“I had only experienced life as myself”: Self-representation of autistic people on Instagram

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Abstract

Representations of autism in the media are often colored by discourses asserting that autism is a deficit or the product of imposed social structures. These discourses stem from the so-called medical and social models of disability. Both offer unnuanced understandings of autism, which affect audiences' views, and impair autistic people's possibilities to recognize themselves in the media. Lived experience of autistic people is therefore overlooked and autistic people are seen as victims of social structures or of their disability. A third model of disability, the predicament model, takes into account lived experiences of autistic people and asserts that autism is at once a biological and social disability that presents itself differently in every autistic individual. This model creates a more nuanced understanding of autism by arguing that we need to take into account autistic voices to better understand how autism is experienced by them. For example, autistic people can assert a more complex and nuanced understanding of autism through self-representation on social media. This research examined such self-representations on Instagram and aimed to answer two research questions: (1) how do autistic people represent autism on Instagram? and (2) how do users engage with and interpret autistic people's portrayals of autism on Instagram? Through purposive sampling, three autistic Instagram creators were selected to examine their representations of autism. Using qualitative multimodal content analysis, ten posts of each account and thirty accompanying comments were analyzed. From the analysis, four categories and their patterns were developed. The first three categories were based on the medical, social and predicament models of disability. These categories demonstrate the way that these models influenced, were present, or were opposed in the creators' representations of autism. The medical model was opposed through the use of irony. The social model was present to explain how living in a neurotypical society is difficult for autistic people, and how autistic people continue to be mistreated. The predicament model fits the creators' representations of autism best because they normalized being autistic through a variety of strategies. Emphasis was furthermore placed on valuing autistic experience, representing lesser-known autistic traits and behaviors, and challenging stereotypes. The fourth category focused on user engagement with and interpretation of the creators' posts, and concludes that users largely adopt the intended meaning of the creators' posts. They are grateful for the representations, relate to the content and engage in conversations with others, thereby building a positive autistic identity and safe space on the internet.

KEYWORDS: *autism, representation, lived experience, Instagram, models of disability*

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1. Introduction

> We read about stereotyped, untrue ‘diagnostic criteria’ for neurodivergent minds, have societal expectations stuck in our heads, or see neurodiversity poorly represented in the media and it becomes difficult to separate truth from fiction. We feel pressure to be a certain way as a neurodivergent human in a neurotypical world. (Hayden, 2022, p. 183)

Chloé Hayden, autistic actress and disability advocate, captures here in her autobiography the discontent of neurodiverse people with current representations of neurodiversity in the media (Botha et al., 2022, p. 442). The media have power to influence society’s beliefs and attitudes towards groups of people, especially in their depictions of minority groups that not everyone is familiar with (Baroutsis et al., 2023, p. 964). Depictions of the ‘other’ may result in positive or negative views on the portrayed persons, and may challenge or reproduce stereotypes. When the media portray one-dimensional, stereotypical views of Autism Spectrum Disorder (ASD), victimize autistic people, or depict autism as a deficit, they often give way to misconduct towards, and marginalization of, autistic people (Jones et al., 2023, p. 2206).

The most common perspectives on autism are rooted in the *medical* and *social models of disability*. The medical model regards autism as pathology and sees traits and behaviors of autistic people as deficits (Constantino, 2018, p. 385; McGuire & Michalko, 2011, p. 163). A harmful outcome of regarding autism as pathology is the potential mistreatment of autistic people and the wish to eliminate the disability. An example of this is the aggression towards autistic residents at the Judge Rotenberg Educational Center in Massachusetts, United States, where staff use shock devices on autistic people for exhibiting autistic traits and behaviors (ADAPT, n.d.; Gonnerman, 2012). Despite (online) protests, voiced concerns from parents, and lawsuits against the center, the Judge Rotenberg Educational Center remains open to this day, and misconduct with shock devices towards autistic residents continues to be standard procedure (McFadden et al., 2021, para. 7; Pilkington, 2018,). Although the center displays an extreme example of mistreatment of disabled people, autistic people continue to be mistreated or are disregarded in everyday life as a consequence of the influence of the medical model on representations and perspectives of autism in society.

Opposing the medical model is the social model of disability, which considers autism to be disabling because the wider social structures in society are unaccommodating autistic people in their daily lives (Constantino, 2018, p. 386). A more recent model within which to consider autism is the *predicament model of disability*. This model focuses on lived autistic experiences, and sees autism as a combination of biological characteristics and unaccommodating social structures. It leaves more room for agency and valuing autistic people, thereby offering possible changes in representations of autism in the media. The essence lies in hearing and amplifying autistic people’s own voices, and creating fair representation as well as validating the variety of autistic experiences (Anderson-Chavarria, 2022, p. 1332).

Representation of any group of people can serve as an important site of meaning-making and understanding of the world (Hall, 2013b, p. 45). Many forms of media have attempted to represent autism, and often these depictions are executed by neurotypical people. Neurotypical people are non-autistic people, and have typical neurological development (Brownlow & O'Dell, 2006, p. 316-317). Colored by the one-dimensional and stereotypical narratives of autism based on the medical and social models, these depictions are often limited in their displays of different aspects of autism (Baroutsis et al., 2023, p. 963; Belcher & Maich, 2014, p. 109-110), resulting often in delayed diagnosis of autistic people who cannot connect with the narrow depictions of autism in the media. Neurodivergent scholars Bertilsdotter Rosqvist et al. explain that such delayed diagnosis and subsequent forced following of neurotypical social rules has negatively impacted their wellbeing (2023, p. 3). Considering the possible harmful consequences of inaccurate representations, and the fact that autism is not uncommon, as 1 in 100 people are estimated to be autistic (World Health Organization, 2023, Key Facts section), the societal relevance of this research lies in listening and giving priority to autistic voices to understand how they make sense of, and experience, their disability.

Social media present opportunities for amplifying autistic voices, as the technological affordances of these technologies grant users a degree of agency in representing oneself and constructing their identity to a certain extent. Users can for example share user-generated content to depict themselves online through blogs, videos, and images. Nevertheless, social networking sites' specific affordances, interfaces, and available modes also constrain and guide users in their practices of identity construction and self-representation (van Dijck, 2013, p. 199, 213; Szulc, 2019, p. 258). Certain elements of an identity or group of people can for example be emphasized, while other elements may be diminished.

Nonetheless, considering these limitations, digital technologies also allow for the creation of communities of like-minded people, and social categories such as disability exist in digital spaces as well, creating a common ground on which disabled people can talk about their experiences and relate to each other (Dumitrica, 2019, p. 307, 308; Dyck & Russell, 2020, p. 183). The creation of, and engagement in, an online community can aid disabled people in feeling less isolated through bonding over similar daily experiences. Online communities may also act as a form of activism in opposing stereotypes and wrongful insinuations (Constantino, 2018, p. 383; Tisoncik, 2020, p. 71, 74). In particular, digital technologies have enabled the development and growth of the neurodiversity movement: a movement by and for neurodivergent individuals that advocates for equal treatment of disabled people and regards autism as a natural difference in brain structure (Dyck & Russell, 2020, p. 177). Identity construction for autistic people can be aided by this common group identity, as a group composed of people with the same disability has the ability to construct a positive narrative that normalizes being autistic and validates its members for all the facets of their identities (Anderson-

Chavarria, 2022, p. 1326). Hence, online representation and engagement with other disabled people might challenge dominant negative discourses about autism and give autistic people a positive sense of identity.

Yet, there is little academic research on autistic social media creators and engagement of autistic people. Although autism has been a point of interest in scientific research, most of this research has benefited the medical field and favored the voices of family, therapists, educators, and doctors of autistic people in understanding what autism is and how it is present in individuals (Egner, 2022, p. 352). Such studies may benefit clinicians and parents wishing to understand their children better, but it paints a picture of autism from a neurotypical perspective. Research on fictional media representations of autism, such as in movies and books, on the other hand, has examined whether these representations are accurate (Belcher & Maich, 2014, p. 109). Also, these approaches to studying autism lack inclusion of autistic voices. O'Neil (2008, p. 787) posits the solution to this problem to be scientific research that takes into account autistic voices to understand what autism truly entails. Pellicano et al. (2014, p. 756) further propose that research should involve the autistic community more in order to conduct research catered to their daily lives and challenges, so that appropriate resources may better reach autistic people in need.

Connected to these requests is the call by Ellcessor et al. (2017) about needing to combine disability studies and media studies. Interdisciplinarity would increase our understanding of how media and disability exist and work together, and media studies can benefit from focusing more on lived experiences of disability in analyses (p. 3, 18). The interdisciplinary approach to this study therefore aims to bridge the gap between media and disability studies by underscoring how depictions and ways of framing disability in the media make a difference in the everyday experiences of disabled people. The terminology used, and *how* this is used to phrase disabled people's strengths and challenges, can be of significance on discourses of autism, as well as on autistic people's own identity construction.

Nonetheless, compliance with these requests by involving autistic people in research often resulted in conducting interviews or focus groups, which fall short of exploring self-representation practices of autistic people. Understanding autistic experiences may be best researched by analyzing autistic individuals' output, for example on social media, because it presents opportunities for autistic people to self-narrate personal experiences (Egner, 2022, p. 351) and interact with like-minded individuals, without some of the social barriers often present during conversations, such as needing to make eye contact or understanding implicit social cues (Davidson, 2008, p. 796, 208). Online autistic communities may grant a safe space where sharing about one's disability is encouraged, and examining these representational endeavors can add to a more complex and nuanced picture of lived autistic experiences. The scientific relevance of this research thus lies in including autistic voices in examining and understanding how autistic people experience their disability, the way that dominant discourses, based on the models of disability, may play a role in their everyday experiences, and how autistic people represent themselves in the context of these discourses. Combining media and disability studies also benefits the academic field in underscoring the importance of valuing both approaches in a better understanding of how media and disability are connected.

As Instagram remains a popular social medium with two billion users on the application in the beginning of 2024 (Dixon, 2024, Key Insights section), this research examines representations of autism on Instagram. The research aims to answer the following research questions: (1) *how do autistic people represent autism on Instagram?* and (2) *how do users engage with and interpret autistic people's portrayals of autism on Instagram?* Qualitative multimodal content analysis is employed to answer the research questions and the accounts of three autistic Instagrammers were chosen for the analysis: Louise Chandler, Callum Stephen, and Adrienne Marcellus. Multimodal content analysis takes into account the ensemble of different modes used on Instagram to convey meaning and information about, in this case, representations of autism (Serafini & Reid, 2023, p. 627). It is especially useful in examining posts and comments, as Instagram grants users a variety of modes to employ to create meaning, such as images, videos, captions, hashtags, and audio (Fisher & Aarestrup, 2021, p. 89).

The subsequent chapters are structured according to the following outline. Chapter two provides an overview of past research on representations of autism and considers the medical, social and predicament models of disability, as well as the neurodiversity movement, in shaping these representations. After considering the models of disability and dominating stereotypes of autism in the wider society, the theoretical framework highlights the importance of giving voice to autistic people and their definitions of what it means to be autistic. Chapter three justifies the choice for employing qualitative multimodal content analysis for investigating posts from the three selected Instagrammers and shares the process of constructing the instrument of analysis. This methodological chapter also explains why these three Instagram creators were chosen and the decision for not anonymizing their names to give credit to their perspectives and recognize advocacy efforts for the wider autistic community. The fourth chapter presents the findings according to four categories and their patterns, which demonstrate that discourse stemming from the models of disability can be found in autism representations, but that ultimately autistic people do not consider autism to be pathology nor do they glorify being autistic. These representations, in turn, are mostly appreciated and embraced by users. Lastly, the concluding chapter presents an overview of the findings and answers to the research questions. The chapter ends with some limitations and suggestions for future research.

2. Theoretical framework

This chapter evaluates the narratives surrounding autism as considered in the medical, social and predicament models of disability. It examines past research conducted on representations of autism and argues that many representations continue to center on stereotypes and do not include the diversity of autistic experiences. Studying self-representation of autistic people on Instagram adds to our understanding of the role that problematic narratives of autism have played in marginalizing autistic people, and underscores the importance of securing voice for autistic people in order to normalize autism and construct a positive identity. Finally, as autistic Instagrammers' posts are subject to being commented on and interpreted by other Instagram users, the chapter ends with the importance of studying how these posts are interpreted and engaged with.

2.1. History of autism as a disability

Autism Spectrum Disorder (hereafter called autism), is a neurodevelopmental disability that influences communication and social interactions, and entails repetitive behaviors and patterns such as repetitive motor movements and relying on routines (American Psychiatric Association, 2022, Autism Spectrum Disorder section). Autism can pose challenges in individuals' executive functioning and communication. The disability is often surrounded by stigma and autistic people frequently have to cope with prejudice and wrongful depictions (Constantino, 2018, p. 386). Consequently, autism is considered within the models of disability.

Since the first documentation of autism by Dr. Leo Kanner in 1943, autism has been considered within the medical model of disability. This model regards autism as a medical disorder, focusing on an individual's deficits. For instance, Kanner claimed that autistic children are unable to form meaningful connections because they are innately different from 'normal' children (Kanner, 1943, p. 250). Moreover, the medical model pathologizes the disability and believes that autistic people's behaviors are puzzling and should be cured to fit normative expectations of society (Constantino, 2018, p. 386; Egner, 2022, p. 362; Jaarsma & Welin, 2012, p. 24; McGuire & Michalko, 2011, p. 163). The autism descriptors and diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the international manual for diagnosing psychological disorders, reflect the medical model of thinking about disability. Moreover, the criteria have been argued to be catered to the male experience of autism, disregarding that autism presents itself differently in women and consequently leading to a delayed diagnosis in the latter (Baroutsis et al., 2023, p. 980; Craddock, 2024, p. 1-2; Seers & Hogg, 2021, p. 1556). Moreover, this way of understanding disability as a deficit in human beings is, according to Constantino (2018, p. 385), still the default perspective in society. This makes autistic people prone to internalize the stigma surrounding their disability, and can have negative effects on their identity building, as the focus is on what they lack instead of their skills and traits. Additionally, the medicalization of autism can negatively impact autistic people's agency in social and political life and employment, as they might encounter barriers to enter these domains because of their alleged deficits (Anderson-Chavarria, 2022, p. 1330). Ultimately, the medical model can be said to position autistic people as victims of their disability, neglecting their overall agency and positive strengths or advantageous skills.

