

(Re)presentations of Disability: Images of Persons with Down Syndrome

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## **Abstract**

Disabled people have been misrepresented by mass media for decades. The result of disability misrepresentation is the perpetuation of negative disability stereotypes and models of disability. Disability representation has rarely been informed by authentic first-hand knowledge about what disability is and who disabled people are. As such, representations of disability have been formed from an outsider perspective most commonly based on ableism. This study seeks to explore the ways in which disabled people choose to represent themselves and if this representation is consistent with or resistant to dominant disability narratives. Borrowing from Critical Disability Studies and the concept of disability life writing, this study utilized qualitative content analysis to analyze the visual images, comments, and hashtags of randomly selected data posted to four publicly accessible Instagram accounts. Findings show disabled people choose to represent themselves in ways that resist dominant disability narratives, allowing for expanded ideas of what disability is and who disabled people are.

**Keywords:** self-representation, disability, life writing, social media, Instagram

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## Introduction

Disability. Down syndrome. What those words bring to mind will be largely dependent on how much life experience a person has with disability and Down syndrome (Siebers, 2016; Acuti, Mazzoli, Donvito & Cahn, 2018). For me, there are a myriad of images ranging from the alonfirst time I held my daughter to the twelve year old she now is. Along with these images drawn from my own personal experiences are many others encountered through advocacy and research. Some images are more vivid than others, hold more meaning, elicit stronger emotion. One in particular is burned in my mind. A young woman stands on a beach, a dress of blues and greens floats gently to her feet, long wavy hair blown by a gentle breeze. Ephemeral. Beautiful. Magical.

My experience is unlikely to be the same as that of other non-disabled persons. The majority of temporarily able-bodied individuals have little experience with disability, limiting their first-hand experience and knowledge of what disability is (Siebers, 2016). In the absence of first-hand experience, the gap in knowledge is filled with information from other sources, such as mass media. In cultures dominated by ableism, the most dominant disability narrative in Western culture (Tarvainen, 2019), this information misrepresents disability and perpetuates negative disability stereotypes (Couser, 2016; Haller, 2013; Longmore, 2016). This misrepresentation and reliance on negative stereotypes is far removed from my experiences raising a child with a disability. The struggle, for me, is how to share my own experiences in a way that makes sense to other temporarily able-bodied persons. What might I do and say that might help shift the dominant ableist narrative towards something more representative of what disability is and who disabled people are?

## **The Problem with Normal**

Merriam-Webster's dictionary defines normal as "conforming to a type, standard, or regular pattern: characterized by that which is considered usual, typical or routine", "according with, constituting, or not deviating from a norm, rule, procedure, or principle", "occurring naturally", "approximating the statistical average or norm; generally free from physical or mental impairment or dysfunction; exhibiting or marked by healthy or sound function", "not exhibiting defect or irregularity".

Synonyms for normal include average, commonplace, ordinary, standard, unexceptional, and usual ("Normal", 2021, [www.merriam-webster.com/dictionary/normal](http://www.merriam-webster.com/dictionary/normal)).

"In fact, the very concept of normalcy, by which most people (by definition) shape their existence is in fact tied inexorably to the concept of disability, or rather, the concept of disability is a function of a concept of normalcy. Normalcy and disability are part of the same system." (Davis, 1995, p. 2)

Davis (2017) provides extensive background regarding the socially constructed concept of normal and how it regulates the lives of disabled people. Despite the seeming permanence of the concept of normal, it has not always been with us. It first appeared as a concept in the late 18<sup>th</sup> century constructed out of ideas stemming from a preference for scientific knowledge (Barnes & Mercer, 2003), specifically statistics and eugenics. The reliance on scientific knowledge came from a desire to improve upon the former measuring stick of ideal, which was fraught with insurmountable practical difficulties. The origins of ideal were rooted in the divine, humankind having been created in the image of the divine. For a human to attain equal footing with the divine was simply not possible leaving humans with a, perhaps, resigned acceptance they would never measure up. The rise of statistics, and eugenics along-side it (early statisticians were, coincidentally, also eugenicists) offered an alternative whereby humankind was shown the

possibility of achieving something greater than the current status quo. Consider the work of Darwin, Bell, and Galton, all early eugenicists. The Darwinian theory of survival of the fittest designated disabled people as errors of evolution, an error ideally corrected through elimination from humankind. In 1883, Bell delivered his speech *Memoir upon the Formation of a Deaf Variety of the Human Race* warning of the possibility of a race of deaf persons due to the preference of deaf-mutes selecting deaf-mute partners. Galton's inspiration were the evolutionary writings of Darwin, his cousin, and led to Bell coining the phrase "eugenics" the same year Bell delivered his eugenics-inspired memoir.

It was within this environment of a desire to improve upon humankind that Adolphe Quetelet developed contributions to both statistics and eugenics. Quetelet applied the "law of error", used by astronomers to locate a star. The law of error as applied to humans eventually led to the concept of the average man, an individual considered to be the average of all human attributes, both physical and moral. This was a significant shift from humankind comparing itself to an unattainable ideal since being average was a goal within grasp. More than simply attainable, striving to emulate an average human became desirable. According to Quetelet the average man was the perfect model of human:

"an individual who epitomized in himself, at a given time, all the qualities of the average man, would represent at once all the greatness, beauty, and goodness of that being...deviations more or less great from the mean have constituted ugliness in the body as well as vice in morals and a state of sickness with regard to constitution." (p. 4)

Quetelet's legacy to statistical theory is the concept of normal. Revision of statistical concepts such as "the law of frequency or error" or "error curve" to "normal distribution" curve and looking at the curve from the perspective of mean to median represented an intention to

dissociate preferable outlier traits, such as tallness, from the concept of error while ensuring undesirable traits, such as shortness, remained connected to ideas of error and deviation.

Persons deemed undesirable, or labelled as unfit, were seen as a threat to the fitness of nations. Karl Pearson, head of the Department of Applied Statistics at University College in London, defined the unfit as “the habitual criminal, the professional tramp, the tuberculous, the insane, the mentally defective, the alcoholic, the diseased from birth or from excess”. Information gathered by Pearson’s department included inherited scientific, legal, and economic ability but also hermaphroditism, hemophilia, cleft palate, hare lip, tuberculosis, diabetes, deaf-mutism, polydactyly and brachydactyly, insanity, and mental defect. There was a connection between using statistics as a tool to measure humans and the hope to improve humankind by minimizing deviations from the norm, or the idea that humankind could be improved by the selective elimination of undesirable traits. For disabled people, how humankind could be improved or made more fit created an enduring legacy linking criminality with disability. This manifested in control of disabled people via institutionalization and forced sterilization to avoid what the Nazi’s described as inherited diseases of posterity (Davis, 2017). “We have largely forgotten that what Hitler did in developing a hideous policy of eugenics was just to implement the theories of the British and American eugenicists.” (Davis, 2017, p. 7)

### **A History of Disability and Discrimination**

Western industrialized society is hostage to the idea of normal, a socially constructed concept that impacts every aspect of modern life (Davis, 2017). Anyone or anything seen as falling outside the confines of normal is treated as a direct challenge to the socially constructed concept of what normal is (Barnes & Mercer, 2003). The concept of normal and deviations from it can be traced back to Greek and Roman culture, through the Middle Ages and nineteenth century, to



modern industrial capitalist society (Barnes & Mercer, 2003; Baynton, 2017). Industrial capitalist society's single-minded focus on progress drove the need for interchangeable parts and interchangeable workers, thus giving birth to the idea of normal as synonymous with progress. Normal became essential for progress: anything less than normal presented a direct challenge to the progress of humankind (Barnes & Mercer, 2003; Davis, 2017).

The oppression and marginalization of disabled people stems from this concept of normal with examples spanning the ages: a source of entertainment through humiliation and degradation in Greek and Roman cultures, public displays of physical abnormalities in the Middle Ages, and nineteenth century freak shows highlighting the bizarre and strange (Barnes & Mercer, 2003; Davis, 2017). On the surface, the concept of normal would seem to denote average, usual, and ordinary, yet the concept has evolved to mean much more. Normal, as a functional term applied to societies, implies and assumes most people are or should belong within the norm (Davis, 2017). Anyone deemed to deviate from the norm is, by default, deviant (Davis, 2017). Furthermore, the concept of normal excludes only those individuals and groups considered below average - physically, mentally, or otherwise - while celebrating those deemed above average (Baynton, 2017). Anyone or anything falling outside the norm was, and continues to be, viewed as an obstacle to society's never-ending pursuit of progress and provides a foundation for arguments denying equality to certain groups (Baynton, 2017).

One group of persons significantly impacted by the concept of normal is disabled people (Barnes & Mercer, 2003). Disabled people are seen as suffering from either an abomination of the body or a blemish of character, both of which lay the foundation for stigmatization (Nario-Redmond, 2020). Historically, the concept of disability has been weaponized to prevent certain groups from accessing the same rights and freedoms extended to normal members of society (Baynton, 2017). For example, arguments against allowing women and people of colour to vote

were rooted in ideas that these identities were synonymous with disability thus providing justification for the political, economic, and social inequality suffered by these groups (Baynton, 2017). Attaining equal rights was achieved by denying the association between one's own group and disability, effectively marking disability as a legitimate basis for inequality (Baynton, 2017). While inequality based on race, gender, and ethnicity has been denounced, disability as a foundation for discrimination has traditionally been overlooked (Baynton, 2017). The unjust and malevolent nature of equating race or ethnicity with disability has been documented, but little consideration has been given as to why disability proves such a powerful weapon for inequality, why marginalized groups vehemently deny any association with disability, and what all of this means in relation to society's attitudes towards disability (Baynton, 2017). This oversight made by academics and activists has a significant impact on the unrelenting struggle disabled people face in attaining equality and overcoming stigmatization (Baynton, 2017). Resisting this discrimination requires a non-ableist narrative that shows how disability is culturally created and not a natural and timeless concept (Baynton, 2017; Couser, 2017; Haller, 2010; Longmore, 2017; Schwartz et al., 2010).

### **Disability Representation**

“...you're either a hero or a lazy shit and there is no in between” (Haller, 2010, p.3)

Traditional representations of disabled people are rarely informed by the authentic lived experiences or perspectives of disabled people (Zhang & Haller, 2013; Longmore, 2017). The absence of information from an emic source has resulted in misrepresentation and the use of negative disability stereotypes to bridge the gap in knowledge (Cameron, 2016; Haller, 2010; Longmore, 2017). In the hands of mass media this misrepresentation has the opportunity to permeate all facets of modern society (Haller, 2010; Longmore, 2017). Even use of the term

disability itself is prejudicial in that it implies the problem resides with the individual possessing the disability and not with how society is constructed (Davis, 2017; Haller, 2010). Misrepresentation and the proliferation of negative disability stereotypes has a considerable impact on disabled people, undermining their aspirations, goals, and value as people (Barnes & Mercer, 2003; Zhang & Haller, 2013). Chronic misrepresentation and reliance on disability stereotypes also contributes to the underperformance of disabled people, preventing the attainment of their full potential (Zhang & Haller, 2013). Furthermore, misrepresentation and the continued use of disability stereotypes speak about disabled people as opposed to speaking with them, placing control of the narrative in the hands of outsiders and giving the impression disabled people are unable to speak for themselves (Couser, 2017; Schwartz et. al 2010). These misrepresentations of disability are so powerful and pervasive they overshadow all other individual characteristics or identities, casting disability as an individual's master status, their primary defining characteristic (Couser, 2017). Ultimately, misrepresentation or representation through inaccurate stereotypes results in social oppression, economic disadvantage, and powerlessness, marking disabled people as 'other' and devaluing their worth (Barnes & Mercer, 2003).

Davis (2017) points out the rareness of a main character in a novel having a disability. Literary characters with disability play a minor role or the role of villain both of which reflect how disability is constructed understood in society. The use of metaphors further illuminates how disability is constructed. Using selections from Joseph Conrad's *Lord Jim*, Davis (2017) shows the ways in which metaphor is used to represent "limitations on normal morals, ethics, and of course language" (p. 11).

Early film representations of persons with a visible disability cast them as either a source of humour in slapstick comedy or as villainous characters in dramas (Schwartz et. al., 2010). Nelson (1999) identified seven major disability stereotypes dominant in film and television:

pathetic or pitiable; the supercrip; sinister, evil, and criminal; better off dead; maladjusted/own worst enemy; burden; and unable to live a successful life. These disability stereotypes serve to reinforce the prejudice and stigma heaped upon disabled people. While some progress has been made toward more positive representations of disability (Nelson, 1999), current media representations continue to frame disabled people through the use of negative stereotypes or models of disability (Barnes & Mercer, 2009; Haller, 2010; Zhang & Haller, 2013).

