Speaking for Ourselves: Autism and Barriers to Early Intervention Services in Cape Town

University of Cape Town

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COMPULSORY DECLARATION

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Abstract

There is limited knowledge about autism as a disability in Africa: thus far, most autism research studies have been limited to families in high-income western countries, resulting in a gap in research regarding studies from low-income countries. Despite their vulnerability, people with disabilities have been largely unnoticed as a goal of development work despite disability's economic impact on families and communities, and the associated discrimination, stigmatisation and exclusion. Education has been identified as an essential building block of human and economic development, yet children with disabilities face unequal barriers in accessing educational services and schooling. Focusing on early intervention services is vital for the growth and development of children with disabilities, as early human development services and programmes for young children and families play a critical role in alleviating poverty and achieving social and economic equity.

The aim of this study was to identify the major barriers to accessing early intervention services for autistic individuals in Cape Town and achieving well-being. I drew on Sen's capability approach to inform my theoretical framework.

I used an embedded mixed methods design, with a quantitative questionnaire playing a supportive secondary role in this qualitative study, which included in-depth interviews and some documentary research. The sample consisted of ten participants: five parents of autistic children, and five autistic adults. Qualitative data for this study was analysed using thematic analysis, informed by Miles and Huberman's (1994) process of first and second-level coding. The quantitative data for descriptive statistics was recorded and analysed using Statistical Package for the Social Sciences (SPSS).

This study brought six themes into focus, namely services, financial constraints, practitioners, home environment, stigma, and lack of support services. A variety of recommendations were highlighted by the participants, including an adaptation of services; developing better trained practitioners in autism-specific strategies; making increased parent-training and support services available; together with creating a better system to help support, monitor and guide families and autistic individuals in navigating the field of services.

List of Acronyms

ABA	Applied Behavioural Analysis
ADHD	Attention Deficit Hyperactivity Disorder
AIMS	Awareness; Interest; Movement; Sensory support system
ASD	Autism Spectrum Disorder
CO-OP	Cognitive Orientation to daily Occupational Performance
ECI	Early Childhood Intervention
ESDM	Early Start Denver Model
HANDLE	Holistic Approach to Neurodevelopment and Learning Efficiency
ICF	International Classification of Functioning, Disability and Health
MDGs	Millennium Development Goals
NDP	National Development Plan
NPO	Non-profit organisation
PECS	Picture Exchange Communication System
RDI	Relationship Development Intervention
SPSS	The Statistical Package for the Social Sciences
TEACCH	Treatment and Education of Autistic and related Communication Handicapped children
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNICEF	United Nations Children’s Fund
UN	United Nations
UNDP	United Nations Development Programme
WPRPD	White Paper on the Rights of People with Disabilities
WHO	World Health Organization

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Chapter 1: Introduction

1.1 Introduction

According to the Autism Society of America (2016), autism is a complex developmental disability that commonly appears within the first three years of life. It is a result of a neurodevelopmental disorder that affects the normal functioning of the brain, resulting in poor communication, behavioural and social skills. Autistic individuals have varying degrees of abilities where they may display mild to severe characteristics of the condition and some could be severely affected and require lifelong care and support. There is little knowledge about autism in Africa, where most of the autism research studies thus far have been limited to families in high-income western countries, resulting in a gap in research regarding studies from low to middle-income countries (Durkin et al., 2015; Samadi & McConkey, 2011). Unfortunately, research on autism in Africa and other low-resource environments remains not only limited, but also of questionable quality.

Autism is considered to be a severe disability because of the intense lifelong effects it has on the individual and his or her family. Neurodevelopmental impairments in social interaction, communication, and unusual ways of perceiving and processing information can have serious impacts on the daily functioning of autistic people and, additionally, severely hinder their educational and social achievements (WHO, 2013). Across the world, autistic individuals represent a vulnerable group who are subjected to stigma, discrimination and marginalisation on a daily basis. Poor self-esteem, low self-confidence, limited hope for the future and reduced motivation are all results of stigma and marginalisation. In addition, isolation - an outcome due to stigma as a vulnerable group and marginalisation from society - is a significant risk factor for future mental health conditions (Chan, 2010). According to MacLachlan and Swartz (2009), the vast majority of people living with disabilities live in low-income countries, and most of them are very poor, resulting in a triple vulnerability and multiple oppressions. Despite their vulnerability, people with disabilities have been largely unnoticed as a goal of development work despite disability's economic impact on families and communities, and the associated discrimination, stigmatisation and exclusion. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) confirms the necessity for development efforts to focus on people with disabilities, which entails the mainstreaming of disability issues into strategies for sustainable development (Chan, 2010). Their mission is to "promote, protect and insure the full enjoyment of human rights by persons with disabilities, as well as full equality under the law" (Schulze, 2010: 33).

Education has been identified as an essential building block of human and economic development, yet children with disabilities face unequal barriers in accessing educational services and schooling despite the right to education for all that is protected in the Constitution of the Republic of South Africa (1996). With only five autism-specific government-funded schools, many autistic children in South Africa are left behind (van Schalkwyk, Beyer & de Vries, 2015). The discriminatory practice of excluding children with disabilities leads to further marginalisation of this already vulnerable group (Chan, 2010). The Department of Social Development and UNICEF South Africa (2007) indicated how important the early years are to a child's development, and how critical it is for children who are at risk to be identified so that they have a chance of gaining access to treatment, rehabilitation and their right to education (Department of Basic Education and UNICEF, 2015). According to the World Health Organization's report, *Promotion of health in persons with ASDs and other developmental delays* (2013), it has been demonstrated that early interventions produce the best returns in investment and better results in terms of developmental outcomes and improvement in daily functioning (WHO, 2013). The aim of early intervention services is to limit the number of children forced to battle lifelong impairments (Riccio, 2011). Children with developmental delays or disabilities and their families need to access appropriate early intervention that protects and supports individuals in a timely manner, in order to ensure that their difficulties do not increase and result in further consequences, such as profound exclusion and poverty (WHO, 2012).

According to Amartya Sen (1992), when evaluating the well-being of an individual, one must evaluate their opportunities and not their achievements; therefore, this evaluation of well-being should be measured within the space of capabilities. 'Capabilities' are the real opportunities and freedoms people have to achieve certain outcomes (Sen, 1992). Early childhood is a critical period for these opportunities to form the foundation of lifelong learning and participation in a child's life, while averting potential delays in development and disabilities (WHO, 2012). The capabilities approach as a human development assessment is an important starting point in analysing autistic individuals, their environment and their opportunities to live a fulfilling life according to them (Britz et al., 2013; Robeyns, 2003).

In Cape Town, early intervention services are offered across the Cape Peninsula to people affected by autism who come from suburbs and communities that cut across class. This study will assess these early intervention services in Cape Town that provide formal support to all children with autism and their parents in order to improve children's abilities and enhancing their capabilities (Jabery et al., 2014). By allowing the families of autistic individuals and autistic adults' voices to be heard, I want to critically reflect on the early interventions available in Cape Town and the barriers experienced by parents and autistic adults in receiving and implementing early intervention programmes. This is done by examining whether early interventions available provide opportunities for autistic individuals to enhance their capability set by analysing those social and structural barriers that influence and restrict human development and well-being. This will be done by drawing on Sen's capability approach to well-being to inform my theoretical and analytical framework.

This thesis will use a mixed methods design, with a small quantitative questionnaire embedded within a predominantly qualitative study. I aim to answer my main research question and sub-questions by collecting data from documentary sources, quantitative descriptive statistics and qualitative interviews. A short questionnaire and face-to face individual in-depth interviews are used with the same sample group, which constitutes parents of autistic children, and autistic adults. The data collection methods focus mainly on the respondents' experiences of early intervention services in Cape Town. Although poorer people affected by autism are likely to encounter more challenges, people's economic status in society does not exempt them from experiencing social and psychological barriers and marginalisation. Positionality remains an important variable in my sample, which cuts across class and race, and takes this into account.

I do not approach this research topic as an insider or a total outsider, but as someone who has worked closely with people affected by autism. Over the past seven years, I have been working as a therapist and supervisor for autistic children and a trainer for parents, educators and practitioners in autism-specific strategies. While completing my Master's degree I continued to work in the field of autism. I have been a live-in therapist with families in South Africa, France, Singapore, Israel and Australia, which provided me with first-hand accounts of the relationship, issues and daily struggles that parents and their autistic children face. This background has led me to identify a need in the population to be addressed and develop an understanding which underlies this study.

Considering that the aim of this thesis is for parents of autistic individuals and autistic adults' voices to emerge, this thesis will adopt the use of 'identity-first' language. Autistic adults advised that the use of language that separates a person's autism from their identity, such as 'person with autism', not only undermines the positive characteristics of autism but also perpetuates a negative outlook and the belief that autism is fundamentally 'wrong' way of being. This disability-first or identity-first language aligns with the autism community members who perceive their diagnosis (or their child's diagnosis) to be an accepted part of their identity and characterizes their inclusion in a community (Kenny et al, 2016; Broderick & Ne'eman, 2008).

1.2 Research problem and rationale for the study

Autism spectrum disorder (ASD), like most other intellectual and developmental disabilities, can be found in every nation all over the world, where families tend to provide lifelong care and support to their relative in need (Samadi & McConkey, 2011). Over the last few years, autism has emerged as a major public health concern globally. It is evident that the number of children with ASD diagnoses has been on the rise over the last decade, together with the demand for services (Newschaffer, 2003; Dymond, 2007). Unfortunately, there is a lack of research to update the development of support services in low to middle-income countries (Samadi & McConkey, 2011).

There is little knowledge about autism as a disability in Africa, where most of the autism research studies thus far have been limited to families in high-income western countries (Durkin et al., 2015; Samadi & McConkey, 2011), resulting in a gap in research regarding studies from low-income countries (Tekola et al., 2016; Ruparelia et al., 2016).

Samadi and McConkey (2011) state that approximately all prevalence studies they found were conducted in either Western countries or affluent Asian countries, for example Japan. Information on identifying children with ASD in non-Western countries is limited, where services in less affluent countries for children with special needs are underdeveloped. This dearth of information has led to the unjustified postulation that autism is uncommon in non-Western cultures (*ibid*). According to the Centre for Disease Control and Prevention, 1 in 59 children in America are diagnosed with autism (Baio et al., 2018). While no robust epidemiological studies concerning autism have been conducted, we cannot be certain that rates are lower in Africa than anywhere else (De Vries, 2016). De Vries (2016) believes, however, that, if anything, higher prevalence rates would be more likely, following the same pattern reported in South Africa and other low to middle-income countries concerning the prevalence of intellectual disability, compared to estimates for high-income countries.

Although individuals diagnosed with ASD are increasing, it is still uncertain whether the actual prevalence of autism is on the rise (Newschaffer, 2003; Dymond, 2007). Newschaffer (2003) states that autism was generally thought to be quite rare, although it was known to be one of the most severe childhood neuropsychiatric disorders. Today, however, it is acknowledged that autism comprises a broader spectrum of individuals that does not only include the classic features. According to Newschaffer (2003), increasingly more individuals across the globe have been in search of medical, educational and social services to help address the challenges of autism.

Early childhood is a critical period for opportunities in a child’s life to prepare the basis for lifelong learning and participation, while preventing potential delays in development and disabilities (WHO, 2012). The South African Integrated National Disability Strategy (1997), a White Paper that represents the government's thinking about what it can contribute to the development of disabled people and the promotion and protection of their rights, stresses an understanding of disability as a human rights and development issue, which recognises that people with disabilities are citizens who should therefore enjoy equal rights and responsibilities. Regardless of being more vulnerable to developmental risks, mainstream programmes and services intended to guarantee child development often overlook young children with disabilities (WHO, 2012). Additionally, they do not receive the specific support essential for their rights and needs to be met. The National Development Plan (NDP) recognizes that there are a range of barriers that exist resulting in many people with disabilities not being able to develop to their full potential and recognizes that there is not a one-size-fits-all approach (National Planning Commission, 2011). The Department of Social Development launched the White Paper on the Rights of Persons with Disabilities (WPRPD) in 2016 and states that its vision is for a South Africa that is “a free and just society inclusive of all persons with disabilities as equal citizens” (2016: p.55). This vision is aligned with the National Development Plan 2030 Vision, INDS (1997) and the UNCRPD (1996). The White Paper (2016) recognizes the urgency to break down the barriers that prevent the effective enjoyment of all rights by persons with disabilities and enable people with different types of disabilities to live independently and to participate fully in all aspects of life. Barriers exist for children with disabilities and their families which include inadequate legislation and policies, inadequate services, lack of accessible environments and negative attitudes (WHO, 2012). Furthermore, autistic children are heterogeneous in nature and, as a result, need a varied array of services and support. With the increase in prevalence of autistic individuals, the demands on services and the service delivery system continue to grow (Dymond, 2007).

The first goal of the United Nations Millennium Development Goals (MDGs) was to eradicate extreme poverty, followed by ensuring that all children finish primary schooling as the second goal (Human Rights Watch, 2015). It is apparent that importance should be placed on improving early childhood development (ECD) in order for these goals to be achieved and, although the South Africa government has stated that they have met the United Nation Millennium Development Goal on education, the Human Rights Watch report (2015) has questioned that claim (Grantham-McGregor et al., 2007; Human Rights Watch, 2015). The report conducted by the Human Rights Watch (2015) states that South Africa has failed to provide equal opportunities and protection to children with disabilities concerning schooling, where over half a million children with disabilities do not have access to schooling and hundreds of thousands of children with disabilities in school are not being accommodated (Human Rights Watch, 2015). In South Africa there are no governmental pre-schools and a limited number of autism-specific primary and secondary schools. Van Schalkwyk, Beyer & de Vries, (2015: p.3) state that, at the time of publication, there were only nine autism-specific schools in South Africa - six of them in the Western Cape Province. In the Western Cape, some autistic children wait years to be placed in special needs schools. The proportion of children with autism in Western Cape schools grew 76% between 2012 to 2016, and yet children on waiting lists increased 276% during the same period (Zeliadt, 2017). This results in children only receiving appropriate services years after their initial diagnosis.

In 2015 the Millennium Development Goals (MDGs) and was replaced by the 17 Sustainable Development Goals (SDGs). Included in the SDGs are goal number 3 to "ensure healthy lives and promote wellbeing for all at all ages" and goal number 4 to "ensure inclusive and equitable quality education and promote lifelong learning opportunities for all" (United Nations, 2015: p.14). The 2030 Agenda for Sustainable Development (2015) provides political momentum to push for the realization of the UNCRPD. There are overlaps between the SDGs and the UNCRPD, for instance, the SDG goal number 4 aligns with Article 24 of the CRPD that guarantees the right to inclusive education, at all levels, for persons with disabilities. This human right explicitly includes both equal access to education and equal participation in education (Schulze, 2010). The SDGs advance and increase opportunities for children with disabilities, however, there are clearly still many challenges. South Africa continues to face major social and structural constraints that restrict human development and thus the achievement of the SDGs (Van Schalkwyk, Beyer & de Vries, 2015).

Policymakers have identified that malnutrition and poverty are associated with increased mortality and poor health; however, acknowledgement of its detrimental impact on children's development or of the value of early intervention is limited (Grantham-McGregor et al., 2007). In the last decade, however, children's early years are emerging as a public policy focus around the world, from neurological and biological sciences, economic evidence and programme evaluation results. Early childhood, ranging from the period from prenatal development to eight years of age, is the critical period of development and growth, since what one experiences during those early years can impact outcomes across the entire sequence of an individual’s life. For children who experience disability, it is a critical time for appropriate interventions, which can assist in them reaching their full potential (WHO, 2012).

Across the globe, individuals with disabilities, such as autism spectrum disorder, represent a marginalised and vulnerable group. Autistic individuals experience stigma and discrimination, including unjust deprivation of health services and education (WHO, 2013). Additionally, they frequently experience diminished opportunities to participate and be actively involved in their communities. Worldwide, accessing services and support for autistic individuals are inadequate, where considerable economic, emotional and care burdens are placed on the family members of those with the diagnosis (WHO, 2013). Focusing on early intervention services is vital for the growth and development of children with disabilities, as emphasised by Britto et al. (2011), who states that early human development services and programmes for young children and families are recognised as one of the most promising approaches to alleviating poverty and achieving social and economic equity for the global community. The capabilities approach, which informs this study, identifies those social and structural constraints that influence and restrict human development and well-being that are the root causes of the imbalances identified by such empirical measurements of inequality or information poverty (Sen, 1993; Robeyns, 2003).

1.3 Research questions

For this study, my research questions are as follows:

Central research question:

What are the major barriers to accessing early intervention services and achieving well-being for autistic individuals?

Research sub-questions:

1. What are the existing early intervention services available for autistic individuals in Cape Town?
2. What are the experiences of parents of autistic children, and autistic adults, of the existing early intervention programmes available in Cape Town?

3. Are there any disparities that exist between parents’ views and autistics adults’ experiences of these early interventions?
4. What recommendations do parents of autistic children, and autistic adults, have for improving early intervention services?

Chapter 2: Key concepts and theoretical framework

To determine whether the current existing early interventions services in Cape Town provide opportunities for autistic individuals to achieve well-being by helping them to enhance their capability set, Sen's capabilities approach to well-being will be used as a theoretical approach. This chapter will proceed to review the key concepts used in my central research question, namely, autism; early intervention services; barriers; and well-being; and will be discussed where relevant in relation to the theoretical framework. I draw on Sen's capabilities approach to well-being because, firstly, it highlights the central role of human diversity in its conceptual construction. The capability approach is a suitable interpretative framework for analysing and assessing the lives of the disabled. Secondly, the capabilities approach permits the consideration and understanding of disability as the interrelation of circumstantial and individual elements, establishing equality in terms of possibilities and choices, which many of the disability models have failed to do (Robeyns, 2016; Terzi, 2005).

2.1 Understanding disability

Autism is a complex developmental disability that commonly appears within the first three years of life. It is a result of a neurodevelopmental disorder that affects the normal functioning of the brain, resulting in poor reasoning, communication, behavioural and social skills. Additionally, autistic individuals may exhibit restricted and repetitive behaviours (hand flapping, rocking, etc.), have unusual responses to people or attachments to objects, and resist changes in routines. In some cases, aggressive and/or self-injurious behaviour may occur (Bercow, 2008). Autism is considered to be a severe disability because of the intense lifelong effects it has on the individual and his or her family. Disability has been described in different disciplines and for various reasons, from medical and sociological to political perspectives. These disability definitions have been established and used in a variety of contexts (Mitra, 2006).

For most of history, the medical and social models have been used as contrast opinions to defining disability. The medical model of disability attributes disability to the problem of the individual, and the impairment is considered by the physical or mental 'problem' that the individual has (Mitra, 2006; Bakhshi & Trani, 2006). This 'problem' of an individual is seen as being a result of an injury, disease or medical condition. Mitra (2006) states that with this model, people are considered disabled on the basis of not functioning as a 'normal' person is able to; disability activists and organisations have considered this view to be biased.

The social model's definition of 'disability' suggests that the emphasis placed on the physical condition of persons with disabilities must move towards an emphasis on tackling the oppression that persons with disabilities experience in society (Disabled People's International, 1982). The model suggests that the structure of the society in which they live does not accommodate their impairment (Bakhshi & Trani, 2006). A social representation of disability relocates the focus from the individual to society – from an individual model (biological causes of impairment) to a social model (societal causes of exclusion and oppression). Considering the social model, disability is now more critically defined as the limitation or loss of opportunities to participate in the mainstream life of the community on an equal level with others due to physical as well as social barriers (Disabled People's International, 1982). This social interpretation of redefining disability as that which is created socially is based on attitudinal, environmental and social barriers, and that which is experienced by an individual.

The World Health Organization (WHO) has integrated the medical and social models and developed the International Classification of Functioning, Disability and Health, also known as ICF (World Health Organisation, 2002). This model looks at disability as a combination of individual, institutional and societal factors that demarcates the environment within which a person with an impairment lives (World Health Organisation, 2002; Bakhshi and Trani, 2006). According to the ICF model, disability originates in the health condition which brings about the impairment and then leads to limitations in activities and restrictions in participation within given contextual aspects (Mitra, 2006). According to the WHO (2012), disability can occur at three levels: firstly, an impairment in body function or structure; secondly, a limitation in activity, such as the inability to read or move around; and thirdly, a restriction in participation, such as exclusion from school.

Mitra (2006, p. 243) states that the ICF is the closest definition of disability found under Sen's capability approach and, as such, "the ICF can be understood as a specific application of the capability approach". However, Bakhshi and Trani (2006) remark that there are limitations to the ICF, one being that the ICF model emphasises the body, individual limitations and participation, but fails to highlight the interaction between the individual and society in the definition of disability. Furthermore, the definition is limited in that it does not contemplate the intention of individuals. Mitra (2006) further states that for the ICF to be a useful definition under the capabilities approach, the definition would have to account for economic constraints and the economic environment of the individual.

In the philosophy of well-being, numerous philosophers have implied or argued that the capability approach may be particularly appropriate for understanding the well-being of human beings and of those with disabilities in particular (Robeyns, 2016). The capability approach has been used by scholars to address disability as an interaction of three factors: 1) personal characteristics, such as a physiological impairment, 2) available resources, and 3) the economic, socio-political and cultural context surrounding the individual (Mitra, 2006; Dalkilic & Vadeboncoeur, 2016). As an evaluation tool, the capability approach can assess disability and the conditions that make it disabling through examination of the impairment of the individual, the necessary resources available and the social context, and how the interaction of these conditions limits an autistic individual’s capabilities (Mitra, 2006; Dalkilic & Vadeboncoeur, 2016). The capabilities approach will be explained further in the following section.

2.2 The capabilities approach to well-being

According to Amartya Sen, people must have the freedom (capabilities) to be what they want to be, to live their lives according to their choices. Sen (1992) states that ‘functionings’ are the beings and doings that individuals have reason to value. Examples of functioning are being educated, reading, being adequately nourished, communicating or having self-respect. ‘Capabilities’ are the real opportunities and freedoms people have to achieve these valued functionings. Capabilities do not involve a physical or a mental ability; instead, it is rather understood as a practical opportunity and, therefore, potential functionings that are feasible for the person to achieve. The focus of development thus increasingly becomes a person’s capability set, or their substantive freedom to lead the life they value. Functionings represent the ‘outcome’ component, while capabilities are the ‘freedom’ component in this approach (Sen, 1992; Terzi, 2005; Robeyns, 2005). Sen (1992) argues that the evaluation of well-being should be measured within the space of capabilities and not functionings, thus evaluation should focus on opportunities and not achievements. These capabilities, if available, allow effective choices for individuals in terms of what they want to be. Looking at it in a practical way, it means that people, or in this case an autistic individual, must be able to have the opportunity to be educated, feel part of a community or be able to work. This study aims to find whether the existing early interventions in Cape Town help autistic individuals achieve well-being by providing them with these opportunities to enhance their capability set.

By looking at impairment and disability within the capability approach, it is needed to reframe these concepts in terms of functionings and capabilities. Impairment is a personal feature that may affect certain functionings and therefore become a disability. Consequently, disability is a restriction of functionings (Terzi, 2005). For example, an autistic individual may have language impairment which, if other modes of communication are not taught (which can be achieved through early intervention therapies), could negatively affect communication as a functioning. This is the result of the intertwining of personal with social and circumstantial features. For an autistic individual, they may find a way to communicate that is not through language, for example by using gestures or sign language, but if the receiver does not understand his/her gestures or sign language, the autistic individual is not able to communicate effectively and let his/her needs and wants known. It is in this way that personal and social circumstances affect an individual. In the end, within this outline, disability is conceptualised as a limitation on relevant capabilities in relation to both impairment and the construction of social and environmental arrangements. Therefore, re-evaluating impairment and disability in terms of capabilities suggests taking into account what the full sets of capabilities one person can choose from are, and evaluating the impact of impairment on these sets of freedoms (Terzi, 2005). It suggests, furthermore, to consider the interface between the individual and the environmental characteristics in evaluating what circumstantial foundations may lead impairment to become disability, and how this impacts on capabilities. In this way, impairment and disability are elements to be accounted for when considering what a person is actually able to be and do (Terzi, 2005).

