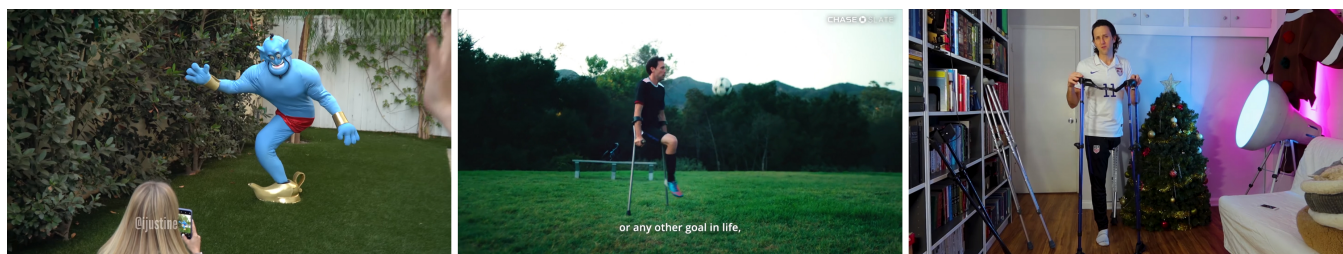


# “It’s not wrong, but I’m quite disappointed”: Toward an Inclusive Algorithmic Experience for Content Creators with Disabilities

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**Figure 1:** Video capture of YouTuber “Josh Sundquist” reproduced with his permission: He is wearing a “Genie in a bottle” costume, plays soccer, and introduces his crutch.

## ABSTRACT

YouTube is a space where people with disabilities can reach a wider online audience to present what it is like to have disabilities. Thus, it is imperative to understand how content creators with disabilities strategically interact with algorithms to draw viewers around the world. However, considering that the algorithm carries the risk of making less inclusive decisions for users with disabilities, whether the current algorithmic experiences (AXs) on video platforms is inclusive for creators with disabilities is an open question. To address that, we conducted semi-structured interviews with eight YouTubers with disabilities. We found that they aimed to inform the public of diverse representations of disabilities, which led them to work with algorithms by strategically portraying disability identities. However, they were disappointed that the way the algorithms work did not sufficiently support their goals. Based on findings, we suggest implications for designing inclusive AXs that could embrace creators’ subtle needs.

## CCS CONCEPTS

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

## KEYWORDS

algorithmic experience, people with disabilities, content creators, YouTube, inclusive design

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## 1 INTRODUCTION

There is a growing movement of people with disabilities who present multifaceted aspects of their disabilities as content creators on social media [27, 80]. On YouTube, Robin, who has cerebral palsy, shares a video of herself playing a wheelchair rugby game or practicing dancing [100]. The comedian Sundquist, who lost a leg as a child, went viral with videos of Halloween costumes such as “Genie in a bottle” and “Baby Groot,” which creatively used his one-legged appearance [99]. In addition, many TikTok creators with disabilities stand against common misconceptions about disability through short videos featuring their everyday hardships and conquests [2, 69]. Video platforms provide opportunities for people with disabilities, who have endured skewed representations of disabilities shaped by mainstream media [38, 45], to present their real lives with disabilities and their own narratives.

In social media, algorithms that classify, associate, and filter countless sources of information [23] play a critical role in making decisions, such as which audience members to deliver content to and whether content includes elements that violate community guidelines. Therefore, creators with disabilities strategically interact with various algorithms to spread their content to people all over the world; this set of interactions and experiences with algorithms can be called an algorithmic experience (AX) [6]. The most distinctive

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aspect of creators with disabilities in social media AXs is that they not only upload content about disability, but also place disability-related keywords and photos in titles, descriptions, and thumbnails, which the algorithm cites to promote their content [97]. This also means that the AXs of creators with disabilities can be affected by how the algorithm manages the topic of their disability.

However, recent studies have pointed out that the algorithms embedded in multiple products or systems have inherent risks of providing non- or less-inclusive experiences to users with disabilities [42]. Existing machine-learning algorithms used for moderating human conversations classified text mentioning “disability” as more harmful [49]. AI algorithms that identify objects in autonomous vehicles may fail to recognize a person in a wheelchair as a pedestrian [92]. In particular, TikTok has recently garnered controversy for classifying creators with disabilities as “users vulnerable to cyberbullying” and preventing their content from appearing in the algorithmically curated “For You Feed” when such content reaches a threshold number of views [67]. Although algorithms that either contain biases or are not sensitive to disability topics can negatively impact the AXs of creators with disabilities, there remains a lack of studies on how inclusive current AXs are for creators with disabilities.

We addressed this research gap by conducting semi-structured interviews with eight YouTube creators with disabilities. We focused on exploring YouTube creators’ (YouTubers’) experiences because of their rich, direct, and close interactions with real-world algorithms while managing their channels and content. In addition, YouTube provides various data that allows creators to review and analyze the results of its algorithm’s operation in “YouTube Creator Studio”; it enables YouTubers with disabilities to gain a deeper understanding of how content that reveals their disabilities is handled by the algorithm. To understand the YouTube AX of creators with disabilities and examine how inclusive they find the current AX, we tried to answer three research questions through interviews:

- RQ1: What unique goals do creators with disabilities have while presenting their disabilities on YouTube? How do they interact with YouTube’s algorithm to achieve those goals?
- RQ2: How do content creators with disabilities perceive the inclusiveness of YouTube’s algorithm? What factors have influenced those perceptions?
- RQ3: What challenges do creators with disabilities face when interacting with YouTube’s algorithm?

Our findings illustrate that offering informational support for people with disabilities and correcting public misconceptions about disabilities are underlying goals for creators with disabilities. These goals have led creators to try to understand the characteristics of the algorithm and strategically present their disability identities based on that understanding. In this process, they perceived that the content distribution algorithm treats disability in the same way as other topics, but they were disappointed that it could not reflect their unique contexts and needs. They also faced several challenges in presenting their identities as intended due to the algorithm’s influence. Building upon our findings, we discuss the inclusive issue of AX for creators with disabilities and suggest design implications for enhancing inclusive AXs to reflect creators’ values in algorithms.

As a first attempt to explore the AXs of content creators with disabilities, our work makes the following contributions: 1) An empirical study to understand the perceptions and interactions of creators with disabilities toward algorithms; 2) The identification of factors that influence the AXs of creators with disabilities; and 3) The proposal of implications for designing inclusive AXs that reflect the identities and values of creators with disabilities.

## 2 RELATED WORK

### 2.1 Use of video-based platforms by people with disabilities

How the media portrays people with disabilities can influence the broader public’s attitudes toward people with disabilities [44]. Although attempts to depict a positive image of people with disabilities have increased, for a long time, the media has shown scarce representations of people with disabilities or portrayed them in stereotyped or negative ways [12, 21, 34, 50, 82]. For example, Bond’s study [12] analyzing depictions of physical disability from more than 400 episodes of children’s television programs in Japan found that characters with physical disabilities were rare, and a majority of characters with physical disabilities were depicted using stereotyped representations such as being morally good, attractive, and satisfied with life. Gardner and Radel [34], who analyzed American newspapers and television for references to people with disabilities, discovered that only about one-quarter of items portrayed people with disabilities as persons capable of independent living and contributing to society. Moreover, Huws and Jones [50] also investigated depictions of autism in British newspapers and reported that autism was portrayed in a standardized and homogenized way that failed to recognize human diversity.

In recent days, a growing number of people with disabilities have expressed various aspects of their lives with disabilities through video-based social media that focuses on media sharing. Bromley [14] analyzed 147 videos uploaded by YouTube creators with disabilities and reported that creators with disabilities shared real-life experiences with their disabilities through videos in which they expressed their personal stories and provided instructional and public service content. “How-to videos” generated by people with disabilities show how they successfully cope with chronic health conditions and recorded high numbers of views, suggesting their potential as a learning tool for people with disabilities to acquire useful life skills [63]. Creators with disabilities not only reveal their disabilities, but also construct their own identities through media creation [24]. They strive to challenge “societal constructs of disability” created by mainstream media sources and improve public awareness of their disabilities through their content [24, 85]. Duval et al. [25] proposed technology designs by analyzing videos of TikTok creators with disabilities and found that some of these creators’ videos attempted to educate the general population on disability topics. Considering that people with disabilities suffer a distorted representation produced by mainstream media [38, 45], video platforms give them a chance to directly discuss their disabilities as creators. Although video platforms are positioned as a critical medium to convey the voices of creators with disabilities, few studies have explored whether this platform type sufficiently serves their unique characteristics and purposes.

## 2.2 Algorithmic Experience (AX)

In social media, users inevitably interact with algorithms that play significant roles in managing their content by prioritizing, classifying, associating, and filtering numerous information [23]. Alvarado et al. stated that making those interactions with and experience of algorithms explicit can be called an algorithmic experience (AX) [6]. Oh et al. also described AXs as a “new stream of research on user experience” and emphasized a user-centric perspective on algorithms [71].

