

Service Delivery and its Implications for Quality of Life in Autism Spectrum Disorder

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Abstract

Background. Previously published studies suggest that adults with autism spectrum disorder (ASD) and parents of ASD-diagnosed children experience, independently, poor quality of life (QoL) and poor service delivery. However, few extant studies investigate possible associations between service delivery experiences and QoL outcomes. Moreover, the existing body of knowledge on ASD-diagnosed individuals and ASD-affected families is incomplete because studies generally (1) emerge from high-income countries, ignoring the fact that residents of low- and middle-income countries (e.g., South Africa) often face substantial environmental, health, and infrastructural burdens, and (2) do not use comprehensive measures of QoL and service delivery, thus making it difficult to identify specific targets for improvement. *Objectives.* Across three independent studies, I undertook a comprehensive examination of service delivery experiences and QoL, and relations between them, in a sample of South African adults with ASD and parents of ASD-diagnosed children. *Methods.* Overall, the dissertation employed a mixed-methods design. In Study 1, which collected both quantitative and qualitative data, 15 adults with ASD completed a set of questionnaires measuring service delivery experiences, psychological distress, and QoL. Three of those individuals also completed one-on-one interviews detailing their service delivery experiences. In Study 2, which collected only quantitative data, 200 parents of children with ASD completed a similar set of questionnaires as did the Study 1 sample. In Study 3, which collected only qualitative data, 33 parents of children with ASD participated in focus-group interviews that detailed their service delivery experiences. *Results.* Across studies, data were consistent in indicating elevated levels of psychological distress, relatively poor QoL, and significant associations between the two. Quantitative and qualitative data suggested a marked lack of appropriate services. Problems included diagnostic delays, little ASD-specific training and poor ASD knowledge among healthcare professionals, high service-associated expenses, and a lack of (a) standard early interventions, (b) services and information available to young autistic adults post-school, (c) emotional support for parents, (d) ASD awareness in the community, (e) vocational/career training or supported employee training for adults with ASD, and (f) little workplace support for ASD-related sensory challenges. Finally, path analyses of the largest quantitative dataset indicated direct and indirect relations between child's ASD severity, familial SES, and parental service delivery experiences, and psychological distress; ultimately, these factors combined to account for a significant proportion of the variance in parental QoL. *Conclusions.* This novel and comprehensive

investigation is the first to show that, in a LAMIC setting, (a) adults with ASD and parents of ASD-diagnosed children experience high levels of psychological distress, poor QoL, and shortfalls in almost all aspects of service delivery, and (b) there are interrelated pathways between child's ASD severity, family SES and service delivery experiences, parental psychological distress, and parental QoL. By understanding these constructs and the relations among them, while taking into account the additional challenges (e.g., resource limitations, socioeconomic stressors, high burden of disease) families and communities in LAMIC contexts might face, policymakers and service delivery providers can implement targeted support to optimise the daily functioning of ASD-diagnosed individuals and their families.

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CHAPTER 1: Introduction

The current dissertation focuses on the service delivery experiences of individuals with autism spectrum disorder (ASD) and the impact those experiences have on their quality of life (QoL) and that of their families. The novelty of the studies described here is threefold: First, I used comprehensive measures of both service delivery experiences and QoL; second, I recruited samples of ASD-diagnosed adults and parents of ASD-diagnosed children from a culturally and socioeconomically diverse low- and middle-income country (LAMIC) population; and third, the largest of the studies used path analysis to examine direct, indirect, and interacting influences of family socioeconomic status (SES), severity of the child's autism-related problem behaviours, comprehensive aspects of the family's service delivery experience, parental social support, and parental psychological distress in predicting overall parental QoL.

ASD is a heterogeneous neurodevelopmental disorder characterised by an array of behavioural signs and symptoms. According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychological Association [APA], 2013), ASD is marked by two core deficits: impaired social communication and restricted repetitive or stereotyped behaviour. Surrounding this core are complex behavioural, cognitive, and emotional impairments which together mean that ASD-diagnosed individuals and their families require several interrelated services (e.g., speech therapy, occupational therapy) and resources (e.g., online and in-person parent support groups) provided by multiple different governmental and non-governmental sources. In South Africa, as in many other LAMICs, there are relatively few such sources dedicated to ASD-diagnosed individuals. Hence, the provision of adequate and appropriate services and resources for these individuals and their families is challenging.

The literature suggests that adults with ASD, and parents of children with ASD, experience elevated levels of psychological distress and poor quality of life (Dardas & Ahmed, 2014; Ghaziuddin & Zafar, 2008; Gillott & Standen, 2007; Saldana et al., 2009) and also have negative service delivery experiences (e.g., around the diagnostic process and other healthcare interactions; Brett et al., 2016; Crane et al., 2016; Howlin & Moss, 2012; Taylor et al., 2012). Few published studies examine associations between service delivery experiences and QoL in those populations, however, no study in this literature examines a comprehensive set of such experiences while using comprehensive measures of QoL.

Equally important, no published research investigates associations between family SES, severity of the child's autism-related problem behaviours, the family's service delivery experience, parental social support, and parental psychological distress in predicting the overall QoL of parents of with an ASD-diagnosed child. South Africa provides an ideal setting in which to explore such associations given its widely varying ranges of SES as well as the prominent health, environmental, and infrastructural shortcomings present in many of its communities.

The primary aims of the current dissertation were to fill those knowledge gaps. I attempted to do so across three separate studies, using a diverse LAMIC sample. Study 1 examined, using both quantitative and qualitative data collected from adults with ASD, availability of services and resources, service delivery experiences, psychological distress, and overall QoL. Study 2 examined, using quantitative data collected from parents of children with ASD, availability of services and resources, service delivery experiences, psychological distress, and overall QoL. Analyses within that study allowed development of a statistical model describing relations between parental SES, parental social support and psychological distress, child ASD severity, and familial service delivery experiences, and the influence of these factors (independently and collectively) on parental QoL. Study 3 examined, using qualitative data only, service delivery experiences of parents of children with ASD.

The dissertation is structured as follows. Chapter Two provides a concise description of the current ASD diagnostic criteria, including the recent DSM-5 changes and the impact this may have on the provision of services to ASD-diagnosed individuals. I then provide a review of the literature on (a) the experiences of psychological distress and QoL in parents of children with ASD and in adults with ASD, (b) the services delivery experiences of parents of children with ASD and adults with ASD, and (c) the relations between service delivery experiences and QoL in adults with ASD and in ASD-affected families. This literature review summarises the pertinent information that has been published in the scientific literature, both globally and in South Africa, and identifies the major knowledge gaps that are addressed in the subsequent empirical chapters. Chapter Three presents the first empirical study, Chapter Four presents the second empirical study, and Chapter Five presents the third empirical study. The final chapter (Chapter Six) provides a general discussion of the findings, describes the key limitations present across the three empirical studies, and outlines directions for future research in this area.

CHAPTER 2: Literature Review

Autism Spectrum Disorder: Signs, Symptoms, Associated Behaviours

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterised by two core deficits: social communication and restricted, repetitive, or stereotyped behaviour (American Psychiatric Association, 2013). Outside of this core, several different affective, behavioural, and cognitive signs and symptoms are associated with the disorder, with presentation typically being manifest before age 3 years. These include difficulty with (a) identifying and regulating emotions, (b) sensory processing that may result in meltdowns, and (c) understanding more complex social language such as metaphors, irony and jokes. ASD-diagnosed individuals may present with all, or with only a few, of these signs and symptoms (National Institute of Mental Health [NIMH], 2018). Therefore, the various signs and symptoms may be present in different combinations in each ASD individual (Kabot et al., 2003). Moreover, signs and symptoms range in severity so that some children require a great deal more support than others.

For these reasons, clinicians must be keenly aware that autism is emphatically a spectrum disorder. Because of the variety of signs and symptoms with which ASD is associated, and the varying degrees to which each affected individual displays those signs and symptoms, those making diagnostic decisions (e.g., is ASD the appropriate diagnosis and, if so, where on the spectrum does the child fit?) must focus not only on the *types* of behaviours that are present but also on their *severity* (Witwer & Lecavalier, 2008). Clinicians making diagnostic decisions must also consider the fact that ASD often presents with one or more comorbid clinical conditions (e.g., intellectual disability, epilepsy, sleep disturbances, motor function difficulties, tuberous sclerosis complex, fragile X syndrome; Maski, Jeste, & Spence, 2011). This fact again emphasises the heterogeneity of ASD.

Another important consideration in the diagnostic process is that the clinical manifestation of ASD is sometimes associated with a variety of cognitive strengths and special skills. Research studies indicate that, in some autistic individuals, these strengths and skills are displayed on tests of general intellectual functioning, literacy, and mathematics (see, e.g., Howlin et al., 2009; Jones et al., 2009). In other studies, parents report on isolated strengths in music, reading and vocabulary, memory, and visuospatial and drawing abilities (Bennet & Heaton, 2012; Bolte & Poustka, 2004; Meilleur, Jelenic, & Mottron, 2015). These

strengths and skills must be considered when making a diagnosis and determining the support needs of autistic individuals.

Furthermore, it is important to note that ASD is a lifelong condition and that therefore support should be considered not only for the individual's childhood years but for the full lifespan.

Epidemiology of ASD

Trends in epidemiological research suggest a general rise and increase in ASD prevalence over the past 30–40 years (Fombonne, 2003; Kogan et al., 2009; Matson & Kozlowski, 2011; Nicholas et al., 2008; Tidmarsh & Volkmar, 2003; Willemsen-Swinkels & Buitelaar, 2002). For instance, the prevalence of ASD increased from 0.1–0.4 per 1000 children in the 1980s to 2.0–7.0 per 1000 children in the 1990s. Recent CDC statistics indicate an even higher prevalence, with an overall average of 16.8 per 1000 children (1 in 59) diagnosed with ASD across 11 sites in the United States (Baio et al., 2018). The World Health Organization (WHO), however, estimates a global prevalence rate (1 in 132 people) that is lower than that in the United States. Nonetheless, that estimate suggests that 16% of the world's population might be diagnosed with ASD (Hodges, Fealko, & Soares, 2020).

Numerous reasons have been offered for the increasing prevalence of ASD diagnoses. These reasons include changes to diagnostic criteria (e.g., from separate categories such as Pervasive Developmental Disorder-Not Otherwise Specified [PDD-NOS], ASD, and Asperger's syndrome to a single diagnosis of ASD), the inclusion of outpatient data in estimates, increased awareness and understanding of ASD among both families and healthcare professionals, and better recognition of ASD symptoms across different ethnic groups and in girls (early studies focused largely on white boys and their characteristic presentation; Hansen, Schendel, & Parner, 2015; Hodges et al., 2020).

Of particular pertinence to this dissertation given the characteristics of its samples is recent literature indicating that there are sex differences in the presentation of ASD (Gould & Ashton-Smith, 2011; Rynkiewicz et al., 2016). Hence, although epidemiological literature generally reports an over-representation of boys in the population of ASD-diagnosed children, there may be significant numbers of girls who go undiagnosed or who are misdiagnosed because their clinical presentation does not match the expectations of healthcare professionals (Lai et al., 2015). For instance, Bargiela et al. (2016) reported a late diagnosis in their sample ($N = 14$) was due to the woman masking their behaviours, which led professionals to believe they were not on the ASD spectrum. Hence, medical and

psychological professionals must take urgent steps to gain awareness of signs and behaviours that might be more characteristic of a female ASD presentation so that all people on the spectrum might benefit equally from early diagnosis and support.

Recent Changes to ASD Diagnostic Criteria and Consequent Implications for Service Delivery

Historically, clinicians and researchers have found it challenging to characterise ASD adequately and to create consensus diagnostic criteria. Since 1980, each new revision of the DSM has included a different characterisation and differing sets of criteria. Currently, the DSM-5 combines the formerly separate categories of social interaction deficits and communication deficits to form the single category of social-communication deficits. Therefore, an ASD diagnosis is now based on symptoms in two core domains: social-communication and restricted/repetitive behaviours. Moreover, the DSM-5 characterisation of ASD suggests it is a single spectrum disorder rather than being comprised of several discrete subtypes (e.g., autism, Asperger's syndrome, Rett's disorder, childhood disintegrative disorder), each with its own set of diagnostic criteria. According to the DSM-5 subcommittee that proposed these changes, removing the separate subtypes and emphasising a single spectrum better reflects the pathology, signs, and symptoms of ASD (Swedo, 2010).

The extent to which these changes may impact the delivery of services to individuals with ASD is currently uncertain, however (Grant & Nozyce, 2013; Halfon & Kuo, 2013; Volkmar & Reichow, 2013). For example, Huerta and colleagues (2012) found that the DSM-5 criteria showed adequate diagnostic sensitivity across all the groups they studied, including children under the age of 4 years, girls, and verbally and cognitively able children (see also, Kulage et al., 2013; Worley & Matson, 2012). However, Taheri and Perry (2012) found that, in their sample of children ($N = 131$; aged 2 years 10 months – 12 years 7 months) diagnosed with ASD and PDD-NOS, only 63% of the total sample received a diagnosis of ASD. Furthermore, most were individuals originally diagnosed with ASD (81%), with only 17% of the PDD-NOS individuals receiving an ASD diagnosis using new the DSM-5 criteria. Mattila et al. (2011) and Taheri and Perry (2012) also found that higher-IQ individuals were less likely to meet the new diagnostic criteria than they had been to meet older criteria. These findings suggest that some children who had been eligible for services under previous diagnostic criteria might have found themselves ineligible for the same services since the DSM-5 criteria came into widespread use, even while experiencing significant impairment.

Regardless of whether and how changes to diagnostic criteria affect delivery of services to individuals with ASD, the variability of clinical presentations across the spectrum is still certain to pose major challenges to governmental and non-governmental sources of assistance. Variation in types of signs and symptoms, and in their severity, makes establishing appropriate and suitable services for each individual with ASD an exacting task. For example, an individual with severe language impairments and marked sensory challenges will require different interventions and educational services from one with fluent language functioning and mild behavioural difficulties. Accounting for such variability during the process of case formulation can result in a lengthy diagnostic process and in inefficient provision of treatment resources. Such negative service delivery experiences can have negative effects on the quality of life in ASD-affected families.

Contextual Factors Influencing Service Delivery Research in Low- and Middle-income Countries

Investigations of service delivery experiences in low- and middle-income countries (LAMICs) such as South Africa must consider numerous socioeconomic, political, infrastructural, and burden-of-disease factors that are not typically present in high-income countries (HICs). For instance, many LAMIC populations are characterised by stark economic inequality: the most recent World Bank's GINI coefficient for South Africa (2014) was reported as 63.0 in comparison to 41.5 for the United States (2016), 33.2 for the United Kingdom (2015), 35.8 for Australia (2014), and 28.2, 27.5, 29.2 for Denmark, Norway, and Sweden (2015), respectively. In South Africa, the number of individuals living in poverty (defined using the upper-bound poverty line (UBPL) index of R992 per person per month) has remained relatively constant, with only a slight decrease in the amount of people living below the poverty line (e.g., 66.6% in 2006 compared to 55.5% in 2015) over the past decade (Statistics SA, 2017). This stagnation is influenced by an almost-nil increase in gross domestic product (GDP) per capita since 2014 and by an overall unemployment rate that exceeds 25% (and rises to more than 50% in young adults aged 15 to 24 years in 2017; World Bank, 2019).

These economic disparities are, in large part, an enduring consequence of South Africa's apartheid history. For instance, the legislated disparities that existed pre-1994 (e.g., White people having preferential access to better-quality schooling, healthcare, and jobs) are still, to some degree, present in contemporary South Africa. The vast majority of Black

people in this country continue to experience oppression, discrimination, and economic impotence.

The South African population also carries a high burden of disease. For instance, the overall estimated prevalence rate of HIV is 13.1%, with 7.52 million people estimated to be living with the disease (Statistics South Africa, 2018). Furthermore, the World Health Organization recently estimated an incidence of 322,000 case of active tuberculosis (World Health Organisation [WHO], 2019). Another burden of disease with relatively high incidence in South Africa is stroke, which is responsible for approximately 25 000 deaths annually (Bertram et al., 2013).

A high burden of disease coupled with a stagnating economy means that the health needs of many South African citizens are not being met (Gaede & Versteeg, 2011). Additionally, studies indicate the need for infrastructural development and maintenance in accordance with the growing demand for services and to encourage economic growth; aging, inadequate, and poor quality infrastructure can negatively impact the delivery of services to people within a community (Perkins et al., 2005; Ntjatsane, 2017). Another impact on the healthcare needs for families in South Africa is the general lack of healthcare personnel due to the emigration of many qualified professionals; one-third of healthcare professionals trained in South Africa seek employment internationally post degree (Burch & Reid, 2011; Health Systems Trust, 2011; Labonte et al., 2015). Furthermore, a large proportion of healthcare professionals are located in the private sector in comparison to the public sector. For instance, the Health Systems Trust (2011) report noted that South Africa has a lower ratio of healthcare professionals in comparison to other countries (e.g., Brazil has 17.31 doctors per 10 000 people compared to 5.43 doctors in South Africa), and that the majority of healthcare professionals (approximately 70%) in South Africa are in the private sector. It is important to note, however, that there are significant regional differences in healthcare provision in South Africa. For instance, provinces such as Gauteng and the Western Cape that feature major cities and financial centres fare much better than the rural provinces such as the Eastern Cape and Limpopo (Day & Gray, 2008; Gaede & Versteeg, 2011).

All these factors influence availability of, as well as access to, appropriate and effective services for ASD-affected South African families. Hence, one must consider such influences when examining service delivery experiences and the impact they have on the quality of life of ASD-diagnosed individuals and their families.

Quality of Life in ASD-Diagnosed Adults and ASD-Affected Families

The World Health Organisation (WHO) defines quality of life (QoL) thus: “Individuals’ perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns” (The WHOQOL Group, 1995, p. 1405). This broad concept encompasses a person’s physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of the environment (Mugno et al., 2007). Schalock (2004), in a widely-cited review, listed the main domains included in QoL research as (1) emotional wellbeing; (2) interpersonal relations; (3) material wellbeing (including employment, housing, and financial status); (4) physical wellbeing; (5) self-determination; (6) personal development (including education); and (7) social inclusion and human rights. Clearly, QoL is a multidimensional construct that requires examination using comprehensive measures that ensure all its aspects are assessed.

However, not all QoL studies in the ASD literature use such comprehensive measures. Many employ measures of single aspects of the construct, such as the emotional wellbeing of individuals and families. These indirect measures of QoL include the Coping Inventory (Carver et al., 1989), the Center for Epidemiologic Studies-Depression Scale (CES-D; Knight et al., 1997; Radloff, 2000), the Parenting Stress Index (PSI; Abidin, 1995), or even single questions asking about level of independence, mental health, or physical health. Only a few studies in this literature use comprehensive measures that examine multiple domains of the construct. These direct measures of QoL include the World Health Organisation Quality of Life Scale Brief Version (WHOQOL-BREF; The WHOQOL Group, 1998), the Health-Related Quality of Life questionnaire (Bayliss et al., 1998), and the Comprehensive Quality of Life Scale (ComQol; Cummins, 1997).

QoL in parents of children with ASD. Being a parent to a child with ASD can have many negative mental health consequences. Several studies from settings as different as the United States, Australia, and Thailand suggest that parents of children with ASD experience elevated daily levels of stress, fatigue, and/or depression, have less time for social and recreational interaction, and are more likely to suffer marital and other relationship strife (see, e.g., Benson, 2006; Davis & Carter, 2008; Bitsika & Sharpley, 2004; Boyd, 2002; Ingersoll & Hambrick, 2011; Montes & Haltermann, 2007; Phetrasuwan & Miles, 2009; Sharpley et al., 1997). Another strand within this research field suggests that parents of children with ASD experience significantly more psychological difficulties than parents of children with a

different chronic illness or developmental disorder, such as Down Syndrome (see, e.g., Abbeduto et al., 2004).

Only six published studies (one each from Jordan, India, Italy, South Africa and two from Taiwan) have examined multiple domains of QoL in parents of children with ASD using the gold standard measure, the WHOQOL-BREF (Alhazmi et al., 2018; Dardas & Ahmed, 2014; Mugno et al., 2007; Perumal et al., 2014; Shu, 2009; Tung et al., 2014). These studies are consistent in reporting poorer QoL across multiple domains in parents of children with ASD compared to parents of controls. For instance, Mugno et al. (2007) noted significantly lower scores in the domains of physical health, social relationships, and psychological health in parents of children with pervasive developmental disorder than in parents of children with mental handicap and cerebral palsy.

These apparent multi-domain QoL impairments in parents of children with ASD demonstrate the need for further in-depth and comprehensive examination of the construct in order to obtain a holistic understanding of their everyday functioning and to better understand possible relations between, for instance, psychological distress and QoL.

QoL in adults with ASD. Studies of US and UK samples indicate that adults with ASD frequently report experiencing elevated levels of depression, anxiety, and/or stress relative to controls (Ghaziuddin et al., 2002; Ghaziuddin & Zafar, 2008; Joshi et al., 2013; Sterling et al., 2007; Stewart et al., 2006). For instance, Gillott and Standen (2007) reported that adults with ASD were almost three times more anxious than demographically-matched adults with intellectual disability.

Hearteningly, several studies in this literature examine QoL from a multidimensional perspective. For instance, in their review, Aryes et al. (2018) describe 14 such studies, with four (one each from Canada, Germany, Japan, and Taiwan) using the WHOQOL-BREF (Jennes-Coussens et al., 2006; Kamio et al., 2012; Kamp-Becker et al., 2010; Lin, 2014). Within that group, a consistent finding is the participants reported poor QoL in the social domain. However, some inconsistency is just as easily observable. For instance, whereas Kamio et al. (2013) found that adults with ASD reported poorer QoL in the psychological health domain than in any other WHOQOL-BREF domain, Kamp-Becker et al. (2010) observed the poorest QoL in both the physical health and psychological health domains.

One minor but intriguing thread in this literature makes the distinction between actual received support and perceived support. For instance, Renty and Roeyers (2006a) examined the association between QoL and support services (i.e., the types of support individuals with ASD receive) in a Belgian sample of adults with ASD. The authors described support

services as including actual or perceived formal and informal support. Formal support was defined as services being provided by professionals (e.g., diagnosis, interventions, educational support). Informal support, in contrast, was defined as that emanating from family members, community members, and support groups. Results suggested a significant association between QoL and perceived informal support, but no significant associations between QoL and any form of actual support. The extent to which support characteristics impact QoL in adults with ASD will be discussed in detail later in the review.

As was the case of parents of children with ASD, the apparent multi-domain QoL impairments in adults with ASD demonstrate the need for further in-depth and comprehensive examination of the construct in order to obtain a holistic understanding of their everyday functioning and to better understand possible multivariate relations between, for instance, psychological distress, social and other support structures, and QoL.

QoL in ASD: Limitations of existing research. The small body of research investigating quality of life in adults with ASD, or in parents of ASD-diagnosed children, is marked by some significant limitations. Three of the most important of those limitations are (a) the lack of consistency among studies in terms of the choice of QoL measure; (b) the lack, in some studies, of psychometrically sound measures of mental health problems and psychological difficulties (e.g., depression, anxiety, and stress); and (c) the lack of focus on samples from LAMICs. Below, I discuss each of these in turn.

As noted earlier, some studies in this literature use direct, comprehensive measures of QoL while others use indirect measures that focus on single aspects of the multidimensional construct. This situation gives rise to two major problems. First, it is difficult to make accurate across-study comparisons when the basic operational definition of QoL is not universally agreed upon. Second, studies that use only indirect measures as a foundation for making inferences about QoL may deliver results that are, at the very least, misleading. The impact of ASD on a family is multidimensional and complex in nature, and so focusing only on a single domain of functioning (e.g., psychological health) is problematic (Summers et al., 2005).

Making inferential processes even more challenging is the fact that different comprehensive measures deliver data on different aspects of the construct. For instance, studies using the WHOQOL-BREF can comment on an individual's physical health, psychological health, social relationship health and environmental health, whereas those using the Com-QoL can comment only on material well-being, productivity, intimacy, safety, place in the community, and emotional well-being.

Although it is preferable for studies to use direct comprehensive measures of QoL rather than indirect single measures, those that use *only* the former are nonetheless somewhat limited in their inferential power. Specifically, they may not provide an in-depth perspective on the psychological state of the ASD-affected individual. For instance, the WHOQOL-BREF items concerning psychological distress include only general questions regarding satisfaction with and enjoyment of life, mood, body image, and the extent to which one finds one's life meaningful. No in-depth questions ask directly about other psychological factors that affect QoL, such as anxiety-provoking or stressful experiences or coping strategies that might be applied to manage such experiences.

Hence, to deliver a holistic understanding of QoL, and of how different components of the construct (e.g., levels of psychological distress and physical ill-health) might interact with one another, it is essential for research studies to include both direct and indirect measures of the construct.

Regardless of which QoL measures are or are not used by studies in this research field, there is a marked lack of work emerging from LAMICs. This is problematic given that, as noted earlier in this chapter, residents of LAMICs face numerous health, economic, and social challenges that are typically not present in HICs and that may influence their physical, cognitive, and emotional functioning, social relationships, and overall quality of life. Hence, many of the extant findings in this literature may not be generalizable to LAMIC populations. Much more research should focus on how, in a LAMIC like South Africa, QoL is affected not only by the presence of ASD but also by the interacting forces of familial socioeconomic status, level of social support and other resources, and other environmental factors.

To date, only one published study has examined associations between ASD and QoL in a South African sample using the WHOQOL BREF. Alhazmi et al. (2018) found significantly lower scores, across all four major domains of measurement (e.g., physical health, psychological health social relationship, and environment domains), in parents of children with ASD compared to parents of typically developing children. Interestingly, the lowest reported QoL domain score was that related to environment domain; this finding is in contrast to the literature which has generally reported poorer QoL in the psychological, physical and social relationship domains rather than the environment domain. However, the reported study did not investigate the possible interacting forces and associations between familial socioeconomic status, level of social support and other resources, and other environmental factors and QoL in their sample.