In contrast, the social model of disability contends that autism is a socially constructed disability; the result of imposed social structures. Constantino (2018) describes this as "People are disabled by society, not by their bodies" (p. 386). Autistic people may still experience 'impairments' with regards to their bodies, but they are disabled in principle because society does not accommodate these impairments, and, in turn, this can negatively impact their identity construction. Their difficulties are produced due to an unaccommodating socio-cultural environment, which would inhibit disabled persons from participating in society. Conversely, people would not be disabled anymore if certain changes are made in society (Dunn & Andrews, 2015, p. 258; Ejaz, 2020, p. 784; Ellcessor et al., 2017, p. 5; Seers & Hogg, 2021, p. 1562). While the development of the social model can be seen as progressive in moving away from describing autistic people as deficient, the model has still received criticism. It disregards disabled people's agency in portraying them as victims of imposed social structures and an exclusionary society (Anderson-Chavarria, 2022, p. 1331). At their core, both the medical and social model have been critiqued for dehumanizing disability experiences and victimizing disabled people, both rejecting disabled people's agency and their competency to act upon social structures.

Contrasting the medical model, and building to a certain extent on the social model, is the neurodiversity movement. Not an official disability model but a social movement, it regards autism as a natural variation in human brain structure and biology, meaning that society unequivocally includes a distinct amount of neurodiverse people. Advantages and unique, valuable skills of autistic people are emphasized, and the call for accepting 'difference' is heard within the movement. Differences in neurodiverse people are framed in such a way that these differences are seen as valuable, blurring the boundary between normality and abnormality (Constantino, 2018, p. 383, 390; Dyck & Russell, 2020, p. 176; Egner, 2022, p. 351; Jaarsma & Welin, 2012, p. 21, 23, 27). The movement does recognize autism as a disability and emphasizes that neurodivergent people experience significant challenges in their lives because of their disability (Anderson-Chavarria, 2022, p. 1334). Nevertheless, as emphasis is placed on 'difference', the view of autism as a disability within the movement is perceived as a product of the mismatch between the autistic individuals' biology and their social environment or culture (Constantino, 2018, p. 387; Egner, 2022, p. 351). This narrative borrows from the social model because it insinuates that there is a social bias in the form of a mismatch and unaccommodating environments, sometimes disregarding that autistic traits themselves can make communication, maintaining relationships and employment difficult enough (Ellcessor et al., 2017, p. 8). Some autistic people have explicitly explained that their autism itself disables them, for example in their employment due to poor visual perceptions and motor skills (Constantino, 2018, p. 388). This illustrates that autism should be considered as a disability not only due to the construction of society, but also due to its own nature.

The neurodiversity movement is a step forward in understanding disability as a combination of biological factors and social milieu (Jaarsma & Welin, 2012, p. 28), by taking away the blame from disabled individuals and placing emphasis on the celebration of differences. It furthermore requests for acceptance of autism as a disability and way of being, opposing the binary definitions of normal and abnormal.

Anderson-Chavarria (2022) recognizes that the neurodiversity movement "has evolved our understanding of autism to such an extent that the autism experience can no longer be adequately situated within either medical or social models of disability" (p. 1335). Therefore, she has devised a new model for thinking about disability: the predicament model. This model recognizes the biological and social constrictions of autism, while considering it as an individualized experience.

According to the author, the predicament model does better justice to lived autistic experience by recognizing people's agency in representing all aspects of being autistic, and thereby facilitates positive identity building. With this, Anderson-Chavarria means that autistic people are reclaiming their rights for autistic identity building from society; autistic people's identity has long been determined by society, setting them apart as 'the other' and having their agency neglected (Tisoncik, 2020, p. 70). The predicament model facilitates a representation of all aspects of being autistic by listening to autistic voices and recognizing their use of agency in acting upon social structures that may inhibit them from comfortably living as an autistic person. The model therefore deals with the relation between agency and structure differently from the medical and social models, in recognizing that is it not *only* brain structures or social structures that disable autistic people, and that autistic people can use their agency to act upon exclusionary facets of society. Moreover, it shines a light on advantages such as being detail-oriented, challenges like being sensitive to sounds, lighting and crowds, and the lesser-known aspects not always mentioned in the DSM-5 and the media (Baroutsis et al., 2023, p. 963). An example of the latter is the significant persistence of social anxiety in autistic individuals, which is not always connected to being autistic but remains a central challenge for many autistic people (Hudson et al., 2023, p. 212). Following the predicament model to understand autism may result in gaining more understanding of how one autistic person can experience something as disabling, while another autistic person may not, since it is a unique experience (Anderson-Chavarria, 2022, p. 1325, 1332-1335). This resonates with the general claim made by autistic people that if you have met one autistic person, you have indeed just met *one* autistic person. Everyone is different and autism does not have one particular look (Healis Autism Centre, 2020, para. 1).

The importance of considering different models of understanding autism lies in the impact that these models can have on autistic individuals. The predicament model would understand autistic people's lived experience, taking into account what every individual thinks of their traits. This focuses less on what they appear to lack or how society would be disabling them. Indeed, there are autistic people who feel they are being disabled by society, or who maintain that they lack certain skills that enhance struggles in everyday life. However, the predicament model suggests looking at how autistic people *experience* the world and listening to their lived experiences, regardless of whether portrayals of these experiences fall within the social or medical models.

In contrast to the medical and social models, the predicament model seems to be a progressive step forward in attempting to understand autistic people better. Nevertheless, none of the models present a hard truth for understanding disability, as "models are never truth but ways to simplify complex phenomena to make them understandable" (Constantino, 2018, p. 386). Autism is a spectrum, therefore everyone perceives and experiences it in a distinctive, personal way. As it remains a disability affecting people's being and functioning in society, it is crucial to take every individual experience into account by listening to autistic people's own representations and experiences of being disabled, and analyze how others interpret these experiences (O'Neil, 2008, p. 787, 792, 795).

Terminology matters in talking about disability. Person-first language, such as 'person with autism' separates the individual from their identity as a disabled person, implying that autism does not – or should not – play a substantial role in an individual's daily life. Consequently, this terminology stigmatizes being disabled (Gernsbacher, 2017, p. 861). Identity-first language, such as 'autistic person' depicts autism as a fundamental aspect of an individual's identity, influencing their daily experiences and shaping how they interact with and live in the world (Kenny et al., 2016, p. 443). Autistic people attach great value to the ability of self-identification, and have expressed their preference for identity-first language (Bottema-Beutel et al., 2021, p. 23). Subsequently, throughout this thesis, the term 'autistic people' is used, opposed to 'person with autism', as it does better justice to the autistic experience.

2.2. Media representations of autism

In line with the changing models of disability, narratives of autism are changing as well. The media play an important role in this change, as depictions of autism in the media can have effects on viewers' opinions of and attitudes towards autistic people (Baroutsis et al., 2023, p. 964, 978; Ejaz, 2020, p. 785). The lack of positive and nuanced representations, or the existence of outright negative portrayals of autism, can for instance lead to increased exclusion and stigmatization of autistic people (Harnett, 2000, p. 26-28). Although this effect is recognized, findings of previous studies indicate that mainstream media continue to base their understanding of autism on the medical model of disability, echoing the claim that the default perspective of autism in society at large is pathology and disorder (Constantino, 2018, p. 385; Nordahl-Hansen et al., 2018a, p. 352). This perspective can result in *ableism*: the belief that disabled people are less than non-disabled people, and that disabilities should always be cured in order for the disabled person to be a valuable member of society (Bottema-Beutel et al., 2021, p. 19). Autistic people are then often dehumanized, excluded from many facets of society, and ‘othered’ due to this residing stigmatizing perspective, as it implies that autistic people are abnormal, ‘less than’, and should be changed or avoided (Egner, 2022, p. 353; Robinson & Highcock, 2024, p. 173).

To illustrate this medicalized perspective, Jones et al. (2023, p. 2213) found that contemporary representations of autism in fictional media remain focused on the dominant view of autistic people being burdens to society, with restrictive and repetitive characteristics, having high-support needs and acting as savants. Individuals’ agency is then often neglected, and their traits and behaviors belong to a set of stereotypes that continues to perpetuate the idea that autistic people are abnormal. Stereotypes are often used in the media to depict certain phenomena. It is therefore not uncommon for people to base their understanding of a certain phenomenon that they are not familiar with on a set of stereotypes. Stuart Hall explains that stereotyping entails the reduction of people to a few, simple key characteristics, generalizing a social phenomenon. We need these simplifications to mentally classify people into certain categories in order to make sense of the world and people around us (Hall, 2013a, p. 247). These stereotypes can color and shape our understanding of autism, especially when people do not experience this disability themselves and have to rely on the few characteristics of autism that they have in their minds’ classificatory schemes.

Draaisma indeed explains that our general perception of autism can be “thought of as a *set* of stereotypes” (2009, p. 1476) that simplifies neurotypicals’ understanding of autism. In his study, he found that media representations of autism are often based on stereotypes. To identify an autistic movie character, this character is often portrayed as a genius with superhuman skills and special abilities. For example, the much debated movie *Rain Man* (Levinson, 1988) is the epitome of a movie that portrays stereotypes such as the savant-like abilities, as present in its main character (Bennett et al., 2019, p. 106; Lester et al., 2014, p. 142). Because of its popularity, this characterization of autistic people as having innate genius abilities continues to be perpetuated. Whereas these savant-like skills are portrayed as something positive and useful to own, this depiction diminishes the autistic person to a set of characteristics that Draaisma found does not reflect reality. Likewise, Belcher & Maich (2014, p. 109) conclude that autistic characters in movies are often portrayed as superheroes overcoming odds that do not match autistic people’s reality and everyday challenges. Portrayals of special abilities and exorbitant talent create a gap between portrayals of autism in the media and the experiences of autistic people who do not own special abilities. This can result in autistic people feeling unworthy and unvalued if they do not have these skills, and it disregards the real challenges that they may face in life (Bennett et al., 2019, p. 108). The general view of autism thus gets perpetuated through stereotypes, while the expert view of autism – of those that are autistic – gets discredited (Draaisma, 2009, p. 1477-1479).

Other stereotypes frequently employed in media representations of autism are the infantilization of autistic people, depicting autistic people as dangerous and without empathy, excessive portrayal of sensory sensitivities and stimming, and autistic characters being non-verbal (Jones et al., 2023, p. 2206, 2209, 2210; Loftis, 2021, p. 103; Treweek et al., 2019, p. 760). Stimming refers to repetitive movements to regulate oneself (American Psychiatric Association, 2022, Autism Spectrum Disorder section; Hayden, 2022, p. 47-55). A by-product of the infantilization of autistic people is that autistic adults are often erased from mainstream debates and representations surrounding autism. Autistic children are often the center of attention in the media, eliminating autistic adults' existence and struggles in political, social and work environments (Loftis, 2021, p. 95).

Attempts at incorporating more positive and nuanced media representations are ongoing, with the goal of including more diverse autistic characters that reflect the disability better than hurtful mainstream representations. Alternative, more nuanced and positive portrayals of autism would help in challenging stereotypes and change popular narratives. But difficulty lies in accurately representing a phenomenon that one may not have sufficient knowledge of. It would then make sense to take into account autistic perspectives in creating such media products. The Netflix series *Atypical* (Gordon et al., 2017-2021) depicted autistic character Sam and tried to incorporate autistic traits accurately. Whereas the portrayal of Sam employed *more* stereotypes than other mainstream portrayals, and thus in a sense granted audiences a broader understanding of autism in the form of stereotypes, this character was played by a neurotypical, white male, whose autistic traits were meticulously in line with the DSM-5 autism criteria (Kurchak, 2021, "*Atypical*'s shortcomings," para. 4, 7; Nordahl-Hansen, 2017, p. 837). Inclusion and representation of autism fell short, as no autistic voices were present in the creation and depiction of this character.

Often when media representations have been deemed successful in encompassing true and diverse autistic experience, their success depended on the collaboration with actually autistic people (Jones, 2022, p. 14). For example, the television series *Heartbreak High* has included autistic character Quinni, who is played by Chloé Hayden, an active autism acceptance advocate (Hayden, 2022, p. 208; Heaton, 2022-present). In consultation with Hayden's own experiences, Quinni's portrayal shows how autism may present itself in women, which is different from autism in men (Baroutsis et al., 2023, p. 980; Craddock, 2024, p. 1; McCrossin, 2022, section 3.3), foregrounding traits such as stimming, masking and having meltdowns (Hayden, 2022, p. 136-146, 39-60). Being especially present in women, masking refers to hiding one's autistic traits to 'pass' as neurotypical in order to be accepted in society (Hull et al., 2017, p. 2525). Stimming and having meltdowns may also be different for women, as women are inclined to diminish their stims or internalize meltdowns to reduce risks of being excluded from neurotypical society.

