

MyAutsumeFamilyLife: Analyzing Parents of Children with Developmental Disabilities on YouTube

KATYA BORGOS-RODRIGUEZ, Northwestern University, USA

KATHRYN E. RINGLAND, Northwestern University, USA

ANNE MARIE PIPER, Northwestern University, USA

While parents of young children regularly make decisions about sharing content about their child or family online, we know less about how they create, produce, and share video-based content of children with stigmatizing experiences¹. Through an analysis of publicly available content on YouTube, supplemented with semi-structured interviews, we report on the ways in which parents of children with developmental disabilities produce, share, and interact with others through videos of their children's experiences. Our analysis finds that parents disclose child information on YouTube to build authenticity, connect with others, advocate for social change, and justify monetization and child involvement. We discuss tensions between parents' practices and the ethical complexities of sharing and studying parent-generated content featuring children with disabilities.

CCS Concepts: • **Human-centered computing** → **Human computer interaction (HCI)**.

Additional Key Words and Phrases: parents; disclosure; YouTube; children; developmental disabilities

ACM Reference Format:

Katya Borgos-Rodriguez, Kathryn E. Ringland, and Anne Marie Piper. 2019. MyAutsumeFamilyLife: Analyzing Parents of Children with Developmental Disabilities on YouTube. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW, Article 94 (November 2019), 26 pages. <https://doi.org/10.1145/3359196>

1 INTRODUCTION

Parents of young children regularly make decisions about whether, what, and how to share information about their children online. Prior work has examined how parents make these decisions on social media sites (e.g., Facebook, Instagram) and blogs, where parents connect with family, friends, and other acquaintances [3, 10, 68, 77]. Increasingly, parents are also sharing about their children with large public online audiences, such as through YouTube videos and channels dedicated to their child, some of which have millions of views and subscribers. The emerging culture of YouTube “microcelebrities” [1] and platform affordances for monetization based on video views and channel subscriber counts raise new considerations for parent-generated content that features children. Indeed, many prominent YouTube channels that feature a child as the central figure have emerged [61, 62].

¹We would like to caution readers that some of the content presented in this paper describes children with disabilities in distress and may be upsetting to some readers.

Authors' addresses: Katya Borgos-Rodriguez, kborgos@u.northwestern.edu, Northwestern University, Evanston, IL, USA; Kathryn E. Ringland, kathrynringland@northwestern.edu, Northwestern University, Evanston, IL, USA; Anne Marie Piper, ampiper@northwestern.edu, Northwestern University, Evanston, IL, USA.

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than the author(s) must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from permissions@acm.org.

© 2019 Copyright held by the owner/author(s). Publication rights licensed to ACM.

2573-0142/2019/11-ART94 \$15.00

<https://doi.org/10.1145/3359196>

Prior work examines why and how parents share about their children on YouTube and become “family influencers” [1], highlighting benefits of making their narratives visible. Still other work examines children who create their own videos for sharing online [65, 86], who mirror many of the practices of adult content creators. Although all online content involving children raises important ethical considerations, producing and sharing video content portraying the lives of children with disabilities who may be nonverbal and experience stigmatized behaviors (e.g., sensory meltdown) raises new questions around disclosure, privacy, and consent. The present paper focuses on parent produced YouTube content about and featuring their children with developmental disabilities, such as autism, attention-deficit/hyperactivity disorder (ADHD), sensory processing disorder (SPD), or other neurodevelopmental disorders.

Both children with developmental disabilities and their parents experience stigmatization [34, 49, 85], whether directly or as “courtesy stigma” by association [46]. This stigma can make life as a parent even more difficult [56], as parents feel others (e.g., public, extended family) blame them for their child’s behavior [70], perceive the need to overly manage their child in public settings [76], and often experience feelings of isolation [85]. Consequently, both offline and online, parents seek ways to normalize their child’s experience by publicly disclosing their child’s disability-related identity [76] and find community with other parents with shared experiences [5]. Although prior work reveals the ways in which parents use online social platforms to seek information, offer and receive social support, and navigate stigma associated with developmental disabilities [4, 5], we know less about why and how these individuals produce and publicly share original content, such as videos, related to the experience of developmental disabilities.

To deepen our understanding of parental disclosure practices online, we report results from an analysis of publicly available content on YouTube (e.g., videos, channel descriptions, comments), focusing in-depth on 36 YouTube channels created by parents of children with developmental disabilities. In an effort to contextualize our analysis of content on YouTube, we conducted semi-structured interviews with six of the content creators whose channels were included in our analysis. Our analysis reveals four main aspects of these parents’ creation and sharing practices: (1) connecting with audiences by constructing an authentic image of life with a child with a developmental disability; (2) supporting other families by sharing lived experiences; (3) advocating for social acceptance and public awareness of developmental disabilities; and (4) justifying content monetization and child involvement. Based on our analysis, we discuss tensions between parents’ practices and the ethical complexities of sharing this content publicly to large online audiences and studying parents’ online content as part of research.

2 RELATED WORK

The present paper brings together prior work on practices and norms around parent online disclosure, online interaction involving parents of children with developmental disabilities, and studies of video-based content production and sharing online.

2.1 Online Disclosure Practices of Parents

Increasingly, parents of young children are creating, sharing, and interacting through content related to their children on online social platforms, with sites such as Facebook and Instagram being notable examples [6, 10, 18, 25]. A recent survey study in the United States revealed that 56% of the mothers and 34% of the fathers that participated shared information related to parenting in social media [31]. Indeed, this practice of “sharenting” [15], a term referring to parents sharing information about themselves and their children online, has been studied with respect to social networking platforms [3, 68, 69, 77] and parent blogging [16]. Through “sharenting” parents stay in touch with family, friends, and other acquaintances by exchanging photos and updates on their

lives as a family. Sharing online is also a way parents seek information related to parenting (e.g., new mothers [9]).

While some families may find sharing about parenting or their children to be beneficial, parents must deal with the added responsibility of being the “voice” for their children when representing themselves and their experiences as families online [2, 16]. Some parents, particularly those of children with language delays or disabilities, have expressed their discomfort with the task of representing their child online [16]. In all cases, parents are responsible for analyzing the tradeoffs between receiving social support through their published content and the implications this may have on their children both immediately and in the future [3, 16, 18, 23]. As an illustrative example of the implications for children, a study by Minkus, Liu, and Ross [66] revealed that information about a child (e.g., name, date of birth, address, facial identification) can be learned automatically from their parents’ public Facebook photo albums. Given this, other work has identified parents’ practices around disclosure of content in online spaces [3, 23]. For example, in the case of Facebook, parents typically take advantage of privacy features and are mindful of their networks to control the breadth of the audience that will have access to the content they post [3].

2.2 Online Interaction and Parents of Children with Developmental Disabilities

While a few studies have examined online participation of individuals with developmental disabilities themselves [21, 22, 75], a more extensive literature details the ways in which parent caregivers, including some of children with developmental disabilities, engage in online interactions associated with these roles. Sharing and interacting online can be particularly valuable for parents of children with developmental disabilities. These parents often have unique questions and experiences compared to other groups of parents [4]. Online interaction can help them come to terms with their new role as the caregiver of a child with a disability [48, 54] and exchange information and social support with other people [4, 5, 54]. These parents are faced with a number of additional responsibilities, including becoming familiar with a wide variety of treatment options for their children, deciding which therapies to engage with for their children, and taking their children to additional doctor, therapeutic, and skills-based appointments throughout the week. In addition to this, parents must also compare competing advice and recommendations of care, all while balancing how these different forms of care will impact the overall household [79].

By sharing about themselves and their families online, parents receive a variety of benefits that include social support and access to resources shared amongst themselves in their respective groups [75]. Parents of children with disabilities may use social media to learn more about negotiating for health and education services for their children, or what others have called networked empowerment [5]. In a related study, parents reported feeling judged less in online spaces, although they still felt the need to post socially appropriate content online (e.g., achievements rather than “negative” content) [4]. Researchers have also found that parents grapple with ways to keep themselves and their children safe from harm (both physical and emotional) in online spaces, which is often made more challenging by their child’s disability [74]. Although these studies provide insight into how parents of children with developmental disabilities interact on a wide range of online platforms (e.g., Facebook, Twitter, dedicated websites), we know less about how they produce and share content on predominantly video-based online social platforms such as YouTube.

2.3 Video-based Content Production and Sharing

Previous work has examined publicly-available videos shared on YouTube to study groups of individuals and community practices around the platform [29, 51, 53, 60, 72, 78]. This work elaborates the different ways stigmatized and minority groups, such as older adults [51], people with vision impairments [78], trans [72], homebound [29] and individuals with a chronic illness [53, 60], share

their lived experiences through self-generated content shared on YouTube. In one notable example, Liu et al. [60] studied how health vloggers share personal videos on YouTube documenting their life experiences. In particular, content creators use video to connect more deeply with viewers through “show-and-tell” behaviors (e.g., showing the viewer how a device works) and capturing life experiences as they happened (e.g., experiencing confirmation of a diagnosis). Other work has examined how YouTube celebrities, particularly within the beauty guru community, connect with audiences by creating content that portrays themselves as “real” or “reachable” [41]. Still others have examined the practices of youth themselves who create and share video-based content online. For example, McRoberts et al. [65] studied a group of youth YouTube content creators and found that many of them acknowledged their viewership and incorporated community-building practices of popular adult YouTubers, such as requesting viewers to subscribe to their channels or follow them on social media platforms. Others have noted how youth with autism create videos as a means of educating others about their disability and empower their own self-expression [74]. Much of the literature in this area, however, focuses on content produced by the individuals who are focal within the videos themselves rather than parent-generated content featuring children. The studies that do exist examined parent- or caregiver-generated YouTube content to understand device usability and adaptations for children [7, 52] rather than parents’ motivations for creating, sharing, and promoting this content in the first place.

3 METHOD

Our method involves an iterative process of data collection and analysis, which included a preliminary search for YouTube videos related to children with developmental disabilities, identification and analysis of 36 parent content creators, and supplementary interviews with a subset of these content creators.