Service Delivery to ASD-Diagnosed Individuals and ASD-Affected Families

Generally, the term *service delivery* denotes a complex construct that includes all areas of support and resources provided to individuals through both public and private channels. In ASD research specifically, service delivery investigations have had numerous foci, including (a) the diagnostic process, (b) the availability of treatments and interventions, (c) education, and (d) general healthcare resources and costs. Regardless of the specific focus of any individual study some universal truths guide endeavours in this field. First, increasing ASD prevalence rates (perhaps due to rising public and professional awareness of the disorder and changing service eligibility regulations) mean there is an increasing demand for service delivery to diagnosed individuals and affected families (Neggers, 2014; Shattuck & Grosse, 2007). Second, service delivery is thinly stretched because increased awareness and prevalence rates are accompanied by the fact that ASD-diagnosed individuals access a greater number of health services, and have more contact with health professionals, than most other individuals with disabilities. Moreover, individuals with ASD require longer consulting times and incur a greater health cost in comparison to children with other developmental disorders (Liptak et al., 2006).

A large part of the reason for this high service demand among ASD-diagnosed individuals is that they tend to carry many medical comorbidities (e.g., seizure disorders, attention-deficit/hyperactivity disorder, sleep disorders; Bauman, 2010). The nature of the required support services will vary depending on the type and severity of the comorbid condition(s). For instance, ASD-diagnosed individuals with severe ADHD may require both pharmacological and psychosocial interventions to improve their everyday functioning.

In the next several sub-sections, I examine findings on the current state of the research into various aspects of ASD service delivery, both globally and in South Africa.

Service delivery to ASD-diagnosed children. Literature on the availability (and lack thereof) of services to children with ASD focuses predominantly on the diagnostic process. Other areas of (lesser) interest are services related to interventions and therapies, and to education. Regardless of its focus, most of this literature emerges from HICs, with little to no focus on services in LAMICs.

The diagnostic process in ASD. The diagnostic process is the first, and possibly most important, step in service delivery. It is crucial that this step is completed as early as possible to (a) ensure interventions can be accessed timeously, and (b) help lessen the negative psychological effect (i.e., mood changes, increased stress, and frustration) a delay in

diagnosis has on families. Only after a definitive diagnosis is made can the next essential steps be taken. These steps include (a) providing appropriate therapeutic services, (b) developing a support and possible intervention plan, and (c) helping parents adapt to having a child with ASD by providing essential information and access to appropriate support services (Moh & Magiati, 2012; Nissenbaum et al., 2002).

A definitive diagnosis of ASD can be made when the child is as young as 30 months. Research indicates, however, that definitive diagnostic statements are typically made between 3 and 7 years, with many studies reporting values toward the higher end of the range (Brett et al., 2016; Mandell et al., 2005; Siklos & Kerns, 2007; Valicenti-McDermott et al., 2012). This definitive diagnosis is typically made only after a long process featuring multiple assessments and referrals (Crane et al., 2016; Goin-Kochel et al., 2006; Siklos & Kerns, 2007; Young et al., 2003; Wiggins et al., 2006). Not surprisingly, parents are often dissatisfied with this process. They report seeing several professionals (some multiple times), and often being told to ‘wait and see’ in order to determine whether the child truly has a developmental delay or whether the problems stem from a ‘phase’ s/he is going through (Moh & Magiati, 2012; Crane et al., 2016; Goin-Kochel et al., 2006; Siklos & Kerns, 2007). Furthermore, parents report that communication from healthcare professionals tends to be poor, and that they are given little immediate post-diagnostic support and information (Daley, 2004; Osbourne & Reed, 2008; Wiggins et al., 2006; Young et al., 2003).

The ASD diagnostic process in LAMICs. Few published studies present data from LAMICs on the ASD diagnostic process and related interactions with healthcare professionals. One pertinent finding, however, is that most autistic children from African countries tend to be diagnosed after the age of 8 years (see, review, Bakare & Munir, 2011). This finding is consistent with the global observation that there is often a delay between families noticing symptoms and them seeking professional help, and then a further delay between the initial medical appointment and the definitive diagnostic statement (Crane et al., 2016; Howlin & Asgharian, 1999; Ozonoff et al., 2009; Siklos & Kerns, 2007; Young et al., 2003; Wiggins et al., 2006). Factors influencing both the presence and lengths of these delays are (a) community awareness and understanding of what ASD is and how it presents, (b) healthcare professionals’ knowledge about and experience with ASD, and their skills in dealing with autistic individuals, (c) degree of networking and collaboration between healthcare professionals and other service providers, (d) healthcare professionals’ knowledge of what services are available for ASD-diagnosed children and their families, and ways to go

about accessing those services (see e.g., Atun-Einy & Ben-Sasson, 2018; Balfour, 2007; Hooper, 2009; Hutton et al., 2016; Rahbar et al., 2011; Rhoades et al., 2007).

Findings from unpublished Masters theses examining the diagnostic process in South Africa suggest some reasons why definitive diagnostic statements regarding ASD are reached relatively slowly in the local context (Balfour, 2007; Hooper, 2009; Swanepoel, 2003). In those studies, parents reported that the healthcare professionals with whom they interacted were vague, confusing, and contradictory in their communications, were often dismissive and unhelpful in their attitudes, and hence could not give them a clear understanding of the etiology of the child's behavioural problems. Overall, then, these South African parents reported that the diagnostic process was characterised by inappropriate referrals, multiple suggested interventions, and excessive costs, and hence was frustrating, time-consuming, and stressful.

A handful of studies from South Africa and other sub-Saharan African countries confirm that the knowledge of healthcare professionals regarding ASD is limited in LAMIC settings (see, e.g., Bakare, Agomoh, et al., 2009; Bakare, Ebigbo, et al., 2009; Bakare et al., 2015; Igwe et al., 2011; Mitchell & Holdt, 2014). For instance, Hutton et al. (2016) found that their sample of medical professionals practicing in the KwaZulu-Natal province of South Africa had a basic understanding of ASD but lacked knowledge about specific behavioural symptoms of ASD. They did note, however, that tertiary medical professionals had a better understanding of ASD than community care professionals.

Hooper (2009) noted that another possible reason for delays in South African families receiving definitive diagnostic statements regarding ASD may be due to elements of the country's public health policy. The policy dictates that concerns and symptoms must first be presented to nursing staff or to general practitioners (GPs). Then, should further consultations with a specialist be deemed necessary, GPs or nursing staff must refer the patient to secondary healthcare institutions (e.g., regional or district hospitals with relevant specialist's present). It is only from there that families can be referred to tertiary healthcare institutions (e.g., generally academic and tertiary hospitals that provide ASD diagnostic assessments and interventions), and it is only after that that a definitive diagnostic statement can be made. My own extensive engagement with healthcare professionals and academic authorities in the field of ASD in the Western Cape province of South Africa suggests that diagnostic expertise exists primarily at a tertiary level. Hence, it is important that nurses and GPs have a better understanding of developmental delays and of ASD, are able to detect these delays, and have

insight and knowledge into the referral process and management of the behavioural symptoms in order to ensure a faster and more efficient diagnostic process (Mubaiwa, 2008).

The ASD diagnostic screening and assessment in LAMICs. Although a great deal of ASD research (see, e.g., Ashwood et al., 2015; Falkmer et al., 2013; Stewart & Lee, 2017; Zwaigenbaum et al., 2015) focuses on the utility and psychometric properties of diagnostic screening measures such as the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2014) and the Social Communication Questionnaire (SCQ; Rutter et al., 2003), and of diagnostic instruments such as the Autism Diagnostic Observation Schedule (ADOS-2; Lord et al., 2012) and the Autism Diagnostic Interview Revised (ADI-R; Rutter et al., 2003), there is no single, universally accepted and used ASD screening and diagnostic tools. This problematic aspect of the ASD early detection process is magnified in LAMICs because research suggests it is especially difficult to diagnose ASD while taking into consideration cross-cultural and linguistic variation, regional differences in SES, and other pertinent factors (Wallace & Pinto-Martin, 2008).

Two recent reviews highlight the lack of robust LAMIC research into ASD diagnostic tools. Stewart and Lee (2017) noted that many studies investigating the use of screening tools in LAMICs do not provide specificity and sensitivity data. Franz et al. (2017) confirmed the lack of peer-reviewed published screening and diagnostic data from LAMICs, noting that only two studies in their review sample were conducted in sub-Saharan Africa. Both studies (one from Tanzania and one from Uganda) reported significant limitations. For instance, although a screening tool (23-question screener; 23Q) was successful in identifying high risk ASD children in a Ugandan sample, no full-length standard tool was used to confirm the diagnostic impressions.

To my knowledge, only three small studies have examined the utility of ASD screening tools in South Africa. Chambers et al. (2017) screened for ASD in an isiZulu sample of 26 children (15 children with no reported developmental delays and 11 children with suspected ASD referred by clinicians; age range 12 -24 months) in KwaZulu-Natal. They used the Early Screening for Autism and Communication disorders tool (ESAC; Wetherby et al., 2012), the CSBS-Developmental Profile Behavior Sample (Wetherby & Prizant, 2002), the Systematic Observation of Red Flags in ASD tool (SORF; Wetherby et al., 2002), as well as the ADOS-2 to confirm diagnosis. Findings suggested that the screening and diagnostic tools successfully identified children with ASD in the sample. For instance, the sample of children that presented with ASD had higher scores on the ESAC and SORF, indicating more reported ASD behaviours and ‘red flags’ in comparison to children without

developmental delays; ESAC mean scores were 32.60 for the suspected ASD sample compared to 12.50 for the sample without developmental delays.

Data from an unpublished Master's thesis by Stephens (2012) indicated the potential utility of the M-CHAT for use in South Africa. The pilot study sample consisted of 64 parents of children with diagnosed ASD ($n = 16$), children diagnosed with other developmental disorders ($n = 8$), and typically developing children ($n = 40$), aged 18 months to 4 years 11 months. Findings indicated that the M-CHAT was able to successfully distinguish between (a) ASD and typically developing children, and (b) ASD and other developmental disorders (aside from one participant). However, further validation of this measure was recommended given the small sample size.

Another unpublished Master's thesis by Basson (2017) also gave evidence for the utility of another low-cost and easy-to-administer screening tool (Autism Spectrum Disorder Screening Questionnaire [ASDSQ]; De Vellis, 2012) in South African ASD samples. The sample consisted of 16 children (aged 6 – 9 years); 8 ASD-diagnosed children and 8 neurotypical children. Findings indicated that the ASDSQ was able to successfully identify ASD behaviour within the sample; all 8 children diagnosed with ASD were distinguished from the 8 neurotypical children using the ASDSQ. However, the small sample size indicates the need for further validation of this measure.

The lack of ASD screening and diagnostic tools that are fit for purpose in LAMICs like South Africa is extremely problematic given that early screening reduces the average age of detection and also gives access to early intervention, which can, in turn, reduce family stress and improve outcomes for both the child and the family (Fillipek et al., 2000; Koegel 1992; Zwaigenbaum et al., 2015).

Aside from the methodological limitations with the tools used to diagnose ASD, the need for a multi-disciplinary approach to ASD diagnosis is also found in the literature both globally and in South Africa (Siklos & Kerns, 2006; Taylor et al., 2016). In South Africa, an ASD report from Solidarity Helping Hand (2011) noted a need for such an approach, however, such multi-disciplinary teams (e.g., consisting of neurologists, paediatricians, psychologists, psychiatrists, and speech and language and occupational therapists) are not readily available. The implications of this paucity of multi-disciplinary diagnosis is that children are often only diagnosed by a single professional rather than a team of trained professionals, increasing the need for parents to go from one specialist to the next. In the state system, single professional diagnosis leads to a time consuming and lengthy process as parents face long waiting times in between appointments. However, for families in the private

sector, multiple specialist appointments are not only a time consuming and lengthy process but also costly.

Current healthcare: Interventions and therapies for ASD. A wide range of interventions and supports have been reported in the ASD literature ranging from alternative therapies (e.g., music and equine therapy) to evidence-based interventions (e.g., Picture exchange communication system [PECs] and social skills training; for a review, see Wong et al., 2015). However, the findings from such studies require replication using larger sample sizes to determine the efficacy of the interventions (see, e.g., Howlin et al., 2009; Mandell et al., 2005; Wong et al., 2015). Medication use is commonly reported in the ASD literature (see, e.g., Hollander et al., 2003; Madden et al., 2017; Spencer et al., 2013; Wong et al., 2015). For instance, Mandell et al., 2008 reported that 56% of the sample used one type of medication, with 20% prescribed more than 3 types of medication, concurrently. Furthermore, the most commonly reported medication included neuroepileptic drugs (31%), followed by antidepressants (25%) and stimulants (22%). The financial burden associated with interventions is also commonly reported (see, e.g., Jarbrink et al., 2003; Liptak et al., 2006; Sharpe & Baker, 2007).

There are limited peer-reviewed published studies on interventions in LAMICS. In South Africa, one study has examined the well-known evidence-based Picture Exchange Communication System (PECS) intervention program for children with ASD. Findings showed improved requesting and length of verbal utterances, however, it was only a pilot study with two participants thus requiring replication with a larger sample (Travis & Geiger, 2010). Louw et al. (2013) reported on medication use in a South African sample of 65 children with ASD; 24.6% of the sample used at least one type of medication with antipsychotics being the most commonly reported type of psychotropic. However, no other research has comprehensively examined the varying types of interventions (or the efficacy of such support), in a South African sample of ASD children. Given the benefits of early interventions for overall outcomes in ASD, not knowing what is (and is not) available, or effective, in South African communities is problematic when trying to improve intervention service provision.

Educational resources for ASD-diagnosed children. In the international literature, several studies examine a wide variety of interventions and supports available to children with ASD at school and outside of the schooling structure. These include social skills training, social stories, sensory integration, and cognitive-behavioural modification (see, e.g., Hess et al., 2008; Kasari & Smith, 2013; Machalicek et al., 2007). However, once again, the

varying types of interventions and lack of research on their efficacy makes determining which intervention services are available, appropriate and effective, challenging.

Similar to the lack of research on the diagnostic process and current healthcare supports in LAMICs, there is paucity of information on educational resources in such contexts. In South Africa, according to the ASD report by Solidarity Helping Hand (2011), the World Health Organization (WHO) reported that, in 2011, approximately 2.2-2.6% of South African school children had a learning disability, with only 16% percent of these attending Learners with Special Educational Needs (LSEN) schools. Furthermore, a survey within the ASD report found that most LSEN schools are situated in urban areas (Stacey & Jacklin, 2011). This situation is problematic for ASD children living in under-resourced peri-urban and rural areas, who do not have access to special schools and thus require alternative schooling (e.g., home schooling) or boarding facilities.

Regarding ASD specific schools, data from unpublished Master's theses noted a limited availability of suitable ASD specific schools, with most schools being considered elitist and unaffordable. Furthermore, with a lack of inclusion in mainstream schooling, ASD children are required to attend special needs schools, as there is nowhere else for them to go (Balfour, 2007; Swanepoel, 2003). As a result of these problems, many parents of children with ASD turn to home schooling or private schooling. Similar findings concerning schooling for children with ASD (i.e., lack of ASD specific schools and inclusion in mainstream classes) have been reported in European and American studies (Dymond et al., 2007; Nesbitt, 2000; Renty & Roeyers, 2006).

Given that most studies focusing on ASD service delivery primarily concern children with ASD, a neglected focus in the literature is the provision of services to adults with ASD. Autism does not cease to exist after childhood, and adults with ASD have a different set of special needs and required supports to help achieve independence (Hendricks, 2010). Furthermore, adults with ASD service delivery experiences, such as information regarding available, appropriate, and effective childhood services, may help address some issues present with services for children with ASD (Dymond et al., 2007).

Service delivery to adults with ASD. The limited research examining services provided to adults with ASD has, typically, focused on samples from the United Kingdom, North America, and Canada (Howlin et al., 2005; Howlin & Moss, 2012; Lattimore et al., 2002; Shattuck et al., 2011; Taylor et al., 2012). Only one peer-reviewed study to date has examined transitional services for young adults with ASD in South Africa. However, the study presents only the perspective of professionals, and of parents of young adults with

ASD. No study, to my knowledge, has examined actual adults with ASD service delivery experiences.

Occupational resources and supports, and in turn the amount of independence individuals have, is the predominant focus of service delivery experiences of adults with ASD. This leaves other aspects of service delivery underserved (e.g., current healthcare, supports and interventions). However, given the heterogeneity of ASD, it is important to conduct a comprehensive examination of all supports and services to try determine which interventions and services provide the best outcomes for an ASD-diagnosed individual (Taylor et al., 2012).

Ongoing healthcare resources. Adults ASD current healthcare findings focus on interventions and supports available to adults with ASD, and the financial burden associated with such treatments. A systematic review by Lorenc et al. (2017) noted that exposure to certain cognitive-behavioural therapies and social skills interventions has a positive impact on social relations, autism-related symptoms, and empathy of adults with ASD. However, few previously published studies report on actual therapies, interventions, and supports used by adults with ASD. Furthermore, studies in this area report inconsistent findings and varying methodologies (e.g., some studies make use of case studies whereas others have large sample sizes, and some use quantitative measures, whereas others use qualitative measures; Cunningham, 2014; Gantman et al., 2012; Hillier et al., 2007b; Laugeson et al., 2015; McVey et al., 2016). Given the inconsistencies and methodological differences, it is challenging to determine what supports and interventions are currently being used by adults with ASD, or the efficacy of such treatments. Aside from the noted limitations, studies report high costs associated with intervention and support services (Sharpe & Baker, 2007; Sheinin, 2006). There is no published research regarding the availability and use of interventions and supports to adults with ASD in South Africa.

Occupational resources. Findings indicate inadequate services relating to employment and independent-living arrangements for young adults with ASD (Howlin et al., 2005; Howlin & Moss, 2012; Shattuck et al., 2012; Taylor et al., 2012). Poor service provision at this stage is problematic given that the years after leaving school are a fundamental time for young adults to build a solid foundation to enable a positive transition into adulthood (Shattuck et al., 2012). Employment is noted as a challenging achievement for adults with ASD; a recent study by Roux et al. (2013) reported only 53% of adults with ASD were employed in comparison to 62-80% of adults with other disabilities. Furthermore, of those that are employed, findings suggest that adults with ASD work fewer hours and earn

less than adults with other disabilities (Cimera & Cohen, 2009; Lawer et al., 2009). Thus, it is essential to identify beneficial and effective services that allow an adult to obtain successful employment, which may in turn, increase the potential for independent functioning (Taylor et al., 2012).

In the literature, two types of employment are generally reported by individuals with a disability; sheltered employment and supported employment. In sheltered employment, individuals generally report receiving lower wages and work in a segregated group setting with other individuals with a disability. In supported employment programs, individuals work in an integrated setting but receive on-site workplace support and training. In ASD literature, sheltered and supported employment programs have reported high levels of success in meeting the specific needs of individuals with ASD (Garcia-Villamizar & Hughes, 2007; Wehman et al., 2012). However, due to limited research, the success of these programs must be interpreted with caution.

Vocational rehabilitation (VR) services are a formal system that provide support designed specifically to help individuals with disabilities (including adults with ASD) in locating and maintaining employment (Chen et al., 2015; Hendricks, 2010; Howlin et al., 2005; Shattuck et al., 2012; Taylor et al., 2012). Such services include vocational guidance, training, job-placement, and support in the workplace. However, findings suggest that services offered through VR programs for adults with ASD are more expensive than VR services provided for other disabilities and are inadequate in providing the necessary support when locating appropriate employment (Cimera & Cowan, 2009; Lawer et al., 2009). However, despite advances in promoting VR services and supported work for individuals with disabilities globally, only a limited number of individuals work in sheltered settings; most are unemployed (Lattimore et al., 2006; Taylor et al., 2012).

An example of a VR service for adults with ASD, particularly those with more challenging ASD symptoms and behaviours, is employment behavioural training. For instance, this training may focus on either identifying task preferences or teaching specific job-related behaviours within a supported work framework (Shattuck et al., 2012). Task preference assessment identifies work preferences for adults with severe disabilities beginning a supported job. This form of service ensures that individuals with a disability have the option to express and obtain their preference of work (Lattimore et al., 2002). Teaching specific job-related behaviours on the other hand occurs on-site, with the individuals receiving instructions while completing their work. A review by Shattuck et al. (2012) suggests that work-place behavioural interventions are effective. With employment leading to

greater independence, which in turns provides the basis for an improved quality of life, it is essential for adults with ASD to obtain and maintain successful employment (Hendricks, 2010; Taylor et al, 2012). There is no previously published research on occupational resources for adults with ASD in South Africa.

Impact of service delivery on QoL. For individuals with disabilities, as well as their families, QoL is an important outcome of service delivery. Inadequate and problematic service delivery experiences can cause frustration and added stress for individuals and family. However, there are limited findings examining the association between aspects of ASD service delivery and the impact it may have on psychological functioning and overall QoL in individuals with ASD and their families.

Impact of service delivery on QoL: Parents of children with ASD. Previously published research emerging from the UK and Canada has investigated the association between parents' psychological state (e.g., levels of stress and depression) and their service delivery experiences. For instance, high levels of parental stress were associated with a parent reports of a poor collaboration between professionals and a greater number of professionals consulted (Mansell & Morris, 2004; Moh & Magiati, 2012; Siklos & Kerns, 2007). However, findings have also suggested that chronic parental stress is associated with the severity of ASD behaviours and symptoms (Dempsey & Keen, 2008; Hastings & Brown, 2002; Ingersoll & Hambrick, 2010; Miranda et al., 2019). Given the above reported association, is important that researchers consider the severity of ASD behaviours when investigating the extent to which elements of service delivery impact QoL of parents of children with ASD.

Furthermore, there are inconsistencies present in the literature concerning the impact service delivery has on the psychological distress of individuals with ASD and their families. For instance, findings suggest that both formal (e.g., medical services and interventions) and informal (e.g., family assistance and support groups) services may help reduce stress and depression in parents of children with ASD (Benson, 2006; Hastings & Brown, 2002; Weiss, 2002). On the other hand, Rivers and Stoneman (2003) found that increased interaction with formal services does not influence the emotional wellbeing of parents of children with ASD, and in some cases, may actually cause elevated stress and depression. Therefore, in order to obtain a complete understanding of service delivery and QoL experiences of parents of children with ASD, and address the gaps and discrepancies within the literature, researchers must not only investigate the association between QoL and service delivery, but also the potential influence of additional impacting factors such as ASD severity and socioeconomic status.

Impact of service delivery on QoL: Adults with ASD. Research suggests that overall QoL for adults with ASD can be improved by changing certain environmental factors, including aspects of service delivery. For instance, Kamio et al. (2012) found that early diagnosis is associated with improved QoL for adults with ASD. With early diagnosis, children with ASD may receive support and interventions at an optimal age for development which in turn may lead to improved overall outcomes in adulthood. However, the authors did not report an association between other service utilisation (e.g., receiving regular professional advice, participating in some therapeutic programs, and receiving educational aid) and QoL in their adult ASD sample. A review by Hendricks (2010) reported that secured employment and income, which provides adults with ASD more independence and stability, leads to improved overall QoL (Hendricks, 2010).

Furthermore, Renty and Roeyers (2006) identified a difference between the impact actual received support and perceived support have on QoL of adults with ASD. Typically, studies have not distinguished between actual received services versus perceived support services. Renty and Roeyers (2006) were the first to distinguish between the two types of services as well as between informal (e.g., family support and support groups) and formal (e.g., medical services, supported employment and interventions) support services in adults with ASD. With regards to formal support, findings indicated no significant association between received services and QoL, but a significant association between the number of unmet services and QoL. Therefore, it is important to determine not only what services individuals are receiving but also the services they feel are lacking in their communities.

In contrast to received support services, perceived support refers to the perception that one's network and surroundings are ready to provide support and aid if needed. Regarding informal support, Renty and Roeyers (2006) and Hansson et al. (2003) found that the QoL and personal wellbeing of adults with ASD was strongly associated with the perception that support was available rather than the actual availability of support services. These findings suggest that psychological distress in adults with ASD may be reduced when an individual perceives support as adequate. Therefore, when examining the impact services have on the QoL of adults with ASD, research must also take into account the individual's perception of available support.

Service delivery and QoL: South African Context. There are three key problems with the lack of research within a South African ASD population. First, the lack of comprehensive QoL findings regarding families with children with ASD makes it difficult to establish whether these families have poor QoL, or which areas of their life they view most

negatively. Second, without understanding the limitations and problems present with aspects of ASD service delivery in South Africa, it is difficult to establish which areas need improvement. Third, given the possible association between aspects of ASD service delivery and QoL (reported in the literature), it is essential to examine this association in a population from a LAMIC like South Africa while taking into consideration all the additional burdens present in such communities. For instance, given the healthcare burdens present in South Africa, findings indicate that prioritizing of individuals with infectious diseases (such as HIV and TB) happens to the detriment of management of other neuro-developmental disorders and disabilities, such as ASD, that are not associated with high mortality rates, but that nonetheless cause significant and lifelong impairment (Mubaiwa, 2008). The gaps and limitations in the adult and parent ASD literature show a fundamental need for further ASD research, using a culturally and socioeconomically diverse South African ASD sample, focusing on (a) services available to children and adults with ASD, (b) QoL of parents of children with ASD and of adults with ASD, and (c) the association between service delivery and QoL while taking into account additional factors such as ASD severity, family resources, and socioeconomic status.

CHAPTER 3: Study 1 – Service Delivery and Quality of Life Experiences of Adults with Autism Spectrum Disorder

Abstract

Introduction. No published study of adults with autism investigates both quality of life (QoL) and access to clinical, educational, and social services. Indeed, few studies focus on either QoL or service delivery independently. Moreover, extant research is limited because studies (1) emerge almost exclusively from high-income countries in the global north, and (2) do not use comprehensive measures of QoL (e.g., they focus on individual psychological distress and ignore social support structures) or of service delivery (e.g., they focus on employment-related services and ignore healthcare). The lack of research emerging from low- and middle-income countries is problematic because (1) individuals in such countries are likely to face additional burdens (e.g., poverty, infrastructural resource limitations) that may affect the services they receive and their QoL, and (2) in the absence of relevant data, one cannot identify specific areas of service delivery or QoL that should be targeted for improvement.

Objectives. This mixed-methods descriptive and relational study examined self-reported QoL and experiences of service delivery in a sample of South African adults with ASD.

Methods. Fifteen adults with ASD completed a set of questionnaires that measured psychological distress, perceived social support, multiple aspects of QoL, and several facets of service delivery. Three provided qualitative data, responding to open-ended questions that sought to provide a more in-depth perspective on the shortfalls of ASD service delivery.

