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Self-advocacy on Social Media: Disabled Content Creators' Experience in Challenging Stigma Around Disability

Laura Santa Marta Morais de Almeida

Dissertation

presented as partial requirement for obtaining the Master Degree Program in Information Management

NOVA Information Management School
Instituto Superior de Estatística e Gestão de Informação

Universidade Nova de Lisboa

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Self-advocacy on Social Media: Disabled Content Creators' Experience in Challenging Stigma Around Disability

By

Laura Santa Marta Morais de Almeida

Master Thesis presented as partial requirement for obtaining the Master's degree in Information Management, with a specialization in Marketing Intelligence

Supervisor: Professor Teodóra Szabó-Douat

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STATEMENT OF INTEGRITY

I hereby declare having conducted this academic work with integrity. I confirm that I have not used plagiarism or any form of undue use of information or falsification of results along the process leading to its elaboration. I further declare that I have fully acknowledge the Rules of Conduct and Code of Honor from the NOVA Information Management School.

Laura Almeida

Lisbon, February 29th, 2024

DEDICATION

To everyone who has helped me throughout this process, I would like to express my deepest gratitude. This dissertation could not have been brought to life without the incredible people I leaned on during this time.

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To Pedro, who endured a lot of sleepless nights and moody mornings and took care of the furry kids when I couldn't.

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Personal Note

Disability advocacy plays a crucial role in raising awareness and creating change for society in general, as well as other people with disabilities, in particular. I believe social media, despite all its flaws, can be a great tool to bring accurate representation to the center stage of society, because without it, this dissertation would not have been possible.

ABSTRACT

Fighters, inspirational, and unhappy are terms often associated with People with Disabilities. Disability has historically been an uncomfortable, unspoken-about reality that society has treated like the elephant in the room, but the important work of advocates over the years has made significant changes along the way. Can today's digital society and social media generation advance this change even more?

In this dissertation, there was a focus on how content creators with disabilities are using their social media platforms to self-advocate. To further understand this reality, a Netnographic approach, composed of two studies, was conducted: the first focused on Social Media Analysis, while the second was centered on a thematic analysis of eight in-depth interviews, with Disabled Content Creators (DCC). The first study resulted in five main themes: Community-Building, Sharing of Content Aligned with DCC's Preferred Subjects, Adopting Content Strategies, Considering Accessibility and Adapting to Platform-related Nuances; while the second study, saw four main themes emerged: Community, Awareness, Education and Online/Offline Symbiosis. Sub-themes were also found in both studies, which are presented and discussed further. This dissertation aims to raise awareness to the potential that social media presents in demystifying stigma around disability, by allowing disabled content creators to share their lived experiences in an authentic way, as opposed to the often-stereotypical ways traditional forms of media portray it. Studies with this focus could prove useful for these media outlets to become more proactive in learning from and working with the Disabled community when talking about disability. This thesis also encourages further qualitative research in both Disability Studies and Social Media studies in order to better understand the experiences of disabled people online and contribute to making our society more inclusive.

KEYWORDS

Disability Advocacy; Disabled Content Creator; Self-Advocacy; Social Media; Disability Representation.

Sustainable Development Goals (SGD):



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Change never happens at the pace we think it should. It happens over years of people joining together, strategizing, sharing, and pulling all the levers they possibly can.

Gradually, excruciatingly slowly, things start to happen, and then suddenly, seemingly out of the blue, something will tip.

Judy Heumann (Mother of the Disability Rights Movement)

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LIST OF ABBREVIATIONS AND ACRONYMS

Alt-Text	Alternative Text
ADA	Americans with Disabilities Act
CC	Closed Captions
CP	Cerebral Palsy
DCC	Disabled Content Creator
GLAAD	Gay and Lesbian Alliance Against Defamation
EAA	European Accessibility Act
ICF	International Classification of Functioning, Disability and Health
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer
MD	Muscular Dystrophy
PWD	Person with a disability OR People with disabilities
SCI	Spinal Cord Injury
SDGs	Sustainable Development Goals
SM	Social Media
TA	Thematic Analysis
TFM	Traditional Forms of Media
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization
WCAG	Web Content Accessibility Guidelines

TERMINOLOGY

Language Disclaimer

In the context of this dissertation, it has become important to familiarize myself with language and terminology related to disability and the disability community. As such, I have conducted extensive research and personally gained insights from disabled people to, hopefully, better serve the community and academia with this paper. I have interchangeably used both person-first language and identity-first language throughout this dissertation, bearing in mind that there is no right way to refer to someone and that, ultimately, everyone must respect each person’s preferences when it comes to language. I would also like to add and recognize that the terms I chose to use throughout my dissertation might not be universally accepted.

Language has the power to greatly influence how people with disabilities feel and are viewed or treated in society. The use of outdated or derogatory terminology can reinforce negative stereotypes and contribute to the ongoing stigmatization that disabled people have faced for years. By using inclusive and respectful language, we can create an environment that welcomes everyone, that contributed to dismantle barriers to accessibility and understanding.

Term	Definition
Ableism	“discrimination in favour of able-bodied people” (The New Oxford Dictionary of English, p.4) “unfair treatment of disabled people by giving jobs or other advantages to able-bodied people” (Oxford Advanced Learner’s Dictionary, p.3)
Accessibility	“how easy something is to reach, enter, use, etc. for somebody with a disability.” (Oxford Advanced Learner’s Dictionary)
Advocacy	“public support for or recommendation of a particular cause or policy.” (The New Oxford Dictionary of English)
Activism	“the policy or action of using vigorous campaigning to bring about political or social change.” (The New Oxford Dictionary of English)
Cerebral Palsy (CP)	“a group of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination. CP is caused by damage to or abnormalities inside the developing brain that disrupt the brain's ability to control movement and maintain posture and balance. The term cerebral refers to the brain; palsy refers to the loss or impairment of motor function.” (Cerebral Palsy, n.d.)
Curb-cut effect	“illustrates the outside benefits that accrue to everyone from policies and investments designed to achieve equity” (Blackwell, 2016)
Disability	“Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).”

	(WHO & The World Bank, 2011, 4)
Disablism	“discrimination or prejudice against disabled people” (<i>Disablism and Ableism Disability Charity Scope UK</i> , n.d.)
Intersectionality	“The interconnected nature of social categorizations such as race, class, and gender, regarded as creating overlapping and interdependent systems of discrimination or disadvantage; a theoretical approach based on such a premise.” (“Intersectionality,” 2023)
Ullrich Congenital Muscular Dystrophy (UCMD)	“UCMD is a form of congenital muscular dystrophy with specific features: the joints of the hands and feet have ‘bendiness’ or ‘hyperlaxity’, while the elbows, hips and knee joints have ‘contractures’ or ‘tightness’; the spine can have a curvature (scoliosis) or rigidity (stiffness); respiratory muscle weakness and insufficiency develops over time, with the need for night-time non-invasive ventilation by the mid-teenage years.” (<i>Ullrich Congenital Muscular Dystrophy - Overview Muscular Dystrophy UK</i> , n.d.)
Patronizing	“treat with an apparent kindness which betrays a feeling of superiority” (The New Oxford Dictionary of English); “to treat sb in a way that seems friendly, but which shows that you think that they are not very intelligent, experienced, etc.” (Oxford Advanced Learner’s Dictionary).
Retrofit	“to install (new or modified parts or equipment) in something previously manufactured or constructed” (“Retrofit,” 2024)
Slacktivism	“willingness to perform a relatively costless, token display of support for a social cause” (Kristofferson et al., 2014, p. 1149)
Spinal Cord Injury	“damage to the bundle of nerves and nerve fibers that sends and receives signals from the brain. The spinal cord extends from the lower part of the brain down through the lower back.” (“Spinal Cord Injury,” n.d.)
Stigma	“a set of negative and unfair beliefs that a society or group of people have about something” (“Stigma,” 2024)
Tokenism	“the fact of doing something only in order to do what the law requires or to satisfy a particular group of people, but not in a way that is really sincere.” (Oxford Advanced Learner’s Dictionary)
Universal Design	“The intent of universal design is to simplify life for everyone by making products, communications, and the physical environment more usable by as many people as possible at little or no extra cost. Universal design benefits people of all ages and abilities.” (<i>Disability and Health Inclusion Strategies CDC</i> , 2020)
Web Accessibility	“Web accessibility means that websites, tools, and technologies are designed and developed so that people with disabilities can use them. More specifically, people can: perceive, understand, navigate, and interact with the Web contribute to the Web”

Models of Disability*	Definition
Biopsychosocial Model	“Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).” (WHO & The World Bank, 2011, p. 4)
Charity Model	“PWDs are victims of circumstance who should be pitied” (Retief & Letšosa, 2018, p. 6)
Cultural Model	“While the medical model and the social model each focus on only one factor in their approach to disability, the cultural model focuses on a range of cultural factors. Such factors may include medical and social factors but are by no means limited to these factors. Accordingly, the cultural approach does not seek to define disability in any specific way but rather focuses on how different notions of disability and non-disability operate in the context of a specific culture.” (Retief & Letšosa, 2018, p.6)
Human Rights Model	“The human rights model is an improvement on the social model of disability, and it is a tool to implement the CRPD” (Della Fina et al., 2017, p.41)
Medical Model	“Disability is seen as a medical problem that resides in the individual. It is a defect in or failure of a bodily system and as such is inherently abnormal and pathological. The goals of intervention are cure, amelioration of the physical condition to the greatest extent possible, and rehabilitation” (Olkin, 1999, p. 26).
Social Model	“Disability according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on.” (Oliver, 1996, p.33)

*There are more models of disability, the ones displayed were the ones mentioned in the dissertation

1. INTRODUCTION

Historically, there has been evidence that people with disabilities have been outcasted, disregarded, and put aside. Examples include being forced to partake in freak shows for the amusement of nondisabled people (Sandell et al., 2005) and the Ugly Laws, in the United States (US), that forced disabled people to stay inside their houses, especially targeting those with less socioeconomic power (Schweik, 2009).

As a way to oppose ongoing discrimination, the “self-organization of people with disabilities and (...) the growing tendency to see disability as a human rights issue” (WHO & The World Bank, 2011, 3) acted as catalysts for change. The now internationally recognized Disability Rights Movement started in the US with major highlights being the passing of the Civil Rights Movement in 1964, as well as the 1977 sit-ins that led to the signing of section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA), in 1990. These events have been greatly inspired by the Black community’s and the Women’s civil rights movements (Hurst, 2003) and were boosters for change globally.

Social movements advancing civil rights were instrumental in progressing disability advocacy. The Self-Advocacy Movement, in particular, could be traced back to the People First movement (Longhurst, 1994; Williams & Shoultz, 1984).

With the modernization of the world in the recent past, a shift in social movements in general and in the disability community’s in particular, occurred – digital advocacy presents a new, powerful way for a single person to reach a larger audience, and social media, specifically, is a platform with the potential to showcase new narratives in a much more interactive and organic way, contrasting with a singularly dominated reality by mainstream forms of media. The topic explored in this dissertation is driven by this possibility of social media giving voice to people who have historically been silenced, to people who now get the chance to tell their stories, replacing a past dominated by a society that did not consider this community’s viewpoints.

In this way, it felt only natural that this exploratory study was centered around testimonies of disabled people who do exactly that: sharing their lived experience on social media to an audience who, before, had no way to access the information they share and reach them.

Gap in research:

In the literature review process, little research was found that explored how social media is used for advocacy by disabled people. Gopaldas and DeRoy, call researchers to “investigate intersectional patterns of invisibility (...) in contexts such as social media” (2015, p.359). At the same time, while qualitative research of disabled people’s experiences is already a reality in academia, in-depth perspective of people from this community using social media to advocate is scarce (Bowen et al., 2017; Caldwell, 2011; Kreider et al., 2020; McConnell et al., 2018). Bitman (2021) has addressed this in regards of autistic people, people who are hard-of-hearing and people who stutter.

The decision to consider content creators who are also activists due to the assumption this group may look at social media from a more strategic point of view, with the intent of reaching and engaging with as many people as possible. In fact, only a few studies were found that highlighted the reality of disabled content creators who may use social media to advocate, while the most commonly

found either only considered disabled influencers (Bonilla-del-río et al., 2022; Södergren & Vallström, 2022), or chose to focus on a single platform to analyze (Shpigelman & Gill, 2014a, 2014b). Furthermore, some of the most relevant research on the topic is from 2017 or older, and while most of these may still prove relevant nowadays, it was also important to consider some more recent efforts. Some of these have identified how events like the Covid-19 pandemic and the use of digital technologies have allowed disabled people to maintain a connection with loved ones (McCausland et al., 2021) and work remotely (Kanter, 2022). Other researchers highlighted, however, that there was also great potential for further exclusion and possibility to perpetuate ageism (Seifert, 2020), so it may be relevant to consider the side of technology that creates a greater divide. It is also important to note that it is still a far-off reality for some people depending on geographical situations or socioeconomic statuses, who can become further deprived of information, in comparison.

