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AUTISTIC COMMUNITY AND SOCIAL CHANGE



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I want to acknowledge the autistic and neurodivergent communities online for their dedication to advocating for acceptance. The subject of this thesis is important to me because one year ago I was diagnosed with autism and ADHD while on autistic burnout. I couldn't understand myself and the reason I behaved and felt the way I was, because I was undiagnosed. I thought I might be autistic, but I didn't truly believe it because I had the stereotypical view of autism in my mind. Then started seeing posts about autism from autistic people and when I decided to help myself, I got my diagnosis. Subsequently, I started searching more thoroughly about autism. When I saw information on social media, I wanted to check the validity of it with other sources, especially science articles, but there was some or no sufficient information about traits and other related subjects. That is when I realized that the autistic community online while advocating for a more inclusive society, can greatly help autistic people. This is true not only for autistic people but for all neurodivergent people.

## ΠΕΡΙΛΗΨΗ

Η online αυτιστική κοινότητα, μέσω των κοινωνικών δικτύων δημιουργεί ασφαλείς χώρους για τα αυτιστικά άτομα να μοιραστούν τις εμπειρίες τους, να ενημερωθούν, να αποκτήσουν γνώσεις και να δημιουργήσουν μια αίσθηση κοινότητας, ενώ ταυτόχρονα προσφέρουν υποστήριξη. Αυτή η διπλωματική στοχεύει να διερευνήσει τον αντίκτυπο των αυτιστικών λογαριασμών των μέσων κοινωνικής δικτύωσης στις στάσεις, τις αντιλήψεις και τις πιθανές δυναμικές κοινωνικών αλλαγών εντός της online αυτιστικής κοινότητας. Για το σκοπό αυτό, διεξήχθη έρευνα μεικτής μεθόδου χρησιμοποιώντας τον διαδοχικό επεξηγηματικό σχεδιασμό. Τα αποτελέσματα δείχνουν ότι το περιεχόμενο που μοιράζονται οι λογαριασμοί των μέσων κοινωνικής δικτύωσης αυτιστικών ατόμων έχει σημαντικό αντίκτυπο στη αλλαγή των αντιλήψεων για τον αυτισμό σε μια πιο αποδεκτή προς τα αυτιστικά άτομα κοινωνία. Επιπλέον, τα αποτελέσματα υπογραμμίζουν τη δυνατότητα για ευρύτερη κοινωνική αλλαγή μέσω της αμφισβήτηση των στερεοτύπων και της προάσπιση της κοινωνικής ένταξης. Τα ευρήματα υποδηλώνουν ότι τα μέσα κοινωνικής δικτύωσης έχουν τη δυνατότητα να χρησιμεύσουν ως πλατφόρμα όχι μόνο για ενημέρωση, αλλά και για προσωπική ανάπτυξη και ενδυνάμωση μεταξύ αυτιστικών ατόμων, η οποία ευθυγραμμίζεται με τις ευρύτερες κοινωνικές αλλαγές που σχετίζονται με τη νευροδιαφορετικότητα.

Λέξεις κλειδιά: Αυτισμός, χαρακτηριστικά, μέσα κοινωνικής δικτύωσης, αναπηρία, νευροδιαφορετικότητα

## ABSTRACT

The online autistic community is creating safe and supportive spaces for autistic individuals to share their experiences, access valuable information, and build a sense of community, through social media. This thesis aims to explore the impact of social media creators on attitudes, perceptions, and potential social change dynamics within the online autism community. For this purpose, mixed-method research was conducted using the sequential explanatory design. The results show that the content shared by autistic social media creators has a significant impact on shifting perceptions of autism in a more inclusive and accepting direction. In addition, the results highlight the potential for broader social change driven by challenging stereotypes and advocating for inclusion. The findings suggest that social media have the potential to serve as a platform not only for information but also for personal growth and empowerment among autistic individuals, which aligns with the broader societal changes related to neurodiversity and inclusion.

Keywords: Autism, traits, social media, disability, neurodiversity, identity-first language

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# INTRODUCTION

Autism until recently was viewed as a neurodevelopmental disorder, based on deficits and characterized by difficulties in social communication and restricted repetitive patterns of behavior, interests, or activities. However, since the 1990s, the neurodiversity movement and the autistic community have started a paradigm shift in the view of autism. In more recent years, autism awareness has increased and that has led to diagnostic criteria changes that are more inclusive, diagnosis accessibility, conversations about accommodations to the educational and workplace environment, form of more accurate terms, autism research that is respectful and through the lens of disability and not of deficits and autism acceptance. Despite these changes, autism still lacks a more accurate representation and acceptance. It is important to note that autism is amongst the most highlighted neurodivergences and yet is still widely misunderstood. Also, every year the prevalence increases, and while this shows progress, the understanding of autism is in its infancy. There is a possibility that this is the result of the deficit-based perspective research, with a focus on children. Additionally, the exclusion of autistic people from autism research is happening because participants are primarily parents of autistic children and the intense focus on children is another possible result.

The misrepresentation and misinterpretation of autism, along with the need for awareness and acceptance, is the reason autistic people advocate loudly online for social change. Autistic people have first-hand knowledge and experience that share to build a more accurate view of autism while raising awareness and that can lead to social change. Autistic individuals and, generally, the autistic community use social media to share their experiences, inform others, and change people's perspectives. This thesis aims to study autistic social media creators that encourage attitude changes while exploring the resulting impact on other autistic people and the potential for social change it can bring. Moreover, the objectives are to identify patterns and themes in the online autistic community to inform a questionnaire that will be able to answer the research questions related to social change.

Further, the first chapter discusses the brief history of autism in psychology from 1900 to today. Additionally, it explores what autism is as a disability and outside of the deficit view of the medical model while analyzing some key characteristics and

challenges autistic people experience, such as bottom-up processing, stimming, inertia, sensory issues, meltdown, shutdowns, burnout, and masking. The second chapter reviews the meaning of the term neurodiversity along with the history of neurodiversity paradigm and movement, as well as the autistic community and autism research. It explores the way the autistic community has formed and changed the way autistic people view themselves and autism while advocating for social change. Also, it discusses how autism research has been viewed for most of the history of autism through the lens of neuronormativity and the medical model while using deficit-based language. However, recently, more participatory and intersectional research has been conducted that respects autistic people and their experiences while using more inclusive and accurate language. The third chapter explains in detail the reasons this research is needed, the method used, and the research design used. Further, it mentioned the research aim, objectives, research questions, and methodology. The fourth chapter analyzes the data from the qualitative and quantitative research that was conducted. The fifth chapter explores analytic and critical thinking on primary results and analysis. The sixth and final chapter addresses the wider understanding of attitude changes, the impact they have, and the potential for social change they can bring.



# Chapter 1

## Autism

### 1.1 The Brief History of Autism

The first mention of autism was in the first decade of 1900 by the psychiatrist Eugen Bleuler who wanted to describe schizophrenic patients who were socially withdrawn (Monk, Whitehouse & Waddington, 2022). Later, autism was first described as a distinct condition by Leo Kanner and Hans Asperger in two distinct papers around the same time. It should be noted that mentions of ‘feral’ children were reported as early as the 1700s. In 1938 Hans Asperger, a pediatrician and child psychiatrist, conducted independent research on children, which was a reference to ‘autistic psychopathy’. Later, in 1943, Leo Kanner published a paper that presented research based on 11 children who exhibited a unique set of characteristics. He described these children as having a " pervasive developmental disorder" and emphasized the early onset of the condition, as most of the children showed signs from infancy, naming it infantile autism. In 1944, he published his postdoctoral thesis that described his conceptualization of autism. These papers presented some similar characteristics of difficulties in social communication and interaction, as well as repetitive patterns of behavior and interests, but also had different concepts of what autism is and how it presents itself. (Chown & Hughes, 2016; Czech, 2018; Kadiri, 2022; Rosen, Lord & Volkmar, 2021)

Kanner’s research became widely known, in contrast to Asperger’s work, which for many years remained relatively unknown outside of German-speaking countries. (Chown & Hughes, 2016). In the 1980s, Asperger's research got international recognition and became popular (Czech, 2018). It is important to note that recent evidence indicates that Kanner may have been exposed to Asperger's ideas earlier than previously thought (Chown & Hughes, 2016).

Hans Asperger had a problematic role. He accommodated himself to the Nazi regime and gained career opportunities. He joined several organizations affiliated with National Socialism that publicly legitimized race hygiene policies. He actively

cooperated with 'euthanasia' program for children that is responsible for the forced sterilization and homicide of disabled children at the Spiegelgrund 'euthanasia' facility. The controversy surrounding Asperger's past and his ties to national socialism poses a significant ethical challenge in the context of autism research and its representation (Chown & Hughes, 2016).

The progression to understanding autism in the following years continued with important developments. In the 1960s, psychodynamic explanations, such as the "refrigerator mother" theory of psychologist Bettelheim, which blamed mothers for causing autism in their children due to the lack of maternal warmth, were adopted. This theory has been discredited (Rosen, Lord & Volkmar, 2021; Krcek, 2013). Subsequently, the Diagnostic and Statistical Manual of Mental Disorders (DSM) of the American Psychological Association (APA) has played an important role in shaping the conceptualization of autism and its categorization over time. In DSM-II, there was a description of children that was a reference to Kanner's work, but it was classified as a 'childhood schizophrenic reaction'. A decade later, in 1980, DSM-III was published adding autism to a new category of conditions called Pervasive Developmental Disorders (PDDs). The description provided was specifically directed at young children, naming it 'infantile autism'. There was an additional diagnosis of 'residual infantile autism' that was for people who no longer continued to exhibit the characteristics of infantile autism. The diagnosis criteria were very problematic and strict, so the revised edition of DSM-III-R changed the name of the condition to 'autistic disorder', which was more flexible in the criteria and included all ages and developmental stages of children (Kadiri, 2022; Rosen, Lord & Volkmar, 2021). In the following decade, both the ICD (International Classification of Diseases) and the DSM-IV added the diagnosis of Asperger syndrome (Rosen, Lord & Volkmar, 2021; Chown & Hughes, 2016). In DSM-IV, autism spectrum disorder (ASD) was characterized by multiple subcategories, such as autistic disorder, Asperger's disorder, and PDD-NOS (Rosen, Lord, & Volkmar, 2021). Furthermore, both DSM-5 and ICD-11 (2022) use autism spectrum disorder as a unitary classification of core symptoms, but they have distinct approaches to describing differences within groups, with DSM-5 adopting a dimensional approach and ICD-11 retaining a multicategorical system. Also, include specifiers for non-ASD co-occurring medical and psychiatric conditions. In addition, DSM-5 provides severity levels in the core symptom domain to capture individual variation. On the other hand, ICD-11 differentiates individuals based on their history

(e.g., regression) and intellectual and language abilities. (Kadiri, 2022; Rosen, Lord & Volkmar, 2021).

## 1.2 Autism Explained

The initial description of autism was based on the medical paradigm of child psychiatry. It is typically understood as a disorder of brain development. In other words, autism is a complex neurodevelopmental disorder characterized by sensory sensitivities, patterns of repetitive behavior, and difficulties with social interaction and communication that exist on a spectrum. However, the increased activism has been advocating to rethink the way autism is framed (Pellicano & Houting, 2021; Bolton & Ault, 2019; McCoy et al., 2020; Walker, 2021).

Autism is a neurological developmental disability that appears to be largely genetically heritable. It involves a complex interplay of different genes and unique brain connectivity patterns in each autistic individual. Compared to neurotypical milestones, autistic people often experience delays in social and emotional skills. The possible cause for this is that autistic people develop their social skills independently, due to the lack of suitable methods that neurotypical people use to teach other neurotypical people. Autistic brains exhibit specific and widespread differences in the processing of information, which are vastly different from neurotypical standards. These differences affect decision-making, impulse control, emotional processing, attention regulation, and rapid intuitive processing of complex situations. Furthermore, autistic brains seem to exhibit greater diversity compared to the wiring of neurotypical brains, while showing increased excitation in neurons, leading to indiscrimination of stimuli, no matter the unimportance of them, causing the miss of important information. This means that they are susceptible to being easily distracted by minor stimuli and potentially overlooking significant ones. Consequently, at sensorimotor and cognitive levels, autistic people have more intense experiences (Price, 2022; Walker, 2021). Additionally, autism is highly diverse. There are common neurological traits, but presentation, reaction, and experience vary widely between individuals and can manifest paradoxically (Price, 2022; Walker, 2021). For example, being hyper-fixated on a task can lead to completely ignoring a different stimulus that needs attention, or

other times there is a lack of concentration because there are distracting stimuli that a neurotypical brain would be able to ignore (Price, 2022). In the context of a neurotypical build society, autistic people are inherently disabled to some degree of sensory, cognitive, developmental, and social levels (Walker, 2021).

Further, autistic individuals typically interact with the world using a methodical bottom-up processing approach. In contrast, allistic individuals adopt a more top-down perspective, quickly assessing new environments and making intuitive assumptions about navigating them. When autistic people encounter new environments, they carefully analyze and interpret individual details, requiring more time and attention to form a comprehensive understanding. Additionally, autistic individuals show increased attention to detail. They tend to focus on specific elements while sometimes missing the broader context. This detail-oriented approach extends to social interactions, where they might emphasize facial features over overall expressions, often resulting in difficulties recognizing faces and reading emotions. Autistic people tend to rely on logic and reason, rather than emotion or intuition when interpreting the world around them. Also, they struggle to habituate to familiar situations or stimuli in contrast with neurotypical people. This cognitive processing is a more time and energy intensive assessment of situations, leading to increased sensory sensitivity, challenges in information processing, and a unique way of understanding and navigating their surroundings, while often becoming overwhelming due to the abundance of conflicting data. Furthermore, autism can significantly affect an individual's level of focus on tasks, as well as their sensory experiences, including textures, tastes, and sounds. Autistic people may display intense and specialized interests, called special interests, and tend to adhere rigidly to established rules. The difficulty of interpreting sarcasm and nonverbal cues is common, and deviations from routines or unexpected changes can cause anxiety. Many autistic individuals seek comfort and predictability through repetition, as the external social world can often seem unpredictable. Consistent routines provide a sense of stability, and this preference for familiarity extends to various aspects of their lives, including eating the same foods repeatedly (same foods) and engaging in hyperfocused activities to the point of forgetting basic needs like eating or taking breaks. (Price, 2022).

Furthermore, stimulation is closely related to autism and is characterized by a notable inclination to participate in repetitive physical movements or actions, which serve to elicit specific sensory stimulation (Price, 2022; Walker, 2021; Hayden, 2022).

Pathology-oriented discourse defined stimming as ‘repetitive self-stimulatory behavior’ or ‘self-imposed restricted environment’. Furthermore, stimming is viewed as dysfunctional compulsive or automatic behavior that do not have a use other than the deviation from the “norm” (Walker, 2021; Kapp, 2019). Stimming, as anything that digresses from the performance of normativity, is considered weird and unnecessary actions or symptoms that need to be eliminated, and the result is the stigmatization of autistic people (Hayden, 2022; Walker, 2021; Kapp, 2019). Until this day they are “treatments” and “therapies” for stimming that lack efficacy and ethics (Kapp, 2019). Autistic people have reframed the term "repetitive self-stimulatory behavior" into the more empowering and less medicalized term, stimming, to take back ownership of their narratives. Autistic and nonautistic activists and researchers have recognized stimming as an essential aspect of autistic existence (Kapp, 2019; Walker, 2021). Stimming, or self-stimulatory behaviors, is a common phenomenon observed in both neurotypical individuals and autistic individuals, but autistic people tend to engage in it more frequently, repetitively, and intensely. Stimming is often considered a coping mechanism that helps autistic individuals manage overwhelming sensory and emotional experiences such as anxiety or joy (Walker, 2021; Kapp, 2019; Price, 2022). Stims have the potential to be harmful (chewing their fingers until they bleed or hitting their heads on a hard surface) (Price, 2022; Hayden, 2022). Further, stimming can be categorized into: 1) Visual (night lights, LED lights kaleidoscopes, sensory videos, visual ASMR, gazing at running water), 2) Auditory (listening to running water, loud music, clicking or popping fidget toys), 3) Proprioceptive or kinesthetic (rocking, jumping, pacing, flapping one’s hands), 4) Tactile (fidget cubes, bubble wrap, soft toys, touching objects and surfaces that have appealing textures), 5) Vestibular (spinning, swinging, balancing boards), 6) Olfactory or gustatory (sniffing or tasting appealing things), 7) Verbal (repetition of particular sounds, words, songs or phrases, echolalia), 8) Chew (biting or chewing hard objects, ‘chewellery’). (Price, 2022; Walker, 2021; Hayden, 2022). It is important to note that the understanding of stimming and its research is limited (Walker, 2021; Kapp, 2019).