Results. Most participants reported moderate anxiety, high depression, and high stress levels, all of which were associated with lower levels of perceived support and poorer QoL. Both quantitative and qualitative data suggested a marked lack of services available to adults with ASD (reflected in, for instance, relatively late age of diagnosis, a lack of standard early interventions, little ASD-specific training in medical staff, high cost of appropriately focused interventions, an almost complete absence of vocational/career training or supported employee training, and very little workplace support for ASD-related structural adjustments).

Conclusions. This is the first study to show that South African adults with ASD experience high levels of psychological distress, concomitantly poor QoL, and shortfalls in almost all aspects of service delivery to them. Further research building on these findings is essential to help ensure that these adults receive properly-targeted interventions and appropriate and much needed-support.

Introduction

The specific aims of this study were to provide a preliminary investigation of (a) the support and services currently provided to adults with ASD in South Africa, and (b) the quality of life (QoL) of those adults. Although numerous previously published studies have gathered parent reports regarding issues of service delivery and QoL in samples of children with autism (see, e.g., Abbeduto et al., 2004; Howlin et al., 2009; Mansell & Morris, 2004; Moh & Magiati, 2012; Montes & Haltermann, 2007; Siklos & Kerns, 2006; Shu, 2009), few investigations have examined these issues in samples of adults with autism. Moreover, the scope of focus within the small group of adult ASD studies investigating service delivery is limited, with a primary concentration on employment and independent living (see, e.g., Howlin et al., 2005; Shattuck et al., 2011).

This lack of comprehensive service delivery research is problematic given that adults with autism face various challenges (e.g., wide range of behavioral, emotional, and intellectual impairments, comorbid psychiatric diagnoses) that may impact the number and type of services they require over and above basic employment and shelter. If those services are not available, or are available but are not effective, the patient's already-compromised QoL might be further diminished.

Published studies investigating QoL in samples of adults with autism are also methodologically limited. For instance, they typically use brief measures that focus on individual aspects of QoL (e.g., stress, depression, anxiety) rather than a comprehensive tool (e.g., the WHOQOL-BREF; WHO, 1996) that captures multiple aspects of QoL and that thereby provides an assessment of overall QoL. To my knowledge, only five studies in this literature have used such a comprehensive measure (Jennes-Coussens et al., 2006; Kamio et al., 2012; McConachie et al., 2018; Saldana et al., 2009; Renty & Roeyers, 2006). All five studies reported poor QoL in adults with ASD, particularly in the domain of social relationships.

Of note here is that McConachie et al. (2018) found the WHOQOL-BREF to have good psychometric properties in an adult ASD sample ($N = ##$) recruited from **WHERE**. For instance, the study reported acceptable structural validity of the WHO factor structure for use in autistic samples, and excellent internal consistency ($\alpha = .93$) when compared to UK population data. Convergent and divergent validity, assessed by examining associations between scores on individual WHOQOL-BREF domains and those on measures such as the Hospital Anxiety and Depression Scale (HADS), Interpersonal Support Evaluation List-12

(ISEL-12), total score, and the Craig Hospital Inventory of Environmental Factors-Short Form (CHIEF-SF), also proved excellent.

Of further note with regard to the McConachie et al. (2018) study is that the authors examined the WHO disabilities module and, after extensive interactions with the autism community, successfully created nine additional autism-specific QoL questions. This aspect of the study's findings emphasized the importance of using autism-specific alongside standard measures to complement and enrich QoL research in adults with ASD.

Another pertinent issue in the adult ASD literature is that study samples consist primarily of participants from high income countries (HICs), with research from low- and middle-income countries (LAMICs) lacking. Generalization of results from HICs to LAMICs is problematic because residents of the latter frequently face numerous burdens (e.g., poverty, community-based violence, lack of adequate, available, and/or accessible health resources) not often encountered in the former. These burdens may in turn have a negative impact on service delivery and on the overall QoL of adults with autism. Hence, to gain a better understanding of the way in which poor service delivery might have negative effects on quality of life in ASD, it is helpful to add investigations of LAMIC samples to already-published investigations of HIC samples.

South Africa is a LAMIC whose citizenry face numerous political, economic, and social challenges (e.g., unstable political climate with extensive misappropriation of government funds, widespread unemployment, and high levels of substance abuse). In such a context, it is essential to understand the strengths and weakness of services provided to adults with autism, the way in which the aforementioned burdens and challenges affect the availability and quality of those services, and, ultimately, how service delivery affects QoL. Currently, there is no published research on service delivery and QoL of adults with autism in South Africa.

The current study seeks to address these limitations of the extant literature. Specifically, I set out to gather self-reports from South African adults with ASD, capturing overall QoL by using a comprehensive instrument as well as brief tools focused on stress, depression, anxiety, and social support, and examining multiple aspects of service delivery (including diagnosis, education, health care, education, employment, and social impact).

Methods

Research Design and Setting

This descriptive study used a mixed-methods design, with both quantitative and qualitative data collected. Mixed-methods research designs allow investigations to (a) obtain multiple individual and diverse viewpoints about similar experiences, (b) provide a more complete representation of experiences than either quantitative or qualitative designs alone, (c) use one form of data (usually qualitative) to clarify and elaborate on knowledge gained from the other form of data (usually quantitative), and (d) counter weaknesses inherent in one method (e.g., lack of generalizability of qualitative data) by including another method (see review; Caruth, 2013).

Small-*N* studies, such as this, are well suited for a mixed-methods approach because such designs allow for the relatively small number of individual voices to be expressed both singly and in aggregate. Moreover, such a design was appropriate for use in the current study because, for instance, the chosen standardized quantitative instruments are limited in their ability to allow elaboration on individual experiences regarding problems with particular aspects of service delivery and the impact those have on everyday living. Adding a qualitative element therefore allowed individual experiences to be represented, and for themes that emerged from the quantitative data to be clarified.

Participants were interviewed either electronically or in a private room in the UCT Department of Psychology or their place of employment. All data were collected between April 2014 and June 2015.

Participants

I used convenience sampling to recruit participants. Specifically, I contacted non-governmental organizations (NGOs) and online support groups and scoured existing databases of participants in studies conducted previously at UCT (Ing & Thomas, 2011; Hoogenhout et al., 2017). The specified inclusion criteria were: (a) age ≥ 18 years, and (b) self-reported current clinical diagnosis of ASD, confirmed previously by an appropriately qualified clinician. Individuals were excluded from participation if they were non-verbal or unable to read/understand or respond to basic questions.

The final sample from which quantitative data were collected consisted of 15 adults with ASD (10 men, 5 women) ranging in age from 19 to 48 years. Three of the 15 (all women, ranging in age from 41 to 48 years) comprised the sample from which qualitative

data were collected. The reason for the small sample size for the quantitative data is explained in detail in the limitations section of the study.

Measures

Sociodemographic questionnaire. This instrument (see Appendix A) was designed specifically for the purposes of this study. It incorporated original questions as well as items from the Hollingshead Four Factor Index of Social Status (Hollingshead, 1975), and was available to be completed in either English or Afrikaans. It obtained biographical information (e.g., age, sex, race, home language, family structure), medical information (e.g., history of mental health diagnoses and/or treatment), and details about the participant's socioeconomic status (e.g., current employment status, highest level of education, annual income, and household assets).

Quantitative measures. The instruments described in this section were translated from the original English into Afrikaans by a bilingual member of our research laboratory, and then back-translated into English by another bilingual (first-language Afrikaans) individual. Hence, they were available to be completed in either English or Afrikaans.

Center for Epidemiologic Studies-Depression Scale (CES-D). This 20-item scale was developed specifically for assessment of depressive symptomatology in community samples (Radloff, 1977; see Appendix B). It is an amalgamation of items from the Beck Depression Inventory (Beck, 1996), Zung Self-Rating Depression Scale (Zung, 1965), Raskin Depression Scale (Gardner, 1968), and the Minnesota Multiphasic Personality Inventory depression scale (Hathaway & McKinley, 1942). The possible range of scores is 0-60, with higher scores representing more severe levels of depression. The developers recommend using a cut-off score of 16 to indicate the presence of clinical levels of depression. In this study, I used the CES-D to measure the level of depression experienced by respondents over the 2 weeks prior to administration.

Radloff (2000) reported that the CES-D's internal consistency reliability was .85 for community populations and .90 for psychiatric samples. This scale has been used successfully to measure depression in HIV-positive South African adults (Singh et al., 2008). That study reported diagnostic sensitivity of 91% at a cut-off score of 16. The CES-D has also been used successfully in a study examining stress in mothers and fathers of children with ASD (Davis & Cater, 2008). That study reported high internal consistency for both mothers (Cronbach's $\alpha = .91$) and fathers (.89).

Beck Anxiety Inventory (BAI). This instrument (Beck & Steer, 1993; see Appendix C) is a widely used self-report measure of the presence and severity of current anxiety-related symptoms in adults. Respondents are asked to rate the extent to which they have been bothered by each of 21 symptoms in the preceding week. For each item, the respondent must select whether the symptoms bothered him/her *Not at all* (score of 0), *Mildly* (1), *Moderately* (2), or *Severely* (3). An overall score is calculated by summing the score for each item. Scores ranging from 0-7 are interpreted as indicative of minimal anxiety, 8-15 mild anxiety, 16-25 moderate anxiety, and 23-63 severe anxiety.

This instrument shows good internal consistency (Cronbach's $\alpha = .90$) and test-retest reliability (.83; Beurs et al., 1997). Steele and Edwards (2008), assessing the psychometric properties of a Xhosa-translated BAI in a South African sample, reported good internal consistency (Cronbach's $\alpha = .92$). Regarding the instrument's use in ASD samples, the BAI was part of a study examining relations between sensory processing sensitivity, alexithymia, autism, depression, and anxiety (Liss et al., 2008). That study reported Cronbach's α of .88.

Perceived Stress Scale (PSS). This 10-item instrument (Cohen et al., 1983; see Appendix D) is the most widely used instrument for measuring self-reported perception of current stress in community-dwelling individuals. Specifically, the PSS measures the degree to which respondents consider particular situations in their lives to be stressful. Each PSS item focuses on the respondent's feelings and thoughts over the past month and is rated on a 5-point scale ranging from '*never*' to '*very often*.' An overall score is obtained by reversing response scores (e.g., 0=4, 1=3, 2=2, 3=1, 4=0) for the four positively stated items (items 4, 5, 7 and 8) and then summing across all scale items. The developers recommend interpreting the PSS total score as follows: 0-13, low stress; 14-26, moderate stress, 27-40, high stress. In the current study, I used the PSS to measure participants' current stress levels.

The instrument shows good internal reliability (Cronbach's $\alpha = .84$ to $.86$; Cohen et al., 1983). The PSS has been used in South African research examining the social and economic correlates of depressive symptoms and perceived stress in low-income adults (Hamad et al., 2008). That study reported a Cronbach's α of .72. Regarding its use in ASD samples, the PSS has been used successfully to examine stress in mothers with autism (Phetrasuwan & Miles, 2009). That study reported strong internal consistency reliability (Cronbach's $\alpha = .94$).

Interpersonal Support Evaluation List (ISEL). This 40-item scale (Cohen et al., 1985; see Appendix E) assesses the perceived availability of various kinds of support. The instrument is divided into four subscales: tangible support (perceived availability of material

aid); belonging support (perceived availability of others that one can do something with); self-esteem support (perceived availability of a positive comparison when comparing one's self to others); and appraisal support (perceived availability of someone to talk to about one's problems). On each item, participants rate, on a 4-point Likert-type scale ranging from 'definitely true' to 'definitely false', to what degree the statement applies to them. Hence, the total score can range from 0–120, with higher scores suggesting a greater amount of perceived support. In this study, I used the ISEL to measure the amount of perceived social support adults with ASD have available to them.

The instrument shows good internal reliability (Cronbach's $\alpha = .88$ to $.90$; Cohen et al., 1985). The ISEL has been used in previously published QoL research concerning adults with ASD (Renty & Roeyers, 2006). That study reported internal consistency reliability of $\alpha = .91$. The ISEL has not been used in previously published South African studies.

WHO Quality of Life Scale (Brief Version). This 26-item instrument is an abbreviated version of the World Health Organization (WHO) QoL assessment scale, which uses 100 items to assess overall life satisfaction. The full scale was developed collaboratively, using adults from more than 15 cultural backgrounds, to assess subjective QoL and living conditions (WHO, 1996; see Appendix F). In this study, I used the brief instrument to measure subjective perception of, and satisfaction with, QoL. The scale generates four domain scores (Physical Health, Psychological, Social Relationships, and Environment) as well as a total QoL score, which can range from 26–130.

The psychometric properties of the brief version of the instrument are comparable to those of the full version. Overall, it appears to be a sound, cross-culturally reliable and valid instrument for measuring QoL (Gururaj et al., 2008; Skevington et al., 2004). It has been translated into Taiwanese and used to examine the QoL of caregivers of children with ASD (Shu, 2009). That study reported internal consistency estimates ranging from $.70$ to $.77$ for the four domain scores. The WHOQOL-BREF has been used in a previously published South African study of epileptic patients (Lundgren et al., 2006).

World University's Network (WUN) Scoping Survey: Adult version. I adapted World University's Network (WUN) Scoping Survey (see Appendix G), which was originally designed to collect data from parents about their children, to gather self-reports regarding the support and resources (both public and private) provided to adults with ASD. This survey was created for the purpose of studies such as this one. Given its relatively newness and survey-based characteristics, there are no published psychometric properties.

Appendix H describes, in detail, the differences between the original version of the instrument and the adult-adapted one used here. Broadly speaking, the sections adapted for adults include questions addressing: (1) sociodemographic and clinical characteristics (i.e., these now gather background information about the reporting adult); (2) healthcare system (i.e., information regarding age of diagnosis and health care); (3) community support and educational resources; (4) occupational resources; and (5) impact on daily living (i.e., information on the impact of ASD diagnosis on social relations and household budget). Questions from all five domains were administered to allow for examination of all major elements of service delivery to adults with ASD.

Qualitative measures. I created 6 open-ended questions that allowed participants to share more detailed personal information concerning their experiences of service delivery to adults with ASD in South Africa (see Appendix I). These questions focused on problems, concerns, and frustrations with current services, and impact of poor service delivery (or poor-quality services) on various aspects of their lives. Again, these questions were available to be answered in either English or Afrikaans.

Procedure

Quantitative data collection. Individuals interested in participating responded to my online advertisements or personal telephone calls. Upon first contact, I gave them a summary of the study's aims and procedures. Those who maintained their interest were either, depending on their preference, scheduled for an individual in-person appointment or emailed a URL that linked to a SurveyMonkey (www.surveymonkey.com) page where the questionnaires were hosted. Eventually, 10 participants completed the questionnaires online, and 5 completed them at an in-person session that lasted up to 90 minutes.

Four of the five in-person sessions were hosted at the participant's place of employment; the other was hosted at a psychology research laboratory. Only one researcher (either me or a fellow postgraduate psychology student) and the participant were present during the sessions. The session proceeded as follows: Immediately after the participant arrived at the study venue and was settled at a desk, I obtained written informed consent (see Appendix J). Thereafter, they filled in the sociodemographic questionnaire. This step ensured that the participant met the study's eligibility criteria before completing any other instruments. If the participant met eligibility criteria, the researcher administered the BAI, CES-D, ISEL, PSS, WHO QoL, and WUN Survey, in that order. All questionnaires, aside from the newly developed WUN survey, were administered according to conventional

procedures outlined in the literature and in the various test manuals. Participants who became fatigued during the session were encouraged to take a break and to continue only after they were sufficiently rested.

The participants who completed the questionnaires online accessed the survey site from wherever was convenient for them. The first page of the survey obtained informed consent. Subsequent pages presented the questionnaires in the same order as at in-person administration. Participants were allowed to complete different pages of the online survey at different times (i.e., they could log out after completing a portion, and then log back in to complete the set).

Qualitative data collection. All participants in the sample of 15 were asked whether they would like to participate in the qualitative aspect of the study. Only three replied in the affirmative. Two participants were administered the set of open-ended questions at their place of employment; the other preferred to reply to the questions via email.

Regarding the in-person administrations, I completed both of them using semi-structured interviewing techniques and taking detailed handwritten notes as the participants responded to each of my questions. I allowed the participants to provide as much detail as they liked in their responses. When responses were unclear or if I required further detail, additional prompts were provided. Each session lasted approximately 90 minutes.

Data Management and Statistical Analyses

Quantitative data. I used SPSS (version 25) to complete all analyses, with α set at .05 for all decisions regarding statistical significance. The analytic plan comprised these four major steps:

1. I generated detailed descriptive data for each key sample sociodemographic characteristic
2. I generated similar descriptive data for each of the psychological outcome variables derived from the self-report questionnaires (see Table 1). Furthermore, on the WHOQOL-BREF domain scores, the calculated mean scores were multiplied by 4 as to be directly comparable with scores derived from the full WHOQOL-100.
3. I examined the strength of bivariate associations (using Pearson's r correlation coefficient) within the set of psychological variables.
4. I conducted a detailed descriptive analysis of data from the adult-adapted WUN service delivery survey, with separate analyses for each of the instrument's four

substantive domains (viz., health care, community support and educational resources, occupational resources, and impact on daily living).

Table 1.
Study 1: List of outcome variables and ways in which each was derived

Variable	Derivation / Possible Range
BAI: Total score	Sum across all items; 0-63
CES-D: Total score	Sum across all items (including 4 reverse-scored items); 0-60
ISEL	
Total score	Sum across all items (including 20 reverse-scored items); 0-120
Subscale score: Tangible	Sum across scores on 10 items in the domain; 0-30
Subscale score: Belonging	Sum across scores on 10 items in the domain; 0-30
Subscale score: Self-Esteem	Sum across scores on 10 items in the domain; 0-30
Subscale score: Appraisal	Sum across scores on 10 items in the domain; 0-30
PSS: Total score	Sum across all items (including 4 reverse-scored items); 0-40
WHOQOL-BREF ^a	
Total score	Sum all items; 26-130
Subscale score: Physical	Mean score of 7 items within domain, multiplied by 4; 4-20
Subscale score: Psychological	Mean score of 6 items within domain, multiplied by 4; 4-20
Subscale score: Social	Mean score of 2 items within domain, multiplied by 4; 4-20
Subscale score: Environment	Mean score of 8 items within domain, multiplied by 4; 4-20

Note. BAI = Beck Anxiety Inventory; CES-D = Center for Epidemiologic Studies-Depression Scale; ISEL = Interpersonal Support Evaluation List; PSS = Perceived Stress Scale; WHOQOL-BREF = WHO Quality of Life ^aThe multiplication by 4 here is so that these scores can be directly comparable with scores derived from the full WHOQOL-100.

Qualitative data. I transferred all the handwritten and emailed responses into a single computerized datasheet. I then used thematic analysis (Boyatzis, 1998) to describe the themes that developed regarding service delivery and the impact it has on the lives of adults with ASD in South Africa. If the provided information was going to constitute a theme, I required at least 2 of the 3 individuals who chose to participate in this aspect of the study to respond similarly to a given question.

I chose to use thematic analysis as it allows one to closely examine transcripts and to then identify patterns or themes that emerged within the interviews. Furthermore, given that thematic analysis is not tied to a specific theory like other more complex types of qualitative analysis, I opted to use this method to provide detailed and complex characterisation of the data.

I took an interpretive epistemological stance when conducting the current research. This approach allowed for data collection first and subsequent determination of theories (the themes from the interviews) based on the observed data. Thus, a theoretical sampling strategy was used as the participants were selected based on the phenomenon being studied (i.e., the

services provided to autistic adults). For analyses of the data, I used inductive reasoning as I derived broad-based themes based on specific observations and comments made by the participants during the interview.

Reflexivity. Because the subjective life experiences a researcher carries with him/herself may impact study outcomes (Boonzaier & Shefer, 2006), consideration of these influences is an important aspect of qualitative research. In other words, reflexivity is essential to ensure the researcher continually assesses how his/her life experiences and values influence the study and its findings.

Practical means to achieve reflexivity vary substantially. Not surprisingly, these reflect the nature of the research being conducted, the sociopolitical environment in which it is being conducted, and the socially-determined hierarchical power relations between researcher and participants (Eatough, 2012; Pillow 2003). In this study, the two primary considerations I made in attempting to achieve reflexivity were examining (a) my reason for selecting the research topic, and (b) the influence my own impressions, feelings, and preconceptions may have had on the research during data collection and write up.

Boonzaier and Shefer (2006) argue that a research topic is chosen based on the subjective experiences of the researcher. This is certainly true for the current study. I have been working with children with autism since 2008 and have experienced first-hand the kinds of concerns parents have regarding available therapies and services to children with autism. Similarly, I have noticed the stresses and daily struggles that individuals with autism, as well as parents of children with autism, face. These reflections make it clear that the current research is indicative of my interest in quality of life and service delivery in individuals with autism and their families.

Throughout the course of this research, continuous reflection on my own impressions, feelings, and preconceptions was particularly important given that prior to conducting the study I had heard only negative comments about ASD service delivery in South Africa. This prior experience surely affected, for instance, the wording of my open-ended questions; most questions were posed with a negative reference to service delivery, focusing typically on the problems and challenges adults with autism have faced when obtaining services. To ensure my qualitative data collection was not overly biased by these personal preconceptions, I consulted closely with my supervisors during creation of the questions and ensured that I accommodated their critical feedback.

Ethical Considerations

I obtained ethical approval from the University of Cape Town Department of Psychology's Research Ethics Committee before commencing data collection (see Appendix K).

Consent and confidentiality. All participants provided informed consent for participation. The consent forms assured participants of the confidentiality of their data and of their participation. Furthermore, the information received from the study participants is stored securely; only researchers involved directly in the project, and certain University officials, can view the information.

Risks and benefits. Participants were exposed to minimal physical, social, and psychological risk. They were not asked to perform any potentially harmful tasks. One minor risk was that the participants may have become fatigued during administration of the questionnaires/interviews. To mitigate against that risk, they were encouraged to take breaks as often as needed. A second minor risk is that the questions posed during administration of the questionnaires/interviews may have caused distress for participants. Although no participant reported experiencing any such distress, the research team had plans in place to direct upset or distressed participants to the necessary sources of support. Participants were informed that they could withdraw from the study at any time, with no penalty and with no effect upon clinical or other services being delivered (or potentially being delivered) to them.

Although there are no direct benefits of participation in this research, a greater understanding of the services provided (and those not provided) to individuals with ASD and their families, as well as the impact aspects of service delivery have on the QoL of individuals with ASD and on their families, will help provide key information regarding the shortfalls and limitations of the services provided. This information will help improve future services for individuals with ASD, which may in turn aid in improving the quality of life of individuals with ASD and their families.

At the conclusion of the study, I provided general feedback to all participants in the form of a basic report on the findings.

Costs and compensation. Participants did not incur any costs for participating in the study. Those who completed the study procedures at the research laboratory were reimbursed ZAR100 (approximately US\$9.46 at the time of the study) to cover their travel costs.

Results

Quantitative Analyses

Sample sociodemographic characteristics. The modal participant was English-speaking, right-handed, and single (see Table 2). Participants ranged in age from 19 to 48 years, and most had completed at least 12 years of formal schooling (i.e., had obtained a high school diploma). The age of ASD diagnosis ranged from early childhood (6/7 years) to mid-adulthood (43 years), with most participants ($n = 11$) being diagnosed after the age of 10.

We include descriptive racial data here because the legacy of South Africa's apartheid policies continues to permeate many aspects of life in this country. Under apartheid (i.e., pre-1994, when many of the current participants were children), White people had easier access to higher-quality healthcare and had fewer stress-provoking experiences of oppression and discrimination. Although legislated racial segregation has not existed for more than 25 years, these disparities are, to at least some degree, still present because of historically-engineered imbalances in economic power. (I discuss racially-based disparities in access to services, and in quality of service delivery, in more detail in Chapter 5.) Using the categories employed by the apartheid government (and that continue to be used in South African census data), 14 of the 15 participants in the current sample were classified as White (5 women) while the other participant was Coloured.

Table 2.
Sample Sociodemographic Characteristics (N = 15)

Variable	<i>M (SD) or f</i>
Age	31.73 (8.71)
Sex (Men:Women)	10:5
Home Language (English:Afrikaans:English and Afrikaans)	10:2:3
Handedness (Right:Left:Ambidextrous)	12:2:1
Marital Status (Single:Married:Divorced:Widowed:In Relationship)	10:2:1:0:2
HLOE (Tertiary:High School:Primary School:Other)	7:3:3:2
Annual Household Income (ZAR ^b)	392853.4 (767206.4)

Note. For the variables *Age* and *Annual Household Income*, data are means with standard deviations in parentheses. For all other variables, data are raw numbers. HLOE = highest level of education (Tertiary = 13 or more years; High School = 8–12 years; Primary School = 1–7 years; Other indicates special needs schooling and/or no mainstream-equivalent grades completed).

^bAt the time of the study, the ZAR:US\$ exchange rate was ZAR10.57 to US\$1.

Figure 1 presents details concerning the participants' current employment, with category descriptions following those in the Hollingshead Occupational Scale (Hollingshead,

1975). Of those who were employed, most were described as administrative personnel ($n = 3$) or business managers of medium-sized businesses and lesser professions ($n = 4$). Three participants reported being unemployed, and one was a student.

