broader exposure and narrow in on the tensions that arise when expressions of disability have the potential to become sources of income. My work also investigates what it means to design technologies that support disabled creators' goals. Yet, I engage with technology design cautiously, questioning the role of technology in creative work throughout the process and challenging notions that technologies are always a positive or even desired solution to accessibility barriers. To accomplish this, I employ observations, interviews, and design exploration techniques across modalities (i.e., online and offline) and analyze this data following a grounded theory approach [7]. I plan to analyze creators' work environments, materials, completed artifacts with their surrounding context, and interactions with others in the space. Collectively, my dissertation work addresses the following questions:

- How do disabled creators engage in creating and sharing original content?
- How might people express their relationship to disability or their disabled experiences through creative content?
- How does ableism manifest in and shape disabled content creators' practices?

3 RESEARCH OVERVIEW

Below, I summarize my work to date and outline opportunities for further exploration that lead into the next phase of my work.

3.1 Study 1: Analyzing YouTube Content involving Children with Disabilities

Parents and children with disabilities face stigmatization, which can result in feeling isolated even from their immediate social circles [13, 25]. In an effort to find support, many parents join specialized online groups [1, 2, 19], where they can form connections with other families over shared experiences. Although prior work has studied how parents of children with disabilities participate in online communities where exchanges are primarily text-based, YouTube brings additional questions around community building within a video-sharing platform. In this first study, I examined how parents of children with disabilities (e.g., autism, ADHD) created and managed YouTube channels that revolved around their experiences as a family [5]. My detailed analysis included public YouTube videos, channel profiles and interviews with the parents managing these channels. Through vlogs, Q&A, and other types of videos, parents wanted to capture and broadcast "real" life to provide content that is relatable to other parents of disabled children, and potentially educational to a broader audience. Parents promoted channels and videos about their children's disabled identities and experiences, choosing channel names and content that reflected these (e.g., *MyAutosomeFamilyLife*, *AutismMother*). In some cases, parents generated revenue from their channel content, which they explained helped support their families. This caused notable discomfort among viewers, especially when some video content

involved showing children in distress (e.g., experiencing a sensory meltdown).

This study provided insights on how disability is expressed in a public online space, and the impact this practice can have on broader audiences. At the same time, it revealed tensions around disclosing and expressing disabled identities through the act of creating, as well as monetizing these experiences. These complexities are heightened when we consider who is (i.e., non-disabled parent) creating this content. It is still unknown whether and how the goals around participating in content creation might differ between collaborators and disabled creators themselves. Finally, this study also raises the question of whether and how platforms can support the creative and educational goals of creators without bringing harm and reifying existing social stigma. Study 2 addresses and helps bridge these gaps through an exploration into accessible crafting among blind and visually impaired weavers.

3.2 Study 2: Investigating Accessible Crafting through Audio-Enhanced Weaving

Many studies involving accessibility in technology position disabled individuals as recipients, neglecting their capacity to create and participate in design [12]. Much accessibility research in design and making has focused on developing accessible high-tech tools (e.g., 3D modelling as in [23]), leaving opportunities to investigate more traditional approaches to content creation. Wanting to explore this space, I analyzed creative labor among a group of blind weavers and their sighted instructors to understand weavers' work process, how they value weaving as a form of creative work, and whether new technologies might better support their weaving experiences [4]. Through observations, field notes, video recordings and interviews with community members, this study revealed how weavers attend to the material properties of their workspaces to complete their work and boundaries they have set around technologies with respect to their individual and communal practices. Weavers value their creative labor not only for its relaxing and fulfilling experience, but also as a form of income via selling finished goods. The weaving studio is also valued as a space that brings together individuals with shared interests and identities. Sighted collaborators played an instrumental role in creating access and helping weavers sell their creations. Together, these insights informed the design of *Melodie*, a loom in which weavers can create accessible crafting experiences through audio-enhancements that play upon each interaction. By making these enhancements customizable, weavers can decide whether and how to incorporate this tool into their process. An exploration with various stakeholders revealed different ways in which weavers imagine integrating *Melodie* into their practice. This included thinking about new forms of content creation, such as weavers working alongside sound artists to create musical pieces while simultaneously developing a woven artifact.

