Investigating How People with Disabilities Disclose Difficulties on YouTube

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Video-sharing platforms are increasingly used to share difficulties with disabilities and accessibility barriers. HCI and ASSETS researchers have leveraged online videos to observe how people with disabilities (PWD) interact with the environment and express their special needs. However, there is no systematic examination of how and why YouTubers disclose their every challenge publicly on YouTube. This poster presents a preliminary grounded-theory analysis of 257 video clips made by YouTubers with disabilities that contain barrier and difficulty information. The most common disclosed difficulties relate to social support and societal attitudes. PWDs use YouTube to share knowledge about accessibility challenges and advocate for public changes.

1 INTRODUCTION

People with disabilities (PWDs) use video-sharing platforms such as YouTube to share everyday life stories, present creative work, and exchange information [2]. PWDs present their daily activities and opinions in videos, which contain the challenges and difficulties they have met with social circles, technologies, and the environment. Understanding PWDs' unique needs center accessibility research. Recent research has leveraged online videos to examine PWDs' interaction barriers and identify design opportunities. HCI researchers studied online videos to understand PWDs' particular needs and challenges doing daily activities [1, 6, 8, 9], barriers with the video interactions [3, 7], and ways to have playful experiences [4]. However, there is no systematic examination of how YouTubers with disabilities disclose challenges and difficult experiences. This work presents a preliminary analysis of 257 video clips that mention disability challenges to understand how and why PWDs use YouTube to discourse disabilities.

We collected numerous YouTube videos posted by PWDs and sampled 1,000 video clips containing difficult words. Then the authors performed an analysis of disability difficulties under the environmental barrier framework [5]. Our results indicate that YouTube is primarily used to disclose social support pressures and societal attitudes. PWD YouTubers use the platform to share knowledge and experience with assistive technologies and the environment. YouTube is also used for advocating changes and calling for inclusion. This work builds a foundation for our future quantitative analysis of how PWDs discourse difficulties on video-sharing platforms.

2 DATA AND ENCODING

We took three steps to collect video data. In the first step, we identified disability keywords for five disability categories to search channels of YouTubers with disabilities (Table 1) with YouTube Data API. Then the channels were selected by a mix of programmatic and manual filtering. The included channels must contain at least one disability keyword in the channel description and at least one video. We also exclude channels with "center," "organization," "association," "group," or "mission" in the channel description to remove channels of groups and organizations. Then we manually verified the channel to ensure the videos were about individual PWDs or their caregivers. In the second step, we collected all videos posted by these channels. We keep the videos with closed captions and at least a difficulty keyword in the closed

caption (e.g., "difficult", "difficulty", "disappoint", "challenge", "hard", "impossible", "inconvenience", 96 words in total). This step yielded 16,710 videos made by 431 creators. In the third step, we segment videos into small video clips by the timestamps denoted in the closed caption file (SubRip file). Each SubRip timestamp has a start and ending time and the video's speech text for around a 5-second video segment. We merged 24 consecutive timestamps into one video clip. The start of each clip is the beginning of the first timestamp, and the end is the ending of the last timestamp. All speech texts for a clip are concatenated. Then we only keep video clips with at least one difficult keyword in the speech text. For this poster, we sampled 1,000 video clips for qualitative coding with the disability barrier framework [5].

Disability	Search Keywords
Vision	blindness, low vision, blind, loss of vision, visual impairment
Speech	speech disorders, language disorders, tourette syndrome, aphasia, speech impairment, loss of speech, speech disability, communication disability
Mobility	Amputation, arthritis, cerebral palsy, Charcot-Marie-Tooth disease, Huntington's disease, juvenile rheumatoid arthritis, multiple sclerosis, muscular dystrophy, scleroderma, scoliosis, spina bifida, spinal cord injury, mobility disability, physical disability, wheelchair user, physically disabled
Hearing	deafness, hard of hearing, deaf, hearing loss, hearing impairment
Cognitive & Neural	anxiety disorders, Asperger syndrome, attention deficit hyperactivity disorder, ADHD, autism, autism spectrum disorders, bipolar disorder, down syndrome, fetal alcohol syndrome, intellectual disabilities, mental retardation, learning disabilities, mental health, obsessive compulsive disorder , OCD, post-traumatic stress disorder, PTSD, Williams syndrome, mental health disability

