Use of Social Media by Parents Raising Autistic Children in East London, Eastern Cape, South Africa

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DECLARATION

I, Tina Sisanda Bikitsha, with student number 23B8995, hereby confirm that this thesis, **"*The Use of Social Media by Parents Raising Autistic Children in East London, Eastern Cape, South Africa,*"** is my work and has not been submitted for any degree purposes at any other university. I declare that I am fully aware of Rhodes University's policy on plagiarism and have taken precautions to comply with the regulations.

Signature: TS Bikitsha **Date: 19 December 2024**

DEDICATION

I dedicate this research to my firstborn son, Likhanyile Luminathi Bikitsha. Because of you, I have learnt the true meaning of unconditional love and patience. We have had some challenges but every moment with you has been a blessing, and I am grateful to God for choosing me to be your mom. I love you so much, Parooo.

To all parents raising autistic children, this study is also for you. Your resilience, strength, and efforts inspire me daily. I know sometimes raising an autistic child gets lonely and overwhelming; always remember that you are not alone, and together we can achieve so much.

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ABSTRACT

This study investigates how local parents use social media platforms, focusing on the platforms they use, how they access them, the barriers they face, and the effectiveness of social media in supporting them. Using a qualitative approach and informed by the theoretical frameworks of digital divide and digital literacy, semi- structured interviews were conducted with 10 participants (parents and caregivers), the majority of whom resided in an urban area with one from a township. The findings reveal that social media, especially WhatsApp, Facebook, and YouTube, play an important role in providing emotional support, connecting parents with similar challenges, and information sharing. However, the effectiveness of these platforms is restricted by factors such as high data costs, frequent power outages (loadshedding), limited digital literacy, disinformation, and a lack of South Africa-based online autism support groups. Additionally, the research reveals a gender disparity in social media engagement, with fewer fathers joining online support groups. Recommendations include developing relationships with policymakers to reduce data costs and enhance digital access, creating locally appropriate resources and digital literacy initiatives to improve social media accessibility for South African parents and caregivers of autistic children and, addressing the under-representation of male participants. Future research should include recruiting more fathers and caregivers, particularly in low socioeconomic regions like the Eastern Cape, and parents who lack access to social media due to financial and digital literacy challenges, to better understand their use of social media as parents or caregivers raising children with autism. The researcher’s own experience as a parent of an autistic child provides a unique perspective, which allows a more empathic and authentic understanding of the experiences of the interviewed parents.

I-ABSTRAKTHI

Ngenxa yokushokoxeka kophando kunye nezixhobo zokuncedisa abazali abanabantwana abaphila ne- Autism Spectrum Disorder (ASD) eMonti, eMzantsi Afrika, olu phando luqwalasela nzulu indlela abazali bale ndawo abasebenzisa ngayo amakhasi onxibelelwano. Olu phando lujonga ukusetyenziswa kwala makhasi, indlela abazali abathi bafikelele ngayo kuwo, izinto ezingumqobo ekuwasebenziseni kunye nendima yala makhasi ekubanikeni inkxaso. Ukuqokelela ulwazi, kolu phando kwenziwe udliwano ndlebe kunye nabazali abalithoba kunye nomnakekeli wabantwana omnye. Uninzi lwabathathi-nxaxheba kolu phando luhlala edolophini ze omnye kubo ahlale elokishini. Iziphumo zophando zibonisa ukuba amakhasi onxibelelwano, ingakumbi uWhatsApp kunye noFacebook, adlala indiba ebalulekileyo ekunikeni inkxaso ngokweemvakalelo, ukudibanisa abazali abajongene nemingeni efanayo, nasekwabelaneni ngolwazi. Nangona kunjalo, zikhona izinto ezinqanda ukusebenza ngokupheleleyo kwala makhasi ezifana namaxabiso aphezulu edata, ucimicimi wombane, ukungabinalwazi ngokusetyenziswa kwezixhobo zalemihla ze-intanethi, ulwazi olungeyonyani, kunye nokunqongophala kwamaqela enkxaso kubantu abaphila ne-autism eMzantsi Afrika. Olu phando luphinda lutyhile umsantsa ngokwesini kwindlela ekusetyenziswa ngayo amakhasi onxibelelwano, nalapho bembalwa kakhulu abantu abangotata abathi bazibandakanye namaqela enkxaso kwi-intanethi. Iingcebiso zolu phando ziquka ukwakhiwa kobudlelwane kunye nabankqulunkqi beepolisi ukunciphisa amaxabiso edata, ukuphucula ukufikeleleka kwe-intanethi nokuvelisa izixhobo ezilungele abemi beli. Iingcebiso ziquka namaphulo okuphucula ukufikelela kwabazali kunye nabanakekeli abanabantwana abaphila ne-atutism kwi-intanethi. Amava omphandi, nongumzali onamntwana ophila ne-autism, anika ingqiqo eyodwa kolu phando, nto leyo yenza ukuba awaqonde ngokukodwa nangovelwano amava abazali abathabathe inxaxheba. Olu phando lubalulekile kuba luyongeza kulwazi olukhulayo nolujonge inkxaso efumaneka kumakhasi onxibelelwano kubazali nabanakekeli babantwana abaphila ne-autism. Olu phando lukwamemelela ukuba kuphandwe ngakumbi, kuqukwe nabazali kunye nabanakekeli babantwana abasuka kwiindawo ezisezilalini nezisilelayo, khona ukuze kuqondwe ngokungcono indima yamakhasi onxibelelwano ekuxhaseni iintsapho ezikhulisa abantwana abaphila ne-autism eMzantsi Afrika

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CHAPTER 1: INTRODUCTION

1.1 Background to the Study

Autism South Africa (2023) defines autism spectrum disorder (ASD) as a group of complex neurodevelopmental disabilities. Autism Spectrum Disorder is estimated to affect 1 in every 59 children worldwide (Autism South Africa 2021). There is limited data on the prevalence of children with ASD in non-Western countries, particularly in less affluent nations, where resources for children with any kind of special needs are less developed (Samadi, 2011). According to Daley (2004), studies on children with ASD and its impact on parents have been centered around Western families. Additionally, Samadi (2011) points out that there is limited access to professional services for families with children with ASD living in low- and middle-income countries.

Recent research conducted by Autism South Africa reveals that between 1-2% of the population in South Africa is thought to be affected by autism (Autism South Africa 2021). ASD is viewed as one of the most challenging child disorders for parents to deal with, especially in developing countries like South Africa. The difficulties parents and caregivers of autistic children experience might differ based on personal circumstances, including cultural, economic, and geographical location. Access to diagnostic, intervention, and educational services is a major challenge (Grinker et al., 2012; Mitchell & Holdt, 2014). This leads to parents or caregivers experiencing increased emotional stress and anxiety. Parents of children with ASD often seek additional assistance through social media platforms on their mobile phones and other digital devices.

The medical model still informs interventions in relation to disability. The focus of this model is on detecting a child's deficiencies and addressing them through medical procedures (Oliver, 2013). Parents and caregivers are viewed as passive participants in medical care rather than active caregivers for their children. This necessitates the parents turning to social media sites to seek information and support. The social model of disability, on the other hand, prioritizes the needs of the individual and conceptualizes disability as a mismatch between the environment and the individual's needs (Woods, 2017). An approach based on the social model affords parents the opportunity to advocate for their children's rights and well-being. Cater (2009) suggests that the internet could provide parents access to material related to symptoms and treatments that may benefit their autistic children, they may also use social media to support each other and share coping mechanisms. Similarly, Fleischmann (2005) notes that the internet allows stressed parents of children with ASD to forge ties amongst themselves and extricate themselves from isolation.

Likewise, Livingstone and Blum-Ross (2020) discovered that parents shared their optimism and hope on social media discussion forums, as these platforms give them a place to feel validated and supported so they could see their child as an individual rather than just as someone with a disability. There is evidence that parents and caregivers use a variety of social media platforms, such as Facebook to search for online health information and support groups for people going through related struggles (Cole et al., 2017). Social media can be a helpful tool for educating people with disabilities (and possibly those who care for them) about subjects they might not have access to and could serve as a platform for support groups.

For parents of ASD children, social media support groups offer some benefits that traditional in-person groups cannot offer. These include the flexibility to join from different geographical areas, accessing past discussions and information that can be helpful to them, etc. Even if they do not actively engage in conversations, they can still gain useful insights (Alat, 2017). The downsides of these groups, however, include the potential for getting false information and the absence of nonverbal clues, which can lead to misinterpretation. Scholars such as Wright & Bell (2003) also warn that revealing a lot of personal information may endanger the sender, as researchers or marketers can access the archives of these groups. On the other hand, Clark et al. (2015) point out that “in the age of social media, documenting children's lives in public and sharing the benefits and challenges of parenthood have become societal norms.” This is referred to as Sharenting. For instance, parents have become comfortable posting and disclosing their children's disabilities and chronic illnesses on social media (Siibak & Traks, 2019). However, Otero (2017) is of the view that such parents should think about doing it anonymously.

The study draws from digital literacy and digital divide models to explore how parents or caregivers utilise digital media as coping strategies. Scholarly literature on digital inequalities identifies three levels of the digital divide. The first level pertains to the issue of access to the internet and digital devices. In South Africa, 74.7% of the population have access to the internet as of the beginning of 2024 (Digital, 2023). Despite the high rate of internet use, there is still a significant portion (approximately 25.3%) of the population that cannot access the internet. Furthermore, Mutsvairo & Ragnedda (2019) argue that data access is expensive in South Africa. Due to the cost of digital devices and the equipment required to access the internet, those with low income are less likely to be able to acquire them (Faloye & Ajayi 2022).

The second level pertains to skills and knowledge. Digital skills, which form the basis for digital literacy, refer to the capacity to look for, pick out, understand, analyse, and use information from many digital sources in a particular context (Chetty et al. 2018; Gilster, 1997). The capacity to understand and make use of information from a range of digital sources can be considered a basic literacy in the digital age. In the case of digital devices, individual abilities are likely to develop over time since regular usage promotes a sense of affection for technology, which in turn boosts competence. Using technology effectively requires three types of skills that are sometimes divided into operational, informational, and strategic skills (Van Deursen & Van Dijk 2011).

The third level of the digital divide refers to the benefits or outcomes of the use of digital media. This means that each person's benefit differs because of their ability, inability, and the reasons to utilize digital media (Hildago et al. 2020). On the other hand, Parsloe (2015) asserts that social media may be quite helpful for online advocacy among marginalized populations. Additionally, “the internet, particularly social media, serves as platforms to make people more visible” (Ragnedda & Ruiu 2017, p. 13). This study explores each of these levels in assessing how parents and caregivers use digital technology to support the care that they give to their autistic children and to themselves.

1.2 Research Goal and Questions

The overarching goal of this study is to investigate the experiences and challenges faced by parents or caregivers raising autistic children in East London, South Africa, and how these carers use social media platforms for support in raising their ASD children. The research questions that underpin the study are:

- What kind of social media platforms and apps do parents of autistic children utilize to find support and advice?
- How do they access these social media platforms?

- What obstacles do they face when trying to find health information or support for themselves or their autistic children?
- To what extent is social media effective in supporting parents raising autistic children?

1.3 Methodology

The study employed a qualitative approach as it focused on the social context in which it was conducted (Marshall & Rossman 2014). According to Khothari (2004), qualitative research is a style of investigation that seeks to understand and analyse social phenomena by investigating individuals' subjective experiences, opinions, and meanings. It often entails gathering non-numerical or textual data, such as interviews, observations, or open-ended survey responses, to acquire insights into the complexity and details of human behaviour, attitudes, and beliefs. Additionally, Khothari (2004) asserts that the goal of this approach is to comprehend and interpret data and provide recommendations for additional research rather than necessarily resolving problems.

The study was conducted in East London, where there are two government hospitals that offer free services (e.g., speech and occupational therapy) and three schools that cater to autistic children. East London was chosen for this study because of the city’s diversity of population in terms of race, geographical settings (urban, semi-urban, and rural), language, socio-economic status, etc. The target group of the proposed study consists of ten parents and/or caregivers raising autistic children. The researcher has been in communication with some of these parents through participation in extracurricular activities at two ASD schools in East London. Semi-structured interviews were conducted with participants using a snowball sampling method. Snowball sampling is a method of sampling in which the first participant recruits two more, then those two each bring in two more, and so on, until the number of participants grows rapidly, much like a rolling snowball (Fourie, 2007, p. 447). According to Longhurst (2003), semi-structured interviews are frequently the best method to understand why individuals behave the way they do, what they believe, and how certain policies or events have affected their lives. Data gathered from the participants enabled the researcher to generate deeper understandings of the lived experiences of parents raising autistic children within the context of their use of media. The qualitative approach is fundamentally interpretative in nature, which means that data analysis involved interpreting the sentiments, perspectives, and experiences of parents and caregivers raising autistic children (Curran, 2017). Thematic content analysis was used to analyse the thick and deep data and present dominant or emergent themes that relate to social media practices. Mark & Yardley (2004) agree that thematic analysis is the most appropriate method for any research that seeks qualitative interpretation since it uses systematic components of data analysis. They further state that thematic analysis enables the researcher to correlate an analysis of the prevalence of a topic with some or all the material, providing accuracy and enhancing the research's overall significance.

As a parent of an autistic child, it is important to reflect on my positionality as the researcher. According to Savin-Baden and Major (2023), there are three primary ways that the researcher might determine and develop their positionality. The first step is identifying oneself in relation to the topic, which entails admitting any personal viewpoints that could have an impact on the study. Since the study was inspired by my own experience raising an autistic child and using social media, I am aware that my viewpoints may impact the study, leading to biases. Incorporating verbatim quotes from the parents and reflecting on my own positionality helped to ensure the study's fairness and accuracy. As a second step, researchers should position themselves in relation to the participants by considering both their own viewpoints and those of others. My personal experience may have both a positive and negative influence on the study. It may affect the methodological process and interpretation of the data by helping participants in the study feel at ease and fully express their experiences. As a third step, the environment and the way researchers think have an impact on the study they conduct (Savin-Baden & Major 2023). I allowed the participant to choose a place convenient to them for the interviews, as this gave them a sense of freedom. I was also aware of the emotions that might arise during the interviews.

1.4 Significance of the Study

The study explores how parents of children with ASD in East London, South Africa, use social media to cope with the challenges of caregiving. The significance derives from its ability to address gaps in the literature by focusing on parents and caregivers experiences in the context of a developing country where access to resources, digital literacy and connectivity remain major challenges (Mutsvairo & Ragnedda, 2019). The study provides insightful information on how digital platforms enhance caregiving practices and emotional wellbeing through investigating social media's function as an informational, supportive and advocacy tool (Blum-Ross & Livingstonen, 2020). The findings aim to inform the administrators for online support groups, ASD advocacy organisations, such as Autism South Africa, policymakers, health professionals specialising in neurodevelopmental issues and educators about the needs and preferences of parents raising children with ASD in East London, South Africa. Digital (2023) reported that despite the widespread internet access, 25.3% of the South African population still struggles to connect to the internet

1.5 Overview of the Thesis

In chapter one, I introduced the study and gave a background and the context within which the study was undertaken. I also gave an overview of the problem that the study seeks to address. I then outlined the objective and the research questions, as well as the research design.

In chapter two, I provided a comprehensive overview of the existing literature on ASD, the use of social media by parents and caregivers raising autistic children, and social media support groups. The role of media was also discussed.

In chapter three, the theoretical framework guiding this study was explained and elaborated upon.

In chapter four, I discuss the research design, participant selection, and the interview guidelines used. I also provide a full overview of the method utilised to analyse the data collected. My positionality as the researcher is also problematised and acknowledged. I conclude the chapter with some ethical considerations.

In chapter five, the findings of the research are presented and discussed. The data are arranged into themes that emerged during data analysis and are presented systematically.

In chapter six, I discuss the study's conclusions, highlight its limitations, and provide recommendations based on the findings, while also reflecting on the research process.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

In this chapter, I provide a detailed review of Autism Spectrum Disorder (ASD), starting with an introduction to the disorder and its diagnosis. Furthermore, the chapter explores the emotional journey that parents go through after their children's diagnosis, outlining the challenges and adjustments associated with raising a child with ASD in South Africa. The chapter also covers the use of support groups by parents raising ASD children. Furthermore, it explores the effect of social media platforms on sharing information and experiences about ASD, highlighting the growth of sharenting and what it means for parents who share their experiences online.

2.2 Autism Spectrum Disorder in South Africa

Autism Spectrum Disorder is a group of developmental brain disorders that fundamentally affect a person’s language, communication, and social interaction abilities (*Autism Speaks*, 2023). The word “autism” originates from the Greek word autos, which means "self." Its diagnosis came into being in 1943, when Leo Kanner’s report on 11 children showed signs of restricted BEHAVIOUR and poor social skills. This marked a turning point in the history of the study of autism. Since then, the condition now known as autism spectrum disorder has appeared more frequently in the literature (Mthombeni & Nwoye, 2018). Understanding autism as a spectrum disorder highlights the fact that it is not a one-size-fits-all diagnosis. Each person with autism has a unique set of capabilities and challenges. As a result, support and intervention strategies must be individualised to meet the unique needs of each individual. This realisation is essential to developing effective educational, therapeutic, and social support systems that can accommodate the distinct needs of people with autism. As a result, some individuals with ASD may require extensive assistance in their everyday lives, while others may require less assistance and, in rare circumstances, live totally independently (Autism Speaks, 2023). Statistics South Africa (2019) estimates that children under the age of 15 make up 28.8% of the overall population. Meanwhile, research estimates show that 169,268 children under the age of 15 are estimated to have autism based on a 1% expected prevalence and may require education and other methods of interventions (Pillay et al., 2022).