To explore this reality, research questions were drawn for two studies: the first focused on analyzing the accounts of 141 disabled content creators online, totalizing 261 accounts analyzed, while the second went further on to consider the in-depth perspectives of these creators and how they experience social media for advocacy.

Research Question (Study 1)

- RQ1: *What is the experience of Disabled Content Creators like, when self-advocating on social media?*

Research Question (Study 2)

- RQ1a: *What motivates DCC to advocate on social media?*
- RQ1b: *What outcomes do DCCs identify as the result of their work on social media, when challenging society's stigma around disability?*
- RQ1c: *How do DCCs compare their advocacy work on social media, to the representation of disability on traditional forms of media?*

Contributions of literature

The present dissertation may serve research around social media and self-advocacy, as well as contribute for at least three Sustainable Development Goals: 3, 10, 11 and 16. At the same time, by exploring this often-underexplored experience of PWD, this study may prove relevant to help fulfil two of the objectives on the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD): Articles 8 and 9. Article 8 of the Convention discusses the need to bring awareness to disability, whilst combating stereotypes and other harmful practices in regards of PWD, whilst Article 9 mentions Accessibility and the need for independent living and access to opportunities on an equal basis (United Nations, 2006).

In the following chapter, a critical review of past literature is outlined for a better understanding of the research that will later be presented.

2. LITERATURE REVIEW

This chapter has been divided into two fundamental parts which relate to the research questions and aim to present the relevant literature gathered to better understand the overall research on Disability Advocacy, Representation of Disability, Disabled Content Creators and Social Media.

2.1. SOCIETY'S STIGMA AROUND DISABILITY AND DISABILITY ADVOCACY ONLINE

As a starting point, it felt crucial to explore how stigma is intimately, historically connected to disability and how this leads to the need for advocacy, both offline and online.

2.1.1. Disability and Stigma

Disability is a very complex subject. One that does not have a universally accepted definition. As such, several models have surfaced, over the years, to try to illustrate the diversity that disability entails. For the purpose of this dissertation, five of these models of disability are highlighted, as well as a framework proposed by the World Health Organization (WHO).

Disability has been described as “part of being human”, an “integral to the human experience”, being the result of “the interaction between health conditions (...) and a range of environmental and personal factors.” (WHO & The World Bank, 2011). The latter part of this definition marks the distinction between the medical model of disability, which centers one’s disability as something that needs fixing (Della Fina et al., 2017), and the social model, which views society and the environment around the disabled person as being the real disabling factor, not their bodies (Oliver, 1996). It would appear that, as a way to accommodate both perspectives, to demonstrate how disability should not be seen as purely medical nor purely social, the International Classification of Functioning, Disability and Health (ICF) proposes a new approach with the **bio-psycho-social model**:

Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).

(WHO & The World Bank, 2011, 4)

Most literature around disability and how it is viewed and written about, have often made a distinction between the medical and social models of disability, favoring the latter, by mentioning environmental barriers as the real disabling element (Shakespeare, 2006).

At the same time, three other models are important to mention: the charity model of disability, which frames the disabled person as being pitiful and deserving of charity, for the sole reason of having a disability (Finkelstein, 1993); the cultural model of disability, that some scholars theorize as “a political act of renaming that designates disability as a site of resistance and a source of cultural agency previously suppressed” (Snyder & Mitchell, 2010, p.10), contrasting itself from the social model of disability, that mainly views the inaccessible environment as the source of one’s disability; and the human rights model, that has been noted to be a disability justice model, rather than simply a disability model. This approach looks at disability as a human rights issue and is about “*taking into account the social factors that impact disabled people and about writing inclusion and equality into the law*” (Ladau, 2021, p.41).

The models that served as a way to guide the thinking of the researcher were the social model, the biopsychosocial model, the cultural model, and the human rights model. Contrastingly, the medical and charity model are important in showcasing society's stigma around disability.

Because it feels important to highlight disabled people's perspectives, disability rights activist Alice Wong's take on what disability is for her seems to be appropriate:

"Disabled people have always existed, whether the word disability is used or not. To me, disability is not a monolith, nor is it a clear-cut binary of disabled and nondisabled. Disability is mutable and ever-evolving. Disability is both apparent and nonapparent. Disability is pain, struggle, brilliance, abundance, and joy. Disability is sociopolitical, cultural and biological. Being visible and claiming a disabled identity brings risks as much as it brings pride". (Wong, 2020, p. xxii)

Disability is often associated with stigma and preconceived ideas about, which has been studied in the context of disability inclusion (Waltz & Schippers, 2021). Bogart et al. (2019) analyzed how the stigma one may be exposed to varies depending on whether their disability is congenital or acquired, with the latter being, overall, the one where most stigma is identified. The same could also be studied for the type of disability one has or depending on its degree within the same disability. That is to say that someone with a non-apparent disability (for example, a chronic illness, such as Crohn's disease), may suffer less stigma than a person who has a visible disability, such as someone in a wheelchair. Another case may be someone with Cerebral Palsy (CP) who may have a visible limitation walking, and another person with the same type of CP who does not have any apparent physical impairment.

Stigma is oftentimes used as an umbrella term for other categories that have been used to describe the kind of oppression disabled people face. It feels relevant to understand some of the systems of oppression disabled people face. For the purpose of this dissertation, two were chosen to be further analyzed: **implicit bias** and **systemic ableism**.

Implicit Bias

Implicit bias, or unconscious bias can be defined as a set of beliefs that dictate our thoughts or actions in a way that discriminates against others (Fitzgerald & Hurst, 2017; Friedman, 2019; Huang et al., 2023). When it comes to people with disabilities, this bias can be unintentional, and the result of discomfort, lack of knowledge or lack of awareness, for example.

Some scholars have approached how implicit bias is present in society, with most offering insights in relation to healthcare professionals, who have been noted to perpetuate these types of biases (Iezzoni et al., 2021), with an apparent tendency to approach this topic in relation to developmental or cognitive disabilities (Fitzgerald & Hurst, 2017). While important, the fact that most studies found had these professionals as the target, could mean there is still an intrinsic medical perspective around disability that can also be seen in academia. It would be interesting for authors to explore how this translates into other areas of society and in regards of other disabilities.

Contrastingly, other studies also show how changing the way we perceive others and ourselves can reduce discrimination (Dovidio et al., 2007).

'Inspiration porn' is a term that was first coined by late disability rights activist Stella Young (TEDx Talk, 2014) to refer to the way people find disabled people inspiring for reasons that would not be inspiring if those people were not disabled. It is often a question of intent and effect. While we can acknowledge that implicit bias can be a factor in informing this type of inspiration, the effect it has on disabled people may be the perpetuation of stereotypes.

Systemic Ableism

Ableism is the prejudice against disabled people in favor of nondisabled people and has been deeply rooted possibly due to the continuous presence of the medical model of disability thinking in today's society. The term disablism, less commonly used within the community nowadays, is defined as the direct prejudice against people with disabilities. For the purpose of the dissertation, the term ableism was used.

Internalized Ableism

Internalized ableism can be characterized as ableism that people with disabilities have towards themselves. For Campbell (2008), it comes into play when there is an "*a priori* presumption of ableness" (p. 156), to which the disability is opposed to. This can mean that disabled people wish to achieve a normativity often imposed by society, as the socially acceptable thing to be.

As a way to showcase the discrimination people with disabilities face, several scholars and organizations have tried to list some types of barriers that are useful to understand, when talking about areas of society ableism can touch. The ones that are usually the most present in research were attitudinal, communicational, physical, policy, programmatic, social, transportation and technological (Disability and Health Disability Barriers | CDC, 2019; Newman et al., 2017; Scheer et al., 2003).

The Importance to Recognize Intersectionality

One of the biggest problems encountered when it comes to ableism is the intersectionality of disability with other minority groups. Several studies have argued this need to consider the representations of disability with intersectionality in mind, considering race, gender, ethnicity and sexual orientation (Brown et al., 2017; Gopaldas & DeRoy, 2015; Nölke, 2018; Reber et al., 2022), as well as intra-disability differences, meaning the combination of different types of disabilities impairments, that may change their severity across one's life (Tsatsou, 2021, 2022).

That focus on the intersectionality of disability with other minority groups suggest that people tend to suffer ableism for each of those identities (Miller, 2017). At the same time, intersectionality plays an important role, but other minorities do not always keep the realities of disabled people in mind.

When it comes to advocacy, studies show its potential to influence public perception, raise awareness, foster change in policies (Schermuly et al., 2021), as well as foment community building (Seelig et al., 2019). It is rather relevant for PWD, given the lack of opportunities in several aspects of society, such as education, employment or the perception of inability to properly participate in society (Carvajal & Ferreira, 2019; Moodley & Graham, 2015). These figures seem to also be dependent on factors such as socioeconomic status, the geographic reality or political one.

As such, it is also proving relevant to consider how the Internet has played a role in how advocacy has developed and what that may represent for people with disabilities.

Having diverse voices at every table has proven beneficial, however, the inclusion of certain minorities can be easily taken to a place of tokenism, where the person is there to simply fill the inclusion box, without actually being heard. Tokenism is an understudied subject that is extremely relevant to consider in relation to the disability community. The little body of research found was either dated back to over twenty years, or considered other minorities such as women (Yoder, 1991), or a specific disability, as is the case of Hutton et al. (2011), that considered people with intellectual disabilities. These authors argue that self-advocacy is rather important in challenging tokenism, but is oftentimes ineffective, when they depend on others to make their voice heard. This is the case for some people with developmental disabilities – it is stated that, when tokenism is in play, it is most likely a question of lack of respect.

2.1.2. The Importance of Disability Advocacy Online

Disability activism has paved the way to changing people's lives by forcing politicians to act. This change seems to depend on public opinion and exposure to be effective, more so in an increasingly online world. This world is a source and driver for influencing public perception and the place where a lot of the conversation is. Social media is one of the most prominent places in this regard and plenty of political bodies have taken to social and rely on it for decision making (Mann, 2018).

The need for advocacy may also be associated with the fact that stereotypical views that deem people with disabilities unfit to equitably participate in society, which may affect them at an employment level, in voting rights or accessing spaces with the same right a nondisabled person does.

Caldwell (2011) identified resistance, connection with disability community, reclaiming disability and personal transformation, interconnection with the disability rights movement and bonding with social justice and interdependency as the main outcomes of disability advocacy on social media.

“online activism is a valuable and legitimate form for people who can't travel or in some cases can't leave the house” (Wong, 2020, p.136).

2.1.2.1. Digital Advocacy and the Digital Divide

The digital era has offered a potential alternative for disabled people to be part of a world that has presented a number of barriers, making it challenging to navigate it. The disability rights movement is one that can benefit greatly from the remote aspect of digital advocacy (Gleason et al., 2020) given the ability to reach more people through a digital tool, instead of exclusively in-person, avoiding environmental or physical barriers. Movements such as #CripTheVote on Twitter are a good example of this way of advocating (Mann, 2018). Nevertheless, it is also crucial to bear in mind that the exclusion felt in the physical world may also be felt online.

Some authors have used the social model of disability to argue that the extension of the disabling physical environment to an online environment could also be looked at as digital disability (Goggin & Newell; 2003, 2007). Furthermore, Ellis and Kent (2011) designed a digital disability model based on the digital design of accessibility of internet platforms, with four stages: technology being accessible

but not widely distributed; technology being widely distributed but inaccessible; a third stage where the accessibility in these technologies is retrofitted; and the fourth stage is one where everything created is accessible from the beginning. One interesting point about the first phase of this model is an example where they highlight that in the beginning of social media, due to its simplicity, it was more accessible to assistive technology devices. These were tools that allowed people with disabilities to access information, such as screen readers.

Baumgartner et al.'s (2021) qualitative research shows how this paradox of the use of digital media by PWD may unfold. While pointing out benefits to its adoption, such as the ability to access information through assistive technology (with examples from the blind community, for instance), they also present barriers which they categorize as “technical”, “editorial”, “financial” or “individual cognitive and attitudinal barriers” (p.85-87). This would translate into, for instance, a lack of knowledge in technology usage, technology-dependency or inability to access technology for financial reasons (Baumgartner et al., 2021).