Table 1. Keywords used to search YouTube channels of PWD

3 DATA ENCODING

We used the disability barrier framework [5] to guide the generation of barrier sub-categories. The framework suggests six types of barriers of PWD: *IT access*, *social support and societal attitudes*, *systems and policies*, *economic*, *built environment*, *natural environment*, *assistive technology*, and *transportation*. Four authors split the 1,000 video clips and annotate whether it mentions the six barrier themes (multi-categorical annotation). After categorization, IT access and assistive technology clips are combined into one barrier theme since many YouTubers mention assistive software and technologies. The built environment, natural environment, and transportation barriers are all related to environmental factors, and they have 22 clips in total. Therefore, we combine the clips of those three themes into one theme. Then the four authors used affinity diagramming to group the clip notes. The final sub-themes can be seen in Table 2.

4 RESULTS

25 clips from 223 videos contain at least one difficulty under the barrier framework [5]. The rest of the clips are either no difficulty statement (e.g., "no problem" or "accept a challenge"), general difficulties unrelated to disabilities (e.g., a hard math problem), or general hardship with the disability (e.g., "my problems with bipolar disorder"). All comments in this section are paraphrased for privacy protection [?].

Social Support and Societal Attitudes. The largest sub-theme is disclosing or discussing the self-stigma with disabilities or the shame or negativity caused by the disability. For example, in one video, a YouTuber with a physical disability mentioned that "Physical disabilities are aggravating since they make you feel like you're bothering everyone else." Some other videos call for stopping self-stigma, such as one video mentions "We should probably stop apologizing because you aren't truly sorry. It's simply a means of defusing the issue and making it less awkward." Some YouTubers talk about the problems with other people's lack of awareness of their disabilities. For example, one YouTube discloses that "It's quite aggravating for me because I'm dealing with a variety of issues relating to my ataxia that few people understand." Some difficulties are caused by others' stigma, making PWDs feel excluded or isolated. A YouTuber shared their experience "I believe that new individuals in my life may feel unable to accept me due of my troubles, which may be rather scary to them." YouTubers with disabilities also mentioned the lack of support or communities. Like one video mentions "When no one is at home, this is how I travel around. Because of my Ehlers-Danlos Syndrome and back problems, it's a little challenging." Thirteen clips are about social problems caused by communication impairment. For example, "People who are hard of hearing have no idea how to speak in a public situation with someone who does not have a hearing

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	Sub-theme	Definition
IT & assistive technologies	Video game	Accessibility issues with video games
	Closed captioning	Issues caused closed captioning or the lack of captioning
	Comm. and AAC* tool	Hindrance of communication caused by technologies
	Assistive software	Problems with assistive features in software (e.g., screen reader and magnifier)
	Web & app	Accessibility issues with websites, mobile apps, or computer software
	Assistive device	Barriers with assistive hardware, devices, and tools (e.g., wheelchair and hearing aid)
Social support & societal attitudes	Social stigma	Stigma of disability; PWDs being isolated or excluded due to discrimination
	Disability awareness	Social issues caused by neglecting, misconceptions of, and nonrecognition of disabilities
	Social support	Difficulties caused by lack of social support or communities
	Communication	Social barriers caused by communication difficulties or impairments
	Self-stigma	Difficulties caused by PWDs' self-stigma, shame, or negativity caused by the disability
	COVID	Difficulties caused COVID-19, social-distancing, quarantine, and PPE
Systems & policies	Healthcare	Lack of medical treatment or information, or the poor quality of treatment and healthcare
	Education	Problems, discrimination, or inaccessible learning in education and childcare
	Government	Problems with the authorities such as government, legislation, and public policies
	Employment	Barriers in job market, employment, and workplace
	Business & service	Barriers in commercial services, business, and recreational services
Environment & transportation	Residential	Problems with private and residential space, including building environment and home appliances
	Public facility	Barriers found in a public environment or commercial facilities
	Transportation	Barriers with vehicles and transportation systems
	Natural environment	Problem caused by the natural environment, weather, or climate
Econ		Problems caused by inadequate economic or allocation of financial resources

