PARENTAL PERCEPTIONS OF THE EDUCATIONAL NEEDS OF CHILDREN WITH GENETIC CONDITIONS LEADING TO INTELLECTUAL DISABILITIES

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Date Of Submission: 25 July 2022

Summitted to the University of Cape Town in partial fulfilment of the requirements for the degree MMedSc Genetic Counselling

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Declaration

I, Sinead Cameron-Mackintosh, hereby declare that the work on which this dissertation/thesis is based is my own original work (except where acknowledged otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Abstract

South Africa has a unique and challenging setting for special needs education. Historically, children with disabilities were separated and marginalised from their neurotypical peers, especially those from African rural communities. Since 1994 and throughout the formation of the new government, several documents and laws have been put in place to rectify the previous injustices and discriminations.

In South Africa, over 210 000 students have one or more disabilities, and only roughly 513 government schools are equipped to support children with these disabilities. These schools include mainstream and designated special needs schools (SNS). Thus, there are limited schooling choices (government or private mainstream school/SNS, or home-schooling) for parents and caregivers of children with disabilities. Little is known about the difficulties parents and their children with genetic conditions that lead to intellectual disability face. These children often have multiple challenges resulting in their varying special schooling needs.

This qualitative study aimed to explore the parents' perceptions of their child's needs regarding their special needs school. Potential participants were identified from the genetics clinic database at Red Cross War Memorial Hospital in Cape Town (RCWMH). Nine participants were interviewed using a semi-structured interviewing method, conducted telephonically or via an online platform (Zoom) (In-person interviews were not possible due to COVID restrictions). Interviews were recorded and transcribed using Descript software. The data was then analysed using thematic analysis.

Three themes emerged from the data: 1) Child and Family, 2) The School Journey, and 3) The School's Operations. The children have their own health challenges that impact those around them, such as their immediate and extended family. Participants highlighted that when the family did not understand the condition, they were less likely to support and help care for the child. Finding a school and, more importantly, finding the right school for their child was difficult for most participants as they faced hurdles such as long waiting lists, mixed-ability classes and expensive school fees.

Participants complimented certain aspects of the school’s operations, such as parent support group meetings.

On the other hand, complaints included poor communication from the school. The participants also recommended changes they would like to see at the schools, such as outdoor activities and sports for the children. The results showed key areas where parents need help and support. There are several areas where genetic counsellors could play a role in supporting these families. These include facilitating family communication, appropriate referrals and advocacy.

This research could help with more efficient school placement of children with a genetic condition leading to intellectual disability, especially those with more than one disability or health challenge. Understanding what parents and families with children at special needs schools endure may help healthcare and educational professionals provide support and assist them with the child's educational needs. This research could also assist special needs schools in addressing the parents’ concerns and identifying what methods and processes parents find beneficial. This study identified further opportunities for future research, such as research into the roles and limitations of genetic counselling in special needs education and family communication.

“*Education is the most powerful weapon which you can use to change the world.”*

- President Nelson Mandela

Dedication

To my family and friends both far and wide.

To my incredible parents, Zig & Leanne, who supported and nurtured my curiosity and inspired me to reach for my dreams. I am forever grateful for all the opportunities you gave me.

To my “little” brother, Liam, thank you for always putting things in perspective and teaching me it’s okay to “just chill” sometimes.

To Brad, for being there through undergrad, honours and masters. You are my biggest source of warmth and comfort.

To Amy, one of the strongest fighters I have the privilege of knowing. You, and your story, inspired this entire journey for me, and I will never forget that.

To Margs, who always had so much faith in me and drove me to pursue everything I wanted.

To the extraordinary parents of children with special needs who inspired and participated in this research.

Acknowledgements

This would not have been possible without my participants, who gave up their time to tell me their stories. I hope I did your stories justice and that others can find inspiration in reading them.

To my supervisor, A/Prof Tina-Marié Wessels, thank you for your guidance and advice throughout the process, both for this research and my counselling.

To my co-supervisor, Kalinka Popel, your input and support have been indispensable. You encouraged me every step of the way.

Thank you to my fantastic colleagues that helped with recruitment and are always available for a chat. Andrew, Lisa, and Willem, I am so glad we went through this together, and I know you will all go on and do amazing things.

To my friend and mentor, Deanah, thank you for all the guidance and help from the beginning.

To my friends Akira, Emily, Joy, Kameron, Lanti, and Sarah, who will always have a special place in my heart.

And my grandparents, that did not get to see me get here but that I know would be proud.

To my extended family, especially my cousin Ryan, who is an inspiration to everyone he meets.

Thank you to my unofficial family, the Blatches, Frodshams, Martins, Venters, Gogo, and Norma.

To Bev, Dave, and Kirst for always making me feel part of your family and for all the love and support I found there.

To Jarryd and Kovu, for all the wine, advice and free therapy. It undoubtedly made this year, and healthcare in general, so much better. Limpopo is lucky to have the two of you, and I know you will thrive there.

Last but not least, I do not have all the words that describe how much I love and appreciate you, but I will try:

- A massive thank you to Brad; you believed in me even when I didn’t. I love you, and I couldn’t have done this without you.

- To Liam, although we drive each other crazy, I couldn’t have wished for a better sibling.

- A heartful thank you to my mom, who was always free for a chat even when I was walking back after a semester test at night and just wanted to speak to you. As much as I joke about our daily phone calls, I don’t know what I would do without them.

- To my dad, I am eternally thankful for everything you do and sacrifice for me. I appreciate everything you do for me and that you take such an interest in Genetics. You taught me to follow my passion, no matter how difficult the journey would be, and now the goal is within sight!

Table of Contents

List of Abbreviations

ADHD -	Attention-Deficit/Hyperactive Disorder
ADLs -	Activities Of Daily Living
ASD -	Autism Spectrum Disorder
CDG -	Care Dependency Grant
CHD -	Congenital Heart Defects
DBE -	Department of Basic Education
DBST -	District-based Education Support Teams
DOE -	Department of Education
DSD -	Department of Social Development
DWCPD -	Department of Women, Children and People with Disabilities
GIQ -	General Intelligence Quotient
ID -	Intellectual Disability or Intellectual Delay
LD -	Learning Disability
OT -	Occupational Therapy
RSA -	Republic of South Africa
RCWMH -	Red Cross War Memorial Children's Hospital
SA -	South Africa
SBST -	School-based Support Teams
SDGs -	Sustainable Development Goals
SEN -	Special Education Needs
SNS -	Special Needs School
UN -	United Nations
UNESCO -	United Nations Educational, Scientific and Cultural Organisations
UNICEF -	United Children's Fund
USA -	United States of America
USD -	United States Dollar

List of Tables and Figures

Chapter One: Literature Review

1.1 Chapter Introduction

Literature relevant to this research is reviewed in this chapter, highlighting the gaps and challenges in special needs education in South Africa (SA). The chapter concludes with the research question, aims, objectives, and rationale for this research.

There is a significant gap in the literature concerning parents' experiences and perceptions of special needs education in Cape Town, SA. There is some literature on this issue of special needs education in countries overseas, such as the United States of America (USA) and Australia. However, this literature may not be translatable to the South African setting. Both South African special needs schools (SNS) and families with children with special educational needs face unique challenges in a developing country. Therefore, these overseas studies are referred to and compared with the data collected in this research project but may not be completely true for the South African setting.

The literature for this project was collected using database search engines such as Google Scholar, ScienceDirect, Scopus, PubMed, and Medline. Numerous terms were used to search, such as special needs education, intellectual disability, South African special schools, genetics AND intellectual disabilities, COVID-19 AND education, COVID-19 AND special needs.

This chapter is arranged into subheadings as follows:

- A Brief History of Special Needs Schools in South Africa
- Definition and Characterization of Intellectual Disability
- Genetic Aetiology of Intellectual Disability
- Parent's Perceptions of Their Child's Schooling Needs
- Support Systems
- The Impact of COVID-19 on Education

1.2 A Brief History of Special Needs Education in South Africa

The pre-1994 South African education system promoted segregation and marginalised children with disabilities, especially those from African rural communities (Pather, 2011). Learners with various disabilities were classified as having special educational needs and were kept separate from learners without disabilities (McKinney & Leslie, 2016:310). The resources available for these children with disabilities were ineffective and unjust (Department of Education [DOE], 2001:36). In an attempt to rectify the injustice and discrimination experienced during Apartheid, the new government (The African National Congress) aimed to equalise opportunities, address and prevent previous political, economic and social disparities that affect the majority of South Africans (McKinney & Leslie, 2016:309). The Constitution section 9(3) specifically states that no person "*may be unfairly discriminated against on the basis of disability*." Thus, all children's rights to basic education were also preserved (Republic of South Africa [RSA], 1996a:6, & RSA, 1996b).

Since 1996 SA has signed numerous acts, goals, and declarations with organisations such as the United Nations Educational, Scientific and Cultural Organisation (UNESCO), the United Nations (UN), the United Children's Fund (UNICEF), and the Sustainable Development Goals (SDG's) (UN, 2000; UN, 2015; UNESCO, 1994). The South African government also issued Education White Papers, developed School-based Support Teams (SBST) and District-based Education Support Teams (DBST) and national policies aimed at providing an empowering educational environment (Department of Basic Education [DBE], 2010; DOE, 2001; DOE, 2005). These events set the stage for the current education system; however, there is a lack of data and information regarding the effectiveness of these previous efforts (Department of Social Development [DSD], Department of Women, Children and People with Disabilities [DWCPD] & UNICEF, 2012:7). Figure 1.1 shows the timeline of the events mentioned above.

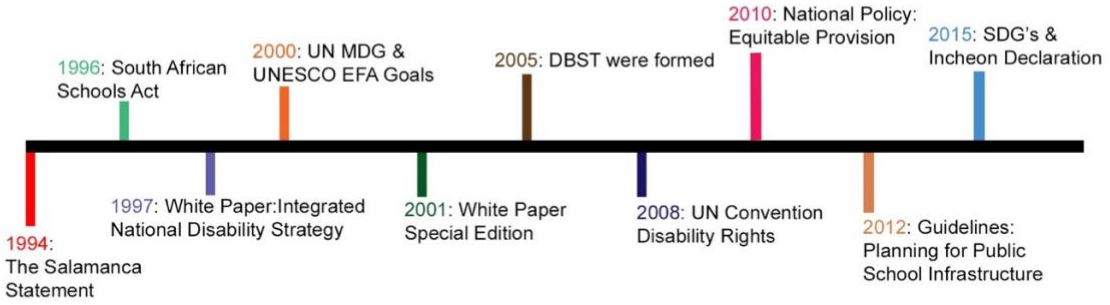

Figure 1.1: A Timeline from 1994 to 2015 depicting the acts, goals, and declarations South Africa has signed (UNESCO, 1994; UN, 2000; DOE, 2001; DOE, 2005; DBE, 2010; DSD, DWCPD & UNICEF, 2012:7; UN, 2015).

There is sparse evidence reported on access to early learning for children with disabilities in preschool. A 2006 study reported that only 25% of children between 0-6 years who received the Care Dependency Grant (CDG) went to a crèche or child-minding centre (DSD, DWCPD & UNICEF, 2012:7). The CDG is an R1 980 (± USD$115) per month "*grant to take care of a child who has a severe disability and is in need of full-time and special care*" that is provided by the SA government (South African Government, 2022). Even if children with disabilities do access early learning, it is usually in an informal community setting with individuals, such as the mothers of disabled children, who facilitate the "*stimulation programmes*" (DSD, DWCPD & UNICEF, 2012:7). The average monthly cost of raising a child with ID in 2011 in SA was estimated at R1 624 - R 5 255 (USD$95 - USD$308), this is from the last published census in SA (Hanass-Hancock & Deghaye, 2016:45). Taking inflation into account, in 2022 the average monthly cost is closer to R2 891 - R9 357 (USD$170 - USD$549). The cost of raising a child with ID exceeds the CDG grant, thus adding to the difficulties of providing access to school, especially if a caregiver generates no additional income.

In SA, the number of full-service schools (schools prepared to support various disabilities) has increased from 30 in 2008/2009 to 513 in 2010/2011 (DSD, DWCPD & UNICEF, 2012:7). In 2012 roughly 110 300 students with disabilities attended mainstream schools, and SNS had approximately 105 000 students. However, research has suggested that children with disabilities are significantly less likely to attend school than non-disabled peers (DSD, DWCPD & UNICEF, 2012:7). Additionally, the learners with disabilities who have access to school have a higher drop-out rate than non-disabled learners (DSD, DWCPD & UNICEF, 2012:7). In South Africa, teachers in both mainstream and SNS have also identified problems such as lack of electricity, photocopiers, appropriate seating, a safe and inviting school atmosphere, and limited human resources such as rehabilitation therapies, psychologists, and remedial teachers (Pather, 2011:1105-1106). Additional barriers to education include transportation, recreational facilities (such as sports fields and equipment), challenging admission systems, and lack of information. Furthermore, attitudes, beliefs, and misconceptions of society regarding disability represent significant barriers to the schooling of children at SNS (Cramm et al., 2013:32; Martínez, 2015:42).

1.3 Definition and Characterisation of Intellectual Disability

Special education needs (SEN) learners include a wide variety of students with a range of cognitive, emotional, physical, behavioural, and intellectual or learning disabilities. These students show various abilities and academic potential (Kang & Martin, 2018:320). Internationally, the number of children with SEN is increasing annually. In the United Kingdom, students are classified as having SEN if they have significant difficulty learning compared to their peers (Demetriou, 2020:3). In SA, the terms used are intellectual disability or intellectual delay (ID) and can be classified based on general intelligence quotient (GIQ) test scores (Adnams, 2010:437). These ID categories are illustrated in the graph below (Figure 1.2; Williams & Na, 2017).

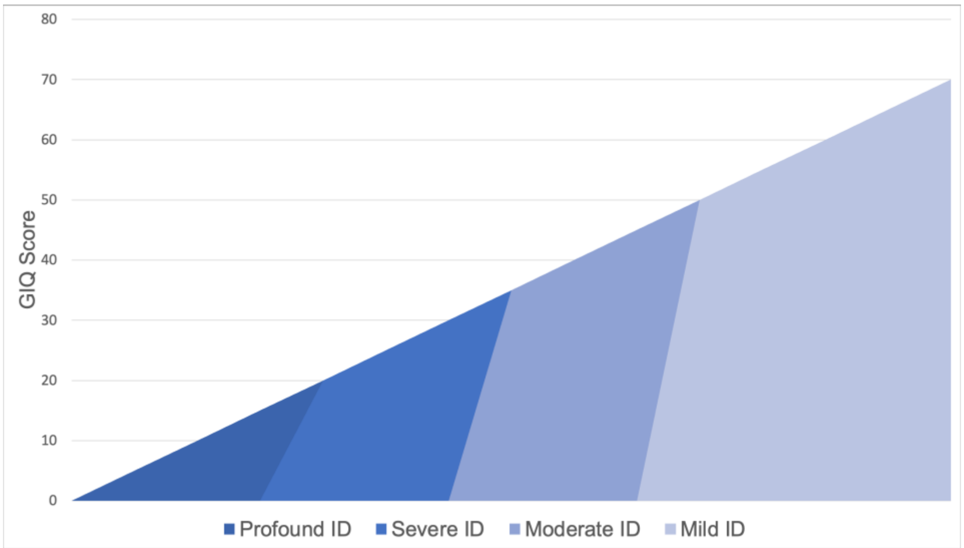

Figure 1.2: The GIQ Ranges of Intellectual Disability Categories (Williams & Na, 2017).

The diagnosis of ID is made based on how severe the adaptive functioning deficit is in the individual. Up to 50% of ID co-occurs with behavioural, mental, and emotional health disorders (Hronis et al., 2020:62). These disorders may include depression, autism spectrum disorder (ASD), and attention-deficit/hyperactive disorder (ADHD). In turn, these disorders add to the general functional disability of affected people. They can increase the burden on themselves and their families, who are already dealing with developmental and physical challenges (Opoku et al., 2020:1). These neuropsychological deficits have been seen in memory, learning, attention, language, and executive functions (Hronis et al., 2020:63). Support systems and support needs are sometimes implemented to improve the deficits that affect these children with ID. Assessed support needs can be used to classify subgroups of ID and ASD (Shogren et al., 2017:866). Knowing the kind of support children need to participate in educational and cultural activities can help create a more inclusive environment. "Inclusive" refers to an organised effort to reach marginalised children and incorporate the approach with all dimensions of education policy (Aldersey, 2012; Cramm et al., 2013:32). Although there is talk of introducing an inclusive education system in SA, this is not without possible complications. One such complication may be that it could perpetuate segregated schooling because as much as the policy may be aimed at any educational setting, it is clear that it is intended for SNS settings (McKenzie, 2021:56; McKenzie, Shanda & Aldersey, 2021:42). In SA, the main form of SEN teaching is through established SNSs. Thus, this study looked specifically at SNSs and not inclusive mainstream schools.

There is limited data on the frequency and types of developmental disabilities among children in underdeveloped parts of the world, such as parts of SA (Giarelli et al., 2009:1298). Kromberg et al. (2008:91) suggested that 3.6% of all children in SA have an intellectual disability. This was based on their study of 6,692 children with ID in Limpopo province. There are inconsistencies in the reported disability levels of children across areas such as geographical location, age, other socioeconomic characteristics, and sex (DSD, DWCPD & UNICEF, 2012:6). Additionally, there is limited data on the aetiology of ID in SA (Adnams, 2010:437).

However, a South African based study in the province of Limpopo found that of this population group studied, 6.3% had an acquired cause, 73.1% were idiopathic, and 20.6% of children with ID had a congenital cause (Kromberg et al., 2008:91). Congenital causes can include genetic conditions characterised by ID such as 22q11.2 deletion syndrome, Kleefstra syndrome, Renpenning syndrome, Bardet-Biedl syndrome, Coffin-Lowry syndrome, Williams syndrome, Cornelia de Lange syndrome, Fragile X syndrome, Pallister-Killian syndrome and Down syndrome. Depending on the nature of the genetic condition, some may present with physical disabilities in addition to ID (Karam et al., 2015:1209).