## 1.3 Autistic challenges

Autistic individuals face many challenges as part of their autistic experience. Some of them are inertia, sensory issues, meltdowns, shutdowns, burnout, and masking. Autistic inertia is characterized by the difficulty of starting and stopping activities and is described as a mental state of being ‘stuck’ for an extended period, frozen, incapable of taking action. That means that autistic people may face challenges with starting, stopping, or switching tasks in everyday life or breaking activities into smaller tasks so they can complete them, such as cleaning the kitchen or applying for jobs. Neurotypical people may assume that autistic people are lazy or apathetic but autistic inertia is strenuous both physically and emotionally (Buckle, 2021; Phung, 2021; Price, 2022). The severity of it depends on the situation and the person, but it can be exhausting and paralyzing (Phung, 2021).

The different cognitive processing often comes with sensory issues. The sensory issues are atypical and intense reactions to sensory stimuli and can widely vary from person to person. Autistic people can experience hypersensitivity or hyposensitivity (Sibeoni, 2022). Hypersensitivity is when individuals are feeling sensory stimuli from external sources and don’t have the ability to “ignore” unwanted sources, such as car horns, or the chatter of people in a café and can lead to sensory avoidance. Sounds, smells, bright light, and even touch can cause physical pain. Autistic people can experience a lot of pain when brushing their teeth or have difficulties with eating because of textures or smells. Hyposensitivity is when individuals have a reduced sensitivity to sensory stimuli which can lead to sensory seeking (Sibeoni, 2022 Hayden, 2022). Also, people with tactile hyposensitivity may not be able to identify pain. Additionally, individuals can struggle with sensory overload that can be debilitating and cause irritability and intense reactions, such as meltdowns and shutdowns. On the other side, autistic people who experience sensory overload can become confused and struggle to hear and communicate or complete tasks (Hayden, 2022 Price, 2022).

Furthermore, meltdowns are intense reactions to overwhelming situations or environments. The causes of a meltdown are varied, from sensory overload to intense emotional happiness or social demands, frustration, and challenges with communication. Any situation that causes an autistic person to feel overwhelmed can result in a meltdown that is accompanied by the loss of control of their behavior (Lewis & Stevens, 2023; Hayden, 2022; Phung, 2021). Autistic meltdowns can be expressed both verbally and physically depending on the individual, which means that it can appear as anxiety, crying, shouting, screaming, self-harm, or outward aggression such as kicking or biting. (Phung, 2021; Price, 2022; Lewis & Stevens, 2023). Signs of imminent meltdown are increased irritability and stimming, lack of communication abilities and focus, anxiety, and changes in voice and body language (Hayden, 2022). Autistic

shutdowns can be triggered by the same causes as autistic meltdowns and have the same internal chaotic experience, but externally they present differently. A shutdown is internalized and quieter than a meltdown, while frequently going unnoticed. Often individuals withdraw from their surroundings and appear to dissociate or zone out (Phung, 2021; Price, 2022; Hayden, 2022). The characteristics an autistic person can present are reduced communication, withdrawal to a quiet space without lights, forgetting simple tasks, becoming completely still and silent, and lying down or sitting in a fetal position (Phung, 2021; Hayden, 2022).

Autistic burnout is described as a state of exhaustion with reduced functioning and tolerance to stress that can become chronic (Price, 2021; Arnold et al., 2023). The characteristics of autistic burnout can present as withdrawal, degrading of skills, exhaustion, anxiety, heightening of autistic traits, reduced or loss of speech lack of motivation, stupor, reduced memory capacity and concentration, fatigue, and executive function problems. Also, can manifest as sleep difficulties, increased meltdowns and shutdowns, lethargy, frustration, hopelessness, sensory sensitivity, reduced energy, and ability to mask, communication difficulties, difficulty with emotion processing, and the need to isolate in order to recover (Price, 2021; Arnold et al., 2023; Higgins et al., 2021; Hayden, 2022). Autistic burnout differs from depression or non-autistic burnout, but often getting misdiagnosed as depression since it can present as such or a major depressive episode (Higgins et al., 2021; Price, 2021). Autistic people cannot navigate the world built for neurotypical people. Stressors in everyday life, such as social expectations and misunderstandings in social interaction and communication, can cause autistic burnout. Additionally, autistic traits that can challenge autistic people may cause burnout; some of these traits can be sensory sensitivity, difficulties with interoception, alexithymia, or masking. Interoception is defined as the sense that a person has of knowing their internal body state. Alexithymia is described as the inability to identify emotions. Masking is the camouflaging of autistic traits and is the most linked characteristic with autistic burnout (Arnold et al., 2023; Higgins et al., 2021).

Masking is the modification of autistic social behavior or any presentation of autism that differs from the traits and characteristics autistic people present (Price, 2021; Cook et al., 2021). Masking involves the adapting of behavior to cope with the predominately neurotypical social environment while giving the impression of being more capable in social situations and communication (Bradley et al., 2021; Cook et al., 2021). Masking is a means for autistic people to navigate neuronormativity and social expectations so they can ensure education and employment and develop friendships and partnerships while preventing mistreatment or ableism (Cook et al., 2021). Additionally, not all autistic people can mask, and it is interesting to note that those who can, may not be aware that they are masking. Masking offers autistic people the opportunity to protect themselves from discrimination. Autistic individuals who aren't able to mask face much more discrimination due to the reactions to their traits from those

who can. However, masking can have severe consequences. It can lead to exhaustion, isolation, meltdowns, shutdowns, burnouts, anxiety, loss of identity, substance or alcohol abuse, eating disorders, mental health problems, detachment or dissociation, and delayed diagnosis (Bradley et al., 2021; Price, 2021; Cook et al., 2021).

In conclusion, there are many traits and challenges autistic people face, but very limited literature. Especially research that focuses on the autistic experience and not on the medical model view of autism that is deficit-based. For example, autistic burnout has been discussed within the autistic community for a decade, but the literature is sparse, and only in the last couple of years have started conducting research focused on this subject (Arnold et al., 2023).



## Chapter 2

# Advocacy for Autism

### 2.1 Neurodiversity

Neurodiversity is defined as the idea of natural variation in neurological traits and cognitive abilities. Often referred to as similar to biological diversity but in a developmental context. This implies that neurological differences in different types of brain are natural and thus beneficial. The definition of neurodiversity is in contrast to the core of modern psychological science and clinical research, which is the inadequacy of anything that diverges from the perceived neurological norm (Stenning & Rosqvist, 2021). This term was coined by the sociologist Judy Singer in 1999, in an attempt to better understand and acknowledge autism that was deeply misunderstood at the time (Price, 2022). This label enfolds a variety of neurodevelopmental and cognitive differences and includes not only autistic people, but also people with ADHD, dyslexia, Down Syndrome, Tourette's, Obsessive- Compulsive Disorder, Borderline Personality Disorder, dyspraxia, dyscalculia, brain injury, and many more (Stenning & Rosqvist, 2021; Price, 2022; Arnaud & Gagné-Julien, 2023). However, the term itself contains both neurodivergent and neurotypical people. Neurodivergent refers to people whose neurocognitive functions diverge from the normative and neurotypical refers to people whose neurocognitive functions are what is considered 'normal' and socially acceptable (Kapp, 2020; Walker, 2021). Today, neurodiversity has evolved into a multifaceted term, and there are various interpretations and discussions about it (Larry Arnold, 2023; Stenning & Rosqvist, 2021; Arnaud & Gagné-Julien, 2023).

The neurodiversity paradigm is defined as a specific approach that involves the natural and valuable form of human diversity and the notion that the normativity of the human brain is culturally constructed, rejecting it as invalid. It is in the same context as other forms of diversity in humans, such as gender and ethnicity. There is no 'normal' standard or the 'right' way to exist, and this phenomenon of normativity creates inequalities in the social context (Walker, 2021). In contrast to neurodiversity when those differences are embraced, it creates social change that leads to inclusion and the

empowerment of people to improve their lives on their own terms (Ryan & Milton, 2023; den Houting, 2018; Walker, 2021). Depending on the context and the theoretical perspectives, the neurodiversity paradigm can be referred to as the neurodiversity framework or neurodiversity approach/es. The core of neurodiversity, though, incorporates intersectionality and, in some cases, the social model of disability. (Dwyer, 2022; den Houting, 2018; Botha & Gillespie-Lynch, 2022) Intersectionality is a framework for understanding the way social identities like gender, ethnicity, and sexuality are interconnected and create distinctive experiences (Smooth, 2013). In the context of neurodiversity and more specifically autism, that is interpreted as understanding the challenges and disadvantages created and interconnected by other forms of societal oppression. Additionally, intersectionality aids in understanding the differences within the neurodivergent and autistic communities. (Kapp, 2020; Botha & Gillespie-Lynch, 2022). The social model of disability is a framework that defines disability as a form of oppression created by society. That implies that all the challenges, disadvantages, and marginalization that disabled people experience have been socially created (Lawson & Beckett, 2021; Krcek, 2013). The social model of disability can give an understanding of the challenges autistic people face and inform the physical and social environmental changes that can be developed to minimize these challenges (den Houting, 2018; Kapp, 2020).

The Neurodiversity Movement is a form of activism, a social justice movement that aims for equality, autonomy, respect, civil rights, and societal inclusion of neurodivergent people while simultaneously fighting against the pathologization of neurodivergence that is rooted in neuronormativity and, by extension, the medical model (Kara, Giwa Onaiwu & Kariuki, 2022; Walker, 2021; Chapman, 2021; Stenning & Rosqvist, 2021; Kapp, 2020). The movement promotes awareness, self-acceptance, public understanding, and acceptance of neurodivergent people (Kara, Giwa Onaiwu, & Kariuki, 2022; den Houting, 2018; Stenning & Rosqvist, 2021). The movement of neurodiversity adopts a comprehensive and inclusive approach to understanding neurological and cognitive differences. It also uses group-based identity politics to challenge stigmatization and restore positive identity for neurodivergent individuals (Kapp, 2020). Additionally, intersectionality is integrated into the movement of neurodiversity. Whereas the social model of disability is supported and stands against the medical model, the activist movement recognizes the existence of inherent weaknesses in some disabilities like chronic pain, and not only the limitations set by

the social environment (Kapp, 2020). It is important to note that there are many opinions and debates about various topics within the movement like language when referring to autistic people (Kara, Giwa Onaiwu, & Kariuki, 2022).

## 2.2 Autistic community

Currently, there is a significant ongoing transformation in the perception of autism. This transformation is evident through advocacy efforts, activism, and discussions within the academic field (Pellicano & Houting, 2021). It is important to note that along with the neurodiversity movement, an online autistic community has been raising awareness and information about autism (Bolton & Ault, 2019). In the early 1990s, autistic people were starting to connect via the internet and that was the start of the creation of the online autistic community and the autistic rights movement. The need for the autistic rights movement was a result of the pathology paradigm and the medicalization of autism which portrayed autism as a “disorder”, leading to the marginalization, and stigmatization of autistic people. Consequently, autistic people were harmed, and traumatized by their families and medical professionals.

The autistic community and autism have emerged as a social identity and culture, offering accepting spaces for autistic individuals to embrace their unique experiences. By recognizing the importance of an intersectional approach, which considers the various identities (e.g., gender and sexual minorities, ethnicity) and experiences of autistic people, the community promotes the positive development of autistic identity, informed by the identities of other marginalized groups of people can belong (Arnaud & Gagné-Julien, 2023; Botha 2021; Botha & Gillespie-Lynch, 2022; Walker, 2021). This community reframes personal difficulties as a politicized struggle, empowering autistic individuals to find strength in collective action. Connectivity provides opportunities for individuals to connect, learn from role models, and offer social support across time and space. To support this growth, it is essential to assess and address structural and constant stigma, while supporting and integrating autistic cultural customs and practices that promote positive characteristics such as authenticity,

pride, belonging, and collective advocacy (Botha 2021; Botha & Gillespie-Lynch, 2022)

Specifically, autistic people have formed a supportive and empowering online community that embraces their unique differences and challenges the stigma they face. This community expresses frustration and anger towards nonautistic individuals who perpetuate negative stereotypes and advocate for a cure for autism. Instead, they resist the medicalization of autism and demand active inclusion in research and decision-making processes. Through the motto ‘nothing about us without us’, they call for collaboration with autistic individuals in shaping the narrative around autism (Bolton & Ault, 2019). It should be mentioned that research that examines the decision-making process of disabled social networks shows that media activists strategically personalize their content by sharing personal stories and experiences, emphasizing the unique challenges and perspectives of their disabilities. They carefully weigh the potential risks and benefits of publicly revealing their disabilities in the context of social media activism. Disabled activists use social media as a platform to construct alternative narratives, challenge ableist attitudes, and promote a more inclusive understanding of disability (Bitman, 2021). This community is a powerful platform where autistic voices unite, fostering solidarity and resilience in the face of discrimination and prejudice, as they work towards broader understanding and acceptance in society (Bolton & Ault, 2019).

In recent years, numerous review papers, perspective pieces, and books have emerged reflecting this shift. The traditional medical approach, while instrumental in shaping autism science, has been criticized for its narrow, deficit-focused perspective on autism. As a result, this approach has imposed limitations on the understanding of autism. Both autistic advocates and autism scientists are increasingly advocating for a replacement of the conventional medical paradigm. For this reason, it is important to raise awareness and pieces of knowledge based on the lived experience of autistic people (Pellicano & Houting, 2021; Kara, Giwa Onaiwu & Kariuki, 2022). This social change towards autism holds promise for a more inclusive and comprehensive understanding of it, driven by the empowerment of the autistic community (Kara, Giwa Onaiwu & Kariuki, 2022).

## 2.3 Autism Research

Activist movements such as the neurodiversity movement, critical autism studies, and mad studies are pushing for a change in the medical field and research. These movements are focused on challenging psychiatric conceptualizations and categorizations as well as the institutions and practices that are associated with them (Ryan & Milton, 2023; Woods et al., 2018; Arnaud & Gagné-Julien, 2023; Beresford, 2019). Critical autism studies have recently gained traction in the academic field. At the core of autism studies is the creation of emancipatory analytical frameworks and theoretical and methodological approaches to study autism, and its nature while respecting the differences in the spectrum of autism. while also enabling narratives to challenge the deficit-focused discourses and explore power relations within the autism field (Ryan & Milton, 2023; Woods et al., 2018). Mad Studies is a user-led movement of people who have been labeled as "mad" or "mentally ill". It challenges the traditional medical model of mental illness and advocates for a more inclusive approach to understanding and addressing mental health issues. It is based on the experiences of mad people and promotes the use of terms that are less stigmatizing and more respectful to acknowledge for the diversity of lived experiences. Mad Studies demands recognition, inclusivity, and self-determination while simultaneously considering psychiatry as a dominant, influential and oppressive institution (Arnaud & Gagné-Julien, 2023; Beresford, 2019).

Autism research has been instrumental in shaping society's perception of autism. The majority of research until a few years ago was heavily influenced by the medicalization of autism (Cooper et al., 2020; Botha, 2021). This has led to perpetuating dehumanization and marginalization of autistic people. In addition, claims of objectivity are dishonest because research accounts and theories about autism often reflect normative values, leading to dehumanizing narratives. These narratives, while claiming to be objective, can have profound effects on the lives of autistic individuals, shaping how they are treated in society (Botha, 2021). Medical professionals, psychiatric establishments, organizations, autism researchers, and anyone who uses medicalized language, e.g., "treatment", and "symptom", are part of the medical model

view of autism and spreading harmful theories, such as the “global health crisis”, when referring to the increasing of autism diagnosis (Walker, 2021).

