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### Members of the Disability Community and their Perceptions of Disability Representation in the Media: A Qualitative Study

By

### **Stephanie Cragg**

A Dissertation Submitted to the Faculty of Graduate Studies through the Department of Psychology in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy at the University of Windsor

Windsor, Ontario, Canada

2024

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### Members of the Disability Community and their Perceptions of Disability Representation in the Media: A Qualitative Study

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August 26, 2024

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#### ABSTRACT

The media can have a strong impact on our perceptions of many topics, including disability. Disabled individuals are underrepresented in the media, and many disabled characters are presented in terms of stereotypes. This can have an impact on perceptions of disability, particularly for non-disabled individuals who may not have many interactions with disabled individuals. Additionally, very few studies have been conducted that look at the perspectives of disabled individuals on disability representations in the media. This study sought to address this gap in the literature by using online focus groups of disabled individuals to watch and discuss media representations that have been perceived to be controversial within the disability community. The three disabilities that were the focus of this study were Turner Syndrome, autism, and mobility impairments requiring the use of a wheelchair. The media portrayal that was watched in the Turner Syndrome focus groups was the episode 'Clock' from Law and Order: SVU. The media portrayal that was watched in the autism focus groups was the episode 'Antarctica' from Atypical, and the media portrayal that was watched in the mobility impairment focus groups was the episode 'Dream On' from Glee.

The research questions that were the focus of this study were: 1) What are the perspectives about controversial portrayals of various disabilities in the media by individuals who have been diagnosed with those disabilities? 2) How could these portrayals impact perceptions of stigma regarding disabilities? and 3) How can disabled characters be portrayed to be more diverse and nuanced and to reduce stigmatizing beliefs towards disabilities?

In total, 34 participants were involved in this study across seven focus groups: three focus groups for Turner Syndrome participants (n=11) (including a pilot test), two focus groups for autistic participants (n=11), and two focus groups for participants with mobility impairments requiring use of a wheelchair (n=12). Reflexive Thematic Analysis (Braun & Clarke, 2022) was used to identify themes and subthemes. Evaluating perspectives of controversial media portrayals led to two main themes: "I liked that" and "That doesn't sit right with me". Participants appreciated disability representations that were relatable and respectful and critiqued disability representations that they could not relate to, featured disability tropes and stereotypes, and those that were felt to be unrealistic based on their disability knowledge or experiences. Participant perspectives regarding how portrayals could impact stigma led to two main themes: "That's harmful" and "That's helpful". Participants felt that media representations of disability could negatively impact stigma by reinforcing ableism and stereotypes and positively impact stigma by subverting stereotypes and educating viewers. The final research question on how disabled characters could be portrayed to be more diverse and nuanced and to reduce stigma led to five main themes: "Address the barriers", "Celebrate diversity", "Do your research", "Give us the stage", and "Be positive". Participants wanted to see barriers in the industry for disabled actors removed, greater diversity in disabled characters, increased disability research and consultation, more disabled individuals in front of and behind the scenes, and more positive and nuanced storylines. This study is one of the few that focuses on the voices of disabled individuals regarding how their disabilities are portrayed in the media and details several suggestions for the media and entertainment industries to create more nuanced and diverse disabled characters and storylines.

### DEDICATION

There are many people who I would like to dedicate this work to. Firstly, to all of the participants who were willing to share their thoughts and experiences with me. I truly value your trust. Also, to all of my family and friends for all of your unwavering support throughout this entire process.

#### ACKNOWLEDGEMENTS

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### Members of the Disability Community and their Perceptions of Disability Representation in the Media: A Qualitative Study

#### **CHAPTER I: Introduction**

Disability portrayals in the media have been a topic that has been heatedly discussed within the disability community and the entertainment industry for decades. Many of these critiques center around the disability stereotypes frequently used in portrayals, the inaccurate information or sensationalized portrayals of symptoms that can be seen in media representations, and disabled characters being played by non-disabled actors (for example, see Ingram, 2016). A recent media portrayal that has faced critiques from the disability community is the movie *The Witches*. In this portrayal the witches displayed physical characteristics of ectrodactyly, missing one or more fingers from their hands, which was used to portray the witches as scary and to be feared (Galuppo, 2020). Members of the disability community noted that this physical characteristic was not present in the book that the movie was based on, and therefore was added by the creators without considering the impact of those affected by ectrodactyly (Galuppo). Such portrayals can have a strong impact on viewers and their attitudes towards disabilities, particularly if viewers have not had any first-hand experience or connections with disabled persons. For some viewers, such portrayals may be the first time they have encountered certain disabilities, potentially increasing the impact of such portrayals.

Characters with disabilities are also significantly underrepresented in the media. The Gay and Lesbian Alliance Against Defamation [GLAAD] Media Institute (2021) noted that only 3.5% of characters that were series regulars on television were identified as having a visible or invisible disability in storylines. Furthermore, Galuppo (2020) noted that according to the USC's Annenberg Inclusion Initiative, only 1.6 percent of characters with spoken lines had a disability in the top 100 most financially successful films of 2018, even though approximately 25 percent of the American population has been diagnosed with a disability, according to a 2018 report from the Centers for Disease Control and Prevention. Based on these statistics, disabled persons represent a market of approximately one billion dollars according to the U.S. Census Bureau (as cited by Galuppo). It is apparent that disabled persons are a large segment of the population that are not seeing themselves represented in the media, and as such the entertainment industry is missing out on potential opportunities and viewers. Media representations can also impact how individuals in the disability community view their own disabilities, which could impact their self-image and self-esteem.

Changes are starting to be seen within the media and entertainment industries. Social media has allowed many disabled persons to have a voice, discuss their perspectives and experiences, and educate non-disabled people about disabilities and disability issues. Many of the media portrayals perceived to be problematic could also be eliminated by individuals in the entertainment and media industries engaging in greater consultation with individuals in the disability community and hiring them for roles both in front of and behind the camera. By including the input and involvement of disabled persons, many of the stereotypes and inaccurate information in portrayals could be eliminated, and more diverse and nuanced portrayals and views could be fostered. Increasing disability representation will also allow media and entertainment organizations to reach a large segment of the population and obtain more viewers and support from within the disability community. The research which was conducted for this dissertation was a qualitative exploration of the perceptions of disabled persons on media representations of their disability. The introduction will begin with situating myself as a researcher and my interest in disability representation and the media, as well as an outline of the theoretical and methodological positioning of the research project. The introduction will then move into a discussion of the impact of the media and the impact of media representations of disabilities, as well as the theoretical lenses that were used to explore these topics during the qualitative study. Then the methodology and procedures of the study will be discussed. Finally, the results of the qualitative research project will be discussed, as well as the strengths, limitations, impact, and knowledge translation goals of the study results.

Before proceeding, I want to discuss my language choices in this paper. Following the wording and justification used by disabled author Amanda Leduc (2020) after numerous consultations with the disability community, I have chosen to use identity-first language when referring to disabled persons. Leduc compared identity-first and person-first languages and noted that identity-first language places the disability as an important part of the person and how they navigate and experience their world, while person-first language places the primary consideration on the individual as a person and their disability as secondary. When discussing these language options further, Leduc noted that disability activists generally agree that although the reasoning behind personfirst language means well, it creates a separation between disability and identity which can serve to perpetuate the idea that disability is negative.

#### **Situating the Researcher**

First, I would like to discuss my personal identities and experiences and how they have led to my interest in this research topic. I was born with a disability called Turner Syndrome which was diagnosed when I was four years old. I also acknowledge that I hold relative privilege within the Turner Syndrome community, as I am affected mildly by the syndrome. The most noticeable aspects of Turner Syndrome that I have experienced are short stature (I am 4'2") and hearing loss requiring hearing aids (Charney & Smillie, 1987; Deal, 2008). As a result, I do not experience many of the comorbid health issues connected with Turner Syndrome. When I was obtaining my undergraduate degree in developmental psychology at the University of Windsor, I decided to write my undergraduate thesis on the effects of Turner Syndrome on the self-esteem and body image of women with the diagnosis (Cragg & Lafreniere, 2010). This project put me in contact with the Turner Syndrome Society of Canada, which assisted me with advertising my study and recruiting participants. The Turner Syndrome Society of Canada invited me to present my research findings at their annual conference, and a year later invited me to become a member of their board of directors. Since that time, I have served as the secretary on the board of directors, and I finished my term as the board president in 2020.

These experiences also led to my interest in wider disability issues and advocacy. In 2010 when I was obtaining my Master's in Social Work at the University of Windsor, I became a student member of the School of Social Work and Disability Studies Accessibility Planning Committee, which was creating an accessibility plan to be implemented within the school of social work and the disability studies program. This committee was a uniquely student-driven and led grassroots initiative focused within specific campus departments. As a student member, I was also involved in a research project to document the history and development of the committee through interviewing previous and current faculty and student members of the committee. This research led to presentations regarding the accessibility awareness committee, recommendations on how to implement grassroots accessibility initiatives, and disability representation and inclusion in the media at several annual Accessibility Awareness days at the University of Windsor.

My dissertation topic also arose from my interest in entertainment and the arts. I have been participating in community theatre in Windsor for over 20 years. During this time, I have had the opportunity to get to know so many wonderful individuals and to participate in productions that have raised awareness of and addressed many important social issues. However, I have also experienced challenges related to my height, such as determining pairings of roles, such as when two actors are playing a couple, based on the similar heights of actors. I have also witnessed a significant lack of characters and actors with disabilities within the theatre community and in the wider entertainment industry. One experience that led me to this topic was viewing an extremely inaccurate representation of Turner Syndrome in the media, which greatly frustrated me. While researching media representations of Turner Syndrome for a paper, I found that at the time, the sole fictional representation of a character with Turner Syndrome was in an episode of Law and Order: Special Victim's Unit, called Clock (Wolf et al., 2006, 26 September). The episode featured a missing teenage girl diagnosed with Turner Syndrome and has been very controversial in the Turner Syndrome community due to its inaccurate portrayal of the medical facts related to Turner Syndrome, as well as its

extremely sensationalized representation of the syndrome. This media portrayal will be discussed in greater detail in the methodology section.

#### **Theoretical Positioning**

Next, I would like to center my project in relation to my ontological and epistemological theoretical positioning. Ontology is defined as how individuals consider and understand reality and existence (Denzin & Lincoln, 2011). Based on my experience in the disability community and the previous research I have conducted on disability issues, the ontological framework from which I operated was relativism. The relativist ontology suggests that multiple realities exist, and that reality is created and influenced by an individual's perceptions, experiences, and environment (Ponterotto, 2005). My experiences within the disability community have exposed me to the wide variety of experiences that can exist within individuals with the same diagnosis. Consistent with this framework, and given that I researched the subjective experiences of media representations and perceptions of disability and the media, I believed that the responses of participants could have been influenced by their own personal experiences, culture, and environment.

The epistemological framework from which I operated was constructivistinterpretivist. Epistemology is defined as how individuals come to know their reality (Denzin & Lincoln, 2011). Constructivists–interpretivists believe that reality is socially constructed and that the researcher-participant interaction is essential to encapsulate the participant's lived experience (Ponterotto, 2005). The interpretive approach views meaning as connected to interpretive methods that shape the human experience (Liggett, 1988). Individuals who use an interpretive lens view truth and meaning as social

creations connected to language and discourse within greater society (Liggett). An interpretivist lens is important when considering disability, as how individuals are defined and labelled can impact their identity and maintain the dominance of certain groups (Liggett). For example, through an interpretivist lens, Titchkosky (2001) stated that the phrase 'persons with disabilities' not only serves the purpose of separating the individual from their disability, but could represent disability as a negative concept that can only be understood by its connection to individuals. This positioning arises from my background in social work. While I was obtaining my master's degree in social work, I became much more aware of the impact of social structures and institutions on individuals, as well as the diversity of values and experiences within communities. Additionally, as I engaged in the research methodology of online focus groups, participants' perceptions of the media portrayals could have been influenced by other individuals in the focus group. Furthermore, due to my perceptions being shaped by my personal experiences living with a disability, I may have interpreted information obtained from participants in a way that is different from how other researchers would.

The theoretical frameworks that informed the current research were critical disability theory and cultivation theory. These theories will be discussed more in-depth in the following chapter. Cultivation theory and the media approaches mentioned in the literature review represent how past research has been situated, and I took a more critical focus towards disability representation. I selected critical disability theory as this theory examines the connection and relationship between disability, the individual's response to their disability, and the individual's social environment (Hosking, 2008, September). This has relevance to media perceptions of disability, as media representations can not only

impact how non-disabled individuals view disability, but can also impact how disabled persons view themselves and their disability (for example, Zhang & Haller, 2013). Critical disability theory also suggests that disabled persons need a voice in society, as the language and images used in media and social institutions to represent or discuss disabilities can influence how disabilities are perceived by others (Hosking). As there is a lack of studies which include the perceptions of disabled persons in relation to how disabilities are portrayed in the media, I would like to increase their voices and include them in the research and knowledge translation process.

Cultivation theory states that the media can independently contribute to an individual's perception of social reality, and holds that individuals who consume media more frequently can be more significantly shaped by the media that they consume (Gerbner et al., 2002). As many of the media representations of disability are negative, or reinforce stereotypes or exaggerations of symptoms, it is important to consider the effect that these portrayals may have and how more positive, diverse, and nuanced portrayals can be cultivated. Cultivation theory also states that media representations of minorities are often created by individuals in the majority population (Morgan et al. 2015). As such, disabled persons need to contribute to how their disabilities are portrayed. Furthermore, a lack of cultivation research on representations of disability indicates that this is an area that needs to be examined. Cultivation theory was selected as it has been influential in communications research to explore the social and cultural impact of the media we consume (Morgan et al.). However, a recent review of the literature in the PsycINFO database in February 2024 revealed a yearly decrease in the number of articles focusing on cultivation theory being published since 2021. This may be a result of the changing

media landscape and the increase in popularity of streaming. It is possible that cultivation theory as a whole may not be as applicable in this era of streaming and widely available entertainment options, however, researchers have suggested that further study of factors which may produce cultivation effects, such as the perceived realness and diversity of representations and their impact on societal beliefs and changes, are still needed in regard to disability representation (Sauermilch et al., 2024). As a result of this finding, the theoretical focus and application of cultivation theory took on a different lens during the analysis phase, which will be discussed in more detail in the discussion section. In my dissertation research, I used findings from research conducted on factors that could influence cultivation effects, primarily perceptions of realism and empathy relating to the media portrayals, to ask individuals in the disability community whether they felt these factors had an influence on their perceptions of the media that they watched for the study. I also applied a constructivist/interpretivist lens by encouraging participants to determine their perceptions of the relevance of these factors, which could be influenced by and relate to their lived experiences.

#### **CHAPTER II: Literature Review**

#### The Impact of the Media on Attitudes and Beliefs

In the last few decades, the media has become increasingly prevalent in our lives. Advances in technology such as the internet, smartphones, tablets, and streaming services have provided a wide variety of entertainment and viewing options that can be accessed with increasing ease. Research studies have demonstrated that entertainment and news media frequently reflect a culture's current beliefs and values, and often serve to shape a culture's future attitudes and beliefs (Rider, 1994). One area which such an impact can be seen is in representations of disabled persons and various disability issues. Media such as popular television shows can have extremely important cultural impacts and can often reflect and co-create ableist perspectives and ideas of what is 'normal' (Vertoont, 2018). For some individuals, their only experience of the disability community or of particular disabilities may be from the media and entertainment that they consume.

The impact of the media can vary based on the content of the portrayal, and as a result, the attitudes and beliefs of the individuals who consume the media could be negatively or positively affected. An example of this double-edged sword can be seen in an analysis of portrayals of Joseph Merrick, otherwise known as 'the Elephant Man', which was conducted by Ablon (1995). The author interviewed 72 individuals and family members affected by Neurofibromatosis 1, the diagnosis that was mistakenly perceived to have impacted Mr. Merrick, as well as several health professionals familiar with the diagnosis. Several of the medical professionals interviewed indicated that the various media portrayals of Mr. Merrick's life had led to a significant increase in the research and treatments available for Neurofibromatosis 1 (Ablon). However, many individuals and family members felt that the media portrayals had had an overall negative impact on their perceptions. Many individuals diagnosed with Neurofibromatosis 1 had been mistakenly informed when diagnosed that Mr. Merrick had received the same diagnosis. These individuals expressed their fears of attending support groups, stating that they were apprehensive that they would see individuals who looked like 'the Elephant Man' (Ablon). While Mr. Merrick's condition continues to have some uncertainties surrounding it, two Canadian scientists defined his condition as 'Proteus Syndrome'

which is more rare and severe than Neurofibromatosis 1 (Cohen, 1988; Tibbles & Cohen, 1986).

This review examines the literature on physical and developmental disabilities, as well as mental illness. Both disabilities and mental illness have been portrayed negatively and stereotypically in the literature. However, the stereotypes associated with each diagnosis are different. Individuals diagnosed with a disability are often stereotyped as victims, reliant on others, weak, inept, and heroic (Nario-Redmond, 2010). Individuals diagnosed with a mental illness are frequently associated with crime, violence, and volatility (Francis et al., 2004). While this dissertation focuses on physical and developmental disabilities and not mental illness, it was felt that it was important to incorporate the mental illness literature, due to the fact that both mental illness and some disabilities such as autism could be considered more invisible disabilities; not readily apparent upon viewing a person. Additionally, while cultivation theory has not been frequently used to examine the impact of the media on perceptions of disability, it has been used to examine viewers' attitudes towards mental illness (Morgan & Shanahan, 2010). As a result, much of the literature on the impact of the media on the attitudes and perceptions of viewers and the factors that can influence media effects comes from research examining portrayals of mental illness. Due to this, the literature relating to mental illness can contribute to and benefit research on media representations of disability and can provide insights into media factors which may have an impact on the attitudes and perceptions of viewers towards disability.

#### Factors that can Impact the Effectiveness of the Media

Several factors present in media representations appear to have an impact on whether the media representation will impact the attitudes and beliefs of viewers. A question many researchers have investigated concerns the quantity of media viewings that are required to impact attitudes and perceptions, and researchers have conducted studies to determine how many screenings are required to influence viewers. In an early study in this area, McGinnies et al. (1958) examined the effects of mental health-focused educational films on participants' attitudes towards mental illness using three films that were frequently used in educational initiatives and created by the National Film Board of Canada. Two of the films, *The Feeling of Rejection* and *The Feeling of Hostility*, focused on causal factors of various personality disorders, while the third film, Breakdown, focused on the institutionalization of individuals with psychiatric disorders. The authors noted that prior to this study, previous studies conducted by researchers in this area had demonstrated that solitary films could impact the attitudes of viewers and that group discussions after viewings could also enable changes. The researchers conducted two studies to evaluate the impact of the quantity of media viewed as well as the impact of discussion boards on perceptions of mental illness and found that while watching the series of educational films had a significant impact on participant opinions, further analyses revealed that only the film *Breakdown* produced these results (McGinnies et al.). This study demonstrates the complexity of evaluating the impact of the media and indicates that multiple factors relating to the quantity of media consumed may need to be taken into consideration when attempting to use the media to influence the attitudes and perceptions of viewers.

Another factor that impacts the perceptions of viewers is the way in which characteristics and symptoms of disabilities are portrayed. Media portrayals can exaggerate or sensationalize information, which can influence the attitudes and beliefs of viewers. Johnson and Riles (2018) examined the impact of the media on attitudes and stigmatizing beliefs toward mental illness using a sample of 359 American college students enrolled in a communications class who were asked to recall a character with a mental illness, describe the character and their reaction to them, and complete a questionnaire on perceptions of mental illness and television viewing habits. When asked to describe the character that came to mind, over one-third of participants (n = 121)described characters who displayed severe symptoms of mental illness, and 96 participants described characters who displayed stereotypical personality attributes such as being violent or dangerous, or acting 'crazy'. Additionally, participants who described characters with more severe symptoms and stereotypes were more likely to apply the same beliefs toward mental illness and describe feeling uncomfortable interacting with someone with a mental illness, while participants who watched more hours of television were more likely to overestimate the prevalence of mental illness in the general population and the percentage of individuals with a mental illness who have engaged in dangerous behaviours (Johnson & Riles).

Another example of the impact of sensationalized media portrayals can be seen in a study conducted by Riles (2018). A sample of 646 participants were randomly assigned to watch clips from *Bates Motel*, *Criminal Minds*, *Hannibal*, *NCIS*, and *The Following*, featuring characters diagnosed with mood or anxiety disorders portrayed in a negative manner. Results from the study indicated that individuals who were exposed to the more vivid media portrayals of mental illness reported more negative attitudes towards mental illness and a greater desire for social distance. Additionally, participants who engaged in higher levels of overall media consumption reported a greater desire for social distance from individuals diagnosed with a mental illness (Riles). These findings demonstrate the significant and wide-reaching impact that the manner or tone of portrayals can have on viewers.

The labels used in the media to describe disabilities can also have a significant effect on the attitudes and beliefs of individuals. A study conducted with 113 undergraduate students and 77 community members in Louisiana used labels of schizophrenia that varied in levels of political correctness and included 'consumer of mental health services', 'person with severe mental illness', 'person with schizophrenia', and 'schizophrenic' (Penn & Nowlin-Drummond, 2001). The researchers found that participants who read the label 'consumer of mental health services' reported lower levels of negative affect, perceptions of dangerousness, and desire for social distance than participants who read the other two labels. Additionally, participants named fewer symptoms directly associated with a diagnosis of schizophrenia and also viewed individuals as more responsible for their current condition when they read the label 'consumer of mental health services' than when they read the other two labels. These results indicate the importance of carefully considering the labels used in the media; while the consumer label resulted in less negative stigma, it also communicated less relevant information regarding the diagnosis. Additionally, vague labels could result in individuals filling in the missing information with preconceived mental images, which could result in increased stigma (Penn & Nowlin-Drummond).

Transportation theory could also explain the strong impact that media can have on attitudes and beliefs. According to transportation theory, viewers are transported when they immerse themselves in the plot due to a strong identification with the character and are immersed in the narrative (Caputo & Rouner, 2011). Due to transportation, it was hypothesized that fiction and nonfiction media could have differing impacts on attitudes and beliefs, as fictional media could cause viewers to engage in more critical judgements (Caputo & Rouner). To evaluate this theory, Caputo and Rouner had 137 participants view a film based on the true story of an individual's experiences with depression that featured several stereotypical representations. Participants were randomly told that the film was fictional or factual before viewing it, and then afterwards completed a questionnaire on their impressions of the film and perceptions of mental illness. Results from the study indicated that labelling the film as fiction or nonfiction did not have an impact on participants' beliefs, but the perceived relevance of the film was partially mediated by a greater personal identification with the character, indicating that participants who identified with the character felt that the film was more relevant. Participants with greater perceptions of relevance also expressed less desire for social distance from individuals with a mental illness (Caputo & Rouner). These findings indicate that having relatable and relevant representations of disability could lead to similar results.

### The Longitudinal Impact of the Media

Research has also demonstrated that media can have an impact on individuals long after the viewing, and that the language used in media representations can have a significant impact. Evidence of bias exists within media reports when discussing issues

such as mental illness, and there are strong suggestions that individuals in the general public continue to associate a connection between mental illness and violence, particularly in relation to schizophrenia (Chan & Yanos, 2018). Philo et al. (1994) conducted a content analysis of local and national media in Scotland and found that approximately two-thirds of the media either mentioned or implied a connection between mental illness and violence. Other themes frequently seen in the media were sympathy, self-harm, portrayals of individuals with mental illness as comedic, and critiques of mental illness definitions and labels. To explore these results further, the authors had 70 participants with varying levels of experience with mental health services write newspaper stories relating to several real-life newspaper headlines and dialogue relating to an episode of the show *Coronation Street* featuring a character with mental illness, answer open-ended questions regarding the exercise and their beliefs about mental illness, and participate in an interview. Findings indicated that participants who did not have personal experiences with mental health services were more likely to be influenced by the media in believing that there was a link between mental illness and violence, and overall participants were able to very accurately reproduce the language that is frequently seen in the media (Philo et al.). This indicates that language and associations that are frequently repeated in the media can have a long-term and significant influence on the perceptions and attitudes of viewers.

Media representations can often be so powerful that misperceptions and inaccurate information can linger long after attempts have been made to correct them. In the study conducted by Philo and colleagues (1994), approximately half of the participants who recognized the newspaper headline regarding an arson attack on a child

which was used for the exercise were not aware that the story had been found after publication to be false. Additionally, some participants in the study indicated that the media had a greater impact on their views of mental illness than did their own personal interactions with individuals with a mental illness. A study conducted by Philo (1997) found similar results. During a focus group conducted by Philo, a participant revealed that they associated a diagnosis of mental illness with violent acts, despite frequently visiting and interacting with a relative receiving long-term psychiatric support. When asked about the source of their beliefs, the participant stated that they had been impacted by television movies (Philo). Another focus group participant who was a user of mental health services discussed their concerns for the future, based on the portrayals of mental health they witnessed in children's programs while watching them with their child. The participant stated that children's shows frequently portrayed individuals with mental health issues as 'crazy' and mentioned that the show *Looney Tunes* portrayed this image quite frequently (Philo). When talking about the show, the participant mentioned that the Looney Tunes cartoon frequently used the words 'nutter' and 'crazy' in almost every other phrase. This is quite concerning, as these media portrayals may be the first exposure that a child has to such individuals, which could have a significant impact on the formation of their perceptions of mental illness and disabilities.

Another example of the longitudinal impact of media can be seen in a study conducted by Chan and Yanos (2018). The authors conducted an online study that had participants read a newspaper article about a violent incident with ambiguous details regarding the cause and surveyed them on their recall and perceptions of mental illness immediately after and one week after reading the article. The researchers also randomly included a line that mentioned that the individual involved in the incident had a history of schizophrenia but did not link the diagnosis to the cause of the incident. After reading the article, almost half of the participants who read that the subject of the article was diagnosed with schizophrenia stated that mental illness was the cause of the violent incident, compared to 21% of the participants who were not provided with the diagnosis information, and these beliefs generally remained one week later. Additionally, while participants from both conditions were equally able to remember unambiguous information from the article, participants who read the article with the diagnosis information generated significantly more false positives on items which implied that the subject displayed stereotypical behaviours relating to mental illness (Chan & Yanos). These results indicate that it may take much more work to mitigate the harm that can occur from inaccurate information or connections that are created by the media. It may not be enough for changes to occur through individuals who create the media engaging in further research and considering the impact prior to releasing the media item.

#### Interventions to Reduce the Impact of Media Representations

Several interventions appear to diminish the impact of the media and positively impact the perceptions and beliefs of viewers. Research has demonstrated that stigmatizing beliefs can often be reduced through education or personal contact with the community experiencing the stigma (Corrigan et al., 2001).Similarly, a study conducted by Penn and colleagues (2003) with 163 undergraduate students randomly assigned participants to watch a documentary and complete a questionnaire evaluating their mood, their rating of the documentary, perceptions of stigma towards schizophrenia, and several measures to disguise the aim of the study. Findings indicated that participants who viewed the film on schizophrenia reported less blame and responsibility towards individuals with schizophrenia and viewed schizophrenia as more changeable than individuals who did not view that film. The authors concluded that personal contact may be needed in combination with education in order to significantly impact beliefs (Penn et al.), and it is possible that a similar combination may be effective for disability as well.

Media portrayals can have a negative impact even when media organizations attempt to address such concerns during media viewing. To evaluate the effect of an information trailer on the attitudes and beliefs of viewers, Wahl and Lefkowits (1989) had undergraduate students enrolled in an introductory psychology course watch a madefor-tv film based on the real-life events of a man who killed his wife while he was out on a day pass from a psychiatric hospital and complete a questionnaire on their perceptions of mental illness. One group watched the film with informational trailers inserted at various points in the film stating verbally and in writing that the events in the film were not a reflection of individuals with mental illness and that such individuals were no more likely to be violent than individuals not diagnosed with a mental illness, while others either watched the film without the trailers or watched an unrelated film. Results indicated that while the trailer did not have an impact, participants who watched the film were significantly more likely to perceive individuals with a mental illness to be dangerous and require hospitalization and reported feeling less sympathy for them and a lower desire for community interactions with them, The authors theorized that these results could be due to the fact that entertainment media is not solely informative; it draws viewers in and can emotionally affect them (Wahl & Lefkowits). Based on this theory, how immersive and emotionally gripping a portrayal of disability is could have a

significant impact on viewers, even when facts and information are provided to attempt to counteract the message.

The way that disability and disability issues are framed may also have an impact on the perceptions of viewers. More positive or nuanced portrayals and framing of various issues within the media could reduce stigma and negative attitudes and beliefs in viewers (Wahl & Lefkowits, 1989). There is some evidence that positive and nuanced portrayals of various issues are becoming more commonplace. Henson and colleagues (2009) evaluated the coverage of mental illness in 538 pieces of television content in Australia and found that over half of the items that they evaluated consisted of humaninterest stories that were framed in a positive manner, while 29 percent of the items portrayed a neutral tone. Approximately 60 percent of the 264 television items that featured individuals with a mental illness were framed in a neutral or positive manner, and individuals with mental illness were often portrayed as 'one of us' (Henson et al.). However, research has found that these positive framing trends may not be occurring for all types of disabilities. A study conducted by Winterbotham et al. (2023) looked at 168 Australian newswires, print, and radio news sources and how they represented intellectually disabled individuals and noted some more positive frames developing in relation to the advocacy work being conducted by parents and advocates; however, there was a lack of frames focusing on intellectually disabled adults (Winterbotham et al). The researchers also noted that while many issues relating to intellectually disabled individuals, such as housing, care responsibilities, and abuse or mistreatment were framed in a negative perspective, publications that were more local or regional had a higher rate of positive news stories than larger, more metropolitan news sources

(Winterbotham et al.) The repetition of such messages could be important when considering the impact that framing can have on attitudes and beliefs (Sieff, 2003). Media frames can organize and simplify information, and repetitiveness can reinforce information or perceptions (Sieff). Frames are linked to a specific set of items and are stored in an associated network in our memory; when an individual's brain recognizes an aspect of the frame, their long-term memory activates closely related concepts or associations (Sieff). Because frames are so easily accessible, they can be extremely effective (Sieff). Consistently framing such issues as disability in a positive and nuanced way could create more positive associations in viewers which could result in more positive attitudes and perceptions.

### **Cultivation Theory**

Cultivation theory has been considered to be one of the most valuable communication and media theories developed in the past 50 years to explore the social and cultural impact of the media we consume (Morgan et al., 2015). The theory focuses on the impact of the media on the attitudes and beliefs of individuals (Gerbner et al., 2002). Cultivation theory arose from the Cultural Indicators project initiated in 1967, which focused on tracking the content of television dramas, with an emphasis on representations of violence in the media (Gerbner, 1998). According to cultivation theory, the media can independently contribute to how people perceive their social reality, and people who consume media such as television more frequently are more likely to be shaped by the media that they consume (Gerbner et al., 2002). This is especially concerning regarding representations of individuals who are members of minority communities, as the representations of minority groups in the media are often created by individuals who are members of the majority population (Morgan et al.). One of the central concepts of cultivation theory that represents extreme cultivation effects is mainstreaming, which is the impact that heavy media viewing can have on shaping a culture's shared values and perceptions (Gerbner).

Cultivation effects can be defined as the impact that media portrayals have on the perceptions and beliefs of viewers (Potter, 2014). In cultivation literature, there are two forms of cultivation effects: first-order and second-order (Potter, 1991). First-order cultivation effects are related to demographic information and refer to the impact that the media has on how a viewer estimates the probability of certain characteristics or events occurring in reality (Jin & Jeong, 2010), such as an individual overestimating the number of individuals who have undergone plastic surgery after watching a television show featuring individuals undergoing cosmetic surgical procedures. Second-order cultivation effects refer to the relationship between television viewing and an individual's or society's general beliefs or values (Jin & Jeong), such as a viewer perceiving their neighbourhood as more dangerous after watching a film set in a similar location where a violent event occurs to a character. Potter (1991) found evidence that first-order and second-order cultivation effects are separate constructs, have an asymmetrical relationship, and that first-order cultivation effects appear to influence the formation of second-order cultivation effects. Cultivation theory anticipates that cultivation effects will be observed in the heaviest consumers; however, even moderate cultivation effects could have significant consequences (Gerbner, 1998).

# Factors That Can Influence Cultivation Effects

Several factors may influence or mediate cultivation effects according to various research studies. Research in cultivation theory has revealed that some genres of media that have a greater relationship with the variable being studied may impact cultivation effects more than others (Reizer & Hetsroni, 2014). The authors distributed a survey to 188 students attending a university in Israel who were currently in a relationship of at least three months duration and had them answer questions relating to their media consumption and the qualities of their current relationships. Results indicated both general and genre-specific viewing effects; individuals who viewed more media had lower levels of relationship commitment, and individuals who watched more romancerelated media content reported lower levels of relationship satisfaction and more intense relationship conflicts (Reizer & Hetsroni). These results were not seen when the authors looked at other media genres, which indicates that when attempting to use the media to impact the perceptions and attitudes of viewers it is important to consider the genre that may have the greatest desired impact. Studies have also indicated that the variety of media consumed could have an impact on cultivation effects and that individuals who are only exposed to one source of media may experience stronger cultivation effects (Vergeer et al., 2000). This indicates that it may not be enough to focus on a single media format to change viewers' perceptions of disabilities and that viewers may need to be exposed to more positive representations across a wide variety of media channels and formats.

The concepts of distance and transportation can also have an impact on cultivation effects. Distance relates to how closely the viewer relates to the character or situations they are viewing in the media, while transportation relates to how immersed the viewer is in the story they are watching (Bilandzic, 2006). Bilandzic theorized that the perception of information viewed in the media as close or distant could impact how a viewer processes information and constructs attitudes and that media distance consists of two factors. The first factor is the amount of distance resulting from the viewer's perceived personal connection to the situations and characters being portrayed in the media source, also referred to as experiential closeness. The second factor relates to the viewer's amount of engagement in the media source, also referred to as mediated closeness. Bilandzic viewed the interaction between experiential and mediated closeness as dynamic, with viewers who felt that the media portrayal was more relevant also being more engaged and vice versa. The author stated that television viewers generally approach media content with preconceived beliefs, knowledge, and attitudes which become activated during viewing; feeling transported by media content can lead to information being actively encoded in the brain, while feelings of distance could lead to more passive engagement and less effective encoding. Transportation effects were also noted in a study conducted by Bilandzic and Busselle (2008), who distributed questionnaires measuring cultivation perceptions, transportability, exposure and enjoyment of various genres, and demographics to participants and then had them view three films of three different genres on three consecutive nights one week after completing the questionnaire. The authors found that the levels of transportability reported in the initial questionnaire were positively correlated with perceptions of transportation during the films one week later; no cultivation effects were noted at lower levels of transportation, but significant cultivation relationships were noted in participants who had transportability scales that were one scale point above the midpoint, indicating

that there may be a threshold of transportability that needs to be reached to achieve strong cultivation effects (Bilandzic & Busselle). These studies demonstrate that in order to change the perceptions of viewers, media creators need to create characters and scenarios that are relatable and that emotionally draw viewers in. Additionally, it may take greater levels of transportability for any effects to be noticed.

Identifying or empathizing with the characters can also impact the effects of cultivation on viewers. Mutz and Nir (2010) evaluated the impact of fictional television on attitudes towards political and criminal institutions. A total of 86 participants were randomly assigned to watch an episode of *Law and Order* under high and low empathy conditions and which framed the justice system in a positive or negative light and complete a questionnaire on their levels of empathy and perspectives on various criminal justice issues. Results indicated that empathy mediated the cultivation effect; only individuals who viewed the media portrayal under high levels of empathy were impacted by the positive or negative narratives. Similar results were found in a study conducted by Timmermans and colleagues (2019), who found that participants who identified with characters who were single felt that information relating to the characters in the media was more personally relevant, and processed information regarding singlehood to a greater extent than participants who were in relationships. Results also indicated that being in a relationship appeared to protect women from being susceptible to the cultivation effects of romantic media content relating to the fear of being single. These findings indicate that the perceptions of viewers on social issues can be influenced by encouraging them to empathize with characters. This could be a method to encourage

viewers to support disability initiatives and policies and have a more positive perspective toward disabilities.

Finally, cultivation effects also appear to be influenced by the realism of the media portrayal. Potter (1986) distributed a questionnaire to a sample of university and high school students which assessed their demographics, television viewing habits, and perceptions of the reality of the television that they watched, and then questioned them about their perceptions of the world as mean and violent two weeks later. Potter found that individuals who considered the media representation to be realistic were more likely to view the world as mean and violent. Based on these results, if disabilities and characters with disabilities are consistently presented in a more diverse and nuanced manner, viewers may cultivate a more positive and nuanced perception of disabled persons and wider disability issues.

### Critiques of Cultivation Theory and Gaps in Cultivation Research

Several critiques have been made of cultivation theory in the literature. A frequent criticism is that Gerbner and his colleagues grouped together all viewing habits and did not consider individual genres (Morgan & Shanahan, 2010). They also note that researchers may need to consider reducing the components of cultivation theory to the micro-level (Morgan & Shanahan). Potter (2014) noted that in recent years it appears that researchers have been moving away from the original conceptualization of cultivation theory by focusing on the receivers of media messages rather than the media messages themselves (Potter). Shrum and colleagues (2005) also noted the importance of media literacy to the cultivation effect. They argued that researchers and educators need to enhance media literacy by not just teaching individuals to critically think about the

information presented in the media, but also to recognize judgements in the media and how the processes that can influence the judgements of media consumers work (Shrum et al.). The heuristic value, empirical support, and precision of cultivation theory could be improved by considering the impact of social institutions, evaluating a wider variety of media than television and film, and by detailing cultivation theory and the variables being examined in more specificity (Potter). Finally, as mentioned earlier, current trends in the psychological literature appear to show that research focusing on cultivation theory has been on a decline in recent years, perhaps due to the changing media landscape and the increase and variety of streaming options that are currently available.