1.4 Genetic Aetiology of Intellectual Disability

As outlined above, several genetic conditions can affect intellectual and cognitive functioning in affected individuals. Table 1.1 contains some genetic conditions and shows the variation in underlying aetiology, severity and associated medical concerns of different genetic conditions.

Table 1.1: A Summary Of Some Genetic Conditions Associated With Intellectual Disability.

Genetic Condition	Genetic Cause	Inheritance Pattern	ID Categories	Medical Challenges	Notes	References
22q11.2 deletion syndrome	22q11.3 microdeletion of ±3Mb	Autosomal Dominant	Generally reduced GIQ scores. 1/3 normal development 1/3 mild learning problems 1/3 moderate learning problems.	90%< communication difficulties ±93% behavioural, psychological and psychiatric problems. 50-85% significant CHD, 20% have tetralogy of Fallot. otolaryngeal anomalies in 75%< 30-60% hypocalcaemia at some point, and may have immune system complications.	There is marked intrafamilial variability of expression.	Firth, H. and Hurst, J. 2017:624.

X-Linked ID	Xp11.4p11.3 deletion	X-linked	Moderate to severe	Short stature Low weight Microcephaly Scoliosis Speech delay	Highly variable depending on size of deletion and genes involved	Catino et al., 2022.
Pallister-Killian Syndrome	Mosaic Tetrasomy 12p	Chromosomal	Most affected individuals present with severe to profound ID	53% epilepsy 40% structural heart defects 87% ophthalmologic issues 19% are legally blind 77% hearing loss		Izumi & Krantz, 2014.
Kleefstra Syndrome	*EHMT1* gene or deletion at 9q34.3	Autosomal Dominant	Most have moderate to severe ID.	Severe expressive speech delay 50% CHD 10-30% renal defects 30% seizures	Behavioural problems such as ASD, sleep disturbances, mild self-injurious	Ciaccio et al., 2018.
Renpenning Syndrome	*PQBP1* gene at Xp11.23	X-Linked	In males: moderate to severe ID	CHD Renal hypoplasia Palatal anomalies Seizures Atrophy	Typically, female carriers are unaffected	Cho et al., 2019.
Bardet-Biedl Syndrome	14 Different Genes (BBS Genes)	Autosomal Recessive	61% learning difficulties 50-91% developmental delay	93% rod-cone dystrophy 63-81% polydactyly 72-92%Obesity 53% Renal anomalies 54-81% speech delay	There is marked intrafamilial variability of expression.	Forsythe et al., 2018.
Coffin-Lowry Syndrome	*RPS6KA3* gene at Xp22.12	X-Linked	Males: moderate to severe ID Females: mild to moderate ID	Progressive kyphoscoliosis: • 47% of males • 32% of females Cardiovascular disorders • 14% of males • 5% of females 30% hearing loss 20% Stimulus-induced drop attacks	Neuropsychiatric concerns Behavioural problems Progressive spasticity or paraplegia Sleep apnoea Stroke	Lv et al., 2019.

Williams Syndrome	7q11.23 Microdeletion	Autosomal Dominant	Developmental delay with very variable ID, from low/average to severe with the majority having mild ID.	80% CHD 75% supravalvular aortic stenosis 25% discrete supravalvular pulmonary stenosis 40% renal artery stenosis 15% of infants have hypercalcemia	Strengths in language, poor visuospatial skills, overfriendly personality, short attention span and anxiety	Firth, H. and Hurst, J. 2017:113.
CHD - Congenital heart defects						

1.5 Parent's Perceptions of Their Child's Special Needs School

Parents or caregivers are typically the strongest advocates for their children, especially when their child has special needs and are unable to advocate for themselves, such as children who are nonverbal or have challenges with communication. Additionally, children with special needs may also have health complications along with ID. In keeping with this, parents also want the best for their child in all aspects of life, including academics. Children with ID may not always be able to write formal exams and follow mainstream curriculums, but parents still expect their child to learn, develop and grow at school. Some parents may expect their child to finish school with basic life skills like feeding and using the toilet independently. Alternatively, some parents may expect their child to leave their SNS with enough skills or progression to be integrated into mainstream schools afterwards (Bajwa-Patel & Devecchi, 2014; Opoku et al., 2020:7; Thomas et al., 2018:99). These expectations are coupled with anxiety and worry regarding their child's future, especially when the parents or caregivers are deceased (Asa et al,. 2020:2).

Effective parent-teacher communication is also crucial for optimising education, service provision and the child's skills improvement. There is often parental concern about what happens at school. Bullying, not fitting in and unhappiness are significant concerns for parents of children at mainstream and SNS (Broomhead, 2019:878; Hodges et al., 2020; Salmivalli, 2010). Moreover, children with SEN are more likely to be bullied and socially excluded from their classmates (Frederickson et al., 2007). This also applies to the general community in which the child and family belong (Opoku et al. 2020:5). Since some children with ID are nonverbal or have speech impediments, parents rely on and expect the school staff to efficiently communicate with them regarding their child's development and daily activities. However, this communication is complicated and multi-faceted with numerous dimensions; previous studies reported that parents and teachers have difficulty communicating their concerns and generating solutions to these concerns. Additional barriers to effective parent-teacher communication include "*lack of trust in the school system and systemic inequities maintaining hierarchical relationships, particularly for families from under-served communities*" (Azad, Marcus & Mandell, 2020:2; Cascio & Racine, 2022:13).

The relationships between the school staff and parents as well as with the children are important to all parties involved. Parents need to feel like they are being heard and taken seriously by the staff (Krane & Klevan, 2019:75; Leenders et al., 2019:521). Parents have first-hand and invaluable knowledge about their children and have information to share with the staff that could benefit the child. Parents have previously expressed that they want to contribute this "*first-hand knowledge and engagement for their child*" (Erbeli, 2019; Krane & Klevan, 2019:75). The teacher-student relationship has "*been recognised as pivotal in student's motivation, learning and achievement*" (Hale, Fox & Murray, 2017; Krane & Klevan, 2019:75). The relationship is especially crucial to adolescents' emotional and psychological development since teachers are part of their daily lives. Following this, parents believe that teachers should create and encourage a nurturing environment in the classroom (Krane & Klevan, 2019:75; Majoko, 2019:9; Thornberg, 2018:148).

Some parents believe that SNS' role is to help relieve the caregiver's burden by providing somewhere for the child to go during the day (Ramasubramanian et al., 2019:177). This gives the parent time to participate in other activities such as leisure time or work and financially aid the family. The caregiver burden is a severe problem faced globally, with women generally taking on most of the challenges. The burden can be psychological, social, and financial since some caregivers are single parents and may have no income if they cannot work due to childcare responsibilities (Asa et al., 2020:2). A Ghana-based study by Opoku et al. (2019) highlighted that in developing countries, access to information, skills training, employment, education, and support systems are significant challenges caregivers face.

1.6 Support Systems

Caregivers have previously stressed the importance of support systems and services provided by healthcare professionals and their families and social environment. These professional support services include social workers, psychologists, rehabilitation therapies such as occupational therapy (OT), medical doctors and genetic counsellors (de Verdier, Fernell & Ek, 2020:1922; Fernández-Ávalos et al., 2020:720). These services can and do often help with SNS referrals and placements. Once in a SNS, the staff and other parents can also be sources of support and guidance. In a 2020 Swedish study with children with ASD and blindness, some parents reported that the need for support varied across the children’s ages and was possibly more prominent in earlier years. In contrast, some parents reported that they felt they needed continuous support and that the support and guidance from the staff was important (de Verdier, Fernell & Ek, 2020:1924; Gobrial, 2018:7).

Support groups in person and online are also sources of guidance and advice for parents of children with genetic conditions and ID. Parent-run support groups provide an opportunity for parents to discuss their concerns and struggles with other parents who have similar experiences and can relate to the associated challenges. This can help to decrease social isolation and develop self-acceptance, self-confidence, self-efficiency, and a sense of personal worth for caregivers (Wynter et al., 2015:70). Family members and their local community also provide emotional and logistical support, which has been shown to protect parents from psychological distress. These support systems are frequently used by people in Africa, with many parents being described as relying on extended family for support (Oti-Boadi, 2017:1). Family support can be from both immediate and extended family, and often the sibling(s) of the child with ID are key pillars of support (Williams et al., 2010:49). The siblings sometimes initially struggle to accept that the child with ID may need more attention and time from the parent(s). Due to this, the siblings may feel excluded, confused, anxious and angry. A study based in Pakistan found that, with time and guidance, the siblings generally accept their sibling's diagnosis and challenges and become protectors, friends, and mentors (Fayyaz, Sajjad & Suleman, 2012:37).

1.7 The Impact of COVID-19 on Education

After the first COVID-19 case was recorded in SA at the beginning of March 2020 (Abdool Karim, 2020), the South African government declared a national state of disaster on 15 March 2020 (Labuschaigne, 2020). To try to limit and contain the spread of the virus, SA was placed under a "hard" (level 5) national lockdown on 27 March 2020. Under level 5, all non-essential services were closed, including schools and universities (COVID-19 Online Resource and News Portal, 2020). The government adjusted the restriction levels following the COVID-19 cases in the country, with level 5 being the strictest and level 1 having the fewest restrictions. The government advised that wherever possible that people work and learn from home. These "stay-at-home" restrictions have had a significant impact on everyone, especially on people with ID and their families. The closure of schools meant parents had to home-school their children, whether the schooling continued online or stopped altogether (Bailey, Hastings & Totsika, 2021). Even with the country lifting certain restrictions since 1 May 2020, some schools had not reopened to all students, and even where schools had opened, some parents had chosen not to send their child(ren) back to school yet. Parents' hesitance to send their children back to school was generally based on the inherent uncertainty around COVID-19 waves and the numerous lockdown level changes (Figure 1.3), especially if their child was immunocompromised (Jeste et al., 2020:826).

Figure 1.3: A timeline of the different lockdown levels in SA between 26 March 2020 and 1 November 2021 (COVID-19 Online Resource and News Portal, 2020).

With these children being out of school for extended periods, they did not all have access to the services provided at the school, such as physiotherapy, speech therapy, and OT. These lapses in crucial therapies may have resulted in deficits that would eventually worsen the disparities already affecting these vulnerable children. Since regular rehabilitation therapies aim to maintain or improve motor and speech skills, the cessation of these therapies can negatively affect the children's abilities and possibly result in regression (Cacioppo et al., 2021:4). There is also the possibility of regression due to the absence of social interactions and physical activity. This is a significant concern for parents who either had to try to provide these therapies themselves or take the child to external services, which created financial and logistical challenges (Cacioppo et al., 2021:4; Dhiman et al., 2020:2). Some of these children thrive when they have a routine. The uncertainty that arose from the pandemic could create anxiety and confusion and result in behavioural and emotional problems that the parents need to deal with. Combined, this can disrupt everyday family life and cause stress for the parents and siblings (Ren et al., 2020:2).

1.8 The Rationale for the Study

Understanding concerns regarding inclusion and parental needs and perceptions have been the emphasis in research for decades. However, as mentioned earlier, there is a lack of research regarding this in developing countries such as SA. The issue of access to adequate SNS and supportive services is more complex and does not only include the parents’ perspectives. Parents who have a voice to communicate their needs are empowered and already have access to school. However, in SA, most parents are not empowered due to poor social circumstances, finances, family support, distance to school, and availability of schools. Previous studies have looked at parental welfare in areas such as resilience, the supporting functions of informal social support, the uplifting effect of positive emotions, the relationship between the parents’ centre of control and happiness, the role of specialists as advocates of coping techniques, and the significance of formal support services (Clark & Adams, 2022:39; Olsson & Roll-Pettersson, 2012:69). In SA, parents' perspectives are not always sufficiently understood or considered in educational decision making. In many instances, children with special needs are not getting the educational support they need from their schools. Education has been shown to allow for an essential pathway for children with ID to get specialised training to improve their independence and reduce the caregiver burden (Opoku et al., 2020:2). The previous South African study based in Cape Town focused on special needs schooling of children with ASD specifically (Mithimunye, Roman & Pedro, 2018). Although there may be some overlap in educational challenges, there could be different difficulties faced by South African parents with children with a broader range of conditions. Therefore, as mentioned above, understanding parents' needs and perceptions is paramount in understanding the support they, their family, and community, need to function and thrive in society. This is why this research is studying this one aspect of the perceived needs of the children at the SNS as part of a minor dissertation.

Genetic counsellors' roles are to help the family adapt to the genetic diagnosis and help facilitate the family access to the appropriate healthcare and social support systems and resources (Skirton et al., 2015:453). Genetic counsellors provide practical and psychosocial support for an affected individual and their family (Kohzaki, 2014:2). Once a child has been diagnosed with ID, appropriate and adequate interventions such as rehabilitation therapies need to be implemented to prevent further progression of the condition or provide supportive care for the child (Shrivastava, Shrivastava & Ramasamy, 2016:30). Genetic counsellors work within this multidisciplinary team and refer and consult with these and other specialities (Kohzaki, 2014:2; Sefotho, Ferreria & Lushozi, 2021:94).

Genetic counsellors can assist affected children by facilitating appropriate therapies and support for children with ID through special needs schooling and by extending benefits to affected children in different aspects of daily life and family life (Hodgson & Gaff, 2013; Shrivastava, Shrivastava & Ramasamy, 2016:31). Therefore, a good understanding of the schooling needs of a child with an ID can help genetic counsellors support affected children and their families through appropriate referrals for schooling. Genetic counsellors can then also help to address any concerns that may arise regarding the educational needs of the child.

On a personal level, the rationale for this study included a personal interest in education and especially in special needs education. I have family friends with a child with ASD, and they were struggling to find a suitable crèche and primary school for him. In addition, I know a few teachers who specialise in remedial and special needs education. They would often talk about the different children they have in their classes and how it was sometimes difficult to understand and manage all their various challenges and abilities in one classroom. The post research reflection is found in Appendix E.

1.9 Aims and Objectives

1.9.1 Research Question

What are the perceived school needs of parents who have a child with a genetic condition leading to intellectual disability who are attending a special needs school?

1.9.2 Aim

To study parents' perceptions of their child's needs regarding a special needs school.

1.9.3 Objectives

- To understand the family support system that helps with the care and education of the child(ren) attending a SNS
- To determine the parent's perception of their child's experiences at school.
- To determine if the child's educational needs are being met at school as perceived by their parent(s)/guardian.
- To determine the parent's current challenges regarding the educational needs.
- To explore what parents feel their child's needs are and what support and services are provided by the special needs school.

Chapter Two: Methodology

In this chapter, the rationale for conducting a qualitative research study, the particulars of participant recruitment, data collection and analysis are discussed. The validity and reliability of the research and the ethical considerations are also presented.

2.1 Research Design

Qualitative research creates opportunities to study the origin and possible reasons for a phenomenon. It also allows the researcher to codify the experience and understand its relationship with the phenomenon (Williams & Moser, 2019:44). This study aimed to investigate parents' perceptions of their child's needs from their SNS, and, a phenomenological approach was used. Phenomenology is based on the study of an experience from an individual’s perspective. Phenomenological approaches are founded in a paradigm of personal knowledge and subjectivity and highlight the significance of personal perspective and interpretation. This approach is “*powerful for understanding subjective experience, gaining insights into people’s motivations and actions*” (Lester, 1999:1). The traditional phenomenological approach was not strictly followed but rather a constructive paradigm with a phenomenological approach was used. This approach is best suited to this research study because it aimed to gain insight into the parents’ experiences, perspectives, and actions.

2.2 Research Population and Sample Size

2.2.1 Research Population

This study explored parents’ or guardians’ perceptions of their child’s SNS. Inclusion criteria required mothers, fathers and/or guardians of children with ID stemming from genetic conditions who attend SNS in Cape Town to participate. The children, therefore, needed to be of school-going age, which typically ranges between 6 and 18 years old. Children could be attending both public (government operated) and private (independently operated) SNS in the city of Cape Town.

Candidates that did not speak English would have been excluded. Participants’ English proficiency needed to be sufficient for interviews to be conducted in English alone. Genetic services at Red Cross War Memorial Children’s Hospital (RCWMH) are conducted mainly in English with few sessions requiring a translator, and so most potential candidates met the criteria. No potential candidates that did not speak English were encountered in recruitment, and therefore none were excluded based on language proficiency.

2.2.2 Research Setting and Recruitment

Suitable participants were identified through the Division of Human Genetics' databases (~800 paediatric patients per year). The division provides specialist medical genetic and genetic counselling services at Red Cross War Memorial Children's Hospital (RCWMH) at a weekly clinic. Appropriate participants were those attending the Genetics clinic at RCWMH with their child(ren). This is because the children seen at RCWMH by Genetics require specialist follow up and management because of their genetic condition. Although the same families are managed at other clinics and specialities (such as the Developmental Clinic), this study focused on ID with a genetic cause, hence sampling from the Genetics patient database was the appropriate database to identify participants who meet inclusion criteria. Qualitative research needs to intentionally seek participants that can best answer the research question being investigated (Luciani et al., 2019:157). Purposive sampling was done to ensure that the appropriate sample group was recruited to address the research questions adequately.

Suitable individuals were contacted by the staff in the Division of Human Genetics. They were informed about the research project, and if individuals were interested, their details were given to the researcher. Thereafter, the researcher provided an information sheet (see Appendix A) via email or SMS or in person, depending on the circumstance. Willing participants were then invited to individual interviews.

Recruitment and interviews took place from 19 May 2021 to 10 September 2021. Interviews were arranged by the researcher to suit the participants' schedules. If the interviews were conducted over a video call, then the researcher sent the participant a meeting invitation ahead of time. This process is shown in Figure 2.1.