Most research on autism focuses on topics such as behavior, genetics, and causes. Additionally, autism was considered a childhood condition and that is evident from the large number of research studies since 94% of them are for children and adolescents (Jang et al., 2014; Botha & Cage, 2022). The people participating in autism research are mostly family members (61%) and professionals (24%), while autistic participants are only 9%. This confirms that autism researchers tend to not include autistic people, resulting in research topics that are disconnected from the needs of the autistic community (Botha & Cage, 2022). Consequently, there is a plethora of autism research for autistic white male children. On the contrary, many marginalized intersectional identities are underrepresented in autism research, and that includes individuals of different races and ethnicities, levels of support needs, socioeconomic statuses, different ages, communication modes, sexualities, and gender identities or expressions (Cascio, Weiss & Racine, 2021).

In recent years, there has been an influx of good practices in autism research, and that means including autistic people in the research process and knowledge production. Actively seeking and valuing the perspectives, insights, and experiences of autistic people to inform research and decision-making is imperative. This leads to a comprehensive understanding of their experiences. This challenges researchers to go beyond surface-level inclusion and to engage in more empathetic and participatory research methods. Researchers must engage in a constant dynamic learning process of autism and adapt their approaches to avoid becoming static in their understanding of it, ensuring that their work remains respectful, equitable, and relevant to the lived experiences of autistic individuals (Arnaud & Gagné-Julien, 2023; Botha, 2021). Moreover, transparency and openness in autism research are important (Botha, 2021).

Autism researchers must go beyond mere data collection and analysis and pursue research that positively impacts the lives of autistic individuals and the broader autistic community. Unquestionably, it is important to address the real-world challenges faced by autistic individuals, promote their well-being, and contribute to a more inclusive and supportive society. It is necessary to be aware of the challenges in transitioning to more respectful and equitable research practices, especially when working with diverse communities. Researchers must engage in a broader conversation about how autistic individuals are treated during knowledge creation, ensuring that their voices are not just

superficially included but genuinely respected, valued, and considered in decision-making processes (Botha, 2021; Kara, Giwa Onaiwu & Kariuki, 2022).

## 2.4 Language in Research

The language people choose to use when talking about autism and autistic people mirrors the existing beliefs and attitudes but also shapes how they understand and view autism. Additionally, words can influence perspectives, potentially contributing to an inaccurate understanding of autism that is filled with misconceptions and stereotypes. That can lead to stigmatization and stereotyping of autistic people (Buijsman, Begeer & Scheeren, 2023). Traditionally, medical science and professionals have used language rooted in the medical model that describes autism through the lens of deficits. The term used can be offensive to autistic people and imply that they need to be 'fixed' to conform to the normative 'superiority' of neurotypical people (Dwyer et al., 2022; Pellicano & Houting, 2021; Monk, Whitehouse, & Waddington, 2022). The use of such terminology has faced scrutiny from the neurodiversity movement, the autistic community, and autistic researchers because it can negatively affect the attitude of society toward autistic people (Monk, Whitehouse & Waddington, 2022). Consequently, there is a growing consensus that the language employed to discuss should prioritize the viewpoints and choices of autistic individuals themselves (Dwyer et al., 2022; Monk, Whitehouse & Waddington, 2022). Autistic people prefer a terminology that directly addresses the distinct experiences of autistic individuals. In addition, it offers a more precise portrayal of the strengths and specific aspects in which autistic individuals might require support to improve their quality of life (Monk, Whitehouse & Waddington, 2022). It is important to note that people have their perspectives and opinions, which means that someone can find something offensive that someone else considers non-offensive (Keating, 2022; Bolton & Ault, 2019).

The main conversation is about the use of language in autism research and the autistic community. First, the use of identity-first language (autistic person) or person-first language (person with autism). Some autistic individuals advocate for identity-first language (IFL), such as "autistic person," as they believe that it acknowledges their inherent identity and recognizes autism as an integral part of who they are. On the other hand, person-first language (PFL), like "person with autism," seeks to prioritize the person over the condition. Person-first language has been more prevalent in autism

research. The term "person on the autism spectrum" is often preferred to person-first language. Researchers and professionals must engage in open communication with autistic individuals and respect their language preferences, ensuring that their voices are heard and valued (Dwyer et al., 2022; Buijsman, Begeer, & Scheeren, 2023).

Furthermore, other terms that are discussed in autism research and within the autistic community are "low-high functioning" labels and support descriptors. Support descriptors mean if an autistic person has low or high support needs. Although autism research and science used mainly the "low-high functioning" labels, this is generally thought of as inaccurate and isolating. Consequently, this leads to autistic people who are thought of as "high-functioning" missing the support they need and autistic people who are thought of as 'low functioning' getting infantilized (Keating, 2022). Autistic people are highly diverse, which means that they have different traits and manifestations of them, but also that traits and their intensity can change over time (Kapp, 2023).

In conclusion, although the above terms are the most studied, many medicalized terms need different perspectives to respect and accurately describe autistic people. Some of the medical terms and the suggested alternatives are 1) Disorder to Disability, 2) Autism Spectrum Disorder to Autism, 3) Comorbid to Co-occurring, 4) Deficit to Area of challenge, 5) Symptoms to Traits or Characteristics, 6) Restricted interests to Specialized interests. These are some of the terms that can be changed to more precise language that describes the autistic experience (Monk, Whitehouse & Waddington, 2022; Dwyer et al., 2022).



## Chapter 3

### Methodology

#### 3.1 Introduction

The online neurodivergent community and the autistic online community, especially on social media, have been trying to change the narrative of the normative and medical view of autism and support neurodivergent people. The autistic social media creators, that focus on that aspect, are striving to debunk stereotypes and myths about autism, but also share information and lived experiences of autistic people while raising awareness and acceptance of it. Moreover, autistic social media creators make content to help other autistic people and encourage them to be themselves. Additionally, each autistic person is different and has a unique perspective and understanding of how they experience autism, giving them a distinctive way of sharing about it. Consequently, autistic social media creators have different goals and emotions about being autistic and the autistic community. For example, some of them are hopeful and want to raise awareness and acceptance of autism, some wish to empower autistic people, while others are angry about stereotypes and misconceptions about autism outside but also from inside of the autistic community and want to debunk them. It is important to note that, as long as all the voices are heard and there is a conversation going on, the autistic community will move forward.

The autistic online community is a way for autistic people to have support, discover themselves, and learn how to navigate the neurotypical society. Autistic social media content can take many forms. It can be informative and share information about traits and characteristics, based on knowledge or lived experience. It can give tips on how to handle the challenges of autism, such as meltdowns or burnout. It can provide options about school and work accommodations, how to ask them, and reassure them that it is entirely acceptable to ask for them. It is important to note that social media is

an option for the more marginalized and intersectional identities to share their thoughts, that otherwise would be ignored.

Furthermore, autism research should focus on what the autistic community and autistic people need, while considering people of all ages, ethnicities, genders, and support needs. For that reason, the autistic community on social media is the optimal source for autism researchers to find themes, concepts, subjects, patterns, and trajectories. There are many terms, areas, and issues that autistic social media creators are discussing, but there is not sufficient literature or there is no research or even mention of those within research papers. Some of those are verbal shutdown, semi-speaking/semi-verbal, black-and-white thinking, a strong sense of justice, autistic inertia, self-diagnosis, same foods, infodumping, autistic joy, and unmasking. Again, it should be noted that most research is not participatory and does not involve or represent medium and high support needs of autistic people, adults, other ethnicities or races (except white), women, LGBTQA+ people, genders beyond the binary, autistic people with intellectual disability, and many others.

Additionally, the autistic online community since the 1990s has started a paradigm shift regarding autism and it continues to this day. There is significant progress in many areas. Some researchers use participatory approaches and use respectful language. The DSM-5 and ICD-11 have changed diagnostic criteria and that made the diagnosis a little more accessible. There is an increased awareness of autism, and there is an established Autism Pride Day on 18 June. Further, social media is an effective means for social change. Social change is any aspect of a social form, procedure, or pattern that is modified and changed through social processes (Farooq et al., 2021). Consequently, social media are efficient platforms to advocate, raise awareness and acceptance of autism, and foster social change.

### 3.2 Mixed Methods and Research Design

The restrictive literature focused on a specific group of autistic people along with the insufficient variety of subjects that interest the autistic community is a gap that needs to be rectified. To be able to study the attitude changes around autism, we need first to identify the themes that the autistic community discusses. The multiplicity and

immediacy of themes and trajectories of autism found in social media is a sufficient medium with a wealth source of information that comes from autistic people. For this reason, this thesis uses mixed methods. Mixed methods emerged in the last 20 years, as an alternative to the two established research methods of qualitative (QUAL) and quantitative (QUAN). There are many definitions of mixed methods. One of them is defining mixed methods as a type of research that both qualitative and quantitative methods in a single study while the researcher moves seamlessly between these two (Teddlie & Tashakkori, 2009). Recently, the mixed methods have integrated all phases of the two research methods, and that includes worldviews, data collection, analysis, theories, approaches, or interpretations of results while forming a separate methodological orientation (Creswell & Plano Clark, 2018; Teddlie & Tashakkori, 2009).

First, the current mixed-methods research design is informed by the intersectionality framework, the transformative view, the emancipatory theory, and the participatory approach while emphasizing lived experiences. Intersectionality is a theoretical framework that is based on the grounds that the identity of individuals cannot be understood considering social positions, such as race or gender, independently, but rather as conjointly formed (Bauer, 2021). The transformative view has in central importance the need for social justice and human rights for marginalized communities, such as women, and people with disabilities. Additionally, in mixed methods, the emancipatory theory aims at choosing a theoretical stance that is advocating for underrepresented or marginalized groups, such as a feminist theory, a race theory, a queer theory, or a disability theory (Creswell & Plano Clark, 2018). The participatory approach is defined by the intention of involving participants to help or contribute to shaping research in areas such as design, data, or findings (Cumbo and Selwyn, 2022). Finally, the present thesis emphasizes the autistic lived experiences, meaning that the importance of autistic viewpoint on their lives is a key point for the analysis.

Finally, the research design is the exploratory sequential design, which consists of three phases. The first phase is the collection and analysis of qualitative data (Cumbo and Selwyn, 2022). The second phase is the development of quantitative materials, such as questionnaires informed by qualitative data analysis. The third phase is the collection and analysis of quantitative data. Furthermore, in the current thesis, there were, respectively, three phases. In the first phase, a qualitative media content analysis was

conducted. The second phase involved the development of a questionnaire informed by the results of the qualitative research. The last phase was the statistical analysis of the questionnaire data. This design was chosen due to the lack of literature that contains themes that the autistic community is interested in, while also using a respectful attitude towards autistic people and isn't focused on the medical view of autism. Another reason for the selection of this design is the untapped source of a medium, such as social media, that is one of the main platforms for advocating for autism and the social change it can bring to the attitude of society towards autism and autistic people.

### 3.3 Research Aim, Objectives, and Questions

Neurodivergent individuals use social media to share their experiences, inform others, and change people's perspectives about being neurodivergent. Specifically, the autistic community has been very active in promoting attitude changes. The purpose of this paper is to study individuals who encourage attitude changes and explore the resulting impact on other autistic people and the potential for social change it can bring. Additionally, it explores the relationship between autistic social media creators and the community they created (autistic followers). It specifically focuses on how this dynamic relates to their perceptions of autism and the broader social change it can bring. The objectives of this thesis are to detect themes that are highlighted by the autistic community to inform a questionnaire tailored to the trajectories the community has set leading eventually to personal and social change. Each phase of the research has its research questions:

- Qualitative research (Content of autistic social media creators)

Identify concepts, patterns, trajectories, and directions of the content of autistic social media creators.

- Questionnaire development

To develop a tool specific for autistic people to assess their experience with social media focuses on autism and how that has changed their attitudes and views of it.

Quantitative research (community) To study:

1. What is the main source of information about autism that autistic people use?
2. Do autistic people have a lot of knowledge about autism-related topics from social media?

3. Do autistic social media accounts help autistic people?
4. How do autistic social media accounts help autistic?
5. Has the perception of autism changed since they started following neurodivergent content creators?
6. Is awareness on social media important to autistic people?

### 3.4 Sampling

The first step of the research design for the current thesis was to find the appropriate sample to maximize the optimal results for both qualitative and quantitative research. The sampling that was chosen is purposeful or purposive sampling which means that there is an intentional selection of knowledgeable or experienced participants of the concept being explored (Creswell & Plano Clark, 2018; Palinkas et al., 2015). Specifically, the criterion strategy was selected, which is characterized selection of participants that meet the predetermined criterion of importance set by the researcher (Palinkas et al., 2015). The sample of participants for the qualitative research was autistic social media creators. The sample of participants for the quantitative research was autistic people who follow the social media creators that were chosen for the qualitative research.

### 3.5 Qualitative Research

First of all, the platform that was chosen was Instagram for its accessibility. After the selection of 5 participants for the chosen platform, there was a sorting of the 60 most recent posts (pictures or videos) relevant to autism to identify the topics of discussion within the online autistic community. The posts were analyzed with the thematic analysis and the Dedoose program. Thematic analysis aims to identify and categorize patterns develop relevant themes and answer the researcher's research question (Jnanathapaswi, 2021). The most sufficient form of the data was inserted into the program while there was familiarization with the data. Next was the analysis of the data with the thematic analysis following the next steps: 1) the generation of codes, 2)

the grouping of codes into categories, 3) the comparison of categories to locate connections between them, 4) the formation of themes based on the categories and their connections (Christodoulou, 2023).

This analysis was chosen to assist with the development of the questionnaire. To create the questionnaire, the thematic analysis was studied from the finish to the beginning. First, the themes were placed as parts of the questionnaire. Each part consisted of its categories, and each was a cluster of questions that contained the most used codes based on the number that was applied in the analysis. The questionnaire was uploaded to Google Forms and was shared to the social media of the participants from the qualitative research. Since the construction of the questionnaire was a result of qualitative research that involved autistic social media creators, it was deemed necessary that the participants in the quantitative research be connected to the online community the creators have formed. It is important to note that participants were asked to give their feedback on parts of the research. Each participant was asked for their feedback on the code application of their posts, on the categories and themes, and on the questionnaire. This was a choice led by the participatory approach, while also checking the correctness of the research by autistic people since this research is about autistic people.

### 3.5 Quantitative Research

The quantitative data consisted of 155 filled questionnaires and the tool that was used for the data analysis was with the IBM SPSS Statistics software. Data preparation was performed, such as data screening and data cleaning, to handle missing data and to identify and address any anomalies. Following, the data were imported into the program. The data analysis procedures encompassed a sequence of steps tailored to address the research questions. Initial analyses involved the calculation of descriptive statistics, including using the 'frequencies' function in SPSS to measure the demographic questions. Subsequently, new variables were made to derive meaningful composite scores. The descriptive analysis was used to calculate the mean of the new variables. Additionally, Spearman correlation analysis was employed to assess the strength and direction of associations between variables. Also, the Kruskal-Wallis test

was used to compare the distributions of the dependent variable across multiple groups to determine if there are significant differences. Spearman and Kruskal-Wallis tests were used because they were nonparametric tests since the variables were ordinal. The results of these analyses were integral in drawing meaningful conclusions from the dataset and addressing the research objectives.

## Chapter 4

### Data Analysis

#### 4.1 Qualitative Data Analysis

The qualitative research was necessary for this thesis to pinpoint the subjects the online autistic community discusses and then inform a questionnaire with the results of it. The reason for creating this questionnaire is that this research aims to study the changes in attitudes and the possible social changes the online autistic community can bring. That is not possible based on the current existing literature. To study the attitude changes, first, there is a need to study the themes that the online autistic community is interested in, advocates for, and is dedicated to advancing positive change, awareness, and acceptance of autism. Social media is a tool to access the platforms of the autistic community. Therefore, the current qualitative research involved the thematic analysis of 60 posts of 5 autistic social media creators. From this analysis themes, trajectories, and ways autistic people like to share their perspective. In the program that was used, were uploaded 300 media consisting of pictures and videos that were shared on the app Instagram. Additionally, these media were described by 228 codes and applied 1201 times, and from those codes were derived 16 categories and 4 themes.