Cultivation theory has also not often been applied to examining disability representation. As of February 2024, the sole article found in the psychological literature which evaluated media representations of disability using cultivation theory evaluated 607 descriptions of primetime television dramas on five television networks in Japan from 1993-2002 (Saito & Ishiyama, 2005). This article found that only 1.7 percent of the characters representing 11 percent of television dramas had a disability, and that the most prevalent disabilities represented were mobility disabilities, intellectual disabilities, and visual impairments. Additionally, the majority of characters with disabilities were young, and the number of female characters with disabilities was double that of male characters. The authors hypothesized that according to cultivation theory, the lack of representation of disabilities could foster distorted perceptions of disabled persons in viewers who consume a large amount of media; this could include not realizing that disabilities are more prevalent in older populations, and believing that disabilities are more prevalent in females than males (Saito & Ishiyama). One article in the communications and media literature was found to use cultivation theory to evaluate television viewer's attitudes toward deaf and hard-of-hearing individuals (An et al., 2012, May). 211 participants were randomly assigned to watch one of three episodes of the television show *Switched at Birth*, which features several characters with hearing impairments, and complete a preand post- questionnaire. Results indicated that watching the episode improved participant attitudes towards the Deaf community regarding their work capability, a desire to engage in social interactions with them, and in reduced perceptions of deafness as a handicap (An et al.). However, participants were more likely to feel that Deaf individuals should learn to speak or read lips and should avoid speaking in sign language. The authors also noted that the episodes that included a greater number of positive messages resulted in greater attitude changes (An et al.). As such, it appears that aspects of cultivation theory can continue to be effectively applied to evaluating and improving representations and perceptions of disability in the media.

## **Disability Representation in the Media**

Film, television, and other media can have a strong impact on a culture's perception of disability, and of individuals who have been diagnosed with disabilities. Positive representations of disabilities can show viewers the capabilities that disabled persons have and can lead to a more positive view and greater acceptance of disabled persons (Rider, 1994). Dillon and colleagues (1980) viewed television as a tool to change a society's attitudes towards disabled persons and stated that more diverse and nuanced portrayals of disabled persons could occur if disabled persons were more frequently integrated into the media. However, all too often the images of disabled persons in the media portray stereotypes and exaggerations.

Several common stereotypes are frequently seen in media portrayals of disability. Hunt (1991), a writer and activist with a disability, reviewed media portrayals of disabled persons and found ten common stereotypes. Some of these stereotypes include characters with disabilities presented as sad or pathetic, as someone with superpowers or with the ability to overcome their disability, as burdens, and as non-sexual (Hunt). A thematic content analysis of 20 Disney and Pixar animated movies released between 2008-2018 revealed that many of these negative disability stereotypes continue to be seen, and many disabled characters were used as sources of comedy or pity (Holcomb & Latham-Mintus, 2022). Stereotypes that were seen frequently in these films were disability as a representation of evil or old age (Holcomb & Latham-Mintus). An example of disability as representing evil could be seen in the character of the stuffed bear Lotso in Toy Story 3 (Unkrich, 2010) who was the villain of the film and walks with a cane, while an example of disability representing old age could be seen in the character of Mama Odie in The Princess and the Frog (Clements & Musker, 2009) who was an old voodoo seer whose blindness was also used as a source of comedy (Holcomb & Latham-Mintus). Another frequent stereotype seen is that of the savant, someone with incredible talents which often serve to emphasize their difference from others (Whititngton-Walsh, 2002). An example of this is in the film My Left Foot (Sheridan, 1989), a biographical film about the extremely successful painter Christy Brown who lived with cerebral palsy. Another common stereotype is the disabled person as living a life of isolation (Whittington-Walsh). Examples of this stereotype in films include the character of Quasimodo in *The* Hunchback of Notre Dame (Trousdale & Wise, 1996) who lives a life of isolation in a church bell tower, and Boo Radley in To Kill a Mockingbird (Mulligan, 1962), who lives

in isolation and is feared by the townspeople. Films also frequently portray individuals as being miraculously cured of their disabilities (Whittington-Walsh). Examples of this include the film *Forrest Gump* (Zemeckis, 1994), where Forrest suddenly can break free of his leg braces as a child and becomes a running and ping pong phenomenon as an adult.

The savant stereotype is frequently seen in portrayals of autism (Draaisma, 2009). Conn and Bhugra (2012) reviewed 23 movies from 1969-2010 which featured characters diagnosed with various autistic spectrum disorders. The authors noted the 'savant' stereotype became increasingly prevalent in portrayals after the success of the movie *Rain Man*, and that many such portrayals have involved abilities which have become increasingly unrealistic. Other themes noted in the movies were miracle cures and innocent and childlike personalities and behaviours. Characters with autism were also frequently paired with a neurotypical character who is psychologically distressed. The authors stated that in many of the movies autism is generally used as a device to foster increased audience empathy with characters such as a child diagnosed with autism, a parent, or a medical professional (Conn & Bhugra). Characters with autism are also frequently used to imply to viewers that individuals with autism can teach wise lessons to neurotypical individuals (Draaisma). These portrayals often reveal a discrepancy with the amount of in-depth research on autism that many actors, writers, and directors stated in press tours that they undertook when making the project (Draaisma).

Infantilization is another stereotype seen frequently in media portrayals. Stevenson and colleagues (2011) explored how autism was represented by parents, charities, the news, and the media, and noted many instances of infantilization. The authors reviewed 49 websites of state and regional chapters of the Autism Society of America and found that many of the sites neglected to represent autistic adults. Of the 152 photos reviewed across the various websites, 95 percent were of children. Eight of the websites reviewed had photos of autistic adults, but each website only displayed a single photo of an adult with the diagnosis. Furthermore, often in the media reviewed parents of autistic children were consulted as spokespeople. The authors additionally reviewed 105 fiction books which featured characters with autism and found that 90 percent of the characters were children. As a result of these frequent interpretations, the myth that autistic adults do not exist or are extremely rare can be perpetuated (Stevenson et al.). Similar results were observed in a study conducted by Tang and Bie (2016), where 85 percent of articles in Chinese newspapers implied that autism only affects infants and children.

Another example of infantilization can be seen in the first season of the television show *The Voice: Australia* which was analyzed by Ellis (2014). Ellis reviewed videos and social media discussions related to contestant Rachael Leahcar, who is visually impaired. The author noted that the wording and images used in the show to describe Rachael perpetuated the sweet innocent stereotype. During the competition, Rachael's image transitioned from wearing jeans to wearing pastel or white dresses, and her staging was structured to make her appear even smaller than her already petite appearance (Ellis). Other terms frequently used to describe Rachael on the show and on social media include 'courageous', 'angelic', 'amazing', 'an inspiration', and 'special' (Ellis). One interesting aspect of this study was the information and awareness raising that occurred within the comments on social media; a common theme in the comments was the suggestion that Rachael was moving ahead in the competition due to receiving sympathy votes due to her disability, with which the other singers could not compete (Ellis). Several commenters replied to such comments and brought up the accommodations that disabled persons are entitled to, and the systemic oppression that disabled persons face in their daily lives (Ellis).

The supercrip is a very common stereotype seen in the media. The creation of this stereotype relates to the 'freak shows' of the late 19th and early 20th centuries (Schalk, 2016). In the supercrip model, disabled persons are presented as special, inspirational, or sometimes even superhuman (Haller & Zhang, 2013). These individuals are often portrayed as people who have to fight with their disability in order to achieve success and overcome their limitations (Silva & Howe, 2012) Such narratives often can be seen as a reflection of the minimal expectations that society has for disabled persons (Silva & Howe). Additionally, the supercrip stereotype can set unrealistic expectations for disabled persons, insinuating that they can overcome their disability if they have enough willpower (Schalk). Three subcategories of the supercrip stereotype were discussed by Schalk; in the regular supercrip stereotype, which is often seen in news stories and reality television, disabled persons are portrayed as engaging in commonplace tasks. This can serve to reinforce the image that disabled persons are not like everyone else (Schalk). The glorified supercrip stereotype is seen in news, biographies, and documentaries, and portrays disabled persons who are frequently white and wealthy engaging in impressive activities such as mountain climbing or participating in the Paralympic games (Schalk). The final supercrip stereotype is the superpowered supercrip; this is a stereotype most

often seen in fictional television shows and movies in which a disabled person is the recipient of supernatural powers or abilities (Schalk).

The supercrip narrative is frequently seen in media covering athletic events such as the Paralympic games. An example of this can be seen in a study conducted by Falcous and Scott (2023) which examined the media narratives surrounding one of New Zealand's most well-known Paralympians, swimmer Sophie Pascoe. She has won multiple medals at the Paralympics, received the New Zealand Order of Merit in 2009, and was the country's flagbearer for the opening of the 2018 Commonwealth Games (Falcous & Scott). The researchers examined 349 articles that spanned 15 years of Pascoe's career, from January 2005-September 2020 and found that the supercrip narrative and her disability was a recurring focus throughout the timeline of her career, and her successes were framed as her triumphing over her disability through her use of determination and willpower (Falcous & Scott). McPherson and colleagues (2016) examined 86 articles and reports focusing on Paralympic athletes from 30 Scottish media sources from May 2013-July 2014, which was the time before, during, and after the 2014 Commonwealth Games in Glasgow, Scotland. The authors noticed a change in the narratives over the time period; the emphasis changed from portraying the athletes as 'different' to 'one of us'. Also, the narratives surrounding the athletes became more commercialized, presenting the athletes as 'stars'. The authors theorized that the representations could demonstrate a new category of the supercrip narrative, which they called the postcrip. The postcrip stereotype was defined as a more glamorous version of the supercrip narrative, one which makes their disability almost invisible, and which neglects the prejudices and exclusion that disabled persons often experience in society

(McPherson et al.). Another example of the supercrip narrative can be seen in the advertising campaign that was associated with the London Paralympic Games in 2012 (Swain & French, 2000). The campaign was called 'Freaks of Nature' and focused on the amazing athletic abilities of the athletes, with two of the athletes referring to themselves as 'freaks of nature' (Swain & French).

In extreme instances, these portrayals have been defined as 'inspiration porn' (Grue, 2016). Inspiration porn has been described by Grue as when a disabled person that is viewed as undesirable overcomes their disability or the challenges associated with it through physical strength and willpower. The term began being used in August 2010 and is connected with the comedian and disability activist Stella Young (Grue). Two main images are associated with inspiration porn: in the first image, an individual with a visible disability is shown engaging in a physical activity. This image is often accompanied by a description or slogan that fosters a sense of inspiration in the viewer (Grue). Such images often serve to continue the objectification, mystification, and devaluation of disabled persons (Grue). The second image frequently seen in inspiration porn involves a disabled person engaged in ordinary, everyday tasks (Grue). Often these examples of inspiration represent disability as problems within individual bodies which must be conquered or fixed (Goethals et al., 2022).

An additional stereotype is the fact that men and women with disabilities are often portrayed more homogenously in the media than men and women without disabilities (Nario-Redmond, 2010). Nario-Redmond conducted a study in which disabled and nondisabled individuals were asked in small groups about probability estimates and their perceptions of stereotypes of various groups including disabled males, disabled females, non-disabled males, and non-disabled females (Nario-Redmond). The author found that disabled men and women were associated with the same stereotype labels in seven of the top ten stereotypes, including dependent, asexual, incompetent, weak, unattractive, heroic, and passive. The stereotype labels of non-disabled men and women fell along more traditional gender stereotypes (Nario-Redmond). The author noted that disabled men were also stereotyped as inferior, lazy, and angry, while disabled women were stereotyped as socially excluded, vulnerable, and poor. Additionally, disabled women were never labelled as feminine by any of the participants, were rarely labelled as nurturing, and were almost always considered as unfit parents (Nario-Redmond).

Another example of homogenous portrayals can be seen in a study by Foss (2014), who reviewed 240 representations of deafness and Deaf culture in 40 television shows ranging from 1987-2013. Deaf characters and the Deaf community were often discussed in the media as a homogenous group, and as individuals who were considered to be vulnerable, savage, incapable, and desiring a cure. Foss provided the example of an episode of *Law and Order* where the Deaf community was referred to as 'the Deaf' and was described with the words 'handicapped' and 'disadvantaged'. In some television episodes, Deaf characters are not even treated with the capabilities to make choices over their own bodies; in an episode of *House*, a Deaf character's objections towards receiving a cochlear implant are overruled not once but twice (Foss). After the character rips out the cochlear implant that was installed by Dr. House and the medical professionals, the character's mother makes the decision to have it replaced, even though the Deaf character continues to object (Foss).

Disabilities may not be represented in the media very frequently in some countries, which could also impact the perceptions of individuals regarding disability and disability issues. Phillips (2012) used the Russian and Ukrainian terms for 'invalid' to evaluate articles from some of the popular newspapers in Ukraine and noted that many newspapers only published stories on disabilities once a year, on December 3<sup>rd</sup>, the United Nations International Day of Disabled Persons. The accounts in the newspapers often focused on disorder, and framed disability as an individual, family, and social tragedy. Articles often portrayed disabled individuals either as pitiful, criminals, aggressive, and/or dangerous or as heroic and attempting to overcome their disability. Phillips also noted that special privileges for disabled persons were often framed as a threat in the newspaper articles reviewed. Similar results were observed in a study of five prominent newspapers in China that focused on stories relating to autistic individuals (Tang & Bie, 2016). The authors noted that 56 articles portrayed autistic individuals as savants or with special talents, 43 articles portrayed autistic individuals as victims, and 16 articles portrayed autistic individuals as violent or dangerous. Tang and Bie also noted that as of the time when they conducted their research, no programs had been initiated in China to reduce stigmatizing beliefs relating to autism.

Over the past decades, Hong Kong has been making some positive progress in the area of disability representation. Lam and Wong (2024) conducted a content analysis of all of the episodes of the television series *A Wall-less World*, a show produced by Radio Television Hong Kong (RTHK) which has been airing since 2010 and focuses on stories relating to various physically, mentally, and neurologically disabled characters. A unique aspect of this television show is that it uses a wide variety of genres, perspectives, and

voices such as docudrama, documentary, and dramatic fiction to tell the character's stories (Lam & Wong). The researchers noted that the show has progressed from a focus on the medical model of disability in the first two seasons where characters were shown overcoming their need for assistive devices towards a focus on neurodiversity and strengths in later seasons (Lam & Wong). Another significant change throughout the seasons was a reduction in appearances and focus on authority figure characters and an increase in focus on the first-person experiences of the disabled characters (Lam & Wong). While *A Wall-less World* has had a positive impact by working to push back against disability stereotypes, the researchers noted some critiques, including not showing a wide spectrum of how neurodiversity can be experienced and primarily only hiring disabled actors for characters that have visible disabilities; the neurodiverse characters are played by neurotypical actors (Lam & Wong).

In contrast, the United Kingdom has several notable instances of progressive disability representation in its media and entertainment industries; in fact, in December 2019, the BBC stated that they would strive for more well-rounded and distinct portrayals of disability and disabled characters (BBC, 2019, December 3). The popular and longrunning television show *Coronation Street* is an example of these intended changes (Wilde, 2021, January 5). Wilde, a PhD in Disability Studies and soap opera fan, wrote about the development of disabled characters and storylines during the past two decades; noting that the show currently has two disabled actors in regular roles and two disabled actors in recurring roles. One of the regular characters Izzy, played by Cherylee Houston, has been given a storyline as a successful parent, and characters Shona Platt and Johnny Connor have also been given storylines that subvert disability stereotypes (Wilde). In 2020 the character Shona had an accident that resulted in a brain injury; her husband was portrayed as extremely supportive, and her storylines featured the challenges of adapting to her new life as well as comedic elements that Wilde described as "gentle and respectful" (paragraph 11). In 2018 the character of Johnny was diagnosed with Multiple Sclerosis, and this diagnosis has been portrayed as a part of him but has not been the sole focus of his character (Wilde). It has also not been portrayed as a tragedy or negatively impacted his personality (Wilde).

Another example is the actor Liz Carr, who won an Olivier Award in 2022 for her portrayal of Dr. Emma Brookner in the play The Normal Heart (Saner, 2022, May 10). The character uses a wheelchair due to a polio diagnosis, and as far as Carr is aware she was the first disabled actor to play the character in a production of the play (Saner). She also recently appeared in the popular streaming series *The Witcher* and *Good Omens* (Saner). Carr also recently left the show Silent Witness, where since 2012 she had played forensic examiner Clarissa Mullery (Main, 2020, February 5). During her time on the show, she provided input on lines and phrasing related to disability and advocated and fought for her character to have storylines that subverted disability stereotypes, including a supportive and kind love interest (Mair; Saner). Additionally, near the end of her time in the series, a new producer and writer gave her character the compelling storyline of navigating decisions regarding care for her mother who had been diagnosed with terminal cancer and dementia, providing a rare occurrence of a disabled person being portrayed in the media as a caregiver, and not the individual needing care (Main).

Other examples of prominent disabled actors from the U.K. are Mat Fraser and Lenny Rush. Mat Fraser was born with underdeveloped arms due to thalidomide

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(Wiegand, 2020, July 21). He began working with the theatre company Graeae, which is deaf and disability-led, in the mid-1990s and recently appeared in *American Horror Story* (Wiegand). He also wrote a series of monologues for the BBC, all performed by disabled individuals (BBC, 2019, December 3). Lenny Rush is a teenage actor who was diagnosed with a form of dwarfism called spondyloepiphyseal dysplasia congenita (Saner, 2023, November 16). He won a Bafta in 2023 for his role in *Am I Being Unreasonable* and will be appearing in the upcoming season of *Dr. Who* (BBC, 2023 June 15). When learning more about this actor it was interesting to note that the article written by the BBC focused solely on Rush's recent accolades and acting roles, and did not mention his disability.

### The Impact of Social Media on Disability Representations

Social media has only recently begun to be studied in relation to representations of disability, but studies and articles have revealed instances of stereotypes and negative representations of disability being perpetuated on social media. This can often be difficult to address due to the speed at which information can be shared across social media platforms. One example can be seen in memes which are frequently shared across platforms such as Facebook, Twitter, and Instagram (Hadley, 2016). Memes are defined as images with captions relating to something culturally relevant that are distributed through social media (Hitt, 2013, June 7). Hadley found three main categories of memes relating to disability. The first category of memes was termed 'the charity case' and involves images of disabled persons with captions that encourage non-disabled individuals to pity them and help them improve their lives (Hadley). These memes are often created by individuals or agencies wanting to help or raise money for the disability community (Hadley). The second category of memes is 'the inspiration', and it involves photos of disabled persons accomplishing things with captions that encourage people to overcome obstacles and not look for excuses (Hadley). These memes are often created to inspire non-disabled people and often foster feelings of guilt in disabled persons for not overcoming their disability (Hadley). The final meme is 'the cheat', which shows an individual, either with a disability or who appears to be non-disabled, with a caption stating that they are lazy and that if they can handle basic functions that they should be working and should not be considered disabled (Hadley). This meme is one of the most frequently shared online and is often created by individuals who feel the need to engage in social policing (Hadley).

Social media has also been used to harass and bully individuals with a disability, and unfortunately, procedures to prevent such actions continue to be difficult to implement or are implemented extremely sporadically. As one example, Melissa Blake (2020, August 26) a disability activist and freelance writer diagnosed with a genetic disorder called Freeman-Sheldon syndrome that affects her bones and muscles has written several articles discussing the harassment and bullying that she has experienced online. She detailed receiving comments under her pictures calling her a 'blobfish', and 'disgusting', and stating that she should be banned from posting photos because of her appearance. Blake's photo was also used by people on the social media platform TikTok for a meanspirited prank called the New Teacher Challenge, where parents show their child a photo of a person with a disability, tell the child that this person is going to be their teacher, and film their child's reaction. Blake described how violated she felt at the comments and non-consensual use of her picture and disclosed that when she has reported such instances on platforms such as TikTok and Twitter very often she has received a reply that their terms of use were not violated.

As a result, disabled individuals often engage in techniques to engage in social media in ways that they feel they can be authentic but also protect their identity. In one study, Bitman (2022) looked at the social media use of 29 autistic, Hard-of-Hearing, and individuals who stutter, individuals whose disabilities would not typically be apparent through social media communications. Bitman conducted in-depth interviews with participants regarding their perceptions and disclosure of their disability, their average social media use, and their disability presentation both online and offline. Participants mentioned engaging in such behaviours as displaying and moving between different identities on different social media platforms, as well as reducing their communication on platforms or with accounts that were connected with offline acquaintances (Bitman). Many participants worked to create more inclusive social media environments by connecting with disability groups and pages and autistic women participants mentioned the difficulties and complexities of their intersectional identities which often led to the creation of multiple social media profiles (Bitman). Similar findings were found by Hill (2023), who conducted semi-structured interviews and examined the Twitter and Instagram posts of five disabled women between the ages of 16-25 who were living in the UK and noted that all of the young women mentioned hesitating to share their personal experiences with disability and discrimination due to perceptions of shame, stigma, and internalized ableism. Some participants discussed navigating this by being selective of who they follow on various forms of social media, as well as having anonymous or private social media accounts that they use to discuss disability topics and participate in

disability groups (Hill). Another technique that several participants used was to distance themselves from what they posted and avoid harassment and negative feedback from others by retweeting others' posts and avoiding using the first person when writing their own tweets (Hill). As such, due to fears of bullying and stigma, many disabled voices may be hidden or congregate in spaces primarily consisting of disabled individuals, which could reduce their power and the impact that they could have on non-disabled individuals.

#### **Positive Media Representations of Disability**

There have been indications that media portrayals of disability are becoming more positive; however, there remains room for improvement. Positive portrayals of disability are essential, as they can not only impact non-disabled viewers, but can influence perceptions of those in the disability community as well (Zhang & Haller, 2013). A study conducted by Sauermilch et al. (2024) which examined three adult television shows (Atypical, Parenthood, and The Good Doctor) and three children's television shows (Sesame Street, Arthur, and Dinosaur Train) featuring autistic characters in lead or recurring guest roles found that when considering representing autistic characters in ways independent of their diagnosis most of the television shows featured positive portrayals of autistic characters and noted that the children's programs had a significantly more positive character valance than the adult programs (Sauermilch et al.). In terms of how autistic characters were represented experiencing and navigating challenges connected to their diagnosis, the majority of the programs demonstrated positive or neutral portrayals of autistic characters (Sauermilch et al.). Such positive disability representation is critical, as a survey of 390 members of the disability community from 18 countries found that

positive portrayals of their disability led to increased positive perceptions of disability identity, while negative portrayals led to an increased negative disability identity (Zhang & Haller). Similarly, Black and Pretes (2007) viewed and analyzed 18 films from 1975-2004 featuring lead characters diagnosed with physical disabilities and found that the majority of films portrayed disabled characters who had fully developed personalities, and that some of the films portrayed disabled characters who had positive interpersonal relationships with others. Findings also indicated that while positive changes have been made in reducing stereotypes of disabled persons as being dangerous or sources of pity, media representations continued to portray disabled persons as being asexual and incapable of normal functioning in daily life (Black & Pretes). Additionally, seven films perpetuated the idea that it is better to die than to live with a disability (Black & Pretes). One aspect noted by Black and Pretes was the lack of romantic relationships in the films. Additionally, the authors noted that characters with disabilities were frequently portrayed interacting in the community, but rarely shown in employment or education settings. These findings indicate that while there are instances of disabled characters being portrayed more positively, many negative stereotypes remain.

Often the most well-rounded and nuanced portrayals of characters with disabilities have disabled persons acting in the roles or involved in the creation of the media content. Some recent examples mentioned by Wilde (2022) took place in the UK and include *Crip Tales*, which was created by Mat Fraser, a disabled actor and writer and involved a series of monologues created and performed by disabled individuals and focusing on disability experiences. Another initiative was the episode *Hen Night* in the BBC's *Culture in Quarantine*, which is a monologue from the perspective of the disabled

character Jessica who is navigating the first Covid-19 lockdown shortly after her hen, or bachelorette, night (Wilde). Jessica is portrayed as having a vibrant social life, an interest in sex, and a career, and the monologue also raises awareness of the challenges and fears that many disabled individuals felt during the Covid-19 pandemic, including a lack of care services and supports and fears for their health (Wilde). Other examples of this can be seen in the web-magazine 'Ouch!', which is funded by the BBC (Thoreau, 2006). *Ouch!* is staffed by individuals with various disabilities, which has resulted in very different representations than are often seen in the mainstream media. In 2004, Thoreau evaluated 48 articles from various sections of the *Ouch*! website. Thoreau noted that most authors did not disclose their specific diagnosis, and that authors used non-medical terms when describing themselves. Approximately 22% of the authors indicated that they were 'disabled people', or simply referred to themselves as 'people'. Thoreau also noted the frequent use of language to foster a sense of community among disabled persons. Authors would often use 'us' or 'we' when discussing groups of people with disabilities and would use terms such as 'disability community', 'visually impaired community', and 'blind community'. Overall, the representation of disabled persons on the website was of a group of multidimensional people with a wide variety of interests, and writers established their authority through disclosing their personal experiences and the control they had over their representation (Thoreau).

Another media portrayal that broke away from conventional representations of disability is the film *Dance Me to My Song*. The film features a main character, Julia, living with cerebral palsy (Simpson & Matthews, 2012). The character was played by Heather Rose, an actor with cerebral palsy, and she also was a co-writer of the script

(Simpson & Matthews). The authors noted that in the film Julia transitions from being portrayed and viewed as a 'victim' to a woman who is empowered in several areas of her life. Julia is also portrayed as a multifaceted individual who just happens to have a disability (Simpson & Matthews). Furthermore, similar to the portrayals in the *Ouch*! web magazine, the film places a focus on the personal experiences of Julia and her engagement with them (Simpson & Matthews). Additionally, disability is portrayed as a part of Julia's identity, but not the central part, and as something that does not need to be cured (Simpson & Matthews). These examples show the benefits of involving disabled persons in the creation and portrayal of characters with disabilities and when discussing disability issues.

Social media has also been used by disabled persons to fight back against stereotypes and educate non-disabled individuals about disabilities and disability issues. According to Ignagni and Abbas (2008) newer media formats such as social media may be extremely effective in challenging non-disabled norms. There are several ways in which this can be accomplished. Hadley (2016) discussed how many individuals in the disability community are using a concept called culture-jamming and creating and disseminating their own counter-memes throughout social media. An example of such culture-jamming is the '*This is What Disability Looks Like*' (2012) project, where disabled persons create a meme consisting of a photo of them engaging in a daily aspect of their life with the caption 'This is What Disability Looks Like'. Another example is the 'See the person...not the normalcy' memes created by Rachel Cohen-Rottenberg (2013). These memes subvert the typical inspiration, charity, and cheat memes by using photos and captions relating to non-disabled individuals (Cohen-Rottenberg). However, in order for such initiatives to work it is recommended that multiple memes from multiple sources are deployed, and the memes should include links to pages or organizations that are already of interest to non-disabled individuals (Hadley).

Several disabled individuals have also used social media to combat instances of bullying. In one example, Melissa Blake (2020, September 30), a disabled writer and activist, discussed how she and others took back power and control after experiencing bullying and harassment online. For a year she posted a daily selfie on social media, accompanied by a message and the hashtag MyBestSelfie (Blake, 2020, September 30). She noted that she began to experience more confidence and body-esteem and was contacted for interviews by several media outlets such as PEOPLE, Good Morning America, and the BBC (Blake, 2020, September 30). Over that year, her social media followers grew from 7,500 to 10,000 (Blake, 2020, September 30). Currently, Blake has approximately 236,000 followers on Instagram (Blake, n.d.). Disability activist Carly Findlay and author/motivational speaker Lizzie Velasquez have also experienced online harassment due to their disabilities (Blake, 2020, August 26). Both of these women have responded by creating posts and responding to negative comments to educate individuals about their disabilities (Blake, 2020, August 26). Findlay noticed that after she commented on a negative post the comments turned from vile to more sympathetic (Blake, 2020, August 26).

Disabled individuals have also been involved in creating and highlighting representations of disability within the artistic and cultural spheres. One such initiative was conducted through Re•Vision: The Centre for Art and Social Justice, founded at the University of Guelph by Carla Rice (Rice & Mündel, 2018). The goal of this centre and the initiatives that they engage in is to use the arts to study and challenge how differences are portrayed in various settings (Rice & Mündel). The methodology used by the centre is arts-based and adapted from the methods for digital storytelling, modelled from the trueto-life monologues frequently seen on the radio or in live theatre, which was created by the StoryCentre (formerly called the Centre for Digital Storytelling) in Berkeley, California in the 1990's (Benmayor, 2008, Lambert, 2013). Re•Vision and the individuals connected with it have created over 300 multimedia videos, in addition to conducting workshops on theatre and creating multimedia stories which are often led by individuals who d/Deaf and/or disability-identify (Chandler et al., 2018).

In one project conducted by Re•Vision, called *Mobilizing New Meanings of Disability and Difference*, participants consisting of disabled individuals and healthcare workers created multimedia stories surrounding the theme of changing disability perceptions in healthcare (Mitchell et al., 2018; Mykitiuk et al., 2015; Rice et al., 2015; 2016; 2017). To provide participants with the skills needed to create these media pieces, the centre conducted ten multimedia creation workshops in three different areas of Ontario from 2012 to 2015 using a multidisciplinary research team consisting of disabled researchers, non-disabled researchers, and healthcare providers (Montgomery et al., 2019; Viscardis et al., 2019). More recently, Rice et al. (2022) used a subset of the videos created during the *Mobilizing New Meaning* project to examine the concept of interference, how ableism interferes with how participants have experienced difference, as well as the impact of the media devices, research environments, and the videos created by participants. Re•Vision has also engaged in live theatre projects; one such project, called *Small Acts of Saying* was a 50-minute performance that involved a cast of nine women and gender-queer actors and was co-developed and co-written by disabled actors and was performed more than six times within several Ontario educational and healthcare settings (Chandler et al., 2018). The individuals involved in the performance worked for more than a year and a half together and with a dramaturge who was Mad-identified and had significant experience working with experienced and inexperienced performers (Chandler et al.).

These various initiatives have led to collaborations between individuals connected with Re•Vision and other creative and disability-focused organizations; these include Tangled Art + Disability, and Creative Users (Chandler et al., 2018). Tangled Art + Disability was initiated in 2003 and was previously known as the Abilities Art Festival (Tangled Art + Disability, 2024a). Its goals are to highlight and employ disabled artists, encourage their creativity, and foster opportunities and partnerships for disabled artists (Tangled Art + Disability). Since its inception, it has held nine yearly festivals, worked with hundreds of disabled artists, and shared their work with thousands of audience members (Tangled Art + Disability). Creative Users Projects is a disability-led national organization working to create the first online community for Deaf and disability artists and foster opportunities for them to share their work and network with other artists with comparable experiences (Creative Users Projects, n.d.). They also create resources to assist artistic individuals and organizations with reducing barriers and widening their audiences (Creative Users Projects).

#### Gaps in Disability Representation Research

A majority of studies on disability representation in the media are content analyses of various forms of media. A lack of research has also been conducted on how

television programs positively and negatively represent disabled characters, particularly autistic characters, in terms of characterizations unrelated to their diagnosis and how they navigate challenges connected to autism within storylines (Sauermilch et al., 2024). Additionally, few studies consult disabled persons regarding media portrayals. Studies that do consult disabled persons often reveal important inputs and perspectives. In one study, Ross (1997) conducted 33 focus groups with 384 disabled individuals and asked participants about their attitudes and perceptions of disability representation on television. Many of the participants disclosed that they believed that television representations frequently used the perspective of disability as a tragedy, made disability the main focus of the character, and often neglected to show portrayals of characters with disabilities who led ordinary lives and were working through their disability in ways that reflected more nuanced and diverse experiences, which they felt was due to a lack of lived experience with disability amongst individuals working in the media. Other critiques from participants included a lack of dramatic television roles for disabled actors and the frequent use of wheelchairs to represent disability (Ross).

In another study, Haller and Zhang (2013) distributed surveys to 390 disabled individuals from 18 countries. Participants felt that the media did not provide nuanced and diverse depictions of disabilities and used more stigmatizing frameworks of disability, such as the medical model, the social pathology model, the supercrip model, and the business model (Haller & Zhang). The medical model presents disabilities as an illness which requires a cure, for which individuals are reliant on medical professionals, while the social pathology model presents disabled persons as burdens on the state, which provides them with support as a gift (Haller & Zhang). The business model is seen in the news, when disabled persons are presented as costly for society and businesses (Haller & Zhang). The findings from these studies demonstrate the valuable perspectives that disabled persons have, which could provide significant benefits to the media and entertainments industries and their representations of disability.

### Impact of Institutions on Media Representations of Disability.

Several institutions appear to have an impact on the representation of disability in the media; however, this is an area that has not been widely investigated in the literature. One institution that appears to have a significant impact is the education system. Inclusive classrooms have become much more prominent in recent years, integrating students with disabilities and working to reduce stereotypes and negative perceptions of disability (Hodkinson, 2012). However, in spite of these positive changes, teachers have mentioned not feeling like they had received the necessary knowledge and training to teach in inclusive classrooms (Cook, 2001). Additionally, studies have revealed a lack of materials related to disability in the education system. Hodkinson reviewed materials from four random elementary state schools in England and examined 494 electronic items, 4485 illustrations, 930 photographs, and 59 video clips to evaluate how disability was represented and noted that the schools significantly lacked materials related to disability and impairment information and issues. Only two books referenced disabilities or characters with disabilities; one electronic textbook discussed the topic in 28 words, mentioning an occupational therapist assisting a child with a wheelchair; a representation which framed disability as a medical deficit and could enforce the power differential between medical practitioners and disabled persons. The other electronic storybook spent 46 words referring to a disabled character that was a pirate with a

traditional eye patch and wooden leg, who was portrayed as the inept and ridiculous villain of the story. Hodkinson further noted that a positive narrative of disability was not present in any of the materials, and there were no images or representations of individuals with intellectual disabilities. This lack of educational and fictional classroom materials that incorporate disabled characters could be a reason for educators feeling unprepared to engage in inclusive teaching, and an increase in such materials, both in the classroom and in educational training, could reduce such perspectives and provide more positive experiences for disabled students.

A lack of education on disability and disability issues within the news media has also been demonstrated. Potts et al. (2023) analyzed 22,345 articles published between January 2000-December 2019 in three widely read Australian newspapers and found prominent negative language use in relation to disability and disability issues. The researchers noted the frequent use of the social pathology model, but less frequent use of the medical and supercrip models (Potts et al.) More progressive models were either rarely seen, as in the case of the minority/civil rights model or were not present at all, as in the case of the cultural pluralism model (Potts et al.) the minority/civil rights model is defined as the belief that disabled individuals have valid political concerns and a desire for improvements to be made, while the cultural pluralism model is defined as disabled individuals being seen as diverse, perceived the same as non-disabled individuals, and as not receiving unwarranted focus (Clogston, 1990). Such findings indicate that negative disability perspectives continue to be perpetuated in the news, and one reason could be a lack of journalist education regarding disability and disability issues. Hardin and Preston (2001) evaluated 21 of the most frequently used journalism textbooks to determine the

quantity and quality of the coverage of disability issues and disability representation in them. Of the 21 textbooks evaluated, only eight had information relating to disability. Those textbooks were further evaluated using 11 guidelines recommended by several disability and journalism organizations, which included using sources diagnosed with disabilities to discuss topics unconnected to disability, including more members of the press with disabilities, discussing an individual's disability status only when it is relevant to the story, prioritizing the person rather than the disability when writing about an individual, and also discussing environmental barriers when discussing disability. The results of the review indicated that none of the eight textbooks met all 11 of the recommended guidelines, and that only two textbooks demonstrated a significant focus on disability issues (Hardin & Preston). This lack of education on disability and disability issues could explain the many stereotypes often seen in portrayals of individuals and characters with disabilities in the media.

Some initiatives have been undertaken to educate individuals interested in pursuing careers in the media, and positive results have been noted. Recently, Media Diversity Australia (2021) released a Disability Reporting Handbook which educates journalists and provides strategies for representing diverse individuals in all forms of media, placing a focus on intersectionality, violence against disabled individuals, and naming strategies. Additionally, Dale and colleagues (2014) conducted a study to evaluate the effectiveness of a teaching intervention on mental illness, how it is represented in the media, and its impact on the knowledge and attitudes of 54 student filmmakers. The training initiative consisted of a two-hour lecture focusing on mental illness facts, definitions, misrepresentations, media depictions, and the impact of stigma. The lecture was followed by a short series of film clips featuring nuanced, diverse and sensitive portrayals of mental illness, as well as an opportunity for student discussion and questions. Results of pre-and-post questionnaires measuring disability knowledge and attitudes indicated that the intervention had a significant positive impact on student attitudes and knowledge, and that knowledge appeared to be simpler to impact than attitudes. Several participants also indicated to the researchers that they intended to portray characters with mental illness with more accuracy and sensitivity in the future, although a follow-up study was not conducted (Dale et al.). These findings are extremely encouraging, and continuing to implement such initiatives within the media and entertainment industries could lead to more positive disability representations.