Table 2. The sub-themes of disability barriers in [5]. *AAC standards for Augmentative and Alternative Communication

disability." YouTubers also share their challenges with COVID. In one video about how the coronavirus affects blind people, the YouTuber says *"Hand sanitizer was becoming increasingly difficult to hold. It was becoming a serious issue."*
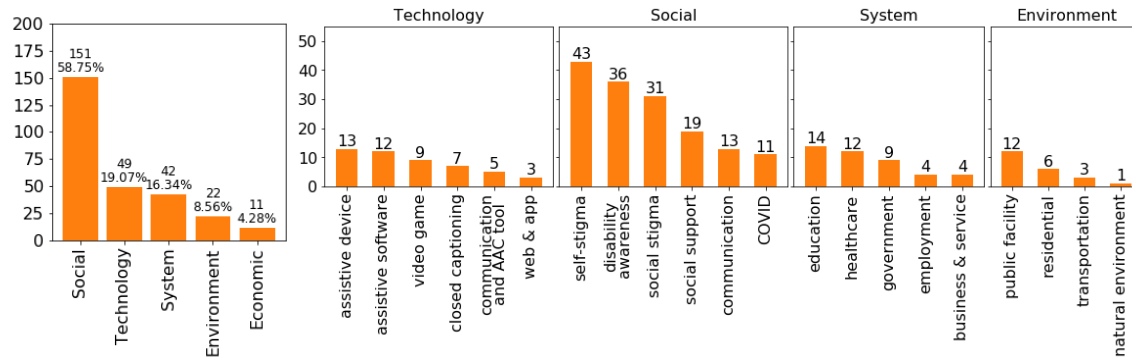

Fig. 1. The distribution of videos in each of the sub-themes.

IT Access and Assistive Technologies. 49 video clips are about problems with IT or assistive technologies. The most mentioned technologies are assistive hardware (13 clips) and software (12 clips). For example, a YouTuber with a motor disability shows how they take a bath and mention the chair texture can hurt skin (Figure 2a). In another video, a YouTuber with vision impairment demonstrates the problem with the magnifier feature (Figure 2b). Nine clips are

about the accessibility barriers in video games. For example, a game YouTuber with vision impairment mentions the fog effect makes the text hard to read (Figure 2c). Seven clips discuss problems with closed captioning. For example, one YouTuber argues that YouTube should not remove community captions because *"You're just alienating a large population of people by saying things like, 'uh catch you later,' or 'uh farewell, we don't need you viewing the movies."* Five video clips mention problems with communication tool and AAC such as hearing aids and sign languages. Three clips mention mobile or web software problems that contain barriers (Figure 2d).

(a) A YouTube explains the texture of bathing chair can hurt skin.

(b) A video shows a problem with magnifiers when reading comments.

(c) A YouTube gamer mentions the fog can make text hard to read.

(d) A kid is struggling with using an iPad with the left hand.

(e) A YouTuber tells a story about hitting a stone and overturn the wheelchair.

(f) A YouTuber shows it is difficult to use a regular ladder to fix the smoke detector.