Early intervention can be defined as treatment programmes that begin before the child reaches the age of five, due to the increased brain plasticity and ability to acquire communication and behavioural skills in this period (Erba, 2000). Early intervention therapies, also known as interventions, encompass programmes or sessions designed to promote children's development. Early intervention services are the organisations and places that provide these intervention therapies. A service might provide one or many types of interventions (raisingchildren.net.au, 2016). By applying the example used above, if one's hope is to help an autistic individual with a speech impairment to achieve the functioning of 'communication', the purpose of accessing early intervention services is to assist the individual with their speech impairment, where the intervention aims to increase their speech and language skills. This, in turn, will help enhance autistic individuals' capabilities to help them achieve the functioning of 'being able to communicate'. In this way, early intervention services target specific areas of support needed in the individual's development.

Early interventions can be seen in aiding or enhancing an individual’s capability set through educational achievements that allow an individual to convert skills, knowledge and competencies into capabilities to act as fully participating, active citizens. The aim of early intervention services is to limit the number of children forced to battle lifelong impairments (Riccio, 2011). A range of factors can result in a person being ‘disabled’, combined with available resources. These resources may encompass services provided by the government, community support and considerations within the family (Bakhshi & Trani, 2006). Disability, therefore, is formed as a result of the inadequacy of available resources and barriers in the social environment, which result in the limitations of capabilities and functioning (Terzi, 2005; Dalkilic & Vadeboncoeur, 2016).

Inclusive Education South Africa (2006) defines a barrier to learning as “anything that stands in the way of a child being able to learn effectively. Barriers to learning are not limited to intrinsic barriers but they can also be societal/environmental barriers. For example, extreme poverty, abuse or neglect will all act as barriers to a child’s learning.” This study aims to look at what the social and structural barriers are that influence and restrict autistic individuals from accessing these early interventions.

Chapter 3: Methodology

My study encompassed an embedded mixed methods design with predominantly qualitative methods. I aimed to answer my main research question and sub-questions by collecting data from document research, quantitative descriptive statistics and qualitative interviews. Mixed methods including survey questionnaires and qualitative one-to-one interviews were used with the same sample group, predominantly focusing on experiences of early interventions in Cape Town. The qualitative data are supported by quantitative data in the form of a questionnaire that preceded the qualitative interviews. The questionnaire design was informed by research collected from document and internet searches and a literature review, where the aim was to map out all relevant existing interventions in Cape Town. Qualitative interviews were the main focus in this study to gather in-depth, rich data in order to answer my central research question: "What are the major barriers to accessing early intervention services and achieving well-being for autistic individuals?"

3.1 Research design

This study took on an interpretive approach. Within this tradition, the aim of the human sciences is defined as understanding, not explaining, the people. People are conceived not primarily as biological organisms, but first and foremost as conscious, self-directing, symbolic human beings (Babbie & Mouton, 2008). The phenomenologists emphasise that all human beings are engaged in the process of making sense of their worlds. We continuously interpret, create and give meaning to, define, justify and rationalise our actions. According to an interpretive position, the fact that people are continually constructing, developing and changing the everyday interpretations of their worlds should be taken into account in any conception of social science research (Babbie & Mouton, 2008). In this study, I tried to understand and describe participants' interpretations of their experiences of early intervention services and the barriers they perceive in accessing these. In addition to this, I was interested in learning how early interventions are perceived in helping autistic children achieve well-being, or how these barriers prohibit this from happening, according to the participants.

3.1.1 Embedded mixed methods design

The embedded design is a mixed methods design which includes the collection of both quantitative and qualitative data, but one of the data types plays a supplemental or supportive role within the overall design. The basis for this design is that a single data set is not enough, that there are different research questions that need to be answered, and that each type of question requires different types of data. Researchers can use this design when they need to include quantitative data to answer a research question within a largely qualitative study (Creswell & Plano Clark, 2007). Since this study concerns the early intervention services in Cape Town, it is therefore, firstly necessary, to explore what the existing early intervention services available in Cape Town are. Secondly, exploring the knowledge of participants and their perceptions surrounding these interventions, including their approaches, is important if we are to understand what the barriers are in accessing them. A quantitative data collection method, for example a structured questionnaire, can be embedded within a qualitative methodological design. An embedded design can use either a one-phase or a two-phase approach for the embedded data (Creswell & Plano Clark, 2007).

This study was conducted in two phases which encompass qualitative and quantitative methods. The first phase entailed the mapping out of all early intervention services available in the Cape Town region. While it is important to understand what is currently available in the Cape Town region, it furthermore informed the development of a short questionnaire which was administered in the second phase of the study. Mapping out all the intervention programmes currently available in Cape Town together with a thorough literature review, helps us to document, describe and classify what the current early interventions available are, what type of approaches they encompass and what organisations and companies provide these interventions. Mapping out these services helped answer my first sub-question: “What are the existing early intervention programs available for autistic children in Cape Town?”

The development of a new instrument further aimed to help explore what the current knowledge is in society surrounding the different available early interventions, together with key questions regarding experiences of these early intervention services among parents of autistic children, and autistic adults. Through the quantitative method, this new tool supplemented any information obtained from qualitative interviews and aided in the understanding of the major barriers that exist in accessing services for autistic individuals. Additionally, this tool proactively aimed to allow for any potential difficulties, such as autistic adults not being able to answer a qualitative question for any reason(s), and provided some answers and clarity on questions. Precautions were taken in light of the understanding that circumstantial factors play a role and that autistic adults may have difficulty in answering questions in the way that they would like, and the development of a new instrument was considered to help ease certain situations if possible. Moreover, it was noted that parents of autistic children, and autistic adults, may have different experiences concerning early interventions and may perceive different barriers; therefore, the questionnaire would help determine whether they have the same thoughts on early interventions and the possible barriers around them, which participants may not explicitly mention in qualitative interviews.

A thorough literature review was conducted to determine whether there were any existing questionnaires that would be beneficial to this study. Considering the specificity of the target audience (a small, local sample group) and the relevance to the study (the location in which this study occurs and the existing early intervention services that are currently available in Cape Town), I undertook the task of developing my own questionnaire. The questionnaire contained both quantitative and qualitative questions.

In the second phase of this study, the short questionnaire, which was developed in the first phase, was administered, together with qualitative, semi-structured interviews with all the participants, informed by the information retrieved from the first phase. Adamson *et al.* (2004), found that utilising self-completed questionnaires followed by a semi-structured tape-recorded interview provided triggers that generated interesting data and stimulated conversations relating to participants' perceptions and definitions of complex issues. The authors advocate this approach, which they subsequently named 'questerviews' as a method for integrating qualitative and quantitative methods. By analysing four separate studies that combine questionnaires followed by in-depth interviews, the authors found that these methods not only encouraged detailed narratives, but also highlighted the complexity of people's views (Adamson et al 2004, p. 142).

Qualitative research differs from quantitative research in that qualitative methods aim for in-depth descriptions and understanding of actions and events. The main concern to keep in mind with a qualitative approach is the importance of understanding social action in terms of its specific context rather than attempting to generalise findings to a theoretical population, as would typically be more feasible with a large-scale quantitative approach (Babbie & Mouton, 2008). The aim of the fieldwork was to answer my overall central research question: "What are the major barriers to accessing early intervention services and achieving well-being for autistic individuals?". Phase 2 further focused on answering the last of my three sub-questions: "What are the experiences of parents of autistic children, and autistic adults, of the existing early interventions available in Cape Town?"; "Are there any disparities that exist between parents' views and autistics adults' experiences of these early interventions?" and "What recommendations do parents of autistic children, and autistic adults, have for improving early intervention services?”

Table 1: Research Outline

Research Process	Data collection methods	Study objectives	Target Research Question
PHASE 1			
Part 1: **Mapping of early intervention services in Cape Town**	Internet search and analysis of secondary data	Document, describe and classify: 1) What the current existing early interventions available in Cape Town are; 2) what type of approaches they encompass and; 3) what organisations and companies provide these interventions	Sub-question 1
Part 2: **Instrument design**	*Step 1*: Literature review *Step 2*: Questionnaire design *Step 3*: Pilot study	• Explore the knowledge, experiences and perceptions of participants with regards to the provided list compiled of the existing early intervention services in Cape Town • Design a questionnaire that will accommodate autistic adults and supplement information provided in face-to-face interviews	
PHASE 2			
Fieldwork with participants	Self-administration of the short questionnaire	To better understand: 1) the access to information and knowledge surrounding interventions; 2) experiences of the availability and accessibility of these interventions to participants; 3) And the participant groups' perceptions of the type of approaches they encompass e.g. ABA	Main research question Sub-question 2 Sub-question 3 Sub-question 4
	Face-to-face, semi-structured in-depth interviews	• Obtain rich information and identify the major barriers experienced by participants in accessing early intervention services in Cape Town.	

		• Allow the voices of the receivers of these early interventions to emerge	

3.2 Sampling

I used a purposive sampling technique for this small-scale mainly qualitative study, which led me to choose a sample that matched the research purpose. The target audience (N=10) consisted of five parents who have autistic children under 18 years of age, and five autistic adults over the age of 18 who have engaged with early intervention services. Additionally, the sampling criteria required that all participants reside in the Cape Town area, South Africa. As many autistic children experience difficulty in expressing their strengths, weaknesses and needs for support, parents are often the primary source of information about their child's needs (Dymond et al., 2007). It is for this reason that I chose to target parents of autistic children. Secondly, the writings of autistic adults provide an indication of the challenges encountered during childhood in identifying and obtaining appropriate disability-related support and is, therefore, the reason why I decided to approach autistic adults too (Dymond et al., 2007). Autistic adults could provide us with significant information, but few have been involved in previous research studies. This is a marginalised grouping of people and, in this study, I was interested in their voices emerging, where the focus is on those that are on the receiving end of the services and what their experiences and thoughts are. In this way, I hoped to explore whether the support needs of families correspond to the well-being of autistic children as described by autistic adults.

In order to gather my research participants, I firstly approached Autism Western Cape, an NPO that aims to "empower individuals with autism spectrum disorders (ASD), their families, communities and all impacted, working towards inclusion through acceptance, advocacy, education, awareness and support" (autismwesterncape.org.za, 2018). Autism Western Cape helped me identify my research participants. Fortunately, I have been working in the field of autism for the past few years. I have a working relationship with Autism Western Cape and Autism South Africa, who indicated that they were willing to help me in my research project, and to put me in contact with research participants.

I created a visual advertisement that Autism Western Cape agreed to post on their Facebook page. Containing all the relevant information about the study, its ethical obligations and my contact details, the advertisement was aimed at parents of autistic children and asked for voluntary participations in the study. The response was overwhelming, and it was heart-warming to know that many parents felt passionately about this study and were willing to participate. I chose parents based on locations, who contacted me first and their availability for meetings during my period of fieldwork.

To gather autistic adults to participate in my study, I contacted an autistic adult who is on the administrative board of a very popular, closed Facebook group. This Facebook group aims to help autistic individuals by having autistic adults and members of the community participate in discussions over important and pressing topics that help inform and generate knowledge and relate their experiences among this community. After a few weeks of discussions about my research topic, the aim of my study, together with building a rapport, she was willing to put me into contact with a few other autistic adults who she believed would be able to assist in my research. I contacted these autistic adults personally, provided them with information about myself, my working history in the autism community, my research topic and the ethical requirements of my study and asked if they were willing to participate.

Taking into account my history of working in the field of autism, I did not contact or interview any participant familiar to me in order to avoid potential biased opinions. I met all the participants in this study for the first time. Below is a summarised table of the demographic variables of the participants in this study.

Table 2: Demographics of participants (N = 10)

Participant Information		**N**
Gender	Males	2
	Females	8
Age (Years)	18-35	2
	36-45	7
	46-55	1
'Race'	White	7
	Coloured	3
	Black	0
Preferred language	English	10
	Afrikaans	0
Marital status	Single	4
	Married	5
	Divorced	1
Employment status	Employed	4
	Unemployed	6

In South Africa data on the incidence, prevalence, and impact of autism is severely lacking. There are currently no reliable prevalence studies indicating figures for South Africa. Diagnostic and intervention services, particularly at the state level, are scarce and standardised assessment tools in multiple languages are not available. Research findings also indicate that autism is under-diagnosed and under-identified in low socio-economic communities (Malcolm-Smith, Hoogenhout, Ing, Thomas, & de Vries, 2013). The history of inter-generational poverty, together with a national unemployment rate of 27.2 percent (Statistics South Africa 2018), means that in many poorer families, the income has to be shared among all the family members, thereby decreasing the proportion of income available for disability-related services. Furthermore, cases from disadvantaged communities may not be referred by doctors for assessment, owing to lack of available services. Stigma, lack of access to medical interventions, under-diagnosis, and some cultural misperceptions lead to many autistic individuals going undiagnosed, resulting in a misrepresentation of the true autism prevalence rates in South Africa (Schlebusch, Samuels & Dada, 2016; Malcolm-Smith et al, 2013). This is to some extent evident in the participants' demographics presented above, where white responds were overrepresented and there were no black respondents. The age range of the participants is 23 years to 51 years old. All parents of autistic children are females and the only two autistic adults, who volunteered to participate in this study, were men. The difficulty of living with a disability is evident in the employment status, where over half of the participants are unemployed. Qualitative researchers study phenomena in their natural settings, attempting to make sense of, or interpret the meanings people bring to them (Creswell & Plano Clark, 2007). Participants were interviewed where they felt the most comfortable and at a location of their choice. I was aware that the services across the Cape Peninsula are offered to people who come from the suburbs and working-class communities that cut across class; therefore, I aimed to target people from this cross-section and tried to reach different corners of Cape Town. I thought, for example, that some barriers were likely to be related to social class, making it an important aspect to explore. The locations of where the interviews took place can be found below:

Table 3: Location of participant interviews

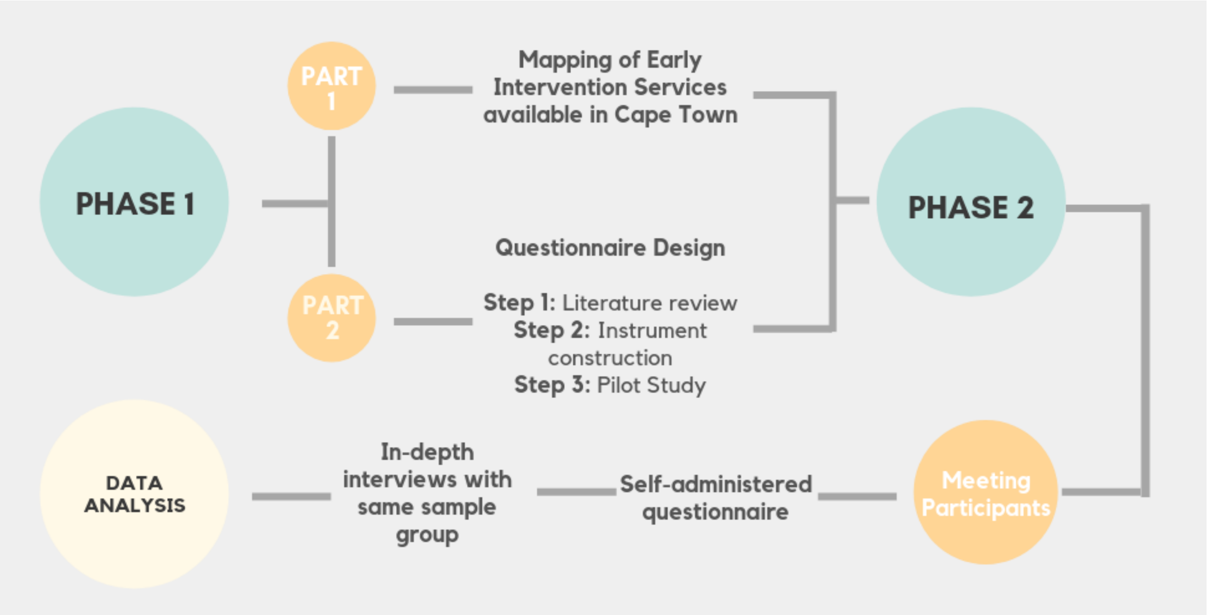
Participant:	**Interview locations**
Parents of autistic individuals	
1	Constantia
2	Table View
3	Rondebosch
4	Woodstock
5	Kensington
Autistic adults	
6	Atlantis
7	Stellenbosch
8	Muizenberg
9	Cape Town city
10	Athlone

As this study is a largely qualitative one and takes on an interpretive approach, only 10 participants were chosen to participate. This study aims to gather in-depth rich information and depths of understanding regarding the research topic. Owing to the time constraints and available resources for a minor dissertation, it was only in my capacity to interview a small group of participants. I made every effort to include information-rich cases in order to enhance the quality of the data.

3.3. Data collection

Data for this study was collected over two phases. Below is the outline of the data collection process followed by a detailed explanation of each process.

Figure 1: Data Collection Process



3.3.1 Phase 1

Part 1: Mapping of services in Cape Town

In order to address the first sub-question, namely "What are the existing early interventions available for autistic children in Cape Town?", I undertook an internet search and analysis of secondary data to map out the existing early intervention services in Cape Town. I searched for any organisation or company that provides early intervention therapies for autistic children outside of schools in Cape Town and surrounding areas. The reasoning for this is that many autistic children are not yet of school-going age when they receive their diagnosis and, moreover, many autistic children struggle to access schools. Van Schalkwyk, Beyer & de Vries (2015) state that there are several years-long waiting lists for autism-specific schools, resulting in children only receiving appropriate interventions three or four years after their diagnosis when they are accepted to these centres or schools. Most children, however, are not so fortunate in receiving specialized education care. There are only nine autism-specific schools in South Africa, where six of them are in the Western Cape Province. Considering the population of 52 million people and the small number of schools in the context, evidently, many children are not able to access these facilities (Van Schalkwyk, Beyer & de Vries, 2015). Finding early intervention services outside of school environments was, therefore, of key importance to ensure that the mapping of these services included early intervention services aiming to target all autistic children. Additionally, I searched for any website or document that had a list available of the existing early intervention services in Cape Town. I took note of the companies or organisations' names, the type of therapies they offer and the location of these services.

The rationale behind the internet search of the available early intervention services was that internet searches are the most popular way of accessing information. In scenarios of having no contact, such as a professional, practitioner or a network, most people tend to turn to the internet for further information.

By mapping out the existing early interventions in Cape Town using a literature review and analysis of secondary data from documents and a thorough internet search in this first phase of this study, the aim was to further understand the early interventions available, the type of services offered, and the placement of these services. Furthermore, the mapping of the services assisted in the development of a questionnaire that was administered in the second phase of the study. The development of a questionnaire helped me to fairly quickly gather and better understand the experiences and major barriers to accessing existing early interventions and achieving well-being for autistic individuals. This quantitative tool was designed with the aim of gathering, organising, and measuring information about existing early interventions in Cape Town and is used to provide basic descriptive statistics.

Part 2: Instrument construction

Keeping in mind that this study was largely qualitative, a quantitative instrument was developed in the form of a questionnaire to determine parents' of autistic children, and autistic adults' knowledge of existing early intervention services and organisations or companies that provide these services in Cape Town. Furthermore, it would help us gain a better understanding of the circumstantial evidence, available resources and underlying relations among these factors found in the study, informed by the theoretical framework, by triggering responses and stimulating conversation. In the study completed by Adamson et al (2004), where they analyse four separate studies combining qualitative and survey methods, the authors found that the completion of questionnaires before in-depth interviews took place acted as an ice-breaker and gave the participants a chance to relax. Additionally, it stimulated conversations that provided rich and complex information about respondents' perceptions of the given topic. For this reason, this technique was adopted when researching a vulnerable group regarding sensitive topics.

The importance of understanding the amount of knowledge of the currently available early intervention services and, furthermore, the type of approaches they encompass, would help inform us about the access to information and knowledge, the availability of these interventions to the general Cape Town population, and the perceptions of the type of approaches they encompass. Moreover, it would provide us with clarity on whether these services, according to their parents, accomplish helping autistic children to achieve well-being. We would also gain a better understanding of whether these services accomplish helping autistic adults to achieve well-being, according to their own experiences. The instrument construction phase took place in three steps, where 1) a literature review was conducted to review any existing quantitative methods to aid the construction of a new instrument, 2) the design of the questionnaire took place and, 3) a pilot test of the questionnaire was conducted to identify and correct any problematic issues.

Step 1: Literature review

The first step in developing this quantitative tool was to conduct a literature review in order to analyse and review any existing literature and quantitative methods that would be able to inform the development of this questionnaire. As the target population is specific to this study, and as there has been no known study on early intervention services conducted in Cape Town, there was not one single tool suitable for this study; therefore, I undertook the task of developing a new instrument, based on literature and my experience in the field of autism.

I reviewed existing research to identify questions and methods which might guide the creation of my instrument. In a study conducted by Jabery et al. (2014), where the researchers investigated the perceptions of parents of autistic children regarding services in Jordan, they developed a questionnaire consisting of five sections. Informed by the study conducted by Jabery et al. (2014), I developed a similar questionnaire, dividing my questionnaire into five sections, (2014) with two differences. My questionnaire addressed five elements: demographics, parents'/autistic adults' knowledge of the existing early intervention services, type and number of received services, parents' experiences of these services, methods and difficulties of obtaining services, and what participants perceived to be needed and essential services. Where the study Jabery et al. (2014) contains questions regarding parents' satisfaction with services, my questionnaire did not. Although social validation questions were included in the questionnaire, as will be explained later, these are more general questions and they do not target satisfaction levels with reference to specific early intervention services. Instead, this was explored through experiences of early intervention services in the qualitative section in my study. Additionally, my questionnaire included items focusing on participants' knowledge of existing early intervention services as well as participants' experience of early intervention services in order to help answer my sub-question: "What are the experiences of parents of autistic children, and autistic adults, of the existing early intervention services in Cape Town?"

A relevant study conducted by Dymond et al. (2007), using an open-ended survey questions to investigate recommendations for improving school and community-based services for autistic children in the state of Virginia, likewise focused on the demographics as well as perceptions of parents of children with ASD concerning the services available for their children. Demographics and perceptions were found to be of importance in improving the level of services provided for autistic individuals and their families (Jabery et al., 2014; Dymond et al., 2007). In this questionnaire, the participants responded to prompts by selecting from predetermined answers (among others, Likert scales). The questionnaire is a combination of scales, lists and closed-ended quantitative questions and open-ended qualitative questions.

Section 1 of the questionnaire contains information-gathering questions regarding demographics. This was to gain basic information and insights to compare and analyse the two sub-groups, namely parents of autistic children, and autistic adults, should it be needed in the study.

Section 2 of the questionnaire examined participants' knowledge of the existing early intervention services. This was informed by the mapping of the early intervention services available in Cape Town: a list was made of, firstly, all the early intervention services available in Cape Town and, secondly, all the existing organisations and companies that offer these intervention therapies in Cape Town. In question 2.1, participants were asked to indicate 'which interventions they know of or have heard of before', informed by Lock et al.'s study (2008) on *Service Delivery Innovations for Autism Spectrum Disorders in the State of Texas,* In their study, the authors state that the term 'being familiar' with something means having knowledge of or an awareness of these interventions. In question 2.2, the same question was asked, this time with regards to the organisations or companies that provide these interventions. In question 2.3, participants were asked which of the interventions, as indicated by them in question 2.1, they, or their child, have personally tried.

In section 3 of the questionnaire, the type and number of received services were addressed. Questions 3.1 to 3.4 involves closed-ended questions where a list was provided from which the participants could choose. After having indicated which interventions the participants have undergone, questions 3.1 to 3.4 further explored the number of interventions, sessions and time periods in which these interventions occurred to gain a better understanding of the participants' experiences and interactions with these early intervention services. Furthermore, questions 3.5.1 to 3.5.4 made inquiries regarding the current services available in Cape Town and aimed to support answers to the main research question of this study. These questions asked the participants to choose from a Likert scale that contained a positive, negative and even-point scale response in the form of 'Agree', 'Disagree' and 'Neither agree nor disagree'.

