Research Articles and Essays

Exploring the Development of Disability Identity by

Young Creators on Instagram

Kristen Tollan,

York University, Toronto, Department of Communication and Culture

Abstract

This paper explores how disabled youth use social media to express their identity. Using Swain & French's (2000) affirmation model and methodological principles of photovoice, the study took Instagram photos from eight participants for analysis, with the results discussing trends in the disability experience in connection to personal expression.

Keywords: disability, social media, youth

Social media platforms like Facebook, Twitter, and Instagram have become a controversial yet undoubtedly popular use of technology. Baym (2010) explains that new developments of technology come with one of two common reactions: fear or enthusiasm. Fear emerges from the idea that communication has become shallower, threatening the quality of personal relationships. However, for others, excitement emerges. For these people, new means of communication offer opportunities for deeper, more diverse and more numerous connections across the globe (Baym, 2010). The latter reaction has inspired this research. This paper explores how these evolving methods of communication influence and are influenced by those in society who are often marginalized and overlooked: particularly, disabled youth. To fill the gap in this area of research, the present study examines trends in social media usage by disabled young adult participants in relation to the formation of their identity and self-expression.

Current Literature

Online access for disabled people

Communication technology is increasingly prevalent in the lives of young people ages 11-25, with youth representing the largest group of social media users in Western culture (Walker, King & Hartman, 2018; Park & Calamaro, 2013). Scholars began using social media more frequently as a tool for garnering knowledge about experiences of youth participants, explaining that "online data collection methods may be among the most effective methods for collecting data on adolescents and young adults (13-24 years old)" (Walker, King & Hartman, 2018, p. 45). They argue that using social media as a research tool may be more ecologically valid for specific populations, including vulnerable youth like those with disabilities. Disabled people are more vulnerable to social exclusion and isolation, along with associated psychological difficulties linked to these issues (Dobransky & Hargittai, 2016). However, Guo et al. (2005) found that internet use could significantly

reduce these social barriers to inclusion for disabled people by providing access to education, information, and social networks. Shaw and Gant (2002) also examined the impact of internet usage on the psychological health of its users. In their study of undergraduate students in a psychology class who chatted anonymously amongst each other online, Shaw and Gant (2002) found that internet usage is beneficial to users, associated with lower levels of depression and loneliness and higher levels of self-esteem and perceived social support. Obst and Stafurik (2010) discuss the internet in relation to disability by examining internet-based communication methods for people with physical disabilities. The authors propose the idea that communication over the internet can enhance the overall wellbeing of physically disabled users through opportunities for connection.

Identity development

Dunn and Burcaw (2013) state that identity refers to "conceptions of the self, expressions of individuality, and accounts of group affiliation. Identities define us because they contain traits, personal characteristics, roles, and our ties to social groups" (p. 149). In their article, Dunn and Burcaw (2013) conducted a literature review of various publications relating to disability identity. They found six key themes across six narrative articles that reflected ways in which disability identity is developed. The themes included communal attachment, affirmation of disability, self-worth, pride, discrimination and personal meaning. Dunn and Burcaw (2013) concluded that "disability identity entails a positive sense of self, feelings of connection to, or solidarity with, the disability community [… and that] a coherent disability identity is believed to help individuals adapt to disability, including navigating related social stresses and daily hassles" (p. 148). The authors believe that a coherent disability identity could serve as a tool to help one adapt to their disability and navigate the struggles associated with being a part of a marginalized group.

Cameron (2010) also examined, in his research aptly titled "Does Anybody Like Being Disabled?", the idea of disability identity. One question addressed in his paper was "how useful of a concept is 'disability identity' as a tool to people with impairments in making sense of their own experience?" (p. 260). Cameron (2010) argued similarly to Dunn and Burcaw (2013) that disability identity allows people with impairments to directly address the personal tragedy ways of thinking that are consistently shown in society, particularly in the media. Belonging to a social group of disabled people allows one to make sense of the ideas of inadequacy and resist them.

Research Paradigm & Theoretical Position

Online platforms have been used as spaces for disability-related content more and more frequently, with opportunities for dialogue and collaboration making them increasingly popular. The present research takes on a novel approach to examining disability through these platforms. Being disabled is typically seen as negative; though it is important to recognize and articulate the struggles related to being disabled, it is also crucial to consider the idea that not all experiences of having a disability are negative ones. The social model has been recognized as allowing this positive paradigm shift.