The cause for ASD is still not known. However, Kolevzo et al. (2007) believe that a child’s risk of developing ASD may be increased by certain factors. These include having aged parents, such as those in their late 30s and older, having a family history of the disorder, carrying specific genetic abnormalities such as Down Syndrome or being extremely underweight at birth (National Institute of Mental Health, 2023). According to Sandin et al. (2014), an individual’s risk of developing autism spectrum disorder increases twofold when they have a parent with the disorder and by ten times when they have a sibling with the disorder. On the other hand, Xie et al. (2015) point out that “the age of parents at the time of a child's birth has been linked to an increased risk of ASD, especially when the father is over 40 years old at the time of the child's birth.”

There is little information available on the prevalence of ASD in South Africa. Its prevalence in the country is based on international statistics (Malcom-Smith et al. 2013). Approximately 1 out of every 59 children worldwide is diagnosed with ASD. The number of cases has increased over time, and the chance of having ASD differs dramatically between social groups and geographical areas (Zeiden et al., 2022). Even though ASD has been estimated to affect 1-2% of the South African population, the autism community in South Africa is sometimes described as neglected. Pillay et al. (2022) argue that despite South Africa being a signatory in the World Health Organization on comprehensive and coordinated efforts for management of ASD, the country has not yet established any national policies that govern the management of ASD services. Similarly, Lord et al. (2022) discovered that ASD is often poorly addressed by governments and policymakers, and it is rarely given priority because of other socioeconomic and public health issues that these governments are faced with. Demands on government resources are causing the services for autistic spectrum disorders to be neglected” (Franz et al., 2018, p. 151). For this reason, diagnostic intervention services in South Africa are limited and those that are in place are severely overburdened.

Disability can be interpreted as a form of punishment or misfortune in certain cultures, resulting in families refraining from getting a diagnosis or treatment for their child. This avoidance tends to be caused primarily by the fear of social stigma, which can lead to isolation and discrimination (Karaca et al., 2021). Even though this is the case in some cultures, Autism South Africa (2022) highlights the importance of early detection and management of developmental disorders such as Autism Spectrum Disorder.

Furthermore, they assert that assessment and diagnosis are not the same process, diagnosis assesses if an individual meets the conditions necessary for a label to be applied, but assessment provides thorough information about the individual. The disorder is diagnosed by a group of medical experts who thoroughly examine a patient's behaviour and developmental progress. In 2013, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was released in its fifth edition by the American Psychiatric Association. Doctors and other medical professionals now use this handbook for diagnosing and treating a variety of mental and behavioural disorders, including ASD (Autism Speaks, 2023). Furthermore, the American Academy of Paediatrics (AAP) (2022) notes that “all children should be screened for developmental delays during their 9-, 18-, 24-, and 30-month child visits”). It is important to understand that ASD is not a disease. It is not something that can be cured; however, early detection is essential (Autism South Africa, 2020). According to Maart and Jelsma (2014), different cultural conceptions and societal understandings of health and disability may result in unequal parental access to and provision of health and social services for their children, depending on a parent's belief system. In accordance with the Centre for Disease Control and Prevention (CDC) (2022), ASD has a variety of characteristics, such as:

- “Social communication and interaction skills: Individuals with ASD sometimes have trouble with eye contact, responding to their names, displaying facial expressions, and interpreting social language
- Language skills: language development may be delayed and following directions may be challenging
- Movement abilities: walking and dressing abilities may be delayed
- Cognitive skills: may have various learning methods; some may be very good at word recognition yet poor at comprehension, while others may be very good at calculations but not as good at solving practical arithmetic problems
- Sensory experiences: reactions to sound, smell, taste, sight, or feel may be unusual
- Restricted and repetitive patterns: may display compulsive interest, follow or participate in a repetitive activity
- Eating and sleeping habits: may have strange eating and sleeping habits, as well as gastrointestinal challenges and,
- Seizure activity: some people with ASD may have epilepsy or seizure disorder” (CDC, 2022, pp. 1–3).

Given the above characteristics, it is imperative to keep in mind that particular individuals who do not have ASD might present the symptoms described. These characteristics can make life challenging for those with ASD, as the way they function in different domains of life can be greatly affected by these traits. According to Golson (2022), differences in social communication and engagement across African cultures compromise ASD diagnosis. Direct eye contact and social interactions are not always appreciated in some cultures; they are regarded as a sign of disrespect, although repeated behaviours and activities are accepted (Uono & Hietanan, 2015). The researchers further stated that these variations in culture make it challenging for Western diagnostic methods to capture the entire spectrum of behaviours linked with ASD in African societies.

Autism South Africa’s (2022) report shows gender discrepancies in the diagnosis of ASD, revealing that diagnoses occur more commonly in boys than in girls, with gender ratios ranging from 4:1 to 5:1. Despite encountering comparable social understanding challenges, girls with ASD have unique distinguishing characteristics. Notably, girls with ASD perform better than their male counterparts on the spectrum in terms of expressive behaviours. This includes the ability to maintain reciprocal discussions and easily interact in verbal and nonverbal activities. Furthermore, Hiller, Young et al. (2014) provide insight into the behaviour of females with ASD. Their research found that, compared to their male counterparts, females with ASD typically displayed fewer and distinct interests. They further point out that “these girls show less object concentration than guys with ASD.” These elements work together to imply that the way ASD manifests in girls entails distinct traits that set them apart from the boys on the spectrum. Despite the fact that certain traits may differ, raising a child with ASD poses various challenges regardless of the child's gender (Chambers et al., 2017). South African parents and caregivers may face specific challenges due to the region's circumstances, such as access to specialist resources, public knowledge, and cultural attitudes about ASD as stated above. According to Cole et al. (2017), parents and caregivers of children with ASD experience increased stress due to the complexity of the symptoms.

Likewise, Alhazmi et al. (2018) argue that the quality of life of parents of children with ASD is lower across all domains in a cohort of South African parents when compared to parents of typically developing children. Moreo et al. (2022) highlight a unique challenge in South Africa, stating that ASD is frequently underdiagnosed and misdiagnosed. For example, Sithole (2023, p. 1) describes the challenges that a mother encountered following her son’s diagnosis:

> My child was misdiagnosed with autism without having a proper diagnosis done to him. I even had him screened for autism at Chris Hani Baragwanath Academic Hospital. After assessing him, the medical professionals there determined that he was not autistic. This has been extremely challenging for me, and I feel I have let my son down.

The above outlines a South African parent's firsthand experience with an autistic child who was misdiagnosed. In South Africa, misdiagnosis of autism spectrum disorder is a serious problem. Highlighting the extent of the problem, Professor Petrus de Vries of the University of Cape Town's Psychiatry Department reported in 2018 that just 10% of people with ASD in South Africa receive a correct diagnosis (Harvey and Meyer, 2018). This figure emphasizes the underlying challenges that contribute to misdiagnosis, including inadequate access to expert diagnostic services, socioeconomic factors impacting symptom interpretation, and a lack of knowledge and training among healthcare professionals about ASD, as alluded to by De Vries (2016). The development and wellbeing of children with ASD as well as their parents and/or caregivers can be impacted if this problem results in delays in providing them with the required support and interventions. Given that cost-free disability-related interventions are heavily overburdened and scarce, parents sometimes have to rely on expensive private disability-related intervention programs for their child with ASD (Saloojee et al., 2007). The authors further argue that despite the fact that some South African parents of children with ASD have private medical insurance, such schemes do not cover the long-term expenses of impairment since these services are too expensive.

2.3 Parental Journey after a Child’s Diagnosis

Raising a child is an important milestone in human existence, which involves a demanding duty for parents. When a child gets diagnosed with a medical condition or disability, it can significantly affect the parents, leading to sad emotions such as anger, self-blame, shame, denial, and helplessness (Wright, 2008). Similarly, Yacoob et al. (2021) are of the view that when parents learn that their children have a disability, shock is usually the primary emotion. This is frequently followed by refusing to accept the diagnosis, along with feelings of anger and uncertainty about the unknown road ahead.

Parents of children with disabilities battle with the diagnosis and may find themselves denying what they see (Hemming & Akhurst, 2009). These parents perceive the fear of stigma and denial as preventative measures that prevent their children from being excluded from society or considered less important than children without disabilities. (Tigera & Makhubela, 2019; Yacoob et al., 2021). Likewise, Mickelson (1997) argues that parents who have children with developmental delays or ASD diagnoses tend to attach more stigma to the disorder compared to other parents. The researcher further asserts that these parents can feel alone and isolated, especially in the early stages of their child's diagnosis, because they are usually unaware of other parents going through similar situations.

Various studies on parental problems in remote contexts indicate that, when confronted with disability diagnosis and dealing with challenges, some parents may resort to abandoning their kids (Bunning et al., 2017). According to Hemming & Akhurst (2009), the manner in which health professionals disclose the diagnosis of a child and the time it takes to provide assistance to a parent dealing with all the challenges of having a disabled child sometimes put parents in a difficult situation. Wright (2008) notes that mothers of disabled children may go through major life-altering experiences, such as being forced to quit their job. This may lead to challenges in their professional and financial lives.

Parents or caregivers of ASD children may experience financial anxiety and depression due to the high expense of therapy, special education programs, treatment, and assistive technology (Sharp & Baker, 2011). According to a report by the South African Security Agency (2023), the Care Dependency Grant (CDG) is the primary form of social protection provided to South African parents and caregivers of disabled children. This grant is capped at R2,090 per month. The criteria for qualifying for the CDG in South Africa is parental or caregiver income; a single parent cannot earn more than R86,280 per year, and if married or in a partnership, their combined yearly income cannot exceed R172,560 (Department of Social Development, 2023). A study by Trafford (2023) reveals that a small portion of the population exceeds the income criteria for this grant. This highlights the issue of the missing middle: parents and caregivers who are financially ineligible for the grant but still cannot afford quality health care. While this group is a minority, Trafford notes that they face major challenges. Additionally, Trafford

& Swart 2023 noted that the national minimum salary for care dependency grants in South Africa is R4,405.79 per month, and this demonstrates a significant discrepancy between the grant amount and the minimum wage. In the worst-case scenario, a single parent earning R8000 a month would be ineligible for the grant, resulting in them spending half of their salary hiring an assistant. According to South African Revenue Services (2023), caregivers and parents of disabled children are eligible to claim certain qualifying medical expenditures through medical expenses tax credits. To qualify for this benefit, both the parent and the licensed medical practitioner must fill out the Income Tax Return-Disability Deduction form (ITR-DD). This process includes the provision of confirmation of the diagnosis, medical aid contributions, out-of-pocket medical charges, transportation, and medical therapy receipts (SARS, 2023).

Learners with disabilities in SA, including those with ASD, tend to encounter serious barriers to proper education. According to Dass & Rinquest (2017), due to transportation challenges, special needs public schools are difficult to reach and frequently overcrowded. This forces parents to make costly decisions, such as enrolling their children in expensive private schools or paying for pricey private transportation (Kiru & Cooc, 2017). As a result, some parents use social media to share information, seek support, and advocate for better educational opportunities for their ASD children (Dehoff et al., 2016). In an article published by the *Daily Dispatch* (Velaphi, 2022), an Eastern Cape mother of an autistic child stated that:

> The fees are so expensive for us as parents with children with autistic children. This is so exhausting, on April 1 we had a march as parents raising autistic children who are battling to find schools that cater for their needs and conditions. There are so many parents who are struggling to find schools that cater for the needs of our children; as a result, some of them are sitting at home. It is very expensive to find a school that caters for the needs and conditions of autistic children.

Another parent pointed out that “it is not easy for us as parents; while we battle for society to understand our children, we are also battling for the government to provide schooling for our children” (Velaphi, 2022). Additionally, Velaphi (2022) noted that there are only two secondary schools in the Eastern Cape province that are particularly designed to cater for pupils who have ASD and different levels of intellectual functioning, namely, College Street Secondary School in East London and Quest Secondary School in Gqeberha. Due to a scarcity of schools for children with ASD, the aforementioned schools have long waiting lists. Additionally, the admission process includes interviews,

and one condition for admittance at College Street Primary School is that the child must be potty trained. This requirement presents major challenges for parents with children with ASD, as some struggle with potty training due to the nature of the condition.

Bertolotto et al. (2024) found that parents and caregivers of children with ASD face various difficulties in the toilet training process. Their study states that children with ASD face more struggles controlling bowel movements and adapting to new routines compared to their typical growing peers. Furthermore, College Street Primary School does not yet have an after-care programme; therefore, parents are responsible for picking up their children between 12:20 (phases R and 3) and 13:30 (phases 4,5 and 6). Such a situation can be emotionally draining for parents who work full-time and do not have other options for their child's care after school.

Research conducted by Medical News (2016) illustrates that due to guilt, helplessness, and lack of awareness, parents find it difficult to control their child's conduct and provide for their needs; they may feel guilty and powerless. Some mothers may believe that they are the cause of their child's condition. This perspective may be influenced by a variety of factors, including cultural norms, societal influences, and even a lack of understanding of the complexity of ASD. Similarly, a study carried out in South Africa revealed that parents or caregivers of children with ASD faced challenges such as limited understanding of autism, insufficient social support, and a lack of information (Franz et al., 2017). Meanwhile, Weiss et al. (2014) argue that raising a child with ASD without adequate understanding can be emotionally draining for parents. Parents health information-seeking behaviours may differ depending on their socioeconomic level, educational background, and the condition of their children. As a result, parents from lower income brackets tend to rely on information gatekeepers, such as social workers, to gain relevant information, whereas those from higher socioeconomic backgrounds are more likely to seek information on their own to assist with decision-making (Walker, 2009). Gardner et al. (2010) found that parents with a higher level of education are more likely to actively explore literature to acquire essential information.

Autism Awareness Day is recognised on April 2nd of each year. As a global effort, its purpose is to improve awareness and recognition of ASD while advocating for the acceptance and inclusion of people with autism (Tonge & Bretten, 2000). In East London, non-profit organisations, such as Autism South Africa, actively encourage involvement by urging people to wear blue “Light up the Bulb”, which represents support for the ASD society and their families. At the same time, schools such as College Street Secondary School contribute to awareness by hosting family days and extending invitations to the entire Buffalo City community, including occupational and speech therapists, ASD non-profit organisations and families raising ADHD children. Local media outlets, including radio stations and newspapers such as the *Daily Dispatch*, conduct interviews with parents and ASD representatives in the province. While having an official day for ASD awareness is important, implementing constant efforts throughout the year is imperative for the development of a more enlightened society. Ongoing campaigns to raise awareness may help break down barriers, eradicate stigma, and promote a culture that values and celebrates people's uniqueness.

Considering the complexities of ASD, parents frequently interact with a significant number of health care team members, such as psychologists, medical practitioners, educators, and social workers, as well as speech language and occupational therapy professionals (Huws et al. 2001). With so many healthcare professionals likely involved, parents may be uncertain where and how to seek or pay for interventions, as well as which therapeutic choices and resources are most suited to their children. Cole et al. (2017) argue that these services are not often adequately incorporated, resulting in elevated stress for parents, unfavourable health outcomes, and marital problems in couples. Likewise, it has been observed that health professionals often fail to recognise the psychological discomfort and information demands that parents or caregivers of children with disabilities experience (Gona et al., 2018). Additionally, Dura-Vila (2010) points out that parenting a disabled child has substantial effects on both parents and families. He goes on to elaborate that one possible outcome for a parent is the frustration of being neglected by their spouse when there is a definitive diagnosis that a child is permanently disabled; in most cases, the mother is left with a disabled child. Furthermore, Dura states that in the absence of the father, deserted mothers must fend for themselves, resulting in emotional and physical strain. This problem is not exclusive to mothers of disabled children; it is estimated that two out of every three SA children have only one parent recorded on their birth certificate (Duma, Tshabalala & Mji, 2021). Meanwhile, research by Luther et al. (2005) observed that mothers of children with ASD sought medical attention and took antidepressants more frequently than fathers.

However, based on one's belief system, certain parents of children with disabilities, including ASD, might explore alternative options. These may consist of visits to medical doctors, consultations with traditional healers, and seeking guidance based on their belief systems, which may be traditional, such as witchcraft and religious beliefs. These parents seek something that may assist and change their situation (Tigera & Makhubela 2019). Mazibuko et al. (2020) argue that the shortage of skilled healthcare personnel in public healthcare institutions makes it challenging to provide proper care and support to caregivers following a diagnosis. This lack of assistance might be especially obvious when coping with conditions like ASD. The society may also stigmatise the condition due to a lack of awareness, making life even more difficult for parents and caregivers (Mthimunye, 2014).