The flip side of the potential challenges for minorities, has been recognized as the digital divide among scholars, (Chadwick et al., 2013; Cho & Kim, 2022), however, there is much controversy about the subject. Some argue that digital solutions further contribute to create inequalities and inequities, for those who cannot access it, conceptualized as the digital divide and it is highly dependent on a number of factors.

A possible way to battle these inequities, would be to bet on solutions such as ones who follow the curb-cut effect. The Curb-cut effect was first coined by Blackwell (2016) as a way to highlight how investments in accessibility benefit everyone and not only the people they supposedly cater to. That is the case with curb-cuts, that were created with the goal to create access for disabled people, but ended up benefiting parents with strollers or skaters, for instance. If more people took accessibility as a standard, then maybe some gaps our society faces would not be so wide.

Retrofitting accessibility is also interesting to consider in this case, as it represents the cost (both monetary and in time) of remaking, rebuilding something that was inaccessible to make it accessible. This can happen at a physical level, but also at a digital one Wentz et al. (2011). As a way to guide and avoid inaccessibility, the World Wide Web Consortium (W3C) published a set of guidelines to be implemented that would guarantee better accessibility of internet sites, which are today known as the Web Content Accessibility Guidelines (WCAG). Despite existing law that relying on these guidelines, such as the ADA or the European Accessibility Act to be implemented by 2025, barriers to participation in society for people with disabilities continue to exist (Keates et al., 2000) and, as Wentz et al. (2011) point out “These benefits will remain in the realm of the potential, however, until disability rights laws shift from a philosophy of retrofitting to a philosophy of born-accessibility.”, which goes in accordance with the fourth stage of the Digital Disability model proposed by Ellis and Kent (2011).

One could also argue that the increasingly digitized world, has made digital advocacy possible for people with disabilities, to showcase their authentic reality, while bearing in mind that a lot still needs to be done to ensure that policies are followed to make it so.

Some authors have also empirically shown how some of those guidelines may pose problems for disabled people trying to access the Internet (Power et al., 2012), however, it appears more recent research would be better suited to assess the common state of the WCAG's accessibility.

While digital advocacy can significantly contribute for PWD's increase in participation, it also appears to be relevant to discuss how traditional forms of media can influence the way people with disabilities are viewed in society, thus affecting their perceived value in being a member of society as much as nondisabled people.

2.2. DISABILITY REPRESENTATION AND ADVOCACY

As disability is a diverse, intersectional subject, some scholars seem to have found it important to continuously include people with different experiences in their research (Moodley & Graham, 2015; Nölke, 2018; Reber et al., 2022; Tsatsou, 2022). No one person is representative of an entire community, but there are likely some common hurdles when navigating the world. Studies that highlight an authentic disability experience contribute to creating more accurate representations of what disability is, in a society that has historically misrepresented and stereotypically portrayed disabled people. At the same time, in a rapidly changing digital environment, it could be argued that the findings of research based on reality of the beginning of the century, may no longer portray what younger generations, who have grown in the digital era, face.

2.2.1. Disability Representation in Traditional Forms of Media

Representation has been noted to be important, within the disability community, to create a sense of belonging among its members as well as in demystifying disability in the eyes of society. The media appears to present the potential to either challenge or reinforce the stigma and the stereotypes society has had for a long time (Saunders et al., 2018).

In the digital era we live in, the media has the potential to bring awareness of disability through representation, be that in television, movies, advertising, or the news. It has also been shown to play a significant role in shaping cultural assumptions about ability (Ellcessor & Kirkpatrick, 2017).

Several studies that approach this impact have found that traditional media often portrays disabled people stereotypically and not frequently, leaving their audiences with one-dimensional views of disability

The negative aspects of representation seem to occur when there is a lack of it, or none at all, but also when it misleads the public regarding what disability "looks like". Examples would be casting a nondisabled actor to play a disabled person and doing it in a non-authentic way. This would be negative because the audience would create an idea of what that disability is and is not. Implicit bias might grow from representation that follows these patterns.

Evidence of how media represents disabled people has been gathered as early as Barnes' (1992) research, which generated a plethora of stereotypes, namely, "Pitiable and Pathetic" (p.7), "Sinister and Evil" (p. 11), a "Burden" (p. 15) or "Incapable of Participating Fully in Community Life" (p. 17). These stigmatized views appear to have been rooted in the Medical Model of Disability. However, one seemingly positive representation mentioned in Barnes' work was the representation of disabled

people as normal. While beneficial, these would be characters showcased fewer times, in secondary roles.

It could be argued that tokenism may also influence media to portray disability in any capacity. In a society where being apparently diverse is trendy, including people with disabilities in any capacity could be perceived as a positive effect. However, mindlessly including for the sake of including, may not actually be inclusion.

Next, it feels important to distinguish two very relevant areas where disability is represented and may have an influence in the way society perceives it: News and Advertising; and TV and Film.

News and Advertising

Findings from Haller et al., (2006) show how portrayals of disability in news media in particular have shifted for the better, however, many other studies show how long it will be until we have accurate representations of disability (Jones & Harwood, 2009).

Just like the case of inclusion of people with disabilities in society, representation of this community has been historically forgotten or misdealt with in advertising and other forms of mainstream media. A study showed that only 3% of total advertising portrays people with disabilities (Nielsen, 2022). Gopaldas & DeRoy (2015), for instance, highlight how disabled people, among other minority groups, were often left out of magazine covers.

The media, marketing and advertising industries have an opportunity to help break down social stigmas around disability by making people with disabilities more visible. (Nielsen, 2022)

TV and Cinema

Several qualitative studies have given voice to people with disabilities regarding the representation of disabled characters in television, who claim that the media portrays them stereotypically (Dean & Nordahl-Hansen, 2022; Haller & Zhang, 2014; Jones, 2022). Plenty of grey literature focuses on this very topic as well.

A study conducted by the Gay & Lesbian Alliance Against Defamation (GLAAD) found that between 2022 and 2023, only 4.5% of series' regulars, were LGBTQ characters with disabilities (GLAAD, 2023). The organization states that "Television has a long way to go in telling nuanced stories of people with disabilities and empowering those from the community to tell their own authentic stories." (GLAAD, 2023).

The media, and TV and Cinema, in particular, may use language that is not appropriate in terms of reinforcing stigma and beliefs that have been wrongly associated with disability. Generally speaking, they tend to depict disabled characters in one of 3 ways: inspirations, villains or victims, which has been noted to translate to the offline world. Geena Davis Institute (2023) also identified representation pitfalls, that serve as examples on what to avoid while creating disabled characters; these examples are: (1) "**The Supercrip**: A disabled character who "overcomes" their disability to achieve greatness, and they are "inspiration" for non-disabled people." and (2) "**The Unspoken Autistic**: This character is written with autistic characteristics, but often not labeled as such. Their social misunderstandings are played for laughs." Geena Davis Institute (2023). People tend to identify

with what they consume, and the community has been vocal about how misrepresentations of disability in mainstream media have been damaging their day-to-day lives, which is something academia should further study.

“Characters with disabilities were rarely shown, were not in leading roles, and had almost no romantic attachments. The failure to acknowledge the complex lives of disabled people leads to portrayals that rest on their disability. Further, children with disabilities do not get to see themselves on screen. Disability representation can be increased without reducing disabled characters to their disability.” (Geena Davis Institute (2023, p.31).

Another relevant aspect to consider is that, in terms of mainstream media, the majority of findings are from the US, which shows that further research is necessary to depict other realities realistically. Statistically wise, that were found in the United States of America.

It could be argued that a lack of accurate representation of people with disabilities in traditional forms opens space for social media to be a platform for them to be seen, on their own terms, which is something that will be further analyzed in the following chapter.

2.2.2. Disabled Content Creators on Social Media

Social media has an estimated 5.04 billion active users (Statista, 2024) across different platforms, particularly Facebook, Instagram, and TikTok.

Literature shows how it has become important to foster a sense of belonging and community building or to connect with friends (Foster & Pettinicchio, 2022; McCabe & Harris, 2020; Shpigelman & Gill, 2014a, 2014b). For people with disabilities it seems to also be particularly for exchange and activism (Ellis & Goggin, 2015; Harris & Mccabe, 2017), which may prove relevant in enhancing authentic portrayals of the disability community. It has also been highlighted how blogs have provided a way for disabled people to express themselves through media since the early days of social media (Ellis & Goggin, 2015), but also more recently (Casey, 2020; 2023; Nielsen, 2023).

Studies from Shpigelman & Gill (2014a, 2014b) only considered Facebook in their analysis, which has since been matched by other important social networks, such as Instagram or TikTok that should also be considered. In their first study, Shpigelman & Gill (2014a) state that participants had not tried advocating on Facebook, which is something that will be addressed in the present dissertation.

2.2.2.1. The Creator Economy

As social media grows, so does the creator economy, which may provide that new way to see disability has gained a new light. Although there is no official definition for content creator as well as for influencer, several sources do distinguish both terms but there seems to be a tendency to use them interchangeably, meaning a content creator can also be an influencer and vice-versa.

In this way, a content creator can be defined as a person who focuses on “creating content that engages their audience”, such as “how-to guides, ‘day in the life’ series, tips and tutorials, beautiful photography, engaging videos”, while an influencer shares “how they live their lives, promoting the products and services they use along the way”, with the purpose of influencing “their followers to do or buy something”. It was decided to use the term “content creator(s)” hereinafter, because all participants interviewed identified as such but not all identify as influencers.

While there are several studies made on the rising of the creator economy, it seems that only a few have focused on disabled content creators or in disability advocacy through social media, by individual creators. In fact, most of the research found on social media as an advocacy tool has focused mainly on advocacy groups or non-profit organizations (Guo & Saxton, 2014; Johansson & Scaramuzzino, 2019). Findings from those papers suggest that advocacy is done in more of a one-way communication as a way to raise awareness about the organization, rather than a two-way stream.

In the few studies found of people with disabilities taking control of their own narratives and sharing their authentic, lived experiences with disabilities (Bonilla-del-río et al., 2022; Södergren & Vallström, 2022; Staniewski & Awruk, 2022). It would be interesting to see the impact that these creators could have in helping to build a more accurate representation in cooperation with traditional media, given the potentially significant reach on a daily basis. One such example is a 2022 study by Nielsen, that shows how engagement with disabled content creators' accounts on branded were 20.5% higher in campaigns (Nielsen, 2022). For the sample analyzed, branded posts by disabled content creators tended to outperform those created by nondisabled creators, both in media value and engagement.

2.2.2.2. The Social Media Paradox

While social media has the potential to bring enormous advantages to millions of people, researchers have also highlighted its downsides, having nominated it “the dark side of social media” (Baccarella et al., 2018, 2020). The internet and, in particular, social media may also negatively influence user's offline social networks and integration, or showcase a reality online that does not correspond to the reality in the offline one, a term coined as slacktivism that expresses a “willingness to perform a relatively costless, token display of support for a social cause” (Kristofferson et al., 2014, p. 1149) without the real intention to further pursue that cause. An example is simply liking a post. Other studies, however, argue that slacktivism may have the effect of interesting people into offline activism.

Furthermore, accessibility barriers that were commonly identifiable in the physical world in the form of physical, attitudinal and communicational barriers have been transposed to the digital one (Tsatsou, 2021). The lack of accessibility has been maintained to a certain degree, giving space to a digital divide between disabled and nondisabled people. This digital divide has been thoroughly documented regarding other minorities, yet it seems fewer studies include disability. That is something that a few researchers have pointed out as well: the fact that diversity-related topics, oftentimes don't consider disability (Andrews et al., 2019).

Despite acknowledging the relevance of these findings, the present research chose to focus on the possible positives that may stem from disability advocacy through social media, contrasting with the stereotypical and harmful portrayals that other forms of media might adopt, which were covered in this chapter.

3. METHODOLOGY

The main purpose of this dissertation was to explore how disabled content creators use social media as a self-advocacy tool, with the goal of challenging society's stigma around disability. Attempting to fulfill this purpose will hopefully contribute to exploring how to build a more inclusive society by challenging its preconceived notions and harmful behaviors.

A social media analysis, as well as in-depth interviews were undertaken, which made qualitative research appropriate as a method of analysis.