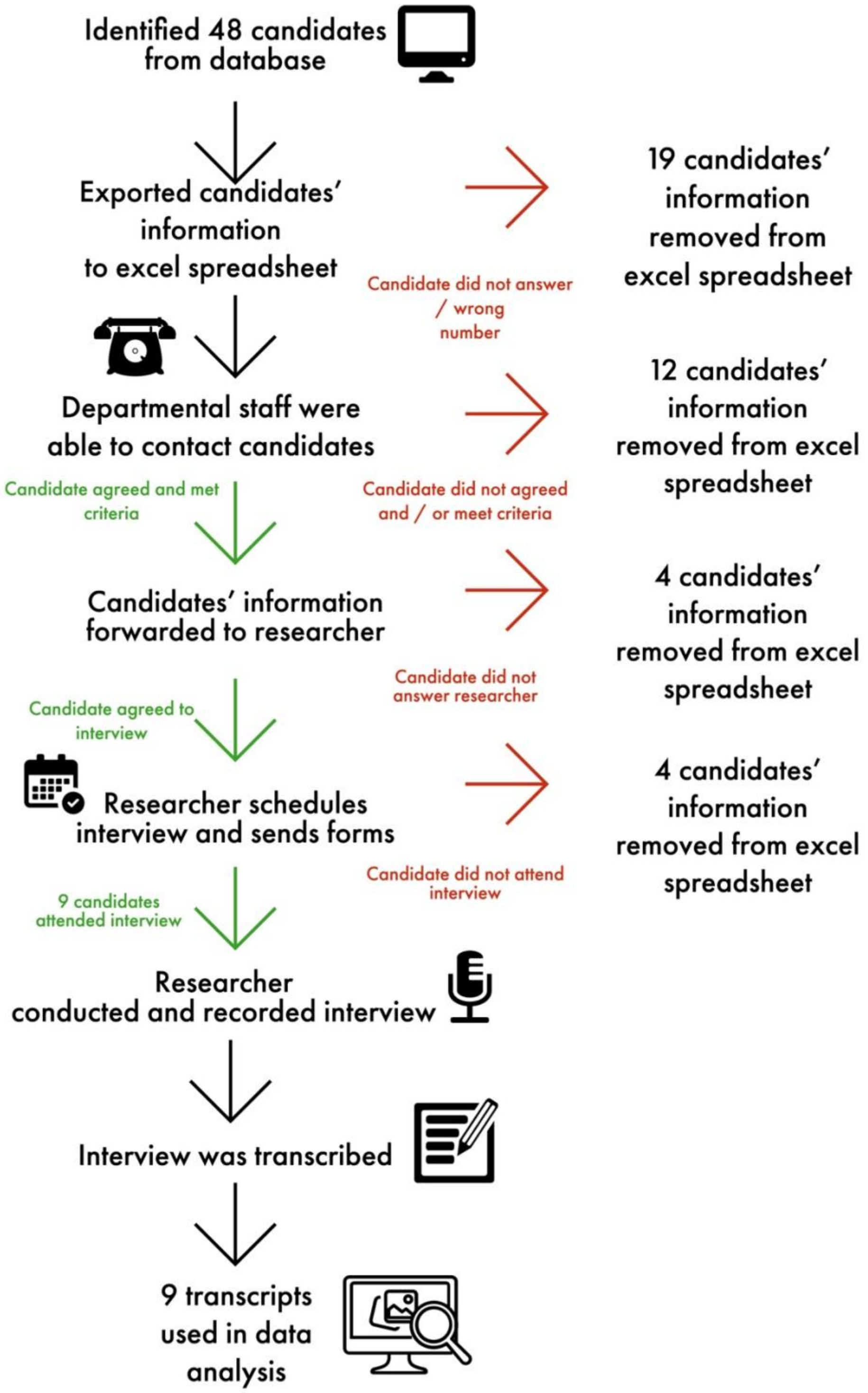

Figure 2.1: Summary of the events from candidate recruitment to data analysis.

2.2.3 Sample Size

Forty-eight candidates were initially identified from the departmental database. Of these 48, 19 candidates were not reachable by telephone, 12 candidates did not meet the criteria, and12 candidates did not meet the inclusion criteria. Of the 17 candidates that were eligible, four candidates were not reachable by the researcher, four candidates did not attend the scheduled interview. Thus, the final sample consisted of nine participants. These participants, were mothers of children at SNS were interviewed, the sessions recorded and transcribed verbatim. The researcher aimed to interview between 10 and 25 individuals. After conducting and analysing the seventh interview no new information was obtained from the interviews. However further interviews were conducted to ensure that saturation was reached. It was then decided, by the researcher and supervisors, that additional interviews were not necessary. Data saturation is reached when no new data appears from the last transcripts (MacFarlane, Veach & Leroy, 2014:200). Saturation is important because it supports the conclusions of the research study (Lowe et al., 2018:192). With retrospective regards to saturation, although it was strived for during data collection and analysis, it may not have been necessary or even truly reached (Braun & Clark, 2021).

2.3 Data Collection

The participants were asked to provide sociodemographic information (Appendix B) about the child's age and school attendance as well as the family structure. This short questionnaire survey was either emailed and completed (and emailed back to the researcher) by the participant before the interview or completed telephonically by the researcher before the interview questions began. The method depended on what was easiest for the participant and whether or not they had access to email. The survey provided information on the child's age, their diagnosis, and their current health challenges of the child.

Thereafter individual interviews were conducted as means of data collection for this study. These interviews were semi-structured and were conducted and recorded telephonically or over video call. The interviews lasted 30 to 90 minutes. Semi-structured interviews are commonly used in qualitative studies as they allow for some versatility and flexibility in the question guide, and the interviewer can tailor follow-up questions based on participants' answers (Kallio et al., 2016:2955). This further allows for participants' verbal expressions and enables the participants to focus on issues that are important to them. This type of interview style allows for a diversity of responses instead of being hindered by standard or expected answers (Cridland et al., 2015:78). The rigidity of the question guide can be adjusted depending on the research question and purpose. So that it acts as a guide to explore the research topics by collecting similar information types from participants (Kallio et al., 2016:2955). These elements of semi-structured interviews were appropriate to this study that aimed at collecting rich data on parents' perceptions. Popular qualitative interviewing methods (such as semi-structured or open-ended) create a valuable basis for performing phenomenological interviews (Bevan, 2014:138).

The interviews focused on the questions on certain topics but also allow some flexibility with answers from participants that led the research into a deeper understanding of the experiences around having a child at SNS. Likewise, this style of interview allows for the question guide to be updated and reviewed, which was necessary for this study as it progressed. The sociodemographic form and question guide can be found in Appendix B and Appendix C, respectively.

In light of the COVID-19 pandemic, there was a need for physical distancing and many universities closed worldwide (The University of Cape Town included in 2020). Additionally, most hospitals were restricted to essential in-person services only (RCWMH included). This impacted research activities internationally and was found to affect research applications, participant recruitment, and general progress (Saberi, 2020:2232). To adapt to this, all the interviews were telephonic or virtual (remote interviews) to limit the COVID-19 exposure risk to both the participant and the researcher. Remote interviews are also cost-effective, eliminating travel time. They are more convenient for parents of children with special needs because they do not need to bring their child to an interview or find someone to take care of the child at home during the interview. Similar points about remote interviews include benefits such as being more time effective, being seen as less invasive and thus possibly improving the chance of participation (Farooq & de Villers, 2017:311).

In this study, the remote tools used were telephones and Zoom, which is a cloud-based videoconferencing tool that includes online meetings and secure video recordings. Secure recordings are crucial in research settings since they allow for highly sensitive data protection. Zoom also enables real-time communication with participants worldwide through computers, tablets or cell phones. In a 2019 study by Archibald et al (2019:4), 69% of the participants reported that Zoom helped create and preserve rapport with the researcher. Some of the challenges with Zoom previously reported included low internet bandwidth, out-of-date hardware or limited camera or microphone function. However, the study concluded that the benefits of using tools such as Zoom "*significantly outweighed the challenges encountered*" (Archibald et al., 2019:4).

In this study, Zoom was used for three of the nine interviews; on average, these interviews were 20-30 minutes longer than telephone interviews. There were few to no issues with connection, sound, visuals or dropped calls while using Zoom. These sessions were generally held after working hours or on weekends since it was more convenient for the participants who attended work during the week.

The other six interviews were conducted telephonically. There were some challenges experienced with poor sound quality and dropped calls, but these challenges were overcome, and the interview questions were all completed. Farooq and de Villiers (2017) compared interview methods and presented arguments for both traditional (in-person) and alternative (telephonic) interview modes. In the case supporting telephonic interviewing, it is argued that telephonic interviews allow for a better balance of power between interviewer and interviewee. This then can encourage participants to speak openly and may provide more control to the interviewee to navigate the interview towards areas that they feel are important. The distance between interviewer and interviewee may result in fewer visual distractions in the interview as well as help reduce some of the bias towards the interviewer (Farooq & de Villers, 2017:293).

Overall, for this study, the researcher felt that it was beneficial to have remote interviews. This is because with social distancing protocols in place, the convenience and cost-effectiveness of not travelling for the interview outweighed the challenges faced in telephonic interviews. COVID-19 did delay the progress of the research through delays in ethics approval and participant recruitment since the university and some clinical staff were working remotely in 2020 and 2021. Nonetheless, on the whole, COVID-19 was not a major hindrance to this study since it was relatively easy to conduct interviews once participants were recruited.

2.4 Data Analysis

The audio recordings of the interviews were transcribed using Descript. Descript is a security software tool that can turn audio voice files into text rapidly and at a low cost (Descript, 2020). After the recordings were transcribed, the data was organised manually and analysed using thematic analysis as outlined below.

2.4.1 The Framework Approach to Qualitative Data Analysis

Both Hodges et al. (2020) and Mithimunye, Roman and Pedro (2018) used Braun and Clark's framework for thematic analysis because it is not linked to any specific theoretical approach (Braun & Clark, 2006). This allows for flexibility in the analysis of transcripts and provides a "*rich and detailed, yet complex account of data*" (Hodges et al., 2020).

These steps they provided are as follows:

1. Familiarising yourself with the data and transcribing
    - Reading and re-reading the transcripts, writing down initial thoughts
2. Generating initial codes
    - Coding interesting features of data systematically across the data set, organising data relevant to each code.
3. Searching for themes
    - Organising codes into possible themes, collecting all data relevant to each possible theme.
4. Reviewing themes
    - Ensuring that themes work in relation to the coded extracts and the entire data set, and "*generating a thematic map of the analysis*".
5. Defining and naming themes

- Continuing analysis to process the specifics of each theme and the general story the analysis tells, creating clear definitions and names for each theme.

6. Producing the report
    - The final chance for analysis and selection of vivid, compelling exact examples. Final analysis of the chosen extracts and relating the analysis to the research question and literature.

This is a useful framework for research analysis; therefore, it was used to analyse the interviews after data collection. The implementation of this framework and summary of events from recruitment to analysis are shown in Figure 2.2.

Two pilot interviews were performed before the official interviews began. The first pilot interview was conducted with a colleague, and afterwards, the question guide was revised. The second pilot interview was conducted with a candidate who has a child at a SNS to test the question guide, and afterwards, the question guide was revised.

Once the first three interviews were transcribed and analysed, a research meeting was held with the researcher and co-supervisor to discuss the results and to modify the question guide to better align the questions to the research aim and objectives. After nine interviews, another meeting was held with the primary and co-supervisors to discuss the results and emerging codes.

Both supervisors then assessed the codes and compared them to the codes from their blind transcript readings. Once the codes were finalised, they were grouped into categories. As discussed in Chapter 3, there was an overlap of categories between themes, making it challenging to separate the themes and subsequent subthemes. The researcher rearranged the categories several times and discussed them with the supervisors, as shown in Figure 2.2. After further assessment and discussion, the final themes and subthemes were agreed upon and are described in Chapter 3.

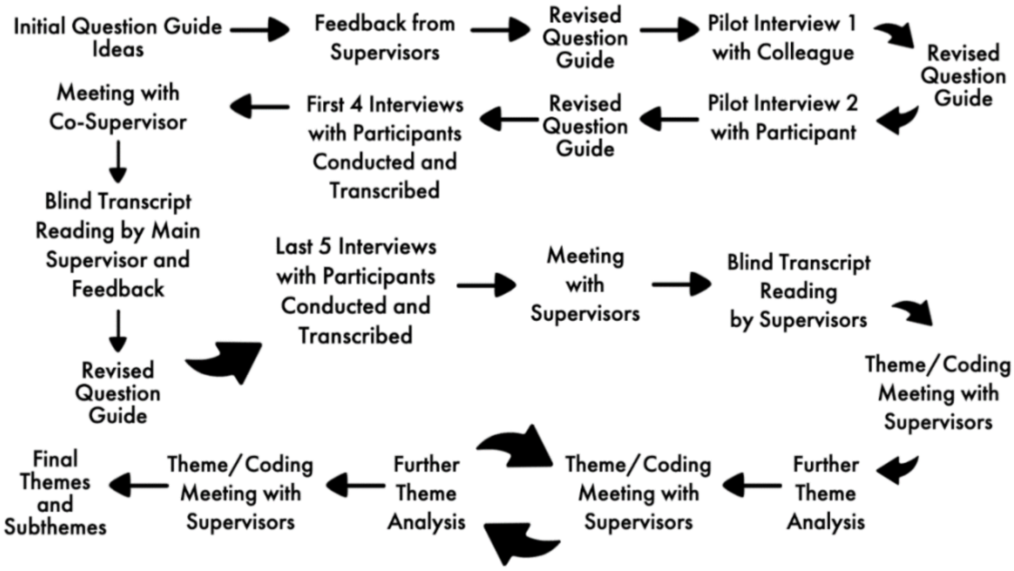

Figure 2.2: The implementation of a framework approach to qualitative data analysis.

2.5 Validity and Reliability

Validity and reliability are crucial and fundamental features in evaluating good research. Validity is associated with what and how well an instrument can measure data. Reliability is associated with the trust that someone can have in the data obtained with the instrument. In other words, validity is represented by the accuracy of the data, while reliability is represented by the stability of the data. These features increase transparency and limit the chances of researcher bias in qualitative research (Mohajan, 2017:2). The information sheet (Appendix A), sociodemographic survey (Appendix B), and question guide (Appendix C), and consent form (Appendix D), were all proofread by both supervisors. This step meant that the documents were all relevant and extensive to answer the research questions and aims. Likewise, the approach outlined in Figure 2.2 was followed. This method allowed for feedback, revision and adaptation of the research procedure and transparency in the process. Furthermore, the supervisors were involved in the data analysis to assist with accurate interpretation of the data, reduce researcher bias and boost confidence in the results. In addition to validity and reliability, reflexivity is essential in reducing research bias. Research reflexivity is a critical reflection of the researcher's position on the topic and how this position is taken into account in the research. To achieve this, steps were taken to be more aware of the researcher's cultural, social and political background and to focus on the interviewee's perceptions and voices (Watt, 2007). A post-research reflection can be found in Appendix E.

2.6 Ethical Considerations

2.6.1 Ethics Approval

Ethics approval was granted by The University of Cape Town, Faculty of Health Science, Human Research Ethics Committee (HREC: 114/2021). Permission was also granted from RCWMH to access the parents of the hospital's patients (RCWMH: RCC 269) as well as the Western Cape Health Department (WC_202104_038). The approval documentation is found in Appendix F.

2.6.2 Informed Consent

One of the important purposes of informed consent is to present participants with sufficient information so they can evaluate the pros and cons of their alternate choices and select the option that suits their personal values, needs and beliefs (Rogers & Johnson, 2021:76). In accordance with the Declaration of Helsinki, in this study informed consent was obtained through consent forms (Appendix D) before the start of the interviews. Participants could ask questions and clarify any uncertainties before signing the consent form. This was to ensure that they fully understood the research project and the consent form. The consent form was only provided in English. The consent form was either emailed to the participants to sign and send back to the researcher or verbal consent was obtained prior to the start of the interview. If verbal consent was obtained, it was recorded as part of the interview recording.

2.6.3 Confidentiality

The principal goal of medical privacy and confidentiality is the "*protection of the patient's interests*." In research, after consent from the participant, the data should be anonymised (ten Have & Gordijn, 2014:126). This was done by changing individuals' names to a participant number (e.g., P01). This made the participant and their family unidentifiable. Additionally, only researchers directly involved in the research (researcher, supervisor, and co-supervisor) had access to the data collected. The data was stored securely, both physically and digitally. Any hard copies of information were secured in the postgraduate student office in the division, and digital information was password protected. Once the data is no longer needed, it will be safely discarded after completion of the study and after publication.

2.6.4 Risks and Benefits to Participants

This qualitative research project was a low-risk study. However, there was the potential risk that parents or guardians may have become upset if they spoke about issues that were already emotionally charged. To minimise any discomfort, participants were assured that they could abstain from answering any question that they did not wish to answer and that they could have withdrawn from the study if they felt the need without this affecting their current or future medical care. Participants were ensured that they would be referred as appropriate (such as to psychology or social worker services) should it have become evident during the interviews that they were distressed or if any other unmet needs were identified. Most participants said that they appreciated being able to talk about their challenges raising their child with SEN and may have felt that it was helpful. As such, referrals to psychology services were not necessary during the nine interviews.

The potential benefits for participants were that the research could help raise awareness of families' issues and needs of children with ID in SNS. These issues and needs might then be addressed by the SNS and lead to fewer problems relating to the parent's concerns. This research could also help parents feel that their voices and opinions are being heard and taken seriously regarding their child's education.