2.4 The Role of Media and Representation of Autism Spectrum Disorder

The media has become a key source of communication, and the desire of individuals to talk about what emerges in the media has an outstanding influence on shaping public opinions and social conduct (Kang, 2013). Similarly, as Fourie (2010) notes, the media remains an essential institution in society, as it impacts how we understand several social dynamics, including ASD. Additionally, Sousa (2023, p. 4) noted that in a society driven by increasing interconnection and technological reliance, the importance of media and information should not be understated. People interact with various types of digital media, including news, narratives, and videos, which can have a major effect on forming our perspectives, attitudes, and behaviours. In light of this, the media fulfils the following functions:

- **Information**

  The media informs people about events and societal trends, and it plays an important role in how the public understands health issues (McQuail, 2000). This information dissemination plays an essential role in raising awareness and understanding of conditions such as autism, as it can influence society's attitudes and norms. In addition, the surveillance function includes the dissemination of useful information regarding daily living, such as updates on health, social developments, and political issues (Steinberg, 2007).

- **Correlation (interpretation)**

  The media can be responsible for explaining, interpreting, and also commenting on the meaning of information and occasions, offering support for well-known authority and norms, socialising, coordinating separate exercises, supplying to consensus building and setting orders of priority, and by doing so, selecting the status of the topic (McQuali, 2000). Beyond providing information, the media offers context and interpretation, influencing how society views ASD (Steinberg, 2007). This interpretive function is critical because the portrayal of autism has the potential to either educate or reinforce stereotypes and discrimination.

- **Continuity**

  Media represents cultural norms and recognises the presence of cultural groups, which contributes to the continuation of social understanding (McQuail, 2000). This is essential in the representation of autistic people because accurate portrayals can help normalise different challenges or experiences.

- **Entertainment**

  The media provides entertainment by presenting narratives and characters that connect with audiences. While this can be a form of escapism (Hanson, 2016), it also raises issues about the types of narratives given regarding autism. Popular media frequently emphasises autistic individuals struggles and shortcomings rather than their strengths (Jones & Harwood, 2009).

- **Mobilisation**

  According to McQuail (2000), the media can advocate for social concerns and rally public support. This function is important in the context of autism, as media advocacy can serve to emphasise autistic people’s needs and rights, fostering a more inclusive society. Fourie (2018) states that the media has a responsibility to the public, such as disseminating accurate and objective information as well as setting agendas for community concerns.

The collaboration of these roles is seen in how media portrayals of ASD can influence public awareness and perceptions. Media representations of autistic people frequently promote negative stereotypes, portraying them as either highly gifted or socially weak, which can lead to discrimination and shame (Nordahl-Hansen et al., 2018). For example, Fontes and PinoJuste (2021) found that widespread preconceptions regarding autism can discourage those with autism from admitting they have the condition, further contributing to negative societal attitudes regarding ASD. While some media portrayals, such as those in popular programmes like “The Big Bang Theory and Rain Man, have been criticised for their oversimplified and often negative portrayals. There are emerging storylines that attempt to represent autism more accurately. South African soap operas, such as Generations: The Legacy and 7de Laan, are beginning to cast actors with disabilities for major roles, indicating a good shift toward inclusivity (Swartz, 2010). However, despite being cast in prominent roles, these characters may receive minimal screen time, which can diminish their overall effect for several reasons. When characters with autism appear briefly, audiences may not have enough exposure to properly comprehend or relate to their experiences.

The media’s power over health storylines extends to controversial topics such as the disproved link between the MMR vaccine and ASD. Despite the lack of scientific evidence supporting these claims, media coverage had a substantial impact on public opinion and vaccine hesitancy (Holton et al., 2012). According to Pearce et al. (2008), the media plays an important role in moulding public attitudes toward the MMR vaccine, as parents frequently rely on it for vaccination information. This reliance is concerning, especially since many parents lack the medical understanding required to properly evaluate media content. The negative coverage of the MMR vaccine autism dispute resulted in a significant drop in public trust in the vaccine’s safety in the early 2000s (DeStefano & Shimabukuro, 2019). This shows how media portrayals can spread misinformation and influence public health practices, highlighting the importance of accurate representations in health-related discussions.

According to Alper (2023), communication researchers are becoming more interested in investigating how new media affects underrepresented groups in academic literature. Alper further notes that communication researchers investigate how technology can both enhance and harm the visibility, inclusion, and representation of these groups. With few exceptions, disability and its relationship to social, cultural, and political life are frequently misunderstood. This misunderstanding masks the complicated ways in which disability connects with other aspects of human diversity. It also excludes disabled people from crucial theoretical and philosophical conversations (Ellcessor, 2016). While Franz et al. (2017) argue that there is a considerable gap in the proportion of ASD research undertaken in low- and middle-income (LMIC) countries compared to high-income (HIC) countries. Their study's scoping review, for example, revealed that less than 1% of global ASD research was conducted in Africa. Even though Franz's study did not directly compare the proportion of research in all (LMIC to HIC), it was evident that the majority of ASD research originated from HIC, where the minority of individuals with ASD reside. This reflects a larger pattern in African research, where the continent's overall contribution to global scientific efforts is very low. Sub-Saharan Africa continues to invest much less in research and development compared to the other parts of the world. On average, the region spends less than 1% of its Gross Domestic Product (GDP) on research and development, with estimates ranging from 0.42% to 0.5% (NACOSTI, 2021).This differs substantially from the increasing research and development investments reported globally. For instance, according to Ritchie and Roser (2024), Europe allocates approximately 2.1% of its GDP, Asia invests roughly 2.5%, and North America leads with 2.7%. The global average for research and development investment as a share of GDP is around 2.2%. As Jones (2022, p. 1) puts it, “There is a need for greater diversity, accuracy, and positive portrayals of autistic characters within entertainment media.”

Neurodivergent individuals, their parents, and caregivers are increasingly sharing their own experiences and conducting their own investigations (Rosqvist, 2023). According to Gillespie-Lynch (2014), the rise of modern media channels, such as social media, has increased the availability of an additional spectrum of social identities and connections associated with ASD. For example, hashtags such as #ActuallyAutistic, #AskingAutistics, and #BlackAutisticLivesMatter on X, as well as South African Facebook groups like "Seems like it's my destiny and “I am Autistic but I can,” These platforms have helped to connect individuals on the autism spectrum, as well as their parents and caregivers, regardless of their geographical location. However, Sausa (2023) argues that people on the autism spectrum experience both obstacles and opportunities when it comes to navigating the complicated world of media.

2. 5 Social Support Groups

Researchers continue to investigate techniques for developing technologies that are interactive for children with special needs (Alper, Harcaded, & Gilutz, 2012). Previous studies explored the potential of computing techniques to assist caregivers of children with special needs, such as gathering behavioural data automatically, enabling collaborative decision-making, and introducing wearable sensors for children (Ammari et al., 2014). The researchers assert that the use of modern technology to care for children with ASD is a growing study area. Hong et al. (2012), for example, suggest an online mirror concept, which allows young adults with ASD to seek guidance from reliable family members and professional social networks. Moreover, the use of social networking platforms has shown potential in improving relationships and offering support for parents of children with autism by means of diversified networks and support groups (Hong et al., 2013). Ammari et al. (2014) emphasise the importance of thorough information for parents and caregivers of special needs children, such as managing time and psychological demands, accessing community resources, creating future plans for their children, and understanding their children's rights.

As highlighted in the previous section by Dura-Villa (2010), caring for an autistic child may cause an emotional strain on a parent or caregiver. Therefore, it is very important to prioritise both the child and the emotional support needed by parents and caregivers. Life becomes even more difficult for those caring for someone with ASD due to the lack of experts who truly understand the challenges of autism spectrum disorder, especially when cultural misunderstandings are involved.

Therapeutic and medical professionals may assist parents of autistic children by recommending looking for either formal or informal support groups (Cole et al., 2017). In addition, the reasons that lead a parent to seek out a support group include a lack of extended family support structures, a growing trend toward self-help groups, and recommendations from health professionals for parents to get more involved in the development of their child's care (Child Mind Institute, 2023).

Autism Parenting Magazine (2023) describes support groups as “a group of individuals with similar experiences or problems who offer each other positive reinforcement, comfort, and advice." Law et al. (2002) affirm that support groups are volunteer groups of people who have similar issues in their health or daily lives. The researchers further state that these parent groups are voluntary and can be led by professionals or parents, serving the primary purpose of companionship and support, dissemination of information, and experience sharing.

According to *Autism Parenting Magazine*, joining an autistic support group may assist a person with autism or their caregiver feel less isolated, share ways of dealing with particular instances, seek professional assistance, express frustrations safely with no judgments, and avoid depression. On the other hand, Huws et al. (2001) (cited in Cole et al., 2017) found that parents perceptions of support could mitigate the impact of stressful events by enabling them to let go of troubling feelings, share experiences that are common, and obtain information about how to care for their child with ASD. Meanwhile, findings by Cole et al. (2017) revealed that parents are extremely satisfied with the sense of agency and belonging received by participating in a support group. The researchers further note that by providing opportunities for parents to interact with others and obtain additional support, the challenges of getting the support needed may be reduced. Despite financial constraints for support services in South Africa, some organisations provide assistance to families and individuals with ASD, including support groups and training, such as Autism South Africa.

Autism South Africa is a non-profit organisation dedicated to raising autism awareness, acceptance, education, and advocacy across the country. Given a significant national presence, the organisation gives assistance and resources to all nine provinces of the country. Autism South Africa additionally offers a list of service providers, including hospitals and medical specialists, in each province. Individuals may reach out to regional representatives in their respective provinces to obtain access to their face-to-face support groups.

Taylor (2011) asserts that, while traditional support groups for parents are accessible in South Africa, access to these groups is challenging due to a number of different situations. This may include a lack of public transportation and childcare constraints (Duma et al., 2021). Similarly, Eide et al. (2015) argue that travel distance and transportation tend to be more challenging in many rural places. Parents frequently worry about who will look after their children while they attend these support meetings.

On the other hand, Alat (2017) points out the importance of physical attendance at these face-to-face meetings, as it becomes a key factor in ensuring the success of the group's longevity. However, after comparing traditional support groups to digital support groups, parents reported getting more assistance online than offline (Ammari et al., 2014). The researchers further conclude that, given the challenges they encounter, parents with special needs children are increasingly using the internet to search for resources, seek information, and find social support. Meanwhile, Mankoff et al. (2011) observed that when mainstream medical advice does not match the realities of patients with chronic disease, they turn to online social media support groups for resources and information, while forming new relationships and identities along the way. It is worth noting that online groups are especially effective for people who find it challenging to join in-person support groups. These obstacles include living with stigmatized disorders such as mental disorders or constant isolation as a result of physical impairments or caregiving duties (Cater, 2009).

2.6 Social Media

The word social media emerged in 1994, but it gained prominence in the mid-2000s as Web 2.0 technologies gained recognition. During the present era of electronic interaction, numerous types of digital interaction, such as text, photos, and videos, have completely transformed the way individuals connect and exchange information, often resulting in the formation of virtual communities (Sweet et al., 2020). The researchers further point out that social media often includes social networking sites like Facebook, LinkedIn, and Pinterest; microblogging tools like X and Tumblr; and media sharing platforms like Instagram and YouTube. Each of the tools enables users to share information and communicate with others while creating online communities based on shared interests. Meanwhile, Bucher (2015) notes that being sociable on social media entails forming relationships using adaptive algorithmic design. Each click, share, like, and post assists to create connections and relationships. As a result, the network constantly expands and changes, eventually converting into a network of networks. Social interaction in social media is not fixed; it is a continuous process of connection and participation. Due to social media, the modern definition of community has evolved. Previously, it required physical proximity. It now includes connecting with individuals even if you have never met them in person. According to Skinner & Schaffer (2006), the internet empowers users by providing access to scientific information and social support networks that enable them to transform into knowledgeable participants in their healthcare services.

Some internet users seek medical guidance from healthcare professionals or reputable offline sources; users share health information with one another, and this information can be inaccurate at times (Bujnowska-Fedak, 2015). Even so, social support can be overlooked if patients do not actively seek informational or emotional support from family and friends or if these support networks fail to match the needs of the individual (Skeels et al. 2010). According to Foster (2016), when the above-mentioned mainstream health information fails to suit the lived experiences of caregivers or patients with chronic illnesses, these often turn to social media platforms for advice and resources, establishing new relationships and identities in the process. The use of social media for exchanging knowledge, gaining information, seeking emotional support or advice and connecting with online communities has increased significantly over the years.

Mendelsohn (2010) notes that posting statuses on social networking sites can disclose whether a mother has postnatal depression or if her child has developmental impairments. This practice reveals how people utilise social media to engage in conversations concerning their children.

Social media has a significant influence on how parents raise their child with ASD Furthermore, social media provides internet users with a platform to discuss and exchange views on a range of topics. Families with autistic children as well as individuals with autism often share their own stories on social media. This evolution has turned social media into an invaluable tool for members of the public struggling with similar challenges. As a result, social media platforms are a valuable resource for autism-affected individuals and families, establishing meaningful relationships while encouraging the sharing of resources and advice in ways that are both accessible and engaging. Autism Speaks, for example, strives to raise awareness of ASD by encouraging people to join social media groups where they can share their experiences and seek help from others (Autism Speaks, 2023). Research evidence from Saha & Agarwal (2016) showed that family members experiences shared on social media, primarily through blogs, Twitter, and Facebook, shed light on different aspects of autism.

Parents of children with ASD declared that other parents with ASD were their primary source of information and guidance (McCabe, 2007). Whereas, Huws et al. (2001) assert that this drive for parent relations with other caregivers with children with ASD has connected parents to the internet and online support groups. Additionally, Hamm et al. (2013) found that parents and caregivers prefer social media over traditional forms of communication. This highlights the significant role of social media in caregiver relationships and its relevance in current caring practices.

According to Burton et al. (2013), autism emerges as one of the most talked about health concerns on freely accessible mother blogs. Even though this is the case, Saha and Agarwal (2016) point out that while there are benefits of online information storage on many health issues. There are several misleading information online related to various medical conditions, such as autism.

Parents of disabled children possess the skills to provide mutual assistance to one another (Kerr & McIntosh, 2000). Meanwhile, Fox & Hoy (2019) argue that parents have traditionally been viewed as protecting their children from the possible harms of media exposure and involvement; they are now increasingly viewed as (potential) violators of the rights of their children and overall well-being. The reason for this is the common practice of “sharenting” – “the habitual use of social media to share news, images, etc. of one’s children” (Fox & Hoy, 2019, p. 1). Considering that some parents engage in sharenting by disclosing information about their children online, one must question the degree of such sharing.

2.7 Sharenting

In the previous section, I briefly addressed the concept of sharenting, defining it as the constant posting of personal information about one's children on social media platforms. In this section, I explore this phenomenon, reviewing its effects and complications within the context of current parenting practices in the digital era. Sharenting comes from the terms share and parenting. This refers to sharing child images on social media, regardless of the child's consent. According to Udenze & Bode (2020), parents who post details about their children's lives on Facebook or blogs can interact with friends and family, get affirming comments, and feel encouraged to continue sharing details about their own and their children's lives. Similarly, Mendelsohn (2010) is of the view that the use of social media platforms by mothers has been most widely defined by “Mommy

Blogging," in which women upload public blogs tracking and reflecting on their children's lives, offering advice to fellow parents, and advocating parenting-related items. Bode (2020) highlights that parents' public sharing of personal information frequently produces pleasant feedback, such as a like, share, or unexpected comment. Such stimuli then motivate a parent to keep sharing personal information in public forums.

While they go through the difficult phases of parenthood, sharing helps parents of children with disabilities feel less alone. On the other hand, a trend has emerged in which some parents, sometimes known as influencers, share videos of their child with autism experiencing strong emotional states, often referred to as meltdowns. According to Rodriguez et al. (2019), these parents claim that such videos receive the most views and provide a chance for earnings from content. However, many families emphasise that their primary objective is to provide support and establish a feeling of community (Goggin & Ellis, 2020). Sharenting which leads to data mining of childhood, may begin before the child is even born. For instance, it is becoming quite common for expecting parents to set up a social media account for their unborn child before they are even born (Leaver, 2015). Research conducted by Morris (2014) provides additional evidence for such an occurrence by highlighting the active participation of parents, especially mothers, on social media platforms. Furthermore, Morris states that 89% of moms with newborns have made status updates about their children on Facebook, and over 97% have uploaded images of their children. It appears that social media platforms have become a vital part of modern ways of parenting. The connection between digital platforms and parenting not only reflects social trends in communication and self-expression, but it also raises concerns about privacy, consent, and the long-term consequences of children's digital records. As Sibaak and Traks (2019) pointed out:

> The long-term effects of sharenting on people remain unclear; it is evident that sharenting creates an online record for the child, which may result in undesirable outcomes such as breached privacy, identity theft, and possible shame for the child.

In South Africa, both the Children's Act (38 of 2005) and the Protection of Personal Information (POPI) Act play an essential role in protecting children's rights, especially their privacy and protection from online risks. The Children's Act (38 of 2005) emphasises children's rights to privacy and protection from danger. Furthermore, the Act stresses that children have the right to freely express their opinions and participate in choices that impact their future (South Africa, 2005). This implies that parents have the responsibility of protecting their children from potential risks of the internet, as they are the gatekeepers of their children's private information online. A recent *Daily Dispatch* online article supports this assertion:

> An East London father of a four-year-old is fuming after a school posted pictures of his autistic son naked on the school's social media page. The father, who is not being named to protect the dignity of the child, said he saw the pictures on Sunday after they were posted on the School's Facebook page. In her response to the article, Autism SA regional development officer, Antoinette Bruce-Alexander, said the school had no right to post a compromising picture. With the POPI Act as it is at the moment, and the parent did not give any consent, the child's face must be blocked out and no reference must be made to the child's name. This goes for any minor child, Bruce-Alexander said.
>
> (Gosa, 2024, p. 1).