HCI researchers have made numerous attempts to understand how users interact with algorithms that play specific roles in social media, such as through recommendations or curation [4, 5, 28, 52, 77, 79]. For example, Rader and Gray examined user beliefs about algorithmic curation on Facebook [77]. Eslami et al. [28], who redesigned a Facebook news feed and compared the effects of the curation algorithm, found that some participants were unaware of the existence of the curation algorithm. Alvarado et al. [5] examined middle-aged users’ beliefs about the YouTube video recommendation system through semi-structured interviews. They identified factors that affected users’ perceptions of algorithmic recommendations and grouped them into four user belief categories: previous actions, social media, recommender system, and company policy. Ma and Kou [64] explored the AXs of YouTube creators related to algorithmic content moderation by analyzing the discussion data of the ‘r/youtube’ subreddit. They discovered that YouTube creators complained that YouTube did not offer accurate reasons for its algorithmic punishment, and they collectively built knowledge about how the content moderation algorithm works to avoid demonetization.

On the other hand, several bodies of work [6, 15, 95] focused on the AXs of overall systems in which several algorithms work in combination. Bucher [15] explored situations in which users were aware of the invisible Facebook algorithm and how they made sense of it by analyzing tweets and conducting interviews. She classified people’s reactions to the influence of Facebook algorithms into six categories. For example, she found that users felt that they worked to get the algorithm’s attention and could not get enough likes or comments due to the algorithms, which she called a “popularity game.” Based on these findings, Bucher proposed the term “algorithmic imaginary,” to express how people imagine, perceive, and experience algorithms. Wu et al. [95] explored how content creators on YouTube make sense of the YouTube algorithm through interviews, content analysis, and wiki surveys. They identified three algorithmic personas that creators formed based on their experiences working with algorithms: Agent, Gatekeeper, and Drug Dealer. Algorithms acting as an agent signify a friend who promotes users’ channels on YouTube. A gatekeeper algorithm is like a being who determines whether their content gets views. Algorithms with the personas of drug dealers imply a role of keeping the audience addicted to the platform. In addition, Wu et al. illustrate how these personas affect the behavior of creators in an AX. For example, YouTubers orient themselves toward the agent persona by identifying algorithms’ tastes so that the algorithms will favor them. Conversely, some YouTubers work against a drug dealer persona that keeps viewers addicted to the platform by generating videos that would not be favored by the algorithms.

In reviewing these previous studies that explored AXs, we found that algorithmic experiences (AXs) are closely related to the user experiences (UXs) of algorithm-embedded products or services. Although a shared definition of UX is not available, the notion of a UX, introduced by Norman [68], usually refers to all aspects of the interaction between end-users and a product or service. Therefore, referring to Alvarado et al.’s argument that the interaction with and experience of an algorithm can be called an AX [6], an AX can be viewed as the user experience (UX) between the algorithm and the end user. One interesting point we captured from previous works about AX is that users interacted with the algorithms through the platforms or services that employed them. For example, Facebook users experienced content curation algorithms while using Facebook, and YouTube creators interacted with content distribution algorithms through YouTube. Considering that algorithms are organically connected to systems’ functions and features, it seems difficult to clearly separate the user’s AX from the UX of an algorithm-embedded system. In line with this, in our paper, we decided not to investigate the YouTube experience of creators with disabilities and their AXs separately. Instead, we explored the creators’ holistic YouTube experiences ranging from content creation, dissemination, and management to interaction with viewers. Then, we regarded YouTube AX as an experience that can be either directly or indirectly influenced by algorithms among those overall YouTube experience.

## 2.3 Inclusive issues for People with disabilities

The extensive application of AI algorithms to various products and systems around us has brought opportunities for people with disabilities to participate in previously inaccessible activities [60, 74]. Many studies have been conducted to improve the quality of people with disabilities’ everyday experiences with AI algorithms. For example, researchers attempted to help people with vision impairments identify objects through an image recognition algorithm [53], and developed an AI system that could assist with their online shopping activities [84]. Hamid and Tarau [46] introduced an algorithm-based automatic summarization that provides the essence of a news item or article in a condensed form for people with vision or language difficulties.

Despite the benefits that AI algorithms provide people with disabilities to help them overcome physical and cognitive barriers that they often face in their everyday lives, several recent studies have pointed out that algorithm-embedded systems or AI product possess the potential to be less inclusive for users with disabilities [32, 39, 42, 43, 86, 89, 92]. In the aspect of AI ethics for people with disabilities, researchers have presented the concept of fairness and inclusivity, which can be regarded as somewhat analogous, as separate notions. Trewin mentioned that for AI fairness, the algorithm models should work equally well on members of diverse groups without incorporating social bias [89]. For AI inclusivity, Morris suggested that it is related to how effective the AI or algorithm-infused systems are for diverse user populations [66]. Our study intends to explore not only how YouTube’s algorithm treats disability-related content but also whether there is any problem in employing the algorithm embedded in YouTube by creators with disabilities. In this sense, we used the term “*inclusive issue*” as

a concept that encompasses the fairness of the YouTube algorithm itself and the inclusivity of the YouTube system in the context of the algorithm.

This inclusive issue could occur when data for training the algorithm contains social bias. As previous studies [11, 35, 65] raised the possibility of biased training data related to race and gender, Hutchinson et al. [49] also presented evidence of biases related to disabilities in existing machine learning models and training data. In a public dataset used to develop natural language processing (NLP) models for classifying text, Hutchinson et al. found that negative phrases such as homelessness, gun violence, and drug addiction were often discussed in relation to mental illness. They argued that these associations could result in disability-related terms being treated undesirably in NLP models. Moreover, they demonstrated that machine learning models for moderating conversations categorized texts that mentioned the word “disability” as more “toxic.”

Another underpinning cause in the inclusive issue for people with disabilities is the lack of data on this group to train algorithms. Since people with disabilities are a relatively small proportion of the overall population and there are countless types and levels of disabilities, it is difficult to obtain sufficient data to reflect the diversity of this group [89]. Even if such data is collected, it is highly likely to be disregarded or treated as an outlier [89]. The lack of data on disability groups can pose risks in many of the technologies and contexts in which algorithms are employed. Facial recognition algorithms, which are already applied in criminal justice and interview support software, can misinterpret the facial expressions of individuals with autism or Down syndrome [42]. There is a risk that AI-based conversational agents might not properly recognize the spelling or phrasing from users with dyslexia [42]. In addition, several papers have described the possibility that automatic transcription tools using speech recognition may not identify various speech patterns used by people such as those with hearing impairments [39, 42, 78, 86, 89]. Kane et al. [54] stated that sensor systems might fail to respond in consideration of the various body shapes of people with physical disabilities, such as wheelchair users. To address this problem, Park et al. [72] suggested factors to consider when designing online infrastructure that enables people with disabilities to contribute to various types of AI-relevant data.

However, whether such inclusivity issues affect the interactions between creators with disabilities and algorithms in video-based social media remains underexplored. Just as concerns that algorithms can classify and eliminate people with disabilities based on their social media behavior without their consent [66], if an algorithm is not sensitive to disability-related topics, it carries the risk of providing negative AXs to creators with disabilities who reveal disabilities in their content.

### 3 STUDY DESIGN

Our study seeks to explore whether the YouTube AX of creators with disabilities is inclusive by investigating their perceptions toward algorithms, and characteristics and challenges during their AX. Thus, we constructed an exploratory interview study aimed at eliciting creators’ experiences and viewpoints accumulated over their long-term use of YouTube.

### 3.1 Participants

To recruit YouTubers with disabilities who reveal their disabilities in their content, we searched for phrases on YouTube and Google in Korean such as: “YouTuber with a disability,” “Creator with disability,” “YouTuber with vision impairment,” “YouTuber with hearing impairment,” “YouTuber with a physical disability,” “YouTuber with a developmental disability,” “People with vision impairment,” “People with hearing impairment,” “People with a physical disability,” “wheelchair,” and “autism.” We used four criteria to choose YouTubers with disabilities (or their YouTube channels) suitable for our study: 1) creators who either directly or indirectly reveal their disabilities in their channels; since this study requires recent experience of continuously interacting with algorithms 2) creators who have uploaded videos within six months from June 1st when recruitment was conducted; 3) at least ten videos must be uploaded to the channel; 4) creators with disabilities should engage in channel management, not simply work as performers. Based on these criteria, we found a total of 28 disability-related channels in Korea (vision impairment: five, hearing impairment: 10, developmental disability: one, limbless disability: one, physical disability: 10, and Tourette’s syndrome: one). To diversify participants’ disabilities, we immediately reached out to a relatively small number of channels about developmental, limbless disability, and Tourette’s syndrome. We also contacted channels of YouTubers with vision, hearing impairment, and physical disabilities sequentially in the order of their number of videos. We sent emails or Instagram DMs to creators of 20 channels (vision impairment: four, hearing impairment: 10, developmental disability: one, limbless disability: one, physical disability: 10, and Tourette’s syndrome: one), and nine participants from eight channels responded that they would participate in the study (vision impairment: three, hearing impairment: none, developmental disability: one, limbless disability: one, physical disability: two, and Tourette’s syndrome: one). All participants were Korean and Table 1 shows detailed participant demographics and information about their channels.