3.1 Identifying Initial Videos Related to Developmental Disabilities

As the first step, we identified user-generated content related to children with developmental disabilities that was publicly available on the video-sharing platform YouTube. Our focus in this first phase was to look broadly at the types of videos that concern people, primarily children, with developmental disabilities and their sensory-related experiences. Similar to previous studies of user-generated content on YouTube (e.g., [7, 52]), we built a set of search queries by combining disability-related search terms (e.g., autism spectrum condition, sensory processing disorder, attention deficit hyperactivity disorder) with sensory-related search terms (e.g., sensory integration, sensory play, fine motor skills, visual attention). We generated these keywords based on feedback from specialists who work with children with sensory-related needs, including occupational therapists, educators, and experts in developmental disabilities and learning disabilities. We used 14 disability-related search terms and 7 sensory-related search terms for a total of 98 search term combinations. For each query, we considered all results returned, or the first 50 video instances in cases where a greater number of videos became available. We reviewed the titles and description of all videos and removed any that appeared unrelated to our broader area of inquiry (i.e., videos not directly related to children, sensory experiences, or developmental disabilities). For example, some of these uploads included videos associated with biking, real estate and car repairs. This process resulted in 1274 unique videos.

We randomly sampled 300 of the 1274 videos for detailed review and analysis. Among the sampled videos, we found many instances of commercially available product reviews, promotional videos for clinics, educational videos about developmental disabilities, and sensory play activities that had no clear indication of being specifically designed for children with developmental disabilities. As we watched these videos, we analyzed them and took notes based on our observations. In

addition to analyzing the content of the video artifact, we visited the uploaders' public profiles to get a sense of the backgrounds and descriptions of the content creators. These content creators included people with varying levels of training, such as occupational therapists, speech language pathologists, learning disabilities experts, teachers, adults with developmental disabilities, parents, and other caregivers.

3.2 Focused Analysis of Parents as Content Creators

During our initial phase of data collection and analysis, we observed a particularly interesting but understudied type of content: YouTube channels and videos created by parents documenting the experience of life with a child with a developmental disability. To understand the practices, motivations, and concerns of these content creators, we shifted our analytic focus from a content analysis that aims to categorize types of videos (e.g., [52, 65, 86]) towards a qualitative analysis of why and how parents create and share content about the experience of living with and caring for a child (or children) with a developmental disability.

3.2.1 Identifying Parent Content Creators. Given our research focus on parent practices, our unit of analysis shifted from individual videos on YouTube to content creators who identify as a parent of a child with a developmental disability (i.e., not a trained or paid professional). To identify these content creators, we iteratively traced through usernames, channel descriptions, titles of videos, video descriptions, comments, and details of the videos themselves (e.g., individuals in the video, setting/environment, experiences shared). We also identified additional parent content creators through video collaboration announcements (e.g., two content creators announce a collaborative project at the beginning of their respective videos), a "shout out" to other content producers in the middle of a video, individuals interacting through comments, and those mentioned in the "related channels" tab of a content producer's public profile.

In total, we identified 36 YouTube parent content creators, each of whom maintained a unique channel (see Appendix 2). We refer to the content creators as "CC##" throughout the paper. All parents in our sample create and share content related to a child with autism, ADHD, or sensory processing disorder. For each content creator, we visited their public profile and noted their join date and availability of external media (e.g., email, social media, blogs, personal websites) to get a sense of their online presence. For each of the identified parent content creators, we conducted a detailed analysis of the content creator's channel, reviewing their profile, viewing an assortment of their videos, reading comments on videos (top 5 comments or entirety of comments if video had less than this amount), and making notes on our observations. We watched 10 videos per content creator or the entirety of their collection for cases where the creator had less than 10 videos uploaded on their channel. In terms of which videos we sampled, we analyzed those that were most popular (i.e., video with the greatest number of views), had a particular temporal ordering (e.g., first and most recent), and those identified through purposeful sampling that appeared to be information-rich cases. Our analysis of videos was contextualized by understanding the content producer's channel as a whole, other videos on their channel, and comments from viewers (including top comments). Throughout our process, we continued to take detailed notes and write analytic memos.

3.2.2 Interviews with Parent Content Creators. To better understand parents' practices and contextualize their online content, we invited all content creators that had an email address publicly available on their channel profile (n=23) to participate in an interview. In total, six content creators (see Table 1) agreed to participate in an interview. These six parents maintained active YouTube channels dedicated to the topic of interest with a collective total of more than 2,000 videos and 150,000 subscribers. As with other content creators in our analysis, we analyzed a total of 10 videos per interviewee channel. While all content creators monetize their content in some way (e.g.,

Table 1. Description of interview participants' self-identified gender identity, their child's (or children's) diagnosis, and approximate video and subscriber counts (to preserve anonymity). Note that P101 has three sons diagnosed with autism.

Participant ID	Parent Gender	Child Gender	Child Diagnosis	Video Count	Subscriber Count	Monetizes Content
P101	F	M	Autism	200	60,000	Yes
P102	F	M	Autism	400	Undisclosed	Yes
P103	M	F	Autism	100	3,000	Yes
P104	F	M	ADHD	300	1,000	Yes
P105	F	M	ADHD	200	10,000	Yes
P106	M	M	Autism	900	80,000	Yes

sharing affiliate links or generating revenue from views), monetization of content was not a criteria for inclusion. Interviews were conducted over the phone or on Skype and lasted from 32 minutes to 1 hour (49 minutes on average). Participants were located in the United States and the United Kingdom. We used a semi-structured interview protocol that focused on their role and experience as a parent of a child with a developmental disability, the content that these parents have shared on YouTube, and their interactions on the platform (see Appendix A). All participants received a \$50 Amazon gift card for their time. These interviews were transcribed and analyzed alongside the online content described above. As noted in Table 1, interview participants are referred to as “P###” throughout our writing.

3.3 Data Analysis

Our approach follows from constructivist grounded theory method [24], in which data collection and analysis are intertwined as ongoing activities and involve a process of constant comparison. We began a process of open coding parent-generated videos, video descriptions, comments and channel descriptions, and our own notes on content. Example initial codes include ‘motives’, ‘real life’, ‘disclosure of disability’ and ‘sharing experiences’. Importantly, we conducted interviews in parallel with our analysis of online content, purposefully allowing our observations of what we found online to inform the questions we asked in the interviews and vice-versa. All data (i.e., video excerpts, comments, interview transcripts) were analyzed and coded together in an iterative fashion, through which we developed and refined our resulting themes. Throughout our process, we wrote analytic memos and engaged in constant comparison of these data with other data and data with related concepts, such as theories of self-presentation [44] and literature from disability studies [27, 42, 50]. The research team met regularly to discuss observations and wrote additional analytic memos based on our discussions. Through this process, we analyzed our data to understand parents’ motivations and goals as well as tensions associated with sharing this content publicly through YouTube.

3.4 Ethics and Positionality

This study was approved by our university Institutional Review Board. Although YouTube video data may be considered public to researchers, we took several precautions in an attempt to respect and protect the identity of individuals who did not explicitly choose to participate in this study. As with other studies of YouTube where researcher ethics are particularly important (e.g., [65, 86]), we report our findings collectively whenever possible. In cases where referencing specific videos (e.g., quotes, description box content, viewer comments) is necessary, we report a paraphrased version of

the original text to avoid using direct quotes as suggested by others [20, 67]. Finally, we consciously chose to only keep original links to videos rather than download the artifacts. This decision was made to help preserve the uploaders' right to edit or entirely remove their content from our dataset at any time (e.g., by making it private or taking down from YouTube). One parent removed videos featuring their child during the revise and resubmit phase of publication. We exclude their data from our detailed analysis but in our findings section note the nature of their content removal given the topic of study. This means that our final analysis focuses on 35 parents and their channels.

Constructivist grounded theory asserts that our own experiences and backgrounds will inherently shape the analytic process. In this work, the authors come from a variety of backgrounds, including parents of young children, and have extensive experience working with individuals with developmental disabilities and their caregivers. Our own experiences and backgrounds will always be informed by our prior knowledge and our relative positions on the research team. Two authors are parents, and all authors have had some experience with interacting with children with developmental disabilities and their caregivers ranging from 1 to 13 years. We approach our analysis with a lens of both the social construction of disabled identities and that of intersectionality (i.e., that intersecting marginalized identities lead to unique experiences of oppression) [28, 30]. We do this to prioritize the children with developmental disabilities and their parents rather than others in this space, such as medical doctors, therapists, specialists, and teachers. That is, we bring an analytic frame of disability as a social category and a valued aspect of identity, which is in contrast to viewing disability as a deficit, focusing on cures, or seeking ways to mitigate 'negative' behaviors. Further, this framing positions these children and their parents as a marginalized group due to the stigma and oppression they experience related to both disability and their roles as children and parents.

4 FINDINGS

For context, we first briefly describe the nature of parent-generated videos posted to the channels that were the focus of our analysis (also see Appendix 2). The number of videos available on each content creator's channel varied greatly, with one channel having less than ten videos and others having several thousand videos to date. In terms of the videos themselves, we observed instances of parents sharing tips on how to work with children, life updates, and documenting children's behaviors (e.g., stimming, meltdowns). Parents also shared insights about what the diagnosis process involved, answering questions from their viewership and sharing glimpses into their daily lives as a family through video logs or "vlogs." Children were not necessarily present in the videos, but would at least be referred to at some point in each video. We observed instances of children being documented since birth all the way through their teenage years, although it is not possible to identify the precise ages of these children because several content creators do not share this information and others have posted videos over many years. The length of these videos ranged from 30 seconds (e.g., capturing a child's particular stimming habits) to 31 minutes (e.g., parent sharing their thoughts on ADHD medication). The number of views per video and engagement via comments also varied greatly. Some videos had 10s or 100s of views and others had several million views. Similarly, some videos had no comments and others had hundreds of comments.

It is important to note that, while we were conducting this study, YouTube disabled the comments section for a majority of the videos on the platform involving minors. This was done in an attempt to protect children from predatory and obscene comments that were being left on various videos [71, 84]. Recent changes in platform policies regarding comments on videos featuring children underscore the importance of understanding the practices, goals, and considerations of parents who maintain YouTube channels that focus on children with developmental disabilities. Towards this end, our analysis identified four key aspects of these parents' creation and sharing practices,

which involve (1) connecting with audiences by constructing an authentic image of life with a child with a developmental disability; (2) supporting other families by sharing lived experiences; (3) advocating for social acceptance and public awareness of developmental disabilities; and (4) justifying content monetization and child involvement.

4.1 Connecting with Audiences by Presenting Authentic, “Real Life”

While all online content and interactions are performative in nature [45], our dataset contained a wide range of videos, text descriptions, account profiles, and comments that emphasize the “real” rather than “fake” or overly produced nature of content. Families describe themselves on their channel profiles, video descriptions, and the video content itself as depicting “real life,” “a real family vlog,” and “real ADHD.” Through this, parents disclose aspects of their lives, relationships, and families that help build a sense of authenticity. As prior work reveals for other content producers, these individuals are not naive to audiences’ desire for “real” or “authentic” content and aim to depict their own lived “reality” as a way of connecting with viewers, which others have called calibrated amateurism [1].