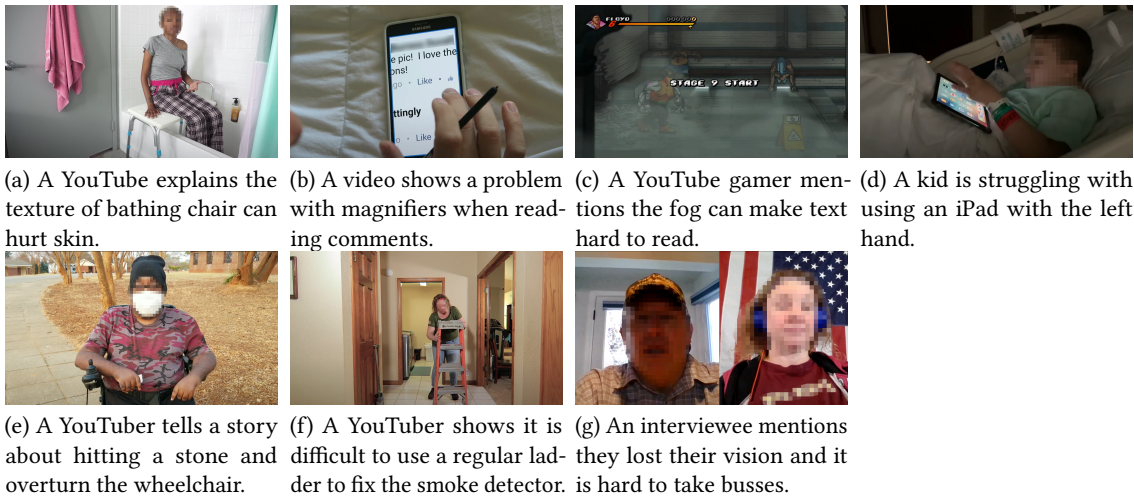(g) An interviewee mentions they lost their vision and it is hard to take busses.

Fig. 2. Top: Example videos showing difficulties with IT Access and Assistive Technologies. Bottom: Example videos showing environment and transportation difficulties

System and Policies. System and policy barriers relate to the availability of and access to the systems to support participation. In our data, 14 videos mention barriers within the education system, 12 mention issues with the healthcare system, and nine complaints about public agencies or policy problems. For example, one YouTuber with vision impairment mentions their struggles in a new semester that *"The first week could be difficult since you're getting used to learning a new way around somewhere, or making sure the new equipment works, and that everything is in working order."* Another YouTuber with bipolar disorder comments about the healthcare that they need *"additional information on the therapy's disadvantages and criticisms so that we can see both sides"* About public policies, one video mentions that *"For her (the daughter's) back issues and muscle problems, I was really interested in getting some CBD oil cream (a compound found in marijuana). We live in a place where none of it is yet legal."* Employment and business and services have four videos mentioning them.

Environment and Transportation. 22 video clips mention problems with the environment. In this theme, barriers with public and commercial facilities are mentioned the most with 12 clips (e.g., Figure 2e). Six clips show their problems at home when using tools to complete daily tasks (e.g., Figure 2f). Three clips talked about challenges taking transportation or navigating the environment (e.g., Figure 2g). One video mentions the challenge of the cold weather.

Economic. Eleven videos mention economic difficulties. For example, one video mentioned a financial issue with social security that "*money is very tight for a lot of people, especially those people living on a fixed income.*"

5 DISCUSSION AND FUTURE WORK

YouTube for Knowledge-Sharing. YouTube is commonly used for sharing personal experiences with technologies and public and private environments. Disclosing the difficulties may help other people to avoid similar challenges. YouTubers share their experiences with assistive tools and software features. Gamers speak about the accessibility challenges when playing games. PWDs also share their difficulties with public facilities and everyday tools. For other people with similar disability challenges, these videos are valuable experiences they can learn from. Therefore, video-sharing platforms could recommend such videos to help PWDs avoid problems or obtain solutions. For designers, YouTube can be a data source to discover accessibility issues with their products and design. Design framework and theories are needed to guide analysis of online videos for accessibility examination.

YouTube as a Place for Disclosing Social Pressure. Our preliminary analysis suggests that the most common difficulties disclosed by YouTubers are problems with social support and societal attitudes. PWDs reveal the self-stigma and negativity caused by disabilities, indicating YouTube is a place for disclosing social pressure. Our work finds six challenges related to social support and societal attitudes: self-stigma, disability awareness, social stigma, lack of social support, communication challenges, and COVID-19 challenges. The prevalence of social difficulty disclosure indicates that future HCI and accessibility research need to pay attention to the social and emotional needs of PWD. Accessibility technologies need to be designed to offer dignity and shield against stigma. YouTube videos can be used to examine the social situation and societal attitudes that hurt PWD. Future research could leverage YouTube videos to investigate PWDs' need for social respect and mental support. But it should also be noted that using YouTube data to infer the commonality of PWD difficulties and accessibility barriers may introduce statistical bias, since whether YouTube creators have the same disability distribution as the overall population needs future investigation.