Likewise, books written by autistic people are well-appreciated by the autistic community, for example the books *Maar je ziet er helemaal niet autistisch uit* [But you don't look autistic at all] (Toeps, 2019), and *Can you see me?* (Scott & Westcott, 2019). These books often offer realistic autism representations, without employing harmful stereotypes or the medical model perspective of autism needing to be 'cured' (Barrio et al., 2021, p. 174; Jones, 2022, p. 14). Their representations of autism move away from what Jones et al. (2023) call “a one-dimensional view of autism” (p. 2210) that focuses on the stereotypical male autist and an overrepresentation of sensory sensitivities. The more positive portrayals of autism reflect nuance and emphasize not only the hardships but also personal strengths, such as being hyper-empathetic and a resistance to lying. This signifies autistic people’s humanity, agency, and uniqueness (Jones et al., 2023, p. 2211).

Understanding how the media portray autism is valuable for understanding how autistic people may be treated as a consequence of those portrayals. Additionally, collaborating with actually autistic people can help improve media depictions of the disability. Nevertheless, research can benefit from focusing on autistic self-representation. As mentioned, we need to listen to autistic voices to reach a complete understanding of autism. O’Neil (2008, p. 787) demonstrated surprise at the realization that there continues to be stigma surrounding autism, even though there is a relatively high number of autistic people in society. As mentioned earlier, in 2023, it was estimated that 1 in 100 people are autistic (World Health Organization, 2023, Key Facts section). Davidson (2008, p. 802) partly fulfilled the need for listening to autistic people by researching their self-advocacy practices online, concluding that autistic people create community as well as a collective voice that contests stereotypical and medicalized views of autism. Davidson’s line of research demands future research to further analyze online presence and self-representation of autistic people.

2.3. Social media

Social media are increasingly popular sites for communication and community formation, as well as identity building and self-representation. Presenting oneself on social media can have an effect on people’s understanding of their own identity and that of peers (Dumitrica, 2019, p. 308; Klier et al., 2014, p. 473; Szulc, 2019, p. 258, 260). Lee (2017) showed the value of self-representation of marginalized communities on social media by studying how Twitter (now called ‘X’) was used by Black people. Lee found that Black people used the social medium to challenge stereotypical views of Black people in mainstream media. They did so by employing resistance tactics of redefining what it actually means to be Black, providing counter-narratives and testimonies that opposed negative narratives about Black people created by mainstream media, and they built community to nurture more activist causes and organizations (Lee, 2017, p. 7-12). Social media thus proved to be an effective tool in positive narrative and identity construction. These strategies are not restricted to one social medium.

Likewise, as being autistic is an important and all-encompassing facet of one’s identity (Kenny et al., 2016, 443), autistic people may benefit from using social media and online community to make sense of their identity and understand how autism fits within it. Moreover, social media seem to remove certain communication barriers that autistic people face in real life, such as needing to make eye contact, interpreting body language, and needing to respond without a delay (Davidson, 2008, p. 796). Therefore, it is worthwhile to respond to the call for hearing autistic voices by studying their self-representation practices on social media. Egner refers to self-representation as self-narratives that help autistic people to “make sense of our experiences, identities, and how we understand the world” (Egner, 2022, p. 353). Focusing on self-representation can thus facilitate nuanced understanding of how autistic people experience autism by amplifying thoughts, ideas and feelings of autistic people, perspectives that have been ignored for too long (Egner, 2022, p. 354).

To illustrate, engaging in conversation around topics such as the challenges or joys of being autistic, and sharing personal experiences, can be ways in which people make sense of their disability and positively construct their identity and create an online community (Dyck & Russell, 2020, p. 183). This online community, for example the autistic community on Instagram, values connection, companionship and a shared purpose. For instance, O’Neil (2008, p. 792) explains how autistic people have used the internet to form community for the purpose of self-advocacy and reaching out to others to share their perspectives. Moreover, in online communities, different communicative strategies can be used to define oneself and articulate experiences, such as the use of irony and humor. For example, identity is sometimes performed through using humor and sarcasm in discourse around disability to make fun of one’s own situation, while simultaneously critiquing unjust conduct towards autistic people in society (Lewin-Jones, 2015, p. 83). Irony is also occasionally employed on social media. Irony involves an oppositional relation between that which is explicitly presented and its implicit intended meaning (Burgers et al., 2011, p. 189). This does not mean that irony is always negative, merely that what is presented can mean something different on a deeper level. Alternatively, social media posts with an educational element or tone of voice signify the need of autistic people to explain to audiences what being autistic means to them and construct their identity accordingly.

An example of how autistic people use social media for self-representation is provided in Egner’s (2022) research on how Twitter is used by autistic people to build community through the hashtag #ActuallyAutistic. This hashtag and other resistance tactics are employed by autistic people to construct personal narratives and resist stereotypical and inaccurate portrayals of autism (Egner, 2022, p. 357-365). Egner’s findings on identity construction and opposing stereotypes echo Brownlow & O’Dell (2006, p. 317-320), who examined autistic people’s use of online chatrooms. They found that autistic people interacting with each other are finding their voice online and constructing their identity through positive terminology that does justice to autistic experiences. The sharing of expert knowledge (i.e. knowledge from autistic people) of autism further helps in challenging stereotypes and negative perceptions of autism. Anderson-Chavarria (2022, p. 1326) further asserts that participating in an online community that shares the same disability aids positive identity construction, as the disability is normalized and valued by its members.

Besides using ‘correct’ and positive terminology, such as ‘autistic’ instead of ‘person with autism’, symbols are ways to claim and represent an individual or group identity and thus also a focus of contestation. Specifically, the puzzle piece is a global symbol for autism. This symbol is especially used by non-autistic people and organizations, such as the much-critiqued American organization

Autism Speaks that wishes to ‘cure’ autism (Robinson, 2020, p. 226, 228). The puzzle-piece imagery is associated by the general public with incompleteness, imperfection, and the state of being unsolved, and thus is reflective of the medical model of disability. It implies that autistic people are missing cognitive pieces and that autism itself is a puzzling condition that is hard to understand and should be eliminated from society (Gernsbacher et al., 2018, p. 118-119, 123-124; McGuire & Michalko, 2011, p. 163-164). Autistic people object to using the puzzle piece symbol because they find it an offensive, dehumanizing way of setting them apart as ‘the other’, and it insinuates that autistic people are missing crucial pieces for living a fulfilled life. It also perpetuates the myth of autistic people as being eternal children at heart, as the puzzle piece is often used in childhood settings and research on autistic children (Gernsbacher et al., 2018, p. 119; Grinker & Mandell, 2015, p. 644; Pellicano et al., 2018, p. 83). Instead, autistic people favor the use of other symbols, such as the infinity symbol, which appears as both rainbow and gold colored. The infinity symbol represents and celebrates the entirety of the autism spectrum and aims to capture the endless variations and possibilities of being autistic (Johnson, 2021, para. 16; TheLonleyRobot, 2022). This mirrors the predicament model of disability. Although using symbols is not specific to social media posts, the existence of emojis in the form of a puzzle piece and infinity symbol create specific opportunities for people to use these in their comments and posts to emphasize or challenge certain perspectives of autism.

All in all, social media can allow for the recognition of autistic people’s agency and provide them with a digital space equipped for community building, constructing their identity, and sharing knowledge that may challenge traditional conceptions of being autistic. Welch et al. (2022, p. 656) highlight that indeed, autistic people promote, and wish for, an insider-informed autism framing, meaning that autism is represented by autistic people. This would equip neurotypical people with expert information from autistic people to gain a nuanced understanding of autism. Consequently, moving away from a negative and stigmatizing view of autism, and towards a more nuanced representation, would have a positive impact of autistic individuals’ lives.

While multiple social media platforms allow neurodivergent activism of users, such as through the use of the hashtag #ActuallyAutistic and educating users about autism, Instagram has not yet been a prevalent site of academic research in studying autistic voices. By allowing users to share photos and videos with captions, comment on posts and create stories, Instagram presents itself as a social medium where strong autistic voices can thrive, critique media depictions of autism, build community, and support meaning-making processes through sharing expert knowledge of autism (Croteau & Hoynes, 2019, p. 281; Hudson et al., 2023, p. 211-214).

2.4. Interpreting representations

Analyzing the autistic Instagrammers’ posts in themselves is not enough to understand how autism is represented on Instagram and how this nurtures an autistic identity and community. Self-representation practices through Instagram posts of autistic creators, like all other representations, need to be interpreted by, in this case, Instagram users. Merely focusing on posts can only grant assumptions of how users interpret these, and it loses the context of the user/audience interactions. The conjunction between posts and comments gives a more in-depth understanding of how posts are received.

Certain content in posts and captions can prompt users to leave a comment on the post. This requires users to engage in an active reading of the post with regards to textual, visual and aural elements. Hall (2013b) proposes that a message's meaning – in this case, that which the Instagrammer posts – is decoded by the reader. One post contains multiple possible meanings, also called *polysemy*. This gives audiences the opportunity to create different interpretations (Croteau & Hoynes, 2019, p. 270). Meaning is then not fixed, and the same post may be interpreted differently by different Instagram users. For example, a user may interpret the posts according to one or more of the discussed disability models, and the comments' tone and content may be reflective of these models. This could be emphasized by the difference between neurotypical and autistic people. Neurotypical people are not autistic, and therefore might learn something from the message in autistic creators' posts, for example by forming more nuanced narratives about autism because a post discredits dominant stereotypes. Or they could disregard the message and insist on their own perspective of autism. Contrarily, autistic people may identify with the content of a post and feel seen, therefore interpreting the post in a different manner than a neurotypical person.

Exposure to positive and accurate representations of autism in fictional media may elicit a somewhat more optimistic and nuanced attitude towards autistic people by neurotypical people (Jones et al., 2023, p. 2214). This prompts the question whether non-fiction portrayals of autism shared by autistic people may also evoke a more understanding and nuanced attitude of users. For example, a post addressing autistic joy, presenting it in an encouraging tone of voice, with bright colors and an optimistic caption about being yourself, may incentivize users to comment correspondingly. In other words, the comments may reflect a positive interpretation of the post, for example through the lens of the predicament model of disability, as it focuses on being yourself and embracing your autistic traits. Users could then interpret it according to this model. Comments from autistic people may exist along the lines of encouraging to be yourself, or sharing about one's own experiences of autistic joy. Neurotypical users may learn from this post that autistic joy is natural and normal for autistic people, challenging the mainstream notion that autistic people behave in a peculiar way (Tisoncik, 2020, p. 70). The encouraging, positive tone in both the post and comments promotes certain meanings, as the interpretation of the post may have been different had the post, for instance, presented content in a negative or accusing way. Of course, posts may not always elicit a positive response, and it is possible for discrepancies to exist between the content of a post and the way in which the audience interprets it. Analyzing audiences' interpretations of autistic Instagrammers' posts is important, as they can shine a light on how the wider, dominant discourses surrounding autism may be active in our understanding of autism and treatment of autistic people.

Nevertheless, audiences do not have unconstrained agency in their interpretations. The construction and presentation of a post can guide audiences towards a certain interpretation (Croteau & Hoynes, 2019, p. 271), which Hall (1980, p. 169) refers to as the preferred or intended meaning encoded in a cultural text. Additionally, an individual's cultural and social codes, as well as being autistic or neurotypical, influence the way a post is interpreted, which elements may be highlighted for that person, and which connotation they find in the post's content. If an Instagram user has grown up in a socio-cultural environment where disability was seen as pathology and a condition to be cured, this user may for instance interpret the posts accordingly, believing that autism should be cured and thereby rejecting possible intended meanings of the posts suggesting autism is normal and a disability to be accepted. Conversely, interpretation may also happen in a negotiating manner or even by completely adopting the message of the creators.

In this theoretical framework, I have discussed the social, medical and predicament models of disability, as well as the neurodiversity movement, which serve as active discourses in forming society's definition of autism, and influence media depictions of autism. An overview of extant research on media representations has been provided, which suggests that stereotypes persist in media portrayals of autism. Research further demonstrates that there are better and worse representations of autism in the media and that improvements are ongoing. Social media are also a prominent space for self-representation. The chapter therefore further advocates for the need to seriously take into account autistic voices and self-representations on Instagram in order to better understand how autistic people experience being disabled, how they represent this online, and the way that audiences receive and engage with these depictions. I believe this framework is helpful in conducting research on Instagram posts of autistic people and the accompanying comments with the aim of answering the research questions: (1) *how do autistic people represent autism on Instagram?* and (2) *how do users engage with and interpret autistic people's portrayals of autism on Instagram?* The next chapter discusses qualitative multimodal content analysis for conducting the research, and explains, among other things, how the instrument of analysis was constructed.

3. Method

This chapter discusses qualitative multimodal content analysis and its appropriateness for studying autistic self-representation on Instagram. Previous research pertaining to the study of autistic representation is discussed for justifying the units of analysis: Instagram posts shared by autistic people and accompanying comments. Purposive sampling is discussed for the selection of Instagrammers and their posts. Finally, the operationalization and subsequent construction of the instruments of analysis for posts and comments are specified.

3.1. Methodology

This research focuses on representational practices of autistic people on Instagram and the consequent interpretation of their posts by Instagram users. Therefore, the following research questions will be answered: (1) *how do autistic people represent autism on Instagram?* and (2) *how do users engage with and interpret autistic people's portrayals of autism on Instagram?*

As the research centers on meaning-making processes, the study is qualitative in nature. A qualitative approach facilitates understanding of social phenomena by searching for meaning in the data and allowing for contextual understanding of the social world (Bryman, 2016, p. 33, 394-396). In this case, meaning is created by representing and discussing autism on Instagram. Specifically, the research focuses on how autistic individuals make sense of their disability and how their representations in turn confirm or contradict dominant views of disability or traditional discussions of autism, which are reflected in, for example, the disability models. Moreover, the research focuses on audience readings of those representations by autistic creators. A close reading of the data provides rich and complex interpretations, which are fruitful in understanding social meanings around and representations of autism, and what these meanings may imply (Braun & Clarke, 2006, p. 78). The research is rooted in a constructivist paradigm, meaning that the data were analyzed with the understanding that reality is not static and social phenomena are subject to being continuously changed through social interaction (Bryman, 2016, p. 29). Moreover, both deductive and inductive approaches were used to construct the instruments of analysis in order to analyze the data.