## **Disability Theories**

Several models and theories relating to the area of disability have been discussed in the literature. One of the most prominent models used to discuss or represent disability is the medical model. In the perspective of the medical model, disabled persons experience exclusion due to their disability, and social institutions should provide health services to assist disabled persons in having a more normal life (Stamou et al., 2016). According to the medical model, there are several ways in which disabled persons can change their circumstances to have a life more comparable to non-disabled people: by obtaining a cure, by bravely living with the disadvantages and barriers they experience in society, by fighting such barriers related to their disability, by psychologically adapting to their disability, and by obtaining the protection of a non-disabled person (Stibbe, 2004). The medical model also subscribes to the belief that people with disabilities would prefer to be nondisabled (Vertoont et al., 2022). Due to these perspectives, the medical model has been criticized since the 1970s (Stamou et al.). One such criticism of the medical model is the fact that it associates disability with loss and deficits (Thoreau, 2006).

The social model is another model of disability which has become prevalent, and it is currently the most approved approach to disability and disability issues among disability researchers (Thoreau, 2006). It was created and is initiated by the experiences that disabled persons face in a society that has many barriers (Swain & French, 2000). A core tenet of the social model is the belief that societal and physical barriers are the factors that most contribute to disabilities, and that social activism is needed within the disability community in order to address and remove such barriers (Stibbe, 2004). A critique of the social model is the fact that it separates the concepts of disability and impairment, which could still allow disability to be seen as a personal tragedy even in the event that all societal barriers are eliminated (Swain & French). Another model of disability is the minority model. In this model, disability is considered to be a minority culture, similar to ethnicity and gender (Stamou et al., 2016). Other disability models which are not as prevalent in the media include the minority model (Liggett, 1988) and the affirmative model (Swain & French). A description of each of the disability models and theories mentioned can be viewed in Table 1.

Table 1

|               | Description   |
|---------------|---|
| Medical Model | Disabled individuals are excluded because of their disability and social and medical services should work to help them be more like non-disabled individuals (Stamou et al, 2016) |
| Social Model  | Disabled individuals are disabled due to social and physical barriers in society (Stibbe, 2004)   |

Disability Models and Theories in the Literature

| Minority Model                | Disabled individuals are a minority culture and should be<br>considered as special interest groups to have their voices heard in<br>policy and government (Liggett, 1988)                             |
|-------------------------------|---|
| Affirmative Model             | Disabled individuals and their lives and experiences have benefits,<br>and they should have control over their bodies and the treatments<br>they choose for their disabilities (Swain & French, 2000) |
| Critical Disability<br>Theory | Disability is a social construct with many complex factors relating<br>to the environment, the disability, and a person's response to their<br>disability (Hosking, 2008, September)                  |

## Critical Disability Theory

An alternative to the models frequently used to present disabilities in the media is critical disability theory, which states that disability is a social construct, and that there is a complex connection and relationship between disability, an individual's response to their disability, and the social environment in which they live (Hosking, 2008, September). Another tenet of critical disability theory is that the social environment often fails to meet the needs of disabled persons and that disabled persons need a voice in society, as the language and images used to portray disabilities can influence how disabilities are perceived (Hosking). Critical disability theory also states that the way that information is communicated, accessed, and interpreted can disadvantage individuals in minority populations (Castrodale, 2017). Additionally, critical disability theory values and appreciates difference, and does not attempt to judge or fix individuals who demonstrate differences (Castrodale). Studies and research in critical disability are also often intersectional and explore the impact of the multiple identities within each individual (Goodley, 2012). The intersectional focus of critical disability theory has led to connections with other critical theories, such as critical race theory, feminist theory, and critical queer studies (Meekosha & Shuttleworth, 2009; Wilton & Fudge Schormans, 2020). This can be seen in crip theory, which is an emergent theory in the area of critical disability studies that combines aspects of feminist theory, queer studies, and critical disability studies and works to overturn the presumption of able-minded, able-bodied, and heterosexual individuals as the norm (McRuer, 2006). In this way, crip theory prioritizes individuals and experiences that do not fall along binary labels, and using the term 'crip' is a way for disabled individuals to regain control of language and challenge standards of normalcy (Santinele Martino & Fudge Schormans, 2021).

Critical disability theory, and critical disability studies in general, have also been influenced by the long-standing oppression that disabled individuals have experienced in all aspects of society (Charlton, 1998). The concept of oppression is related to the idea of power and control, and the awareness that relationships between individuals and groups are experienced along the binaries of superiority/inferiority and dominant/subordinate (Charlton). Charlton has written about the dimensions of oppression that disabled individuals experience and notes that the oppression experienced by disabled individuals mirrors that of other marginalized groups. This conception of disability oppression notes the importance of the political economy in repressing disabled individuals and impacting their 'otherness' in society (Charlton). Other dimensions of oppression can be seen in other aspects of cultures, such as the way that negative beliefs about disability are internalized by both disabled and non-disabled individuals (Charlton). According to this concept, disability oppression is upheld and perpetuated through a cycle of power and beliefs that emphasizes this oppression as normal and enforces the binaries of superior/inferior and normal/abnormal (Charlton).

Several gaps have been noted in the academic literature on media representations of disability which could be addressed through a critical disability lens. Before the research study conducted by Haller and Zhang (2013), no research studies had asked disabled persons about their perceptions of media representations of their disability. Additionally, Dahl (1993) stated that it is difficult to locate the precise effects of the media on the beliefs of the general public, and that public thoughts and opinions may be impacted by what they see or hear. Furthermore, within media representations of disability, the literature has demonstrated that there is a lack of non-stigmatizing, diverse, and complex characters with disabilities in the media, and a lack of characters portrayed by actors with disabilities (Gilman, 2013, May 20; Haller & Zhang).

#### **The Present Study**

For this qualitative research project, I looked at controversial representations of disabilities in the media through the perspectives of individuals with those specific disabilities. The research project attempted to address these gaps in the literature by adding to the literature that examines disability representation in the media from the perspectives of individuals in the disability community, and by examining the impact of controversial media portrayals of disabilities on perceptions of stigma within the general community. Participants viewed a media portrayal of their disability that has been considered by the disability community to be controversial and discussed in a focus group their perceptions of the portrayals and how the portrayals could impact levels of stigma relating to disabilities. To consider some of the factors that could impact the

cultivation of media messages, participants were also asked about the realism of the media portrayal and their identification and levels of empathy with the characters featured in the media portrayals. The three disabilities that were the focus of this qualitative study were Turner Syndrome, mobility impairments requiring the use of a wheelchair, and Autism Spectrum Disorder.

## **Turner Syndrome**

Turner Syndrome is a rare genetic disorder that was discovered by Dr. Henry Turner in 1938 (Charney & Smillie, 1987). Turner Syndrome primarily affects cis women, and approximately one in every 2,500 cis women is born with the diagnosis (Deal, 2008; Rovet, 1993). I would like to acknowledge that Turner Syndrome can impact individuals in the nonbinary and trans communities as well, but the majority of research is conducted with cis women. Turner Syndrome is the result of a completely or partially missing X-chromosome, and the impacted chromosome affects the body's ability to absorb growth hormone and produce estrogen and progesterone hormones (Deal). A diagnosis of Turner Syndrome can occur throughout the lifespan; approximately one-third of the diagnoses occur in utero or shortly after birth, one-third of diagnoses occur in early childhood, and one-third of diagnoses occur in adolescence or adulthood (Charney & Smillie).

The most noticeable physical feature of cis women diagnosed with Turner Syndrome is shortness of stature (Deal, 2008). The average adult height of cis women with Turner Syndrome is approximately 4'7 or 4'8", but final height can be enhanced slightly through growth hormone therapy if it is initiated at a young age (Charney & Smillie, 1987; Orten, 1990). Additional difficulties often faced by cis women diagnosed with Turner Syndrome include diagnoses of infertility, hearing loss, heart abnormalities including aortic dissection and hypertension, and nonverbal learning disabilities (Charney & Smillie; Pinto, 2008; Wide Boman et al., 2004). Individuals with Turner Syndrome also produce a lower amount of sex hormones due to the impacted chromosome; adolescents with Turner Syndrome frequently require hormone replacement therapy in order to initiate puberty, and due to this many cis women diagnosed with Turner Syndrome Syndrome often can appear younger than their genuine age (Orten; Rolstad et al., 2007).

### **Mobility Impairments**

Mobility impairments can be defined as restrictions in daily activities that are caused by difficulties or the inability to engage in specific movements (Bizier et al., 2016). Approximately 7.2 percent of Canadian individuals over the age of 15 were diagnosed with a mobility impairment as of 2016, with a prevalence rate reaching 20.5 percent in individuals aged 65 and older (Bizier et al.). As a result, mobility impairments can be considered as one of the three most frequently reported disabilities, in addition to pain and flexibility difficulties (Bizier et al.). Research has indicated that mobility impairments often exist with other comorbidities; in a 2012 survey, approximately 95.9 percent of adults with a mobility impairment reported at least one other diagnosis, with pain-related impairments mentioned by 82.9 percent of participants (Bizier et al.). In the same study, individuals between the ages of 15 and 24 who were diagnosed with mobility impairments reported frequent comorbidities of pain-related impairments, flexibility impairments, and cognitive impairments (Bizier et al.). Individuals with mobility impairments frequently engage in physical therapy in order to increase their ability to engage in and participate in various daily and social activities (Beaudoin et al., 2019).

Mobility impairments can be associated with a variety of diagnoses. One frequent cause of mobility impairments is an injury to the spinal cord (College of Applied Health Sciences at the University of Illinois at Urbana-Champaign, n.d.). Various impairments can result from spinal cord injuries depending on the area of the spine that is affected; spinal cord injuries could result in quadriplegia, the inability to move the limbs and trunk of the body, or paraplegia, the inability to move the lower trunk and limbs (College of Applied Health Sciences at the University of Illinois at Urbana-Champaign). Individuals diagnosed with quadriplegia often use an electric wheelchair, while individuals with paraplegia can use their upper body and may use a manual wheelchair (College of Applied Health Sciences at the University of Illinois at Urbana-Champaign). Other causes of mobility impairments can include amputation of limbs, arthritis, back ailments such as scoliosis and degenerative or herniated disks, cerebral palsy, fibromyalgia, and neuromuscular ailments such as multiple sclerosis and muscular dystrophy (College of Applied Health Sciences at the University of Illinois at Urbana-Champaign).

#### Autism

Autism Spectrum Disorder (ASD) is a neurological disorder that impacts a person's behaviour and how an individual communicates and connects to the people and environment in their lives (Autism Ontario, n.d.). ASD is considered to be a spectrum disorder, therefore each person diagnosed with ASD will experience the diagnosis to a different extent (Autism Ontario). ASD is one of the most frequently diagnosed developmental disabilities; a survey conducted by the Public Health Agency of Canada (2018), revealed that 1 in 66 Canadians between the ages of five and 17 has been given a diagnosis of ASD. Of the entire Canadian population, a diagnosis of ASD is seen in one to two percent of individuals, meaning that approximately 135,000 individuals in Ontario have a diagnosis of ASD (Anagnostou et al., 2014). Research has indicated that males are four times more likely to be diagnosed with ASD than females (Public Health Agency of Canada). Over half of diagnoses occur before the age of six, and over 90 percent of diagnoses occur before the age of twelve (Public Health Agency of Canada). ASD can be caused by several factors, including genetic, epigenetic, and nongenetic, or a combination of these factors (Anagnostou et al.)

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013), several criteria must be met for a diagnosis of ASD. The first criterion is difficulties with social communication and interaction which occur across several contexts; these can include difficulty engaging in or starting social interactions, difficulties with verbal or nonverbal communication, and difficulties in creating and maintaining social relationships (American Psychiatric Association). The second criterion includes repetitive or restricted behaviours and interests; this can include repeated speech or behaviours, difficulties in adjusting to change or creating ritualized behaviours, an intense fixation on specific items or interests, or an increased or decreased reaction to environmental stimuli (American Psychiatric Association). These criteria must be witnessed in the early developmental stages of the individual and must significantly impact the individual's ability to function in daily life (American Psychiatric Association).

ASD can also include a range of severity and levels of support according to the DSM-5 (American Psychiatric Association, 2013). The DSM-5 has categorized the impact of the diagnosis into three levels; level three is categorized as individuals who

require extremely substantial support. Level three can be defined as individuals who display significant limitations in nonverbal and verbal communication and who engage in extremely inflexible, repetitive behaviours which impact all areas of their life. Level two is categorized as individuals who require considerable support. Level two can be defined as individuals who have noticeable limitations in nonverbal and verbal communication and who engage in inflexible or repetitive behaviours that are noticeable by others in a variety of situations. Level one is categorized as individuals who require support in some areas. Level one can be defined as individuals who require support to assist with verbal and nonverbal communication and with engaging in more flexible behaviours to cope with change (American Psychiatric Association).

#### **Research Questions**

Several research questions were proposed for this qualitative research project: The first research question was: what are the perspectives on controversial portrayals of various disabilities in the media by individuals who have been diagnosed with those disabilities? The second research question was: how could these portrayals impact perceptions of stigma regarding disabilities? The final research question was: how can characters with disabilities be portrayed to be more diverse and nuanced and to reduce stigmatizing beliefs towards disabilities?

#### **Methodological Framework: Focus Groups**

The methodology that I used for my dissertation research was online focus group studies. Focus groups were initiated in the social sciences in the early 1940s (Liamputtong, 2011). The focus group is led by a moderator who uses a script and list of questions and prompts to ensure that the research topics are covered effectively (Schneider et al., 2002). The moderator initiates the topics, keeps participants on task, keeps track of the discussion time, and encourages quiet participants to share their opinions (Schneider et al.). The goal of focus groups is to initiate conversations regarding participant opinions on an issue and to reveal group consensus on any relevant topics or opinions (Cyr, 2015). Data collection in focus groups is based on the various perspectives and experiences revealed by the conversations within the focus groups (Morgan, 1996). Focus groups can produce data concurrently at individual, group, and interaction levels (Kidd & Parshall, 2000). The individual level of analysis can be used for triangulation, the group level of analysis can be used to assess validity of measurement items during pilot testing and reveal differing interpretations or considerations of questions, and the interaction level of analysis can be used to explore various topics and perspectives (Cyr). Interactions between focus group participants can reveal differing perspectives between group members and can also reveal insight into the construction of a group consensus (Cyr). Focus groups provide many benefits to researchers. By fostering conversations and debates, the researcher can gain insight into what participants think and the source of their thoughts and opinions (Bratton & Liatto-Katundu, 1994; Cyr). Furthermore, focus groups are useful to study marginalized groups and discuss sensitive topics (Liamputtong; Madriz 1998; 2003).

Recent advances in computer technology and the Internet have allowed researchers to conduct focus groups online (Woodyatt et al., 2016). Online focus groups can be conducted in two formats: synchronous and asynchronous (Stewart & Williams, 2005). Synchronous focus groups occur in real-time and resemble face-to-face conversations, while asynchronous focus groups occur over an extended period of time, such as an online message board (Stewart & Williams). The first online focus groups were conducted using asynchronous, message board discussions; now online focus groups can be conducted synchronously using chat rooms and video conferencing, allowing researchers to interact with participants across a wider geographic region and participants who may be in minority groups (O'Connor & Madge, 2003). It is recommended that online focus groups consist of between six and eight participants in order to engage in more smooth and accurate transcription (Bloor et al., 2001).

Benefits of online focus groups are that as they occur in a virtual setting using the participant's own location and technology, researchers are able to reduce travel time and costs for both themselves and participants, and the technology that can be used in online focus groups can also save time and money on transcription (Reid & Reid, 2005). Synchronous online focus groups have several benefits over asynchronous focus groups; the real-time discussion can create more rich and detailed discussions amongst participants, and emotions and debates can occur more freely (Stewart & Williams). Additionally, video focus groups allow for participants and the moderator to see and react to body language and other nonverbal cues, as well as to verbal cues such as laughter, inflections, and interruptions (Schneider et al., 2002).

Online focus groups also face several challenges. Technological issues and hacking into the online conference room may occur (Oringderff, 2004). Due to this, moderators of online synchronous focus groups need to have excellent moderating and technology skills in order to moderate the discussions effectively and address any technological issues that may arise (Stewart & Williams, 2005). Additionally, the information obtained from not just online focus groups but focus groups as a whole is usually unable to be generalized, as sample sizes are small and participants are limited to individuals with access to the internet and technology needed (Franklin & Lowry, 2001; Schneider et al., 2002). Another challenge can be gaining access to participants; often a gate keeper must be contacted and provide their approval before participants can be contacted and provide consent (Stewart & Williams). Furthermore, response rates may be challenging to obtain, and it is advised to approach more individuals than are needed to compensate for participants who rescind their consent or are absent from the focus group (Bloor et al., 2001; Stewart & Williams). An additional challenge is the fact that while the researcher informs the participants of the importance of confidentiality, the researcher cannot guarantee the confidentiality of participants or information discussed in the focus group once the study is over (Oringderff, 2004).

#### CHAPTER III: Methodology

#### **Participants and Recruitment**

Participants for the focus groups were recruited through organizations that support individuals with the specific disabilities that are the focus of the project, as well as through online support groups. I selected the three disability diagnoses of Turner Syndrome, mobility impairments requiring a wheelchair, and autism as they represent a wide variety of experiences. Turner Syndrome was selected as it is a disability not widely known about in the general public, and at the time this dissertation was proposed, the representation in the episode of *Law and Order: SVU* was the only fictional media representation of Turner Syndrome in movies or television, which could have a significant impact on viewers. Mobility impairments requiring a wheelchair were selected as research studies have indicated that wheelchairs are the item most frequently associated with disabilities and the media frequently uses non-disabled actors to portray characters in wheelchairs. Autism was selected as it can be considered to be an invisible disability and has a wide range of stereotypical representations associated with it in the media. As the participants for the focus groups were from very specific populations, a variety of recruitment methods were utilized. For the focus groups of individuals with Turner Syndrome, participants were recruited through the Turner Syndrome Society of Canada. Participants for the focus groups of individuals with mobility impairments requiring the use of a wheelchair were recruited from the Beyond Disability Network. Finally, participants for the focus groups of individuals with autism were recruited from Autism Ontario, Autism Canada, and the Asperger/Autism Network. Participants from all categories were also recruited through the Facebook group Disability Study Recruitment Canada as well as through snowball sampling.

When contacting organizations and online support groups for participant recruitment, I approached the directors of the organizations and the moderators of the online support groups, and informed all directors, moderators, and community gatekeepers of my identities as a member of the disability and arts communities to form a positive rapport and connection and to indicate my interest and experience in this area of research. Representatives from all sites where recruiting took place signed an electronic permission form allowing recruitment and advertisement to take place on-site, which outlined the purpose of the study as well as how the site was expected to assist with recruitment. Once permission was obtained, advertisements were placed with the organizations and online groups. Due to the Covid-19 pandemic that took place during recruitment, participant recruitment and contact with organizations to assist with participant recruitment took place online. Organizations were asked to promote the study advertisement on their social media, websites, and through emailing their membership. Participants who expressed interest in participating in the focus groups were informed that they could share the study information with any individuals they knew who met the study criteria and were interested in participating. During participant recruitment, I collected demographic data in order to obtain diversity in ages, ethnicity, genders, and, particularly, the amount of time since participants received their disability diagnoses. Each participant received a \$30.00 Amazon gift card for their participation. Gift cards were sent to the participants' email addresses as a token of appreciation for their time and to thank them for sharing their opinions and experiences.

Participants were eligible for the focus groups based on several inclusion and exclusion criteria. Participants were eligible for the study if they met one of the following conditions:

- a formal diagnosis of Turner Syndrome
- a diagnosis of a mobility impairment that requires use of a wheelchair for at least 80% of a person's daily activities
- a diagnosis of autism with level one severity as defined by the DSM-5 (American Psychological Association, 2013).

Additionally, participants were eligible to participate in the focus groups if they demonstrated that they were able to provide informed consent, which was assessed by reviewing the consent form at the beginning of the focus group and providing participants the opportunity to ask questions before providing a final verbal consent. Individuals who were diagnosed with one of the eligible disabilities for less than six months were excluded from the study, as they were newly navigating their disability, accessibility needs, and the changes that the diagnosis brought to their life. When I received expressions of interest from individuals after the maximum number of focus group participants had been obtained, I informed them of this fact, thanked them for their interest, and offered to place them on a waitlist in case any participants withdrew from the study before the focus groups were conducted or if additional focus groups needed to be added. I also offered to send a summary of my findings to those participants once the study was completed.

#### **Procedure and Materials**

The proposed study was conducted through several online focus groups. It was anticipated that using focus groups would allow for a dialogue between participants and would allow participants to share their perceptions, opinions, and experiences (Kitzinger & Barbour, 1999). By doing this, participants may realize that they are not alone in their thoughts and experiences, and this may serve to foster a greater sense of community. For this study, seven focus groups were conducted; two focus groups were conducted for each eligible diagnosis in order to enable a variety of perspectives and experiences on the topics being discussed beyond what could be obtained by the dynamics of just one group. One additional focus group featuring two participants with Turner Syndrome was used as a pilot test, and the transcript from that session was used in the analysis. According to Kitzinger and Barbour, focus groups subles can range from three groups to over 50 groups. The number of focus groups was selected for this study due to the timeline of the doctoral dissertation process and the availability of resources. Each focus group ran between two to three hours long. The desired number of participants was between five to

eight per focus group, as recommended by Kitzinger and Barbour, and this was achieved in all groups other than the pilot test and the second mobility impairment group, which had four participants. It was also intended that the number of focus groups and participants in each group would provide for rich data, diverse perspectives and experiences, and would also allow for manageable transcription and analysis within the research timeline.

Each focus group consisted of individuals with a specific disability diagnosis. As mentioned, the three diagnoses selected for this study were Turner Syndrome, mobility impairments requiring the use of a wheelchair, and autism with level one severity. These groups were selected based on the controversial media portrayals selected for the focus groups, which were frequently mentioned as controversial in articles discussing portrayals of disabilities (for example, Ingram, 2016; Media Smarts, n.d.). Due to the pandemic, the focus groups were held online using Zoom, as the platform was frequently used by individuals during the pandemic and allowed for accessible access through phone or computer technology. Additionally, due to the anticipated wide geographic dispersion of participants, online focus groups were considered to be more effective.

The focus groups consisted of a series of semi-structured questions. Additional questions were added to the interview guide in order to gain further details on the perspectives or experiences of participants or if an aspect of disability representation or stigma was presented during the focus groups that was not anticipated during the construction of the original interview guide. As mentioned earlier, the focus group questions were piloted and evaluated by two individuals with Turner Syndrome to assess their relevance and to enquire if there were any additional questions that should be asked

in the focus groups. Based on the feedback from the pilot test participants, a question was added that asked: what are your perceptions of the number of individuals in the entertainment industry with disabilities? A copy of the focus group script and guide can be viewed in Appendix A.

All focus groups were video recorded online through Zoom and transcribed verbatim using Microsoft Stream. The Microsoft Stream transcripts were then edited by research assistants and reviewed by me to ensure that multiple individuals could evaluate the trustworthiness of the transcriptions prior to coding. This also allowed me to analyze and consider the nonverbal behaviours of participants as I was reviewing the transcriptions and analyzing the data. Participants were emailed a link to the consent form on Qualtrics approximately one week before the date of the focus group. The consent form that participants received included 1) an outline of the procedures of the study; 2) consent for their voice and image to be recorded during the focus group; 3) consent for their words to be transcribed and included verbatim as quotations in the manuscript resulting from the study; and 4) consent to use their desired pseudonym for the manuscript. A copy of the consent form can be viewed in Appendix B. In the consent form, participants were provided with my email address and were informed that they could contact me to ask questions or could ask questions at the focus group when the procedures and consent were discussed.

Demographic data was collected online through Qualtrics through a link that was sent to participants with the consent form approximately one week before the focus group. Participants were asked to complete the consent form and demographic survey by three days before the date of the focus group. A copy of the demographic questions can

be viewed in Appendix C. A Zoom link and a copy of the main interview questions were sent to participants approximately two days before the focus group. Participants watched the media portrayal together during the focus group after the procedures and consent were reviewed and prior to the focus group questions taking place. Individuals that participated in the Turner Syndrome focus group watched the episode *Clock* from *Law* and Order, SVU (Wolf et al., 2006, 26 September). Individuals with mobility impairments requiring the use of a wheelchair watched an episode of *Glee* called *Dream* On, focusing on the character of Artie who is in a wheelchair and dreams of walking (Falchuk & Whedon, 2010, 18 May). Individuals with autism watched an episode of Atypical called Antarctica (Rashid & Gordon, 2017, August 11). The media portrayals were available on the researcher's personal streaming services or were purchased through an iTunes account created for the research project. When finalizing my procedures and legalities regarding sharing the media portrayals used in the study, I spoke with the psychology librarian at the Leddy Library at the University of Windsor as well as the copyright expert. They advised me to consult regarding screen sharing with Apple to determine the copyright requirements, and after speaking with several individuals, I was referred to the Canadian Intellectual Property Office. The individual from the office that I spoke to over the phone said that they believed that if participants were viewing the media portrayal through screen sharing, had no access to the media portrayal outside of the viewing, and if I purchased the episodes used for the study, that it should fall under fair dealing laws and that I would not need to obtain direct permission from the media creators. Additionally, to accommodate as many accessibility needs as possible, the episodes selected for the focus groups were assessed to ensure that closed captioning and

if possible, described video were included as viewing options. When participants were sent the link to the consent form and demographic survey, they were also sent a document with the main focus group questions in it. This allowed them to gather their thoughts and was also intended to reduce their anxiety before the focus groups. Participants were also provided with the Zoom link and were sent a reminder email the day before their focus group.

After the focus group was completed, participants were contacted by email the next day and asked if they had any thoughts or opinions that they wanted me to know about that they did not feel comfortable discussing in the group, or if any thoughts occurred to them after the focus group was finished that they would like me to know about. This allowed any participants who may have been shy or intimidated during the focus groups to be able to contribute their thoughts and opinions regarding the media representation and media portrayals of disability. Participants were given one week to reply and were informed that if no feedback was received by that time, then it was assumed that they were comfortable with what they expressed during the focus group. While several participants wrote to say how much they enjoyed the focus groups and did not have anything to add, two participants from the autism focus groups reached out to provide additional information; one participant provided me with the contact information of a researcher studying media representations of autism as well as some links to news articles about media representations of disability, and one participant provided me with the in-depth answers that they had written for each question to use during the focus group discussion and which they elaborated on afterwards. A copy of the follow-up email script can be viewed in Appendix D. At this time participants were also thanked for their

involvement and contribution and were sent their gift cards electronically. A chart detailing the sequence of the procedures that participants experienced can be viewed in Appendix E. While recruiting participants, the initial recruitment did not elicit any participants for the mobility impairment focus groups. A more targeted version of the recruitment flyer was created and cleared by the University of Windsor's REB which can be viewed in Appendix F. The second round of recruitment resulted in an influx of email inquiries. Additionally, all the participants in the first focus group that was held kept their cameras off for the entirety of the focus group session. In order to sort through the enquiries and try to pinpoint any potential spam or bot responses for the second focus group, revisions were made to the email script, consent form, demographic questionnaire, and focus group script and were cleared by the University of Windsor's REB. Interested individuals were informed that a wide range of participant demographics were being sought and that completing the consent form and questionnaire was not a guarantee that they would be selected for the focus group. Additional questions were also added regarding their specific disability diagnosis and the process of how they were diagnosed, as well as the province, territory, or state that they were currently living in to allow me to cross-reference the information with the location data provided by Qualtrics. Participants were also encouraged to keep their cameras on during the introductions and discussion during the focus group. Copies of the revised materials can be found in appendices G-J.

#### **Selected Media Portrayals**

All media portrayals were selected due to their controversial perceptions within the disability communities and the fact that all portrayals involved non-disabled actors portraying characters with disabilities. Furthermore, all media portrayals were fictional and were approximately the same length, originating from hour-long television or streaming shows.

#### Turner Syndrome

The episode *Clock* from *Law and Order*, *SVU* (Wolf et al., 2006, 26 September) focuses on the disappearance of 17-year-old Janey, a gifted teenager who has Turner Syndrome. She had been living with her father and grandfather, who were extremely overprotective of her. The investigators discover that Janey has run off with her father's 30-year-old assistant Greg, as they had been involved in a secret, consensual relationship with each other and want to live together. Once Janey is found, her father files a Person in Need of Supervision request in court to force Janey to remain at home with him and stop her from seeing her boyfriend. Janey decides to file for emancipation and asks the court to allow her to make her own choice to move in with Greg and start their life together. Janey ends up winning her case and she and Greg leave the court together.

This episode was selected as it generally provided an extremely inaccurate and sensationalized view of Turner Syndrome. For example, the investigators frequently refer to Janey as 'a child' or 'trapped in the body of a child' even though she is 17, extremely intelligent, and past the age of consent. They also imply that anyone who would be romantically interested in a person like Janey must be a pedophile. Furthermore, there is medical misinformation regarding Turner Syndrome that is portrayed in the episode. The investigators state that women with Turner Syndrome rarely grow breasts or have periods, and that they have a short window of time to have a normal sex life before going into menopause. This information is false, as breast development and periods can occur through hormone therapy, and through hormone therapy individuals with Turner Syndrome can undergo menopause at a typical age (Orten, 1990; Rolstad et al., 2007). The episode is extremely controversial in the Turner Syndrome community due to the stereotypes, over-sensationalization of Turner Syndrome, and inaccurate medical information (for example, Ingram, 2016). A final critique is that the actor portraying Janey did not have a diagnosis of Turner Syndrome.

## Mobility Impairments

The episode of *Glee* called *Dream On* focuses on Artie, who is in a wheelchair after a car accident when he was a child and who dreams of walking again (Falchuk & Whedon, 2010, 18 May). When the students in the Glee club are asked by a school board auditor to write down their dreams, the auditor crumples up Artie's paper listing his dream of walking again and becoming a dancer and throws it in the garbage. Artie's friend Tina takes the paper out of the garbage and reads it. She shows Artie a new study detailing spinal cord research that could help him walk again, and he experiences disappointment when he learns that the therapy may not be available until years in the future. The school guidance counsellor helps Artie with the disappointment that he experiences. Tina offers to dance with Artie in their upcoming performance, and Artie declines, instead deciding to just sing during the performance.

This media portrayal was selected as it demonstrates the 'search for a cure' narrative. Artie's friend Tina makes it a priority to search the internet for potential cures and research being conducted on spinal cord injuries, and there is a dream sequence in which Artie dreams that one of the cures worked and he can walk and dance extremely well (Falchuk & Whedon, 2010, 18 May). It also demonstrates disabled persons placing themselves on the sidelines, as Artie declines Tina's offer to dance with her during the

performance and encourages her to select a non-disabled member of the Glee club instead (Falchuk & Whedon). Additionally, the portrayal of Artie is often criticized in the disability community, as a non-disabled actor played the character (for example, Davis, 2009, December 7; Gilman, 2013, May 20).

## Autism

The episode of *Atypical* called *Antarctica* (Rashid & Gordon, 2017, August 11) focuses on Sam, a teenage boy with autism. Sam has a therapy session with his therapist Julia to work on his emotional expression and understanding and mentions his interest in girls to her. Julia informs him that individuals with autism can go on dates and have relationships. Sam's friend Zhaid starts to help Sam look for a relationship, and Sam goes on a couple of unsuccessful dates. At the end of the episode, it is revealed that Sam has a crush on his therapist Julia, and he wants to ask her on a date.

I selected this media portrayal as individuals diagnosed with autism have viewed the portrayal as promoting the 'naive' stereotype and sensationalising symptoms of autism (for example, Gillespie-Lynch et al., 2020). Early in the episode, Sam expresses interest in his therapist's suggestion of donating his brain to science after he dies, but quickly changes his mind when his mother tells him to say no. His sister then tells him that he is easily bossed around (Rashid & Gordon, 2017, August 11). Sam is also quick to take the dating advice of his friend and the internet without considering the quality of the advice (Rashid & Gordon). An additional example from the episode is Sam's mother meeting with his therapist to state that Sam is not capable of dating due to his lack of understanding of nonverbal cues (Rashid & Gordon). Another critique is the fact that the actor portraying Sam is not on the autism spectrum.

## **Ethical Considerations**

While formulating this qualitative study it was imperative to contemplate potential ethical considerations that could arise during the research process. This was especially crucial due to the perceived vulnerability of the populations participating in the study. Ethical issues have been considered from both participant and researcher perspectives. In terms of participants, participation, confidentiality and anonymity limitations and expectations, as well as withdrawal procedures were provided in the consent form and reviewed at the beginning of the focus groups with an opportunity to ask clarification questions. Before watching the media representations, participants were informed that the representations may involve sensitive portrayals and discussions of sexuality and relationships. Accessibility was also an extremely important consideration; in the consent form participants were offered the opportunity to state any accommodations needed to participate in the study and were provided with the opportunity to have a support worker or family member assist them during the focus group. While no participants involved family or support workers in the focus groups, accommodations provided included using closed captioning while watching the media representations, writing responses in the chat, brief breaks during the focus groups, and using identity-first language. Finally, in order to protect the anonymity of participants, I used pseudonyms for participants when transcribing and coding the data and writing up the analysis. Participants were given the choice of name that they wished to use and signed the consent form consenting to the use of their desired pseudonym. If participants listed their actual name as their pseudonym, they were contacted and asked to select another pseudonym. Participants who did not provide an alternate pseudonym had one

created for them by me. During the focus groups, participants were informed that they could use their actual name or pseudonym as their sign-in name on Zoom, but that only their pseudonyms would be used in the transcripts and final manuscript.

An ethical consideration which was essential for me to consider as a researcher was the process of self-disclosure. In participant recruitment advertisements and during the focus groups I self-disclosed my diagnosis of Turner Syndrome and my involvement in the arts community which led to my interest in this research area. By self-disclosing and identifying myself as an insider and a member of the arts community, I hoped to demonstrate that I am planning to use the results of my study and my insider status to benefit the disability community and to create change within the arts community. I also hoped that this would encourage individuals in the disability community to participate in the study. I also believed that this would help participants to feel more comfortable in disclosing their perceptions and experiences in the focus group setting.

I also need to acknowledge that my experiences in the disability and arts communities could have an impact on my role as a researcher and how I interpreted the perceptions brought up in the focus groups and created the resulting themes. I anticipated that my insider status might present the most challenges during the Turner Syndrome focus groups. In order to address this, I engaged in reflexivity by journaling throughout the entire research project. Through journaling before and after the focus groups, as well as during data coding, I worked to become more aware of how my thoughts and experiences have impacted my opinions and considered how I would remain impartial as I moderated the discussions. As an additional check on my reflexivity and data interpretation, a copy of the initial themes was sent by email to each participant to confirm that the themes corresponded with what they remembered talking about during the focus groups and participants were asked for input if they felt that there were any discrepancies. Of the four participants who initially responded to the email, two participants reviewed the themes and both stated that they approved of the themes and did not have any modifications. Finally, journaling also allowed me to better understand how my perceptions influenced my determination of certain themes and provided insight into the source of any interpretation discrepancies in my coding and creating themes if participants felt that different themes occurred during the focus group discussions.

#### **Data Analysis**

A thematic analysis was conducted to analyze the transcripts resulting from the focus groups. This method of analysis was chosen as it is often used to examine the views and opinions of participants, as well as how social perceptions are constructed (Braun & Clarke, 2006). In particular, reflexive thematic analysis was used, as defined by Braun & Clarke (2022). The authors stated that in reflexive thematic analysis, the coding process is integral to the development of themes, as themes develop from the coding, as opposed to using coding to find pre-developed themes. Reflexive thematic analysis also involves complete data immersion by the researcher and focuses on the individual skills and experience that the researcher has that can benefit the analysis process (Braun & Clarke, 2020; 2022).

Thematic analysis has several benefits, including the flexibility it allows, the ease of learning the methodology, its accessibility to researchers new to qualitative research and to the general public, its usefulness for participatory research, and its ability to summarize and provide thick descriptions of data (Braun & Clarke, 2006). This methodology also allows researchers to generate new insights, raise awareness of similarities and differences across data, produce results that can inform policy, and provide data that can be socially and psychologically interpreted (Braun & Clarke). The authors also detailed several challenges and limitations related to thematic analysis, including making the methodology too flexible, needing to use an anchoring theoretical framework in order to generalize findings, and experiencing difficulties in maintaining continuity and contradictions through individual narratives. The authors also noted that there can be a lack of credit for thematic analysis as a methodology among researchers.

The thematic analysis was conducted using the six steps identified by Braun & Clarke (2006). The first step in the analysis was transcribing and familiarising myself with the data. This involves immersion in the transcription and data and writing down ideas for coding and themes that occur through reading the transcripts (Braun & Clarke). Reflexive thematic analysis is an interpretative and reflexive procedure (Braun & Clarke, 2020; 2022). In order to expedite the transcription process and to provide some accommodation for my hearing difficulties, I used captioning through Microsoft Stream to assist with initially transcribing the focus group recordings into a Microsoft Word document and hired research assistants to assist with verifying that the transcripts corresponded with the focus group recordings. Once the personally identifying information of participants was removed, transcripts and videos were shared privately with the research assistants through OneDrive, and the research assistants' access was terminated once their work was completed. I wanted to be as involved and immersed in the data as possible, so I assisted with the data transcription review and edits to ensure that the transcriptions exactly corresponded with the focus group recordings.