My analysis of weaving helps inform future technologies that support varying forms of engagement with accessible content creation tools, are respectful of users' boundaries around technology use, and prioritize agency in the creative process. Yet, other aspects of creative work among disabled creators remain less explored. At various instances throughout this study, some weavers expressed a desire to have their disabled identity associated with their creations,

and to have their work recognized among the broader public (e.g., social media, local radio stations). There is still much to learn about preferences and consequences in disclosure of disabled experiences alongside personal work. In a society where capitalist and ableist ideals have deemed economic productivity a “dominant metric for human worth” [14], and disclosure of disability has been previously linked to limiting employment opportunities [22], it is important to understand the nuances around disclosure in content creation, which has already become an important source of income for some disabled individuals [16]. Finally, there is much to learn about how different creators come to understand the meaning of value in their labor. This understanding is important in the collective effort to design tools that better support creators’ various goals. My remaining dissertation work will further explore these remaining questions.

3.3 Study 3: Understanding Content Creation and Disability in Online Marketplaces

In the next phase of my work, I will analyze how disabled creators promote and sell their work in online marketplaces. I will study: (1) whether and how creators express their disabled identities through creative content; (2) how they use online tools to promote and sell their work; and (3) how creators value their labor and manage complexities with monetization. Though limited work has studied the potential to monetize content online, questions remain around how disabled creators value their work and construct their own definition of value. Furthermore, there are opportunities to study how creators’ definitions surrounding value might come into tension with existing sociotechnical understandings of value and what it means to monetize content involving disabled experiences.

I will conduct online observations to identify and analyze virtual shops owned by creators with disabilities. Online marketplaces, such as Etsy, are spaces where the tensions with monetizing content related to disability might be more explicitly brought out, given the primary goal of these sites is facilitating the selling of goods. Although I will begin this study by identifying creators on Etsy via keywords related to disability and creative work, I will extend my analysis to other spaces (e.g., Twitter, personal websites) where disabled creators might promote and sell products by tracing their online presence. Broadening this search into the larger ecosystem will allow me to get a better understanding of where disabled creators are selling and how they are using different online tools and spaces. As with my previous studies, I will complement insights from online observations with semi-structured interviews with creators based in the United States. Insights from this study will further reveal how disabled content creators approach their creative labor, and how future content creation tools might better support their goals.

4 EXPECTED CONTRIBUTIONS

My dissertation research makes empirical, practical and conceptual contributions. First, it reveals the ways in which disability and ableism shape content creation and how this content is shared across three different contexts. With this, I also uncover the roles non-disabled collaborators and technologies have in the creative process. Second, I contribute insights into how technologies can both support disabled creators and introduce new complexities to

their work. Finally, my work will contribute to existing theories of accessibility that move away from problematizing disability, and instead focus on supporting creative expression and recognizing creative labor among people with disabilities. Insights from across my three projects can inform the design of future technologies that support disabled creators’ labor without reifying existing stereotypes and stigma.

5 BIOGRAPHICAL SKETCH

I am a PhD candidate in Technology and Social Behavior at Northwestern University and am advised by Prof. Anne Marie Piper at The University of California, Irvine. My main line of research focuses on understanding the experiences and technology use practices of disabled content creators. This knowledge can inform the design of new tools that support creators’ needs and personal goals, while respecting boundaries around how these technologies should be integrated into their process. Before joining the Ph.D. program at Northwestern University, I completed a B.S. in Computer Engineering at the University of Puerto Rico at Mayaguez. As both an undergraduate and graduate student, I have taken on leadership roles to organize initiatives that offer support and mentorship to other Hispanic/Latinx students pursuing careers in computing fields. The CSCW 2021 DC will be held as I navigate the last year of my doctoral degree. Participating in the DC will provide an opportunity to present my work to date and receive career advice that can help me identify next steps beyond the PhD. From my participation in the DC, I would like to receive feedback as I analyze my data and unpack the ways in which technologies (and HCI research) can better support and amplify the labor of disabled content creators. I also hope to contribute to the CSCW DC by sharing my experiences conducting online research and designing accessible tools for content creation.

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