Longmore's (2017) in-depth analysis of the charity poster child is one example of the pervasive nature of disability stereotypes in media. The charity poster child evolved from the use of specific strategies proven successful in generating sympathy and pity in able-bodied potential donors. The rigorous screening process applied to potential poster children was a measure of their appropriateness as a charity poster child. Specific characteristics deemed essential for success included selecting a child over an adult, appearing helpless and vulnerable, having a visible disability without seeming too disabled or different, and possessing telegenic and physically pleasing qualities. Each characteristic considered desirable in a poster child was part of a marketing strategy intended to maximize financial donations from the able-bodied public. This successful marketing strategy is responsible for the creation of a very specific disability stereotype: the helpless and vulnerable child, weak as a result of their disability, and deserving of financial support to help them live a normal life. The influence of this stereotype was far reaching, impacting not only the perceptions of the general public, but business executives, lawmakers, and the policies they create. The poster child icon locks disabled people into a one-dimensional representation, perverting opportunities for disabled people to be seen as colleagues, employees, or equals.

Zhang and Haller (2013) describe mass media representations of disabled people as problematic, relying on one of three models of disability: the medical model, the social pathology

model, or the supercrip model. Each of these models frame disability in a way that creates a misunderstanding of what disability is and who disabled people are. The medical model of disability creates the perception that disabled people are reliant on health professionals for cures or maintenance by framing disabled people as sickly, helpless victims whose lives are worth less than that of able-bodied persons. The social pathology model portrays disabled people as disadvantaged, needing to turn to society for help and support. This model may also portray disabled people as taking advantage of their disability in an effort to gain access to privileges and accommodations. Finally, the supercrip model depicts disabled people as superhuman, achieving extraordinary goals despite their disability. Each model is detrimental to the disability community by framing disabled people negatively, as with the medical and social pathology model, or by creating unrealistic expectations of what disabled people can achieve, as with the supercrip model. Zhang and Haller (2013) suggest the best way to represent disabled people is to abandon stereotypes and report from their perspective.

Siebers (2017) shows how pervasive ableism is within our culture and lays open the assumptions underlying dominant narratives of disability that perpetuate disability stereotypes and the misrepresentation of disabled people. His discussion of the ideology of ability reveals the quagmire disabled people face in addressing these misrepresentations. In simple terms, the ideology of ability is the presumed preference for ablebodiedness. At its most extreme, it serves to bestow worth by setting the baseline for human value. The ideology of ability positions ability as the supreme indicator of human worth: the lesser the ability, the lesser the human being. This worth is questioned only in the face of disability and never in its absence.

Siebers (2017) points out numerous tensions at work within the ideology of ability, tensions that form the foundation for disability stereotypes and misrepresentation. Consider the following:

- Ability determines worth: the lesser the ability, the lesser the worth.
- The able body is capable of great transformation; new experiences are opportunities for improvement. The disabled body is limited in its capacity for change. New experiences are obstacles.
- Disability is owned by the disabled individual; ability defines a common, shared human characteristic.
- Non-disabled people have the right to choose when to use their body in an able-bodied way (elevator or stairs, for example). Disabled people must strive to be as non-disabled as possible at all times.
- The value of a human life is never questioned in the context of ability, only disability.
- Loss of ability equals a loss of sociability. Disabled people are angry, bitter, self-pitying, or selfish, incapable of seeing beyond their own pain to consider the feelings of others.
- Disabled people who identify as disabled are psychologically damaged. They would feel better about themselves if they could think of themselves as able-bodied

Siebers (2017) references specific disability stereotypes discussed elsewhere in the literature. For example, the ideology of ability assumes it is better to be dead than disabled, one of the nine stereotypes discussed by Nelson (1999). The ideology of ability also assumes disability can be turned into an advantage by providing opportunities for acquiring special abilities, an idea in keeping with the supercrip model discussed by Zhang and Haller (2013).

Disability stereotypes and misrepresentation persist, in part, due to the assumptions society makes about what disability is (Tarvainen, 2019). Misrepresentation and disability stereotypes also persist due to a lack of knowledge about disability amongst the able-bodied population (Siebers, 2017) as well as the impact of mass media on the kind of information disseminated to the

general public (Haller, 2010). Describing the obstacles created for disabled people created by mass media, Colin Cameron (2016) writes:

Attempting to change the course of a conversation is difficult if those with the loudest voices only let you join on their terms. As the media persist in holding a conversation which represents disability as individual limitation or tragedy, it has proved hard for disabled people to shift this. (p. 95)

Mass media in Western culture contributes significantly to the legitimization and perpetuation of disability stereotypes (Haller, 2010; Longmore, 2017; Schwartz et al. 2019). Members of the mass media engage in disseminating culturally created narratives, the myths that communicate the stories of a culture (Haller, 2010). The narrative constructed by members of the mass media around disability constructs, in turn, reality for the reader, viewer, and listener. The non-disabled public, lacking in first-hand knowledge about what disability is, are told what stories deserve attention, what to think about these stories, and how to think about them (Haller, 2010; Siebers, 2017). Content analysis of news media has shown journalists, videographers, and photojournalists continue to hold narrow views about disabled people, make assumptions about who disabled people are, based on socially constructed stereotypes, and lack the knowledge and expertise to report on disability in a non-stigmatizing way (Zhang & Haller, 2013). While disabled people are more visible in mainstream media compared to other marginalized groups, this visibility occurs at the expense of disabled people via objectification and a lack of control over their own image (Couser, 2017). Countering disability stereotypes and misrepresentation requires person-centred depictions of persons with disabilities living real, authentic and normal lives (Couser, 2017; Zhang & Haller, 2013, Schwartz et al., 2010).

## **Social Media and Disability Representation**

The rise of disability life writing, autobiographical accounts chronicling real life experiences living with a disability, has literally moved a myriad of disabilities from the margins to the mainstream (Couser, 2017). These autobiographical accounts are vital in countering some of the common stereotypes Western society holds regarding disability (Zhang & Haller, 2013). According to Haller (2010), life writing provides more than moving the marginalized to the mainstream and a push back against negative disability stereotypes. Life writing draws attention to what activists and academics have previously overlooked, that is, the inequity of disability being used as a reasonable foundation for inequality (Baynton, 2017). As Davis (2017) states, life writing is the cultural manifestation of a human rights movement, a way of reversing ideas about what it means to be normal. It creates visibility where there was none and raises the status of disabled people (Haller, 2010).

Once virtually non-existent, first person accounts of life with a disability are becoming more common and take many forms including articles and full-length novels (Couser, 2017). One of the most popular platforms used by disabled people is internet news media and social media platforms (Haller, 2010). Accessible to anyone with a computer or mobile device, internet news media and social media platforms are bringing disability information written from the perspective of disabled people to the forefront (Haller, 2010). Internet based news and social media are able to provide what mainstream media traditionally has not – attention to people and topics often overlooked or presented in a way that does not reflect the reality and perspectives of disabled people (Haller, 2010; Glesne, 2016; Laestadius, 2016). The increased popularity and improved access to internet based and social media is changing not only how disabled people engage with the non-disabled public, but also how other members of the disability community engage with one



another (Haller, 2010). For disabled people, the use of social media allows users to build networks of friends, support, and reduce the degrees of separation and isolation with each connection made creating an opportunity to break down stereotypes and clichés (Haller, 2010).

Couser (2017) describes the self-representation of disabled people as life writing, an act that serves as a critical response to the traditional misrepresentation of disability in Western culture. The average able-bodied individual is armed with a narrow, socially constructed definition of normal, which necessitates categorizing disabled people as “other”. To alleviate the inevitable fear and discomfort experienced by able-bodied persons, disabled people are expected to account for their otherness by providing an explanation of how their disability came to be. The explanation must conform to ableist narratives that describe what disability is. The explanation must also alleviate any discomfort experienced as a result of the non-disabled confronting the disabled while confirming the disability occurred as a consequence of action taken by the disabled person, that is, they brought the disability upon themselves. As Harriet McBryde Johnson (2017) writes:

...they don't want to know. They think they know everything there is to know, just by looking at me. That's how stereotypes work. They don't know that they're confused, that they're really expressing the discombobulation that comes in my wake. (p. 496)

Couser (2017) provides six critical insights about what disability life writing, or disability autobiography, is and how it functions as a critique of culturally created disability stereotypes. These insights state disability life writing is: (a) a critique of how disability has been traditionally represented, (b) a challenge to socially constructed views and expectations of what disability is, (c) a self-representation of life experiences written by a disabled people, (d) a critique of oppressive structures and systems, (e) a path to controlled access to and an alternative perspective about the lives of disabled people, and (f) a way to counter the medical model of disability.

## **Research Purpose**

The purpose for this research extends beyond academic interest and curiosity. My daughter has Down syndrome and as a parent I have an interest in quashing any and all things that contribute to her marginalization and oppression. At the same time, I am eager to promote those things that facilitate her well-being and reaching her full potential, breaking the glass ceiling of disability, so to speak. My personal reasons for engaging in research provide a place to start, but to shift the dominant narrative there needs to be more (Clandinin, 2013). According to Clandinin (2013), the practical justifications for research are those things seeking to shift or change current knowledge. Berube (1997) states “...every representation of disability has the potential to shape the way ‘disability’ is understood in the general culture...” (p. 4-5). The practical justifications for this study demand a shift or change in the way society perceives disabled people. The dominant narrative surrounding disability has, for too long, been controlled from without, effectively overlooking or minimizing the voices of disabled people (Haller, 2010). In choosing to focus on how disabled people choose to represent themselves, there is an opportunity to shift the narrative toward a more authentic discourse that represents what disability is, who disabled people are, and how disabled people engage in society (Couser, 2017; Glesne, 2016). Therefore, the purpose of this unobtrusive qualitative content analysis is to explore the ways disabled people chose to represent themselves and to determine if these representations are consistent with or resistant to dominant ableist narratives.

## Methods

### Why Qualitative Research?

Qualitative research allows for the telling of a story, a story grounded in human experience that seeks to introduce or change a narrative surrounding a specific phenomenon (Creswell, 2013). Qualitative researchers strive to tell the story from the perspective of the participant, at the same time recognizing the researcher's own biases will impact the research process (Glesne, 2016). The stories told reveal the understandings and meanings we make of what is seen and experienced in the natural world (Jones, Torres & Arminio, 2014) and lead to the understanding that multiple truths exist, constructed by the world in which we live (Glesne, 2016; Jones, Torres & Arminio, 2014).

The decision to pursue a Master's degree was, I thought, a path that would allow me to re-enter the workforce. Previous training and clinical experience gained as a registered midwife did not transfer well to other areas of employment. In addition, I had chosen to remain home with my family for nine years leaving me with few employment options. There was no specific intention to further my knowledge about disability through academics, yet it would be impossible to overstate the impact disability has had on my academic life. Pursuing graduate studies afforded the opportunity to gain a deeper understanding of the experience of disability in our family and in a broader sense. Borrowing from Glesne's (2016) description of qualitative research, I want to make sense of the dominant narratives that surround disability and to explore the ways in which these narratives might be shifted to reflect the lived experiences of disabled people.

The purpose of this study is to explore how disabled people chose to represent themselves and to determine if these representations resist ableist narratives. How disabled people choose to

represent themselves, what they choose to include or exclude from self-representation is not something easily quantified or expressed in numerical terms. Human experience is inherently subjective and consists of multiple truths (Jones, Torres & Arminio, 2014). Reducing the human experience to numbers implies an objectivity that does not exist and seeks to simplify the messiness of life to simple sums (Mulcahy, 2015). Approaching content analysis from a qualitative perspective allows the data to reveal ability and disability as socially constructed concepts (Siebers, 2017).

Quantifying the data analyzed in this study without including a deeper analysis is consistent with the characterization of content analysis as a simple research method (Elo & Kyngas, 2008). It would be possible to count and report the number of images containing a certain number of pre-determined criteria or themes (Jones, Torres & Arminio, 2014). However, this counting would fail to reveal the story contained within the images and prevent the uncovering of certain values and beliefs (Jones, Torres & Arminio, 2014). A qualitative approach offers the opportunity to create a deeper understanding of the phenomenon of interest. In being open to another way of looking at the data, in asking what might be learned by taking another approach, there is the opportunity to shift, even if it is ever so slightly, how we think about what disability is and who disabled people are (Jones, Torres & Arminio, 2014).

### **Conceptual Framework**

This unobtrusive interpretive qualitative research study proposes the use of content analysis to explore how disabled people choose to represent themselves. Unobtrusive research methods allow researchers to collect data without interacting with participants (van den Hoonaard, 2019). Data analysis is based on materials that already exist and the data collection process does not affect the materials to be analysed (Haller, 2010; van den Hoonaard, 2019).

Anything created or altered by people can act as a source of data for unobtrusive research including maps, letters, advertisements, and trash (van den Hoonaard, 2019).