For the purpose of this dissertation, qualitative research was the method chosen, because there was a need to analyze the subjective experiences of individuals, focusing on understanding a problem that is complex and underexplored. A Netnographic approach was followed as proposed by Kozinets (2010, p. 61): (1) Definition of research questions, social sites or topics to investigate; (2) Community Identification and Selection; (3) Community-participant observation and Data Collection; (4) Data analysis and Iterative Interpretation of Findings; (5) Write, Present and Report Research Findings.

This method has been widely used in Social Sciences drives and focuses more on meaning rather than precision, when compared to ethnography. As previously mentioned, the purpose would be, firstly, to explore and understand the online behaviors of disabled content creators who use their social media platforms to self-advocate and share their lived experience of disability (Study 1). Secondly, and after identifying patterns and themes, those elements were key to create a questionnaire that would be used for in-depth interviews with disabled content creators, in which they would share their own experiences when advocating on social media (Study 2). After analyzing all data, bridges were made between the initial results and themes emerged from the interviews. The latter allowed the researcher to gain a broader understanding of how the participants chose to behave online (Kozinets, 2015), when it comes to advocacy.

This chapter will cover four of the five steps mentioned, while the writing and presenting of the results will be done in chapter five.

3.1. DEFINITION OF RESEARCH QUESTIONS

The main research question intended to answer was RQ1: *What is the experience of Disabled Content Creators like, when self-advocating on social media?* For this purpose, two studies felt necessary: the first would focus on the Social Media analysis of disabled content creators, while the second would use in-depth interviews, one of Kozinets's (2015) called 'Complementary Methods' for netnography, with disabled content creators. For this purpose, sub-questions felt natural to be added to study 2, after reviewing the literature and with the rationale that it would be possible to understand the personal experiences these creators had even further.

The main Research Question (RQ) that was intended to be explored was:

- RQ1: *What is the experience of Disabled Content Creators like, when self-advocating on social media?*

The following sub-questions were drafted, so has to further the problem on a deeper, more detailed level.

- RQ1a: *What motivates DCC to advocate on social media?*
- RQ1b: *What outcomes do DCCs identify as the result of their work on social media, when challenging society's stigma around disability?*
- RQ1c: *How do DCCs compare their advocacy work on social media, to the representation of disability on traditional forms of media?*

3.2. COMMUNITY IDENTIFICATION AND SELECTION

Study 1 – Analysis of Social Media Accounts

For the analysis of social media accounts, Instagram, LinkedIn, TikTok, YouTube and Twitter were the ones chosen, after a previous familiarization with the behavior of disabled content creators online. In the end, a bigger focus was given to Instagram and LinkedIn, due to the number of accounts chosen to analyze. For this purpose, 261 accounts were chosen from 141 disabled content creators online, following a convenience methodology. These creators could have any type of disability and have their accounts managed by themselves, and not third parties. In total, sixteen different nationalities were considered, with the community being largely composed by women (75,18%), and over twenty different types of disabilities considered (with the most prevalent being Chronic illnesses (such as Crohn's disease or Ehlers-Danlos Syndrome), Cerebral Palsy, Limb differences, blindness/visual impairment, Spinal Cord Injuries and Autism).

Appendix A shows a detailed overview of the demographics of this data, including nationality (if known), gender (if known), type of social media platforms analyzed as well as the disabilities of the users whose accounts were analyzed (if known). The idea was to get an intersectional approach of how people advocated online.

Study 2 – In-depth Interviews with DCCs

The sample for the in-depth interviews also followed a convenience methodology, which focused on choosing people who have a physical disability, who identified themselves as content creators and had social media accounts that were managed directly by themselves (not by families or associations). Participants were reached either via Instagram or email and were given a brief explanation of the nature of the study – exploring the ways they used social media as a self-advocacy tool.

A content creator was defined as a person who creates content for social media that did not necessarily receive monetary compensation for their work, distancing from the definition of influencer.

The final sample was composed by eight disabled content creators from five different countries (Portugal, Honduras, the United States of America, Venezuela and Brazil). In terms of the selection process, it was found of paramount importance that the participants had different backgrounds, so that the intersectionality that is intimately intertwined with disability was represented (Brown et al., 2017; Gopaldas & DeRoy, 2015; Moodley & Graham, 2015; Nölke, 2018). In this way, in the group of eight participants, aged between 20 and 34 years old, there were four people from the LGBTQIA+ community, two from the Latinx/Hispanic community and one from the Latinx-Hispanic/Black

community. All participants were physically disabled: four participants had Spastic Cerebral Palsy, two participants had Spinal Cord Injuries, one participant had Spastic Quadriplegia Cerebral Palsy and one participant had Ullrich Congenital Muscular Dystrophy (UCMD). All participants are active users of at least one of the following social media platforms: Instagram, TikTok, Facebook and X (former Twitter).

3.3. COMMUNITY-PARTICIPANT OBSERVATION AND DATA COLLECTION

The data collection required analyzing social media accounts and conducting in-depth interviews (discussed further in this chapter), which would represent a large text-based output that would be better analyzed through the lenses of qualitative research.

Study 1 – Analysis of Social Media Accounts

For the analysis of disabled content creators' posts across several platforms, the time gap was chosen to be between the 1st of September 2022 and the 1st of December 2022. These posts were mainly written or spoken in English or Portuguese, with few exceptions in which they spoke Spanish.

Study 2 – In-depth Interviews with DCCs

For study 2, a semi-structured approach to in-depth interviews would guide it, with a questionnaire that was informed by the literature review and the results from Study 1.

The in-depth interviews were conducted online, using the online meeting platform Google Meet and lasted between 54 minutes and 2 hours and 22 minutes. The data collection occurred between the 17th of January and the 21st of February of 2022 and were held in the preferred language of the participants (either English or Portuguese). All interviews were transcribed after they occurred and translated, in the case of Portuguese-speaking participants' interviews. All participants were informed about the purposes of the research and aspects that would be taken into consideration to ensure their privacy, and all agreed to participate. All names were replaced with pseudonyms when presenting the data collected.

The in-depth interviews followed a semi-structured approach, with a previously set of questions that could be adaptable, according to each participant's experience, as the interview unfolded. For the creation of this set of questions, several aspects took importance: Study 1, which informed the themes emerged from the analysis of DCCs account Media and Cultural studies, Critical Disability and Social Inclusion studies, which revealed relevant subjects such as acceptance, belongingness, empowerment, equality and respect (Licsandru & Cui, 2018). These would later inspire codes for research, following a hybrid approach between deductive and inductive coding (Braun & Clarke, 2006, 2021).

3.4. DATA ANALYSIS

Study 1 – Analysis of Social Media Accounts

Throughout the time of data collection, handwritten notes and Excel were important tools in analyzing the types of posts and the content these creators made. This was made as a sort of diary, where the most recurring instances were noted and would later lead to themes, in case those instances stood out.

Study 2 – In-depth Interviews with DCCs

Concerning data analysis for the in-depth interviews, the option was to use the Reflexive Thematic Analysis Framework from Braun and Clarke (2006, 2021), embedded in the larger Netnographic approach. A content analysis followed, as well as a hybrid approach of both inductive and deductive coding.

The first step of the thematic analysis was getting familiarized with the data. The choice was made to aggregate all interviews into one full script, where each question would encompass answers from all participants. This allowed for a full reading of the transcript and a better understanding of the bigger picture, which also proved useful during the iterative processes of creating codes and elaborating themes, later on.

The second phase relied on coding the data. A line-by-line coding process was followed, with In-Vivo coding, considering the exact responses of participants.

The third stage was about elaborating themes (Braun & Clarke, 2021), which was a slightly different approach from Braun and Clarke's initial framework presented in 2006 – "searching for themes" (p.89). The authors clarify that themes should not simply emerge from the data; the researcher must have a critical view.

In steps four and five, themes were reviewed, and finally defined and named. Of these steps, four themes were set, with ten subthemes, which will be presented in the next chapter, fulfilling the method's sixth step: reporting the results.

A deeper understanding of the findings is the last step on Kozinets' (2010) netnographic approach, which will be covered in chapter four.

4. RESULTS AND DISCUSSION

In this chapter, an overview of the key findings of both will be presented, followed by the interpretation and discussion of these results.

4.1. STUDY 1 – ANALYSIS OF SOCIAL MEDIA ACCOUNTS

After a thoughtful analysis of the social media accounts of 141 creators and 261 accounts, five main themes emerged, with nine subthemes associated. The themes were (1) Community-building; (2) Content alignment with DCC's preferred subjects; (3) Content Strategies; (4) Accessibility and (5) Platform-related nuances. So as to respect the identities of content creators, it was decided to provide an explanation of what their content showed, rather than sharing the actual accounts of those creators. A general explanation can be provided about the results of this study. Disabled Content Creators who advocate on social media seem to present an eagerness to share, not only their perspectives, but to learn from others. They leverage their platforms to showcase their preferred-subjects, while linking them to their lived-experience. They seem to accomplish this, in part, because of an apparent strategy, which may or may not be consciously applied, that seems to interest people who are more aware of social matters. DCCs also present a natural tendency to present content they feel is accessible to their audience, in a true "practice what you preach mentality" and taking ownership when that is not the case. Finally, a number of differences appear when we compare how DCCs use each social media platform to advocate.

4.1.1. Community-Building

The positive effects of a sense of community have been reported by a number of scholars (Kim & Qian, 2021; Kožuh & Debevc, 2020; Liu et al., 2018) and that seems to show in the content people with disabilities share online. Disabled content creators seem to really foster content made with people from their community as well as to create a community of their own, online.

Example: A woman with CP shares a video on TikTok, on World Cerebral Palsy Day, in which she celebrates three years of starting to post videos of herself walking and sharing her visible disability, to hopefully raise awareness. She thanks the support of community she has created and connected with since the start. (October 6th, 2022)

Collaborating with other creators also seems to allow them to reach larger audiences and keep the conversation going.

Example: a reel posted of two blind women walking down a street with their canes. A trendy music is going, and the caption is allusive to the fact that blind women are powerful, confident, and glamorous, also highlighting how great it is to share moments together. (November 23rd, 2022 – Instagram).

These advocates show they care about their community and their opinions, engaging with their audiences in their comment sections, but it is unclear whether this audience is composed by a majority of fellow disabled people or not.

4.1.2. Sharing of Content Aligned with DCCs Preferred Subjects

The way disabled content creators advocated on social media seemed to be related to a theme or subject close to them. They appeared to have areas of interest they prefer to highlight on their social media that they then showcase in the context of their lived experience. The most recurring themes that inspired content were Travel, Fashion and Beauty, Lifestyle, the Media, and Advocacy.

4.1.2.1. Travel

This type of content seems to generate a lot of engagement and encompasses several possibilities to advocate through awareness. It is very common to see content creators who focus on travel content showing how they experience air travel, the processes of hospitality services in several destinations, guides on what to do in those destinations, but also how services respond when things do not go according to plan, for instance. Calling out ableist services is one very recurring theme related to the travel industry. This can be the experience of wheelchair users, who get their mobility aids treated as luggage or, for instance, people who are deaf or HoH who may not be aware that the gate they were supposed to board in has changed, because the only evident notice given was a spoken one.

Example 1: a woman who is a wheelchair user is told she is unable to use the toilet on a plane because there is no aisle chair on board. The only solution was to drag herself down the airplane's aisle to get to the toilet. This woman shared her experience, and it went viral online, with over 16 million views on TikTok and over 30 million views on Instagram, reaching a number of media outlets and made the community more aware, while encouraging them to take action — sharing, commenting, identifying the airline to force them to take a stand. (September 20th 2022, on Instagram)

Example 2: a deafblind woman shows how a street light sign offers a tactile option to understand whether she can cross a street in London.

4.1.2.2. Fashion/Beauty

Fashion and beauty content seem to be a big part of some of these creators' life. Some of the ways people share this is by sharing how they do their make-up, accessible products, fostering Universal Design. At the same time, they also share their participations in campaigns and paid ads, where they highlight products from brands.

Example: A woman with Osteogenesis Imperfecta shares a video on Instagram, in which she is on a hair salon while working on her computer. She highlights how her stylist and the salon itself are accommodating the needs she has voiced (October 29th, 2022).

4.1.2.3. Lifestyle

This is one of the most common approaches to content. In these types of postings, DCCs are doing everyday tasks while talking about their disability, they can show how they put their wheelchair into their car or how they navigate parenthood, for instance.

Example: on October 7th, a deaf woman who has several chronic illnesses made a YouTube video sharing how her partner and herself are teaching both British Sign Language (BSL) and spoken English to their one-year-old child.