Public Advocacy with Online Videos. Our result suggests YouTube is also used to advocate for solving accessibility problems. YouTubers with disabilities discuss their issues with education, healthcare, government, and employment systems to share their struggles and raise public awareness of accessibility challenges. The discussion of technological and environmental problems indicates that PWDs want their voice heard. YouTube has a culture of creating community and opinion leaders. Disclosing challenges with systems and policies could promote public changes. Future research should examine the role of online videos as a new way of accessibility advocacy and their effects on public awareness. It will be interesting to study how YouTubers use video-sharing communities to call for action and solve common accessibility challenges. Meanwhile, researchers need to examine the challenges of accessibility advocacy. It will be interesting to investigate whether and how creators exaggerate video content and use other attractive techniques to engage the viewers.

REFERENCES

[1] Katya Borgos-Rodriguez, Kathryn E Ringland, and Anne Marie Piper. 2019. MyAutsomeFamilyLife: Analyzing Parents of Children with Developmental Disabilities on YouTube. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW (11 2019). https://doi.org/10.1145/3359196

[2] Barbara E Bromley. 2008. Broadcasting Disability: An Exploration of the Educational Potential of a Video Sharing Web Site. *Journal of Special Education Technology* 23, 4 (12 2008), 1–13. https://doi.org/10.1177/016264340802300401

[3] Dasom Choi, Uichin Lee, and Hwajung Hong. 2022. "It's not wrong, but I'm quite disappointed": Toward an Inclusive Algorithmic Experience for Content Creators with Disabilities. In *CHI Conference on Human Factors in Computing Systems.* 1–19.

[4] Jared Duval, Ferran Altarriba Bertran, Siying Chen, Melissa Chu, Divya Subramonian, Austin Wang, Geoffrey Xiang, Sri Kurniawan, and Katherine Isbister. 2021. Chasing Play on TikTok from Populations with Disabilities to Inspire Playful and Inclusive Technology Design. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21).* Association for Computing Machinery, New York, NY, USA. https://doi.org/10.1145/3411764.3445303

[5] Joy Hammel, Susan Magasi, Allen Heinemann, David B Gray, Susan Stark, Pamela Kisala, Noelle E Carlozzi, David Tulsky, Sofia F Garcia, and Elizabeth A Hahn. 2015. Environmental Barriers and Supports to Everyday Participation: A Qualitative Insider Perspective From People With

Disabilities. *Archives of Physical Medicine and Rehabilitation* 96, 4 (2015), 578–588. https://doi.org/10.1016/j.apmr.2014.12.008

[6] Franklin Mingzhe Li, Franchesca Spektor, Meng Xia, Mina Huh, Peter Cederberg, Yuqi Gong, Kristen Shinohara, and Patrick Carrington. 2022. "It Feels Like Taking a Gamble": Exploring Perceptions, Practices, and Challenges of Using Makeup and Cosmetics for People with Visual Impairments. In *CHI Conference on Human Factors in Computing Systems (CHI '22)*. Association for Computing Machinery, New York, NY, USA. https://doi.org/10.1145/3491102.3517490

[7] Xingyu Liu, Patrick Carrington, Xiang 'Anthony' Chen, and Amy Pavel. 2021. What Makes Videos Accessible to Blind and Visually Impaired People?. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21)*. Association for Computing Machinery, New York, NY, USA. https://doi.org/10.1145/3411764.3445233

[8] Woosuk Seo and Hyunggu Jung. 2021. Understanding the community of blind or visually impaired vloggers on YouTube. *Universal Access in the Information Society* 20, 1 (2021), 31–44. https://doi.org/10.1007/s10209-019-00706-6

[9] Johann Wentzel, Sasa Junuzovic, James Devine, John Porter, and Martez Mott. 2022. Understanding How People with Limited Mobility Use Multi-Modal Input. In *CHI Conference on Human Factors in Computing Systems (CHI '22)*. Association for Computing Machinery, New York, NY, USA. https://doi.org/10.1145/3491102.3517458