Chapter Three: Results and Discussion

3.1 Chapter Introduction

The study results are presented and discussed in this chapter. The findings are presented as themes which describe the participants' experiences of their child's needs at SNS. Three major themes emerged from the data, and these are described and discussed in conjunction with available literature. Direct quotes from the interviews are presented to illustrate the participants' views. It is also essential to frame the findings of this research in the context of SA being a developing country with particular challenges that may not be encountered in more developed countries.

3.2 Socio-Demographic Data of Participants

Although not specifically surveyed, there were black, coloured and white participants in proportions that represent the general population of the genetics clinic at Red Cross. The children's ages ranged from seven to 15 years old, and they were diagnosed with a wide variety of different genetic conditions and associated health challenges (descriptions of these can be found in Table 3.1). Although not explicitly targeted, only 22.22% of the participant's children were female (Figure 3.1). Additionally, all participants were the mother of the child with special needs, and the majority of the participants were married (66.67%; Figure 3.2); most families had more than one child at home (66.67%) with fewer families who have additional extended family members living at home with them (22.22%; Figure 3.3). All the children went to different SNSs except for the children of P07 and P08 who attended the same private SNS. The different services provided at the different SNS are outlined and compared in Table 3.2.

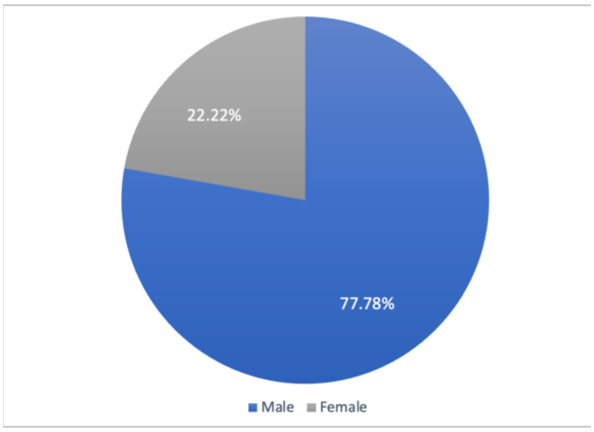

Figure 3.1: Sex of Participants' Children at SNS

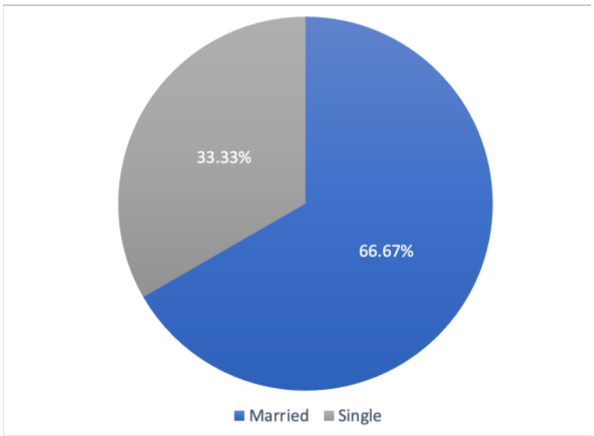

Figure 3.2: Relationship Statuses of Participants

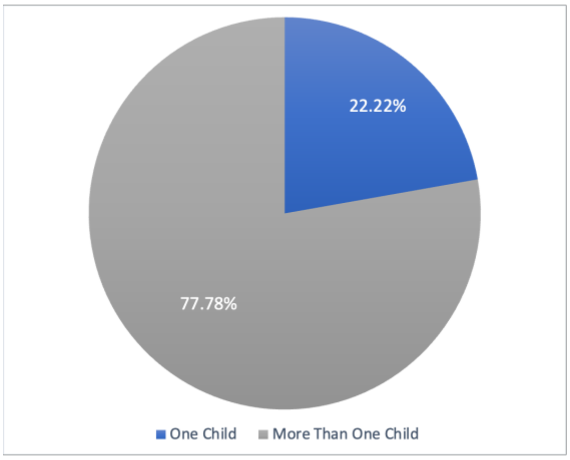

Figure 3.3: The Number of Children at Home with the Participants

Table 3.1: The Socio-demographic data on the child and the family structure

Participant Code	Genetic Condition	Age (Years)	Sex	Current Challenges	Family Structure
P01	22q11.2 deletion syndrome	12	Male	• Moderate ID, • ASD • Severe anxiety with several phobias • Required surgery on his feet • Mobile	• Single mother (divorced) • Only child • Employed
P02	X-Linked ID	7	Female	• Moderate ID • Hypotonia • Speech delay • Mood swings • Mobile	• Married • 5 children • Employed
P03	Pallister-Killian Syndrome	10	Male	• Severe ID • Unable to stand, walk, talk • Impaired vision and hearing.	• Married • 3 children • Employed

P04	Kleefstra Syndrome	10	Male	- Moderate ID - Speech delay - Mobile	- Married - Only child - Lost job due to COVID
P05	No Diagnosis	9	Male	- Moderate ID - Impaired hearing - Poor growth - Mobile	- Single mother - 2 children - Employed
P06	Renpenning Syndrome	9	Male	- Moderate to severe ID - Developmental delay - Impaired vision - Mobile	- Married - 2 children - Niece - Employed
P07	Bardet-Biedl Syndrome	10	Female	- Moderate ID - Impaired vision - ASD - Mood swings - Poor motor skills - Polydactyly - Asthma - Mobile	- Married - 2 children - Employed
P08	Coffin-Lowry Syndrome	14	Male	- Moderate ID - Low bone density - Seizures - Spinal stenosis - Incontinence - Kyphosis - Speech delay - Requires wheelchair	- Married - 2 children - Employed
P09	Williams Syndrome	15	Male	- Moderate ID - Cardiac complications - Allergies - Mobile	- Married - Only child - Aunts - Cousins - Unemployed

Table 3.2: The data on the school services

Participant Number	**Government or Private School**	**Transport**	**Food Parcels**	**Inhouse Therapies**	**Aftercare**
P01	Government	Provided	Provided	Provided	Not Provided
P02	Government	Provided	Provided	Provided	Not Provided
P03	Government	Provided	Provided	Provided	Not Provided
P04	Government	Provided	Provided	Provided	Not Provided
P05	Government	Provided	Provided	Provided	Not Provided
P06	Government	Provided	Provided	Provided	Not Provided

P07 and P08	Private	Not Provided	Not Provided	Provided at Additional Cost	Provided at Additional Cost
P09	Government	Provided	Provided	Provided	Not Provided

3.3 Identified Themes

As described in Chapter 2, thematic analysis was used to analyse the data collected in this study. The investigation revealed several codes grouped into 16 categories, then six subthemes, and finally into three main themes, as shown in Table 3.3 below. The categories were described as follows: advocate, COVID-19, support, family and siblings, the child's attributes, relationships, fitting in, previous schooling, getting into school, progress, the future, services, communication, satisfaction, guidance, and government. It should be noted that specific categories (support, COVID-19, and advocate) formed part of more than one sub-theme and, by extension, the main theme. This is because the categories were woven into multiple aspects of the themes that emerged from the data, which results in some overlap between themes.

Table 3.3 The Sub-Themes and Main Themes

Main Theme	Sub-Themes
Child and Family	Family Life
	The Child as an Individual
The School Journey	Getting There
	Growth and Development
The School's Operations	How the School Functions
	It is a Two-Way Street

3.4 Child and Family

Participants felt that raising a child with special needs was complex and challenging and that they needed help and support from their families. A child with SEN does not exist in isolation but rather as part of a family and community. The impact and influence of a child with SEN is described under two subthemes, "Family Life" and "The Child as an Individual".

3.4.1 Family Life

Raising a child with SEN and trying to maintain a healthy work and social life was a “juggling act” for most participants. They spoke about the impact that having a child at SNS had on the lives of the entire family and how they, as a family, had to make certain decisions and adjustments around the child and their particular needs.

> *“I'm still juggling now. And work is... There is a large workload. The schoolwork load is hectic. It's tiring. I get home at seven at night, and I have to come sit with homework. I wanted to pull my hair out of my head. Even now, though, it's just exhausting. I feel like I'm constantly drained other than work. You know, I'm just a mother. All the time, there's no time for nothing, I don't have time for anything else.”* - P01, 12y old son with moderate ID. Only child.

Parents had to take on new roles, such as advocating for their child, especially when they have challenges communicating and advocating for themselves. Several participants felt a duty to protect and advocate for their child even with their own family. Participants noted that the need to advocate resulted from individuals’ misunderstanding, particularly regarding the child’s genetic condition. They felt they had to make the family members understand and be more open-minded about the child and their condition. This was sometimes due to the child being unable to express themselves, so their parents would be the ones explaining their struggles and that the child needed the love and help from their family members.

> *“So when I go back home, I just ask them to be open-minded about the situation, not because of myself, but for my son. And he needs all his family members to help and support him. And with everything that he's been through, he needs someone to be there for him.”* - P04, 10 yr old son with moderate ID. Only child.

The participants that did have to advocate and explain to their family, faced some stigma from family members that were not willing to accept or understand the diagnosis. One participant said that her in-laws blamed the father for his drug use leading to the child’s diagnosis of Kleefstra syndrome. Another participant did not want to take her child to the one set of grandparents because they are not accepting, and she feared they would harm her child as a way to cure her.

> *"Hubby comes from a different province. Okay. They believe in traditional ceremony. I mean, there's no traditional ceremony, they can't eradicate the BBS10 [gene]. No child of mine is going to be cut."* - P07, 10yr old daughter with moderate ID. One sibling.

The stigma and barriers to acceptance that some participants faced within their families have been described before. A Tanzania-based study found that parents discussed stigma in several ways. Some said that the culture "*looks negatively on people with disabilities*" and see it as a "*bad omen*". Or people used derogatory terms to describe people with ID (Aldersey, 2012). While one participant (P05) in the current study said there were some cultural differences between her nuclear family and her extended family, no participants mentioned that family members used degrading language towards or about their child with ID.

These barriers to understanding and acceptance sometimes meant that there was less family support for the parents. The participants relied on family members to help with caretaking and emotional support, as explained by participants who had help from their grandparents in taking the child to their therapies and aunts who babysit.

> *"My mum and dad are there, they are still alive. So, they normally care for us, when he comes out of school, they will be the ones that look after him until his sister comes from school and then they'll go back home together. And then I normally knock off at 4:30 from work. And then we are all together again at night."* - P05, 9 yr old son with moderate ID. One sibling.

The lack of support caused participants to feel more isolated. One participant (P01) explained her strained relationship with her ex-husband's family and said they are not supportive or understanding of her son's condition. This meant that she felt like she was isolated and that she had to care for her son alone. The participant also felt like the family did not accept her son or his diagnosis, which further ostracised them from the paternal side of the family.

"I was on my own for a while, and it was frustrating, and it was hard. They [her in-laws] don't understand, they don't want to accept".- P01, 12y old son with moderate ID. Only child.

As discussed in Chapter 1 (Section 1.6), family support (logistical and emotional) can protect parents from psychological stress from taking care of a child with special needs. This present study correlates with previous research on how parents of children with ID rely on their families for support. Oti-Boadi (2017:1) described how sometimes the stigma associated with the ID, such as traditional and religious beliefs, could hinder parental engagement with support from the family, friends and community. This was also found in the current study, as some participants (P01, P04, P07 and P09) felt isolated from certain parts of the family and community because of their child's genetic condition and ID.

Feelings of isolation were further exacerbated because participants had to adapt their social life outside of the family to accommodate their child. A few participants spoke about staying at home to reduce infection risks, and their children may have phobias that prevented them from attending particular social gatherings. One participant said it is more important to stay at home with her son than go to parties. This meant that participants were further isolated from friends and family due to their child's condition.

Limiting social engagements was not the only sacrifice participants brought up in the interviews. The sacrifices ranged from changing daily living schedules, to getting their child to school early to changing the layout of their new home. The participants had to change their plans and goals for their family's future to accommodate their child's needs. For P06, her son had issues with his vision and would often walk into things, so they redesigned rooms like the bathroom to help him navigate the house.

"We just had to change our plan. Like we are currently building our house back home. We had to change some of the big pictures we'd been thinking about him.

Now accommodate him, because we thought we had the original plan... It was for a normal child. We had hoped that he was going to be fine. But now, because it is going to be a lifetime thing... the plan of the house actually had to change. Because of that, his bedroom had to change. The way it is going to be built, the bathroom has been changed. Everything. Just to accommodate him." – P06, 9yr old son with moderate-severe ID. One sibling.

Changing life plans, expectations and relocating for special needs schooling were described in various degrees in the present study. Some participants (P05, P07 and P09) moved closer to the school and to the health facilities their child attended. These changes may disrupt other family members in different aspects of their own lives, such as other children's schooling, parents' jobs and the family's distance from other family members. These sacrifices can put additional stress and pressure on the caregivers, cascading into relationships, employment and personal wellbeing (Asa et al., 2020:2; Gobrial, 2018:7; Ramasubramanian et al., 2020), which was seen in this study. The issue of stigma around the child affecting the parent's social life was not significant in the present study other than for one participant who had problems with her community not understanding or accepting her son's diagnosis of Williams Syndrome.

These sacrifices can put further stress and pressure on the parent(s), possibly affecting relationships, work and personal wellbeing. Parents of the child with SENs experienced challenges within their marriage, and in some cases, partners went for couples counselling or broke up. The strain appeared to come partly from taking care of their child's medical and developmental challenges and trying to decide what is best for their child. Participants expressed concern regarding whether or not they made the best decision for their children in different aspects of their lives.

"We took a lot of strain, my husband and I, and there were really hard times. PaedsPal[1] has also helped us quite a bit to keep us together with therapy. I've had to go to therapy and stuff. It's a hard pill to swallow. Cause also you don't know if you're

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[1] Paedspal is a Western Cape based paediatric palliative care not for profit company that provides palliation for children with life-limiting conditions (Paedspal Paediatric Palliative Care, 2022).

doing the right thing or if you are making the right decision." – P08, 14yr old son with moderate ID. One sibling.

It was essential to the participants that the child's siblings understood and accepted the genetic condition. One participant felt strongly that the immediate family needs to set an example on how to treat her daughter. The community will see if her neurotypical son does not show understanding and patience.

> *"We need to set the example for outsiders [people outside of the family] about how we treat her."* - P07, 10yr old daughter with moderate ID. One sibling.

However, getting the siblings to understand and accept their sibling's diagnosis was challenging. Most of the siblings took time to become understanding, compassionate and willing to help their siblings. Older siblings tended to take on a more nurturing and motherlike role and help their sibling with SEN with activities and physiotherapy home programmes from the school physiotherapist. In these situations, it was helpful when the siblings were supportive and assisted with caring for the child.

> *"In the beginning, it was difficult because my [neurotypical] son didn't quite understand, but now, as she gets older, they do help me a lot with her. And you know, once you start accepting that she's a special needs child, it's like everything falls into place"* - P02, 7 yr old daughter with moderate ID. Four siblings.

One study found that the benefits of having a sibling with special needs included "*increased family closeness, increased sibling sensitivity to the ill child and caregiving, and increased sibling maturation*" (Williams et al., 2010:49). These findings correspond with the results of this study. Most participants had multiple children, and they spoke about how the neurotypical child may have started off feeling left out or wanting more attention. But, with age and education on the condition, the neurotypical sibling learnt to accept the situation and became more understanding and empathetic to their sibling with SEN and other people.

The other children sometimes served as a reminder that the child at SNS was neurologically different and delayed compared to their siblings. For P06, watching the younger child overtake his older brother developmentally was difficult because it highlighted her son's challenges. It also made her concerned about who will care for her son when she and her husband are no longer there since the child already depends on his younger brother for help.

"Looking at the little brother trying to help the big brother with everything is a little bit hurtful to see. You know, usually, the big brother helps the little brother. Looking at him depending on the little brother... it is a little bit scary to think of what his future might be" – P06, 9yr old son with moderate-severe ID. One sibling.

Some of the older neurotypical children embraced their siblings with special needs and tried to include them as much as possible. Whether it was taking them to the library or inviting them to school sporting events, this inclusion was noteworthy to the participants because they were often concerned about their child not having friends and being excluded from activities. Being included was also appreciated by the child as it made them happy to be involved.

"I'm pretty sure that having a brother that's got special needs is also harsh… but my [neurotypical] son has been awesome in that he's embraced it… at primary school and high school he didn't worry to hide his [special needs] brother away, he came to hockey matches and stuff… he would smile because he's involved" - P08, 14yr old son with moderate ID. One sibling.

Literature has described the importance of family as a representation of the social environment for the child with ID and that siblings also have an essential role in the social, psychological and emotional adjustment of the child with ID. Furthermore, siblings and parents are crucial in helping the child with ID adjust to society and their communities (Fayyaz, Sajjad & Suleman, 2012:38). For many of the children in the study, their neurotypical siblings are their social connections to other children and to more social engagement than what they experience at home.

Data was collected during the pandemic, and it was found that many challenges of raising a child at SNS were exacerbated by the COVID-19 pandemic, with social distancing restricting family gatherings and schools and businesses closing during lockdown. Parents had to shoulder even more responsibility and home-school their children and either continue working or lose their jobs during lockdown. As discussed in Chapter 1 (Section 1.7), the COVID-19 lockdown levels changed repeatedly, and each level came with different restrictions and regulations. While parents were returning to work, schools were not open until much later. These regulations led to frustration, isolation and financial hardships for everyone, which most of the participants highlighted, such as P01, who had to home-school her son after a hard day at work.

One participant (P04) said that they or their partners had lost her jobs due to COVID-19 or had to stay home without pay to take care of her children, creating additional problems for the family. Families were also separated due to COVID-19 restrictions, which meant that extended families who are support structures were not as directly involved in the child's caregiving as before. Participants also said that their child found COVID-19 confusing and disruptive, such as wearing a mask, and did not understand the separation from family and friends. Similar findings were described by Bailey et al. (2021), who also reported some negative impacts of the pandemic in terms of loss of income, deaths of family members, increased parental stress, and the loss of support structures in families with SEN. COVID-19 restrictions can be seen as a change in daily routine, especially for school-going children when schools are closed. Some children with ID thrive with a routine and may become emotionally upset when the routine changes (Ren et al., 2020:2). This could contribute to why participants in the current study reported their child being disrupted and confused by the COVID-19 regulations.