There are several ways in which content creators in our study go about constructing authenticity in terms of their family image and experience with disability. First, the affordances of video as the medium of choice may contribute to a sense of closeness between content creators and their audiences. P103 from our interviews described video to be “*more perceivable*.” Similarly, in their channel description another content creator shares, “*I have seen lots of web pages and social media for families who have kids with autism but not many on YouTube. I really want an Autism Mother Community here on YouTube. I feel like when you can see someone visually but may not know them in your everyday life, there is a connection that you make*,” (CC8). The choice of camera focus and setting (e.g., child interacting, parent narrating, scene in a particular location) and various editorial decisions all contribute to the “realness” of these videos, as others have shown with other YouTube celebrities [41]. Although parents edit their videos to include introduction sequences, logo graphics, music, and scene transitions, the content of the video itself has qualities that other scholars (e.g., [26]) have noted as signaling realism and authenticity. For example, it was common to experience shaky camera angles and lower resolution video quality or audio. As they navigated spaces, content creators would often switch between the front and rear cameras of their devices, the latter done particularly when they wanted to communicate with the audience more directly. Interestingly, prior work suggests that certain styles of interaction while filming a vlog are positively co-related with the average level of attention (i.e., views) these vlogs receive [13]. For example, videos where vloggers are talking for a longer period of time receive more views. These choices in medium and filming style collectively contribute to families’ construction of authenticity and connection with their audience.

In terms of the video content, parents construct the realness of life and disability by filming their families as they engage in seemingly ‘ordinary’ activities and invite the viewer into the privacy of their own home, sometimes even bringing attention to household messiness and the need to clean their home environments. This depiction of ordinary activities and routines can be understood as part of the normalization of life with a child with a developmental disability [32, 57]. They describe capturing both “good” and “bad” days with their children in an effort to present “truth and reality.” For example, one content creator states in the description box in one of her videos:

“We are a happy family that likes to have fun and aren’t fake. You won’t see us being fake vloggers about our family. Our integrity matters more than views. We have lots of friends and family who also watch our videos. I promise what you see is complete reality and truth. You will see the worst of our family and the best of us. All of us have a story to

share. It isn't always pretty but I promise it's always realistic. These videos are family memories and not just for you. I don't see a purpose in making videos that aren't the truth. You can count on us to be honest and transparent about everything. But when leaving a comment, remember that we're real people and not actors on a television show.” (CC10)

This and other content creators' promises to present only the “truth” as well as the “worst of our family” may encourage viewers to feel a deeper sense of connection with the content creator by viewing the family as relatable, and therefore increasing the likelihood they are seen as a “real” or authentic family [41]. As one example of this, P106 explained in an interview:

“There was a lot of people explaining what autism was... What the ten signs of autism are or, you know, various things like that, but there was very little... I don't think there is another video on YouTube where we talk about the time that he took off all his clothes on the supermarket, lied on the floor, started screaming and wouldn't leave... you don't get that from the more academic content.”

As this parent suggests, their goal is to present a broader, more “realistic” view of developmental disabilities than what is offered by clinical resources or “academic content.” To achieve this, parents documented one or more aspects of their day-to-day experiences and uploaded them on their channel. These experiences include, but are not limited to, daily routines and life updates (e.g., improvements in communication skills, changes at school). The settings varied depending on what families were doing the day the video was recorded, but the most common filming location was the family's home. Through these in-home videos, parents presented configurations of their children's sensory rooms and custom home-based sensory play or learning activities. Appearances in these videos were not limited to a parent and their child, but also often included other family members such as a spouse and children's siblings. Describing one of the videos, a content creator wrote, “*although our main focus is everyday experiences with autism, no one in the family should feel left out,*” (CC33). Therefore, while many of the channels appear to be managed by one parent, much of the content produced and shared online seems to become a family endeavor. That is, parents are portraying the collective experience of disability that occurs through interaction between child and parent as well as interaction with one's larger family group and within society, providing important social context that helps build authenticity.

4.2 Supporting Other Families by Sharing Lived Experiences

Our analysis reveals that these parents create and share content about their child and their experience with developmental disability as a way of supporting other families, but they do so in ways that take advantage of the affordances of YouTube as a primarily video-based platform. Prior work by Ammari and Schoenebeck [5] described the concept of networked empowerment, or how parents connect with other families, share resources and promote health advocacy through social media sites. While this previous study provides insight into practices surrounding parents of children with developmental disabilities connecting and supporting each other on Facebook, we examine these practices in the context of YouTube, where video demonstrations, instructional commentary within a home environment, and footage of child behaviors are central.

Many videos shared by parents in our analysis involved the parent standing or sitting down in front of their camera to discuss a predetermined topic. These videos were typically instructional in nature and revolved around a specific topic (e.g., signs of ADHD, sensory sensitivities). Other videos combined techniques, with parents sitting or standing in front of the camera for a portion of the video, but at certain points of the video they incorporated other clips (e.g., child playing) as a way to provide additional context while narrating. Among the topics discussed in these videos, parents shared the process they underwent to obtain a diagnosis, parenting advice, product reviews,

and techniques that families have learned over the years to help children with sensory regulation (e.g., weighted blankets, Wilbarger Brushing Protocol). They also shared tips for parents struggling with situations such as toilet training their children and how they manage hygiene, something that can be difficult given the sensory overload that comes as a result of activities such as bathing, brushing hair, or putting on deodorant.

Sometimes parents would demonstrate the use of products or techniques with the help of their child. As an example, the mother of a child with sensory processing disorder shares a video that discusses techniques for sensory regulation that the family uses at home. One technique they shared, which presents an interesting use of resources available at home, involves the child sliding down the staircase that leads to the second floor of their home while sitting or lying on their stomach. After the child demonstrates what they mean to the camera, the parent says, *“when he started doing that, I was very scared, right? But... so long as he is wearing these soft sweatpants,”* (CC18). Relatedly, some parents shared therapy sessions both at home or in a clinic setting with the intention of helping others by providing ideas to those who may not have the resources to take their children to a therapist. In the description to one of these videos, the uploader wrote, *“I made this video for parents interested in doing occupational therapy in their home because insurance won’t cover it for their child, or because they don’t have the services where they live. These are fun activities used in therapy and are great techniques for your child,”* (CC10). Thus, these parents created and shared content as a way of opening up resources to other parents who may have less access to therapists or knowledge of home-based therapy activities.

While prior work indicates that new parents turn to YouTube for product reviews [9], our analysis reveals that these families view interaction on YouTube as both an informational resource and way to connect with other parents with similar experiences. One instance of connecting through information sharing occurred when parents documented specific behaviors and signs that they noticed in their children that they believe relate to their developmental disability. Many parents expressed initial uncertainty about their child’s diagnosis and turned to YouTube for information. In a video where they retell the story leading up to their child’s autism diagnosis, one parent shares, *“It was difficult to accept even when we received the diagnosis, to be honest. For me, I wasn’t sure if I would hear him talk, or whether I could ever talk to [him],”* (CC25). Parents wanted to see and learn from the experiences of other parents, particularly when faced with the need to make sense of their child’s behavior or understand a diagnosis. For example, one parent described searching YouTube videos to understand whether their child might have a developmental disability:

“Before I took [child’s name] in to get diagnosed, I went to YouTube and I started typing in ‘what are the signs of autism?’ And so, all these videos popped up... and I realized that other people were filming their experiences and stuff, I was like ‘okay, let me start following some families and keep up with them and see what they’re going through and how they’re navigating things’ - ‘cause everything is different... I follow a lot of families now.” (P102)

As P102 and others explained, viewing the behaviors and interactions of other children whose parents revealed that they had a developmental disability was an important way in which parents newer to the topic learned about and understood their own child’s behaviors. Aligning with previous work on the experiences of having a child with autism [85], parents in our analysis also expressed feelings of isolation, including isolation from family and friends, and used YouTube as a way to relate to others. P103 explained, *“I was looking for really something to relate to... just because it was a really isolating experience. We didn’t know anybody with autism and we didn’t have any friends or family that had an experience with this.”* Similarly, P105 said that their *“closest homeschooling mentors and friends are other YouTube moms... it became like a close friendship... it’s just been good to*

have a community of moms who... you know, know your life... even if nothing comes out of this, I'm glad I did it for having made some good friends." These connections with others, however, occurred through the process of publicly disclosing family experiences and information about their children. Although there are many questions around publicly sharing information about a child with a developmental disability to a large online audience, which we discuss below, one benefit may be that parents newer to the topic could more informally learn about and engage with this content without needing to join disability-specific private groups (e.g., Autism groups on Facebook). Stigma around developmental disabilities affects both children and their parents [34, 49, 85], and informally learning from other parents who post publicly may be a more approachable resource for some [4, 5, 9, 68].

Together, many of these parents not only connect by sharing information with each other about products and diagnoses, they also help coach each other in new ways of interacting with and engaging their children. For instance, one parent uploaded a video where she shared a low-cost sensory play activity that involved mixing cornstarch, water and food coloring in a bowl. She explains the purpose in putting together this activity by stating, *"I already know that [child] is not going to like the first activity we're doing this week because it will be very messy... and that's one of his sensory sensitivities... but it's okay to be messy occasionally, and as his mom, that's something I'm trying to get his hands, feet and body to understand,"* (CC4). Upon dipping the child's hands inside the bowl, he immediately begins to cry. A viewer shared some words of advice in the comments sections based on their own experiences with their daughter, *"the one thing I recommend is to go slow, REALLY slow. The greatest advice I received was to never force his hand into anything and it worked."* The comment appears to be well received by the uploader of the video, who thanks the viewer and adds, *"I really like to know how other mothers have achieved things,"* (CC4). As another example, another parent (who also has a channel dedicated to their child) commented on one of P104's videos and noted shared observations about their children. P104 responded to them saying, *"I am the mother of a young one dealing with SPD that was actually FINALLY diagnosed with a form of autism recently. We look for anything that we can learn from, but having other mothers sharing their own experiences clearly... such a blessing! Thanks a lot for this."* Thus, these parents create and share content on YouTube as a way of supporting other parents of children with developmental disabilities in understanding and interacting with their own children.