The raw data, comprising posts of photos or videos, were managed and organized using Dedoose. Prior to analysis, was conducted data cleaning and editing to remove any formatting inconsistencies. First, to each post were applied codes that consisted of the main topic discussed (e.g. c36 – Stimming), the type of information (e.g., c25 - Lived experience), and other themes that were present (e.g., c64 - Fidgets/stim toys, c215 - Sensory seeking, c31 - Accommodations/accessibility, c200 - Workplace environment). Following, the codes were grouped into 16 categories. It is important to note that there was a significant quantity of subjects mentioned in different perspectives. Autistic joy, which there isn't any literature as a trait of autism to this date, was mentioned in informational posts or lived experience posts that discussed the feeling of autistic joy or what can evoke autistic joy or the stereotyping and



discrimination of autistic adults experiencing autistic joy in public. Additionally, among the codes most applied were 27 (Figure 1. Most applied codes).

Codes	
c1 - Self-advocacy	c36 - Stimming
c2 - Self-empowerment	c37 - Unmasking
c3 - Raising awareness	c41 - Autism awareness
c6 - Medical model representation of autism	c46 - Challenges of autism
c7 - Ableism	c50 - Sensory issues
c13 - Informative	c51 - Communication and social difficulties
c14 - Debunking stereotypes	c57 - Special interest
c17 - Public misconception of autism	c76 - Masking
c19 - Discrimination	c88 - ADHD
c20 - Stigma	c92 - Diagnosis
c25 Lived experience	c100 - Stereotypes
c26 - Online peer-to-peer support	c150 – Co-occurring physical and mental conditions
c31 - Accommodations/Accessibility	c166 - Self-discovery post-diagnosis
c33 - Disability	

Figure 1. Most applied codes

Moreover, the 16 categories are 1) Autism traits, 2) Diagnosis, 3) Gender and sexuality 4) Social injustice, 5) Stereotypes 6) Co-occurring conditions, 7) Type of information, 8) Autistic challenges, 9) Transforming perspectives, 10) Support - accommodation, 11) Mental health, 12) Representation, 13) Social realities, 14) Terms 15) Autistic people 16) Different opinions (Figure 2. Categories). The categories with the most codes are 1) Traits, 2) Social injustice, and 3) Transforming perspectives.

	Categories
C1	Autism traits
C2	Diagnosis
C3	Gender and Sexuality
C4	Social injustice
C5	Stereotypes
C6	Co-occurring conditions
C7	Type of information

C8	Autistic challenges
C9	Transforming perspectives
C10	Support - accommodation
C11	Mental health
C12	Representation
C13	Social Realities
C14	Terms
C15	Autistic people
C16	Different opinions

Figure 2. Categories

From these categories were generated four themes. To identify themes and their connections to each other, the one-mode network matrix was used. In the two one-network matrices, the connections between the categories appear. The categories C1 (Traits) and C15 (Autistic people) are closely related and have the most connections. While C9 (Transforming perspectives) and C7 (Type of information) are close to those categories, they are closely connected with C4 (Social injustice) and C5 (Stereotypes). Additionally, C4 (Social injustice) and C5 (Stereotypes) are connected closely together with C1 (Traits) and C15 (Autistic people). The category that could be described as central is C15 (Autistic people). Followed by C1 (Traits), C4 (Social injustice), C5 (Stereotypes), C9 (Transforming perspectives) and C7 (Types of information). Strongly associated with C15 (Autistic people) are C2 (Diagnosis), C8 (Autistic Challenges), and C10 (Support-accommodation). Additionally, closely linked are C13 (Social Realities) with C4 (Social injustice and C5 (Stereotypes). Moreover, C6 (Co-occurring conditions) and C11 (Mental health) are connected, while C3 (Gender and Sexuality) and C12 (Representation) are associated with C15 (Autistic people). The category C14 (Terms) is firmly connected with C1 (Traits) and C15 (Autistic people). Lastly, C16 (Different opinions) is distantly linked with C15 (Autistic people).

One-mode network for identifying connections among categories																
	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10	C11	C12	C13	C14	C15	C16
C1	1	1		1	1	1		1		1	1	1	1	1	1	1
C2	1	1		1	1	1					1				1	
C3			1												1	
C4	1	1		1	1			1	1			1	1	1	1	
C5	1	1		1	1	1			1	1		1	1		1	
C6	1	1			1	1		1		1	1				1	
C7							1		1						1	

C8	1			1		1		1		1	1	1	1		1	
C9				1	1		1		1					1	1	
C10	1				1	1		1		1					1	
C11	1	1				1		1			1		1		1	
C12	1			1	1			1				1			1	
C13	1			1	1			1			1		1		1	
C14	1			1					1					1		
C15	1	1	1	1	1	1	1	1	1	1	1	1	1		1	1
C16	1														1	1

Figure 3. One-mode network

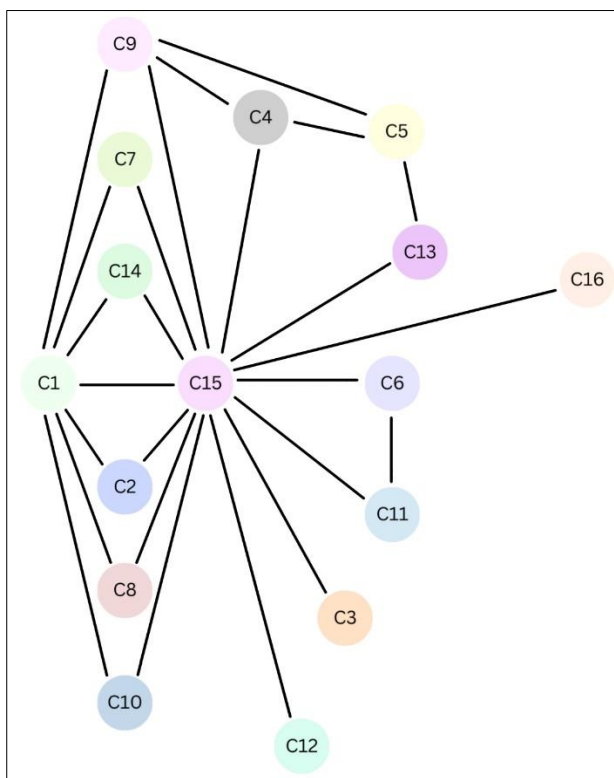


Figure 4. One-mode network

### 3.1.2 Theme Analysis

The themes that emerged from the above analysis were 1) Autistic experience, 2) Health, 3) Biases, and 4) Shifting Narratives. The autistic experience consisted of C1 - Autism traits, C15 - Autistic people, C10 - Support – accommodation, C12 - Representation, C3 - Gender and Sexuality, and C8 - Autistic challenges. The theme Health was formed by C11 - Mental health, C6 - Co-occurring conditions C2 – Diagnosis. Additionally, the theme Biases is constructed from categories C4 - Social

injustice, C5 - Stereotypes, and C13 - Social Realities. Lastly, the theme Shifting narratives was composed of C9 - Transforming perspectives, C14 - Terms, C7 - Type of information, and C16 - Different opinions.

The Autistic experience theme revolves around autistic people and the way they experience this world that is based on a neuronormative society. Autistic people are at the center of this theme and are closely connected with Autism traits and Autistic challenges. The autistic people category consists of autistic adults, autistic children, and the autistic community and is deeply connected with Autistic traits, which is the category with the most codes and a topic the autistic online community has numerous conversations about it. This category revolves around multiple areas of focus and topics. Some of the traits the online community discusses are c101 - Autistic joy, c161 - Frustration, c169 - Prosopagnosia, c178 - Heightened sense of justice and altruism, c57 - Special interest, c62 - Alexithymia, c91 - Infodumping, c154 - Ways of autistic people show affection, c155 - Telling about similar experience, c163 - Black and white thinking, c159 - Sensory processing differences, c179 - Task initiation, c210 - Safe food/same food, c60 - Understimulation, c59 - Overstimulation, c36 - Stimming c50 - Sensory issues, c51 - Communication and social difficulties, c52 - Executive dysfunction, c56 - Bottom-up processing, c58 - Interoception issues, c61 - Emotional regulation, c76 - Masking, c85 - Autistic burnout, c90 - Literal thinking, c53 - Meltdown, c54 - Shutdowns, c115 - Intellectual disability, c207 - Feeling others emotions deeply and c118 - Speech differences. Autistic traits are detrimental to the way autistic people experience the world. For example, literal thinking is a trait that can affect the way autistic people interact with society and society interacts with autistic people. Moreover, the category Challenges include codes such as c78 - Negative impact of masking, c86 - Internalized ableism, c116 - Lateral ableism, c63 - Feeling like not fitting in / outsider, c75 - Difficulties in employment, c69 - Existing in this world as an autistic person is inherently traumatic and anything that derives from the autistic traits that the autistic individuals struggle or have difficulties with them. For example, sensory processing differences can cause light and hearing sensitivities, sleep problems, or pain.

Support and accommodations are an integral part of autistic people since it helps them manage challenges, such as overstimulation. Support refers to support systems, such as parents, family, caretakers, friends, partners, or online communities. Accommodations refer to stim toys, earplugs, sunglasses, noise-canceling headphones,

special interest items, written instructions, quiet spaces, and many more. Additionally, representation revolves around the entertainment industry, such as series and movies, that either presents an autistic character or an autistic-coded character, meaning they attribute autistic traits to characters without explicitly labeling the character autistic. Moreover, gender and sexuality include femininity, non-conforming gender expression, such as non-binary, and autistic gender expressions, such as autigender or neurogender. Consequently, this theme represents the way autistic people exist and interact in this world.

Following, the health theme is about everything that involves physical and mental health. Diagnosis, co-occurring conditions, and mental health are the categories of this theme. Diagnosis includes codes, such as c24 - Undiagnosed autism, c214 -Late diagnosed autistic, c22 – Misdiagnosis, c190 Negative effect of undiagnosed autism, c42 Impact of awareness on diagnosis, c44 - Diagnosis increase, c93 - Self-diagnosis c96 - Inaccessible diagnosis, c181 - Late discovered autistic and c120 - Autism and mourning the life thought I'd have. Furthermore, this category focuses on the impact diagnosis can have on an autistic person. Co-occurring conditions refer to mental and physical conditions/disabilities/differences an autistic person can have. That includes among other, c149 - Hypermobility / EDS (Ehlers-Danlos syndrome), c158 - Social anxiety, c187 - CPTSD (Complex post-traumatic stress disorder), c196 - PDA (Pathological demand avoidance), c229 – ARFID (Avoidant restrictive food intake disorder), c230 - GAD (Generalized Anxiety Disorder), c88 - ADHD (Attention deficit hyperactivity disorder), c106 – BPD (Borderline personality disorder) and the challenges that the overlapping can cause. For example, EDS can cause an increase in sensory overload resulting in a meltdown or a shutdown. Additionally, the category mental health consists of c135 - Trauma c136 - Trauma as a result of being neurodivergent, c142 - Increased risk of suicide, c151 - Healthcare c157 - Talking therapy, c185 - Negative self-talk c48 - Autism friendly medical professionals c89 - Benefits of special interests. Consequently, this means that this category includes both positives and negatives of mental health. For example, many autistic individuals have trauma or CPTSD because the way they exist in this world is inherently traumatic to them. On the other hand, special interests can have many positive benefits to the mental health of autistic people especially when they're able to infodump (an intense and detailed discussion or monologue about a special interest) about it. In conclusion, this theme is about the overall health of autistic people and covers important aspects of it.

The third theme is biases, and it involves the social injustice, stereotypes, and social realities categories. All of whom describe the difficulties autistic individuals experience in society. Social injustice is a multi-dimensional category with many adversities autistic people experience in everyday life. That includes c80 - Violence, c81 - Antisemitism, c131 - Racism, c194 - Sexism, c19 - Discrimination, c20 - Stigma, c17 - Public misconception of autism, c18 - Insufficient knowledge of autism by medical professionals, c6 - Medical model representation of autism, c5 - Person-first language used by professional, c84 - Negative impact of societal pressure, c83 - Mistreatment (medication/therapy), c8 - Behavior modification, c49 - Asperger's, c121 - Misinformation, c119 - Lack of autism awareness, c87- Social prejudice towards persons with disabilities, c225 - Services for autism only serve children, c124 - Disorder. Social injustice is connected to intersectionality since many autistic people face discrimination not only for their autistic identity but also for identities such as gender, sexuality, ethnicity, race, and more. Furthermore, stereotypes result in obstacles in many ways. Some of them are c107 - Everyone's a little autistic, c108 - Autism is a childhood condition, c109 - Only boys can be autistic, c11 - Stereotypical view of autism, c110 - Autism is a mental illness, c111 - Autistic "look", c112 - Autistic are savants, c113 - Autistic have no empathy, c195 - Autism is for men and BPD is for women, c164 - You don't look autistic, c165 - My (insert barely related person) has autism and you're nothing like them, c188 - Autism affects children and c198 - Weird. An example of the consequences stereotypes cause is that women often are undiagnosed or misdiagnosed because stereotypically autism mostly appears in males. Social realities describe the more broader barriers autistic people face in society and involve codes such as c74 - Cost of living, c218 - Social roles and expectations, c217 - Capitalism, and c102 - Neurotypical world. Social realities are the pressure and demands of society from autistic people. For example, autistic people due to their disability expend their income to accommodate for it. Also, in Capitalism individuals are often assessed and valued based on their earning power, employment status, and productivity, which means that the value of people is assessed by their ability to work. That results in autistic people often “lose” their value since they often struggle to get employed or maintain a job position. The difficulty in employment can stem from many factors (e.g., sensory issues, stigma, or discrimination).

Finally, the theme shifting narratives revolves around the process of changing perspectives, while empowering autistic people. The first category in this theme is

Transforming perspectives which is about raising awareness and acceptance in society, but also personally. Codes such as c73 - Self-acceptance, c41 - Autism awareness, c45 - Advocacy, c14 - Debunking stereotypes, c29 - Autism acceptance, c3 - Raising awareness, c2 - Self-empowerment, c1 - Self-advocacy, c125 - Needing acceptance, c16 - Redefining norms, c160 - Autistic traits are not childish, c130 - I am more than a case, c129 - Autism acceptance needs to include all autistics, c70 - Being autistic is who I am and it's the way I experience the world, c189 - Opting out of using high low functioning labels, c139 - I am not a broken neurotypical, c55 - Social change, c47 - Nothing about us without us, and c152 - Solution proposition are characteristic of this category, describing the effort of autistic social media creators to empower the online autistic community in parallel with changing the portrayal of autism in society. In addition, Terms are an important part of changing perspective because the terms shared in the autistic community represent more accurately the autistic experience and depiction of it. Terms such as c220 – Neurotypical, c33 – Disability, c199 – Allistic, c15 - Support needs descriptors, c138 – Neurodivergence, and c82 - Intersectionality are meaningful to autistic people to describe their narrative. Furthermore, the type of information that autistic media creators use is a tool they use to describe their opinions and experiences. The Type of information that emerged are c25 - Lived experience, c26 - Online peer-to-peer support, and c13 – Informative. Lived experience is sharing their personal autistic experiences, while informative posts are conveying facts, data, and explanations. Online peer-to-peer support can have both of those types since they can provide helpful suggestions or advice. For example, an informative post about sensory issues can offer recommendations for stim toys or ways to avoid sensory overload. Lastly, different opinions refer to the differences the autistic community can have within but also the autism community in general.

In conclusion, the data analysis has provided insight into the lived experiences of autistic individuals, highlighting the multifaceted nature of autism and the themes surrounding autism. Also, has delved into the complexities of autistic people navigating in a neurotypical world while highlighting the importance of advocating for a more inclusive and accepting world for autistic individuals.

Themes			
Autistic experience	Health	Biases	Shifting Narratives
C15 Autistic people	C2 Diagnosis	C4 Social injustice	C9 Transforming perspectives
C1 Autistic traits	C6 Co-occurring conditions	C5 Stereotypes	C7 Type of information
C8 Autistic challenges	C11 Mental health	C13 Social Realities	C14 Terms
C10 Support - accommodation			C16 Different opinions
C3 Gender and Sexuality			
C12 Representation			

Figure 5. Themes

## 4.2 Development of Questionnaire

The development of the questionnaire was an integral part of the current thesis, in order to conduct the quantitative research and answer the research objectives and questions. The aim of this thesis is to study the changes in attitudes and perspectives about autism in the autistic online community. To achieve an accurate depiction of the context of the online autistic community the development of the questionnaire design specifically for this reason, was necessary. Moreover, the results of the qualitative research provided the guidance and design of the questionnaire. The questionnaire was constructed using the themes as different parts of it. The categories were treated as a means of prioritization. The codes indicated the topics that should appear in the questionnaire based on the number of applications and the connection to the other codes on the first step of coding. However, is important to note, that for the questionnaire to be functional adaptations were made were appropriate.