The epistemological and ontological underpinnings of interpretivism are well suited to this study, one that seeks to explore and understand how disabled people choose to represent themselves. Ontologically, interpretivism holds that the world is socially constructed, complex, and dynamic (Glesne, 2016). Interpretivists emphasise the “meaning people make rather than facts” (Jones, Torres & Arminio, 2014, p.17) and reject objective ideas that a universal truth exists. Rather, knowledge and understanding are never complete and because they rely on both context and perspective, they are always in flux, composed of many layers (Glesne, 2016; Jones, Torres & Arminio, 2014). Rejecting the idea of objectifiable facts, interpretivists use the stories people tell about their lived experiences to illuminate the meanings people make of their lives (Jones, Torres & Arminio, 2014).

## **Methodology**

Once considered a simple method of quantification, qualitative content analysis is a stand-alone method to analyze qualitative data (Elo & Kyngas, 2008). Similar to other qualitative research methods, qualitative content analysis is interested in exploring meaning and interpretation (Scheier, 2012). Scheier (2012) states qualitative content analysis has three key characteristics: it reduces data, it is systematic, and it is flexible. Graneheim, Lindgren, and Lundman (2017) define qualitative content analysis as a method with a focus on subject and context that allows researchers to describe both manifest and latent content. Three different approaches to content analysis are described - inductive, deductive, and abductive – and the choice of method is guided by the research question (Graneheim, Lindgren & Lundman, 2017). An inductive approach to content analysis begins with the researcher searching for patterns

within the data, described as categories or themes. The researcher moves from data to a theoretical understanding (Graneheim, Lindgren & Lundman, 2017). Deductive content analysis begins with the researcher selecting a concept or existing theory about the phenomenon being studied (Graneheim, Lindgren & Lundman, 2017). The data is tested against the selected concept or theory (Graneheim, Lindgren & Lundman, 2017). Finally, abductive approaches entail moving back and forth between inductive and deductive approaches to create a more complete understanding of the phenomenon (Graneheim, Lindgren & Lundman, 2017).

According to Hsieh and Shannon (2005), content analysis is a research method that provides knowledge and improved understanding of the phenomenon under study. Here, content analysis is seen as a group of analytic approaches set on a spectrum. On one end are impressionistic, intuitive, and interpretive analyses with systematic, strict textual analyses on the opposite end. The approach chosen depends upon the researcher and the research question of interest. Hsieh and Shannon (2005) contend content analysis has not been well defined, nor have procedures been well detailed.

Hsieh and Shannon (2005) reference conventional, directed, and summative content analysis. Conventional content analysis aims to describe a particular phenomenon and is most often used when existing theory or literature is limited. If prior research or theory about a specific phenomenon exists, a directed approach may be employed. This approach seeks to validate or expand existing research or theories and is a more structured approach as compared to conventional content analysis. Lastly, summative content analysis seeks to explore and understand the contextual use of content. This approach most often begins by identifying and quantifying certain words or content, the manifest analysis, and moves on to interpretation of the underlying meanings of the content, the latent analysis.

Elo and Kyngas (2008) consider content analysis to be a method to analyze written, verbal, or visual communication messages. It provides researchers with a system to objectively describe and quantify phenomenon. Through the use of content analysis large amounts of data can be reduced to a lesser number of concepts or categories that describe the phenomenon under study. The authors describe two approaches to content analysis: inductive and deductive. The inductive approach to content analysis is appropriate when there is limited knowledge about a particular phenomenon. Full immersion in and open coding of the data leads to the creation of concepts or categories intended to fully describe content resulting in increased knowledge and understanding. When extant knowledge and theory about the phenomenon of interest is available, the deductive approach may be used. Available knowledge or theory is operationalized by constructing an analysis framework or categorization matrix to code data according to the categories created. Inductive content analysis moves from specific to general while the deductive approach moves from general to specific. Noting an absence of information regarding how to apply content analysis as a method, Elo and Kyngas (2008) suggest three main phases – preparation, organizing, and reporting - for the analysis in both inductive and deductive approaches. This study is most consistent with deductive content analysis as described by Elo and Kyngas (2008).

Generally, content analysis involves two levels of data analysis (Elo & Kyngas, 2008; Graneheim, Lindgren & Lundman, 2017; Haller, 2010; van den Hoonaard, 2019). First, manifest analysis describes content that is immediately evident and observable (Graneheim, Lindgren & Lundman, 2017; Haller, 2010; van den Hoonaard, 2019). This stage of analysis requires the researcher to provide a literal or concrete description of the data (Graneheim, Lindgren & Lundman, 2017; Haller, 2010). In contrast, latent analysis of data involves teasing out what the

data implies, bringing the researcher to a deeper understanding of the data (van den Hoonaard, 2019), providing a system that allows researchers to express inference in a concrete way (Haller, 2010; Hsieh & Shannon, 2005). This study proposes both manifest and latent analysis of the data selected for inclusion.

Content analysis is vital to understanding modern society by allowing the self-representations of individuals and groups involved in artifact production to be explored (van den Hoonaard, 2019). The ways in which documents are created tell us a great deal about the people who have created them and the society they live in (van den Hoonaard, 2019). Artifacts are created in specific ways that include or exclude specific elements of reality. The elements of reality included or excluded in an artifact raise questions about how and why the artifact was created in a specific way. At the same time, reactions elicited from the artifacts final form can be observed and documented (Haller, 2010; van den Hoonaard, 2019). Haller (2010) writes that content analysis tells us “who said what to whom, why, how, and with what effect”. This study seeks to explore how disabled people choose to represent themselves and if the representations are consistent with or resistant to dominant disability narratives. Content analysis is concerned with understanding society through artifact exploration and is an ideal methodology for this study.

### **Data Source Selection**

This unobtrusive qualitative research study utilized purposive sampling to select data sources that would allow exploration of the phenomenon of interest. Purposive sampling assumes the researcher seeks to discover, understand, and gain insight about a specific phenomenon (Merriam & Tisdell, 2016). As such, the sample selected must be capable of providing a rich and in-depth understanding of the phenomenon of interest (Jones, Torres &



Arminio, 2014; Merriam, 2009; Palys, 2008). This type of sampling typically occurs before data is collected and is guided by criteria established to ensure sampling fulfills the stated purpose of the research (Merriam & Tisdell, 2016).

Data source selection for this study began by establishing criteria that would allow for exploration of how disabled people choose to represent themselves. A review of the literature revealed consensus that disabled people are misrepresented as a result of outsider representation based on dominant ableist narratives (Couser, 2017; Longmore, 2017; Zhang & Haller, 2013). Countering ableist narratives relies on self-representation or representation from the perspective of disabled people, or emic perspective (Couser, 2017; Longmore, 2017; Zhang & Haller, 2013). Thus, any data source included in this study must be created by a person with disability or be created from the perspective of disabled people.

Disability is an umbrella term used to capture a wide variety of conditions that may or may not be visible (Ontario Human Rights Commission, n.d.). Disabilities may be physical, mental, cognitive, or sensory and vary in effect and severity from one individual to the next. The variability and complexity of disability prevents a single universal definition generalizable to all disabled people (Federal Disability Reference Guide, 2013). Despite variability in the experience of disability, what disabled people experience in common is stigma and marginalization (Cameron, 2016; Haller, 2010). This stigma and marginalization is not experienced equally across all types of disability. Under the umbrella term of disability exists a hierarchy of disability that places persons with intellectual disability at the bottom (Deal, 2003; Nario-Redmond, 2020). As such, persons with intellectual disability may be more vulnerable to the negative impact of socially constructed disability stereotypes (Cunningham & Glen, 2004; Zhang & Haller, 2013). Stereotypes applied to intellectually disabled people include the perpetual child, incompetent but loving, dependent, lazy, and unmotivated (Nario-Redmond,

2020). These negative stereotypes impact how intellectually disabled people are received socially, educationally, and professionally (Nario-Redmond, 2020).

It is well documented that Down syndrome is the primary genetic cause of intellectual disability (Bittles, Bower, Hussain & Glasson, 2007; Fox, Moffett, Kinnison, Brooks & Case, 2019; Phillips & Holland, 2011). Cunningham and Glenn (2004) note the most distinctive and recognizable characteristics of Down syndrome are physical appearance and intellectual disability, neither of which are valued in any culture. Advances in non-invasive prenatal testing for Down syndrome has resulted in a decrease of the number of children with Down syndrome being born (Hill et al., 2017). The figures vary from country to country with a 30% fewer in the United States, 50% fewer in the Netherlands, 48% fewer in England and Wales, 55% fewer in Australia, and China, and 94% fewer in Taiwan (Hill et al., 2017). A systematic review by Natoli, Ackerman, McDermott and Edwards (2012) revealed pregnancy termination rates based on genetic screening positive for Down syndrome ranged from 61.40% to 93.30%. Individuals who survive prenatal genetic screening and pregnancy termination are subjected to a variety of measures that work to marginalize and oppress: the medical communities reluctance or refusal to treat life threatening conditions, pressure to prevent persons with Down syndrome from reproducing, restrictions on where and how persons with Down syndrome can live, and treatments such as facial reconstructive surgery and instructional approaches to encourage conformity to the norm (Cunningham & Glenn, 2004). My personal interest in Down syndrome in connection with the degree to which persons with intellectual disability are marginalized and the limited information available regarding disability narratives and intellectual disability (Nario-Redmond, 2020) resulted in the selection of persons with Down syndrome as a source of data for this study.

Two criteria were employed in the selection of data sources for this study. These criteria include: (a) an individual or group of individuals with Down syndrome, and (b) evidence of self-representation or representation from the perspective of disabled people. Data sources identified as meeting these criteria were subjected to the additional criterion of having a publicly accessible social media presence with a view to conducting unobtrusive research (van den Hoonaard, 2019). These criteria led to the purposive selection of Madeline Stuart's, Chelsea Werner's, A.B.L.E. Ensemble's, and G-Mc's Homies with Extra Chromies Instagram accounts as data sources for this study.

Madeline Stuart's path to fame began in 2015 when before and after photographs depicting a 23-kilogram weight loss were posted to social media and went viral. The dominant story about Madeline centres on her career as the world's first supermodel with Down syndrome. At the same time, the story of how Madeline came to be a regular on international fashion catwalks highlights her decisions to eat for health and engage in regular physical activity and also speaks to her passion and advocacy for disabled people to live their best lives. Madeline's micro-celebrity status (Khamis, Ang & Welling, 2017), combined with her publicly accessible Instagram account, provides access to data relevant to exploration of the phenomenon of interest. Madeline Stuart's active presence on social media in combination with her having Down syndrome make her Instagram account an ideal source of data to explore how disabled people choose to represent themselves and what this representation says about dominant disability narratives.

The majority of children with Down syndrome face cognitive and developmental delays (Pace, Shin & Rasmussen, 2010) and Chelsea Werner was no exception. Walking later in life than her non-Down syndrome peers, medical professionals prophesied Chelsea would face low muscle tone over the course of her life ([www.chelseaworldchampion.com](http://www.chelseaworldchampion.com)). Medical expertise

not-with-standing, Chelsea embarked on an early journey of physical activity, specifically gymnastics ([www.chelseaworldchampion.com](http://www.chelseaworldchampion.com)). Chelsea's dedication and determination led to her now well-established career as a successful gymnast turned model and micro-celebrity ([www.chelseaworldchampion.com](http://www.chelseaworldchampion.com)). Chelsea is a four-time gold medal recipient at the U. S. Special Olympics National Gymnastics Championships four times and has won the International Down Syndrome Championship in 2012 and 2015 ([www.chelseaworldchampion.com](http://www.chelseaworldchampion.com)). Her success as a gymnast eventually segued to a modelling career with appearances for P&G, H&M, and Aerie. Catwalk appearances include New York Fashion Week, Los Angeles Fashion Week, Catwalk for a Cure, and Macy's Fashion Show ([www.chelseaworldchampion.com](http://www.chelseaworldchampion.com)). Chelsea has been featured on the Today Show, in Teen Vogue, and recently signed with WeSpeak modelling agency, an agency committed to representing models who defy mainstream beauty ideals ("Champion Gymnast & Model with Down's Syndrome Challenges The Media's Ideas of Beauty", 2015). Chelsea's social media presence is credited as playing a significant role in launching her modelling career (Saha, 2019). Recognizing that persons with Down syndrome are underrepresented in the beauty world Chelsea has vowed to advocate for change ("Champion Gymnast & Model with Down's Syndrome Challenges the Media's Ideas of Beauty", 2015; Saha, 2019).