The second stage of the analysis was creating the initial codes (Braun & Clarke, 2006). This stage involves systematically reviewing the data and identifying relevant themes (Braun & Clarke). The authors also noted the importance of paying attention to stories and perspectives that differ from the majority of the data, as these could reveal interesting and important findings. Braun and Clarke (2019; 2020; 2022) stated that reflexive thematic analysis does not use a coding framework; coding is a more organic process. The initial codes were created by using the software ATLAS.ti. This software was selected because I am familiar with it and have used it before when conducting qualitative coding as a research assistant. Additionally, I engaged in printing and cutting up lines of the transcripts to highlight themes in sections of text where multiple themes were noted when necessary. In order to fully immerse myself in the data, I was the sole coder and engaged in consultation with my supervisor after drafting the initial themes and subthemes. Additionally, in order to ensure that the codes and themes were representative of participant experiences and perspectives, member checking was conducted with participants.

Braun and Clarke's (2006) next stage was exploring transcripts for themes. At this stage, it is essential to consider the relationships between codes, themes, and various levels of themes (Braun & Clarke). In reflexive thematic analysis themes should be considered as the product of coding and the process of developing themes (Braun & Clarke, 2022). I reviewed the initial codes developed during the critical analysis and sorted them into themes using a thematic map and table, along with compiling a Microsoft Word document of relevant excerpts from the transcripts for each theme (Braun & Clarke, 2006).

The fourth stage was revising the themes by reviewing the coded extracts for clear patterns and evaluating the relevance of the themes in relation to the entire data set (Braun & Clarke, 2006). I first created themes within the focus groups for each disability. I also looked across groups to see if there were any common themes. The fifth step was naming and defining the final themes by defining their essence and boundaries, as well as determining the sub-themes within each theme (Braun & Clarke). This is done by reviewing the quotes pulled for each theme and organizing them into a narrative (Braun & Clarke). When creating the final names for themes and subthemes, some names such as 'That's Helpful' and 'Give Us the Stage' were developed to describe a general overview of participant perspectives while others such as 'I Learned Something Today' were inspired by participant quotes.

The final stage was writing the manuscript (Braun & Clarke, 2006). The main findings from the analysis are illustrated through thick descriptions to demonstrate the depth and breadth of the transcript data, present compelling examples of themes, and create a strong narrative (Braun & Clarke). During the analysis process and the writing of the manuscript I also consulted with and followed Braun & Clarke's fifteen-point checklist for conducting and writing a thematic analysis. A copy of the checklist can be viewed in Appendix K. I also referred to Braun and Clarke's (2020) tool for evaluating thematic analysis manuscripts as I wrote my manuscript. A copy of the tool can be found in Appendix L.

As mentioned earlier, during data transcription and analysis, I worked to achieve data trustworthiness and quality through member checks and engaging in reflexivity (Nowell et al., 2017). Member checks were conducted once the focus groups had been transcribed. Participants in each focus group were sent a copy of the initial main themes determined through the analysis and were given 10 days to submit any comments or edits. The participants were informed in the email with the themes, that if they had not replied once the 10-day deadline was up, that it would be assumed that they approved of the themes created from the thematic analysis. Throughout the entire process, I also kept a journal in order to engage in reflexivity and document my thought process during the research study. I engaged in critical journaling throughout the process and after each focus group in order to reflect on each stage of the process and consciously reflect on my background and experiences and how they impacted my perceptions and development of themes. This allowed me to help form themes during the data analysis and to notice connections that may be missed if reflexivity is not engaged in. Additionally, journaling allowed me to reflect on my own experiences, privilege, biases, and values and their potential impact on my analysis.

#### **CHAPTER IV: Results**

#### **Participant demographics**

A total of 34 individuals participated in the study; of these, 11 participants were diagnosed with Turner Syndrome, 11 participants were diagnosed with autism, and 12 participants were diagnosed with a mobility impairment requiring the use of a wheelchair. Corresponding with the inclusion criteria, all participants self-identified as residing in Canada or the United States and as having received their diagnosis from a licensed medical professional. Turner Syndrome participants had an age of diagnosis ranging from in-utero to 22 years of age. The two Turner Syndrome participants who identified as multicultural specified their ethnicities as English Canadian/Indigenous and Pakistani/Kashmiri respectively. Autistic participants had an age of diagnosis ranging from 25 months to 39 years of age. The three autistic participants who identified as multicultural specified their ethnicities as Ashkenazi Jew/Western European/Scandinavian, English American, and Latin/American/Caribbean respectively. Additionally, the two autistic participants who reported other forms of employment identified as receiving disability income and as being self-employed respectively. Mobility impairment participants had an age of diagnosis ranging from 6 to 48 years of age. The mobility impairment participant who identified as multicultural specified their ethnicity as Afro-Latina. Further information about the participant demographics can be viewed in Table 2.

Table 2

| Variable         | Turner Syndrome<br>participants (n =<br>11) | Autism participants<br>(n = 11) | Mobility<br>impairment<br>participants (n =<br>12) |
|------------------|---|---------------------------------|--|
| Age in years     |   |                                 |  |
| M                | 30.45                                       | 28.54                           | 27.42  |
| SD               | 6.25  | 7.74                            | 7.72   |
| Range            | 22-40                                       | 20-42                           | 22-51  |
| Gender Identity  |   |                                 |  |
| Male (%)         | 0 (0.00)                                    | 2 (18.18)                       | 6 (50.00)  |
| Female (%)       | 11 (100.00)                                 | 6 (54.54)                       | 6 (50.00)  |
| Non-binary (%)   | 0 (0.00)                                    | 3 (27.27)                       | 0 (0.00)   |
| Ethnicity        |   |                                 |  |
| Scandinavian (%) | 0 (0.0)                                     | 0 (0.0)                         | 0 (0.0)  |
| British (%)      | 0 (0.0)                                     | 1 (9.1)                         | 0(0.0)   |
| English Canadian |   | · · ·                           |  |
| or American (%)  | 7 (63.6)                                    | 2 (18.2)                        | 2 (16.7)   |
| French Canadian  | 2 (18.2)                                    | 1 (9.1)                         | 0 (0.00)   |
| W. European (%)  | 0 (0.0)                                     | 2 (18.2)                        | 0 (0.0)  |
| E. European (%)  | 0 (0.0)                                     | 0 (0.0)                         | 0 (0.0)  |

Descriptive Statistics for Participants

| S. European (%)    | 0 (0.0)                 | 0 (0.0)  | 0 (0.0)    |
|--------------------|-------------------------|----------|------------|
| Far Eastern (%)    | 0 (0.0)                 | 0 (0.0)  | 0 (0.0)    |
| African (%)        | 0 (0.0)                 | 1 (9.1)  | 8 (66.7)   |
| Caribbean (%)      | 0 (0.0)                 | 0(0.0)   | 1 (8.3)    |
| Middle Eastern     |                         |          |            |
| (%)                | 0 (0.0)                 | 0(0.0)   | 0(0.0)     |
| Latin American     |                         |          |            |
| (%)                | 0 (0.0)                 | 1 (9.1)  | 0(0.0)     |
| Central American   |                         |          |            |
| (%)                | 0 (0.0)                 | 0(0.0)   | 0(0.0)     |
| Indigenous (%)     | 0 (0.0)                 | 0(0.0)   | 0(0.0)     |
| Multicultural (%)  | 2 (18.2)                | 3 (27.3) | 1 (8.3)    |
| Highest level of   |                         |          |            |
| education          |                         |          |            |
| Some elementary    |                         |          |            |
| school/ elementary |                         |          |            |
| school graduate    |                         |          |            |
| (%)                | 0 (0.0)                 | 0 (0.0)  | 0 (0.0)    |
| Some high school   |                         |          |            |
| (%)                | 0 (0.0)                 | 2 (18.2) | 0 (0.0)    |
| High school (%)    | 0 (0.0)                 | 1 (9.1)  | 1 (8.3)    |
| Some college (%)   | 0 (0.0)                 | 1 (9.1)  | 2 (16.7)   |
| Some university    | ~ /                     | × /      | . ,        |
| (%)                | 2 (18.2)                | 0 (0.0)  | 1 (8.3)    |
| College graduate   | ~ /                     | × /      | × /        |
| (%)                | 3 (27.3)                | 3 (27.3) | 1 (8.3)    |
| University (%)     | 4 (36.4)                | 2 (18.2) | 6 (50.0)   |
| Master's degree or | ()                      | - ()     |            |
| other similar      |                         |          |            |
| degree (%)         | 2 (18.2)                | 1 (9.1)  | 1 (8.3)    |
| PhD/MD or similar  | - ()                    | - (>••)  | 1 (0.0)    |
| degree (%)         | 0 (0.0)                 | 1 (9.1)  | 0 (0.0)    |
| Student status     | <b>a</b> (10 <b>a</b> ) |          |            |
| Yes (%)            | 2 (18.2)                | 2 (18.2) | 0(0.0)     |
| No (%)             | 8 (72.7)                | 9 (81.8) | 12 (100.0) |
| Enrollment         |                         |          |            |
| Full-time (%)      | 2 (18.2)                | 2 (18.2) |            |
| Part-time (%)      | 0 (0.0)                 | 0 (0.0)  |            |
| Year of Study      |                         |          |            |
| 1st year (%)       | 0(0.0)                  | 0(0.0)   |            |
| 2nd year (%)       | 2 (18.2)                | 1 (9.1)  |            |

| 3rd year (%)      | 0(0.0)   | 1 (9.1)  |          |
|-------------------|----------|----------|----------|
| 4th year (%)      | 0 (0.0)  | 0 (0.0)  |          |
| Other (%)         | 0 (0.0)  | 0 (0.0)  |          |
| Employment Status |          |          |          |
| Full-time (%)     | 8 (72.7) | 1 (9.1)  | 5 (41.7) |
| Part-time (%)     | 0 (0.0)  | 2 (18.2) | 3 (25.0) |
| Not currently     |          |          |          |
| employed (%)      | 3 (27.3) | 6 (54.5) | 4 (33.3) |
| Other (%)         | 0 (0.0)  | 2 (18.2) | 0 (0.0)  |

Regarding the forms of accommodations that participants requested, two participants requested captions used during the videos, two participants requested breaks during the session, and one participant asked that identity-first language be used when speaking to them. Finally, one participant asked for the chat feature on Zoom to be used. The rest of the participants stated that they did not have any accommodation needs. Additionally, no participants elected to bring family or support workers with them to the sessions.

## **Research Questions**

## Research Question #1

Regarding research question number one: "What are the perspectives on controversial portrayals of various disabilities in the media by individuals who have been diagnosed with those disabilities?", two main themes were identified. A table of the themes and subthemes can be viewed in Table 3.

## Table 3.

| Research Question  | Main Themes   | Subthemes   | Notes  |
|--|---|---|--|
| 1. What are the<br>perspectives<br>on<br>controversial<br>portrayals of<br>various<br>disabilities in<br>the media by<br>individuals | • I liked that<br>(positive aspects<br>of media<br>portrayals)                      | <ul> <li>That's me! (aspects that participants could relate to)</li> <li>Disability done right (effective disability portrayals)</li> </ul>   | • Similar hopes and<br>dreams mainly seen in<br>mobility impairment<br>focus groups  |
| who have<br>been<br>diagnosed<br>with those<br>disabilities?   | • That doesn't sit<br>right with me<br>(negative aspects<br>of media<br>portrayals) | <ul> <li>I don't see myself<br/>(aspects that<br/>participants did not<br/>relate to)</li> <li>That's a caricature<br/>(disability stereotypes<br/>used in the media)</li> <li>That's unrealistic<br/>(aspects that were not<br/>representative or<br/>inaccurate)</li> </ul> | <ul> <li>Infantilization and<br/>passive stereotypes<br/>mainly seen in Turner<br/>Syndrome focus groups</li> <li>Disability as a source<br/>of comedy seen mainly<br/>in autism focus groups</li> <li>Sensationalized<br/>aspects of disability<br/>mainly seen in Turner<br/>Syndrome and autism<br/>focus groups</li> <li>Inaccurate medical<br/>information, lack of<br/>disability<br/>representation, and lack<br/>of description of<br/>disability mainly seen<br/>in Turner Syndrome<br/>focus groups</li> </ul> |

Themes and Subthemes for Research Question #1

# Theme 1: "I Liked That".

The first theme was "I liked that" which was defined as components of media portrayals, including both the media portrayal watched in the focus group and other media portrayals that participants could think of, that participants reacted positively to. This theme was broken into two subthemes: "That's me!" and "Disability done right".

### Subtheme 1: "That's Me!".

The first subtheme: "That's me!", referred to aspects of disabled characters that participants stated that they felt a commonality with. Participants discussed relating in various ways to the characters that were in the media portrayals that were watched during the focus groups, and also discussed how the aspects they related to had varying levels of significance. One important aspect where participants discussed feeling a connection with disabled characters was in some of the disability characteristics seen in the characters with their disability. For example, many of the participants in the Turner Syndrome focus groups related to being shorter than their peers and not going through puberty at the same rate as others their age, characteristics that were used to describe Janey in the *Law and Order: SVU* episode. Many of the participants in the Autism focus groups stated that they could relate to the sensory needs displayed by Sam in the episode of *Atypical*, including sensitivities to noise and preferring hard touch to soft touch:

And I totally relate to the got to have hard touch and not soft, I had to ask my massage therapist, my mom does not like hard touch, and I apparently tend to when I hug people or squeeze people's hands, I don't know that I'm putting too much pressure. But for me, soft touch is often quite uncomfortable. And my massage therapist told me like, pretty much nobody else likes it as hard as you do. (Jac, participant in autism focus group)

Another disability characteristic which was found relatable to many autistic participants was when Sam had a word stuck in his head and kept repeating it out loud. As one participant stated: "I really related to like when he says that, 'Oh, sometimes the phrase can get stuck in my head and it's just like repeats over and over and over and over'. And I was like, 'Wow, I feel that'." (Sparrow, participant in autism focus group). While listening to participants during the focus groups and reviewing the transcripts, it was apparent that participants valued seeing characters that experienced their disability in similar ways, which could make participants feel less alone in their feelings and experiences.

Other important aspects of characters that some participants related to were the challenges that they experienced, as well as the hopes and dreams that they had. Participants who mentioned relating to the challenges and/or hopes and dreams that characters experienced often brought up experiencing similar challenges as well as hopes and dreams, which could serve to reduce the sense of isolation that can often occur with a disability diagnosis. Furthermore, seeing how characters positively and negatively navigated experienced challenges as well as worked towards their hopes and dreams could also have real-world applications if similar situations are experienced. Several of the Turner Syndrome focus group participants mentioned relating to how the character Janey was made fun of by her classmates and not taken as seriously when she was running for school council:

I related to um when she was on, on the stage for the students council and, and everybody was kind of like ridiculing her. I definitely remember certain like school projects and stuff, you know, having what I was saying, being challenged uh more by people in my class if I was making the presentation for the class or um because I've been like a singer and performer for so long, I used to like, dress up in costumes and sing musical theatre songs at assemblies and stuff like that. Not everybody was uh very kind about it to get back in the day. (Wren,

participant in Turner Syndrome focus group)

Several participants in the mobility impairment focus groups stated that they could relate to the sense of isolation that Artie felt seeing his friends being able to dance while he couldn't.

Well, uh, as for me I also do identify with him, uhm especially the parts where I felt like there was a sense of isolation. The part where the girl actually chose another guy to dance with rather than him, because for him he wasn't in a position to do, uh, to dance. So for me, in my case, I do, as I mentioned it, I like swimming. That is the interest that I actually had since I was young, but unfortunately things happen. And yeah, I was, I was, I got a car accident uh and later on uh I was confined to a wheelchair, so for my friends, some of my friends actually they do know how to swim. So as friends I do tag along with them and I actually do see them doing the same and I cannot be, I cannot be able to join them, so to some extent it kind of makes me feel so sad and I feel like they cannot understand that. (Snowy, participant in mobility impairment focus group)

Relating to the hopes and dreams of characters was primarily mentioned in the mobility impairment focus groups, but also occurred in the Turner Syndrome focus groups as well. Several participants in the mobility impairment focus groups mentioned that like Artie, they also had dreams of being able to do activities that were impacted by their diagnosis, with one participant disclosing: "…I loved cycling. Now I keep hoping to cycle…" (He, participant in mobility impairment focus group). Another participant in the mobility impairment focus group).

miracle treatment through medical research. Multiple participants in the Turner Syndrome focus groups stated that they could relate to Janey's desires for a romantic relationship and a biological child, with one participant revealing:

I also I didn't have a serious boyfriend at 17 either, but I really wanted one [laughs, Michelle nods] like, you know, that's something that I can definitely relate to, is uh just wanting to be like that normal teenager and having a relationship. Having that boyfriend when you see everybody else pairing up and then you kind of feel like, like, "Why? Why is that not happening for me? Like, why? Why am I not in a relationship?" And her um her wanting to have wanted to use her opportunity to uh to have a child like I, I can understand that too, uh you know, if there was any way that I could have had a biological child, I probably would have taken it. Maybe not to the same extreme as her. But, you know, I, I definitely would have tried convincing my parents at like 17, 18, "Hey, you know, like this my one shot, like, I don't care if you have to, like, you know, freeze an egg or something so I can use it later. Like, I want to be able to have a biological child. And this is my one shot, so I'm going to do something about it". So I can relate to that aspect of it. (Babs, participant in Turner Syndrome focus group)

Other aspects of characters that participants mentioned relating to during the focus groups were their family dynamics. In particular, participants who mentioned relating to family dynamics presented in the media representations watched during the focus groups brought up the overprotectiveness of family members, particularly parents. Several participants in the autism and Turner Syndrome focus groups discussed how they related to the overprotective parents seen in the episodes of *Atypical* and *Law and Order:* 

*SVU*. When discussing parental overprotectiveness, many participants in the Turner Syndrome focus groups stated that they believed that it stemmed from their short stature and parents perceiving them as younger than their actual age. This overprotectiveness can have wide-reaching implications for disabled individuals, as mentioned by one participant in the autism focus groups:

And the thing was like having overprotective parents just in this instance is that Sam will never understand that if he doesn't go through it and trial and error, of "I'm going to go there and I'm going to see if she wants to go out with me" etc. um I don't know, like if I was like, I'm making sense, but I just mean that all protective and overbearing parents are actually an obstacle towards development. Like with certain education programs where they're developed-they're like, the goals are so diminished compared to your typical students. And where you're headed is just like, it's a much simpler level than where you're supposed to be headed or where, as in your typical students of your age are headed, that it puts you at a disadvantage in terms of what you can later on, what you can study, if you can go on to study at university, and what kind of like different um trainings you can take on and what jobs you can have. Because you're not equipped to actually function in any kind of higher-ish level of, you know, academia or work. And I feel like there's a whole kind of patronizing system. And also, like can be very patronizing some like little cocoon, where it starts with the family.

(Twizzlers, participant in autism focus group)

As a more minor connection, many participants also noted that they had similar interests as characters with their disability. One participant in one of the mobility

impairment focus groups, Natalie, noted that they also had a passion for dancing like Artie in the episode of *Glee* that was watched during the focus group. Additionally, several participants in the autism focus groups noted that they related to Sam's interests in animals and research. As one participant noted: "Well, I very much relate to the way he draws pictures. I'm a visual artist also who loves animals, loves drawing animals, and I also relate to the animal facts, and, and just loving reciting the animal facts. I actually relate a lot to the character." (LoompaBates2141992, participant in autism focus group). Another participant noted a similar desire as Sam in *Atypical* to learn about and share their interests with others: "I identify with the kind of like encyclopedic knowledge of the thing that you're really interested in and, and just like that kind of compulsion to share that and you know, uh, I want to kind of connect over those things." (Lee, participant in autism focus group).

On the whole, during the focus groups participants made it clear that they valued relating to the disabled characters that they see in the media, particularly in the disability characteristics that they display, the challenges and hopes that they have, their family dynamics, as well as personalities and interests. Just like anyone, disabled individuals want to see themselves represented in what they watch and feel like they have characters that they can relate to and connect with on significant levels.

#### Subtheme 2: "Disability Done Right".

The second subtheme: "Disability done right", was defined as portrayals of disabled characters that participants felt were accurate, respectful and relatable. Several focus group participants who stated that they were not able to relate to the characters or situations which were presented in the media representations were able to describe characters from other media that they felt were more representative of themselves and their experiences. One participant stated that they could relate to the character of Tina Belcher from the television show *Bob's Burgers* who they mentioned as referred to as autistic in an early episode: "Um, but, what I like about Tina is that she is me in my early teens: very nerdy, liking cute boys, likes horses, likes video games, writes fanfiction..." (Max Niccals, participant in autism focus group). Additionally, one participant in the Turner Syndrome focus group contrasted the portrayal of Janey with the character Gwen, a character with Turner Syndrome who is the main character in the Book *The Condition* by Jennifer Haigh that she found to be more relatable and relevant to her personal experiences:

Um, I think it [the book *The Condition*] was relatable. She was older um and sort of becoming um active in dating and that and that kind of thing with, with all this other, like family drama surrounding it. But she was sort of like becoming more independent. Um, and to be honest, I found them more realistic looking back now and having seen the depiction of Janey in SVU, that it's a little more realistic to see someone in her later twenties, thirties um branching away the way she was doing at that point in her life. (Samantha, participant in Turner Syndrome focus group)

An extremely important aspect of disability portrayals that participants mentioned during the focus groups was portrayals in which disabled characters were played by disabled actors. In fact, during many of the focus groups, participants either asked if the disabled character in the media portrayal that was watched was played by a disabled actors or mentioned that they were already aware that the character was played by a nondisabled actor. An example of a media portrayal that had a disabled actor playing a disabled character that was provided by one participant was the television show *Speechless*:

One portrayal, I would say is really good of disability in media is, is um and actually played by a person with a disability is, is um *Speechless* where the actor who plays the boy with cerebral palsy. Now I'm not sure if he uses a wheelchair in real life, but he, the actor, really does have cerebral palsy. So the boy with cerebral palsy is played by an actor with cerebral palsy. (LoompaBates2141992, participant in autism focus group)

Participants also discussed several benefits of having disabled actors playing disabled characters, including adding an element of increased authenticity to the portrayal, as well as the importance of disabled people seeing individuals like them in the media that they watch. One participant in the Turner Syndrome focus groups discussed the benefits of having disabled actors playing disabled characters by saying:

I'm like, that would have been cool if she did like, that they hired someone with it. Like, it would just make that connection. You know like, like "this and that actress has that" you know it would make it that, that connection better. I don't know if that makes sense, like you can relate to that character more. (Ann, participant in Turner Syndrome focus group)

Several participants also discussed the importance and need for the entertainment and media industries to be open and transparent about their casting and research of disabled characters to better inform audiences about the accuracy of the portrayal, particularly if non-disabled actors are playing disabled characters:

And then I think you should be open with the audience as well, that like this, like, you know, this person may not actually have the, the disability, but we put effort into researching it and we consulted with people who have it so that, you know, the audience doesn't get the wrong idea about the actor or actress [Jill nods]. Yeah, I think that would be like probably the best way to go about it um because like if an actor or actress were to take on, you know, portraying a character with a certain disability, then the audience, you know, who might not take the time to like actually research the actor or actress they may just associate the actor or actress with that disability um and kind of see them as having it, even if they might not. So I think, yeah, being like pretty straightforward about the whole process um is really important for people who are casting these characters. (S. R., participant in Turner Syndrome focus group)

Some participants revealed positive perspectives towards portrayals of disabled characters that were handled with respect, even if the actor portraying the character did not have the disability that was being portrayed. While many participants stated a preference for disabled actors playing disabled characters, seeing disabled characters and storylines that were handled respectfully by the actors, writers, and directors was a very important factor as well:

I absolutely love *The Good Doctor*...Anyway, um, I like *The Good Doctor* because even though it does have some stereotypes in it, it's not that, like, it's not disgusting in a way. Like some portrayals are. It does good for the autism community to see autistic people, and not the ones who can mask so well that they pass for neurotypical most of the time. It does us good to see someone who's in a high-level job, who's got an education, has overcome a lot of roadblocks like Shaun has. He came from an abusive background and now he's doing well in his residency after med school, uh, despite the challenges he's faced and despite not being able to mask as well as a lot of people. Um, I can relate a fair bit actually. Uhm, just the way he looks, the way he holds himself awkwardly, is kind of a similar way to how I move, and I think it does a pretty decently good job...But I think the actor, despite not being autistic, plays the role superbly. In fact, so well that I had to look up: Is the actor for Shaun Murphy autistic? No, but as far as I understand, they did um heavily consult with the autism community and try to be as sensitive as possible in that regard. (Jac, participant in autism focus group)

In general, it can be stated that participants valued media portrayals of disabilities that they felt were respectful and relatable to disabled characters and disability experiences, which included portrayals in which disabled actors played disabled characters. Participants also felt that it is important for individuals in the media and entertainment industries to be open and transparent when disabled characters are played by non-disabled actors as well as the casting process that goes into selecting the actors that play the characters.

### Theme 2: "That Doesn't Sit Right With Me:.

The second theme was "That doesn't sit right with me", which was defined as aspects of media portrayals of disability that participants had negative reactions to. This was broken up into three subthemes: "I don't see myself", "That's a caricature", and "That's unrealistic".

#### Subtheme 1: "I Don't See Myself".

The first subtheme: "I don't see myself", referred to aspects of disabled characters that participants did not feel a connection to or did not feel related to their experiences. Participants discussed not relating to several aspects of the media portrayals that they watched during the focus groups, including such aspects as differences in disability characteristics, different interests, different personalities, differing amounts of social support and family dynamics, and different strengths. As with the earlier subtheme "That's me!", the factors that participants mentioned not connecting to had varying levels of significance. An important factor mentioned by participants was not connecting with the way the disability was presented in media portrayals. Regarding presenting different disability characteristics, several participants in the autism focus groups discussed how they frequently masked symptoms in daily life, which is not often represented in media portrayals like Sam in *Atypical*:

One way that I didn't really identify with the character [of Sam] that I think I've said this before, but I, I mask. Like I, I certainly. I've gotten 'But you look normal' when I disclosed my autism I get 'You look normal' and it's like I'm actually off-offended by the 'but you look normal'. It's like well, what's autism supposed to look like? (LoompaBates2141992, participant in autism focus group)

Additionally, participants brought up the fact that many disabilities have a wide range of symptomology and presentations which can be experienced in a variety of ways by those diagnosed with the disability. Some participants in the Turner Syndrome group discussed experiencing different disability characteristics than the character of Janey in *Law and Order: SVU*, due to the fact that the definition of syndrome means that there are a wide variety of characteristics which can be experienced differently by each person diagnosed with Turner Syndrome:

Yeah. [pause] And just like the syndrome itself. Like we all have different health issues or whatnot [Cactus nodding in agreement] that comes along with it. Like it's so different from person to person that it would be hard just to say that every single person with Turner Syndrome is this or that, you know? (Ann, participant in Turner Syndrome focus group)

Another impactful aspect in which several participants noticed differences between their personal experiences and the media representations they watched during the focus groups was in their amounts of social support and their family dynamics when compared with the characters with their disability. Some participants discussed having more positive experiences than the character in the media portrayal, such as having family members who encouraged their autonomy or a supportive friend group, while others discussed having more negative peer and social experiences when compared to the disabled characters in the media portrayals watched during the focus groups. A participant in one of the mobility impairment focus groups, Bunny, noted that when they were in school they did not have something at school for them to look forward to, as Artie from *Glee* had with the Glee Club, and one participant in the autism focus groups noted that the many social supports that Sam had in *Atypical* was very different from their own experiences:

For me, one of the things that was really different was that Sam-and I've seen the whole show, so I'm not gonna give any spoiler alerts, but I'll just say that globally Sam always has someone reassuring to go to. Like even with the meltdown, he always has someone to go pick him up. He always has someone to like, give him the Cliff notes, explain him through it, um, rescue him, like make him feel better. He doesn't get a whole lot of pushback. He doesn't get shamed. He doesn't get really bullied that I've seen? Um, like, even when he has trouble, it's kind of funny and he always has Zahid, his friend from Techtropolis there, or his family, or even though his sister like picks on him it's kind of cute and funny. Um, so he has a lot of saviors and so the circumstances around him are really supportive, so we kind of never really see like the depths of despair [Chrissy nods]. We never really touch on like the dark side, the, the comorbidities of like extreme depression, um, suicidal ideation, anything like that. Um, I don't know how we could make that funny? But it's really, that's definitely something that's completely missing, um, and it's a big missing in terms of my experience. (Jane Babineaux, participant in autism focus group).

Additionally, while some participants found that they could relate to the overprotective family members seen in the episodes of *Atypical* and *Law and Order SVU*, others mentioned that their family dynamics growing up were very different and that their parents and other individuals in their lives encouraged their independence and treated them age-appropriately. One participant in the Turner Syndrome focus groups noted that they had never been treated as younger than they were by family members, peers, or coworkers, while another stated: "Umm… Well, I didn't have overly protective- well I

had protective, I didn't have overly protective parents like she did. Um I was given a lot of space to kind of make my own mistakes, do my own things growing up." (Allison, participant in Turner Syndrome focus group).

Participants also discussed personal differences in interests, strengths, and personalities compared to the disabled characters in the media representations that they watched during the focus groups, which impacted their sense of connection with the character. One example of these differences occurred during a discussion regarding the episode of *Law and Order: SVU* shown during the Turner Syndrome focus groups, where two participants discussed how their priorities differed from the character of Janey when they were the same age as her:

Cactus: I was like, but like I didn't feel the urge to have a baby when I was 17 [laughs].

Ann: Exactly. That's, that's kind of what I was meaning. Like it was a bit – like she's still a kid. I was in high school at 17 [laughs] (participants in Turner Syndrome focus group)

Several of the participants in the Turner Syndrome focus groups also commented on the fact that Janey was described in the episode as being extremely bright in the areas of math and sciences, which was very different from their strengths growing up and is something that is often noted in the medical literature as frequently being a challenge for individuals with Turner Syndrome:

I, I definitely have to agree with that. But that kind of gave me a jolt just because that's that's the one thing you hear sort of across the board is, "Oh, yeah, math is a struggle." Oh, and I totally wasn't in science. I was a language and arts girl. Like, that's where I excelled. I wasn't - no interest in sciences and math at all. But it's possible. It's possible. (Samantha, participant in Turner Syndrome focus group)

Participants also commented on differences between their personalities and the personalities of the disabled characters in the media portrayals that were watched during the focus groups. Often these differences led to a negative perspective of the character. For example, one of the participants in the mobility impairment focus groups discussed how they felt that their personality differed from Artie's personality from the episode of *Glee* that was watched during the focus group:

So, so, unlike Artie, uh, I was kind of very active and I didn't take very many things personal, and I didn't care for my failures and so that way I, I, I was able to move around and, and interact with my friends without the pity, you know? He's kind of shown in a way as though he's weak and people need to come and help him to do something. So that is the biggest difference uh with my experience. (Ricco, participant in mobility impairment focus group)

Some participants stated that the ways in which they did not relate to the characters were relatively minor, and many were able to find ways to relate to characters in the media portrayals that were watched during the focus groups. Additionally, some participants who did not relate to the characters in the media representations watched during the focus groups were able to think of and discuss characters in other media portrayals that they related to. However, some participants brought up and discussed the impact of not finding or seeing characters that they could relate to in the media. This lack of representation can have a significantly negative impact on disabled individuals, particularly those who are members of multiple under-represented populations. One participant in the autism focus groups discussed never seeing their ethnicity or interests represented in autistic characters:

And also question number two, differences between experiences with autism and like, you know, yourself and the show, um personally speaking, the elements of classism and ethnicity slash race...Um, where I come from is, to be blunt, not a good place. And growing up autistic there, I feel like every time I look at the media for representation of people with my condition, I don't see any sort of resonance with it. So often I see representations of autism being very much like we saw in the show today. Almost exclusively the uh reserved very much STEMinterested, technology-interested, almost exclusively, you know, white people. I mean I'm pretty guero [means fair complexion in Spanish] you know but I'm, I'm

Lack of representation and visibility of various disabilities and characteristics in the media and its potential negative impact on young viewers was also discussed by a participant in the Turner Syndrome focus groups. This was a particular concern for participants in the Turner Syndrome focus groups, as when these focus groups were conducted the only fictional representation of Turner Syndrome on television was Janey in the episode of *Law and Order: SVU*:

a Mexican. (Auster Ezrian Luna, participant in autism focus group)

Well, it makes. I don't know if it's not like a visible thing in media. It makes you feel more different I guess like especially. Maybe for the younger group, more so 'cause I think as adults like we'd more come to terms with who we are and are happy with ourselves, but uhm, being influenced, watching like, well, "I don't look like that teenager", or "I don't look like that lady". I'm short she you know,

like just not seeing an example of who you are on TV...Um. Thinking you're different, like "Oh nobody on TV looks like me". And this goes for, like all disabilities too, right?... But like, I find disabilities in general just aren't represented well on TV. (Ann, participant in Turner syndrome focus group)

Overall, when participants discussed media portrayals that they had negative perceptions about, they frequently brought up disabled characters and storylines that they could not relate to. This included different disability characteristics, different amounts of social and family support, as well as different strengths, interests, and personalities. This lack of representation can have a negative impact on disabled individuals, particularly young disabled people who may still be navigating their identities.

#### Subtheme 2: "That's a caricature".

The second subtheme was "That's a caricature". This referred to tropes or stereotypical disability traits that participants noted in characters with their disability, both in the representations that were watched during the focus groups as well as in other portrayals of their disability that participants referenced. These stereotypes included infantilization, characters portrayed as asexual, savants, characters lacking hope, characters portrayed as passive, disabled characters as a source of comedy, and disabled characters as underestimated. Infantilization stereotypes were mainly discussed in the Turner Syndrome focus groups in relation to the character of Janey, how other characters discussed her, and other characters' perceptions of her ability to determine her actions and choices. Some participants theorized that many of the stereotypes seen in the way that Janey was thought about and discussed in the episode could be due to the fact that the character was perceived mainly through a male lens, as all of the significant investigators focusing on her case were male:

Um it definitely painted like a picture of innocence um and like being very childlike for her um, which, like, you know, isn't really the case? Like she, she's a 17-year-old girl, like. And they acted so shocked um at the thought of her like, you know, like exploring her sexuality, like, you know, um like doing things that like normal 17-year-old girls would do. Um so, you know, I think if they did have more of that female perspective, that would definitely be like reduced a little bit. (S.R., participant in Turner Syndrome focus group).

Infantilization was a stereotype that was also mentioned by participants in the autism focus groups. Some participants in the autism focus groups discussed infantilization stereotypes that they felt were seen in Sam in *Atypical*, and how these stereotypes are often seen in addition to or connected with asexual stereotypes in media portrayals of autistic characters: "Um, I feel a lot of people when autistic, a lot of times when autistic people get portrayed, they are like infantilized a lot. And like dating and sex are seen as things that like, oh, they can't aspire to that. Like they're like too innocent or like, too clueless." (Sparrow, participant in autism focus group).

The connection between infantilization and asexuality stereotypes was also seen as occurring in the Turner Syndrome media representation that was shown in the focus groups, and two participants in the Turner Syndrome focus groups discussed stereotypes of asexuality in relation to the character of Janey as well as how these stereotypes could have a negative and harmful impact not only on individuals with Turner Syndrome but also on individuals who may be interested in having a romantic relationship with them: Cactus: So like I feel like that could also contribute to like the whole like, uhm, you know, just like desexualizing almost like girls with Turners Syndrome, like oh like you know how they talk about how she's sexualized and things like that. So that could also contribute to like the desexualization of like girls who have Turners Syndrome, 'cause they're like "Oh you know like I can't be interested in this woman because she has Turners Syndrome, oh she's short". Um, but you know, like uhm you know, like like, it really takes, like it really takes woman, like it really like it takes, like it contributes to like just the idea that, um, women with Turners Syndrome can't be like, like they can't be adults. Basically, and they can't have a sex drive–

Ann: Yeah.

Cactus: – They can't, they can't have like, how they can't think about, like, you know what I mean? Like they can't think about sex

Ann: [Talking over Cactus] Only pedophiles would -

Cactus: Yeah, yeah, or like they can't have normal like dating lives. They can't have like um, you know, it's almost like it's almost like, like it's saying like, "Oh, like you're like a freak if you are interested in somebody who have Turners Syndrome" basically. And that's like, that's extremely hurtful. (participants in Turner Syndrome focus group)

A stereotype that was discussed by participants as being frequently seen in media portrayals of autistic characters was the savant stereotype. Some participants in the autism focus groups discussed this stereotype, and one participant compared the portrayal of Sam, who they felt did not display the savant stereotype, to another currently popular autistic character on television, Dr. Shaun Murphy in *The Good Doctor*, who they felt did display the savant stereotype:

I would say *The Good Doctor's* a really good portrayal. Again, *The Good Doctor* shows a character who's about ten years older than, than Keir Gilchrist's character [Sam], but The Good Doctor, Dr. Sean Murphy, Freddie Highmore's character. He plays the character again someone who's-now Keir Gilchrist's character is a little more typical of autism in that he's, he's smart, but he's not a savant. *The Good Doctor*, Dr. Sean Murphy's an autistic savant, which is quite rare. (LoompaBates2141992, participant in autism focus group).

Other stereotypes that were mentioned by participants during the focus groups were disabled characters presented as passive, lacking hope, and/or as underestimated. The passive stereotype was mainly mentioned by participants in the Turner Syndrome focus groups regarding the character of Janey in *Law and Order: SVU*, and they also discussed the significant impact of this stereotype on viewers due to the fact that at the time that the focus groups were being conducted, this portrayal was the only non-fiction portrayal of Turner Syndrome on television or cinema:

Yeah, yeah like I just, yeah like I don't know, like I feel like, I feel like it's just it's just really unfortunate that there's like, there's like, I think that's the only portrayal of Turner Syndrome on, like, on TV or like a movie, that's really the only one. And it's just it's such a like a, yeah, like it's, it's just, like the fact that she didn't really get like a um, she didn't really get a main role really. The character, she was kind of like a side, like a side character. She's just like... But I feel like and, uh, so it's like she didn't really get her, like much her own story. She's kind of just like, she kind of just like, a like a passive character in the show. (Cactus, participant in Turner Syndrome focus group)

Media stereotypes of disabled individuals as lacking hope were also discussed by participants during the focus groups. For example, one participant in the mobility impairment focus group discussed Artie's storyline in *Glee* and his focus on walking and how it could promote a feeling of hopelessness in individuals who watched the portrayal:

So people will tend to, to, to imagine that people in wheelchairs are, are very sad and have so much unfulfilled dreams because all their dreams are associated with are standing up and, and dancing, and so they, there isn't much that they could do when they're seated. So, I think that would be a really negative impression.