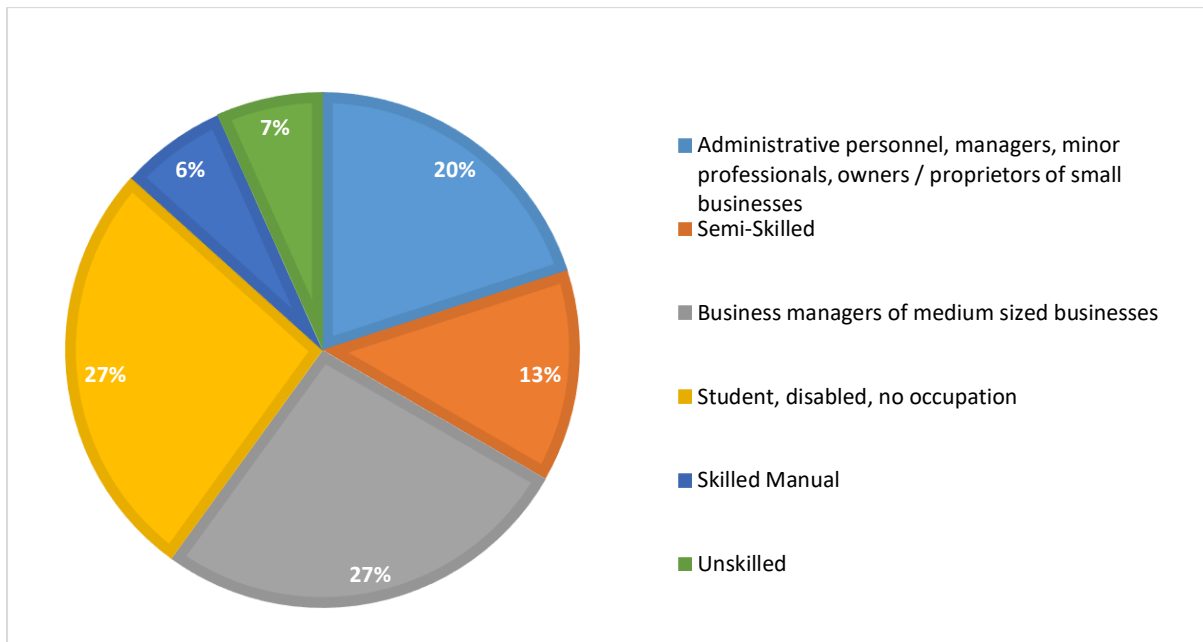


Figure 1. Employment classifications for the current sample of adults with ASD ($N = 15$).

Annual household income ranged from the category of ZAR0–35 000 to that of >R526 000 (see Figure 2). Here, the largest grouping of participants ($n = 4$) was in the lowest possible income range. Of note, however, is that three participants reporting earning more than ZAR526 000 annually.

To put these statistics in context, the most recent available census data indicate that the average annual household income in South Africa is ZAR103 204 per year (De Wet, 2012). More recent and detailed data in this regard are provided in an August 2016 report by one of South Africa's largest financial institutions, Standard Bank ("How many SA households earn more than R200 000 per month", 2016). The report estimated that 62.3% of household incomes fell within the lowest income bracket (viz., < ZAR86 000 per annum), whereas 11.4% fell within the set of middle- to high-income brackets (viz., ZAR400 000 to > 2.36 million per annum). Hence, whereas the lowest-earning 4 participants in the current sample are of typical South African socioeconomic status, the 3 highest-earning participants are not.

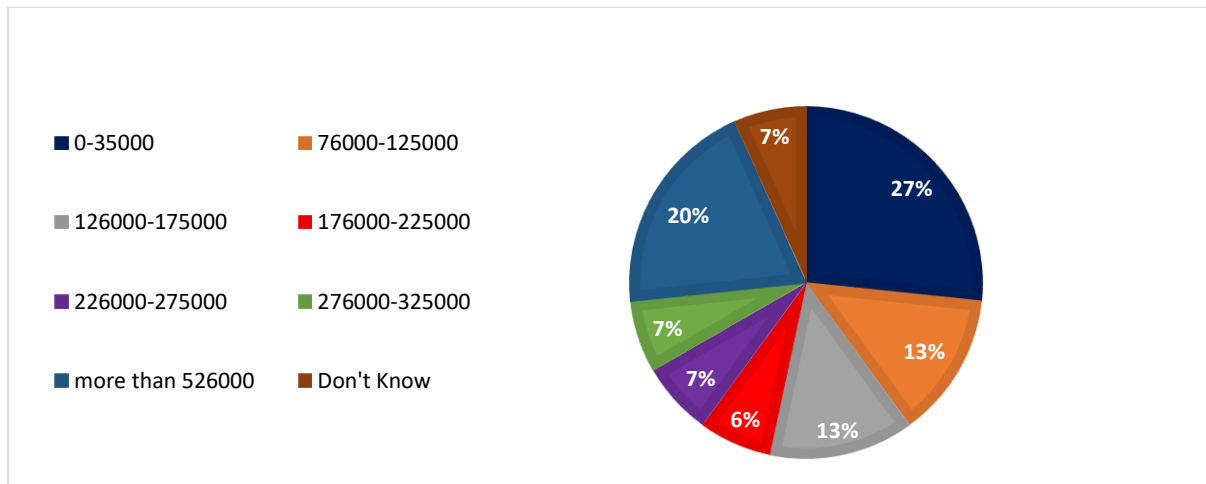


Figure 2. Annual household income ranges for current sample of adults with ASD ($N = 15$).

Most participants reported experiencing at least one concurrent psychiatric or medical condition (see Figure 3). The most commonly reported of these conditions was depression ($n = 9$). Of note here too is that most participants reported using some form of prescription medication ($n = 10$), and almost half ($n = 7$) reported experiencing visual difficulties. More details regarding participants' medical conditions are presented below (see *Part IV: WUN Service Delivery Data*).

In summary, the sociodemographic information presented here illustrates, to some extent, the diverse characteristics of South African autistic adults. For instance, age of diagnosis varied widely, as did occupational status and monthly income. On the other hand, the homogeneity in some variables (e.g., most participants were White and English-speaking, almost all were independent with stable employment) suggests that this small sample may not have been representative of the population of autistic adults in South Africa.

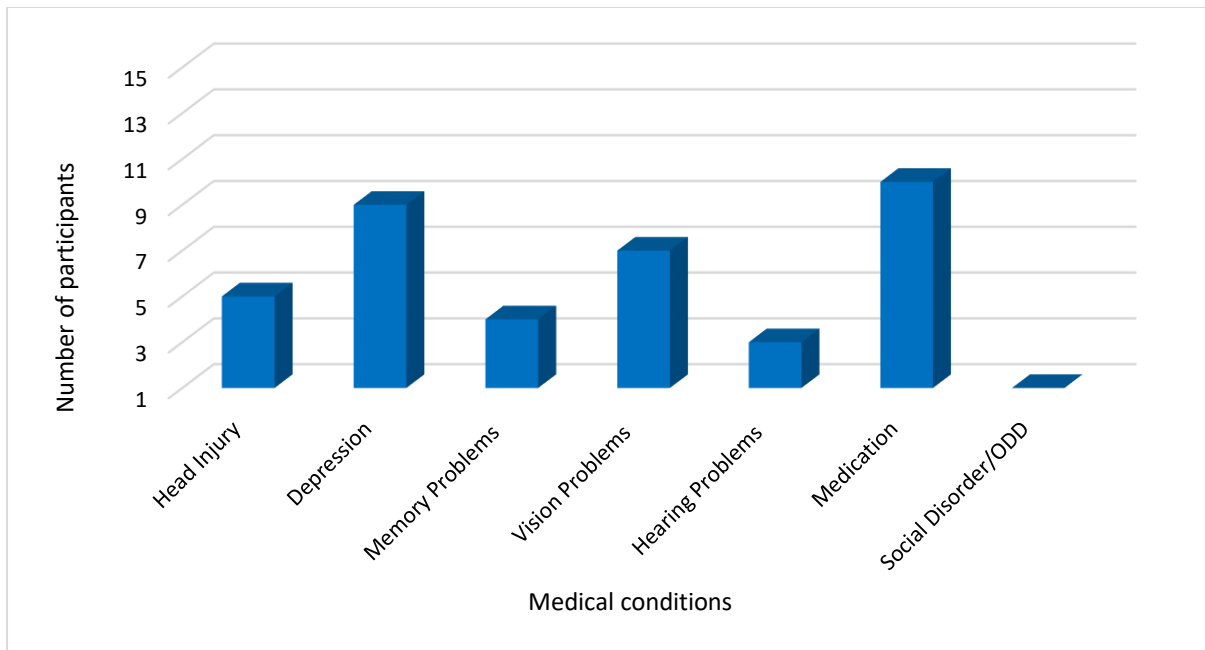


Figure 3. Additional self-reported medical conditions and difficulties for current sample of adults with ASD ($N = 15$).

Sample psychological characteristics. The sample's average BAI score fell in the range conventionally regarded as indicating moderate levels of anxiety (Beck & Steer, 1990). Following the same convention, 8 participants (53.33%) had BAI scores in the range indicating low anxiety, 3 (20%) in the range indicating moderate anxiety, and 4 (26.67%) in the range indicating high anxiety.

The sample's average CES-D score fell above the conventional clinical cut-off score of 16 (Knight et al., 1997; Radloff, 1977). Nine participants (66.67%) scored above that threshold.

There are no standard cut-off scores or descriptive ranges for ISEL scores. Hence, it is somewhat difficult to interpret the reports of the current sample. What is clear, however, is that there was significant variability in individual experiences of interpersonal support. In terms of Total Support, for instance, 3 participants (20%) scored 65 or below (i.e., below the 50th percentile), whereas 4 participants (26.67%) scored 96 or above (i.e., above the 80th percentile). This type of variation reflects the data pattern across the four sub-scales.

The sample's average PSS score fell in the range conventionally regarded as indicating moderate levels of stress (Cohen et al., 1983). Following the same convention, 2 participants (13.33%) scored in the range indicating low stress levels, 8 (53.33%) in the range indicating moderate stress levels, and 5 (33.33%) in the range indicating high stress levels.

I interpreted WHOQOL-BREF scores using the preliminary normative data, based on a sample of 904 community-dwelling residents of the Australian state of Victoria, provided by Hawthorne et al., (2006). Those normative data consist of age- and sex-adjusted means and standard deviations for each domain score. As Table 4 (see Appendix L) shows, in this sample self-reported quality of life was poorest in the domain of Physical Health and best in the Social domain. In fact, the latter domain was the only one in which the sample average z -score held a positive value. Examining individual reports, 9 participants (60%) reported significantly poor quality of life ($z < -1.00$) in the Physical Health domain and 5 (33.33%) reported similarly poor quality of life in the Psychological Health and Environment domains. Somewhat surprisingly given that ASD is often regarded as a disorder of social communication and interaction, only 2 (13.33%) participants reported poor quality of life in Social domain.

Table 3.
Sample Psychological Characteristics (N = 15)

Measure	<i>M</i>	<i>SD</i>	Range
BAI	22.53	16.75	1-52
CES-D	24.27	13.41	5-44
ISEL			
Total	79.80	25.31	33-113
Tangible Support	21.40	6.28	9-28
Belonging Support	17.27	8.31	4-30
Self-Esteem Support ^a	18.79	5.91	5-28
Appraisal Support	22.80	7.98	6-30
PSS	22.93	9.30	6-40
WHOQOL-BREF			
Total	84.33	13.62	62-107
Physical Health	12.99	2.74	7.42-17.14
Psychological	12.98	2.80	8.67-17.33
Social Relationships	14.53	3.50	6-20
Environment	13.77	2.95	8-17.5

Note. BAI = Beck Anxiety Inventory; CES-D = Center for Epidemiologic Studies-Depression Scale; ISEL = Interpersonal Support Evaluation List; PSS = Perceived Stress Scale; WHOQOL-BREF = WHO Quality of Life. ^a*n* = 14; one participant did not complete one question on this instrument and could not be contacted for a response.

Bivariate correlations. Given the small sample size, the data described below must be interpreted cautiously. There were strong associations between total scores on almost every pair of psychological questionnaires (see Table 4).

BAI scores were significantly positively correlated with CES-D scores ($p = .009$) and with PSS scores ($p = .013$), and were also significantly negatively correlated with WHOQOL-BREF scores ($p = .023$). Similarly, CES-D scores were significantly positively associated with PSS scores ($p < .001$) and were significantly negatively associated with both ISEL scores and WHOQOL-BREF scores, $p = .010$ and $p < .001$, respectively. PSS scores were significantly negatively associated with both ISEL and WHOQOL-BREF scores, $p = .006$ and $p < .001$, respectively. Finally, ISEL and WHOQOL-BREF scores were significantly positively associated, $p = .019$.

Taken together, these associations indicate that, unsurprisingly, participants who were more anxious also tended to be more depressed and to appraise more events as being stressful. Furthermore, those who reported higher levels of psychological distress tended to also report experiencing lower levels of interpersonal support and a poorer quality of life. A further point to note here is that the presence of comorbid depression and/or anxiety (a presence indicated by the significant correlations observed above) might have influenced the

primary outcomes being considered here (especially quality of life). It is worth bearing this in mind as one interprets the rest of the results presented in this study.

Table 5.

Bivariate Correlations: Total scores on psychological questionnaires (N = 15)

Variable	1	2	3	4	5
1. BAI	1.00	.651**	.624*	-.098	-.580*
2. CES-D		1.00	.894**	-.641**	-.806**
3. PSS			1.00	-.673**	-.824**
4. ISEL				1.00	.595*
5. WHOQOL-BREF					1.00

Note. Data presented are Pearson's r correlation coefficients. BAI = Beck Anxiety Inventory; CES-D = Center for Epidemiologic Studies-Depression Scale; ISEL = Interpersonal Support Evaluation List; PSS = Perceived Stress Scale; WHOQOL-BREF = World Health Organization Quality of Life - BREF.

* $p < .05$. ** $p < .01$.

WUN service delivery data. Descriptive analyses of information derived from each of the four substantive WUN domains are described below.

Health care. Eleven of the 15 participants (73.33%) reported no current involvement in any form of intervention/therapy targeted at their ASD symptoms (see Figure 4). The other four participants each reported using multiple other types of behavioral (e.g., those shown in Figure 4, as well as yoga and an autism optimisation group [a social media group that provides a platform for autistic individuals to answer questions posed by parents of autistic children]) and pharmacological interventions (e.g., those shown in Figure 4, as well as an anti-convulsant medication [Epilim], a central nervous system stimulant [Ritalin], and electrolytes and tissue salts).

Nine participants (40%) reported exposure to some form of intervention/therapy as a child (e.g., speech therapy, occupational therapy, physiotherapy, psychotherapy, pharmacotherapy, and art, wood, and clay therapy).

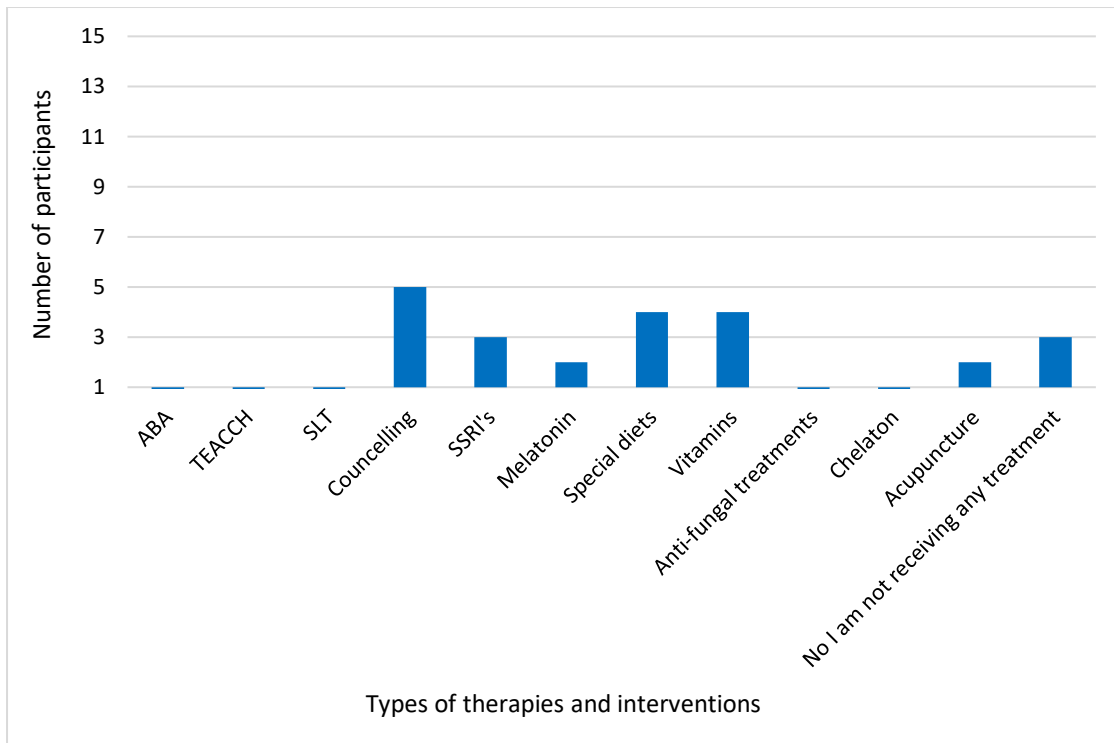


Figure 4. Current therapies and interventions for the current sample of adults with ASD ($N = 15$). ABA = applied behavioral analysis; TEACCH = Treatment and Education of Autistic and Related Communication Handicapped Children; SLT = Speech and Language Therapy; SSRI = Selective Serotonin Reuptake Inhibitor.

Five of the 15 participants (33.33%) reported having no health insurance. Of the other 10 participants, 2 reported that their health insurance covered “all” of their medical needs, 1 reported that it covered “most” of those needs, 4 reported that it covered “some”, and 3 reported that it covered “none.”

No participant reported that access to relevant services was hindered by what their home language was (e.g., by not speaking English as a first language).

Community support and educational resources. Regarding the social support aspect of this domain, Figure 5 shows participants’ responses to being questioned about various forms of community-based services and resources. Although reports indicated that most of the enquired-about services and resources were available to participants, in many cases they reported not using those services or availing themselves of those resources. Community-funded therapies and career development were endorsed as being the most notable areas of need. Of further note here is that two participants reported being unaware of any available services/resources in their community.

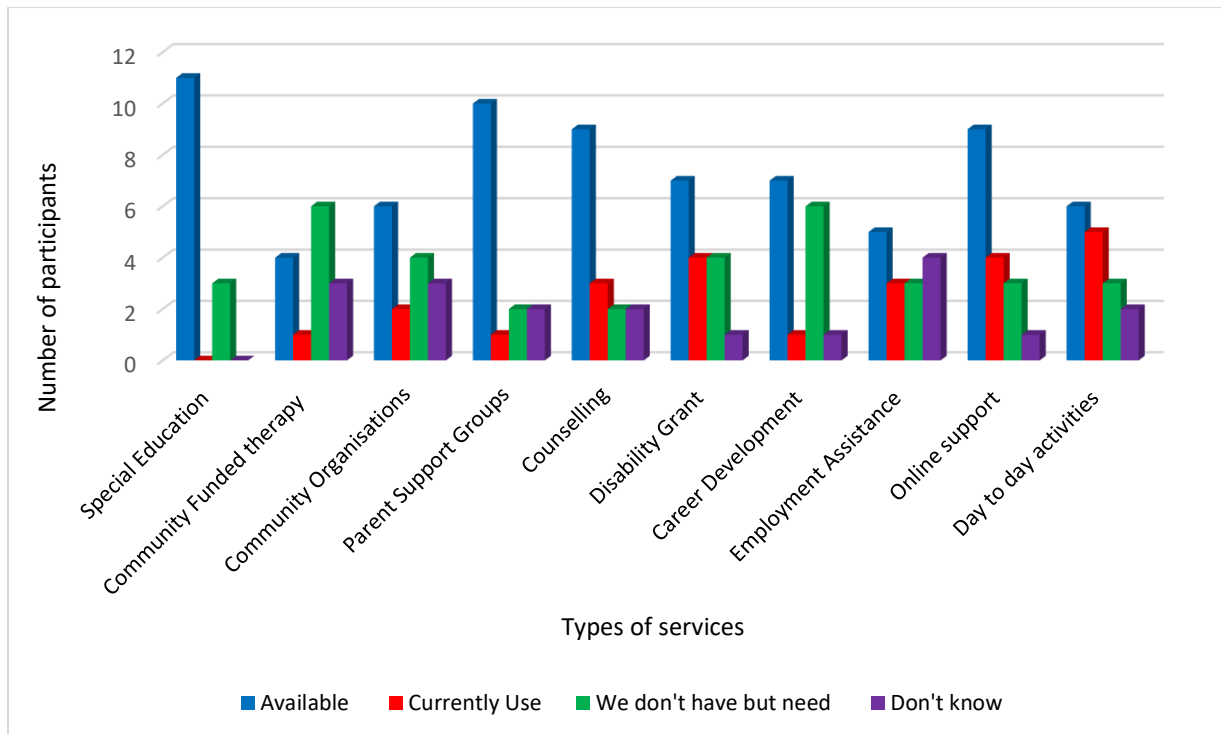


Figure 5. Available services in the community reported by a sample of adults with ASD ($N = 15$).

A separate item addressed the question of why, if services are available, they are not used. As Figure 6 shows, sizeable minorities of participants checked boxes indicating that services were too expensive ($n = 5$; 33.33%), not effective ($n = 4$; 26.67%), or located too far away ($n = 3$; 20%), or that waiting times were too long ($n = 3$; 20%). Also of interest here were the responses participants gave under the 'Other' response option: (1) business environments are not geared for autism-related problems (e.g., sensory problems), and (2) people who manage the services are often not knowledgeable about the full spectrum of autism.

Although most participants ($n = 7$, 46.67%) reported that the government-sponsored disability grant was available to them, only four indicated that they actually received such a grant (with the amount of the allowance ranging from ZAR1200-ZAR1350 per month).

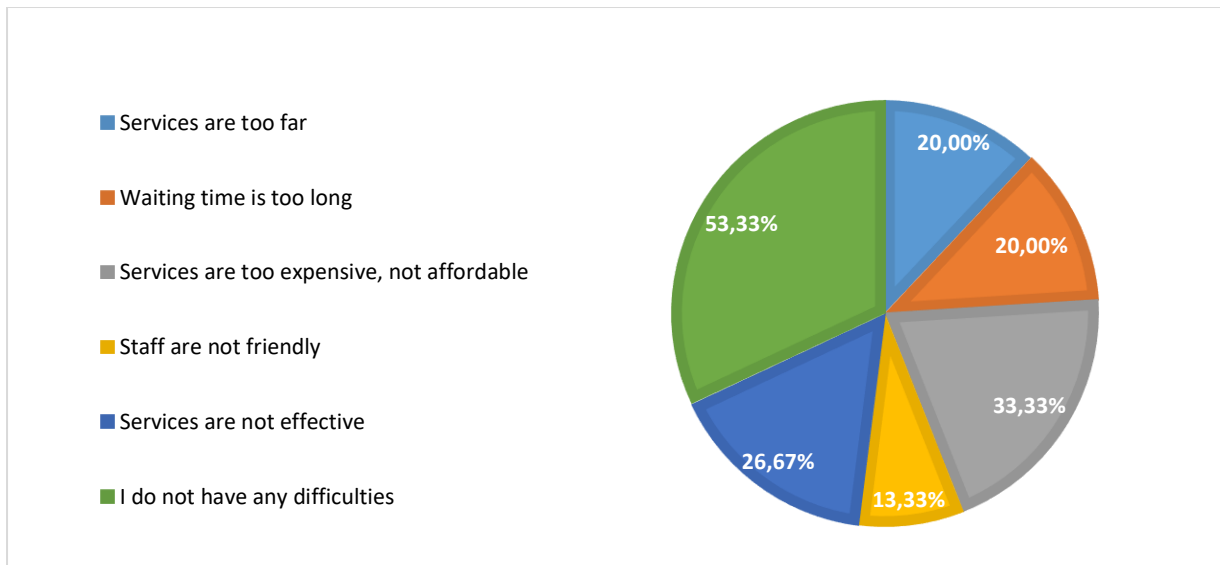


Figure 6. Reported problems with current services within the community by a sample of adults with ASD ($N = 15$).

Regarding the education aspect of this domain, questions focused on the institution at which participants had received most of their formal academic instruction. Only four participants (26.67%) reported attending an autism-specific school. Regarding educational programs at the school they attended, most ($n = 9$; 60%) reported not receiving any one-on-one instruction, and only one (6%) reported receiving between 5 and 10 hours of instruction a week. Most ($n = 8$; 53.33%) reported not receiving any of the standard ASD interventions (e.g., Applied Behaviour Analysis, Social Skills, Auditory & Sensory integration, TEACCH) at school.

Occupational resources. Three of the 15 participants (20%) reported not being employed at the time of the study (see Figure 7). Those who were employed worked in a range of different jobs: graphic designer, cataloguing and metadata librarian, business analyst, English teacher, project manager, tutor, clerical worker, groundsman, assistant cook, and security guard.

Most of the employed participants ($n = 11$; 73.33%) reported working more than 10 hours a week, with a range of 20-50 hours. Nine (60%) reported that their employer knew about their condition, while 8 (53.33%) reported both that employers had made workplace adjustments for them and that their co-workers knew of their condition. Seven (46.67%) reported making an equivalent amount of money to other employees in their workplace; 5 (33.33%) reported earning less.

Of note here is that all employed adults reported not receiving any career development or job training from an NGO, government agency, or similar.

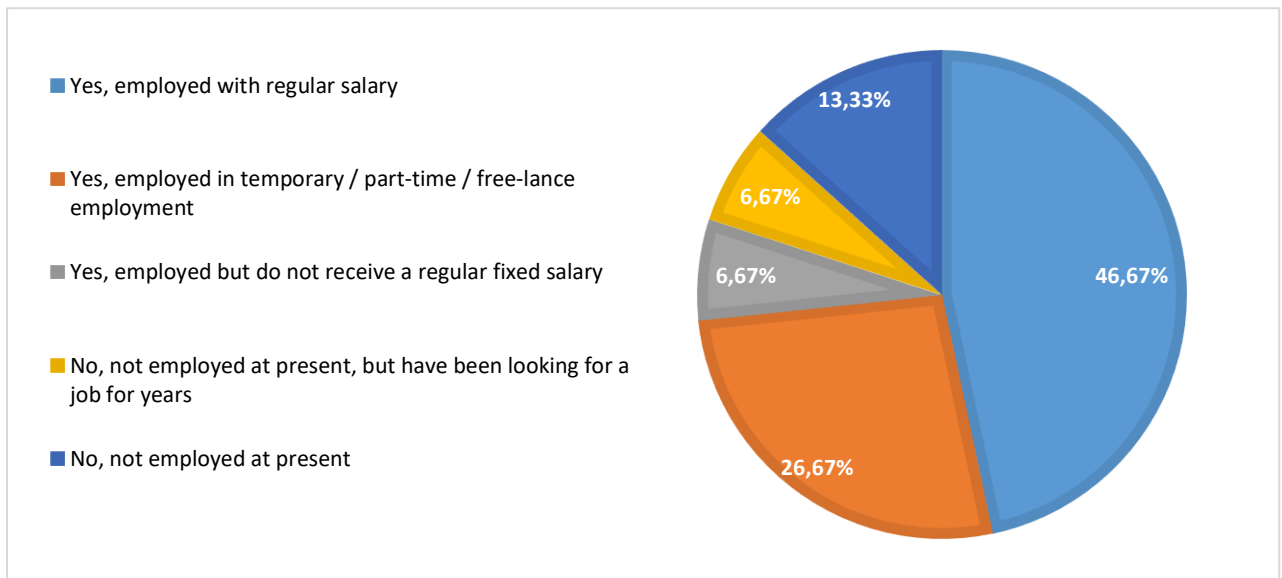


Figure 7. Employment data for the current sample of adults with ASD ($N = 15$).