The POPIA seeks to regulate the handling of personal data, particularly that of children. This Act mandates individuals and companies to handle private information ethically and cautiously, ensuring that it is collected, retained, and disseminated effectively. When parents disclose their children's information online, they should be mindful of the POPI principles, which highlight transparency, consent, and accountability.

Steinberg (2018, pp. 879–881) highlights the following measures as guidelines parents can consider implementing to mitigate the risks associated with sharenting:

- Parents should familiarise themselves with the privacy guidelines of the platforms they use to share content.
- Parents should establish notifications to inform them when their child's name shows up on a Google search result.
- Parents should consider sharing anonymously at times.
- Parents should be cautious before disclosing their child's exact whereabouts.

On the other hand, Na and Zhang (2019) assert that parents are generally quite cautious about their children's health information. They are concerned with information credibility and accuracy, and they have their own set of standards to guide their judgments. For example, parents might evaluate the accuracy of information based on its sources and personal experiences. Walker (2009) found that parents of ASD children often ignore suggestions supplied by authorities such as the government or provided by individuals with little expertise regarding childcare.

2.8 CONCLUSION

In this chapter, I discussed the literature related to Autism Spectrum Disorder (ASD) and the experiences of parents raising children with ASD in South Africa. I started by discussing ASD within the South African context, pointing out the diagnostic challenges and the limited availability of support services in a resource-limited country. I then discussed the emotional process parents go through after their child's diagnosis, noting the changes and challenges they confront. This was followed by a discussion of the function of social support groups, such as face-to-face and online groups, in giving emotional and practical support. I also looked at how the media influences public perceptions of ASD, addressing the positive as well as the negative elements of representation. Lastly, I discussed how social media can serve as a valuable tool for interaction and learning while taking into account the barriers presented by digital inequalities and a lack of digital literacy. In the next chapter, I explore the theories of digital divide and digital literacy, which form the theoretical foundation of this study.

CHAPTER THREE: THEORETICAL FRAMEWORK

3.1 Introduction

In this chapter, I expand on the theoretical frameworks of the study, namely, digital divide and digital literacy. These frameworks provide essential insights into challenges and benefits associated with inequalities in access to technology and digital skills. They serve as a lens to explore how these discrepancies influence parents and caregivers ability to utilise social media as a support tool while raising children with Autism Spectrum Disorder (ASD). In an era where digital technologies play an increasingly important role in shaping societies, the issue of digital inclusion has become a prominent issue on the global agenda. The digital divide, which includes inequalities in access, cost, and digital literacy, has the potential to exacerbate the existing inequalities (Mishi & Anakpo, 2014).In South Africa, notably in the Eastern Cape, factors such as high data costs, limited internet access caused by loadshedding, and different levels of digital divide among parents and caregivers influence how they use social media for assistance. Many parents raising ASD children rely on platforms such as WhatsApp to interact with schools, therapists, and other caregivers; however, challenges such as language barriers, misinformation and security concerns prevent effective engagement (Cole et al,2017).Similarly, digital literacy goes beyond just having access to technology; it includes the skills to find, understand, and use the online information. This chapter delves more into concepts of digital dive and digital literacy, both of which are essential for understanding the challenges that parents and caregivers experience when accessing digital tools. These frameworks not only inform the research methodologies discussed in this chapter but also guide the analysis of the findings in chapter five.

3.2 Digital Literacy

Digital literacy is defined by Hobbs (2021, p. 4) as the knowledge, skills, and mindset needed to effectively utilise social media and the internet. It incorporates all the skills required to effectively navigate the digital world, evaluate data critically, and establish meaningful online relationships. Hobbs definition includes the following five components:

- Accessing: Digital literacy entails having the skills and resources required to access and obtain data from multiple media reports and to also effectively interpret conversations.

- Analysing: Digital literacy comprises the skill to critically evaluate media content by understanding the methods, such as biases, and anticipated outcomes employed by media creators.
- Creating: Digital literacy entails the ability to generate relevant media messages using a variety of media production tools and approaches. In this regard, Hobbs encourages innovative thinking and confidence in personal expression.
- Reflecting: This promotes contemplation on personal and social values, including the impact and influence of media on both individuals and communities.
- Taking Action: Digital literacy comprises the skills needed to take informed and ethical action, such as campaigning for media fairness, engaging in media activism, and utilising media for constructive social change.

According to Hobbs (2021, p. 9), the concept of digital literacy is part of a broader spectrum of terminologies that have emerged due to the recognition by different people, academic researchers, and knowledge communities of the significance of learning new skills when navigating the 21st century's media-rich world. Eshet (2004, p. 103) refers to digital literacy as "a modern-day survival skill that assists users to overcome the challenges and barriers they experience online”. These include not just technical skills for utilising digital technologies but also cognitive and socio-emotional skills for interacting with digital data and communities.

Third et al. (2013) explored an intergenerational education program in Australia where adults and young people learnt about internet safety and digital literacy together. Their Living Lab initiative aimed to improve parents’ digital literacy while also promoting safe online involvement for their children. This non-hierarchical learning environment encouraged trust and shared responsibility for technology use. The study found that the model improved parents’ digital literacy, familiarity with online safety controls, and understanding of the benefits of active online participation (Good et al., 2015). This perspective remains particularly relevant in the context of digital literacy for parents of children with ASD, as it empowers them with the skills required to facilitate their children’s secure and effective online participation.

Digital media are rapidly being recognised as essential tools for participating in numerous parts of modern life, such as social relationships, career prospects, and general quality of life (van Deursen & van Dijk, 2014). However, extensive research has shown that digital inequality, which stems from a lack of access to technology or insufficient abilities to utilise it, may have an enormous effect on relationships among individuals and livelihoods (Dobransky & Hargittai, 2016). According to Jaeger (2012), this is especially relevant in the context of disability, which is a substantial source of variety and inequality in society. Considering this, assessments of disability in connection to digital media usage have not kept up with research of other social causes, illustrating gaps in understanding how digital literacy impacts those with disabilities and their families. Apart from technical access, digital inequality includes autonomy of use (i.e., freedom and convenience of accessing the Internet), different skill levels, availability of support, and the particular uses of the Internet (DiMaggio, 2004). These technical discrepancies frequently point to greater social injustices, as individuals from lower socioeconomic backgrounds and racial or ethnic minorities are unable to utilise the Internet than their richer counterparts. When it comes to the use of social media by parents raising ASD children, digital platforms as well as virtual communities can provide essential support network access to resources and information for ASD management (Neitzel and Ritterfeld 2023). However, low-income parents and other individuals who lack computer literacy can struggle to access these vital resources. Lack of ability to form relationships with online support groups or access educational resources can worsen feelings of seclusion while hindering the sharing of useful approaches and perspectives (Bunning et al., 2017). Kumm (2021) asserts that bridging the digital divide for these parents is thus crucial, not solely for their own mental health but also to enhance their children's developmental results with ASD. Bridging this gap through initiatives such as providing reasonable internet access, digital literacy education, and improving the accessibility of online information can assist reduce existing economic and social disparities and biases, fostering a more inclusive digital environment within the community. As digital exclusion can intensify the differences amongst different users and reinforce existing economic and social disparities and biases (Sousa, 2023, p. 66). Continuing on the challenges of digital exclusion, now turn to the concept of the digital divide, which further explores the inequalities in access to technology for these parents and caregivers.

3.3 Digital Divide

Africa’s digital landscape is as diverse as its geographic areas. While certain areas boost a thriving technology ecosystem, a substantial part of the population experiences barriers that prevent them from taking full advantage of the benefits of the digital age. Limited access to electronic devices, a lack of technological expertise, internet connectivity, and social differences are among these obstacles. The term “digital divide” refers to the range of disparities between people who have access to digital technology and the necessary skills and those who do not have access (Sousa, 2023, p. 64). On the other hand, the World Bank (2023) defines digital inequality as the disparities in access to digital technologies between high- and low-income countries. These barriers disproportionally affect marginalised communities, including families raising children with disabilities. Research conducted by the International Telecommunication Union (ITU 2023) revealed that 2.6 billion people, or one-third of the global population, remained offline in 2023, highlighting the constant inequalities in digital access. Groups have insufficient access to digital technology due to high expenses and an overall lack of infrastructure, including intermittent electricity supplies and a shortage of Information and Communication Technology (ICT) facilities (Qigui et al., 2018). According to Cullan (2001), various research and policy publications around the digital divide highlight specific groups who suffer significantly in their use of ICT. Individuals with low literacy skills, the unemployed, the elderly, single parents, those living in remote or rural areas, low-income individuals, and individuals with disabilities are among these groups. This is particularly relevant in the context of parents raising ASD or children with disabilities, as they often face unique challenges in accessing support and resources online.

Fixed-broadband services accounted for more than 80% of worldwide Internet traffic in 2022, highlighting infrastructure gaps in underdeveloped regions. The World Bank (2023) report on the digital dividend emphasises that while digital technologies are spreading globally, the developmental advantages of utilising these technologies remain concrete to more educated and affluent parts of society. This inequality in access is more concerning for families raising disabled children, especially due to the scarcity of resources in underdeveloped countries, which rely mainly on digital platforms for support, educational resources, and social connections.

Grech (2009) provides a significant insight into how digital barriers impact individuals with disabilities, arguing that the challenges extend beyond simply having access to technology. For parents of children with disabilities, bridging digital inequalities is more than just having access to the internet, it also means having the tools, expertise, and social support to properly utilise online resources. In South Africa, the cost of mobile data remains a significant concern. Research ICT Africa (2022) discovered that South Africa has some of the continent's highest mobile data prices, worsening digital exclusion.

Platforms like WhatsApp have merged as preferred online tools for parents raising ASD children due to their low cost and ease of use. While WhatsApp is a cost-effective communication tool, it cannot replace larger platforms such as Facebook and YouTube, which supply greater content and resources (Barker, 2019). As previously noted, the digital divide includes a number of factors that contribute to unequal access to technology, such as socioeconomic and geographic inequalities. For parents of children with ASD in South Africa, the historical and social context of digital access is caused by the inequalities that have existed since colonialism. As Grech (2015) points out, many disability study models, especially those drawn from Eurocentric perspectives, often fail to account for the unique challenges experienced by individuals in the Global South, where colonial legacies continue to affect disability understanding and support systems.

In South Africa, these colonial histories can be seen in how families of children with disabilities, such as those with ASD, often depend on informal networks and community-based care rather than official institutional structures. Decolonising disability studies entails shifting away from Western-centred frameworks and acknowledging how local realities affect the experiences of families. Nguyen (2021) emphasises the relevance of decolonial approaches in disability studies, which aim to dismantle these Eurocentric and put more focus on local understanding, experiences, and needs. In various parts of the world, including SA, this means addressing both physical and digital access inequalities. These inequalities are more apparent for families with children with disabilities, who often encounter difficulties obtaining proper resources for their children and participating in online networks. Digital exclusion is a crucial issue that affects not only people with disabilities but also their families, especially in terms of obtaining valuable information, but it also leads to increased social isolation and prevents participation in online support groups (Guirebner & van Haasteren, 2022). Despite these challenges, digital inequalities can foster digital empowerment, defined as the ability to fully participate with and benefit from digital technologies, which can be a beneficial tool for social inclusion (Webster et al., 2017).

Digital empowerment enables parents to and to manage their children’s daily struggles and needs and build connections with caregivers and online support groups. Achieving this requires tackling both technical and social barriers through affordable internet access, digital literacy, and readily available content online.

3.3.1 Digital Inequalities in ASD Parenting

Disparities among South African parents of children with ASD regarding their access to the internet and technological skills can affect how they use social media for information and support (Kumm et al., 2022). The researchers note that modern advances in technology provide the opportunity to significantly enhance access to ASD services at a low cost while also employing a diverse workforce in areas where these resources are scarce or non-existent. However, digital inequalities can influence how parents engage in sharenting, as those with a higher level of digital literacy are likely to better understand the rewards and risks of sharing content online. On the other hand, parents and caregivers with inadequate skills can have difficulty handling their children's presence properly (Robbeets et al., 2024). Additionally, the digital gap due to the lack of limited access to the internet and digital skills can prevent parents of children with ASD in LMICs from accessing the full benefits of these technologies for sharing information and for support tool. Ragnedda & Muschert (2017) proposed a three-level approach that addresses digital inequalities, such as access to the internet, the ability to use it creatively and the motivation to understand it. They further noted that failure at any of these three levels may result in digital inequality. Similarly, Heeks (2022) emphasises that inequality in the Global South is directly connected to lack of access to and efficient use of digital networks, which contributes to existing socioeconomic inequalities.

When it comes to the South African context, Bosch (2020) notes that social media is increasingly used to document life events, retain memories, and design a feed that expresses and shapes their sense of self. Popular social media platforms in the country include WhatsApp, which has the highest user percentage at 93.3%, followed by Facebook at 87.2%, Instagram at 70.5%, and TikTok at 69.3% (Data Reportal, 2023).

According to data from extracted Statista (2024), as of January 2023, South Africa had over 25.8 million active social media users. This figure reflects quite a few of the country's internet users and demonstrates the wide usage of social media platforms in the country, representing a substantial percentage of the population's internet usage.

The majority of South African users are between the ages of 25 and 34, with 59.3% of all internet users in the country active on at least one social networking site (Statista, 2024). Social media also plays an imperative role in information gain, with women more likely than men to seek information and support from a variety of sources, including social media (Duggan et al., 2015).

Changes within society require the acquisition of new skills, particularly those linked to the internet, which is one of the most important channels of communication in modern life. Considering a rise in the amount of information, internet skills should be considered valuable. When these skills are unequally distributed in the population, the consequences can increase existing socioeconomic disparities (Van Deursen & Van Dijk 2011).

3.4 CONCLUSIONS

The theoretical frameworks that underpinned this study were discussed in this chapter. Firstly, I presented the digital literacy framework, highlighting it’s significance in understanding how parents interact with digital media and the skills needed to efficiently navigate online platforms. This approach emphasises the importance of parents not only accessing but critically evaluating, creating, reflecting on, and taking action using digital technology. Secondly, I discussed the concept of the digital divide, which is essential for understanding discrepancies in access to technology, especially in marginalised communities. This concept helped to highlight the limitations that parents and caregivers of ASD children are confronted with. By incorporating these two frameworks, this chapter provided an understanding of how digital inequalities impact the experiences of parents and caregivers raising children with ASD. It also provided a foundation of how digital tools can empower or hinder their search for support and information online. The next chapter will focus on the methodology of the study.

CHAPTER FOUR: METHODOLOGY

4.1 Introduction

In this chapter, I discuss the research design and methods used. The main objective of this study is to explore the impact of digital literacy and the digital divide on the usage of social media by parents raising children with ASD in East London, Eastern Cape. To get in-depth insights into the parents' experiences and perceptions, I used a qualitative research approach. As mentioned in chapter one, ten individuals were chosen using snowball sampling, which means using existing participants to recruit more participants, ensuring that ASD parents with similar experiences were included in the study. Semi-structured interviews were used to gather information from each participant. These interviews aimed to delve into a number of subjects, such as participants access to technology, digital literacy skills, and the impact of social media on their daily lives. I used thematic analysis to analyse the data obtained from the participants. This chapter also presents my own positionality, ethical considerations, and the limitations of the study.

4.2 Study Design

The design of the research guides the researcher through the processes necessary to address the question at hand. A well-planned research design assists to ensure that the methodologies employed to support the study's objectives are appropriate and that the information gathered is analysed correctly (Mcombes & Bhandari, 2021). Before deciding on a research design, I thoroughly studied the three primary methodologies often used in the social sciences, namely, mixed methods, quantitative methods, and qualitative methods. After reviewing the advantages and disadvantages of each design, I was able to choose one that was appropriate for my study, research question, and objective. Hence, I settled on conducting a qualitative study. This approach developed from the behavioural and social sciences as a means of comprehending human beings' unique, dynamic, and holistic character (Cresswell, 2017). Contrary to quantitative research, which uses numerical data to acquire knowledge about the world, qualitative research is not concerned with transforming verbal symbols into numerical data; participants and/or researchers' words are utilised to provide insights into the phenomena under investigation (Hogan et al., 2009). Kidd et al. (1996), as cited in Schonfeld & Mazzola (2012), discovered that qualitative approaches are preferred over quantitative approaches when little is understood about a phenomenon. This observation validates my decision to adopt a qualitative approach for this study. As stated in chapter one, there is little information available on how parents raising children with ASD in South Africa use social media.

Brennen (2021, p. 17) notes:

> Qualitative researchers analyse evidence for authenticity, credibility, and validity by placing it in the appropriate ethnic, gendered, cultural, political, economic, and historical context. Qualitative researchers employ a variety of methods when evaluating evidence, including triangulation, reflexivity, long description, and collaboration. To confirm and validate information, triangulation takes into account several sources of evidence. This can be accomplished by analysing data from various sources, such as conducting interviews with a variety of people on the same topics. It may also be accomplished by analysing evidence on the same topics or concerns using various methodologies, such as combining participant observations with in-depth interviews and textual analysis.