(Ricco, participant in mobility impairment focus group).

Considering that in the episode Artie also spoke to his guidance counsellor about research studies and potential medical breakthroughs, the hopeless stereotype seen in the media portrayal could also be connected with the search for a cure stereotype, which could further promote a feeling of hopelessness in disabled viewers if they have a similar diagnosis to Artie.

Stereotypes of disabled characters as being underestimated by non-disabled individuals were also seen by participants as appearing in the media representations that were watched during the focus groups. Several participants in the Turner Syndrome and autism focus groups brought up how the characters of Janey in *Law and Order: SVU* and Sam in *Atypical* were underestimated by others and viewed as not being capable of making important decisions in their lives. One example of this stereotype was seen in how Janey was underestimated by Detective Stabler in court: One thing I can relate to is how um she was kind of underestimated by the other characters in the show. An example of this would be in the, in that court, in the trial, they asked the um, the detective if they, if he thought that she would be able to hold down a job. And he said, "I guess, I guess she could hold on a job"

[Michelle and Wren nod]. (Zoey, participant in Turner Syndrome focus group)

Another example of this stereotype was seen in how Sam's family reacted to him announcing that he was considering donating his brain to science after his death after it had been brought up as an option by his psychologist:

Man, in the beginning, I HATED that interaction with them around the table where he comes back and says the psychologist asked if he wanted to donate his brain. The mom's response just absolutely disgusted me! It's like some people think we're not able to make our own decisions. Um, really? Do... We need to be allowed to have our own opinions. Have our own [pause] um decisions. It's his brain, after all. [Noise interference] and they think of him as being easy to control and stuff. (Jac, participant in autism focus group)

In both of these examples, the disabled characters had their decision-making skills questioned by other, non-disabled individuals, even though both characters were portrayed as very intelligent, capable individuals; Janey attended a gifted school and excelled in math and science, while Sam was able to balance high school and working a part-time job at Tech-tropolis.

Finally, a stereotype that was discussed mainly by participants in the autism focus groups was disabled characters and storylines used as a source of comedy. One participant discussed Sam's portrayal in *Atypical* and how they felt it relied on him and his behaviours being found as weird or funny by viewers:

I feel like I would love to see a lot more autism representation on screen, but I feel like a lot of times portrayal falls on when it's comedy. It looks like, "Ha-ha, this person's weird, isn't that funny?" And how is which I do feel is happening here a lot like "Ha-ha he smiled weird. Isn't that funny?" I would rather if the comedy comes from other elements, right? Or if it doesn't come from just the weirdness because I feel like the only weirdness, the only comedy was like just based on his weirdness (Sparrow, participant in autism focus group).

Another media portrayal that was frequently discussed in relation to this stereotype was the movie *Music*, which was directed by Sia and had recently been released at the time that the focus groups were taking place. It was interesting to note that this movie was discussed by numerous focus groups, even focus groups that did not have autistic participants. Several participants in the autism focus groups discussed their negative feelings regarding the characterization and how they felt that it was being used for comedy:

You know, it feels like that. Someone calls you autistic, they're calling you an idiot, basically. And it just [pause] I feel that the paradigm of representation needs to fundamentally change or else these things will exist continually not to be something for us, but they exist as basically autistic minstrel. Something to laugh at us with. (Auster Ezrian Luna, participant in autism focus group)

Finally, another example of the comedy stereotype that was mentioned in the focus groups was the character of Dr. Dixon in *Gray's Anatomy*, whose difficulties with

socialization were noted as frequently being used for comedic effect in the show. One participant discussed the strong impact that this portrayal had on their viewing of the show:

...And um in Gray's Anatomy, there's a character, Dr. Dixon, who, and she's a profoundly gifted surgeon, um autistic. And I loved her until they started mocking her on the show. She's like a figure of fun? And she also has, like zero social skills... She's this gifted surgeon. But yet, she'll come into a room and say like, "Oh. Your son died!. Ok, onto the next patient" or whatever. It's just terribly written. She's just there to be like a stock figure, a figure of fun, a plot point. And it's, it's insulting. And I actually couldn't watch the show much past, like, when I realized what they were doing with her character. Um, it was horribly ableist and made me kind of give up on the whole show. (Jane Babineaux, participant in autism focus group).

On the whole, participants discussed having negative reactions to media portrayals that displayed instances of disability stereotypes such as infantilization, savant, asexuality, and disability as a source of comedy. Participants noted several media portrayals which displayed stereotypes and also mentioned the negative repercussions that these stereotypes could have, as well as how it impacted their viewing and enjoyment of the particular media.

# Subtheme 3: "That's unrealistic".

The third subtheme: "That's unrealistic", was defined as aspects of television and movie storylines focused on disabled characters that participants felt were not representative of their disability experience or that could promote inaccurate ideas regarding disability and disability issues. This included a lack of positive storylines and disability representation, disability as the focus of the character, a lack of description of disability, sensationalized aspects of disability, inaccurate medical information, and a lack of diversity in representations of disabled characters. Several participants across all of the focus groups stated their belief that negative disability storylines are more frequently seen in the media, with one participant stating that they have never viewed a positive portrayal of their disability:

I guess just as like a-it's, it's going to hit as hard as a hammer-but I've never actually seen a positive portrayal of autism in my life. At least from what I've seen, from all the stuff that I've seen. Um, and part of this just goes into the difficulty of portraying it and also societal positions on it. (Auster Ezrian Luna, participant in autism focus group).

Participants across all focus groups also felt that there was a general lack of disability representation in the media, both for disabled individuals as actors and characters as well as those working behind the scenes. This was particularly noticed by several participants in the Turner Syndrome focus groups who revealed that they could not think of any other fictional media representations of Turner Syndrome when asked:

And I think that in itself is a problem that like I knew it was going to be this episode of SVU that we were going to be watching. I did research and I racked my brain, and it was really like the only kind of portrayal that came up. So, the fact that like there's only one like really well-known and the other one I could think of was the Mystery Diagnosis, where at the end the mystery diagnosis is Turner Syndrome um like and just the fact that the only portrayals we can think of are like medical or like police drama related. (Babs, participant in Turner Syndrome focus group).

Another aspect of the representations of disabled characters that were shown during the focus groups that many participants felt was not representative of their experiences was that the character's disability was often the main focus of the storyline. One example mentioned during the mobility impairment focus groups was in relation to the character of Artie in *Glee*, where the episode in which he had a main storyline was focused on his disability and the challenges that he experienced. In the case of this particular episode, Artie was focused on working to overcome his leg paralysis so that he would be able to achieve his dream of dancing:

Uhm, I think um I kind of resonate with what Lexxy has just mentioned uh because for me, as I mentioned, I feel like it's more for his character as, as, as if compared with other people, I feel I felt like it was only about dancing. They didn't actually get to show about his life uh, yeah outside that, so I didn't get like that much on that, so for me I feel like that might make people want to stigmatize us because uhh I feel like it's sort of probably, probably problematic because uhm he's always longing to like sort of dance and, and uhm that's basically it, and that's, there's nothing outside that, so yeah. (Snowy, participant in mobility impairment focus group).

Another example of disability focus noted by a participant in the Turner Syndrome focus groups was the fact that Janey's storyline in *Law and Order: SVU* was focused more on her disability and people's perceptions of it than on her personality, strengths, and

accomplishments. As a result, Janey's character was not as fully developed as it could have been, and her strengths were either minimized or discounted:

But I saw a lot of the male characters still kind of reinforcing the negative images of how people were viewing her and how a lot of her identity was focused on her appearance and, and not necessarily her accomplishment. She was going to a gifted school, a school for gifted people. Um she was excelling in math and science. Um I mean, so that really was an that was sort of dismissed, I think. So, yeah. I think that would kind of leave a bad impression on anyone who didn't really know the sort of facts, I guess, of or seeing her for, for who she actually is. (Samantha, participant in Turner Syndrome focus group).

Another aspect of the storyline in *Law and Order: SVU* that participants in the Turner Syndrome focus group felt was unrealistic was the manner in which Turner Syndrome was presented and described in the episode. Several participants noted that they felt that the description of Turner Syndrome was vague and lacked medical details related to Janey's experiences in the episode: "And they didn't mention anything about how women with Turner's- Well yes, we typically are shorter than average. We can use growth hormone when we were younger to achieve a decent height." (Zoey, participant in Turner Syndrome focus group). This was interesting considering the fact that many prominent characters in the episode were police investigators, medical professionals, or family members of Janey who would be expected to either want more detailed information on the diagnosis to get a better understanding of Janey or who would have knowledge of Turner Syndrome and be able to provide a more detailed description. Additionally, participants in the Turner Syndrome focus groups also noted what they perceived as inaccurate medical information related to Turner Syndrome that was presented in the episode. One participant, Ann, noted that in the episode it was stated that individuals with Turner Syndrome do not grow past the height of a 10-year-old and that in reality there are some individuals with Turner Syndrome who reach closer to average height. Other participants discussed the unusual hormone treatments that were mentioned in the episode:

Zoey: They also tried to connect testosterone with being used to increase her bone density, which is what they would use estrogen for. That's one of the reasons why estrogen replacement therapy is so important is because an estrogen deficiency can lead to low bone density and eventually a high risk for breaking your bones or osteoporosis [Babs and Stephanie nod]. So it wouldn't be testosterone that they would use. They would use estrogen and progesterone.

Samantha: You're right. You're right. I think they tried to get the science right and the medical treatments, but they got a little mixed up.

Babs: Failed.

Zoey: They whiffed it. Yeah, they failed [laughter and smiles from the group] (participants in Turner Syndrome focus group)

This instance of medical misinformation was noted as significant due to the fact that Turner Syndrome is not widely known about within the general population, so for many individuals unfamiliar with Turner Syndrome this episode may be their first introduction to it.

Another aspect of the media representations that were watched during the focus groups that participants found to be unrealistic when compared to their experiences were instances in the television episodes that they felt sensationalized aspects of their disability. For example, one of the participants in the autism focus groups shared their perceptions on how the psychologist in *Atypical* described autism in a scene and the impact that they felt that the wording chosen could have on the perceptions of viewers:

But when she was saying like, "Oh, people on the autism spectrum", and then she said something like "and they have very specific preoccupations". The specific wording of preoccupations made me feel really icky because honestly, not even the DSM calls it preoccupation. The DSM, which has a lot of problems, even calls it like restricted and repetitive interests and behavior. Which sounds fairly neutral. Like a restrictive interest sounds way more neutral than like, a very specific preoccupation. Which sounds, honestly, really gross! (Sparrow, participant in autism focus group).

Similarly, several participants in the Turner Syndrome focus groups discussed their negative reactions to how Turner Syndrome was described by various characters in the episode of *Law and Order: SVU*.

Zoey: And I don't think I would go as far as to say that people with Turner's are adults trapped in children's bodies. I wouldn't go that far.

Babs: That line was disgusting.

Zoey: Yeah.

Babs: It made my skin crawl.

Zoey: Yes, we may look a little bit younger than we are, but I wouldn't go as far as to say adults trapped in children's bodies. (participants in Turner Syndrome focus group) Participants noted the very strong language terms used in the episodes to describe various aspects of their disabilities and noted that they did not correspond to their own feelings about their disabilities and the various symptoms connected with their diagnosis. The language used also tended to generalize individuals with autism and Turner Syndrome to imply that all individuals experience similar symptomatology.

Finally, when discussing their perceptions of other media representations of their disability that they could think of, participants discussed a lack of diversity in many disability portrayals. As briefly mentioned earlier, a lack of ethnic diversity was mentioned, and some participants in the autism focus groups discussed a lack of female and non-binary representation in autistic characters. This was something that was of particular importance to participants as the majority of participants in the autism focus groups reported their gender identity as either female or non-binary:

...and I agree with like, most portrayals of autism in media are like white males, right? Like, I can think of a couple. I can think of one non-white autistic character that I've ever seen in media that is like explicitly stated to be autistic. And it is from a short film and it's the character for Pixar's Loop, and that's like the one character I could think of. (Sparrow, participant in autism focus group).

A lack of diversity and variability in how their specific disabilities have been presented in the media was also noted by participants, with one participant in the autism focus groups discussing the lack of representations of more significant forms of autism or the comorbid diagnoses that can be associated with it:

It feels not only that representation of autism is, as people said, often based solely on race, class, socialization, interests. But I feel that there is very little, if any, representation of people with autism who have more serious and often trying issues tied to it. Other disabilities. Um. A very large percentage of people with autism are completely nonverbal. And there is almost no representation of this ever. A very large percentage of people with autism have issues even understanding, you know, communication and language. They, they have other issues that-some of them have like seizures as part of their condition. Um, epilepsy can be tied to autism. And it's actually one of the leading causes of death for young people with autism. And it feels like nobody mentions this. They only focus on um autistic people with, I guess, um, who, who have some level of communication, conventional socialization. (Auster Ezrian Luna, participant in autism focus group).

Across the different contributions from participants, when discussing media portrayals of disability that they had negative reactions towards participants brought up portrayals that they felt to be unrealistic, such as those that sensationalized or inaccurately represented aspects of the disability, that were primarily negative, or lacked diversity. These representations could impact viewers' perceptions of disabilities and disabled individuals, particularly if they are not familiar with the disability being portrayed.

# **Research Question #2**

Research question number two was: How could these portrayals impact perceptions of stigma regarding disabilities? Two themes were identified relating to this research question. A diagram of the themes and subthemes can be viewed in Table 4.

#### Table 4.

| Research Question   | Main Themes  | Subthemes   | Notes   |
|---|--|---|---|
| 2. How could<br>these<br>portrayals<br>impact<br>perceptions of<br>stigma | • That's harmful<br>(aspects that<br>could increase<br>stigma) | <ul> <li>Promotes ableism</li> <li>Promotes stereotypes</li> <li>Sanitized disability<br/>(disabilities toned down<br/>for non-disabled viewers)</li> </ul>   | • Sanitized<br>disability mainly<br>seen in autism<br>focus groups          |
| regarding<br>disabilities?  | • That's helpful<br>(aspects that<br>could reduce<br>stigma)   | <ul> <li>Subverting stereotypes</li> <li>I can do this<br/>(overcoming barriers and<br/>increasing self-<br/>confidence)</li> <li>I learned something<br/>today (providing<br/>disability education)</li> </ul> | • I can do this<br>mainly seen in<br>mobility<br>impairment focus<br>groups |

Themes and Subthemes for Research Question #2

#### Theme 1: "That's harmful".

The first theme was "That's harmful", which was defined as components of media portrayals of disability that participants felt could have a wide impact and potentially lead to greater stigmatizing beliefs towards disabled individuals from people who viewed them. This theme was broken into three subthemes: "Promotes ableism", "Promotes stereotypes", and "Sanitized disability".

# Subtheme 1: "Promotes ableism".

The first subtheme: "Promotes ableism", was defined as ways in which media portrayals could encourage negative viewpoints towards disabled individuals or could promote or perpetuate non-disabled biases or perspectives. When discussing media portrayals of disability, both the ones that were watched during the focus groups and other portrayals that participants could think of, participants often related situations that happened in the media portrayals to experiences in their personal lives and often noted similarities in how they were treated by others which they felt reflected views shown in some of the media representations. These viewpoints could be such things as making assumptions about what disabled individuals are capable of, as discussed by a participant in the mobility impairment focus groups:

Well, I also think that when people see you in a wheelchair, they automatically assume you can't do anything without help...Uh like I live on my own, so I haven't really felt that different from people unless I go out somewhere, I feel like I'm a liability. People say, "Oh we've got to do this, and we have to fold up the wheelchair and put it in the van, and do all this stuff", just so I can go to a show or something, but I can do it. So, people don't realize that I'm still a normal person, I just don't have a leg. (Jim, participant in mobility impairment focus group)

One participant in the Turner Syndrome focus groups discussed assumptions that people made regarding her decision-making ability, similar to the experiences of Janey in *Law and Order: SVU* and the perspective that Detective Stabler had towards her:

Yeah, I think, I think similarly, a lot of people, uh you know, sometimes can, view us as being younger than we are, or maybe not capable of making our own decisions. And you know, um a lot of heavy-handed influence uh in my past. I can say definitely on decisions I've made, um just from the feeling of people thinking that uh that I haven't been capable of making decisions for myself. (Wren, participant in Turner Syndrome focus group).

Such media portrayals and personal experiences could foster a sense of internalized ableism within disabled individuals, and this internalized ableism could be present in some disabled individuals who work in the entertainment industry and could influence disability storylines. One participant noted the potential for internalized ableism to be present in disabled individuals who have influence on media representations, stating "But, you know, if they have internalized ableism? Just because you have an autistic person writing doesn't mean that they're-they don't have internalized ableism that they have to deal with." (Gus, participant in autism focus groups). In more extreme instances, these ableist viewpoints could lead to disabled people being perceived as 'an other', completely separate individuals from the non-disabled population, as mentioned by one participant in the autism focus groups:

Um, and it feels like most representation is at least implicitly negative because of how we aren't looked at as just people. We're looked at as 'an other'. As something-to use the word that's probably been used within all of us since we were kids: "special", you know, but not in the good way. We're this outside identifier that doesn't exist on the same level as other people. We have to be coddled to, or we have to be corrected. Um, and it feels like this pervasive narrative or metanarrative applies to every single interpretation of autism I've ever seen. (Auster Ezrian Luna, participant in autism focus group).

In essence, one way that participants feel that certain media portrayals of disabilities could increase or perpetuate stigma towards disabled individuals is by promoting ableism and showing disabled individuals as being different from non-disabled individuals. This could result in instances of disabled individuals being considered as 'an other', or in internalized ableism among disabled individuals.

### Subtheme 2: "Promotes stereotypes".

The second subtheme: "Promotes stereotypes", was defined as ways in which media portrayals of disabled characters and storylines encourage disability stereotypes among individuals who view them. Participants pointed out several stereotypes that they noted could be perpetuated by examples within the media representations that were watched during the focus groups. One example of the stereotype of disabled individuals as lacking hope and unable to live normal lives, and the harmful implications connected with it, was discussed in relation to some of the worries that Sam's parents displayed in *Atypical*:

So that stigma of, "Oh my God, they're not going to lead a normal life" [Gus uses air quotes when she says the words normal life] is really harmful when sometimes normal, what other people consider-what society considers normal, isn't exactly healthy and good. Especially for an individual. (Gus, participant in autism focus group).

Additionally,, a participant in the Turner Syndrome focus groups noted stereotypes regarding the infantilization of individuals with Turner Syndrome perpetuated by the episode of *Law and Order: SVU* and how these stereotypes could have an impact not only on disabled individuals, but on individuals who may want to form romantic relationships with them:

Uh well, first of all um, you know, and probably not just the people who actually have Turner's, but the people who um, you know, might date women with Turner Syndrome, obviously, you know, being called a pedophile was not a great thing. And if they feel that, like this media representation represents uh what people actually of people who date people with Turner Syndrome, then that might be a problem right? like they might second guess if they would get into a relationship with the person that Turner's because of how they might be perceived. (Babs, participant in Turner Syndrome focus group).

Participants also discussed other examples of media representations that they felt promoted disability stereotypes. An example of promoting the stereotype of disabled lives as not worth living was mentioned by a participant in the mobility impairment focus groups regarding the movie *Me Before You* and how it could lead to assumptions about the quality of life of disabled individuals:

Um I would say *Me Before You* also because at the end um he, he died. He chose to commit suicide just because he was in too much pain. Um and then um, he I think he just leaves the assumption that everybody who has, like, mobility issues is in pain. So, um just that assumption is the negative impact that I just got from that movie. (Bunny, participant in mobility impairment focus group).

Generally, participants felt that some disability representations in the media could be perpetuating negative perceptions and stigma towards disabled individuals by promoting disability stereotypes, such as the stereotypes that they discussed in the previous subtheme "That's a caricature". This could include specific stereotypes regarding the capabilities of disabled individuals and could also be as significant as the viewpoint that disabled lives are not worth living.

Subtheme 3: "Sanitized disability".

The final subtheme: "Sanitized disability", was primarily seen in the autism focus groups and was defined as ways in which disabled characters and storylines were perceived to have been made more comfortable and palatable for non-disabled viewers by either downplaying aspects such as symptomatology and comorbidities or by using an inspirational lens, such as showing disabled individuals dating and seeking love. Overall, participants felt that a wide range of autism representation in the media, both fiction and nonfiction, was often created, written, and/or edited through the lens of non-disabled viewers. During one of the autism focus groups, participant Auster Ezrian Luna mentioned that they felt that generally stories of autistic characters are created to be shown to non-disabled individuals to make them feel good about themselves, either by making them laugh or making them feel like they learned something. Additionally, several participants in the autism focus groups engaged in a dialogue about how they felt that specifically dating shows centred around autistic individuals are usually formatted for the benefit of non-disabled individuals and promote the idea of disabled individuals as inspiring:

Max Niccals: It exact-with the caste system, definitely, and with *The Undateables* and like autism, *Love on the Spectrum* and everything. It's almost like inspiration porn for neurotypical people.

Chrissy: Yeah

Jane Babineaux: Yeah

Max Niccals: It's like, "Oh, wow. They can date people. It's beautiful! So cute!" Jane Babineaux: Yeah... "They're so cute and I'm so normal and healthy and thank God I'm not them. Wooo." (participants in autism focus group) To summarize, a final way in which participants felt that certain media representations of disability could perpetuate negative perceptions and stigma towards disabilities and disabled individuals was by presenting a sanitized version of disability. By doing this, the media representations erase many of the challenges or uncomfortable parts of disability in order to make the portrayals more comfortable to non-disabled individuals. This can serve to give non-disabled individuals an unrealistic perception of disabled individuals and their lives.

### Theme 2: "That's Helpful".

The second main theme: "That's helpful", was defined as significant and widereaching ways in which media portrayals of disability could encourage viewpoints that are more positive towards disabled individuals within both disabled and non-disabled individuals. This was broken up into three subthemes: "Subverting stereotypes", "I can do this", and "I learned something today".

# Subtheme 1: "Subverting Stereotypes".

The first subtheme: "Subverting stereotypes", was defined as when participants felt that specific media representations of disabled characters and storylines went against common stereotypes of disability that are often seen in the media. During the focus groups, participants discussed ways that they felt that the media representations that we watched subverted stereotypes, even if they disagreed with many other aspects of the portrayal. This was particularly seen when participants discussed the episode of *Law and Order: SVU* and the character of Janey. The fact that Janey was written and portrayed as

a very strong-willed person was very much appreciated, as discussed by two participants in the Turner Syndrome focus groups:

Ann: But I guess also, even though, I didn't, I don't know, but that she made her own decision in life and was like... I guess, I guess that's probably with the strongwilled thing like... OK, she made that choice to be with that guy. Whether that was right or wrong. But she stood up for herself and was like no, 'This is what I want.' And you know, so like I think that's good too for showing that like [pause] 'cause, I don't know...

Cactus: Like just the fact that she was kind of strong-willed, was like...

Ann: Yeah 'cause children, a 12-year-old wouldn't like, I don't know, like it kind of shows that making adult choices -

Stephanie: Right.

Ann: -and can be independent and that kind of thing I guess is... Good. Whether the choice was right or wrong. But uhm. I think that's another positive. (participants in Turner Syndrome focus group)

Several participants in the Turner Syndrome focus groups also mentioned that they appreciated that Janey was portrayed as an intelligent character who attended a gifted program, which is often counter to many disability representations:

Ann: Yeah. So, like, I also liked how they made her like smart. They didn't have, um they didn't like "dumb her down" – [air quotes] Stephanie: Right.

Ann: – if you know what I mean. Like they didn't, like they said she was very smart, she's good at math and science, like hey, some people with Turners do have

struggles with math and science, but there's many that do well. And she said she wanted to go to school for, I think she said business or something, like her dad. Stephanie: Yes, yes, she said business.

Ann: So, I like that portrayal, 'cause like I went to university, you're in university. You know, like a lot of people with Turners go to university! So, like that kind of portrayal was [pause] good, 'cause they didn't be like, 'Oh she can't ever do anything'. (participants in Turner Syndrome focus group)

Participants also discussed other media representations that they could think of which they felt subverted disability stereotypes, even if there were aspects that they had issues with. Many participants mentioned that they appreciated representations of disabled characters as determined. This can be done by showing how disabled individuals cultivate and use their strengths, as mentioned in a book that had been read by one participant:

Autism can both be a disability and an asset. I like the social model of disability best, because it emphasizes finding your niche which supports your weak points, possibly turning them into assets, while making your strong points shine. Much as I didn't like the book *The Power of Neurodiversity*, this was one thing I did like, an example of how in one context this boy was rather disabled, but in another context, what disabled him became an asset. (Jac, participant in autism focus group).

Ultimately, across the different focus groups participants discussed several media representations of disability that they felt in some ways could reduce negative perceptions

or stigma towards disabled individuals. One way that they felt those media representations accomplished this was by subverting common disability stereotypes, such as showing disabled characters as being smart, strong, and determined. Participants were able to note such positive instances even in media portrayals that had aspects that they criticized or disagreed with.

### Subtheme 2: "I Can Do This".

The second subtheme: "I can do this", was defined as ways in which media representations of disabled characters and storylines were found by participants to have aspects that could result in disabled individuals who watched the representation feeling more positive about themselves and their disability. This was mainly referenced by individuals in the mobility impairment focus groups. One way in which participants felt that some media representations accomplished this was by showing disabled characters thinking outside of the box and cultivating interests that used their strengths, as one participant perceived Artie in *Glee* doing at the end of the episode when he decided to focus on his singing ability rather than dancing:

Ok, uh, for me also, uh it sort of raises their self-esteem that like it indicates people that if you can't do this thing if you're limited, maybe because of your impairment, you can't walk and dance or you can't do certain things, then you can choose something different that you can do, maybe while seated or with your impairment. Like if you can't dance, he was able to sing and he could sing well. If you can't maybe run around or do something that needs you to move, you can do something different like painting or something like that. So, sort of it educates them, yeah, and encourages them to try out other things that are possible. (Her, participant in mobility impairment focus group).

Participants also brought up other examples of media representations that they felt could increase the self-confidence of disabled individuals. One way that they felt that portrayals accomplished this was by showing disabled characters going after and achieving their goals and dreams, while also feeling positive about themselves before they achieved them. An example of this was noted by a participant when discussing the character of Gwen in the book *The Condition*:

I think just how she never really gave up on what she wanted to do, regardless of what her family felt she should be doing. Um she stayed single for a long time, but she was like that because that's just she was happy with her life, too [Wren nods]...I think she kind of learned that she had to appreciate herself first before she could do anything else too. (Allison, participant in Turner Syndrome focus group).

Across the contributions from the various focus groups, participants praised disability representations showing disabled characters as succeeding or overcoming obstacles, as well as feeling positive about themselves. In turn, these portrayals could not only increase the confidence and self-esteem of disabled viewers, but they could also show non-disabled viewers the various strengths that disabled individuals have and the many achievements that they can accomplish, which could lead to more positive perceptions of disabled individuals.

Subtheme 3: "I Learned Something Today".

The third and final subtheme: "I learned something today", was defined as ways in which media representations were felt by participants to educate individuals about disabilities and disability issues. Several participants felt that this was a positive and necessary role of media representations as they noted that a lack of community awareness of disabilities remains:

...And part of this could be a cultural thing because oftentimes, you know, all my family is like, 'What the hell is autism? Like, that doesn't mean anything to me. You just need to be normal and stuff.' Like, there is a lot of ignorance on mental conditions within minority communities, personally speaking through my experience... (Auster Ezrian Luna, participant in autism focus group).

During the focus groups, participants also discussed a lack of disability awareness within communities that would have some knowledge about the topic, such as education and healthcare communities. One of the participants in the Turner Syndrome focus groups discussed their personal experiences with a lack of awareness of Turner Syndrome within the medical community:

I definitely related with people not fully understanding what Turner's Syndrome is. Like, even when I was younger. I would have to do it. Sometimes when I would see my doctors, I would- who weren't endocrinologists. I would have to explain to them what Turner Syndrome is and they wouldn't know...So I definitely related with that aspect because not very many people understanding her condition. (Zoey, participant in Turner Syndrome focus group)

Several participants disclosed that even if they did not fully relate to or have positive feelings towards specific media representation of their disability, these representations could still provide benefits by initiating conversations surrounding disability and disability issues and allowing disabled individuals to share their thoughts and knowledge:

I think it's a great starting point for conversation. I, I would love to see more shows with different characters who are autistic from different backgrounds with different plots and different story arcs, um and this be like one of the points in the constellation. But I found personally that it's a great talking point, like 'Oh, have you seen *Atypical*? Well Sam, the main character, is autistic, and he's one autistic character among many in the world'. But-and then we start talking about the plot and the scrapes that he gets into, and I can use that as like, 'Well, I actually experience it like this and like that'. Um, so I've actually found it, it's a, it's a good icebreaker... (Jane Babineaux, participant in autism focus group).

Furthermore, when discussing the topic of disabled characters played by nondisabled actors, some participants brought up the benefits of education as a reason why they would understand the casting choice if casting agents and directors chose to go with a well-known actor to play the role of a disabled character:

...it would still give some like education and awareness about that disability just by being portrayed in media. If even if they couldn't find an actor who actually had that disability. So for example, the SVU episode, like it still gives awareness to Turner Syndrome, uh even if they didn't have an actress who had Turner Syndrome. (Jill, participant in Turner Syndrome focus group). It is important to note that when discussing the topic of non-disabled actors playing disabled characters, many participants stated that their overall preference was for a thorough effort to be done to seek out disabled actors to play disabled characters.

To summarize, participants brought up the importance that educating community members about disability can play, and mentioned this could be a positive outcome even with disability representations that had aspects that they criticized or disagreed with. This is especially important for disabilities that are not widely known, or for individuals who may not have had any personal interactions with disabled individuals.

# **Research Question #3**

Research question number three was: How can disabled characters be portrayed to be more diverse and nuanced and to reduce stigmatizing beliefs towards disabilities? A diagram of the themes and subthemes can be viewed in Table 5.

Table 5.

| Research Question  | Main Themes   | Subthemes  | Notes |
|--|---|--|-------|
| 3. How can<br>characters<br>with<br>disabilities be<br>portrayed to<br>be more<br>diverse and<br>nuanced and<br>to reduce<br>stigmatizing<br>beliefs | • Address the<br>barriers (resolve<br>barriers to disabled<br>individuals in the<br>media and<br>entertainment<br>industries) | <ul> <li>Where are we? (lack of disabled characters, actors, and industry employees)</li> <li>Importance of image/visuals</li> <li>Disability in the shadows (individuals hiding their disability)</li> <li>Safety concerns for disabled actors</li> </ul> |       |
| towards<br>disability?   | • Celebrate diversity<br>(more diverse<br>disabled characters)  | <ul><li>More demographic diversity</li><li>Show the spectrum of disability</li></ul>   |       |

Themes and Subthemes for Research Question #3

| • Do your research<br>(thoroughly<br>research disabilities)                     | <ul> <li>Talk to us (consult with the disability community)</li> <li>Make space for us (more disabled individuals behind the scenes)</li> </ul>  |  |
|---|--|--|
| • Give us the stage<br>(more disabled<br>actors and workers<br>in the industry) | <ul> <li>That's not us (inauthentic casting)</li> <li>Accommodate us</li> <li>Encourage us</li> <li>More of us</li> </ul>  |  |
| • Be positive (more<br>positive and<br>nuanced characters<br>and storylines)    | <ul> <li>More than just disability</li> <li>Breaking through barriers</li> <li>Subvert stereotypes</li> <li>Be honest (show honest and complex aspects of disability)</li> <li>Give us control (disabled people influencing the storylines)</li> </ul> | • Normalize<br>treatments<br>mainly seen<br>in autism<br>and Turner<br>Syndrome<br>focus<br>groups |

# Theme 1: "Address the Barriers".

Five themes were identified relating to this research question. The first theme was "Address the barriers", which was defined as factors within the entertainment industry that participants viewed as either challenges for disabled individuals in the media and entertainment industries or as deterrents for individuals casting or directing media representations and which need to be addressed. This theme was broken into four subthemes: "Where are we?", "Importance of image/visuals", "Disability in the shadows", and "Safety concerns for disabled actors".

Subtheme 1: "Where are we?".

The first subtheme: "Where are we?" was defined as the perceived lack of disabled characters, actors, as well as disabled individuals working within the industries more generally. This was a barrier that was mentioned by individuals across all focus groups. Some participants brought up the fact that a lack of known disabled actors can be a barrier as casting directors often try to bring in known names to help with promoting the movie: "And I think what I've heard is that one of the reasons they often pick known actors, the problem is there's not enough autistic people of a certain age or, or demographic in the industry, and that's what we were discussing before." (LoompaBates2141992, participant in autism focus group). Additionally, several participants noted that they could not think of any actors that had their specific disability, which could also prove to be a barrier when casting characters with that disability: "…Maybe you guys know them, but I don't know any actresses who actually have Turner Syndrome. I don't know if there's anybody that's well-known that has it." (Babs, participant in Turner Syndrome focus group).

A lack of disabled characters or actors that resonated with participants could be an explanation for why some participants felt that they found more disability connection with characters that were not expressly disabled but had qualities that mapped on with the disability community, as discussed by a participant in one of the autism focus groups:

I just wanted to answer that question in saying that, um, I think most of the best representations that I felt for autistic characters were by accident and that they weren't actually meant to be autistic people...But I related to them a lot, like Anne with an E. She seems autistic to me. And she's wonderful, and they represent her really great, but you know, you could, you could also look at it as, "Okay, I'm reading more into it than I want-then I, then I'm putting my emotions into it and stuff". So, it's hard to say, you know, if these characters really are autistic or not. But I think the best rep-the best things that I found have been [pause] not on purpose. [laughs] (Gus, participant in autism focus group)

Overall, during the focus groups participants discussed several barriers that they noted within the media and entertainment industries that need to be addressed which could potentially be reasons for the lack of disabled actors and employees and which could lead to negative disability representations. One barrier that participants mentioned was the lack of disabled characters and storylines in the media. As a result of this, some participants noted relating more to characters that were not labelled as disabled but that they felt had strong connections to the disability community.

### Subtheme 2: "Importance of Image/Visuals".

The second subtheme: "Importance of image/visuals" was defined as participant perceptions of appearance as being an important factor when casting roles, which could prove to be a barrier for disabled actors. One participant noted that they felt that image was a more prominent consideration in North American media compared to other parts of the world:

I think that's really the industry the way that it is. You know, they're making money. So that's kind of what North American audiences go for. Like they, they kind of want the best-looking person rather than the most talented person. Like, it's very much a visual thing. Um so I think that's where it stems from. Like if you look at countries like Australia and different, different parts of the world, it's not so, so much the way that it is in North America where it's all a visual and that's all they care about is, you know, the look. They care more about talent there. They care more about like the story than they do just what, what it looks like on screen and that's what our audiences are buying into. (Wren, participant in Turner Syndrome focus group).

The impact that stigmatizing beliefs and preconceived assumptions that casting agents, directors, or producers could have regarding disability and the impact that they could have on casting disabled actors was also mentioned by a participant in the Turner Syndrome focus groups. She discussed the experiences that a disabled actor friend has had when auditioning:

Um I've definitely heard that when I mentioned earlier uh having a friend who is a blind actress um and not getting chosen for parts to play blind characters um and getting to like the final three um actresses that they were choosing between but not getting chosen uh in the end, um she does like dye her hair purple and believe in like different bright colors and things like that, which people don't associate being blind because like dyeing your hair bright colors, people perceive it's a very visual thing. So, they're like people assume blind people wouldn't dye their hair those colors. Um so those casting agents, when they don't pick her, they say, "You don't look blind because you dye your hair these colors". And so, we won't get, we won't get brownie points for casting a disabled actor because you don't look like you're blind because you dye your hair purple. (Jill, participant in Turner Syndrome focus group). To summarize, another barrier that participants noted in the media, particularly within North American media, was the tendency to prioritize image and the appearance of actors over other qualities. This could lead to fewer opportunities for disabled actors. Additionally, individuals involved in casting decisions could have preconceived notions of what disabled individuals look like, which may have been reinforced in the media, and could result in biases against casting certain disabled actors.

### Subtheme 3: "Disability in the Shadows".

The third subtheme: "Disability in the shadows", was defined as various reasons why actors may not feel able to disclose their disability status, which may act as a barrier not only for currently working actors, but also for disabled individuals who may have an interest in acting or being involved in the entertainment industry. Participants discussed various reasons for this lack of disclosure, including employment fears and perceptions that disability does not relate to or impact their work, as discussed by two participants in one of the Turner Syndrome focus groups:

Cactus: There probably are lot more people with Turner Syndrome in Hollywood and stuff but like we just don't know about it because they're probably like a lot more quiet about it 'cause they don't want to like, maybe like it's affecting employment or effects like, different opp- Like opportunities that they may, that may arise.