Previous studies on autistic experiences employed interviews with autistic people and included more diverse voices and communication methods for participants than traditional ways of interviewing, such as the inclusion of communication through communication cards and AAC devices. Communication cards are cards with standard phrases on them to help users communicate their needs and answer questions, while AAC devices are used to click on images that produce words and sentences instead of users having to speak themselves (Courchesne et al., 2022, p. 1126; Tesfaye et al., 2023, p. 1144). While this has allowed for more autistic voices, often left out of academic conversations around autism to be considered, exploring other avenues of communication that can foster a deeper understanding of lived autistic experiences remains important. Arguably, social media allow autistic people to amplify their voice. Additionally, non-verbal people may be better accommodated in their participation on social media, as these can grant them ways of communicating by typing out responses, contrary to needing to be verbal (Chapman, 2019, para. 2; Davidson, 2008, p. 798, 801). Furthermore, previous research centering on social media use by autistic people often relied on surveys or interviews on users' consumption of and production on social media (Hersinta, 2019, Method section; Suzuki & Inagaki, 2021, p. 2048-2051). Without idealizing the extent to which social media harbor the power to challenge societal structures, the literature suggests that social media allow users to present themselves online, facilitate identity construction practices, and provide community formation (Dumitrica, 2019, p. 307-309, 315; Szulc, 2019, p. 260). Hence, content analysis of autistic Instagram users' posts and accompanying comments from all users presents a new direction for research.

Qualitative multimodal content analysis was employed to answer the research questions and analyze Instagram posts and comments. Multimodality centers around the understanding that meaning is created through the combination of different elements, or modes, of the phenomenon under study. Although the written text is often the sole subject of study when studying meaning-making and representational practices, it is not the only important factor to study. Textual language is just one of many modes that contribute to meaning when it comes to Instagram posts and their representational practices (Jewitt, 2015, p. 70). Multimodality therefore considers different modes and their conjunction to understand how meaning-making happens, without separately analyzing different elements or phenomena. This research thus pays special attention to the intertextuality with regards to posts, comments and reactions to comments, in order to understand how different modes create meaning and portray messages.

A multimodal approach is necessary to properly understand the variety and richness of Instagram posts and the way they employ different modes of meaning-making, such as written text, images, audio, video and hashtags (Fisher & Aarestrup, 2021, p. 89). This approach considers distinct modes of Instagram posts, and the way these elements co-exist and work together to create meaning and representation around the topic of autism. Indeed, modes in their singularity can create meaning, but it is the combination, or ensemble, of different modes that provide us with more information about representation and contexts (Serafini & Reid, 2023, p. 627). Moreover, Jewitt (2015, p. 70) emphasizes that meaning is created by people's specific choices of which modes to use and in which order. Thus considering the modes in their conjunction rather than separating them does justice to Instagram-based communication, and tells us more about meaning-making around the topic of autism.

A multimodal content analysis offers opportunities for identifying underlying patterns across and within the data, and answers the call for moving beyond the more traditional ways of qualitatively analyzing social phenomena (Bryman, 2016, p. 563; Serafini & Reid, 2023, p. 624). Also, taking into consideration the relationships between the affordances and limitations, as well as relationships, of

Instagram modes, increases the rigor and trustworthiness of multimodal content analysis (Serafini & Reid, 2023, p. 624).

3.2. Sample and data collection

Following Serafini & Reid (2023, p. 629-644), after the research questions were established, the units of analysis were defined and the sample was constructed. The units of analysis are Instagram posts created and shared by autistic individuals, and comments under those posts. Three Instagram accounts were chosen using purposive sampling with the following sampling criteria: (1) being an autistic creator, (2) having at least 20.000 followers, and (3) having a public Instagram account.

Each of these criteria are important for different reasons. First, it was necessary to ensure that the posts under analysis were created by autistic individuals. Thus, accounts were selected on the basis of an autism disclosure in the individual's Instagram bio or highlight feature. The amount of followers was based on the concept of micro influencers, which are creators that have "follower numbers in the four- or five-digit range" (Alassani & Göretz, 2019, p. 252-253), ensuring credibility and engagement from followers (Tafesse & Wood, 2021, p. 4). Finally, having a public Instagram account was a necessary criterion to ensure the data were publicly available.

After purposive sampling with these criteria, the following Instagram accounts were chosen for analysis: @allforthedopamine, @neurodivergent_lou, and @autistic_callum_. As autism encompasses, and is present in, a variety of experiences and people, the three accounts are reflective of this diversity in terms of their content, gender and nationality.

@allforthedopamine is the account of Adrienne Marcellus (they/them), living in the US. Adrienne is an autism, ADHD and OCD specialist therapist who shares about their own experiences with these and provides advice to their followers. At the time of writing, their account has 35.8K followers and 470 posts. No age was disclosed online but is believed to be below 35. Adrienne posts both videos and images on their account.

@neurodivergent_lou is Louise Chandler (she/her), 22 years old and living in the UK. She has 317K followers, 1006 posts, and she presents herself as an autistic advocate. Louise mostly shares carousel posts, meaning that one post includes several (usually between one and 8) images.

@autistic_callum_ is Callum Stephen's (he/him) account. He is 28 years old, queer, and also lives in the UK. His account has 167K followers and 539 posts. Callum both shares videos and images. Some of his images are screenshots of his Tweets (posts shared on Twitter).

Purposive sampling was similarly used for the selection of posts. Per account, the first ten most recent posts dealing explicitly with autism were selected. In total, 30 posts were collected. Appendix B provides an overview of the posts. Data collection happened in March and April 2024, which, incidentally, included Autism Acceptance Month in April (ASAN, 2021). Therefore, priority was given to the most recent posts in contrast to, for example, most popular posts per Instagrammer, as the posts about Autism Acceptance Month were fruitful to incorporate in the analysis. Consequently, finding posts that dealt with representations of autism was not too difficult during this month. All posts stem from March 21 to April 29, stopping the data collection process for each account whenever the ten posts criterion was reached.

Besides the posts, comments were analyzed. As comments differ in length and depth, the first 30 comments per post were analyzed (Janssen & Verboord, 2024, p. 7). In total, 900 comments were selected, posted by 664 different Instagram users. This selection includes users' comments as well as reactions to comments, to take into account intertextuality in relation to the different modes of the posts and the relation to conversations occurring in the comments. The comments could be posted both by autistic and neurotypical people, as there are not always clear identity markers providing this information about an individual. This fits the research, as the aim is to understand how autistic people represent autism on Instagram, *and* how these representations are being read, as visible in comments.

Data collection was done by myself. After the three accounts were selected, ten posts per account were chosen. If posts consisted of images, they were screenshot and entered in a Word document. When it concerned a video, this post was screen recorded and saved on my laptop. A still image of the video was consequently included in the Word document. In both cases, the posts were transcribed in the Word document as well, to prevent losing context with regards to what is being said in a video instead of only focusing on the visual aspects. All selected comments were also screenshot and transcribed, after which they were added to the Word document. Of each post, metrics were included, such as the total amount of likes and comments and when the post was uploaded.

3.3. Operationalization

The models of disability still often lead our opinions on and discourses surrounding autism. Based on previous research (Constantino, 2018, p. 386; Jaarsma & Welin, 2012, p. 24), the medical model is understood as considering autism as a medical deficit or disorder. Thus, I expected the medical model of autism to become visible in posts through the use of deficit-based language, including medicalizing autism, talk about hardships and not being able to overcome them, 'othering' and/or patronizing autistic people's experiences and hurtful names or comments towards autistic people in the comments, such as the words 'retarded,' 'stupid,' 'idiot,' 'spaz,' and 'moron'(Arciuli & Shakespeare, 2023, p. 18; Dyck & Russell, 2020, p. 178; Ejaz, 2020, p. 799; Hayden, 2022, p. 180; Tisoncik, 2020, p. 69). Negative comments could be made on how an individual behaves, for example by criticizing the behavior belonging to autistic traits, such as stimming. In contrast, one may expect autistic Instagrammers to mention elements of the medical model of disability even if critically, for example, to criticize and disprove the medicalization of, and misconceptions about, autism (Egner, 2022, p. 358). Denotations and connotations of both the posts and comments were analyzed to see whether they reflected different models of disability, and to uncover the deeper cultural meanings they held. Analyzing connotations is useful in uncovering implicit meanings that may reside in posts and comments. These connotative elements of posts and comments are context-dependent, relying also on the different Instagram modes, and reflect a larger context than the explicit, or denotative, meaning (Schreier, 2013, p. 173).

The social model of disability considers society to be disabling autistic people due to inaccessible structures and social barriers in society, not merely due to autism itself (Constantino, 2018, p. 386; Dunn & Andrews, 2015 p. 258; Seers & Hogg, 2021, p. 1562). Instagram posts and comments were then analyzed by seeing whether the discourse in and surrounding a post reflected the social model, for example through expressing the autistic experience as a product of society and not of autistic traits.

The predicament model considers the lived experiences of autistic people and the way that autistic traits themselves can be disabling, instead of only blaming society's unaccommodating structures. It aims to help autistic people reclaim their identity by giving a nuanced perspective of all the challenges and gifts that being autistic encompasses (Anderson-Chavarria, 2022, p. 1335). The presence of the predicament model was analyzed by considering which hashtags were used to reflect the autistic experience, for example #ActuallyAutistic (Egner, 2022, 357), the phrasing claiming true representation in itself. The wording of different autism traits was also considered. For example, 'stimming' is a word often used by autistic people to mean behaviors used to regulate one's emotions and sensory needs (Hayden, 2022, p. 47-55). Stimming is medically explained in the DSM-5 as repetitive behavior (American Psychiatric Association, 2022, Autism Spectrum Disorder section). Both wordings imply the same aspect but signal a difference in attitude towards the behavior. Whereas repetitive behavior implies the feeling of rigidness and strangeness (medical model), stimming merely connotes a way of acting for an autistic person (predicament model). Additionally, autism traits and experiences shared by the Instagrammers were considered on whether they elaborated on the lesser-known instead of common traits of autism, such as autistic joy and masking (Hayden, 2022, p. 141-146). This adds to the notion that every autistic individual is unique and no experience can be generalized (Healis Autism Centre, 2020, para 1.; Nordahl-Hansen et al., 2018b, p. 636), giving voice to the subjective variability in every individual autistic experience (Anderson-Chavarria, 2022, p. 1335).

Instagram provides users the possibility to include captions with every post. These captions can contain any piece of information, and Marwick (2015, p. 143) explains that they can be seen as identity cues. The information shared by autistic Instagrammers in their captions can signify many facets of being autistic. The text can be activist in nature, with the desire to refute stereotypes and myths about autism (Davidson, 2008, p. 797; Egner, 2022, p. 358). Or it can represent the lived autistic experience more generally, through providing other users with information about the disability. Humor can be used to create a lighthearted atmosphere around sensitive discourse on autism, for example to portray the disability in a more accessible way (Lewin-Jones, 2015, p. 83; O'Neil, 2008, p. 792). This alters the connotation of a caption or comment about autism and requires a close reading of the text to understand what is meant with those particular representations of autism. Captions' denotations and connotations thus were important elements to analyze, as they signify characteristics of the creator that posted them and autism more generally.

Captions may be paired with hashtags, which can be descriptive of the content of the image or video, or insinuate something else (Giannoulakis and Tsapatsoulis, 2016, p. 127). Hashtags used in the captions and comments in this research were analyzed to see which aspects of the post they reflected. Additionally, they were analyzed to see whether they represented the autistic experience in general, or had the desire to discredit stereotypes or criticize certain views of autism, and whether they created a sense of community around the disability (Egner, 2022, p. 352, 358, 361). #ActuallyAutistic, for example, signifies an autistic experience, whereas #ASD may imply the presence of the medical model of disability in a post or comment, as ASD is the term used for autism in the DSM-5. Therefore, terminology is an important element to consider in the self-representation of autism. Terminology and use of symbols can be reflective of the models of disability. In a similar fashion as the hashtags, use of 'autistic person' reflects the predicament model of disability, whereas 'person with autism' reflects the medical model (Constantino, 2018, p. 385). Likewise, the use of the infinity symbol reflects the predicament model, whereas the puzzle piece echoes the medical model (Gernsbacher et al., 2018, p. 118-119, 123-124; Johnson, 2021, para. 16; McGuire & Michalko, 2011, p. 163-164). Both terminology and symbols were considered in the analysis of posts and comments to uncover their significance and understand their wider meanings and reflections of discourses surrounding autism.

Comments under posts, and comments under comments, were analyzed as well to understand how the portrayed autistic experiences and information were interpreted by other Instagram users, and how these users may commence conversations with each other around the topic of autism and disability in general. This highlights the importance of intertextuality, as comments referring to an element portrayed in the image or video posted, may be in response to another comment, or may refer to one's own experiences with autism.

3.4. Instruments of analysis

In order to secure the validity and reliability of the research, it is necessary to make transparent the steps taken in the development of the analytical framework for data analysis. Part of the analysis was deductive, meaning that existing theories about Instagram use and representations of autism were used to create initial theory-driven categories (Hsieh & Shannon, 2005, p. 1281). The deductively developed categories were the medical, social and predicament models of disability. Alongside this, an inductive approach was used to create categories that were not present in previous theories, based on underlying elements in the posts with regard to text, visual aspects of images, animations, aural aspects, and short videos (Molder et al, 2022, p. 679). Both approaches are drawn upon to increase the rigor and trustworthiness of the data analysis and interpretation (Serafini & Reid, 2023, p. 629). Based on previous research and the concepts in the operationalization, instruments of analysis were developed for this study.