Section 4 includes questions regarding participants' experiences of these interventions that were directly aimed at informing sub-question 2, together with the main research question. Questions were developed based on a study by Leadbitter et al. (2018), who created *The Autism Family Experience Questionnaire* (AFEQ) through focus groups and online consultation with parents, which reflected parental priorities. For the aim of this study and the development of my questionnaire, questions were tweaked, and language usage was changed to fit the purpose of this study and to suit my target population. Questions 4.2 to 4.3 contain qualitative questions to supplement the quantitative responses and asked participants to give specific answers directly related to their experience of specific early intervention services. This included which intervention, if any, they felt had been the most helpful and, in addition, which intervention, if any, had not been helpful to the participant. Question 4.5 was a social validation question regarding the satisfaction levels experienced by the participants with regards to the overall experience of early intervention services in Cape Town.

Section 5 of my questionnaire includes questions regarding methods used to obtain services, as well as parents' perceived desired services and difficulties obtaining these services. This section was developed with the aid of questions from the questionnaire utilised in the Bercow Report, which encompassed a review of services for children and young people (ranging from birth to age 19) with speech, language and communication needs (Bercow, 2008). Again, questions were altered where needed to suit the purpose of this study. Questions 5.2 to 5.8 included questions that aimed to socially validate these services available and asked for the parents and autistic adults' evaluations of available services, for example, their satisfactions levels towards these services. Jabery et al. (2014) states that the body of research conducted on service delivery documented the importance of examining the satisfaction and dissatisfaction of parents of autistic children concerning received services. I also believe that it is important to ask autistic adults about their validation of these services, as they have first-hand experience of undergoing these intervention therapies. Question 5.9 asked participants to describe, in a qualitative manner, what their ideal early intervention looks like. The aim of this question was to supplement my qualitative interview questions by helping inform sub-question 4, namely "What recommendations do participants have for improving early intervention services?"

Step 2: Questionnaire design

Keeping in mind the target population and the fact that this study was administered by one person, the questionnaire was designed in a way that made it possible for it to be self-administered by the participants before the qualitative interview questions were asked. This also set the tone for the interview and triggered experiences or memories by participants that they perhaps wished to share, allowing for richer in-depth information. As the researcher, I was also close by when the participants completed the questionnaire in the event a participant required clarity regarding any question or needed guidance in completing it.

When designing the questionnaire, I developed response formats which included mostly structured closed-ended questions and some less-structured open-ended questions. Participants were given a series of information-gathering, list-format, Likert scale and qualitative questions to respond to. The aim of the questionnaire was to help the participants respond to questions easily and, additionally, help facilitate and reduce the amount of time needed in coding and analysing the data by the researcher, while accumulating and summarising responses efficiently. As structured responses would limit the researcher's ability to gain a full understanding of the participant's response, in some cases, qualitative questions were additionally included to allow for a broader response from the participants. This mainly quantitative tool was aimed at supplementing the qualitative interviews that were conducted in the second phase of the study.

It was noted that language is an important aspect in the development of a questionnaire. For this reason, two questionnaires were developed, one aimed at parents of autistic children and another aimed at autistic adults. Although English was not all participants' first-language, everyone was proficient in English. Questions were developed with simpler English use in mind and, importantly, "identity-first" language was also used in the questionnaire. Having worked closely with the autism community, I understood the importance of using "identity-first" language. This involves using the terminology of an 'autistic person' instead of using the terminology of person-first language, such as 'person with autism'. The autism community's arguments in this regard are that autism is a part of them; it is not something that can be separated and therefore is part of their identity (Kenny et al, 2016; Broderick & Ne’eman, 2008). Against this background, it was important to consider this in the questionnaire: firstly, out of my respect for the autism community and, secondly, considering that autistic adults are part of my participant group.

Step 3: Pilot study

A pilot study was conducted to help identify and correct any problematic issues with the questions that were asked before the questionnaire was administered to the participants. Hassan et al. (2006) states that a pilot study is vital in a research study to help identify any potential problems and limitations in the research instrument before the implementation of the research instrument. After the questionnaire’s development, I approached a mother of an autistic child, whom I have been working with over the last few years, to complete my questionnaire and review the instrument for any language discrepancies, inappropriate flow of questions or anything that seemed to her to be missing from the questionnaire. Upon receiving her feedback, I made a few adjustments to both questionnaires (one for the parents of autistic children, the other for autistic adults) and developed my final questionnaires - ready to be used in the second phase of my study. Please see Appendix B for the complete questionnaire.

3.3.2 Phase 2

For the qualitative part of my study, I conducted individual face-to-face, semi-structured in-depth interviews with the same sample group in the second phase. After sampling my research participants, I asked each participant to meet me at a location where they felt comfortable. This included a variety of settings, including coffee shops, work offices, participants’ homes or institutions where a participant may be residing, and even the beach. This was done for all participants to feel comfortable in an environment of their choice, especially keeping in mind autistic adults and their sensory needs. I conducted the interviews in a friendly and relaxed manner. I wanted the participants to feel free to express their experiences, feelings and motivations. I had a few questions prepared, but I was open to the way in which participants wanted to express themselves. All the interviews conducted were audio recorded.

Open-ended questions in interview schedule were used to further explore the research themes and elicit experiences from autistic children’s parents and autistic adults to provide a rich in-depth understanding that a quantitative tool would likely not have been able to provide. Disability, as has been shown, results in capability limitation and is relational both to impairments and the design of social arrangements (Terzi, 2005). The capability approach informed my questions and served as a framework within which to analyse how disability results from the interaction between individuals' personal characteristics, available resources and their environments (physical, social and political). This was achieved through exploring participants' experiences of their available resources and perceived barriers in their environment that limit the capability set in helping achieve well-being for autistic individuals. The interviews aimed to allow the voices of the receivers of these early interventions to emerge, and also explored detailed information about these early interventions, for example, experiences of different types of early intervention programmes; the intensity of the engagement; family involvement; and when and how interventions were introduced.

Below are examples of questions used in the interview schedule. See Appendix A for the interview schedule that guided the in-depth interviews.

Major barriers experienced by parents of autistic children or autistic adults

1. Please describe what barriers or issues, if any, limit your ability to seek the best early interventions for your child.
2. Please describe what barriers or issues, if any, limit your ability to implement specific strategies and/or interventions at home.

Experiences of early interventions available in Cape Town

3. Please describe your experiences with the particular early intervention that your child/you is/were receiving.
4. Please describe what about these early interventions you believe works and the benefits of these interventions for you or your family.

Reflections and recommendations

5. In your opinion, what is needed to improve the lives of autistic individuals and families of autistic individuals?
6. In your opinion, what do you recommend early intervention services to encompass that is missing from existing services that you know about?

Questions 1 to 4 aimed to inform the central research question of this study - to investigate the major barriers experienced and the opportunities that these particular early interventions are providing autistic individuals. Question 3 was aimed at addressing the sub-question: "What are the experiences of parents of autistic children and autistic adults of the existing early available in Cape Town?" Additionally, question 3 combined with question 4 were aimed at helping me look at whether there were "any disparities that exist between parents' views and autistics adults' experiences of these early interventions." Lastly, questions 5 and 6 aimed to help me answer the sub-question: "What recommendations do parents of autistic children and autistic adults have for improving early intervention services?"

Through these data collection methods, I aimed to understand, firstly, whether early intervention services are available in Cape Town and, secondly, whether these interventions help enhance the capability set of autistic individuals and, if not, what the barriers are in the environmental, personal and circumstantial elements that prevent this. This was done by mapping the services in Cape Town and exploring the experiences of autistic children's parents as well as autistic adults in their beliefs of the benefits, restrictions and recommendations in improving the lives of autistic individuals.

I anticipated that potential problems could arise in the in-depth interviews with autistic adults in terms of interacting and responding to my questions, such as unusual long pauses or lack of response. As a result of my work experience with autistic individuals, I have learnt many techniques and skills in understanding and interacting with autistic individuals which equips me to deal with these issues and makes me very suited to conduct these interviews. Similarly, the short questionnaire was designed in such a way as to help elicit responses from participants in a way that may make them feel more comfortable.

3.4 Techniques of analysis

Data for this study includes the text from the transcribed interviews with the participants and the quantitative data obtained from the questionnaire. Data analysis from each method is brought together during interpretation of the study's findings. Data for this study was analysed using a mixed methods approach. A mixed methods design gives the researcher an advantage as there is strength in each approach which, when combined, provides a larger picture from the outcomes of quantitative data together with the procedure of capturing qualitative data (Dymond et al., 2007).

3.4.1 Quantitative analysis

For the quantitative part of my study, I organised and analysed the data obtained from the questionnaire using the Statistical Package for the Social Sciences (SPSS). SPSS is a comprehensive software package used in the statistical analysis of data.

All data from the closed-ended questions in the questionnaire was coded and manually entered into SPSS. Additionally, I created a codebook that contains all the variables and provides a guideline for the coding responses. The codebook contains the name of the variable, the label that is assigned to it and the values assigned to each variable. SPSS allowed me to organise my data and to generate the necessary bar charts and descriptive statistics of the categorical variables, which I report below in my findings chapter. See Appendix C for the codebook for SPSS data gathered from the questionnaire and Appendix D for a screenshot of the data entered into SPSS.

3.4.2 Qualitative analysis

Patton (1984) notes that three things occur when data is analysed: 1) data is organised, 2) data is reduced through summarisation and categorisation, and 3) patterns and themes in the data are identified and linked. After the collection of data was finalised through the completion of the questionnaire and semi-structured interviews with the participants, all recordings were transcribed by the researcher, and all data from the questionnaires entered into the statistical programme, SPSS, that was used for this study. The data obtained from the interviews was analysed using thematic analysis and coding. All voice recordings and transcriptions were evaluated and coded to develop themes and sub-themes. I looked specifically at the themes of major barriers experienced by participants; experiences of early interventions services; and elements affecting the well-being of autistic individuals. I used thematic analysis to analyse the transcribed interviews. This analytical technique is informed by Miles and Huberman's process of first and second-level coding (1994).

Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data. The process of first and second-level coding entails investigating, conceptualising, comparing, categorising and identifying patterns and regularities in the data (Miles and Huberman, 1994). It concisely organises and describes the data set in rich detail.

3.4.2.1 Familiarisation of the data

During and after each interview, notes and observations of participants and their responses were captured, including my reflections as the researcher.

In the first step, the recordings were transcribed by me, the researcher, and thoroughly read to get familiar with and submerge myself in the data, as suggested by Miles and Huberman (1994). Listening intently to the recordings during the transcribing phase helped give me an extra 'sense' of the data (for example, pauses, sighs or cries) and interact with and understand fragments of data in context. This provided valuable input and understanding of the captured data.

Furthermore, closely reading the transcriptions aided in my familiarisation and interaction with the data. Before I proceeded to detailed first-level analysis, I noted down any major topics that emerged and prominent responses and started by drawing mind maps of any connections I saw within the data.

3.4.2.2 First-level coding

In the first-level coding phase, after familiarisation of the data, I made a provisional list of emerging codes and themes that speak to my research questions. The following step in first-level coding was to code all transcripts, which allowed for data reduction. Coding involves assigning unique labels to text passages that contain references to particular categories of information (Miles and Huberman, 1994). Data that has been coded are then brought together and identified as emerging themes (Miles and Huberman, 1994). According to Braun and Clarke (2006), a theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set. When it comes to coding, it is important to see what counts as a pattern or theme, and to consider what size a theme needs to be. By investigating the text with coding, one can link various meaningful segments of text to a particular concept. According to Miles and Huberman (1994), first-level coding is a process of naming and classifying data with a working set of codes. Codes at this stage are mainly descriptive (Miles and Huberman, 1994).

All coding and analysis of the data was done manually without the aid of a computer software programme such as NVivo. Although tedious, the manual coding, sorting, relabelling and connecting of themes submerges oneself in the data. Transcripts were grouped according to the sample’s two sub-groups, namely autistic children’s parents and autistic adults, to organise and classify data. This grouping aided in comparing and verifying whether participants had said similar things and, additionally, identifying any disparities that existed between the two sub-groups. For example, some parents and autistic adults had disagreeing thoughts on whether particular early intervention programmes enhanced the well-being of autistic children. See Appendix E for a segment of a coded transcript using thematic analysis.

3.4.2.3 Second-level coding

According to Miles and Huberman (1994), second-level or pattern coding is a meta-coding process that concentrates on finding relationships in the data. Miles and Huberman (1994) note that at the first level, coding is used as a device for summarising segments of data, while "pattern codes are inferential codes, ones that identify an emerging theme" (De Wet and Erasmus, 2005).

Codes develop categories or themes. After first-level coding, transcripts were re-read, codes were refined, and these codes were ordered, where codes were placed under themes and the frequency of the codes were then noted to understand the chronology and importance of themes (Miles and Huberman, 1994). In the second-level coding phase, the broad first-level codes were organised and arranged in thematic clusters and hierarchies were identified, after which patterns and relationships were identified (De Wet and Erasmus, 2005). This was done through data display, where I created a table form with the four research questions in columns and each participant in rows, where all the codes were entered in the table form. This helped me to start grouping codes together and to create hierarchical relationships between codes, as well as note important quotes of participants that speak to particular categories. Additionally, the data was displayed in a variety of ways to help form patterns and relationships, including creating hand-drawn mind maps and tables of summarised codes and themes. The data display was a continuous process throughout the data analysis phase, where participants were colour coded and codes were displayed according to each participant, drawing connections between codes and themes to categorise and organise the data in the second-level coding phase. See Appendix F for summarised codes and Appendix G for summarised themes.

For example, participants explained the large costs of early intervention services to help autistic individuals achieve well-being; the choices they had between private or public services and how these choices were informed by the quality of the services; the need for medical aid; or their experiences in having to work multiple jobs to access these services. These were all grouped together under the theme 'financial constraints' in accessing early intervention services in Cape Town. 'Barriers' were coded based on the definition of a barrier in chapter 2 and underlined by Sen's capability approach, reviewing any personal or circumstantial elements that limit individuals from enhancing their capability set, according to them.

3.4.3 Verification

Findings were verified by checking and rechecking the data. After making a preliminary list of codes following the interviews and through inductive coding throughout the data analysis phase, I discarded any pre-existing codes which did not fit well with the collected data. Verification contributes to the rigor of the study. I wanted to determine whether the questions asked provided consistent answers over time and whether they measure what they are intended to measure. I also paid attention to questions of rigour when conducting a pilot study of the questionnaire, to determine whether the instrument would be easy to use and understandable to the target audience, while gaining a better understanding of the research questions by having the instrument ask the questions it is intended to ask.

Triangulation of the data was established by utilising quantitative and qualitative methods and, where possible, cross-checking data obtained from the interviews against data obtained from the questionnaires to aid in the reliability of the questions. Triangulation was also achieved by analysing and comparing the responses of the two sub-groups of participants in order to distinguish converges from diverges in the data.

3.5 Ethical considerations

Owing to the discrimination and marginalisation faced by autistic children' parents and autistic adults, this study was approached with sensitivity and understanding that the participants are considered a vulnerable group. Bearing this in mind, a referral system was in place in the event that any participant may feel the need to talk to someone, or if they felt they needed assistance with any matter. Participants were informed about the services of Cape Mental Health, an NPO that offers walk-in counselling services for people with intellectual and psychiatric disabilities and their families. Autistic individuals fall within this psychiatric category. Cape Mental Health agreed to allow me to refer any participants to them for professional assistance. Additionally, the co-supervisor of this thesis is a psychologist who is knowledgeable about autism and she guided the study.

The participants were guaranteed that the information provided would be completely anonymous and that I would not, at any point during the recording or transcribing process, refer to them by name. In relation to the organisations that may be mentioned, reference to the organisations will be made based on the broader public domain information; however, in the recording of my findings, no reference or mention is made to any organisations, only the type of services that they offer. The names of the participants and organisations have been erased from all data transcripts. This study is not harmful to any participants: the purpose of the study was made clear from the onset and participants had full knowledge of the study before they agreed to participate. After all the information about the research was provided to the participants, they were asked to sign an informed consent form. The informed consent form can be found in Appendix H.

Chapter 4: Findings

This study aimed to identify the major barriers in accessing early intervention services for autistic individuals and how these barriers limit their well-being. The study followed two phases where, in the first phase, the priority was to examine which early intervention therapies are available for autistic individuals in Cape Town, which approaches they encompass and the distribution of these services in the Cape Town area, aiming to inform my first sub-question: "What are the existing early interventions available for autistic children in Cape Town?"

The second phase of this study was guided by the main research question, namely "What are the major barriers to accessing early intervention services and achieving well-being for autistic individuals?", followed by the remaining sub-questions: "What are the experiences of autistic children's parents and autistic adults of the existing early interventions available in Cape Town?"; "Are there any disparities that exist between parents' views and autistics adults' experiences of these early interventions?" and "What recommendations do parents of autistic children and autistic adults have for improving early intervention services?"

In the following section, I will proceed to present my findings from both phases.

4.1 Phase 1

4.1.1 Existing early intervention services available for autistic children in Cape Town

Early childhood intervention (ECI) programmes are intended to support young children who are identified as having developmental delays or disabilities. These intervention programmes encompass a variety of supports and services to guarantee and improve children's personal development and resilience, increase family competencies, and encourage and endorse the social inclusion of families and children. Services can be accessed through various settings, such as hospitals, healthcare clinics, early intervention centres, community centres, rehabilitation centres, homes and schools (WHO, 2012).

There is a variety of different early intervention services that exist around the world, but to better understand what interventions are available in Cape Town, I will attempt to explain the different approaches these interventions take. Interventions that are guided by theories that acknowledge the challenges of autism spectrum disorder either target specific areas in development through specific approaches (based on, for example, behaviour) or use a combination of different types of interventions. The aim of looking at the approaches encompassed by these interventions is to help better understand how the interventions enhance the capability set of an individual. Early intervention services target the three main areas of development that autistic individuals struggle with, namely communication, social and behavioural development. Each autistic child is unique; therefore, evaluating which capabilities are needed would be dependent on the individual, his/her resources and social context. As such, it is also important to consider the individual's impairment and essential areas of development when choosing which intervention to use.

In this study, I used an Australian parenting website's, Raising Children Network (2018), categorisation of interventions, as I found it the most useful way of explaining these approaches to interventions in a simplistic manner. According to raisingchildren.net.au (2018), early intervention therapies can be classified into eight different approaches, namely behavioural interventions; developmental interventions; combined interventions; family-based interventions; therapy-based interventions; medical interventions; alternative interventions; and other interventions.

Referencing raisingchildren.net.au (2018), the following are definitions for the types of early interventions found:

- *Behavioural-based approaches*: This approach emphasises the learning of new skills and behaviours, through specialised and structured techniques as teaching tools, and aims to encourage appropriate behaviour.
- *Developmental interventions*: The formation of positive and meaningful relationships is the aim to this approach, teaching communication and social skills in a structured and everyday context. The approach also considers skills to accommodate daily living.
- *Combined interventions:* Often considered the most effective, this approach integrates several interventions and uses new information about autism while doing so.
- *Family-based interventions:* This approach stresses the importance of involving the family in intervention strategies to aid the child in achieving their developmental needs. Parents are at the forefront of making decisions and delivering the intervention. Training, information, support and guidance for parents are included in these interventions. The collaborative relationship between the parent and the professional is of key importance in this approach.
- *Therapy-based interventions*: This approach provides specific therapy to target specific difficulties and is used in combination with other interventions, for example speech therapy.

- *Medical interventions*: This approach involves the use of medication to help improve problems that autistic individuals may experience, for example inattention associated with ADHD.
- *Alternative interventions*: This approach includes a variety of treatments, often not as popular due to not being supported by scientific evidence in the mainstream medical system.
- *Other*: These are all the interventions that do not fall under the above-mentioned approaches and includes a variety of interventions, for example music therapy.

During phase one of my research, I completed a comprehensive analysis of secondary data in order to map out the services available for autistic individuals in Cape Town. Considering that there are a limited number of autism-specific schools in South Africa, that there are no governmental preschools that cater for autistic children and that the statutory school-going age is 7 years, no child with autism under the age of 6 or 7 will therefore have access to public sector early intervention or educational programs (Van Schalkwyk, Beyer & de Vries, 2015). I, therefore, specifically searched for early intervention programmes provided as a service outside of the school environment to better understand what is available for families and autistic individuals who are not able to access schooling or who were diagnosed but are not yet of school-going age. All information provided was found in the public domain. A list of early intervention services in the Western Cape was found on Autism Western Cape's website. After a thorough internet search, however, it became clear that this list was outdated. My findings are listed in Table 4 below.

Table 4: Early intervention therapies available in Cape Town

Approach	**Type of therapy used**	**Organisation/company in Cape Town**
Developmental	DIR/Floor time	▪ Child Development Network ▪ Development and Play Therapy ▪ Inspire Special Needs Tutor Centre
	RDI	
Behavioural	PECS (Picture Exchange Communication System)	▪ SNAP Academy ▪ Khuluma Education
	Video modelling	

	ABA (Applied Behavioural Analysis)	▪ ASAP (Autism Spectrum Adaptive Programme) ▪ Acorn Academy ▪ Centre for Play and Learning ▪ REACH Autism ▪ The Star Academy
Therapy based	Social stories	▪ Et Al Therapy and Learning Centre ▪ Success Therapy Centre ▪ Cape Town Therapy Hub ▪ Polka Spot Early Intervention Centre
	Sensory integration	
	Occupational therapy	
	Speech therapy	
	Physiotherapy	
	Psycho-therapy	
Combined	ESDM (Early Start Denver Model)	▪ SenseAbility ▪ KidStart Junior Academy ▪ Autism Connect ▪ AIMS Global ▪ Mindstretch
	TEACCH (Treatment and Education of Autistic and related Communication Handicapped children/adults)	
	AIMS (Awareness; Interest; Movement; Sensory) Support system	
	HANDLE (Holistic Approach to Neurodevelopment and Learning Efficiency)	
	CO-OP (Cognitive Orientation to daily Occupational Performance)	
Medical	Biomedical	▪ Dr Louise Lindenberg ▪ Stellenbosch Centre for Early Intervention
Alternative	Dietetics	▪ Cape Town Therapy Hub

		▪ Polka Spot Early Intervention Centre
Other	Art therapy	▪ Art Therapy ▪ Zakheni Transformative Arts Centre
Family based	Not applicable	Not applicable

From the secondary data analysis, I found only 21 organisations and companies that provide early intervention therapies in Cape Town and its surrounding areas. Where combined, these organisations make use of seven of the eight approaches listed above. There was no organisation using family-based approaches as its sole approach to autism, making it the least popular approach to autism in Cape Town. Of all the companies or organisations available in Cape Town, a third of them utilise behavioural approaches to autism, making it the most popular approach used in Cape Town, followed by a combined approach (20.8%). While therapy-based approaches were also popular (16.7%), they were often accompanied by alternative approaches to assist autistic individuals. The remaining approaches are dispersed amongst the rest of the companies or organisations that exist in Cape Town.