The social model of disability views disability not as something that a person has (i.e., a physical or mental impairment), but as an oppressive societal relationship in which barriers and lack of access create disablement (Cameron, 2014). Furthermore, social modelists argue that to better the lives of disabled individuals, it is not always rehabilitation or treatment that is needed, but recognition and removal of physical and societal barriers (Cameron, 2014). Using Swain and French's (2000) affirmation model as a theoretical foundation allows expansion on the social model's discussion of disabled identity. Swain and French (2000) argue that the affirmation model is a "non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective" (p. 569). They

developed the affirmation model to directly contrast the personal tragedy model, a dominant view of disability often expressed by able-bodied and neurotypical people, and often internalized by disabled people themselves.

Research Questions

This paper was developed from a larger study, conducted by the author as a thesis study in 2020. The larger study explored the concepts of disability identity and building community. In this paper, the topic of disability identity is the focus. Thus, this paper is informed by one of the three original research questions:

1. How do disabled youth use Instagram to express their identity? What can be seen from both the images and captions they post about their evolving identity and self-concept as disabled, if anything?

Methodology

The purpose of this study was to examine usage patterns on social media by disabled youth. This topic is important to the field because the accounts analyzed in the study, along with the finding that the analysis elicited, can be used as a stepping stone for understanding the ways young people use some of their most favored spaces on the internet. The study shed light on the experiences of disabled youth from their own points of view, demonstrating them as valuable and important resources in academic research.

Research Framework

Deciding on Instagram

The first step was to select a platform that combines both text and image. Instagram, unlike other platforms, such as YouTube or Twitter, is distinct in that it requires the posting of an image or short video, as well as provides the opportunity to caption each post. Memes, images of text, screenshots, creative work, and photos taken by devices other than mobile

phones are all possibilities on Instagram (Laestadius, 2016). Furthermore, Instagram has a privacy feature allowing for accounts to become outright unavailable unless the user approves a follower request. All the accounts chosen for this study were public pages, making them both ethically and physically accessible.

Yi-Frazier et al. (2015) conducted a study using adapted methods of traditional photovoice on Instagram while working with youth with Type-1 diabetes. Drawing on their methods and early photovoice guidelines laid out by Wang and Burris (1997), a methodology was developed that suited the research goals of the present study.

Traditional photovoice methodology

Photovoice is a participatory action research technique in which participants are given a camera and asked to take photos of scenes around them related to a given topic or theme (Yi- Frazier et al., 2015). According to Wang and Burris (1997), photovoice is described as flexible and adaptable, able to meet the needs of a variety of communities and their goals. Yi-Frazier et al. (2015) elaborate further, explaining that photovoice usually involves a group discussion following the photography session(s) in which participants come together to discuss the photos and their experience. Furthermore, they state that using photography in youth populations has been shown to elicit unique and relevant perspectives relating to the young person's point of view, particularly in relation to experiences with play and school. However, it has also been noted that photovoice projects conducted with adolescents usually take more time and coordination than projects done with adult participants (Yi-Frazier et al., 2015). Therefore, Yi- Frazier et al. (2015) adapted this methodology to work best for their needs and involved Instagram as a tool in their photovoice methodology.

Adapting photovoice methodology

Once an understanding of photovoice methods was developed, the works of Yi-Frazier et al. (2015) as well as Gibney (2017) and Miller (2017) were drawn on with adjusted

methods to suit the present study's goals. Yi-Frazier et al. (2015) used Instagram as their primary method of photo collection; Gibney (2017) chose to use publicly accessible content on other social media sites including YouTube; and Miller (2017) used direct interviews with student participants about their social media usage in relation to queer and disability identity-making. Yi-Frazier et al. (2015) more closely followed photovoice methodology through an Instagram-based investigation with youth, which provided a resource for this study in relation to both data collection and analysis. Gibney (2017), in examining how "higher education students who identify as LGBTQ navigate their school and daily life experiences in relationship with their identity on web logs" (p. 2) provided another resource for shaping the analysis of the present study with her research analyzing YouTube and blog content. Miller's (2017) methodology used grounded theory for analyzing specific themes that emerged from their data. Together, these three studies aided in the development of a methodology that would be most effective and useful in the current research.