The Artists Breaking Limits and Expectations (A.B.L.E.) Ensemble, based in Chicago, is a not for profit organization dedicated to theatre and film projects for, with, and by individuals with Down syndrome and other developmental differences (A.B.L.E. Ensemble, n.d.. *What We Do*. <https://www.ableensemble.com/what-we-do> ). The ensemble is supported by a staff of teaching artists and volunteer coordinators that work together with ensemble members to create theatre and film projects (A.B.L.E. Ensemble, n.d.. *Who We Are*. <https://www.ableensemble.com/our-team>). Ensemble productions cover a range of works from

original artists including Shakespeare, Dickens, and Gilbert and Sullivan (A.B.L.E. Ensemble, n.d. *Theatre Projects*. <https://www.ableensemble.com/theatreprojects>). Community outreach, involvement, and performance form the cornerstone of ensemble philosophy (A.B.L.E. Ensemble, n.d. *Diversity, Equity, & Inclusion*. <https://www.ableensemble.com/diversity-equity-inclusion>). Performances at local schools and organizations allow the ensemble to showcase their performances while providing opportunities for discussion around best practices for inclusion.

The philosophy underlying the A.B.L.E. Ensemble recognizes that societal perceptions of disabled people often present a one-dimensional representation dominated by the disability identity and the desire to inspire the able-bodied. Conversations around disability often occur about disabled people as opposed to with them. The ensemble hopes to shift preconceived societal perceptions about disability (A.B.L.E. Ensemble, n.d. *Diversity, Equity, & Inclusion*. <https://www.ableensemble.com/diversity-equity-inclusion>).

G-Mc's Homies with Extra Chromies is a non-profit organization based in St. Catharines, Ontario. The organization is dedicated to the physical, mental, and social well-being of individuals with Down syndrome (G-Mc's Homies with Extra Chromies, n.d. *Home*. <https://www.gmcshomies.com>). G-Mc's provides a wide variety of annual events to meet the goal of improved well-being including group participation in local sporting events, attendance at professional sporting events, opportunities to learn about and participate in new recreational activities, regularly scheduled workouts, and social gatherings. G-Mc's states it is dedicated to achieving a number of goals including opportunities for group members to interact with other group members or individuals from the community, to improve the life skills of its members, and to counter the negative stereotypes often associated with intellectual disability (G-Mc's Homies with Extra Chromies, n.d. *Home*. <https://www.gmcshomies.com>). Recognizing disabled people

may face specific obstacles when accessing community resources G-Mc's Homies with Extra Chromies provides many of its events free of charge to members.

Each of the Instagram accounts selected as a data source for this study provides an opportunity for manifest and latent analysis of the phenomenon of interest. The selection of data sources for this study is not intended to provide understandings and insights generalizable to the greater population or even the population of persons with Down syndrome. The selection of these sources of data is to provide an in-depth description and analysis of how disabled people choose to represent themselves (Laestadius, 2016; Merriam, 2009).

### **Instagram as a Data Source**

Images act as a powerful medium with which to convey meaning (Banks, 2014). Broadly speaking, images are the mental pictures individuals have about an object that impact attitudes and actions (Acuti, Mazzoli, Donvito & Chan, 2018). In short, what we see becomes what we think and feel, and how we act. The human brain has a preference for images over text because they are easier and faster to decode, allowing the brain to retain more of what it sees compared to what it reads ("Visuals vs. Text: Which Content Format is Better, and Why", 2018). Instagram, a popular social and video-sharing networking service (Bohjalian, 2017; Laestadius, Wahl & Cho, 2016), capitalizes on the power of images by being visually based. Launched in October of 2010, Instagram is one of the most popular social media platforms in the world (Laestadius, 2016) and currently boasts more than 700 million active users with 4.2 billion interactions occurring daily (Anagnostopoulos, Parganas, Chadwick & Fenton, 2018). The main advantage of Instagram lies in its ability to share information in a visual form, a feature considered to improve user engagement (Pittman & Reich, 2016). Instagram streamlines the process of linking social network accounts by allowing users to access one-click settings to connect Instagram,

Facebook, and Twitter (Instagram. n.d.). Additionally, Instagram users can easily make their accounts public or private with one click in settings (Bolluyt, 2018). Posts uploaded to Instagram must include an image or a short video, often paired with captions, comments, and hashtags created by the account user. While images and videos alone can communicate meaning and information, the inclusion of captions, comments, and hashtags created by the account user provide context for the visual content (Laestadius, 2016). Hashtags have been identified as a powerful resource to facilitate advocacy efforts (Saxton, Niyirora, Guo & Waters, 2015). Hashtags brand movements and organize messages for the movement allowing like-minded individuals and those not associated with a movement to easily locate information. Hashtags are powerful in that they are user-generated and participatory, helping to develop action communities around a specific issue eliciting acute responses in times of emergency or allowing the development and archiving of knowledge, ideas, and information around a specific issue (Saxton, Niyirora, Guo & Waters, 2015).

As a source of data, Instagram offers unique opportunities for conducting research that combines small sample sizes with qualitative approaches leading to insights and meanings potentially unavailable via other research methods (Laestadius, 2016). Research using Instagram as a source of data typically has one of two goals: to understand Instagram-specific behaviours or to understand secondary phenomena through Instagram (Laestadius, 2016), the latter of which is consistent with this study. For disabled people Instagram offers an accessible platform where disabled people can control what information is shared through authentic life narratives (Couser, 2017; Glense & Tisdell, 2016).

A number of topics have been explored through analysis of visual and textual posts uploaded to Instagram. These include: dietary trends (Pila, Mond & Griffiths, 2017), city branding (Acuti, Mazzoli, Donvito & Chan, 2018), waterpipe promotion (Allem, Chu, Cruz &

Unger, 2017; Ben Taleb, Laestadius, Asfar, Primack & Maziak, 2019), electronic cigarette use (Laestadius, Wahl & Cho, 2016), body positivity (Cohen, Irwin, Newton-John & Slater, 2019), self-presentation (Bohjalian, 2017; Webb, Vinoski, Bonar, Davies & Etzel, 2017), and junk food marketing (Vassalo et al., 2018).

This study proposes the use of four different Instagram accounts as data sources:

Madeline Stuart ([www.instagram.com/madelinesmodelling](http://www.instagram.com/madelinesmodelling)), Chelsea Werner ([www.instagram.com/showtimewerner](http://www.instagram.com/showtimewerner)), Able Ensemble ([www.instagram.com/ableensemble](http://www.instagram.com/ableensemble)), and G-Mc's Homies with Extra Chromies ([www.instagram.com/gmcshomiesextrachromis](http://www.instagram.com/gmcshomiesextrachromis)) Instagram accounts. All data collected from the accounts is publicly accessible, thus anyone with access to the internet could view the same data accessed for this study. Basic metrics for Madeline Stuart's Instagram account as of August 17, 2020 include 211,000 followers, following 1,710 and 1,541 posts at the time of study. While the majority of account posts focus on Madeline Stuart's professional modelling career, posts relevant to Down syndrome awareness and advocacy, as well as posts more personal in nature, can also be found uploaded to the account. Chelsea Werner's Instagram account metrics as of August 17, 2020 include 172,000 followers, following 2,490 and 581 posts. Photo and video content uploaded to Chelsea Werner's Instagram account focus primarily on gymnastics. Additional content includes posts related to modelling, advocacy, and family photos or videos. The A.B.L.E. Ensemble's Instagram account features visual images of ensemble members during practice and performance, as well as support staff images. The Ensemble's Instagram metrics show 924 followers, 1,293 following, and 1,341 posts. G-Mc's Homies with Extra Chromies boasts 1,202 followers, 65 following, and 450 posts. Visual images uploaded to the account feature members involved in a variety of activities including group workouts, social gatherings, and attendance at sporting events.



## Data Collection

This study employed manual collection of data from the Instagram user-interfaces. According to Laestadius (2016), manual collection of data offers a number of benefits to the Instagram researcher. First, it allows the researcher to interact with the data in a way consistent with what the Instagram user intended when they created the content. Manual collection of the data fully immerses the researcher in the data, leading to a familiarity with the data that may not occur with other data collection methods. Lastly, manual data collection offers the researcher the opportunity to assess the relevance of the data during the data collection process. In this way, the researcher is able to collect only data relevant to the research question (Laestadius, 2016). This is in keeping with Merriam's (2016) suggestion that data collection should be purposive.

Qualitative research commonly involves analysis of large amounts of data, which is the case with this study (Schreier, 2012). I approached the images uploaded to a single Instagram account as the total population of data available. The first post uploaded to the Instagram account marked the first unit of available data and the collection period continued until March 31, 2021. Through discussion with my advisor we decided to limit images to those featuring a single individual. To ensure data selected provides a full understanding of the phenomenon of interest, we also decided data should be selected using random sampling from each quarter of a calendar year (January to March, April to June, July to September, October to December) from non-consecutive years. For example, if the Instagram account was created in 2015 images would be taken from each quarter year of 2015, 2017, 2019, and 2021.

I relied on Research Radomizer ([www.randomizer.org](http://www.randomizer.org)) to generate a manageable amount of data for analysis. The use of random sampling is most often seen in quantitative research (Ingham-Broomfield, 2014) and might be considered inconsistent with a qualitative research design. I approached random sampling as a way to minimize my own bias in data selection,

recognizing my preference for specific types of images. At the same time, I understand how data selection guided by images I consider salient may have resulted in a different understanding of the phenomenon of interest (Schreier, 2012).

### **Coding Procedures**

Extant literature provides evidence that mass media representations of disabled people are inaccurate, stigmatizing, and marginalizing (Couser, 2017; Haller, 2010; Longmore, 2017). Resisting misrepresentations of disability based on dominant ableist narratives comes from authentic, real life representations offered by disabled people or representations from the perspective of disabled people (Couser, 2017; Zhang & Haller, 2013). In keeping with deductive content analysis as described by Elo and Kyngas (2008), I operationalized the work of Couser, Longmore (2017), and Zhang and Haller (2013), in a deductive process to create an analysis framework to explore how disabled people choose to represent themselves.

According to Couser (2017) disability life writing should: (1) critique how disability has been traditionally represented, functioning as a response to misrepresentation, (2) challenge socially constructed views and expectations of what disability is, rather than playing to the comfort of the non-disabled, (3) be a self-representation of life experiences written from the emic perspective, (4) critique oppressive structures and systems by resisting and countering the colonizers construction of what disability it (5) provide controlled access to and/or provide an alternative perspective about the lives of disabled people, and (6) counter the medical model of disability; counter the idea that disability reduces quality of life; includes self-acceptance rather than conforming to the colonizers terms. Each criteria was reduced to a few essential words to create six categories for the analysis framework: (1) Critical response, (2) Challenge normative views, (3) Self-representation, (4) Critiques oppressive structures/systems, (5) Controlled access,

and (6) Counter-culture. All three authors state the importance of self-representation or representation from the perspective of disabled people as vital in countering dominant ableist narratives. For this reason, self-representation or representation from the perspective of disabled people was included as a criterion for data source inclusion in this study. This reduces the analysis framework categories to five: (1) Critical response, (2) Challenge normative views, (3) Critiques oppressive structures/systems, (4) Controlled access, and (5) Counter-culture.

Recognizing the work of Zhang and Haller (2013) and Longmore (2017) as consistent with Couser (2017), Zhang and Haller (2013) and Longmore (2017) are absorbed into Couser's (2017) criteria for disability life writing. Zhang and Haller's (2013) discussion of media reliance on three main models to frame disability is consistent with Couser's (2017) assertion that disabled people are expected to conform to a culturally created script of what disability is. Thus, Zhang and Haller's (2013) work is represented in critical response and counter-cultures. Similarly, Longmore's (2017) description of the charity poster child as a disability stereotype is consistent with Couser's (2017) criteria for disability life writing. Specifically, Longmore's (2017) discussion of the charity poster child as intentionally constructed to resonate with and elicit sympathy from the viewer fits with Couser's (2017) challenge normative views and controlled access criteria.

In keeping with current literature using Instagram as a data source (Laestadius, Wahl & Cho, 2016) and to capture as much relevant and meaningful information as possible for each post, the following additional categories were created: (a) image identifiers (Instagram account, date of post), and (b) image filters (image type; type of activity; location; number of people in the post; number of post likes; font; and captions, comments and hashtags). The complete version of the coding manual can be found in Appendix A.

Merriam and Tisdell (2016) assert data collection and analysis occur simultaneously and are dynamic processes leading to category alteration during preliminary analysis. For that reason, it was anticipated that additional updates to analysis framework categories may occur during data collection as part of an iterative and inductive process. Similar methods have been used by Bohjalian (2017); Cohen, Irwin, Newton-John, and Slater (2019); and Webb, Vinoski, Bonar, Davies, and Etzel (2017).