A pilot analysis was conducted to test the instrument of analysis for the posts on its usefulness and feasibility. As the creators central to this research employed different modes to represent autism (video, image, text), a post of each account was incorporated in the pilot analysis to account for all types of data in the material (Schreier, 2013, p. 178-180). The instrument of analysis was deemed useful and feasible with respect to the categories devised from previous research mentioned in the operationalization. For each post, the instrument was used to explore the extent to which the disability models were present. Then, I looked at which strategies were observable in each post to communicate about the models, for example through challenging and/or promoting the discourses related to the models. I paid attention to the different Instagram modes, terminology, symbols, and the use of irony and humor to understand the ways that the creators challenged and/or underscored the models.

Nevertheless, the initial instrument did not do justice to the depth of the comments, conversations in comments, and the meaning of these interpretations. Therefore, a separate instrument of analysis was devised for the comments. This instrument builds upon the existing categories of the disability models. The purpose for commenting, users' opinion of the posts, and terminology used to refer to autism or personal experiences were included as categories, as well as any possible references made to the elements of the posts, to account for intertextuality and multimodality of the posts. To ensure that the analysis of comments still fit the multimodal content analysis, the comments were analyzed in accordance with the posts they belonged to. The comments were analyzed simultaneously with the posts, ensuring no loss of context and taking into account the different modes that the comments could be referring to, such as images, captions, sounds, and hashtags. Appendices A1 and A2 provide the definitive instruments of analysis, which were then used to analyze all collected data. The instruments take into account the intertextuality present within a post and comments, as well as the relations and contradictions between visual and textual elements. I believe these instruments accurately reflect and help analyze the phenomenon under study, and are appropriate for answering the research questions.

After all the data were analyzed using the instruments, analysis happened at the meta level in developing recurring patterns across and in the data. During data analysis, memos were created to process thoughts, organize categories, and construct patterns (Serafini & Reid, 2023, p. 638). Memos increased the rigor of understanding and finding patterns. Moreover, *autonomous counting* (Silverman, 2011, p. 379-382), the counting of certain elements in the sample, was included to give a prevalence of patterns in the data and to increase the validity of the research.

3.5. Ethical considerations

All collected Instagram handles and profile pictures of commenters were anonymized in the dataset, and pseudonyms were used when referring to comments to ensure users' anonymity. The data were safely stored on my laptop's hard drive. In this way, possible harm to Instagram users was minimized, and invasion of privacy avoided (Bryman, 2016, p. 131).

After careful consideration of the nature of the data and contemplation with my supervisor, I decided not to anonymize the autistic creators' Instagram names. Following Egner (2022, p. 355), I also find it important to recognize and give credit to autistic people's views and their efforts of communicating their experiences and being advocates for the wider autistic community. All three accounts, including their posts and comments, were open access at the time of writing. Additionally, the creators are autistic advocates using social media to reach thousands of people and represent true autistic experience. Considering that this research endorses the possibilities for autism self-representation, I believe that no risk of harm is involved in explicitly identifying the creators and doing justice to their hard work in representing autism.

Next to deductively devising categories for the instruments of analysis, a partially inductive analysis of the data allowed for identifying and interpreting patterns independent of connecting the raw data to existing concepts, and therefore fostered an in-depth understanding of the data itself. Additionally, this meant documenting and presenting observations as concretely as possible to nurture *low-inference descriptors*, which help the researcher interpret the data without being influenced by personal perspectives (Seale, 1999, as cited in Silverman, 2011, p. 361). Nonetheless, my positionality as an autistic researcher needs to be mentioned (Tracy, 2010, p. 842). Prior to this research, I was already familiar with autism representations on Instagram, as I follow similar Instagrammers in their journeys of breaking stigma around being disabled and I have connected with fellow autistic people online. It was precisely these connections and stories about lived experiences that inspired me to conduct research on self-representation of autistic people online. My own experiences and immersion in the online autistic community have helped me better understand my own disability and have given me knowledge useful for researching autism. Nevertheless, while my experiences and personal expertise have informed the study, I do not feel that they have introduced undesirable biases in the research. All the data were analyzed using the presented instruments of analysis, ensuring that my own perspectives did not interfere in the analysis and this was done transparently.

This chapter has argued that qualitative multimodal content analysis as the method for analyzing autistic creators' Instagram posts and subsequent comments is fitting in order to answer the research questions. The operationalization and resulting instruments of analysis have been discussed and justified, as well as the sampling method and its outcome. In the next chapter, the results of the data analysis are discussed and the research questions answered.

4. Results

This chapter discusses the results and interpretation of the analysis of Instagram posts by autistic people and the accompanying comments. The first part of the chapter focuses on the posts. For this part, three categories were deductively developed, based on the theoretical framework: the medical, social, and predicament models of disability. After analyzing the creators' use of different Instagram modes and considering the modes in their conjunction, patterns were inductively developed within the categories to understand the way the creators reproduced or criticized the existing disability models in their autism representations. The second part of the chapter discusses the comments on the posts. After analyzing the purpose of comments, opinions on the posts, and the presence of the disability models within the comments, I found that users generally adopt the intended meaning of the posts.

Throughout the chapter, posts will be referred to according to the following abbreviations: LOU# (Louise), CAL# (Callum), and AD# (Adrienne), where the hashtag is replaced with the number of the respective post. Appendix B gives an overview of posts.

4.1. Medical model

From the medical model perspective, autism is regarded as an undesirable condition, with traits and behaviors seen as deficits. The model is focused on what autistic individuals cannot do, consequently presenting the disability as a tragedy that impacts life only negatively (Constantino, 2018, p. 385; Jaarsma & Welin, p. 24, 25). From the data, it became clear that autistic creators Callum Stephen, Louise Chandler and Adrienne Marcellus do not regard autism as a tragedy or deficiency. In fact, they dislike the medicalized conceptions of autism. Across the three accounts, the medical model was only visible in specific occasions where deficiency was opposed by the creators' use of irony and humor.

Whereas challenging aspects or traits may be mentioned, these were never seen or treated as deficits in the selected posts. Instead, the three creators employed irony and humor in their representations of autistic traits and behaviors to convey that most autistic people do not experience their autism as a tragedy. For instance, Adrienne's post about consuming the same drink every morning (AD6) illustrated with an ironic tone how autistic people often rely on sameness and routine. In the video, Adrienne is dancing in their kitchen while enjoying the drink they consume every morning. The text in the video reads: “Autistic me vibing with my morning “same” drink that if I don’t have then my day won’t be ✨okay✨” (see figure 1).

Autistic me vibing with my morning “same” drink that if I don’t have then my day won’t be ✨ok✨

what is your current "same" food and/or drink? ...

Figure 1. "Same drink". Screenshot of video (AD6).

The sparkle emoji, often used on the internet in sarcastic or ironic situations (Broni, 2021), in combination with the sound of the happy music playing in the background, present an oppositional relation between the explicit text and the implicit connotation of the video (Burgers et al., 2011, p. 189). The denotation of the video is that Adrienne is happy with their routine, as they can be seen dancing and enjoying the drink. In contrast, the connotation of the video presents the phantom choice of deciding whether or not to have the same drink every morning, when in reality Adrienne relies on sameness to such an extent that they *need* to have this drink every morning to function. Whilst utilizing irony, the autistic characteristic of relying on sameness is presented, with an underlying informative element indicating that relying on routines can present itself in even the ‘smallest’ things, such as consuming the same drink every day. To neurotypical people, this may seem like a deficit, a trait that makes life for autistic people unnecessarily difficult as relying on the exact same routines is not always possible. However, Adrienne represented this trait not as a deficit or something to combat. Their irony conveys the opposite: autistic people recognize that this may be a challenge, but – at least for Adrienne – this does not necessarily feel as an undesired trait.

Similarly, Callum employed humor in a video about receiving spoken instructions (CAL6). In the skit, an imaginative person gives Callum instructions, which he is quickly writing down verbatim, taking a great deal of energy and many pages in his notebook. Although no autistic trait is explicitly mentioned, the post refers to delayed processing that is often present in autistic people, resulting in being unable to remember everything when spoken to. This can be an unpleasant trait for an autistic person to deal with, as retaining and processing information is difficult and can result in stressful social interactions. However, Callum conveyed that this is not a deficiency in autistic people, as the post does not insinuate that such a challenge cannot be overcome, and he created a funny skit to give an example of dealing with the situation as an autistic person.

Humor and irony are then used to frame autism as a non-tragic existence. While characteristics and behaviors associated with autism were displayed or implied, humor was used to construct an autistic identity in a non-tragic, funny way, simultaneously creating a lighthearted atmosphere that creates a more accessible way of learning about autism (Lewin-Jones, 2015, p. 83; O'Neil, 2008, p. 792). This positive identity performance opposes the medical model that frames these behaviors as undesirable or even dangerous.

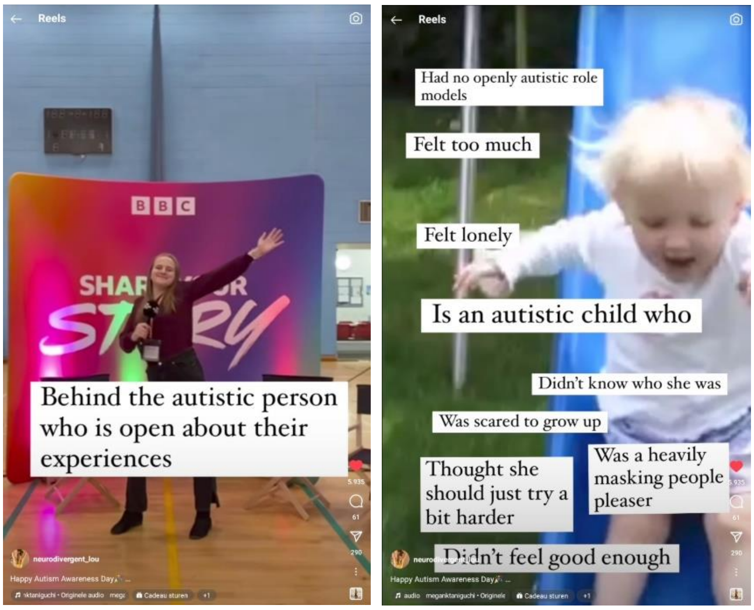
4.2. Social model

The social model believes that autism is a disability due to imposed social structures that inhibit autistic people from participating in society and that do not accommodate them in their daily lives (Constantino, 2018, p. 386; Dunn & Andrews, 2015, p. 258; Ejaz, 2020, p. 784). This deductive category consists of two inductively identified patterns: (1) struggles of living in a neurotypical world, and (2) society continues to mistreat autistic people.

4.2.1. Struggles of living in a neurotypical world

Across the three Instagrammers, the social model of disability was at times partially reproduced. This was visible in descriptions of occasions where the creators felt that living in a world catered to neurotypical people, as an autistic person, was tiring and discouraging. For instance, in a post on delayed processing, Callum mentioned that delayed processing is hard to grapple with when "combined with pressure to give people instant responses" (CAL9). He signified here that delayed processing in itself is not the issue, it is the pressure of society towards autistic people to respond right away that makes experiencing this trait a struggle. Louise reproduced this sentiment when she declared: "To just exist as an autistic person in a rigidly neurotypical world, takes great courage and strength" (LOU8). She applied the notion of being rigid, used often to describe autistic people, to society, indicating that society is making life difficult for autistic people.

A somewhat more explicit way of indicating the social model was seen in Louise's post for World Autism Day (LOU6), which takes place annually on April 2nd. The emotional video depicts Louise as both an inspiring advocate for autism acceptance, and a vulnerable, undiagnosed autistic child who was riddled with insecurities, anxiety and social isolation (see figure 2). A melancholic rendition of The Scientist, a song by the band Coldplay, accompanies the video, with the lyrics "you don't know how lovely you are" (Coldplay, 2002). These lyrics pertain to the core message that Louise advocates: autistic people are worthy exactly the way they are. However, the melancholic sound of the song and nostalgic video build upon the implication that growing up autistic can be isolating, confusing and all-round painful, partly as a consequence of a society not catered to autistic children (Dunn & Andrews, 2015, p. 258). The consequence is often that autistic adults have low self-esteem and do not believe or know that they are valued members of society.



Behind the autistic person who is open about their experiences

Had no openly autistic role models

Felt too much

Felt lonely

Is an autistic child who

Didn't know who she was

Was scared to grow up

Thought she should just try a bit harder

Was a heavily masking people pleaser

Didn't feel good enough

Figure 2. World Autism Day. Screenshots of video (LOU6). Left: Louise at a BBC event to share her story about growing up autistic. Right: Louise as a child on a slide.

Nevertheless, although inaccessible structures are mentioned, nowhere do the creators define themselves to be victims of structures in society. These structures definitely seem to pose challenges to autistic individuals, but the disability is not presented as *only* the product of society's unaccommodating environments, as is proposed by the social model (Dunn & Andrews, 2015, p. 258). The social model is thus present in the representations of the creators because they believe that at least part of their challenges are the results of an unaccommodating society. However, there is more to their story, and to autistic experiences in general, such as inherent autistic traits that influence autistic people's lives. These will be further discussed and presented in the predicament model category later in this chapter.