Impact on daily living. The questions in this domain of the survey gathered information about how the ASD diagnosis affected respondents' everyday life. Most participants ($n = 8$; 53.33%) reported that the diagnosis had caused financial difficulties, with 6 (40%) noting difficulties "to some degree" and 2 (13.33%) noting "definite" difficulties. Unfortunately, the item asking about this information did not require the respondent to specify how those difficulties were associated with the diagnosis (e.g., whether difficulties arose because of treatment expense, limited educational or occupational opportunities, etc.). Separately, however, 10 of the 12 participants who were employed reported not having to cut down on work hours due to their diagnosis.

Qualitative Analyses

Three female participants (ranging in age from 41 to 48 years) provided responses to the 10 open-ended questions described above, and thus provided the qualitative data analysed here. These three women are particularly well placed to comment on service delivery and quality of life in adults with ASD. They are active and well-known within their local ASD communities (e.g., they developed and moderate ASD-focused social media groups) and are often sought out by families with ASD members for advice and assistance. Thus, their responses were based on their personal experiences as well as their broad-based knowledge of the community and the daily struggles faced by ASD families.

Each sub-section below documents a theme that arose from these participants' responses to the open-ended questions. These themes were (1) *lack of ASD understanding by*

local health professionals; (2) high costs associated with services; (3) employment challenges; and (4) how sensory difficulties affect everyday activities. A separate sub-section documents the positive comments that arose within responses to the open-ended questions. To provide detailed examples of what the participants said and still maintain their privacy and confidentiality, each participant was given a pseudonym (DP, MX, and PJ). Of note here is that some of the quotes are paraphrased and/or edited for clarity.

Theme I: Lack of ASD understanding by local health professionals. All three participants stated strongly that many health professionals with whom they have had contact did not have a complete understanding of, for instance, the entire spectrum of behaviours associated with ASD. This lack of knowledge has led to incorrect diagnoses, multiple (and often unnecessary) appointments with health professionals, inappropriate treatment plans, and poor suggestions and referrals for therapies. For instance, MX noted that she had seen seven psychiatrists before she was diagnosed, saying “it was very unpleasant not to be diagnosed and to have people experimenting with you.”

DP: *There are limited psychologists or therapists out there that has insight into autism. Often, part of finding a therapist would be to educate them on almost the very basics of the autistic experience. This, I believe, is probably a direct result of inadequate exposure during both academic training and practical experience, for therapists.*

PJ: *Most people that provide services don't really understand autism. For example, if a child has strange behaviours, or is violent, according to the doctor, there are only two treatments for autism, Risperidone and Ritalin. First problem is doctors see autism as a disorder, as a problem, so they either don't treat the problem at all or they miss it. I think that doctors are afraid of the complexity of autism so they rather want a simple way to look at it, it's as if they have given up.*

With specific regard to their experience of interventions, the participants noted that it was a challenge to find a health professional who could provide therapy and support that incorporated a complete understanding of all aspects of autism (e.g., the everyday difficulties associated with the diagnosis, as well as the strengths displayed by individuals diagnosed with ASD). For instance, MX noted that she consulted with many inexperienced health professionals and was prescribed many medications that were not only ineffective but that

actually increased her sensory, affective, and cognitive difficulties. Ultimately, without consulting the prescribing physician, she decided to discontinue the medication.

Participants noted their preference (some stated it as a need) for interventions to focus on the physical or sensory challenges of autism rather than strictly employing behavioural interventions (e.g., ABA) targeted at improving eye contact or lack of social interaction and thus helping ASD individuals cope better with everyday social situations.

DP: *The impression I get is that ableism and behavioural treatment are still the main messages given to those that are supposed to help autistic people find meaning, acceptance, and value in what is their natural state.*

Theme II: High costs associated with services. Two participants (MX and PJ) reported on how expensive health care is for adults with ASD. MX noted that the initial diagnostic procedure can be lengthy, involving several potentially high-priced appointments. Post-diagnosis, costs escalate because multiple visits with health professionals in private practice are sometimes required and because prescriptions for chronic medications need to be renewed regularly. Moreover, the costs of these medications are not government-subsidized because autism is not on the list of conditions covered by the Prescribed Minimum Benefits programme. Hence, maintaining appropriate levels of treatment over a long period of time may be problematic for adults with ASD.

MX: *The cost of services for autistic adults that are independent is also extremely high. Typically these adults benefit from having regular meetings with a therapist, life coach or another professional with insights into the things they find difficult, to assist with navigating the neurotypical world, in order to succeed in it. This just, over time, could become too expensive and loss of this assistance could result in giving up independence. There are psychologists and psychiatrists that specialize in engaging with autistic adults ... which provides tremendous support, if the autistic adult can afford it - there is no “special” allowance for autistic adults as there is, for instance, for other chronic conditions such as schizophrenia, hypertension, asthma, etc, which is covered by the Government controlled Prescribed Minimum Benefits.*

Theme III: Employment challenges. Two participants (MX and DP) reported that South African adults with autism face specific challenges related to employment. These

challenges include finding an occupation that can accommodate the individual's ASD-related difficulties, a lack of career development and support, and, once employed, ensuring equal pay for equal work. For instance, MX noted that adults with ASD struggle with self-advertising, and so having someone to help them market themselves better, showcasing their strengths, would be of great benefit in the workplace.

MX: *Need the right job for your skills/interest, maybe have someone to help and counsel or facilitate you to settle in – help mediate relationships and explain to people the difficulties you have so that you don't lose those relationships.*

Regarding how jobs fail to accommodate the diagnosed individual, DP reported, “I have lost a number of positions due to interpersonal issues directly related to challenges posed by autism, despite offering excellent work and services in my job.”

DP: *Acceptance that I may not partake in all social initiatives (or partake only partially then leave) without judgement, people being more explicit in their communication and not using the neurotypical approach of hinting at things that are bothering them, hoping that I will attend to it without anyone having egg on their face, people making me aware of when I have “stepped in it”, e.g. when my bluntness may be offending someone, or when I'm stepping on someone's toes or responsibility by doing a task that is not my responsibility. Taking things like team work and social interaction off my performance objectives in the same way you would take walking without a limp or not bumping into things off the list of a person in a wheelchair and a blind person respectively.*

Participants also noted the importance of destigmatizing ASD within the workplace. Both DP and MX noted that adults with ASD often do not declare their diagnosis to employers for fear of either losing the job, receiving unequal pay in comparison to neurotypical colleagues, or other forms of discrimination.

DP: *The most important assistance that I would need is the destigmatizing of the condition, as most adults keep their diagnosis secret from their employer in fear of lack of promotions or continued employment, scapegoating, discrimination (subtle, usually not being able to prove it in a Labour Court); as well as positive engagement*

with employers with regards to the positive aspects of autism and the diversity that it could bring to the workplace (as is happening now in companies such as Microsoft, SAP, etc.).

MX: *I do not declare the fact that I am autistic to any employers. I do find that I need to take roles that are significantly under my capabilities and typically significantly underpaid from those with similar qualifications and abilities that I have, in order to “get away” with not having the social insights and flair, and the abilities associated with navigating ... typically highly political, corporate environments.*

Theme IV. How sensory difficulties affect everyday activities. The participants reported experiencing general sensory challenges in the workplace as well as while completing regular activities of daily living (e.g., shopping, attending therapy, making hospital visits). For instance, MX noted that full-time employment in a traditional workplace is a challenge given the level of distraction and noise present in such environments; for her, freelance work is more accommodating as it provides a quieter environment. PJ also reported changing her work environment to suit her sensory needs. For example, she added better lighting and better sound proofing to her office and noted that she “*wouldn’t be able to work if [it] didn’t have the [sensory] requirements.*” Furthermore, she noted the need for a quiet place during lunch to be able to be by herself. DP also described a need for sensory optimisation of the workplace, noting that “*Planning for sensory challenges are very important ... [others’] understanding the physical discomfort of autism is zero.*”

PJ: *People are not aware of sensory issues autistics face, sometimes even the [individuals diagnosed with Asperger’s syndrome] themselves, especially those that can’t even articulate it. There is also a lack of awareness amongst professionals as to how much sensory issues impede life. Sensory accommodations all over would really be helpful for children to prevent them from having meltdowns. We need more sensory free places; for example, better lighting, facilities to withdraw into a sensory quiet place when in public to get away, in supermarkets places where parents can withdraw with their kids when they having a meltdown, and in airports.*

DP: *I would want things like lower light and noise levels, a more secluded area to work in.*

Positive comments. Two of the 10 open-ended questions were explicitly phrased to elicit positive bits of information (*What would you not want changed about your work environment or the support you receive at work?* and *What wouldn't you change regarding the services in South Africa?*). Even so, the participants appeared to struggle to find positive aspects to their experiences, and in fact DP responded to the second of those questions by stating that, “*After having tried so long to find help, you just give up.*”

It is, however, worthwhile to note that MX was effusive in her praise for the work done by the Western Cape adults with autism support groups. She noted that these groups have made extremely helpful contributions to members' social lives, and have been a valuable source of support and advice for many in the autism community.

MX: *The support groups for autistic adults that are run by autistic adults themselves are making a tremendous contribution to the social life of autistics. I am only aware of groups such as these in Cape Town, though. There are several groups countrywide for the families of autistic adults ... these seem to assist with the lives of the non-autistic family members though, which indirectly may or may not contribute to the autistic person, based on the specific attitude taken towards the understanding and humane treatment of autistic adults.*

Finally, PJ spoke briefly about her positive feelings about her work environment.

PJ: *[My] colleagues are open about autism, are very ADHD (Attention deficit hyperactivity disorder) - and autism-friendly, and are open to all neurotypes. They've allowed me to adjust my office to meet my sensory requirements ... I am very lucky here at my work, they have adapted to me ... so I can use all my strengths. I have a great environment at work, where autism is accepted as having value.*

Discussion

Few published studies have provided comprehensive assessments of service delivery and quality of life (QoL) in adults with autism. Fewer still have emerged from low- and middle-income countries (LAMICs). This lack of research, and of an understanding of where service delivery might fall short and how quality of life is thereby impacted, may have a

serious detrimental impact on the lives of adults with ASD. Without descriptions of what services are not provided to adults with ASD, and without robust characterizations of the efficiency with which existing services are provided, governmental and other policy makers can implement no changes to ensure optimal service delivery to adults with ASD.

The current study therefore aimed to provide a preliminary investigation of the quality of life of South African adults with ASD, and to describe the services provided (and those not provided) to them. I gathered self-reports from South African adults with ASD ($N = 15$ for quantitative data collection, $n = 3$ for qualitative data collection). I measured overall QoL quantitatively by using a comprehensive standardized instrument as well as brief standardized tools focused on stress, depression, anxiety, and social support. I used both quantitative (a 31-item survey instrument) and qualitative (individual interviews structured around 10 open-ended questions) methods to examine multiple aspects of service delivery (including diagnosis, education, health care, education, employment, and social impact).

Who Were the Participants?

Fifteen individuals, ranging in age from 19 to 48 years, completed the quantitative measures. Most ($n = 8$) were English-speaking single men. Of the group of 15, three (all women, aged between 41 and 48 years) completed the qualitative interviews.

The male predominance in the overall sample is consistent with recent findings in the literature regarding sex differences in ASD diagnoses (Werling & Geschwind, 2013). Regarding language, all participants spoke English fluently although it was not the home language for all of them. None of the participants without English as a home language felt that that fact hindered their access to services. It remains unknown, however, whether individuals who are not English-fluent may have more difficulty accessing services.

Regarding education, most participants ($n = 10$) had completed at least 12 years of study (i.e., had obtained a high school diploma). Although many published studies in the literature on adults with ASD do not provide education-related data for their samples, the educational profile of the current sample is similar to those that are reported (i.e., in most cases, participants have completed at least 12 years of formal academic study; Hedley et al., 2017; Hurlbutt & Chalmers, 2004; Jarbrink et al., 2007; Nicolaidis et al., 2015).

Regarding SES, although most participants ($n = 12$) were employed, annual household income varied substantially (e.g., four participants reported earning less than ZAR35 000, whereas three reported earning more than >R526 000). Most published studies in the literature on adults with ASD do not provide fine-grained data on income levels or

other indices of SES, choosing instead to simply characterize their participants as employed or unemployed. (In those studies, most participants report being unemployed; see, e.g., Eaves & Ho, 2008; Hurlbutt & Chalmers, 2004; Jarbrink et al., 2007; Lattimore et al., 2006; Lawer et al., 2009). Confirming this impression, the review by Shattuck et al. (2012) on services for adults with ASD noted that every one of the 23 studies in their sample did not report participant income data. I found only two studies in this literature, both emerging from the United States, which explicitly reported income data. Both were consistent with the current study in noting substantial variation in the data. Taylor and Seltzer (2011) reported that their participants' income ranged from under \$10 000 to over \$160 000, whereas Shattuck et al. (2011) reported a range from \$25 000-\$75 000.

Regarding age at which the ASD diagnosis was made, in the current sample this ranged from early childhood (6/7 years) to mid-adulthood (43 years), with most participants ($n = 11$) being diagnosed after the age of 10. Most recent research studies in this field suggest the ASD diagnosis is usually made between the ages of 3 and 6/7 years (i.e., the upper limit is typically the age at which school entry happens; Brett et al., 2016; Mandell et al., 2005; Valicenti-McDermott et al., 2012). However, few of these studies were conducted in LAMICs, and no South African study has focused on this aspect of the epidemiology of ASD. Nonetheless, the relatively late age of diagnosis reported by most of the current participants is potentially problematic given that, for instance, early diagnosis allows for the implementation of early interventions with the aim of improving outcomes in later years (Yates & Couteur, 2016).

What Did Participants Report about Their Quality of Life?

The current quantitative data indicate that South African adults with ASD reported experiencing poor QoL, with concomitant moderate levels of anxiety, high levels of depression, and high levels of perceived stress. Qualitative reports suggested that QoL was certainly compromised by the effects on regular activities of daily living (e.g., shopping, attending therapy, making hospital visits) of ASD-related sensory challenges (e.g., noise, light, and touch sensitivity). These findings are consistent with those presented in previous studies, all emerging from high-income countries of the global north, examining QoL and psychological distress in adults with ASD (Ghaziuddin et al., 2002; Gillott & Standen, 2007; Sterling et al., 2007; Stewart et al., 2006).

With specific regard to participants' experience of psychological distress, the current analyses detected statistically significant bivariate correlations, in a positive direction,

between scores on the scales measuring anxiety, perceived stress, and depression (suggesting, for instance, that participants reporting higher levels of anxiety also reported higher levels of depression and higher levels of stress). These findings are consistent with those presented in previous studies in this population. For instance, Gillott and Standen (2007) found, using a sample recruited from the English Midlands, a significant association between anxiety and stress in adults with ASD. Sterling et al. (2007) replicated this finding using a sample recruited from communities in Seattle, Washington.

With specific regard to participants' self-reported quality of life, the current analyses of WHOQOL-BREF data suggested poor QoL in the Physical Health, Psychological Health, and Environmental domains, with the first of these being the most problematic. Unexpectedly, self-reported QoL was the best in the Social Relationships domain. In fact, only 2 of 15 participants reported poor QoL in that domain. This is surprising given that ASD is conventionally viewed as a disorder of social communication and interaction.

The current QoL findings are generally consistent with most of those presented in previous studies examining this construct in adults with autism (for a review, see Ayres et al., 2018). For example, Kamio et al. (2013) found that adults with ASD reported poor QoL in the WHOQOL-BREF Psychological Health domain, and Kamp-Becker et al. (2010) observed poor QoL in the Physical Health and Psychological Health domains. Of note here, however, is that all previously published studies that used the WHOQOL-BREF reported poor QoL in the Social Relationships domain (Jennes-Coussens et al., 2006; Kamio et al., 2013; Kamp-Becker et al., 2010; Lin, 2014). There are a few possible reasons for this discrepancy between the current study and previous literature. First, those studies compared reports from their ASD group to reports from matched controls (e.g., neurotypical adults, individuals diagnosed with schizophrenia), whereas in the current study I used normative data from an Australian sample. Second, in the current study I estimated Social Relationship QoL from only two items, which may have undermined the accuracy of reports.

The current analyses detected statistically significant bivariate correlations, in a negative direction, between scores on the scales measuring psychological distress and those on the WHOQOL-BREF (suggesting, for instance, that participants reporting higher levels of depression, and anxiety, and stress also reported poorer QoL). To my knowledge, this is the first study to investigate associations between QoL and measures of psychological distress in adults with ASD.

The current analyses detected significant variability in individual experiences of interpersonal support. For instance, whereas 3 participants reported experiencing poor levels

of total support, 4 reported experiencing good levels. This variability may emerge from the fact that the diagnosis of ASD encompasses a spectrum of varying symptoms and behaviours, and so diagnosed individuals may require different types and levels of support. Where one person may experience a particular level of support as being sufficient, another may experience it as being wholly inadequate. Furthermore, depending on the level of social and communication challenges, one person may require or be interested in more social interaction and support than another.

Only one previous study reports on perceived interpersonal support in adults with ASD. Participants in the Renty and Roeyers (2006) study ($N = 58$ Belgian adults with ASD), which also used the ISEL, reported much higher levels of perceived support than did participants in this study, $M = 110.16 \pm 19.31$ versus 79.80 ± 23.51 . However, both studies found statistically significant bivariate correlations, in a positive direction, between ISEL scores and scores on the QoL measure (i.e., those who reported receiving lower levels of support also reported experiencing poorer QoL).

Regarding associations between perceived interpersonal support and scores on the other scales measuring psychological distress, the current analyses detected statistically significant bivariate correlations, in a negative direction (suggesting, for instance, that participants reporting lower levels of support also reported higher levels of depression and higher levels of stress). To my knowledge, no previous study has investigated this association. This observed relationship (and other significant bivariate correlations within this dataset) requires replication in a larger sample; in small samples such as this, one extreme case can have an outsize influence on the outcomes.

Together, these preliminary results provide some firm foundations for future research studies and clinical interventions. When designing studies, researchers should not measure psychological distress in isolation, or perceived support in isolation, or quality of life in isolation; rather, they should focus on relations between these constructs, and attempt to describe the direction of causal links between them. When designing interventions, clinicians must consider ways in which psychological distress affects QoL and activities of daily living (and vice-versa), and so must adopt a holistic perspective when attempting to improve behavioural outcomes.

What Did Participants Report About Their Experiences of Service Delivery?

Healthcare. Most participants (73%, $n = 11$) reported no current involvement in any form of intervention or therapy targeted at their ASD symptoms. Instead, these individuals

reported that their counselling sessions, supplements, special diets, and medication were targeted at relieving symptoms of other medical conditions (e.g., epilepsy, ADHD).

Although a recent systematic review (Lorenc et al., 2017) indicated that although exposure to some cognitive-behavioural therapies and social skills interventions impact positively on the social relations, autism-related symptoms, and empathy of adults with ASD, few previously published studies report on the therapies, interventions, and supports that are actually adopted by adults with ASD. Within that small literature, findings are inconsistent, and methodologies vary widely (e.g., some studies collect quantitative data, whereas others collect both quantitative and qualitative data; some are case studies, whereas others have relatively large sample sizes; Cunningham, 2014; Gantman et al., 2012; Hillier et al., 2007a; Laugeson et al., 2015; McVey et al., 2016). Hence, it is difficult to know whether adults with ASD actually use the most effective therapies/interventions (and if not, why not).

Certainly, none of the participants in this study reported current involvement in applied behavioural analysis (ABA), CBT, or social cognition therapy (i.e., some of the standard therapies/interventions that have proven positive benefits). One reason for this might be financial. The standard therapies/interventions listed above might be effective, but they are also extremely costly (Sharpe & Baker, 2007; Sheinin, 2006). Given the income of most participants in the current study, lengthy and expensive therapies may not be a realistic possibility. Indeed, one of the prominent themes that arose in both the quantitative and qualitative data analyses was the high costs associated with services and the financial difficulties participants faced post-diagnosis. The participants who provided qualitative reports noted that although they appreciated that involvement in therapy was essential for enabling independence in functional activities, such involvement was financially challenging and often unrealistic. Furthermore, although most participants reported having access to private medical aid/health insurance (in this way, the current sample was similar to that studied by Nicolaidis et al. [2015]), almost all of them stated that their healthcare needs were inadequately covered.

Another possible reason for the lack of current engagement with potentially beneficial interventions/therapies is the experiences of these adults during childhood. Although most participants (60%, $n = 9$) reported contact with speech therapists, occupational therapists, physiotherapists, psychologists, and/or psychiatrists during childhood, no participant reported receiving any of the commonly-used and empirically-based interventions that studies suggest provide the best long-term outcome for children with ASD (e.g., ABA; Wong et al., 2015). This lack of childhood exposure to potentially beneficial interventions/therapies might be

accounted for by participants' relatively late age of diagnosis (recall that the most common report age of diagnosis was >11 years) and/or a simple lack of availability of these programmes in their communities (there is no South African data on the application of ABA, for instance, in local samples).

A third possible reason for the lack of current engagement with potentially beneficial therapies is that participants in this sample have strong negative feelings toward behavioural interventions such as ABA. The qualitative data indicated a strong preference for interventions to focus on physical challenges (e.g., sensory difficulties, apraxia, and communication problems) because these are the most likely sources of immediate distress in both children and adults with ASD. The literature on adults with ASD often ignores these physical and sensory challenges, despite their range and severity and their likely significance for quality of life (Crane, Goddard, & Pring, 2009).

One conclusion from the current data regarding health care issues in South African adults with ASD is this: If one accepts that this sample's healthcare choices and options are representative of others in this country, it is highly problematic that South African adults with ASD cannot afford, or are not provided with, or are not aware of the kinds of interventions/therapies that might benefit their quality of life the most.

Community support and educational resources. When questioned about which of a range of community-based support services are available to them and which are lacking, the participants indicated that community-funded therapies and career development were the most notable areas of need. Relatedly, participants reported that such services were (a) located far away, with waiting times being too long, (b) too expensive, and (c) ineffective. They also reported that service staff were unfriendly.

Qualitative reports were consistent with these survey data. Aside from mentioning the lack of available services, participants also discussed a lack of understanding of autism in the medical profession (a frequent cause of incorrect diagnoses), inappropriate treatment plans, poor suggestions and referrals for therapies, a poor understanding of sensory difficulties by medical professionals, and over-medication or the prescribing of incorrect medication.

The current data, particularly the issues surrounding the understanding of ASD in the medical profession, are consistent with findings reported by Nicolaidis et al. (2015) on the health care experiences of adults with ASD ($N = 39$, data collected via electronic or in-person self-report survey). For instance, those authors noted their participants' experience of stigma associated with autism in healthcare interactions, the perceived lack of knowledge of ASD

among healthcare professionals, and the sensory challenges adults with ASD face in healthcare facilities.

Regarding educational services, participants decried the lack of one-on-one instruction and the limited availability of interventions and supports in the schooling structure. They also noted that a lack of appropriate schooling options (e.g., curriculums featuring autism-specific programs and directed, individually-tailored interventions) forced many parents of children with autism to take up home-schooling alternatives.

The lack of such schooling options and, in turn, a lack of appropriate support and intervention within a formal school structure may have a negative impact on childhood development (Wehman et al., 2014). Research has shown that without adequate scaffolding and support during childhood, adults with autism may face challenges during adulthood that negatively impact their everyday life and their eventual outcomes in terms of independence, employment, and social relations (Howlin & Moss, 2012).

Occupational resources. Consistent with findings from previous studies in this field (e.g., Cimera & Cowan, 2009; Hendricks, 2010), quantitative and qualitative reports both indicated that most participants were employed and received a regular salary but were paid less than other employees with similar training and experience. The thematic analysis suggested that this disparity in pay was attributed to the stigma associated with an ASD diagnosis. For example, two participants reported not disclosing their ASD status for fear of discrimination, losing their jobs, or receiving unequal pay. These workplace effects of ASD-related stigma are commonly reported in the literature (see, e.g., Johnson & Joshi, 2016; Obeid et al., 2015).

Survey data indicated that none of the participants had received any vocational training, and none had been afforded opportunities for career counselling. Qualitative reports suggested that this type of training and support, which would focus on helping an individual with ASD find appropriate employment (e.g., a job that would accommodate ASD-related behavioral difficulties), was viewed as a critical but absent resource. Given that most research on service delivery to adults with ASD focuses on the benefits of vocational training, career development initiatives, and supported employment programs (see, e.g., Howlin et al., 2005; Shattuck et al., 2012; Taylor et al., 2012), the apparent lack of such resources for South African adults with ASD is enormously problematic and points toward an area of great need.

Previously published research suggests that a supportive work environment for adults with ASD is one that features, for instance, task modifications, structural adjustments, and personal mediators to assist with facilitating social relationships (for reviews, see Hendricks,

2010, and Wilczynski et al., 2013). Workplaces that incorporate such supports tend to enable more successful employment, and overall greater independence and stability, for adults with ASD (see review Nicholas et al., 2015). However, the current survey data suggested that not all employed participants worked in an environment that was appropriately supportive.

Qualitative data confirmed the impression that workplace modification and adjustments were a definite need. The types of modifications and adjustments mentioned were improved sensory environments (i.e., better lighting, less distraction and noise, and more secluded office spaces), the aid of a mediator or trainer to help navigate working with other individuals, and a better understanding of autism-related social challenges so that attendance at big corporate events and social gatherings would not be a necessary element of job success.

Limitations

One possible limitation of the study was that qualitative data were not all collected using the same means. Whereas one of the three adults who participated in that portion of the study preferred to complete the questions via email, the other two preferred to answer the questions in person. Furthermore, the in-person interviews were not audio-recorded and therefore complete and perfectly accurate transcriptions were not produced. Instead, during the interviews I wrote the responses down verbatim as much as possible. Naturally, it is possible that I might have missed some information, and that my own biases might have crept into my notes on the interviews. However, Nicolaidis et al. (2019) suggest that the best practice for the inclusion of autistic adults in research is allowing various modes of participation. Therefore, allowing participants to complete the interviews in the ways most suited to and convenient for them may not only have increased the likelihood of participation but also made the research more inclusive overall.