Extant literature using social media as a data source commonly uses multiple coders with intercoder reliability reported as evidence of consensus in coding and increasing the reliability or validity of their study (Allem, Chu, Cruz & Unger, 2017; Ben Taleb, Laestadius, Asfar, Primack & Maziak, 2019; Cohen, Irwin, Newton-John & Slater, 2019; Sandelowski, 1998; Webb, Vinoski, Bonar, Davies & Etzel, 2017). Despite the common use of multiple coders in social media research, all posts selected for inclusion in this study were coded by a single coder, the study author. Merriam and Tisdell (2016) refute the existence of a single, objective reality asserting that multiple, subjective interpretations of reality exist. These multiple, subjective realities would likely result in multiple, subjective interpretations of the data should multiple coders be used (Sandelowski, 1998). While multiple interpretations of the data are welcome, it is not the purpose of this study. It has been suggested that use of a single coder leads to issues of trustworthiness and credibility (Graneheim & Lundman, 2004). In contrast, Sandelowski (1998) asserts knowledge in qualitative research is derived “from deep immersion in the data, profound commitment to purpose, and prolonged engagement...” (p. 467) making the researcher best suited to make sense of the data. Strategies to ensure trustworthiness are discussed in a separate section.

## **Data Analysis**

According to Merriam and Tisdell (2016), data analysis is the process of making sense of the data, a way of making meaning. As such, data analysis need not be quantifiable but can address the nature of the data instead. Analysis is the point at which all data is brought together and reduced into manageable units that are interpreted by the researcher. Merriam and Tisdell (2016) recommend choosing a unit of analysis that is the smallest piece of information that can stand on its own. The researcher must keep in mind the purpose of the study and strive to choose a unit of analysis neither too large nor too small to elicit meaning (Elo & Kyngas, 2008). The unit of analysis in this study was each post randomly selected from the four Instagram accounts selected for this study.

Instagram posts were analyzed for manifest and latent content using content analysis, a method that explores meaning and context, and accounts for interactions between the researcher, concepts, data collection, and analysis (van den Hoonaard, 2019). Manifest analysis involves a detailed description of what is immediately obvious upon observation of the document (Graneheim, Lindgren & Lundman, 2017; Haller, 2010; van den Hoonaard, 2019). This stage of analysis requires the researcher to provide a literal or concrete description of the data (Graneheim, Lindgren & Lundman, 2017; Haller, 2010). Latent analysis of the data will be deductive and involve deciphering what the data implies in an effort to arrive at a deeper understanding of the data (van den Hoonaard, 2019).

The content of each post was visually analyzed and manually coded using the analysis framework (see Appendix A). Manifest analysis began by coding details immediately observable in the image. The process began by applying the image identifiers and image filters to each image selected through random sampling. This included, but was not limited to, font and text size, date of post, number of post likes and study filters, image type, type of activity, location, and number

of people in the post. In addition, captions, comments, and hashtags provided by the account owner at the time the post was made were included in the manifest analysis. The manifest analysis was followed by latent analysis. Each post was analyzed using the analysis framework to explore how persons with disabilities choose to represent themselves. The categories included in the analysis framework for latent analysis of the data include: (1) Critical response, (2) Challenge normative views, (3) Critiques oppressive structures/systems, (4) Controlled access, and (5) Counter-culture.

Categories included in the analysis framework are not mutually exclusive and, as such, one post were coded for more than one category. Consistent with recommendations made by Laestadius (2016), each post was analyzed with the captions, comments and hashtags included with the post by the account user. The inclusion of captions, comments, and hashtags in the analysis process is intended to preserve the context of each post. Similar methods have been used in prior research utilizing Instagram as a source of data to explore body positivity (Cohen, Irwin, Newton-John & Slater, 2019) and Fatspiration/Health at Every Size<sup>®</sup> (Webb, Vinoski, Bonar, Davies & Etzel, 2017).

### **Trustworthiness**

Trustworthiness and credibility can be problematic in qualitative research and trustworthiness strategies are best determined by study design (Eklund, 1996; Sparkes, 1998). This qualitative content analysis study relies on observation of social media as a data collection method and a number of strategies were used to ensure study findings were trustworthy. These strategies included: triangulation; adequate engagement in data collection; rich, thick description; clarification of research bias and subjectivity; and audit trail (Glesne, 2016; Merriam & Tisdell, 2016). Triangulation is the use of multiple methods of data collection and multiple sources of

data (Glesne, 2016; Merriam & Tisdell, 2016). This study relied on four Instagram accounts as sources of data, however, multiple types of data were collected from the sources. Images were collected along with the captions, comments, and hashtags included by the account user on the original post. As Laestadius (2016) asserts, collection of an image without including its accompanying captions, comments and hashtags may result in a significant loss of context. Manual extraction of the data from the Instagram user-interface allowed the study author to be fully immersed in the data and to engage in the data in a way consistent with what the account user intended when the data was created (Laestadius, 2016; Sandelowski, 1998). These methods ensured the researcher was adequately engaged in data collection. Rich-thick descriptions of the data through manifest and latent analysis provide context for the reader and allow readers to follow the conclusions made by the researcher (Merriam, 2016; Sandelowski, 1998). Researcher bias and subjectivity was addressed with a reflexive journal and analytic memos (Glesne, 2016). The intention of recording the ideas, impressions, and hunches of the researcher during data collection and analysis was to express fully the preconceptions and preunderstandings of the study author and to provide context for the specific descriptions and interpretations of the study author (Merriam & Tisdell, 2016). The audit trail was created by providing a detailed description of how data were collected, how categories were developed, and how research decisions were made (Merriam & Tisdell, 2016). All documents described above are available and subject to analysis, the goal being to provide the reader with enough detail to show that the conclusions of the study author make sense (Merriam & Tisdell, 2016; Sandelowski, 1998).

### **Ethical Considerations**

While social media as a data source may present unique opportunities for qualitative research, it also presents some interesting ethical issues around privacy, image reproduction, and

dissemination of results (Laestadius, 2016). Research relying on observation of social media has been described as research not involving human participants (Laestadius, 2016) and, as such, may be exempt from ethics board review (Moreno, Goniou, Moreno, & Diekema, 2013). Likewise, Merriam and Tisdell (2016) note that documenting the public behaviour of public figures is not likely to be construed as an ethical violation. This potential exemption from ethical assessment raises ethical issues around image reproduction and dissemination of research findings in that it allows Instagram researchers to use posted images without securing consent from the account user. For public Instagram accounts, it could be argued the public setting implies no expectation of privacy and therefore, consent. However, Instagram account settings default to the public setting (Bolluyt, 2018). In addition, while users may have public accounts, they may rightfully anticipate their posts will be viewed only by followers of their account. Few, if any, Instagram users would anticipate the use of their posts in academic research (Merriam & Tisdell, 2016). In light of the paucity of institutional guidelines and relevant literature addressing ethical issues around data collected by observation of social media (Moreno, Goniou, Moreno, & Diekema, 2013), care must be taken in protecting the privacy of social media users.

The intention of this study was to err towards protecting the privacy of the account user and to do no harm (Jones, Torres & Arminio, 2014). As such, the following ethical considerations proposed by Laestadius (2016) guided the collection and dissemination of data from each of the four Instagram accounts:

- Is the image created by a celebrity, microcelebrity, or private person?
- Is the image still publicly available on Instagram at the time of dissemination?

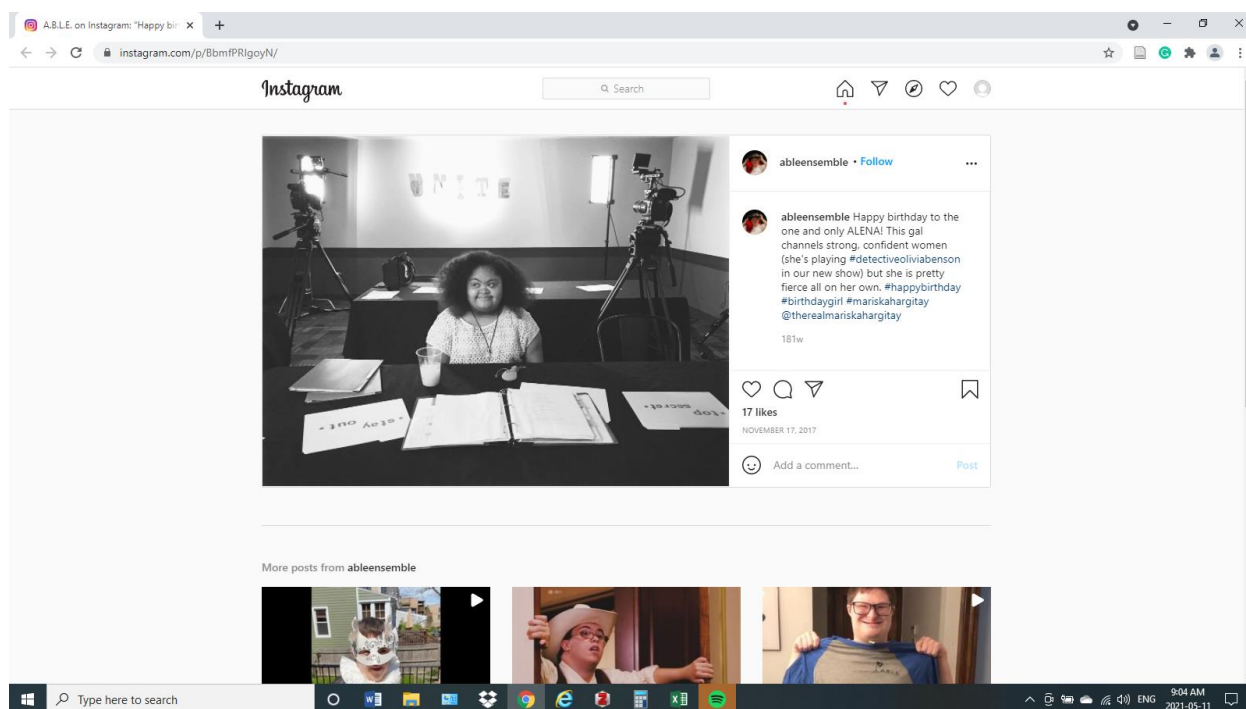


- Does the image depict anything that could be seen as sensitive, harmful, or embarrassing from the perspective of the image creator or pose risks within the creator's particular cultural, economic, emotional, and legal context?
- Did the creator of the image apply a hashtag to the post to render it searchable?
- Does the image allow for the potential identification of a person or location?
- Are several images being reproduced from the account of a single user?
- Does the image depict someone who is not the owner of the Instagram account?

## Findings

Data analysis is an act of interpretation and dynamic in nature (Glesne, 2016).

Trustworthiness relies, in part, on the ability to show how I arrived at my interpretations based on the data in this study (Glesne, 2016). The number of images included in this study along with multiple rounds of data analysis resulted in a large amount of material included in the data analysis process. In consultation with my advisor and committee the decision was made to include one example of the data analysis process in the body of the thesis. A second example has been included in the appendices (see Appendix B).



### ABLE Photo 5

**Posted:** November 17, 2017

**Likes:** 17

**Comment:** Happy birthday to the one and only ALENA! This gal channels strong, confident women (she's playing [#detectiveoliviabenson](#) in our new show) but she is pretty fierce all on her own. [#happybirthday](#) [#birthdaygirl](#) [#mariskahargitay](#) [@therealmariskahargitay](#)

### **Manifest Analysis**

Black and white photo. The room contains two long tables positioned horizontally across the photo and covered in black table clothes. Both tables have papers on them. The closest table has an open three ring binder and file folders. One file folder has the words “stay out” on the front. The other file folder has “top secret” on the front. Two film cameras on tripods are visible. There is a small screen on a stand close to the back wall of the room. Its shadow is very visible on the wall to the right of the photo. The room is painted in contrasting light and dark colours. The upper half of the wall is light with a dark chair rail and darker colour on the lower half. The carpet appears dark and has a rectangle pattern on it. There is a word affixed to the back wall and a bright light shines on it. The word appear to be “unite”, but the light makes it difficult to be certain.

At the front table sits a young Black woman with shoulder length dark, curly hair. She appears to be looking at something off to her right. She is wearing a white shirt with a pattern (difficult to tell what the pattern is) and is wearing a necklace. In front of her is a plastic cup with a white liquid inside – it gives the impression of being milk. There is a small, drawstring bag sitting on the table in front of her and an empty chair beside her. The black back of the chair is visible above the table top.

### **Plausible Assumptions**

- It is the woman’s birthday (re: “Happy birthday to the one and only ALENA!”)
- The woman’s name Is Alena (re: see above)
- The woman is an ABLE Ensemble cast member (re: “she is playing #detectiveoliviabenson in our new show”)
- The role she is playing is Detective Olivia Benson (re: above)
- The woman is perceived to be strong, fierce, and confident (re: “This gal channels strong, confident women...but she is pretty fierce all on her own”)
- The woman is comparable to Mariska Hargitay (re: “#mariskahargitay, @therealmariskahargity)

The woman has Down syndrome (re: physical appearance)

### **First Impressions**

Love the use of the words “strong”, “fierce”, “confident”. Offers resistance to how disabled people are traditionally represented.

Everything about the photo and comments offers resistance to traditional representations and negative stereotypes of disabled people, for example, participation in theatre, playing a Mariska Hargitay role, use of the words “fierce”, “confident”, and “strong” to describe the woman and the roles she plays.