Eight out of the nine participants had disabilities and they all identified themselves as people with disabilities. The other participant (P4-2) was a sister without a disability who runs a channel with P4-1. The average age of our participants was 29.4 years (range: 20–42 years, SD = 7.2); with three males and six females. The type of disabilities our participants had were largely vision impairment, developmental, limbless, physical disability, and Tourette’s Syndrome. Tourette’s Syndrome is recognized as a disability by the Americans with Disabilities Act (ADA) [70], and in Korea, where the experiment was conducted, the Ministry of Health and Welfare implemented a law admitting Tourette’s Syndrome as a disability in 2021. Six participants (P1, P2, P5, P6, P7, and P8) independently manage one channel; one participant (P3) runs two channels (C3-1 and C3-2) alone; P4-1, who has a developmental disability, manages a channel with her neurotypical sister (P4-2) because she found it difficult to create and upload content independently. Each participant has been running their channels for at least eight months and their subscriber numbers are in the range 97–56,700, which enables us to examine their YouTube AX associated in a wide range of situations. Participants were compensated with about \$100 USD (approximate value).

Participant ID	Age	Gender	Type of disability	Channel ID	Number of subscribers	Number of videos	Period from the video upload
P1	22	F	Vision impairment (Total blindness)	C1	56,700	56	1 year 7 months
P2	33	F	Vision impairment (Low vision)	C2	450	27	8 months
P3	32	M	Vision impairment (Low vision)	C3-1	3,030	108	2 years 1 months
				C3-2	97	14	4 months
P4-1	20	F	Developmental disability	C4	553	47	1 year 2 months
P4-2	23	F	-				
P5	42	M	Limbless disability (Use a prosthetic leg)	C5	394	75	1 year 4 months
P6	29	F	Physical disability (Use a wheelchair)	C6	216	29	1 year 5 months
P7	21	F	Physical disability (Use a wheelchair)	C7	540	63	2 years 3 months
P8	33	M	Tourette's Syndrome (Motor and vocal tic)	C8	30,100	132	1 year 6 months

Table 1: Demographics of study participants and information of each participant's channel.

### 3.2 Procedure

**3.2.1 Content Analysis.** Before conducting interviews with participants, we analyzed the characteristics of their channels and videos. This content analysis aimed to identify each participant's perspectives and stance for managing their channel by expressing disabilities. We applied those attributes to prepare customized interview questions.

First, we examined how participants introduced their channels in the "channel information" section, what playlists they made, and whether they used the "community" or "discussion" tabs. In addition, we watched all 551 videos uploaded to participants' channels and crawled the video information using YouTube API. The collected video information included titles, descriptions, thumbnails, tags, view counts, like/dislike counts, and comment counts. We investigated the weight of videos related to disability among participants' videos. The videos we classified as related to disability were those in which disability-related keywords and phrases such as "YouTubers with disabilities," "people with vision impairments," or "wheelchair," were directly written in titles, descriptions, and hashtags exposed to audiences. We also determined that videos were associated with disability when the keywords related to disability were included in hidden hashtags that were not shown to audiences and when disability was a video's topic but not included in the title, description, or hashtags. Then, we categorized the topics covered by the participants' videos. Through iterative tagging and grouping with affinity diagramming [48], we categorized 13 topics related to disability and 25 topics not related to disability. In addition, we scrutinized our crawled data and took notes by focusing on the way the titles, descriptions, and hashtags were written; the characteristics of the videos with many or few views; and changes in channel direction. These notes were reflected when composing the interview questionnaires for each participant. Afterward, we ensured whether the features we extracted matched the participants' intentions in the interviews.

**3.2.2 Interview Protocol.** Due to COVID-19 conditions, all interviews were conducted by either Zoom or phone call (for participants with vision impairments). The studies lasted 44–75 minutes and the

whole process was either audio or video recorded with permission. The interviews consisted of three parts:

First, we began our study by asking questions related to participants' overall experiences as YouTubers. The questions addressed their motivations to become YouTubers, their purpose as YouTubers, what identities they want to reveal in the channel, ways they promoted their channel, communication with audiences, accessibility of the platform, awareness of algorithms, etc.

Second, one of the challenges we faced was that participants' experiences with and thoughts about YouTube algorithms were mostly subconscious; they may not even be aware of them. Therefore, we asked participants to walk us through their YouTube activities as creators to capture their veiled interactions and perspectives in AX. Participants shared their computer screens and stepped through the process of uploading videos and reviewing the analysis for uploaded videos provided by YouTube on the "YouTube Creator Studio" webpage. Furthermore, researchers intermittently asked questions about their algorithmic awareness or reasons for their behavior in specific contexts. This walkthrough session encouraged the participants to increase their awareness of their YouTube AX.

Last, we conducted follow-up interviews to more directly ask about their AX related to disabilities. The interview question covered personal opinions for the relationship between algorithms and disability topics, their own strategies when working with algorithms, challenges in AX, and their wishes for algorithms or the YouTube platform.

**3.2.3 Accessibility & Ethical considerations.** As participants with vision impairments all mentioned that they could not access the Zoom tool due to their physical condition, we conducted their interviews and walk-throughs via phone calls. They all described that they had almost memorized the working processes and UI components of the YouTube platform. Indeed, they proceeded with the walk-through session without difficulty by using their memory and screen readers. If there were any missing parts, the researcher asked additional questions about them.

To ensure that our interview questions were not sensitive to participants, we handed out the interview questionnaires in advance

and asked them to let us know whether they contained inappropriate content or wording. No participants requested corrections for the questionnaire or were told that they were unable to respond. All participants read or listened to the consent form before participating in the study and consent was obtained through audio recordings during the interview. Our study was approved by the Institutional Review Board.

### 3.3 Data analysis.

We transcribed the recorded audio and analyzed quotes using a thematic coding approach [36] with ATLAS.ti [7]. As a first step, one author highlighted all quotes in the transcriptions that corresponded with notable aspects related to our research questions: perception toward algorithms and characteristics and difficulties in their AX. After that, one researcher used open coding to categorize highlighted quotes and generated initial themes. Another researcher read the classified initial themes and quotes and responded with feedback. Based on this, two researchers iteratively added, merged, and generated themes until the themes revealed the most salient topics in our data.

## 4 FINDINGS

In what follows, we present the findings of our study. First, we show the content analysis results of our participants' channels and their videos. Second, we display the goals of our participants as YouTubers and their strategies for interacting with algorithms to achieve those goals. Third, we show perceptions of our participants toward the algorithm's inclusiveness formed based on their AX. Last, we introduce three challenges participants faced while interacting with YouTube algorithms.

### 4.1 Content Analysis

Of the 551 total videos uploaded by our participants, 56.1% were related to disability (Video related to disability: 309, Video unrelated to disability: 242). Among the topics of videos related to disability, "personal experience about disability," which was covered in 189 videos and uploaded at least 12 times for each participant's channel, was the most discussed topic. "Enhancing awareness of disability" and "Offering information associated with a disability" were the next most frequently mentioned topics. In addition, the creators introduced discrimination or unfair anecdotes about disabilities they had experienced in their daily lives, or shared their concerns about how the YouTube algorithm handled the topic of disability. For videos dealing with topics not related to disability, "everyday life or vlog" was the most common topic with 78 episodes. This was followed by topics that some participants consistently posted on their channels, such as "beauty" and "real-time streaming recording" (see Appendix for a detailed table).

We also examined how our participants revealed their disability identities by calculating the proportion of disability-related videos for each channel (Table 2). Participants uploaded videos about disability at an average rate of 56.1% (min = 27.8% and max = 96.3%). All channels' creators considered disability as the main identity or one of several identities. Six of the nine channels (C1, C2, C3-2, C4, C5, and C6) generated videos with disability themes or added

Participant ID	Channel ID	Percentage of videos related to disability
P1	C1	83.9%
P2	C2	96.3%
P3	C3-1	27.8%
	C3-2	57.1%
P4-1	C4	66.0%
P4-2		
P5	C5	94.7%
P6	C6	93.1%
P7	C7	38.1%
P8	C8	34.1%

**Table 2: Percentage of videos related to disability by channel for each participant.**

disability-related keywords to their content information at a relatively high rate of 57.1–96.3% (mean = 81.8%). In addition, most videos from these six channels specified the person's disability in the title or thumbnail image, allowing audiences to immediately recognize the creator's disability.