Firstly, the themes form different parts of the questionnaire. The theme of Autistic experience had a large amount of material that couldn't all be used. Also, not all the categories of this theme were added to the questionnaire, the reason being the importance of connection with codes, categories, and the number of applications of codes within the category. For example, the Gender and sexuality category and the Representation category weren't added to the questionnaire because the code application in the qualitative research was minimal. Also, these categories didn't have many and deep connections with other categories. Additionally, even though the category Autistic people was the center of the qualitative research the usage of it wasn't applicable because the questionnaire as a whole was about autistic people. The first part



of the questionnaire was the theme of Autistic experience with the category of Autistic traits being the first since it had the most codes, followed by Autistic challenges and Support and accommodations. It is important to emphasize that because the categories of Traits and Challenges are deeply connected questions about the trait's challenges were added to the Traits part of the questionnaire. Furthermore, the second part of the questionnaire was the theme, Health. This part was presented briefly on the questionnaire due to the limited applications of codes within the categories of this theme. The last theme used in the questionnaire was Shifting narratives. First, the category of Terms was presented, following the category Type of information, and Transforming perspectives which was about the participants' perspective on change of attitudes, social media, and autism. The Transforming perspective category was used as the ending part of the questionnaire due to its importance since it is in line with the research questions. The theme Biases was used within the other categories since it is connected with multiple aspects of autism and autistic people, and it was used in all the parts of the questionnaire. For example, a question about expressing autistic joy more freely due to social media support underlines the existing problem of expressing autistic joy in fear of discrimination, stigma, or "looking childish". On the other hand, there were questions about ableism and discrimination from healthcare services or insufficient accommodations in educational and workplace environments. In addition, the codes were used to form questions about topics. For example, the code c85 - Autistic burnout was used in a series of questions that were structured to answer the research questions. To answer the research question about the knowledge of autistic people was formed the question of whether the participant knows what autistic burnout is. To answer the research question about whether social media help and supports autistic people were formed questions such as if the participants felt more able to accept and accommodate autistic burnout. Lastly, to answer the research question about the way social media helps autistic individuals were formed questions, such as if social media helps handle it more easily.

In conclusion, the development of the questionnaire presented in this study emerged as an indispensable component of the research process, serving as a critical tool for conducting quantitative research aimed at addressing the research objectives and questions. This thesis aims to explore the changing attitudes and viewpoints regarding autism within the online autistic community. To provide a precise representation of this setting, the questionnaire was carefully crafted to suit the distinct

characteristics of this environment. It is imperative to underline that necessary adaptations were made to ensure the questionnaire's functionality and alignment with research objectives. Ultimately, this questionnaire played a pivotal role in capturing the shifting narratives and perspectives within the online autistic community. In sum, the development of this questionnaire had an integral role in facilitating a comprehensive study of attitudes and perceptions changes concerning autism within the online autistic community.

### 4.3 Quantitative Data Analysis

The questionnaire consisted of 7 demographic questions and 97 questions and was filled by 155 autistic participants. First, the frequencies of the demographic questions were analyzed. The first demographic question is about gender and the majority of 155 people 91 were Female (59%), followed by 30 Non-binary (19.4%), 11 Genderqueer (7.1%), 10 Other (6.5%), 7 Male (4.5%), 3 Transgender male (1.9%) and 2 Transgender female (1.3%). The category Other consisted of agender, Gender non-conforming femme, Transmasc non-binary, Gender-fluid, and Autiegender. The second question was the age of the participants was composed of 70 people between 18-25 years old (45.2%), 55 people of 26 -35 years old (35.5%), 24 people of 36-45 years old (15.5%) and 6 people of 46+ years old (3.9%). The third demographic question was about the age of diagnosis and/or identification / self-diagnosis. The larger share was 55 people (35.5%) that were diagnosed at 21-30 years old, followed by diagnosed age of 11 – 20 years old and 31 – 40 years old comprised of 18 people (24.5%) in each category, 2-10 years old were 14 people (9%) and the last category of 46+ were 10 people (6.5%). The next question was the country the participants currently live. The majority of people were from the USA (80 people - 51.6%) followed by Canada (13 people - 8.4%), the UK (10 people - 6.5%), Germany (9 people - 5.8%), Australia (7 people - 4.5%), France (4 people - 2.6%), Spain (3 people - 1.9%) and the Netherlands (3 people - 1.9%). Ireland, Estonia, Austria, Finland, Pakistan, India, Denmark, and Sweden had the same percentage of 1.3% (2 people). Correspondingly, Argentina, Greece, Portugal, Switzerland, Chile, South Africa, UK – Wales, New Zealand, and Scotland had the same percentage of 0.6% (1 people). The fifth demographic question

was the number of years the participants have been engaging with the autistic community. The greater part was 1 – 2 years (71 people - 45.8%) followed by the categories of less than a year (36 people - 23.2%), 3 – 4 years (30 people - 19.4%), and 5 or more years (18 people - 11.6%). The sixth was the number of years the participants have been engaging with the autistic social media accounts. The majority have been engaging for 1 - 2 years (78 people - 50.3%) followed by 3 – 4 years (38 people - 24.5%), less than a year (30 people - 19.4%), and 5 or more years (9 people - 5.8%). The last demographic question was the social media the participants used to learn or be informed about autism. The prevailing percentage was Instagram (111 people - 71.6%), followed by Other (20 people - 12.9%), TikTok (17 people - 11%), Instagram, and TikTok (7 people 4.5%). The category of Other consisted of YouTube, NHS websites, Reddit, Facebook (groups), neuroscience research, Twitter, Pinterest, Discord, Tumblr, blogs, Quora, Patreon, Podcasts, and Substack

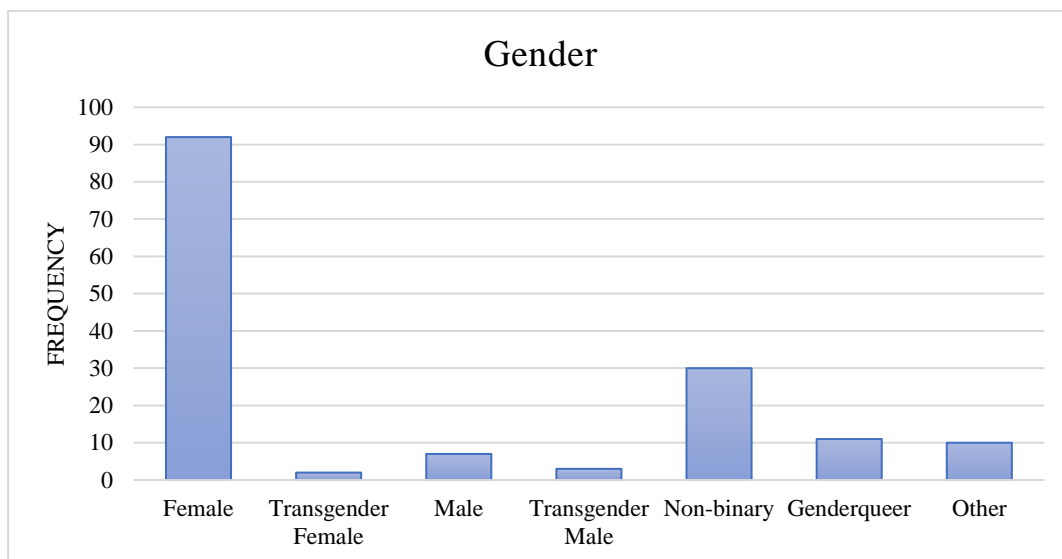


Figure 6. Gender

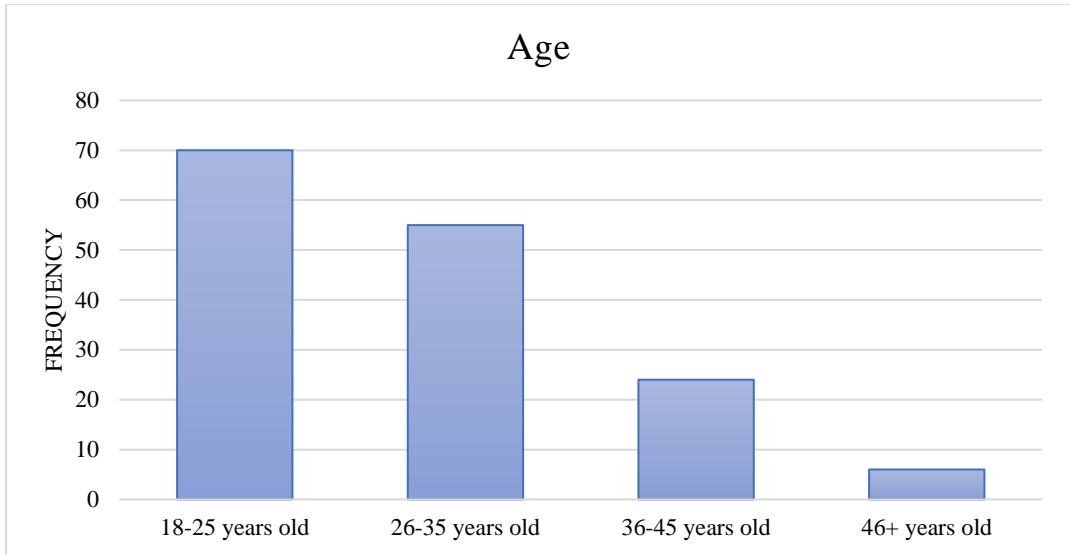


Figure 7. Age

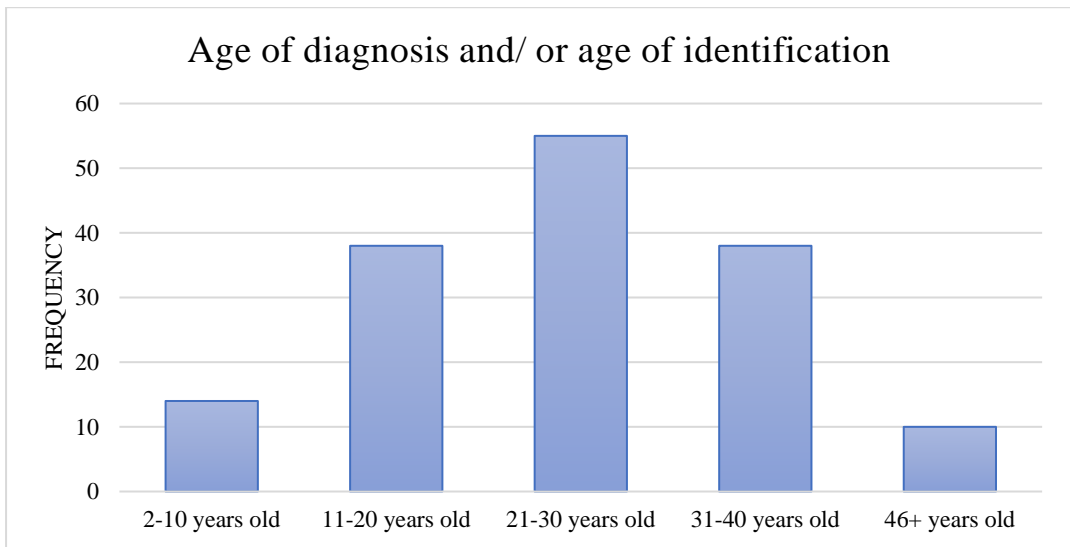


Figure 8. Age of diagnosis and / or age of identification

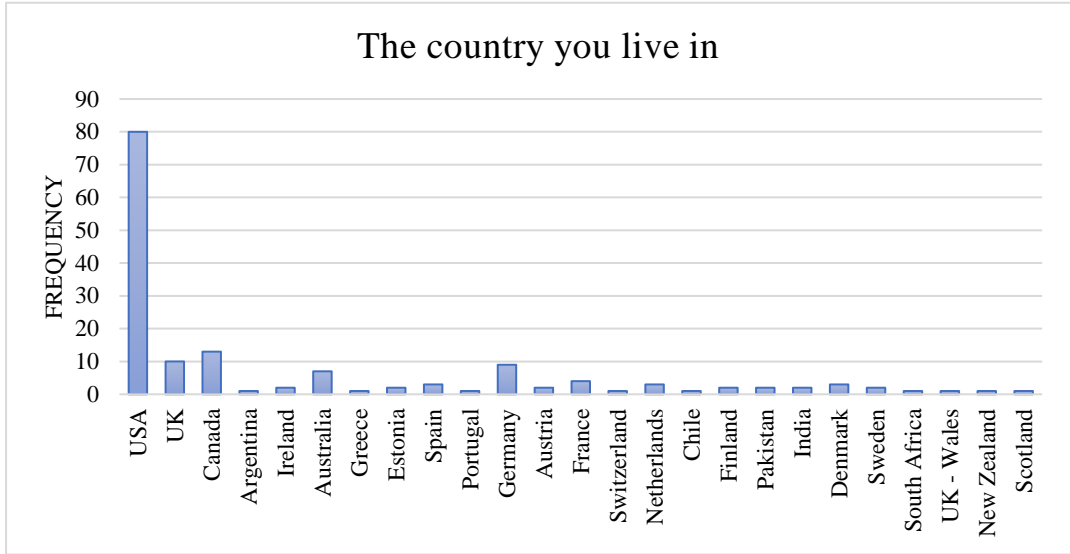


Figure 9. The country you live in

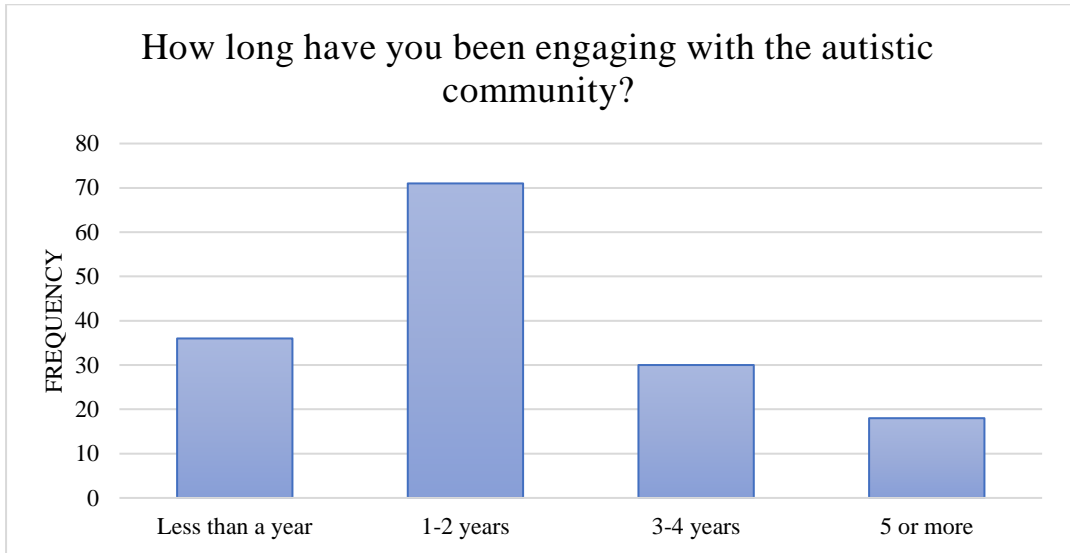


Figure 10. How long have you been engaging with the autistic community?