4.3 Advocating for Social Acceptance and Public Awareness

In addition to content producers' goals of connecting with and supporting other parents of children with developmental disabilities, these content creators also share content on YouTube as a way of advocating for social acceptance and raising awareness among the general public. Across our data, we observed parents articulating their efforts to "battle" stigma and increase social acceptance. Advocacy-related language appears in channel descriptions, such as *"This is our autism family vlog. Battling the stigma of ASD (autism spectrum disorder) with a first hand look into the struggles, joy, and comedy,"* (CC9). Parents also expressed a similar sentiment during interviews:

"Our goal is to raise not only autism awareness, but also autism acceptance throughout the world so that our daughter and everyone with autism can have a fulfilling life without judgement and ignorance." (P103)

"We want the world to be accepting of people like [child name]... We want him, when he's twenty-five, to not have people stare at him in the street... and just be accepted as a member of society and I think we've got a long way to go, we've already come a long way, but we're determined to keep pushing that message." (P106)

The decision for many parents in our study to share content about their children publicly to large audiences on YouTube appears to be largely shaped by their desire to address societal stigma around developmental disabilities. One specific and salient way in which parents sought to raise awareness around developmental disabilities was by producing and uploading content that represents stigmatized or poorly understood experiences. For example, in one of their videos, P102 sits down in front of the camera to discuss the differences between a tantrum and a sensory meltdown. Upon wrapping up the video, she states, *“with this video, I want you to understand that tantrums could happen when children are trying to obtain something they want or need. On the other hand, a meltdown happens when children are feeling overwhelmed because of their feelings or surroundings.”* By showing and narrating the experience of a sensory meltdown, content creators are attempting to educate viewers on how to interpret and understand behavior that is often viewed as socially unacceptable.

While many content creators in our study posted meltdown videos, two channels had meltdown videos that each surpassed 2.5 million views. During our conversation, P101 elaborates on one such video, which is also one of the most popular videos on her channel. The video documents her son experiencing a sensory meltdown at an amusement park. The recording captures the child screaming and attempting to free himself of his father’s grip as they are making their way outside of the establishment. People passing by can be seen turning their attention towards the scene. P101 said:

“I think we created it (meltdown video) when we were naive and just starting out on YouTube... my husband was just like, you know, ‘What do you see? Do you see a brat throwing a tantrum, or do you see a kid who’s, you know, really struggling?’... It’s gotten over something like three million views, which is crazy. But part of it is honestly people just pointing fingers and like, ‘Look at that brat! They need a spanking!’... And, I get it. I mean, my own father actually said that to us...‘give him to me for a week, I will straighten him out.’”

This parent explained that they have since deactivated the comments section due to the overwhelming number of inappropriate comments that were left on the video; this also aligns with YouTube’s recent policy shift to disable comments on content featuring minors. As other work has shown, comments on YouTube about children with developmental disabilities can become quite violent or judgmental [73]. P101 also said that this video received backlash from people interpreting the child’s meltdown as a lack in discipline. Earlier in the interview, the participant attributes this ignorance to autism being an invisible disability [35, 49], something that she has learned from working with her children. Indeed, previous studies have identified offline relationships (i.e., family members, friends, strangers) as significant sources of negative judgment towards families of children with disabilities [4, 85].

Thus, a tension emerges when advocacy and social acceptance comes at the expense of disclosure of a child’s disability and, in some cases, displays of stigmatizing behavior. In putting their child’s developmental disability on public display to potentially large online audiences, families compromise privacy in hopes of achieving social change. At the end of the meltdown video shared by P101, the parent added, *“while unpleasant to watch, we hope you learned something from this video and that it helps friends and families of people with autism.”* Though comments have been disabled for this video, the uploader shared a comment from one of their subscribers in their description box that captures the tension between disclosure and advocacy:

“This is a reflection of my child every day. Thanks for sharing. People don’t get why someone would share something like this. I think it helps other parents so they don’t punish their autistic child. It also helps people learn how to deal with meltdowns. It

is sad, but some families of autistic children do not want to go through the diagnosis process because they believe these children only need discipline and they can handle it by themselves.”

Importantly, P101 recreated and reposted this particular meltdown video during the final phases of our study. In a new voice-over with the same original footage, the parent reflects on their motivations for the first video and acknowledges that many viewers had legitimate concerns with the original meltdown video. With the stated goal of educating others, the parent provides a more detailed description of the behavioral signs they are attending to in their child, how they handled this experience, and refines their language related to meltdowns and tantrums. They also acknowledge losing view counts and ad revenue generated by the previous video (with several million views), and explain that it is worth it to correct misunderstandings around this experience. This example highlights the dynamic and interactive nature of content creators and their audiences, who both contribute to the narratives that are shared online.

Creating and sharing videos of sensory meltdowns can be informative to parents seeking to understand their child's behavior but is also a way that families normalize developmental disabilities, such as autism, to achieve social change. Nevertheless, these videos seem to attract much attention from viewers, evidenced by high numbers of views and extensive comments (before they were removed/deactivated). P106 explained:

“It's always bothered me as well because I know that the videos that gets the most views are the ones where [child]'s distressed or where [child]'s having a hard time. So if he's having a meltdown, if he's struggling with something, um, if he's having a hard time with something, they're the videos that are going to get the most views... because that has real benefit to the people that are watching because that's where as a parent you feel the most helpless.”

That is, content creators struggle with the fact that videos depicting “real” autism and situations where the parent feels “*the most helpless*” can have the highest viewership, whereas more “*happy, fun stuff*,” as P106 later explained, tends to attract fewer viewers. It is worth noting that, even among the content creators we study, there are diverging opinions around the practice of sharing this particular type of content. One parent shared an opposing view on this topic. Through a vlog, he reflects on a meltdown his child had off-camera, “*most of you get why we don't show meltdowns... It's not necessary. You will know what a meltdown looks like when you see it for yourself*,” (CC9). Several individuals responded to this video via comments supporting the decision to not show this content online. “*I completely get why you don't show meltdowns. You share a lot about your lives and deserve some privacy.*” one person added as a comment. Another person commented that they would not show meltdowns either because it is not wise to stop and record it rather than helping the child, and “*A meltdown can be very personal. Some things are better left private.*” Yet another person commented that “*Good! Your child does not need to be put on display for viewers to learn from her.*”

Pushing back on the notion that meltdown videos are inappropriate to post on YouTube, a different content creator who has a son diagnosed with autism and obsessive-compulsive disorder (OCD) added the following description to one of her videos:

“I record my child dealing with OCD, experiencing meltdowns and going to occupational therapy. OCD and autism should be openly talked about. All parents of children with autism have to deal with these situations and I want them to know they are not the only ones. I hope these videos reach people that have no experience with autism. I want to make it normal to them so that parents are no longer judged when they are doing everything they can for their children.” (CC10)

Through these exchanges, we observe that parents must make decisions about whether compromising their children's privacy by disclosing these stigmatizing behaviors is worth their end goals of advocacy and improving social acceptance. Although they may be well-intentioned, as seen in the examples above, there can be unanticipated consequences with sharing these videos. Inappropriate comments and judgment may further solidify stigma to a potentially large online audience, which makes the compromises parents are making even more complex when considering the child and the ways in which these decisions may affect them now or in the future.

4.4 Justifying Content Monetization and Child Involvement

Parents' practices of creating and sharing content on YouTube, through which they aim to inform and connect with other parents and enact social change, are further complicated by unique features of the YouTube platform that allow for monetization and reward viewership. In late 2007, YouTube began its partner program, which allows content creators with sufficient views and subscribers to monetize (i.e., gain revenue from) their channel. In some cases, successful individuals (deemed "microcelebrities" [1]) go on to pursue this full-time as a career. Moreover, parallel to the success of reality television families, family channels are becoming increasingly popular on YouTube [38, 62]. In addition to the inclusion of advertisements at one or more points in the video, we also frequently observed video description boxes that contained affiliate links leading to individual products or lists of "essential products" (e.g., sensory toys) curated by the content creators. Our detailed analysis revealed that a total of 19 out of 35 content creators monetized their content on YouTube. We identified these uploaders by noting the presence of advertisements shown at any point in their videos and/or whether there were affiliate or donation links in their public profiles or description boxes of their videos (see Appendix 2.)

The topic of video monetization came up during interviews both naturally and by explicitly asking participants about their feelings on any form of revenue that is generated from this type of content. Some parents expressed a desire to grow their channel viewership and subsequent revenue to the point that it could replace other full-time employment:

"... I mean my goal is to be able to quit my full-time job eventually because of YouTube... Yeah, that's just kind of what I would love to do." (P104)

"... any revenue that's made through YouTube ... we're hoping that it's going to allow us to focus more on better content going up on YouTube and, um, maybe hopefully stepping away from my normal job a little bit more and be able to focus on something that I am passionate about..." (P103)

In a platform where content creators are rewarded based on viewer engagement, and given the rise in popularity and competition for these views and subscriber counts, it is no surprise that creators must implement various strategies to attract and maintain the attention of their online audiences. The potential to monetize content that features young children, however, raises additional concerns for content producers and their audiences. Distinct from the incentive structure of other social platforms that have been the focus of related work (e.g., Facebook) [4, 5, 68], the ability to monetize content can bring into question parents' motives in producing their videos (i.e., educating versus profiting), especially when these videos involve highlighting children's stigmatizing behaviors that drive viewership (e.g., meltdown videos). Parents in our analysis were not naive to these tensions. They explained that content monetization is a somewhat contentious issue, with P104 saying that this topic can be "a little controversial." Similarly, P106 shared that he "could understand why some people would have an issue with it," particularly if they are not familiar with his family's background and the other type of content that they regularly upload on their

channel. He added, *“we do get quite a lot of criticism online... and the most common criticism we get is I get accused of exploiting [child]’s autism or exploiting disability.”*

Given the potential for audiences to interpret their content production practices as exploitative (and acknowledging that the research team is in fact another audience), parents justify content monetization in several ways. In particular, parents justify monetization of their content by describing the labor they put into content production. P104 explained in an interview, *“I put a lot of work in it and I don’t see any problem getting paid for it. It’s a lot of work, it’s a second job.”* Similarly, P103 noted, *“I don’t think there’s anything wrong with earning money on YouTube and... A lot of it, like, for the ad revenue part of it, I think that’s the easier part about it just because nobody’s personally paying us anything, they’re just watching the videos... so yeah, I think it’s something that will help us in the future provide better content and interact more.”* In addition to justifying monetization through their own labor and that revenue is coming from sponsorships, some parents explained (in interviews and their online content) that the amount of money they receive is minimal and that it is spent on their children:

“I always laugh a little bit when people are like, ‘oh, you’re using your kids to make so much money’ and I’m like, ‘every dollar that goes back into the kids and usually just buys us clothing or something,’ you know what I mean? Like, it’s not a whole lot of money, but it’s more like a hobby I would say, for my husband and me, you know what I mean? And, you know, also something that does good. So, it’s worthwhile.” (P101)

“Also, you probably know that we have an Amazon affiliate link. Now, if you shop there, Amazon gives us like 4% of what you purchase. It doesn’t cost you any more money, we just get 4%... Well, this month we used that money... and we got [child name] a new communication device. So thank you very much for that.” (CC9)

Parents react to the social norms around monetization of content involving their children by conveying a sense of financial transparency to one’s audience, which may help further cultivate a feeling of trust and fend off interpretations of their practices as exploitative. Similarly, P106, who dedicates himself to generating content for his channel as his full-time job, shares in an interview how content monetization has improved his family’s quality of life:

“From my point of view, it’s my full-time job... I don’t see why anyone would resent me for earning money from doing that and I wouldn’t resent anyone else earning money from the work that they put in... I was a well-paid professional person who had to make a decision to give up my job. The only way I was able to make that decision is because I had a novel way to make money to pay the bills... it allows me to be at home when he leaves for school in the morning, be here when he gets back, be around in the school holidays. It allows me to be a much more contributing member of the family, a much better dad. It’s allowed for [child name] to make more progress in the last two years than he’s ever made before.”