"[Lockdown] was a very difficult time. He was at home always wanting to know "why? What's going on? Why do we need to wear a mask?". He fully understands everything now, I am very surprised. Because he didn't like masks and change. So it was very challenging for him to realign with change. Because he likes things to be a certain way. So COVID made him very confused, like "why does he need to wear a

> *mask if he doesn't like the mask". Like the need to sanitise, need to distance, always wash your hands. And if you are sick then you need to stay at home. He knows this, so COVID has done a lot of confusion there. But now he understands it and is aware of it about why he needs to go to school and why he needs to wear a mask. It took a while but now he is there."* - P04, 10 yr old son with moderate ID. Only child.

Not all participants necessarily felt like the pandemic was a negative experience. P02 felt the pandemic allowed her and her oldest daughter to get more hands-on time with her son's therapy and education programmes. The pandemic meant that her daughter was home and was able to care for her son when she went to work, so there was more support at home than before the pandemic. Bailey et al. (2021) found that some families were better off due to having more quality time together because families were more likely to be at home together for longer than before the pandemic.

3.4.2 The Child as an Individual

The various challenges faced by the children in the current study affected their educational needs and what their parents hoped for at school. Some children had difficulties with mental health such as anxiety and phobias, as well as physical health challenges like needing a wheelchair, hypotonia, immunodeficiencies, and vision and hearing loss. Most of the children also had challenges with speech and writing. Therefore, they needed additional support such as physiotherapy and occupational therapy. As much as the children needed similar interventions, the participants all highlighted that their child was an individual and needed individual attention from their parents and teachers.

> *"He always needs attention. More attention. He doesn't need a school that is going to be 15 or 10 [in a class] because he is a slow learner. He needs more attention."* - P09, 15 yr old son with moderate ID. Only child.

Despite having special needs and several challenges, the children also had strengths such as helpfulness and resilience. Participants appeared to have set different expectations for their children based on what they are capable of and what challenges they have. One participant was more proud of her son's polite behaviour, which was mentioned in his school report card, than his grades. She felt that it was important for her son to have manners and that she was pleased with the man he was becoming.

> *"I was so proud of him. He's not the top student, but he's the most well-mannered. And that is what everyone says, the most well-mannered and friendly and a quiet child in the class. But he's doing well."* - P01, 12y old son with moderate ID. Only child.

The parents reported that the children were keen to help with household chores such as cooking and cleaning, and they were amiable, lovable and fun to be around. Participants felt like this showed how the child integrated into the family, and they are capable of doing things for themselves and others.

> *"So when I am busy in the kitchen, maybe washing up or drying off the dishes, she will help me. Or if I am busy cutting potatoes, I must give her also a cutting board, a potato, and I give her a plastic knife, and she will sit on the floor and do her thing."* - P02, 7 yr old daughter with moderate ID. Four siblings.

An important characteristic was that of determination and willpower. One participant (P08) spoke about her son's resilience and how, despite his challenges (such as needing a wheelchair), her son has achieved some of his goals, like completing a cycling race in Cape Town. Participants stressed the need to consider the child as a whole and not just their diagnosis.

> *"There's an individual behind that diagnosis, and that's what you need to look at… The fact that he's had challenges and he still keeps on smiling, he still goes ahead to do what he needs to do. I mean, he's done two Cape Town cycle tours already… My husband pulls him in a buggy, and that was one of the things that he always wanted to do."* -P08, 14yr old son with moderate ID. One sibling.

Participants spoke about how the children would not give up when something was difficult for them, like learning to trace shapes and write and how they came up with alternative ways to complete the challenges presented to them. As described by participants, these traits and attributes of the children can be considered indicators of resilience. There is a marked lack of research regarding the resilience of people with ID and SEN since the literature is more focused on the challenges children with ID and SEN face than the protective factors such as resilience (Clark & Adams, 2022:39). There is little literature to compare with the current study.

Regarding the children’s relationships with their peers, most children had friends at their SNS. One participant (P01) was very proud that at the SNS, her son is more popular and has more friends than at mainstream school and that he has sleepovers with them. She also felt like her son fits in better at the SNS since there are children his age in his class, and his classmates also have special needs. Therefore, her son does not feel so different from his peers.

> *“He fits in [at his school], there are other boys wearing specs, there’s one of the boys with speech deficits, they’re his build. Um, they look funny, like him”* - P01, 12y old son with moderate ID. Only child.

One of the children recently found a new friend at school, and his parents were so happy that the principal sent photos of them playing together on the playground. It was a concern for his parents that he would not make friends at school, so it was a relief when he found someone to play with and who cared about him.

> *“The principal will send us videos of them playing. So they play in the sort of play area at the school and with the cars or whatever. Whatever my son can’t get for himself, his friend is up there “don’t worry, buddy. I got you”. And, he will push my son around in his wheelchair. “No, I’ve got him”. And, just seeing that, that connection is awesome.”* - P08, 14yr old son with moderate ID. One sibling.

Friendship has been described as aiding a child's social and emotional maturation by promoting them to have positive perceptions of themselves and influencing their perspectives and behaviour (Broomhead, 2019:878). Thus, children with friends are less likely to be lonely and depressed than those who do not. Previous literature reported that children generally choose friends with similar traits (like gender and interests), and children with SEN are more likely to be friends with other children with SEN (Broomhead, 2019:878). In the present study, participants reported that their child had made friends at their SNS and highlighted that their friends had similar challenges, making them more relatable to their child. However, even if the friends had different challenges, they were not neurotypical since they also needed to attend a SNS.

Another participant (P04) spoke about the importance of inclusion and said that her son could be himself and be comfortable around his peers. She said this helped his behavioural problems since he used to fight with other children at his mainstream crèche. The two participants who had children attending the same SNS noted that it is an inclusive environment where children can learn safely and are not looked at or judged.

In contrast, when some of the children were at mainstream school before their SNS, they struggled to make friends and were reportedly bullied. This was, understandably, a significant concern for participants. One participant's (P01) son was bullied at both mainstream and special needs schools. However, the bullying was worse at his mainstream school, and he did have more friends at his SNS.

> *"He was just lost in the system. He was at a mainstream school… he was seven. He was being bullied at school… There's still some bullying [at the SNS]. The ADHD kids, sorry that I'm labelling them now. They do tend to be...He is a very gentle boy. He would rather play with girls than play with boys because they are too wild for him. So he would gravitate toward all the more gentle-natured kids. So, some of the boys who are a bit hyperactive… he's somewhat afraid to be around them. And I'm sure that sometimes they tease him, you know because he's so gentle. So, there have been incidents here and there. But, it's always addressed by the school, the kids are all reprimanded or spoken to, so, it's never an ongoing process."* - P01, 12 yr old son with moderate ID. Only child.

In addition, a different participant reported that the bullying happened inside and outside of school, with her son being called a cripple by children in their community.

"Even now, most of the time, I am explaining to him, but, you know, the children in our location... Some are rude and even teasing. No, you are [a cripple] that is why you are attending that school [special needs school]" - P09, 15 yr old son with moderate ID. Only child.

Inclusion and exclusion can be seen as two sides of the same coin (Thornberg, 2018:148). As illustrated above, some participants felt that their child fitted in better at a school with children with similar disabilities. Whereas some participants felt that their child was targeted by bullies because they were different from neurotypical children without disabilities. Fitting in and not fitting in was a concern for participants in this current study, and they worried about how other children treated their children at school and in their community. Participants were reassured when they felt like their child was fitting in with their peers and were worried when they did not because then the child was thought to have fewer friends at school and may be teased.

Parents felt helpless when their child was bullied, especially when they felt the school was not responding or helping to prevent further incidents. It has been reported that parents perceived their role was to protect their child, and they expected teachers to do this in their place at school. This expectation and, importantly, an unmet expectation could cause frustration and a breakdown of the parent-teacher relationship when the child is being bullied (Hale, Fox & Murray, 2017). In the current study, participants did expect some reaction from the school when the bullying occurred between students. One participant said that the SNS staff did their best to address the bullying quickly and that this was helpful.

Most participants found the relationship between their children and their respective teachers very important. One participant highlighted that her son needs connection and love from motherly figures in his life, especially after the loss of his maternal grandmother.

"[Her son] is very empathetic. So, I feel as though the relationships he's built with his teachers, all his teachers, it's an emotional [connection], with a motherly figure. So,

that's important for him, because. All the motherly figures in his life have been... He's gravitated towards that. My mom passed away three and a half months ago, and he took that loss very hard. So yeah, he gravitates towards the females in his life. So having a teacher be there for him, that understanding, who even loves him, listens to him. That is important." - P01, 12 yr old son with moderate ID. Only child.

As with all relationships, they are not always the best fit. Some participants felt like their children's teachers did not always quite understand them, their genetic conditions or their unique challenges and strengths. This was frustrating for participants because they felt their child needed to be understood to progress at school.

"If you know exactly what the Williams syndrome child is, whatever you are teaching him, you always accommodate this kind of child. He was a slow learner. They don't like to write, but they like to play. They like music. They are friendly kids. You see. But their teachers, they know nothing about our disability, our kids. Seriously, my dear. And it's frustrating." - P09, 15 yr old son with moderate ID. Only child.

Children's individuality is critical in their self-development and progression from childhood to adulthood. Most participants stressed the need for the teachers to understand the child as a whole, including their strengths, challenges and genetic condition. Most participants felt that it was important for the teacher to have a good relationship with their child, which could be linked to their understanding of the child. When the participants felt like the teacher did this, they felt their child was growing and progressing at school. This is similar to previous work in Zimbabwe that concluded that teachers needed to be competent to identify and address the children's SENs and create responsive interventions to foster individuality and growth (Majoko, 2019:9). Moreover, Johnston, Widely and Shand (2022:2) showed that children who perceive their teachers to be more understanding and approachable are more likely to improve at school and in their personal lives. Participants in the present study wanted this understanding and acceptance of their child from the staff at the school, but this was not always the case, as described in the next theme.

3.5 The School Journey

Participants stated that getting their child into SNS may have been one of the first hurdles they faced regarding their child’s education, but it certainly was not the last. Most participants felt like their child had progressed and gained new skills and some independence. But, some participants worried about their child’s future after school. These topics are described below under “Getting There” and “Growth and Development”.

3.5.1 Getting There

The process of applying and being accepted into their current school was challenging and tedious for some participants. Some children started at a mainstream school and were eventually accepted into an SNS, some began at an SNS that was not appropriate for them, and some were lucky and found a suitable SNS the first-time round. One participant (P09) is still looking for the right school for her son but is limited by her location and finances.

Part of the struggle participants were or are still facing relates to their child’s specific challenges and strengths. As discussed in Theme 1, the participants’ children had overlapping and unique challenges and abilities. These differences and similarities can make it difficult to find the perfect fit when choosing a SNS because each child is an individual, and external factors impact school choices such as waiting lists, school location, age and finances.

Most participants had children on a school waiting list. The waiting period varied among participants, but for some, the waiting time was so long that they had to be resourceful and made alternative schooling arrangements such as a crèche. Two participants kept their children in crèche so that they could have some schooling experience. Because they were physically smaller than other children their age, they managed to keep them in the crèche for longer than is generally permitted by the crèches. This arrangement was not ideal since the teachers at the crèche were not trained or equipped to teach older children with SEN. Additionally, the participants preferred their children to be at the correct level of schooling for their abilities with children of a similar age.

"We managed to get him in... you know… special needs parents are very resourceful. So, we managed to get him in at crèche because he was small. We kind of could get away with it, sort of, like hiding between the children." - P08, 14 yr old son with moderate ID. One sibling.

Some of the participants were referred to the school through friends who suggested a SNS or had personal experience with one. These suggestions were beneficial, and the participants who chose a school recommended by a friend were generally happier at the new school than at their previous school. However, most participants were referred through the Genetics Clinic or Developmental Clinic at RCWMH. Participants said the process was relatively easy through these clinics, although some still had a waiting list.

The participants that were referred through these clinics valued the professional input from their healthcare workers. For one participant, after her son was asked to leave his first school due to having too many sick days due to poor health related to his diagnosis of 22q11.2 deletion syndrome. She tried to home-school him, which added immense strain on her and her relationship with her son. She felt unsupported and alone since the school staff could not or would not help her find another school for her son. She had to start the school application process all over again, which further delayed her son from attending school.

"The social worker at the [previous] school couldn't help me… [I was] with no plan and no assistance". – P01, 12 yr old son with moderate ID. Only child.

She eventually found help from her local clinic and occupational therapist, who recommended a new school better suited for her and her son. Conversely, even with support from their healthcare professionals, one participant (P08) found the whole school application and acceptance process complicated and frustrating. They were referred back and forth between specialists and schools. The participant (P08) and her husband grew tired of waiting for school placement and the lack of choices for their son, so they created their own private SNS for their son and other children who were also struggling to find a good fit.

Some SNS do not accept children who are still using nappies, which posed a challenge for a few participants. These barriers to participants' children attending a SNS were exacerbated by the school's lack of or limited understanding of the child's genetic conditions.

> *"I chatted to the training director at the time. And I said, so where do I take him because he's seven years old and is not off the nappy. So now what? No school, I mean, I'd gone to the one school, which is close in the area. Everybody said to me, if he is not off the nappy, we, unfortunately, cannot take him. [But] I still need to work. I need to bring in income to put food on the table."* - P08, 14 yr old son with moderate ID. One sibling.

> *"They did not accept him because he was still in nappies at that stage. So, they said that they could not take him because... It was a little bit frustrating, and you know, you're seeing your child growing up and not at school, it is a little bit scary."* – P06, 9 yr old son with moderate-severe ID. One sibling.

Most of the children in this study had rare genetic conditions and additional health problems that schools are unlikely to have experience dealing with. As such, the SNS did not accept these children into schools at the correct age. The issue of SNS exclusion has been described for years and still poses a massive barrier to special needs education. The reasons SNS deny children in nappies or children needing bathroom assistance include a lack of staff to assist with nappy changing or going to the bathroom. Another reason is that sometimes there is no ramp for children in wheelchairs to access the bathroom. In private SNS, a teaching assistant may assist children with going to the toilet and changing nappies, but this is not common in government SNS (Martínez, 2015:42).

In this study, the children in nappies were not accepted into government SNS and had to wait until they were out of nappies. The rejection was due to the lack of available help to change the nappies at school. Of the two children that attended private SNS, one did not use nappies, and the other did use nappies but was accepted into the private SNS anyway. This same child used a wheelchair, and the school placed ramps and sidewalks for him to move around the campus. There was a class assistant at this private SNS, but it was unclear whether this was the deciding factor for the school to accept children in nappies.

The lack of suitable facilities pushed two of the participants to enrol their children in private SNSs, which are substantially more expensive than government SNSs. Private SNS had extra expenses such as aftercare and therapies like OT.

> *"So you've got your normal school fees, and then you've got the aftercare that is exorbitant. But, wow, it's big. And then you get the early drop-off fee. So now at some point you did not cater for almost R10 000 (± USD $585) of a household monthly salary to just be for one child. Obviously we don't want free education, but it's a bit steep."* - P07, 10 yr old daughter with moderate ID. One sibling.

Based on participant responses, the financial implications of having a child with SEN has multiple dimensions. From one perspective, parents cannot always afford private SNS fees; therefore, they send their children to a government SNS that may not suit them. From another perspective, parents pay for private SNS but struggle with balancing the rest of the household budget. Parents stay home to home-school their children but then lose the income they could have possibly generated if they were employed. The participant who founded her own SNS still had financial constraints since they had to pay private fees to keep their son in that SNS. The participant and her husband operated fundraisers for their son and the school so that there was some financial support for parents whose children attended the SNS.

Even parents who send their children to government SNS and access government-funded therapies have the cost of transport to and from clinics and paying for additional supplementary things that their children need. The need for alternative schooling plans has been previously described, as well as parents having to turn to private SNSs at a high financial cost. This places additional pressure on parents of children with SEN because sometimes the options are to send the children to an expensive private SNS or for at least one parent to stay home and home-school them. This means the parent cannot work and provide an income (Mithimunye, Roman & Pedro, 2018:259). This was seen in this study, as all participants raised the issue of needing their child to attend a school. Some participants were just happy for their children to attend any school that would accept them so that the parent(s) could go to work and earn an income. Alternatively, some participants felt that they would rather spend the additional money on a private SNS for their child than send them to a government school that perhaps was not suitable for them. This comparison tells of how having a child with SEN can financially impact the family.

3.5.2 Growth and Development

Participants had several expectations for their children and their SNS based on their unique abilities and disabilities. But, the expectations for the schools were similar in that they wanted the school to care for and nurture their children and create a safe learning and personal development environment. For the most part, these expectations were met, especially the expectations for the children in terms of progression and growth.

> *"In fact, he exceeded my expectations. I thought that he would struggle a lot more, and I was so proud of him, you know?"* – P01, 12 yr old son with moderate ID. Only child.

The participants measured their children's improvement in various aspects of their child's life. Some participants spoke about their child's emotional development and said they could see how the child has improved and is becoming more mature and confident.

> *"He's also grown a bit. I mean, he's 12. This year like I said, always he's grown in confidence. And he's maturing. Yeah. Um, reminded me this morning that he's almost a teenager"* - P01, 12 yr old son with moderate ID. Only child.

Other improvement measurements included writing, drawing, memory, listening to instructions, and academics. For some participants, it was encouraging to read in the school report card that their child was improving scholastically.