The Participants

To be considered as a participant, Instagram users had to meet a few specific criteria. Their profile had to be public. Their age had to be within the range of 18 to 25, therefore considered a young adult but not a minor. Participants who were under 18 were excluded, as this is still classified as a child by legal and ethical guidelines. Finally, the participants had to identify as having some sort of impairment or disability, though a specific diagnosis was not a requirement.

Eight participant accounts were chosen: four accounts selected were followed personally by the author and four were selected through searching the #disability hashtag on both Instagram and TikTok. While the original aim was to use Instagram as the primary source of both participant selection and gathering data, it proved difficult to find suitable accounts through exclusively browsing the #disability hashtag on Instagram. When browsing

on Instagram, the number of photos was overwhelming, with limited filtering options. The majority of popular posts within the Instagram #disability hashtag did not meet the inclusion criteria. Instead the author also searched #disability on TikTok, a more recently popular app, where 41% of the users are within the age range of youth (ages 16-24) (Beer, 2019). Once a participant was chosen from TikTok or Instagram, their content for analysis in the study was drawn exclusively from Instagram.

Data Collection

Laestadius (2016) describes three types of data collection methods for Instagram. The option chosen for this study involved viewing the participants 'Instagram accounts on the app from a user's viewpoint, and then copying photos and captions into a database. To choose the photos and captions that were analyzed, the author went to each of the eight accounts and selected the 21 most recent photos, then downloaded the total of 168 photos (21 x 8 participants) to a computer for easier viewing. Choosing this specific number of photos created more validity, as a consistent amount of photos and captions from each account were examined without the inference of personal selection bias. Following that, all of the photos and their associated captions were collected into a spreadsheet to simplify and organize for analysis. Pseudonyms for participants were used at all times.

Data Analysis

In keeping with the adapted photovoice methodology used by Yi-Frazier et al. (2015), the photos of each participant were first grouped based on visual content. Seven types of photos were classified, including "selfies" (photos of the person, whether taken by others or on their own); old photos (including the person and/and family members/friends – typically scans or photographs of film photography); recent photos with friends, family and/or pets;

landscape photos; celebrity photos; internet memes (a humorous image, video, piece of text, etc., that is copied and spread rapidly by Internet users); and lastly, photos of objects, screenshots, or miscellaneous content.

Caption analysis followed and held the most detail about the participants and their experiences. The captions were analyzed in three stages. Firstly, the author read through the captions of each photo and classified the caption based on major themes that presented immediately. In the second stage, these themes were organized in a chart (seen in Table 1) which helped to see trends more clearly, both in the way they were presented across participants, and also how they connected to the concept of identity.

Results and Discussion

This study examined the content of eight Instagram accounts belonging to disabled youth between the ages of 19 and 24. After analyzing the photos and captions of 21 posts per account, there were trends in the types of images posted, as well as many themes that emerged from the captions. The first type of analysis includes a look the types of images posted. This was used as a way of noting whether there was a visual connection to the concept of disability identity at first glance. The themes observed in the captions are presented as well. Based on the research questions that inform the present research, it was expected that participants who posted more selfies would demonstrate a stronger connection to their identity as disabled, and that captions would reflect that.

Analysis of Image Trends

The results indicated a very diverse spread of image trends across the eight participants. Some posted nearly all selfies (Austin, Ashley) while others favored landscapes (Zoe) or photos with friends and family (Zane). The one type of content that was not posted by any of the participants was memes. These image trends were notable as they indicated

preliminary insight into the caption themes that later emerged from the participants' posts. It was more common for the participants who posted selfies to also share details about their disability and their identity as disabled. However, the image trends did not exclusively predict who would discuss their disability on their Instagram profile. In other cases, such as Zoe, Payton, Ashley and Brittany's profiles, the types of images they posted (landscapes, selfies, writing, etc.) indicated the elements of their lives that were important to them, outside of their disability (e.g., friendships, creativity, travel, etc.). Although the participants never explicitly discussed identity formation in their captions, it became apparent that identity as a concept, particularly in relation to their disability, was pertinent to the participants.

Analysis of Caption Themes

A number of themes were found across the photo captions of the eight participants (seven across multiple accounts and some that were unique to one or two participants). Some themes were grouped into smaller classifications, such as merging the themes of disability and chronic illness as well as mental health, to reflect the interconnected nature of disabling physical and mental symptoms. In doing this, the study ended with four themes for discussion.