Ann: And again, if they're an actor like that doesn't really hinder their acting ability, you know? So, like. Maybe they don't tell it like if there is an actor with it. Yeah, there might be something. It doesn't affect their role, so they don't tell people they have, you know? (participants in Turner Syndrome focus group) During some of the focus groups participants did discuss the issue of disclosing a disability diagnosis, which can often be a very personal and complicated decision and recounted some of their personal experiences and feelings regarding disclosing their diagnoses. One participant when discussing this fact noted that in recent years it seems like more actors have been publicly disclosing a disability diagnosis:

I feel like-okay, cool. I feel like a lot of actors and, like, industry people with disabilities are often, like, hiding it. I think we'll never really know how much, how many there will be. Um, just because it's often dangerous to, like, be like, "Hey, actually I have a disability" or whatever. I think an actor recently came out and said like, "Hey, I'm autistic!". I don't remember which actor it was some- for some sort of movie that had run in it? If anybody remembers, that's cool. But I feel like in recent years I've heard a couple more actors say like, "Hey, actually I'm disabled in X-Y-Z way". And I think that's [pause] pretty cool. (Sparrow, participant in autism focus group).

Generally, another barrier that participants mentioned was the possibility that stigma and barriers within the media and entertainment industries could lead to disabled actors hiding their diagnosis. Disabled individuals may also not disclose their diagnosis if they feel that it does not impact their work. Participants did note that in recent years the media has seen several actors open up and speak about their disability diagnoses; however, it is important to remember that the decision to disclose a diagnosis is very personal and has many complicated factors that can influence it.

Subtheme 4: "Safety Concerns for Disabled Actors".

The final subtheme: "Safety concerns for disabled actors", was defined as factors involved with media projects which could be perceived as unsafe for disabled individuals and as reasons to not hire disabled actors and could prove to be a barrier in hiring disabled actors. One factor which some participants viewed as an understandable reason for hiring a non-disabled actor over a disabled actor was if the disabled individual would not be able to provide informed consent for what they would need to do for the project:

Like if it's some kind of situation um where they're like, um, the person with the disability wouldn't be able to actually have the capacity to understand like what was going on and to consent to doing that, um then I think that would be a situation where like an exception could be made. (S. R., participant in Turner Syndrome focus group).

Another participant noted that concerns for the actor's physical safety due to some of the demands of the role could also be a factor, although they did note that this could be an unlikely situation:

I suppose I would say if there was any type of safety concern for, for the actor or any other actor or crew member for any reason, I can't think of anything that would prevent that at the moment. But I guess that would be sort of a valid concern for not using an actor um with a disability. So maybe say if there was a stunt involved or I don't know, [laughs] I'm trying to think of something. (Samantha, participant in Turner Syndrome focus group)

To summarize, the final barrier within the media and entertainment industries that participants noted as potentially impacting the number of disabled individuals in the industries was potential safety concerns for disabled actors. Some of these concerns were more significant, such as needing to ensure that informed consent could be provided, while others such as physical safety or stunts, would have more ways to be addressed to reduce the barriers.

## Theme 2: "Celebrate Diversity".

The second main theme: "Celebrate diversity", was defined as the need for and importance of increased diverse disability representations. Participants across all focus groups noted that increased diversity in multiple areas is needed in the media and entertainment industries and discussed the potential impact of not having diverse representations:

And makes it seem like really rare or unusual or something like that. Whereas, you know, there's people who use a wheelchair all the time. There's people who are shorter, you know, there's all sorts of things like we're all different. And I find that in the acting world that, yeah, it is kind of more uh homogenous. I think. For lack of a better word. [Jill nods]. (Amelia, participant in Turner Syndrome focus group).

This resulted in two subthemes: "More demographic diversity" and "Show the spectrum".

## Subtheme 1: "More Demographic Diversity".

The first subtheme: "More demographic diversity": was defined as the need for more disabled characters of varying demographic characteristics such as ethnicities, genders, sexualities, and disability. Participants mentioned how this increased diversity could lead to characters that they feel more connected with and are more representative of themselves and their experiences. Several participants in the autism focus groups noted the prevalence of white, male autistic characters in media representations, with one participant stating:

I think I would like more characters who are not white. More characters who are not men. More characters who are not into STEM. I feel like autistic people get framed into STEM. How about art? Lots-I know so many autistic artists, like who are into art, music. I'm an artist. My friends are like artists and into like literature. (Sparrow, participant in autism focus group).

Another participant discussed the need for more ethnic diversity of media portrayals of disabled characters and how their ethnicity played a significant role in shaping their disability experiences growing up:

I guess in terms of representation, something that would be really interesting, and I guess just important would-I'd like to see our condition from the perspective of, I guess culturally not within like the mainstream culture of the United States, but from a minority culture such as my own...There's a lot of intricacies to like, uh, family dynamics that aren't touched on within a lot of mainstream culture, and autism plays into that as well. And I feel that if I wasn't, you know, where I'm from, who I am, my experience as autistic would be completely different. And I feel it would show a lot of people with our condition that, like, you don't have to fit the mould of what it usually is. And that, uh, I guess, I always felt kind of outside of the purview of ASD, um, until I saw that there was another person like me who also grew up in the same culture and also has the condition. And I actually-this meant a lot to me. (Auster Ezrian Luna, participant in autism focus group) Finally, several participants also mentioned wanting to see more non-binary disability representations. A reason for this lack may be due to the frequent use or internal incorporation of the asexual or infantilized stereotypes and not frequently seeing disabled characters in romantic relationships. One participant in the Turner Syndrome focus group noted the need for this and the fact that Turner Syndrome is primarily viewed through a female lens:

I would personally be interested in seeing potentially a character with Turner's Syndrome who doesn't necessarily identify as female. Um I think that's definitely something that hasn't really been exploring. You know, we talk often, we often use the word women when we're talking about people with Turner Syndrome, but I'm sure there's a significant proportion of our community that doesn't identify as female, whether they're non-binary or they're trans women. Sorry, trans men. So um I think that would be an interesting thing to uh explore in writing or on a TV show or something. (Babs, participant in Turner Syndrome focus group).

Across the contributions from the various focus groups, participants want to see a more demographically diverse range of disabled characters that better reflect themselves. Several participants stated that they did not feel that their cultural backgrounds, gender, and sexual identities were represented in current media portrayals and as a result, many of their experiences have not been represented in disabled characters in the media. It was also notable that most participants in the autism focus groups identified as female or nonbinary, which are not often represented in autistic characters. Additionally, the only fictional representation of an adolescent or young adult with Turner Syndrome on television features a cisgender female who is in a heterosexual relationship.

### Subtheme 2: "Show the Spectrum".

The second subtheme: "Show the spectrum", was defined as the need for the entertainment and media industries to show the wide range of ways in which disabilities can manifest and be experienced. Participants discussed just how complex individuals with disabilities are and that addressing these complexities could add to the portrayal:

Yeah, I agree with that. Just that just how complex the – a person with Turner Syndrome can be and um how varied that that can be from person to person with Turner Syndrome. So just to try to even grasp the complexity and, and try to create depth in the character. (Samantha, participant in Turner Syndrome focus group).

One participant in the autism focus groups noted that there is as much variability within the autism community as there is outside of it, and that this is not often shown in media representations of autism:

The biggest thing that kind of irks me is that while it is very true that being autistic is a spectrum, being non-autistic is also a spectrum too. So that's the biggest thing that needs to be realized and fully embraced when writing these things is that we're just as unique as being non-autistic...There are many nonautistic people who don't get married and have relationships or children or do [uses air quotes] normal things. There are a lot of non-autistic people who have disabilities. (Gus, participant in autism focus group). Generally, participants also want to see a more diverse range of disabilities and their associated symptoms and comorbid diagnoses represented in the media. This also includes a diverse range in terms of the severity of the disability in characters. Participants noted that the disability community is just as diverse as the non-disabled community, and having a wider range of diagnostic experiences and symptomology would lead to more individuals in the disability community feeling seen in the media that they consume.

## Theme 3: "Do Your Research".

The third main theme was called "Do your research" and was defined as the need for individuals within the entertainment and media industries to make thorough efforts to research the disabilities that they are planning to represent. Taking this step would add to the authenticity and respectful portrayals The need to conduct thorough research was viewed by participants as an important aspect when creating and writing any entertainment featuring disabled characters or disabled storylines, and particularly when non-disabled individuals portray disabled characters:

If yeah, if you're not going to have a person that actually has a disability play the character, you should at least like um do your, your due diligence and make sure that you're getting an accurate representation. And more than just like, you know, a quick Google search, being like what is this? (S. R., participant in Turner Syndrome focus group).

Two subthemes arose from this category: "Talk to us" and "Make space for us". *Subtheme 1: "Talk to Us".* 

The first subtheme: "Talk to us" was defined as the need for disabled individuals and individuals connected with them to be approached, consulted, and listened to about their disability and experiences. One participant brought up the importance of listening to disabled individuals particularly when they express critiques or concerns. This could serve to address many issues that are currently seen in disability representations and could also serve to avoid many of the negative responses to media representations that have happened in the past:

I think one, that one thing that directors and creators could do is listen to the autistic community even if the autistic community is not saying something flattering. Maybe especially if. I'm thinking of Sia...and the whole *Music* thing. And her first instinct was to just fire back with all of this just horrible, horrible [pause] ableism. Basically, when she said that, that's the point where she should have stopped and listened and been like, "Okay, I can reroute and make a good thing of this". And that might have worked. It might have worked for everyone. But instead, she just kind of plowed ahead with, [pause] well, we all saw what happened. We all saw the train wreck... (Jane Babineaux, participant in autism focus group)

Several participants also discussed the importance of speaking and consulting with individuals connected to the disability community, such as medical professionals or disability organizations:

Um, another thing they could do is I know when they're doing medical shows, they have, like, medical experts who come onto the set while they're filming and producing [Michelle nods], who will let them know if the way that they're doing something is inaccurate. Maybe they could have someone who is an expert in that condition, like Michelle was mentioning, there are societies for Turner Syndrome. They could contact the Turner's Society and say, "Hey, can we have- Can you recommend someone to come out and let us know if we're representing this correct, in a accurate way?" (Zoey, participant in Turner Syndrome focus group).

To summarize, participants want to see that individuals who work in the media and entertainment industries have thoroughly researched the disabilities that they are writing about or portraying on screen. This includes seeking out the voices of disabled people and consulting with the disability community and/or individuals who work with the disability community such as medical professionals. Additionally, the disability community needs to be listened to when they provide critiques or negative feedback. This can ensure that disabled characters and storylines are portrayed with respect and greater accuracy.

#### Subtheme 2: "Make Space for Us".

The second subtheme: "Make space for us", was defined as the need for disabled individuals to be more involved in aspects of character creation and production that are not in front of the camera. This includes things such as being hired as writers, consultants, directors, and producers. This was viewed by several participants as an important consideration whenever disability storylines or disabled characters are being portrayed in the media, but particularly when a non-disabled actor is portraying a disabled character: But I think that we should prioritize disabled people playing disabled characters. And when a non-disabled actor plays a disabled role, I think that-openly disabledexactly. Don't judge a book by its cover-and I think that we should have like actually disabled people, like being involved in the process of like, the characterization. (Sparrow, participant in autism focus group).

Participants frequently discussed their desire for disabled voices to be heard from more frequently in the media and entertainment industries. One participant discussed the importance of disability collaboration and ensuring that disabled voices are heard and that doing this could result in many benefits to the media representation:

I would just say, um you know, I think if someone wants to portray a really great dimensional character with autism, I would also just want them to be making space for people with autism to you know, uh contribute their thoughts, ideas, to be collaborators. If it's a show, to have autistic writers also writing for that show, be talking to people, actually incorporating the voice and not even just doing independent research, but really actually um talking to people and interfacing with people and including their actual voices. (Lee, participant in autism focus group).

Overall, participants want to see more disabled individuals working behind the scenes in the media and entertainment industry, including as writers, directors, producers, and consultants. This could not only lead to more disability representations but also could serve as a way to have more disabled voices heard and as a form of checks and balances to reduce stereotypes and increase the accuracy of representations.

#### Theme 4: "Give Us the Stage".

The fourth main theme was called "Give us the stage" and was defined as the need for the entertainment and media industries to purposely and thoroughly seek out and hire disabled actors and give them opportunities. Four subthemes arose from this category: "That's not us", "Accommodate us", "Encourage us", and "More of us".

## Subtheme 1: "That's Not Us".

The first subtheme: "That's not us", was defined as media portrayals being perceived as less accurate or trustworthy when using non-disabled actors to play disabled characters. One participant, Wren, discussed how positive perceptions of the impact and the realism of the *Law and Order: SVU* portrayal of Janey could be reduced by viewers learning that they did not use an actor with Turner Syndrome: "But yeah, obviously not using an actor that had Turner's, um they missed out on some genuine opportunities to have a realistic portrayal." Another participant in the Turner Syndrome focus groups discussed this inauthenticity as a lack of respect: "I think it also shows that at the time there was a certain lack of a certain lack of respect for portraying something accurately." (Zoey, participant in Turner Syndrome focus group).

Many participants discussed the importance of prioritizing disabled actors playing disabled characters. When discussing disabled actors and disabled characters, several participants noted the complexity of disability, that not all disabilities are visible, and that some disabled actors may not be comfortable with disclosing their disability. For these reasons, several participants discussed the importance of prioritizing but not exclusively limiting disabled actors to playing disabled characters:

My thoughts on that are that we should prioritize disabled actors playing disabled characters. I don't think we necessarily need to limit it, but I-especially when it comes to visible- Well, not especially. I think we should prioritize disabled characters, but especially when it comes to invisible disabilities that might be really stigmatized. I think it's for the same reason that we shouldn't make gay characters be exclusively played by gay actors. You don't know what [pause] like, people are going through... Like, we don't know, like if an actor is a closeted gay person. We don't know if an actor is like actually thinking like, "Oh, you know, I think I might be autistic". So that's the reason why I don't think we should limit it. (Sparrow, participant in autism focus group).

Finally, it was viewed by some participants as being particularly relevant, and important to seek out disabled casting, if the character's disability includes specific physical characteristics:

Yes, that's what I was thinking. Yeah, that are characteristics of that syndrome and if the person didn't have those characteristics to it would be like: "Oh, like what's going on?" You know, like, "Why does that person not look at all like they have that?" or 'cause there are going to be people whatever that syndrome be that knows about it, you know, and would come across as rude and offensive and to that uh, to those people. And I think they need to do, like portray things right and fair, and accurately. 'Cause yeah, like especially if something I think has physical characteristics for the whatever it is, the syndrome or disability? Like hire someone with that 100%. (Ann, participant in Turner Syndrome focus group). Some participants also discussed the importance of casting agents intentionally seeking out actors who have the specific disability that they are trying to represent by creating targeted, very detailed, and clear casting calls:

...Um I've seen an example or heard about it recently for an example of a character um who was in a wheelchair, that they're trying to cast for and so in the like job posting to cast for this character with a wheelchair who uses a wheelchair, they said: We are looking to hold auditions for actors who are in wheelchairs, like we want to cast the person with the actual disability that we're talking about. Instead of having someone who does not use a wheelchair, play a character who is in a wheelchair. So I think having things like that in the job postings, maybe like this character's in a wheelchair, so we're looking to hold auditions for actors who are in and who use wheelchairs...So yeah, just like really giving them opportunities to playing characters with disabilities, giving that opportunities to actors who have that specific disability. I think it's important. (Jill, participant in Turner Syndrome focus group).

Across the various focus groups, participants want to see more disabled actors in the media and the industry to prioritize hiring disabled actors for disabled roles. Additionally, many participants viewed disabled characters that were played by nondisabled actors as having a sense of inauthenticity. This prioritization could be done in ways such as creating targeted advertisements when casting and putting in a thorough search effort. It is also important to note that participants would like to see disabled actors prioritized and not limited, as they not only do not want to see disabled actors limited to disabled roles but noted that many disabilities are invisible, and some actors may not feel comfortable disclosing their disability status.

## Subtheme 2: "Accommodate Us".

The second subtheme: "Accommodate us", was defined as ways in which roles both in front of and behind the camera could be made more accessible for disabled individuals in order to encourage them to seek them out and to succeed in them. Some participants theorized that if disabled individuals perceive the media and entertainment industries as inaccessible or not inclusive that they may not feel that they belong there which could lead to them not pursuing careers in those areas. Creating a more inclusive and accommodating workplace was viewed by one participant as an important way of increasing disabled people's interest in the media and entertainment industries:

I think if they would just be more mindful of making sets more inclusive, then more people would want to step up and be actors and they, they make it so that it does become very exclusive. And so, the other people have to represent us or write about us because of how the whole industry is just organized. (Gus, participant in autism focus group).

Participants provided several suggestions for how the media and entertainment industries could work to increase the inclusivity of their sets and workplaces. Some participants expressed a concern that a lack of knowledge regarding disability accommodations could be a reason why individuals in the media and entertainment industries may be hesitant to hire disabled individuals and that more research and effort regarding disability accommodations should be conducted: ...if um they're trying to cast an autistic person, um figure out, okay, I know there's, there's a spectrum for a reason. There's all sorts of different things, just like in Turner's Syndrome, um, there's all sorts of different ranges of, um things going on. But kind of do your research to figure out, okay, how can I help them, be either comfortable on the side or be able to do like do the movie or the show or whatever. How can we help them come to us, not kind of make the actors or actress fit them, but how can they help the actor or actress be more comfortable on the set and everything. (Michelle, participant in Turner Syndrome focus group).

Another participant discussed the importance of learning and using different forms of communication in the workplace in order to accommodate a wider range of disabled individuals, and that these accommodations could translate from behind the scenes to being shown in representations:

I also think with like the advancements with like technology and, medicine and all that kind of stuff too, like Babs was saying it's, there's different ways to help the actors who might be struggling um with portraying characters and things like that who have that disability. Um it's easier to kind of communicate like um they have like um iPads to help communicate for um people with autism who can't speak. They have different things on the iPad they can use and everything to kind of help communicate and everything. And it'll be interesting to see that portrayed in new things as well, like in things as well. So, if the actors themselves uses that, that would be cool to see that translate onto the screen or into a book too. (Michelle, participant in Turner Syndrome focus group). Generally, participants want the media and entertainment industries to engage in more accommodations for disabled individuals or make more visible the accommodations that are available. The media and entertainment industries can often have a veneer of exclusivity, and promoting accessibility and accommodations could create a more welcoming environment for disabled individuals who are interested in careers in media and entertainment.

### Subtheme 3: "Encourage Us".

The third subtheme: "Encourage us", was defined as ways in which the entertainment and media industries could cultivate and increase the number of disabled actors within the industry. Participants suggested several ways in which they felt that disabled individuals could be supported and encouraged to pursue careers in the media and entertainment industries. The incentives suggested by participants included monetary incentives like increased pay and scholarship opportunities, but also included educational initiatives to cultivate their interests and skills:

Uhm, yeah, so like that would've been so that's, that's the way I think it could really be uh programs, workshops for like kids, um, maybe even like scholarships like specific scholarships and things like that. Like uh, like you know, like to get a degree in like acting or something. (Cactus, participant in Turner Syndrome focus group).

Another incentive that was mentioned by a few participants is the need for disabled individuals to feel supported and encouraged in their employment pursuits by individuals within the media and entertainment industries. One participant, Allison, discussed how feeling encouraged by others, especially those in your desired field, could increase a person's desire to continue pursuing a career in the industry, stating: "So you still have the desire to be there. Um, I guess that's where a lot of the encouragement could come to you too, is encouraging more people with different abilities to get into those fields." Another participant in the Turner Syndrome focus groups discussed the positive impact that feeling encouraged and seeing others like you could have on disabled individuals who are interested in careers in the entertainment industry:

...so I think that's really helpful. 'cause like once you have people like encouraging you and once you have like you know support with your support system like any other, you know you see other people like around you doing it like it was also really helpful that like, like you're like, encourages you yourself. 'Cause like, it was like growing up I don't even think like I don't even think like going to acting or anything like that would ever crossed my mind. 'cause like I've never seen like anybody with Turner Syndrome actually doing it. (Cactus, participant in Turner Syndrome focus group).

To summarize, participants would also like to see initiatives that encourage disabled individuals to pursue careers in the media and entertainment industries. This could include providing scholarships or creating and running workshops for disabled individuals to learn skills related to the industry. This is another way to create a welcoming environment for disabled individuals and encourage more disabled individuals to pursue careers in media and entertainment.

Subtheme 4: "More of Us".

The final subtheme: "More of us", was defined as the need for an increased number of disabled characters and storylines in the media and entertainment industries. Overall, participants expressed seeing a lack of disabled characters and disability storylines in the media. One participant noted that in order for there to be more disabled characters there needs to be more storylines for them: "Yeah. You first off, need the stories written with those abilities or with those disabilities written into them." (Allison, participant in Turner Syndrome focus group).

In many media representations, only one disabled character is featured in the series, episode, or storyline, and oftentimes the majority of their interactions are with non-disabled characters. Several participants across all of the focus groups noted an interest in seeing multiple characters with the same disability interacting with each other or being able to showcase different experiences:

Uhm I also like also like it would also like I feel like it would have been it would have been cool if they had like more than one person with Turner Syndrome on the show too, and it didn't just need to be like one girl who has it like. You know what I mean? Like it would have, but it would be cool to have. It would have been interesting to see like. Maybe you're more than one more than one person and their, their experiences... (Cactus, participant in Turner Syndrome focus group).

Having more disabled characters and storylines would serve to better represent the diverse individuals and experiences within the disability community and provide a wider range of characters that disabled viewers could potentially relate to. One participant discussed the potential benefits to having more disabled characters and storylines which also included encouraging more disabled individuals to pursue acting as well as reducing feelings of isolation:

For me if they could actually feature not just one character like two or three people who are actually disabled having the same mobility impairment, I think that might give on confidence in actually coming just coming up and trying to like audition. And yeah, it wouldn't make someone feel like isolated because it's not just you, you have other people who you can resonate with, with your ideas with, so I feel in that situation it can also encourage other people who'd like to act... (Snowy, participant in mobility impairment focus group).

Overall, participants felt that creating more disabled characters and storylines would encourage more disabled individuals to pursue careers in the media and entertainment industries. If people do not see themselves, they do not feel that there is a place for them. Participants would like to see multiple disabled characters in the same television show or film and would also like to see disabled characters interacting with each other more often to provide a diverse range of experiences and diagnoses.

# Theme 5: "Be Positive".

The final main theme: "Be positive", was defined as a need for increased portrayals that provide a sense of hope and show happy or relatable moments in the lives of disabled characters. Several participants discussed the benefits of more positive disability portrayals, with one participant in the Turner Syndrome focus groups stating: "So if there were um more, more examples and more positive examples of um portrayals in the media, then it would kind of balance out this, this very problematic one that we just watched." (Babs, participant in Turner Syndrome focus groups). Five subthemes were identified from this category: "More than just disability", "Breaking through barriers", "Subvert stereotypes", "Be honest", and "Give us control".

## Subtheme 1: "More Than Just Disability".

The first subtheme: "More than just disability", was defined as the need for disabled characters and storylines to prioritize aspects and situations other than the character's disability. Oftentimes non-disabled characters are portrayed as threedimensional and complex and may navigate multiple identities, and participants would like to see the same consideration for disabled characters. This was viewed by one participant as important in order to show the complexity and intersectionality that each disabled person exists with, and that this does not often occur in disability representations:

I guess first I feel that one of the biggest issues towards representation of people with disabilities, especially like our condition, is that we focus on media being solely about those conditions and not including people who just happen to have this as part of their selves, as their identity. We focus so much on like, I guess representation is hyper focused on one part of a person instead of a person as a whole. It-what it does is it kind of does dehumanize people. And I guess going towards representation, it would be a lot easier to have in a show, in a book, in anything, that if they have a, you know, something like autism, it's better for them to just have that as part of who they are, instead of having the only part of their character being that they're autistic. (Auster Ezrian Luna, participant in autism focus group).

Another participant discussed the importance of showing disabled characters who have strong family, interpersonal, and romantic relationships and who experience the same typical struggles as anyone else would and the positive impact that this could have particularly on younger viewers:

Yeah, that's exactly what I would say, too. I was thinking of, you know, maybe a character who's been through some hurdles um and she's now on the other side of it. She's, she's got some positive relationships in her life, whether it be a partner or good friends or a strong family unit [Babs, Stephanie, and Michelle nod]. And, you know, maybe she's going through some normal adults struggles with, say, building a family or even um entering into a relationship or, or maintaining a relationship, just normal, everyday stuff that shows more positive um light that doesn't kind of um that would show someone say, maybe younger um that's watching or um or parents of a girl with Turner's that can show well it doesn't have to be all tragic and, and, sad and um that it can be, it can be okay. (Samantha, participant in Turner Syndrome focus group).

One aspect that was mentioned by participants across all focus groups was the desire for the disability to not be the character's main label or identity. Several participants mentioned a desire to see a disabled character where the disability is not mentioned or focused on. One positive example that was mentioned by a participant was some segments of the BBC children's show *JoJo and Gran Gran*:

...And they're also, it-they have live-action segments. There's a boy with dwarfism. Now, it's not about: "Oh, this is a boy with dwarfism" or "This boy's doing stuff because they have dwarfism". No, he just happens to have dwarfism.

They don't even mention dwarfism. He's just a child who happens to have dwarfism. He's treated the same as every other child. He interacts with other children and other children interact with him the same way as they would any other child. So, I think, I think that that's what I would want to see. I would want to see a person, a character who just happens to be autistic and multiple characters who just happen to be autistic. And it does- that doesn't have to be the focus. And they mention the autism, but it not be the main focus of it just: Oh, this character is autistic. They also are the character. (LoompaBates2141992, participant in autism focus group).

Overall, several participants mentioned that in the end, they wanted to see disabled characters treated and acting just the same as any other non-disabled character would. One participant stated: "It can be interesting and even inspiring to see movies centered around a disability, sometimes it's nice to see people who just happen to have a disability living their day-to-day life and getting into hijinks right alongside everyone else." (Snowy, participant in mobility impairment group).

## Subtheme 2: "Breaking Through Barriers".

The second subtheme: "Breaking through barriers", was defined as the participants' desire to see disabled characters navigate and succeed when facing challenges. For some participants, examples of overcoming barriers and challenges involved seeing disabled characters in positions of power and high achievement: "Ok, I would like to see a character, you know um who faced a lot of a lot of stigma and lots of problems issues as a result of a, of his impairment. And you know, at the end of the day, he came out strong and was one of the best in his field. Something like that." (Will, participant in mobility impairment focus group). Other participants mentioned wanting to see disabled characters navigate interpersonal and mental health challenges:

Um, I'd like to see character who um, who heals and experiences growth. Um you know uh, we seem to have so many portrayals or like um maybe, maybe even um this image of ourselves right when we were teenagers about how, like, maybe we felt different or we found it hard to relate to other people or to find relationships or things like that...But what I find happens often is like it's kind of just left there. Like, okay, yeah, like she, she's weird and she has trouble making friends or whatever. And that's just that's just how life is for her instead of it's like, okay, so um she, you know, she realizes that she suffers from depression, so she goes and she gets help. And from that, like, you know, she leads a richer life because she was able to, to reach out to, to people that she realized she wasn't so different from, you know, like more a story like that kind of. (Babs, participant in Turner Syndrome focus group).

Finally, often only the prominent and more visual aspects of a disability are shown in media representations, and some of the less obvious but still important medical issues are not portrayed. One participant mentioned the importance of showing and acknowledging the medical struggles that many disabled individuals experience and not glossing over or ignoring them:

...don't be afraid to talk and like, also, like don't be afraid to actually portray like the struggles that people would like they face 'cause like and I feel like a lot of times that they might like whitewashed like, they might be like, try to act like they don't, like we don't face any kind of like differences... You know, I mean like if you're gonna be like, if you do something, really portray somebody with Turner Syndrome yah, like make sure that you portray like this stuff with like growth hormones you know this stuff about going to like the heart issues. (Cactus, participant in Turner Syndrome focus group).

To summarize, another way that disabled characters and storylines can be portrayed in more positive ways is by showing disabled characters overcoming challenges and obstacles, as well as succeeding in various areas such as school and their careers. This could serve to reduce various disability stereotypes present in the media and also open the eyes of non-disabled viewers as to the many capabilities of disabled individuals.

### Subtheme 3: "Subvert Stereotypes".

The third subtheme: "Subvert stereotypes", was defined as portrayals of disabled characters and storylines that portray disabled characters in ways and situations in which they are not normally seen in the media and that avoid common disability tropes. Several participants mentioned wanting to see disabled characters in a variety of genres: "I, I'd love to see a suburban mom navigating work and life in the public school system and autism all at once. And maybe a murder mystery all at once. [laughs] I don't know." (Jane Babineaux, participant in autism focus group). One participant discussed the character of Abed from the television show *Community* as a good example of this and mentioned that they not only appreciated that Abed was ethnically diverse but also that he has a very strong and close friend group. Furthermore, Abed, due to the fact that a specific disability

label is never given to him in the show, could also be another example of the 'accidental disability' that was mentioned by Gus, a participant in the autism focus group:

I really like *Community*. It's a TV show...Um, but I absolutely love Abed in it. Who is autistic without ever being said he is autistic. But he does specifically say that he has trouble making friends and with social skills, etc. And what I also like is that his special interest is not STEM-related at all. It's pop culture. And so, the whole esthetic and the whole themes around *Community*, which is a very original show in the way it's filmed. Um, it is completely like, is kind of based off of his pop culture obsession in that sometimes it's in the style of, let's say, *Pulp Fiction*, and other times it's in the style of, you know, it hasn't happened, but *Harry Potter*. And I mean, it's a very unique show stylistically, esthetically, just in the way it's written and also the way it portrays Abed and the fact that he actually seeks out friends. (Twizzlers, participant in autism focus group).

Another important aspect of portrayals that participants were interested in seeing was disabled characters with a wide range of interpersonal relationships which would better reflect the lived experiences of disabled individuals. Participants across all of the focus groups mentioned their desire to see disabled characters with strong romantic and social relationships. One participant in the autism focus groups mentioned that they appreciated that the character of Sam in *Atypical* was interested in romantic relationships, stating:

So, I do appreciate that this character is actually interested in the world of sex and dating. I'm personally not interested in sex at all, so it's like I can't relate to that at all. It's just not connecting. But I, I definitely see how it is a good potential like

part of the experience to be represented because a lot of times I feel like autistic people are just shut out of that completely. (Sparrow, participant in autism focus group).

Another participant mentioned that many disabled people have a wide range of relationships in their lives, and that they would like to see this focused on rather than disability: "Yeah. Agree. Just kind of that the Turner Syndrome. Well, yes, It's a big part of all of our lives. It's not the only thing that we have going on. We have relationships, whether it be with a significant other, family, best friends, animals even." (Michelle, participant in Turner Syndrome focus group).

Another area where participants wanted to see media portrayals deviate from stereotypes was in the area of disabled characters frequently being portrayed as passive or underestimated. Several participants mentioned appreciating and wanting to see disabled characters who are strong, driven, and intelligent. One participant in the Turner Syndrome focus groups mentioned that they appreciated these qualities in the character of Janey in the episode of *Law and Order: SVU* that was watched during the focus group:

I think with her being a 17-year-old girl, like, she was very driven. She was very, she knew what she wanted for her future [Michelle and Samantha nod]...You know, she wanted to go to business school like her dad. But not every 17-year-old has a future envisioned for themselves, you know, some of them don't really know what they want to do at that point. But she already had a pretty clear picture um of, of her future. And uh so that was another positive attribute they gave to her, that she was pretty advanced for a 17-year-old in that sense, too. (Wren, participant in Turner Syndrome focus group).

Another participant mentioned wanting to see a disabled character portrayed as strong and possibly serving as a challenge to other characters: "I think a portrayal of a strong character who is disabled, not a soft one. A strong character who even uh, uh the normal guys and the people who are not impaired feel challenged by as compared to, you know, somebody who's put on the sidelines..." (Ricco, participant in mobility impairment group).

Across all of the focus groups, participants discussed wanting to see disabled characters that do not follow the usual disability stereotypes and tropes. They want to see disabled characters having romantic relationships, active social lives, and as smart, driven individuals. This would provide more positive examples not only for non-disabled viewers but for disabled viewers as well.

### Subtheme 3: "Be Honest".

The third subcategory: "Be honest", was defined as portrayals of disabled characters and storylines that accurately portrayed disability, in all of its positive and negative aspects. This accuracy was viewed as a positive by many participants as it demonstrates that the individuals creating the portrayals did their research on the disability and value truthfulness. Honest portrayals were also viewed as important for individuals who may be newly navigating a disability diagnosis:

I can just imagine an, a new parent um maybe still pregnant or maybe just had a baby and discovered that the baby had Turner Syndrome. And watching that episode, I just getting maybe that's their first sort of introduction to it [everyone nods] and, and getting so much misinformation um from the media portrayal that, I mean, it's, it's nerve-wracking enough for a new parent to see something that would cause them more anxiety and more-have more worry. (Samantha, participant in Turner Syndrome focus group).

Participants discussed several ways in which they felt disability portrayals could more honestly represent the disability experience. One way in which several participants felt that this could be done is by showing disabled characters experiencing and navigating ableism from others:

It'd be nice to be like, have it shown as like people don't believe you're autistic because like, a lot of the media representations are like: "Duh, they're autistic. Here's this very stereo-very stereotypical, sorry, portrayal of this". And by the book sort of thing. And it's like, okay, well what about the people who like get um doubted if they're autistic and things like that? (Chrissy, participant in autism focus group).

One aspect of disability that is often not discussed in disability representations is the impact and importance of the environment in how disabled individuals navigate their daily lives. Several participants also mentioned wanting to see disabled storylines include or discuss the impact of the environment on disabled characters and their experiences:

I would love to invite them to look at the social model of disability and how an environment could disable an individual or enable them and then just kind of make the diagnosis of autism just: oh, you know, it's part of their character, but it's not the like elephant in the room. It's not like its own plot point in and of itself...I would love to see that modelled in, in cinema. That would be a wonderful thing to see. Like, it's not just the individual's responsibility and people aren't just swooping in as saviours, but this is how everyone accommodates and just, you know, smooths things out and then lets them move forward so that they could have a really beautiful story arc that maybe isn't so autism dependent. That would be cool. (Jane Babineaux, participant in autism focus group)

Additionally, many disabled characters are created with the disability already in place, which loses the opportunity to portray and have discussions surrounding the initial diagnosis and navigating a new disability. Several participants mentioned that they were interested in seeing disability portrayals that involve disabled characters discovering their diagnosis and coming to terms with their disability.

I think it would always be interesting to see someone find out that they have Turner Syndrome or they're pregnant with a baby with-that has Turner Syndrome to kind of see the, those kind of struggles, too. And like the research they do or not even necessarily research, but like how they find out the information that they do and things like that. I think that could be an interesting take on things as well. Just to see kind of that aspect of it, too. (Michelle, participant in Turner Syndrome focus group).

The topic of disclosing a disability diagnosis is something that is very personal and challenging which often has to be navigated by disabled individuals, and several participants mentioned wanting to see characters navigate this in the media:

And I think that's the right way you know for [Stephanie coughs] parents to approach that. Um I remember specifically like uh being on a date with a guy that I met online, and it was it wasn't a good date to begin with, but uh he brought up, you know, we've been walking for maybe an hour or so, like on a walk. And uh he brought up a child that he knew that had Turner Syndrome. I think it was the child of a friend of his or a relative. And he just, he said that this, this little girl, "oh, what a mess she was" and all these things and just mentioned it to me and asked, "Have you heard of Turner Syndrome?" And it was a bad date. So, I was like, "Well, I don't really want to reveal too much to this person," but part of me wished that I had spoken up and corrected the things that he discussed that day and all of that. But uh it was sort of a moment of, "Do I tell him that I have it or does he already suspect that I have it? Is that why he's bringing this up to begin with?" Um, but it was just an interesting position to be in. And I'm sure things like that occur in all of our lives at some point. [Michelle nods] But it would have been interesting to the episode to see a little bit more realism and how she approached disclosing it to the people in her life. [everyone nods] (Wren, participant in Turner Syndrome focus group).

Finally, several participants in the autism and Turner Syndrome focus groups mentioned wanting media portrayals to normalize showing the treatments and medical interventions that disabled individuals often use:

...like maybe going to the heart doctor should be represented, you know, like just things that people have Turner Syndrome do, like have you ever seen a little girl on a TV show give herself growth hormone shots? Like that would be like taboo. You know? Like it's, I've never seen that and It's something that I would say probably most Turner's girls go through now. Um, that's just common like they give growth hormone shots every day... (Ann, participant in Turner Syndrome focus group). Caring for mental health was another important aspect of the disability experience and one that is not often shown in media representations. Another participant mentioned that they appreciated the inclusion of therapy that Sam participated in in the television show *Atypical*: "Yeah, I'm-I don't know. I like that they had therapy in there and I-like I think – I mean - lots of people need therapy, not just like autistic people, but having that on screen is really nice to normalize it and stuff. So that would be cool to have more of that." (Chrissy, participant in autism focus group).

Overall, showing honest portrayals of disability which include disabled characters navigating the positive and negative aspects of disabled life as well as the various medical needs connected with various disabilities could serve to create more positive viewing experiences for disabled viewers by showing them experiences that are relatable to their lives, can reduce their sense of isolation, and increase their confidence and competence in navigating their disability. It would also more positively and realistically represent the disability experience for non-disabled viewers.