The most notable and obvious limitation of this study is its small sample size. Despite exhaustive recruitment efforts, there was an obvious resistance to participation among South African adults with autism. This resistance was expressed directly to the research team, with specific comment about this project, and indirectly via public statements (e.g., on Facebook groups) about research participation generally. The source of this resistance is tied strongly to some of the themes that emerged from the collected data (e.g., the fact that interventions were focused on behavioral rather than physical challenges, despite the latter being a much more prominent concern for patients themselves). Potential participants who refused to be involved in this study indicated that they felt their concerns were ignored by autism researchers in South Africa (e.g., one Facebook poster stated, “I want to know what we have to do to get our

research priorities to the top of the autism research agenda in our own city and country since they do not listen to us”). Hence, many members of the South African autism community feel at odds with researchers. They feel no sense of kinship with them, no convergence of interest, and no desire to further a research agenda that, in their view, does not address their main concerns.

Despite repeated assurances, across multiple forums, that this research project would be focused strongly on the concerns of South African adults with autism, the final sample size was only 15 ($n = 3$ for the qualitative data collection). Moreover, most of these participants were from middle- to high-SES backgrounds and had verbal communication abilities which possibly enabled them better access to services and employment opportunities. Therefore, it impossible to explore ways in which differing economic circumstances affect, for instance, the types of services available and the access to those services. Given that this is the first study of its kind to emerge from a LAMIC setting, it is unfortunate that the sample was not more socioeconomically diverse.

The sample was also not geographically diverse. All participants except one lived in the Western Cape, a province that is relatively well-resourced in terms of healthcare-related service delivery and autism-specific supports. Had we been able to recruit a nationally representative sample we might have found interesting provincial differences in QoL and experiences of service delivery.

A larger sample size would also have allowed the use of focus groups for qualitative data collection. The value of such groups over individual interviews is that they might have encouraged more unstructured back-and-forth discussion and, consequently, a broader range of themes to develop. Hence, one might have gained more in-depth perspectives on service delivery and the way it affects the QoL of adults with autism in this country.

Hence, the generalizability of the current findings is limited. Although the data presented here are novel (e.g., this is the first study to present findings regarding service delivery and QoL in a LAMIC sample of adults with autism), and although the study provides a platform for further investigation relations between service delivery and QoL, replication of the findings with a larger, more diverse, sample is essential.

Summary, Conclusions, and Future Directions

The current study, although preliminary in nature and limited in the ways described above, is novel in that it provides information not only on service delivery and quality of life in a sample of adults with autism, but also in that it explores the association between those

two variables and that it does so using self-report (not parent or collateral report) data collected from individuals who are resident in a low- and middle-income country (LAMIC). Moreover, unlike most previously published studies in this field, the current research design featured comprehensive measures of service delivery and QoL (including multiple measures of psychological distress).

The first set of findings suggested that South African adults with autism experience relatively high levels of psychological distress, and that this experience of depression, anxiety, and stress was associated with poorer QoL. This association suggests an obvious target for intervention if one wishes to improve QoL in this population. Similarly, the association between lower perceived social support and poorer QoL suggests that intervention programs might seek to aid adults with autism in obtaining more, and better, assistance from their immediate families and surrounding communities. In summary, given the impact all these factors have on an individual's daily life, further research to develop an in-depth understanding of the additional psychological challenges adults with ASD face is essential in order to provide the appropriate support and intervention to allow for optimal everyday functioning.

The second set of findings suggested that South African adults with autism experience numerous difficulties related to service delivery. These difficulties include late diagnosis, a limited range of available interventions and therapies, financial burdens associated with interventions and therapies, limited one-on-one instruction and interventions in the schools, and a lack of employment training, supported employment programs, and career development. Furthermore, there were strong reports regarding (a) the lack of understanding of autism by medical professionals resulting in incorrect diagnoses, referrals, and medication prescriptions, and (b) an ever-present stigma associated with autism, stretching from medical interactions through the workplace and across general daily activities. Two participants who provided qualitative data did, however, make some positive comments about the services they had received. Both noted with enthusiasm that ASD-specific support groups have had a positive impact in the community, and one reported that her workplace had made several physical adjustments to accommodate her sensory challenges.

As noted above, however, the study is limited by its small sample size and its preliminary findings require replication in larger samples that are more representative of the population of adults with ASD. Nonetheless, the findings are valuable not only because of their novelty but also because they complement and extend existing studies in the field. Overall, the current study suggests there is a strong need for further investigation into, for

instance, the way in which psychological distress affects QoL in adults with autism and into how those individuals experience of service delivery might be improved. Furthermore, the findings demonstrate the need for further examination into the associations between the experience of service delivery and overall QoL of adults with ASD. Such future investigation might eventually lead to a better understanding of how service delivery shortfalls might be remedied and how the daily functioning of adults with autism might optimized.

CHAPTER 4: Study 2 – Quality of Life in Parents of Children with Autism Spectrum Disorder: Influence of autism-related problem behaviours, socioeconomic status, service delivery experiences, and parent’s psychological distress

Abstract

Introduction. Previously published studies suggest that parents of children with autism spectrum disorder (ASD) experience poor quality of life (QoL). However, no study of these parents investigates the *simultaneous* influence on parental QoL of child age and ASD severity, family socioeconomic status (SES) and service delivery experiences, and parent’s psychological distress. Extant research is also limited because studies (1) emerge almost exclusively from high-income countries, ignoring the fact that individuals in low- and middle-income countries often face additional environmental and infrastructural burdens, and (2) do not use comprehensive measures of QoL, thus making it difficult to target specific domains in need of improvement.

Objectives. A cross-sectional quantitative design examined associations between the above-listed factors and self-reported QoL in South African parents of children with ASD.

Methods. Two hundred parents of children with ASD completed questionnaires measuring the constructs under consideration.

Results. There were significant bivariate correlations between greater ASD severity, greater psychological distress, less social support, and poor QoL. Service delivery data indicated that families experienced diagnostic delays, had limited understanding of effective and appropriate supports, were burdened by service-associated expenses, and felt their activities of daily living were negatively affected by the child’s diagnosis. Finally, path analyses indicated both direct and indirect relations between child’s age and ASD severity, family SES and service delivery experiences, parent psychological distress, and, ultimately, parent QoL.

Conclusions. This is the first study to describe interactive pathways between child’s age and ASD severity, family SES and service delivery experiences, parent’s psychological distress, and their ultimate influence on parental QoL. It is especially important to describe and examine these relations in a LAMIC setting given the additional challenges (e.g., resource limitations, socioeconomic stressors, high burden of disease) families and communities in such contexts might face. By understanding the impact these factors have on parental QoL, targeted supports and improvement to aspects of service delivery can be implemented to try and optimize the daily functioning of children with ASD and their families.

Introduction

In Study 1, a sample of South African adults with autism spectrum disorder (ASD) reported experiencing high levels of psychological distress, poor quality of life (QoL), and a lack of good-quality service delivery related to their diagnosis. Unfortunately, that study's methodological limitations (e.g., a small number of participants completed the quantitative measures, and a small proportion of that number also completed the qualitative measures; all participants were recruited from one province; most participants were from at least the middle-income bracket, and almost all were of the same racial/ethnic background) made it impossible to determine the association between, for instance, QoL and service delivery, and to generalize the findings to the broader population of adults with ASD in South Africa.

The current study set out to address some of those issues. Using a large and diverse sample of parents of children with ASD, I gathered quantitative data regarding their QoL and their experiences of service delivery. Hence, although this study did not obtain information directly from adults with ASD, its findings certainly complement and enrich those presented in Study 1.

Broadly speaking, there is a paucity of literature regarding provision of services to children with autism and their families. Here, the term “services” refers to support provided by private and public entities related to the entire diagnostic process (e.g., identification of behavioral problems and developmental delays, referral to appropriate specialists, the actual diagnostic interview, feedback and recommendations immediately post-diagnosis) as well as to current, post-diagnostic, healthcare (e.g., medications, therapies, interventions, and other forms of support) and education. This lack of research is problematic given the increasing prevalence of ASD globally (Neggers, 2014). As more and more children are diagnosed with autism, it becomes increasingly important to understand which services are available to them and their families. It is equally important to understand which of the available services are appropriate to the child's and family's needs, and which are effective in ensuring that children with autism are identified as early as possible and are then provided the crucial supports that will allow them to reach their full potential.

Of further concern is that almost all published research on autism and service delivery emerges from high-income countries (HICs) in the global north (see, e.g., Brett et al., 2016; Crane et al., 2016; Dymond et al., 2007; Mandell et al., 2005; Renty & Roeyers, 2005). This is the case even though there is no reason to suspect that ASD prevalence is lower in low- and middle-income countries (LAMICs), and every reason to suspect that affected individuals in

LAMICs are more likely to experience service delivery shortfalls (Daley et al., 2013; Durkin et al., 2015). Indeed, the small number of South African studies in this literature suggest there are notable problems with the diagnostic process and with educational services to individuals with ASD.

Moreover, the existing research in this field lacks a comprehensive perspective on all aspects of service delivery to ASD-diagnosed children and their families. Instead, it tends to focus predominantly on diagnosis-related issues, with relatively minor focus on education, interventions, and impact on family (see, e.g., Brett et al., 2016; Crane et al., 2016; Dymond et al., 2007; Goin-Kochel et al., 2006; Jarbrink et al., 2003; Karst & Van Hecke, 2012; Mandell et al., 2005; Osborne & Reed, 2008; Renty & Roeyers, 2006; Shattuck & Grosse, 2007; Wiggins et al., 2006).

Extant research on the QoL of ASD-diagnosed children and their families is blighted by similar issues. First, there are few published studies on the topic. Second, most of that research emerges from HICs (see, e.g., Davis & Carter, 2008; Lee et al., 2008; Mungo et al., 2007; Shu, 2009). Third, most studies in the field do not take a comprehensive or consensus-based view of QoL: They examine individual aspects of the construct (e.g., depression, or stress) using separate instruments, and there is no consistent use of an agreed-upon instrument to measure the overall construct.

These shortcomings in the ASD literature on service delivery and QoL mean that (a) there is little detailed and comprehensive information regarding what services are (and are not) available to children with autism and their families; (b) service providers lack knowledge about which services work, which need improvement, and which need to be made more available/accessible to members of the community; and (c) clinicians, teachers, researchers, and other concerned parties have little understanding of the daily difficulties faced by families containing a child with autism and of how those difficulties may impact on the overall QoL of family members. Of course, this lack of information, knowledge, and understanding is magnified in LAMICs.

The novelty of the current study is not only that it attempts to fill the knowledge gaps and address the shortcomings described above, but also that it assesses *both* service delivery and QoL in a comprehensive manner and measures the magnitude of the association between the two. Certainly, no previous LAMIC study has undertaken a comprehensive investigation of service delivery to autism-affected families, measured numerous aspects of QoL (i.e., general QoL as well as depression, stress, and presence/absence of family support), and assessed the impact service delivery has on the QoL within those families.

In summary, the primary aims of the study described in this chapter are to investigate, using a large and diverse South African sample, (1) the services and supports previously and currently received by individuals with ASD and their parents, (2) the QoL of parents of individuals with ASD, and (3) the strength of association between service delivery experiences and parents' QoL. The significance of this research is that it will address a major gap in the literature on experiences of service delivery, on QoL (measured comprehensively), and on associations between the two, in populations from relatively resource-poor LAMICs in the global south. From an even more applied and locally focused perspective, determining what services are (and are not) provided to South African individuals with ASD will help inform government and other policymakers about areas that might require improvement. Identifying those areas might, in turn, assist efforts to improve the lives of those individuals and their families.

Methods

Research Design and Setting

This study is nested within a larger research project, centered at Hong Kong University and involving sites in six other countries (Australia, Kuwait, Singapore, South Africa, United States, and United Kingdom), investigating service delivery to ASD families. However, most of the measures I used were not a part of that larger project, and the specific aims of the current research extended beyond the bounds of the parent study.

The current study used a correlational research design, with data collected from parents of a child diagnosed with ASD. Participants completed self-report questionnaires related to their experiences of service delivery and their current QoL.

Participants provided their data either via in-person interview (at their home, or in a private room in the Red Cross Children's War Memorial Hospital [RXH] or the UCT Department of Psychology) or via online survey. All data were collected between April 2014 and June 2015.

Participants

The target sample size was 100 participants (based on the minimum number of participants required to conduct path analyses). The actual sample size exceeded this number: Two hundred current caregivers of an individual with ASD participated. Most ($n = 184$; 92% of the sample) were biological parents of the individual with ASD; the rest were adoptive parents, stepparents, or guardians. For the sake of brevity, I hereafter refer to them generally

as “parents.” Among the sample of ASD-diagnosed individuals, most ($n = 188$) were younger than 18 years. For the sake of brevity, I hereafter refer to them generally as “children.”

I used convenience sampling to recruit participants from an RXH neurodevelopmental clinic, autism-specific schools, autism non-profit organisations, autism online support groups, as well as through existing databases of participants in studies conducted previously at UCT that had indicated an interest in participating in future research (Hoogenhout et al., 2017; Ing & Thomas, 2011). The only eligibility criterion applied was that the participant should live with and care for a person with a current diagnosis of ASD. Hence, the sample included parents with ASD children from different provinces in South Africa, with a diverse range of income levels, home languages, and cultural backgrounds.

Measures

I used some of the same measures as in Study 1 (viz., CES-D, and WHOQOL-BREF), alongside some measures specific to this study. The latter are described below.

Each standardized questionnaire was scored following the standard procedures outlined in its test manual. All measures were translated from the original English into Afrikaans and isiXhosa by bilingual members of our Department, and then back-translated into English by other bilingual (first-language Afrikaans, or first-language isiXhosa) individuals. Hence, they were available to be completed in English, Afrikaans, or isiXhosa, depending on the participant’s preference.

Sociodemographic questionnaire. This study-specific questionnaire (see Appendix M) incorporated original questions as well as items from the Hollingshead Four Factor Index of Social Status (Hollingshead, 1975). It obtained biographical information (e.g., age, sex, race, home language, family structure), medical information (e.g., history of mental health diagnoses and/or treatment), and details about the participant’s socioeconomic status (e.g., current employment status, highest level of education, annual income, and household assets).

Vineland Adaptive Behavior Scales, Second Edition (VABS-II). I used the 50 items comprising the Maladaptive Behavior Index (MBI) of the VABS-II (Sparrow et al., 2005; see Appendix N) to assess internalising, externalising, and other types of problem behaviours that may interfere with an individual’s adaptive functioning. These items cover a range of behaviours relating to anxiety, hyperactivity, lying, cheating, and bed wetting, as well as more severe psychiatric symptoms including psychosis, self-injury, obsessions, compulsions, and social interaction difficulties. Each item is scored on a 3-point rating scale (0 = *never*, 1 = *sometimes*, 2 = *often*). Hence, the total MBI raw score can range from 0

(indicating the absence of all problem behaviours) to 100 (indicating the presence of severe behavioural disorder).

The VABS-II developers report that the instrument has a high degree of test-retest reliability, and that each subdomain has an acceptable level of internal consistency (Sparrow et al. 2005). It has been used previously to assess adaptive and problem behaviours in children with ASD (see, e.g., Fulton et al., 2014). Furthermore, the VABS-II has been used in a previously published South African study of children of HIV-positive mothers (Ebersohn et al., 2012).

Autism Behaviour Checklist (ABC). This 57-item scale (Krug et al., 1978; see Appendix O), which is designed for use with individuals aged 18 months to 35 years, aims to determine whether and to what degree the person under observation currently displays a set of typically autistic behaviours. In this study, I used the instrument as a means to capture ASD severity, rather than to confirm the previously-made ASD diagnosis.

The 57 items cover five discrete areas: sensory difficulties (9 items), challenges in relating to others (12 items), stereotype and object-use difficulties (12 items), language problems (13 items), and self-help and social difficulties (11 items). Each item is assigned a score of 1 to 4, with higher scores indicating better ability to differentiate children with autism from mentally handicapped, severely emotionally disturbed, deaf and blind, and neurotypical children. For example, the item “Rocks self for long periods at a time” is scored as 4, whereas “Repeats phrases over and over” is scored 3, “Walks on toes” is scored 2, and “Cannot point to more than 5 named objects” is scored 1. Respondents are instructed to circle each item that describes a behaviour currently manifested by the person under observation. There is no limit placed on the number of items that might be circled.

The total ABC score, then, is obtained by adding the score assigned to each circled item. This total score can range from 0 (no items circled, indicating no autism-typical behaviours are currently present) to 157 (all items circled, indicated the current presence of all autism-typical behaviours specified by the questionnaire).

The instrument’s developers report split-half reliability of .87 and interrater reliability of .95 (Krug et al., 1980). The ABC has not been used in previously published studies of South African samples, although it is widely used in many other countries (Hastings & Johnson, 2001; Marteleto & Pedromonico, 2005; Rellini et al., 2004; Volkmar et al., 1988).

Parenting Stress Index Short Form (PSI-SF). This 36-item scale (Abidin, 1995; see Appendix P) assesses parental stress as it relates to the child’s most prominent functional characteristics and/or problems.

The PSI-SF is a direct derivative of the full-length PSI. The 36 items are distributed across three clinical sub-scales: Parental Distress (items assessing the parent's feelings of being trapped in the parenting role), Parent-Child Dysfunctional Interaction (items assessing the nature of relations between parent and child), and Difficult Child (items assessing parent perceptions about their child). Like the full-length PSI, each item is rated on a 5-point Likert-type scale with options ranging from (1) *Strongly Agree* to (5) *Strongly Disagree*. Hence, the possible range of scores is 0–180, with higher scores indicating higher levels of parental stress.

Embedded within the PSI-SF are 7 items that comprise the Defensive Responding (DR) scale. This scale acts as a reliability index, indicating whether parents responded truthfully or in a defensive manner. Respondents with raw scores < 10 have questionable reliability. Reasons for this lack of reliability might be related to a minimising of parental stress, a belief of being more competent than the average parent, or not caring enough about the child to feel stressed by his/her difficult behaviours (Abidin, 1995).

The instrument's developer reported that (a) Total Stress scores on the full-length PSI correlated at .94 with Total Stress scores on the PSI-SF, (b) scores on the full-length PSI Parent Domain correlated at .92 with scores on the PSI-SF Parental Distress subscale, and (c) scores on the full-length PSI Child Domain correlated at .87 with scores on the PSI-SF Difficult Child subscale (Abidin 1995). He also reported that test-retest reliability coefficients for the PSI-SF Total Stress score and the three subscale scores ranged from good to excellent (i.e., $\alpha = .68 - .85$). Similarly, internal consistency reliability of the four scores reportedly ranged from $\alpha = .80 - .91$.

The PSI-SF has been used in research examining parental stress in mothers and fathers of children with ASD (Davis & Carter, 2008). That study reported good internal consistency and test-retest reliability (Cronbach's α ranging from .84 to .92 for both mothers' and fathers' total scores). The PSI-SF has been used in a South African study examining the parenting stress of caregivers of children with HIV. That study translated the PSI into Zulu and Sotho and reported good test-retest reliability (Potterton et al., 2007).

Family Resources Scale (FRS). This 30-item scale (Dunst & Leedt, 1987; see Appendix Q) assesses the adequacy of tangible resources (e.g., money to pay monthly bills, health care for the family, etc.) in homes with young children. The specific resources under consideration are those required to be able to meet the needs of the family as a whole. Each item is rated on 5-point Likert-type rating scale (1 = *not at all adequate* to 5 = *almost always adequate*), with respondents also given the option of a *Not Applicable (N/A)* answer. (In the

current study, I assigned responses of N/A a score of 0.) Hence, higher scores indicate better access to and adequacy of the resources in question.

The instrument shows good internal consistency (Cronbach's $\alpha = .92$) and test-retest reliability ($r = .52$; Brannan et al., 2006). The FRS has not been used in previously published studies of South African samples or ASD samples.

Family Support Scale (FSS). This 18-item scale (Dunst & Leedt, 1987; see Appendix R) assesses the perceived level of family and social support to which parents have access. The respondent is asked to rate the amount of support s/he receives from various sources (e.g., family, friends, the community, etc.). Each item is rated on 6-point Likert-type rating scale (0 = *not available* to 5 = *extremely helpful*). Hence, higher scores indicate a higher perceived level of family and social support.

The scale's developers report that the instrument shows good internal consistency (Cronbach's $\alpha = .77$; Dunst & Leedt, 1987). Hanley et al. (1998) reported that test-retest reliability of .80 for the total score and between .35 and .76 for the various subscales. The FSS has been used in a study examining stress in parents of young children with ASD (Honey et al., 2005), but has not been used in previously published studies of South African samples.

World Universities Network (WUN) Scoping Survey: Parent version. The multi-site research project within which this study was nested developed this instrument (see Appendix S) to obtain comprehensive information regarding various essential aspects of service delivery to individuals with ASD. Researcher's at all seven study sites collaborated to ensure that (a) the survey contained items that were specifically relevant to ASD, and (b) all questions were applicable and suitable for administration in different languages and across cultures.¹

The survey comprises four different sections, each dealing with a separate domain of inquiry: (1) sociodemographic and clinical characteristics (i.e., background information about both the parent and the child); (2) healthcare system (i.e., information regarding current health care, pre- and post-diagnosis contact with these systems, as well as the process of diagnostic assessment itself); (3) community support, educational, and occupational resources; and (4) social and economic costs (i.e., information on the impact of ASD diagnosis on social relations and household budget). Questions from the last three domains,

¹The WUN survey used in Study 1 was an adapted version of this instrument. Whereas the original survey, as used here, directed its questions to parents of children with ASD, the adapted one directed its questions to adults with ASD.

especially, allow for examination of all major elements of service delivery (from both government and the private sector) to ASD individuals and their families in South Africa.

Procedure

Parents interested in participating responded to my online advertisements, emails, or telephone calls. Upon first contact, I gave them a summary of the study's aims and procedures. Those who maintained their interest after that initial contact were either, depending on their preference, scheduled for an individual in-person appointment or emailed a URL that linked to a SurveyMonkey (www.surveymonkey.com) page where the questionnaires were hosted. Parents were given as much time as they needed to decide whether they wanted to participate in the study. If they were uncertain after I had relayed the summary information, I asked if they wanted more details and if they wanted more time to consider participation in the study. If they confirmed that they needed more time, I contacted them again after a few days had passed.

In-person administration. Seventy-four participants (37% of the sample) chose this mode of administration, which consisted of a single session hosted at either the participant's home, an office space at RXH, or a psychology research laboratory. The session, which lasted 90-120 mins, proceeded as follows: Immediately after the participant arrived at the study venue and was settled at a desk, the researcher (either me or a fellow postgraduate psychology student) obtained written informed consent (see Appendix T). The participant then completed the sociodemographic questionnaire. This step ensured that study eligibility criteria were met before any other instruments were completed. If the participant met eligibility criteria, the researcher administered the ABC, VABS-II MBI, PSI, CES-D, FSS, FRS, WHOQOL-BREF, and WUN Scoping Survey, in that order. All questionnaires, aside from the newly-developed WUN Scoping Survey, were administered according to conventional procedures outlined in the literature and in the various test manuals. Participants who became fatigued during the session were encouraged to take a break and to continue only after they were sufficiently rested.

For isiXhosa and Afrikaans participants, a translator was present to help answer questions and address problems.

Online administration. One hundred and twenty-six participants (63% of the sample) chose this mode of administration. The participant accessed the survey site from wherever was convenient for them. The survey's first page obtained informed consent. Subsequent pages presented the questionnaires in the same order as at in-person

administration. Participants were allowed to complete different pages of the survey at different times (i.e., they could log out after completing a portion, and then log back in to complete the set).

Data Management and Statistical Analyses

I used SPSS (version 25) to complete all analyses, with α set at .05 for all decisions regarding statistical significance. The analytic plan comprised five major steps:

1. I generated detailed descriptive data for each key parent and child sociodemographic characteristic and each key child clinical characteristic. Information regarding these variables was derived from both the sociodemographic questionnaire and the first section of WUN Scoping Survey.
2. I generated similarly detailed descriptive data for each outcome variable derived from the VABS-II MBI, ABC, PSI, FRS, FSS, CES-D, and WHOQOL-BREF (see Table 6). Note that all outcome variables were raw scores with these exceptions: (1) the VABS-II outcome variables were age-adjusted scaled scores (AASS), with transformation from raw scores to AASS completed following tables contained in the test manual (Sparrow et al., 2005); and (2) for the WHOQOL-BREF domain scores, calculated mean scores were multiplied by 4 so as to be directly comparable with scores derived from the full WHOQoL-100.
3. I examined the strength of bivariate associations (using Pearson's r correlation coefficient) between outcome variables derived from the VABS-II, ABC, PSI, FRS, FSS, CES-D, and WHOQOL-BREF. This analytic step might be regarded as a preliminary stage of the Path Analysis (Step 5), as it provides a rough idea of which variables might warrant inclusion in the final model predicting parental QoL.
4. To characterize the sample's service delivery experiences, I conducted detailed descriptive analyses of data from each of the three substantive domains of the WUN Scoping Survey (viz., healthcare system; community support, educational resources, and occupational resources; impact on daily living).
5. Using AMOS structural equation modelling software, I conducted a Path Analysis to determine the role of SES, autism-related problem behaviours, and aspects of service delivery in predicting the QoL of parents of children with ASD. Informed by theory and findings from previous studies in the field, I specified a theoretical

(conceptual) model. I then tested a series of models derived from the theoretical model. Figure 8 presents the base path specified and tested.