What is missing – direct reference to disability.

### **My Reaction**

There is power in this photo. Something about her sitting at a table alone, surrounded by theatre equipment. She is in charge, she makes decision, she is someone you want to know. The

comments impact my reaction, provide insight for who this actor is and what it is like working with her.

## Analysis Framework

### Introduction

We will be using this coding sheet to identify and code data randomly selected for inclusion in this study. Data will be randomly selected from publicly accessible Instagram accounts exhibiting self-representations or representations from the perspective of disabled people.

### Manifest Analysis

#### Image Identifiers

Manifest analysis of the data will begin with the following categories to identify specific images included in the study should we need to do so on a case-by-case basis.

IMAGE NO:     ABLE 5                   (Running total on the number of image)

POST DATE:    17/11/2017           (Date the image was posted)

LIKES:           17                   (Number of likes image received)

The following categories will be used in the manifest analysis of data randomly selected for inclusion in this study. Manifest analysis will include a detailed description of what is immediately observable in the data.

IMAGE\_TYPE (Identifies image as photo or video)

photo
-------

FONT (Size and type of font used in the post)

Neue Helvetica
----------------

LOCATION (Physical location as shown in image. E.g. gym, dance studio, theatre, park)

Theatre rehearsal space
-------------------------

ACTIVITY (Description of activity taking place in the image)

Theatre related activity (rehearsal possibly)

PPL (Concrete details regarding people included in the image E.g. physical characteristics, clothing, etc.)

Adult female sitting behind a table visible from mid torso up. Shoulder length, dark, curly hair worn down, white short sleeved shirt, necklace, looking to her right. Long table covered in black cloth. Binders and papers resting on top of the table. Cameras and lights visible in background

CPTNS/CMNTS/HSHTGS (Captions, comments and hashtags included with the post by the account owner)

Happy birthday to the one and only ALENA! This gal channels strong, confident women (she's playing #detectiveoliviabenson in our new show) but she is pretty fierce all on her own.  
#happybirthday #birthdaygirl #mariskahargitay @therealmariskahargitay

## Latent Analysis

### Analysis Framework

The latent analysis of data randomly selected for inclusion in this study will be guided by the categories listed on the following pages. Coding items in this section are adaptations of the five criteria Couser (2017) uses to define disability life writing and consistent with the work of Longmore (2017) and Zhang and Haller (2013).

RESPONSE (disability autobiography provides a response or retort to traditional misrepresentations of disability in Western culture)

\*See ABLE 1

COUNTER/CHALLENGE (disability life writing provides a counter or challenge to cultural script of being responsible for their disability)

\*See ABLE 1

CRITIQUE (disability life account provides a narrative that critiques oppressive structures and systems)

Themes present in image in evidence of critique: empowerment, acceptance/self-acceptance, confidence, ability/competence, fun, sense of purpose

ACCESS (disability life account provides controlled access to their lives; provides readers with a disability life account that counters the medical and mainstream media)

- Image represents perspective of person with disability (a day in the life of an actor)
- Authentic, real-life image: not posed, planned, serving purpose other than insight into theatre life for this actor
- Negative disability stereotypes and models not in evidence; countered by themes of fun, ability/competence, sense of purpose, empowerment

QUALITY OF LIFE (disability life account counters medical ethics; counters moralizing, objectifying, pathologizing, and marginalizing representations of impairment and peoples experiences of disability)

Themes providing evidence of quality of life: sense of purpose, empowerment, acceptance/self-acceptance, belonging/community, fun, ability/competence, success/accomplishment
---

This study sought to explore the ways in which disabled people represent themselves and to determine if these representations are consistent with or resistant to dominant ableist narratives. Exploring the representations of disabled people began with an inductive, iterative analysis of the data guided by Doucet (2007). Multiple rounds of manual and visual data analysis revealed numerous themes providing insight about how disabled people choose to represent themselves. The complete list of themes and subthemes is available in Appendix C.

Determining if disabled people represent themselves in ways consistent with or resistant to dominant ableist narratives relied on a comparison of the themes revealed by the data to the analysis framework I developed from the available literature, (previously in this document, see Appendix A). Accepting that disabled people are misrepresented through negative disability stereotypes and models of disability, the themes generated during multiple rounds of data analysis were compared to the analysis framework in order to elicit evidence of consistency with or resistance to dominant ableist narratives.

Study data consistently showed disabled people representing themselves in ways resistant to dominant ableist narratives. This resistant provides a disability counter-narrative that positively reframes and reimagines what disability is and who person with disability are. All the data in this study provide evidence of positive disability representation.



Initial rounds of data analysis guided by Doucet (2007) generated numerous subthemes. Iterative data analysis resulted in the reduction of the subthemes to six major themes. A complete account of subthemes and the resulting themes is available in Table 1.

## **Themes**

Iterative and inductive data analysis revealed numerous themes in the data. To ensure analysis was not limited by a restrictive analysis framework (Van den Hoonaard, 2012) the first three rounds of data analysis were guided by questions posed by Doucet (2007). Each round of analysis revealed subthemes that were later reduced to six themes. Table 1 provides complete details for all subthemes revealed through the initial rounds of data analysis, including the reduction of subthemes to themes. Themes revealed during final rounds of data analysis include affirmative disability ownership, sense of belonging, loving life living a big life, driving change, and don't tell me: I'll show you. Each of these themes is discussed in detail in the following section.

### **Affirmative Disability Ownership**

“I realized in order to empower myself, I must own my diagnosis and advocate for what I experienced in myself.” (Haller, 2010, p. 11)

This theme provides evidence of rejection traditional models of disability representation. Such models include the medical, rehabilitation, tragedy and social pathology model, each of which portrays disabled people as broken, damaged, in need of treatment, reliant on society, and/or better off dead because of their disability (Davis, 1999; Zhang & Haller, 2013). The affirmative disability ownership theme involves individuals with disability claiming their disability in a positive way.

Much of disability representation relies on minimizing the appearance of disability (Longmore, 2017) or representing aspects of the disability to elicit specific reactions in the non-disabled viewer (Couser, 2017; Longmore, 2017). How the disability is represented is decided by outsiders often lacking first-hand knowledge of what disability is and who disabled people are (Couser, 2017; Haller, 2010; Zhang & Haller, 2013). The data in this study provided a counter-narrative to this type of representation. Images revealed disabled people engaged in events such as birthday celebrations, community activities, career related events, and personal interests in ways that neither minimize the presence of disability nor sought to highlight only those aspects thought to be important to the non-disabled public. More than this, some images showed positive affirmation of the disability in ways consistent with the presence of pride.

Examples of images consistent with this theme include G-Mc's 6, CW 11, MS 8, and ABLE 5.

Hashtags consistent with the affirmative disability ownership theme include such #extrachromosomeextraawesome, #seetheability,, #rethinktherunway, and #changingthefaceofbeauty. Comments consistent with this theme include “This gal channels strong, confident women (She’s playing #detectiveoliviabenson in our new show) but she is pretty fierce all on her own.”, “DON’T FORGET TO BE AWESOME!”, “...as we share my trailblazing journey of diversity and inclusion.”

### **Sense of Belonging**

“...the experience of being excluded and misrepresented – from media, from mainstream libraries, archives and museums and even from community archives – has severely negative consequence on one’s sense of belonging or place in the world.” (Caswell et al, 2017, p.16)

Caswell, Migoni, Geraci, and Cifor (2017) discuss the ontological, epistemological, and social impacts communicated to traditionally misrepresented or underrepresented communities

that they exist and belong. The simple fact these self-representations exist is evidence of belonging. Diving deeper into the data it is evident the images reflect the different ways disabled people might belong: through membership in community organizations based on sport, theatre, dance, drama or as part of larger communities such as modelling. In displaying evidence of belonging, these images show disabled people have a place in society resisting misrepresentations that characterize disabled people as misfits, or maladjusted outcasts (Haller, 2010; Schwartz et al. 2010). The images that act as resistance to traditional misrepresentations also serve to communicate the presence of community for disabled people.

Images consistent with the sense of belonging theme include ALBE 7, GMC 5, CW 1, and MS 12. Belonging was in evidence through hashtags such as #inclusion, #whatibringtomycommunity, #gmcshomiesextrachromies, #niagara, #downsyndrome, #MilkTalent, #gymnastics, #model, #disability. Comments that spoke to belonging were “So happy we can be part of your new home, Jack!”, “G-Mc’s would like to wish our gal Sophie a Very Happy 14<sup>th</sup> birthday today.”

### **Loving Life**

...and might actually feel comfortable with our lives if it wasn’t for all those interfering busybodies who feel that it is their responsibility to feel sorry for us, or to find cures for us, or to manage our lives for us, or to harry us in order to make us something we are not i.e. ‘normal’ (Swain & French, 2000, p. 577)

This theme provides an alternate narrative to disability (mis)representation as framed as inconsistent with living a meaningful, fulfilled life. Examples from the data that evidence the loving life theme are seen in ABLE 3, GMC 2, CW 7, and MS 6. Hashtags consistent with the theme included #extrachromosomeextraawesome. #love, and #happy. Comments consistent with

the loving life theme include, but are not limited to “loving it”, “Don’t forget to be awesome”, “happy”.

### **Living a Big Life**

“Autobiography, then, can be an especially powerful medium in which disabled people can demonstrate that they have lives, in defiance of other common perceptions of them” (Couser, 2016, p. 435)

The living a big life theme serves as an alternate narrative to dominant disability narratives that frame disabled people as limited in what they can aspire to and achieve. Life unfettered by able-bodied expectations provides disabled people the opportunity to pursue self-defined goals. While this theme could be seen as consistent with the supercrip stereotype.

Haller (2010) discusses how mainstream media uses the supercrip stereotype to report on successful disabled people as an oddity or one of a kind example to appease the public and conform to ableist narratives. I contend only disabled people are positioned to decide which disability representations may or may not be labelled as supercrip. The able-bodied know nothing of the barriers and discrimination faced by disabled people and so cannot give context to the supercrip treatment. Therefore, it is only from within the disability community that this label can be properly applied.

Living a big life can be seen in numerous images included in this study including ABLE 9, G-Mc’s 3, CW 6, and MS 4. Hashtags consistent with the living my big life theme include #theatreinchicago, #ladiesman, #MiLKTalent, and #model. Comments that speak to the living my big life theme can be seen in “We got to play with #costumes for the first time in rehearsal tonight!”, “We are super excited to announce our latest signing, Champion gymnast and trailblazer Chelsea Werner.”, “Getting ready for the ceremony to start @socialawards”.

## Driving Change

“Don’t just talk about it, *be* about it” (Desnoyers-Colas, 2019, p. 104)

This theme includes the different ways change is addressed in the data. Fundraising and non-profit initiatives aimed at inclusion, improving diversity, disability awareness, and advocacy are all part of the driving change theme. This theme was represented differently in the Instagram accounts of individuals (Chelsea Werner, Madeline Stuart) as compared to group accounts (ABLE, GMC). Images, comments, and hashtags posted to the accounts of Madeline Stuart and Chelsea Werner consistent with the driving change theme included evidence of agency and gave the impression of intentional engagement in specific activities that would drive change and shift dominant disability narratives. An example is provided by the image and accompanying comments of MS 8 featuring Madeline Stuart as spokesperson for International Women’s Day. In comparison, posts uploaded to the Instagram accounts of G-Mc’s and ABLE lack the same sense of agency and could be construed as more consistent with Longmore’s conception of philanthropic work where images of pathetic and vulnerable disabled people were used to fundraise money that would treat, cure, and eliminate disability. An example is the use of the hashtag #openheartopenmind, which I initially found problematic (noted in memos). Iterative data analysis allowed for a deeper understanding of the data included in this study reveals a very different approach to fundraising where monies raised are used to provide disabled people to live their best lives. This type of fundraising is resistant to Longmore’s (2016) description of charity fundraising and consistent with organizations taking on a disability ally role (Anicha, Bilene-Greene & Burnett, 2018).

The use of hashtags to highlight theatre, sport, or modelling engagement are consistent with driving change because they identify images of disabled people engaged in activities inconsistent with dominant disability narratives. Hashtags such as #whatibringtomycommunity,

#appliedtheatre, #artsed. #artseducation, #theatrechicago fall into this category and though they may not appear to be related to driving change, these hashtags speak to what disabled people can accomplish when they are not limited by socially constructed concepts of disability.

Additional images providing evidence of the driving change theme are MS 7, CW 8, ABLE 2, and GMC 3. The driving change theme is evident in numerous hashtags including #crowdfunding, #hatchfund, #donors, #downsyndromeawareness, and #extrachromosomeextraawesome. Comments consistent with the driving change theme include “Did you know our film #TheSpyWhoKnewMe was made possible by the over 140 individual contributions to our #crowdfunding campaign on @hatchfund?!”, and “I’m so excited to share that I just signed with @milkmodelmanagement in London GB”.