The four themes for discussion from the photo captions are visualized in Table 1 below, as well as a list of other less commonly seen themes that were mentioned, organized by individual. The author's first impression was that the disability theme and the social media trends theme would connect more closely to the concept of identity.

Table 1. *Thematic comparison of participant captions*

Four Discussion Themes

	Disability, chronic illness, and mental health	Family, friends, pets	Positivity, gratitude and giving back	Social media trends
Chelsea W.	x	x	x	
Brittany A.	x	x	x	x
Zoe W.		x		
Zane V.	x	x	x	x
Alexis S.	x	x	x	x
Payton L.	x	x	x	x
Austin G.	x	x	x	x
Ashley M.	x	x	x	x

Other Themes
Chelsea W. — living life to the fullest; growing up; home
Brittany A. — living an ordinary/normal life; writing/work/school; home
Zoe W. — living and ordinary/normal life; writing/work/school; home; LGBTQ; travel
Zane V. — none
Alexis S. — school/work; sports; religion/church
Payton L. — school; uniqueness; resiliency
Austin G. — none
Ashley M. — ballet

Discussion of Themes

Social Media Trends

"Social media trends" as a theme encompasses the use of hashtags in captions, as well as posting content relating to popular, often viral, trends. Zane, Payton and Austin most commonly followed trends with their content, which reflects the fact that these three participants, along with Ashley, were found on TikTok, a platform that thrives on viral content. Furthermore, the use of hashtags and creating "viral" content allows Instagram users to be found by others outside of their immediate or "real life" circle and expand the reach of their content.

One participant, Austin, is a rising TikTok star, with 12 million likes and nearly 500 thousand followers. Living in the United States, he has cerebral palsy (CP) and is also hard of hearing. Much of his popular content deals with having CP and his experience as

disabled. Something unique about Austin's account is that some of his more viral videos show him using American Sign Language to perform popular songs. He also often performs trends like TikTok dance routines while discussing disability at the same time, usually through the use of captions. On Instagram, his first 21 photos contained 20 selfies and a photo with his mom. Austin's account featured disability as a theme on occasion, but most commonly focused on social media trends and overall positivity.

Zane's profile included hashtags in every post, including ones relating to his disability (#downsyndrome, #dslove, #worlddownsyndromeday, #321). Zane was found on TikTok. Zane has Down Syndrome and is 19 years old, residing in the United States. On TikTok, he creates popular videos with his older brother. At the time of this research, Zane and Peter had 3 million followers on their TikTok account, and nearly 72 million likes. Their joint Instagram profile has 71,000 followers. On Zane's individual account, his bio has the phrase "Changing Perspectives One Heart at a Time | Down Syndrome." It is important to note that Zane and Peter share the Instagram account that was analyzed in this study. Therefore, it is Peter who typically writes the captions seen on the account. Understanding the concept of identity in relation to Zane and his disability is thus mediated through Peter's voice and his conceptualization of his brother's disability as an ally to the community, rather than a disabled person himself.

Payton included the hashtag #actuallyautistic on one Instagram post, but the majority of her hashtags were related to increasing her visibility on social media, including ones like: #followme, #photooftheday, #fashion #self and others. Payton was also found on TikTok, where she has a significant following of 540,000 people and 8 million likes. Since the original research was conducted, her TikTok following has grown to over 2 million users. While some of her content is following TikTok trends, her most "viral" content talks about her living with autism and what autism is like for a young person, especially a girl. Her

Instagram account has over 40 thousand followers, most of whom likely found her from TikTok, as is indicated by her bio ("ya i'm that autistic girl"). Payton is 20 years old and Canadian. The make-up of her first 21 photos was almost entirely selfies, with 81% or 17 photos being of her and the remaining 4 including Payton and friends. Payton did mention disability in her posts on occasion, but more commonly, her friends and family, as well as some social media trends were themes seen in her captions.

Two other participants also had unique patterns of hashtag use in their posts. Chelsea included no hashtags in her posts, perhaps indicative of the fact that she did not profit off her social media posts and already had a rather large following from her public speaking and advocacy work. Brittany, a twenty-four-year-old resident of the United States and the oldest participant, lives with a diagnosis of Spinal Muscular Atrophy Type 2 (SMA 2). Brittany and the author are personal friends who rather found each other on a blogging site. Brittany is also close friends with another participant, Zoe, who she has known for 11 years. Zoe is the single participant from outside of North America, residing in the United Kingdom. She is diagnosed as having autism and mental illness and identifies as disabled. Zoe and Brittany met online through a fan-fiction website, and the author met Zoe through Brittany.