Concerns around monetization and the perception that parents are exploiting their children are countered by parents sharing narratives around the own work they put into content production and the benefits their child receives from this (i.e., spending revenue on specific assistive devices). Additionally, parents justify their practices by describing how they involve their children in deciding whether and what to post online. As others have argued [3], uploading content about one’s children online, particularly when this involves disability related experiences or identities, raises concerns about the extent to which children are involved in decisions of sharing content about themselves. Reacting to these tensions, several content producers explicitly mentioned that content involving their child has only been posted with their child’s approval. For example, the mother of a child with autism states the following in a video where she was discussing the topic of hygiene and how it relates to her son:

“And before I receive any hateful responses, [child] gave me permission to record him. Whenever [child] is filmed, we always go over the recordings together and make sure that he approves. [Husband] and I are serious about our children’s privacy. We are respectful of their wishes, and this includes our older children.” (CC17)

This suggests that others on YouTube are pushing back (e.g., through comments) on issues of child consent to record and share videos online. Similarly, P106 explained a shared set of rules and practices that he and his child developed:

“We have a rule where he says ‘no camera’ or ‘stop filming’ or puts his hand up, he knows the camera is going to go away... So, we give him a lot of control over what he feels comfortable sharing or not. He understands YouTube anyway, so he knows it’s going on the internet. He watches the videos that he’s in, so he knows what’s on there... if he were to watch a video back and becomes distressed on what he was watching, we take that video down because we don’t want him to be upset about anything that we’re sharing in these videos.”

The ways in which child involvement and online privacy decisions are negotiated become even more nuanced in the context of developmental disability, where a child may not be able to verbally express their wishes. Further questions of child involvement in content creation and sharing came up when a parent discussed (in a posted video) her own feelings about documenting her daughter’s experiences with a developmental disability since she was a child. Interestingly, now that the child is considered an adult, the parent described being conflicted about the appropriateness of disclosing private information pertaining to her daughter. Coincidentally, partway through our study this content creator removed all of her YouTube content that involved her daughter. While we exclude this content creator from our detailed analysis, we purposefully make note of her removal of content related to her recent reflection on her daughter’s privacy and status as an adult. Previous work suggests that children do not hold an innate right to privacy but receive their rights to from their parents gradually as they grow older [8], and here we see how parents play a fundamental role in both sharing and making decisions around removing content. Understanding how children’s rights to privacy online are negotiated and enacted by others is an active area of research (e.g., [16, 69]), and our analysis further highlights complexities with consent and privacy considerations for diverse groups of children. We contend, however, that children of all ages and abilities are unlikely to fully understand the consequences of sharing information with large, public online audiences, particularly given that adults have a tendency to misunderstand differences between one’s actual and imagined audiences [58, 59, 63].

5 DISCUSSION

Our findings build on and extend a growing literature that examines how parents create content, share experiences, and engage with others through online spaces [4, 5, 9, 16, 54, 68]. Here, we revisit our findings in light of both parent goals and the ethical complexities of parent-generated content featuring children with developmental disabilities.

5.1 Representing and Reimagining Disability

From one perspective, these parents’ content creation and sharing practices on YouTube can be viewed as important cultural work that involves representing and reimagining disability. Non-disabled individuals oftentimes rely only on representations within the media to construct their understandings of people with disabilities [50]. Indeed, media can serve a pedagogical function in educating others about social realities of disability and the individuals that inhabit them [55]. Titchkosky argues that disability texts in the media and news are informed by cultural assumptions

about disability and normalcy, and these expressions of disability are rich sites of study that can lead us towards reading and writing disability differently [82]. Indeed, scholars have noted a shift in the way disability is understood more broadly; individuals with disabilities are being acknowledged for their contributions, not in spite of their disabilities [73, 81]. Similarly, Garland-Thomson asserts that this reimagining of disability “accomplishes significant important cultural work. First, it shows disability as a significant human experience that occurs in every society, every family, and most every life. Second, it helps us accept that fact. Third, it helps integrate disability into our knowledge of human experience and history and to integrate disabled people into our culture” [42]. Other scholars have added that this shift in the way we imagine disability, denoted cultural resymbolization, is essential to achieve significant social change towards equality for people with disabilities [33].

As part of their advocacy work, parents create and maintain specific identities around disability both as parents and as a larger family-unit. Other literature has shown how individuals with developmental disabilities themselves create content, including some YouTube videos, to reflect their own identities as those with disabilities and in doing so work to redefine what it means to be disabled [73]. In our analysis, individual videos, channel profiles, text descriptions, and interactions through comments are as much about being a parent or caregiver as they are about the child with a developmental disability. That is, interactions through YouTube reveal the ways in which parents construct and present disability-related identities in association with and as part of their child’s disabled experience. Parents claim disability through their channel names and descriptions (e.g., Autism Mother). Other content creators describe themselves as an “autism family” through their channel descriptions, aligning the family collectively with a disabled identity. Moreover, disability is purposefully presented as a family endeavor in which no family member, including siblings without a developmental disability, should be “left out.” Hence, parents sustain disabled identities through relations embodied by both the content itself and creation practices, effectively representing and reimagining disabled life in new ways.

5.2 Children’s Role in Online Disclosure

Although these parents positively frame their online disclosure through social advocacy and support, they must make complex tradeoffs around disclosure with respect to their child’s right to privacy and control over what is shared online. In our analysis, we observed community members negotiating norms around this disclosure within the context of the YouTube platform. This practice of video sharing brings forward important considerations pertaining children’s rights to consent and control over the online representations of disability that are being crafted by their parents. Questions of representation, consent, and privacy are further complicated when their position as individuals with disabilities may cause them to have less say, due to not speaking fluently or others not acknowledging that they have the ability to express their desires [64, 79]. This dual marginalization has the potential to lead to a child not being offered the choice to consent to the disclosure of aspects of their identity, for potentially longer into their life. Indeed, it is unclear if, given the choice of consent, whether a child – any child, not just one with a developmental disability – could truly consent to the disclosure of their private information in a public online space such as YouTube.

Although the present study is a first step, additional research on how children with disabilities and their caregivers create ‘rules’ about what information can be disclosed publicly or not is needed [3, 74], particularly as these children grow older and are subject to others forming impressions of them based on this online content. In fact, in this study, there is an inherent problem with representation of the child’s identity and opinions because everything is filtered through the parent. We really only know what the children think about these public videos through the videos themselves and

from what the parents are choosing to report. Limited prior work examines these issues from both the parent and child perspectives, though we know that children have articulated a preference towards parents not sharing information about them that is “overly revealing” or that show them in a “negative” as opposed to a “positive” light [69]. These authors also found that both parents and children believe that parental figures do not ask their offspring for consent as often as they should. Our analysis, however, reveals the complexities of how disability experience (e.g., being non-verbal) can inherently compete with a child’s ability to consent, have control over the way their disability is represented online, and form their own definition of what is socially too revealing or “negative.”

5.3 Tensions Between Multiple Online Audiences

Parent’s conceptions of who will view their online content shape whether and how they disclose information online, particularly related to sensitive or stigmatizing information [3, 4, 14]. Prior work, however, has shown that people have a tendency to misunderstand differences between one’s actual and imagined online audience [58, 59, 63], both now and in the future, and underestimate their audience size [12]. Although YouTube provides visible metrics for video views and channel subscriber count, questions arise regarding who is viewing the content and how various audiences interpret both the content and content creation practices. The notion of “gaze” informs how we understand the ways various audiences “see” or interpret mediated content in different ways [11, 43]. One salient example is the parent video intended to educate others about stereotypical child behaviors (e.g., stimming, meltdowns), which caregivers feel are poorly understood by their own extended families, friends, and society at large. In particular, parents described creating this type of content to educate viewers on the differences between sensory meltdowns and tantrums. By narrating videos of a child experiencing a sensory meltdown, parents are encouraging and prompting a new way of seeing behavior (i.e., a child who is overwhelmed by their environment rather than intentionally defiant). That is, they are using the medium of video to attune viewers to skilled ways of looking at behavior, or professional vision [47], that they have adopted as a parent.

Meltdown videos, however, point to a tension between multiple audiences. When intended to educate the outgroup, or people who do not currently identify with this particular community of parents and their children, meltdown videos in particular are subject to an “ableist gaze” [27]. That is, while content producers may create and share meltdown videos to promote social acceptance, these presentations of disability remain subject to interpretation through ableist ideals of what is socially appropriate behavior within a given context. This is particularly problematic when widely viewed videos receive judgmental and disparaging comments from viewers, which may ultimately reinforce and perpetuate the stigma content producers are trying to dismantle. Ultimately, an “ableist gaze” that sensationalizes and decontextualizes disabled life may become even more visible online when these videos and associated comments are promoted by ranking algorithms.