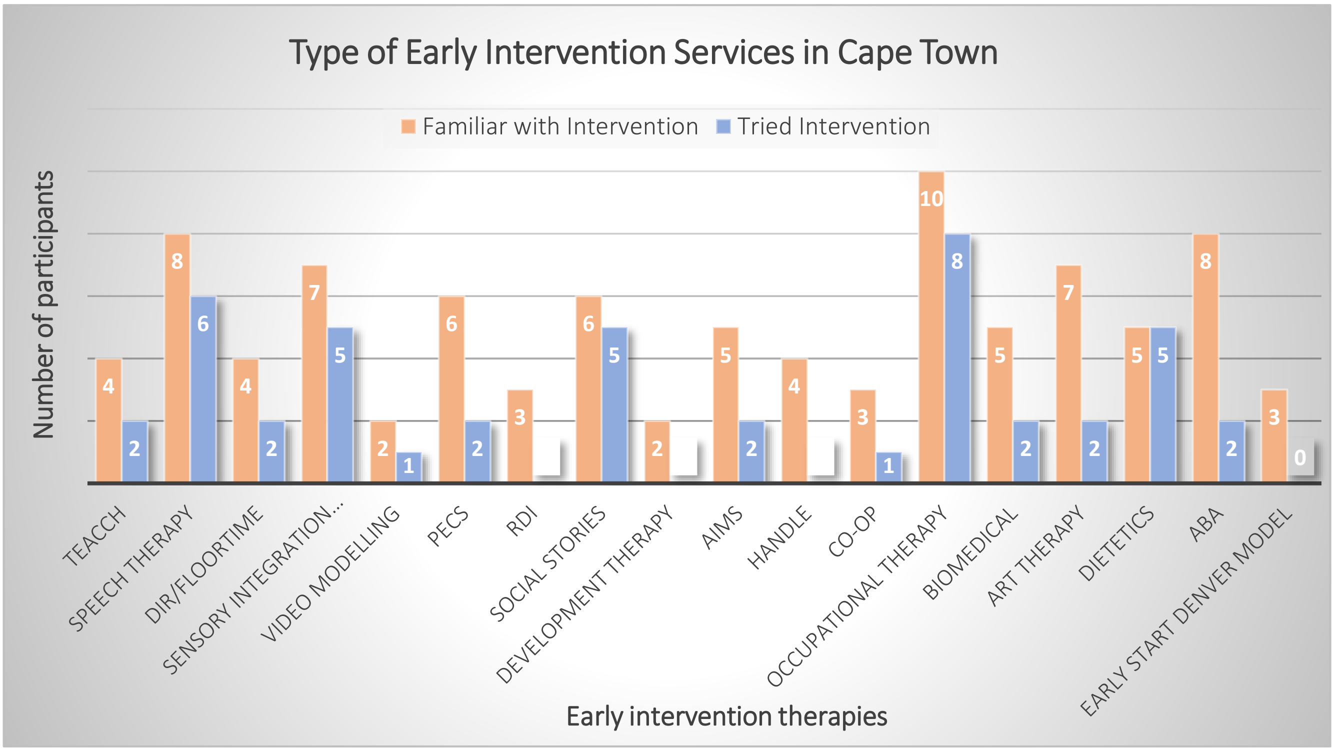
*Figure SEQ Figure * ARABIC 2: Map of early intervention organisations and companies and corresponding approaches in Cape Town area*

The localities of these companies and organisations are dispersed across the Cape Town region, and the findings show that these are the only companies or organisations that provide early intervention services for autistic children in need. Considering the lack of access to schooling for children with disabilities, this shows us the limited number of interventions available, as well as the limited variety of available interventions for those seeking early intervention services in their area. This could include either children who are not yet of school-going age, children who are in school or children who are not able to access an appropriate school.

Although there are companies and organisations that provide early intervention therapies in Cape Town, it is evident that the number of interventions available in the Cape Town region is limited. It is clear that not all autistic children are able to access these services when one considers the global autism rate (about 1% to 2% of the population is diagnosed with autism), increasing prevalence of autism as a result of a growing awareness and knowledge, and better trained practitioners. There remains a large gap in service provision for those in underprivileged areas, considering that most service provision organisations and companies are clustered in the city centre or the Durbanville and Bellville suburbs.

Knowledge regarding the variety of interventions also varies and can be ascribed to numerous possible reasons. When participants were asked which intervention therapies they have heard of before and which interventions they or their children have tried before, all participants were familiar with occupational therapy, followed by speech therapy and applied behavioural analysis (ABA) therapy as the most well-known intervention therapies. Additionally, occupational therapy remains the most accessed form of therapy, with speech therapy as the second most used therapy. Half of the participants (50%) noted that they have tried sensory integration therapy, social stories and dietetics. From this, we can see that therapy-based interventions are the most used approach among the participants, followed by behavioural approaches as the second most used approach by participants. None of the participants have tried Relationship Development Intervention (RDI), development therapy or the Early Start Denver Model (ESDM) before. Reasons for this could range from the lack of educational tools to train practitioners, educators or parents in a variety of methods and approaches to the lack of information available to and accessible by the public concerning these therapies. These reasons were further explored in the second phase of this study and will be discussed in the following section. Please see Figure 3 for my findings regarding the distribution of knowledge and use of existing early intervention therapies.

Figure 3: Participants' knowledge and use of existing early intervention services



4.2 Phase 2

4.2.1 Major barriers

A number of themes and sub-themes emerged relating to the main research question: “What are the major barriers in accessing early intervention services and achieving well-being for autistic individuals”. These themes emerged from the data through first and second-level coding and include services; financial; practitioners; familial support; stigma; and lack of support services.

Table 5: Themes and sub-themes relating to the major barriers experienced in accessing early intervention services and achieving well-being for autistic individuals

Theme	**Sub-themes**
Services	• Lack of information • Lack of variety of services • Lack of accessibility of services • The type of existing services is limited • Lack of availability of services (especially for under-educated, underprivileged individuals that are also culturally sensitive)
Financial constraints	State vs Private - The State provide limited amount of services one can access - Lack of professional practitioners available at state hospitals, including trainees implementing the services - Limited support from organisations - Emotional strain on the family and psychological impact
Practitioners	• Negative language (hopelessness feedback) • ‘I know better’ approach • Dependence on practitioners and impact they have on family • Lack of integration and collaboration between practitioners • Lack of guidance provided to navigate the field • Lack of knowledge and understanding of autism amongst practitioners
Home environment	• Familial support • Lack of acceptance by parents • Lack of a sense of love and belonging • Lack of understanding • Sense of responsibility as parents and consequent pressure

	- Physical environment
Stigma	- The influence of media - Societal expectation placed on parents - Language used that perpetuates negative stereotypes - Stereotypes that have consequences on quality life, proper health care and employment - Implications in accessing schools - The need for autistic individuals' voices to be heard
Lack of support services	- Lack of guidance by organisations and practitioners in navigating the field of services - Lack of accommodability and capacity by schools and centres - Lack of a system in place that helps monitor and guide parents and autistic adults. - Limited support by government and lack in awareness of the demand and need for services in Cape Town - Limited organisations available to help assist and enable autistic individuals

A. Services

With regards to the actual early intervention services available in Cape Town, all the participants emphasised that the lack of information about early intervention services, small variety of interventions, limited accessibility, insufficient type of services available and lack of availability of services all contributed as barriers to accessing the best early interventions and achieving well-being for autistic individuals.

All the participants highlighted that there is a serious "lack of information available" about early intervention services. These include information about the programmes and resources available in Cape Town, how and with which medical professionals and practitioners to get into contact, and how to create an environment and implement intervention strategies that will benefit an autistic child, whether it is at home or in the school environment. Additionally, 9 of the 10 participants did not agree with the statement: "There is enough information regarding early intervention services in Cape Town".

Closely related to the lack of information available is the type of information available and, in turn, how this influences parents' decisions in choosing which interventions to utilise to optimise the well-being of their autistic child. Most participants noted that the internet is their biggest resource for information but, as one participant points out, “you have to kind of be very vigilant as a parent. Because, there's some stuff out there that is actually not conducive to any child, or adult.” Therefore, not all information available on the internet is helpful to the well-being of an autistic individual. Participant 9 acknowledged this issue too, stating that most information found on the internet originates from the United States, a country that condones certain therapies which he, as an autistic adult, is strongly against as he believes that these apparently popular therapies being promoted are not healthy for the well-being of an autistic individual.

The type of existing early interventions is of key importance to all participants, whether a parent of an autistic child, or an autistic adult. Completing the questionnaire, 9 of the 10 participants disagreed with the statement that “It was easy for me to find an early intervention programme that suits the needs of autistic children”, while 6 participants agreed that they were still looking for an appropriate early intervention service that suits the needs of their autistic child. Participants questioned the quality of the available services they were accessing, where 7 of the 10 participants indicated that early intervention services in Cape Town were ‘in need of improvement’ and only one participant indicated that they were ‘satisfactory’. Talking about the experiences of particular early intervention services with participants, the type of intervention an autistic individual accesses and undergoes is crucial to the development and well-being of the child (or adult). Many participants indicated that there are particular centres that offer early intervention therapies that have been forceful, abusive, do not listen to the needs of the child and do not adapt to the individuality of children. Additionally, some therapies used in early intervention services come from a pathologising perspective instead of an embracing perspective. This has a strong negative impact, not only on the well-being of the child but on the family as well. Participant 7 explains her experience at a centre in Cape Town that provides early intervention services:

> *“They claim that they do Floor time and TEACCH. It's like this whole cocktail therapy but the principles are based on ABA. There was a young girl, I started to get to know the kids there, for nine months she didn't speak. They tried a lot of stuff... I think of those kids… It was also said that if the children don't want to listen, then hurt them where the parents can't see. So, it is the ears, turn the ears, somewhere on the elbow... it was a therapist that came out with this. She contacted me when she left. So, I can put you in contact with her as well.”* [Interview with Participant 7, 2018]

She later goes on to explain:

> *"You will get results, you will, but your child will pay. I promise you he will… That child is in that room, they have to do what that therapist says. They have to. That is what ABA is, you have to comply. It's… it's terrible."* [Interview with Participant 7, 2018].

It is apparent that the approach that certain interventions and practitioners embrace takes on the idea of changing the child in order to achieve results, or the 'normalisation' of the autistic child, which often involves result-based therapy. It is evident that therapeutic interventions that try to 'intervene' in the child's development and not assist the child with his/her needs and opportunities, can be harmful and abusive.

From the analysis, it is clear that the lack of availability and poor accessibility of the existing early intervention services also create a barrier for autistic individuals in receiving the best early intervention services. Although 6 participants agreed that there is a variety of services available for autistic children, 9 of the 10 participants disagreed with a subsequent statement: "There are enough early intervention services available for autistic children in Cape Town". Participants noted that, although early intervention services in Cape Town exist, accessing these services are not always possible. A variety of reasons emerged, the most prominent reasons including: services not being available in their surrounding areas and the need for services to be closer to their home; the number of therapists available being limited or non-existent in their surrounding areas; services that are too expensive; and the capacity of intervention centres not meeting the demands of autistic individuals.

Additionally, all participants disagreed with the statement: "All the necessary resources are available in supporting autistic children with early intervention services." Participants also highlighted that all the information and resources available are, firstly, westernised and, furthermore, assume some sort of level of education. There are very little to no resources available for under-educated, underprivileged individuals that are also culturally sensitive and available in a multitude of languages that would meet the needs of our diverse and multicultural country. Together with the lack of availability of services for underprivileged individuals and no available multicultural services, there is also a shortage of 'early intervention' services for autistic adults. Participant 8, an autistic adult, reasons as follows:

> *"Thing is - early intervention is one thing when you get diagnosed as a child, but I... posit perhaps that 'early intervention' as a phrase should also apply for adults who are newly*

> *diagnosed. To go, 'Okay, this is the earliest we can intervene and what can we do now. What barriers are there for this person now?' And in fact, there are far fewer programmes for adults than for kids. What do we do? What do you do if you're an autistic kid and you get all the care and support, now you turn into an adult, what do you do? Screwed. You have to make it all by yourself and do it all by yourself. With what is available."* [Interview with Participant 8, 2018]

The well-being of autistic individuals should not stop when they grow up. Owing to the lack of information about autism and shortage of services available, many autistic adults who were diagnosed have not yet received support to help them cope or opportunities to achieve their full potential. This has, in part, also been the result of a late diagnosis. It seems that there is a lack of availability of early intervention services for autistic adults in Cape Town, as there are limited services that take into consideration autistic adults' needs and the 'early' support needed for their well-being, even after their 'later' diagnosis.

B. Financial

Financial barriers emerged from the data as a major theme, where 9 of the 10 participants disagreed with the statement: "Early intervention services in Cape Town are cost-effective." 'State versus private' sub-themes arose from the data, involving barriers in accessing early intervention services through the state, or accessing early intervention services through private companies or organisations.

Many participants mentioned that the state options are very limited, and the services provided are of a lower quality. Long waiting periods to access these early intervention services are also an issue, as one participant claims that she had an eight-month waiting period before she was able to access state-provided services at a hospital in Cape Town. Other barriers include the lack of professional practitioners available at state hospitals, including trainees implementing the services, and the limited amount of services one is able to access. Participant 3 describes her experience with the state options as follows:

> *"They have the OT and speech therapy students doing their hours. So, you can go and you can get a free session, you can go to a [state] hospital but you have to go there and hope they have time. And it's like once every two weeks or if you're lucky. And for intervention care, that needs to be kind of all the time. You don't have the luxury of once a week maybe kind of sort of, plus it is a trainee. It's not actually a professional, you know. So, I've found the state options, actually not options at all in terms of what I wanted my child to achieve*

> *because he would never gain any traction and momentum with therapy."* [Interview with Participant 3, 2018]

Participant 4 continues to speak about barriers, financial constraints and state hospitals:

> *"I mean if you are in a lower income bracket, there is no service actually available to you. Have you been to [state hospital], it's disgusting. But a friend of mine's son, he is now five, he was diagnosed last year from [that hospital.] And they said to the mother, 'It's okay, he's been diagnosed with autism spectrum. There's a school they could put him into to tie his shoes and button his top and to cook for himself and brush his teeth.' And that psychologist from [that hospital], that's the advice that she has given this woman. And because she doesn't have medical aid and she doesn't have the finances to go out and get a second opinion. She said, 'That's what they said' and I said, 'Do you look at your child and say to yourself, that's what he is going to become'. But if you don't have the money..."* [Interview with Participant 4, 2018]

Accessing private early intervention services has emerged as being equally difficult due to the enormous financial strain it places on families. As one participant states:

> *"Also because of my income, I'm also earning too much money to access those [state] services. So, there's a problem but I don't earn enough money to give him the actual amount of intervention care he needs because it's just too expensive."* [Interview with Participant 2, 2018]

Private sector services are therefore only accessible to people within the middle to high-income bracket and not accessible to the lower-income class. Although some services may be available at a lower cost than others, in order to receive the best care possible and achieve well-being, one needs to target the individual needs of autistic individuals to help create an environment that is optimal for their learning and create real opportunities to achieve their valued functionings. Although financial constraints are experienced by both the lower and middle-income class, it is the poorer people affected by autism that are likely to encounter more challenges, such as poor services. All participants explained the challenges with this, as they cannot access state services, but can only afford limited services or one early intervention at a time. Participants described their experiences in having to save money, learn from the resources available so that they can implement these services at home, and their struggles with accessing schools that they can afford who are capable of working with autistic individuals. Some participants also stated that certain private sector centres scare parents into receiving as much intervention as possible to achieve the best result, *"because obviously, if you are made to believe your child is autistic so you 'need to help them and you need to catch it early and use the window period because the neuroplasticity'… is how they get parents hooked*" [Interview with Participant 7, 2018]. From the data, it is also evident that the financial barriers place an emotional strain on the family and can have a large psychological impact. Participant 7 states:

> "*So, you as a parent, you sit there like 'What now?' And then they start telling you about: 'You know, kids can really progress if you bring them here, but he will need 40 hours, we recommend 40 hours.' That's... It's very expensive. It's… crippling actually. Financially crippling! … It is a very emotional thing, you know, when you tell a parent we can help your child, but it is going to cost!"* [Interview with Participant 7, 2018]

As state hospitals try and deal with the interests and needs of the public as a whole, they cannot meet the demand and do not have the capacity to cater for all autistic individuals in the Western Cape, no matter the income bracket. This can also be due to a variety of reasons, including the lack of understanding of the needs of autistic individuals and the prevalence rates that are continuously increasing.

C. Practitioners

Practitioners, with whom the parents or autistic adults have engaged, emerged as a major theme from the transcripts when asked to describe the major barriers in accessing early intervention services. It is evident that the diagnosis of the autistic individual is the first step in the journey in helping the child achieve his/her well-being, where most autistic adults from this study acknowledged that receiving the label of 'autistic' helped them better understand themselves and how to cope. However, as we explore the sub-themes, practitioners become a barrier in a variety of ways, which include negative language, an 'I know better' approach, dependence on practitioners, the lack of integration between practitioners, the lack of guidance provided and the lack of knowledge or understanding of autism.

How one approaches the subject of autism is a major factor that can have a large impact on the autistic individual's life. The use of negative language by practitioners is evidently a major barrier in accessing the best early intervention services. Parents of autistic individuals all recall the moment their child was diagnosed and what impact the negative language and hopelessness feedback given by practitioners had on them. As Participant 7 describes:

> *"After that she gave us the... whole sentence of... 'I'm so sorry you probably don't want to hear it but your child is autistic'. And so that kind of left us with the feeling of... We were devastated because of the language she used was like a death sentence. I mean I've got a totally different outlook now."* [Interview with Participant 7, 2018].

The hopelessness feedback conveyed by practitioners can have a large impact on the parents' decision on how to help their child achieve well-being, and what the next steps would be in order to receive early intervention care. Participant 4 describes her experience as follows:

> *"Went to the psychologist and he had diagnosed my son with ADHD and said that [my son] is mentally retarded and he will never pass grade 7. So, I need to take my child out of school in grade 7, pat myself on the back and say, 'job well done.'"* [Interview with Participant 4, 2018]

Participant 3 describes the same hopelessness feedback as follows:

> *"The neurologist said, 'This is the diagnosis. It's highly unlikely that he'll ever speak and he's not likely to have any meaningful relationships aside from you and his father. So, the best you can do is kind of help him to cope in a world that he'll never understand and will never understand him'. And at the time I said, 'He's two. You're kind of giving him a really bad prognosis for two'. And she said, 'I'm just trying to be realistic here.'"* [Interview with Participant 3, 2018]

Participants from the study also felt that the practitioners lacked an understanding of autism and the uniqueness of each autistic individual. Only one of participants agreed to the statement: "There are enough qualified practitioners who undertake these interventions". Participant 8 states:

> *"Doctors. Cause, you know, what do you call the guy that graduated at the bottom of his class in medical school? [You still call him] Doctor."* [Interview with Participant 8, 2018].

Even though practitioners may be qualified, the participants felt that practitioners lacked the knowledge of how to work with autistic children and would rather seek out practitioners who were specialised specifically in autism, of which there is a shortage. Participants explained the challenges in finding practitioners, for example a speech therapist, who not only was qualified but understood how to work with autistic children specifically. Not finding therapists who know how to work with autistic children resulted in limited progress in helping and supporting the child, and financial loss for participants.

Participants felt that practitioners using a ‘one size fits all’ approach to autistic individuals are a barrier, as Participant 8 says:

> “*If you’ve met one autistic person, you've met one autistic person”.* [Interview with Participant 8, 2018].

Participant 8 describes the importance of adapting to the individuality of autistic individuals to achieve well-being:

> “*Because again about neurodivergence… you can't make any predictions based on that for others. So… actively trying to understand and learn about them as an individual, will show an appreciation of valuing them as they are. It's like I always say: ‘We can't know what something truly is until we stop telling it what we think it ought to be.’”* [Interview with Participant 8, 2018]

Not understanding the individual needs of autistic individuals or in the lack of trying can be most detrimental to the well-being of autistic children. Medication was a reoccurring theme that emerged throughout interview data. Participants described their experiences of their children, or themselves (in the case of autistic adults), when on medication. Although there were mixed opinions on the use of medication for autistic individuals, it became clear that the participants agreed that for practitioners, medication became an easy solution to help ‘fix’ autistic children without exploring other options of treatment or intervention.

> *“Oh ja, early interventions... treating kids who are getting drugged. Ritalin and Concerta and Rispidol. A big issue that gets me very hot under the collar. Yeah, where there's absolutely no attempt, is actually made to, before the child gets put on any of this, you know, check the electrolytes, do an absolute thorough type of check of electrolyte and metabolites. Check and compensate for deficiencies, you know, maybe for taurine deficiency for example, you fix that and all of a sudden, kids are not hyperactive anymore, they don't need Ritalin. So, you know just an awareness from around... that is an early intervention as far as I'm concerned. There's very little as far as I can see, that it's actually happening around that.”* [Interview with Participant 9, 2018]

The lack of integration between practitioners also arose as an issue, as participants described the negative consequences to the health of autistic individuals resulting from the lack of communication between the different practitioners that the parents were working with. Each practitioner had a different approach to working with the child and, additionally, different practitioners were medicating the same child. One participant described how, due to this, her child ended up in hospital and she, as a result, realised the importance of having one practitioner oversee the child's whole programme.

From the analysis, it was apparent that the participants felt that practitioners took on a superiority complex or an 'I know better' approach. Participants described how they have often been made to feel like they are not good enough, that their opinions about their child do not matter and that very few practitioners listen to the parent's concerns regarding their child. Only one of participants agreed that practitioners who undertake intervention services listen to their concerns. Parents have described how this negatively impacts their self-esteem in how to support their child and implement these interventions in the home environment, as they repeatedly felt that they are not fit for helping their child. Participant 3 describes the importance of recognising the worth of the parents' opinion as follows:

> *"I think a lot of people do go into these situations and they are like, 'ah this is a doctor, have to respect what they say and they're smarter than me and she wouldn't make a mistake. What do I know?' And because it was my child I was a little bit like, 'I don't care what you say. I know this child and I spent every day with him and I know his potential better than this one-hour assessment.'"* [Interview with Participant 3, 2018]

Not only is it important to listen to the parents' concerns but from the analysis of the transcripts, it is evident that it is imperative to listen to actually autistic individuals too. More than anyone, they have the knowledge and experience of what works and what doesn't. Keeping in mind the individuality, listening to autistic individuals will help practitioners adapt and learn what the best approach is to work with autistic individuals.

The 'I know better' approach by professionals also creates a dependence on practitioners by the parents. Although not explicitly explained by parents as a 'dependence', this became a reoccurring sub-theme, as parents described their experiences with practitioners and placing faith in their opinions. As there is a lack of information available about autism and the interventions available in Cape Town, parents become dependent on practitioners for their advice, knowledge, resources and guidance. This results in parents becoming too reliant on practitioners' 'expert' opinion, and even being bullied into paying more money and taking certain approaches or interventions with their child, which may not necessarily be beneficial to their specific child's well-being. Families with autistic children and autistic individuals themselves are a vulnerable group. Practitioners have too much power over parents and families, and how they use it should be noted.

Participants felt, however, that there was a general lack of guidance by practitioners in navigating the field of services. After the initial diagnosis, parents feel lost and very alone and are reliant on practitioners to help them find their way and choose the best early intervention that is available for their child. As one participant says:

> *"It really feels like a jungle that we are navigating sometimes. Honestly, it does."* [Interview with Participant 2, 2018]

This is where the use of language, understanding and respect for individuality becomes important. Participant 3 describes the challenges with the practitioners below:

> [To the practitioner] *"Don't tell people go away and cope. Don't tell people never speak or never this. Try to give them a realistic outlook but don't kill their hope of ever achieving anything with their child. Also, children on the spectrum make achievements in their own lives that may not be what neurotypical children achieve but in their own lives are still incredible. So, focus on that stuff too. And don't send someone away with an A4 piece of paper with a list of names. That tells me nothing. It also didn't tell me which one to my specific child was better than anyone else. Every child is so different, and you should know that. But you gave me a one size fits all list of people I had to go eliminate as I phoned them, so ja."* [Interview with Participant 3, 2018]

Another important aspect that arose from the data was the approach adopted by practitioners in working with autistic individuals in early intervention programmes. The actual practitioners play an important role with whether autistic children thrive in intervention programs and whether parents decide to stay with a particular intervention programme or not. Parents mentioned that the acceptance, understanding and relationship that the therapist has with the child is of key importance, and that became possible through understanding the individual needs of the child and adapting programmes to the requirements of that child.

D. Home environment

The home environment plays a major role in whether autistic children are able to access the best early intervention services. Familial support, understanding and acceptance by parents, pressure placed on parents and the physical environment shapes the family's decisions, resources and attitude with regards to accessing and implementing services in the home environment.

Autistic adults acknowledged that at times, their parents were their biggest barrier in accessing early intervention services.

> "*My mother, it is mostly my mother. My mother didn't care. She didn't care to bother with me. And I didn't have a father, he never showed up. So, the main barrier was my parents. Cause they just got pills and suppressed my problems instead of dealt with it*." [Interview with Participant 8, 2018].