Meanwhile, for the three channels (C3-1, C7, and C8) in which participants dealt with their disabilities on average at a lower rate of 33.7%, participants also addressed topics other than disability as additional channel identities. P7 considered "beauty YouTuber with disability" another identity for herself, and combined makeup and disability content on her channel. In addition, since P8 regarded his tic symptom as just a little piece of his life, he uploaded content with a variety of themes besides disability, including parodies, songs, and food reviews. Channel C3-1, which mentioned disability at the lowest rate of 27.8%, initially uploaded videos both about reviewing food and visual impairments, but subscribers who expected videos about food reviews unsubscribed, expressing discomfort over the topic of disability in their comments. This led P3 to separate his channel into two (C3-1 for introducing chicken menus, C3-2 for disability content) in order to provide any information about his disability in the C3-1 channel as much as possible.

Moreover, we compared the average view counts of videos related to disability to the average view counts of videos unrelated to disability for each channel to investigate whether association with a disability affected the number of views. As shown in Table 3, the average view counts of videos related to disability were higher than those of videos unrelated to disability in all channels except for the C3-1 channel, which focused more on introducing foods. We will describe how our participants understood this result and applied their understanding to interact with the algorithms below.

### 4.2 Goals and Expectations towards Youtube AX (RQ1)

RQ1 concerned the goals of our participants as creators who reveal their own disabilities. We identified that our participants had a unique core goal related to identity presentation as people with disabilities and attempted to convey meaning through the videos

Participant ID	Channel ID	View Count Mean (Standard Deviation)		The ratio of “Means of videos related to disability” to “Means of videos unrelated to disability”
		Videos related to disability	Videos unrelated to disability	
P1	C1	152628.553 (496063.501)	17198.333 (15747.654)	8.875*
P2	C2	954.654 (1209.472)	373.000 (0.000)	2.559*
P3	C3-1	892.933 (682.328)	4543.333 (11813.367)	0.197
	C3-2	265.885 (250.290)	115.000 (165.626)	2.312*
P4-1 P4-2	C4	1286.065 (1650.750)	979.438 (1467.960)	1.313*
P5	C5	811.169 (1060.968)	137.000 (50.166)	5.921*
P6	C6	618.222 (786.217)	127.000 (72.125)	4.868*
P7	C7	723.083 (804.990)	389.103 (347.448)	1.858*
P8	C8	75001.644 (351286.523)	3710.977 (10422.859)	20.211*

**Table 3: The average and standard deviation of view count for disability-related videos and non-disability-related videos and the ratio of “view count means of videos related to disability” to “view count means of videos unrelated to disability.” The “\*” mark indicates that the view count means of disability-related videos was higher than that of non-disability-related videos.**

they created. However, participants also had multiple sub-themes when running their YouTube channels. In addition, they devised interaction strategies of using the YouTube’s content distribution algorithm to deliver videos to their target audiences. Some participants modified their strategies over time, and participants with multiple goals applied different strategies to each video within their channels. In this process, we found that participants had different practices in presenting their disability identities. Some participants modified their strategies over time, and participants with multiple goals applied different strategies to each video they uploaded. Below, we introduce largely three goals our participants had and how they manifested their disability identities to achieve those goals. We also illustrate their strategies to exploit specific algorithmic features in expressing their disability identities.

**4.2.1 Disability as a channel topic for monetization.** YouTube, in keeping with its slogan of “Broadcast Yourself,” is a platform where anyone can upload videos, providing our participants with a space to share their anecdotal stories. In this space, some participants appreciate being able not only to document their lives, but also to understand and embrace their disability identities. For example, P2, who recently lost her sight, was able to accept the fact that she now lives with a disability while sharing her own experiences through YouTube. P5 had one leg amputated and got a prosthetic leg as a result while working as a YouTuber, and the entire process was recorded as a video and uploaded to his channel. Initially, he was reluctant to accept his change, but a video of him climbing and swimming with his prosthetic legs was highly viewed, motivating him to try new things while wearing prosthetics.

Furthermore, some participants desired to become professional creators to gain financial benefits by getting more people to watch their videos. They said that given the limited career options available to people with disabilities, YouTube offers them new opportunities to earn money. In addition to gaining advertising revenue through content, they directly advertised their sponsorship accounts on the channel or sought to create external works such as interviews and speeches through YouTube activities.

*It may not be easy for people without disabilities to understand, but for people with disabilities, health is critical. If I work hard when I am not feeling well, I am left with various aftereffects. So, I think that life as a YouTuber, like a freelancer, suits me better because I can work while taking care of my conditions. (P7)*

Participants with the goal of earning revenue thought about ways to make more money while telling their own stories; this motivated them to understand the properties of the YouTube algorithm in depth by analyzing the results related to video distribution and monetization. As a result, some participants noted that disability-related videos recorded relatively higher numbers of views (Table 3), consistent with the analysis reported in Section 4.1. They believed that disability is a topic that stimulates audiences’ curiosity in the competitive YouTube market. Based on this, some participants considered highlighting their disability identities to potential audiences as a branding strategy that helped distinguish them from other creators and could increase views to generate advertising revenue. As an example of specific actions for this branding strategy, P3 and P8 included “People with vision impairment” (C3-2) and “Tic Disorder”



(C8) in their channel names. P5 used “Robotman,” which describes his condition with a prosthetic leg, as his channel name. To entice audiences to click on their videos, some of them struggled to create catchy titles that would highlight their disabilities. In some cases, participants mentioned their disabilities in the titles of videos even though the videos did not directly discuss the disability, as in “A Morning Subway Commute of A Person with Vision Impairment” (P2).

**4.2.2 To seek and offer informational and social support for people with disabilities.** Many of our participants also valued online communication with other people with disabilities through their content. Particularly, some of them (P4 and P6) actively sought social connections with audiences who could empathize with their stories because they had relatively limited offline opportunities to meet people with similar experiences.

*People talk about their experiences in the comments. When I uploaded my story, some people said things like, “I have a physical disability with a brain lesion, and this is how I ride the bus.” So, I thought the comments could provide another means of communication. Some people reply to comments on the videos; I thought it could be someone else’s experiences or stories, not just content.* (P6)

With altruism in mind, some participants (P3, P5, and P6) created videos to deliver helpful information to people with disabilities or those related to them. These participants wanted to help others with disabilities by sharing their special disability-related experiences and knowledge; they provided reviews for assistive devices, such as prosthetic limbs and watches for people with vision impairments. Some participants provided information about boarding planes or visiting concerts in wheelchairs.

*They (people with disabilities) must find out, step by step, how to do things like board a plane or attend a concert in a wheelchair. I hope other people will wander, or struggle, a little less with the help of this video because sometimes people with disabilities can’t go places as a result of having insufficient information.* (P6)

To achieve this goal, some participants (P3, P4-1, P4-2, P5, and P6) created videos with topics such as discussing disability with their viewers (e.g., Tell me your story about disability (C4)) or providing disability-related information (e.g., Is there a map application for people with disabilities? Please install it now! (C7)). They expected YouTube’s content distribution algorithm to target and expose these videos to audiences with disabilities or those who are interested in disability. This expectation made them mainly reveal their disability identities in these videos. For example, two participants (P5 and P6), in videos corresponding to this goal, deliberately included keywords related to disability in the video’s titles and hashtags referenced by the distribution algorithm and refrained from using hashtags unrelated to disability. Additionally, P5 and P6 inserted hashtags about specific disabilities, such as prosthetic limbs and osteodystrophy, to increase the probability of reaching audiences with specific disabilities who need their videos’ information.

*In the past, when I uploaded videos without any particular strategy, not many people with disabilities or prosthetics watched them. But, once I put the words prosthetic leg and orthosis in my titles and added the word disability or the name of the prosthetic leg to my tags, I actually saw that many of those viewers (people with his disability or their relatives) watched my videos.* (P5)

Remarkably, our participants reported that videos clearly expressing their disability identities in their content had significantly higher average viewing duration, which is one of the critical metrics the monetization algorithm uses to judge viewer engagement [96], than their other videos. They assumed that the algorithm distributes their content to those who are interested in disabilities. This means that they created content by targeting such viewers interested in disabilities through an distribution algorithm, and as a result, audiences naturally watched their entire videos to the end with interest. Therefore, our participants evaluated that this practice helps them not only meet their goals of reaching people with disabilities but also be well received by the monetization algorithm.

**4.2.3 To present diverse representations of disability for the public.** All our participants highlighted that pursuing diversity was their core goal and an underlying driving force for running their channels. Participants said they wanted to inform as many people as possible about real-life disability experiences through their channels. They were disheartened that the mainstream media focuses on delivering fragmentary images of people with disabilities, causing the public to perceive people with disabilities as pitiable and in permanent need of help. Therefore, they wanted to provide diverse representations of disability through YouTube, especially to people who have little experience with disability, and inform them that people with disabilities do not need sympathy.