4.2.2. Society continues to mistreat autistic people

According to the messages implied within the posts, autistic people will undoubtedly benefit from a shift in society's discourse from deficit-based narratives towards autism affirmations and acceptance, allowing for a better accommodating society to be developed in which they are not seen as the undesired 'other', but as valid and valuable members of society. As Bertilsdotter Rosqvist et al. (2023, p. 17) infer about necessary shifting narratives surrounding ADHD, autistic people should also be regarded as a minority group of people with agency, even if living with their sometimes challenging disability in a society that values neurotypical brains, with subsequent barriers to rightful participation.

From the data, this pattern was observed in posts about society remaining exclusionary and discriminating towards autistic people, summarized by Louise as a “rigidly neurotic world” (LOU6). Whereas autistic people are often seen as rigid, for example in their adherence to routines or plans, here Louise again applied the notion of being rigid to society. She insinuated that society also adheres to, and only accepts, certain behaviors and ways of existing. Autistic people are often made to change in order to fit in society, but in turn, society is not changing in favor of autistic people.

The creators were critical of having to adapt their behaviors in order to fit in and not be seen as the inferior ‘other.’ Accepting autism is widely preached in April during Autism Acceptance Month, but when autistic people actually exhibit traits and behaviors associated with autism, they are often not accepted, seen as inferior, or dehumanized, argue Robinson & Highcock (2024, p. 172-173). This was illustrated in Callum’s video showing him smiling excessively in an imaginative social situation (CAL5). He explained that smiling excessively hurts his face and jaw, but he continues to smile because otherwise people will assume he is “miserable” when he uses his regular facial expression. He smiles for the other person, thus masking his true facial expression, in order to be accepted and to avoid wrong insinuations. This echoes Hull et al. (2017, p. 2525) in their explanation of autistic people feeling the need to mask their traits or challenges in order to be accepted in society or ‘pass’ as non-autistic.

In a somewhat different way, Adrienne criticized society’s unwillingness to accommodate autistic people in a post on work accommodations (AD7). This post requested autistic and ADHD people to engage in conversations about accommodations that would help them at work. However, the caption suggested that society will not create appropriate accommodations anyway, when Adrienne said: “Comment below what work accommodations have and/or would help you the most? ….. (if we lived in a perfect world of allowing for accommodations).” The underlying thought implies that autistic people are not truly listened to by the people who can make a difference for them in everyday life, such as employers or policy makers. It seems to be the autistic people’s self-representations and activism that can truly make a difference for autistic individuals. However, these efforts may be especially important within online communities such as Instagram, without necessarily being adopted by the wider society.

4.3. Predicament model

The predicament model of disability understands autism as an individualized experience that is caused both by biological and social factors. By considering and valuing every autistic experience, this model emphasizes the variability of being autistic, and denotes that while some people experience traits as disabling, others may not. The essence of this model is captured within its normalization of autism and subsequent encouragement of positive identity building (Anderson-Chavarria, 2022, p.

1325, 1332-1335). The data demonstrated that the predicament model reflects best the perspectives and representational endeavors of all three creators in their attempts to normalize autism.

The Instagrammers employed the following strategies to normalize autism: (1) sharing the reality of being autistic, (2) denouncing and challenging stereotypes, and (3) stressing the importance of using appropriate terminology.

4.3.1. Sharing the reality of being autistic

This deductively developed strategy, based on the predicament model's idea of focusing on lived experience (Anderson-Chavarria, 2022, p. 1335), was present across all three accounts. It entails sharing the reality of what it means to be autistic by providing everyday typical experiences. These can be, for example, dealing with poor hygiene, feeling misunderstood, and experiencing sensory sensitivities. The creators shared these realities according to their own, distinctive posting style. This strategy is connected to defining autism and autistic people as normal, as different ways that autism can be present in individuals was presented, thereby indicating that this variability is normal and valid. Reality was depicted through posting about different traits and behaviors belonging to autism. Some traits were well-known, whereas others were less well-known or not known to be connected to autism by the wider public because of a rigid understanding of autism. The creators then made sense of those aspects of their autism that are not commonly presented in the media (Egner, 2022, p. 356).

For instance, in her post about autistic burnout (LOU1), Louise educated users on the topic of autistic burnout, what this may entail, and how burnout developed in her own life. The post includes a guide to navigate autistic burnout and an early warning signs list, useful for autistic people to consult when they suspect they may be experiencing this. Moreover, difficulties Louise endured before she realized she was autistic were discussed, when she mentioned: "before I realized I was autistic, I would often pass of [*sic*] my autistic burnout as something else. I had only experienced life as myself, so I didn't realize that everyone else wasn't having the same struggles that I was." Louise implied that there are still many autism associated traits and behaviors that are less known, especially in women, which in turn are not normalized, resulting in stigmatization of autistic behavior or the possibility of delayed diagnosis (McCrossin, 2022, section 3.3; Treweek et al., 2019, p. 760).

Likewise, Callum shared a post about a particular way of stimming (CAL4), which may be less well-known than common ways of stimming often portrayed in the media, such as hand flapping. The post, a screenshot of one of Callum's Tweets, demonstrates the attraction that autistic people may feel towards a particular line in a song. This is then linked to behaviors of stimming and echolalia, the latter meaning the constant repetition of words, phrases or sounds (American Psychiatric Association, 2022, Autism Spectrum Disorder section). The caption builds upon the image by explaining Callum's own experience with this phenomenon, when he stated:

> My autistic brain is always attracted to one particular line in a song and will sometimes sing it on repeat for days, weeks or even months. Often this line is the “hook”, but it isn’t always! Do you ever sing one line of a song on repeat? 😁 ⬇️ (CAL4)

Stimming and echolalia were presented as normal autistic behaviors, detached from the stereotypical representations of excessive stimming in children that reside in mainstream media (Jones et al., 2023, p. 2209-2210). Callum’s example therefore also shows that there are various ways of stimming. Louise built upon the notion of embracing stimming as a normal activity by openly stimming in one of her posts (LOU4), using a tangle (a fidget toy). Her depiction confirms that autistic children grow up to be autistic adults, and therefore adults will continue to exhibit their traits. This in turn challenges the inaccurate belief that autism is childhood disability (Loftis, 2021, p. 95-96). The educational nature of these posts echoes autistic people’s use of Twitter in their quest for making sense of their own behaviors that are not represented in mainstream media and thus not known to the wider society (Egner, 2022, p. 356).

By sharing how traits may be expressed, apart from the conventional DSM-5 categories of how autism is believed to be present in individuals (American Psychiatric Association, 2022, Autism Spectrum Disorder section), the creators provided a complex and nuanced understanding of autism. Using the resistance tactic of redefining what it means to be disabled (Lee, 2017, p. 9-10), they construct an autistic identity from a credible, autistic perspective, outside of the medical model of disability (Egner, 2022, p. 358).

4.3.2. Denouncing and challenging stereotypes

The second strategy visible across the accounts was the attempt at breaking stereotypes. Stereotyped depictions of autism reduce autistic people to a simplified version of the disability (Hall, 2013a, p. 274), focusing often on a few characteristics instead of the disability in its entirety. Frequently, an overrepresentation of lacking empathy, having sensory sensitivities and engaging in stimming is present, impacting neurotypicals’ ideas about autism accordingly (Jones et al., 2023, p. 2206-2210; Treweek et al., 2019, p. 760).

Stereotypes were implicitly challenged and explicitly denounced. An example can be seen in Callum’s video about autistic demeanor (CAL3, see figure 3). The denotation of the video is the discrepancy between outward, often emotionless demeanor and inward, expressive emotions from an autistic perspective. Callum demonstrates that he is aware of this discrepancy. The connotation of the video then signifies that Callum *does* experience emotions of happiness even if it does not show, and this juxtaposition is simply something that more autistic people experience. The sound selected for the video underscores that this type of demeanor is normal, everyday occurrence for Callum, through the lyrics “But I been like this, I been like this” (Trainor & T-Pain, 2024). The stereotype that autistic people are emotionless or lack empathy was therefore discredited through the video (Treweek et al., 2019, p. 760).

This one is for all the autistic people who often think they look really happy and enthusiastic, but ...

Figure 3. Autistic demeanor.
Screenshot of video (CAL3).

In another post, Callum more explicitly denounced the stereotype of autistic people supposedly being disinterested in other people (CAL1). He refuted this stereotype by explaining that, instead of not interacting with other people because of being disinterested in others, many autistic people have a small social battery, experience social anxiety, or fear being rejected. He explained: “None of these are signs of disinterest. Instead they are signs of different social needs, trauma, challenges understanding others intuitively, and fearing upsetting others.”

One post (AD8**)** presented seemingly contradicting autism traits that can be present in the same autistic individual (see figure 4). Adrienne expressed that this is a common occurrence, but not often recognized or taken seriously because it seems to contradict the one-dimensional view of autism

Have endless easy conversations with some & feel painful to socialize with most others

Be very expressive around special Interests but struggle to be expressive otherwise

Have high pain

Enjoy novelty but need certain parts

Figure 4. 'Contradicting' traits that can be present in one individual. (AD8).

that proposes that autism has one look. With this post, then, the stereotype that autistic people look a certain way, or all behave the same, was challenged. The caption further elaborated that for an autism diagnosis, an individual needs to match all the diagnostic criteria, not just those traits represented in the image. This alluded to the harmful phrase that 'everyone is a little autistic', by explaining that you are not a little autistic if you experience one of the traits expressed in the post. Louise further elaborated on this phrase in her post titled "They say everyone's a 'little autistic' but not everyone…" (LOU10). She gave examples of how changes in plans, being fixated on a task, and an overload of sensory input can be experienced by neurotypical people as well, but are experienced differently and more intense by autistic people, due to their disability. Adrienne and Louise both criticized and refuted the harmful phrase that 'everyone is a little autistic'.

Redefining autistic behaviors and refuting established, harmful stereotypical exhibitions of traits relate to Egner's findings on Twitter use by autistic people. Her findings indicate that autistic individuals reframed negative narratives of autistic behaviors into "positive stories and advantageous skills" (Egner, 2022, p. 362). However, none of the creators engaged in redefining autistic traits and behaviors into more *positive* matters than they truly are. Autism was not glorified, nor presented as a tragedy. This differs from the way that autistic people in Egner's research have utilized Twitter.

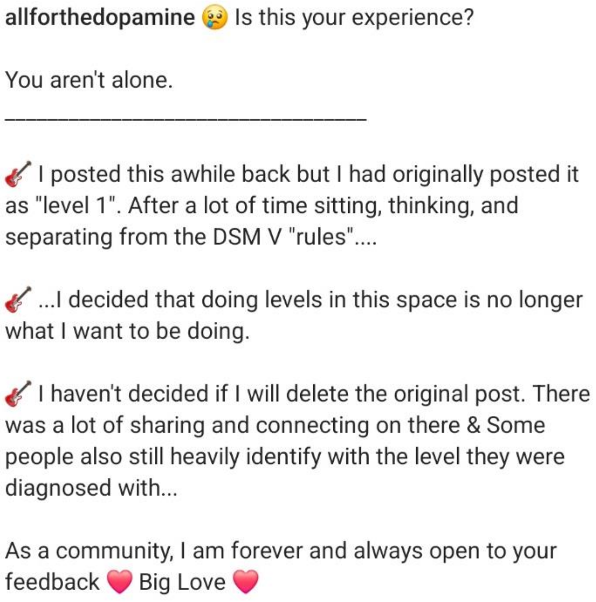
To normalize autism, Callum did engage in the resistance strategy of reframing autism as a positive experience in his post for World Autism Day (CAL7). Not through glorification but by vouching for self-acceptance did Callum imply that being autistic is okay and this should be normalized. His post focused on self-acceptance, which was seen when he mentioned: "I hope that today (and every other day) you can accept your entire self and see that you matter and that you're important, valid as you are, and equal to everyone else." He further encouraged his viewers to consider being autistic as positive by inspiring them to engage in autistic behaviors, by stating: "I hope that you can acknowledge today by doing something that honours your autism! For example, maybe you could schedule some time for engaging with your special interests?"

4.3.3. Importance of using appropriate terminology

Representing autism from an autistic perspective, vowing for acceptance and embracing both negative and positive elements, includes the need for using terminology appropriate to this message. As Kenny et al. (2016, p. 443) explained, since ideological beliefs surrounding autism are in the process of shifting from a medical perspective towards a more social one, terminology is changing with these shifts. Indeed, throughout the posts, the creators (re)produced the predicament model by utilizing identity-first language. For example, the term 'autistic' person instead of 'person with autism' was commonly used. Additionally, disclosing their own autism in their Instagram bio or highlight feature, all creators positioned themselves as autistic, indicating the fundamental role autism plays in their lives. 'AuDHD', a term popular in online disability communities that signifies the co-occurrence of ADHD and autism, was also employed by the creators to position themselves. AuDHD is common in neurodivergent people, and the term is praised in online communities (Craddock, 2024, p. 1-2) and further examined in recent academic research (Bertilsdotter Rosqvist et al., 2023, p. 3-4).

Hashtags were not used as regularly as I expected. While Adrienne consistently employed hashtags for every post, Louise only used them twice and Callum never used hashtags. Whenever hashtags were used, they generally did reflect the creators' use of terminology connected to the predicament model. For instance, the hashtag #ActuallyAutistic, which Egner (2022, p. 357-358) found was used to portray true autistic experience and identity, was used by Louise and Adrienne. Additionally, hashtags such as #Disability (LOU3; LOU4), #autisticandproud (AD4; AD6), #audhd (AD5; AD6; AD7; AD9; AD10), and #autismreality (AD9) were used to portray autistic realities, identities and experiences.