There is a frequent lack of acceptance by many parents, which results in the neglect of their autistic children. Additionally, the lack of acceptance sees parents trying to 'normalise' their child. Participant 7 explains:

> *"You know, it depends on the parent. So, I think if the parent doesn't accept their child, they will drop them off at a place and… 'Do what you need to do because we need to fix our child and he needs to go into Mainstream'. Then you get other parents like me that is questioning, 'What is happening here? Why, why, why are these things happening?'"* [Interview with Participant 7, 2018].

Autistic adults also explain how parents' lack of acceptance prohibited them from receiving the label of 'autistic', which was a barrier in them being able to understand themselves and understand what help and support they needed. Parents of autistic children in this study supported this argument and it was found that many partners, mostly the fathers of autistic children, were not accepting or understanding, which resulted in the abandonment of their autistic child. Participant 4 explains:

> "*My ex-husband said either you put him in a home or you walk out, and I walked out… And the report came out that my son actually felt threatened by his father and he felt put down a lot by his father because there was something wrong and he could pick that up… The report*

> *from the psychologist was that he felt, in my home, more secure than with his father."* [Interview with Participant 4, 2018].

The lack of understanding and acceptance by parents and other family members can have a large psychological impact on the parents and on the autistic individual and can affect their sense of love and belonging. Being an already vulnerable group in society places immense strain on one's belief in self, and the need for love and support from those closest to you can have a lifelong psychological impact on an individual. An autistic adult explains:

> *"A big barrier is often the lack of understanding and acceptance from families just to go 'okay, we're willing to acknowledge that there's something different about you.' That's not just you being a bad kid or a wilful miscreant but you're different, you're weird and you're strange but you're worthy of love and belonging. And we accept you the way you are, and we'll work this out together. We'll find help.' That's lacking in so many cases that's keeping people down, keeping them in situations where they have to suppress and mask who they really are. And that kills."* [Interview with Participant 10, 2018]

Without the acceptance, understanding and support from parents and those closest in the home environment, autistic individuals are prevented from receiving the right early interventions suited to their needs - interventions that promote and support them. With neglect and denial from parents and society, participants state that autistic individuals are forced to 'mask' their behaviours and their quirks, either through the wrong kinds of therapies or as protection mechanism for themselves, but this results in their real needs not being met. Participants emphasise the danger of this, as it results in frequent suicides among autistic individuals if they do not feel a sense of belonging in a world that is not so accepting.

Familial support is an important factor when helping autistic children achieve well-being through early intervention services. Whether it is support from one's parents or support from one's partner, the persistence and hope one has to maintain as a parent is integral to the well-being of an autistic child. Participants explained the immense feelings of loneliness and helplessness in navigating the services, and understanding not only autism, but their child. Parents are the voices of their children and the people who are in the position to fight and stand up for their child and their well-being, against practitioners, therapists, schools and society. As one participant stated:

> *"And I say to parents, 'You're so intimidated by the fact that that is a psychologist. Or that is a paediatrician and you see what they say is always the best. But you know your child better than anybody else. So, you can't tell me if that person is not telling you, in your heart and you know it is wrong and you still accept it and you haven't said anything and vocalised what you feel, that is even worse!' And parents are not speaking out."* [Interview with Participant 7, 2018].

From the qualitative data, it became evident that this has placed an immense amount of pressure and responsibility on parents. As an autistic adult states, one gets the "autism mum phenomena". After the initial diagnosis of autistic children, the pressure faced by parents from practitioners are immense; the negative language and approach that many practitioners take, combined with the stigma that exists, leads to parents tending to start to feel a sense of guilt for having an autistic child and for the burden that is placed on society attributable to the stigma that exists. The well-being of parents of autistic children is felt to be often overlooked yet is vital to the well-being of their children. A sense of responsibility is placed on parents, and how they respond to the pressure will decide whether autistic children are pushed in the direction of choosing interventions that encompass love, support and understanding, or in the direction of 'fixing', 'normalising' and modifying autistic behaviours though these interventions.

Parents acknowledge the importance of implementing intervention strategies in the home environment, as this is where the child can learn and grow, in turn contributing to the generalisation of intervention strategies. Implementing interventions at home also results in financial savings. The physical environment is an important factor in accessing early intervention services, as these services often take place in the home environment too. Sixty per cent of participants disagree with the statement: "It is easy for me to implement an intervention programme". The physical environment is instrumental in the success of learning for autistic individuals, as their sensory and emotional needs ought to be met. Changing the physical environment to be without clutter, to be calm, relaxing, nurturing and safe, helps autistic individuals thrive. Adapting the environment and implementing resources helps autistic individuals learn routine and predictability - on which they thrive - and helps them cope. The home environment is the first place where children learn and the place where they implement their early intervention strategies. Alternatively, participants who have found that living in an unsafe community, prohibits them from successfully implementing intervention strategies at home, due to the lack of freedom and movement that their bodies need.

E. Stigma

Stigma was found to be a contributing barrier to accessing early intervention services for autistic individuals. Parents described their feelings of isolation and rejection and the negative consequences on their and their child's mental health. Parents described how their self-esteem is often influenced, where often they have times where they want to give up or do not believe in their capability of helping their child in the best way possible. Pressures placed on parents by society because of societal expectations have a large impact on parents' behaviours and decisions concerning their child, as one participant explains:

> "*I mean, why am I going to push something. Why am I going to push him if... if... What is my goal here? Is my goal to give him a good education and get to know him or is it to force him in a society where he's actually not welcome. Because he's not welcome."* [Interview with Participant 8, 2018].

Parents related their experience in public as onlookers regularly react negatively to the autistic individual's behaviour, where parents are often thought of as bad parents or the child is perceived as misbehaving. The child's different behaviour is labelled negatively, and stereotypes are attached to autistic individuals. This results in the rejection, isolation and exclusion from social norms and social status. Consequently, this often leads to discrimination. As a result, autistic individuals are robbed from a quality life, proper health care and, later, good jobs. Participant 3 describes her experience with the public and their opinions below:

> *"Everyone around me was thinking he was badly behaved and I was a bad mother because I wasn't disciplining him and I was just letting him have his tantrum which is super inconvenient to everybody else who is, like, wanting to carry on their lives in silence and I, at one point, seriously contemplated like making business card sized things to hand out to people to say, 'My child has autism spectrum disorder, this is not a tantrum and bad behaviour. Go look it up and stop giving me shit.'"* [Interview with Participant 3, 2018]

Participant 1 describes her experience as follows:

> *"I think one thing that made quite a difference is if there had been more understanding or more awareness amongst the general populace. Because if you look at people that are seeing the behaviour, their immediate thought is that maybe, you know, 'They can't control their child.' And of course, you as an individual, I would rather crawl under the floorboard than be associated with my child when they are misbehaving or something, it makes it*

> *very difficult, because I'm not going to educate you. I'd probably just quickly hustle him out of the building or something, or pacify him in some way, or pop a pill into his mouth if I don't have a solution, but I have to consider that. But I don't want to give him a pill just because, you know. I want to be sure that he really needs that. Ja, so that is the difficulty of that, the education of the masses really."* [Interview with Participant 1, 2018]

The contrast between the above two participants shows how the public opinions and fear of embarrassment and exclusion can influence a parent and their behaviour towards their child. This, in turn, determines the approaches and early intervention programmes that parents choose for their child. As mentioned before, parents may then choose to incorporate interventions that help support the individual, or interventions that will help 'normalise' the child and mask their autistic behaviours.

Recently, a new Afrikaans movie about a family and their experience with their autistic child was released in South Africa, called 'Raaiselkind', translating to 'Riddle child' in English. Parents explained how media influences people's opinions and contributes to the stereotyping of individuals and the perpetuation of stigma.

> *"But if you think about it, could they not think that there is a parent that is in this mom's situation who is actually thinking or toying with the idea of 'I can't cope with my life', 'I want to kill myself or my child'. Where is that kind of awareness? So, I feel the awareness was more like 'Shame, poor parents', 'Oh, I'm so glad I don't have an autistic child'. Because you should read those comments [to the movie, Raaiselkind]... it is horrifying, like, 'Thank God I don't have an autistic child!' Hundreds and hundreds and hundreds. Hundreds of parents."* [Interview with Participant 7, 2018]

Autistic adults describe the importance of listening to autistic individuals. If their voices are allowed to be heard, they are able to break down these barriers and stereotypes and voice their opinions on what works for autistic individuals, especially in terms of early intervention services, how one can communicate with autistic individuals and how to understand them in order for children and adults to cope. Autistic adults' frustration often emerges throughout the data, as they believe that their feedback regarding their experiences should be at the forefront, and not misrepresented by the media. Participant 9 explains:

> *"I think a lot of the stigma comes from that. From this kind of idea that you know autistic children are a burden. We are 'Raaiselkind[ers]', that we are a 'raaisel' that needs to be*

> *solved, you know? 'Dammit, just listen to us.' Yes, the parents do go through a lot, but we are here too even if we can't speak, we have ways of communicating and forcing us to speak is not productive, finding alternative ways for us to communicate, you will discover that we are not quite as stupid as we seem to be."* [Interview with Participant 9, 2018]

The influence of the media does not only reach parents, families and their homes but can have consequences as far-reaching as schools. Parents explain how stigma perpetuated through the media can lead to discrimination and have an impact on accessing the right support for their autistic children. As participant 7 states:

> "*And I can tell you now because of the release of this movie, my child is probably not going to get into school because who wants a 'Raaiselkind'.*".

The importance of accessing schools is paramount, yet autistic individuals struggle to access crèches and schools. Schools are one place where children may receive early intervention services at a reasonable cost, within school hours and in the same area, eliminating many of the barriers that exist in accessing early intervention services. Stigma, however, reinforces stereotypes of autistic children and specific 'problem behaviours', in turn limiting the accommodating ability of schools.

> *"Filling in application forms and there's always the question about that and do I say yes. And then they put my application to one side, or do I lie and say no and then get my child into a school and then say, 'Oh by the way, he's got this'. So, I found that kind of questioning about his… developmental difficulties… like a moral issue. Should I lie and get him a place in school that he has every right to be in? Or should I tell the truth and know that we will never get into that space?"* [Interview with Participant 3, 2018]

The stigma that exists worms its way through the networks of society to family members, schools and practitioners, and is evident in the language used by people. Language used in the information provided, language used by practitioners and the language used by schools all creates barriers to accessing the right kind of interventions and achieving well-being for autistic children. Language matters as it shapes perceptions and has a bearing on how the wider world interacts with the autistic community. Under the medical model of mental health, autism is considered as 'dysfunctional' and a disorder. Neurologically different minds are not celebrated or encouraged in a society that only sees what is wrong, instead of celebrating differences and enabling strengths. Having a negative outlook on autism, using words such as 'normalisation', ‘cure’, ‘bad’ behaviour, ‘naughty’ or ‘person with autism’, all look at autism in the negative sense and, therefore, creates negative thoughts of ‘fixing’ (Mcmillan, & Pigea, 2016). Schools do not want to take on this responsibility and practitioners provide hopeless feedback to parents - making parents feel incompetent and shameful, as if they have placed this burden on society – these factors all influence the decisions made in terms of which early interventions to access. Participant 8, an autistic adult, explains the importance of language:

> “*Language is a big barrier, the language we use around and for these conditions and people. Differently, if not creates but perpetuates a barrier and we need to change our language that we use to speak about these things. So, we as humanity need to change the language about how we speak about it... disability and accessibility in general. It doesn't help if a sub-culture or a sub-group adopts the use of a certain word or set of words that… that'll help them internally. But it needs to spread if it's… if that word is to have power in society, power to change. In the end, words change the world*.” [Interview with Participant 8, 2018]

F. Lack of support services

A major barrier that emerged from the data is the lack of support services available. Participants described their frustration and loneliness after the initial diagnosis of autism and the lack of guidance by organisations and practitioners in navigating the field of services and what the following steps would be to provide the best help and intervention for autistic children. Additionally, with regards to the available support, they described the lack of being accommodating and offering capacity.

Participants felt that there is a lack of a system and/or non-governmental organisations available to help support and enable families and autistic individuals. Of the organisations that do exist, participants felt that the demand on them is too high; they lack the finances, resources and capacity to meet the needs of parents and autistic individuals in the Western Cape.

Participants also felt that the support from government is insufficient and that the government is not aware of the demand and need of services that exist in Cape Town and the rest of the country in order to ensure the mental health of autistic individuals and their families. Support for parents of autistic children is limited; support services within the home environment, such as care workers or qualified au pairs, are near to non-existent; and the number of willing and accommodating schools are restricted. As found from the questionnaire data, 8 of the participants indicated “how health and education services work together to provide services” are “in need of improvement”. Participant 4 explains:

> *"So, I thought, 'if I leave today and you never hear from me again you don't know what happened to my child. Government doesn't know what happened to my child. My neurologist doesn't know and doesn't care what happened to my child, it's up to me and everything then becomes on me to ensure the development success of my child.' Nobody's checking up on me or the well-being of the child. Nobody. I have to proactively go to those things seek them out. I also have the money to take him to the appointments or the limited amount of money."* [Interview with Participant 4, 2018]

4.2.2 Experiences of autistic children's parents, and autistic adults, of intervention services in Cape Town

Parents of autistic children, as well as autistic adults, describe a variety of experiences with regards to early intervention services; the type of therapies and its approaches, benefits and downsides; the home environment; and beneficial programmes.

Fifty per cent of participants agreed with the statement that "early intervention services are beneficial to autistic children', while half of participants neither agreed nor disagreed with the statement. By analysing the data, though, all of the parents of autistic children agreed with this statement while all the autistic adults neither agreed nor disagreed with the same statement. This could be ascribed to the lack of available services and variability of available services in the past, when the autistic adults were younger, or perhaps to the lack of services available for autistic adults in the present. Alternatively, the result could be ascribed to not having positive experiences of the specific early interventions that were available to them as children.

Half of the participants indicated that they "are satisfied with early intervention services available for autistic children in Cape Town". Most participants indicated that they see the benefit in occupational therapy, psychotherapy, speech therapy and the AIMS (Awareness; Interest; Movement; Sensory) approach. All participants indicated that they believe occupational therapy has been the most beneficial and pointed to its positive impact on themselves and/or autistic children. Additionally, participants explained that psychotherapy has helped them to cope and better understand themselves and their children. Participant 4 states:

> "*You know when my son was seven, do you know that I phoned Discovery and asked what their procedure for a lockdown of 72 hours is, at the age of seven! He's now 13 and I prefer to stay home with him than I do with his sister.*" [Interview with Participant 4, 2018]

This participant’s view indicates the mutual positive benefits resulting from the right early intervention services; helping her son with coping mechanisms as well as improving her experience as parent. Participants also indicated that early intervention services helped teach them as parents and/or autistic individuals how to identify their sensory needs, develop emotional coping strategies, determine the functions of their behaviour and learn a mode of communication. This, in turn, helped change the family dynamics and created a safe and nurturing home environment in which these intervention strategies were able to be implemented. Participants, however, did not feel that there was one early intervention that according to them addressed all the areas of an autistic child’s development - they had to seek and apply different therapies at the same time to meet the holistic needs of the child.

Learning how to adapt the home environment to meet the needs of the child has proven to be a great benefit for autistic individuals and their families. Learning from practitioners, participants believe, is of key importance to help adapt and implement these strategies in the home environment. Additionally, due to the lack of access and availability of schools, participants view the home environment as an opportunity to learn, save on costs and create a home-school environment that is safe and nurturing for autistic individuals. All parents indicated that the lack of support makes adapting the home environment challenging and believe that incorporating parents into intervention services and home programmes would help parents better understand the services and how to help their child when outside of ‘therapy hours’.

There were mixed reviews about Applied Behavioural Analysis (ABA) therapy, where two parents supported the benefit of this intervention, while all autistic adults and a few other parents are strongly against this intervention. 8 of the 10 participants felt that ABA therapy is abusive, focuses on academics, is results-driven and does not value the child for who they are. Additionally, medication also received mixed reviews among parents and autistic adults, where adults were hesitant of the use of medication and parents described the need for it. ABA therapy and medication will be further discussed in the next sub-question.

All participants indicated that the approach used by a practitioner, school or parent in their interaction with autistic individuals is what determines the success of the early intervention programme and goal they have for an autistic child. Valuing the individual for who they are, focusing on positive and small achievements, being attentive and listening to the child’s needs are what benefits the child, improves their self-esteem, ensures that they have fun and contributes to the positive mental health of the individual.

4.2.3 Disparities between parents' views and autistic adults' experiences of early interventions

Parents of autistic children, and autistic adults, all want the best for autistic individuals, understanding the difficulties autistic individuals face every day and doing what they feel is best for an autistic individual to thrive in a world that is not very accommodating. There are, however, some disparities in the thoughts, actions and opinions about certain early intervention services between the parents of autistic children, and autistic adults.

Autistic adults are in the position of voicing their experiences, their concerns and their opinions, but seldom get the opportunity for their voices to be heard. Parents and organisations are the voices of autistic individuals, a voice so strong that research and adaptations to services and interventions are made according to their views. It is, however, imperative that we listen to autistic adults, as their experience is at the forefront of knowledge and accessibility to the journey in supporting the mental health of autistic individuals.

From my analysis of data, there are three early intervention services where there is a disagreement in thoughts and views of participants. These include applied behavioural analysis, medication and dietetics. ABA therapy is, notably, the most popular early intervention programme that autistic individuals undergo, whether in Cape Town or around the world. It takes a behavioural approach and is undertaken by the majority of companies and organisations in Cape Town. Two parents support this approach and explained that they saw great improvement in their child but, as one mom admits "*it was that particular therapist with my particular son*", giving credit to the practitioner and not the approach. Participant 9, an autistic adult, explains his thoughts:

> *"Yeah. I've encountered parents you know, who say 'I've seen such a great improvement from applied behavioural analysis' (laughs), I have to bite my tongue and try to explain to them why it might be an improvement as far as you're concerned. It's just not for long term... long-term health of your child, it's actually not."* [Interview with Participant 9, 2018].

Another parent, who is also an autistic adult herself, describes her experience of applied behavioural analysis:

> "*I could see his anxiety going up. He didn't want to go to school anymore. I sent them videos, I showed it to them. I said, 'look here. My son doesn't want to come'. ... And then they will*

> *say something like 'It's the defiance, it will always go worse before it goes better'. Always an answer, but I know my child. There were a few things there that I'm rather not going to say. Um, I gave two weeks' notice. I just couldn't take it anymore. I was so emotional. I was so scared.*" [Interview with Participant 7, 2018]

Autistic adults describe ABA therapy as 'abusive', 'forceful', not listening to the child's concerns, focusing on everything that is 'wrong' - a therapy that teaches autistic individuals to mask their behaviours instead of accepting, embracing and helping them cope and meet their needs. Throughout the transcripts, parents and autistic adults describe different situations of physical abuse and bullying by particular practitioners in ABA sessions in order for autistic children to be compliant and show results. This has a profound negative impact on an autistic individual and although one can see visible differences in their behaviour and actions, their unmet needs can have a lifelong impact on and struggle with their mental health. As one autistic adult explains:

> *"I mean it's a scary reality but the average life expectancy for autistics is under 50 and therefore the biggest killer, suicide. Biggest driver behind suicide - masking. It's why I'm not, I can't ever step into a job situation again that requires me to do that."* [Interview with Participant 8, 2018]

It was evident that some parents seek visible differences in their children while autistic adults explained that major differences for them was internal. Making sense of the world, behaviours, having coping strategies and understanding their sensory needs are not necessarily explicitly visible, but they felt calmer and more comfortable in group environments and society as a whole.

One parent describes how adapting the diet didn't work for her son, however, many of these experiences evolved around the mother's time, availability and patience to implement this at home, all contributing to why diet did not work. For autistic adults, they highlight the importance of diet for them, believing it is one thing that you can control. As one participant explains, diet, whether autistic or not, plays a role in an individual's life, believing in healthy foods and listening to your body's reaction to foods, and describes seeing the difference in her child within three days. This, however, does not work for each individual as it is time-consuming and need to make pre-prepared meals, which not all parents can do. It is important to understand the variability of autistic individuals.

The last of the interventions that have differing views amongst parents and autistic adults involves medication. Medication arose throughout the data at several points in the transcripts with parents and autistic adults. All parents described their experiences with practitioners and psychiatrists, all prescribing medication for autistic children, some having disastrous effects, where not finding the right fit of medication or over medicating the child has left children in hospital. One parent describes her son on Atarax at the age of 8 years old, another parent describes her child on antidepressants, amongst others, at the age of 6 and a half and many parents describe the need for Ritalin. The ease of prescribing medication can be problematic and can often be viewed as the easy solution to helping a child. Participant 7 describes her thoughts:

> *"... but for some reason it seems like it is the most expensive disability in the world! It's crippling. It destroys marriages. I mean... That's why we can't afford facilitation at the mainstream. We just can't. And also, I don't know if it's going to be worth his anxiety. There might be the thing that maybe we should try medication, for him to be able to fit in to control those anxiety levels. And I don't think that that is fair. I'm not saying there is no need for medication. At some point in your life, if it's identified and it can help, then yes, but it shouldn't be a solution for your child to fit into mainstream. They are so young; their brains are still developing."* [Interview with Participant 7, 2018].

For autistic adults, they are strongly against the use of medication if it is firstly, not identified and secondly, if it is not the choice of the autistic individual. Participant 6 describes her experience as "hell" trying to "fix" herself after she stopped taking the medication that was prescribed to her. Adults explain that it is not the only solution, is often used to suppress emotions and behaviours and believe more research needs to be done in order to explore the use of medication and the deficiencies that are perhaps the cause of certain behaviours and lack in focus.

4.2.4 Recommendations from participants about improving early intervention services

Acceptance, understanding and inclusivity by society are central to the participants' views about improving the lives of autistic individuals and adapting early intervention services. Support services, knowledge and guidance provided by organisations, practitioners and government for parents is also in need of improvement in order for parents and caretakers to support the well-being of autistic individuals.

From the analysis, only one of the participants agree that there is enough awareness of autism in Cape Town and the surrounding areas. Participants acknowledge that although some people are aware of autism, or have heard the term ‘autism’, there is a dire lack in understanding autism together with accepting autism. Participants felt that there is a lack of understanding and acceptance of autistic individuals by practitioners and schools which create barriers in accessing services and limit the ability to improve the well-being of autistic individuals. Without acceptance, the child is not valued for who they are, interventions seek to ‘normalise’ autistic children and children are forced to adapt to the environment and conform to societal expectations, instead of adapting the environment to fit the child. Participant 9 explains what early interventions need to encompass in order improve the lives of autistic individuals:

> *“... when the autism accepting, so any intervention that doesn't seek to change, modify, prevent autistic behaviour. But it tends to work with it ... Eliminate. Look at diet, look at sensory issues etc. etc. and yes and then things like alternative communication methods are successful and they are beneficial when they, when they don't seek to fix but when they seek to support.”* [Interview with Participant 9, 2018]

Participant 8 corroborates the above participant and says the following:

> *“Definitely starting with acceptance and loving kind support of the individual. Not pathologising their condition but embracing it and being positive about it instead of treating it like a disease that needs to be cured*." [Interview with Participant 8, 2018]

All participants felt that interventions services should adapt, be less rigid, incorporate fun and interesting activities and be aware that the child is still developing. To improve understanding and acceptance, there is a need for education amongst schools and practitioners. Participants felt that having the government or organisations provide more training opportunities in autism specific strategies and sending teachers on courses to work with neurodivergent children will be a great benefit to educate and create more opportunities and understanding for autistic individuals.

Additionally, parents expressed the need for parent-training. This would help parents to also understand autism better, better equip parents to help their children and implement strategies in the home environment. Participants acknowledged the benefits from learning how to create homemade sensory toys, communication methods and emotional coping strategies, amongst a few, from inexpensive materials which can be used in the home environment. Many parents felt capable of implementing and providing the early intervention service for their own child yet felt they did not have the education or support to do so. As participant 7 explains, *"But now you know it's always this thing "Oh no, you can't be the therapist" and that is something I wanted to add is parenting training, in the home… How do I cope? I can't pay someone to stay there from 9 to 5. I mean all of a sudden after 5 the rules fall off. We have to generalize everything, you know, the rules apply."* [Interview with Participant 7, 2018]. This was felt, would also be of great benefit for communities and individuals in the lower income bracket. From this analysis, it was found that parents have become increasingly dependent on professionals for help, therefore receiving training in helping their children would create opportunities for autistic children to increase their capabilities, especially in the home environment, improve the emotional well-being of the parent and the child and save on financial costs, eliminating a few of the barriers that exist in accessing early intervention services.