*On TV and in existing media, people with disabilities are often portrayed as pitiable and miserable beings, in a fragmentary way, because people don’t know (about people with disabilities), and it’s rare to see us in public. So, let’s just take videos of us living joyfully and show them to people around us. That’s the great thing about YouTube: anyone can speak.* (P6)

Moreover, some of our participants (P6 and P7) tried to publicize the difficulties they face (e.g., school violence, employment cancellations, and wheelchair rides on public transport) and use their voices to change our society. For example, P7 stated that she experienced many societal barriers as a person with a disability; however, she could not resolve those problems by filing individual complaints. Therefore, she aimed to empower her voice by educating more people about her struggles through YouTube.

*My final goal is to inform people about wheelchair mobility issues. For example, currently, only one in ten restaurants is wheelchair accessible, but people don’t know about this unless they experience it. So, I thought I could bring social change by discussing this on YouTube.* (P6)

In pursuit of this goal, our participants generated videos such as those capturing the dynamic activities of people with disabilities



(e.g., Robotman with Prosthetic Leg Oeosa Dullegil Hell Training (C5)), which are rarely covered in the media, or directly expressing their opinions about promoting disability awareness (e.g., Do not allow dogs? Please don't shout at guide dogs for people with vision impairments (C1)). Moreover, they wished the algorithm would distribute these videos to viewers who know little about disability. However, through statistical data provided by YouTube, they found that an overwhelmingly high percentage of viewers who watched disability-related videos flowed into the video by directly searching for disability-related keywords or receiving recommendations for those videos after watching similar disability-topic videos. Our participants believed this metric indicates that the algorithmic distribution seldom recommends disability-related videos to audiences who are uninterested in disability.

Based on this belief, in the case of videos with these goals, our participants decreased focus on revealing disability identity in the video information referenced by the distribution algorithm and instead tried to include themes and keywords that were popular and highly viewed by the public to "ride the big algorithm wave" (P2) or "make connections with viewers without disabilities" (P4-2). As an example, some participants (P4-1, P4-2, P6, P7, and P8) created content relating their disabilities to social issues or topics covered by numerous other YouTubers.

*In the case of my video originally titled "Virtual Housewarming Party with a Wheelchair," I looked up considerable virtual house party videos, their titles, and how other creators were doing their room tours. So, I changed the title to "Virtual Housewarming Party" and added "Customized for Wheelchairs." Thus, I guided people who wanted to watch room tour videos to also find my video for a wheelchair-accessible house. (P6)*

The participants who attempted to express less of their disability-related identities in their content tracked keywords that led viewers to their channels. By analyzing changes in inflow from keywords, they rated that this practice effectively attracted viewers who were uninterested in disabilities. In fact, P7 uploaded content applying that strategy, such as discussing disability while doing her makeup with brand-new cosmetic products (e.g., Fall Makeup for Cool Skin Undertone/GRWM/Talking About the Interview at a Broadcasting Station and Doing Makeup Together!), and as a result, the top four keywords that created viewer inflow into her channel were all related to the beauty products she reviewed in her video. Additionally, viewers who visited the channel through popular topics were inclined to watch other videos about disability in the channel after watching videos with popular themes. Consequently, our participants thought that concealing the disability to some extent and utilizing favored themes in their content was a helpful strategy that allowed viewers to naturally become interested in disability.

#### 4.3 Perception of creators with disabilities toward the inclusiveness of algorithms (RQ2)

Our participants formed perceptions of how the YouTube algorithm addresses disability in distributing content to viewers by developing

strategies to achieve disability-related goals with the algorithm and analyzing its results. Notably, none of our participants felt that YouTube's algorithmic content distribution discriminated against disability-related topics or creators with disabilities. They thought disability was one of the many topics managed by the YouTube's distribution algorithm, and they did not have experiences that made them feel like the algorithm unevenly distributes videos regarding disability-related subjects as compared to other subjects.

*I think it (disability) is just one category. There is nothing special about it, nor is the algorithm discriminatory toward it. It seems that disability is just one of the many categories, like food shows and travel. Also, although it is good and necessary to increase people's awareness about disabilities, I think it is far more unfair for YouTube to do things for only creators with disabilities. It's the result of everyone's hard work. (P8)*

*This approach is clearly indicated in the YouTube Algorithm Guide, which says that YouTube does not prioritize or promote any particular categories or topics. It treats all categories and topics equally, and just pushes the content that people most want to see. I think that's the right way, and it actually works that way. Consider that not all videos dealing with vision impairments have unconditionally high views. Videos' elevated view counts are not because the videos are about disability, but rather because their creators have been significantly exposed to the public by appearing in mainstream media or being introduced by more prominent YouTubers. So, I don't think there is any choice of algorithm for specific topics. (P3)*

Although our participants did not think the algorithmic distribution discriminated against disability, they were disappointed that it was difficult to achieve their unique goal within the current algorithmic system. They said that so far, there seems to be little attempt to explore the special context or needs of creators with disabilities and reflect these issues in the algorithm.

*In terms of accessibility and diversity, the YouTube algorithm itself is still in its infancy. There is very little data on users with disabilities, and there have been very few attempts to find out what we want, so I feel our needs are not properly reflected. (P5)*

In particular, our participants stated that algorithms that diffuse content to audiences tend not to sufficiently serve their needs to inform wider audiences about their disabilities. All our participants desired to combat biases against disability in the real world by delivering videos with various representations of disabilities to people who are uninterested in disabilities. However, as mentioned in Section 4.2.3, they were concerned that if they included disability-related topics or keywords in their content, it seemed to stagnate and not spread to viewers who are indifferent to disabilities because of the characteristic of a personalized algorithm that recommends content related to viewers' search histories, relevance [79] and subscription information [81]. Furthermore, P6 noted that in real life, people with disabilities are often unable to interact with people without disabilities because of their physical conditions and that

this barrier seems to persist even on YouTube because of the way distribution algorithms work.

*Maybe it's like a lake, a stagnant lake. (P2)*

*Many people go to spas for massages, but they don't know much about massage parlors run by people with vision impairments; there's a huge difference in costs. So, I created a video (to provide this information), but most people who watched it and sympathized with the challenges were people with vision impairments or who work in that industry. I don't think this has spread to the broader population. It's not wrong, but I'm quite disappointed. (P2)*

Faced with these limitations, some participants (P4-1, P4-2, P6, P7, and P8) devised ways to reach wider audiences by revealing less about disability and adding popular topics more, as illustrated in 4.2.3. Although many participants rated this strategy as a fairly effective method, some participants (P6 and P8) worried that adopting this strategy prevented them from focusing on their disability stories as they originally intended and led them to tell different stories.

#### 4.4 Challenges while interacting with algorithms (RQ3)

In this section, we address several key challenges our creators with disabilities faced while engaging in YouTube AXs. The first and second challenges pertain to participants trying to exploit the nature of the algorithmic content distribution, which in turn prevents them from expressing their disability identities as they wish. The third challenge involves the content moderation algorithm's decision to demonetize disability-related content and its impact on our participants. Moreover, we depict how our participants reacted and behaved when confronted with each challenge.

**4.4.1 A dilemma arises in presenting disabilities.** Our participants reported that they were uncertain about how they should signal their identities and share their disabilities on their YouTube channels. As explained in Section 4.2, to attract targeted audiences, our participants attempted to reveal more or less information about their disabilities in their videos. However, the channels' ratios of disability-related videos to total videos highlighted new concerns to them regarding subscriber management.

Participants who uploaded high proportions of disability videos on their channels reported that although disabilities are a topic that can induce more clicks on videos, attracting new subscribers using only disability topics is difficult because there are limited disability-related topics that can be addressed.

*I recognized this problem while comparing the two channels (C3-1 for introducing food and C3-2 for disability content). Disabilities are not a popular topic for attracting subscribers. Looking at the number of subscribers, it is not increasing on the disability channel (P3).*

This concern led them to increase the proportion of videos that discuss disability by sharing various types of other experiences—such as cooking or camping—without explicitly mentioning their disabilities in the titles, keywords, or thumbnails on the channel. Additionally, aligned with the findings of Section 4.2.3, this

change made viewers watch videos about disabilities in their channel after watching videos of topics other than disabilities, thus increasing the number of channel subscribers.

However, diversifying topics on the channel by reducing the proportion of videos discussing disability topics raised another challenge. Because their existing subscribers had mostly subscribed to their channels to watch disability-related content, view counts sharply dropped if non-disability-related videos were posted. Consequently, participants who aspired to present diverse topics other than disabilities were forced to consistently post disability topics to satisfy existing subscribers' expectations.