5.4 Weighing the Benefits and Costs of Online Disclosure

Throughout this study, parents, through their videos, channels, and interviews, expressed a number of different benefits or motivations for uploading videos and maintaining their YouTube channels. These included: connecting to those with a shared lived experience, advocating for social change and creating public awareness of disabilities, and, for some, as a means of income. What is noticeably absent from this list is a direct benefit for the children at the center these videos. Monetizing content is viewed by some online and offline audiences as exploiting both their children and disability. This interpretation compromises the content creators’ credibility and true intentions. Pushing back on this interpretation and offering a positive reframing, caregivers articulate the benefits of generating revenue from the content that they are sharing online (e.g., sustaining their family, purchasing goods for the child, creating more content). Nevertheless, advertisements and video sponsorship

deals are abundant, raising further questions around the evolving community norms and ethics of how parents monetize family life, disability, and their children.

Putting the ethical issues of monetization aside, which are specific to YouTube primarily, the broader ethical tension then becomes about whether the parent's need for social connection and their drive to create social change is perceived to outweigh the child's need for privacy and control over their own online identity. Parents may not be fully cognizant of the decisions they are making here: choosing to forgo their child's privacy for their own support and to (hopefully) impact larger society. While it is natural for these parents to seek support, putting their child with a disability on public display comes with risks. These risks include exposing their children to unwanted attention from strangers, increased risk for bullying online or offline, disclosure of sensitive information, or potential for future discrimination as the child becomes an adult (who may want a job or to live independently) [80]. There is further uncertainty here as this is an area not widely researched. Much of the research is about risks to children as they are independent actors in and consumers of social media content, rather than as actors in another person's content. More research is needed to truly understand the nuances of the risks and costs to children and their families as they engage in large-scale, public online sharing.

5.5 Studying Parents and Children with Marginalized Identities

Increasingly, researchers are turning to YouTube as a way of studying children and their parents behavior with and through technology [1, 7, 52, 65, 74]. The ethics of conducting research using user-generated online content, however, is an active topic of debate (e.g., [36, 37, 39, 40, 83]). Brown et al., [19] argue that the sensitivities of research ethics should align with those being studied, and others assert that those with marginalized identities or experiences must be "handled with care" [17]. Given our topic of study, we purposefully avoid including images from videos and obscure text-based content to make the identities of individuals more difficult to find online [20]. We also aim to provide an account of parent practices online that center their priorities and goals, supplementing analysis of online content with first-person interviews with the content creators themselves.

Although the present paper centers the parent perspective in analysis, this topic of study also requires a more critical perspective: one that is more protective of a child's digital footprint, skeptical of how this data could be used for harm now and in the future, and suspect of whether parents should be posting this information online at all. Indeed, prior work provides sufficient warrant for concern [66]. In bringing this more critical perspective to bear on our analysis, however, we must acknowledge the potential further marginalization of parents who may already feel isolated and are experiencing very real and challenging life circumstances. Moreover, the ethics of whether parents should share this information online must be understood through the lens of normalization and how these parents may perceive their child and family life as 'normal' [32, 57]. That is, researchers may be 'outsiders' that see sensational behavior posted online rather than the everyday normal of family life and child interactions. As researchers with identities as parents, we reflected on and discussed our own emotional responses to certain content (e.g., meltdown videos), which shaped our interpretation of parent practices. Thus, the lenses and identities we bring to analysis must be considered as part of, not distinct from, ongoing ethical debates.

We also argue that researchers are not just accountable to the treatment of individuals and their online data but also to the narratives they tell through the analysis and reporting of results. As a research community, it is our ethical responsibility to learn from parents' efforts in spreading awareness and promoting understanding of their children's experiences. As others have done with children with autism in online communities [73, 75], we can examine their self-presentation of disability and advocacy work as a way of understanding which systems of oppression and

normative social forces they are pushing back against. Research efforts that focus on ‘normalizing’ or ‘changing’ the individual represent disability in a particular way: they portray that there may be a ‘right’ and ‘wrong’ way of being within a society. Instead, we can learn from parents’ advocacy work to reshape our own research agendas and create new tools to support their unique needs. For example, we can see parents’ decisions to disclose details about their child’s life publicly on YouTube as indicative of gaps in practical family support as well as a reaction to harmful stigma.

6 CONCLUSION

Participating in the production and consumption of publicly available videos on YouTube related to children’s experiences with developmental disabilities enables parents to make their experience of life with developmental disabilities visible, connect with others with whom they have shared lived experiences, and enact social change. Through this process, however, parents must make decisions about whether and how to disclose experiences that are stigmatizing and negotiate nuanced challenges around obtaining child consent and receiving revenue from this content, including audience perceptions of these practices. The present case analysis of parent content creators on YouTube enriches our understanding of how parents disclose information about their children online in an effort to receive social support and perform advocacy work. Through this, the present study also highlights multiple ethical issues associated with sensitive disclosures, privacy, child consent, and monetization of content in online spaces, which provide fertile ground for subsequent research.

7 ACKNOWLEDGEMENTS

We thank all of the content creators who participated in our interviews as well as those whose data we analyzed on YouTube. This work was funded in part by NSF grant IIS-1522921. Kathryn Ringland is supported by the National Institute of Mental Health (T32MH115882). The content is solely the responsibility of the authors and does not necessarily represent the official views of the funding bodies.

A SEMI-STRUCTURED INTERVIEW GUIDE

- (1) Tell us about your experience working with a child with sensory needs.
 - What have you learned about working with the child?
 - Are there any resources that have been particularly useful?
 - How have you come to understand the child's particular sensory needs?
- (2) Tell us more about the sensory experience(s) that you present in your video(s).
- (3) How do you go about creating new sensory experiences for the child?
- (4) What motivated you to start uploading content on YouTube?
- (5) Is there a particular type of video that gets the most attention from viewers?
 - Why do you think that is?
- (6) What do you hope to achieve by sharing your experiences online?
- (7) Are there any other websites where you post content?
- (8) Do you engage with your viewers? If so, in what ways?
 - Who is your audience?
- (9) Have you connected with other content creators that upload content similar to yours?
- (10) Is engaging with caregivers on YouTube different from participating in other online support platforms?
- (11) Are there any differences between resources provided by doctors or clinicians as opposed to resources shared by caregivers on YouTube?
- (12) What are your feelings on revenue that is generated from this type of content?
- (13) In what ways, if any, has uploading your content online changed your life?

B CONTENT CREATOR CHANNELS

Below, we summarize the profiles of the parent content creators included in our analysis. Note that video and subscriber counts have been rounded to the first significant figure to preserve anonymity. Also note that, as explained in section 3.4, CC3 was no longer included in our detailed analysis after we noticed they removed all video content from their channel during the revise and resubmit phase of publication.

Determining whether a channel is monetized is not straightforward (e.g., advertisements may appear at some point in the video but this does not always mean that the uploader gains revenue from views). Furthermore, there are several different ways in which content creators may profit from the traffic on their videos. Therefore, in addition to advertisements, we considered the presence of affiliate and donation links in the description boxes of videos or channel profiles as criteria to determine whether the content creator monetizes their content. We establish our criteria for a "yes" as instances where we found advertisements while watching the creator's content and/or affiliate (e.g., Amazon, services) or donation (e.g., Patreon links, PayPal addresses) links. We did not flag instances where only advertisements were found because this is not necessarily an indication that the content creator is gaining revenue from their video. For cases in which there was not a clear indication, we opted to leave this blank to avoid making incorrect assumptions.

We identified seven major categories of channel content by examining content creators' profile descriptions and analyzing their videos. The content in each of these categories includes: documenting the families' lives through vlogs (D); sharing homeschooling plans and tips (H); mothers discussing their experiences with giving birth, pregnancy and motherhood (M); information and resources such as process to obtain a diagnosis (I); advice to other parents on working with children with developmental disabilities (A); opening up to viewers about the content creators' experiences as parents (P); and topics related to health and well-being such as food and dieting (W).

Table 2. Summary of the content creator profiles included in our analysis.

Content Creator ID	Child Diagnosis	Video Count	Subscriber Count	Monetizes Content	Join Date	Content							
						D	H	M	I	A	P	W	
CC1	Autism	<10	3,000		2013	✓							
CC2	SPD	400	7,000	Yes	2016		✓	✓	✓	✓			
CC3	(removed)												
CC4	Autism	60	300		2016	✓							
CC5	Autism	200	60,000	Yes	2015	✓			✓		✓		
CC6	Autism	4,000	10,000		2012				✓				
CC7	ADHD	300	1,000	Yes	2017			✓	✓	✓			✓
CC8	Autism	40	200		2014	✓		✓	✓	✓			
CC9	Autism	700	100,000	Yes	2010	✓			✓	✓			
CC10	Autism	2000	200,000	Yes	2013	✓							
CC11	Autism	200	4,000		2014				✓	✓			✓
CC12	SPD	1,000	50,000		2013	✓							
CC13	Autism	100	900		2011				✓				
CC14	Autism	300	2,000	Yes	2011	✓				✓			
CC15	Autism	400	Undisclosed	Yes	2011	✓			✓				✓
CC16	Autism	400	9,000		2014	✓		✓	✓				✓
CC17	Autism	600	90,000	Yes	2015	✓		✓	✓				✓
CC18	SPD	600	30,000	Yes	2016	✓		✓	✓		✓		✓
CC19	Autism	100	3,000	Yes	2009	✓			✓				
CC20	ADHD	200	10,000	Yes	2016		✓	✓	✓	✓			
CC21	Autism	900	80,000	Yes	2017	✓							
CC22	Autism	100	4,000		2017	✓			✓	✓	✓		
CC23	Autism	100	300		2008	✓	✓		✓	✓	✓		
CC24	Autism	70	200	Yes	2014	✓			✓	✓			
CC25	Autism	100	6,000		2017	✓			✓	✓	✓		
CC26	Autism	20	20,000	Yes	2017	✓			✓				
CC27	Autism	200	7,000	Yes	2013	✓			✓	✓			✓
CC28	Autism	50	100		2018	✓							
CC29	ADHD	100	100	Yes	2017	✓			✓	✓	✓	✓	✓
CC30	ADHD	<10	30		2017				✓	✓			
CC31	Autism	1,000	300,000	Yes	2013	✓		✓				✓	
CC32	Autism	60	200	Yes	2017	✓			✓	✓			
CC33	Autism	30	100		2019	✓							
CC34	Autism	<10	5,000		2017	✓			✓	✓			
CC35	Autism	600	7,000	Yes	2011	✓		✓	✓	✓			
CC36	Autism	1,000	10,000		2012	✓		✓	✓	✓			