### **Don’t Tell Me; I’ll Show You**

“Once you take control of your narrative, you can start to stand up for yourself, and other people stop limiting you for who you are.” (Okello et al., 2020, p. 433)

This theme speaks to the ways in which disabled people choose to narrate their own story, what they decide to reveal to the world around them. Any of the images included in this study are examples of this theme because they show disabled people engaged in activities best described as falling outside ableist narratives. MS 8, CW 1, ABLE 5, and GMC 6 provide excellent examples. Hashtags consistent with the don’t tell me, I’ll show you theme include #extrachromosomeextraawesome, #model, #changingthefaceofbeauty, #gymnastics, #seetheability. Comments that provide evidence of this theme are “Rachel was one of our founding ensemble members, perhaps best known for starring as Tabitha Link in our #spymovie #thespywhoknewme.”, “Walking fotlr [sic] the amazing @sanchezfasion at @theartsfashion at

@LAFashionweek”, “Chelsea has won the Special Olympics US Championships four times and is a two-time World Champion.”

Table 3 details how themes relate to the framework analysis categories. Framework analysis categories are not mutually exclusive and so themes may be consistent with more than one analysis category. For example, the “don’t tell me; I’ll show you” theme is consistent with RESPONSE, CHALLENGE/COUNTER, and ACCESS framework analysis categories. A total of thirty-nine images are included as data in this study. Each image provides evidence for each of the five framework analysis categories. For this reason, I contend that every image included in this study provides an example of self-representative disability life writing grounded in lived experience that creates a counter-narrative controlled from the subject position.

## Discussion

The purpose of this study was to explore the ways in which disabled people represent themselves and to determine if these representation are consistent with or resistant to dominant ableist narratives. Publicly accessible Instagram accounts owned by disabled people or managed by organizations dedicated to the perspective of disabled people were analyzed via inductive and deductive content analysis. The results of this study reveal disabled people choose to represent themselves in ways resistant to disability (mis)representation in mass media. Self-representation as seen in the data included in this study serves to provide a counter narrative to dominant disability narratives allowing the viewer, disabled or non-disabled, to reimagine who disabled people are and what it might mean to live with disability.

Current critical disability literature points out that disability has been negatively framed by mass media. Yet, findings from this study reveal a marked absence of negative disability stereotypes (e.g. maladjusted, own worst enemy, better off dead, personal tragedy) as well as negative models of disability (e.g. the medical, rehabilitation, or social pathology). This could be explained by a number of factors. First, disability (mis)representation in mass media has rarely been informed by the lived experiences of disabled people leading to representations constructed by the able-bodied. First-hand accounts of life as experienced by disabled people provides very different ways of representing disability reflecting an emic perspective. Another contributing factor is the data for this study comes from Instagram accounts managed by persons living in the developed (North American/European) world impacting the degree of oppression and marginalization. Class intersects with disability in ways that exacerbate marginalization and oppression (Charlton, 1998). This may explain why these models of disability are absent from



the data while acknowledging that disabled people are poor and powerless regardless of geographical location (Charlton, 1998).

The disability representations included in this study extend beyond one-dimensional representations of individuals. In representing themselves as multidimensional persons engaged in a variety of non-disability related activities and pursuing numerous interests disability is relegated to the role of just one characteristic, as opposed to the dominating characteristic or master status, of the individual (Couser, 2017). Thoreau (2006) discusses similar findings in her exploration of the self-representation of disabled people in *Ouch*, a BBC-owned magazine written and produced predominantly by disabled people.

The data included in this study not only reveals resistance to dominant ableist disability narratives, it presents evidence of an affirmation model of disability. The affirmation model of disability is described by Swain and French (2000) as a “non-tragic view of disability and impairment that encompasses positive social identities...grounded in the benefits of life style and life experience of being impaired and disabled” (p. 569). This model of disability is most commonly seen when disabled people take control of their narrative and present their lived experiences from their personal perspective (Stamou, Alevraidou & Soufla, 2016; Thoreau, 2006). In this way, disabled people are able to frame their lived experiences in ways that highlight the benefits of life with a disability, something rarely accomplished by the able-bodied as a result of beliefs firmly rooted in the tragedy or medical models of disability. This model of disability moves beyond the social model, which frames disability as originating not with the individual in possession of the impairment, but in the environmental and social structures that surrounded them. Said another way, it is the attitudes and physical environment that disable individuals with impairments. It is through these positive disability self-representations that narrative of disability can shift from marking disabled people as in need of treatment and cures to

persons with differences that should be acknowledged and accommodated (Couser, 2011), demanding the right to be as they are, different and equal (Swain & French, 2000).

This study provides an opportunity to reimagine what disability is and who disabled people are. The ways disabled people choose to represent themselves as presented in this study provides a pathway from disability as personal tragedy to an affirmation model of disability. Controlling their narrative and representing disability from their own lived experiences reframes disability as a positive, even beneficial experience:

“We are not usually snapped up in the flower of youth for our domestic and child rearing skills, or for our decorative value, so we do not have to spend years disentangling ourselves from wearisome relationships as is the case with many non-disabled women,”  
(Swain & French, 2000, p. 577)

The fashion industry appears to be moving quickly towards inclusion of disabled people, be it on the runway, in television or magazine advertisements, or more inclusive fashion. Such initiatives may be evidence of a genuine shift towards a more inclusive fashion industry or may be tokenism (Clymo, 2021). Another consideration is what types of disabilities are being represented: models with Down syndrome have been used by a number of companies in advertising campaigns (for example Target, The Gap). This could signal the beginning of companies shifting to more inclusive practices, however, it must be noted that only certain kinds of models with a certain kind of look which adheres to dominant beauty standards are included. This may be an area for future exploration.

There is a marked absence of dominant ableist narratives across the Instagram accounts included in this study. A superficial exploration of the images would lead me to conclude that disabled people do not see themselves in negative ways. Reflecting on the use of artifacts as a data source, I recognized I must consider not only what is included in the data, but what is

missing, and why (Van den Hoonaard, 2019). There is intent in leaving out the negative, be it to construct a brand, as in the case of Madeline Stuart and Chelsea Werner, or to promote an organization in a positive way as with A.B.L.E. Ensemble and G-Mc's Homies with Extra Chromies. The images included as data in this study lead me to question the intent behind the omission of dominant ableist narratives, a question that needs to be addressed to Instagram account owners. This may be an area for future exploration.

The representations included in this study are predominantly collaborative. During the initial rounds of analysis, I was uncomfortable with the amount of collaboration as it led me to question how self-representative the images are. I considered that these representations as the work of nondisabled people striving towards a particular agenda – a daughter's celebrity, monetary gain, constructing a non-profit organization's reputation. However, I contend that the collaborations evidenced here are examples of partnerships between marginalized individuals and their allies. Allies are individuals who benefit from automatic, unearned power and privilege as a result of membership in a dominant social group and who choose to engage in activities that systemically empower marginalized individuals and groups (Scholz, Roper, Juntanamalaga, & Happell, 2019; Veer, Zahrai & Stevens, 2021). Anicha, Bilen-Green and Burnett (2018) note that being an ally not only involves entering into relationships for the purpose of pursuing shared goals, but also engaging in advocacy to support a cause, and being accountable to and with those with whom alliances are forged. Recent social justice movements, such as #MeToo, BLM, and Truth and Reconciliation have highlighted the need to question dominant hegemonies and explore how to dismantle systems of oppression. This critical work of persisting and resisting frequently falls to those most effected, often with personal and professional consequences (Lee & Cunningham, 2019; Teetzel, Frederick, Hums, & Alagaraja, 2020), and inevitable fatigue and exhaustion (Desnoyers-Colas, 2019). Meaningful and positive change must be informed by the

emic perspective, however, there is a crucial role for allies to play (Munin & Speight, 2010; Scholz, Roper, Juntanamalaga, & Happell, 2019). Thus, Roseanne Stuart speaking for Madeline during interviews (Amplify, 2017) is acting as an ally to mitigate the ableist preference for the spoken word (Gomez-Victoria & Pava-Ripoll, 2021) and G-Mc's Homies with Extra Chromies providing opportunities for crossfit workouts is not an act of isolating individuals with Down syndrome away from the ableist gaze but the provision of an exercise environment that meets the needs of its clients.

It is imperative to address the issue of people first versus identity first language. This study has been a process of learning and, in many ways, unlearning. In its original draft this document used people first language. One of the final edits included changing all people first language to identity first language. Raised in an ableist society and despite connections with the local disability community I was informed that people first language was the most inclusive and respectful way to refer to disabled people. Numerous disability scholars and writers have discussed how people first language seeks to hide or obscure the presence of a disability (Crossman, 2019; Ellis, 2006). The use of people first language perpetuates the medical model of disability while identity first language situates disability in a way consistent with the affirmation model of disability (Swain & French, 2000). Consultation with my advisor and external examiner resulted in my decision to use identity first language throughout the document..

The images included in this study feature intellectually disabled people alone. Nario-Redmond (2020) discusses the power of negative disability stereotypes and the impact these stereotypes have on disabled people. When nondisabled people encounter representations of disabled people that conform to negative disability stereotypes, it is easy to accept the representations as accurate and factual. However, when nondisabled people encounter

representations of disabled people that fail to conform to dominant ableist narratives, it is easy to dismiss such representations as unauthentic or an exception to the norm. In this study, intellectually disabled people are featured alone as a result of data selection criteria decided upon to facilitate the manifest analysis of the images. In contrast to the images included in this study, many of the images uploaded to the four Instagram accounts featured groups of individuals, specifically images from A.B.L.E. Ensemble and G-Mc's Homies with Extra Chromies. Furthermore, the presence of multiple images featuring intellectually disabled people engaged in a variety of activities, often in connection to an organization to which they belong, serves to provide a counter-narrative to dominant ableist narratives that situation intellectually disabled people as less desirable, socially acceptable, or competent as compared to nondisabled peers.

### **Study Limitations**

This study utilized qualitative content analysis to explore the ways in which disabled people choose to represent themselves. While content analysis offers many benefits, it is described as a less established analysis process that might create challenges for the researcher (Cho & Lee, 2014). As a single researcher working on this study, I could not address all the available data provided by each of the Instagram accounts included. Qualitative content analysis is both time-consuming and labour intensive (Cho & Lee, 2014). The methodology combined with the volume of available data and the time available to complete a Master's thesis limit my ability to analyze the complete set of posts uploaded to each Instagram account. As a result, it is possible that themes relevant to the research question were missed. Similarly, the amount of data available changes with each additional post uploaded to a specific Instagram account. Posts uploaded after the end date used in the study were not included in the set of data from which

random samples were taken, again making it possible that specific types of representation were not included in the study.

This study sought to explore self-representation or representation from the perspective of disabled people. The information available regarding Instagram account management is not sufficient to determine with certainty who makes decisions regarding which images are posted and what comments are provided. This impacts the extent to which agency and self-representation may or may not be present in the data.

While I may have greater insight into the lived experiences of disabled people and believe that disability self-representation is vital to understanding what it means to live with a disability, I do not have a disability myself (Couser, 2000). I have been raised in an ableist society and in the process of unlearning almost everything I thought I knew about disability. I have tried to question what I think I know while understanding I will make mistakes. Ideally, decisions regarding the selection and inclusion of images in a study such as this one would not be made by me but by disabled people. Given the opportunity, disabled people may have a different interpretation of the data than my own, presenting an area for future exploration.

The lack of publicly accessible social media accounts managed by persons with Down syndrome limits data availability. Additionally, disabled people who choose to make their social media accounts publicly accessible may differ from disabled people who choose to keep their social media accounts private. For example, Madeline Stuart and Chelsea Werner are Instagram micro-celebrities and Instagram Influencers. Their Instagram accounts are curated toward a goal of elevating a brand. For these reasons it must be recognized that these Instagram accounts may not be representative. Member checking could be a way to resolve this limitation. However, because the data in this study comes from publicly accessible social media accounts and does not involve human participants, checking is not possible.

Finally, the data included in this study represents individuals who are white and reside in developed countries. As such, intersectionality is largely absent from this study (Charlton, 1998). Future research could explore how disability is represented in less developed countries

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## Appendices

### Appendix A:

#### Analysis Framework

##### **Introduction**

We will be using this coding sheet to identify and code data randomly selected for inclusion in this study. Data will be randomly selected from publicly accessible Instagram accounts exhibiting self-representations or representations from the perspective of disabled people.

##### **Manifest Analysis**

##### **Image Identifiers**

Manifest analysis of the data will begin with the following categories to identify specific images included in the study should we need to do so on a case-by-case basis.

Column \_\_\_\_: IMAGE\_NO: \_\_\_\_\_ (Running total on the number of images)

Column \_\_\_\_: POST\_DATE: \_\_\_\_\_ (Date the image was posted)

Column \_\_\_\_: LIKES: \_\_\_\_\_ (Number of likes image received)

The following categories will be used in the manifest analysis of data randomly selected for inclusion in this study. Manifest analysis will include a detailed description of what is immediately observable in the data.