*Until now, it seems that people visit my channel for disability- and prosthetic-related content, so when I make videos that are off-topic, I feel that people are reluctant to watch them. For example, the videos I upload of cooking or gardening with my son receive significantly fewer views than my disability-related videos. So, I had to decide whether to continue making videos about my disability. (P5)*

Our participants were faced with the dilemmas of failing to attract new viewers if they increased their proportions of disability-related videos and potentially losing existing subscribers if they concealed their disabilities in their channel. In facing this dilemma, they tried to devise their own strategies to increase subscribers and grow their channels by adjusting the proportions of videos about disability-related topics. For example, P3 described his C3-2 channel as “a test channel that attempts to attack algorithms,” trying to explore the correlation between subscribers and algorithmic distributions through multiple trials. On one trial, he deliberately and consistently uploaded only disability-related videos for several months. On another trial, he deleted disability-related words from the titles of all uploaded videos. For each trial, he tracked whether the distribution algorithm exposed more of his videos and how view counts and numbers of subscribers were affected. Despite various experiments, he eventually concluded, “I don't know what the algorithm is anymore.” He became unsure of his experiment because so many factors could influence the algorithm, and he still struggled with how to express his disability on his channel.

**4.4.2 Yielding to the power of algorithm.** As findings about their goal revealed, our participants aim to inform as many people as possible about disability through their videos. Participants strived to reach out to larger audiences by applying various strategies, including using keywords relevant to current social issues, to achieve this goal. One of the strategies frequently used by our participants was creating videos by benchmarking the topics or ideas discussed in viral videos about disability to benefit from content distribution algorithms that promote highly viewed videos. However, these videos often depicted disability in a distorted or exaggerated manner in the form of clickbait. A participant provided us with a notable example: “Would You Steal Money From a Blind Man? - Social Experience,” video [98] which had 31.43 million views. This video shows situations in which people steal money from people with vision impairments when these individuals hand money over to passersby. This participant was concerned that such controversial content could mislead the public to perceive people with disabilities as being in helpless, just as the mainstream media has done.

*There are many social experiment videos that involve people with disabilities. Most of them present situations such as when a person with a disability cannot do something or what happens if a person with a disability asks for help, and those videos get high views. I'm a little upset that many people watch those videos. (P1)*

Our participants explained that they also recognize this problem but sometimes are tempted to benchmark such content, thus inducing clickbait.

*I don't want to make my videos like that, but it is popular. To increase views, do I have to use the same title but with a different story? (P1)*

P8 and P3 actually uploaded videos with the provocative titles, "Tic Disorder, Ready to Die" and "YouTuber with Vision Impairment in His 30s Gives Up Everything," respectively. They baited viewers, and, as intended, those videos received relatively high numbers of views. However, both participants concluded that these choices bred adverse effects in the end because audience members who were sincerely worried expressed anger toward the creator. Additionally, viewers were confused by the fact that the creators were exploiting their disability as clickbait and ruining the value they initially sought: promoting disability awareness.

*I was saying, "I can be independent, and please respect our self-esteem." But in a video like that (a stimulating video), I was like, "I'm actually uncomfortable with this, and I can't do this and that." I thought going back and forth like that was bad even if it resulted in increased views (P3)*

To avoid being swayed by the temptation to produce such distorted content, some of those participants (P3 and P8) eventually tried to move away from algorithmic influence and performance indicators. Instead, they focused on the stories they intended to convey. Specifically, P3 and P8 tried to ignore the view and subscription numbers offered by the YouTube Creator Studio as much as possible because they thought caring about these numbers would emotionally influence them, leading them to create content portraying disabilities in an unintended way to increase those numbers.

*I don't look at the stats anymore these days. When I first started the channel, I visited the stats page several times a day. I was so frustrated and discouraged when subscribers dropped or when views decreased. I kept becoming greedier while trying to figure out what to do. I realized it would be toxic if things continued that way. (P8)*

**4.4.3 Uncertainty hurts creators with disabilities.** While all the participants except P3 and P8 performed creator activities based on metrics such as views, viewers' inflow routes, and comments throughout their AXs, there were events that required them to rely on guesswork to solve problems. The first case was when the content moderation algorithm filtered some participants' disability-related content. When P5 posted a video reviewing his new prosthetic leg, he experienced an automatic replacement of a thumbnail containing a photo of his injured body. P1 received a yellow dollar sign, signifying demonetization of his video, but managed to restore that video's monetization status by replacing the word *blindness* in the

title with other words. During these processes, participants were not given any explanation of which parts of their videos caused the trouble and, based on speculation, responded by modifying elements related to disability.

*When I uploaded a thumbnail, what I uploaded didn't show up, and something else came out. So, I asked other YouTubers, who told me to cover up the affected area because YouTube may judge it as a sexually sensitive image. I covered it up and re-uploaded the image. Then, it worked. But there are other thumbnails on my YouTube feed that are much more lewd, so it was strange that mine was filtered. (P5)*

Another problem arises when content distorting or even maliciously disparaging disabilities goes unfiltered. Some participants pointed out that although they have reported channels that imitate or ridicule people with disabilities, the sanctions do not seem to work well. The participants also did not know why that content was unrestricted, and they conjectured that disability-related content does not seem well-regulated compared to other topics because only a few people watch it.

*Of course, the yellow dollar sign should be attached to content that makes fun of disabilities even if audiences don't report it. For almost a year, people often commented on, disliked, and reported this type of content, but compared to politics or other subjects, the number of viewers and the viewers' collective power are low. Algorithms are sensitive to viewers, but viewers' reactions to disability-related topics are unnoticeable, so the reports seem to be ignored until they exceed a certain threshold. (P3)*

Interestingly, when the causes of the moderation algorithm's decisions were unknown, our participants suspected that the disability-related topic might be the source of the problem. One participant (P1), whose content was filtered several times, was even frustrated and believed—understandably—that their use of disability-related keywords was the reason. Participants formed this concern regarding YouTube's algorithmic content moderation by reflecting on their own attempts to restore demonetized videos (P1, P3, and P6) or collectively discussing this problem through online chat with other YouTubers with disabilities who had experienced similar cases (P5 and P8). Through such retrospective reflection or collective discussion, our participants who experienced algorithmic content filtering expressed that the algorithm is unprepared for sensibly moderating disability-related content, possibly because of insufficient data on disability-specific cases.

## 5 DISCUSSION

In this study, we aimed to investigate the characteristics of creators with disabilities in AX and understand their perception of the algorithm's inclusiveness in the video platform. We found that our participants shared the goals of providing informational support to people with disabilities or correcting the public's misconception of disability through their content. To pursue these goals, they strategically expressed their disability identities while adjusting factors that can influence algorithms.

Building on our findings, we discovered that our participants' AX in the process of achieving their goals was mainly associated with two algorithmic features: 1) algorithmic content moderation and 2) algorithmic distribution.

First, our participants reported various cases in which the content moderation algorithm punishes harmful content according to YouTube's guidelines. What is distinctive in YouTube's algorithmic content moderation is that it not only suspends user accounts [30] or makes content invisible to other users [17, 19, 91], like any other social media platform, but also punishes creators by demonetizing their advertising revenue generated from their content [16]. Given that many of our participants considered creator activity a new opportunity to gain economic benefits despite their physical difficulties, demonetization could be considered a critical measure for them. Therefore, our participants made numerous attempts to recover their filtered content and collectively theorized what caused algorithmic moderation similar to the findings of previous studies [1, 64]. Adding to this, they could form their own hypotheses regarding how the content moderation algorithm deals with disability.

Moreover, participants expected algorithms to distribute their videos to their target audiences. On the one hand, participants tried to find ways that the algorithm actively exposes their disability videos to audiences who directly search with disability-related keywords. On the other hand, participants also tried to identify the characteristics of recommendation algorithms that can deliver their videos to participants who do not directly search for disability videos. As participants inferred from their experiences, algorithmic recommendation, which plays a major role in delivering creators' videos to viewers even more than searches [103], is built to suggest what viewers want to watch [103, 105]. This made our creators piggybacked the trends that more viewers are likely to watch to get views, aligned with findings of previous research [95].

At the same time, creators faced challenges related to their identity presentation in their AX. Below, we discuss how creators with disabilities negotiated their original identity in their AX based on our findings. We then conclude by discussing how inclusive the AX the current video platform provides is for creators with disabilities.

## 5.1 Identity negotiation in AX

In Goffman's dramaturgical approach, which conceptualizes people as performers on a stage called everyday life, he assigns the "front stage" as a place where individuals perform in front of their audience and the "back stage" as the place where individuals are left alone, without their audiences [37]. We view YouTube as a front stage, where content creators with disabilities put on performances. Hence, our participants valued YouTube as a channel for self-expression by sharing their everyday lives with disability without uncomfortable glances and advocating for their communities. Furthermore, they were keen to guide front-stage audiences to the impression that living with disabilities is not always challenging but normal by showing various aspects of their everyday lives, such as going camping, applying makeup, and reviewing food.

As the creators interacted with the algorithm to reach a larger audience, they negotiated the identity they originally intended to

express. YouTube's content distribution algorithm, which is sensitive to viewers' behavior, mainly refers to numeric data views, sharing, likes/dislikes, and watch time to determine viewers' satisfaction and engagement for each video [103, 105]. YouTube Creator Studio also provides such data to help creators create strategies for their content or channel promotion. In addition, in terms of the growth of the channel itself, our participants monitored whether the number of subscribers increased or decreased. This numeric data is almost the only way creators can perceive their invisible audience from the back stage, which drives creators to focus on "raising their numbers." As a result, our participants negotiated their identities by hiding, exaggerating or even distorting their disability images rather than remaining loyal to their original intention, depending on the number of views they garnered.