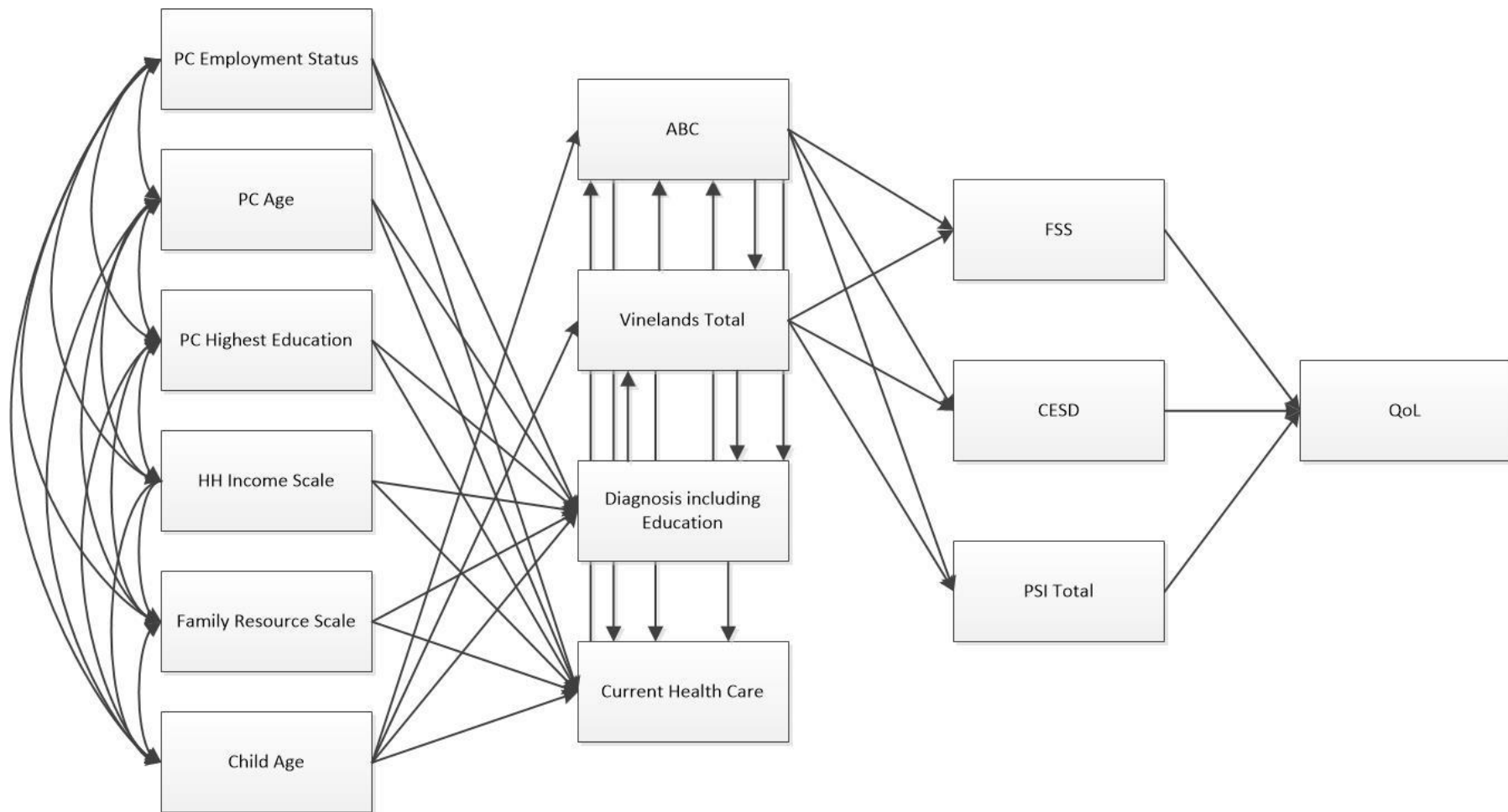


Figure 8. Path Analysis: Graphical overview of the conceptual model. This model tests and captures multiple causal relationships between the variables of interest (sociodemographics, ASD-related behaviours, service delivery outcomes, psychological distress, and overall quality of life in ASD children and their families).

Table 6.

Study 2: Outcome variables and ways in which they were derived

Instrument / Outcome variable	Derivation	Possible Range
VABS-II		
Internalizing Behavior	Sum across scores on 11 relevant items, transform into scaled scores	12 - 24
Externalizing Behavior	Sum across scores on 10 relevant items, transform into scaled scores	11 - 24
Maladaptive Behavior Index	Sum across scores on all 50 items, transform into scaled scores	10 - 24
ABC (total score)	Sum across scores on all 57 items	0 - 158
PSI-SF		
Parenting Distress	Sum across scores on the 12 items comprising the sub-scale	0 - 60
Parent Child Dysfunctional Interaction	Sum across scores on the 12 items comprising the sub-scale	0 - 60
Difficult Child	Sum across scores on the 12 items comprising the sub-scale	0 - 60
Total	Reverse score 3 items (14, 22, 33) then sum across scores on all items	0 - 180
FRS (total score)	Sum across scores on all 30 items	0 - 150
FSS (total score)	Sum across scores on all 18 items	0 - 90
CES-D (total score)	Reverse score 4 items (4, 8, 12, 16) then sum across scores on all items	0 - 60
WHOQOL-BREF		
Physical Health	Mean score of all 7 items within domain, multiplied by 4	4 - 20
Psychological Health	Mean score of all 6 items within domain, multiplied by 4	4 - 20
Social Relationships	Mean score of all 3 items within domain, multiplied by 4	4 - 20
Environment Health	Mean score of all 8 items within domain, multiplied by 4	4 - 20
Total	Sum across the 4 derived domain scores	16 - 80

Note. VABS-II = Vineland Adaptive Behavior Scales, Second Edition; ABC = Autism Behavior Checklist; PSI-SF = Parenting Stress Index Short Form; FRS = Family Resource Scale; FSS = Family Support Scale; CES-D = Center for Epidemiologic Studies-Depression Scale; WHOQOL-BREF = World Health Organization Quality of Life Brief.

Results

Sample Characteristics: Sociodemographic and clinical variables

Parents. The sample ranged in age from 24 to 69 years. Most were women ($n = 176$; 88% of the sample). Most spoke English as a home language, although a significant minority were isiXhosa speakers. The participants were split across four provinces: $n = 1$ from the Eastern Cape, $n = 13$ from Gauteng, $n = 10$ from Kwa-Zulu Natal, and $n = 176$ from the Western Cape. The majority of both mothers and fathers had completed at least some tertiary education, with only a small proportion having completed fewer than 8 years of formal schooling (i.e., having not entered high school at all). Although reports ranged widely in terms of occupational status, the largest proportion of mothers were homemakers while the largest proportion of fathers were classed as administrative personnel, managers, or minor professionals (see Table 7). Note that some demographic data is missing from the Table due to the reporting parent (a) being reluctant to provide complete information (e.g., regarding income or highest level of education), or (b) being unfamiliar with details of the other parent (e.g., father is no longer involved in the child's life, has moved away, or has died).

As noted in Study 1, we include descriptive racial data here because the legacy of South Africa's apartheid policies continues to permeate many aspects of life in this country. Under apartheid (i.e., pre-1994, when many of the current participants were children) White people had easier access to higher-quality healthcare and had fewer stress-provoking experiences of oppression and discrimination. Although legislated racial segregation has not existed for more than 25 years, these disparities are, to at least some degree, still present because of historically-engineered imbalances in economic power. (I discuss racially-based disparities in access to services, and in quality of service delivery, in more detail in Chapter 5.) Using the categories employed by the apartheid government (and that continue to be used in South African census data), most parents in the current sample self-identified as White ($n = 78$; 39%), followed by Black ($n = 54$; 27%), Coloured ($n = 56$; 28%), Indian ($n = 7$; 3.5%), Asian ($n = 1$; 0.5%), and Other ($n = 4$; 2%).

Table 7.
Sample Sociodemographic Characteristics: Parents (N = 200)

Variable	M (SD) or f (%)
Age (years)	41.33 (8.32)
First Language	
English	114 (57)
Afrikaans	17 (8.5)
Bilingual English-Afrikaans	15 (7.5)
isiXhosa	41 (20.5)
Bilingual isiXhosa-English	2 (1)
Bilingual English-Other	3 (1.5)
Other	8 (4)
Highest Level of Education (years)	
Mother	
≥ 13 (at least some tertiary education completed)	115 (57.5)
8-12 (at least some high school completed)	82 (41)
1-7 (at least some primary school completed)	3 (1.5)
Don't know	0 (0)
Father	
≥ 13 (at least some tertiary education completed)	109 (54.5)
8-12 (at least some high school completed)	66 (33)
1-7 (at least some primary school completed)	8 (4)
Don't know	17 (8.5)
Employment (Hollingshead occupational code)	
Mother	
Higher executives, major professionals	12 (6)
Administrative personnel, managers, minor professionals	38 (19)
Business managers of medium sized businesses and other	40 (20)
Clerical and sales, technicians, small businesses	20 (10)
Skilled manual labour	9 (4.5)
Semi-skilled labour	4 (2)
Unskilled labour	9 (4.5)
Student/Disabled/No occupation	11 (5.5)
Homemaker	57 (28.5)
Don't know	0 (0)
Father	
Higher executives, major professionals	32 (16)
Administrative personnel, managers, minor professionals	40 (20)
Business managers of medium sized businesses and other	38 (19)
Clerical and sales, technicians, small businesses	8 (4)
Skilled manual labour	20 (10)
Semi-skilled labour	22 (11)
Unskilled labour	7 (3.5)
Student/Disabled/No occupation	12 (6)
Homemaker	4 (2)
Don't know	17 (8.5)

Table 8.

Sample Economic Characteristics: Parents (N = 200)

Annual Income Range (ZAR)	f (%)
0 - 35 000	36 (18)
36 000 - 75 000	18 (9)
76 000 – 125 000	15 (7.5)
126 000 - 175 000	10 (5)
176 000 – 225 000	12 (6)
226 000 - 275 000	13 (6.5)
276 000 – 325 000	7 (3.5)
326 000 - 375 000	9 (4.5)
376 000 – 425 000	9 (4.5)
426 000 - 475 000	7 (3.5)
476 000 – 525 000	11 (5.5)
> 526 000	42 (21)
Missing	11 (5.5)

Note. ZAR = South African Rands. Over the duration of the data collection, the average ZAR:US\$ exchange rate was 10.57:12.78.

As Table 8 shows, annual household income ranged widely. An illustration of this diversity is that the highest proportion of participants ($n = 42$; 21% of the sample) reported an income in the highest bracket (> ZAR526 000) and the second-highest proportion ($n = 36$; 18%) reported an income in the lowest possible bracket (ZAR R0-35 000). Unsurprisingly, this economic diversity matches the reported occupational diversity.

To put these statistics in context, the most recent available census data indicate that the average annual household income in South Africa is ZAR103 204 per year (de Wet, 2012). More recent and detailed data in this regard are provided in an August 2016 report by one of South Africa's largest financial institutions, Standard Bank ("How many SA households earn more than R200 000 per month", 2016). The report estimated that 62.3% of household incomes fell within the lowest income bracket (viz., < ZAR86 000 per annum), whereas 11.4% fell within the set of middle- to high-income brackets (viz., ZAR400 000 to > 2.36 million per annum). In the current sample, 34.5 % of parents reported a household income that fell within a lower income bracket (viz., < ZAR 125 000; $n = 69$). The same number reported a household income that fell within a middle- to high- income bracket (viz., >ZAR376 000).

Children. The sample ranged in age from 3 to 28 years. Most were male ($n = 175$; 87.5% of the sample), a sex differential consistent with recent findings regarding autism prevalence in the general population (Werling & Geschwind, 2013). Unsurprisingly given the language characteristics of the parent sample, most spoke English as a home language,

although a significant minority were isiXhosa speakers. Most had at least one sibling, and most were either the first- or second-born child in the family (see Table 9). Within the child sample, 8 parents reported that their child was not born within South Africa (4%).

Given the abovementioned reasons for the inclusion of racial data, and again using the categories employed by the apartheid government (and that continue to be used in South African census data), most children in the current sample were White ($n = 70$; 35%), followed by Black ($n = 58$; 29%), Coloured ($n = 61$; 30.5%), Indian ($n = 6$; 3%), Asian ($n = 1$; 0.5%), and Other ($n = 4$; 2%).

Table 9.
Sample Sociodemographic Characteristics: Children ($N = 200$)

Variable	<i>M (SD) or f (%)</i>
Age (years)	10.22 (4.98)
Sex	
Female	25 (12.5)
Male	175 (87.5)
First Language	
English	137 (68.5)
Afrikaans	9 (4.5)
Bilingual English-Afrikaans	6 (3)
isiXhosa	40 (20)
Bilingual isiXhosa-English	1 (0.5)
Bilingual English-Other	0 (0)
Other	7 (3.5)
Number of Siblings	
0	31 (15.5)
1	97 (48.5)
2	51 (25.5)
3	14 (7)
4	7 (3.5)
Number of Older Siblings	
0	85 (42.5)
1	78 (39)
2	25 (12.5)
3	11 (5.5)
4	1 (0.5)

Parent reports indicated that most children in the sample ($n = 115$; 57.5%) had received an ASD diagnosis before the age of 3 years. The great majority ($n = 177$; 88.5%) had been diagnosed by the age of 6 years. The oldest reported age of diagnosis was 24 years.

Parent reports also indicated that a substantial minority of children in the sample ($n = 59$; 29.5%) had been diagnosed with an intellectual disability. They also indicated that many children in the sample experienced or displayed communication problems ($n = 175$; 87.5% of the sample). There were also reports regarding the presence of prominent sensory difficulties (vision problems, $n = 22$, 11%; hearing problems, $n = 15$, 7.5%), memory impairment ($n = 23$, 11.5%), epilepsy ($n = 10$; 5%), asthma ($n = 8$; 4%), psychiatric disorders (depression, $n = 12$, 6%; oppositional-defiant disorder, $n = 11$, 5.5%; attention-deficit/hyperactivity disorder, $n = 59$, 29.5%), and history of head injury ($n = 14$, 7%).

Sample Characteristics: Child Behavioural and Parent Psychological Characteristics

VABS-II. According to the test developers, AASS < 18 indicates “average behavior” (i.e., minimal levels of maladaptive behaviours), whereas scores of 18-20 indicate an elevated level of maladaptive behaviour and scores of 21-24 indicate clinically significant maladaptive behaviour (Sparrow et al., 2005). Hence, the data presented in Table 10 suggest that, for parent reports on the Internalizing Behavior and Externalizing Behavior sub-scales, and on the overall Maladaptive Behavior Index, the mean AASS indicated elevated levels of maladaptive behaviour within the sample of children. However, for each individual outcome variable, most children had a score that fell into the clinically significant range (Internalizing Behavior, 56% of participants, $n = 112$; Externalizing Behavior, 52.5%, $n = 105$; overall MBI, 53.5%, $n = 107$).

ABC. I classified scores following the rubric provided by Oro and colleagues (2014): > 70 , moderate-severe; 45-69, mild; 20-44, borderline; < 20 , minimal present currently. Hence, the sample’s average score fell within the moderate-severe range (see Table 10). The severity of parent-reported current symptom presentation ranged widely across children, however. Although the largest proportion of parents ($n = 110$; 55%) reported moderate-severe ASD behaviours in their child, substantial numbers reported the presence of mild ($n = 51$; 25.5%) and borderline ($n = 31$; 15.5%) ASD-type behaviours.

PSI-SF. According to the test developer, a total raw score > 90 indicates a clinically significant level of parental stress, and raw scores > 33 on the Parental Distress and Difficult Child sub-scales and > 27 on the Parent-Child Dysfunctional Interaction sub-scale are considered clinically elevated (Abidin, 1995). Hence, the data presented in Table 10 suggest that, on average, participants in this sample were experiencing (a) clinically elevated levels of stress within each of the three sub-domains, and (b) clinically significant levels of overall parent stress. In fact, 147 parents (73.5% of the sample) scored above the clinical threshold of

90. The analogous proportion for the sub-scales were Parental Distress, $n = 125$ (62.5 %); Difficult Child, $n = 129$ (64.5%), Parent-Child Dysfunctional Interaction, $n = 134$ (67%). Four respondents (2% of the sample) scored below < 10 on the Defensive Responding index, indicating questionable reliability in those cases. I chose to retain their data, however.

Table 10.
Sample Psychological Characteristics (N = 200)

Instrument / Outcome Variable	M	SD	Actual Range	Possible Range
VABS-II^a				
Internalizing Behavior	20.74	1.82	13 - 24	12 - 24
Externalizing Behavior	18.46	2.22	12 - 24	12 - 24
Maladaptive Behavior Index	20.19	1.89	14 - 24	12 - 24
ABC (total score)	69.96	27.59	3 - 139	0 - 158
PSI-SF				
Parenting Distress score	36.04	9.95	12 - 60	0 - 60
Parent-Child Dysfunctional Interaction	30.69	7.60	14 - 60	0 - 60
Difficult Child score	36.62	8.54	14 - 60	0 - 60
Total	103.34	21.70	54 - 156	0 - 180
FRS (total score)	103.87	28.53	0 - 150	0 - 150
FSS (total score) ^b	33.95	14.17	5 - 80	0 - 90
CES-D (total score)	19.01	12.21	0 - 55	0 - 60
WHOQOL-BREF				
Physical Health	14.42	2.77	4.60 - 20	4 - 20
Psychological	13.58	3.03	5.33 - 19.33	4 - 20
Social Relationships ^c	13.49	3.40	4 - 20	4 - 20
Environment	12.97	3.13	6 - 19.50	4 - 20
Total ^c	54.15	10.21	24.74 - 75.10	16 - 80

Note. VABS-II = Vineland Adaptive Behavior Scales, Second Edition; ABC = Autism Behavior Checklist; PSI-SF = Parenting Stress Index Short Form; FRS = Family Resource Scale; FSS = Family Support Scale; CES-D = Center for Epidemiologic Studies-Depression Scale; WHOQOL-BREF = World Health Organization Quality of Life Brief (higher scores here indicate higher satisfaction with overall as well as domain-specific quality of life).

^a $N = 198$; two parents did not complete all the questions.

^b $N = 199$; one parent did not complete one question.

^c $N = 196$; six parents did not complete one question in the Social Relationships domain.

FRS and FSS. There are no published or standard cut-off scores or descriptive ranges for these scales. Many previous studies compare the scores of a patient group to those of a control group and base their interpretation of available resources and support on the

magnitude of between-group differences (see, e.g., Brannan et al., 2006; Honey et al., 2005). Of course, this option is not available in the current study, and hence it is somewhat difficult to interpret the current sample's reports. What is clear, however, is that there was significant variability in the resources available to each family as well as the perceived support received by the parents (see Table 10). In terms of family resources, for instance, 3 participants (20% of the sample) scored 65 or below (i.e., below the 50th percentile), whereas 4 participants (26.67%) scored 96 or above (i.e., above the 80th percentile). Similarly, in terms of support, for instance, 155 participants (77.5% of the sample) scored 45 or below (i.e., below the 50th percentile), whereas only 3 participants (1.5%) scored 72 or above (i.e., above the 80th percentile).

CES-D. The sample's mean total CES-D score fell in the range conventionally regarded as indicating significantly high levels of depression (recall that this threshold is scores > 16; see Table 10). Overall, 111 parents (55.5% of the total sample) scored above that threshold.

WHOQOL-BREF. As in Chapter 3, I interpreted the WHO-QOL BREF scores shown in Table 10 using the preliminary normative data provided by Hawthorne and colleagues (2006). Recall that those normative data are based on responses from a sample of 904 community-dwelling residents of the Australian state of Victoria and consist of age- and sex-adjusted means and standard deviations for each domain score. As Table 11 (Appendix U) shows, in this sample self-reported quality of life was, on the average, poor across all domains. In the Physical Health domain, 55 participants (27.5% of the sample) reported significantly poor quality of life ($z < -1.00$). The analogous numbers in the other domains were comparable: Psychological, $n = 60$ (30%); Social Relationships, $n = 65$ (32.5%); and Environment, $n = 75$ (37.5%). In contrast, far fewer participants reported very good quality of life ($z > 1.00$) in each domain (< 10% of the sample in each case).

Bivariate Correlations: Child behavioural and parent psychological characteristics

As Table 12 shows, almost every one of these outcome variables was statistically significantly associated with every other one. Moreover, the associations were in the expected directions. For instance, regarding parent reports about child behaviour, ABC total score was significantly positively correlated with the VABS-II Internalizing Behavior, Externalizing Behavior, and overall Maladaptive Behavior Index age-adjusted scaled scores, $p < .001$ in each case. Unsurprisingly, each VABS-II AASS was significantly positively associated with the other two, $p < .001$ in each case. Together, this set of associations suggests that (a) the

more parents reported autism-specific behaviours and symptoms, the more they also reported general maladaptive behaviours, and (b) the more parents reported internalizing maladaptive behaviours, the more they also reported externalizing maladaptive behaviours.

Regarding parent self-reports about psychological distress and quality of life, analyses detected the expected associations. For instance, each PSI-SF score correlated positively with CES-D total score, $p < .001$ in each case (in other words, participants who reported higher levels of parental stress also reported higher levels of depression). Similarly, all the WHOQOL-BREF scores correlated negatively with CES-D total score, $p < .001$ in each case (in other words, participants who reported poorer quality of life also reported higher levels of depression). Generally speaking, participants who reported higher levels of parental stress also reported poorer quality of life and lower levels of interpersonal support (as measured by the FSS). Relatedly, the analyses detected significant positive correlations between FSS total score and WHOQOL-BREF Total score, Psychological Health domain score, and Social Relationship domain score, $p < .001$ in each case (in other words, those who reported receiving more interpersonal support also reported experiencing better quality of life).

Regarding relations between the child's behaviour and the parent's psychological distress, the analyses again detected the expected associations. For instance, the VABS-II MBI AASS was significantly positively correlated with (a) each PSI-SF score, $ps < .001$, and (b) the CES-D total score, $p < .001$, and was significantly negatively correlated with (c) WHOQOL-BREF Physical Health, Psychological Health, Social Relationships, Environment, and Total scores, $ps < .011$. In other words, parents who reported more maladaptive behaviours in their children also reported more parenting stress, more psychological distress, and poorer quality of life.

Finally, it is worthwhile noting that FRS score did not correlate significantly with any other outcome variable under consideration.

Table 12.

Bivariate Correlations: Scores on instruments measuring child behavioral and parent psychological questionnaires (N = 200)

Instrument / Outcome Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
6. VABS-II MBI	1.00	.76***	.79***	.48***	.53***	.31***	.32***	.56***	.02	-.09	.37***	-.27***	-.24**	-.26***	-.19**	-.18**
7. VABS-II Internalizing		1.00	.47***	.29***	.41***	.29***	.30***	.42***	-.03	-.20**	.34***	-.26***	-.21**	-.22**	-.22**	-.13
8. VABS-II Externalizing			1.00	.35***	.44***	.27***	.28***	.56***	.08	-.04	.32***	-.22**	-.19**	-.23**	-.17*	-.11
9. ABC (total score)				1.00	.33***	.21**	.24**	.37***	.07	-.07	.26***	-.25***	-.12	-.14*	-.16*	-.29***
10. PSI-SF Total					1.00	.85***	.82***	.82***	.12	-.25***	.56***	-.56***	-.43***	-.55***	-.45***	-.41***
11. Parental Distress						1.00	.55***	.49***	.09	-.30***	.64***	-.67***	-.49***	-.67***	-.58***	-.47***
12. PCDI							1.00	.56***	.09	-.15*	.33***	-.34***	-.26***	-.33***	-.29***	-.26***
13. Difficult Child								1.00	.13	-.16*	.39***	-.35***	-.29***	-.32***	-.22**	-.26***
14. FRS (total score)									1.00	.08	.09	-.09	-.11	-.11	-.07	-.07
15. FSS (total score)										1.00	-.12	.25***	.09	.28***	.39***	.09
16. CES-D (total score)											1.00	-.69***	-.61***	-.71***	-.47***	-.41***
17. WHOQOL-BREF Total												1.00	.82***	.85***	.78***	.73***
18. Physical Health													1.00	.69***	.49***	.57***
19. Psychological Health														1.00	.66***	.47***
20. Social Relationships															1.00	.43***
21. Environment																1.00

Note. Data presented are Pearson's r correlation coefficients. *Note.* VABS-II = Vineland Adaptive Behavior Scales, Second Edition; MBI = Maladaptive Behavior Index; ABC = Autism Behavior Checklist; PSI-SF = Parenting Stress Index Short Form; PCDI = Parent-Child Dysfunctional Interaction; FRS = Family Resource Scale; FSS = Family Support Scale; CES-D = Center for Epidemiologic Studies-Depression Scale; WHOQOL-BREF = World Health Organization Quality of Life Brief.

^a $N = 198$; two parents did not complete all the questions.

^b $N = 199$; one parent did not complete one question.

^c $N = 196$; six parents did not complete one question in the Social Relationships domain.

* $p < .05$. ** $p < .01$. *** $p < .001$.

WUN Scoping Survey: Service delivery data

Section I: Healthcare system. In this section of the survey, parents answered questions about their child's contact with healthcare professionals and systems at these stages: (a) pre-diagnosis, (b) during the process of diagnostic assessment, (c) immediately following completion of the assessment (i.e., during the feedback session), and (d) currently.

Pre-diagnosis. Although there was some variation in when the child's behavioural and/or developmental difficulties were noticed, most parents ($n = 156$; 78% of the sample) reported they had become aware/been made aware before the child turned 4 years old ($M = 26.55 \pm 19.56$ months; range = 0-14.5 years). There was also variation in who first noticed these difficulties. In most cases ($n = 110$; 55% of the sample), a professional (e.g., pediatrician, psychologist, teacher, general practitioner, specialist doctor, nurse) alerted the parents. In many cases, however, either a parent ($n = 54$; 27%) or a grandparent ($n = 12$; 6%) noticed first.

As Figure 9 shows, the largest proportion of parents ($n = 77$; 38.5% of the sample) took their child to a healthcare professional within 1 month of behavioural and/or developmental difficulties being noticed. Of note, however, is that 23 parents (11.5%) waited for more than a year before taking such action.