> *"It was such an emotional day because she gave me the report. And then when I took it... Cause I wasn't expecting to see that they write them as normally as they were able child's [report] seven six, five or seven. Excellent. And everything so when I saw the report. Oh, I was blown away. She burst out into tears, and I asked her, "why are you crying?". Cause I was also now crying. And then she said, "I'm crying because the teacher did tell me that I made it. I passed and I passed very well". But I never thought she would be able to do it..."* – P07, 10 yr old daughter with moderate ID. One sibling.

Some participants were happy that their child was more independent and could do things like butter toast and make tea for themselves. Other improvement measurements were more basic physical activities like potty training, standing in a standing frame, and sitting unaided for longer periods. Participants who had children with speech difficulties were happy with their speech improvement because it helped them communicate better.

> *"I am glad to say that there has been a lot of improvement there [with his speech]. So, it is better now than before... Before it was just sounds but there are words coming out now. He is trying to build sentences for himself, so it's better."* - P04, 10 yr old son with moderate ID. Only child.

Another sign of progress was that the child no longer needed therapies like physiotherapy because they had improved enough to stop attending.

These findings support previous literature on parental expectations of their child with SEN and ID. Some parents have been reported to have high expectations for their children at SNS or children with SEN in mainstream schools (Opoku et al., 2020:7). Other parents, such as those in a Ghana-based study, reported that they were happy if their child could learn activities of daily living (ADLs) such as feeding, bathing and dressing themselves. They did not expect their children to acquire employable skills. The authors suggest that the parent's expectations could be shaped by the common perception in Ghana that children with ID are a liability to society due to their dependence on other people. The researchers argue that having these "low" expectations may mean that parents do not invest or put more effort into their child's education and that the expectations should be discussed with the professionals helping to teach and manage the child (Opoku et al., 2020:7). Parental expectations and input have been shown to influence the child's expectations of themselves and their capabilities. Combined, this indicates that parental expectations predict parent behaviour and the child's academic outcomes (Thomas et al., 2018:99).

However, every participant also felt there was still room for improvement and growth for their child, with most participants hoping their child could attend a mainstream high school after grade 7. The idea of transitioning to a new school to attend high school was worrying and daunting for some after the struggles they had getting their children into their current school. Still, they were hopeful that the current school would help them find a suitable placement for their children. For older children, participants were worried about what would happen when they turn 18 and were no longer in school. One participant spoke about the importance of teaching children ADLs such as cooking so they could be more independent and possibly move onto a skills-based education centre or even be employed.

"That [independence] is important because once they are 18 and they need to be out of school, then what? But if they can make a scramble egg… If we have programs outside school, once they hit that sort of 18 age, where they can skills- learn. What was nice when we were over in America is that the one boy was at a skill school, so they would teach him how to... he would be able to go and work in like a fast food takeaway place type of thing, and do a specific job there. But he would still be able to provide to the economy or provide a service to them, to the community. That's what we need. We need more of those type of things. So it's not only for when they're at school, we need to look also further than that. Because they are high functioning, special needs kids. I think it's that if you can mimic what is out there, like sort of the bag packers, at supermarkets, they've got special need adults that work there. I

> *mean, they are packers and they do a bloody good job, you know?"* - P08, 14 yr old son with moderate ID. One sibling.

Many participants shared this fear of the future for their children. The fear of what comes after school and what will come after the parents or caregivers are no longer there or able to care for their children with ID. Children at SNS have ongoing needs, which may change as the child grows up and becomes an adult, and parents fear for what the future may hold for them. In response to this fear and the child's ongoing needs, parents have been known to seek additional support to try to pre-empt any uncertain situations that may arise. It has also been shown that the need for additional support is greater than the availability of support services such as counsellors and formal and informal institutions (Sefotho, Ferreria & Lushozi, 2021:94). The current study supports these findings, with participants vocalising their concerns about the future, what their children may need as they grow up, and what will happen after they turn 18 or leave school. Additionally, these participants felt like the SNS staff should be preparing the children for life after school with essential life skills. As per P08's quote above, there is a need for a transition programme to help the children at SNS transition into the workforce where there is support for them to gain independence.

For all participants, a current fear is the impact of COVID-19 on their child's health and schooling. Participants found lockdown stressful since they had to look after the child at home and their siblings and, in some cases, still had work to go to or do from home. This meant that for some of the children, their parent(s) were too busy to necessarily go through schoolwork or do activities all day as they did at school. The decrease in engagement and activity made participants worried that their children would not improve as quickly and that they would forget what they learnt at school if it was not consistently reinforced.

> *"I think because it affected mostly the learners because you see... they are..., they are already slow learners, so if you're gonna stay at home more… then their improvement is not going to be good. Because they forget easily…"* – P09, 15 yr old son with moderate ID. Only child.

Most participants worried that the pandemic had affected their child's progression and may have led to regression. Children at SNS generally also require additional rehabilitation interventions such as OT and physiotherapy (often all occurring at the SNS). Due to COVID-19, most children could not be physically supported by their respective rehabilitation facilities. In some situations, there was a shift to telephonic or virtual support, with the caregivers receiving instructions or help on what to do with the child at home (Dhiman et al., 2020:2). The current study also described the complications of remote rehabilitation services, with participants having to take on that additional burden with limited experience. Participants found their child's therapies to be invaluable in their progression, and therefore, a decrease in the service was a concern that the hard-earned progress may be lost.

3.6 The School's Operations

The present study included participants with children at different SNS and some that were once at mainstream schools in the Cape Town area; this highlighted some differences between various educational institutes. The positives, negatives and recommendations are detailed and discussed in this third and final theme.

3.6.1 How the School Functions

The schools run differently regarding logistics, class sizes and additional in-house services. As illustrated in the quote below, one participant had a particular issue with mixed-ability classes. She felt the mixed ability classes were holding her son back because the children with different challenges may impact his education quality and progression. This concern was shared with another participant who moved from a SNS with mixed ability classes to a school with smaller and more ability-specific classes.

> *"There is something that is not right about the special schools because our child[ren] have got different syndromes or genetic diseases. They have different disabilities, but you can find they've got five child[ren] in one classroom with different disabilities. So, for my child, or any child, it can also affect your child. Once he saw that the friend is slow [and] can't speak. My son doesn't have a problem with his speech, but he is in the same classroom with a child with the speech problem. So that means that can also affect him because most of the time you're spending the time at school*

> *with children that have speech problems, he can end up not improving to speak like the home language, because he is staying most of the time at school with children that are struggling to speak."* – P09, 15 yr old son with moderate ID. Only child.

Mixed ability classes can be found in SNS and inclusive mainstream schools. There is much debate on whether or not ability-specific or mixed ability services are better for the people that need them. It was previously found that for people with autism, most participants favoured autism-specific services. However, a number of participants in that study favoured different levels of autism specificity for various services (Cascio & Racine, 2022:13). Participants in the present study did not specifically praise the mixed ability classes at their SNS. Compared to mainstream schools, participants said they were much happier with their child's class size and the individual attention they received at their SNS.

Some participants felt their child was overlooked at mainstream school, and the teachers did not have enough time and experience to help them reach their potential. Once the child moved to a SNS, the teachers could dedicate more time to them and assist them with remedial education if needed. The participants also felt that SNS teachers were more educated in teaching children with SEN and ID than mainstream teachers.

Participants expressed the different concerns that they had with their child's SNS. Some participants were worried about the frequency at which their child got physiotherapy or speech therapy, while others were worried about access to music classes, computer rooms and horse riding. Notably, these concerns appeared to be linked to their child's health challenges. If the child did not have a speech problem, then the participant did not worry about whether or not the school had a speech therapist in-house but instead wanted the child to have access to computers to assist with his school work. The lack of information made it challenging to determine what therapies and services were available at each SNS. Some participants did not need the therapy and were unsure if the SNS offered it.

The participants with children at government SNS did not have to pay extra for therapies and services like aftercare and transport, but this was not the case for the two participants who have children at the same private SNS. At this school, therapies and aftercare were at extra cost to the parents, besides the costly school fees. When asked what the biggest problem is at the school, they both said the funding was.

> *"Mainly funding. Being able to keep up with the school fees is the biggest thing. And that is my worry that if we run out of funds and are unable to pay the school fees... I probably will end up then just keeping him at home. It is just not fair to him. So yeah, so that's a problem."* – P08, 14 yr old son with moderate ID. One sibling

One crucial aspect shared by nearly all participants was teacher-parent engagement and feedback. This came in different forms between the different SNS. One school used to (pre-COVID-19) have parent and staff meetings on a few Saturdays a year to provide feedback to parents, address any concerns and create a platform for teacher-parent interactions. Participants stressed the need for feedback to know how best to help their children.

> *"Yes, without a doubt [communication is important]. Especially with his special needs, he won't come to me and tell me, "Mom, we did this at school today" like a normal kid, you know. So, I expect it from the carer that's working [at the school] to communicate with me and just tell me, "Listen here like we see he is lacking this or that"… things I can help improve where he is concerned. I didn't even know what my son was doing there really… Basically, for me it was like my child is just sitting in the buggy the whole day and he doesn't get what he is supposed to get. So what use is it sending him to the school, where we can do the same thing at the home, whatever they do with him there I can do at home with him."* – P03, 10 yr old son with severe ID. Two siblings.

Some participants praised their school, and some criticised the lack of communication at their current SNS or previous mainstream school. As highlighted in the quote above, some children at SNS are nonverbal or struggle to express themselves. Therefore, parents expected the school to update them on what the child did, how they are doing, and areas that need improvement. The forms of communication ranged from phone calls, WhatsApp messages, Zoom and notes in the child's schoolbook.

The COVID-19 pandemic changed how schools worked. While the schools were closed, some participants received homework and activities to keep their children busy and engaged. However, some participants did not receive any work or communication from the school. Since schools reopened, timetable adjustments had to be made to ensure safety protocols (such as social distancing) were adhered to. Depending on their rotation, some participants only sent their children to school two to three times a week. The schedule change was initially confusing and upsetting for the children, but participants reported that they eventually settled into a routine.

> *"I don't think she still understands about COVID, but, she like just go with the flow cause like Tuesday she goes to school and Thursday. So the other day, she showed me the calendar, and I was a bit confused cause I didn't understand what she was saying. So I think they are learning the month of the year, so when I told her January, February, March and she like went, with the flow. So like I say, she is adapting to school and taking notes, and it's just the communication."* - P02, 7 yr old daughter with moderate ID. Four siblings.

As mentioned in Section 3.5.2, parents also had to take on the role of the teacher as well as their previous family roles. The added pressure of COVID-19 on families with children at SNS highlighted the need for more logistical and emotional support from the SNS staff. This need was not met for all participants, with some not hearing from their SNS at all during the school's shut down in 2020, and they had to make their own plans to teach and entertain their children. Some SNS checked in on parents frequently, gave homework through activities or videos and provided food parcels at drop-off points.

> *"The staff made, for the older kids, they made booklets and stuff. For the kids in his class, they did videos with the teacher as if she was teaching them in their own classrooms so that's how they videoed it and then sent it to us. And a lot of the work is sort of repetition, so just having to just play those videos over and over. And then*

obviously the puzzles and the extra Play-dough and that kind of thing. So that is sort of what they basically did for us. They could not give us too much as well because it then becomes overwhelming" - P08, 14 yr old son with moderate ID. One sibling.

COVID-19 changed the interaction and communication between parents and teachers. This also meant that parents could not fully explain their child's genetic condition and specific challenges, thus emphasising the importance of open and regular communication between parents and staff. The importance of better communication has been discussed in recent literature, with a shift towards introducing methods of communication in some overseas teaching training programmes (Gisewhite et al., 2021: 598; McKenzie, Shanda & Aldersey, 2021:42). This shift towards including parents in the discussion about their child is not specifically well studied in the case of a genetic condition causing the SEN and ID. In the current study, there is a desire from most participants that the SNS staff are aware of their child's genetic condition and have some background knowledge of it.

3.6.2 It is a Two-Way Street

A topic that came up in every interview was that of guidance. Participants wanted guidance from the SNS staff regarding their children and what they can do, as parents, to help their children meet their own goals. Participants also wanted the staff to recognise and value their expertise in their children and their respective genetic conditions.

"I know they are well educated. They went to university and studying the disabilities and what... But they don't know exactly... they study about the thing. They don't experience like us. I didn't do the disability management, whatever, but I experienced it. They don't understand us as parents." – P09, 15 yr old son with moderate ID. Only child.

This idea of parental experience through living with the child was echoed by another participant who described the situation as a two-way street. In that, the teachers and the parents have something to learn and gain from each other.

> *"I live with this person on a daily basis… I know [them]. You [the parents] do requests [for additional therapies], but they [the teachers]can recommend it. It's a two-way street, right?"* - P07, 10 yr old daughter with moderate ID. One sibling.

As per the opening quote for this subtheme, one participant felt that parents had more practical experience than the staff even though they studied education at tertiary institutes. She thought they did not understand the parents' perspective. She also reported that the SNS staff had not heard of Williams syndrome before, and when she met with them, they were Googling it during their meeting. This speaks to the section below regarding teachers' experience and knowledge of genetic conditions concerning ID and SEN.

Participants expected their children's SNS teachers to be educated and familiar with their children's LD and SEN. Participants acknowledged that their children could not attend a mainstream school because they have additional challenges that a mainstream school may not be equipped to assist with all of their special needs.

> *"She can't go to a normal school, so she needs to go to a special needs school because they have more experience than I do."* – P02, 7 yr old daughter with moderate ID. Four siblings.

For some participants, professional input was a major driving factor in sending their child to SNS. Participants felt that the teachers had more knowledge than they did, so it was important for the child to be taught by someone with the skills and training they received by obtaining an education degree or diploma. Some participants valued the guidance and suggestions from the staff, from aspects like homework to what diet supplements and type of pencils to buy, but also had valuable experience to share with the professional educators.

> *"So, because we wanted him to go and be taught, um, with the people who are qualified for children like that."* – P06, 9yr old son with moderate-severe ID. One sibling.

A less well-studied aspect of special needs education is the teacher's knowledge and experience of genetic causes of ID and SEN. A paper that tried to measure teachers' understanding of the heritability of ID highlighted the deficit in both teachers' understanding of genetic conditions causing ID and SEN and a lack of research on the topic (Erbeli, 2019). It is difficult for teachers to know about all the genetic conditions that cause ID or SEN. This study focused on the parent's perceptions and did not study the teacher's knowledge or experience of genetic conditions that cause ID and SEN. Therefore, teachers' understanding of genetic conditions cannot be assumed for the present study.

There are benefits to the teachers' better understanding of genetics and how genetic conditions differ from other ID causes. Genetic causes of ID generally include other health and developmental concerns that are possibly not experienced with other causes of ID. Parents are the people who have had to adapt and develop different ways of helping their children. One participant spoke about her method of waking up her son when he falls asleep during school but felt that his first SNS did not listen to her. Consequently, he would sleep through most of the day and not receive the necessary therapies and stimulations.

It has been shown in previous research that each party tends to keep to their respective roles within the parent-teacher dynamics. These roles typically include teachers being advice-givers and parents being advice seekers. Thus, only the teachers' expertise is recognised, and the parent's expertise is typically overlooked. (Leenders et al., 2019:521). This is very similar to what was found in the present study, where some participants view teachers as advice-givers, and the participants wanted to receive advice. They felt that their lived experiences with their children made them experts in their own right regarding their care, especially when the participant was well versed in their child's genetic condition and associated medical challenges alongside their educational challenges.

For some participants, any SNS was better than none, but others wanted more from their SNS and even moved schools to find a better fit.

"For now, we haven't had any problems since he started in January. We haven't had any complaints so far, we are just happy that he's at school. Maybe that is why we are not seeing such problems. But we will see as time goes on, but for now, I think that they are trying their best." – P06, 9 yr old son with moderate-severe ID. One sibling.

The participants who were grateful for their child to (finally) be accepted into any SNS did not have many complaints or suggestions for the school. They were mainly happy for the child to have somewhere to go during the day, be taught by a qualified teacher, and interact with other children with ID and SEN. The other participants who were satisfied with their SNS were because the school met their expectations, and participants felt it was the best school for their child. Each participant had pros and cons regarding their children's school.

Although most participants were satisfied with their children's SNS, some felt the school could do more. Even the participant who created her own SNS said she is open to suggestions and recommendations for improving the SNS.

"I'm a type of person. Where, uh, we always need to make sure we raise the bar. So there's always room for improvement. There are always things we can do differently. Um, I don't know everything. Um, but if somebody else comes along and they say, you know, have you tried this, maybe we can implement that, open to those ideas." - P08, 14 yr old son with moderate ID. One sibling.

The participants that were satisfied with their SNS reported that good communication between teachers and parents and the teachers' understanding that the child has more challenges than only SEN were valuable factors that led to their overall satisfaction. Some had severe medical challenges that impacted their daily living and might require them to miss school. When factors like communication and understanding were not met, the participants were more likely to be dissatisfied with their SNS. One participant (P09), in particular, is very dissatisfied with her son's SNS and hoped to move to a different SNS.

"I am applying to another school because I am not satisfied with this one. Even though I don't know how I am going to be able to afford the fees. That is the other disadvantage that we get as a parent with a disabled child. You don't get the benefits for our child and the special schools they are very, very expensive." - P09, 15 yr old son with moderate ID. Only child.

Interestingly, some participants who had children at government SNS felt that a private school would meet their expectations and be better equipped to teach their child. However, the participants whose children attended private SNS still felt that there was room for improvement and had the additional strain of higher school fees. Although the two participants who had children at the same private SNS were overall satisfied, they felt that the staff's communication and understanding of their child's genetic condition could improve.

Participants' satisfaction was multidimensional and based heavily on what they expected from their children and the school. If the child could learn academic skills, then the participant expected them to improve in this area. However, if the child could only learn life or physical skills, then the parents expected them to improve in these areas instead of academically. Bajwa-Patel and Devecchi (2014) similarly reported that parents of children with SEN had different expectations of the child and the SNS. If the children could learn academic skills, parents were more likely to expect academic achievements from their children and were disappointed if they did not achieve those goals. If the child was not able to learn scholastic skills and instead was able to learn essential life skills, then the parents were satisfied when the child did achieve this.