The intent appears to be demystifying certain situations that would be deemed outstanding to accomplish for the simple fact that the person has a disability. Another possible reason for this to be a common approach, could be to show how inaccessibility is one of the most disabling factors they face on a daily basis. It seems important to these creators to create visibility to hopefully challenge stereotypes long present in society.

4.1.2.4. The Media

Often, could we see advocates calling out ableist media with film and TV being amongst the largest. At the same time, it was also talked about as being extremely powerful in fighting said ableist portrayals.

There seemed to be a general interest in moving forward from the issues they highlighted, by sharing great examples of accessibility and inclusion, in their eyes. They seemed to be trying to be a part of the solution.

4.1.2.5. Advocacy

There is a strong presence in content in general, with some advocates choosing to directly address the situations, or by creating a more engaging content that is more welcoming to conversation.

Example: An autistic non-binary person talks about how some doctors directly discriminate against people with disabilities, claiming they do not want to see them. In this IG reels, they put snippets of studies on screen with information that corroborates their claims.

These creators are also joined together in both creating and shedding light on initiatives that will advance the rights of people with disabilities. One such example is the **Rights on Flights campaign**, that was created in light of the awareness raised to the lack of accessibility and access to equitable treatment by airlines and other air travel players.

4.1.3. Adopting Content Strategies

Besides choosing to highlight content that aligns with one's preferences, DCCs also seem to adopt certain strategies to reach a larger audience.

4.1.3.1. Humor as a conversation-starter

It appears some content creators use a lighter mood, or even humor to bring people together and raising awareness in a way that invites conversation and identification. Oftentimes people in the comments

Example: On October 17th, 2022, a woman who is a wheelchair user discusses, in a humorous way, whether a wheelchair user would be considered (or not) in the fire drill of a hotel. In this scenario, the hotel did not have any specific measures for wheelchair users to escape during a fire. In the caption, some more aspects were highlighted, according to specific articles, such as the fact that not all elevators are safe to use, that there are certain mobility aids that can be used to assist people with limited mobility and the possible existence of refuge areas for them to go when everyone else gets evacuated, which may could still prove dangerous, in some scenarios (reality in Portugal).

This Instagram reel started a conversation about this subject, with people acknowledging they had not considered this fact and a larger discussion was had about what could be done to better this situation.

It could be interesting to study whether humor can be used to challenge stereotypes and make people step away from the “othering” of disabled people. There are stand-up comedians, such as Tina Friml or Maysoon Zayid, known to use their disability as an ice breaker on their shows.

Example: A woman with cerebral palsy who is a comedian shares content about her performances online, shared a video on TikTok, of one of her shows, in which she approaches how she doesn't suffer from cerebral palsy, she suffers from people. This video reached over 3 million views (November 13th, 2022).

4.1.3.2. Engagement

Disabled Content Creators are often present in creating content that brings people to talk about the matters that they stand for. As such, they start conversations and then actually have them. They seem to want to nurture the relationship they intended to establish when they decided to start sharing online in the first place.

4.1.3.3. Staying up to date with Trends

One of the ways many DCCs choose to make content is by leveraging trends, such as audio, themes or other relevant topics of the moment, while showing their perspective of disability. This seems to be intentional in raising awareness and starting conversations around disability in a more seamless way.

Example: a man who is an amputee of both legs uses Taylor Swift's song 'Anti-Hero' to say he is not overcoming his disability, and that the real problem is ableism (October 27th, 2022).

4.1.3.4. Resources

Given that DCCs generally recognize their experience is their own and no one else's, they are usually straightforward in sharing valuable information and content outside of their own lived experience. Possible causes for this drive seem to be the acknowledgement that disability is diverse and intersectional (which is something very often encountered in DCCs content) and/or a place of ignorance and wanting to learn more themselves. Not everyone needs to know everything all the time, and DCCs seem to pass the microphone whenever possible so more awareness and education may take place.

4.1.4. Considering Accessibility

The majority of accounts analyzed have at least one accessibility concern when it comes to their content. This means that, in order to tackle social media's lack of accessibility in some capacity, DCCs do the work manually to create more inclusive content. That could be captioning their videos, providing transcripts for videos. The pattern of providing transcripts seemed more consistent in members from the Blind and/or Deaf communities.

They also choose to highlight accessibility when they see it, as much as they highlight inaccessibility when they experience it.

Example 1: a woman who is a wheelchair user shows how accessibility can be applied on landmarks that are often said to be “untouchable” due to the historic value they possess: a platform to get up a set of stairs that is embedded in the Portuguese typical pavement “Calçada Portuguesa” (November 25th, 2022).

Example 2: A blind woman who had a guide dog talks about how all glass doors and windows can be a challenge for them. Whether the person has some remaining sight and can’t understand which is which or the dog that may also mistaken the doors for the windows (November 14th, 2022)

4.1.5. Adapting to Platform-related Nuances

There were also differences in platforms. LinkedIn was more curated, most likely due to it being a platform. TikTok seemed to provide content in a way that is consumed faster, which could be beneficial for awareness purposes, while Instagram seemed to show the best engagement, having a combination of photos, reels, longer video formats and a seemingly more appealing way to interact with one another. Creators seemed to leverage it quite well. In this same line of engagement, X also allowed for in-depth insights from creators and their communities. Lastly, YouTube, allowed for a deeper, more in-depth understanding of each creators’ points of view, and was one of the most informative platforms.

At the same time, the accessibility of these social platforms is mentioned, with X being one of the most appreciated, until Elon Musk decided to fire the entire Accessibility team, that was said to do an outstanding job in building an accessible environment on the platform. Several advocates voiced their opinions in disbelief and outrage after learning of Musk’s decision and some others started wondering whether they would consider deleting their accounts in protest.

Example: A woman who is deafblind shares her thoughts on seeing people being fired as Elon Musk dismantled the accessibility team from then-Twitter. She also reposts tweets from other advocates who find this downsizing very damaging for the disability community and takes the time to thank this dedicated team for their hard work (November 4th, 2022).

Instagram was one of the platforms where it felt content creators had to do the most to make sure their content was accessible, by manually creating accessibility features, such as captions, image descriptions or video transcripts.

This study was important to get an idea of how DCCs experience social media as advocates. However, in order to further understand the dynamics that these creators have in sharing on social media, it felt necessary to conduct in-depth interviews, because the analysis from a nondisabled researcher, can be skewed and not consider important aspects, necessary to comprehend this choice of sharing online. From the themes that emerged from this analysis, it was possible to create a structure for the questionnaire (Appendix B), which was divided into 3 main parts:

- A) Disability-related questions;
- B) Social Media Journey;
- C) Demographic questions.

Within part A) “Social Media Journey”, four subtopics were approached:

1. Daily interactions;
2. Barriers faced;
3. Ableism;
4. Awareness about disability.

Within part B) “Social Media Journey”, five subtopics were approached:

1. Beginning of social media journey;
2. Resonance of representation of disability in society and the media;
3. The role of disability advocacy on social media towards education;
4. Strategy behind social media;
5. Community-building.

As for part C) “Demographic questions”, participants were asked questions about age, nationality, sex, gender, race/ethnicity, sexual orientation, highest degree, social status (these demographics can be found in Appendix C).

4.2. STUDY 2 - IN-DEPTH INTERVIEWS WITH DISABLED CONTENT CREATORS

After conducting a thematic analysis of the eight in-depth interviews, it became clear that each participant views their experience as unique, not intending to make their views represent an entire community, but rather motivating their audiences to listen to a variety of people with disabilities. It would also be interesting for academia to further explore different realities, which is discussed in the Limitations chapter. Bearing this aspect in mind, it was possible to identify similar experiences across the participants’ testimonies that allowed for the creation of a User Story that identifies these patterns on the journeys of the participants, on social media, when self-advocating. Four main themes were identified: Community, Awareness, Education and Online/Offline Symbiosis, as well as ten subthemes.

Non-thematic contextualization information

While every participant clearly stated that a big part of their platform was dedicated to advocacy, they also mentioned how it also allowed them to go beyond the scope of disability advocacy, that they wanted to be seen as more than a disability-related page, they are sharing their own reality and do also want people to have a learning experience, which will become evident in the discussion of the results.

Self-Advocacy “Disclaimer”

All participants identified themselves as activists for the rights of people with disabilities and feel social media is a great way to advocate, as it drives public opinion and allows them to have their voices heard louder than before.

User Story

The story, as previously mentioned and shown in figure 1, starts with the motivations DCCs felt to start advocating online. A lack of presence of disabled people in decision-making positions, the assumption of inability that society places upon people with disabilities simply because of their disability, the lack of information, a lack of interest in inclusion, the preference for other minorities, the uncomfortable reality that disability poses, the unknown/not knowing how to act.

Disability is often associated with an inability to participate, or be a member of society, be that at a business level, or in society in general. For these advocates, social media is, unequivocally, a platform that allows them to reach areas that would otherwise be denied entry.

For the majority of participants, starting to share on social media was seen as an act of simply showing their day-to-day lives and experiences in an organic, spontaneous way. Some started with their inner circle, others blogging. The first aspect the participants pointed out as a motivator to start sharing was the amount of ableism they faced on a daily basis, from people being uncomfortable around them, to asking inconvenient, intrusive questions to even inappropriately touching them and/or their mobility devices without permission, with the premise of wanting to help. Internalized ableism also came into play at this point, with some of them stating they were not fully accepting of their disabled identity.

On a second note, the lack of representation of disability in media in general, and accurate representation, in particular, was also crucial in encouraging them to share their experiences. They wanted to be the representation they did not have growing up, or after they acquired their disability. To this day, some of these creators claim they do not have a specific strategy for their advocacy on social media, being more important to them to share their authentic experiences as they go. At the same time, there is a general wish to have a clearer strategy so they can challenge the stigma around disability in a better way. Figure 3 shows the most commonly used words by participants in the in-depth interviews, when referring to their experience on social media.

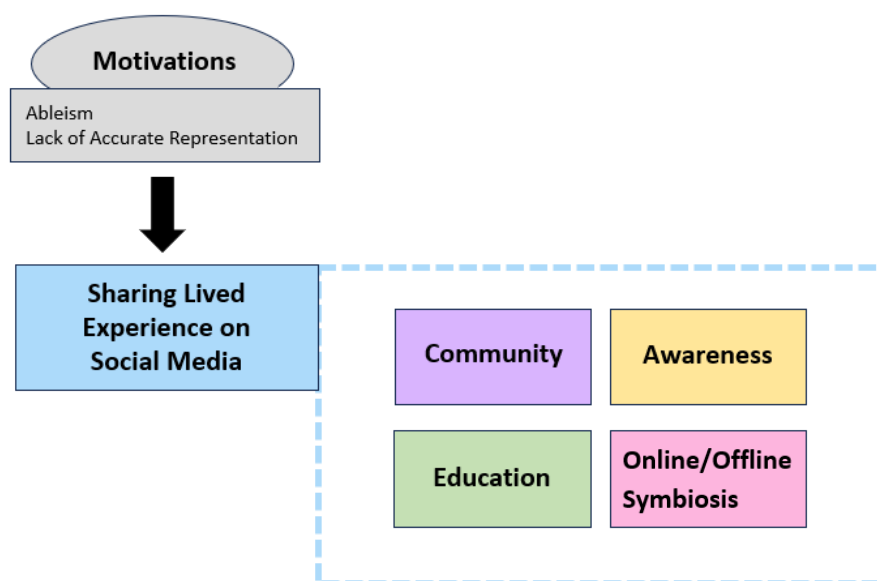


Figure 1 - Representation of how motivations to advocate lead to themes found (Study 2)

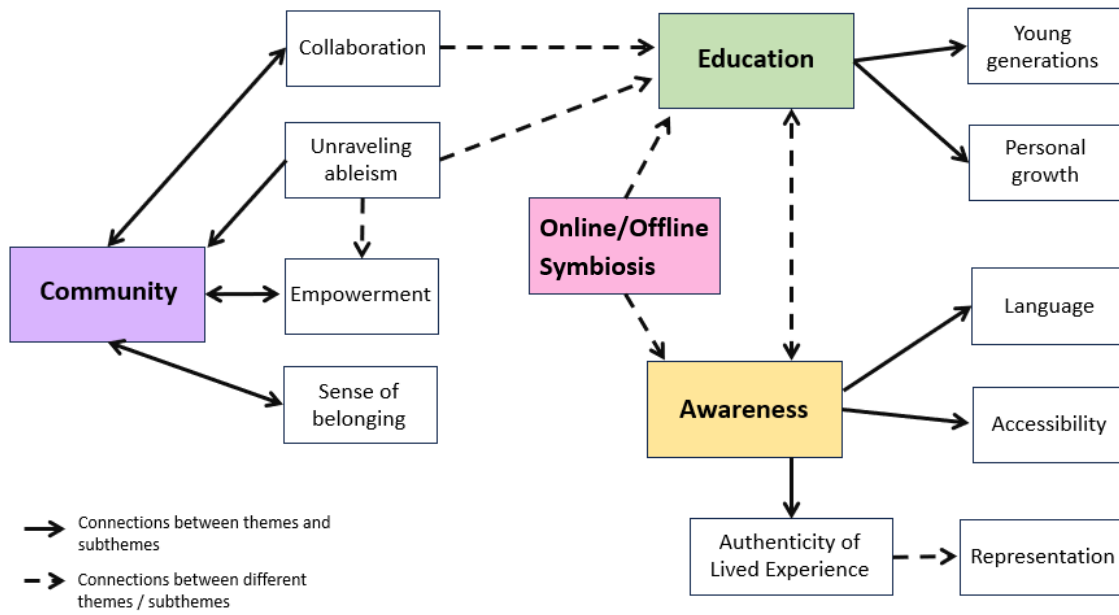


Figure 2 - Themes and subthemes found and respective connections



Figure 3 - Word Cloud with the most predominant expressions related to the themes found

Next, an in-depth analysis and interpretation of the results is presented.