The need for support services arose as a key argument in what is needed to improve early intervention services. Parents felt that having a system in place by the government that guides, navigates and monitors the progress and well-being of autistic children and their families would help parents emotionally and psychologically, as parents would feel less pressure, feel less isolated from society, have support and understand what the best next steps are in the journey of helping their child receive the needed services in achieving well-being. Receiving generic information that each parent after the diagnosis of their child receives, parents explained the psychological impact and strain in navigating the field and services after the diagnosis, receiving little support and guidance, which in turn, is a drawback in accessing services in a timely manner. Participant 3 explains:

> *"She told me to go to a neurologist. So, I did because I could afford to take him there. Then when I got there, and I got the diagnosis she followed her protocol and she told me what I needed to do and I need to contact [this] school and the other state school and put his name on a waiting list. And that was it! Then it was up to me to figure it out. And I wish that there was an 'Okay this child has this diagnosis. Here is the protocol that we follow for intervention care. And this is how you follow that journey. Depending on what your child*

> *has, you to go left or right.' But there is no system that can be put into, that follows you and tracks you, like…"* [Interview with Participant 3, 2018]

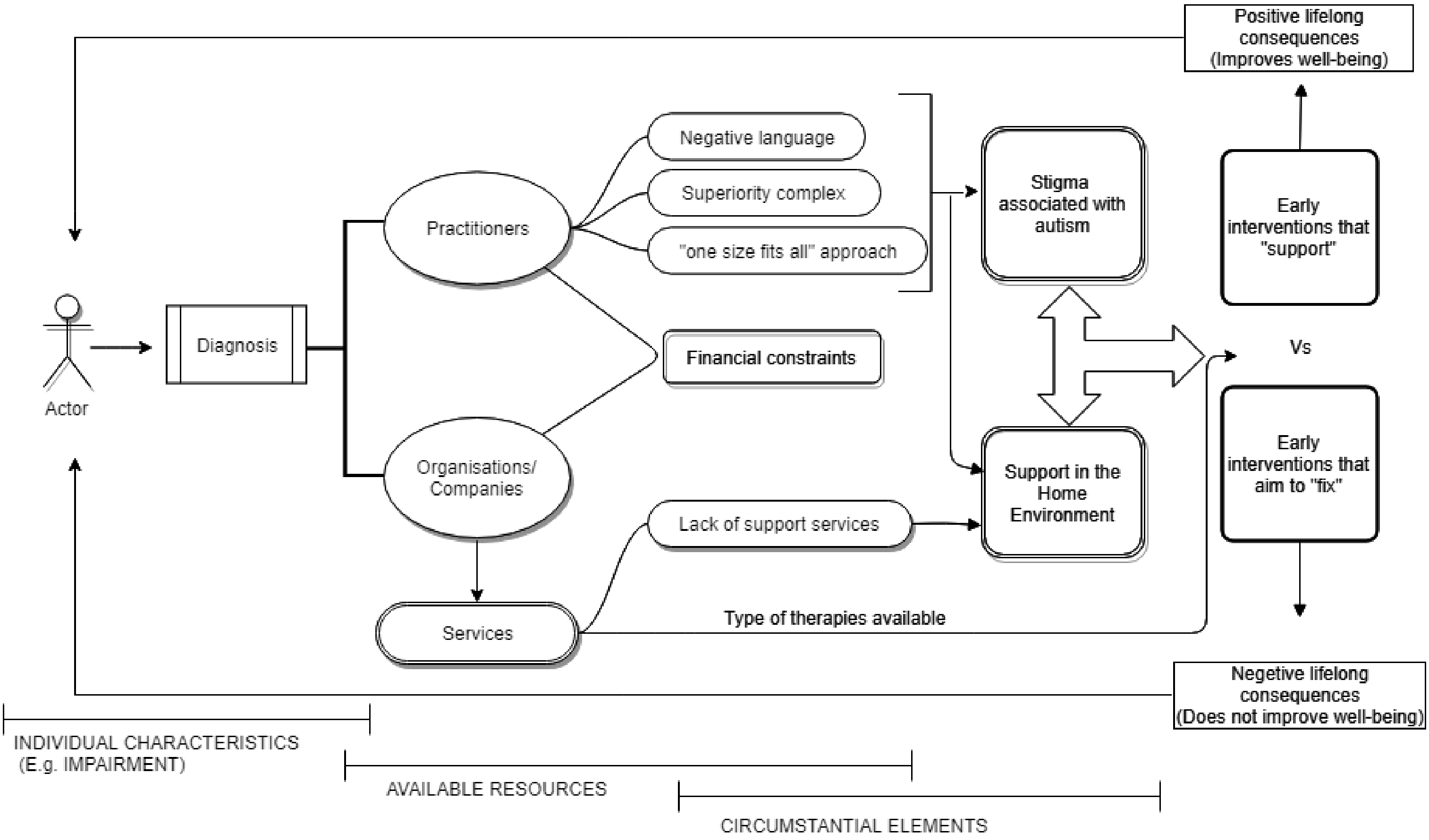
Together with having a system in place that tracks the progress of autistic children after their diagnosis, two-thirds of the participants felt that support groups for parents would be beneficial, in helping parents interact, understand they are not alone and learn from other parents in what works and what doesn't work with regards to services and strategies. Support groups for autistic children was also suggested, for autistic children to not feel isolated and learn strategies and techniques from other actually autistic individuals in how to how to cope and build on social skills with a group of individuals that does not discriminate.

Lastly, 8 of the 10 participants suggested that having an early intervention centre, which encompasses a variety of early intervention services by autism specific practitioners, together with the support services needed, all available in one location or building, would help eliminate many of the barriers that exist in accessing early intervention services. All participants felt that having these support services together with early intervention services will help the mental health of families, to learn from a community of people that is on the same journey, implement strategies at home, increase understanding and acceptance, and discard stereotypes that marginalise a group of individuals that the world can learn so much from.

Chapter 5: Discussion and recommendations

From the findings it is clear that there are major barriers that exist in accessing early intervention services in Cape Town and achieving well-being for autistic individuals. This study brought six themes into focus, namely services, financial barriers, practitioners, home environment, stigma, and lack of support services, each containing its own sub-themes. The capabilities approach is a helpful framework to evaluate the lives of autistic children and their well-being. By examining the loss of opportunities and choices through the interrelation of personal characteristics, the availability of resources and the social context, we are able to identify the barriers that exist in relation to the social and circumstantial conditions in accessing appropriate early intervention services for autistic individuals in Cape Town. Barriers were identified by means of the findings of this study - contributing to the existing knowledge of autism and services in Cape Town and South Africa. Below is a figure that shows, with the help of the Capability Approach, this study's findings of the major barriers encountered by autistic people in accessing these early intervention services in Cape Town.

Figure 4: A capabilities approach framework of the major barriers encountered by participants in accessing early intervention services in Cape Town



Participants have explained that barriers to accessing the right kind of interventions, that assist autistic individuals, start the moment their child is diagnosed as autistic. Being in contact with practitioners and organisations has a major influence on how parents might view, understand and accept autism and their child and, consequently, sets the tone for the course of their journey. Unfortunately, the lack of information and resources available for early intervention services contributes to parents of autistic children becoming dependent on practitioners and their opinions. It has been found that there is a lack of understanding of autism within the healthcare sector and many practitioners, whether qualified or not, do not consider the individuality of and customized support required by autistic individuals. This limits the opportunities that autistic individuals and their parents have in accessing the right kind of services for their child. These findings complement a study done by Dymond et al. (2007), who states that a critical element affecting the delivery of services is the existence of sufficiently trained personnel. People who provide services to autistic children (for example doctors, school personnel, therapists, etc.), often lack specific training in autism spectrum disorders (ASD). If those who provide the services are ineffective in their delivering, then the availability of these services does not help because those who need them cannot access them. Another factor contributing to the struggle of finding services for autistic children results from a shortage of qualified providers available to implement the service (Dymond et al., 2007). Additionally, this study found that many practitioners also tend to have an ‘I know better’ approach or superiority complex, not listening to the needs and opinions of parents, not validating their input and, on the other end, not listening to the voices of autistic adults. This can result in extremely negative consequences for the self-esteem of both the parents and the autistic individuals.

Lack of guidance by practitioners, government or organisations leaves parents feeling lost, pressured and hopeless in steering and navigating the different opportunities and services available for their child. This is worsened by one of the biggest sub-themes, namely negative language, used by practitioners or professionals. The hopeless feedback provided after the initial diagnosis combined with the lack of guidance contributes to the loss of opportunities for autistic individuals, which can result in a negative outlook on autism by parents and lead to them not accepting their autistic child, or influencing the type of early intervention services they seek.

The findings of this study are all underlined by societal stigma, which is perpetuated by the media and practitioners. Stigma contributes significantly to stereotypes and increasing discrimination in accessing schools and social activities. Stigma results in barriers in the home environment, too. This can be seen in parents, partners, family members and/or society's lack of understanding, acceptance and support, which often results in autistic individuals having low self-worth and diminished sense of belonging. Combined with the large amount of pressure and responsibility placed on parents, this all contributes to psychological or personal barriers. This study has shown that the lack of information, the poor quality of the information, and limited availability and accessibility all contribute to limitations in accessing early intervention services. Stigma, however, is one of the major barriers that prevents autistic individuals from accessing opportunities, and influences the decisions about what type of intervention, if available, to access.

In terms of the type of services available, there is one major factor that we need to question. This is whether the available early intervention therapies enhance the set of capabilities of individuals and provide the quality of education and training that supports autistic individuals and gives them the knowledge and skills that increase their opportunities to achieve their valued "functionings". Examples of effective training and support include the opportunity to be educated, feeling part of a community or being able to work. More in-depth research and analysis of the various interventions available in Cape Town and surrounding areas are required and essential to analyse the potential of various interventions for enhancing the capability set of autistic individuals. This study has highlighted the disparities between autistic children's parents and autistic adults, showing their varying viewpoints on the benefits of certain early intervention therapies. Applied behavioural analysis leads early intervention therapy for autism across the globe; however, this study shows the intense disapproval from eight of the ten participants who talked about the detrimental effects that this therapy can have on the well-being of individuals it is supposed to help. This confirms that the way in which we analyse these intervention therapies needs to be adapted. Instead of looking for 'evidence' in a change in the child's behaviour or skills, analysis should focus on whether the intervention provides opportunities for autistic individuals to achieve certain functionings, keeping in mind the well-being of these individuals. I have found Sen's capability approach a valuable approach to evaluating the lives of autistic individuals and early intervention therapies. The advantage of using Sen's capability approach as an evaluative tool is the importance placed on the interaction among the individuals' personal characteristics, available resources and environment and how this can form disability. Disability, as has been demonstrated, is a consequence of capability limitation and is relational both to impairments and to the design of social arrangements (Terzi, 2005). Moreover, impairments affect functionings and become disability under certain conditions but not under others. Therefore, disability implies impairment, but the reverse does not necessarily hold.

Choosing the 'right' type of intervention is important, as it will be a deciding factor in whether or not autistic individuals are provided with opportunities for achieving the well-being they value. Choosing the right type of intervention is, however, influenced by stigma, available information, the available services, finances, practitioners' opinions and the people around one. A major recommendation from autistic adults in this study is to provide services that are supportive, understanding and contribute to the unique characteristics of an individual, instead of having early interventions that want to modify, change or prevent autistic behaviour. As autistic adults explain, the consequences of 'masking' autistic behaviour can be drastic in the long run, and we need to start questioning why we place children in early intervention care – in order to support autistic individuals, or to 'intervene' and change them so that they are able to fit into a society that is not very accommodating.

This field is starting to see new, innovative intervention processes that draw attention to adjusting and changing elements of the person's environment, including schools, to aid participation-based outcomes. This is in contrast to other approaches which aim to change the person's abilities or behaviour. Highly resourced research settings have provided evidence of effective service delivery models for autism and other developmental disorders; however, the need to adapt these models to different contexts and 'real-world' settings remains challenging (WHO, 2013). Research that can highlight the significant indicators for assessing the effect of interventions at community, family and individual levels is vital in enabling the development of new models of affordable care. This would include participation from those closest to autistic individuals, as well as take into account the financial implications of these interventions (WHO, 2013). There continues to remain a gap in the research on autism intervention strategies from low and middle-income countries.

Of the limited autism studies conducted in Africa, a few specify a lack of awareness and knowledge about autism, a severe shortage of trained personnel and inadequate mental healthcare facilities (Bakare & Munir, 2011), validating the findings of this study. Although global awareness has increased dramatically, including in Africa, there is still limited knowledge about autism across all levels of African society, from public and social care sectors to education, healthcare and governments (De Vries, 2016). This study shows not only the need for awareness but the need for understanding and acceptance, not only from families and healthcare workers, but from society in general.

A recent report produced by Ruparelia et al. (2016) of an autism meeting, attended by 47 delegates from 14 African countries, emphasised the lack of available autism services all over Africa and the necessity to raise awareness and develop autism screening, training and service strategies in Africa (Ruparelia et al., 2016; Tekola et al., 2016). Dymond et al. (2007) describes that services for individuals with ASD have been unavailable, limited, inappropriate, inaccessible and costly (Dymond et al., 2007). Recognising and identifying infants and children with ASD without being able to provide them with access to interventions is one of the major practical and ethical difficulties (Ruparelia et al., 2016; De Vries, 2016). The importance of accessing adequate early intervention services is, therefore, vital to ensuring the mental health and well-being of autistic individuals.

De Vries (2016) states that, although the prevalence of autism is increasing, it is questionable whether there will ever be an adequate number of skilled therapists who can provide individual work with African autistic children. Nevertheless, most children in Africa have a parent or carer. Consequently, a large interest in parent/carer-led interventions is on the rise, predominantly where facilitation and training can be provided by non-expert ‘coaches’ (De Vries, 2016). Even non-specialist providers in school and community settings are emerging with evidence that they can effectively deliver interventions, which includes parent-mediated interventions and behaviour modification approaches, to autistic children and children with intellectual disabilities (WHO, 2013). This study confirms one of the leading recommendations by parents that they receive parent training and help in implementing what they learn in supporting their autistic child. Parents felt that it would also assist in their understanding of their autistic child. Providing training to parents and carers will help eliminate barriers that include financial constraints, dependence on practitioners, challenging home environments and few support services, as there will be more trained personnel in autism-specific strategies (at a lower cost) who would be able to assist in the home environment.

In addition to parent training, I have identified a need for more non-profit organisations that can help support, guide and provide inexpensive services or training to parents or autistic individuals. Autistic children are heterogeneous in nature and, as a result, need a varied array of services and supports tailored to their needs. With the increasing prevalence of autistic individuals, the demands on the services and the service delivery system also continue to expand and intensify (Dymond, 2007). It is clear that the existing organisations in Cape Town are overwhelmed and cannot meet the needs and demands of the autism community. Similarly, support from government should be improved by helping in guiding, navigating and creating a support system that can monitor the well-being of autistic individuals and individuals with other neurodevelopmental disorders. Small steps can be made as a starting point in improving and adjusting the current resources. For example, a webpage could be created by the Western Cape Government or by Autism Western Cape that provides information about:

- Early intervention services
- The types of approaches that exist
- Research behind these interventions
- What interventions are available for autistic individuals
- Testimonials about these interventions from parents and autistic individuals
- Where these interventions are located
- Collaboration with existing organisations, professionals and, most importantly, the autistic community.

There is also a need for more support services by non-profit organisations for parents and autistic individuals. This study has shown that with the stigma that is evident in society, parents feel isolated, pressured, lonely and excluded. Psychosocial support or support groups for parents would be extremely beneficial to the well-being of parents and their autistic children. Receiving support and understanding that one is not alone in this journey would also assist with information, guidance and a sense of worth.

From the findings, it becomes clear that the autistic community is feeling silenced, where their opinions are overlooked by ‘experts’ and decisions are made for them and not with them. It is vital that society starts listening to autistic individuals whose experiences and opinions, at the forefront of knowledge and expertise, can help shape and adapt intervention programmes that will assist in meeting the needs of autistic children in achieving better outcomes. Additionally, language plays a major role in the lives of autistic individuals and their families. There is an urgent need to change how society talks about autism.

Chapter 6: Conclusion

The first few years in life are crucial in providing the right opportunities and the tools for children to achieve their full potential. This is particularly true in a society where children are extensively exposed to barriers to development, whether it is poverty, poor healthcare and nutrition, or limited stimulation (Grantham-McGregor et al., 2007). Autism is considered to be a severe disability because of the intense, lifelong effects it has on the individual and his or her family. Across the world, autistic individuals represent a vulnerable group who experience stigma, discrimination and marginalisation on a daily basis. Regardless of their vulnerability, people with disabilities have been largely unnoticed as a goal of development work despite disabilities economic impact on families and communities, and the associated discrimination, stigmatisation and exclusion. The period of the most rapid biological and neurological development occurs between inception and five years old. It is therefore imperative for children with disabilities to receive early identification and intervention and access to integrated services that promote early childhood development (Department of Education and UNICEF, 2015). The aim of this thesis was to answer my central research question: “What are the major barriers in accessing early intervention services and achieving well-being for autistic individuals in Cape Town?”

This thesis utilised an embedded mixed methods design within a predominantly qualitative study. I answered my main research question and sub-questions by collecting data from documentary sources, quantitative descriptive statistics and qualitative interviews. A short questionnaire and face-to face individual in-depth interviews, were used with the same sample group, which constitutes parents of autistic children, and autistic adults, largely focusing on their experiences of early intervention services in Cape Town. The capabilities approach to well-being was used as the theoretical framework for this study because it highlights the central role attached to human diversity in its conceptual construction, and also permits the consideration and understanding of disability as the interrelation of circumstantial and individual elements. Many other disability models failed to have such a holistic view and focused on unmet needs and owned resources instead (Robeyns, 2016; Terzi, 2005).

This study is not without limitations. The small local target group and the specificity of this study, the questionnaire is context-specific and therefore cannot be expected to yield the same results under different circumstances nor to generalise “quantitative findings” to the population. The questionnaire was designed for the specific purpose of this study and only used to supplement qualitative findings by exploring participants' knowledge of existing early interventions and their approaches, and additionally, stimulating conversation in the in-depth interviews. However, if the questionnaire is expanded, it can be used as a starting point for future research. If it is adapted and translated into African languages (mainly isiXhosa in the Western Cape) the sample for the study could be increased.

This study has shown that there are barriers that exist that prevent families and autistic individuals from accessing early intervention services and achieving well-being. While there seems to be a lack of adequate services in Cape Town and across Africa, services - whether limited, unavailable, inaccessible, inappropriate or little information available - was only one theme that emerged from this study. This study brought six themes into focus, namely services, financial constraints, practitioners, home environment, stigma and lack of support services, each containing its own sub-themes. It is apparent that there has not been a major research focus on what the barriers are in accessing these services in Cape Town or across South Africa, whether these services are available or not, and a variety of reasons were posited for the inaccessibility of these services. The importance of this finding is paramount in helping and assisting autistic individuals in achieving well-being. We need to become aware of the environmental, psychological and social factors that all play a role in order to adapt, change and implement strategies that would help support this marginalised and vulnerable group, ranging from children all the way through to adults.

Findings from this study reveal a dire need for, and recommends, more sufficiently trained practitioners in autism-specific strategies, including the training of parents and carers to help those closest to the autistic individual understand and support those in need. An improvement in support services is vital for the well-being of autistic individuals as well as their parents: either through increased attention and awareness by government or through an increase in the number of non-profit organisations that have the capacity to provide workshops and support groups. Moreover, another recommendation stems from the need for a better system which helps parents to navigate the field of services, with adequate information about the variety of services available. Additionally, it is essential to have an increased number of services available that focus on being supportive, understanding and contributing to the individualistic characteristic of an autistic individual, instead of having early interventions that want to modify, change or prevent autistic behaviour.

Not enough attention is given to enabling individuals with neurological disorders to be accepted for themselves and to discover and celebrate their strengths, while finding a place in society that values their differences instead of their deficits. The capabilities approach, which can assess disability and the conditions that make it disabling, is a valuable tool that evaluates the individual and circumstantial elements, where parents, teachers, practitioners and society in general can adapt and modify the environment to fit the child, instead of changing the child to fit the environment. Early intervention services can enhance an individual’s capability set through educational achievements that allow an individual to convert skills, knowledge and competencies into capabilities and limit potential delays in development, making it possible to act as fully participating, active citizens. Providing appropriate services, support and opportunities is vital in ensuring that autistic children get the best possibilities to fulfil their potential and live a life according to them. Recognising the beauty and value in differences is a great first step. With more awareness, understanding and acceptance in society, differences can be recognised for the depth and dimension they bring to the human condition.

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Appendix A: Interview schedule

Interview questions:

1. Please describe what barriers or issues, if any, limit your ability to seek the best early interventions for your child; and
2. Please describe what barriers or issues, if any, limit your ability to implement specific strategies and/or interventions at home.
3. Please describe your experiences with the particular early intervention that your child/you is/were receiving.
4. Please describe what about these early interventions you believe works and the benefits of these interventions for you or your family
5. In your opinion, what is needed to improve the lives of individuals and families living with Autism Spectrum Disorders?
6. In your opinion, what do you recommend early intervention services to encompass that is missing from existing services that you know about?

Appendix B: Questionnaire

Questionnaire for parents of autistic children

Section 1: Demographics

Respondent:

1.1. Gender (tick one): MALE ☐ FEMALE ☐

1.2. Date of Birth: ____

1.3. Race: ____

1.4. Language preferred ____________________________________

1.5. Marital status: _______________________________________

1.6. Employment status: ____________________________________

1.7. Relationship to autistic child: ___________________________

1.8. Age of child: ____

Section 2: Parents' knowledge of the existing early intervention services

2.1. **Please indicate which interventions you know or have heard of before (mark with an x):**

Early intervention services			
1. TEACCH		2. Occupational therapy	
3. Sensory Integration therapy		4. Speech Therapy	
5. DIR/Floor time		6. Video Modelling	
7. PECS (Picture Exchange Communication System)		8. RDI (Relationship Development Intervention)	
9. Social stories		10. Developmental therapy	
11. AIMS (Awareness; Interests; Movement; Sensory; System) Approach		12. HANDLE Approach (Holistic Approach to Neurodevelopment and Learning Efficiency)	

13. CO-OP (Cognitive Orientation to daily Occupational Performance)		14. Biomedical approach	
15. Art therapy		16. Dietetics	
17. ABA (Applied Behavioural analysis)		18. Early Start Denver Model (ESDM)	

2.2. Are you familiar with any of the following organisations or companies? Please indicate which ones by marking with an x.