Interestingly, Adrienne mentioned their former use of the term 'level 1 autism' (AD3), which creates a harmful and inaccurate hierarchy of the autism spectrum by introducing functioning labels. Functioning labels suggest that some autistic people's struggles are "minimal and do not matter" (Hayden, 2022, p. 159) because they have low support needs or can mask their traits better, whereas individuals that require more support are seen as less valuable or even incapable (Lester et al., 2014, p. 146). This narrative was contradicted by Adrienne when they explained how engaging in conversation with the online autistic community has changed their perspective on functioning labels and terminology. Although some users may still identify with the functioning level they were previously diagnosed with, Adrienne decided not to use this term anymore (see figure 5). This reflects the value of using appropriate terminology in establishing a positive and valuable autistic identity that the broader community can relate to.



allforthedopamine 😢 Is this your experience?

You aren't alone.
____

🎸 I posted this awhile back but I had originally posted it as "level 1". After a lot of time sitting, thinking, and separating from the DSM V "rules"....

🎸 ...I decided that doing levels in this space is no longer what I want to be doing.

🎸 I haven't decided if I will delete the original post. There was a lot of sharing and connecting on there & Some people also still heavily identify with the level they were diagnosed with...

As a community, I am forever and always open to your feedback 💗 Big Love 💗

Figure 5. Caption explaining the use of 'level 1' autism (AD3).

By reproducing phrases that affirm autistic identities, autism was further normalized. For instance, in Louise's post for Autism Acceptance Month (LOU3), she mentioned: "Just like neurotypical people are all different so are autistic people. If you have met one autistic person then you have met one autistic person! All autistic people have different strengths, struggles, traits and needs." Louise reproduced the popular statement that if you have met one autistic person, you have indeed just met one autistic person (Healis Autism Centre, 2020, para. 1). Similarly, Adrienne mentioned in one of their captions: "I do not speak for every autistic person, nor is this diagnostic. I'm speaking to those autistic folks who have this experience 🥰" (AD2). The caption contains the hashtags #autisticadults, #actuallyautistic, and #autisticcommunity, further reinforcing actual autistic experience. Both Louise's post and Adrienne's caption mirror the aim of the predicament model in understanding better how one autistic person can experience particular traits as disabling, while another autistic person may not (Anderson-Chavarria, 2022, p. 1332).

The use of symbols further emphasized the message of self-acceptance and autism as a valid way of existing, for instance by posting the infinity symbol. Employing this symbol, as opposed to the puzzle piece that is often used in medicalized autism narratives, suggests resistance of cultural narratives regarding autism as a deficit and a puzzling disability that should be cured (Gernsbacher et al., 2018, p. 123-124; Grinker & Mandell, 2015, p. 644; McGuire & Michalko, 2011, p. 163). This was further illustrated in one of Louise's posts, providing positive affirmations for autistic people that underscore autistic people's worth (LOU8). Paired with the rainbow infinity symbol (see figure 6), which honors the diversity and variations within autism (Johnson, 2021, para. 16), it celebrates autistic identity, thereby also implicitly opposing the medical deficit narrative. In fact, the presence of the infinity symbol indirectly draws attention to the absence of the puzzle piece across the three accounts, and resists the harmful inferences fabricated by the puzzle piece imagery.

Your experiences are real, even if other people have very different experiences to you. You are valid.

Figure 6. Affirmation for autistic people with infinity symbol (LOU8).

The use of appropriate terminology and symbols, such as identity-first language and the infinity symbol, underscores the value of self-identification of autistic people. Autism is normalized through these attempts at positive identity constructions. Moreover, utilizing language that autistic people themselves regard as important and beneficial, creates less stigma surrounding the disability and may contribute to less internalized ableism or negative identity construction (Bottema-Beutel et al., 2021, p. 19, 23).

In sum, through presenting a multitude of ways that autistic traits and behaviors can be expressed, connecting these to personal experiences, formulating these with appropriate terminology, and challenging existing stereotypes, the autistic creators oppose the one-dimensional view of autism often present in the media (Jones et al., 2023, p. 2210). Employment of different modes such as images, videos, sounds, captions and hashtags further increased and supported the creators' message that autism is, and should be treated as, normal.

4.4. User engagement

This second part of the results focuses on the engagement of users with the posts. The Instagrammers' overarching message that being autistic is normal and should be accepted was mostly interpreted by Instagram users according to the intended meaning. These interpretations may have been led by users' social and cultural codes, the particular construction of posts and representations, and by being an autistic or neurotypical Instagram user (Croteau & Hoynes, 2019, p. 271; Hall, 1980, p. 169). For example, the combination of neurotypical and autistic commenters illustrates how different users may relate to the content differently and have various purposes for adopting the intended meaning. Of the 664 commenters in the sample, 11% distinctly positioned themselves as autistic or neurodivergent, either through formal or self-diagnosis. An even larger group of commenters reported to relate to the content of posts or shared similar experiences to those of the creators; the amount of autistic commenters may therefore be higher than explicitly disclosed. Other users expressed being neurotypical, for example by stating that one is a parent of an autistic child. This amounted to only 1% of users. Others did not position themselves as one or the other.

There were exceptions in the adoption of the intended meaning, where the intention for commenting seemed to center on purposefully dismissing (elements of) a post. One example of such an exception is Jakob's response to Louise's post that challenges the phrase that 'everyone is a little autistic' (LOU10). Jakob commented: "Yes. Absolutely everyone is a little autistic." This comment was not meant as constructive criticism but was meant to dismiss the post. In the conversation that followed under his comment, users were quick to educate Jakob on why it was harmful to claim this.

After examining the comments, several patterns were found that further demonstrate users' adoption of the intended meaning of the posts: (1) expressing gratitude, (2) relating to the content, and (3) engaging in conversations.

4.4.1. Expressing gratitude

Autistic users often expressed gratitude for the representation of autism via thankful remarks targeted directly at the post and sometimes at the creators’ overall presence on Instagram. Commenters highlighted that they feel validated in their autistic identity. For instance, Marie replied to one of Louise’s posts (LOU2): “❤️ I feel whole reading your posts. I feel seen, understood, protected. Thank you so much.” Bodie expressed the same sentiment under one of Adrienne’s posts (AD1): “Thank you so much for this post, this is so important and something I’ve been learning more about and trying to take control of recently! ❤️″.

Likewise, neurotypical commenters – who distinctly positioned themselves as neurotypical – reported being grateful for the representation, but differently from autistic people. Neurotypical people were grateful for the creators and their posts for spreading awareness of autism in a more nuanced way than fictional media often do (Jones et al., 2023, p. 2214), and for gaining more understanding of how autism may affect people in their immediate surroundings. For example, Tara expressed her gratitude in saying: “Thank you for advocating for little girls like mine. Sending you so much love Lou 🖤” (LOU6). Moreover, Abigail commented: “I have a 12 years old son and he is asperger. His nickname is also Lou 😊. Thank you so much for sharing your Experience! It really helps a lot to understand all the things that he feels!” (LOU6). These examples illustrate that gratitude was expressed differently among neurotypical and autistic people, and commented on with diverging purposes.

Apart from the influence of social and cultural codes, such as being neurodivergent or neurotypical, the ability to guide certain interpretations lies in the construction of a post. This was illustrated in Callum’s post for World Autism Day (CAL7). As discussed, this post placed emphasis on self-acceptance of autistic people in a celebratory tone. It does not leave room for negotiating the core messages of autism acceptance, equality for autistic people, and the day being anything other than a joyous one. The comments reflected this joy in their positive and celebratory reactions, for example when Evan commented: “Thanks so much for the lovely words and encouragement ❤️.” Likewise, Odile celebrated the post and engaged with the caption that asked users what they are doing to celebrate today: “Yes beautiful post! I’m going to read this evening too 🤍.”

4.4.2. Relating to the content

Overwhelmingly, comments were posted to share an individual’s experience. These shared experiences often built upon the content of the respective post by referring to a particular element, such as caption or image. The reactions were occasionally prompted by a creator’s request for sharing experiences in the comments, and other times of one’s own accord. Different modes, such as caption, image, video, and sound, worked together to create meaning and prompt users to engage with the post, and allowed for a richer representation of autism, as opposed to using only one mode such as image or text. For example, with regards to Adrienne’s video on stimming to regulate transitioning to another activity (AD5), Jacelyn related to the post and engaged with the caption that asked users if they relate to this. She said:

> Ahahahahaha the timing of this. I just sat in my car for an hour after my doc appointment sippin my drinky drink and listening to my favorite song rn on repeat so I could work up the ooomph to do the next thing hahaha. 😹🤌 (AD5)

Jacelyn’s humorous tone matches and reproduces the core message of the post, which suggests that this behavior may be fun to experience but is also a normal occurrence for autistic people.

Negative personal experiences were also shared, for instance by criticizing negative conduct towards autistic people. This mirrors the underlying criticism directed at society and its continued mistreatment of autistic people, as mentioned in the Instagrammers’ partial adoption of the social model. Autistic people dislike being treated as inferior, and Vanya described her experience of being treated as inferior as: “Get talked to like I’m an uncooperative idiot by my boss” (LOU5). Vanya’s experience reflects the dominant contemporary discourse centered on the medical model of disability, which Constantino (2018, p. 385) explained remains the default perspective of understanding of, and conduct towards, autism. The ableist perspectives resulting from the medical model can result in autistic people feeling less valuable than neurotypical people (Bottema-Beutel et al., 2021, p. 19), and consequently they are at risk of overexerting themselves to be productive and adhere to neurotypical standards. Instances where autism *was* celebrated and normalized by wider society, for example through efforts of American organization Autism Speaks during Autism Acceptance Month, seemed to ring true *only* during that month according to commenters. Afterwards, the view that autistic people are weird and ‘less than’ neurotypical people is re-introduced, as Luna mentioned:

> Over here in the US, it’s been so dominated by the Blue Organization (@ut1$m $p34ks) that it’s become like Pride month - stores sell a bunch of stuff, then ignore/discriminate against us the rest of the year. And we’re fighting the ‘it’s just a trend!’ thing as well. 🤷🏻‍♀️💜 (LOU3)

In addition to relating to specific elements of posts, users also connected to, and reproduced, the terminology used by the creators to represent autism. The commenters, regardless of positioning oneself as autistic or not, predominantly employed terminology appropriate to the autistic community and experience. Most often, ‘autistic person’ was used, as well as ‘autists’ and ‘autistics’, and when discussing autistic traits, these were described using terminology connected to autistic experiences instead of the medicalized perspective of autism. Finley illustrated this when they said: “I am self-diagnosed audhd and I stim” (LOU3). Finley reproduced the sentiment connected to autistic experience, instead of mentioning ASD and ‘having’ ADHD. Symbols were utilized by commenters to further reproduce and relate to the message of a post, for example when Raina used the rainbow infinity symbol to express their gratitude for one of Louise’s posts, when they commented: “💕 ♾️ 🌈” (LOU5). Kaiden more descriptively related to a post with the neurodiversity symbol when she replied: “I connect to what you’re saying ♾️” (AD2).

4.4.3. Engaging in conversations

Sometimes, conversations were initiated unrelated to a post’s content. For instance, users shared their experience of traumatic autism diagnostic assessments. Another user shared her doctor’s unwillingness to even start a diagnostic process because the user did not match the conventional DSM-5 categories at first glance. Conversations among users were happening in the comments to support these people, give advice, and relate to each other. Sharing such vulnerable personal details bears witness to the creators’ posts and profiles as safe spaces, where users feel free to share and relate to each other on the basis of their disability. Additionally, employing the mode of video to create a safe environment around a serious subject seemed to help in prompting users to share their vulnerabilities and have meaningful conversations. Adrienne created such a safe space for conversing on the topic of body consent in autistic people (AD1). They shared a video of themselves sitting in their room, alone, sharing their experience of granting consent in a relationship as an autistic person, explaining how this may be difficult for autistic people. Their calm body language and tone of voice were successful in supplying users a space where they conversed about their experiences and challenges with body consent. Hence, Instagram itself was also demonstrated to be an accessible medium to most autistic people, mirroring Davidson’s (2008, p. 795-797) findings on the usefulness of digital technologies for autistic people to communicate and connect to each other. In fact, the data showed that some commenters were present across the three accounts, connecting and conversing with other users. This seems to confirm ideas of community building not only on one, but multiple accounts on Instagram.

At times, users wanted to converse with a creator about elements of a post, for example with regards to terminology. To illustrate, whereas Callum called April 2nd World Autism Day, Louise opted for Autism Awareness Day and called the entire month of April Autism Awareness Month. While not necessarily wrong, the phrasing struck a chord with commenters. They were unhappy with the word ‘awareness’, as became apparent in their comments about needing acceptance instead of awareness. Parker formulated it like this: “Why do you call it awareness and not acceptance month?” (LOU3). Anne was more informative in conveying why ‘awareness’ should not be used, when she explained: “Autism Acceptance Month, it doesn’t need to be aware, people are aware that autism exists, it just needs to be accepted more so” (LOU3).

Nevertheless, users were always respectful in their interactions with the creators and other users. Within the sample, there were no instances where users employed deficit-based language or hurtful and stigmatizing words to refer to autistic people, like ‘idiot’, ‘retard’ or ‘moron’, nor were negative comments made on how the autistic creators behaved in their videos (Arciuli & Shakespeare, 2023, p. 18; Dyck & Russell, 2020, p. 178; Ejaz, 2020, p. 799; Hayden, 2022, p. 180; Tisoncik, 2020, p. 69). This reflects users’ desire to engage in respectful conversations with other autistic people and create a safe space online where deviating perspectives on autism may be debated and identity can be constructed (Dyck & Russell, 2020, p. 183).

5. Conclusion

This research focused on the Instagram posts of Louise Chandler, Callum Stephen, and Adrienne Marcellus, and the comments on their posts, to answer the research questions: (1) *how do autistic people represent autism on Instagram?* and (2) *how do users engage with and interpret autistic people's portrayals of autism on Instagram?* Using qualitative multimodal content analysis, four categories and accompanying patterns were identified in the data. This final chapter discusses key findings, answers the research questions, and explores theoretical implications of the results. Finally, some limitations to this specific research are discussed, as well as suggestions for future research to focus on.