Several previous studies [22, 31, 75] also examined how marginalized groups of users negotiate their identity in various social media platforms. One of the important findings of these studies was that users' decisions whether to actively present or suppress their identities were affected by who can see their posts to ensure their social safety. For example, some LGBTQ users refrained from revealing their identities on platforms where their posts could be viewed by family members or co-workers who do not embrace or advocate their identity [22]. In our study, creators with disabilities were already presenting their disability to some extent on YouTube in terms of advocating for the disability community. However, they negotiated their identities, influenced by their belief on the algorithmic distribution they empirically learned. These findings also resonate with prior studies that showed groups of underrepresented creators (e.g., women of color, LGBTQ people, immigrants, and Arab Americans) believed that the social media algorithms suppressed their social identities. Therefore, they chose to present the aspects that would likely cause the algorithm to promote their videos [55]. Our study participants also felt that the way YouTube's content distribution algorithm works created an atmosphere in which creators with disabilities could not sufficiently express their identities and values, resulting in a sense of disappointment. Thus, the current AX provided by the video platform, whose success is defined by conventional metrics, can be improved by acknowledging other values beyond views and likes to maintain the genuine identity of creators with disabilities.

## 5.2 Is this an inclusive algorithmic experience?

The algorithm can make discriminative decisions by learning data samples that are not representative of the entire population or contain biased information [9, 20, 42, 49, 104]. For example, some researchers have demonstrated that several existing machine-learned models for moderating conversations assort texts with the word "disability" more likely to be harmful [49]. Once the algorithm trained in a biased way against disability is embedded in an AI product or system, users with disabilities could not access it or could suffer a critical disadvantage from its decision [32, 42, 89, 92].

In our paper, we also captured cases in which YouTube's content moderation algorithm seems to make discriminatory decisions regarding disability-related content. A thumbnail photo of our participant's injured body was not uploaded and was automatically

replaced with another picture. Moreover, other participants reported that their videos about disability were often demonetized. In addition to our participants, one YouTuber with hearing impairments claimed that YouTube had demonetized her videos in which she talked about life with a disability, and other YouTubers with disabilities who heard her story agreed with her, commenting that they had similar experiences [8, 58, 59]. However, we cannot assert that our participants experienced algorithmic discrimination because YouTube does not disclose specific data on how the content moderation algorithm works, and there is no clear evidence that the algorithm possesses bias against disability due to its opacity and inscrutability [51]. Therefore, we rather focus on how our participants reacted to these cases. When the algorithm filtered participants' videos without noting the exact cause, they responded by modifying disability-related factors in their content. In addition, if videos mocking disabilities were not regulated, creators speculated that few reports of such content would be made due to the small number of people interested in disability. These reactions from our participants are highly similar to what LGBT YouTubers thought when their videos were demonetized because they used words like "trans" or "transgender" in their titles [29, 93]. As reported in previous work, technology's ambiguity and uncertainty are the core of the emotional experience of racism [88], and uncertainty in algorithmic decision making can make this minority group wonder whether this pattern constitutes discrimination. Such questions can also undermine trust between creators with disabilities and the system using the algorithm, leading them to perceive the system as less inclusive.

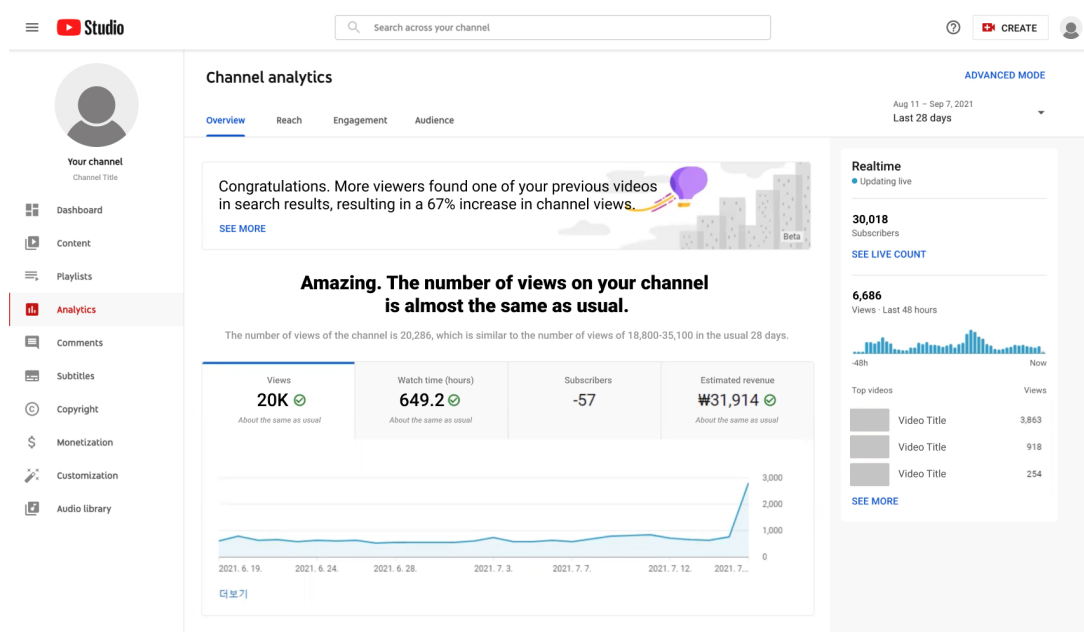
Unlike YouTube's content moderation, our findings reveal how our participants perceive algorithmic content distribution's inclusiveness. Researchers have made multiple efforts to understand how people perceive fairness in algorithmic decision making [10, 40, 47, 56, 61, 73, 83, 90, 94]. In particular, researchers have discovered that people's perceptions of the algorithm's fairness varies based on several factors, such as gender [90], race [83], education level [90], and occupation [56]. By echoing those prior studies, we can also discern that the discriminatory treatment our participants experienced in reality and their efforts to combat such discrimination could be factors that shape their perceptions of the fairness of YouTube's algorithmic distribution. When we asked participants how they felt the algorithmic distribution treated disability, they noted that disability seems just one of the many topics the YouTube algorithm handles. For example, P3 thought that YouTube does not prioritize or push any particular category or topic, and P8 said, "I think it is far more unfair for YouTube to do something only for creators with disabilities." All of our participants outlined that "the algorithm treats disability in the same way as any other subject," as opposed to the discrimination they experienced in real life, which in turn led them to perceive that the algorithm does not discriminate against disability. Moreover, our findings that creators with disabilities wanted to be treated in the same way even if they do not benefit from the algorithm add diversity to the findings of previous studies that people rate algorithms more fairly when the algorithm acts in their favor [90]. If so, as our participants expressed, is the current video platform's AX inclusive for creators with disabilities in terms of content distribution?

The experiences and challenges our participants face in pursuing their goals by presenting disability identities can be considered a latent inclusive issue. An inclusive AI system refers to a system that is effective for diverse user populations [89]. Taking a broader perspective, a previous study argued that users' contexts, needs, and expectations should be taken into account for inclusiveness in AI systems [33]. Unlike other creators, as stated in a previous study [62], our participants also wanted to let the public know about the discrimination they encountered in reality on YouTube, where anyone can have a voice. However, after many attempts and analysis, they found that disability-related content is less likely to reach audiences indifferent to disability. This finding led our participants to believe that the content distribution algorithm, which works based on personalized recommendations, does not sufficiently consider their unique contexts and goals. Furthermore, as P6 noted, although participants strived to overcome the barrier between people with and without disability offline, they were disappointed that they faced limitations to do so because of another barrier the algorithms generated. In light of this, the algorithmic content distribution in the video platforms might not discriminate against disability in the sense that it treats disability the same as other subjects, but it seems to provide an experience that does not adequately embrace the subtle context and needs of creators with disabilities. Keeping this perspective in mind, we claim that inclusive AX goes beyond providing users with an accessible and fair experience and should help users achieve their distinctive goals and values, consistent with previous attempts to design algorithms sensitive to stakeholders' values [106].

### 5.3 Design implications for inclusive AX of creators with disabilities

Throughout the discussion, we extracted the values our participants pursued in their AX. First, they appreciated expressing their disability identities as they intended without compromising their identity due to the algorithm's influence. Second, they hoped that the system in which the algorithm was embedded would reflect their specific contexts and needs. In this section, we present design implications to foster an inclusive AX that could support the values of creators with disabilities. Proposed implications originated from the experiences and challenges encountered by creators with disabilities revealed in our study. Because we focused on reflecting the values pursued by creators with disabilities in AX, some of the implications are also applicable to creators without disabilities who have other unique needs. Additionally, our suggestions start with enabling creators to seek and preserve their value in AX and end with promoting diversity in AX by accumulating data over a long period.