Given the interpretive and exploratory nature of my thesis, which seeks to explore the use of social media by parents raising ASD children in East London, South Africa, qualitative methodology is deemed essential. Researchers focusing on children and young people can employ a qualitative approach to gather empirical data about the social world by involving parents in discussions about their lived experiences and behaviours (Magidigidi et al., 2023). According to Creswell and Miller (2000), qualitative research is conducted to advance our understanding of cultures, ideas, and values, human experiences, and circumstances, in addition to generating theories describing what people have experienced. Similarly, Babbie & Mouton (2001) define qualitative research as an approach that provides the researcher with an insider’s perspective on social action. The primary objective of this approach is to describe, understand, and interpret social action rather than simply explaining phenomena. As a result, the main objective of this research, which focuses on attitudes and experiences, is qualitative in nature. The qualitative research approach also contributes to the discovery of unfamiliar phenomena such as stressors and coping strategies. A qualitative approach allowed me to gain an in-depth understanding of participants’ personal experiences and viewpoints. Additionally, qualitative research aims to get to the heart of what actually happened to the participants, what led them to the decisions that they made, and how the decisions that they made came to take the form that they eventually did (Curry et al., 2009). There are concerns raised regarding qualitative research. These include the difficulty in determining the extent to which the researcher's bias affects the findings (Mwita, 2022). Additionally, Mwita argues that qualitative research results in huge amounts of data, which are time-consuming for analysis. I addressed the stated concerns by thoroughly recording each participant's response, ensuring to document what they actually said rather than what I expected or would have wanted to hear. According to Creswell (2014), qualitative research has several designs. Examples of designs include phenomenology, ethnography, grounded theory, historical studies, action research, and case studies. I adopted a phenomenological approach, as stated in chapter one, that the overarching goal of this study is to investigate the experiences and challenges faced by parents or caregivers raising autistic children in East London, South Africa, and how these carers use social media platforms for support in raising their ASD children. Phenomenological studies investigate the living experiences of people regarding something they have experienced and provide a full insight and awareness of the meaning such individuals ascribe to their experiences (Munhall, 2012). Creswell and Poth (2016) observed that participants' life experiences are important in guiding various qualitative approaches and making sense of the research findings. They further note that the phenomenological approach is particularly known for its use of the structured data analysis formula established by Moustakas (1994), which helps researchers effectively analyse their research data. I employed structured interviews to collect consistent and comparable data from parents or caregivers of ASD children. This approach allowed me to gain insight into their individual experiences while remaining focused on relevant questions regarding their challenges and perspectives. For example, during these interviews, I explored specific barriers that these parents encounter when accessing digital resources, which has a direct influence on their capacity to seek help and information online. This structured method also gave useful information on digital inequalities, highlighting how social and economic factors impact their access to and engagement with online platforms.

4.3 Research Site and Participants

The present study was carried out in East London. East London is part of the Buffalo City Metropolitan Municipality in the Eastern Cape Province. It is also referred to as eMonti and is located on South Africa's southeast coast. It is the second-largest city in the Eastern Cape. According to the Department of Cooperative Governance and Traditional Affairs (COGTA, 2021), the city has a population of about 1.4 million, with the majority residing in the areas surrounding the city.

The majority of the population is in the young working age bracket, which ranges from 25 to 44 years. The second largest population is children aged 0 to 14 years, followed by adults aged 45 to 64. The age group of 65 years and older makes up the smallest portion of the city’s population. Buffalo City’s overall population is made up of 86.68% African, 6.68% White, 5.80% Coloured, and 0.84 Asian people. The most widely spoken languages in the city are isiXhosa, English, and Afrikaans. As stated in chapter one, one of the primary reasons to conduct the present study in East London was due to the city’s diverse population in terms of race, geographic location, language, and socioeconomic level. It is also the city where I, as the researcher, reside while raising an autistic child.

East London has thirty community health clinics, two community health centres, nine mobile medical centres and two specialised hospitals. Despite their seemingly high number, the city’s clinics are overcrowded and overburdened, which affects the service delivery (Pillay et al., 2021). The city’s economy is mainly dependent on the automobile manufacturing industry, as Daimler Chrysler owns a plant in the city. Some of the city’s residents work in the industrial sector, which includes the automotive industry as well as the textile, pharmaceutical, and food processing industries (East London Property, 2024). In 2023, the Buffalo City Metro had a total of 6,340 houses that had electricity- only lighting.

A total of 23,500 houses had electricity for lighting and other purposes, whereas 30,400 households did not have any electricity (COGTA, 2023). Despite the above information, East London had the most households with electricity for lighting and other purposes. According to Data Reportal (2024), there were 118.6 million active cellular mobile connections in South Africa as of early 2024 and having electricity is crucial for charging these devices on a regular basis. In 2023, 91% of homes in East London had access to a mobile phone and 80% to a television.

The COVID-19 pandemic, which began in late 2019 and continued into 2020 and 2021, prompted a global shift from in-person to remote interactions, with a heavy reliance on technology for communication, information dissemination, education, and research. According to Patel (2020), measures that were taken to mitigate the spread of COVID-19, including the suspension of in-person learning and social events, as well as the closure of essential services such as respite care, social distancing, and stay-at-home requirements, had a significant impact on families with autistic children. These families encountered more challenges, including children demonstrating additional behavioural problems, which parents had to deal with during this time (Colizzi et al., 2020). In addition, Dalton et al. (2020) note that when many services closed, parents were compelled to take on various roles, which expanded their responsibilities and increased pressure and stress levels.

During these challenging times, I reached out to Ms. Antoinette Bruce-Alexander, Autism South Africa's Eastern Cape representative. She informed me about Autism South Africa's online workshops that were conducted during the pandemic and invited me to participate. My participation in these workshops allowed me to connect with a variety of people, which eventually led to the formation of a WhatsApp support group. The group consisted of mothers and caregivers of ASD children, as well as health professionals such as audiologists, speech therapists, and occupational therapists. When I began my research, I had already established relationships with some of the parents through participation in extracurricular activities at Autism Sinethemba Early Intervention Pre-School and College Street Primary School in East London. During the pandemic, social media became more than just a means of communication; it became an important support system for some of the parents and caregivers of autistic children struggling with the effects of the global pandemic.

4.4 Target Population and Sampling Technique

For this study, I needed to find individuals who were easily accessible, willing to provide information, and had relevant experience with the subject under investigation. For a study on the use of social media by parents raising ASD children in East London, this involved finding parents or caregivers who had some level of interaction with social media to explore their experiences and challenges. I identified ten caregivers who could provide thorough information and/or share experiences of their social media usage. Guest et al. (2006) observed that six to twelve participants tend to be sufficient for qualitative studies, particularly when the sample consists of participants who share comparable characteristics. I concluded the recruitment process. To ensure diverse perspectives, I selected individuals from different racial backgrounds, In SA race and gender influence how people access and use social media. Racial differences in accessing technology frequently influences how different communities interact with online platforms (Aylward, Gal-Szabo & Taraman, 2021).

Additionally, to gather a diversity of opinions and perspectives, both females and males formed part of the study. Reyes et al. (2022) discovered that women engage in interpersonal activities online, whereas men might show a preference to use social media for gaming and entertainment instead of seeking psychological informational assistance.

I established a fieldwork plan of action, which started with sampling. Sampling plays an important role in qualitative research since the purpose of most qualitative researchers is to explore phenomena in their natural surroundings. Sampling in qualitative research enables the researcher to locate people or areas that contain information that can be researched in great depth (Marshall & Rossman 2014). At first, I used non-probability sampling when selecting the participants. Bacher et al. (2019) noted that a non-probability sampling method entails selecting a sample using non-random criteria. Kim (2022) notes that non-probability samples offer the advantages of faster data collection, lower costs, and greater accessibility to hard-to-reach participants, such as parents of ASD children who might be hesitant to participate in research due to privacy concerns. Non-probability sampling methods include snowball sampling, convenience sampling, quota sampling, and purposive sampling.

Although I had already formed relationships and interacted with some of the parents and caregivers through online workshops and children's school functions, the sensitivity of the study made some of them feel uncomfortable in participating. I opted to use snowball sampling to address this challenge. Noy (2008) describes snowball sampling as a method where the researcher finds participants by using contact information given by other participants. Noy further notes that snowball sampling is sometimes employed as the principal vehicle through which participants are recruited or as an auxiliary means that assist researchers in enriching sampling groups and contacting new participants and social groupings when traditional contact routes have dried up. As mentioned in chapter one, I had previously interacted with other parents through ASD schools, which gave me a starting point for recruitment.

Any South African parent or primary caregiver of an autistic child who resides in East London would have been considered a suitable participant for this study. However, in qualitative research, the primary objective is to gain a deep understanding of human experiences, which requires an in-depth analysis of each individual's experience. Therefore, I considered a small group of participants suitable.

Vasileiou et al. (2018) noted that smaller sample sizes enable qualitative researchers to acquire more focused data and analyse data effectively.

The study approved plan specified that the study would involve ten participants. Five of the participants were educators who requested to be interviewed in their work offices. They were between the ages of thirty-four and fifty-five and consisted of one male. Three other participants were unemployed and were interviewed in the parking lot at College Street Primary School. The school is located in a quiet suburb, and the parking lot is usually very quiet and peaceful during classes. These participants were between the ages of twenty-five and forty-nine and included one male who is a primary caregiver. One participant was a male nurse aged fifty-five and he also chose the school parking lot as an interview site. Another participant was a records officer at a higher education institution in East London, and the interview took place in her office. Lastly, I also interviewed the Regional Development Officer for Autism South Africa, Eastern Cape. She is fifty-five years old. The interview was conducted in her home office. The sample of this study included a diverse group of participants, comprising three white women, two Ghanaian men (one of whom had a Ghanaian and Xhosa background), one Indian female, one Coloured male, and three Xhosa females. This diversity is especially important because different ethnic groups are commonly overlooked in autism research, which has traditionally concentrated on white families (Harris et al., 2020).

The following table presents a description of the participants demographic information:

Participant code	Gender	Age group	Ethnicity	Profession of participant	Number of children with ASD
P1	Female	30-40	White	Preschool Teacher	2
P2	Male	50-60	Black /Ghananian	Lecturer	1
P3	Female	50-60	White/Afrikaner	Regional Development Officer, A-SA	1
P4	Female	40-50	White	Deputy Principal	1
P5	Female	30-40	Black /Xhosa	N/A	1
P6	Male	50-60	Coloured	Nurse	1
P7	Female	50-60	Black/Xhosa	N/A	1
P8	Male	20-30	Black/Ghananian	N/A	1
P9	Female	40-50	Black/Xhosa	Records Officer	1
P10	Female	40-50	Indian	Teacher	1

4.5 Data Collection Methods

Taherdoost (2021, p. 10) describes data collection as “the process of acquiring data in order to obtain insights into the topic under investigation.” As a result, information is gathered directly from the identified and selected sample group. Ruslin et al. (2022) suggest that the method used for collecting data should be based on the type of information that one aims to explore in the study. Interviews are one of the most fundamental methods of research since they include asking participants questions and obtaining answers. Similarly, Rubin (2011) noted that the main objective of interviews is to delve into the personal experience of an individual or a group of individuals. Interviews are classified into three types, namely unstructured, structured, and semi- structured interviews. Unstructured interviews are used to explore people's complex behaviours without classifying them, which may limit the scope of the study (Zhang & Wildemuth, 2016). Because these types of interviews are not structured according to a set format, it was going to be difficult for me to identify and classify themes consistently as I used thematic analysis to analyse data. The questions in a structured interview are carefully planned and follow a set pattern, tightly controlling the information provided by the participant (Luo & Wildemuth, 2009). The interview is structured in this way simply because the researcher asks a specific number of questions in a predetermined order and affords a limited range of response options. I did not choose the structured interviews, as they are quite formal and may not delve deeply into the specific ways parents utilise social media. The set of questions and fixed options for answers could prevent participants from sharing all of their personal experiences or unexpected insights, which are essential for understanding their individual viewpoints (Budree, Fietkiewicz & Lins, 2019). Hence, I conducted semi-structured interviews to allow participants to express their perspectives and experiences in their own distinctive manner, rather than being limited to prescribed responses.

According to Ruslin et al. (2022), semi-structured interviews are particularly effective for qualitative research given that they allow researchers to collect thorough data and supporting evidence from participants while remaining focused on the study's topic. Furthermore, they provide flexibility and adaptation, enabling researchers to maintain direction, unlike unstructured interviews, where the direction may not be as controlled. When conducting a study like this with a small number of participants, it is recommended that the interviewee determine the pace of the interview, and slight changes from the interview guide are usually acceptable (Jamshed, 2014). A semi-structured interview guide is used during semi-structured interviews. An interview guide, according to DiCco-Bloom & Crabtree (2006), is a prearranged list of questions the interviewer needs to cover. Castillo-Montoya (2016) notes that the primary goal of an interview guide is to ensure that the same questions are posed in each interview and that all relevant subjects are discussed with each participant. To make optimal use of interview time, interview guides help evaluate responses more methodically and thoroughly while keeping the interview focused on the main objectives (Jamshed, 2014). To add structure to the interviews, I prepared an interview guide (see Appendix A). Before the interviews began, I collected signed informed consent from each participant, sharing the consent form with them ensured that they understood the objective of the study as well as their rights. Each interview took about forty-five minutes (45) to an hour. The participants were interviewed individually at a location and time convenient to them. I recorded the interviews with a voice recorder and took thorough notes to document nonverbal clues as well as my observations. Jamshed (2014) explains that recording the interviews helps the researcher to focus on the interview content and vocal cues, allowing the transcriptionist to provide verbatim transcripts of the interview later.

4.6 Data Analysis

Switching from fieldwork to analysing research texts was quite challenging for me, not only as a researcher but also as a mother raising an autistic child, because I particularly use social media for support and information. This complexity was caused by the challenge of transforming the rich, personal, and at times emotional experiences shared by parents in the field into formal, academic language. Scholars like Alhamzi and Kaufmann (2022) argue that this complexity stems not just from humans' complex nature but also from the fact that every individual's life is affected by a variety of circumstances, including psychological aspects, cultural influences, and social norms. As a result, describing and analysing someone's experience can be filled with ambiguity and uncertainty. The process demanded careful balance between remaining authentic to these parents' voices and experiences and maintaining the strict standards of academic rigour. However, as a qualitative researcher, I understood that data analysis in qualitative research is exploratory and aims to identify themes or patterns. As a result, the approach I used required preparing and organising the data for analysis, followed by creating themes based on the data.

A thematic analysis method was utilised to analyse the data collected. Thematic analysis is a process of identifying, analysing, and interpreting patterns of meaning (themes) in qualitative data (Clarke & Braun, 2016). The researchers further argue that the objective of thematic analysis is to identify and interpret significant features, guided by the research questions, rather than just summarising data. All the field notes that were taken during the interviews were stored on my phone, computer, and flash drive. All recorded interviews were transcribed verbatim. I followed the steps for thematic analysis outlined by Maguire & Delahunt (2017). The first thing I did was to familiarise myself with the information I had collected.

I thoroughly read each participant's responses and contacted parents or caregivers with clarifying questions if any of the answers were unclear. The follow-up questions were conducted through phone call or via WhatsApp message. The second step was to compare the responses and generate initial codes, which required arranging the data in a consistent and systematic way. The third step was to search for themes that emerged from the participants' responses and that were relevant to the research questions, as highlighted by Clarke and Braun (2016). The major themes identified highlighted the key points of the participants' experiences. These themes were thoroughly reviewed to ensure that they appropriately represented the data. In addition, the answers from the participants were compared with existing literature. The fourth step entailed exploring the themes and removing irrelevant data. The fifth step was establishing the themes and, finally, writing up the overall research findings and interpretations. I also included direct quotes from participants to emphasize key themes and to give substance to those themes.

4.7 Researcher's Positionality

Positionality is typically determined by locating the researcher's position with respect to three areas: the subject under investigation, the research participants, the research design, its context, as well as the process (Holmes, 2020). Similarly, Aber (2006) defines positionality as the researchers positioning in relation to the context and the participants of the study. It is influenced not only by the researcher's own decisions but also by the views of others, including participants in the study, gatekeepers, and other contributors throughout the research process. The literature frequently describes researcher positionality as a clear separation between insider (emic) and outer (etic) viewpoints (Huberman & Miles, 2002). Insiders are regarded as part of the community within which they are conducting research, while outsiders are deemed outside of the group they are studying.

My positionality was shaped by my dual role as a researcher and a mother raising an autistic child, whose experience in social media strongly informed my perspective. The combination of personal experience and being a researcher influenced my research motivation, how I conducted the research, particularly how I formed the relationships with the participants, and also how I interpreted data. Working closely with the participants helped me understand their challenges and opinions better.