5.1. Key findings

This study has shown that, in the selected accounts, autism on Instagram was represented as a disability that is the product of intrinsic autistic traits and behaviors, and inaccessible social structures residing in a neurotypical society. Nevertheless, autistic people were not represented as mere victims of these structures or their reality: their agency was demonstrated in the creators' ability to challenge social structures and stereotypes, asserted in the messages they communicate, and shown through their self-representation practices in general. Being autistic was not glorified, nor diminished to a tragedy. Emphasis was further placed on acceptance of autistic traits and behaviors as disabling – not because they are deficits, but because they inherently disable individuals in everyday life (Jaarsma & Welin, 2012, p. 24). In turn, with a few exceptions, users accepted the intended meaning of the creators' posts. Through the few exceptions of not adopting the intended meaning, it became apparent how the overall majority of the commenters *did* accept and built upon the intended meaning, and were grateful for the autistic creators' representations of autism. Users engaged with these portrayals in a number of ways, such as through relating to the posts and sharing personal experiences of the traits or behaviors represented, expressing gratitude for the representations, and engaging in conversations with other users.

With respect to the posts, three categories and their patterns were identified to answer the first research question. The first three categories correspond to the three models of disability. Discourse surrounding the medical model was demonstrated to be minimally present in posts and across the accounts. Where the medical model was mentioned or referred to, it was to criticize it through the use of humor and irony. The creators thus opposed deficiency-based discourse about autism.

Secondly, the presence of the category of the social model suggests that the autistic creators partly reproduced the social model in their representations of autism by demonstrating that living in a neurotypical world, as an autistic person, is challenging. A world that does not properly accommodate autistic people can have negative effects on their identity and self-acceptance, or even dehumanize them and represent them as inferior to neurotypical people (Robinson & Highcock, 2024, p. 173). The posts relying on this model further implied that autism as a disability is still not accepted in society and at times even disregarded (Constantino, 2018, p. 385). Employing the social model in representational activities did not make these posts diminish autistic people's struggles to merely being the product of an unaccommodating society. In fact, partly reproducing the social model echoes Jaarsma & Welin (2012, p. 28) when they declare: "What is also needed is a discourse about the detrimental effects of an autism-incompatible and autism-phobic society on the well-being of autists." Certainly, an autistic individual's challenges are not merely constituted by their inherent disabling traits, but also by society at large.

The predicament model arguably deals better with this complexity by recognizing that every autistic experience is unique, valid, and constituted by biological and social factors, that may impact an autistic individual's identity (Anderson-Chavarria, 2022, p. 1323, 1335). As a third category, the predicament model was seen in the normalization of autism and the emphasis on self-acceptance and value of autistic identities. By sharing the positive, negative, and in-between realities of being autistic, using appropriate terminology, and challenging stereotypes, the creators contradicted the notion that autistic identities should be hidden or avoided, and moved away from the one-dimensional view of autism present in the media (Egner, 2022, p. 353, Jones et al., 2023, p. 2210). As autistic people often find themselves represented by society in "othering fashions" (Anderson-Chavarria, 2022, p. 1325), their identity is in turn constructed for them by these perpetuated portrayals, often based on just a few, simplistic characteristics (Hall, 2013a, p. 247). The findings demonstrate that the autistic creators and commenters alike benefit from representing autism according to their own experiences, highlighting those facets that are important to their identity and that impact them on a daily basis, and paying less attention to those elements that they do not resonate with. Autistic identity was thus valued and positively constructed by the selected creators, outside of the pre-determined notions of what autism should entail according to the DSM-5.

For commenters, these representations by autistic creators also demonstrated to be beneficial. The creators established a safe space for Instagram users to share vulnerable experiences and realities about oneself and provided depictions of the entire autism spectrum that can be used for positive identity construction. Interpretations of the posts generally expressed the same sentiment across the accounts: commenters were grateful for and celebrated the creators' endeavors for autistic representation, and the posts consequently were interpreted by the commenters according to the intended meanings. At times, this was influenced by their social and cultural codes (Hall, 1980, p. 169), seen for example in their connection to the posts by disclosing their own autism diagnosis. Other times, the construction of the posts left little room for negotiating the meaning, for instance through encouraging texts that established autistic people's worth.

Although the initial intention of examining the comments was to see how different people interpreted and engaged with the posts, the majority of commenters were autistic or neurodivergent, and only 1% of users was neurotypical. This was established through self-positioning as autistic or neurodivergent, as well as the majority of users relating to multiple autistic traits and behaviors. Some users were also active in commenting on posts across the three selected accounts. Commenters therefore seemed to be a self-selected group of neurodivergent people who actively sought information about, and representations of, autism, and connections with other disabled people. This seems to confirm ideas about community building of autistic people on social media (Davidson, 2008, p. 802; Egner, 2022, p. 357). Furthermore, this underscores the value of considering the autistic creators' representations of autism in conjunction with the commenters' engagement with these representations, to better understand practices of community building, representations of autism, and re-establishing autistic identities (Dyck & Russell, 2020, p. 183).

In conclusion, the discussed categories and patterns suggest that the selected autistic creators represented autism from their own, lived experiences and emphasized that being autistic is the combination of biological traits and societal structures. In contrast to dominant media representations of autism, self-representation of autistic people redefined what it means to be autistic according to personal experiences, and demonstrated the lesser-known traits and behaviors that are often not present in popular media representations of autism. The creators and commenters believe that autistic people should be accepted and valued as they are, and ultimately, autism was normalized through the representations of the autistic creators. Through positive identity building within the autistic community present across the three accounts, sharing personal experiences, relating to others, and criticizing the wider societal structures that can occasionally make life extra difficult for autistic people, creators and commenters alike demonstrated their agency in taking control of their own narratives and encouraging each other to stay true to themselves and advocate for their needs. It is the predicament of being autistic, of experiencing useful skills and challenging traits, that make autism a disability. It is about the highs and lows in life, made more complicated by one's differently-wired brain than those of neurotypical people.

5.2. Theoretical implications

While the aim of this research was not to prove the use or disregard the models of disability, the results do indicate that the medical model was challenged in efforts of self-representation on Instagram, and the social model was present in both posts and comments to illustrate how social structures can have an impact on autistic people's lives. On a meta level, the results demonstrate the value that the predicament model of disability can have for autistic Instagrammers and their followers. This model "makes room for a multidimensional, nuanced understanding of the highly variable and individualized autism and autistic identity experiences" (Anderson-Chavarria, 2022, p. 1337). The model does justice to autistic experiences by taking into account how these facets apply to autistic individuals' everyday lives. It considers both the strengths and challenges, without glorifying or pathologizing the disability. The findings have shown that the three autistic creators reproduced this sentiment by expressing the value of autistic lived experiences and by sharing how autistic traits may present differently in every individual, starting with their own experiences of these traits.

As Welch et al. (2022, p. 656) demonstrated, autistic people value autistic-led representations of autism, which includes expert knowledge of how the disability affects individuals. The perspectives of the creators central in this research shared more than a one-dimensional view of the disability, and showed that some dominant discourses do not capture their experiences well enough. Therefore, I believe this research has added to a better understanding of the way that particular discourses surrounding autism can make a difference in how we view the disability, and how autistic people represent autism. Moreover, the research underscores the value for autistic people of using Instagram for self-representation practices and the creation of online communities. These elements of this research can benefit the scientific field in both media and disability studies. Disability studies may advance in their understanding of the variety of media representations of disability that exist, beyond textual analysis of representations (Ellcessor et al., 2017, p. 4). As the findings suggest, multiple modes can aid in representing disability, and focusing only on text limits our understanding of how autistic people represent themselves. In turn, media studies can benefit from understanding how being disabled has an impact on how individuals live their daily lives and how they choose to present themselves online. Focusing on lived experiences and disabled people's self-expressions and agency can improve representations of autism, because these are nuanced perspectives that shine a light on the lesser-known aspects of disability, and in turn can enhance wider society's understanding of autism.

5.3. Limitations and future research

It is important to acknowledge that my research is not without certain limitations. Although conducting qualitative multimodal content analysis has facilitated a better understanding of the way that multiple modes aid, and are used for, representations of autism, the extensive amount of time necessary to analyze a single post and its comments resulted in a relatively small sample size of data, with regards to the amount of posts and profiles selected to analyze. Although the sample size was in line with the methodological guidelines (Janssen & Verboord, 2024, p. 7), the study would have been richer had more Instagram accounts been included in the sample. Moreover, whereas the chosen creators were diverse in terms of gender expression, nationality, and type of content shared on Instagram, they still represented a fairly Western-centered perspective of autism, as two creators are from the UK and one is from the US. As seen in the findings and creators' representations, autism is a personal, unique disability, and capturing all its facets is not possible while focusing on just three creators. A suggestion for future research is therefore to study the way in which creators in other cultures and parts of the world represent autism on social media, and whether they employ or challenge the same or different narratives from the ones discussed in this research. As Ejaz (2020, p.

801-804) mentions, Indian remakes of American movies about autism differed in their portrayals of the disability, according to their social and cultural contexts. Therefore, creators with different cultural backgrounds may have different opinions on and representations of autism. Additionally, other aspects and traits of autism may be represented than the ones central in the representations by Louise, Callum and Adrienne, for example by non-verbal autistic people. Their representations may highlight other challenges than the ones discussed.

Another suggestion for future research is to focus more on community building in autistic spaces on social media. The results of this study imply that being active in autistic communities on Instagram can indeed be helpful in constructing a positive identity for minority groups of people (Dunn & Andrews, 2015, p. 262; Egner, 2022, p. 353). If these are safe spaces where autistic people feel relatively free to speak about aspects of their disability, future research should focus on analyzing the variety of other social media platforms with active autistic communities to further paint a nuanced picture of autism. Connected to this is the avenue for future research into audience's perspectives of autism based on self-representations of autistic people. As Jones et al. (2023, p. 2214) suggested, fictional portrayals of autism can influence audience's acceptance and understanding of autism, but it remains unclear to what extent and how these portrayals influence opinions. Likewise, media and disability studies can further research how self-representation practices of autistic people on social media have an effect on audiences of these depictions, for example by conducting in-depth interviews with social media users or conducting a broader content analysis focused solely on audience reception. This in turn may benefit our understanding and future acting upon (mis)conduct towards autistic people on the basis of misconceptions of the disability within neurotypical people.

All-in all, I hope this research has done justice to autistic lived experiences and the efforts of autistic creators in representing their strengths and challenges. I hope that future research continues to look beyond the rigid, conventional perspectives of autism rooted in harmful discourses, and instead values autistic people as they are and listen to their stories of resilience.

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Appendices

Appendix A1: Instrument of analysis posts

Post name (LOU, CAL, AD), date of post, amount of likes and comments.

Description of post: …

Transcription of text within image/video/caption: …

The transcribed text is highlighted according to the medical, social, and predicament model in their corresponding colors.

Modes to pay attention to	**Medical model**	**Social model**	**Predicament model**
Image			
Video			
Caption			
Hashtags			
Sound(s)			
Symbols			
Terminology			

Appendix A2: Instrument of analysis comments

Comment	**Opinion on post** (grateful for/dismissive of (meaning of) post, celebrating post's representation of autism or not etc.)	**Purpose of comment** (position self, disclose autism, interact with others, share own experiences, mention stereotypes, contradict/build on post, form community, help each other etc.)	**Medical / social / predicament model of disability**	**Terminology**	**Reference to elements of post**

Appendix B: Overview of posts

Post	Title/ brief description of post
LOU1 [Image]	As an autistic person, I am constantly wondering am I experiencing autistic burnout or am I physically ill?
LOU2 [Image]	As an autistic person, the ‘small things’ frequently feel like the world is shaken upside down
LOU3 [Image]	8 things to know this Autism Awareness Month
LOU4 [Video]	The irony that the first day of Autism Awareness Month is April fools’ day
LOU5 [Image]	I’m autistic, of course I…
LOU6 [Video]	Behind the autistic person who is open about their experiences is an autistic child who…
LOU7 [Image]	Hygiene tips for autistic people
LOU8 [Image]	Affirmations for autistic people
LOU9 [Image]	The autistic urge to overpack
LOU10 [Image]	They say everyone’s a ‘little autistic’ but not everyone…
CAL1 [Image]	Stereotype of autistic people being uninterested in other people
CAL2 [Image]	Autism and treating objects like people
CAL3 [Video]	Autistic demeanor
CAL4 [Image]	Autistic people are often attracted to one particular line in a song
CAL5 [Video]	Autistic me smiling at everyone so nobody think I’m miserable
CAL6 [Video]	Autistic ADHD me writing down instructions verbatim
CAL7 [Image]	World Autism Day post
CAL8 [Image]	Autism & hair
CAL9 [Image]	Delayed processing and the consequence of letting others get away with bad behavior
CAL10 [Video]	Autistic me nodding my way through a conversation when I can’t formulate a verbal response quickly enough
AD1 [Video]	Autism & body consent

AD2 [Video]	Autism & connecting to others by relating to own experiences
AD3 [Image]	Autistics & “invisible” disability: shows classic iceberg example of (in)visible aspects of autism
AD4 [Image]	Autism & different types of thinking
AD5 [Video]	Stimming to transition to another activity
AD6 [Video]	Autistic me vibing with my morning “same” drink that if I don’t have my day won’t be ok
AD7 [Image]	ADHD & Autism community opinion: work accommodations
AD8 [Image]	Autism reality: both can exist. Shows opposing autistic traits that can be present in individuals
AD9 [Image]	Autism & smells
AD10 [Image]	Autism & gender as a mask