Early intervention companies and organisations in Cape Town			
1. SenseAbility		2. Centre for Play and Learning	
3. Onspectrum		4. AIMS Global	
5. Kidstart Plus		6. Cabonado Energy Autism centre	
7. Behaviour Therapists		8. Ernie Els Centre	
9. Polka Spot Early Intervention		10. Child Development Network	
11. SNAP Academy		12. C.A.R.E	
13. Khuluma Education		14. Bonteheuwel Special Care Centre	
15. Art therapy		16. Et Al Therapy and Learning Centre	
17. UniQminds		18. Mindstretch	
19. ASAP (Autism Spectrum Adaptive Programme)		20. REACH Autism	
21. Autism Connect		22. Success Therapy Centre	
23. Acorn Academy		24. Cape Town Therapy Hub	

25. Dr. Louise Lindenberg			

2.3. Please indicate which interventions has your child personally tried:

Early intervention services			
1. TEACCH		2. Occupational therapy	
3. Sensory Integration therapy		4. Speech Therapy	
5. DIR/Floor time		6. Video Modelling	
7. PECS (Picture Exchange Communication System)		8. RDI (Relationship Development Intervention)	
9. Social stories		10. Developmental therapy	
11. AIMS (Awareness; Interests; Movement; Sensory; System) Approach		12. HANDLE Approach (Holistic Approach to Neurodevelopment and Learning Efficiency)	
13. CO-OP (Cognitive Orientation to daily Occupational Performance)		14. Biomedical approach	
15. Art therapy		16. Dietetics	
17. ABA (Applied Behavioural analysis)		18. Early Start Denver Model (ESDM)	

2.4. Is your child currently undergoing an early intervention?

Yes / No / Don’t know

2.5. If yes, please indicate the type of intervention:

____

Section 3: Type and number of received services

Circle the best option for the following questions:

3.1. My child is/was undergoing ______________ early intervention service/s

1 / 2 / 3 / 4 or more

3.2. How many hours does/did your child spend in one (intervention) session?

30 minutes to an hour / 1 to 2 hours / 3 to 4 hours / 5 to 7 hours / more than 8 hours

3.3. How much time per week does/did your child participate in the early intervention programme?

1 to 3 hours / 4 to 6 hours / 7 to 9 hours / more than 9 hours

3.4. How many interventions have you implemented over the course of your child's childhood to this date?

1 / 2 / 3 or more

3.5. Please indicate whether you agree or disagree with the following statements:

	Agree	**Disagree**	**Neither agree nor disagree**
3.5.1. There is enough information regarding early intervention services in Cape Town			
3.5.2. There are enough early intervention services available for autistic children in Cape Town			
3.5.3. There are a variety of services available for autistic children in Cape Town			
3.5.4. There are enough qualified professionals who undertake these interventions			

Section 4: Parents' experiences of these services

4.1. Please indicate whether you agree or disagree with the following statements:

	Agree	**Disagree**	**Neither agree nor disagree**

4.1.1. I struggle to understand some of the early interventions that are available			
4.1.2. I am satisfied with the early intervention programme that my child is busy undergoing			
4.1.3. My child is making progress with his/her early intervention programme			
4.1.4. Early intervention services are beneficial to my child			
4.1.5. I am satisfied with the early intervention services available for autistic children in Cape Town			
4.1.6. I feel that professionals who undertake interventions services listen to my concerns			
4.1.7. Working with early intervention therapists or professionals helps me feel confident about helping my child when he/she is not in therapy			
4.1.8. I am confident that I understand my child's level of development			
4.1.9. I feel better knowing how to help my child progress through working with early intervention practitioners			
4.1.10. Professionals don't understand my family's needs			
4.1.11. It's a continual battle to get the right help for my child			

4.2. Which intervention, if any, have you felt has been the most helpful thus far? Briefly explain why.

____

____

4.3. Which intervention, if any, have you felt has not helped your family? Briefly explain why.

____

____

4.4. What has been your biggest struggle in accessing early intervention services?

____

____

4.5. Overall, my experience with early intervention services in Cape Town are:

Excellent / Good / Satisfactory / In need of improvement

Section 5: Methods and difficulties of obtaining services and parents perceived needed services

5.1. Please indicate whether you agree or disagree with the following statements:

	Agree	**Disagree**	**Neither agree nor disagree**
5.1.1. It was easy for me to find an early intervention programme that suits my child			
5.1.2. It is easy for me to access early intervention services			
5.1.3. It is easy for me to implement an early intervention programme			
5.1.4. I am still looking for an appropriate early intervention service that suits my child			
5.1.5. I am unable to let my child undergo an intervention because of certain barriers (e.g. finances, transport, etc.)			
5.1.6. I am unable to implement an early intervention programme in my home environment			
5.1.7. Early intervention services in Cape Town are cost effective			
5.1.8. All the necessary resources are available in supporting my child in the early intervention services			
5.1.9. There is enough awareness of autism in Cape Town and surrounding areas			
5.1.10. Available interventions in Cape Town are not enabling autistic children to reach their full potential			

Circle the best answer for the following questions:

5.2. Early intervention services in Cape Town are:

Excellent / Good / Satisfactory / In need of improvement

5.3. In terms of improving children’s outcomes, early intervention service standards are:

Excellent / Good / Satisfactory / In need of improvement

5.4. The information I needed to find early intervention support for my child/myself was:

Easy to find / Not easily available / Not available at all

5.5. The quality of information available was:

Excellent / Good / Satisfactory / In need of improvement

5.6. In my local area, access to training and development opportunities for family members are:

Excellent / Good / Satisfactory / In need of improvement

5.7. In my local area, the expertise of school staff and others in the children’s field (e.g. health workers, early years’ workers, children’s social workers) to identify and deal with children’s needs is:

Excellent / Good / Satisfactory / In need of improvement.

5.8. How health and education services work together to provide these services are:

Excellent / Good / Satisfactory / In need of improvement.

5.9. What does your ideal intervention look like?

____

____

____

Appendix C: Codebook

Code book for SPSS

Section 1: Demographics

Respondent:

Name	**Label**	**Values**
Gender	Q1.1	1- Male 2- Female
Date of birth	Q1.2	
Race	Q1.3	1- White 2- Coloured 3- Black 4- Indian 5- Other
Language preferred	Q1.4	1- English 2- Afrikaans 3- Xhosa 4- Zulu 5- Other
Marital status:	Q1.5	1- Single 2- Married 3- Divorced
Employment status	Q1.6	1- Employed 2- Unemployed
Relationship to autistic child	Q1.7	1- Mother 2- Father 3- Guardian
Age of child	Q1.8	

Section 2: Parents' knowledge of the existing early intervention services

Known_interventions	Q2.1: Please indicate which interventions you know or have heard of before	1- TEACCH 2- Occupational therapy 3- Sensory Integration therapy

	(Early intervention services)	4- Speech Therapy 5- DIR/Floor time 6- Video Modelling 7- PECS (Picture Exchange Communication System) 8- RDI (Relationship Development Intervention) 9- Social stories 10- Developmental therapy 11- AIMS (Awareness; Interests; Movement; Sensory; System) Approach 12- HANDLE Approach (Holistic Approach to Neurodevelopment and Learning Efficiency) 13- CO-OP (Cognitive Orientation to daily Occupational Performance) 14- Biomedical approach 15- Art therapy 16- Dietetics 17- ABA (Applied Behavioural analysis) 18- Early Start Denver Model
Known_organisations	Q2.2: Are you familiar with any of the following organisations or companies?	26. SenseAbility 27. Centre for Play and Learning 28. Onspectrum 29. AIMS Global 30. Kidstart Plus 31. Cabonado Energy Autism centre 32. Behaviour Therapists 33. Ernie Els Centre 34. Polka Spot Early Intervention 35. Child Development Network 36. SNAP Academy 37. C.A.R.E 38. Khuluma Education

		39. Bonteheuwel Special Care Centre 40. Art therapy 41. Et Al Therapy and Learning Centre 42. UniQminds 43. Mindstretch 44. ASAP (Autism Spectrum Adaptive Programme) 45. REACH Autism 46. Autism Connect 47. Success Therapy Centre 48. Acorn Academy 49. Cape Town Therapy Hub 50. Dr. Louise Lindenberg
Used_interventions	Q2.3: Please indicate which interventions has your child personally tried:	1- TEACCH 2- Occupational therapy 3- Sensory Integration therapy 4- Speech Therapy 5- DIR/Floor time 6- Video Modelling 7- PECS (Picture Exchange Communication System) 8- RDI (Relationship Development Intervention) 9- Social stories 10- Developmental therapy 11- AIMS (Awareness; Interests; Movement; Sensory; System) Approach 12- HANDLE Approach (Holistic Approach to Neurodevelopment and Learning Efficiency) 13- CO-OP (Cognitive Orientation to daily Occupational Performance) 14- Biomedical approach 15- Art therapy 16- Dietetics

		17- ABA (Applied Behavioural analysis) 18- Early Start Denver Model
Use_of_current_intervention	Q2.4: Is your child currently undergoing an early intervention?	1- Yes 2- No 3- Don't know
Type_of_intervention	Q2.5: If yes, please indicate the type of intervention:	

Section 3: Type and number of received services

Number_of_interventions	Q3.1: My child is/was undergoing (blank) early intervention service/s	1- 1 2- 2 3- 3 4- 4 or more
Hours_per_session_interventions	3.2: How many hours does/did your child spend in one (intervention) session?	1- 30 minutes to an hour 2- 1 to 2 hours 3- 3 to 4 hours 4- 5 to 7 hours 5- more than 8 hours
Hours_per_week	Q3.3: How much time per week does/did your child participate in the early intervention programme?	1- 1 to 3 hours 2- 4 to 6 hours 3- 7 to 9 hours 4- more than 9 hours
Number_of_interventions_in_childhood	Q3.4: How many interventions have you implemented over the course of your child's childhood to this date?	1- 1 2- 2 3- 3 or more

Name	**Label**	**Values**

Q351	Q3.5.1: There is enough information regarding early intervention services in Cape Town	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
	Q3.5.2: There are enough early intervention services available for autistic children in Cape Town	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
	Q3.5.3: There are a variety of services available for autistic children in Cape Town	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
	Q3.5.4: There are enough qualified professionals who undertake these interventions	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing

Section 4: Parents' experiences of these services

Name	**Label**	**Value**
Q411	Q4.1.1: I struggle to understand some of the early interventions that are available	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q412	Q4.1.2: I am satisfied with the early intervention programme that my child is busy undergoing	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing

Q413	Q4.1.3: My child is making progress with his/her early intervention programme	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q414	Q4.1.4: Early intervention services are beneficial to my child	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q415	Q4.1.5: I am satisfied with the early intervention services available for autistic children in Cape Town	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q416	Q4.1.6: I feel that professionals who undertake interventions services listen to my concerns	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q417	Q4.1.7: Working with early intervention therapists or professionals helps me feel confident about helping my child when he/she is not in therapy	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q418	Q4.1.8: I am confident that I understand my child’s level of development	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing

Q419	Q4.1.9: I feel better knowing how to help my child progress through working with early intervention practitioners	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q4110	Q4.1.10: Professionals don’t understand my family’s needs	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q4111	Q4.1.11: It’s a continual battle to get the right help for my child	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q42_qual	Q4.2: Which intervention, if any, have you felt has been the most helpful thus far? Briefly explain why.	
Q43_qual	Q4.3: Which intervention, if any, have you felt has not helped your family?	
Q44_qual	Q4.4: What has been your biggest struggle in accessing early intervention services?	
Q45	Q4.5: Overall, my experience with early intervention services in Cape Town are:	1- In need of improvement 2- Satisfactory 3- Good 4- Excellent

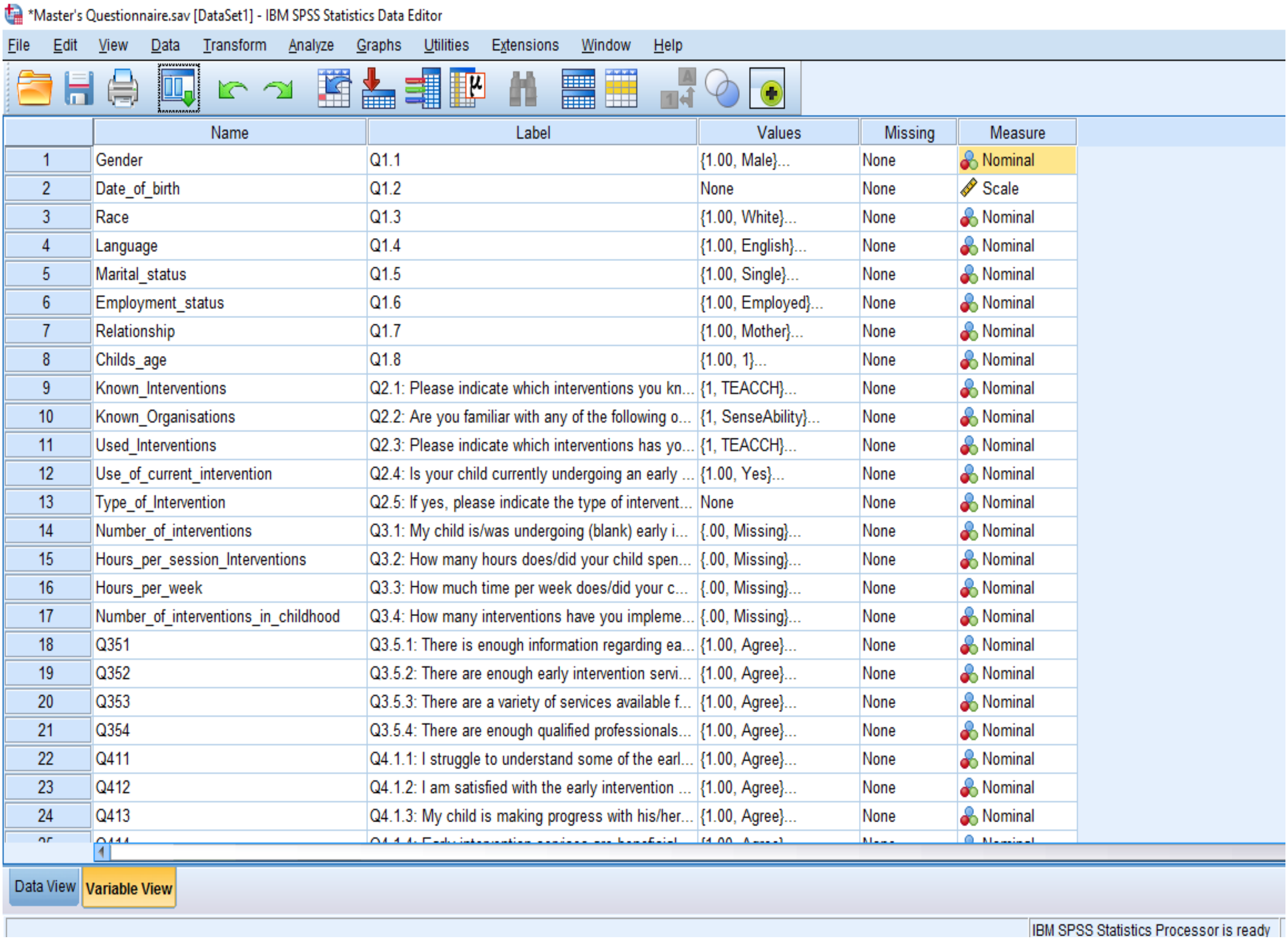
Section 5: Methods and difficulties of obtaining services and parents perceived needed services

Name	**Label**	**Value**
Q511	Q5.1.1: It was easy for me to find an early intervention programme that suits my child	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q512	Q5.1.2: It is easy for me to access early intervention services	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q513	Q5.1.3: It is easy for me to implement an early intervention programme	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q514	Q5.1.4: I am still looking for an appropriate early intervention service that suits my child	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q515	Q5.1.5: I am unable to let my child undergo an intervention because of certain barriers (e.g. finances, transport, etc.)	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q516	Q5.1.6: I am unable to implement an early intervention programme in my home environment	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing

Q517	Q5.1.7: Early intervention services in Cape Town are cost effective	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q518	Q5.1.8: All the necessary resources are available in supporting my child in the early intervention services	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q519	Q5.1.9: There is enough awareness of autism in Cape Town and surrounding areas	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q5110	Q5.1.10: Available interventions in Cape Town are not enabling autistic children to reach their full potential	1- Agree 2- Disagree 3- Neither agree nor disagree 4- Missing
Q52	Q5.2: Early intervention services in Cape Town are:	1- In need of improvement 2- Satisfactory 3- Good 4- Excellent
Q53	Q5.3: In terms of improving children’s outcomes, early intervention service standards are:	1- In need of improvement 2- Satisfactory 3- Good 4- Excellent
Q54	Q5.4: The information I needed to find early intervention support for my child/myself was:	1- Not available at all 2- Not easily available 3- Easy to find
Q55	Q5.5: The quality of information available was:	1- In need of improvement 2- Satisfactory 3- Good

		4- Excellent
Q56	Q5.6: In my local area, access to training and development opportunities for family members are:	1- In need of improvement 2- Satisfactory 3- Good 4- Excellent
Q57	Q5.7: In my local area, the expertise of school staff and others in the children's field (e.g. health workers, early years workers, children's social workers) to identify and deal with children's needs is:	1- In need of improvement 2- Satisfactory 3- Good 4- Excellent
Q58	Q5.8: How health and education services work together to provide these services are:	1- In need of improvement 2- Satisfactory 3- Good 4- Excellent
Q59_Qual	Q5.9: What does your ideal intervention look like?	

Appendix D: SPSS



*Master's Questionnaire.sav [DataSet1] - IBM SPSS Statistics Data Editor

	Name	Label	Values	Missing	Measure
1	Gender	Q1.1	{1.00, Male}...	None	Nominal
2	Date_of_birth	Q1.2	None	None	Scale
3	Race	Q1.3	{1.00, White}...	None	Nominal
4	Language	Q1.4	{1.00, English}...	None	Nominal
5	Marital_status	Q1.5	{1.00, Single}...	None	Nominal
6	Employment_status	Q1.6	{1.00, Employed}...	None	Nominal
7	Relationship	Q1.7	{1.00, Mother}...	None	Nominal
8	Childs_age	Q1.8	{1.00, 1}...	None	Nominal
9	Known_Interventions	Q2.1: Please indicate which interventions you kn...	{1, TEACCH}...	None	Nominal
10	Known_Organisations	Q2.2: Are you familiar with any of the following o...	{1, SenseAbility}...	None	Nominal
11	Used_Interventions	Q2.3: Please indicate which interventions has yo...	{1, TEACCH}...	None	Nominal
12	Use_of_current_intervention	Q2.4: Is your child currently undergoing an early ...	{1.00, Yes}...	None	Nominal
13	Type_of_Intervention	Q2.5: If yes, please indicate the type of intervent...	None	None	Nominal
14	Number_of_interventions	Q3.1: My child is/was undergoing (blank) early i...	{.00, Missing}...	None	Nominal
15	Hours_per_session_Interventions	Q3.2: How many hours does/did your child spen...	{.00, Missing}...	None	Nominal
16	Hours_per_week	Q3.3: How much time per week does/did your c...	{.00, Missing}...	None	Nominal
17	Number_of_interventions_in_childhood	Q3.4: How many interventions have you impleme...	{.00, Missing}...	None	Nominal
18	Q351	Q3.5.1: There is enough information regarding ea...	{1.00, Agree}...	None	Nominal
19	Q352	Q3.5.2: There are enough early intervention servi...	{1.00, Agree}...	None	Nominal
20	Q353	Q3.5.3: There are a variety of services available f...	{1.00, Agree}...	None	Nominal
21	Q354	Q3.5.4: There are enough qualified professionals...	{1.00, Agree}...	None	Nominal
22	Q411	Q4.1.1: I struggle to understand some of the earl...	{1.00, Agree}...	None	Nominal
23	Q412	Q4.1.2: I am satisfied with the early intervention ...	{1.00, Agree}...	None	Nominal
24	Q413	Q4.1.3: My child is making progress with his/her...	{1.00, Agree}...	None	Nominal
25	Q414	Q4.1.4: Early intervention services are beneficial...	{1.00, Agree}...	None	Nominal

IBM SPSS Statistics Processor is ready

Appendix F: Summarised codes

Appendix Removed

	Main: Barriers	**Experiences of participants of the existing early interventions**	**Disparities between parents and autistic adults**	**Recommendations for improving early intervention services and well-being of autistic individuals**
Participant 1	Lack of variety. Lack of knowledge of autism and services available Internet helps. **Financial** – can't employ someone full-time. [Autism-school] helped him work in groups. Reliant on school for information (Basics) Practitioners insistence on medication without knowing what medication Practitioners lack of knowledge of how to work with autism specific kids. **Stigma** - "can't control the child". - shame as parents. - need to control child **Lack of support system** Lack of accessibility of services.	"Hold him down" "tree-treatment" (in nature) Horse-riding (5 years) - couldn't ride but beneficial physically and mentally Art therapy - "didn't help much, he stayed in a dream world". Music therapy - overall helpful. Helps him calm down Medication at 8 - school psychiatrist suggested [atarx - became distressed]	Parents seek visible differences vs Autists feel	More understanding or more awareness. Less stigma.

	Felt helpless to help the way he needed (didn't understand him) Lack of understanding (why would he not sit by the table)	At 18y - Lithium [bipolar? or just lack of understanding of autism?] - Worrying about all medication but difficult as a parents to control for everything else Forceful with therapies.		
Participant 2	Lack of Guidance - What is autism. Lack of INFO - on programs and resources. **PRACTITIONERS**: Qualified but still lack understanding (diagnosis) Also dependent on their finances and what they charge. Finding the 'right' one. Time consuming (all day). Too reliant on expert opinion. Need to be specialised in autism. **FATHER**: Doesn't get along with child. Only child (social skills). Lack of cooperation (between partners) - makes it lonely journey. (support) [Seeks help but doesn't get from closest]	Home school environment works. - ENVIR. NB - size and amount of people. - Easier to control external factors. - Constantly adapt. Mainstream school: Bullying - Doesn't support needs of child (exec. fun.) Someone who can provide good discount? Lonely world but understand not only person who struggles. **O.T:** Joburg - Not good	Reliant on 'expert' opinion.	Home school environment Practitioners: Good understanding, kind, someone with autistic relative (background). ORGANISATIONS: Faster process. Understand the needs. Approachability. Family therapy Interventions in close proximity. **EARLY INTV CENTRES:** Creches (Link to waiting school period). Cost effective. Trial period: To see whether the place would be a good fit. Benefit or not from environment Parent plans: More education for parents.

	Denial of autism [him and son] Guilt? Blame on mother. Doesn’t face problem like own mom. No acceptance. Low self-esteem. **SERVICES**: Available but not accessible (financial) Constant change/adaption (Pract. +services) Low quality (sometimes eg Joburg) **EMPLOYERS**: Not understanding. Lack of knowledge. Doesn’t understand the needs. **SUPPORT** (lack): Become reliant and dependant on others opinions (whatsapp group). **STIGMA**: Afraid of judgement. ‘Follows the crowd’. **ENVIRONMENT**: Unnatural and not predictable (school). **ORGANISATIONS**: Limited organisations. Only voice for autists and parents. Not approachable. Big impact. Already feel judgement from others. Need someone understanding.	CT - Great but it was **Practitioner**. - understanding, communicates, passion for people. Need experience in autism or specialisation. BUT: Experience doesn’t show quality necessarily. Can be ab/used by practitioners. <u>Whatsapp group:</u> Bad experiences with “expert”: Misdiagnosis, superior complex, not accepting attitude, negative language,prescribes meds easily. Bullied by practitioners. Financial impact. QUOTE pg 9. (Jungle)		Education of children too - Rid of bullying. More understanding

Participant 3	**Family** - Availability from parents - support - What works for parent and not child. - Available time of parent - Lack of understanding of different approached Variability of children **Practitioners** - collaboration works - Dependences on advice - Disconnect between practitioners. - Lack of coherence - Lack of understanding autism specific strategies - Lack of integration between networks - Lack of info (given a list) - 'One size fits all' approach - Negative/Hopelessness feedback [get quote] - Need collaboration between network - Superiority complex (quote) - make depend - Lack of guidance to navigate services. - Lack of Individuality of children - relationship with child NB - How they approach children (warm, loving, fun, trust)	Implement OT in home environment - NB Parent involvement (sit in sessions) - key to success and generalising in home etc. Persistence and hope NB (quote) Home environment works - was able because of finances. ABA successful - particular therapist with her particular child - More about the therapist. (vs abusive) Dietary didn't work for mom - practitioner also not thinking of welfare of child	ABA worked for her Dietary didn't work [Can find quote - with variability of children]	Support system and Check-in system. Westernized resources and services. Offer services in other languages besides English. AWARENESS. Educating people in what autism is AND what it looks like. STIGMA Lack of awareness by society. Lack of understanding. Puts pressure on Parents. Need for streamline service and system in place with tracking methods. (quote) Navigation system UK check-up system. Can learn from international countries.