REFERENCES

- [1] Crystal Abidin. 2017. #familygoals: Family Influencers, Calibrated Amateurism, and Justifying Young Digital Labor. *Social Media + Society* 3, 2 (April 2017), 2056305117707191. <https://doi.org/10.1177/2056305117707191>
- [2] Meryl Alper. 2017. *Giving Voice: Mobile Communication, Disability, and Inequality*. MIT Press.
- [3] Tawfiq Ammari, Priya Kumar, Cliff Lampe, and Sarita Schoenebeck. 2015. Managing Children's Online Identities: How Parents Decide What to Disclose About Their Children Online. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*. ACM, New York, NY, USA, 1895–1904. <https://doi.org/10.1145/2702123.2702325> event-place: Seoul, Republic of Korea.
- [4] Tawfiq Ammari, Meredith Ringel Morris, and Sarita Yardi Schoenebeck. 2014. Accessing Social Support and Overcoming Judgment on Social Media among Parents of Children with Special Needs. (June 2014). <https://www.microsoft.com/en-us/research/publication/accessing-social-support-and-overcoming-judgment-on-social-media-among-parents-of-children-with-special-needs/>
- [5] Tawfiq Ammari and Sarita Schoenebeck. 2015. Networked Empowerment on Facebook Groups for Parents of Children with Special Needs. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*. ACM, New York, NY, USA, 2805–2814. <https://doi.org/10.1145/2702123.2702324> event-place: Seoul, Republic of Korea.
- [6] Tawfiq Ammari, Sarita Schoenebeck, and Daniel M Romero. 2018. Pseudonymous parents: Comparing parenting roles and identities on the Mommit and Daddit subreddits. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 489.
- [7] Lisa Anthony, Yoojin Kim, and Leah Findlater. 2013. Analyzing User-generated Youtube Videos to Understand Touchscreen Use by People with Motor Impairments. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '13)*. ACM, New York, NY, USA, 1223–1232. <https://doi.org/10.1145/2470654.2466158> event-place: Paris, France.
- [8] David Archard. 2014. *Children: Rights and Childhood, 3rd Edition (Paperback)* - Routledge. <https://www.routledge.com/Children-Rights-and-Childhood-3rd-Edition/Archard/p/book/9780415724869>
- [9] Louise Barkhuus, Elizabeth Bales, and Lisa Cowan. 2017. Internet Ecologies of New Mothers: Trust, Variety and Strategies for Managing Diverse Information Sources. <https://doi.org/10.24251/HICSS.2017.276>
- [10] Mitchell K Bartholomew, Sarah J Schoppe-Sullivan, Michael Glassman, Claire M Kamp Dush, and Jason M Sullivan. 2012. New parents' Facebook use at the transition to parenthood. *Family relations* 61, 3 (2012), 455–469.
- [11] John Berger (Ed.). 1987. *Ways of seeing: based on the BBC television series with John Berger* (reprinted ed.). BBC [u.a.], London. OCLC: 246190402.
- [12] Michael S. Bernstein, Eytan Bakshy, Moira Burke, and Brian Karrer. 2013. Quantifying the Invisible Audience in Social Networks. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '13)*. ACM, New York, NY, USA, 21–30. <https://doi.org/10.1145/2470654.2470658>
- [13] Joan-Isaac Biel and Daniel Gatica-Perez. 2011. VlogSense: Conversational behavior and social attention in YouTube. *ACM Transactions on Multimedia Computing, Communications, and Applications (TOMM)* 7, 1 (2011), 33.
- [14] Lindsay Blackwell, Jean Hardy, Tawfiq Ammari, Tiffany Veinot, Cliff Lampe, and Sarita Schoenebeck. 2016. LGBT Parents and Social Media: Advocacy, Privacy, and Disclosure During Shifting Social Movements. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 610–622. <https://doi.org/10.1145/2858036.2858342> event-place: San Jose, California, USA.
- [15] Alicia Blum-Ross. 2015. 'Sharenting': parent bloggers and managing children's digital footprints. <http://blogs.lse.ac.uk/parenting4digitalfuture/>
- [16] Alicia Blum-Ross and Sonia Livingstone. 2017. "Sharenting," parent blogging, and the boundaries of the digital self. *Popular Communication* 15, 2 (April 2017), 110–125. <https://doi.org/10.1080/15405702.2016.1223300>
- [17] Janne CH Bromseth. 2002. Public places—public activities. *Methodological approaches and ethical dilemmas in research on computer-mediated communication contexts. SKIKT Researchers—Researching IT in context, University of Oslo*, 33–61.
- [18] Anna Brosch. 2016. When the child is born into the Internet: Sharenting as a growing trend among parents on Facebook. (2016).
- [19] Barry Brown, Alexandra Weilenmann, Donald McMillan, and Airi Lampinen. 2016. Five Provocations for Ethical HCI Research. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 852–863. <https://doi.org/10.1145/2858036.2858313>
- [20] Amy Bruckman. 2002. Studying the amateur artist: A perspective on disguising data collected in human subjects research on the Internet. *Ethics and Information Technology* 4 (2002), 217–231. Issue 3.
- [21] Moira Burke, Robert Kraut, and Diane Williams. 2010. Social Use of Computer-mediated Communication by Adults on the Autism Spectrum. In *Proceedings of the 2010 ACM Conference on Computer Supported Cooperative Work (CSCW '10)*. ACM, New York, NY, USA, 425–434. <https://doi.org/10.1145/1718918.1718991>

- [22] Thais Castro and Ulrike Lucke. 2016. Socialization of People with Autism Through Social Networks. In *Universal Access in Human-Computer Interaction. Users and Context Diversity (Lecture Notes in Computer Science)*. Springer, Cham, 193–202. https://doi.org/10.1007/978-3-319-40238-3_19
- [23] Charlotte Chalklen and Heather Anderson. 2017. Mothering on Facebook: exploring the privacy/openness paradox. *Social Media + Society* 3, 2 (2017), 2056305117707187.
- [24] Kathy Charmaz. 2014. *Constructing Grounded Theory*. SAGE.
- [25] Grace Yiseul Choi and Jennifer Lewallen. 2018. "Say Instagram, Kids!": Examining Sharenting and Children's Digital Representations on Instagram. *Howard Journal of Communications* 29, 2 (2018), 144–164.
- [26] Aymar Jean Christian. 2009. Real vlogs: The rules and meanings of online personal videos. *First Monday* 14, 11 (Oct. 2009). <https://doi.org/10.5210/fm.v14i11.2699>
- [27] Krystal Cleary. 2018. Disability Studies. *Feminist Media Histories* (2018). https://www.academia.edu/36368350/Disability_Studies
- [28] Kimberle Crenshaw. 1991. Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review* 43, 6 (1991), 1241–1299. <https://doi.org/10.2307/1229039>
- [29] Hilary Davis, Jenny Waycott, and Shou Zhou. 2015. Beyond YouTube: Sharing Personal Digital Stories on a Community Display. In *Proceedings of the Annual Meeting of the Australian Special Interest Group for Computer Human Interaction (OzCHI '15)*. ACM, New York, NY, USA, 579–587. <https://doi.org/10.1145/2838739.2838771> event-place: Parkville, VIC, Australia.
- [30] Lennard J Davis. 2016. The disability studies reader. (2016).
- [31] M Davis, SJ Clark, DC Singer, K Hale, A Matos-Moreno, and AD Kauffman. 2015. Parents on social media: Likes and dislikes of sharenting. *CS Mott Children's Hospital, University of Michigan Health System* 23, 2 (2015).
- [32] Janet Deatrck, Kathleen Knafl, and Carol Murphy-Moore. 1999. Clarifying the concept of normalization. *Journal of Nursing Scholarship* 31 (1999), 209–214.
- [33] Nancy L. Eiesland. 1994. *The Disabled God: Toward a Liberatory Theology of Disability*. Abingdon Press. Google-Books-ID: 4v3YAAAAMAAJ.
- [34] David Farrugia. 2009. Exploring stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness* 31, 7 (2009), 1011–1027. <https://doi.org/10.1111/j.1467-9566.2009.01174.x>
- [35] Heather A. Faucett, Kate E. Ringland, Amanda L. L. Cullen, and Gillian R. Hayes. 2017. (In)Visibility in Disability and Assistive Technology. *ACM Trans. Access. Comput.* 10, 4 (Oct. 2017), 14:1–14:17. <https://doi.org/10.1145/3132040>
- [36] Casey Fiesler and Nicholas Proferes. 2018. "Participant" Perceptions of Twitter Research Ethics. *Social Media + Society* 4, 1 (2018), 2056305118763366. <https://doi.org/10.1177/2056305118763366> arXiv:<https://doi.org/10.1177/2056305118763366>
- [37] Casey Fiesler, Alyson Young, Tamara Peyton, Amy S. Bruckman, Mary Gray, Jeff Hancock, and Wayne Lutters. 2015. Ethics for Studying Online Sociotechnical Systems in a Big Data World. In *Proceedings of the 18th ACM Conference Companion on Computer Supported Cooperative Work & Social Computing (CSCW'15 Companion)*. ACM, New York, NY, USA, 289–292. <https://doi.org/10.1145/2685553.2685558>
- [38] Keegan Fornoff. 2017. Vlogging Is Killing the Reality TV Stars. <https://studybreaks.com/tvfilm/vlogging-is-killing-the-reality-tv-stars/>
- [39] Christopher Frauenberger, Alissa N. Antle, Monica Landoni, Janet C. Read, and Jerry Alan Fails. 2018. Ethics in Interaction Design and Children: A Panel and Community Dialogue. In *Proceedings of the 17th ACM Conference on Interaction Design and Children (IDC '18)*. ACM, New York, NY, USA, 748–752. <https://doi.org/10.1145/3202185.3210802>
- [40] Christopher Frauenberger, Amy S. Bruckman, Cosmin Munteanu, Melissa Densmore, and Jenny Waycott. 2017. Research Ethics in HCI: A Town Hall Meeting. In *Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '17)*. ACM, New York, NY, USA, 1295–1299. <https://doi.org/10.1145/3027063.3051135>
- [41] Florencia Garcia-Rapp and Carles Roca-Cuberes. 2017. Being an online celebrity: Norms and expectations of YouTube's beauty community. *First Monday* 22, 7 (July 2017). <https://doi.org/10.5210/fm.v22i7.7788>
- [42] Rosemarie Garland-Thomson. 2005. Disability and Representation. *PMLA* 120, 2 (2005), 522–527. <https://www.jstor.org/stable/25486178>
- [43] Rosemarie Garland-Thomson. 2009. *Staring: How We Look*. Oxford University Press. Google-Books-ID: z0ZdbczUo4C.
- [44] Erving Goffman. 1959. *The Presentation of Self in Everyday Life*. Doubleday.
- [45] Erving Goffman et al. 1978. *The presentation of self in everyday life*. Harmondsworth London.
- [46] I. Goffman and Erving Goffman. 1963. *Stigma; Notes on the Management of Spoiled Identity*. Prentice-Hall. Google-Books-ID: 0RAVAAAAMAAJ.
- [47] Charles Goodwin. 1994. Professional Vision. *American Anthropologist* 96, 3 (1994), 606–633. <https://doi.org/10.1525/aa.1994.96.3.02a00100>
- [48] Jean W. Gowen, Deirdre Schoen Christy, and Joseph Sparling. 1993. Informational Needs of Parents of Young Children with Special Needs. *Journal of Early Intervention* 17, 2 (April 1993), 194–210. <https://doi.org/10.1177/>