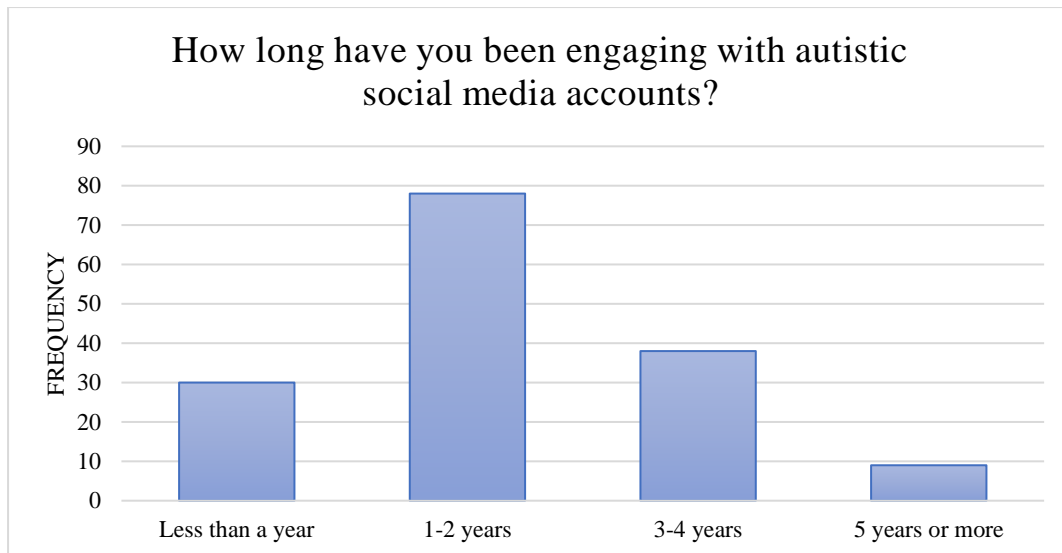


Figure 11. How long have you been engaging with autistic social media accounts?

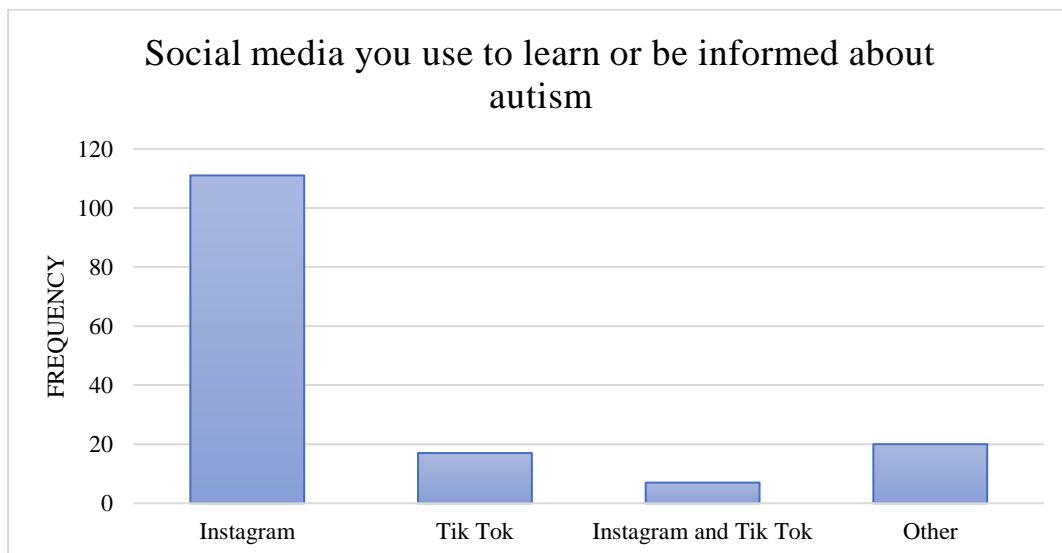


Figure 12. Social media you use to learn or be informed about autism

Subsequently, 12 new variables were created utilizing the compute variables function to derive meaningful composite variables to further the level of analysis. Consecutively, Cronbach's alpha was measured for all the new variables. The current data consists of 12 different categories, the number of items of them, and Cronbach's alpha which is a measure of internal consistency and coherence reliability, indicating the extent to which the items within each variable measure the same underlying composition and construct. Simply put, it evaluates whether the items in a scale are

correlated with each other and, therefore, whether they are likely measuring the same thing. The predetermined threshold is 0.70. The Cronbach's alpha values in this dataset range from 0.723 to 0.894. The first section was composed of all the questions of the questionnaire to check for internal consistency and the indication showed high consistency at 0.894 with 15 items. The rest variables measured from the highest of 0.880 with 16 items to 0.723 with 6 items. The reliability analysis of the above variables has indicated a high level of internal consistency among the items. This result surpasses the predetermined threshold of 0.70, thus demonstrating strong reliability for the questionnaire measurement scale.

Variables	Cronbach's Alpha	N of items
Knowledge about autism traits	.880	16
Knowledge about autism terms	.880	11
Support of autistic people	.877	15
The way social media supports autistic people	.777	9
Perception of autism	.894	15
Routine and repetitiveness	.723	6
Autistic joy	.802	4
Overwhelm responses	.853	10
Internal awareness	.795	6
Masking and unmasking	.753	4
Sensory processing	.781	6
Executive dysfunction	.859	9

Figure 13. Reliability statistics

Following the analysis plan was conducted a descriptive analysis to understand and explore the data's overall patterns before delving into more advanced analyses. The data presents the mean of 12 new variables that showing in Cronbach's alpha table. Among these variables, the variable Masking and unmasking has the highest mean at 4.3387, indicating a relatively higher central tendency within its values. While variable Executive dysfunction exhibits the lowest mean at 3.4953, suggesting a lower central

tendency compared to the other variables. The means of the remaining variables fall within this range, with values ranging from 3.4953 to 4.3387. Since most variables are above 3.4 to 4.3 the current descriptive analysis indicates that, on average, the responses or measurements are leaning towards the positive end of the scale. In other words, the data suggests a positive outcome.

Variables	Mean
Knowledge about autism traits	4.0576
Knowledge about autism terms	4.1015
Support of autistic people	3.7006
The way social media supports autistic people	3.9412
Perception of autism	3.9703
Routine and repetitiveness	3.9161
Autistic joy	3.8581
Overwhelm responses	3.9052
Internal awareness	3.5978
Masking and unmasking	4.3387
Sensory processing	4.0957
Executive dysfunction	3.4953

Figure 14. Descriptive Statistics

Successively, the Kruskal-Wallis test was executed for the variables consisting of traits and challenges. Kruskal-Wallis is a non-parametric statistical test used to assess whether there are statistically significant differences among two or more independent groups or treatments.

In the current data, the Kruskal-Wallis test was used to assess potential differences in the distribution of routine and repetitiveness scores across different age categories at diagnosis and/or age of identification. The results of the test, with a p-value of 0.202, did not reach statistical significance. Similarly, autistic joy had a p-value of 0.513, the test results do not provide sufficient evidence to reject the null hypothesis. For the variable representing overwhelm responses, the test yielded a p-value of 0.108, which is not statistically significant at the 0.05 alpha level. Consequently, we maintain the null hypothesis. The internal awareness variable with a p-value of 0.469, does not provide substantial evidence to reject the null hypothesis. Correspondingly, masking and unmasking variable, had a p-value of 0.315, which does



not reach statistical significance. Additionally, the sensory processing variable had a p-value of 0.321, which is not statistically significant at the 0.05 alpha level. Lastly, for the variable representing executive dysfunction, the p-value was 0.056, which, although not significant at the conventional alpha level, approaches significance. Despite this, we still retain the null hypothesis.

The analysis involves a series of independent-samples Kruskal-Wallis tests to examine whether the distribution of various variables (Routine and Repetitiveness, Autistic Joy, Overwhelm Responses, Internal Awareness, Masking and Unmasking, Sensory Processing, and Executive Dysfunction) remains the same across categories of Age of Diagnosis and/or Age of Identification. This suggests that, based on the Kruskal-Wallis tests conducted, there aren't significant statistical differences and remain relatively consistent in the distributions of these variables based on age-related categories.

Hypothesis Test Summary

Null Hypothesis	Sig.	Decision
The distribution of Routine and repetitiveness is the same across categories of Age of diagnosis and/ or age of identification.	.202	Retain the null hypothesis.
The distribution of Autistic joy is the same across categories of Age of diagnosis and/ or age of identification.	.513	Retain the null hypothesis.
The distribution of Overwhelm responses is the same across categories of Age of diagnosis and/ or age of identification.	.108	Retain the null hypothesis.
The distribution of Internal awareness is the same across categories of Age of diagnosis and/ or age of identification.	.469	Retain the null hypothesis.
The distribution of Masking and unmasking is the same across categories of Age of diagnosis and/ or age of identification.	.315	Retain the null hypothesis.
The distribution of Sensory processing is the same across categories of Age of diagnosis and/ or age of identification.	.321	Retain the null hypothesis.
The distribution of Executive dysfunction is the same across categories of Age of diagnosis and/ or age of identification.	.056	Retain the null hypothesis.

Figure 15. Kruskal-Wallis Test

Similarly, the Kruskal-Wallis test was conducted to determine significant differences in the distribution of responses regarding the variables of support of autistic people, the way social media supported autistic people, and perception of autism, across

different age categories at diagnosis. The support of autistic people variable had a p-value of 0.646 and did not reach statistical significance at the conventional alpha level of 0.05. As a result, we retain the null hypothesis. Additionally, the variable the way social media accounts have helped autistic people, with a calculated p-value of 0.756, does not provide sufficient evidence to reject the null hypothesis. For the variable representing the perception of autism, the p-value was calculated at 0.709, which is not statistically significant at the 0.05 alpha level. Thus, we maintain the null hypothesis.

The analysis involves independent-samples Kruskal-Wallis tests to investigate whether the distribution of three variables (Support of Autistic People, The Way Social Media Supported Autistic People, and Perception of Autism) remains the same across categories of Age of Diagnosis and/or Age of Identification. This indicates that, based on the Kruskal-Wallis tests conducted, the p-values exceeded the conventional significance level and do not provide support for rejecting the null hypothesis, suggesting that the distribution of these variables may not significantly vary based on age-related categories.

Hypothesis Test Summary

Null Hypothesis	Sig.	Decision
The distribution of Support of autistic people is the same across categories of Age of diagnosis and/ or age of identification.	.646	Retain the null hypothesis.
The distribution of The way social media supports autistic people is the same across categories of Age of diagnosis and/ or age of identification.	.756	Retain the null hypothesis.
The distribution of Perception of autism is the same across categories of Age of diagnosis and/ or age of identification.	.709	Retain the null hypothesis.

Figure 16. Kruskal-Wallis Test

Finally, Spearman's correlation test was conducted to explore the relationships between five variables related to autism: Knowledge about autism traits, Knowledge about autism terms, Support of autistic people, The way social media supports autistic people and Perception of autism. The Spearman correlation test assesses whether there is a statistically significant correlation between two variables.

Firstly, there was a strong and statistically significant positive correlation ( $\rho = 0.698$ ,  $p < 0.001$ ) between knowledge about autism traits and knowledge about autism terms. This suggests that individuals who possess more knowledge about autism traits

tend to also have more knowledge about autism terms. Additionally, a moderate and statistically significant positive correlation was observed between knowledge about autism traits and the support of autistic people ( $\rho = 0.559, p < 0.001$ ). Similarly, there was a moderate positive correlation between knowledge about autism traits and the perception of how social media accounts have aided autistic individuals ( $\rho = 0.506, p < 0.001$ ). Similarly, Knowledge about Autism Terms is positively correlated with Support of Autistic People ( $\rho = 0.425, p < 0.001$ ) and The Way Social Media Accounts Supported Autistic People ( $\rho = 0.365, p < 0.001$ ).

Moreover, Support of Autistic People is strongly positively correlated with The Way Social Media Accounts Supported Autistic People ( $\rho = 0.710, p < 0.001$ ). Additionally, the Perception of Autism exhibits positive correlations with all other variables (ranging from 0.428,  $p < 0.001$  to 0.818,  $p < 0.001$ ). Lastly, knowledge about autism traits was also moderately and positively correlated with the perception of autism ( $\rho = 0.428, p < 0.001$ ). These findings indicate that individuals with greater knowledge about autism traits tend to have more positive perceptions of social media accounts' helpfulness for autistic individuals and a more favorable view of autism in general.

In summary, the Spearman correlation analysis of variables related to autism has unveiled valuable insights into the interconnection between knowledge, perceptions, and support in this context. Specifically, we found that a strong positive correlation exists between knowledge about autism traits and knowledge about autism terms, underlining the synergy between these two dimensions of understanding. Furthermore, individuals with a greater grasp of autism traits tend to hold more positive beliefs about the efficacy of autistic social media accounts in supporting autistic people and maintain a more positive perception of the impact of social media on autistic individuals. These correlations highlight the potential impact of knowledge on shaping attitudes and perceptions concerning autism and its support systems.

	Knowledge about autism traits	Knowledge about autism terms	Autistic social media accounts have helped autistic people	The way social media accounts have helped autistic	Perception of autism
Knowledge about autism traits	1.000	.698	.559	.506	.428
Knowledge about autism terms	.698	1.000	.425	.365	.362
Autistic social media accounts have helped autistic people	.559	.425	1.000	.710	.818
The way social media accounts have helped autistic	.506	.365	.710	1.000	.643
Perception of autism	.428	.362	.818	.643	1.000

Figure 17. Spearman's rho

# Chapter 5

## Discussion

### 5.1 Introduction

The current thesis investigates the impact of autistic social media creators on the attitudes, perceptions, and potential social change within the autistic community. The aim is to understand how these content creators influence the autistic community. To achieve this, the research is divided into three main objectives. First, the qualitative research seeks to identify and analyze the themes, patterns, and directions within the content produced by autistic social media creators. Second, it aims to develop a specialized questionnaire tailored to autistic individuals, enabling the assessment of their experiences with social media content related to autism and its effects on their attitudes. Finally, through quantitative research, this thesis studies various aspects, including the sources of information about autism preferred by autistic individuals, changes in their perceptions of autism resulting from engagement with neurodivergent content, its impact on their daily lives, positive transformations in concepts like empowerment and reduction of negative ones like ableism, discrimination, and stigma. Furthermore, it explores the broader social changes that may arise from this interaction.

### 5.1 Qualitative research

The qualitative research conducted for this study was instrumental in pinpointing the subjects of discussion within the online autistic community, which in turn informed the development of a questionnaire. The qualitative analysis involved the examination of 60 posts created by five autistic social media creators. A total of 300 media items, including images and videos from Instagram, were analyzed by 228 codes, applied 1,201 times. These codes were then grouped into 16 categories and, subsequently, formed four overarching themes. The primary themes that emerged from the analysis include "Autistic Experience," which encompasses discussions around autism traits, challenges, support, accommodation, representation, and gender/sexuality. "Health" encompasses aspects related to the physical and mental well-

being of autistic individuals, covering topics like diagnosis, co-occurring conditions, and mental health. "Biases" explores the social injustices, stereotypes, and social realities that autistic individuals face in society, including discrimination, stigma, and barriers in various forms. Lastly, "Shifting Narratives" focuses on changing perspectives and empowerment within the autistic community, including efforts to raise awareness, acceptance, and accurate portrayal of autism in society. These themes encompass personal experiences, challenges, advocacy, support, and the broader societal context in which autistic individuals exist. Additionally, the study highlights the importance of using accurate and inclusive terminology to describe the autistic experience and emphasizes the role of social media in fostering community, empowerment, and changing societal narratives surrounding autism. Overall, the research provides deep insights into the lived experiences of autistic individuals and the range of issues they face while advocating for a more inclusive and accepting world.

The thematic analysis reveals that the online autistic community in social media plays an important role in shaping the discourse surrounding autism. Autistic social media creators use their platforms to share lived experiences, educate their audience, and challenge societal misconceptions about autism. The analysis demonstrates that content trajectories span diverse aspects of autistic life, from sensory processing differences to the challenges of navigating a neurotypical world. This content is multifaceted, reflecting the complexity of autism and the diverse needs and experiences within the autistic community. Furthermore, the analysis indicates that online autistic communities offer autistic people practical advice and coping strategies, particularly in dealing with sensory sensitivities and communication difficulties. Also, the analysis reveals that the content of autistic social media creators includes advocacy posts to reduce negative concepts such as ableism, discrimination, stigma, and the internalization of negative attitudes such as internalized ableism. Through education and advocacy posts, the content creators challenge ableist and discriminatory beliefs in society. By fostering understanding, they combat the stigma surrounding autism. Additionally, followers are less likely to internalize negative stereotypes, as they are exposed to alternative narratives that emphasize neurodiversity and the strengths of autistic individuals.