Zoe had a more unusual selection of content in this study, with her Instagram photos displaying a majority of landscape photos (48%). Selfies were only 14% of her first 21 photos. Her Instagram bio described her pronouns (she/they) and also stated that she identifies as a "queer poet & storyteller based in [location]." Zoe's themes did not discuss disability at all, focusing rather on her work as a writer, her travel experiences, her friends and family and LGBTQ+ issues.

Brittany used hashtags frequently in similar ways to Zane and Payton; however, there was a notable difference in that many of Brittany's posts included her own writing, and even the posts that were not related to her advocacy work showed the prevalence of disability

awareness and activism in her life. Hashtags related to her writing included: #authorsofinstagram #authorlife #writersofinstagram #ownvoices #criplit #sciencefiction #fantasybooks. Further, Brittany posted selfies including hashtags like #livemoremagic #myeverydaymagic #spinalmuscularatrophy #spinalmuscularatrophytype2 #disability #disabilityawareness #disabledandcute #disabledpeoplearehot #disabledfashion. The hashtag #myeverydaymagic is popular among people of all abilities, with photos posted sharing a similar aesthetic of light colors, flowers and other visually pleasing content. However, in the context of a person with a disability using this hashtag for her selfie, something more could be indicated which connects to the idea of disability identity. Brittany lives with SMA Type 2, a severe disability that is also a visible disability. Brittany strives to make disability a more prevalent part of the literary landscape and also non-fiction spaces, as evident by her use of the #ownvoices hashtag. Perhaps by using hashtags like #myeverydaymagic, Brittany is attempting to normalize the everyday activities of disabled bodies and their own existence in social media spaces, which are often filled with glamourized, able-bodied celebrities and influencers. Brittany's attempts at normalizing disability also speak to the first research question of this study– how disabled youth express their identity through photos and captions on Instagram. In viewing Brittany's photos and captions, it is clear that she views her disability as a prominent part of her identity. However, she also recognizes the normalcy of being disabled, no different than her identifying as a "storyteller, space babe [or] fairytale enthusiast" (taken from Brittany's Instagram bio). It could also be said that Brittany's Instagram patterns show an owning of her disability, something that is in keeping with the social model and the affirmation model of disability. The affirmation model (Swain & French, 2000) provides the opportunity for disabled people to choose how they identify. Here, Brittany demonstrates an interchangeable identity that reflects her unique characteristics and the freedom to be who she wants to be on any given day.

These ideas coincide with a point drawn in Cameron's (2007) article on disability narratives, in which he states that there is a "normality genre" in popular media (specifically films, but arguably, it can be seen in writing and television as well), in which disabled people perform the "alien" role, as if in a science fiction story– "representing a threat to the fabric of normal decency, which has to be resolved… in order that normality can be preserved or restored" (p. 502). He then goes on to state that this resolution typically happens by means of death or curing the character's disability. However, writers like Brittany include characters with disabilities who are the protagonists, yet do not face untimely deaths or overcome their impairments. She further emphasizes this in her own life through the reclaiming of her identity as the protagonist of her story with her own "everyday magic."

Payton and Ashley's accounts provided interesting results in this area as well, as both posted almost entirely selfies, and had very limited content associated with their disability (Payton has Autism and mental health issues, while Ashley deals with Anorexia Nervosa and undiagnosed physical issues). Instead, their themes focused much more heavily on the things that interested them, such as fashion, makeup, dance and other "typical" hobbies for girls. This aligns with Hill's (2017) study on disabled girls' self-representation practices online, in which she states that "disability is often framed as a problem or lack, and that experiences of disability for girls appear to trump or silence other experiences, such as those of sex and gender, and the intersections that exist between these" (p. 114). It is highly likely that these girls, whose content on other social media platforms focuses heavily on their disability, curate their Instagram accounts more carefully as a way of normalizing *other* aspects of their life, outside of their disabilities.

Ashley, found on TikTok, is currently undiagnosed but deals with chronic illness. Currently using a NG tube for feeding, she speculates that she has Ehlers-Danlos Syndrome as well as some type of gastrointestinal illness. Ashley is 24 years old and lives in Canada.