4.2.1. Community

Community was a theme that influenced almost every theme and subtheme, either directly or by leading to them. All participants felt that social media has allowed them to create a community of like-minded people and how this community was a great gift that allowed for a greater sense of belonging, that was said to feel stronger amongst fellow disabled people.

4.2.1.1. Sense of Belonging

Some people defend that belonging can be the next step after accessibility and inclusion. It is more than having access or feeling like a third party is including them. Most participants shared experiences that pointed to the feeling of truly belonging, feeling seen, heard and understood.

“it really is just giving me a voice that I traditionally wouldn't have without social media. It's allowed me to create and be part of a community and feel seen and heard where and related to and vice versa because in my own personal life, like while everyone is like so supportive of me and accepting and everything, they don't have that lived experience of disabilities.”

- Rose

4.2.1.2. Collaboration

Collaboration was one of the topics that was most praised throughout the interviews. Participants highlighted the power in numbers and in showing true intersectionality both by collaborating with people with disabilities other than their own, but also with people with disabilities from other minority groups. The collaborative aspect within the disabled community deserves to be further explored by academia, as it is still underexplored. The literature review pointed to the fact that diversity-related research still leaves disability out of the picture, in favor of other minorities.

“We follow back and support each other, and they're part of my community. I feel like they've helped me so much to. Feel that I'm not alone, and then that I am not the only one living those experiences which. In the past, I would have never thought there's so many things that I will see online from disabled creators.”

- Olivia

*“I'm just an ally. An ally in this, you know, and somebody who's willing to fight the fight for the win and you know, just. Umm. Collaborative efforts like, I think like, like the community really has each other. When when sh*t hits the fan, like would you really have each other? We're like, we're like a second family.”*

- Mary

“Always, I always do, I love it, yeah, but it's, it's a lot harder because most of my friends don't live here (...) In the camera, we complement each other very well. (...) We've always tried to expand each other's network, right? Because not everyone who follows me follows her and vice versa. So it's quite interesting. It's very fruitful, because we increase the engagement and also the views, so everyone wins.”

- Taylor

In another perspective, by working with brands or organizations, which may or may not be disability-related, these content creators have seen that their efforts were recognized and considered by these brands. However, there were also cases where the lack of accessibility was a reality and the assurance of continued work on improving accessibility was not guaranteed.

4.2.1.3. Unraveling Ableism

Society can learn about disability in the first person, from people with lived experience of disability. One of the aspects that stigmatization theory points out is the lack of will to disclose the stigma associated with them (Yang et al., 2007). It would be interesting to explore whether being present on social media can contribute to alleviating this effect, or not.

For the participants, going about unraveling ableism can come in many forms, such as shedding light on inaccessible products or services when they find them or advocating to fight tokenism. Although not every participant had felt it personally, they do recognize it is a reality in the community and that they wish to use their voice to challenge it. This belief is contrary to one of the points Hutton et al. (2011) make where their self-advocacy is conditioned by staff or service organizations. In the case of this research, the ways in which these creators advocate are not conditioned by external parties.

They also mentioned how they use social media to call out ableist approaches to content on traditional forms of media. Rose gives an example of the importance of having people with disabilities both in front of the camera and in the backstage.

“And with social media, by us being able to call out certain pieces of media, it's holding whatever organization that put that piece out accountable. And if they do put something out that is ableist or they have someone who's not disabled directing it or writing the story and whatever it is, we're showing, we're telling everyone on social media that it's really important to have disabled people in the room for those types of things, so that moving forward they can avoid this or they can avoid being called out because they're addressing it and then applying that moving forward”.

- Rose

Another point that was heavily mentioned by almost all participants was the fact that stigma and ableism were aspect they also had to unlearn themselves. Internalized ableism is one of the faces of discrimination and is a result of consistently making people believe they are less than, inferior, or in need of a cure, which could be traced back to both the medical and charity models. Participants mentioned how social media allowed them to feel more connected than before, which is consistent with studies that show how social media can foster social inclusion and community. A good example is Theresa's, who has Cerebral Palsy, and mentioned how she was determined to find a cure for her disability, during a year she was out of school due to surgeries. This can relate to the definition Campbell (2008) provided of a disabled person wanting to achieve normativity.

Theresa shares how she began sharing her experience in her blog, in an attempt to demystifying her disability herself:

“I was out of school for a year because I had 2 surgeries. (...) it was a year that I was determined to find a solution for my disability, this was it. My moto was, this is it, my moto. (...) Because until then I had only seen my disability as a negative thing, a thing that belittled me in the eyes of society, because it was what I was taught, right? (...) and sometimes you don't have to talk. (...) I started writing [on her blog] and started finding it funny.”

- Theresa

For most participants who mentioned the importance of sharing on social media for challenging their own internalized ableism, one of aspects that was evident, was the empowering feeling they got from acknowledging and actively addressing their negative perceptions of themselves. One of the aspects that made it more impactful for them was when their disability was non-apparent, when they would get comments such as “you are almost normal”, “I could barely tell you have a disability”. These sorts of euphemisms, as if having a disability is a non-desirable trait, influenced participants’ experiences. Taylor shared their point of view, as someone whose Cerebral Palsy affects their movement, but is often non-apparent to society.

“I think you imagine a person who doesn't walk, who doesn't talk, who doesn't live, you know and that's why I started on the internet because I needed to have that reference. It was very difficult to distance myself from the image. A person with a disability, because I am a person with a disability, which is physical, which is visible, but which is less visible, right? In my case, then, people have an imaginary created about what it is to have a disability and I started to talk about other viewpoints.”

- Taylor

4.2.1.4. Empowerment

The majority of participants claimed that before starting to share on social media, they were not comfortable with their disabled identity, going further by saying that sharing was the catalyst to make them feel empowered to accept their disability and disclosing it more freely. Empowerment is seen as a two-way stream by participants. They feel the community they’ve built empowers them, while also recognizing they have made a difference in other people’s lives.

This sense of empowerment seemed to grow as they realized the reach they started to have, through their combined following base across all social media platforms and by feeling they were working towards the same goal of reaching accurate representations of disability and true inclusion, with people who saw them and heard them.

“very positive side, which I think is a channel for us to talk, and talk about it, for us to create a community of people who are interested in evolving socially, in creating a more inclusive society. And for me, the benefits outweigh the disadvantages in that aspect, for example, up until now, before social media, you were dependent on what? From the media - mainly television, newspapers and radio – who, in the media, is disabled? Nobody. No, there are no people, so far. Nowadays you are beginning to see more of this concern with inclusion, but even so, in a very wrong way, sometimes very wrong”.

- Theresa

4.2.2. Awareness

Being a generally uncomfortable topic to discuss in society, participants feel that raising awareness to what is like to live with a disability and debunking historically kept stereotypes is, to them, a powerful use of their platforms.

“I think social media gives people the opportunity. Let’s say, for example, I’m watching a show and there is a very ableist storyline about someone with a disability. I can go on social media and talk

about it and give people that awareness of ([for example], 'this is why this specific show or storyline is ableist, and here's the way it could have been or should have been so').

- Rose

Participants also felt that Covid played a big part in the amount of people they were able to reach and the awareness they raised, because of the fact that they were creating more content during this time.

"There's no doubt about it. I had 2000 followers before the pandemic and less than 1 year later in the same year. In fact, in 7 months, I had 24000."

- Taylor

4.2.2.1. Language

On her book "Demystifying Disability: What to Know, What to Say and How to be an Ally", Emily Ladau, a disabled woman herself who gathered testimonies of PWD, explores certain words and expressions that the disabled community tends to dislike or consider as ableist, always making a very important note that each person's experience is different and that, ultimately, their preferences should be respected.

"There isn't one single way to talk about or think about disability. But (...) it's important to think about how we talk about disability, because the way we talk shapes how we think, and the way we think shapes how we talk." (Ladau, 2021, p.10)

Every participant mentioned the importance of language related to disability, a topic approached in their social media journey, due to the fact that they feel people do not know what or how to say express themselves around people with disabilities and have a certain feeling of discomfort. This is the case both online and offline, with the latter being the most frequent. These terms come in the form of euphemisms, patronizing tones or infantilization of the person they are addressing. In other cases, particularly in in-person encounters, the person will not even address the disabled person, rather opting to speak to whoever is with them. Implicit biases, and the stereotypical representation of disability that society has been accustomed to by the media both seem to play a very important role in perpetuating these views. That is why these advocates tend to talk about language on their platforms.

"the way of writing of people who write in the media, their language used is not, in my opinion, the most inclusive, because it raises the question of sensationalism and also of the victimization of people with disabilities"

- Mercedes

One thing most participants with Cerebral Palsy mentioned was the fact that the name of their disability was one of the factors that caused the most discrimination.

"I'll tell people I have Cerebral Palsy and they'll act completely surprised because I don't fit the notion of CP because I look non-disabled, so I think it's important, you know, that you be mindful and

respectful of all the different varieties of disabilities that exist and how they're still considered disabilities.”

- Mary

“When I started on the internet, (...) and even today, when you type Cerebral Palsy on YouTube, for example, a lot of doctors appear talking, so it's always a hospital, medical view, you know? It's never someone telling their own story. And why don't we tell our own story? So, today, if you search on YouTube, you'll find a video of me, from 2017, talking about it. There are several things I say that I don't even agree with anymore, but it's important because it's part of our journey. We regret it, we say it and we don't like it. But there's someone there telling their own story, you know?”

- Taylor

4.2.2.2. Accessibility

One seemingly important aspect mentioned by both Mercedes and Theresa is the distinction they make between accessibility and inclusion: while the first means you are allowed in whichever scenario presented; the latter means you want to be in that scenario. Mercedes, being a wheelchair user, stated how, oftentimes, places she goes to do not have an accessible entrance, but do have a “back door” or alternative entrance. This may be seen as accessible, but not really welcoming, or inclusive. These are aspects that may fall under the categories of both physical and attitudinal barriers, which she states she focuses on in her content.

One other aspect that seemed to stand out throughout these interviews was the fact that PWD want to be seen as the consumers they are but are oftentimes excluded from accessing products or services due to barriers imposed by society and businesses. This

Participants also felt that one way they could advocate was by sharing their interests and how they intersect with their disability. For instance, Mary is very into fashion, so her content is very drawn to this topic, alongside lifestyle. For Theresa, for instance, as a Law Student, she is always very eager to bring news about legislation that advances the rights of people with disabilities, in Portugal and in Europe, for instance. For Rose, while she tends to take a more spontaneous approach, she loves to travel, so she shares her experiences of traveling with her mobility aids, for instance.