The findings suggest that the content shared by autistic social media creators helps autistic people who interact with social media to gain insights into the lived experiences of autistic individuals, which contributes to a more nuanced understanding

of autism. As autistic content creators challenge stereotypes and provide accurate information through their posts, they empower their community to adopt more inclusive and accepting attitudes toward neurodiversity. They promote greater acceptance, understanding, and support for neurodivergent individuals. Moreover, the online autistic community on social media advocates to increase awareness, reduce discrimination, and a more inclusive societal discourse surrounding autism. While the full extent of the possible changes may require further study, the analysis suggests that online autistic communities have the potential to foster a more inclusive society.

### 5.3 Questionnaire development

The development of the questionnaire in this study became a crucial step towards achieving research objectives centered on understanding the changes in attitudes and perspectives within the online autism community. The qualitative research provided the foundation and structure for constructing the questionnaire, with themes derived from the qualitative analysis forming the different sections of the questionnaire. The questionnaire effectively captures the multifaceted nature of the online autistic community, offering a comprehensive tool to answer the research questions. It serves as a bridge between the qualitative insights gained and the quantitative data required to further explore the dynamics of attitude changes, social media influence, and perceptions of autism. Thus, the development of this questionnaire played an integral role in facilitating an in-depth examination of shifting narratives and perspectives within the online autistic community, contributing significantly to the overall research endeavor. Lastly, this questionnaire, aimed to capture not only the surface-level changes in attitudes but also the deeper shifts in perspectives and experiences related to autism. It sought to understand how individuals within the community have been empowered, how their perceptions of autism have evolved, and how these changes have impacted their daily lives.

## 5.4 Quantitative research

The analysis of the questionnaire data, consisting of responses from 155 autistic participants, provided valuable insights into the demographics and internal consistency of the survey instrument. The demographic data revealed a diverse participant group, with a significant representation of female and non-binary individuals. Moreover, participants spanned a wide range of ages, diagnostic experiences, and geographic locations, emphasizing the global and multifaceted nature of the online autistic community. It is important to note that the majority of the participants were women and genders outside of the binary, which are both underrepresented minorities in research. Additionally, research has shown a link between autism and gender non-conformity, but the reasons for this link have not been studied in a sufficient amount (Schiltz et al., 2023). The autism community has already suggested that many autistic people identify with queer genders because gender is a social construct and autistic people tend to be less responsive to normativity societal expectations and normative roles. This is an example of the lack of participatory approaches, research aimed at the needs of autistic people and the autistic community has already addressed a subject that research has not adequately addressed. Also, the internal consistency demonstrated that the questions within each variable effectively measured the same underlying constructs. This reliability is essential for ensuring that the survey instrument accurately captures the intended aspects of the participants' experiences and attitudes. Descriptive analysis of the newly created composite variables showed that, on average, participants' responses leaned toward the positive end of the scale, suggesting a generally favorable outlook regarding their engagement with the online autistic community. This initial overview laid the foundation for more advanced analyses aimed at exploring specific aspects of the data in greater detail.

Kruskal-Wallis tests were employed to examine potential differences in variables related to traits, challenges, autistic joy, overwhelm responses, internal awareness, masking and unmasking, sensory processing, and executive dysfunction based on age-related categories. These variables with the demographic question of the age of diagnosis and/or identification were selected because people who were diagnosed in childhood have different experiences than those who were diagnosed or self-diagnosed in adulthood. These experiences can be negative or positive. For



example, getting diagnosed in childhood could help the child know why they experience the world the way they are, but that does not exclude the fact that they may face discrimination, stigma, and ableism from family, friends, educational, or healthcare environment causing them to internalize those attitudes. Correspondingly, autistic people diagnosed in adulthood can have experiences such as family and social circle telling them that they are exaggerating about sensory issues or to stop moving their arm that way because it is not appropriate and there is nothing that justifies their behavior. That can lead to feelings of shame, second-guessing actions, or feelings of being different without knowing what is ‘wrong’ with them since they are not adhering to the normative rules of society. These examples could cause differences in the view, knowledge, and experience of traits. However, the results of these tests indicated that there were no statistically significant differences in the distribution of these variables across different age groups. This suggests a consistent experience and perception of these aspects within the online autistic community, regardless of when individuals were diagnosed or identified as autistic. Similarly, Kruskal-Wallis tests were conducted to assess differences in the distribution of responses related to support for autistic people, the impact of social media on autistic individuals, and perceptions of autism, again based on age-related categories. On the same note as the above choice, the age of diagnosis and/or identification question was selected because autistic people have different experiences based on the age of diagnosis or self-diagnosis. These tests revealed no statistically significant differences, indicating that the age at which individuals were diagnosed did not significantly affect their views on these critical aspects of the online autistic community.

Furthermore, Spearman's correlation analysis unveiled meaningful relationships between variables related to autism knowledge, support, and perceptions. The support and knowledge that the online autistic community gives through lived experience and informative posts can positively shape the perception of autism an autistic person has, but also their self-acceptance. Knowledge on autism topics, either on traits or accommodation along with support such as how to prevent shutdowns or ask for accommodations, can help autistic people in everyday life, but also potentially shape perceptions that can lead to social changes. These findings underline the significance of the online autistic community in fostering positive attitudes and support for autistic individuals while highlighting the importance of knowledge dissemination and awareness within social media.

The research questions of the qualitative research aim to study the relationship between social media, the perception of autism, and social change. The first research question is about identifying the main source of information about autism that autistic people use. The second question refers to the knowledge about autism-related subjects from social media. The third research question is studying if autistic social media accounts have helped autistic people. Additionally, the fourth question is about the way autistic social media accounts have helped autistic. The fifth question is about the change in the perception of autism since they started following autistic content creators. Lastly, the sixth question is about the importance of awareness of social media to autistic people.

To answer the first question the data reveals that Instagram is the predominant source of information about autism for the majority of autistic individuals in the study, with 71.6% of participants citing it as their primary source. This suggests that Instagram plays a pivotal role in providing information and fostering awareness about autism within the autistic community. It is important to note that the means for sharing the questionnaire was Instagram.

Furthermore, for the second question, the findings indicate a strong positive correlation between knowledge about autism traits and knowledge about autism terms, with individuals who possess more knowledge about autism traits also tending to have more knowledge about autism terms. This suggests that autistic content creators and correspondingly social media contribute to increasing knowledge about autism-related subjects among autistic individuals. Moreover, the questionnaire responses suggest that autistic individuals who actively participate in the online autistic community tend to possess a deeper understanding of both autism traits and terminology. This finding underscores the potential educational impact of social media platforms within the autistic community. It suggests that by following neurodivergent content creators and engaging with autistic social media accounts, individuals gain knowledge about various aspects of autism. This acquired knowledge not only enhances their own understanding but also likely contributes to a more informed and supportive community. Consequently, social media platforms can play a crucial role in disseminating information and fostering a sense of unity and shared knowledge among autistic individuals, ultimately contributing to a more informed and empowered community.

Moreover, to answer the third research question, the results imply a positive impact of autistic social media accounts, with a moderate positive correlation between

knowledge about autism traits and the support of autistic people. Additionally, the questionnaire responses indicate that engagement with autistic social media accounts has had a positive impact on the lives of participants, such as increased feelings of support and empowerment as a result of their interactions on these platforms. Additionally, the data suggests that these online communities foster a sense of connection and understanding among autistic individuals, which can be particularly valuable in combating feelings of isolation and discrimination. These findings highlight the potential of social media as a powerful tool for creating safe and supportive spaces for autistic individuals to share their experiences, access valuable information, and build a sense of community. Overall, the data supports the idea that autistic social media accounts serve as important resources for providing support and encouragement to autistic individuals, ultimately contributing to their well-being and self-empowerment.

The data analysis for the fourth question indicates that across multiple dimensions, there is an increase in the comfort, self-acceptance, and ability to navigate the everyday lives of autistic people, after following autistic media creators. The mean of questions related to comfort in public settings, expressing joy, understanding oneself better, using accommodations, dealing with stereotypes, and requesting accommodations was 3.9, signifying a positive shift in these areas. This means that the everyday lives of autistic people have improved in some way due to the attitude and perspective changes toward autism. Autistic people may struggle less with their traits or handle better discrimination and ableism without internalizing them. The findings underscore the role of social media in promoting positive changes in various aspects of the lives of autistic individuals. Autistic media creators and their content have contributed to greater comfort and self-acceptance, which are fundamental for well-being. Moreover, online autistic communities have played a role in fostering a sense and empowerment, enabling individuals to better manage challenges like autistic burnout and advocating for accommodations. These results suggest that social media has the potential to serve as a platform for not only information but also personal growth and empowerment among autistic individuals, which aligns with the broader social changes related to neurodiversity and inclusion.

Additionally, the results of the fifth research question indicate a positive shift in perceptions across various dimensions related to autism. The mean scores for all the questions in this category exceeded 3.9, indicating a substantial and positive change in participants' opinions. These findings suggest that following autistic media creators

have had a significant impact on how individuals perceive autism and related aspects such as stimming, meltdowns, masking, sensory processing, and executive dysfunction. These findings suggest that the content shared by neurodivergent content creators has the potential to influence perceptions positively, fostering greater understanding, awareness, and acceptance of autism. Participants reported positive changes in their opinions about not only themselves as autistic individuals but also in their overall perception of autism. These shifts in attitudes can contribute to more inclusive and supportive environments for autistic individuals and signify a promising pathway for fostering greater acceptance and understanding of autism in society. It also highlights the role of online platforms in reshaping societal attitudes toward neurodiversity by providing a platform for authentic self-expression and education. Overall, the results imply that neurodivergent content creators on social media have a substantial impact on shifting perceptions of autism in a more inclusive and accepting direction.

Lastly to answer the sixth research question the results support the importance of awareness of social media for autistic individuals and reveal a strong agreement among participants. A significant majority, comprising 71% of the respondents, strongly agree that awareness of social media is important for autistic people. An additional 26.5% agree, with only a small 2.6% expressing a neutral stance. These findings underscore the pivotal role of social media in raising awareness about autism and its associated issues within the autistic community. The overwhelmingly positive response indicates that social media platforms, particularly those created and maintained by autistic individuals, serve as powerful channels for knowledge, promoting neurodiversity, and fostering a sense of community among autistic individuals. The data suggests that these platforms are not only viewed as sources of information but also as tools for advocacy and empowerment.

## Chapter 6

### Conclusion

This thesis delves into the impact of autistic content creators on the attitudes, perceptions, and social change dynamics within the autistic community and generally in social media. The online autistic community consists of diverse voices and experiences. Qualitative research played an important role in discerning the themes and patterns that resonate within the online autistic community. The analysis of posts from five autistic social media creators showed the content, spanning the entire spectrum of autistic life. These themes show the complex web of issues encountered by autistic individuals. Moreover, the research emphasized the significance of precise and inclusive terminology in describing the autistic experience. Autistic social media creators utilize their platforms to share lived experiences, educate their community, and challenge societal misconceptions. Their multifaceted content trajectories spanned sensory processing differences, the challenges of navigating a neurotypical world, and much more. Importantly, this discourse had tangible effects on the daily lives of autistic individuals, providing practical advice, reducing isolation, and significantly decreasing negative concepts such as ableism, discrimination, and stigma. The online autistic community, through education and advocacy, combatted ableist and discriminatory beliefs in society, ultimately fostering understanding and reducing the stigma surrounding autism. The impact of autistic social media accounts can extend beyond personal experiences, influencing the broader perceptions of autism within the community. By challenging stereotypes and providing accurate information, they empowered their autistic people to adopt more inclusive and accepting attitudes towards neurodivergence. This, in turn, fostered a sense of community and solidarity among the online autistic community, creating a supportive space for dialogue. The potential for broader societal change catalyzed by these creators is evident, with increased awareness, reduced discrimination, and a more inclusive societal discourse surrounding autism on the horizon. Additionally, engagement with autistic social media accounts yielded a positive impact and resulted in positive shifts in various aspects of their lives, enhancing comfort, self-acceptance, and the ability to navigate daily challenges. The data also revealed significant positive changes in perceptions of autism across various

dimensions, fostering greater understanding and acceptance. The overwhelming consensus about the importance of awareness on social media for autistic individuals underscored the role of online platforms in raising awareness and promoting autism awareness and acceptance.

Apart from this, it is worth mentioning that while there is a constantly increasing amount of literature that studies autism outside of the medical model, there is still a lack of literature that is in line with the needs of the autistic community. It is crucial to study autism through the lens of autistic people's needs and experiences. As for future research, it is critical to note that online autistic communities in social media are an optimal source for identifying the needs of the communities and should be considered by researchers. This can be applied to all forms of neurodivergence. Lastly, it would be interesting to conduct similar more comprehensive research, while studying the attitude changes of both neurodivergent and neurotypical people.

In conclusion, this thesis shows the transformative power of autistic social media creators within the online autistic community. Their content promotes acceptance, understanding, and support for neurodivergent individuals. Social media and autistic social media accounts can change attitudes, opinions, and perspectives. Though, it is important to note, that social media is a platform that hosts many voices and is not always positive, and even though the majority of participants had positive experiences with social media, not all people have. The online autistic community potential to lead to social change through the discussions happening, such as new terminology, definitions of traits through the lived experience of autistic people, more accessible diagnosis, and reduced diagnosis discrimination due to gender, race, ethnicity, or socioeconomic status, increase the provision of accommodations to educational or workplace environment, an increase of healthcare services for autistic adults or increase of autism-friendly medical professional. Online autistic community in the last twenty years have achieved a lot, such as more inclusive diagnostic criteria, more participatory research, funding, and autism awareness. Consequently, social media can be a tool for further achievements concerning autism awareness and acceptance.

## References

- Arnaud, S., & Gagné-Julien, A.-M. (2023). The new self-advocacy activism in psychiatry: Toward a scientific turn. *Philosophical Psychology*, 1–24. <https://doi.org/10.1080/09515089.2023.2174425>
- Arnold, L. (2020). Autonomy, the critical journal of interdisciplinary autism studies. *Autistic Community and the Neurodiversity Movement: Stories from the Frontline*, 211-220. <https://doi.org/10.1007/978-981-13-8437-0>
- Arnold, S. R., Higgins, J. M., Weise, J., Desai, A., Pellicano, E., & Trollor, J. N. (2023). Towards the measurement of autistic burnout. *Autism*, 13623613221147401. <https://doi.org/10.1177/13623613221147401>
- Bauer, G. R., Churchill, S. M., Mahendran, M., Walwyn, C., Lizotte, D., & Villa-Rueda, A. A. (2021). Intersectionality in quantitative research: A systematic review of its emergence and applications of theory and methods. *SSM-population health*, 14, 100798. <https://doi.org/10.1016/j.ssmph.2021.100798>
- Beresford, P. (2020). ‘Mad’, Mad studies and advancing inclusive resistance. *Disability & Society*, 35(8), 1337-1342. <https://doi.org/10.1080/09687599.2019.1692168>
- Bitman, N. (2023). ‘Which part of my group do I represent?’: disability activism and social media users with concealable communicative disabilities. *Information, Communication & Society*, 26(3), 619-636. <https://doi.org/10.1080/1369118X.2021.1963463>
- Bolton, M. J., & Ault, L. K. (2019). *Brief Report: Exploring Some Aspects of Social Activism in the Online Autistic Community*. Center for Open Science. <https://doi.org/10.31234/osf.io/nqkgr>
- Botha, M., & Cage, E. (2022). “Autism research is in crisis”: A mixed method study of researcher’s constructions of autistic people and autism research. *Frontiers in Psychology*, 13, 7397. <https://doi.org/10.3389/fpsyg.2022.1050897>
- Botha, M., & Gillespie-Lynch, K. (2022). Come as You Are: Examining Autistic Identity Development and the Neurodiversity Movement through an Intersectional Lens. *Human Development*, 66(2), 93–112. <https://doi.org/10.1159/000524123>
- Botha, M., Hanlon, J., & Williams, G. L. (2021). Does language matter? Identity-first versus person-first language use in autism research: A response to

Vivanti. *Journal of autism and developmental disorders*, 1-9.  
<https://doi.org/10.1007/s10803-020-04858-w>

Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2021). Autistic adults' experiences of camouflaging and its perceived impact on mental health. *Autism in adulthood*, 3(4), 320-329. <https://doi.org/10.1089/aut.2020.0071>