Her TikTok is popular for her content relating to disability, but also for her dances and other on-trend videos. On TikTok, Ashley has over 70,000 followers and nearly 800,000 likes. Her Instagram focuses on a different part of her life – her experience as a ballerina. Her Instagram bio reads: "Ballerina; Documenting my journey through the ups and downs of my personal struggles mentally and physically through dance." As would be expected, dance was the most common theme across her captions and photos, although disability, friends and family, positivity and giving back were evident as well.

Payton is also known on TikTok for posting content dispelling myths about girls with autism. On Instagram, however, Payton and Ashley post pictures with their friends and other "ordinary" activities that are outside of the realm of frequent doctor's visits and psychiatric diagnoses. Payton and Ashley's accounts connect with the discussion of identity, particularly in relation to the choice of identifying as disabled (or not). As described in Dunn and Burcaw's (2013) work, there are key aspects of disability identity, such as pride, self-worth and personal meaning. However, some people with impairments don't develop their self-worth from their impairments, like Payton (Watson, 2002). It is also important to note that Payton identifies as autistic, a group whose members often title themselves as neurodivergent rather than disabled. In this case, her identity is fluid, and at times may be represented or referred to as neurodivergence or disability, while at other times, she chooses to identify based on other important aspects of her life.

Disability, Chronic Illness and Mental Health

Across the captions analyzed from all of the participants, disability showed up frequently, but was also often separate from chronic illness and mental health. For instance, Brittany commonly discussed her diagnosis of Spinal Muscular Atrophy as her disability, but never mentioned any mental health diagnoses as a disability. She still discussed mental health in her posts, focusing on it more as a common aspect of human nature rather than a disability.

Payton, in contrast, has diagnosed mental health issues and talks about them alongside her discussions surrounding autism. Disability was discussed at times purposefully with a clear intent to demonstrate a point, whereas other phrases about disability were said in a more casual, commonplace way. For example, in her April 9, 2020 post, Alexis wrote about her service dog assisting her in dealing with her high heart rate (due to Postural Orthostatic Tachycardia Syndrome or POTS). She then easily segued into talking about her homework and basketball activities.

Alexis, who has a fairly large social media following, with 7600 followers on her account at the time of the study, was found through her work as a disabled model for a popular clothing line. The make-up of her Instagram account included 17 selfies out of the first 21 photos, 3 miscellaneous and one with a friend. Her bio read "chronically ill semi-functional human; owner of [company]; crushing stereotypes, kissing fish, cutting down on waste; service dog [name]." Alexis's profile paid frequent attention to disability related topics, including her diagnosis of Ehlers-Danlos Syndrome among other unknown conditions, as well as her work and school life, sports, and religion.

In contrast to Alexis, Brittany typically wrote captions centered around one main topic, often disability-related but not always. Her post on March 8, 2020 read: "We have the first presumptive coronavirus case in Minnesota. Which is something. I'm officially on lockdown, which means I'm wearing nothing but pajamas and listening to my embarrassing playlist of bubblegum pop to keep my spirits up. It's not fun being immunocompromised in a world full of germs. I'm fighting tooth and nail to keep from falling into a depressive episode, so naturally, I'm writing a blog post about it."

Outside of the disability-related hashtags, three participants posted about disability most frequently and in-depth – Chelsea, Alexis and Brittany. Chelsea is the only participant who is no longer living. She had a very large online following at the time of her death;

however, this study has upheld her anonymity in keeping with the protocols of the research. Chelsea was a 21-year-old living in the United States at the time of her death. She died from complications associated with a lung transplant. She was living with cystic fibrosis and was undergoing a double-lung transplant surgery in 2018 when she passed away. Therefore, her data is the oldest, chronologically, covering the timeframe of January to September 2018. Chelsea's profile was the most diverse in terms of types of photos and all four of the common themes were evident on her profile, with a particularly high amount of posts talking about disability.