### Subtheme 5: "Give Us Control".

The final subtheme: "Give us control", was defined as disabled individuals controlling the disability story or media portrayal. Participants noted several ways in which this could be done. One way that was mentioned by a participant is by disabled individuals telling their own stories from their own perspectives.:

Jac: It would be funny to make a reverse comedy where it's totally from an autistic person's perspective joking on the weirdness of the neurotypical population. I've seen some memes that kind of do that, and I actually find it kind of funny. I joke with my mum who is the only NT [neurotypical] in my family and say she's weird and she says I'm weird and we laugh. It's nothing bad Sparrow: LOL that would be hilarious

Gus: OMG I love that idea of a reverse comedy! (participants in autism focus group)

Participants noted that disability stories do not need to be tragic, and that there is comedy in them as well. One example of a disabled individual who some participants viewed as successfully sharing and finding the comedy in disability experiences is the autistic comedian Hannah Gadsby:

Jac: I don't know if any of you guys have heard of Hannah Gadsby. She's an autistic comedian and-

Sparrow: She's hilarious.

Jac: Oh, she's a hoot. I love I really [coughs] excuse me. Recovering from a cold. But yeah, she is hilarious, and she makes her autism traits into a joke. And I sometimes do that too...

Gus: Hannah is a great, great representation of how to laugh at being autistic properly. And she might not be perfect, but she is a very good example of what I would love to see more of, of laughing with her, not at her. (participants in autism focus group)

Another way is by having disabled individuals influence portrayals and storylines that have been created by others. Two participants in the Turner Syndrome focus groups theorized on how the *Law and Order: SVU* episode could have been different if an actor with Turner Syndrome had played Janey and provided input in the story: Ann: Maybe she could have provided more input on Turner Syndrome too to the show.

Cactus: Yeah, exactly. Yeah, so she could have been like, um, "Why are you saying that like only like who have, only pedophiles are interested in people with Turner Syndrome?" Like, like and then um, just provide, Yeah, provide a more like even just like medical information on it and stuff like that. (participants in Turner Syndrome focus group)

In the end, disabled individuals want to be seen, their voices to be heard, and to be portrayed as people just like anyone else, with a range of emotions, experiences, and dreams. As Sparrow, a participant in one of the autism focus groups stated: "We are not robots. We're people, with feelings, and likes, and dislikes, and we want to date people, and we want to not date people [laughs]. And we want to like, have experiences just like anybody else, really, which I feel like a lot of times is forgotten."

## **Relationships Between Main Themes**

While reviewing the themes and the participant data connected with them. several relationships were noted between the main themes related to the three research questions that were the focus of this study. A diagram demonstrating the relationships can be viewed in Figure 1.

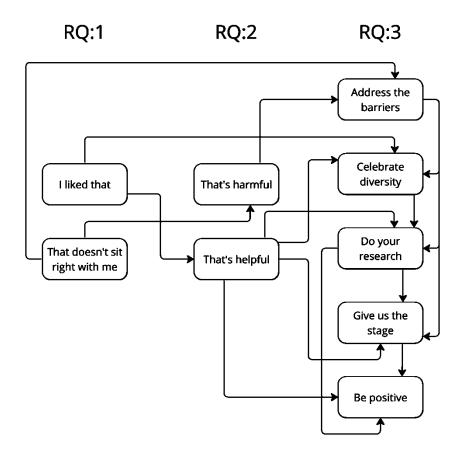


Figure 1: Relationships between main themes

Aspects of media representations that participants discussed in the theme I Liked That, such as aspects of disabled characters and their experiences that they could relate to as well as disabled characters and storylines that were respectful and relatable, could impact aspects talked about in the theme That's Helpful, such as the wide-reaching benefits for non-disabled and disabled viewers of disabled characters that subvert stereotypes, overcome obstacles and achieve goals, and storylines that can educate viewers on disability and disability issues. These two themes could influence several themes in the third research question, such as participants wanting to see the media and entertainment industries engage in creating more diverse disabled characters and disability representations, consulting with and hiring more disabled individuals, increasing the number of disabled characters and storylines, and creating more positive and relatable storylines for disabled characters.

Aspects discussed by participants in the theme That Doesn't Sit Right With Me, such as not relating to various aspects of disabled characters, characters and storylines that use disability stereotypes and tropes, and aspects of media portrayals that participants perceived as unrealistic or inaccurate, could influence aspects of media portrayals that could have a wide impact on viewers, as discussed by participants in the theme That's Harmful, including media portrayals that promote ableism and stereotypes and make disability issues and disabled characters more comfortable for non-disabled viewers. These two themes were considered to be connected to the theme Address the Barriers, as they could be perpetuated by the barriers in the media and entertainment industries that participants view as potentially negatively impacting the number of disabled individuals working in the industry, which could in turn could result in the perpetuation of ableism and stereotypes in the media. Addressing the barriers was viewed as connected to the additional themes in the third research question, as creating more diverse disabled characters and encouraging and accommodating disabled individuals could lead to more disabled individuals in the media which could reduce stereotypes and tropes and create more relatable characters and storylines. Finally, researching disability and consulting disabled individuals could lead to more disabled individuals in the media, as well as more positive and honest disability storylines and portrayals.

#### **CHAPTER V: Discussion**

#### **General Discussion**

This study examined the perspectives of disabled individuals regarding media representations of their disability, the current involvement of disabled individuals within the media and entertainment industries, and suggestions on what they would like to see in the media and entertainment industries going forward. In total, 34 participants were involved in the focus groups conducted for this study: 11 participants with Turner Syndrome, 11 participants with autism, and 12 participants with mobility impairments requiring the use of a wheelchair. Participants were over the age of 18, residents of Canada or the United States, had received a diagnosis from a licensed medical professional, had received the diagnosis more than six months before the focus group, and had access to the technology to use Zoom. Focus groups were selected as the methodology as it corresponds with critical disability theory, which states that disabled individuals need their voices heard. This method also can foster a greater sense of community by connecting disabled individuals and allowing them to share their experiences and perspectives together. In total, seven focus groups were conducted: three focus groups for participants with Turner Syndrome (including the pilot test of the study), two focus groups for autistic participants, and two focus groups for participants with mobility impairments requiring the use of a wheelchair. Participants watched a media representation of their disability together and then discussed it and the media and entertainment industries using a semi-structured interview guide.

Three research questions were asked during this study: What are the perspectives on controversial portrayals of various disabilities in the media by individuals who have been diagnosed with these disabilities? How could these portrayals impact perceptions of stigma regarding disabilities? How can disabled characters be portrayed to be more diverse and nuanced and to reduce stigmatizing beliefs towards disability? The research questions and the themes that were found relating to each of them will be discussed in greater detail below.

# What are the Perspectives on Controversial Portrayals of Various Disabilities in the Media by Individuals Who Have Been Diagnosed with These Disabilities?

Two main themes were found concerning this question. The first theme was "I liked that" which referred to aspects of disabled characters and disability portrayals and storylines that participants reacted positively to. Two subthemes were noted: "That's me!" and "Disability done right". Participants discussed several ways that they related to the disabled characters in the portrayals that they brought up during the focus groups, such as similar disability characteristics, similar personalities and interests, similar challenges and dreams, and similar family dynamics. When discussing media portrayals of their disability, participants also brought up portrayals that they found to be effective, such as portrayals that were felt to be relatable and respectful. Participants also noted the positive impact of portrayals that had disabled actors playing disabled characters.

It is important to note that participants were not assessed for pre-existing familiarity with the media representations that were watched during the focus groups. However, throughout the focus groups participants brought up their familiarity with the media that we watched. A wide range of familiarity was found in the participants; some participants were not familiar with nor had ever watched the media portrayal, others had heard of the media portrayal but had not watched it, while others had watched a varying amount of the television series that the portrayals were selected from. Some participants mentioned wanting to watch the media representation but had not had the opportunity yet, and that they appreciated the focus group finally giving them the opportunity to watch it. Of participants who had previously watched the various television series, some mentioned that they loved the show and had watched all of the episodes, while some mentioned having a dislike for the show after watching an episode and not continuing on with the series. Additionally, the specific disability that participants were diagnosed with could have had an impact on how they perceived the media representations that they discussed during the focus groups. For example, Turner Syndrome and autism, while being diagnosed at various ages, are present from birth, while mobility impairments may be present from birth or may be acquired at a wide range of ages. As a result, participants in the mobility impairment focus groups may have had different disability and life experiences than participants in the Turner Syndrome and autism focus groups, which may have impacted their perspectives and viewpoints on the media representations.

Although cultivation theory (Gerbner, 1998) was a primary theoretical framework relevant to the present study, the recent increase in streaming platforms and the wide variety of media that is currently available to people on their televisions, computers, tablets, or phones may indicate that cultivation theory in its original form may not have as significant of an impact on viewers as it once did. Furthermore, the wide media landscape may mean that cultivation effects may not be as strong or applicable for disabilities that have a greater number of representations but may still be in place for disabilities such as Turner Syndrome that have extremely limited media representations. However, in line with Morgan and Shanahan's (2010) suggestion that the components of cultivation theory should be reduced to the micro level, results from the focus groups suggest that several factors found to influence cultivation effects could be seen in media representations of disability and could impact the perceptions that viewers have towards disabilities. These factors will be discussed throughout this section in line with the various research questions and themes. As found by Mutz and Nir (2010) identifying or empathizing with characters was found to increase cultivation effects in viewers, and an essential aspect of media representations of disability that participants brought up during the focus groups was how important it is to them to relate to the disabled characters that they see on screen. They want to see their experiences, demographics, and interests represented in what they watch, and it is very possible that if there are more disabled characters represented in a wide range of people and experiences that disabled viewers find themselves relating to also. This could foster a more positive perspective of disabilities amongst non-disabled individuals.

The second theme: "That doesn't sit right with me" referred to aspects of disabled characters and storylines that participants reacted negatively to or expressed concerns about and had three subthemes associated with it. These subthemes were: "I don't see myself", "That's a caricature" and "That's unrealistic". During the focus groups, participants discussed several ways in which they did not relate to disabled characters that they brought up, including having different disability characteristics, different interests and personalities, different amounts of social support and family dynamics, and different strengths. The second subtheme, "That's a stereotype", related to the various stereotypes that participants felt were present in media representations of their disability.

These stereotypes included presenting disabled individuals as infantilized, asexual, savants, lacking hope, passive, sources of comedy, and underestimated. The stereotypes mentioned by participants correspond to many of the disability stereotypes noted in the literature by Hunt (1991), Nario-Redmond (2010), and Whittington-Walsh (2002). The final subtheme, "That's unrealistic", related to the aspects of disabled storylines that participants reacted negatively to or expressed concerns about. This included a lack of positive storylines related to disability, a lack of disability representation, disability as the focus of the character, a lack of description of the disability, sensationalized aspects of disability, inaccurate medical information, and a lack of diversity.

As mentioned by a participant in the Turner Syndrome focus group, inaccurate medical information can have a significant impact on individuals, especially when they are newly receiving a disability diagnosis:

And that's the issue with syndrome. So like, you do read all these articles and all these sites and because it's such a spectrum where, yeah, someone can have absolutely every single thing going on with them and others. So it's you end up being or our parents end up being told all these things that diagnosis or we're told all these things that diagnosis and it's so inaccurate for a lot of it because it's automatically something that: "Oh, I'm going to have all this stuff" or "They're going to have all this stuff" and yeah, or not that it's inaccurate, I guess, but it's almost kind of fearmongering to a degree [Wren and S.R. nods]. (Allison, participant in Turner Syndrome focus group).

This fear is very much in line with Ablon's (1995) discussion of the events that occurred surrounding the media portrayals of Joseph Merrick, known as 'the Elephant Man'. When

it was mistakenly reported in the media that Merrick had been diagnosed with Neurofibromatosis 1 many individuals who discovered that they had the same diagnosis reported being fearful of attending support groups as they were concerned that they would see individuals who looked like his portrayal (Ablon).

A lack of demographic and disability representation within the media could lead to instances of first-order cultivation effects, which are defined as how demographic information shown in the media can impact viewers perceptions on the real-life distribution and occurrences of those factors (Jin & Jeong, 2010). If viewers are not seeing certain demographic characteristics or disability presentations represented in the media, this could lead them to underestimate the number of individuals in certain populations that have those disabilities. These first-order cultivation effects could lead to certain populations being under-diagnosed with certain disabilities and not receiving the supports and resources that they need. It is also important to consider the intersectionality of identities that many individuals experience and that first-order cultivation effects regarding demographics could also intertwine with second-order cultivation effects regarding more general beliefs such as feelings of safety (Jin & Jeong):

I think that a lot of autism research is very, very white and like a lot of reasons that people of colour don't get diagnosed, it's like can be like cultural things or safety things, right? Like you hear a lot about meltdowns, but can you imagine like a visibly like non-white person having a meltdown in public that could be like, really have really bad consequences? So, then that's something that they might learn to internalize, like stimming or something. Like whenever I am like around cops, I'm like, "oh my God, I have to act very normal even if I'm not committing like any sort of crimes just because it's like... It's very it's very like white, right. And like, people of color in general have to sort of, could be very controlled about the things that we do and that I believe can hide a lot of like autism traits. (Sparrow, participant in autism focus group).

Furthermore, many of these insights from participants correspond with the results of studies of disabled individuals and their perceptions of the media conducted by Ross (1997) and Haller and Zhang (2013). As also mentioned by the participants in the study conducted by Ross, participants in the current study also noted representations of disability as a tragedy, a focus on disability as the main aspect of many disabled characters, and a lack of disabled individuals in the media. In line with the participants from the study conducted by Haller and Zhang, participants in the current study also discussed a lack of diverse representations of disability. These similarities indicate that negative portrayals of disability are still apparent and that changes in the media still need to be made, at least within the North American media context. In fact, as discussed during several of the focus groups, around the time that the first focus groups were occurring the movie *Music* by Sia was released, which was criticized not only by the focus group participants but by others in the autism community for the stereotypical way in which the autistic main character of Music was portrayed as well as the fact that a neurotypical actor was cast to portray her (Bacardi, 2020 November 20).

### How Could These Portrayals Impact Perceptions of Stigma Regarding Disabilities?

Two main themes were identified from this question. The first theme was "That's harmful", defined as aspects of disabled characters and storylines that participants felt perpetuated negative views towards disability and disabled people. Regarding increasing

stigma, three subthemes were noted: "Promotes ableism", "Promotes stereotypes", and "Sanitized disability". When discussing ways in which they felt that media representation promoted ableism, participants mentioned showing characters being treated differently than non-disabled individuals, the potential for disabled individuals to be seen as 'an other', and the potential for media portrayals to promote internalized ableism. In the second subtheme: promotes stereotypes, participants discussed ways in which they felt that media portrayals promoted disability stereotypes and the impact that this could have on viewers. The final subtheme involved media portrayals that participants felt were sanitized for non-disabled viewers.

The second theme was "That's helpful", defined as aspects of disabled characters and storylines that participants felt promoted positive views towards disability and disabled people or provided benefits to the disability community. This included three subthemes: "Subverting stereotypes", "I can do this", and "I learned something today". The first subtheme: subverting disability stereotypes, included participant examples that they felt deviated from the traditional and stereotypical ways in which disabled characters have often been presented. This included portraying disabled characters with such characteristics as being strong, intelligent, and determined. The second subtheme involved disability portrayals and storylines that participants felt could improve the selfconfidence of disabled individuals who watch them and show disabled competency to non-disabled viewers. This could in turn potentially reduce internalized ableism. The final subtheme: representation as education, included ways in which participants felt that disability representations could inform viewers about disabilities and disability issues such as introducing people to disabilities that they may not have heard of before and addressing a potential lack of awareness of disabilities in some communities.

When discussing disability representations that they felt positively and negatively toward, as well as the impact of those disability representations, as theorized by the relativist perspective (Ponterotto, 2005), participants frequently linked the media portrayals they were discussing to their own experiences, culture, and environment. This occurred even in instances when they were not directly asked about their experiences. Many participants stated that they wanted to feel represented and see themselves on screen. For some participants, due to factors such as demographics or experiences, this is something that has not yet occurred:

I would love to see more stuff like that. Um, more female characters, more diverse characters of different backgrounds, so that maybe like one day there could be a character more like me out there and I can be like: 'That's my experience.' I have yet to actually look on screen and see someone kind of like me. (Jane Babineaux, participant in autism focus group).

Disabled characters being labelled and portrayed as 'an other' could lead to what is known in cultivation theory as distance effects, defined as how close viewers feel to the characters or situations in the media that they are consuming (Bilandzic, 2006). If viewers feel separated and less connected to the character and storyline, they could experience lower levels of experiential and mediated closeness, defined as connections to the character/situation and engagement with the media respectively (Bilandzic). These two concepts are viewed to be dynamic, with relevance impacting engagement and vice versa (Bilandzic). Connection and engagement with the information being viewed can also have an impact on how viewers engage with information that confirms or contradicts their assumptions. It is theorized that information that contradicts the preconceived notions of the viewers could be internally processed and encoded if the viewer is engaged with the media as opposed to viewing the media in a more passive manner (Bilandzic). This internal processing and debating could lead the viewer to determine that the media information is inaccurate if it does not match their preconceived notions (Bilandzic). If viewers are engaged with disability representations and find them relevant to their own lives, this could lead to them more thoughtfully engaging with and processing the disability representations that they see, and as a result, they may become more adept at noticing media inaccuracies.

# How Can Disabled Characters be Portrayed to be More Diverse and Nuanced and to Reduce Stigmatizing Beliefs Towards Disability?

Five main themes were identified from the data related to this research question. The first theme, "Address the barriers" encompassed aspects of the media and entertainment industries that could prove to be barriers for disabled individuals seeking careers in those industries and that need to be improved. Participants discussed a lack of known disabled actors or disabled individuals working behind the scenes, the media's tendency to focus on an actors appearance over other aspects, the possibility of disabled individuals in the industry feeling the need to hide their disability diagnosis, and aspects of work that casting agents and directors may feel are unsafe for disabled individuals and may influence their decisions to not hire disabled individuals. The second theme, "Celebrate diversity", related to participants' desire to see more diverse disabled

characters. This included the desire to see a wider range of demographic representations

of disabled characters, as well as a greater range of representations of how the same disability could be experienced, including comorbid diagnoses that are not often shown in the media. The third theme: "Do your research", related to participants' desire to see the media and entertainment industries conduct more thorough research on disabilities. Participants felt that ways that this could be accomplished were by individuals in the media and entertainment industries meeting and consulting with disabled individuals, organizations and other individuals connected to the disability community, as well having more disabled people working behind the scenes in the media and entertainment industries. The fourth theme: "Give us the stage", related to participants' desire for more disabled actors. This encompassed participants perceiving non-disabled actors playing disabled characters as inauthentic, suggesting ways in which the media and entertainment industries could accommodate and foster disabled individuals, and wanting to see more disabled characters and storylines in the media. The final theme, "Be positive", was expressed as participants' desire for more positive and relatable disability storylines and disabled characters. Participants discussed several ways that this could be accomplished, including creating well-rounded characters that were not defined by their disability, showing disabled characters succeeding and overcoming obstacles, creating disability portrayals that do not follow common disability tropes, writing disability storylines that are realistic to disability experiences and show both positive and challenging aspects, and having disabled people take control of the narrative and tell their stories.

Diversity was a very important aspect mentioned by participants; not only diversity in terms of the demographics and diagnoses of disabled characters, but also a diverse range of genres and scenarios for disabled characters to be portrayed in. Participants expressed a desire to feel more represented in media portrayals of disability, and for disabled characters to be represented in a wide range of scenarios, including those in which disability is not a focus of the character, or is perhaps not even mentioned at all. These desires and the potential impact connected with them may be related to transportation theory and a study conducted by Caputo and Rouner (2011). The authors found that participants who watched a portrayal of mental illness and identified with the character felt that the media portrayal had more relevance to them, and in turn reported a lower desire to maintain social distance from people with a mental illness that they may encounter (Caputo & Rouner). An increase in the diversity and relevance of storylines and portrayals of disabled characters in relation to the perceptions of non-disabled viewers could potentially lead to transportation effects, which in turn could lead to more positive viewpoints towards disabled individuals. Furthermore, as Bilandzic and Busselle (2008) theorize that a specific threshold of transportation may need to be reached in order for viewers to experience strong cultivation effects, there may be a need for a wider range of disability portrayals that are engaging and relatable to non-disabled individuals in order to produce cultivation effects that could lead to more positive perspectives of disability.

The importance of ensuring that disabled individuals have their voices heard and have an influence on the language used to discuss disabilities and disability issues is an important tenet of critical disability theory, as this can impact how disabilities are perceived by non-disabled individuals (Hosking, 2008, September). Additionally, as mentioned by participants, the need for more disabled individuals to be physically present both in front of and behind the camera could also be an impactful method in changing perspectives towards disabilities. As theorized by Penn et al., (2003), personal contact may be necessary, in addition to educational initiatives, in order to create significant changes in beliefs. If more disabled individuals are hired in the media and non-disabled individuals working in the media begin having more regular interactions with disabled colleagues, this could serve to normalize disabled individuals and reduce many of the stereotypes that are often seen in media portrayals of disabled characters. This impact could lead to these more positive behaviours becoming normalized, even on projects that do not involve disabled individuals.

Additionally, having disabled characters portrayed in a wide variety of media and a range of genres could also impact cultivation effects (Reitzer & Hetsroni, 2014; Vergeer et al., 2000). As cultivation theory research has demonstrated, the connection between the desired variable and the genre of media could influence cultivation effects (Reitzer & Hetsroni). If disabled characters are not represented in a wide variety of genres, as participants perceived during several focus groups, this could lead to stronger cultivation effects related to factors connected with that genre. For example, if disabled characters are not seen in genres like romantic comedies or in romantic storylines, this could potentially increase the cultivation effect of disabled individuals as asexual. Viewing a wide variety of media has also been found to have a negative impact on cultivation effects, with the authors theorizing that individuals who are exposed to a sole media source could experience greater cultivation effects (Vergeer et al.). This is an extremely impactful finding for disabilities such as Turner Syndrome, which at the time of this study only had one fictional representation in the media and indicates the need for an increased number and range of disability representations. In relation to Turner

Syndrome, it is very hopeful that there will be changes in the near future, as recently the television show *The Good Doctor* introduced an infant with Turner Syndrome who is in the process of being adopted by Dr. Morgan Reznick, one of the main characters (Schwartz, 2023, April 17).

Finally, the way that media representations are framed could have a significant impact on viewers. The concept of framing has been found to impact the attitudes and beliefs of viewers, and media frames that are repetitive can reinforce beliefs or information (Sieff, 2003). Media frames are connected to specific items or criteria and are stored in a related network in our brains, which is activated in long-term memory when individuals view things that are connected to these frames (Sieff). Participants pointed out several instances where they felt that media representations were perpetuating ableist viewpoints, and Falcous and Scott (2023) noted that such frames have been criticized for reinforcing non-disabled individuals as the norm, making disability a person's primary identifier, and assuming that disabled individuals are not as worthy as non-disabled individuals. If the media frequently and consistently portrays disability in more negative ways, as perceived by several participants in the focus groups, this could lead to individuals internalizing these frames. This could explain some of the perspectives and experiences that participants discussed in focus groups:

And I've had um, I've had experiences where a principal of mine in elementary school stated to my mom, "Can she even learn?" and just underestimated me [Wren shakes her head in disapproval] and other students with disabilities just because of the disabilities that we had. (Zoey, participant in Turner Syndrome focus group). Experiences such as this are examples of why more positive frames surrounding disabled characters and disability issues are perceived by participants as being strongly needed in the media to counter the many negative frames that are seen. However, it is important to note that disability is an extremely complex aspect and experience, and that many individuals tend to think of disability in extremely simplified binary frames: e.g., that disabled individuals are weak and require assistance from non-disabled individuals or that disabled people are inspirational and brave (Goethals et al., 2022). Disability needs to be represented in complex and variable groupings of frames and counter-frames in order to break through such stereotypes and preconceived notions (Goethals et al.).

## Suggestions for the Media and Entertainment Industries

As discussed throughout the results section of this document, during the focus groups, participants provided several suggestions for the media and entertainment industries regarding disability representation and how to encourage more disabled actors and disabled individuals who are interested in working in various aspects of production behind the camera. Below is a brief summary of their suggestions as well as some ways in which these suggestions could be accomplished:

1. Address the barriers that currently exist in the media. Educate individuals involved in casting, writing, and directing on the conscious and unconscious stigma and ableism that they may have towards disabilities and disabled individuals, as well as the concept of internalized ableism. This could be done through workshops led by or heavily involving disabled individuals. It is also extremely important to have inclusive and accommodating workplace settings. One way that this could be accomplished is by ensuring that all staff members in

the areas of writing, directing, producing, and casting undergo Equity, Diversity, and Inclusion training, as well as potentially hiring disability consultants to provide education on common work and communication accommodations as well as to be involved in ensuring that workplaces are meeting the accessibility needs of disabled actors and staff members. A more inclusive and welcoming environment could encourage more disabled individuals to pursue careers in the media and entertainment industries and could also lead to them feeling more comfortable in openly disclosing and talking about their disabilities.

2. Do your research. Thoroughly research the disabilities that are being represented or discussed in the media. This can be done by consulting with disabled individuals and individuals connected with the disability community, such as doctors and other medical specialists and practitioners. Another suggestion is to have more disabled people working behind the scenes and engaged with character creation and representations. This includes having more disabled writers, directors, producers, and casting directors. By conducting thorough research, consulting with the disability community, and hiring more disabled people behind the scenes, the media can ensure that the medical information that is being presented about the disability is accurate and that disabled characters are acting and speaking in ways that resonate and feel truthful to individuals with those disabilities. Furthermore, this can potentially reduce disability stigma in individuals who view the media portrayals by ensuring that they are being educated with factually accurate information. It is important to consider that

media representations may be some individuals' only experiences of disability or specific disabilities.

- 3. Have more diversity in disability portrayals. Create disabled characters that have a diverse range of ages, ethnicities, gender and sexual representations, and disabilities. It is also important to think about how a person's different identities can interact with each other and impact their experiences. Furthermore, create characters that represent a wide range of how specific disabilities can present in people, as well as the other medical conditions that are frequently associated with specific disabilities. Disabilities are extremely complex and not one-size-fits-all, and individuals may experience the same disability in very different ways. It is extremely important for individuals to feel represented in the media that they watch. Having more diverse portrayals serves to make disabled individuals feel more represented, as well as to potentially reduce stigma and assumptions regarding disabilities.
- 4. **Prioritize disabled actors**. Consider creating incentives such as scholarships and educational and practical workshops in areas like writing, acting, directing, and producing to encourage disabled individuals to pursue careers in the media and entertainment industries. Having more disabled characters and storylines is another way in which disabled individuals may feel more interested in pursuing careers as it may make them feel like they are welcome in the industry and that they have more opportunities to be successful. Also, prioritize casting disabled actors for disabled characters. Conduct thorough casting calls by creating casting calls that prioritize disabled actors in their wording and by thinking outside the

box and posting open casting calls on social media and with disability organizations. This could widen the search area significantly, increase the audition pool, and potentially provide introductions to some extremely talented individuals who otherwise may not get noticed.

5. Have more positive and honest disability representations. Show more disability stories that have positive messages and avoid primarily showing disabled lives as tragedies. Additionally, show more representations of disabled characters overcoming obstacles and succeeding in multiple areas of their lives such as careers and relationships, both romantic and platonic. It is also important to show representations of disability that are true to life and show characters dealing with the positive and challenging aspects of disability such as coping with ableism and environmental barriers, as well as aspects common to disabled life such as discovering and disclosing their diagnoses and navigating medical treatments. Additionally, create disabled characters and storylines where disability is not the main focus or identifier of the character. Furthermore, portray disabled characters in situations and storylines that they are not commonly seen in and that avoid many of the common stereotypes that are often seen in the media. For example, show disabled characters as strong, intelligent, and driven, rather than passive, asexual, infantilized, or for comedic effect. Create and develop disabled characters in the same way as non-disabled characters. Finally, encourage and promote disabled individuals telling their own stories and providing input on stories that have already been created and are in the process of being filmed. Taking these steps can normalize and reduce stigma towards disabilities and

create greater education and awareness for individuals who may otherwise have few interactions with disabled individuals.

When conducting the focus groups and coding the main themes and subthemes, it was noted that some of the perspectives and recommendations had what could seem to be contradictory elements, such as wanting disability not to be the main focus of the character but also wanting to see characters deal with disability issues such as ableism and medical treatments. This reflects the complexity of disability and disability issues and how diverse the disability community is in their experiences and perceptions, which contrasts with the stereotype of disabled individuals as homogenous (Nario-Redmond, 2010). This finding also relates to the fact that participants mentioned that disabled people are as varied as non-disabled people, and that they want to see disabled characters portrayed as nuanced as non-disabled characters who often have dualities or contradicting aspects or personality traits.

#### **Strengths and Limitations**

Several strengths of this research study were noted. One strength was that the method of the study, focus groups, allowed disabled individuals to have an opportunity to share their voices and have their thoughts and perceptions heard. Additionally, participants were able to have a dialogue with others with their disability diagnosis, which fostered a greater sense of community, and in some instances led to participants connecting over shared experiences or perceptions. This could make participants feel less alone in their thoughts and experiences, particularly if participants previously did not have many interactions with others with their diagnosis.

An additional strength of this study was the diversity of participants. As mentioned earlier, participants came from a variety of cultural backgrounds, and the autism focus groups primarily consisted of individuals who identified as female or nonbinary. As the majority of autism representations in the media are of young, white males it is extremely important to hear the thoughts and perspectives of individuals who do not fit into that mold and who are not often represented. A final strength of this research study was the level of engagement participants displayed toward the topic of disability representation in the media. Many participants were already familiar in various ways with the media portrayals watched during the focus groups, and the fact that so many participants were able to think of other media representations of their disability when asked indicates that this is a meaningful topic for them and something that they likely thought about prior to participating in the study.

When considering this research study, several limitations were noted. The first limitation was the fact that participants self-reported their disability status and information, leading to a lack of ability to confirm that participants had the disability that they claimed to. Recruiting from disability organizations was one method of increasing the likelihood of reaching disability populations. These issues were attempted to be addressed by revisions to the demographic survey and interview script to collect more detailed disability and location information, as well as to encourage participants to keep their cameras on during the introductions and focus group discussion.

A second limitation of the study is that participants were recruited from disability support groups and organizations, and as such are currently receiving supports and resources. This places them in a position of advantage over disabled individuals who are not members of such organizations and may not have the opportunity to have their voices and experiences heard. As such, the perspectives of participants in this study may differ from disabled individuals who do not receive such supports. While my work can not represent all disabled perspectives, it is important for future research to engage in recruitment beyond disability organizations and support groups. This could be done through conducting recruitment through social media advertisements.

An additional limitation is the fact that many participants in the mobility impairment focus groups kept their cameras off throughout either the majority or the entirety of the focus group sessions. While all participants did participate verbally and some did briefly turn on their cameras during the introductions, allowing me to verify that actual individuals were participating in the study, when transcribing and coding the data I had to rely on their words and intonation, and lost out on the valuable information and input that non-verbal communication such as facial expressions and body language can provide.

The final limitation is the power differentials and interpersonal influences present in the project. As the data was collected in focus groups, it is possible that individual participants may not have felt comfortable openly disagreeing with the perspectives of other group members. Attempts were made to reduce this possibility by providing participants with the opportunity to privately share their perspectives after the focus group sessions had concluded. Additionally, as the researcher who asked the questions during the focus groups and was responsible for the thematic coding and the selection of quotes to be used in the manuscript, this gave me a lot of power in the process, and as a disabled individual, I have my own experiences and perceptions that could impact how I interpreted participant comments and coded themes. I attempted to address and reduce this by engaging in reflexivity by journaling throughout the entire research process. Additionally, I provided participants with a copy of the final themes and subthemes that were created after data analysis was completed. Participants acted as member checks and were encouraged to contact me if they felt that any of the themes did not match with what they spoke about during the focus groups.

#### **Future Directions**

Future directions in this area of study could involve examining a wider range of disabilities and their media representations. While generalizability was not a goal in this study, the focus groups were used to highlight individual participant voices. Future studies could add to the voices of individuals in the disability communities that were focused on in this study or could incorporate the voices of other disability groups. For example, individuals with diagnoses such as deaf/hard of hearing, Down Syndrome, visual impairments, and cerebral palsy could watch media representations of their disability and provide input. Some of these disabilities are not frequently represented in the media, and these populations may be less likely to be consulted or studied due to this An additional future direction of study focusing on increasing the diversity of disability diagnoses would be to conduct heterogeneous focus groups consisting of a participants with a wide variety of disability diagnoses, rather than the homogenous focus groups that were conducted in the present study. This would serve to highlight a wider range of disabled voices and experiences, but also could lead to fostering a sense of community among individuals with differing disability diagnoses. These studies would also be an excellent opportunity to seek participant feedback on the effectiveness of media

accessibility components such as closed captions and described audio. This could also serve to increase the generalizability of the current research findings and provide more evidence to support the perspectives of the disabled participants to individuals in the media and entertainment industries in order to encourage change.

Another future direction is to further examine the impact of cultivation theory and the factors that have been found in the media to impact and mediate cultivation effects. It is suggested that cultivation theory be reassessed and potentially redefined in order to determine its relevance with today's media landscape, as well as to identify which factors that have been found in the past to influence cultivation effects remain impactful. The media factors should also be studied more in relation to perceptions of disabled characters by non-disabled individuals. One way that this could be accomplished would be to show non-disabled individuals some of the media portrayals of disability that have been discussed both positively and negatively by the disabled participants who were involved in this study and measure their perspectives of disability both before and after watching the portrayals. Participants could also be asked about their perspectives surrounding cultivation factors such as distance, transportation, their connection with the characters, as well as their previous experience and viewing of media involving disabled characters and storylines. This would also serve to increase the literature on cultivation theory and disability and address the current shortage.

A final future direction is to study a wider variety of media formats, including video games and social media and streaming platforms such as Instagram, YouTube, Twitch, and TikTok, and how disability is represented on those platforms. Additionally, the current study focused on scripted series, and the changing media landscape has led to a surge of unscripted and self-created media formats. Many of these platforms allow individuals to curate their own media experiences, which could impact the disability representation that they view and could have an impact on media theories such as cultivation theory. As such, unscripted content such as reality shows or self-published content from content creators on streaming or social media platforms should be examined in more detail in order to assess the impact of representations of disability in these formats on viewers as well as to assess their reach in terms of disabled and non-disabled viewers.

## Social Impact and Knowledge Translation

A primary goal of this research project is to add to the academic literature that examines disability representation in the media from the perspectives of individuals in the disability community. Often the perceptions of disabled persons are lacking from critical analyses of media representations of disabilities, and research has indicated that including the voices and perspectives of disabled persons can result in more diverse, nuanced, and well-rounded representations of disability. By encouraging the input and participation of participants throughout the research project, I hope to create a greater sense of empowerment within the disability community. I also wish to add to the cultivation literature, as there has been a lack of studies that use cultivation theory to examine media representations of disability.

I wish to give back to the organizations that assist with participant recruitment by providing them with a brief report detailing my findings. In the future, I would love for workshops to be conducted for their staff and members to discuss media representation of disabilities and my findings in more detail. This would allow individuals who were either not eligible or not available to participate in the study the opportunity to learn about and discuss media representations of disability. Additionally, it could open up an opportunity for further collaborations with employees or members of organizations who are interested in working towards creating change within the entertainment and media industries.

A loftier goal for this research project is to create a call to social action. Disseminating the results of the study could encourage change in the entertainment industry by educating writers and creators on how to present characters with disabilities more diversely and in a more nuanced manner and informing them of the harm that can occur by perpetuating misinformation and misperceptions about disabilities. The results could also be used to create change in society's perception of disabilities by encouraging directors to recruit more actors with disabilities to play characters with disabilities and to consider casting actors with disabilities for roles where disability is not a primary attribute of the character. This could be implemented at the local Windsor level through community theatre companies, as well as by forming connections with board members of the Windsor International Film Festival. At a wider level, findings could be shared with casting agencies and with various writer's guilds by creating a brochure or brief report that could be distributed to individuals and organizations in the media. Additionally, workshops could be created for individuals in the media that detail the findings and offer suggestions for more positive and grounded representations of disabilities. One way that this could be accomplished is through reaching out to and collaborating with disability activists who are currently working with individuals in the media. An example is Access Activators, an original initiative of the British Council and Include Arts (UK) in partnership with Tangled Art + Disability and supported by the Canadian Council for the

Arts (Tangled Art + Disability, 2004b). The Access Activators consult with and provide training on disability and accessibility to arts organizations and members, with a focus on encouraging the implementation of Relaxed Performances for audience members with autism and other sensory, learning, and communication disabilities (Tangled Art + Disability, 2004b). Currently there are 19 Access Activators across eight provinces in Canada, with six Access Activators in Ontario (Tangled Art + Disability, 2004c).

It is also important to note that the current research findings have applicability to industries and organizations beyond entertainment and the media and could be shared with them in such formats as workshops, brochures, as well as websites and online toolkits. Education systems at all levels could benefit from the research findings and participant suggestions connected to the current study, as Hodkinson (2012) noted a lack of materials related to disability representation and disability issues in classrooms and Cook (2001) noted that many teachers reported feeling unprepared to teach in inclusive settings. The research findings from the current study could assist in addressing these educational gaps by encouraging and providing suggestions on incorporating diverse and nuanced disability representations when selecting course textbooks, media, and additional readings. Incorporating these materials could also serve to further educate instructors on disability and disability issues, as well as the disability stereotypes that are frequently perpetuated. The healthcare industry could also benefit, as some participants mentioned experiencing healthcare providers who appeared to have a lack of knowledge of their disability. Healthcare providers could be encouraged to listen to the voices of their disabled patients and view them as the experts on their disability experience. Additionally, when researching disability, healthcare providers should be reminded of the diversity and variability of disability presentations and experiences within the same disability diagnosis and that disabled individuals are not homogenous. The general public could also benefit from these research findings by increasing their awareness of common disability stereotypes and being encouraged to seek out a wide range of disability representations and storylines in the media, particularly those created by or including disabled individuals. Ideally, focus group participants or other individuals in the disability community could be included in the creation of materials and workshops in order to ensure that they can share their experiences and suggestions and to foster more positive perceptions of disabilities through interactions with individuals in the disability community.