The dissatisfaction was not limited to just the SNS; about half of the participants were also dissatisfied with the South African government's approach to SNS. Participants felt that the government could be doing more for special needs education by assisting with the lack of funding and interest and not making contradicting statements in the media.

"It is strange that the government will say in the media that they are looking and they trying to improve the lives of people with disability. But then there's a lot of red tape

that needs to be conducted when funding needs to be granted, for me that's a contradiction like you're contradicting yourself and being a hypocrite." – P07, 10 yr old daughter with moderate ID. One sibling.

Participants felt that there was a lack of interest from the government and that they were not trying their best to improve the quality of education and care that children at SNS need and deserve. Most participants could not afford private SNS and felt it was the government's responsibility to bridge the gap between private and government SNS in terms of what the schools offer.

"They [the government] can do better... they could be better than what... they are doing now… like [putting] more effort into special care. Special needs schools... look, not everybody can afford those private schools where those children get all those extra things. But with the government, they could at least... yeah." – P03, 10 yr old son with severe ID. Two siblings.

Participants had suggestions on how SNS could improve. These suggestions included providing the students with outdoor games and sports and verbal and written feedback from the professionals providing therapies (such as OT). Participants also spoke about how they would like interactive parent-teacher meetings where they can meet other parents at the school. The one participant who did have this at the school found it very beneficial.

"We have our monthly, or every two months, a parent group that comes together, on a Saturday morning. A support group. And then we have an opportunity there to give your thoughts about how to help the next parent, or how to deal with different things and how to make themselves feel comfortable. So that's a thing for only the parents, that is on a Saturday morning, at the school often with teachers. That is helpful" - P04, 10 yr old son with moderate ID. Only child.

In addition, it might make it difficult for SNS to adapt to suit each child and their specific needs, on top of trying to meet the expectations of each child's family. This is similar to what has been found in other countries in both SNS and inclusive mainstream schools internationally. There is perhaps no instruction manual on creating schools that suit all SEN and LDs (Bajwa-Patel & Devecchi, 2014). This is comparable to what the current study found because there are hundreds of different genetic causes of ID; SNS cannot be expected to be experienced in all of them and have other classes or treatment plans for the different children.

Chapter Four: Conclusions

4.1 Chapter Introduction

The findings, strengths and limitations relevant to this research are reviewed in this chapter. The chapter concludes with the possible implications for special needs education and in genetic counselling practice.

4.2 Conclusion

Numerous genetic conditions can impact intellect and learning abilities, which may confer additional health challenges that add to the complexity of caring for the child (Karam et al., 2015:1209). Although there has been some research into parents' perceptions of their child's SNS, most literature has focused on children with ASD. This gap in research is significant because children with a genetic condition may have more and different challenges than those who only have ASD (Mithimunye, Roman & Pedro, 2018).

This study addressed this gap and focused on the parents' perceptions of what their children with a genetic condition need from their SNS. The needs of a child with SEN, ID and a genetic condition are complex and challenging. What children need from their SNS depends on many factors, making it exceedingly difficult, if not impossible, for SNS to meet every child's and family's needs.

The findings and implications of this study centre around the parents' needs and the needs of children. This study has shown that the parents of children with ID and SEN need more support at home from their families. The emotional and logistical support appears to be related to the family's understanding and acceptance of the child's genetic condition. The importance of having the neurotypical siblings understand their sibling's genetic condition was highlighted. Having them accept the sibling's diagnosis and challenges and becoming more protective and involved in their sibling's life meant a great deal to the participants. When there is a lack of understanding, there is less likely to be a good support structure for the child and the parent(s). This was important to most participants because they needed support from their family members to help them with the care and education of the child, similar to what has been previously reported (Fayyaz, Sajjad & Suleman, 2012:37; Oti-Boadi, 2017:1; Williams et al. 2010:49). When this is lacking, there is less personal time for the parent(s), who have to “juggle” their life, their child(ren)’s needs and sometimes their careers. This can perpetuate the caregiver burden, increasing caregiver burnout, the likelihood of depression, and decreased quality of life (Ramasubramanian et al., 2019:177).

Needing support extended into assistance with school placements and help from the school staff. Participants faced several barriers that they had to overcome before their child began attending a SNS. These barriers included long waiting lists, which have also been described in the preceding literature (Cramm et al., 2013:32, Mithimunye, Roman & Pedro, 2018:259). Some participants were unsatisfied with the SNS they were referred to, so they changed schools and had to repeat the application process. The school application and acceptance process were typically easier for participants who had assistance from the Genetics or Developmental clinics at RWMCH than for participants who applied alone. This could be due to the healthcare professionals offering support through the process with school suggestions and referral letters to try to mitigate the long waiting period. However, some barriers are not easily overcome with the current application processes, and some SNS have a long waiting list that cannot be bypassed.

The need for support and understanding also comes through regarding the communication between the SNS staff and the parents. Participants felt it was important for the teachers to frequently and openly communicate with the parents about the child’s activities and struggles so that both parties can gain and share knowledge on how best to care for and educate the child. Caregivers are the ones that live with the child and have years of experience with them (Krane & Klevan, 2019:75; Majoko, 2019:9; Thornberg, 2018:148). Although they respected the staff’s formal training on SEN, participants felt their experience was also valuable. This was especially true regarding the child’s genetic condition, as most participants thought the SNS staff did not sufficiently understand the diagnosis and what it entails. They thought this lack of understanding negatively impacted their child’s education. The participant spoke about a two-way street and wanted the SNS to consider parents’ suggestions, complaints and compliments and engage with parents on how best to educate and nurture the children at school. This echoed the findings of another SA-based study, which suggested that if teachers were more understanding of the family's history, needs and preferences, they might be able to support better communication and a better medium of communication (McKenzie, Shanda & Aldersey, 2021:42).

Participants shared what they perceived to be their child's experiences and needs at school. Overall, the participants whose children attended mainstream and SNS felt that children attending SNS had better experiences because they were better understood and fitted in more easily. These children made more friends at SNS and had better relationships with their teachers, who seemed to care for them (Hale, Fox & Murray, 2017; Majoko, 2019:9). This was important for participants because they worried about their children being bullied or excluded at school.

All participants felt like their child had progressed since starting at their SNS, even if there was room for improvement. The progression and needs of the child were highly individual, making it difficult to gauge whether the SNS was meeting their educational needs in the parents' perspective. The child's perceived needs were closely linked to their challenges and capabilities. Not all the children could learn academically, and some attended the SNS to learn life skills or to receive therapies (Opoku et al. 2020:7). Similarly, the children in the SNS classes had different abilities and challenges. These mixed ability classes did not work for some participants who felt their classmates were holding their children back. Some participants wanted additional facilities like sports, computers, music classes and horse-riding. Overall, the participants felt the children need more from the education system. They needed more individual attention, and in some instances, mixed ability classes hindered their ability to progress (Cascio & Racine, 2022:13). When the participants felt like there was more than the school could provide, they were more likely to be unsatisfied with the SNS. In some cases, this made the participants change schools or apply to a different SNS that they perceived would meet their needs.

Most participants expressed their concerns about life after school. There is a gap in post-school support (Sefotho, Ferreria & Lushozi, 2021:94). There was a suggestion from a participant about creating a skills training programme to help children with SEN to learn skills that will help them get jobs after school, such as packing shelves and bags in a supermarket. This training programme is not widely considered in SA and could be a way of bridging the gap for people with SEN to gain employment after school. This would require more awareness of the challenges faced by people with genetic conditions, ID and SEN.

Special needs education in SA has undergone multiple acts, goals, and declarations by the government since 1994 in an attempt to equalise opportunities for people living with disabilities (UNESCO, 1994; UN, 2000; DOE, 2001; DOE, 2005; DBE, 2010; DSD, DWCPD & UNICEF, 2012:7; UN, 2015). Despite this, there are limited resources, opportunities and trained professionals to aid with support for these children and their families. This context is slightly different from first-world countries that may have more resources available to the SNS and support service facilities (Cramm et al., 2013:32; Pather, 2011:1105). The SNS may not be able to provide everything the children need, and clinics like Genetics and Developmental clinics may not have the staff and time to become more involved in families and school education.

These gaps in the support structure for families with children with genetic conditions leading to ID and SEN may be filled by the involvement of genetic counsellors if more were employed to increase clinic service capabilities and fill this gap. Although genetic counselling is a relatively new profession in SA, there are some well-defined roles of genetic counsellors internationally, such as providing psychological and practical support for patients and their families (Kohzaki, 2014; Skirton et al., 2015:453). In this context, genetic counsellors could assist with family communication and counselling for adolescent siblings about their genetic condition. These issues could be addressed in the first formal genetic counselling session. Genetic counsellors can see families during their clinical follow-up visits as “check-in” sessions where they can assess needs and arrange referrals for social work, psychology and couples counselling could be done if indicated (Hodgson & Gaff, 2013; Sefotho, Ferreria & Lushozi, 2021:94).

Genetic counsellors are ideally placed to assist with the education of SNS staff regarding genetic conditions, opening the dialogue between staff and parents so that both sides feel valued and heard when discussing the child’s best interests. Advocacy is another role of a genetic counsellor. Increased awareness could also extend to the South African government, namely the department of education. Many participants felt that the government could and should be doing more to support and develop special needs education in SA. Genetic counsellors could also become more involved with school placement and, as advocates, could work towards assisting with developing post-SNS training for young adults with SEN and ID (Sefotho, Ferreria & Lushozi, 2021).

In summary, there are numerous research gaps in genetic counsellors' roles and special needs education. There is much room for improvement in special needs education in SA. Although, some SNS may provide all of the necessary services, this is not the case in most SNS across the country. Children with genetic conditions encompassing SEN and ID deserve a quality education and, where applicable, deserve the chance to gain life skills that will assist them in gaining more independence after school. There are opportunities for partnerships between parents, teachers and healthcare professionals to increase the quality of life and education for children with genetic conditions, SEN and ID.

4.3 Strengths of the Study

To our knowledge, this research project is the first study to examine parents' perceptions of their child's SNS where the children have different SEN, ID and genetic conditions in SA. Previous research focused on SNS where the children all had specific intellectual conditions such as ASD in SA. This research also investigated how the different genetic conditions impacted the family, the child and planning for the future. This research is the starting point for further research into the genetic landscape of SNS in SA and how genetics specialists can help families of these children find the best SNS for their needs.

The study was accessible to all identified candidates because of the remote medium that was used. Candidates all had access to a phone, and there was no additional cost to participate, and it was convenient for them to participate since no travelling was needed. Participants were passionate about their child's education and were very willing to participate, thus producing a rich data set.

4.4 Limitations of the Study

There were some limitations encountered in the current study. These limitations included the time frame in which the study was conducted, the sample population group, and the data collection method.

This study had to be scaled to a minor dissertation level and was meant to be completed within 12 months. However, this was extended due to the COVID-19 pandemic, which interfered with the academic programme of the entire master's degree. The study could not feasibly include too many participants or delve into other areas of special needs education and include more areas across SA (not limited to Cape Town) as may have been possible if this were a full dissertation.

Furthermore, the research was limited to a population group of children that attended the genetics clinic at RCWMH. This could have created a bias since the participants were only those referred to the genetics clinic. There could have been numerous potential participants with children with genetic conditions attending a Cape Town SNS that were not included in this study. Similarly, only mothers were involved in this study. This meant that the perceptions of fathers and other caregivers was not explored directly. There is likely rich and valuable data to be found by interviewing these other perceptions. However, no sample group can be truly unbiased, and as mentioned above, this was a minor dissertation study with limitations on the number of participants and scope of research.

Finally, the argument against telephonic interviews mainly comes from traditionalists that argue that facial expressions and body language are a fundamental part of communication. These visual signs are possibly lost during a telephonic interview, which can cause significant problems for researchers, such as the risk of misunderstanding between interviewer and interviewee, leading to a breakdown in the communication process. Another complication can be the loss of nonverbal data, which traditionalists say detracts from the richness of the data collected (Farooq & de Villers, 2017:294).

In this current study, telephonic interviews were sometimes a challenge. Poor connection, dropped calls, and background noise posed difficulties for the researcher and participant. Dropped calls meant that the researcher had to call the participant back and try to pick up where they left off, which may have disrupted the natural flow of the conversation. Additionally, one participant had to take another call from her employer briefly, and the researcher then had to call back after ten minutes.

Overall, the remote interviews provided valuable and rich data. In light of the global pandemic, remote interviews made the most sense for researchers and participants regarding logistics, health and safety, COVID-19 restrictions, financial, time and convenience.

For these reasons, the results of this study cannot be generalised to all parents of children with a genetic condition that attends a SNS. Nevertheless, this research can serve as a start for prospective research.

4.5 Implications

This study showcased the overall effects and challenges of a child with a genetic condition, SEN and ID, on their family and school environment. Understanding the challenges can help professionals streamline school applications and refer the child to a school better suited to their needs. It can also show where healthcare professionals could provide the school with more information on the condition and make them aware of any other things the child might need. This research could also help education professionals reassess how they communicate with parents regarding the child and see where they can offer more support and what support is more beneficial to the family. For example, creating a parent-teacher group meeting where the parents can develop relationships with the staff and the other parents could be helpful for all parties involved.

The following ideas are suggested for both medical and educational professions to consider when there is a child with a genetic condition, SEN and ID who is either needing to attend a SNS or is already placed in one:

- Available services and support at the school for the child and the family
- Location of the school
- Waiting lists and the likelihood of being accepted/acceptance criteria
- Structure of the school/class sizes etc
- Support for the family (school, medical, government)
- Understanding the genetic condition
- The costs involved in educating a child
- Life after school for these children

4.6 Recommended Research

This study highlighted several gaps in the literature. Although some participants in the current study felt alone and isolated when their family members did not understand their child's genetic condition or their situation, there was no mention of depression or suicidal idealisation which has been described in previous literature (Oti-Boadi, 2017; Asa et al. 2020). This could be due to the researcher not asking specifically about the participants' mental health and could be investigated in future studies. Participants did not specifically discuss how the family helps to integrate the child into the community, but this could be a topic of interest for future research.

There are possibilities for pilot projects that could improve special needs education in different SNS, such as introducing additional classes as suggested above (music, sport and computers). There is also the gap in what happens after school, where a training programme could be implemented to help teach young adults after SNS skills to assist with employment. These are just two examples of possible pilot projects that could be researched and possibly executed.

In terms of the role and involvement of GCs in special needs education, this study has underscored the versatility of GCs in the multidisciplinary team that cares for and works with children with ID and SEN and their families. The study also accentuated the ambiguity of where and how GCs fit into this team. In summary, there are several areas where the role of a GCs is unclear or should be studied further:

- Referrals to support services (such as psychologists, physiotherapy and OT)

- Educating SNS staff on genetic conditions to increase awareness and understanding
- Patient advocacy with regards to SNS
- Do GCs know enough about special needs education and the special needs education system in SA?
- The balance of involvement and over stepping into other professions

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Appendix A: Information Sheet for Participants

Sinead Cameron-Mackintosh Research Project 2021
Ethical clearance given by Human Research Ethics Committee UCT.
Reference number: 114/2021

Dear participant,

A research study is being done at the University of Cape Town (UCT) through the Division of Human Genetics for a minor dissertation for MMedSc Genetic Counselling.

The aim of this research project is to study parents' perceptions of their child's needs at a special needs school.

We hope this study will help to raise awareness and gather more information about the special educational needs of children with intellectual disabilities (ID).

You have been invited to participate in the study because you are a parent/ guardian of a child who has a genetic condition resulting in ID, who attends a special needs school.

To gather information for this research project, an individual interview will be conducted which will take between 60 and 90 minutes. It will be recorded, but all your information will be kept confidential. You will be required to sign a consent form before we begin the interview.

This process is voluntary. If you decide to participate and you no longer feel that you want to be part of the study, you may withdraw at any time. You will be given R50 towards your transportation costs. COVID-19 precautionary measures are in place and we will adhere to these to limit the spread of the virus.

If you have any questions, please contact Ms Sinead Cameron-Mackintosh at 0729559583 or CMRSIN001@myuct.ac.za or Dr Tina-Marié Wessels (Supervisor) at tina.wessels@uct.ac.za or Ms Kalinka Popel (Co-supervisor) at popelkalinka@gmail.com or the UCT ethics committee at 021 650 1236 or hrec-enquiries@uct.ac.za

Kind regards,
Sinead Cameron-Mackintosh

Appendix B: Socio-Demographic Survey

Socio-demographic Survey for S Cameron-Mackintosh Research Project 2020/2021

Participant Code:________

1. How old is your child(ren)?
2. What school is/are your child(ren) attending?
3. What grade is/are your child(ren) in?
4. What year did she/he/they start school?
5. What genetic diagnosis do(es) your child(ren) have?
6. How old were they when they were diagnosed?
7. What current medical challenges do they have?
8. How many other children do you have?
9. Who lives at home with you?

Appendix C: Question Guide and Prompts

Topic Guide and prompts

Opening question

- **What** would you say has been the biggest challenge after you received the diagnosis?
- **What** is your experience having a child at special school?

Personal/family sacrifices to meet the needs of their child

- **How** has your family adapted to having a child with special needs?
    - *If applicable probe regarding other children.*
- **What** big changes have you had to make in the family to help your child with their needs or schooling?

Services available at the school

- **What** was your experience like finding a school for your child?
- **What** are the available support services and resources at the school?
    a. How accessible are the services?
    b. Do you have to pay additional fees for them?
- **What** changes would you like to see that could benefit your child?
    a. What is the most helpful thing about the school?
    b. What is the most problematic thing about the school?
- **What** is the most important thing for you?