	- [Can find **quote** about relationship] - Need to be able to adapt. Environment set-up NB. - Environment - Shared spaced by therapists. - Not equipped for ASD specific. - Highly distracting. Not getting an hour worth out of session? - They try cut down on costs? Different approaches NB **Limited services** - one place **Need for accessibility** - (close to home) - Limited space for children **Financial** - Private vs State options - STATE: [Hospital] - Limited. - Not enough practitioners - Overburdened with cases - Doesn't meet the needs of the child - Trainee's, so not best support one can receive. - Earn too much for state, too little for private (quote) - Lack of access for gap in middle - The best they could with finances. But barrier to accessing the best. - Need resources to implement it at home			- Monitoring progress Health and well-being of citizen priority. SOCIAL Support System missing – NB 1) Diagnosis After diagnosis (What to do) Lack of infrastructure in SA. Lack of social security.

	STIGMA: Prevents access to **schools**. - Moral issues for families Schools - Imagery of schools - Elite schools - Suburbs - Barriers for ‘privileged? - ‘Inclusive’ terminology. ‘Token child’. Lack of understanding of what autism is. - Lack of assistance - Lack of accommodation by schools - Perception of autism - media? Lack of acceptance Pressure on parents - frustration - stigma Sole responsibility of parent. Huge amount of pressure. Feeling of being lost. Alone. Helpless at times? Lack of support. Lack of availability - it assumes some level of education. - What is available for uneducated, underprivileged individuals? Assumes certain resources. - English resources. Lack of culturally sensitive resources and other languages. - Westernized resources.			

	- Information, services, practitioners etc. - Everything offered in English and lack of other languages. Lack of incorporation from other cultures. - How people understand ‘autism’ is different. How they react and respond to it is different, Lack of variety in education too.			
Participant 4	**INTERV**: 4 different separate therapies at a time. Not integrated. LOCATION - drive far. Time-consuming. [Worked from home so possible]. Need flexibility. **PRACT:** **LACK OF AUTISM SPECIFIC PRACT.** - Lack of info to find ones. **LACK of INTEGRATION:** - NEG Consequences - Bad for health/life - Not holistic **LACK OF UNDERSTANDING:** - Nurse in hospital ex. (quote) **HOPELESSNESS** Feedback. (not past gr7). - Dependence (direction) - Language	HAD resources and capacities to provide INTERV. INTERV. Has helped a great deal. Validates the use of Interv. Psych, OT, Speech, Anti-social groups. ALL Beneficial. Positive difference in son. [Used to physically assault mom and sister (hospitalized) - hurt them. Not anymore] Quote. Benefited: Coping skills and behaviour. - changes family dynamic and home environment.	Medication - [6 and a half year old on antidepressants].	Integration. One person/centre who oversees everything. HOME ENVIRONMENT: NB. Inexpensive strategies. PRACT: Need to be listened to as parents. Be included. Navigate and network helps extraordinarily well. Parents like if Pract. have first-hand experiences. To understand needs. ACCEPTANCE. - By family members - By society UNDERSTANDING - As parent, she does what is needed for her son and environment.

	- “Give up” after certain years. **Medicate**: - Do not know strategies to help - Easy solution **FINANCIAL:** Need medical aid. Public vs Private. - Don’t qualify for social grants. Works 2 jobs. - [Hospital] not an option. Don’t provide adequate care. **FAMILY**: Medicate. - Father not accepting (abandonment). Felt excluded. unloved? - Mother lonely and struggling too > Meds to help kid (her?). - HOME ENVIR: - Not safe and nurturing with father. **SERVICES**: INTERVENTIONS - Assist, not change. - Teach how to deal with abilities and disabilities. - Someone can’t always be there. - “Intervene” is not to get rid of “it”. - LACK OF INFO to find interventions (or autism specific pract) - LIMITED OPTIONS **ORGAN-** Lack of them - Demand too high for existing.	Lack of integration - life threatening results (hospitalised). HOME ENVIR: Thrives in safe, nurturing and accepting environment. Inexpensive ways to implement strategies in Home Env - YOUTUBE. As PARENT: Struggle as single mom. Lonely and Isolated. Excluded from society. Not “worthy”. Abandoned		Less ISOLATION of PARENTS - Judged. Excluded. Abandoned by society. INEXPENSIVE OPTIONS: - Lower bracket can’t afford therapies. - Little guidance - Limited options. - Doesn’t provide best. - Hoplessness feedback CULTURAL UNDERSTANDING - Different understanding. - Can’t necessarily have same approach. EDUCATE: In the right way. No “curing” - radio stations - Government: Send teachers on courses INCLUSION of AUTISTIC KIDS: Social groups where they can speak to other children. Know they are not alone. Be included. Safe space.

	- Dependence on them - Lack of guidance - Causes isolation > suicide?			
Participant 5	**PRACTITIONERS**: Not being listened to as parents. Moved from one to another. Struggle started with diagnosis. “Eye contact”. Own initiative with research got diagnosis. Parents intuition. ‘I know better’ - you are not good enough to implement at home. (Low self-esteem/confidence) **PUBLIC vs PRIVATE:** [State hospital]- 8 month waiting period (school going age). **FINANCIAL**: Save money O.T: Lack of integration in home and teaching parents. Can only afford 1 interv at a time. Can’t access creches/schools. **LACK OF SUPPORT:** Dependent on others for support and guidance. To navigate the field. What is needed. Montessori: Send son home at 10 am. After 4 days out of school. - Lack of knowledge and skills by “inclusive” school. Take easy	Montessori: Excluded. Not willing to try. Take easy way out. Not accepting environment. Lack of skills and knowledge for “Inclusive” school. Avoidant. Shift responsibility. “Talk” but don’t apply. Mom attempted educating about kid incorporating O.T. to develop strategies. Neg outlook and feedback from start. **O.T:** Great but didn’t address all needs. Behav. still an issue. + school. Incorporated parents - benefited from learning, inclusion and knowing what child is doing. Guided parents i.t.o. sensory needs and what can be done. Guidance helped direct. Research showed how. Home-made.		**SUPPORT**: Receives from parents who are accommodating. Support in home-envir. (siblings/resources/structure) **PRACTITIONERS**: Include parents. **PARENT-TRAINING:** How to implement strategies in the home env. **KNOWLEDGE/GUIDANCE**: To adapt home environment and understand needs of their child (O.T). How make home-made inexpensive sensory toys. **AWARENESS and ACCEPTANCE** Parent training **Family counselling.** **More services** (limited) Education and advice in home environment setting. Understanding of Autism

	way out. Not willing to try. Not accepting environment. **ENVIRONMENT**: Accommodating and accepting env. (Issues with diet) Sibling responsibility: Young children who also need attention ENVIR. – Outside is dangerous. Limited mobility. Limited options. **LACK OF SUPPORT SERVICES**: Can't run household and provide therapies at home with limited financial means. **SCHOOL**: Can't access a school (financial and accepting) Long waiting period and waiting list. Limited accommodating schools. Schooling system doesn't fit all children (different ways to learn. Not just how society expects) **LACK OF INFO**: On how to create optimal environment (capabilities). On schooling systems etc. SERVICES: No access to behavioural strategy (financ.) NAVIGATING FIELD	PRACT: Support and guidance. Showed interest. BUT 'I know better' **HOME ENV.**: Adapting home env based on recommendations to meet child's needs are great. Family noticed improvement. BUT neg lang. and advice from PRACT. Benefit from learning from PRAC. BIG FIELD TO NAVIGATE		Support for parents. PROF and PRAC.: To have more knowledge and easier accessible. **LANG**: Optimize not 'cure'. FB Group: Advice and knowledge helps. **ACCESS to SERVICES**: More and **EARLY INTER> CENTRE**: the whole package. **LISTEN to ACTUALLY AUTISTIC individuals**: They have knowledge and a lot to each. **More (Positive) INFO** **INTERVENTIONS:** Should adapt and incorporate fun and interesting things. Be aware child is still developing. Have fun. Learn through play. Less strict and rigid. More fun and interesting.

Adults	Main: Barriers	Experiences of participants of the existing early interventions	Disparities between parents and autistic adults	Recommendations for improving early intervention services
Participant 6	PARENTS: Used medication Avoidant mother and absent father. **Neglect**. Lack of emotions from parents. **Abandonment**. Loneliness. Suppression of emotions Powerless, Not in control, Judged Lack of understanding PRACTITIONERS: Psychiatrist Give easy answer - medication. DIET: For well-being (at organisation) FINANCIAL: For organisation to provide what they can	MEDICATION: "Hell". "Fix myself". DIET: No considerations of diet at organisation and diet is NB. POSITIVE: O.T and Physio - Heard by therapist (took interest about feelings, inner voice came out) - Physical issues that were barriers NEGATIVE: Psychiatry - Meds as solution - ABA NEED: Someone to listen	Against Medication and suppression. Med has to be choice. Except if it is own choice. AGAINST ABA	Acceptance. Understanding. Less stereotyping. Not be put in a box (Quote 13min). [Cheetah metaphor] ORGANISATIONS - should stop stereotype. Also, No cure. No 'fixing'. No suppressors. DIET: Should be considerations. Communication: Accept personal way. No forcing what is 'expected' in society. "Less suppression, more acceptance"
Participant 7	**SCHOOL**: Not willing to accommodate or adapt. Don't want responsibility. **STIGMA**: Label is too big for schools. - Media. Movie perpetuates stigma. Neg thoughts. Impacts on autistic people and thoughts of others. (quote)	**DIET**: WORKS well! Kid less moody in 3 days. Makes eye contact. No dairy, gluten, soya, preservatives. BUT - time consuming. Parents can't always pre-prep meals.	Against ABA	HOME ENV: Someone help set up home env. is great benefit! Society to change: - awareness there but not acceptance yet (son can't attend extra-mural activities) NEED to be listened to as a parent.

	- SCHOOLS. Won’t be accepted due to movie (quote) - Need for ‘fixing’ child. - **LANGUAGE**: Diagnosis - “death sentence”. Negative. Impact. ‘Hopeless’ feedback. (Quote) **SERVICES**: Internet biggest resource of Info BUT not all conductive and helpful to child. - Not accessible. (one therapist in area, 1 day a week) SERVICE (1st Centre): Abusive. Forceful. Not listening to child. Too high expectations of child. Not accommodating. Pain child undergoes. (Quote) - Will get result but child will pay - (Look at experiences) - Physically abusive **SERVICE** **+ FINANCES** - Promote for wrong reasons. To help child vs money obtained. Scare parents into therapy. (Quote). FINANCIAL: Impact on family **CENTRE**: “Progress we make” book.	**PARENTS**: Intuition is NB as parent to know what is right for child. - 2 types (quote). Driven by stigma or health of child? **SERVICE**: Close proximity works. - ABA: Centre makes it seem ‘normal’ - NEG feedback. Focus on what is wrong. Forceful. - STIGMA - Ashamed of what happened. In hindsight can see. - Progress but at what cost? - Approach made kid anxious. Bad exp. - Abusive (where is the line crossed?) Physically ab. (quote) - Not listening to parent or child. - Will get result but child will pay (*Result driven vs capabilities*)		PROPER TRAINING - for therapists, clinicians etc. (an understanding) Therapies revolved around play (why OT is so popular). Assistance in setting up home environment. HOME env is first step to outside world. Holistically – family dynamics etc **ACCESSIBILITY -** **CENTRES for autistic kids – Parent support, social clubs and financially feasible.** **Parent training (quote)**

	PRACT: Use ‘superiority’ to scare parents into therapies. MEDIA: Perpetuates neg INFORMATION: **NOT UNDERSTANDING** that each child is unique. **ACCESSIBILITY**: Not available in area. Drive far distances. 80km a day. Causes anxiety and stress.	**PRACT**: Soft approach works. **HOME ENV**: Great benefit for someone to assist. Routine, predictability, structure. Research own what to do in home eg. magnesium salts. Kid happier, calmer. Techniques at home. Safe space. HOME ENVIR – works and is NB. Simple techniques, predictability. HOME SCHOOLING: Best option. Safe. accepting. no stigma. low arousal. with other parents. Autistic adult as therapist: Amazing. Valued him for who he was and didn’t look at it as a deficit model. (quote)		
Participant 8	Shift in therapies over time	Would have liked to try ritalin as he was very hyper and couldn’t focus.	Highly against ABA (child abuse)	Starting with accepting the individual and support.

	Pathologizing perspective instead of embracing perspective. Knowing they are autistic might have helped with coping skills. Parents: Didn’t want to acknowledge ‘autism’. [trying to help or ‘spare’ him]. Not having the label was barrier in getting help. - Lack of familial support and acceptance - [Understanding and acceptance from families NB - Need to know they are worthy of loving and accepted as they are. - Stepfather (at 16y) - Medicated by psychiatrist but not therapy. - Work the differences out of you. One size fits all - Telling kids what they should be. Not embracing individuality and helping in that way (quote) Stigma - leads to masking, which leads to suicide.	OT is beneficial AIMS - good, and supportive		Not pathologizing, but embracing. Support services or parents and adults. - will help parents to know their is help later on in life - (very lonely world) ABA to be prohibited and recognised for what it is (child abuse) [1;05] Accessibility of services - In terms of time, money and transport. - because of dependce of others.

	Acceptance - step 1 - And having your people behind you - “often the first hurdle where they fail” ‘Early Inter.’ for newly diagnosed adults too. - NB for well-being - Lack of availability - Support services needed Doctors (practitioners)- Quote. - ‘I know better’ approach - Very limited amount willing to listen to autists themselves Language is a barrier - Quote (words change the world			
Participant 9	**INFORMATION:** Most info is from US. ABA promoted as ‘best’. - Get fed wrong information and pushed down wrong paths for therapies. Lack of SUPPORT/GUIDANCE: Fo therapies. **“Autism mum phenomena”:** They are responsible.	**Animal therapy and Equine therapy:** Works well for some and not others. ABA: Against. Works now but long term benefits not good. AAC devices to communicate.	Against ABA Medication - needs to be early intervention (More knowledge)	Counselling for parents. access to resources, training resources, support resources General accommodation approach from Practitioners etc.

	- Made to feel guilty. Autistic kid a burden on society. **STIGMA**: Because of lack of info. Burden and panic. - Media (Raiselkind) - perpetuates negative thoughts - ‘raisel that needs to be solved. Put in a box. - Want to be heard and will break down own barriers. (quote) - Conforming to what society expects people to be like. Not embracing neurodiversity. **LANGUAGE**: Neg in info available and practitioners. **LACK of INFO**: Mostly from US. - Promote neg lang and direct along wrong path. - What is fed to you. (quote) **ACCESS to SERVICES:** **LACK of VOICE (self-advocacy)**: Represented by others.. Not being listened to. Others speak for them. (organisations). Research agenda	**Approach**: Not modifying, accepting and not ‘fixing’ approach works and is needed (quote). OT works.		OT, ACC - Understanding the sensory needs and teaching parents too. - education and understanding of autism and autism needs. - + Acceptance Psychotherapeutic support for parents and families. Need for supportive organisations.

	"Listen to us". We have a lot to see. (quote - stigma) FINANCIAL: - lack of educational support tools. HOME ENVI: How you implement is key to success. – your approach and perspective of autism. Socio-economic conditions: Can't provide necessary resources for growth (child-led households) Lack of Resources: Well-being of parents. Organisations are limited (funding?), Lack capacity. **Practitioners**: general accommodation approach and philosophy from therapists and medical professionals.			

	Schools: Can’t accommodate. Need special education. **Medication** - lack of knowledge/information about metabolic issues. Hindering child’s progress through medication.			

Appendix G: Summarised themes

Findings from coded transcripts

Findings from each transcript according to colour. (A coloured asterisk indicates agreement of another transcript with the finding.)

Participant 1, Participant 2, Participant 3, Participant 4, Participant 5, Participant 6, Participant 7, Participant 8, Participant 9, Participant 10

Theme	Sub-themes and Codes	Additional info/notes
Services	Lack of information***** - On programs and resources - To find practitioners - On how to create optimal environment [capabilities] - Schooling system - Internet biggest resource but not all helpful or conductive* - Most info from US, ABA promoted as 'Best'. - Wrong info leads to wrong paths of therapy. Lack of variety*** - Need to constantly adapt to child's needs* - Lack of accessibility***** - Available but not accessible - Need closer to home* - Time consuming - Space in centres/schools limited - Amount of therapists in area limited - Time available of therapist limited [causes anxiety and stress] Type [existing] Low quality Changing child, not assisting* "Intervene" - (not to get rid of autism)** Centre - Forceful, abusive, not listening to the child, not adapting to child. Exhibits pain on child - Q - [Will get results but child will pay]	Internet help, Reliant on school or info - Early inter. For newly diagnosed adults too. - [Lack of variety, accessibility, **availability**] - NB for well-being

	- ABA - physically abusive - Promote for wrong reasons (e.g. financial) Pathologising perspective instead of embracing perspective Lack of availability - Assumes some level of education - Westernized resources - Lack of for uneducated, underprivileged individuals - Lack of culturally sensitive and appropriateness - Lack of availability in other languages - How people understand ‘autism’ is different + how they respond to it. Environment* - Setup NB - Not ASD specific (distracting)	[result-based therapies vs capabilities approach]
Familial support [Home environment]	Lack of familial support**** - From partner (lack of help) Abuse Lack of acceptance* [Mostly father]** - Guilt? - Abandoned child*, neglect - Loneliness as autistic - Powerless, not in control, judged - Parents not wanting to acknowledge ‘autism’ - Not having the label was barrier - Parents - lonely journey Lack of sense of love and belonging*** - Child needs to know they are worthy of love and accepted as they are Lack of understanding **** - Felt helpless because of lack of understanding - What his needs are vs what parents want child to do/be - Different approaches Sense of responsibility as parents (pressure) - “Autism mum” phenomena - Made to feel guilty	Parental responsibility vs child’s belonging? - Psychological strain NB for child and adult [+acceptance]

	- Kid burden on society - Other siblings too - Well-being of parents also NB Parents needs over children’s Availability of parents Parent’s needs over child’s Parental responsibility** - Lonely, helpless, pressure* - Medicate kids Home environment - not safe or nurturing* - How you implement key to success - Approach and perspective	
Financial	State vs Private - STATE: [hospitals] - Limited. - [hospital] - 8 month waiting period - Not enough practitioners - Overburdened with cases - Doesn’t meet the needs of the child [limited availability] - Trainees, so not best support one can receive. * - Earn too much for state, too little for private (quote)* - Need medical aid - Lack of access for gap in middle - The best they could with finances. But barrier to accessing the best. - Need resources to implement it at home - Limited in finances. Only 1 intervention at a time - Can’t access crèches/schools - Lack of educational support tools Organisations - what they can provide for adults. Impact on family - crippling Socio-economic conditions: - To provide necessary resources for growth - Child-led households?	Can’t have full-time (one on one) employment. Need for school.
Practitioners	Negative language (hopelessness feedback)**Q*Q*Q*Q Scare parents into therapy - Q ‘I know better’ approach*Q**** [Q - quality of doctors]	

	- Make parents feel they not good enough, low self-esteem - Prohibits implementation at home by parents. - Ignorant of parents concerns* - Parents not being listened to - Use ‘superiority to scare parents into therapies - Very limited amount willing to listen to actually autistic individuals. - General accommodation approach and philosophy Dependence on them + impact they have on family**** - Finances and what they charge - Too reliant on ‘expert’ opinion* - ‘Bullied’ by them - Dep. on advice - Causes parents to give up (lang) Lack of integration between practitioners** - Disconnect between pract. - Lack of coherence - Neg consequences - Bad for health/well-being - Not holistic	Part of stigma too
	Lack of knowledge/understanding of autism***** (schools and teachers and how to work with ASD kids) Although qualified - ‘One size fits all’ approach.*** - [Telling kids what they should be] - Each child is unique No individuality [not embracing ind.]*Q - Medicate as (easy) solution**** - [Doesn’t work for all] - Lack of knowledge and info on metabolic issues. Hindering child’s progress through meds. - Not specialized in autism - (nurse in hospital)Q - L.o ASD specific strategies* Insistence on med without knowing what meds Lack of guidance to navigate the field** - Lack of info (A4 size paper list)*	

	Actual Practitioner - finding the right one - Relationship with child NB - Approach - Need to adapt	
Stigma	- Because of lack of info Media* Movie ‘raaiselkind’ perpetuates stigma* perpetuates Negative language= neg thoughts Language* Telling kids what they should be instead of embracing individuality and helping. Q - Language can change the world - Q - Puts kids in a box Schools Imagery of schools (Elite schools) in Suburbs - Barriers for ‘privileged? - ‘Inclusive’ terminology - ‘Token child’. Lack of understanding of what autism is. - Lack of assistance - Lack of accommodation by schools * - Perception of autism - media? - Label too big for schools Difficulty accessing schools - Won’t accept child due to movie Medication* Practitioners Need for ‘fixing’ child Societal expectations* - Conforming to societal expectations - Not embracing Neurodiversity Shame as parents** - Frustration from stigma - “Autism mum” phenomena - Kid burden on society - Parents feel guilt Can’t ‘control’ child + the need to Afraid of judgement, ‘follows the crowd’ Impact on autistic individuals - Knowing they were autistic themselves could have helped with coping skills	Fixing vs supporting Step 1: Acceptance and having your people behind you - “Often the first hurdle where they fail” - Define what interventions/approaches you seek. Define ‘masking’.

	- Want to be heard as autistic individuals and they will help break own barriers - Q - Lack of SELF-ADVOCACY - Not being listened to, others speak for them - Q Stigma leads to “Masking” behaviour, which leads to suicide if not provided right intervention that embraces.	
Language (use under stigma)	Negative* - ‘Fix’, ‘normalisation’, *Q Information available (internet)* - Mostly from US - What is fed to you - Q Media Practitioners**** Diagnosis - “death sentence” + Hopeless feedback Society	Huge negative impact - Link to other themes.
Lack of support services - Organisations - Government - Schools - Employment	Lack of guidance*** - Org. - Navigating the field Schools - bullying Lack of understanding of employers Become reliant and dependent on others opinions (WhatsApp groups) Organisations - Limited organisations**** - Dependences on them - Demand too high on them - They only voice for autists and adults - Don’t feel approachable for parents - Need for understanding from them. - Big impact on parents and society * - Lack of availability can cause harm - Lack of finances* - Lack capacity Schools - Limited available schools* - Lack of support. - Can’t ‘cope’ with autistic child - “Inclusive” but not	Reliant on school or info

	- Lack of knowledge and skills by “inclusive” school - Not willing to adapt/accommodate - Not accepting environment - Long waiting period and waiting list - Schooling system doesn’t fit all, different learning methods, societal expectations* - Need more special education	

Appendix H: Consent form

University of Cape Town

Sociology Department

Consent Form

Title of research project:

Speaking for ourselves: Autism and Barriers to services

Names of Master's student:

Kristin Bartlett

Department/research group address:

Sociology Department

University of Cape Town
Private Bag X3
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Telephone:

082 344 7526 (Mobile)

Email:

Kristinbartlett3@gmail.com

Nature of the research:

Information sheet and one on one interviews as part of a mixed methods research project exploring major barriers of early interventions experienced in Cape Town for autistic individuals.

Participant's involvement:

What's involved: Personal information sheet on early interventions to be completed and one on one interviews with participants that will explore the experiences of early intervention services available for autistic children.

Refreshments will be served.

Please note:

In the event that you feel the need to talk to someone after this interview takes place, please note that you can contact Cape Mental Health, a non-profit organisation who offer walk-in counselling services:

Cape Mental Health,
22 Ivy street, Observatory
Tel: 021 447 9040

- I agree to participate in this research project.
- I have read this consent form and the information it contains and had the opportunity to ask questions about them.
- I agree to my responses being used for education and research on condition my privacy is respected, subject to the following:
  I understand that my contribution to the interview might be included in the Master's thesis and that I can choose not to be personally identifiable.
- I understand that I am under no obligation to take part in this focus group interview.
- I understand I have the right to withdraw from this interview at any stage.

Name of Participant: ____

Signature of Participant: ____________________________

Contact details of participant: _______________________________________

Signatures of Master's student: ______________________________

Date: ______________________________