Accessibility on social media, meaning the actual tools provided by these platforms, was also covered, in the sense of how their accessibility issues may cause a divide within the community, about who accesses content and who does not. As such, every participant stated they take certain measures to ensure accessibility of their content, that are independent from what the platform offers. Some examples include captions on videos, image, and video descriptions on posts and both camel case hashtags (e.g. #CamelCase instead of #camelcase) and appropriate color contrast to improve readability. It was also acknowledged that, in most cases, this simple measure is something that anyone can take advantage of, which is consistent with the concept of the Curb-Cut Effect (Maxwell, 2017) and the fact that “the multiple benefits of online captioning may be a feature, rather than a bug, as online captions are also useful for users in diverse circumstances (such as watching web video on mute), foreign-language audiences” (Ellcessor, 2012, p. 345).

This need to manually creating accessibility to ensure a more inclusive content is, however, consistent with the lack of accessibility on social media highlighted in the literature review.

In terms of using social media to highlight inaccessibility experienced personally, both online and offline, almost every participant had used their platforms to share about these instances, and felt that social media was a powerful space to do so in. The ones who felt strongly, as is the case of Taylor, mentioned how social media drove public opinion, which in turn, may push brands to take this into account.

“Here you have a free pass for people with disabilities for public transportation. And, for example, I was prevented from putting on my ID that I am a person with a disability, because my medical report was from 6 months ago and it has to be up to 3 months. That doesn’t make sense because I’m not going to stop having cerebral palsy. (...) Then I went and posted a tweet talking about it and then they called me to be able to go there and make the ID”.

- Taylor

Despite this, all participants felt that leveraging their platforms’ reach alone would be insufficient, that using an organization’s or business’ own channels is beneficial and should be done complementary to make sure effective change happens.

4.2.2.3. Authenticity of Lived Experience and Representation

For many participants, their sharing about their experiences was a spontaneous and almost unconscious move that they did not expect would turn into actual advocacy online. They were simply trying to be the representation they did not see.

[Sharing about the start of their social media journey] *“I did not plan for any of this. I kind of started with the whole want of just helping people understand that or the whole desire to help people understand that disability doesn't need to be an uncomfortable topic. (...) I started posting online to hold myself accountable of talking through these things because, like I said, I didn't really talk about it before. And by doing that, I started to grow my platform unintentionally. I always kind of just loved using hashtags and stuff. So I would do hashtags, but really with no intention of reaching actual people besides my own little bubble, as I'm exploring these feelings of myself. And then Instagram reels came out and the pandemic happened, and I just started posting more consistently about what I was feeling, what I was going through, and then it just started growing.”*

- Rose

All participants were able to identify several stereotypical portrayals from traditional media, more prominently in movies, growing up. They felt they had no representation of their disability and found social media gave them a place to find it.

“I am so sick of the same story of ‘oh the person gets disabled and then the happy ending is the person walking’. So (...) again you're telling the story that (...) the only happy ending the disabled person can have is if they walk again, if they don't have a disability anymore. I am just so tired of that inspirational porn, I don't mind that they share an inspirational story. That's fine. But why does it have to be the only type of inclusion that we get? (...) Why [was] there (...) not a show out there where there's just a disabled girl living her life, falling in love? Like, why does it always have to be

tragic? I feel like media uses our disability to exploit it and it's just (...) not ok. I just feel like they can go both extremes, they go inspirational way, or they're mean, the villain."

- Olivia

4.2.3. Education

Education appears in this story as a need for a deeper understanding of disability. It is as if the next step after raising awareness. All participants stated that social media can be important to educate society in an increasingly digitized world, and hopefully address misinformation and wrong perceptions of disability. There was an even bigger acknowledgement of the importance of this education for younger generations. The majority of ableist attitudes faced by participants came from people older than them, while children presented them with curiosity, mostly.

Location was also mentioned as an influencer to the naturalization of disability in society. Mary, for instance, stated that in Miami, for example, she found that older generations were more likely to have patronizing behaviors, whilst in New York, people see it as a natural thing.

Theresa made a point about people not learning about ableism, in today's society. She compares ableism to racism. While racism is a generally known term, ableism is still being paid little attention to, a term people are still unaware about.

"you don't learn if you don't want to. Nowadays, you're only ableist if you want to, the same way if you don't know what racism is because you don't want to."

- Theresa

Regarding their lived experience, participants felt strongly that they can provide traditional forms of media with education on how to improve and work towards a more accurate and helpful depiction of disability by including people with disabilities in writing, for example. This could prove helpful to also encourage other co-workers to get educated on disability-inclusive terms and expressions.

"I think for me, personally, I'm really noticing a shift that I hope continues, in having disabled people on the media side. (...) [For example] I did a piece with CBS News a couple years ago now, and it was all about dating with a disability and the person writing the story was disabled themselves, so they have that perspective and that lived experience. Or they're not going to write with an ableist tone because they don't want to see that"

- Rose

In this section, two subthemes emerged: the influence that younger people can have in shaping our society's views, by allowing them to grow with the notion of disability quite present, as well as the education that these participants have experienced by being on social media – about themselves and about others, in a truly intersectional way.

4.2.3.1. Younger Generations

One common conception across every participant's intervention was the opportunity that reaching younger audiences through social media could present. They mentioned that children and teenagers do not usually discriminate when they are on their own, they usually have an adult nearby when it happens.

Most participants also believe this kind of online sharing could be beneficial as material to use in schools, in order to show the lived experience of actual people with disabilities. In this way, they get to see accurate representation in the first person. Teachers come with questions on how to better teach children about disability, asking if they can use their content in their classes.

"I also think that teachers (...), they have asked me permission, for example, to share one of my videos (...) or one of my posts [in class]. I believe that social media, if well explored, can be a study tool in schools. Like, 'we'll watch a video and you're going to have to reflect about it'. I think it can be a study tool, when it is well-made content (with references, etc), I think it is a very powerful tool to educate children".

- Mercedes

At the same time, it was also mentioned that this education will only be truly effective if the education provided by one's family also actively contributes to dismantling those damaging notions of disability, as Mary states:

"If it doesn't come from the home. It's going to come from society, and we know how disabilities are seen in society, but then oftentimes you also have the home creating a weak perception of disability to the children."

- Mary

4.2.3.2. Personal Growth

Sharing on social media has allowed them to also start looking outwards at other inequities in the world in a truly intersectional way. This was both present in people with acquired disabilities, such as Mercedes, who was somewhat unaware of these realities before acquiring her disability, and in people with congenital disabilities, such as Rose.

"there was a moment when I actively thought 'I have to start studying more about this subject and also deliver more informative content about disability'. (...) I'm also inspired by the feedback I get from people who have doubts about certain things or who share certain things with me, which sometimes make me see things differently. And I've also done a very interesting, though sometimes a little painful, work of listening and actively seeking opinions contrary to my own, that is, of listening to people who don't necessarily think the same way I do, for example"

- Mercedes

"I have my lived experience and that's what I share. But the more I've connected with other disabled creators or just disabled people in general, you know, I'm learning a lot about all the additional issues outside of myself. So long story short, going into it, I didn't follow any disabled influencers. I didn't

even know that was a thing. I kind of just went into it, blindly posting what I felt on my heart and what I needed to get out there at the time. And now that it's grown to what it has, I'm adapting every day, wanting to keep up with educating and keeping that authenticity while also learning from other disabled creators that now I follow and I'm friends with, that before I really didn't know about."

- Rose

4.2.4. Online/Offline Symbiosis

By being an online, remote reality, the use of social media provides an important space for disability advocacy that has been greatly highlighted throughout this dissertation. People with disabilities can highly benefit from this reality, in the cases where in-person advocacy is difficult or even impossible. The social paradox that comes from being online is, however, still very much acknowledged, even when participants have more positive things to say about advocating on social media than negative.

Despite feeling that social media is a valid platform for advocacy, some participants still pointed out the negativity that sometimes comes their way, as well as the bubble effect that comes with the community they built, in the sense that they feel that people from that community are truly interested in learning about inclusion, and what that looks like from their own personal viewpoint, but that that is not the case for everyone else in society.

Considering this, in the positive side, every participant identified situations in which where their advocacy work on social media had allowed them to reach other areas of society, either by suddenly reaching a larger audience online with a viral post, starting a business, getting a job because of social media; or by reaching organizations in ways, they would not have been able to, otherwise. They also highlighted the need to go beyond social media in terms of in-person advocacy, which is something some of them had already achieved.

This symbiotic relationship that could be created between the online reality and the offline world was something clearly inherent in the analysis of the interviews. Johansson & Scaramuzzino (2019), for instance, have also shed light on how offline and online advocacy efforts, related to politics, are interconnected. There is, however, no mention to the disability reality, which could be an interesting area to explore, given the tremendous effect that political decisions can have in the lives of disabled people.

Participants believed they would not have gotten some opportunities if they had not had a presence on social media. It served as the launching platform for continuing their important activist work in-person. These opportunities, both in and outside of social media, include advocacy-related work, such as consulting, hosting workshops or public speaking. Parallel to this, one of the most valuable traits identified was the fact that their platform also allowed them to showcase other facets of their life, which made society see them as experts in other areas, outside of disability, which was pivotal in creating job opportunities as well, such as modelling, participating in ads or participating in talk shows within their area of expertise (e.g. Mercedes is a nutritionist who is often invited to speak at a Morning Show).

"Regarding my social networks, and because my work has already come out of them, I feel that I have not only gained a great space in the traditional media, either talking about disability or about nutrition, which is also my profession, as a person with a disability, but also, for example, in a

business perspective, which is an area where productivity is highly valued, meaning you need to be productive, be number-oriented and make money, and the disabled person is not a person who is directly linked to productivity. The fact that I have gained a space in these spaces, talking to companies, to employees, training employees, I think is very important, because I basically enter in an environment that, at first, does not want me there and I feel that, sometimes, I'm struggling to get my message across, that I have to conquer the audience that, at first sight, sees me there and thinks "there she comes to talk about the accident she had and how we all need to be very strong" and then they listen to me and it has nothing to do with it. Then it seems like something turns or clicks and it is exactly what I want."

- Mercedes

5. CONCLUSIONS AND FUTURE WORKS

In order to understand the experience of disabled content creators in their self-advocacy journey on social media, there was a need to, first, understand their behaviors online and secondly, to learn about their experiences in the first-person.

This exploratory research showed how DCCs feel compelled to share their authentic lived experiences online, through their social media channels for several reasons. For one, to challenge the stigma that society has placed upon them, as well as to contrast the stereotypical representation that they see in TFM. They identify a number of reasons for why they believe this happens – a lack of presence of disabled people in decision-making positions, the assumption of inability that society places upon people with disabilities simply because of their disability, the lack of information available in accessible formats, a lack of interest in inclusion, the preference to consider other minorities, the uncomfortable reality that disability poses, the unknown/not knowing how to act. All these are given as possible explanations for stigma and motivations for why they choose to advocate for themselves.

Considering the themes that emerged from this netnographic study, they seemed to stem naturally from what was approached in the literature review. Finding community was undoubtedly the most recurring and significant aspect of their journey of social media and the impact it can have in challenging society's stigma and stereotypical views. The fact that they can have a platform that allows them to raise awareness and provide education from a lived experience point of view is also extremely powerful to these creators, while also recognizing that it would not have been possible if social media was not so relevant in our digital society. Finally, participants realized that, to enact more meaningful change, they needed to go beyond social media. These platforms allowed them to benefit from offline opportunities. that also influence on their online ones, in a truly symbiotic relationship.

Their advocacy work brings benefits for themselves, the community they created and society in general. One aspect Mercedes kept highlighting is that building accessible and inclusive spaces does not exclude anyone, and from a Curb-Cut Effect point of view, everyone can benefit from it, even if they are unaware.

Participants also acknowledged that social media does have its down sides, but despite them, they still find enough positives that justify their presence online.

Marketing and branding professionals could highly benefit from understanding this audience more and how they influence people's perception and their choices.

Also, the majority of participants saw COVID-19 as a catalyst for change in terms of the viability of disability on social media. Some saw boosts in their accounts, some felt more engagement came through and some sought this opportunity to truly start making their stories visible, given the extra time they had, and, in turn, their growing audience also had. The lockdown's effects on social media usage could be related to this feeling presented by the participants.

By providing an accurate representation of what disability is, social media can present traditional forms of media with great knowledge on how to reach disabled people and how to portray them.

Some limitations were encountered in the process of the present dissertation and its research.

The first one was related to the sample, which was chosen based on convenience and practicality.

As a non-disabled person conducting research on disability-related topics, there are also certain viewpoints that may have lacked in this process, so it could prove beneficial to have an increasing number of people with disabilities present in academia, who identify as such, who do work in disability studies. Jones (2022) is an example, as an autistic researcher who worked with autistic academics and participants to get their perspective on autism portrayals in entertainment media.