For Chelsea, it was impossible to post photos of herself on Instagram without her disability being apparent, as she wore a nasal canula at all times to deliver oxygen support to her lungs. However, it was entirely her choice to become an activist in the disability community. Her Instagram account, nearly 2 years after her death, still has 162 thousand followers. Many of her longer post captions were filled with her opinions about living life as a "sick person," but also a young person, and trying to reconcile the two into a high quality of living. Of the 21 posts that were analyzed from her account, four stood out as the most important. In one from June 21, 2018 she discussed losing her apartment to mold toxicity, which is dangerous for anyone, but especially someone with cystic fibrosis. She wrote not only about the struggle of having to find a new apartment in California, but also the "spectacular" way in which her life "fell apart," and the emotions that came from living with a chronic illness whilst trying to live a life she was proud of. Chelsea shared in a June 21, 2018 post that she

> spent the past year just barely holding myself above ground- juggling being sick with the deep incessant need in me to do something of value with my time. I've been exhausted just keeping myself alive and have nothing left to give to the world around me. That has always been my biggest fear in life, that I would spend everything I had "fighting" my illness and have nothing to offer- and for me, living without being able to give something of yourself to the world, living without adding value to the world, is not a life I want…You

can't put your life on hold until your "better" life begins. You have to fight like hell to make sure that the life reflected back at you right now is one you want to be living. I'm not going to let myself live a life I'm resentful of. Not if I live for another three months and not if I live for another 30 years.

The quote emphasizes a few different things about Chelsea's life with a chronic illness, the main one being just how much it shaped her short life and the identity she had. Chelsea often referred to herself as "sick" in her posts, but she also frequently mentioned the life she wanted to lead and how important it was to her to be proud of the legacy she left behind. Instagram provided a platform for Chelsea to express these thoughts and have them received by other youth who felt the same, either with a disability or without. For Chelsea, it was impossible to share parts of herself without also sharing that she was disabled, due to the visible nature of her oxygen support. However, Miller (2017) discusses the contextual management of one's identities. He describes the participants in his study as carefully considering how they would represent themselves in particular online spaces. For Chelsea, perhaps the curation of her Instagram account allowed her to compartmentalize her disability in ways that she could not do in real life. Chelsea's Instagram photos were the most thematically diverse. Furthermore, a lot of her captions discussed her disability, but on her terms. The captions contained Chelsea's own words and thoughts about her disability, rather than perceptions that other people might carry with them when they passed her on the street (such as those attached to idea of personal tragedy). Some of Miller's (2017) participants also discussed the idea of facing judgement on an online platform – either as something they experienced, were actively trying to avoid, or no longer were concerned about, in relation to their queer and/or disabled identities. Chelsea shows a lack of fear in her posts– not fear of death, or judgment, although perhaps an unfulfilled life was one thing she did fear.

Summary of Results

The results indicated that identity was expressed in a variety of ways across the participant profiles. Identity was shown most clearly through the frequency of the participants posting selfies, but also through specific identifying labels used in bio sections, repeatedly included hashtags and the thematic concepts that emerged from each unique photo caption. Each participant demonstrated more than one of the four themes in their posts, as well as other themes that were not addressed by all participants, but rather that were specific to their own individual experiences. Identity was shown through not only the sharing of one's experiences with disability, but also the other elements that made up their life. Normalizing disability as an everyday occurrence and also living life to the fullest were two concepts that, when juxtaposed, actually went hand in hand, as they provided opportunities for the disabled participants to achieve goals and find happiness, whilst also indicating to able-bodied people that the disability experience cannot be generalized.

Conclusions

Technology is advancing rapidly, providing unprecedented opportunities for research and exploration. However, disabled people are often left behind in this modern technological age, included as an afterthought rather than a part of the process from the beginning. Social media and other online spaces provide a unique tool for researching the youth demographic, particularly those with disabilities and severe mental health issues. Instagram presents an opportunity for disabled youth to explore their identity.

This research, shaped by the affirmation model of disability (Swain & French, 2000) examined the profiles of eight young adults with various disabilities. The aim of the paper was to explore the ways that Instagram was used as a platform for self-expression in relation to developing one's identity as disabled. The study's primary strength was the exploration of

the disabled experience through the viewpoint of disability insiders, rather than family members or medical professionals. The study also relied on the affirmation model as a theoretical foundation. In using the affirmation model, the study brings awareness to a model which prioritizes positive identity, encompassing both impairment *and* disability (Swain & French, 2000). The study presented an insider view of disability as experienced by young people, on a platform that is underrepresented in academic research, yet extremely popular and influential in the lives of youth.

Limitations

A limitation of this study is the lack of diversity across the participants. While the diagnoses of the participants were different across each person, other elements of diversity were not as well-represented in the sample. For example, the study participants came from North America and the UK, which are predominantly white countries, and all of the participants in the study were white or white-passing. Furthermore, there were only two male participants, and LGBTQ+ status was disclosed by only one of the participants (Zoe). While these participants met the inclusion criteria of the study, it would certainly improve future studies in this area to include a more diverse sample of participants.