Conducting research as an insider/researcher has a number of effects on the study. At times it was challenging, but sometimes it worked in my favour. For example, some parents/caregivers were very comfortable opening up to me and sharing freely because they knew me. To support this, Chew-Graham et al. (2002) noted that participants may be less cautious or protective with an insider during data collection compared to how they would be with an outsider; this can lead to more authentic data. While some parents assumed I knew the answers to all the questions because I am also a parent with an autistic child, they overlooked the fact that I was the one asking the questions and that the study focused on their social media experiences, not mine. This made it difficult for some participants to fully understand why I was researching issues that they thought I should already know. This is similar to Munthali's (2001) experience, in which he discovered that his position led to him being seen as asking irrelevant questions. Munthali noted that because he was from the community he was researching, participants expected him to have personal knowledge of the issues he was investigating when he conducted research in his own town. I had to explain to them that since autism affects people differently, each child has unique needs, and parents use social media in various ways and that is one of the reasons I was conducting the study.

Being a mother in a similar circumstance as the participants fostered the development of trust and connection; it also required ongoing self-reflection to ensure that the findings of the research were informed by the data provided by the participants rather than by my personal biases. As a researcher, I was aware of the potential biases that might arise from my personal attachment to the topic. In order to keep my interpretations unbiased and focused on the participants' perspectives, I carefully separated my role as a researcher from my identity as a parent. This enabled me to approach each interview and analysis with an open mind and a determination to correctly represent the unique experiences of all participants. As previously stated, my research comprised a diverse group of individuals, including both men and women. I conducted eight interviews in English and two in iSiXhosa. This was not an issue because I could speak and write both languages. However, I had to be aware of how language may influence communication, and my interpretation of the participants answers. Being aware of these differences in language influenced how I gathered and analysed data. According to Munthali (2001), sharing a language with participants is a benefit as it boosts communication, saves time, and helps avoid distortion from the data collected by the researcher.

4.8 Ethical Considerations

Researchers are required to follow ethical guidelines and regulations, as conducting research has the potential for harmful effects on participants; therefore, it is essential for researchers to take precautions to prevent any psychological harm (Savin-Baden & Major, 2023). Ensuring the integrity of the research and the authenticity of the data was crucial, as any form of falsification could undermine the research findings. At the beginning of my research, I was aware of the formal requirements that I needed to follow. Permission to conduct the research was granted after my proposal was reviewed and approved by the Humanities Faculty Research Ethics Committee (HF-REC) at Rhodes University (see Appendix B). After obtaining permission to conduct the research, a formal letter was sent to some parents and caregivers inviting them to participate in the study (see Appendix C). For other parents and caregivers, I made the request at school events and parental meetings at our children’s school. Although the invites were both formal and informal, I made them with respect, as I provided an explanation about the study, their expected role as participants, and outlined their rights.

Participation was voluntary and participants had to sign a consent form prior to the interview (see Appendix D). The consent form was provided to ensure that participants were properly informed about the study and willingly agreed to participate. Obtaining a consent form is an essential and non-negotiable ethical principle when conducting research involving humans. Informed consent entails providing individuals with relevant information about the study so that they understand the implications of their participation. This allows individuals to make an informed and voluntary decision to participate in the study without feeling forced (Stunkel et al., 2010).

The anonymity of nine participants was protected, as they did not want their names disclosed. This was achieved by using pseudonyms to protect their identities. It is important to highlight that, when considering the ethical issues of this research study, I was aware of the potential risks, as my research topic could be sensitive to some parents experiencing difficulties in parenting their autistic children. Furthermore, some of the questions could trigger negative emotions and bring up past and present challenges they have encountered while using social media. I informed the participants about these potential risks as well as emotions that some questions could evoke.

I also made them aware of the person representing Autism South Africa, who conducts ASD educational workshops around the Eastern Cape and also advises and gives support to parents raising ASD children, should they wish to contact her for support. Ms. Bruce-Alexander agreed that her name could be disclosed, mainly because she works for Autism South Africa, and her duties include supporting families of autistic children as well as the autism community. She also has a child with ASD, which significantly impacts her work and enhances her understanding of the challenges that families encounter. I also had to ensure that the participants' privacy was not invaded throughout the interviews. Participants chose the amount of information they wanted to disclose about their personal life, experiences in raising an autistic child, and their use of social media. All the data collected was safely stored on a password-protected laptop, which only I had access to, as well as securely backed up on Google Drive.

4.9 CONCLUSION

In this chapter, the research design and methodology of the study were explained. Challenges of conducting research while also being a parent of an autistic child who uses social media have also been discussed. The next chapter presents data collected through semi-structured interviews and the research findings.

CHAPTER FIVE: ANALYSIS, FINDINGS AND DISCUSSION

5.1 Introduction

This chapter presents and discusses the findings from the data collected for the study. The primary objective was to investigate the experiences and challenges faced by parents or caregivers of autistic children in East London, South Africa, as well as how they use social media for support in parenting their autistic children. The following research questions guided the study:

- What kind of social media platforms and apps do parents raising autistic children utilise to find support and advice?
- How do they access these social media platforms?
- What obstacles do they face when trying to find health information or support for themselves or their autistic children?
- To what extent is social media effective in supporting parents raising autistic children?

The analysis identified three major themes: social media platforms and apps; the difficulties associated with access and accessibility; and the efficiency of social media platforms. These themes are discussed in detail, supported by direct quotes from participants, and contextualised within existing literature. Furthermore, the analysis draws on the Digital Divide and Digital Literacy theories to provide an in-depth understanding of the challenges encountered by these caregivers, that are relevant to every aspect of their experiences and interactions with social media.

5.2 Role of Social Media Platforms and Apps

This theme addresses the first research question: *What kind of social media platforms and apps do you utilise to find support and advice?*

The use of social media platforms by parents and caregivers of children with (ASD) provides valuable insight on how they seek support, exchange information, and address challenges. Analysis shows that participants preferred social media platforms such as WhatsApp, Facebook, and YouTube; one participant liked TikTok. These choices were often influenced by factors such as cost, ease of use, reliability, and the level of support provided by each platform.

5.2.1 WhatsApp

WhatsApp emerged as the most popular platform, with all ten participants reporting that they used it. The app is regarded as affordable because participants stated that data bundles for WhatsApp are far less expensive than those of other platforms, with some bundles costing as little as R1 for 10MB but only valid for an hour. In addition, other participants stated that WhatsApp does not require passwords for logging in, which makes it easier for parents who struggle with remembering passwords and who may be experiencing difficulty with digital literacy.

Statista (2024) reports that by the third quarter of 2023, almost 94% of South African internet users were using WhatsApp, emphasising its importance in connecting people and providing social support. Participant five noted the convenience of WhatsApp: “I use WhatsApp because it is much easier to use compared to other social media platforms such as Instagram and YouTube.” This opinion was reaffirmed by participant one, who said, "The fact that WhatsApp does not even need a password to log in makes things much easier for me; I just click on the app and connect.”

Another advantage that made WhatsApp popular with the participants was its reliability in rural areas, which is important to parents who do not reside in metropolitan areas or who often visit rural areas, as they have families there. This advantage was specifically pointed out by participant seven: “I am able to access WhatsApp and chat with other parents even when I am in a rural area, whereas I am unable to do so on Facebook even if they have enough data.” In support of this , three participants mentioned that in a country like South Africa, where loadshedding often limits access to other forms of communication, WhatsApp is an ideal platform to quickly access needed information. Participants also applauded the fact that the app has introduced voice calls, voice notes, and even video calls, stating that these features have made their lives as carers very easy, as it allows them to video call each other as necessary. This sentiment was echoed by participant one, who said, "WhatsApp allows me to connect with other parents instantly and share advice and support in real-time.” As a mother who is raising two autistic children, when I am overwhelmed, I even video call some of the parents, as I have formed strong bonds within the group.” Participant one also said, “Through the WhatsApp support group, I discovered that I could claim medical expenses, such as occupational and speech therapy sessions, as well as school fees for my two special needs children, from the South African Revenue Service (SARS)."

WhatsApp's ease of accessibility and ability to promote group chats were also alluded to by participant three:

> Participation in WhatsApp groups with other parents and caregivers has been very useful. I share my expertise, prior experiences, and advice, such as eradicating autism myths and recommending medical professionals and schools that cater for ASD in East London. I also share links for the upcoming ASD seminars and workshops via WhatsApp; currently, I am a member of nine online ASD support groups.

Several participants also highlighted its cost-effectiveness, pointing out that it consumes less data compared to other social media platforms. They pointed out that WhatsApp bundles can be purchased for as little as R1 for 10 MB; however, the validity of this bundle is restricted to one hour. Participant five explained that:

> The one-hour validity of the WhatsApp bundle is not a concern for me because I don't need to be on social media daily. As I am unemployed, I cannot afford to buy expensive data bundles. When I have an urgent concern regarding my child's condition, I can easily purchase a WhatsApp bundle and immediately seek guidance.

The majority of participants also stated that they share resources, which helps them feel less isolated. Parents in WhatsApp groups exchange educational resources, such as articles or booklets on managing sensory overload or coping with meltdowns, as well as practical information, such as where to purchase affordable treatment or schools that cater to ASD children. For example, participant two stated that receiving Makaton videos every Monday from his child’s school helps boost the child’s communication abilities. Makaton is a popular Augmentative and Alternative Communication (ACC) system that uses sign language, graphic symbols, and voice (Larkin, 2021). It provides children a voice, whether literal or not, who might not otherwise be able to express themselves.

Participant two stated that sharing resources not only gives useful information, but it also promotes a sense of community and reduces the overwhelming feeling of isolation that sometimes he feels as a father with a child with ASD.

The issue of isolation was also alluded to by participant six, who shared:

> I have attempted to form relationships with other fathers who I met at school meetings to talk about the issues we experience in raising our children. However, I discovered that the fathers were hesitant to discuss their everyday challenges, and some would avoid the topic altogether. The few that were willing to participate did not know how to handle challenges such as sensory overload, informing me that when such instances occurred, their spouses would take over. That is why I finally decided to join the WhatsApp support group to get support

> from other parents, no matter the gender. On the WhatsApp group, there's only four males, including me.

Additionally, participant nine highlighted the role of administrators in WhatsApp groups. He stated that the group administrators tend to be health professionals or parents who have children with ASD; this promotes his trust and comfort in sharing personal experiences. Participant nine also said, "I appreciate that the administrators are both knowledgeable and strict about who joins." It makes me feel secure to express how I feel and sometimes share videos when the child experiences a meltdown".

This is in line with the findings of Niela-Vilén et al. (2014), who discovered that trust in online support groups is essential for members to feel comfortable sharing personal information. The majority of the participants were part of the school WhatsApp groups around East London; some are members of a support group led by an Autism South Africa representative. This particular group includes professionals such as speech and occupational therapists, offering parents access to both peer support and professional guidance. The participant also noted that support groups allow for the sharing of personal experiences while also providing them with direct access to trained professionals who can advise on therapies and approaches. WhatsApp's popularity, which is supported by all ten participants, highlights its credibility as a low-cost, fast messaging app that effectively replaces face-to-face assistance with real-time interactions. Herna et al. (2022) state that WhatsApp is the world's largest messaging app, with over 1 billion users across 180 countries since its introduction in 2009. This highlights WhatsApp's usefulness for the participants as an essential tool to interact, emphasising its advantages such as ease of use, the ability to develop connections with other caregivers that foster a feeling of community, access to cheaper data bundles, and immediate support.

5.2.2 Facebook

According to Statista (2024), Facebook has a penetration rate of over 88% in South Africa, indicating that Facebook's advertising network can reach more than 88% of the population. The platform provides a large prospective user base, with around 22.2 million individuals readily available to be targeted through advertisement. Facebook came out as the second most popular site among the participants. Out of ten participants in the study, nine stated they also used Facebook when seeking guidance and information.

Facebook is an online social network that allows users to create profiles, interact with friends and family, and join groups based on their common interests. When creating a support group on Facebook, there are three privacy options available.

- In public groups, anyone can access the group, its subscribers, and their postings, and any Facebook user is welcome to participate without the administrator's approval.
- Private groups, although anyone may view the group and its members, joining requires permission from the administrator. The content is only available to group members, and these groups require individuals to answer three or four questions to demonstrate their commitment before being accepted.
- Lastly are the secret groups; these groups are only by invitation, and none of the study participants were part of this type of group.

The participants mentioned several groups they follow on Facebook, including Autism Friendly, Moms and Dads Autism/ADHD, Autism Awareness and Parent Support Group, Autism South Africa, Autism Dads, The Autism Cafe, Autism Resources South Africa, Autism Friendly (UK), Autism Moms, Autism Parent Group and Discussion Group, Autism Awareness and Parent Support Group, Autism Matters, I am Autistic but I can, and We are Proud Autism Parents. Notably, out of the sixteen groups the participants are part of, ten supporting groups were created by administrators from abroad, meaning the majority of the participants are members of or access support groups from overseas.

According to Abel, Mochin, and Brownlow (2019), Facebook groups are frequently defined by a shared interest, such as ASD, serving as virtual communities where individuals who share similar experiences can interact. For many users, these groups are not only a significant aspect of their online experience but also an essential component of their real-world support network. In line with this, participants highlighted the importance of Facebook support groups in offering psychological and practical support. Participant seven said, “It is encouraging to see videos of autistic children who, despite their condition, have managed to find employment; some are creating artwork, and their parents assist them in selling these pieces online.” She also stated that “Since my child is nonverbal, hearing other parents’ stories about their children starting to speak at the age of twelve gives me optimism.” The participant also recalled finding out about a self-taught pianist child with autism in East London through a support group, which gave additional encouragement. Participant one echoed the same sentiments and said, “I often read posts about other children’s milestones, which encourages me to appreciate my own child’s development, no matter how small it may seem. I remember the first time my child said ‘bye’. The child was six years old and this was his first word. I was so overwhelmed, I cried and laughed at the same time.

This is in agreement with the findings of Gruebner et al. (2022), who discovered that parents of children with disabilities use social media platforms to celebrate milestones while also seeking hope for their own child's development. The participants expressed gratitude for being part of these groups, exchanging thoughts based on their unique experiences, with participant four stating, “I am happy to share the daily struggles with other parents on Facebook, as I believe we need to be there to support each other, advocate for our children and educate others about autism, as there is a negative portrayal of the condition." Some participants shared that the support groups not only provided information but also changed their perspectives about ASD. Participant five stated:

> My family and I used to believe that my child was bewitched, but after joining a support group on Facebook, I realised that was not the case. Autism affects children from different backgrounds and races. So, being part of the group has helped me understand more about my child’s condition. Even though we are a minority group, it's comforting to see that ASD affects all ethnic groups, and I'm not alone in this.

This experience corresponds with the findings of Gona et al. (2015), who argue that some cultures view ASD as a form of curse or divine punishment for breaking cultural customs. Gona noted that the perception of being a minority among parents of children with ASD stems from both the combination of their unique caregiving experience and societal misconceptions; some communities link ASD to supernatural or cultural phenomena instead of seeing it as a developmental condition. Participant six, who shared that he finally found a support group for fathers only on Facebook, in which, as fathers, they share their experiences and sometimes share artwork of father and son outings. The participant also expressed his relief and happiness in seeing that there are other hands-on fathers with ASD children.

He concluded by stating that "this is something that is very rare, especially in East London; some fathers I have tried to interact with about the challenges of raising an ASD child are ashamed to even talk about their child's condition." Pendry and Salvatore (2015) noted that online communities provide a sense of belonging and shared identity, which resonates with participants’ need for connection.

In addition, participant one pointed out the lack of useful information in some of the South African online support groups:

> I discovered that there are more resources abroad than in South Africa. Even government assistance is more available there, as respite facilities offer much-needed relief to parents. That is one of the reasons I access more support groups from abroad than from South Africa. The groups overseas are serious when it comes to sharing experiences as well as providing assistance, but the groups I follow in South Africa sometimes go for months without addressing anything.

Grech (2009) points out the inequality in resources and support between developed and underdeveloped countries. In developed countries, government assistance and services such as respite care provide necessary support to parents raising ASD children. However, as noted by participant one, such support in SA is minimal, requiring parents and caregivers to fill the gaps on their own; that is why some of the participants rely more on international online support groups.

5.2.3 YouTube

YouTube proved to be a beneficial platform to four participants, in particular for learning purposes. They pointed out that the platform provides instructional videos and relevant content regarding ASD, allowing them to better understand their children’s condition. High data costs due to the apps video content presented a significant challenge, leading some participants to rarely use it or not use it at all. According to Data Reportal (2024), YouTube's potential marketing reach in South Africa decreased by 700,000 users between early 2023 and 2024, reflecting a 2.7% decline. Despite this decline, the app was still accessible to 55.4% of the country’s internet users in January 2024, indicating that more than half of South Africa’s internet users can access the platform, but usage may differ. YouTube, a global video sharing network with the tagline “Broadcast Yourself," has been an effective tool for raising public awareness and providing different perspectives on ASD (Brownlow, O'Dell & Rosqvist, 2013). In the context of this study, YouTube stands out as a video content platform, allowing participants to access a wide variety of visual content, ranging from tutorials to personal experiences relating to ASD. Only a small number of research participants reported using the app on a regular basis for ASD-related content. For these four participants, YouTube remained a useful tool. One participant, who is both a parent and an educator, shared:

> YouTube is a great resource for finding videos and activities I can use in the classroom with my ASD students, and it's also useful for learning how to create structured routines and educational games to support my own child at home. For example, I learnt on YouTube how to develop visual aids for my child's daily routine, such as getting dressed, brushing teeth, eating breakfast, and drinking water, in an organised manner to assist my child keep on track and provide stability and consistency. Even though the process took time, it worked for us. I also found educational activities, such as matching games and puzzles, that assist in improving my child's concentration and cognitive skills.