Regarding the results of this study, it feels important to recognize that all participants who took part had access to technology that may not be readily available everywhere in the world, considering the digital divide that is felt in some countries or societies (Chadwick et al., 2013; Dobransky & Hargittai, 2016; Ellcessor, 2012).

Another limitation may stem from the fact that thematic analysis within qualitative research is subjected to the interpretation of the researcher, who may let her own bias, even if subconsciously, affect the results (Braun & Clarke, 2021).

At the same time, in the process of translating some of the in-depth interviews that were conducted in Portuguese, some meaning might have been lost.

Recommendations for future research include a broader or more heterogenous sample. A broader sample in geographic terms, by including participants from other countries, such as Asian countries, given they have the largest audience in terms of social media usage (Statista, 2023). A different sample should include other types of disabilities, namely non-apparent disabilities or vision and hearing disabilities. At the same time, given intersectionality is deeply intertwined with disability, as previously mentioned, including a larger set of people from diverse minorities would be a great contribution to literature.

Since the group of participants did not experience major barriers using social media, it would be interesting to further explore how people who use assistive technology leverage it to overcome social network's barriers of accessibility and self-advocate as well, as proposed by Hemsley et al. (2017).

Given that disability is such a diverse reality, qualitative research on experiences of disabled people have proven interesting to further understand their reality and how society may adapt to better include everyone. Some research questions may emerge from the present dissertation such as:

- What are the effects that disability self-advocacy through social media has in society? What do nondisabled people feel when consuming content from disabled content creators?
- What is the experience of social media influencers with disabilities whose only source of income is social media? – This may prove interesting, to address the disability employment gap

Another important aspect to consider is how stigma or ableism may prevent people from being educated about what disability is, which impacts everyone in society, but is especially problematic when it comes to younger generations. It would be interesting to conduct a longitudinal study to

explore how children perceive disability over the years and how it changes, while also analyzing the environment around them.

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Appendix A – Demographics and Relevant Information from Study 1

Table 1 - Nationality of Selected Content Creators

Nationality	
American	58
British	28
Brazilian	19
Portuguese	10
Canadian	7
Venezuelan	4
Australian	3
Canadian-American	1
Cuban-Puerto Rican-American	1
Haitian	1
Honduran	1
Italian	1
Japanese-American	1
Mexican-American	1
Puerto Rican-American	1
Taiwanese-American	1
Not disclosed	3
Total	141

Table 2 - Gender of Selected Content Creators

Gender	
Female	106
Male	22
Non-Binary	6
Trans	1
Not disclosed	6
Total	141

Table 3 - Disabilities of Selected Content Creators

Types of Disabilities of DCCs	
Other Rare Diseases or Chronic Illnesses*	31
Cerebral Palsy (CP)	15
Limb Difference	14
Blindness/Visual Impairment	14
Spinal Cord Injury (SCI)	12
Autism	11
Deafness/Hard-of-Hearing (HoH)	10
Attention-Deficit / Hyperactivity Disorder (ADHD)	7
Spinal Muscular Atrophy (SMA)	5
Osteogenesis Imperfecta	4
Deafblindness	3
Down Syndrome	3
Undiagnosed (Wheelchair user)	3
Amyotrophic Lateral Sclerosis (ALS)	2
Post-Traumatic Stress Disorder (PTSD)	2
Burn-Survivor	2
Dwarfism	2
Muscular Dystrophy	2
Obsessive Compulsive Disorder	1
Tourette Syndrome	1
Total	144**

* Including EDS, Crohn's disease, Mafucci Syndrome, Charcot Marie Tooth Disease, Jarcho-Levin Syndrome, Loeys-Dietz Syndrome;

** The reason why the total number of disabilities is not the same as the total number of content creators, is because some of these creators have disclosed more than one disability.

Table 4 - Number of Accounts Analyzed, by Platform

Number of Accounts Analyzed, by Platform	
Instagram	134
TikTok	54
LinkedIn	34
X (former Twitter)	24
YouTube	15
Total	261

Appendix B – Questionnaire of In-Depth Interviews (Study 2)

Questionnaire

A. Disability-related questions

1. Are you comfortable talking about your disability?
2. What type of disability do you have?
3. Can you name your disability?
4. Is it congenital or acquired?
5. If it was acquired, are you comfortable sharing how you have acquired it?
6. Do you use any mobility aids? Do you have a personal assistant?
7. From your daily interactions, what do you think people feel when they see you or think about disability?
8. What type of barriers do you believe people with disabilities face on a daily basis? If you want, you may provide examples of barriers or ableist attitudes you have encountered personally.
9. What does ableism represent to you? Can you elaborate on your thoughts on ableism in society and in the media?
10. What would you like people to know about your disability?
11. Why do you think people should care about disability?
12. Why do you think people should care about accessibility and inclusion?
13. Do you identify yourself as an advocate for the rights of People with Disabilities?

B. Disability-related questions

14. Do you identify yourself as a content creator/influencer?
15. When did you start your social media journey and why did you start? Have you been inspired or influenced by other disabled people to start your advocacy work?
16. What do you use social media for, nowadays?
17. Which platforms do you use, and which is your preferred one and why?
18. You mentioned barriers that you face and that you believe the community faces daily. Which do you focus more on trying to raise awareness to on your social media platform(s)?

19. Do you face any challenges using social media? (e.g. If you have dexterity impairments?)
20. What impact do you believe social media has in bringing awareness to and promoting intersectionality related to disability?
21. Do you believe your platform, specifically, also contributes to bringing awareness to intersectionality?
22. Who are the followers who interact with you the most? And through which ways? What are the main topics they interact about?
23. Who is your target audience?
24. What do you hope people get from following your page (maybe a top 3)?
25. Do you believe social media can be a bridge to tighten the gap between disabled and non-disabled people?
26. Do you believe your journey on social media has made people more aware of what disability is and isn't?
27. What impact do you believe your advocacy work through social media has in regards of fighting the stigma around disability?
28. Have you been reached specifically by disabled people regarding your work on social media? What main topics do people mention when they reach you?

Have you been reached specifically by non-disabled people regarding your work on social media? What main topics do people mention when they reach you?

Social media is also the place where a lot of young people meet, interact, and consume content.

29. How important do you think it is for this younger generation to learn about disability and interact with people from the community?
30. What impact do you believe you have by showcasing your work and your lived experience with disability through social media, on educating the younger generation?

One of the things that I have learned from the community is that there is a lack of representation of disabled people in all areas of society.

31. Do you believe the work that you do on social media has allowed you to have your voice heard at any table? If so, can you share where and how your voice was heard? Which areas in society have you been able to reach through your work on social media?
32. Have you ever felt you were the target of tokenism?
33. What impact do you believe your work on social media has in regards of tokenism towards people with disabilities, when it comes to including them in all areas of society?

Thinking specifically on the area of society we are choosing to focus on: the media.

34. Do you believe that social media, despite its sometimes-negative connotation, is a place where people can get educated about disability?
35. Do you think that, by sharing your lived experience, social media allows for a more accurate representation when compared with traditional forms of media?
36. Compared to traditional sources of media, what impact do you believe your work has in inspiring or driven said platforms to do a better job when it comes to accurate representation of disabled people? Can you share any specific situation if that is the case?

Social media can also be monetized.

37. Do you make money through social media? a. If so, do you have any other income stream other than social? If you do, what else do you work on? If not, what do you do?
38. Has your advocacy through social media allowed you to create more businesses or initiatives? Which ones? Are they disability-related?
39. Have you partnered with organizations or brands through paid ads on your page? Were they disability-related organizations or brands? Can you state any?
40. Which brands do you believe are doing a good job in terms of inclusion overall?
41. Have you partnered with other disabled people to create content? Were they content creators as well? What positive and/or negative outcomes did you get from it?
42. To your knowledge, have you ever inspired other disabled people to share their stories on social media? How about to become advocates themselves through social media?
43. Do you have a social media strategy for advocacy? What is it?
44. Which is your preferred way of content? What do you feel people like the most in your content?

Social media platforms still have a long way to go when it comes to accessibility. However, some efforts have been made throughout the years.

45. Do you take any action in trying to make sure your platform is inclusive? a. If so, what actions do you take?
46. Have your efforts in making your platform inclusive been recognized by the community?
47. Have you ever been called out on the lack of accessibility in your content?
48. Have you ever used your social media platform to highlight inaccessibility in a product, service, organization, or brand (hereinafter mentioned as “service”, simply as a way to make the questions simpler to ask)? Can you describe a situation in which this happened?
 - a. Did you find that your message was shared on social media by others?

- b. **If answered Yes:** If so, did you find that sharing your message reached the service's representatives? i. Were you contacted by any representative? Can you describe what happened? Was the service bettered from the input you brought? Did you use or receive any feedback from people who used the service afterward and saw that the inaccessible issue had been resolved? Do you think you would have reached the service, had you not shared this experience on social media?
 - c. **If answered No:** If you did not see your message shared by others, were you contacted by any of the service's representatives? Can you describe what happened? Was the service bettered from the input you brought? Did you use or receive any feedback from people who used the service afterward and saw that the inaccessible issue had been resolved?
49. Do you think you would have reached the service, had you not shared this experience on social media?
- a. If not, did you try alternative ways of contact and were successful?
50. From your own experience, do you find that social media is a valid and powerful platform to call services out on their inaccessibility or is it enough to reach out to them directly, via their own channels?
51. If so, do you believe that, nowadays, social media alone is enough to truly reach these services and get them to listen, or do you think you always have to contact them via their own channels?
52. What are the main benefits and challenges you have encountered on social media, in regards of your advocacy work?

C. Community

53. Do you think social media has allowed you to build a community of your own? If so, what are the main outcomes you have gained from your community? What do you feel are the main outcomes your community has gained from you?
54. Do you think people have a sense of belonging in the community you have created? a. If so, do you think this sense of belonging is stronger among fellow disabled people, or is it in general?
55. Do you think people with disabilities feel represented by and identify with you, through the content you create on social media?
56. Do you think people with disabilities feel they can take up more space from the sense of community they gained from your presence on social media?

Final questions:

57. If you had to describe disability in 3 words, which would you choose?
58. If you had to describe people with disabilities in 3 words, which would you choose?

D. Is there anything else you want to add?

DEMOGRAPHIC QUESTIONS

Finally, I would like to ask you some demographic and more personal questions. Again, as I mentioned in the beginning, feel free to skip any you don't feel comfortable answering:

1. How old are you?
2. What is your nationality?
3. What is your sex?
4. What is your gender?
5. What is your sexual orientation?
6. With which race(s) or ethnicity(ies) do you identify with?
7. What is your social status?
8. What is the highest level of school you have completed or the highest degree you have received?
9. What is your work situation?

Appendix C – Demographics of Participants of In-Depth Interviews (Study 2)

Table 5 - Demographics of Participants of In-Depth Interviews

Pseudonym	Age	Nationality	Sex	Gender	Sexual Orientation	Race / Ethnicity	Social Status	Highest degree	Work Situation	Disability	Preferred Platforms (By order of preference)
Olivia	26	Venezuela	Female	Female	Heterosexual	Latina / Hispanic	Middle	High School	Employed	Spinal Cord Injury***	Instagram, TikTok, YouTube
Mercedes	34	Portugal	Female	Female	Bisexual	White	Middle	Bachelor's degree	Self-Employed	Spinal Cord Injury***	Instagram, TikTok
Theresa	22	Portugal	Female	Female	Heterosexual	White	Middle	High School	Student	Spastic Cerebral Palsy****	Instagram
Mary	27	Venezuela	Female	Female	Heterosexual	Latina / Hispanic	Middle	Bachelor's Degree	Employed	Spastic Cerebral Palsy****	Instagram, TikTok
Amy	26	Honduras	Female	Female	Heterosexual	Latina / Hispanic / Black	Middle	Bachelor's Degree	Employed	Spastic Quadriplegia Cerebral Palsy****	Instagram
Taylor	22	Brasil	Male	Non-Binary	Homosexual	White	Low	Post-graduate	Self-Employed	Spastic Cerebral Palsy****	X (former Twitter), Instagram, TikTok
Rose	30	United States	Female	Female	Heterosexual	White	Middle	Bachelor's Degree	Self-Employed	Spastic Cerebral Palsy****	Instagram, YouTube, TikTok
Claire	20	Portugal	Female	Female	Bisexual	White	Middle	High School	Student	Ullrich Muscular Dystrophy****	Instagram, Spotify

Acquired Disability; *Congenital Disabilities