Buckle, K. L., Leadbitter, K., Poliakoff, E., & Gowen, E. (2021). “No way out except from external intervention”: First-hand accounts of autistic inertia. *Frontiers in Psychology*, 1592. <https://doi.org/10.3389/fpsyg.2021.631596>

Buijsman, R., Begeer, S., & Scheeren, A. M. (2023). ‘Autistic person’ or ‘person with autism’? Person-first language preference in Dutch adults with autism and parents. *Autism*, 27(3), 788-795. <https://doi.org/10.1177/13623613221117914>

Cascio, M. A., Weiss, J. A., & Racine, E. (2021). Making autism research inclusive by attending to intersectionality: A review of the research ethics literature. *Review Journal of Autism and Developmental Disorders*, 8, 22-36. <https://doi.org/10.1007/s40489-020-00204-z>

Chapman, R. (2021). Neurodiversity and the Social Ecology of Mental Functions. *Perspectives on Psychological Science*, 16(6), 1360–1372. <https://doi.org/10.1177/1745691620959833>

Chown, N., & Hughes, L. (2016). History and First Descriptions of Autism: Asperger Versus Kanner Revisited. *Journal of Autism and Developmental Disorders*, 46(6), 2270–2272. <https://doi.org/10.1007/s10803-016-2746-0>

Christodoulou, M. (2023). The four C’s model of Thematic Analysis. A Critical Realist perspective, *Journal of Critical Realism*. <https://doi.org/10.1080/14767430.2023.2256109>

Cook, J., Hull, L., Crane, L., & Mandy, W. (2021). Camouflaging in autism: A systematic review. *Clinical Psychology Review*, 89, 102080. <https://doi.org/10.1016/j.cpr.2021.102080>

Cooper, R., Cooper, K., Russell, A. J., & Smith, L. G. (2021). “I’m proud to be a little bit different”: The effects of autistic individuals’ perceptions of autism and autism social identity on their collective self-esteem. *Journal of Autism and Developmental Disorders*, 51, 704-714. <https://doi.org/10.1007/s10803-020-04575-4>



- Creswell, J. W., & Clark, V. L. P. (2017). *Designing and conducting mixed methods research*. Sage publications.
- Cumbo, B., & Selwyn, N. (2022). Using participatory design approaches in educational research. *International Journal of Research & Method in Education*, 45(1), 60-72. <https://doi.org/10.1080/1743727X.2021.1902981>
- Czech, H. (2018). Hans Asperger, National Socialism, and “race hygiene” in Nazi-era Vienna. *Molecular Autism*, 9(1). <https://doi.org/10.1186/s13229-018-0208-6>
- Den Houting, J. (2019). Neurodiversity: An insider’s perspective. *Autism*, 23(2), 271-273. <https://doi.org/10.1177/1362361318820762>
- Dwyer, P. (2022). The Neurodiversity Approach(es): What Are They and What Do They Mean for Researchers? *Human Development*, 66(2), 73–92. Portico. <https://doi.org/10.1159/000523723>
- Dwyer, P., Ryan, J. G., Williams, Z. J., & Gassner, D. L. (2022). First do no harm: Suggestions regarding respectful autism language. *Pediatrics*, 149(Supplement 4). <https://doi.org/10.1542/peds.2020-049437N>
- Farooq, K., Siraj Bashir, D. H. Z., Zarar, R., & Sadiq, W. (2021). The Study on the Role of Social Media in Social Change in Society. *International Journal of Innovation, Creativity and Change*. [www.ijicc.net](http://www.ijicc.net) Volume, 15.
- Hayden, C. (2022). *Different, not less: A neurodivergent’s guide to embracing your true self and finding your happily ever after*. Murdoch Books.
- Higgins, J. M., Arnold, S. R., Weise, J., Pellicano, E., & Trollor, J. N. (2021). Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating# AutisticBurnout. *Autism*, 25(8), 2356-2369. <https://doi.org/10.1177/13623613211019858>
- Jang, J., Matson, J. L., Adams, H. L., Konst, M. J., Cervantes, P. E., & Goldin, R. L. (2014). What are the ages of persons studied in autism research: A 20-year review. *Research in Autism Spectrum Disorders*, 8(12), 1756-1760. <https://doi.org/10.1016/j.rasd.2014.08.008>
- Jnanathapaswi, S. G. (2021). Thematic analysis & coding: An overview of the qualitative paradigm. *An Introduction to Social Science Research*, 1-9.

- Kadiri, F. (2022). Autism Spectrum Disorder: The State of Play. *Journal of Psychology and Behavior Studies*, 2(2), 05–10. <https://doi.org/10.32996/jpbs.2022.2.2>
- Kapp, S. K. (2023). Profound concerns about “profound autism”: Dangers of severity scales and functioning labels for support needs. *Education Sciences*, 13(2), 106. <https://doi.org/10.3390/educsci13020106>
- Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). ‘People should be allowed to do what they like’: Autistic adults’ views and experiences of stimming. *Autism*, 23(7), 1782-1792. <https://doi.org/10.1177/1362361319829628>
- Kara, H., Giwa Onaiwu, M., & Kariuki, M. (2022). The neurodiversity movement and community-led rights-based movements in Asia and Africa. *Autism in Adulthood*, 4(1), 1-5. <https://doi.org/10.1089/aut.2021.29002.hka>
- Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., & Sowden, S. (2023). Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation. *Autism Research*, 16(2), 406-428. <https://doi.org/10.1002/aur.2864>
- Kreck, T. E. (2013). Deconstructing Disability and Neurodiversity: Controversial Issues for Autism and Implications for Social Work. *Journal of Progressive Human Services*, 24(1), 4–22. <https://doi.org/10.1080/10428232.2013.740406>
- Lawson, A., & Beckett, A. E. (2021). The social and human rights models of disability: Towards a complementarity thesis. *The International Journal of Human Rights*, 25(2), 348-379. <https://doi.org/10.1080/13642987.2020.1783533>
- Lewis, L. F., & Stevens, K. (2023). The lived experience of meltdowns for autistic adults. *Autism*, 27(6), 1817–1825. <https://doi.org/10.1177/13623613221145783>
- McCoy, M. S., Liu, E. Y., Lutz, A. S., & Sisti, D. (2020). Ethical advocacy across the autism spectrum: Beyond partial representation. *The American Journal of Bioethics*, 20(4), 13-24. <https://doi.org/10.1080/15265161.2020.1730482>
- Monk, R., Whitehouse, A. J., & Waddington, H. (2022). The use of language in autism research. *Trends in Neurosciences*, 45(11), 791-793. <https://doi.org/10.1016/j.tins.2022.08.009>
- Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and policy in mental*

*health and mental health services research*, 42, 533-544.  
<https://doi.org/10.1007/s10488-013-0528-y>

Pellicano, E., & Houting, J. (2021). Annual Research Review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, 63(4), 381–396. Portico. <https://doi.org/10.1111/jcpp.13534>

Phung, J., Penner, M., Pirlot, C., & Welch, C. (2021). What I wish you knew: Insights on burnout, inertia, meltdown, and shutdown from autistic youth. *Frontiers in psychology*, 4981. <https://doi.org/10.3389/fpsyg.2021.741421>

Rosen, N. E., Lord, C., & Volkmar, F. R. (2021). The diagnosis of autism: from Kanner to DSM-III to DSM-5 and beyond. *Journal of autism and developmental disorders*, 51, 4253-4270. <https://doi.org/10.1007/s10803-021-04904-1>

Ryan, S. & Milton, D., (2022). Introduction. In Milton D., & Ryan, S. (Eds.). *The Routledge International Handbook of Critical Autism Studies*. Taylor & Francis.

Schiltz, H. K., McVey, A. J., van Dyk, I. S., Adler, E. J., & Van Hecke, A. V. (2023). Brief Report: Links Between Nonconformity to Gender Norms, Autistic Features, and Internalizing Symptoms in a Non-clinical College Sample. *Journal of Autism and Developmental Disorders*, 53(4), 1717-1725. <https://doi.org/10.1007/s10803-021-05033-5>

Sibeoni, J., Massoutier, L., Valette, M., Manolios, E., Verneuil, L., Speranza, M., & Revah-Levy, A. (2022). The sensory experiences of autistic people: A metasynthesis. *Autism*, 26(5), 1032-1045. <https://doi.org/10.1177/13623613221081188>

Smooth, W. G. (2013). Intersectionality from theoretical framework to policy intervention. *Situating intersectionality: Politics, policy, and power*, 11-41. [https://doi.org/10.1057/9781137025135\\_2](https://doi.org/10.1057/9781137025135_2)

Stenning, A., & Rosqvist, H. B. (2021). Neurodiversity studies: mapping out possibilities of a new critical paradigm. *Disability & Society*, 36(9), 1532–1537. <https://doi.org/10.1080/09687599.2021.1919503>

Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*. Sage.

Walker, N. (2022). *Neuroqueer Heresies*. Autonomous Press.

Woods, R., Milton, D., Arnold, L., & Graby, S. (2018). Redefining critical autism studies: A more inclusive interpretation. *Disability & Society*, 33(6), 974-979. <https://doi.org/10.1080/09687599.2018.1454380>

# APPENDIX I

## Questionnaire

### Gender

- Female
- Transgender female
- Male
- Transgender male
- Non-binary
- Other, please specify.

### Age

- 18-25
- 26-35
- 36-45
- 46+

### Age of diagnosis and/ or age of identification

- 2-10
- 11-20
- 21-30
- 31-40
- 41+

### The country you live in

Your answer

### How long have you been engaging with the autistic community?

- Less than a year
- 1-2 years
- 3-4 years
- 5 years or more

### How long have you been engaging with autistic social media accounts?

- Less than a year
- 1-2 years
- 3-4 years
- 5 years or more

### Social media you use to learn or be informed about autism.

- Instagram

- Tik Tok
- Other, please specify.

To what extent do you disagree/agree with the following statements? Mark with a (v) the cell which corresponds to your choice.

1-totally disagree, 2-disagree, 3= neither disagree/nor agree, 4=agree, 5=totally agree

## Traits

### Routine and repetitiveness

	1=TD	2=D	3=N/N	4=A	5=TA
I have detailed knowledge about the same/safe foods.					
Social media helped me in my relationship with food and the same/safe foods.					
I have detailed knowledge about stimming.					
I have learned a lot about stimming on social media.					
I feel more comfortable stimming in public after following autistic media creators.					
My opinion about stimming has changed after following autistic media creators.					

### Autistic joy

	1=TD	2=D	3=N/N	4=A	5=TA
I have detailed knowledge of autistic joy.					
I have a better understanding of autistic joy after following autistic media creators.					
I feel more comfortable expressing autistic joy in public after following autistic media creators.					
My opinion about autistic joy has changed after following autistic media creators.					

### Overwhelm responses

	1=TD	2=D	3=N/N	4=A	5=TA
I have detailed knowledge about autistic burnout.					
Social media have helped me handle autistic burnout with tips and lived experiences.					
I have felt able to accept that I have autistic burnout without feeling negative about myself after following autistic media creators.					

I have felt able to accommodate the autistic burnout.					
I have detailed knowledge of meltdowns and shutdowns.					
Social media have helped me in handling meltdowns and shutdowns with tips and lived experience.					
My opinion about meltdowns and shutdowns has changed after following autistic media creators.					
I have detailed knowledge of the verbal shutdown.					
Social media have helped me in handling verbal shutdowns with tips and lived experience.					
My opinion about verbal shutdown has changed after following autistic media creators.					

#### Internal awareness

	1=TD	2=D	3=N/N	4=A	5=TA
I have detailed knowledge of interoception.					
I learned about interoception on social media.					
I have felt more able to handle interoception issues after following autistic media creators.					
I have detailed knowledge of emotional regulation.					
Social media have helped me handle emotional regulation with tips and lived experience.					
My opinion about emotional regulation has changed after following autistic media creators.					

#### Masking and unmasking

	1=TD	2=D	3=N/N	4=A	5=TA
I have detailed knowledge about masking and unmasking.					
Social media have helped me in handling masking and unmasking with tips and lived experience.					
My opinion about masking and unmasking has changed after following autistic media creators.					

#### Sensory processing

	1=TD	2=D	3=N/N	4=A	5=TA
I have detailed knowledge about the sensory processing of autistic people.					
Social media have helped me in handling sensory processing with tips and lived experience.					
My opinion about sensory processing has changed after following autistic media creators.					

I have detailed knowledge of overstimulation and understimulation.					
Social media helped me handle overstimulation and understimulation with tips and lived experience.					
My opinion about overstimulation and understimulation has changed after following autistic media creators.					

### Executive dysfunction

	1=TD	2=D	3=N/N	4=A	5=TA
I have detailed knowledge of executive dysfunction.					
Social media have helped me handle executive dysfunction with tips and lived experience.					
My opinion about executive dysfunction has changed after following autistic media creators.					
I have detailed knowledge of task initiation.					
Social media have helped me in handling task initiation with tips and lived experience.					
My opinion about task initiation has changed after following autistic media creators.					
I have detailed knowledge of autistic inertia.					
Social media helped me handle autistic inertia with tips and lived experience.					
My opinion about autistic inertia has changed after following autistic media creators.					

### Challenges

	1=TD	2=D	3=N/N	4=A	5=TA
I have detailed knowledge about autistic challenges (e.g. sensory issues communication and social difficulties).					
I have detailed knowledge about the negative impact of masking on autistic people.					
I have detailed knowledge about hurtful stimming.					
I have detailed knowledge of internal ableism.					
Existing in this world is traumatic for autistic people.					

### Support – accommodation



	1=TD	2=D	3=N/N	4=A	5=TA
Accommodations are important for autistic people.					
Support is important for autistic people.					
Accessibility is important for autistic people.					
Sensory items and stim toys are important for autistic people.					
Autistic people don't receive sufficient accommodations in education.					
Autistic people don't receive sufficient accommodations in the workplace.					
Autistic people don't receive sufficient accommodations in healthcare services.					

### Diagnosis

	1=TD	2=D	3=N/N	4=A	5=TA
I have detailed knowledge of diagnosis.					
I have learned about the diagnosis from social media.					
Autistic people often get misdiagnosed.					
It is difficult for autistic adults to get a diagnosis.					
I believe in self-diagnosis/self-identification/self-discovery.					
My opinion about self-diagnosis /self-identification/self-discovery has changed after following autistic media creators.					

### Mental Health

	1=TD	2=D	3=N/N	4=A	5=TA
I have learned a lot about medical professionals from social media.					
Autistic people face discrimination and ableism in healthcare services.					
Medical professionals do not have sufficient knowledge about autism.					
Autism-friendly medical professionals are important for autistic people.					
I have detailed knowledge of co-occurring conditions and autism from social media.					

### Terms

	1=TD	2=D	3=N/N	4=A	5=TA
I have detailed knowledge of terms related to autism.					
I have learned a lot about terms related to autism from social media.					
I have detailed knowledge of the term neurotypical.					
I have detailed knowledge of the term allistic.					
I have detailed knowledge of the support needs descriptors.					
I have detailed knowledge of the functioning descriptors.					
I prefer using support needs descriptors.					
I have detailed knowledge of the term person's first language.					
I have detailed knowledge of the term identity first language.					
I prefer using identity-first language.					
I have detailed knowledge of the term neurodiversity.					
I have detailed knowledge of the term neurodivergent.					
I have detailed knowledge of the term intersectionality.					

### Transforming perspectives and types of information

#### Information

	1=TD	2=D	3=N/N	4=A	5=TA
I get informed about autism from social media.					
I prefer to be informed about autism on social media.					
I don't prefer to get informed about autism from medical professionals.					
I prefer posts about lived experiences on social media.					
I prefer informative posts on social media.					

#### Participants' Images about change, social media, and autism

	1=TD	2=D	3=N/N	4=A	5=TA
My opinion about autism has changed positively after following autistic media creators.					
My opinion about autistic traits has changed positively after following autistic media creators.					
I believed in stereotypes about autism before following autistic media creators.					
There is a lot of awareness about autism on social media.					
My opinion about myself as an autistic person has changed after following autistic media creators.					
I understand myself better after following autistic media creators.					
I started using more accommodations than before after following autistic media creators.					
Awareness is important on social media.					
Social media and autistic social media creators have helped me in my everyday life.					
I have requested accommodations more easily after following autistic media creators.					
I can deal more easily with stereotypes after following autistic media creators.					
My experience with Instagram posts about autism is generally positive.					