Another participant said:

> My son and I learned how to make customised ASD badges on YouTube. I am now selling them, and we get orders mostly from families and parents of autistic individuals as well as from schools that cater for autism children in East London, especially in April, which is regarded as Autism Awareness Month. This is also something that my son and I enjoy doing together.

Additionally, another participant reported watching The Good Doctor on the platform and noted that the character reminded her of her child, who she feels has unique abilities like the Good Doctor. This participant also stated that she feels her son's inability to speak could be because he is able to communicate with his ancestors and that some of what he sees or experiences from them is not meant to be shared with others. That is why she believes that all children with ASD have special abilities. In conclusion, YouTube provides valuable content that some parents and caregivers of children with ASD use to engage with their children, such as watching videos with them, accessing educational resources, and finding relatable storylines that reflect their own experiences.

5.2.4 TikTok

TikTok is an online social network that enables users to produce, share, and find short videos that normally last between fifteen seconds and ten minutes. Miltsov (2022) noted that families with members with ASD can upload videos on managing their daily lives, including dealing with their attitude, approaches to learning, and communication techniques. According to Dzulkifli et al. (2024), the primary benefit of TikTok's recommendation is that it recommends videos based on what users benefit from and how they make use of this application. Despite the app's popularity in SA, only one participant in the study reported actively using this platform, showing its low popularity among the parents and caregivers in the present study. This may be connected to Tik Tok’s common perception as an entertainment platform intended predominantly for young adults (Omar & Dequan, 2020). According to Datareportal (2023), TikTok has 12.8 million users aged 18 and above, who predominantly use the platform to watch or search for entertainment videos. This explains why the majority of the participants are not using the platform, as TikTok consumes a lot of data, which is costly to those who noted challenges of limited internet access and high data costs.

The one participant who used TikTok stated that she was introduced to the app by her teenage daughter, who has ASD. She likes watching videos uploaded by other parents of children with ASD and follows a specific account involving a mother who shares her story with her ASD teenage son. The participant stated that she has seen great changes in the boy’s behaviour and that these videos have become her preferred content, especially now that her daughter is a teenager and in high school. According to Zenone et al. (2021), the #Autism hashtag was the sixth most popular health-related hashtag on TikTok in 2021. This suggests that TikTok has the potential to promote the public’s involvement, allowing viewers to gain knowledge about the lived experiences, opinions, and desired objectives presented by a wide range of stakeholders, including autistic self-advocates and their families. However, the participants in the current study were females aged 30-40, 40-50 and 50-60, as well as males aged 20-30 and 50-60; this aligns with the age groups that are less represented on TikTok. According to Datareportal (2023), the majority of TikTok users are younger, with females aged 18-24 making up 20.9% of the platform’s audience. This generational difference explains the platform’s limited usage among participants, as TikTok is often perceived as catering primarily to younger users.

5.3 Access and Accessibility Challenges

The themes of Access and Accessibility are combined as they both focus on how the participants make use of social media. Access describes how the participants connect to digital devices and tools such as mobile phones, laptops, data, Wi-Fi, as well as fibre to access social media platforms. Challenges to accessibility, on the other hand, means the challenges they encounter in obtaining and using this information, such as high data

costs, poor digital skills, security concerns, etc. These two components are closely linked, as effective access to social media depends on parents overcoming these challenges. By combining them, I identify both the advantages and disadvantages that affect parents and caregivers' experiences when using social media as a source of support.

The merged themes also give answers to research question two, *how do you access these social media platforms?* as well as research question three, *what are the challenges you are confronted with when seeking health information?*

5.3.1 Accessing Social Media

The analysis shows that the majority of participants use mobile phones to access social media; this indicates a clear preference for smartphone accessibility. Nine out of ten participants use mobile phones, and seven rely exclusively on them. This corresponds with the findings of Donner & Gitau (2009), who noted that mobile phones are often used as the primary or exclusive means of internet access in South Africa mainly because they are affordable and easier to operate compared to computers or fixed broadband connections. Similarly, Chigona et al. (2009) underscored the importance of mobile internet in supporting both communication and socioeconomic activities, making it an essential tool for those individuals living in low-income communities. Gilward et al. (2019) support this reliance by stating that due to poor accessibility to broadband, particularly in rural areas and underdeveloped countries, mobile phones are the most viable alternative for many South Africans. One participant uses only a laptop and smart TV, while the remaining two use mobile phones as well as smart TVs and laptops.

The first participant stated, “I mostly use my mobile phone with data,” while participant two maintained a similar stance, adding, “I use my mobile phone, but I connect through a router and Wi-Fi at my workplace.” This pattern shows the accessibility that mobile phones offer, allowing parents and caregivers to stay connected without the need for extra devices. However, few participants stated using additional devices to access their social media support groups. Participant eight stated, “I use both my laptop and smart TV, while participant nine stated that they alternate between using a mobile phone connected to Wi-Fi and a laptop, indicating that some parents prefer larger screens for a better viewing experience, especially when gathering extensive knowledge. For participants who used other devices such as laptops and smart TVs, having consistent Wi-Fi was noted as essential, as it reduced their reliance on expensive mobile data. Despite the versatility of mobile phones and other tools, the participants reported encountering major barriers when searching for health information on social media. These challenges include information overload, disinformation, security and privacy concerns, high data costs, and digital literacy. The next section addresses these barriers in detail.

5.3.2 Information Overload and Disinformation

Parents and caregivers of ASD children often turn to social media for information and emotional support; however, one major challenge they face in their everyday digital practices is information overload. According to the World Health Organisation (2022), social media platforms such as Twitter, Facebook, YouTube, and Instagram play an important role in disseminating information rapidly, including misinformation that can lead to misunderstanding of scientific knowledge, opinion polarisation, increased anxiety and fear, or reduced access to reliable healthcare resources.

Information overload is a major problem in online health spaces, especially for parents of autistic children who are often faced with conflicting or irrelevant content (Dobrogowska-Schlebusch, 2016). For example, Mackintosh et al. (2005) discovered that parents seeking autism-related information consulted a variety of sources; 88% used books, 86% used online sources, and only 44% used scientific journals. Although the variety of sources improves caregivers' information, it can also make it difficult to choose the most accurate and relevant information for their specific needs. This can be overwhelming and confusing due to the amount of content encountered on a regular basis. According to Bawden and Robinson (2020), information overload occurs when the amount of information exceeds an individual's ability to process it properly, resulting in confusion and poor decision-making. In medical care, this could occur as a challenge in separating relevant from irrelevant information, in the end influencing medical findings and behaviours (Arnold, Goldschmitt, & Rigotti, 2023). Participant one reported that "There is so much information that it is sometimes hard to know what is really relevant and reliable.” Participant five shared a similar experience, adding, “There is an overwhelming amount of information, and I sometimes am not even sure what to believe when it comes to advice and content I find on social media.” Similarly, participant eight said, “There is too much information; hence I made a decision to only watch YouTube videos and movies that relate to my son's condition.”

The issue of misinformation and false information also emerged as a major concern among the participants. Participants pointed out that they struggle with validating factual information due to the amount of and often conflicting opinions they see on social media. Participant two highlighted this issue and said, “There is a lot of false information. I once came across a post where a spiritual healer claimed to cure autism.” Similarly, participant three expressed concerns about disinformation and said, “As someone who works for Autism South Africa, some of the information I see on social media is really shocking, such as people claiming that ASD is curable." Disinformation is defined as information that is false and deliberately created to harm an individual, organisation, social group, or nation, often with financial or political motivations (Mantzarlis et al., 2018). Lastly, participant four said:

> Social media sometimes fails to capture the daily struggles of raising children with ASD. For example, some posts show autistic children who quickly demonstrate significant improvement after trying a particular intervention or product, such as communicating properly or revealing new behaviours. These portrayals overlook the challenges that we as parents encounter, such as the time, disappointments, and persistent efforts that are often part of raising an ASD child. While these stories may bring optimism, they may also raise expectations, leading some of us to believe that we are not doing enough or that something is wrong if our children do not experience the progress.

This underscores how disinformation on social media can increase the psychological stress on parents and caregivers of ASD children. False portrayals of success can put pressure on parents and caregivers leading to feelings of incompetence or guilt when their children fail to demonstrate similar progress. Such disinformation frequently fails to account for the unique developmental paths that ASD children experience; as mentioned in Chapter 1, these unique developments vary between individuals (Ozonoff et al. 2015). As a result, while social media can provide resources, it also has the potential to damage preconceptions and expectations, highlighting the need for more balanced evidence-based information on social media platforms (Skafle, Gaborron & Nordahl-Hansen, 2024).

5.3.3 Security Risks, Privacy and Digital literacy Concerns

Concerns about privacy and security emerged as another major challenge for participants when using social media to access health information and guidance. This highlighted the risks associated with these digital spaces. Participants raised serious concerns about the risks of hacking and the potential of sensitive information that sometimes gets compromised. For example, participant three identified hacking and online security risks as major concerns, highlighting the weaknesses of digital spaces. The participant said, “I had to take down the Autism SA Eastern Cape Facebook group as it was hacked.” This occurrence underscores the challenges encountered in safeguarding security and confidentiality in online support groups. In addition, the participant stated that some parental online support groups turn into marketing and advertising platforms; this compromises privacy and trust. The use of personal information for monetary gain and the shift in the group’s focus from providing assistance and support for parents and caregivers to advertising for products or services further worsen the participants concerns.

These findings align Participant six also emphasised the lack of security and privacy in some online spaces, citing misinformation and false information, which could lead to unintentional exposure of personal information to harmful platforms. This points out the vulnerability of parents seeking credible health information, as misleading or inaccurate content could be used to exploit personal data or lead users to unsafe sites, compromising their confidentiality and safety (Mantzarlis et al., 2018). Surprisingly, most participants reported that they neither post nor share pictures of their children on Facebook due to fear for their children’s safety and also identity theft. This aligns with the concept of sharenting discussed in chapter two. Brosch (2018) define sharenting as the act of parents sharing information about their children in ways that may infringe on

the child’s privacy. One participant noted, "Children have rights too; I cannot just post my child or share his condition on social media without his consent. If I share a picture of him, it’s just a picture of him with his artwork, not of him throwing tantrums.” This issue reflects the important role that the study participants take on protecting their children’s privacy, as well as the potential safety risks connected with sharing personal information online (Livingstone & Helsper 2007). Blum-Ross & Livingstone (2020) point out the societal concerns of sharenting, including identity theft. According to Azmil et al. (2024), sharenting during a pre-verbal development can have a negative impact on their psychological well-being. Similarly, Wen, Teng, and Dhanapol (2022) discovered that adolescents often face negative outcomes as a result of sharenting. These findings align with the participants cautious approach, as they avoid activities that may unintentionally hurt their children in the future.

Digital literacy concerns also emerged as a significant factor. Some participants' limited ability to navigate or assess digital information made them more vulnerable to security risks. Participant ten stated, "I am not all clued up about digital technology, especially the social media sites, so I keep it simple and mostly use WhatsApp and my daughter taught me how to use TikTok." This is similar to a previous study by Livingstone and Helsper (2007), who revealed that poor digital literacy often limits the ability of users to connect with a wide range of online resources and properly manage privacy settings. Rice and Ortiz (2021) point out the importance of digital literacy in allowing individuals to successfully use internet resources. They believe that programmes aimed at improving digital skills could benefit parents and caregivers by allowing them to confidently access and interpret information relevant to their experiences.

Participant five also mentioned challenges with determining reliable information online, stating, "Sometimes I find it hard to tell what is true or false online." These issues imply a possible vulnerability to disinformation and security risks since parents may unintentionally provide personal information to untrustworthy or dangerous sources. These findings support the previous studies on increasing security and privacy risks that users face in digital spaces (Michaelides & Hosszú, 2011).

5.3.4 High Data Costs and Accessibility

Data affordability remains a major barrier to internet access for many South Africans, particularly in economically disadvantaged regions such as the Eastern Cape. High data costs often limit individuals who rely on mobile data instead of Wi-Fi from regularly using data-heavy social media platforms, such as YouTube, Instagram, TikTok, Snapchat, and Facebook. Participant one stated, "I use data, but social media platforms such as Instagram and YouTube consume a lot of it, so I hardly use these platforms." Participant nine reaffirmed this concern, noting that the costs involved with regular data usage make consistent access difficult. Economically disadvantaged cities like East London frequently report data costs as barriers, which often contribute to a digital divide that restricts socioeconomic access. According to Statistics South Africa (2022), 72.7% of families in the Eastern Cape were classed as poor in 2022, whereas Creamer Media Engineering News (2023) states that the Eastern Cape is one of the least connected regions in South Africa, with only 65% of households having Internet access and only 5% having access from home. Even though mobile devices remain the most commonly used way to access the internet, data affordability remains an ongoing issue for many South Africans, as previously stated. According to Ditlhake (2024), South Africa does not meet the UN Broadband Commission’s affordability criteria, with 1 GB of data costing more than 2% of many citizens’ average monthly income. Due to financial constraints, the participants have to restrict their use of specific platforms, limiting their access to a variety of online resources that could assist with coping with raising their autistic children. South Africa Connect (2024) underscores this accessibility issue, stating that high costs and inadequate infrastructure prevent many South Africans from accessing the internet.

Another key concern raised by all ten participants was the issue with connectivity and electricity accessibility, particularly as a result of loadshedding in the city. Participants reported that loadshedding sometimes does not occur at scheduled times and it takes hours for power to come back. This causes significant stress, especially since some of their children are dependent on routine; the issue of loadshedding not only disrupts daily activities but also the ability to engage in online groups when emergencies such as stimming and meltdowns occur in children. In addition to accessibility, participant six further explained that during loadshedding, problems such as cable theft occur in her area. She added that at times she stays without electricity for up to three days, which creates a lot of frustration as she loses connectivity with her social support groups.

The inability to access these online platforms during crucial moments highlights the severe impact of infrastructure challenges on the wellbeing of parents and caregivers (Stahlmann, 2022). Despite social media platforms providing valuable educational tools, emotional support, and connections to other parents and caregivers, these advantages can be significantly reduced when constant accessibility is disrupted by external factors such as loadshedding. While these barriers are significant, it is also essential to look into the effectiveness of social media in supporting parents and caregivers. As I explore the effectiveness of social media in supporting parents and caregivers, participant comments highlighted the significance of these platforms in providing genuine support in times of need.

5.4 Effectiveness of Social Media Platforms

The study's last research question focuses on the effectiveness of social media in supporting parents and caregivers of children with ASD. The theme of effectiveness of social media emerged strongly from the findings, pointing out how social media platforms meet the participants' informational, social, and psychological needs. According to Nagelhout et al. (2018), the success of social media is measured by its ability to provide educational information, build social relationships, and offer emotional support. For parents and caregivers, social media has proven to be an essential tool for obtaining reliable information, connecting with others facing the same challenges, and gaining both mental and practical support (Saha & Agarwal, 2016).

Several participants mentioned how platforms like WhatsApp, Facebook, and YouTube helped them better understand ASD and cope with caregiving challenges while getting emotional support. For example, participant one said, "Social media provides a platform to share or receive valuable information and resources about ASD." Similarly, participant two stated, "It improves understanding and supports informed decision-making about ASD, especially when following reliable pages." Their responses draw attention to social media's significance as an educational platform, which has been confirmed by research evidence to be accessible, with reliable information that can empower caregivers (Hudson, Linnane & Rayner-Smith, 2023).

In addition to educational support, social media promotes community engagement by connecting parents with other caregivers and ASD organisations. Participant three noted that social media provides a platform to reach out to other parents and ASD organisations and this allows her the chance to inform the parental support group of upcoming online workshops, such as those posted on Autism South Africa's Facebook pages and other WhatsApp parental support groups. This reveals how social media grows networks for advocacy and shared learning, both of which can be essential for caregivers seeking social support.

Another important advantage of social media is making emotional support possible. Participant five noted, "Social media platforms such as WhatsApp provide emotional support and positive feedback, as there are also autism experts in the group." Additionally, participant ten emphasised the emotional benefit of social media, stating, “Such efforts provide me with emotional and practical support.” This was further supported by participant four, who highlighted the value of practical tips and tutorials that taught her DIY techniques for coping with ASD-related issues. On the other hand, participant eight noted, “YouTube is very useful because it educates me about soothing meditation for my son, and I have also found someone who has the same qualities as my child.” This shows how multimedia resources can effectively address the unique needs of both the parents and caregivers, offering specific support for dealing with ASD challenges. These findings are supported by research, which suggests that online interactions can help parents and caregivers reduce stress while developing resilience (DeHoff et al., 2016). Their research demonstrates that social media platforms can considerably reduce caregiver strain and promote psychological resilience by providing a place for sharing experiences and gaining emotional support from peers who understand their own unique challenges. Similarly, Daynes-Kearney & Gallagher (2023) note the importance of social media in creating a sense of belonging among parents and caregivers. They point out that these platforms provide opportunities for shared experiences and emotional support, which can be especially valuable for those who struggle to access such services.