Implications for Future Research

Future research could immensely benefit from a larger, more diverse sample in which race, gender, sexual orientation and country of residence and other characteristics were more varied across participants. Intersectionality is a major part of disability studies as a field, considering the ways in which disability interacts with other areas of societal marginalization such as race and sexual orientation. To further examine how these different identities impacted one's portrayal of their disability identity would certainly improve the impact of the research. Identifying as only disabled or only Black or only a woman would lessen the impact of the struggles that are faced when all of these identities meet. Thus, the results of the

present study could vary greatly based on the unique combinations and interactions of social identities.

Furthermore, it would be very interesting to see how the results of the present study translates across platforms other than Instagram. Although this study only examined Instagram as a platform, it was noted that different content could be explored on platforms like TikTok or Facebook. For instance, Payton is known on TikTok for her autism-focused content, and exploring the area of disability-related videos on that platform alone would provide novel and interesting insights into the topics at hand. For instance, looking at commentary on a platform like TikTok could show how the disability-related content is perceived by viewers.

Final Thoughts

The main concept in this study, the development of identity, served as the vessel through which to research the disabled population, the only socially oppressed group which any person can find themselves in at any time. Identity was demonstrated both through expression of being disabled and what that means for a young person, but also through the exploration of other unique traits, qualities and events that make up the life experience of a youth. This was influenced by their online activity on such a novel platform. Through the activism of these participants, living their day-to-day lives as disabled youth, their followers are presented with plentiful opportunities for exploration into what it really means to be disabled and given a reminder of both the diversity and common ground found in the human condition.

References

Baym, N. (2010). *Personal connections in the digital age.* Polity Press.

Beer, C. (2019). Is TikTok Setting the Scene for Music on Social Media? *Global Web Index (Blog).* Retrieved from: https://blog.globalwebindex.com/trends/tiktok-music-social-media/

Cameron, C. (2007). Whose problem? Disability narratives and available identities. *Community Development Journal*, *42*(4), 501–511.

Cameron, C. (2014). The social model. In C. Cameron (Ed.), *Disability studies: A student's guide* (pp. 137-140). SAGE Publications.

Dobransky, K., & Hargittai, E. (2016). Unrealized potential: Exploring the digital disability divide. *Poetics*, *58*, 18–28.

Dunn, D. S., & Burcaw, S. (2013). Disability identity: Exploring narrative accounts of disability. *Rehabilitation Psychology, 58*(2), 148–157.

Gibney, G. (2017). *Queer Heterotopias in Higher Education: LGBTQ Student Identity in Web Logging*. (Unpublished master's thesis). Brock University, St. Catharines, Ontario.

Hill, S. (2017). Exploring disabled girls' self-representational practices online. (Report). *Girlhood Studies*, *10*(2), 114–130.

Laestadius, L. (2016). "Instagram" in L. Sloan & A. Quan-Haase (Eds.), *The SAGE Handbook of Social Media Research Methods.* Sage Publications.

Miller, R. (2017). "My voice is definitely strongest in online communities": Students using social media for queer and disability identity-making. *Journal of College Student Development, 58*(4), 509-525.

Park, B. K., & Calamaro, C. (2013). A systematic review of social networking sites: Innovative platforms for health research targeting adolescents and young adults. *Journal of Nursing Scholarship, 45*(3), 256-264.

Patton, M. Q. (2015). *Qualitative research and evaluation methods* (Fourth Edition). Sage.

Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability & Society, 15(*4), 569-582.

Thomas, C. (1999) *Female Forms: experiencing and understanding disability*. Open University Press.

Thomas, C. (2004). Rescuing a social relational understanding of disability, *Scandinavian Journal of Disability Research, 6*(1), 22-36.

Walker, M., King, G. & Hartman, L. (2018) Exploring the potential of social media platforms as data collection methods for accessing and understanding experiences of youth with disabilities: a narrative review. *The Journal of Social Media in Society, 7*(2), 43-68.

Yi-Frazier, J. P., Cochrane, K., Mitrovich, C., Pascual, M., Buscaino, E., Eaton, L., Panlasigui, N., Clopp, B., & Malik, F. (2015). Using Instagram as a modified application of photovoice for storytelling and sharing in adolescents with Type 1 Diabetes. *Qualitative Health Research*, *25*(10), 1372–1382.