#### Key Takeaways

Before concluding this manuscript, I wanted to summarize some key takeaways from the participants and the main aspects that they would like to see the media and entertainment industries address in order to counteract many of the critiques and barriers that they discussed during the focus groups:

- Participants want the media and entertainment industries to listen to the voices, critiques, and suggestions of the disability community.
- Participants want more diverse disabled characters in the media and to see themselves and their experiences represented in the media that they consume.
- Participants want to see more disabled individuals working in all aspects of the entertainment industry, as well as more storylines in the media that feature disabled characters.

• Participants want disabled characters that are created and portrayed as more than just their disability, and to be represented as complexly as non-disabled characters.

## Conclusion

In conclusion, this study adds to the literature that examines disability representation in the media from the perspectives of disabled individuals. Online focus groups were used to have participants watch and discuss a media portrayal of their disability, as well as provide their perspectives on disability representation within the media and entertainment industries and suggestions for the industries going forward. Participants discussed several positive and negative aspects of media portrayals of disability, including ways in which they did or did not relate to characters, the effectiveness of storylines, disability stereotypes seen in the media, and the ways in which these portrayals were felt to increase or decrease stigma in viewers. Participants also felt that there was a lack of disability representation within the media and entertainment industries, both in front of and behind the camera. Finally, participants discussed several ways in which the media and entertainment industries could improve disability representation, including addressing current barriers for disabled individuals, increasing diversity, conducting more research on disability, prioritizing disabled actors, and having more positive storylines relating to disability and disability issues. Primarily, disabled individuals want their voices to be heard and to be represented with the same thought, consideration, and range as non-disabled characters.

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## **APPENDIX A**

# Focus Group Script and Prompts

Introduction: Hello everyone, thank you so much for being here today. First, I would like to introduce myself. My name is Stephanie and I am a PhD student in Applied Social Psychology at the University of Windsor. I was born with a disability called Turner Syndrome which was diagnosed when I was four, and I also have been an actor in local theatre in Windsor for over 20 years, so I am very excited to discuss this media representation of disability with you and hear your thoughts.

Why don't we take an opportunity to introduce each other before getting started? How about you say your name, where you are currently living, and what your favourite movie is.

[after introductions]

Now I am going to quickly go through the consent form again to ensure that all of you understand what is involved in the study. Please let me know any questions that you have.

[after overview of consent form]

Now I will share my screen, and we will watch the media portrayal that we will be discussing. It is an episode of [name the show and title]. Again, I would like to remind everyone that this episode contains sensitive content regarding dating and relationships.

I would like to start off the focus group by talking about the television show that you watched. Please feel free to share your opinions and any reactions that you had as you were watching it.

- 1. How was the portrayal of [diagnosis] similar to your experiences?
  - How do you feel that this was similar?
  - Do you feel that this would be the same for everyone with [diagnosis]?
- 2. How was the portrayal of [diagnosis] different from your experience?
  - How do you feel that this was different?
  - Do you feel that this would be the same for everyone with [diagnosis]?
- 3. Watching this portrayal, did you identify with the character?
  - To what extent?
- 4. How do you think this portrayal could impact people's opinions of [diagnosis]?

- How does it reduce stigma?
- How does it increase stigma?
- How could the portrayal be improved?

Now I would like to change the topic a bit and ask you about other films and television shows that you can think of that have had characters with [diagnosis]. Take a minute and think of the characters and what you liked and did not like about them.

5. Can you think of any other portrayals of [diagnosis] that could leave a positive impact on people who watch it?

- What aspects of this portrayal do you find most meaningful? Why?
- How did this portrayal have a positive impact on you?

6. Can you think of any other portrayals of [diagnosis] that could leave a negative impact on people who watch it?

• What aspects of this portrayal do you find most harmful? Why?

[If participants can not think of any media representations of their diagnosis]

• What do you think the impact could be of having a lack of portrayals of [diagnosis] in the media?

Now I would like to talk about your thoughts about casting and writing characters with disabilities.

7. What are your perceptions of the number of individuals in the entertainment industry with disabilities?

• How could the entertainment industry incorporate more individuals with disabilities?

8. What are your thoughts on non-disabled actors playing characters with a disability?

- Why do you feel that way?
- In what situations would it be ok?
- In what situations would it not be ok?
- What can be done to change this?

9. If a writer were creating a character with [diagnosis], what would you like them to know?

10. If you could describe a character with your diagnosis that you would like to see, what would they be like?

- How would they act?
- What would their life look like?
- What kinds of relationships would they have?

11. Before we end the focus group today, is there anything else that you would like me to know about any of the questions we talked about today?

Thank you so much for your time today! That was a great discussion, and all of you made some wonderful points and suggestions. I will be contacting you tomorrow to send you your gift card and check in and see if there is anything else you can think of that you would like me to know. Have a wonderful day, and please feel free to contact me if you have any questions.

## **APPENDIX B**

Consent Form



# CONSENT TO PARTICIPATE IN RESEARCH

# Title of Study: Members of the Disability Community and their Perceptions of Disability Representation in the Media

You are asked to participate in a research study conducted by Stephanie J. Cragg and Dr. Kathryn D. Lafreniere, from the Psychology Department at the University of Windsor. The results of this study will contribute to a doctoral dissertation by Stephanie Cragg.

If you have any questions or concerns about the research, please feel to contact Stephanie Cragg at cragg2@uwindsor.ca or Dr. Kathryn D. Lafreniere at lafren1@uwindsor.ca.

## PURPOSE OF THE STUDY

The purpose of this study is to examine the opinions of individuals in the disability community about media portrayals of characters with their disability. You will also have the opportunity to provide suggestions for future portrayals of characters with disabilities. To create a dialogue and environment where thoughts and ideas can be shared and discussed, the media portrayals will be discussed in focus groups made up of other individuals with the same disability.

## PROCEDURE

If you volunteer to participate in this study, you will be asked to:

- 1. Indicate your consent by selecting 'I agree to participate' at the end of the consent form and fill out a short online survey about yourself. You will also receive a list of the questions being asked in the focus group.
- 2. If you are selected for the focus group, you will participate in an online focus group with other people who have the same disability to watch and discuss the media portrayal and suggestions for future portrayals. The focus group session will be no more than 3 hours. The session will take place using the online platform Zoom and will be video and audio recorded.

3. After the focus group, you will be contacted by the researcher the next day to be thanked for your participation and receive your \$30 Amazon gift card. You will also have the opportunity to share any thoughts or perspectives that you did not feel comfortable sharing with the group or that occurred to you after the focus group ended. You will have one week after being contacted by the researcher to provide any additional input.

#### POTENTIAL RISKS AND DISCOMFORTS

It is not anticipated that you will experience any risks outside of what you would experience in daily life and in your average television viewing. Watching the media portrayals and discussing them may stir up some negative emotions. You do not have to share anything in the focus groups that would make you uncomfortable and will have an opportunity to share information privately with the researcher after the focus group has finished.

If you feel uncomfortable with participating in the focus group on your own, you are allowed to have a family member or support worker join you to support you. If you would like to do this, please let me know and provide me their email address, and they will be asked to sign the consent form and will be encouraged to maintain the confidentiality of the information and people who participate in the focus groups.

To avoid any potential barriers or discomforts, please contact the researcher if you have any specific accessibility needs that you would like to be accommodated. I will do my best to meet these needs. Media portrayals will have closed captioning available and described audio and transcripts of the media portrayals will be provided if needed. Additionally, you will be allowed to write your responses into the chat during the focus group if you feel more comfortable expressing yourself in writing than verbally. The researcher or research assistant will ensure that they are actively moderating the chat during the focus groups and addressing any questions or comments that arise in it.

Due to the nature of focus groups, the researcher will maintain the information discussed in the groups in a confidential manner but can not guarantee that participants will do the same. Participants will be informed of this and encouraged at the beginning and end of the focus group to maintain the confidentiality of the other participants and not discuss any of the information brought up inside of the focus group after the group has ended. Anonymity is not possible during the focus groups, but you will be allowed to choose a pseudonym before the focus groups take place. These pseudonyms will be used when writing up the results and when sharing the results with community organizations and in future presentations and manuscripts.

#### POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will have the opportunity to share your thoughts regarding disability representation in the media and provide suggestions that will be shared with individuals and organizations in the media and entertainment industries. You will also have the opportunity to meet others with their same disability diagnosis and create new networks within the disability community.

#### COMPENSATION FOR PARTICIPATION

You will receive a \$30 Amazon electronic gift card to thank you for your participation. The gift card will be emailed to you the day after your focus group.

#### CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential by the researcher and will be disclosed only with your permission.

As mentioned earlier, focus group participants will be encouraged to maintain the confidentiality of the participants and information discussed in the focus groups; however, they will be informed that this can not be guaranteed. If there are certain things that you do not feel comfortable discussing in the group, an opportunity to share those thoughts or opinions privately with the researcher will be provided.

Confidentiality and anonymity will be maintained by the researcher in publications and presentations. Any direct quotes used will be linked with the pseudonym that was selected by you before the focus groups occurred. You will have the opportunity to select a pseudonym in the online survey.

All data (demographic information, audio files, video files, and transcripts) obtained from the focus groups will be saved in password protected files on the researcher's personal computer and will be moved to an external hard drive after the transcription and data analysis is completed. This data will remain confidential after the study has been completed. Any personally identifying information of participants will be kept on an external hard drive in a password protected file and will be kept separate from data obtained from the focus groups. All individual data in used in transcripts, presentations, and manuscripts will only be linked to the pseudonyms chosen by the participants.

#### PARTICIPATION AND WITHDRAWAL

You have the right to withdraw from the study at any time before the end of the focus group session. If you choose to withdraw, any data that was collected before your withdrawal will be used in the analysis and write-up of the research results. Participants who verbally withdraw before the first half of the focus group session will not be eligible to receive compensation and will not be emailed the Amazon gift card. The investigator may withdraw you from this research if circumstances arise which warrant doing so. This includes any disparaging remarks towards other participants and not maintaining a respectful dialogue.

## FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

The researcher will send a copy of the main themes obtained from the data to you to review to confirm that your thoughts and opinions were interpreted accurately. The researcher will then email a summary of the research results to you and will post a summary of the results on the University of Windsor's research webpage, which is provided below.

Web address: https://scholar.uwindsor.ca/research-result-summaries/ Date when results are available:

# SUBSEQUENT USE OF DATA

These data may be used in subsequent studies, in publications and in presentations.

# RIGHTS OF RESEARCH PARTICIPANTS

If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: <u>ethics@uwindsor.ca</u>

# SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE

I understand the information provided for the study **Members of the Disability Community and their Perceptions of Disability Representation in the Media** as described herein. As part of this study, I am agreeing to be video and audio recorded and for my pseudonym and direct quotes to be used in resulting manuscripts and publications. My questions have been answered to my satisfaction, and I agree to participate in this study. I will print a copy of this form.

- I agree to participate
- I do not agree to participate

#### **APPENDIX C**

#### Demographics

Chosen Pseudonym:

1. Age: \_\_\_\_\_

2. What gender identity do you recognise yourself as?

- 3. Which ethnic or cultural group do you identify with?
  - Central American (El Salvador, Honduras, etc.)
  - □ Scandinavian (e.g., Denmark, Sweden)
  - French Canadian
  - **English Canadian**
  - □ British (Scotland, Wales, England, N. Ireland)
  - □ W. European (France, Germany, Holland, etc.)
  - E. European (Russia, Poland, Baltic States, etc.)
  - □ S. European (Italy, Spain, Portugal, Greece etc.)
  - □ Far Eastern (Japan, China, India, Hong Kong, etc.)
  - □ African (specify North, Central, or South)
  - □ Caribbean
  - □ Middle Eastern (Israel, Lebanon, Iran, Iraq, etc)
  - Latin American
  - □ Indigenous (e.g., First Nations, Metis, status/nonstatus Indian)
  - Multicultural (please specify)
- 4. Are you currently living in Canada or the United States?

- Yes
- 🛛 No
- 5. What is the highest level of education you have obtained?
  - □ Some elementary school or elementary school graduate
  - □ Some high school
  - High school graduate
  - □ Some college
  - □ Some university
  - College graduate
  - University graduate
  - □ Master's degree or other similar degree
  - □ PhD/MD or other similar degree

6. Are you currently a student? (if you are not currently a student, please proceed to question 8)

- □ Yes
- 🛛 No
- 7. If you are a student, are you a:
  - □ full-time student
  - □ part-time student
- 8. What is your year of study?
  - □ 1st year
  - $\Box$  2nd year
  - $\Box$  3rd year
  - $\Box$  4th year
  - □ Other (please specify)

9. What is your major?

- 10. What is your employment status?
  - employed full time
  - employed part time
  - □ not currently employed
  - □ other (please specify) \_\_\_\_\_

11. Have you been diagnosed with Turner's Syndrome? (If you have, please continue to the next question)

yesno

12. If you have been diagnosed with Turner's Syndrome, at what age did you receive the

diagnosis: \_\_\_\_\_

13. Have you been diagnosed with a mobility impairment requiring the use of a wheelchair for at least 80% of the day?

yesno

14. If you have been diagnosed with a mobility impairment, at what age did you receive the diagnosis: \_\_\_\_\_

15. If you have been diagnosed with a mobility impairment, what is the diagnosis that

you received?

16. Have you been diagnosed with autism and use minor supports?

yesno

17. If you have been diagnosed with autism, at what age did you receive the diagnosis:

- □ From a licensed medical professional
- □ Self-diagnosed

19. Will you be bringing a family member or support worker with you to the focus group?

yesno

20. If yes, what is their relationship to you?

21. Are there any specific accommodations that you need to help you participate in this study?

Thank you for your participation in this survey! Please finalize your consent to submitting your data before entering your contact information for your Amazon gift card.

□ Yes I agree to submit my data

□ I wish to withdraw my data

<sup>18.</sup> How did you receive your diagnosis?

## **APPENDIX D**

## Follow-up Email Script to Participants

Hello [insert name]

Thank you once again for your participation in the focus group! All of your thoughts and suggestions were very much appreciated.

I hope that you enjoyed the discussion and felt comfortable speaking with everyone. Now that you have had a chance to think about everything that was talked about in the focus group, I wanted to ask if you thought of anything else that you would like to share with me about the topics that we discussed, or if you wanted to share any thoughts that you did not feel comfortable sharing with the group. Any information that is mentioned in my findings will be under the pseudonym that you selected.

If there is anything that you would like to tell me, please reply to this email within one week from today, by [insert date here]. If I do not hear from you, I will assume that you are happy with the information that you shared during the focus group. I will also be emailing you your Amazon gift card today to thank you for your participation.

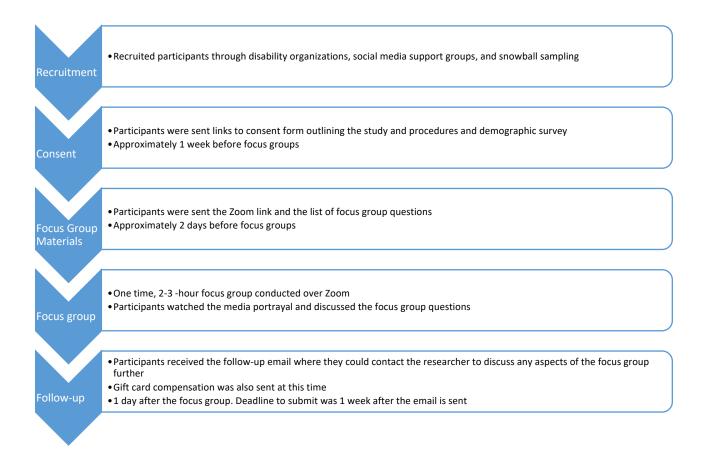
Thank you once again for your time and participation, and I look forward to sharing the results with you.

Sincerely,

Stephanie J. Cragg Ph.D. Candidate, Applied Social Psychology University of Windsor

## **APPENDIX E**

#### Procedural Sequence Chart



# **APPENDIX F**

**Revised Participant Advertisement** 



# Do you Have a Mobility Impairment that Requires the use of a Wheelchair?

# Do you Enjoy Watching and Talking about Television and Movies with People?

If you do, please consider joining this research study. In this study you will be watching a media representation that features a character with your disability and participating in a focus group with other individuals with the same disability to talk about what you watched.

This study is being conducted by Stephanie J. Cragg a Ph.D. student in fulfillment of her dissertation requirement under the supervision of Dr. Kathryn. D. Lafreniere at the University of Windsor.

To be eligible:

- You must have been diagnosed from a medical professional with a mobility impairment requiring a wheelchair for at least 80% of the day and have been diagnosed for over 6 months
- You must live in Canada or the United States
- You must be 18 years of age or older
- You must have an internet connection and a computer or tablet with video and microphone capabilities, or have a phone

# Participants will receive a \$30 electronic Amazon gift card

To find out more information about the study, please contact Stephanie J Cragg at cragg2@uwindsor.ca.

This research has been cleared by the Research Ethics Board of the University of Windsor

Please share this information if you know of anyone who may be interested in participating in this study.

## **APPENDIX G**

## **Revised Email Script**

Hello\_\_\_\_\_,

Thank you so much for your interest in this research study!

My name is Stephanie Cragg, and I am a PhD student in Applied Social Psychology at the University of Windsor. I am also a proud and active member of the Windsor disability and arts communities. If you are selected to participate in this study you will participate in a focus group where you will watch a media portrayal featuring a character with your disability, and talk about the media portrayal with other people with the same disability. This research study is being conducted as part of my Dissertation requirement under the supervision of Kathryn D. Lafreniere, Ph.D. and has been cleared by the University of Windsor Research Ethics Board

If you choose to participate, you will be asked to view and sign a consent form and complete a brief survey about yourself. This demographic information is being collected to help select a variety of individuals to participate in the focus group to make sure that different identities and experiences are represented. Completing the survey does not guarantee that you will be selected to participate in the focus group. If you are selected, approximately one week after this, you will participate in an online focus group where you will watch a television episode featuring a character with your disability diagnosis and discuss your perceptions and thoughts with other individuals who have been diagnosed with the same disability. The focus group will be approximately 2 to 3 hours long. Some episodes may include sensitive content regarding dating and relationships.

To participate in this study:

- You must live in Canada or the United States
- You must have a diagnosis of a mobility impairment requiring a wheelchair for at least 80% of the day from a medical professional and have been diagnosed for over 6 months
- You must be 18 years of age or older
- You must have an internet connection and a computer or tablet with video and microphone capabilities, or have a phone

If you are eligible and interested in participating, please respond to confirm and I will be in contact with you. Thank you again for your interest!

Stephanie J. Cragg Ph.D. Candidate, Applied Social Psychology University of Windsor

# **APPENDIX H**

# **Revised Consent Form**



# CONSENT TO PARTICIPATE IN RESEARCH

# Title of Study: Members of the Disability Community and their Perceptions of Disability Representation in the Media

You are asked to participate in a research study conducted by Stephanie J. Cragg and Dr. Kathryn D. Lafreniere, from the Psychology Department at the University of Windsor. The results of this study will contribute to a doctoral dissertation by Stephanie Cragg.

If you have any questions or concerns about the research, please feel to contact Stephanie Cragg at cragg2@uwindsor.ca or Dr. Kathryn D. Lafreniere at lafren1@uwindsor.ca.

## PURPOSE OF THE STUDY

The purpose of this study is to examine the opinions of individuals in the disability community about media portrayals of characters with their disability. You will also have the opportunity to provide suggestions for future portrayals of characters with disabilities. To create a dialogue and environment where thoughts and ideas can be shared and discussed, the media portrayals will be discussed in focus groups made up of other individuals with the same disability.

## PROCEDURE

If you volunteer to participate in this study, you will be asked to:

- 1. Indicate your consent by selecting 'I agree to participate' at the end of the consent form and fill out a short online survey about yourself. You will also receive a list of the questions being asked in the focus group. This demographic information is being collected to help select a variety of individuals to participate in the focus group to make sure that different identities and experiences are represented. Completing the survey does not guarantee that you will be selected to participate in the focus group.
- 2. If you are selected for the focus group, you will participate in an online focus group with other people who have the same disability to watch and discuss the media portrayal and suggestions for future portrayals. The focus group session will be no more than 3 hours. The session will take place using the online platform Zoom and will be video and audio recorded.

3. After the focus group, you will be contacted by the researcher the next day to be thanked for your participation and receive your \$30 Amazon gift card. You will also have the opportunity to share any thoughts or perspectives that you did not feel comfortable sharing with the group or that occurred to you after the focus group ended. You will have one week after being contacted by the researcher to provide any additional input.

## POTENTIAL RISKS AND DISCOMFORTS

It is not anticipated that you will experience any risks outside of what you would experience in daily life and in your average television viewing. Watching the media portrayals and discussing them may stir up some negative emotions. You do not have to share anything in the focus groups that would make you uncomfortable and will have an opportunity to share information privately with the researcher after the focus group has finished.

If you feel uncomfortable with participating in the focus group on your own, you are allowed to have a family member or support worker join you to support you. If you would like to do this, please let me know and provide me their email address, and they will be asked to sign the consent form and will be encouraged to maintain the confidentiality of the information and people who participate in the focus groups.

To avoid any potential barriers or discomforts, please contact the researcher if you have any specific accessibility needs that you would like to be accommodated. I will do my best to meet these needs. Media portrayals will have closed captioning available and described audio and transcripts of the media portrayals will be provided if needed. Additionally, you will be allowed to write your responses into the chat during the focus group if you feel more comfortable expressing yourself in writing than verbally. The researcher or research assistant will ensure that they are actively moderating the chat during the focus groups and addressing any questions or comments that arise in it.

Due to the nature of focus groups, the researcher will maintain the information discussed in the groups in a confidential manner but can not guarantee that participants will do the same. Participants will be informed of this and encouraged at the beginning and end of the focus group to maintain the confidentiality of the other participants and not discuss any of the information brought up inside of the focus group after the group has ended. Anonymity is not possible during the focus groups, but you will be allowed to choose a pseudonym before the focus groups take place. These pseudonyms will be used when writing up the results and when sharing the results with community organizations and in future presentations and manuscripts.

## POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will have the opportunity to share your thoughts regarding disability representation in the media and provide suggestions that will be shared with individuals and organizations in the media and entertainment industries. You will also have the opportunity to meet others with their same disability diagnosis and create new networks within the disability community.

## COMPENSATION FOR PARTICIPATION

You will receive a \$30 Amazon electronic gift card to thank you for your participation. The gift card will be emailed to you the day after your focus group.

## CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential by the researcher and will be disclosed only with your permission.

As mentioned earlier, focus group participants will be encouraged to maintain the confidentiality of the participants and information discussed in the focus groups; however, they will be informed that this can not be guaranteed. If there are certain things that you do not feel comfortable discussing in the group, an opportunity to share those thoughts or opinions privately with the researcher will be provided.

Confidentiality and anonymity will be maintained by the researcher in publications and presentations. Any direct quotes used will be linked with the pseudonym that was selected by you before the focus groups occurred. You will have the opportunity to select a pseudonym in the online survey.

All data (demographic information, audio files, video files, and transcripts) obtained from the focus groups will be saved in password protected files on the researcher's personal computer and will be moved to an external hard drive after the transcription and data analysis is completed. This data will remain confidential after the study has been completed. Any personally identifying information of participants will be kept on an external hard drive in a password protected file and will be kept separate from data obtained from the focus groups. All individual data in used in transcripts, presentations, and manuscripts will only be linked to the pseudonyms chosen by the participants.

## PARTICIPATION AND WITHDRAWAL

You have the right to withdraw from the study at any time before the end of the focus group session. If you choose to withdraw, any data that was collected before your withdrawal will be used in the analysis and write-up of the research results. Participants who verbally withdraw before the first half of the focus group session will not be eligible to receive compensation and will not be emailed the Amazon gift card. The investigator may withdraw you from this research if circumstances arise which warrant doing so. This includes any disparaging remarks towards other participants and not maintaining a respectful dialogue.

## FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

The researcher will send a copy of the main themes obtained from the data to you to review to confirm that your thoughts and opinions were interpreted accurately. The researcher will then email a summary of the research results to you and will post a summary of the results on the University of Windsor's research webpage, which is provided below.

Web address: https://scholar.uwindsor.ca/research-result-summaries/ Date when results are available: December 15, 2022

# SUBSEQUENT USE OF DATA

These data may be used in subsequent studies, in publications and in presentations.

RIGHTS OF RESEARCH PARTICIPANTS

If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: <u>ethics@uwindsor.ca</u>

# SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE

I understand the information provided for the study **Members of the Disability Community and their Perceptions of Disability Representation in the Media** as described herein. As part of this study, I am agreeing to be video and audio recorded and for my pseudonym and direct quotes to be used in resulting manuscripts and publications. My questions have been answered to my satisfaction, and I agree to participate in this study. I will print a copy of this form.

- I agree to participate
- I do not agree to participate

## **APPENDIX I**

**Revised Demographic Questions** 

Chosen Pseudonym:

1. Age: \_\_\_\_\_

2. What gender identity do you recognise yourself as?

- 3. Which ethnic or cultural group do you identify with?
  - Central American (El Salvador, Honduras, etc.)
  - □ Scandinavian (e.g., Denmark, Sweden)
  - French Canadian
  - **English Canadian**
  - □ British (Scotland, Wales, England, N. Ireland)
  - □ W. European (France, Germany, Holland, etc.)
  - E. European (Russia, Poland, Baltic States, etc.)
  - □ S. European (Italy, Spain, Portugal, Greece etc.)
  - □ Far Eastern (Japan, China, India, Hong Kong, etc.)
  - □ African (specify North, Central, or South)
  - □ Caribbean
  - □ Middle Eastern (Israel, Lebanon, Iran, Iraq, etc)
  - Latin American
  - □ Indigenous (e.g., First Nations, Metis, status/nonstatus Indian)
  - □ Multicultural (please specify)

- 4. Are you currently living in Canada or the United States?
  - □ Yes
  - No
- 5. What province, territory, or state are you currently living in?
- 6. What is the highest level of education you have obtained?
  - □ Some elementary school or elementary school graduate
  - Some high school
  - □ High school graduate
  - □ Some college
  - □ Some university
  - College graduate
  - **U**niversity graduate
  - □ Master's degree or other similar degree
  - PhD/MD or other similar degree

7. Are you currently a student? (if you are not currently a student, please proceed to question 8)

- □ Yes
- 🛛 No
- 8. If you are a student, are you a:
  - □ full-time student
  - **D** part-time student
- 9. What is your year of study?
  - □ 1st year
  - $\Box$  2nd year
  - □ 3rd year
  - $\Box$  4th year

□ Other (please specify) \_\_\_\_\_

10. What is your major?

- 11. What is your employment status?
  - $\Box$  employed full time
  - employed part time
  - □ not currently employed
  - □ other (please specify) \_\_\_\_\_

12. Have you been diagnosed with Turner's Syndrome?

- □ yes
- 🗖 no

13. If you have been diagnosed with Turner's Syndrome, at what age did you receive the

diagnosis:

14. Have you been diagnosed with a mobility impairment requiring the use of a wheelchair for at least 80% of the day?

□ yes

15. If you have been diagnosed with a mobility impairment, at what age did you receive

the diagnosis:

16. If you have been diagnosed with a mobility impairment, what is the diagnosis that

you received?

17. On what basis was the diagnosis made? Provide some detail on the process (for example, the cause, how your diagnosis was detected, the tests you went through) that went into your diagnosis.

18. Have you been diagnosed with autism and use minor supports?

□ yes

19. If you have been diagnosed with autism, at what age did you receive the diagnosis:

20. How did you receive your diagnosis?

**G** From a licensed medical professional

□ Self-diagnosed

21. Will you be bringing a family member or support worker with you to the focus group?

yesno

22. If yes, what is their relationship to you?

23. Are there any specific accomodations that you need to help you participate in this study?

Thank you for your participation in this survey! Please finalize your consent to submitting your data before entering your contact information for your amazon gift card.

- □ Yes I agree to submit my data
- □ I wish to withdraw my data

# **APPENDIX J**

# Revised Focus Group Script and Prompts

Introduction: Hello everyone, thank you so much for being here today. First, I would like to introduce myself. My name is Stephanie and I am a PhD student in Applied Social Psychology at the University of Windsor. I was born with a disability called Turner Syndrome which was diagnosed when I was four, and I also have been an actor in local theatre in Windsor for over 20 years, so I am very excited to discuss this media representation of disability with you and hear your thoughts. Before we start, I would like to mention that previous focus groups have tended to work better when people are in the same room or keep their cameras on, so I would like to encourage all of you to keep your cameras on for the introduction and questions portions of the focus group.

Why don't we take an opportunity to introduce each other before getting started? How about you say your name, where you are currently living, and what your favourite movie is.

# [after introductions]

Now I am going to quickly go through the consent form again to ensure that all of you understand what is involved in the study. Please let me know any questions that you have.

# [after overview of consent form]

Now I will share my screen, and we will watch the media portrayal that we will be discussing. It is an episode of [name the show and title]. Again, I would like to remind everyone that this episode contains sensitive content regarding dating and relationships.

I would like to start off the focus group by talking about the television show that you watched. Please feel free to share your opinions and any reactions that you had as you were watching it.

- 1. How was the portrayal of [diagnosis] similar to your experiences?
  - How do you feel that this was similar?
  - Do you feel that this would be the same for everyone with [diagnosis]?
- 2. How was the portrayal of [diagnosis] different from your experience?
  - How do you feel that this was different?
  - Do you feel that this would be the same for everyone with [diagnosis]?
- 3. Watching this portrayal, did you identify with the character?

- To what extent?
- 4. How do you think this portrayal could impact people's opinions of [diagnosis]?
  - How does it reduce stigma?
  - How does it increase stigma?
  - How could the portrayal be improved?

Now I would like to change the topic a bit and ask you about other films and television shows that you can think of that have had characters with [diagnosis]. Take a minute and think of the characters and what you liked and did not like about them.

5. Can you think of any other portrayals of [diagnosis] that could leave a positive impact on people who watch it?

- What aspects of this portrayal do you find most meaningful? Why?
- How did this portrayal have a positive impact on you?

6. Can you think of any other portrayals of [diagnosis] that could leave a negative impact on people who watch it?

• What aspects of this portrayal do you find most harmful? Why?

[If participants can not think of any media representations of their diagnosis]

• What do you think the impact could be of having a lack of portrayals of [diagnosis] in the media?

Now I would like to talk about your thoughts about casting and writing characters with disabilities.

7. What are your perceptions of the number of individuals in the entertainment industry with disabilities?

• How could the entertainment industry incorporate more individuals with disabilities?

8. What are your thoughts on non-disabled actors playing characters with a disability?

- Why do you feel that way?
- In what situations would it be ok?
- In what situations would it not be ok?
- What can be done to change this?

9. If a writer were creating a character with [diagnosis], what would you like them to know?

10. If you could describe a character with your diagnosis that you would like to see, what would they be like?

- How would they act?
- What would their life look like?
- What kinds of relationships would they have?

11. Before we end the focus group today, is there anything else that you would like me to know about any of the questions we talked about today?

Thank you so much for your time today! That was a great discussion, and all of you made some wonderful points and suggestions. I will be contacting you tomorrow to send you your gift card and check in and see if there is anything else you can think of that you would like me to know. Have a wonderful day, and please feel free to contact me if you have any questions.

# Braun and Clarke (2006) Checklist

 Table 2
 A 15-point checklist of criteria for good thematic analysis

| Process        | No. | Criteria  |
|----------------|-----|---|
| Transcription  | 1   | The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.                           |
| Coding         | 2   | Each data item has been given equal attention in the coding process.  |
|                | 3   | Themes have not been generated from a few vivid examples (an anecdotal approach),<br>but instead the coding process has been thorough, inclusive and comprehensive. |
|                | 4   | All relevant extracts for all each theme have been collated.  |
|                | 5   | Themes have been checked against each other and back to the original data set.  |
|                | 6   | Themes are internally coherent, consistent, and distinctive.  |
| Analysis       | 7   | Data have been analysed – interpreted, made sense of – rather than just paraphrased or described.   |
|                | 8   | Analysis and data match each other – the extracts illustrate the analytic claims.   |
|                | 9   | Analysis tells a convincing and well-organized story about the data and topic.  |
|                | 10  | A good balance between analytic narrative and illustrative extracts is provided.  |
| Overall        | 11  | Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.                         |
| Written report | 12  | The assumptions about, and specific approach to, thematic analysis are clearly explicated.  |
|                | 13  | There is a good fit between what you claim you do, and what you show you have done – ie, described method and reported analysis are consistent.                     |
|                | 14  | The language and concepts used in the report are consistent with the epistemological position of the analysis.  |
|                | 15  | The researcher is positioned as <i>active</i> in the research process; themes do not just 'emerge'.   |

#### **APPENDIX L**

#### Braun and Clarke (2020) Manuscript Evaluation Tool

Table 1. A tool for evaluating thematic analysis (TA) manuscripts for publication: Twenty questions to guide assessment of TA research guality.

These questions are designed to be used either independently, or alongside our methodological writing on TA, and especially the current paper, if further clarification is needed.

- 1. Do the authors explain why they are using TA, even if only briefly?
- 2. Do the authors clearly specify and justify which type of TA they are using?
- 3. Is the use and justification of the specific type of TA consistent with the research questions or aims?
- 4. Is there a good 'fit' between the theoretical and conceptual underpinnings of the research and the specific type of TA (i.e. is there conceptual coherence)?
- 5. Is there a good 'fit' between the methods of data collection and the specific type of TA?
- 6. Is the specified type of TA consistently enacted throughout the paper?
- 7. Is there evidence of problematic assumptions about, and practices around, TA? These commonly include:
- Treating TA as one, homogenous, entity, with one set of widely agreed on procedures.
- Combining philosophically and procedurally incompatible approaches to TA without any acknowledgement or explanation.
- Confusing summaries of data topics with thematic patterns of shared meaning, underpinned by a core concept.
- Assuming grounded theory concepts and procedures (e.g. saturation, constant comparative analysis, line-by -line coding) apply to TA without any explanation or justification.
- Assuming TA is essentialist or realist, or atheoretical.
- Assuming TA is only a data reduction or descriptive approach and therefore must be supplemented with
  other methods and procedures to achieve other ends.
- 8. Are any supplementary procedures or methods justified, and necessary, or could the same results have been achieved simply by using TA more effectively?
- 9. Are the theoretical underpinnings of the use of TA clearly specified (e.g. ontological, epistemological assumptions, guiding theoretical framework(s)), even when using TA inductively (inductive TA does not equate to analysis in a theoretical vacuum)?
- 10. Do the researchers strive to 'own their perspectives' (even if only very briefly), their personal and social standpoint and positioning? (This is especially important when the researchers are engaged in social justiceoriented research and when representing the 'voices' of marginal and vulnerable groups, and groups to which the researcher does not belong.)
- 11. Are the analytic procedures used clearly outlined, and described in terms of what the authors actually did, rather than generic procedures?
- 12. Is there evidence of conceptual and procedural confusion? For example, reflexive TA (e.g. Braun and Clarke 2006) is the claimed approach but different procedures are outlined such as the use of a codebook or coding frame, multiple independent coders and consensus coding, inter-rater reliability measures, and/or themes are conceptualised as analytic inputs rather than outputs and therefore the analysis progresses from theme identification to coding (rather than coding to theme development).
- 13. Do the authors demonstrate full and coherent understanding of their claimed approach to TA?
- A well-developed and justified analysis
- 14. Is it clear what and where the themes are in the report? Would the manuscript benefit from some kind of overview of the analysis: listing of themes, narrative overview, table of themes, thematic map?
- 15. Are the reported themes topic summaries, rather than 'fully realised themes' patterns of shared meaning underpinned by a central organising concept?
  - If so, are topic summaries appropriate to the purpose of the research?
  - If the authors are using reflexive TA, is this modification in the conceptualisation of themes explained and justified?
  - Have the data collection questions been used as themes?
  - Would the manuscript benefit from further analysis being undertaken, with the reporting of fully realised themes?
  - Or, if the authors are claiming to use reflexive TA, would the manuscript benefit from claiming to use a different type of TA (e.g. coding reliability or codebook)?
- 16. Is non-thematic contextualising information presented as a theme? (e.g. the first 'theme' is a topic summary providing contextualising information, but the rest of the themes reported are fully realised themes). If so, would the manuscript benefit from this being presented as non-thematic contextualising information?
- 17. In applied research, do the reported themes have the potential to give rise to actionable outcomes?
- 18. Are there conceptual clashes and confusion in the paper? (e.g. claiming a social constructionist approach while also expressing concern for positivist notions of coding reliability, or claiming a constructionist approach while treating participants' language as a transparent reflection of their experiences and behaviours)
- 19. Is there evidence of weak or unconvincing analysis, such as:
  - Too many or two few themes?

Adequate choice and explanation of methods and methodology

Table 1. (Continued).

- Too many theme levels?
  Confusion between codes and themes?
  Mismatch between data extracts and analytic claims?
  Too few or too many data extracts?
  Overlap between themes?

- 20. Do authors make problematic statements about the lack of generalisability of their results, and or implicitly conceptualise generalisability as statistical probabilistic generalisability (see Smith 2017)?

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