Column \_\_\_\_: IMAGE\_TYPE (Identifies image as photo or video)

--



Column \_\_: FONT (Size and type of font used in the post)

Column \_\_: LOCATION (Physical location as shown in image. E.g. gym, dance studio,

theatre, park)

Column \_\_: ACTIVITY (Description of activity taking place in the image)

Column \_\_: PPL\_NO: \_\_\_\_\_ (Number of people in the photo)

Column \_\_: PPL (Concrete details regarding people included in the image E.g. physical characteristics, clothing, etc.)

Column \_\_: CPTNS/CMNTS/HSHTGS (Captions, comments and hashtags included with the post by the account owner)

## Latent Analysis

### Analysis Framework

The latent analysis of data randomly selected for inclusion in this study will be guided by the categories listed on the following pages. Coding items in this section are adaptations of the five criteria Couser (2017) uses to define disability life writing and consistent with the work of Longmore (2017) and Zhang and Haller (2013).

Column \_\_\_\_: RESPONSE (disability autobiography provides a response or retort to traditional misrepresentations of disability in Western culture)

--

Column \_\_\_\_: COUNTER/CHALLENGE (disability life writing provides a counter or challenge to cultural script of being responsible for their disability)

--

Column \_\_\_\_: CRITIQUE (disability life account provides a narrative that critiques oppressive structures and systems)

--

Column \_\_\_\_: CONTROLLED ACCESS (disability life account provides controlled access to their lives; provides readers with a disability life account that counters the medical and

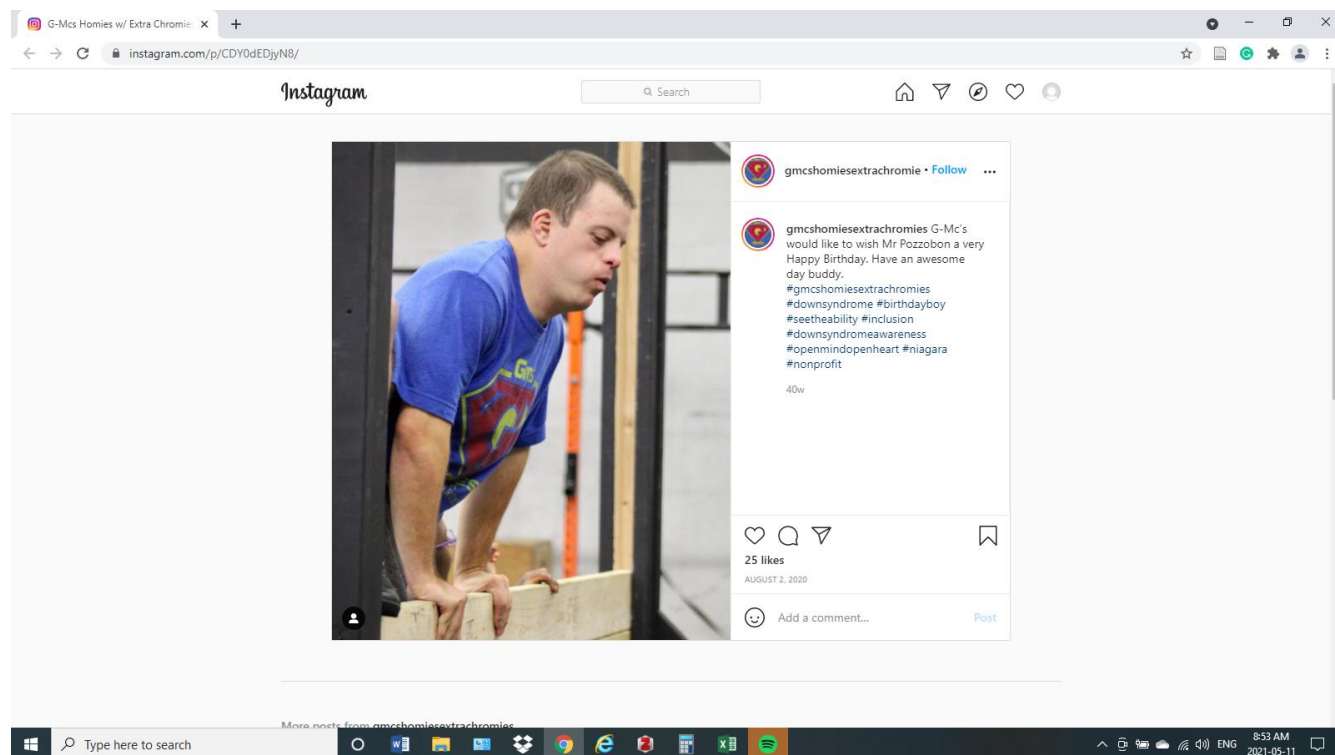
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mainstream media)

Column \_\_\_\_: QUALITY OF LIFE (disability life account counters medical ethics; counters moralizing, objectifying, pathologizing, and marginalizing representations of impairment and peoples experiences of disability)

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## Appendix B



### First Impressions

#### Photo 6

- Action shot resists negative stereotypes and models of disability
- #inclusion suggests advocacy and awareness
- #seetheability suggests not defining disabled people by their disability
- #openheartopenmind suggests sympathy, pity
- Showing participation in a crossfit event resists dominant narrative
- Origins of the photo not confirmed; may not be self-representation

### My Reaction

These photos leave me with a sense of satisfaction and happiness. Having an insiders understanding of the organization impacts how I interpret these photos. I am grateful that others see the importance of providing opportunities for persons with Down syndrome to explore healthy living and socialize (grateful in the context of understanding one of the most significant barriers for persons with disabilities accessing recreation and fitness is a lack of access – access to programs, facilities, instructors, and finances).

Specific to how crossfit works in the G-Mc's organization, G-Mc's has partnered with a local crossfit gym to provide a space, equipment, and volunteers for the G-Mc's members. This service is provided at no charge to the G-Mc's members, which is possible (I assume) through the fundraising G-Mc's does. The volunteers benefit the G-Mc's members in that they are able

to provide guidance and support during the workouts, but the volunteers benefit through the opportunity to engage with disabled people (Haller, 2010; Couser, 2017). This can serve to shift the dominant narrative of disability in Western society.

The photos are very natural i.e. not posed, individuals not styled (as compared to CW and MS). This serves to demystify disability, providing snapshots of ordinary and authentic moments in the lives of disabled people. The supercrip model is absent (IMO) as are the social pathology and medical models of disability. I interpret the photos as “normalizing” (not sure if there is a better way to describe). Quality of life and well-being are present as individuals appear happy, engaged, enjoying the moment, and having fun. There is a sense of celebration as many of the photos are accompanied by comments celebrating a birthday. The range of individuals represented (male, female, older, younger, various body types) helps to show Down syndrome is not one thing or one type of person (resists representations of disability; reminiscent of more alike than different).

Specific to photo 6: I can feel his effort, so focused. There is the impression of strength and great concentration, and resistance to dominant disability narratives in these.

G-Mc's Photo 6

Likes:25

Posted August 2, 2020

Comment: G-Mc's would like to wish Mr Pozzobon a very Happy Birthday. Have an awesome day buddy. #gmcshomiesextrachromies #downsyndrome #birthdayboy #seetheability #inclusion #downsyndromeawareness #openmindopenheart #niagara #nonprofit

### **Manifest Analysis**

- Young man with blond hair appears to be exhaling (cheeks slightly puffed and mouth held in shape of “o”), arms are straight with elbows locked, hands place on top of wood board giving the appearance he is pushing down on the board
- Wearing blue t-shirt with partial logo visible; logo is red and yellow, reminiscent of Superman “S” logo; yellow letter “G” visible at top of logo with red “G” visible below; no other parts of the logo are clearly visible
- Part of a leg bent and shoe just visible on the left side of the photo
- Appears to be a black frame to the left and right of the individual with wooden boards set into the frame
- Photo background is white/grey with black rectangles visible on the wall; vertical orange line also visible in background
- Partial trapezoid shape containing the letter “C”, all in black, also visible
- Another individual is barely visible in the space formed between the young man's torso and arm – side profile of an individual's temple and cheek, arm and lens of glasses

### **Plausible Interpretations**

- The young man is celebrating a birthday (re: “G-Mc's would like to wish Mr Pozzobon a very Happy Birthday”)
- The young man's last name is Pozzobon (re: “Mr Pozzobon”)

- The young man is a member of G-Mc's Homies with Extra Chromies (re: G-Mc's organization wishing him happy birthday, #birthdayboy)
- The photo was taken at a G-Mc's event (re: wearing a G-Mc's t-shirt, visible equipment and background suggests crossfit gym)
- The young man is participating in a G-Mc's crossfit event
- He is climbing over an wooden obstacle (re: wood boards, position of arms and partial leg and shoe visible)

### **Latent Analysis**

- Action shot resists negative stereotypes and models of disability
- #inclusion suggests advocacy and awareness
- #seetheability suggests not defining disabled people by their disability
- #openheartopenmind suggests sympathy, pity
- Showing participation in a crossfit event resists dominant narrative
- Origins of the photo not confirmed; may not be self-representation

## Analysis Framework

### Introduction

We will be using this coding sheet to identify and code data randomly selected for inclusion in this study. Data will be randomly selected from publicly accessible Instagram accounts exhibiting self-representations or representations from the perspective of disabled people.

### Manifest Analysis

#### Image Identifiers

Manifest analysis of the data will begin with the following categories to identify specific images included in the study should we need to do so on a case-by-case basis.

IMAGE NO: GMC 5 (Running total on the number of image)

POST DATE: 11/04/2020 (Date the image was posted)

LIKES: 57 (Number of likes image received)

The following categories will be used in the manifest analysis of data randomly selected for inclusion in this study. Manifest analysis will include a detailed description of what is immediately observable in the data.

IMAGE\_TYPE (Identifies image as photo or video)

photo
-------

FONT (Size and type of font used in the post)

Neue Helvetica
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LOCATION (Physical location as shown in image. E.g. gym, dance studio, theatre, park)

Gym (assumed because it GMC's)

ACTIVITY (Description of activity taking place in the image)

Facing camera

PPL (Concrete details regarding people included in the image E.g. physical characteristics, clothing, etc.)

Female individual, shoulder length blond hair worn down, smiling and facing camera, grey tank top, hands appear to be resting on hips

CPTNS/CMNTS/HSHTGS (Captions, comments and hashtags included with the post by the account owner)

G-Mc's would like to wish our gal Sophie a Very Happy 14<sup>th</sup> birthday today. We hope you have an awesome day and fill up no LOTS of Easter treats! #gmcshomiesextrachromies #birthdaygirl #downsyndrome #seetheability #inclusion #openmindopenheart #niagara #nonprofit



## Latent Analysis

### Analysis Framework

The latent analysis of data randomly selected for inclusion in this study will be guided by the categories listed on the following pages. Coding items in this section are adaptations of the five criteria Couser (2017) uses to define disability life writing and consistent with the work of Longmore (2017) and Zhang and Haller (2013).

RESPONSE (disability autobiography provides a response or retort to traditional misrepresentations of disability in Western culture)

See ABLE 1

COUNTER/CHALLENGE (disability life writing provides a counter or challenge to cultural script of being responsible for their disability)

See GMC 1

CRITIQUE (disability life account provides a narrative that critiques oppressive structures and systems)

Themes present in the image consistent with critique: fun, value/worth, belonging/community, ability/competence, success/accomplishment  
\*first image from this IG data set to include #seetheability

ACCESS (disability life account provides controlled access to their lives; provides readers with a disability life account that counters the medical and mainstream media)

Image offers a counter narrative from the perspective of disabled people with intent to provide representation inconsistent with dominant disability narrative

- Day in the life, moment in time
- Candid, not posed or planned
- Impression of fun, positivity, value, celebration

QUALITY OF LIFE (disability life account counters medical ethics; counters moralizing, objectifying, pathologizing, and marginalizing representations of impairment and peoples experiences of disability)

Themes present in the image consistent with quality of life: belonging/community, acceptance/self-acceptance, fun/celebration, value/worth, ability/competence, success/achievement

## Appendix C

## Themes and Subthemes Generated During Data Analysis

Themes		Subthemes					
Disability Empowerment	Confidence	Pride	Acceptance/ self-acceptance	Disability affirmation	Value/worth	Diversity	Normalizing/ demystifying
Sense of Belonging	community *include theatre, sport, modelling	inclusion	Down syndrome				
Making a Difference	advocacy	awareness	non-profit				
Living a Big Life	modelling/fashion	travel	Down syndrome	Sport	theatre	sense of purpose	
Loving Life	joy/fun	hope	disability	travel	celebration	appreciation	positivity
See the Ability	disability *used here in the sense of owning the disability and representing ability	milestones	competence	achievement/ accomplishment			