Needs of the child

- **What** do you think your child's needs are at school? *Educative vs physical needs*
- **How** do you feel the school is addressing or not addressing the educative needs of your child?
    - Do you feel that there has been an improvement?
- **What** does the school/staff understand about your child's genetic condition?
    - **How** has this impacted the way the handle their education?
- **What** are your current challenges regarding your child's educative needs?
- **How** have these challenges been addressed?
    - If not, what do you think could be done?

Experiences with the school/teachers/extra staff

- **What** has your experience been like dealing with the school and staff?
    - **What** forms of communication do they use?
- **How** are you involved in their education?
- **What** happened during COVID?
    - **How** did they provide support during COVID?
    - **What** was the communication like during COVID?
    - **How** is it now with COVID?
    - **How** has COVID influenced your perception of the school?

Child's experience of the school, i.e., happiness, friends, etc.

- **What** do you think your child's experiences have been at his/her school?
- **What** is their relationship with the teacher like?

If the school carried on this way, would you be satisfied?
Services, support etc.

If you could choose any school, would you still choose this school?

Appendix D: Consent Form

Consent Form for S Cameron-Mackintosh Research Interviews 2021
Ethical clearance given by HREC Reference number: 114/2021

I,____, agree that Sinead Cameron-Mackintosh (SCM) from the division of Human Genetics at the University of Cape Town may interview me for the purpose of providing information about the special needs education of my child(ren). These interviews form part of an institutional research project that includes analysis of parent's perspectives regarding the special needs schooling of their child(ren).

Please indicate your consent for this interview by responding to the conditions below:

	Yes	No
I agree that I am a parent or guardian of a child who has a genetic condition, an ID and attends a special need school.		
I understand the purpose of the interview		
I understand that I am voluntarily participating and can withdraw from this research project at any time without giving any reason		
I understand that I will be given R50 for my travel cost to be able to come to this interview.		
I understand that the interview will be recorded so that the interviewer may transcribe my answers to the questions, and that it will be stored in safe place.		
I understand that my identity will remain private and that my name or other identifying information will not be made known. If names are required for the study the researcher will assign me a false name (pseudonym) in place of my real name.		
I understand that this information may be included in a master's research report, other academic reports and presentations		
I understand that if a research paper is published, that my identity will still remain private		
I understand that there could be no direct benefit for me or my child from participating in this interview		
I understand that this interview will have no negative affect on my child's healthcare or education. **This information will not be given to the school or hospital.**		
This information has been explained to me in-depth and I understand everything.		

Participant Name and Surname (Please print): Signature:

____

Contact number for participant:_________________________

Signature (SCM): Date: ____/______/2021___

Human Research Ethics Committee contact information: 021 650 1236 or hrec-enquiries@uct.ac.za

Appendix E: Research Reflection

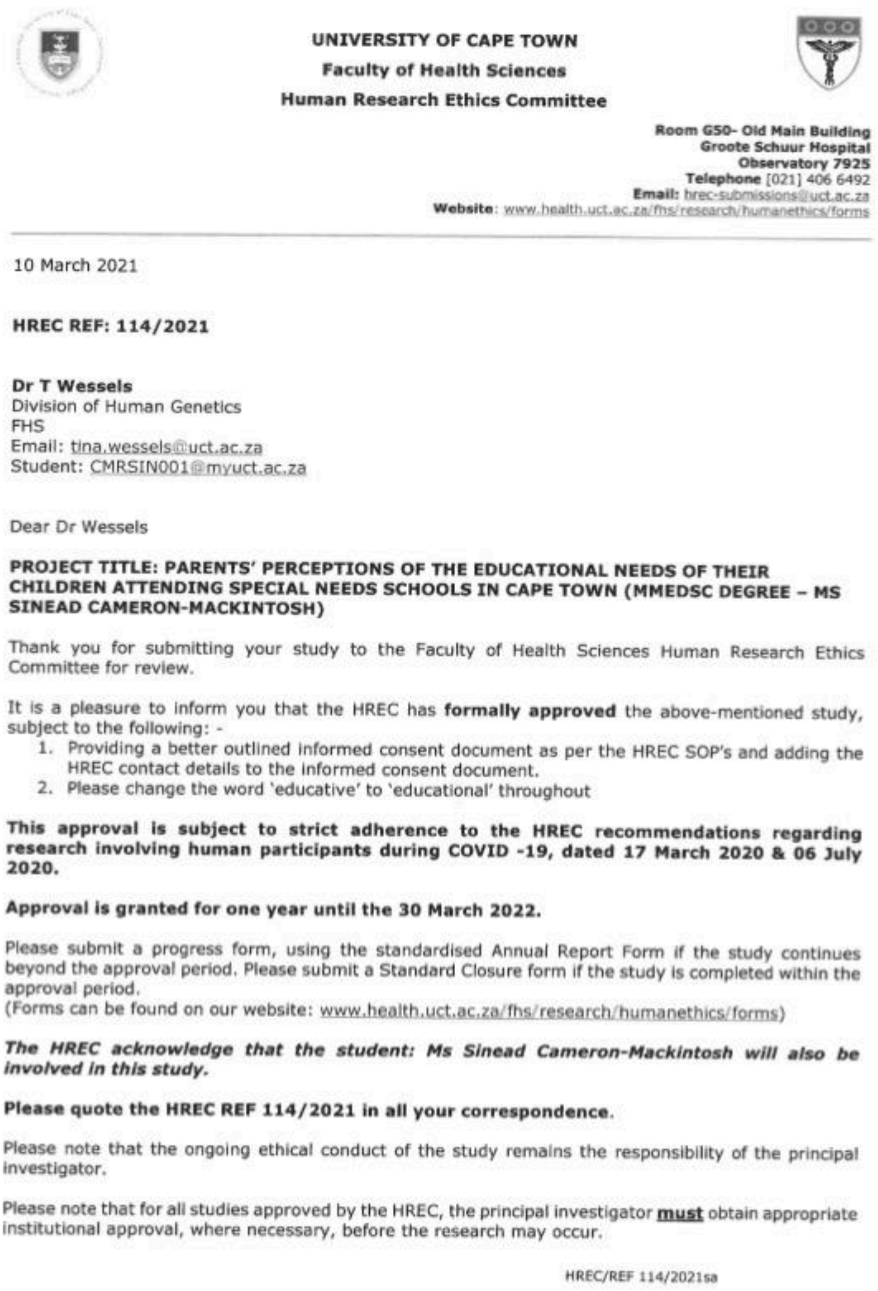
The right and access to education for all has always been a passion of mine. Personally, I know people who have genetic conditions that affect their ability to attend school, and this is where my interest in the subject began. Since I started this master's degree and working in our Genetics clinics, I have heard parents' stories about their struggles with their child's special needs education. At this point, I decided to focus my research on better understanding these untold stories of children with genetic conditions that attend or want to attend a SNS.

The qualitative research was challenging. I come from a quantitative molecular genetics research background, so I had to learn a new way of collecting and interpreting data. Exacerbating this challenge, I began my master's in 2020 and was initially delayed and hindered by COVID-19 restrictions. But, the knowledge and insight I gained through interviews, literature reviews and personal experience are invaluable. It has helped me relate and connect with patients on a deeper and more empathic level.

Just preceding this dissertation's submission, I spoke with a single parent of a child with an undiagnosed genetic condition who had ASD, ID, behavioural and cardiac issues. Her story seemed to embody my research findings. She had no family support because they did not understand his condition. She works full-time to support them and is struggling with school placement for next year. He is currently in a private special needs crèche which is difficult for her to afford, but there is no other option because no one can care for him at home. She disclosed that she is depressed and sometimes suicidal because she is "at her wit's end", and no one seems to be able to help her. At this point, I felt I should at least try to offer some support in the form of basic psychological counselling and a referral to mental health services at her base hospital. I wanted to do more, like help with SNS school referrals and getting her family to understand and support her. It is a challenging and ongoing process for me to know what my role is and how much I should and can get involved.

For me, this research is a starting point for further investigation, but also for genetic counsellors and other healthcare professionals to start thinking about their roles, responsibilities and influence in helping families of children with genetic conditions, ID and SEN. This is likely a long journey, but if it can help even one family like the mother I saw recently, then it will be so worth it.

Appendix F: Research Approval Documents



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

10 March 2021

HREC REF: 114/2021

Dr T Wessels
Division of Human Genetics
FHS
Email: tina.wessels@uct.ac.za
Student: CMRSIN001@myuct.ac.za

Dear Dr Wessels

PROJECT TITLE: PARENTS' PERCEPTIONS OF THE EDUCATIONAL NEEDS OF THEIR CHILDREN ATTENDING SPECIAL NEEDS SCHOOLS IN CAPE TOWN (MMEDSC DEGREE – MS SINEAD CAMERON-MACKINTOSH)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study, subject to the following: -

1. Providing a better outlined informed consent document as per the HREC SOP's and adding the HREC contact details to the informed consent document.
2. Please change the word 'educative' to 'educational' throughout

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020 & 06 July 2020.

Approval is granted for one year until the 30 March 2022.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

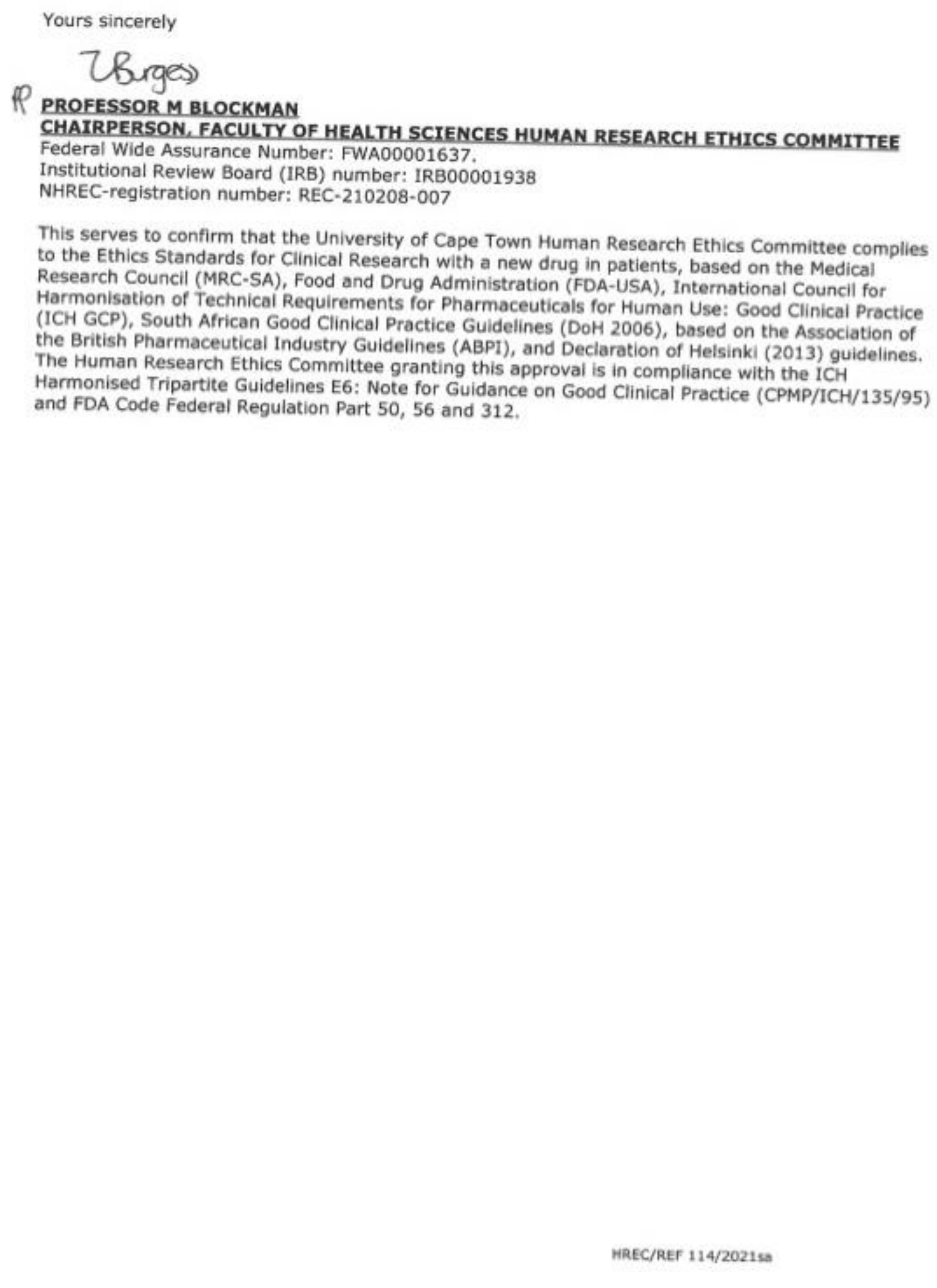
The HREC acknowledge that the student: Ms Sinead Cameron-Mackintosh will also be involved in this study.

Please quote the HREC REF 114/2021 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

HREC/REF 114/2021sa

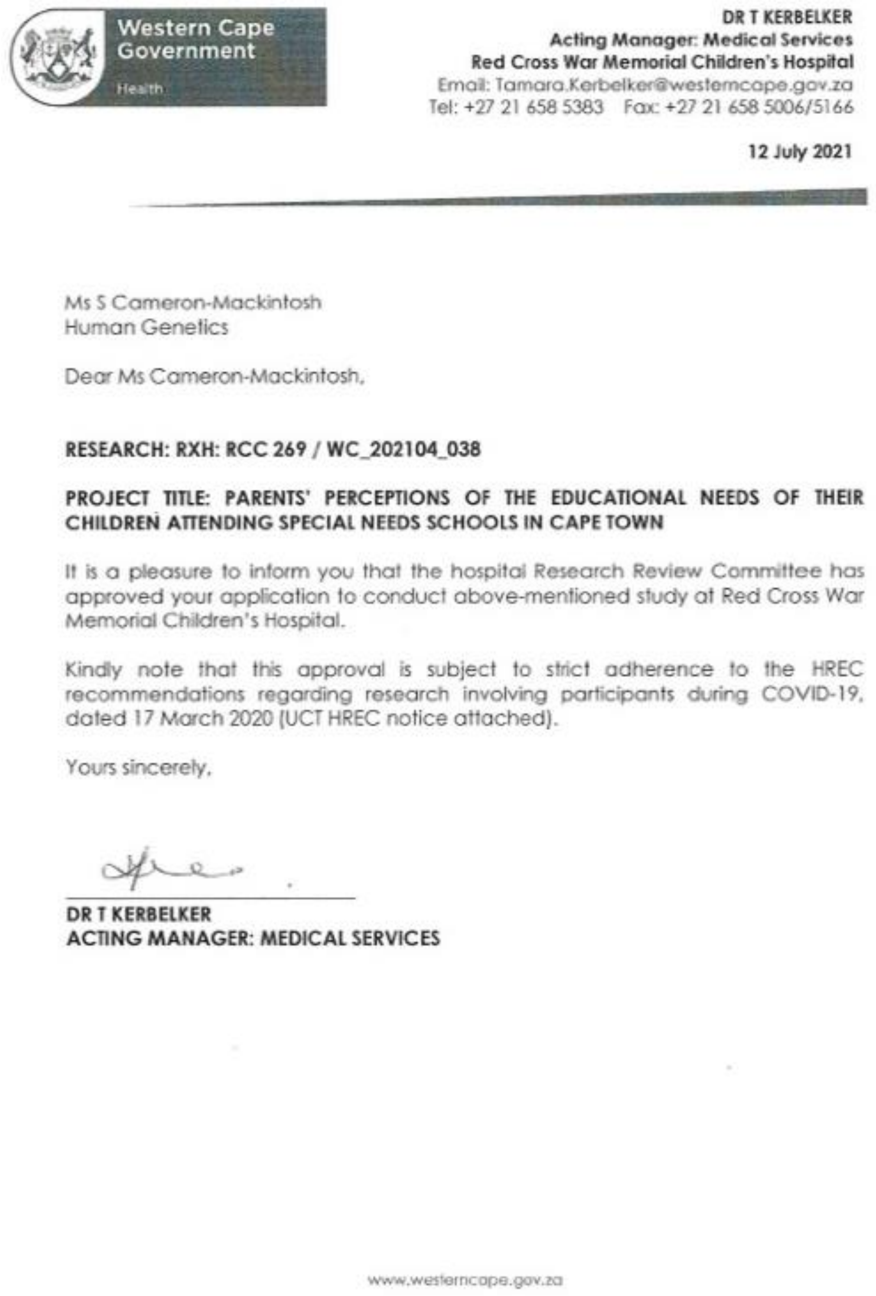


Yours sincerely

TBurgess

PP **PROFESSOR M BLOCKMAN**
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.



Western Cape Government
Health

DR T KERBELKER
Acting Manager: Medical Services
Red Cross War Memorial Children's Hospital
Email: Tamara.Kerbelker@westerncape.gov.za
Tel: +27 21 658 5383 Fax: +27 21 658 5006/5166

12 July 2021

Ms S Cameron-Mackintosh
Human Genetics

Dear Ms Cameron-Mackintosh,

RESEARCH: RXH: RCC 269 / WC_202104_038

PROJECT TITLE: PARENTS' PERCEPTIONS OF THE EDUCATIONAL NEEDS OF THEIR CHILDREN ATTENDING SPECIAL NEEDS SCHOOLS IN CAPE TOWN

It is a pleasure to inform you that the hospital Research Review Committee has approved your application to conduct above-mentioned study at Red Cross War Memorial Children's Hospital.

Kindly note that this approval is subject to strict adherence to the HREC recommendations regarding research involving participants during COVID-19, dated 17 March 2020 (UCT HREC notice attached).

Yours sincerely,

DR T KERBELKER
ACTING MANAGER: MEDICAL SERVICES