105381519301700209

- [49] David E. Gray. 2002. 'Everybody just freezes. Everybody is just embarrassed': felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness* 24, 6 (2002), 734–749. <https://doi.org/10.1111/1467-9566.00316>
- [50] Beth A. Haller. 2010. *Representing Disability in an Ableist World: Essays on Mass Media*. Advocado Press. Google-Books-ID: J6ZVbwAACAAJ.
- [51] Dave Harley and Geraldine Fitzpatrick. 2009. YouTube and intergenerational communication: the case of Geriatric1927. *Universal Access in the Information Society* 8, 1 (April 2009), 5–20. <https://doi.org/10.1007/s10209-008-0127-y>
- [52] Juan Pablo Hourcade, Sarah L Mascher, David Wu, and Luiza Pantoja. 2015. Look, my baby is using an iPad! An analysis of YouTube videos of infants and toddlers using tablets. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. ACM, 1915–1924.
- [53] Jina Huh, Leslie S. Liu, Tina Neogi, Kori Inkpen, and Wanda Pratt. 2014. Health Vlogs As Social Support for Chronic Illness Management. *ACM Trans. Comput.-Hum. Interact.* 21, 4 (Aug. 2014), 23:1–23:31. <https://doi.org/10.1145/2630067>
- [54] J. C. Huws, R. S. Jones, and D. K. Ingledeu. 2001. Parents of Children with Autism using an Email Group: A Grounded Theory Study. *Journal of Health Psychology* 6, 5 (Sept. 2001), 569–584. <https://doi.org/10.1177/135910530100600509>
- [55] Douglas Kellner. 2011. Cultural studies, multiculturalism, and media culture. *Gender, race, and class in media: A critical reader* 3 (2011), 7–18.
- [56] Sydney H. Kinnear, Bruce G. Link, Michelle S. Ballan, and Ruth L. Fischbach. 2016. Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives. *Journal of Autism and Developmental Disorders* 46, 3 (March 2016), 942–953. <https://doi.org/10.1007/s10803-015-2637-9>
- [57] Kathleen A Knafel and Janet A Dearrick. 2002. The challenge of normalization for families of children with chronic conditions. *Pediatric Nursing* 28, 1 (2002), 49–56.
- [58] Eden Litt. 2012. Knock, Knock. Who's There? The Imagined Audience. *Journal of Broadcasting & Electronic Media* 56, 3 (2012), 330–345. <https://doi.org/10.1080/08838151.2012.705195> arXiv:<https://doi.org/10.1080/08838151.2012.705195>
- [59] Eden Litt and Eszter Hargittai. 2016. The Imagined Audience on Social Network Sites. *Social Media + Society* 2, 1 (2016), 2056305116633482. <https://doi.org/10.1177/2056305116633482> arXiv:<https://doi.org/10.1177/2056305116633482>
- [60] Leslie S. Liu, Jina Huh, Tina Neogi, Kori Inkpen, and Wanda Pratt. 2013. Health Vlogger-Viewer Interaction in Chronic Illness Management. *Proceedings of the SIGCHI conference on human factors in computing systems CHI Conference 2013* (2013), 49–58. <https://doi.org/10.1145/2470654.2470663>
- [61] Taylor Lorenz. 2018. Raising a Social-Media Star. *The Atlantic* (2018). <https://www.theatlantic.com/technology/archive/2018/01/raising-a-social-media-star/550418/>
- [62] Sapna Maheshwari. 2019. Online and Making Thousands, at Age 4: Meet the Kidfluencers. *The New York Times* (March 2019). <https://www.nytimes.com/2019/03/01/business/media/social-media-influencers-kids.html>
- [63] Alice E. Marwick and danah boyd. 2011. I tweet honestly, I tweet passionately: Twitter users, context collapse, and the imagined audience. *New Media & Society* 13, 1 (2011), 114–133. <https://doi.org/10.1177/1461444810365313> arXiv:<https://doi.org/10.1177/1461444810365313>
- [64] Anne McGuire. 2016. *War on Autism: On the Cultural Logic of Normative Violence*. University of Michigan Press. https://www.press.umich.edu/7784427/war_on_autism
- [65] Sarah McRoberts, Elizabeth Bonsignore, Tamara Peyton, and Svetlana Yarosh. 2016. Do It for the Viewers!: Audience Engagement Behaviors of Young YouTubers. In *Proceedings of the The 15th International Conference on Interaction Design and Children (IDC '16)*. ACM, New York, NY, USA, 334–343. <https://doi.org/10.1145/2930674.2930676> event-place: Manchester, United Kingdom.
- [66] Tehila Minkus, Kelvin Liu, and Keith W Ross. 2015. Children seen but not heard: When parents compromise children's online privacy. In *Proceedings of the 24th International Conference on World Wide Web*. International World Wide Web Conferences Steering Committee, 776–786.
- [67] Megan A Moreno, Natalie Goniou, Peter S Moreno, and Douglas Diekema. 2013. Ethics of social media research: common concerns and practical considerations. *Cyberpsychology, behavior, and social networking* 16, 9 (2013), 708–713.
- [68] Meredith Ringel Morris. 2014. Social Networking Site Use by Mothers of Young Children. In *Proceedings of the 17th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '14)*. ACM, New York, NY, USA, 1272–1282. <https://doi.org/10.1145/2531602.2531603> event-place: Baltimore, Maryland, USA.
- [69] Carol Moser, Tianying Chen, and Sarita Y. Schoenebeck. 2017. Parents' And Children's Preferences About Parents Sharing About Children on Social Media. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*. ACM, New York, NY, USA, 5221–5225. <https://doi.org/10.1145/3025453.3025587> event-place: Denver, Colorado, USA.
- [70] Susan L. Neely-Barnes, Heather R. Hall, Ruth J. Roberts, and J. Carolyn Graff. 2011. Parenting a Child With an Autism Spectrum Disorder: Public Perceptions and Parental Conceptualizations. *Journal of Family Social Work* 14, 3 (May 2011), 208–225. <https://doi.org/10.1080/10522158.2011.571539>

- [71] BBC News. 2019. YouTube bans comments on all videos of children - BBC News. <https://www.bbc.com/news/technology-47408969>
- [72] Tobias Raun. 2016. *Out Online: Trans Self-Representation and Community Building on YouTube*. Routledge. <https://doi.org/10.4324/9781315599229>
- [73] Kathryn E. Ringland. 2019. "Autosome": Fostering an Autistic Identity in an Online Minecraft Community for Youth with Autism. In *iConference 2019*.
- [74] Kathryn E. Ringland, Christine T. Wolf, Lynn Dombrowski, and Gillian R. Hayes. 2015. Making "Safe": Community-Centered Practices in a Virtual World Dedicated to Children with Autism. In *CSCW 2015*. ACM.
- [75] Kathryn E. Ringland, Christine T. Wolf, Heather Faucett, Lynn Dombrowski, and Gillian R. Hayes. 2016. "Will I Always Be Not Social?": Re-Conceptualizing Sociality in the Context of a Minecraft Community for Autism. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 1256–1269. <https://doi.org/10.1145/2858036.2858038>
- [76] Sara Ryan. 2010. 'Meltdowns', surveillance and managing emotions; going out with children with autism. *Health & Place* 16, 5 (Sept. 2010), 868–875. <https://doi.org/10.1016/j.healthplace.2010.04.012>
- [77] Sarita Yardi Schoenebeck. 2013. The secret life of online moms: Anonymity and disinhibition on youbemom. com. In *Seventh International AAAI Conference on Weblogs and Social Media*.
- [78] Woosuk Seo and Hyunggu Jung. 2018. Understanding Blind or Visually Impaired People on YouTube Through Qualitative Analysis of Videos. In *Proceedings of the 2018 ACM International Conference on Interactive Experiences for TV and Online Video (TVX '18)*. ACM, New York, NY, USA, 191–196. <https://doi.org/10.1145/3210825.3213565> event-place: SEOUL, Republic of Korea.
- [79] Chloe Silverman. 2012. *Understanding Autism: Parents, Doctors, and the History of a Disorder*. Princeton University Press. <https://www.jstor.org/stable/j.ctt7t3n6>
- [80] Elisabeth Stakrud and Sonia Livingstone. 2009. CHILDREN AND ONLINE RISK. *Information, Communication & Society* 12, 3 (2009), 364–387. <https://doi.org/10.1080/13691180802635455> arXiv:<https://doi.org/10.1080/13691180802635455>
- [81] Rosemarie Garland Thomson. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. Columbia University Press.
- [82] Tanya Titchkosky. 2007. *Reading and Writing Disability Differently: The Textured Life of Embodiment*. University of Toronto Press. <https://www.jstor.org/stable/10.3138/9781442683839>
- [83] Jessica Vitak, Katie Shilton, and Zahra Ashktorab. 2016. Beyond the Belmont Principles: Ethical Challenges, Practices, and Beliefs in the Online Data Research Community. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16)*. ACM, New York, NY, USA, 941–953. <https://doi.org/10.1145/2818048.2820078>
- [84] Daisuke Wakabayashi. 2019. YouTube Bans Comments on Videos of Young Children in Bid to Block Predators. *The New York Times* (Feb. 2019). <https://www.nytimes.com/2019/02/28/technology/youtube-pedophile-comments.html>
- [85] Roberta L. Woodgate, Christine Ateah, and Loretta Secco. 2008. Living in a World of Our Own: The Experience of Parents Who Have a Child With Autism. *Qualitative Health Research* 18, 8 (Aug. 2008), 1075–1083. <https://doi.org/10.1177/1049732308320112>
- [86] Svetlana Yarosh, Elizabeth Bonsignore, Sarah McRoberts, and Tamara Peyton. 2016. YouthTube: Youth video authorship on YouTube and Vine. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, 1423–1437.

Received April 2019; revised June 2019; accepted August 2019