**5.3.1 Aligning the algorithm to the creator's value.** One major reason for the problem is that the algorithmic content distribution works in a way that does not align with the goals of creators with disabilities. In many cases, our participants define their target audience as those who are not interested in disabilities. However, the distribution algorithm identifies potential audiences independently based on information such as titles, descriptions, and thumbnails creators provide [102] and the audience's search history or click behavior [79]. Therefore, as our participants speculated, if the content



**Figure 2: One of our participant’s “YouTube Creator Studio” webpage. We translated the elements of the image into English and blurred the title and image of the video for privacy.**

contains only sources about disability, the distribution algorithm is less likely to deliver that content to people who do not search for or watch disability-topic videos. To deal with this problem, our participants attempted to feed the algorithm topics or keywords other than “disability,” for example, creating content that connects trending social issues and their disabilities. However, our participants reported that they could not confirm whether the data entered in this way is actually reflected in the algorithmic distribution. Therefore, we propose that the system should help creators explicitly express the results they want to achieve through the distribution algorithm when uploading content. In the content promotion websites Facebook and YouTube [101], the system receives detailed information, including the advertiser’s goal and the potential customer’s gender, age, region, language, and interests. It even shows expected results according to the user’s setting. Similarly, the video platform could ask the creator information about the target audience’s interests or age for each video. The system could also provide creators with a space to directly write statements about the values and goals they want to pursue in their channel. This practice would allow the distribution algorithm to extract keywords from those statements and reflect them when targeting potential viewers of the creator’s content. Furthermore, on the audience’s side, they could set the recommendation algorithm to suggest content that is far irrelevant to their previous viewing history in their home feed. The system could thus be directed to give viewers opportunities to access a minority group’s underrepresented voice and ultimately embrace the diversity of our society.

**5.3.2 Amplifying the invisible voice of audiences to creators.** In the process of generating videos that their target audiences would like

to watch, some participants try not to explicitly express signals about their disability, while others overemphasize the images of disability. Because the nature of the algorithmic distribution is sensitive to viewers’ satisfaction and engagement, creators want to figure out viewers’ taste by analyzing their behavioral data, which is often expressed in measurable numbers. In addition, the platform interface can also drive creators to concentrate on quantitative indicators. As Figure 2 shows, the platform displays a message to creators informing them of the recent change in the number of views in the “Channel Analytics” tab and shows plenty of detailed numeric data, such as number of subscribers and watch time, helping them strategically manage their channels. In this regard, the system needs to help creators maintain their authentic identity and purpose rather than becoming preoccupied with increasing their visible numbers.

Amplifying the invisible voice of the audience, which visible metrics conceal, for creators could be one way to remind them of their value continuously. First, the system could provide a variety of channels through which audiences can express their opinions about content’s quality and worth; for example, in addition to the current “Comment” tab, with the opportunity to write reasons for their “likes” and “dislikes,” viewers could explain which elements elicited their positive or negative reactions. Second, the platform could actively convey these invisible voices to creators, leading them to continue paying attention to their values. This direction could give creators an emotional reward and motivate them to pursue their values. Conversely, it could allow creators who become distant from the values they initially pursued to reflect themselves.

**5.3.3 Providing a conduit to contribute disability-specific data.** Decisions made by algorithms sometimes create negative user experiences when users are not allowed to provide detailed explanations of their behavior [41]. In our study, the YouTube platform did not inform creators of the exact reasons for algorithmic content filtering. In Section 5.2, we stated that this uncertainty could threaten minority-group creators' trust in the algorithm-infused system and cause them to perceive that this system's AX is less inclusive.

To improve the negative user experience caused by the opacity of algorithms, many researchers have argued that AI and algorithms should offer explainability [76], transparency [26], and scrutability [57]. In video platforms, these approaches could be applied to provide a detailed explanation of reasons for problems that occur, such as "Background image in the thumbnail was found to be a sensitive image that violates advertiser-friendly content guidelines." However, before creators are offered explanations, the decision of algorithmic content moderation must be sensitive to the characteristics of disability-related elements. As our participants supposed, if the content moderation algorithm actually assessed photos of people without limbs due to disability or injury as sensitive content, this decision does not take into account the context of the creators with disabilities. Therefore, to reduce the uncertainty issue in AX that creators with disabilities experience, it seems necessary to proactively collect disability-specific data that the moderation algorithm can utilize in its learning. We propose that the system provide a window through which creators with disabilities can directly contribute data related to disabilities that they produced during their AX. In particular, receiving cases that seem to show that the unique characteristics of people with disabilities have been misjudged might encourage the moderation algorithm to make a decision that takes the context of disability into account in the long term.

## 6 LIMITATIONS AND FUTURE WORK

Our study presents several limitations and challenges. We recognized that our study participants could have been biased because we recruited YouTube creators with disabilities who are all Korean. This selection might have created challenges in investigating diverse identities that creators with disabilities could desire to present and in collecting more cases of algorithms dealing with the topic of disability. The sample size of our study was in line with other that of qualitative studies exploring technology use among people with disabilities, such as people with vision impairment [3, 13, 87] and autism [18]. However, because we failed to recruit creators with various types and severities of disabilities, including hearing impairment, our study's results might not fully cover the characteristics and challenges of people with disabilities.

In our interview study, we investigated participants' AX by examining the overall YouTube experience of creators, from content creation, distribution, and management to viewer interaction. However, our findings regarding creators' experiences with and perceptions of the algorithm mostly focused on content creation, distribution, and moderation. Given that our participants desired to communicate with their viewers and guessed viewers' reactions

through the YouTube Creator Studio, it would be necessary to examine what expectations and perceptions creators have of algorithms regarding communication with viewers.

Moreover, our participants' perceptions of the role or inclusiveness of YouTube algorithms did not vary significantly depending on their disability type. However, we found that people with certain types of disabilities faced challenges in understanding the role of algorithms and the results of algorithmic content distribution. For example, when we asked the participants if they knew about algorithms, P4-1, who has developmental disabilities, answered that she does not know what the algorithm is. Then her neurotypical sister, P4-2, explained to her that "*If you watch videos about the cat, cat videos are constantly being recommended in your home feed. That's the algorithm.*" Since P4-1 lacked understanding and awareness of the algorithm, P4-2 conveyed her understanding of the algorithm in a roundabout way so they could operate their channel together. Furthermore, although participants with vision impairments (P1, P2, and P3) could be aware of the algorithm and work with it on YouTube, they reported that they had difficulties in accurately grasping the results of algorithmic distribution because those results were usually provided as visual data, such as complex charts or graphs. We could not deal with these challenges, for we focused on findings related to the identity presentation of creators with disabilities. However, the difficulties that users with specific disabilities could experience in AX appear to be important issues to be addressed in future studies to improve the accessibility of the system in which the algorithm is embedded.

Our study demonstrates that the inclusive AX of video platforms is highly related to the identity and value of creators with disabilities. Therefore, future works should explore inclusivity issues in AX for other groups of creators who want to express their identity or creators without disabilities who have unique values.

## 7 CONCLUSION

In this paper, we described an interview study in which we investigated the characteristics and challenges of creators with disabilities in their AX while they engage with video platforms. Creators wanted to gain financial benefits, communicate with other people with disabilities, and guide the public toward awareness of disability through their content. These goals drive creators to present their disability identity with their own tactics when interacting with the algorithms. However, we also found that an algorithm-driven video platform provides a negative AX, making it difficult for creators with disabilities to achieve their goals and express their identity as they intended. These findings lead us to discuss the identity negotiations of creators with disabilities and latent inclusive issues of the AX the video platform provides. In addition, we present implications for designing an inclusive AX that reflects the values of creators with disabilities.

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## A APPENDIX: VIDEO TOPICS COVERED BY OUR PARTICIPANTS

Videos related to disability		Videos unrelated to disability	
Topic	Number of videos	Topic	Number of videos
Introducing their own disability	9	Channel introduction and promotion	11
Personal experiences about disability	198	Personal experience or thoughts	26
Information associated with disability	23	Audience Q&A and Stories	25
Enhancing awareness of disability	24	Malicious comments and accusations	4
Discriminative experiences related to disability	9	YouTube revenue	3
Personal thoughts on disability-related issues	4	Introducing YouTube creator equipment	1
Review on disability-related technology/product	31	Real-time streaming recording	31
Reforming assistive devices	2	Apologize	1
Reviewing disability-related content	7	everyday life or vlog	80
Introducing audiences stories about disability	3	Collaboration with other YouTubers	3
Concerns about YouTube algorithms and channel direction related to disability	1	Travel	6
		Nature	6
		Beauty	45
		Reading books	3
		ASMR	9
		Singing	21
		Cooking	12
		Food show	9
		Game	5
		Short drama	1
		Parody	3
		Trending challenge	3