The participants in the study express characteristics similar to those described by Huws, Jones, and Ingledew (2001), who discovered that parents use online forums for a variety of purposes, including making sense of autism, finding meaning, adapting to changes, providing assistance to one another, and sharing their own experiences. This corresponds to how participants described using sites such as WhatsApp and Facebook for guidance and support from other caregivers. These platforms allow them to seek guidance and information while also processing their experiences together with other caregivers, generating a sense of mutual understanding and comfort.

5.5 CONCLUSION

In this chapter, I presented findings from the data collected. Presenting a detailed analysis of the experiences and challenges faced by parents and caregivers of ASD children in East London, South Africa, in relation to their use of social media for support. The study's key research questions were addressed through three primary themes. In the next chapter, I will provide a summary of the findings, draw conclusions based on the research, reflect on the research process, and present recommendations for future research to address the challenges I have identified, including limitations encountered during the research.

CHAPTER SIX: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This chapter concludes the study on the use of social media by parents raising autistic children in East London, Eastern Cape, South Africa. It provides a summary of the key findings, discusses the limitations of the study, presents recommendations for future research and reflects on the research process. The chapter highlights the importance of social media as a valuable tool for parents and caregivers of children with ASD, while also noting the obstacles that limit its effectiveness. In addition, the recommendations aim to improve the digital literacy and social media accessibility within the South African context, particularly in the Eastern Cape, which is one of the country's poorest provinces, by addressing the digital divide, which leads to inequality in access to technology.

6.2 Summary of key findings

The study intended to provide answers to the following four research questions:

- What kind of social media platforms and apps do parents of autistic children utilize to find support and advice?
- How do they access these social media platforms?
- What obstacles do they face when trying to find health information or support for themselves or their autistic children?
- To what extent is social media effective in supporting parents raising autistic children?

6.2.1 Research question one: What kind of social media platforms and apps do parents of autistic children utilize to find support and advice?

The findings revealed that the participants primarily seek support and assistance through WhatsApp, Facebook, YouTube, and TikTok. WhatsApp was the most popular medium, especially for school-related WhatsApp groups, as it provided the participants with meaningful information that assisted them in their journey of raising ASD children. Support groups hosted by Autism South Africa or medical professionals such as occupational and speech therapists were also highly valued.

These findings resonate with research on the benefits of online support networks, particularly in communities experiencing specific challenges (Raymond & Andrews, 2023) . The participant also commended WhatsApp for its low cost, ease of use and ability to communicate with other parents and caregivers in a safe and trusted environment, which is crucial in East London where affordability is a key concern for many parents.

Facebook was also frequently pointed out as the medium providing access to larger and more diverse groups, including groups with participants across the globe. While Facebook provided the participants with valuable information and different experiences of other parents. However, several participants expressed concerns of privacy and reluctance in sharing their children's personal information and experiences with unknown group members. YouTube was cited as an excellent learning tool, with parents able to view videos on therapeutic procedures and insights on managing specific issues. While TikTok was occasionally pointed out, this platform was not popular among the participants. Overall, the participants preferred platforms that were not expensive to use, user-friendly, and reliable, especially being the Eastern Cape residents, where limited financial resources and different levels of digital literacy are affected their social media preferences. This aligns with the digital literacy divide theory, which underlines disparities in access to technology and digital skills that influence how parents interact online support networks.

6.2.2 Research questions two and three: How do they access these social media platforms and what obstacles do they face when trying to find health information or support for themselves or their autistic children?

As noted in Section 5.2, the themes for these two research questions were combined as they both focused on how participants make use of social media. Participants primarily utilised cell phones to access social media platforms, citing that they were the most affordable and convenient. The majority of the participants used prepaid data bundles, with some preferring sites like WhatsApp because of the apps low data consumption. WhatsApp packages for example, could be purchased for as little as R1 for 10MB but their brief validity posed an issue. Participants with Wi-Fi access reported to have more steady and cost-effective connectivity. Loadshedding caused inconsistent access, complicating social media use for the majority of the participants. Digital literacy was pointed out as another obstacle, specifically by participants who were not unfamiliar with navigating social media or verifying reliable sources; this was one of the main reasons participants mentioned utilising WhatsApp, as it is not complicated to use, as mentioned in chapter five. These findings align with the digital literacy model, which highlights that access to technology does not ensure effective usage; skills and understanding are equally important. Participants also raised concerns about misinformation on social media, which required a thorough verification of the advice or resources they come across. Most of online ASD support groups the participants follow are from abroad, which may fail to meet South African families' cultural and practical needs. This makes it challenging for some parents to implement what they learn online in their own situations. This discrepancy concurs with the digital divide theory, which points out disparities in the accessibility as well as importance of digital resources between developed and underdeveloped countries, such as South Africa.

Another disadvantage that was stipulated was the amount of information that was shared on these social media spaces; participants noted that it can be overwhelming or irrelevant to their specific needs. Concerns about privacy and safety were also mentioned, with participants hesitating to disclose sensitive information due to hacking in some online communities.

Other impediments included geographic discrepancy, as some participants often visit rural areas and struggle with connection whilst there, as rural areas in the Eastern Cape often face challenges of poor internet connectivity. This supports the first level of digital divide, where infrastructural limitations cause inconsistent access to digital resources, as well as the second level of digital divide where disparities in digital literacy influence the way individuals interact with online content. These findings emphasise the societal and cultural barriers that influence how parents of ASD children in South Africa particularly in East London in the Eastern Cape, seek assistance through social media. Although online communities allow for interaction and information exchange, their effectiveness is limited by cost, accessibility digital literacy, and the importance of readily available resources to the community at large.

6.2.3 Research question four: To what extent is social media effective in supporting parents raising autistic children?

Social media proved to be a valuable tool for the participants in this study, providing both emotional and practical support. Participants reported that platforms such as WhatsApp and Facebook helped them to connect with other parents who understood their challenges, fostering a sense of community and minimising feelings of isolation. For example, parents found comfort in school WhatsApp groups, where they could share updates on their children's development, seek suggestions, and even receive prompt advice when stimming and meltdowns occur. Social media also worked as an instructional tool, allowing parents to learn about therapies, coping strategies, and fresh approaches for their children. YouTube videos and professional guidance shared in these online groups were beneficial in giving some of the participants confidence in managing their child's needs. However, the successful functioning of social media was affected by the structural barriers that are deeply embedded in the South African and Eastern Cape contexts.

As much as social media was effective for the participants, they also mentioned that some of the information shared could be overwhelming, confusing or not entirely relevant to their unique needs. The digital divide theory proves helpful in describing these discrepancies, given that accessibility concerns posed by high data charges and uncertain internet connectivity, especially during loadshedding, significantly reduced participants ability to successfully access social media. In the Eastern Cape, where rural connections remain a challenge, participants pointed out how insufficient infrastructure impacted their ability to interact with online support groups. While the content offered by international sources is beneficial to the participants, its lack of relevance to the unique needs of South African families points out a significant divide in the effectiveness of social media as a support tool to parents raising ASD children in the Eastern Cape, South Africa.

6.3 Limitations of the study

While this study provides valuable insights, there are some limitations; these are outlined as follows:

The study only included parents and caregivers who actively use social media. As a result, it does not sufficiently represent parents and caregivers who may face challenges accessing these platforms due to financial constraints or a lack of technical resources. This limit signifies that in East London, Eastern Cape, where unemployment is high and digital exclusion is a persistent issue, the findings primarily reflect the viewpoints of individuals with access to resources and neglect the experiences of families with a lower income background or no income at all.

The study predominantly included individuals from urban areas; hence, its findings are limited to the experiences of parents in these areas. The study did not include rural parents and caregivers in East London, who often encounter severe barriers to internet connectivity, infrastructure, and access to social support groups.

This geographic limitation means that the findings did not fully capture the unique problems and demands of parents and caregivers in rural settings, who may face different challenges when it comes to social media usage (Duma et al., 2021). As a result, their experiences are underrepresented in this study.

While snowball sampling was beneficial in reaching out to parents of ASD children in East London, it may have caused selection bias by reducing the different perspectives. Participants with higher levels of digital literacy and access to social media were more likely to be included, whereas those experiencing digital exclusion due to financial restrictions, geographic location and inadequate technological skills were overlooked. This mirrors a greater concern relating to the province’s digital inequality. Despite these limitations, this method allowed the collection of valuable and in-depth insights from individuals who are actively involved in raising ASD children, which is my study's primary focus. Future research should explore alternative sampling methods so as to capture a broader spectrum of different viewpoints, mainly from parents and caregivers who have low digital literacy or internet access challenges.

Lastly, the study focused on specific social media platforms, such as WhatsApp, Facebook, YouTube, and TikTok, as these were popular amongst the participants. There are other online platforms or social spaces that also provide invaluable support to parents and caregivers of children with ASD. Broader research into more platforms could have presented a holistic understanding of the online world for parents and caregivers in East London, Eastern Cape.

6.4 Recommendations

As a parent of an autistic child who resides in East London and also makes use of social media for support, I am well aware of some of the obstacles that parents and caregivers experience in this area. Drawing from the study's findings, I propose the following recommendations:

The study highlighted the importance of improved digital literacy among parents and caregivers. I propose that future research should explore measures that would enhance digital literacy, particularly in economically disadvantaged regions such as the Eastern Cape province. This could include working with local authorities and social workers to implement educational initiatives that strengthen digital skills while promoting the efficient use of social media for guidance and broader knowledge.

The launch of experimental initiatives targeted at promoting digital literacy and social media engagement among parents of children with ASD could provide significant results. The projects could examine the effectiveness of various training programmes, assess parents' use of online resources and explore new strategies to bridge the digital inequality within the province. Collaboration between autism advocates, policymakers and local online groups could assist the design and implementation of these projects, ensuring that they are appropriate for South African language and culture . Using this approach could make online resources accessible and easily understandable to parents and caregivers with different levels of digital literacy. Locally relevant material could assist parents in utilising online platforms with greater efficiency and implementing online guidance into their everyday lives (Adams, 2024).

Future studies should include parents from rural areas of the Eastern Cape province in order to gain a broader understanding of social media accessibility challenges with regard to support needs across South Africa's different regions. To address the underrepresentation of male participants, future research should recruit fathers and caregivers. This would allow for a deeper understanding of fathers' perspectives and experiences, which may differ from those of mothers or other caregivers. Also, future research could use a bigger sample size to obtain an even wider range of experiences.

The lack of representation of parents aged 20–30 highlights the need to explore the experiences of younger parents or caregivers who may use social media differently or face unique challenges in raising autistic children. While this could be related to parental age at birth, which is known to influence the prevalence of ASD, the qualitative nature of this study does not aim to control for such factors. However, future research could consider this demographic to better understand the experiences of younger caregivers.

Administrators for social media support groups should be responsible for ensuring that the content provided within these groups is relevant to their intended purpose and provides accurate and reliable information. The study contributes to the emerging body of literature on digital support for parents and caregivers of autistic children in South Africa and calls for further research that includes parents and caregivers from rural disadvantaged communities to better understand the role of social media in supporting families raising autistic children in South Africa.

6.5 Reflection on the research process

Conducting this study has been overwhelming yet very fulfilling. One of the most significant findings during the research process was the huge effect of the digital divide on parents and caregivers in East London, South Africa. Upon conducting the study, I was anticipating that access to social media platforms would be the main concern, but the findings revealed that factors such as high data costs and limited digital literacy were more prevalent than I had anticipated. The responses from the participants highlighted how these factors prevent them from fully utilising social media as a support tool. While other social media platforms such as Facebook and YouTube were mentioned, WhatsApp emerged as the most popular method for communication and an immediate response support platform. This was unexpected and made me reconsider my initial assumption about which platforms would be most useful to the participants in my study. If I had the opportunity to do this study again, the thing I would do differently is to include a broader range of participants from different geographical areas, especially those in the rural areas of the Eastern Cape. As this could provide a more thorough understanding of how the digital divide affects certain communities. I would also explore more into the role of language and cultural diversity in how individuals use and access social media. While I made an effort to include a diverse group of participants in terms of gender and race, I could have given more attention to how language differences might affect digital literacy and social media. Another reflection is the importance of using semi-structured interviews. The flexibility of this approach allowed the participants to express their experiences in an authentic and detailed manner. I was a bit concerned about using the semi-structured interviews due to the balance and openness. However, I found that it allowed for deeper and more meaningful conversations that revealed details of participant experiences I was not expecting. The semi-structured nature of the interviews allowed for a deeper understanding of the different ways in which the participants interact with social media, especially in an environment where some of them were still learning the digital skills. In conclusion, while identifying areas for improvement, I believe that this study has provided insights into the digital challenges that parents raising ASD children in East London experience. These insights will influence future research efforts.

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APPENDIX A: INTERVIEW GUIDE QUESTIONS

1. What has been one of your most rewarding moments as a parent/ caregiver to (name of the child)? Icebreaker.
2. How old are you?
3. What do you do for a living?
4. Are you married or single?
5. How many children do you have?
6. When was your child diagnosed with ASD ?
7. How old was the child ?
8. How old is the child now?
9. Did you receive counselling after the diagnosis?
10. What kind of digital devices do you have access to at home?
11. How do you access these social media platforms -
12. How reliable is your internet connection?
13. What kind of social media platforms and apps do you utilise to find support and advice?
14. What challenges do you face in accessing internet or using digital device?
15. How comfortable are you with using social media like WhatApp, YouTube or Facebook etc?
16. How often do you use social media?
17. What are the names of online communities or support groups you are part of?
18. What is the effectiveness of social media in supporting you as a parent?
19. What are the negative experiences you have encountered on social media?
20. Do you share pictures of your child on social media?
21. Would you recommend social media to other parents raising ASD children in East London?
22. Is there anything that you would like us to discuss that has not been covered by my questions?

APPENDIX B: ETHICAL CLEARENCE

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Rhodes University Human Research Ethics Committee
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https://www.ru.ac.za/researchgateway/ethics/

Title: Use of social media by parents raising Autistic

children in East London, Eastern Cape, South Africa

Researcher: Tina Bikitsha

This letter confirms that the above research proposal has been reviewed and **APPROVED** by the Humanities Faculty Research Ethics Committee (HF-REC).

Your Approval number is: 2023-7501-8153

Approval has been granted for 1 year. An annual progress report will be required in order to renew approval for an additional period. You will receive an email notifying you when the annual report is due.

Please ensure that the Humanities Faculty REC is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators. Please also ensure that a brief report is submitted to the ethics committee on the completion of the research. The purpose of this report is to indicate whether the research was conducted successfully, if any aspects could not be completed, or if any problems arose that the Humanities Faculty REC should be aware of. If a thesis or dissertation arising from this research is submitted to the library's electronic theses and dissertations (ETD) repository, please notify the committee of the date of submission and/or any reference or cataloguing number allocated.

Sincerely,

Dr Priscilla Boshoff

Chair: Humanities

Faculty

APPENDIX C: LETTER OF PARTICIPATION IN RESEARCH

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TO WHOM IT MAY CONCERN

RE: INVITATION TO PARTICIPATE IN RESEARCH

Dear Participant

This letter serves as an invitation to participate in a research project titled “The use of social media by parents raising autistic children, in East London Eastern Cape, South Africa.” This project is being conducted by a student researcher, Tina Sisanda Bikitsha as part of her Master’s degree in Journalism and Media studies at Rhodes University under the supervision of Dr Chikezie Uzuegbunam and Professor Lorenzo Dalvit in the Faculty of Humanities.

Explanation of the study

This study seeks to explore the experiences and challenges faced by parents or caregivers raising autistic children in East London, South Africa and how these carers use social media for support and share coping mechanisms in raising their ASD children. This will be done through investigating the experiences and challenges faced by parents or caregivers raising autistic children in East London, Eastern Cape, South Africa and how these carers use social media platforms for support in raising their ASD children.

Procedures

Participants will sign consent forms before the commencement of the interviews. Semi structured interviews will be conducted at a place and or venue convenient for the participant**.** The interview will take around 45 minutes to an hour and is very informal.

To accurately document your ideas and reactions, I will ask to record your comments and opinions during interviews. You have the option to obtain a copy of the interview transcripts as well, so you can make sure your thoughts were captured accurately.

What the participant will gain from participating.

Participants will not be paid for participating in the study, is for academic purposes.

By participating in this research project, you might provide a variety of contributions such as personal insights, creation of a supportive community and assistance to other parents or carers in navigating the difficulties of raising or caring for an autistic child in the digital era.

How will the information given be used?

The researcher plans to publish the study's findings as scholarly publications. However, records will remain private and anonymous, and unless you specify otherwise or acknowledge that, as a public figure, your identity will inevitably be known, in which case you agree to and accept the loss of anonymity, your name and identity will not be disclosed to anyone who has not been involved in conducting the research.

The information gathered from you for this study project may be used by the researcher for future projects.

Potential risks for this study.

The research questions have the potential to evoke uncomfortable feelings and memories in relation to the difficulties of raising an autistic child. To address this risk, I have arranged a representative from Autism South Africa to refer the participant to for emotional and professional support should a need arise.

Anonymity of participants

The study is completely anonymous, therefore, it does not require you to provide your name or any other identifying information. If you would like to participate in the study, I will furnish you with the consent letter.

Should you require any further information, please do not hesitate to contact me or my supervisor. Our contact details are as follows:

Tina Sisanda Bikitsha

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Dr Chikezie Uzuegbunam (Principal

Supervisor) Email:

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Prof Lorenzo Dalvit (Co-Supervisor)

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TSBikitsha