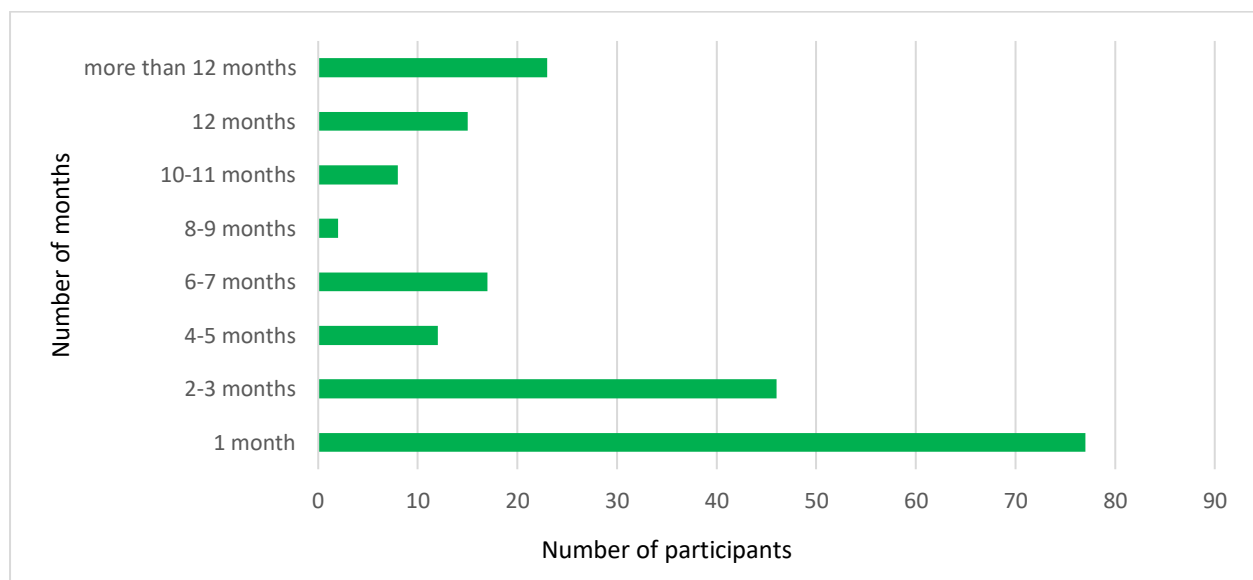


Figure 9. Parent reports regarding the number of months between noticing/being made aware of behavioural and/or developmental difficulties and them taking their child to a healthcare professional ($N = 200$). Of the 23 parents who reported the delay being > 12 months, 14 gave an exact timeframe ($M = 42.92 \pm 32.28$ months, range = 14 months to 10 years).

Figure 10 shows that the largest proportion of parents ($n = 72$) reported consulting a pediatrician first. The next-largest proportion ($n = 32$) consulted a nurse, followed by

psychologist ($n = 30$). Some consulted an allied health professional (e.g., speech-language pathologist; occupational therapist; audiologist; $n = 22$), pediatric neurologist ($n = 11$), general practitioner ($n = 25$) or another medical professional (e.g., ear, nose, and throat specialist; developmental general practitioner; pediatric neurologist ($n = 8$).

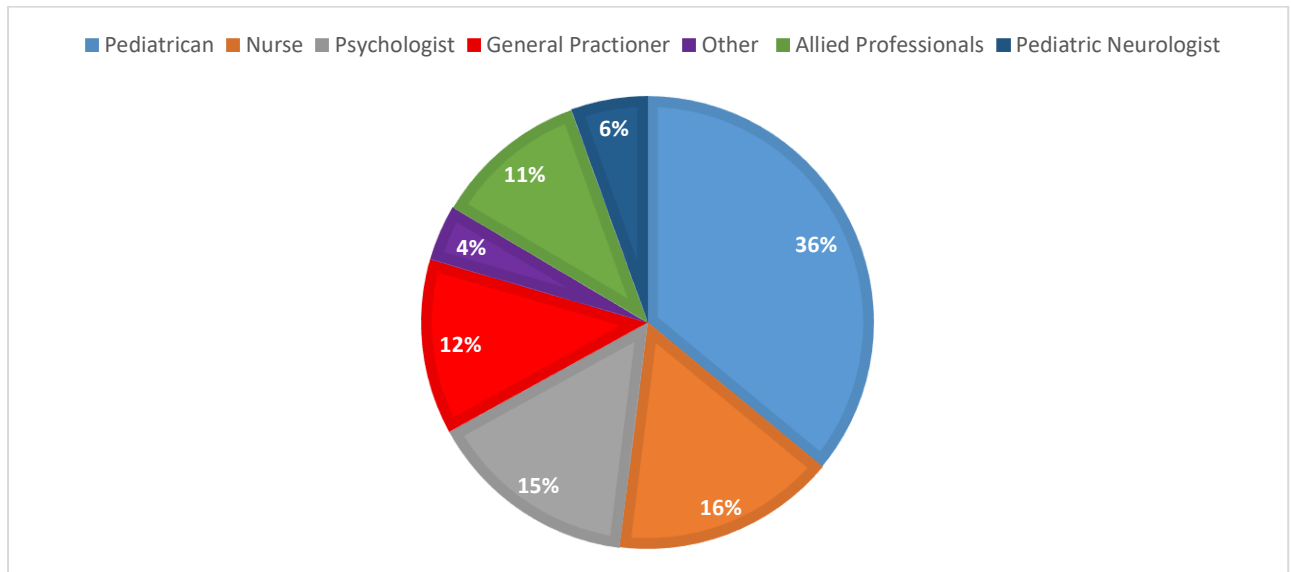


Figure 10. Parent reports regarding the categories of healthcare professionals who were first consulted regarding observed behavioural and/or developmental difficulties ($N = 200$).

Most parents ($n = 118$; 59%) reported that ASD was not noted as a possible diagnosis during this first healthcare consultation. An even larger proportion ($n = 144$; 72%) reported being referred from that first consultant to other services. Speech therapy was the most common referral ($n = 31$; 21.5%). Other referrals included occupational therapy, a combination of speech therapy and occupational therapy, audiology, special needs schooling, autism-specific schooling, and general hospital service.

Parents stated that, at the pre-diagnostic stage, their knowledge of the processes involved in the actual diagnosis was poor. As Figure 11 illustrates, most did not know how much the assessment would cost, how long they would have to wait to get an assessment, the name and the title of the clinician who would do the assessment, how long the assessment process would last (including the number of appointments), and what types of assessments would be conducted.

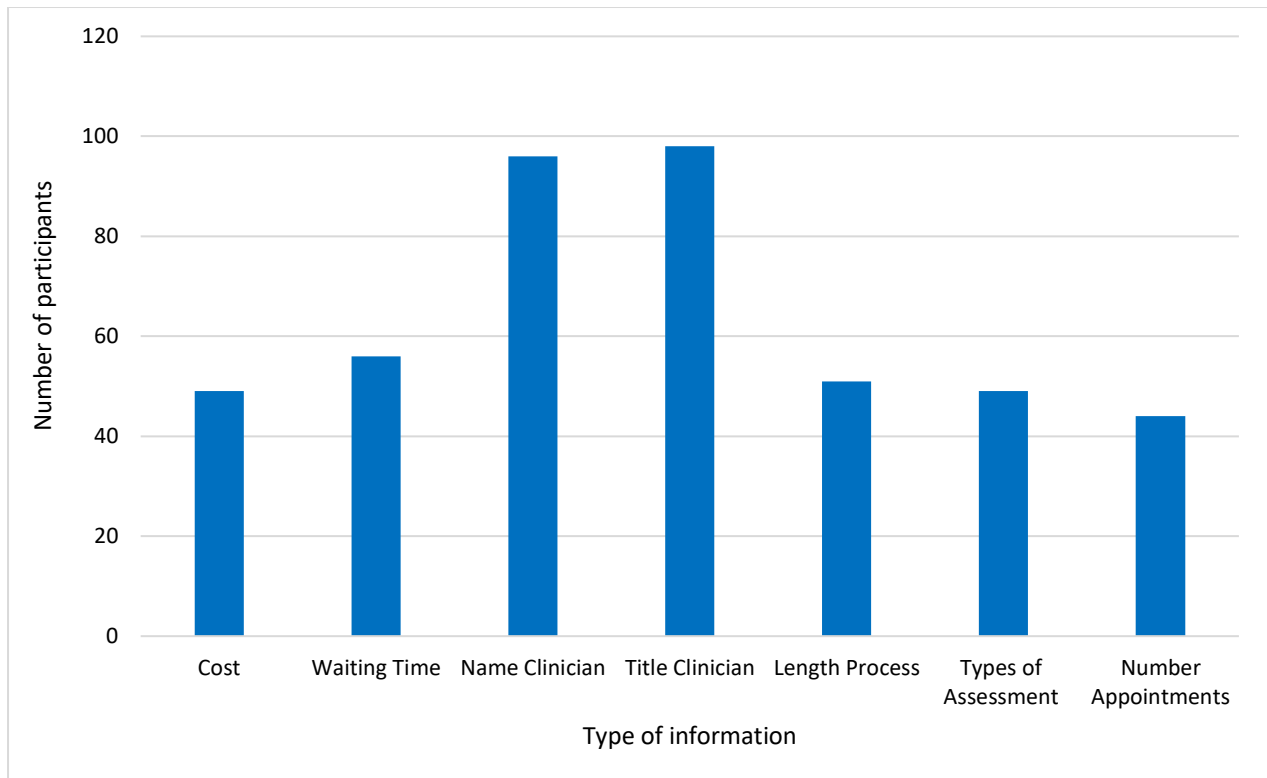


Figure 11. Parent reports regarding the type of information not provided prior to the diagnostic assessment ($N = 200$).

The length of time between attending the first healthcare consultation and beginning the process of diagnostic assessment varied quite widely, $M = 9.88 \pm 24.76$ months, range = 0-48.

Diagnostic process: Assessment. As Figure 12 shows, the largest proportion of parents ($n = 97$; 48.50% of the sample) reported consulting a specialist medical professional (e.g., pediatrician, neurologist, pediatric neurologist) to complete the diagnostic assessment. A substantial number ($n = 81$; 40.5%) reported consulting a psychologist.

Fewer than half of the parents ($n = 70$; 35%) reported receiving a diagnosis from a multi-disciplinary team consisting of two or more health professionals. Most parents ($n = 163$; 81.5%) reported that they observed the diagnostic assessment.

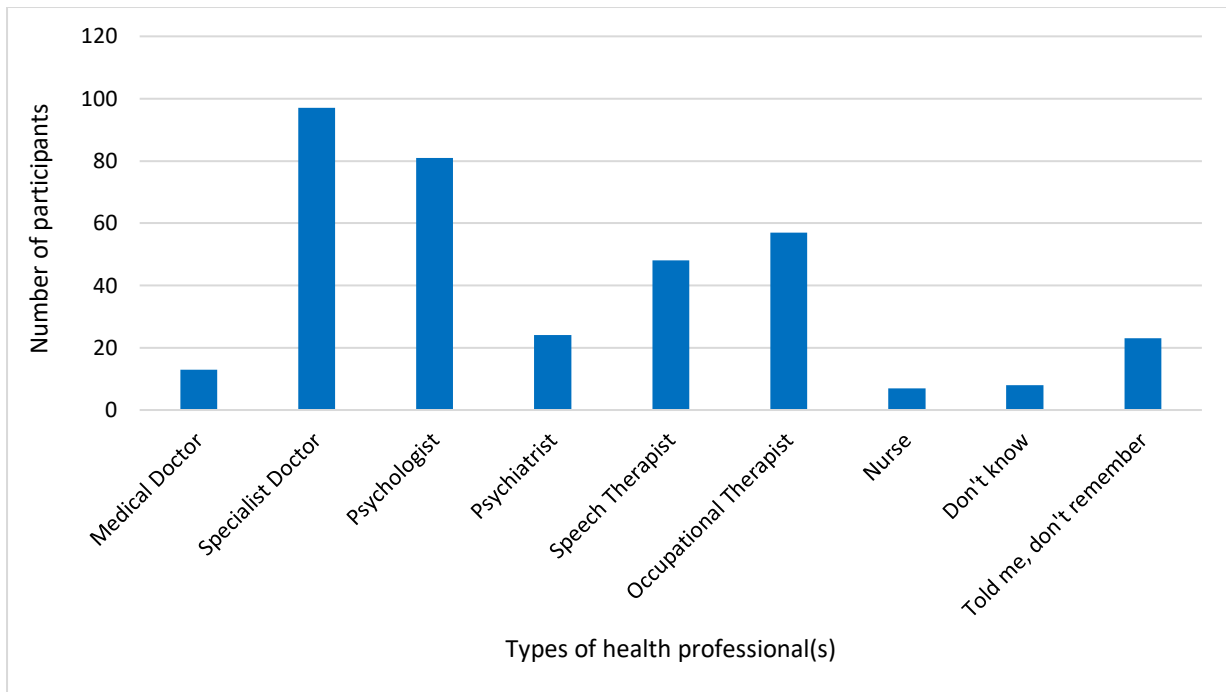


Figure 12. Parent reports regarding the types of health professional(s) present during the diagnostic assessment ($N = 200$). The category “specialist medical doctor” includes pediatricians, neurologists, and pediatric neurologists.

For nearly half of the sample ($n = 98$; 49%), the assessment included all five of what might be considered the core elements of an ASD diagnostic procedure (i.e., clinical interview [including family history], behavioural observation, cognitive assessment, speech and language assessment, and physical examination). Almost every other parent (again, $n = 98$; 49%) reported that their child’s diagnostic assessment included at least one of those core elements.

The most common feature of the diagnostic assessment was a behavioural assessment; 92.5% of parents reported that their child’s diagnosis was based at least in part on such an evaluation (see Figure 13). The next-most frequently included parts of the assessment were the other core elements of an ASD diagnostic procedure: clinical interview [including family history], 90.5%; speech and language assessment, 88%; cognitive assessment, 72.5%; and physical examination, 68%. Of interest is that some parents reported that the diagnostic assessment included an MRI ($n = 28$; 14%), a blood and urine assessment ($n = 47$; 23.5%), or a genetic analysis ($n = 9$; 4.5%).

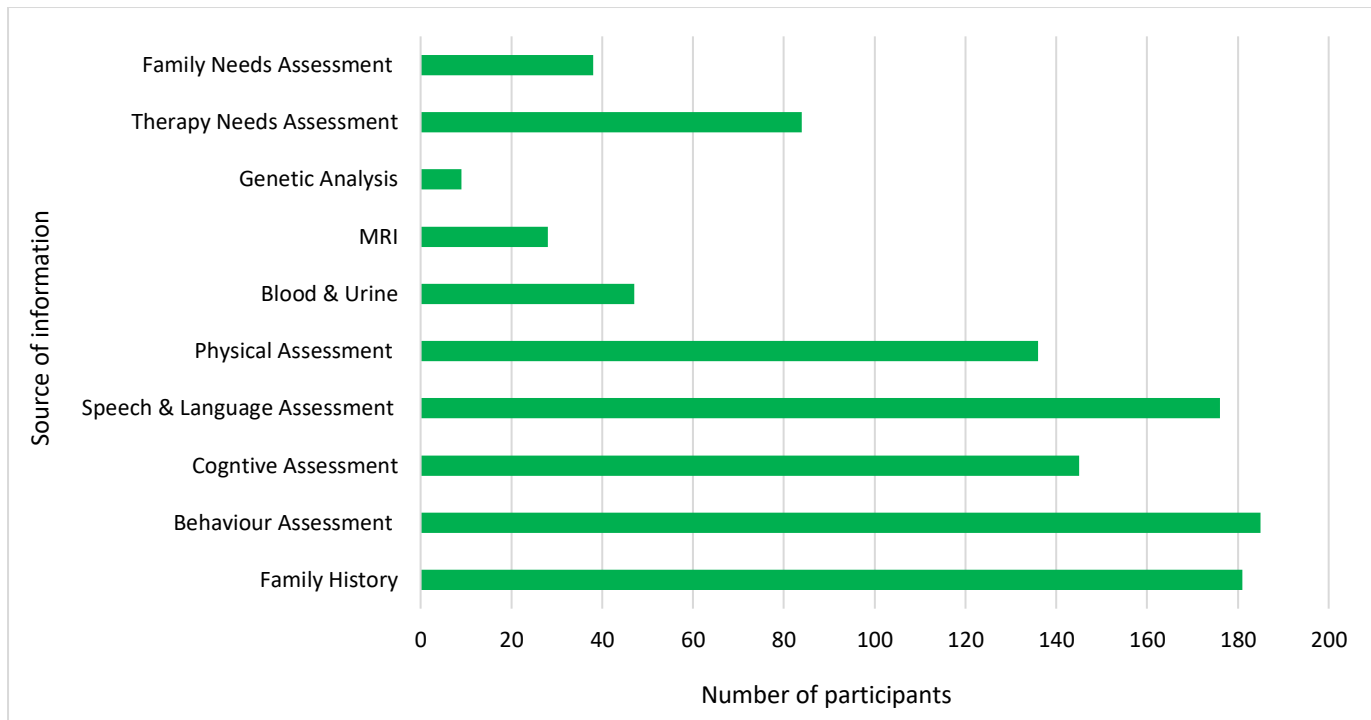


Figure 13. Parent reports regarding the sources from which health professional(s) gathered information during the diagnostic assessment ($N = 200$).

The fact that the assessment itself was a lengthy process is illustrated by the fact that more than half of parents ($n = 112$; 55.45%) reported attending more than one such session. Of that number, 21 parents (18.75%) reported attending 5 or more sessions. Although we do not know the length of any individual session, approximately half of the parents reported that the diagnostic assessment process lasted longer than 2 hours (see Figure 14).

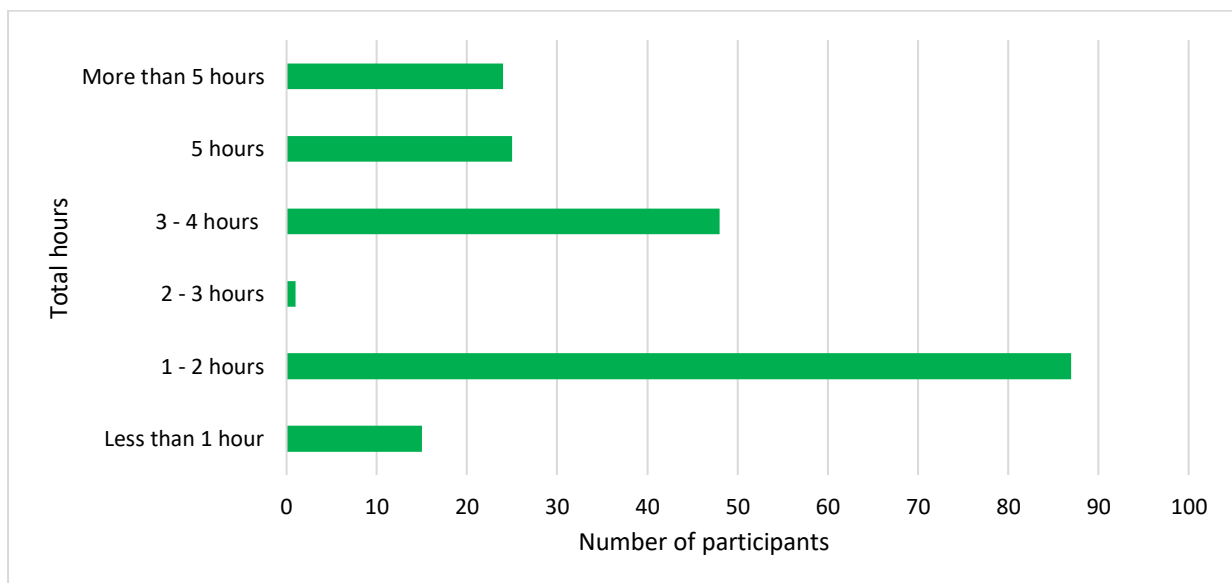


Figure 14. Parent reports regarding the total number of hours spent with the health professional(s) during the diagnostic assessment process ($N = 200$).

Diagnostic process: Feedback. As Figure 15 shows, most parents ($n = 94$; 47% of the sample) indicated that they received a feedback report (either in-person or written) on the same day as the diagnostic assessment finished. A substantial minority ($n = 21$; 10.5%) had to wait for more than a month after the assessment was complete to receive a report, however.

Most parents ($n = 181$; 90.5%) reported receiving in-person feedback from at least one of the professionals involved in the assessment. However, the amount of time the professional spent providing feedback varied greatly. Most parents ($n = 137$; 76% of those who received in-person feedback) reported that the feedback session lasted less than 45 minutes. In contrast, only 11 parents (6%) reported that the session lasted longer than 1 hour.

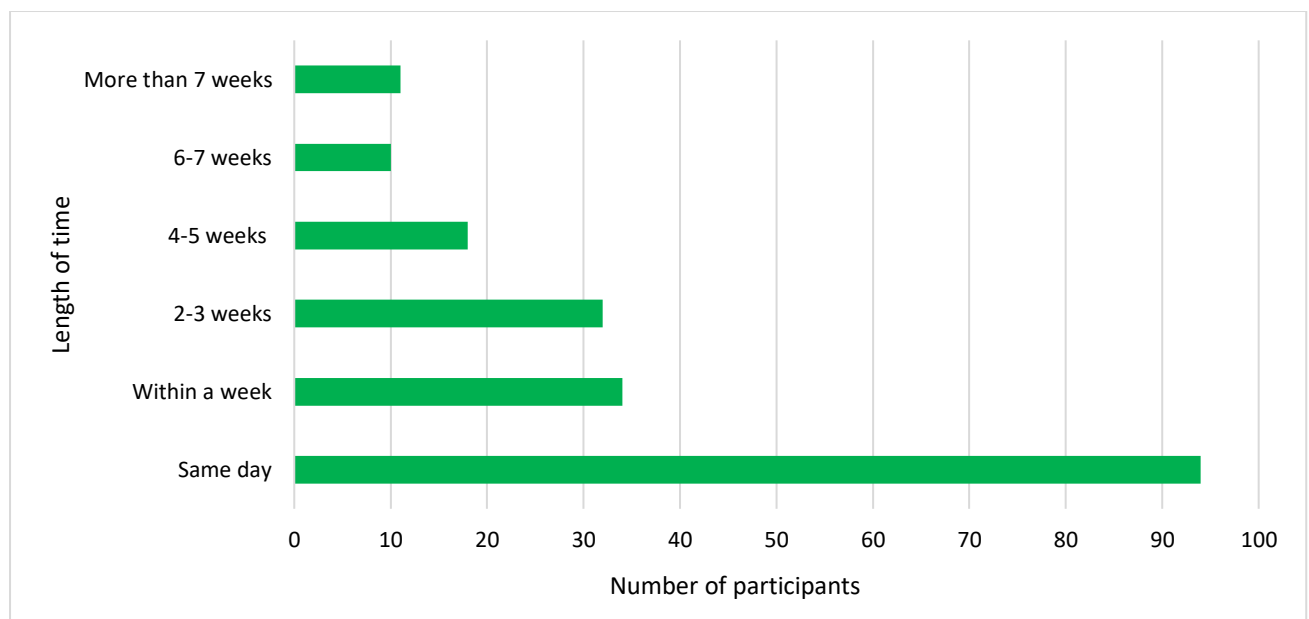


Figure 15. Parent reports regarding the length of time they had to wait before receiving the results of the diagnostic assessment ($N = 200$).

Most parents ($n = 141$; 70.5% of the sample) reported receiving a written report. Of note, however, is that 24 of those individuals (17% of those who received the report) indicated that they did not fully understand its contents.

Parents reported that either the in-person feedback session or the written report incorporated referral to various different services (see Figure 16). The three most common referrals were to special needs education ($n = 152$), speech therapy ($n = 135$), and occupational therapy ($n = 119$). Most parents ($n = 122$; 61%) reported receiving multiple referrals (i.e., 3 or more). Only a small proportion of parents reported receiving one referral ($n = 28$; 14%), with only 12 parents (6%) reported receiving no referrals.

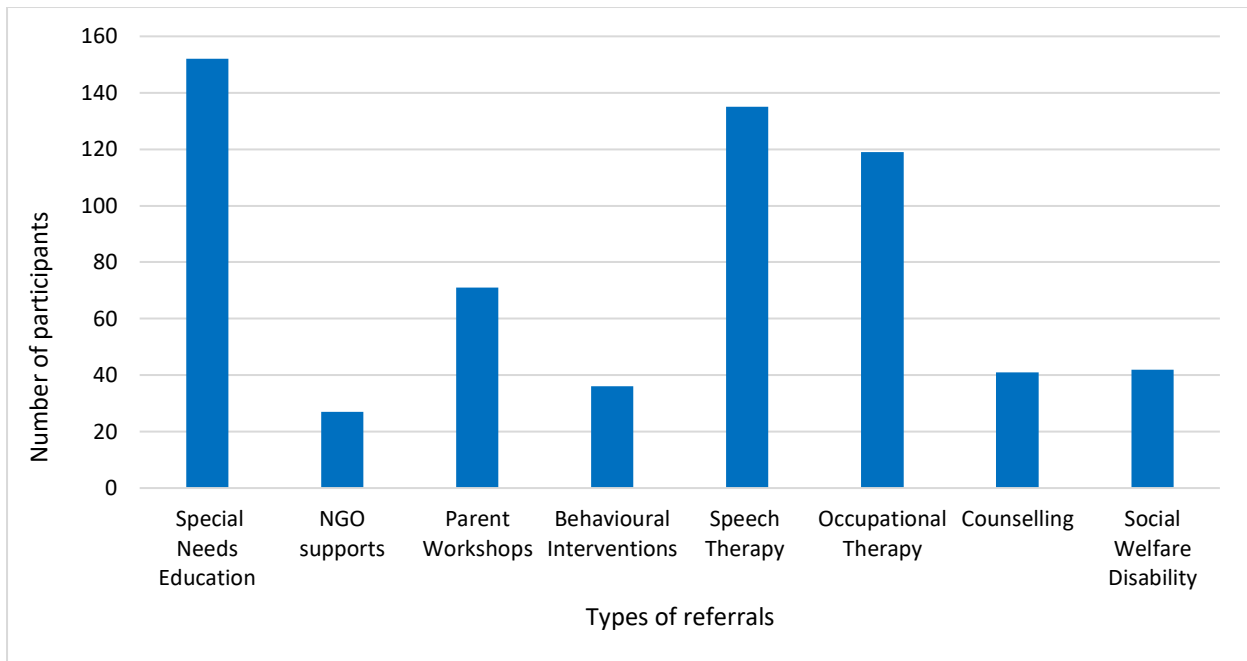


Figure 16. Parent reports regarding the types of referrals the health professionals provided after diagnostic assessment was complete ($N = 200$).

Most parents ($n = 160$; 80% of the sample) reported being satisfied that, at the conclusion of the diagnostic assessment process, the health professional had answered their ASD-related questions. A smaller percentage, but still a majority of the sample ($n = 107$; 53.5%) reported being satisfied with the diagnostic process.

After the diagnosis process was completed, 33% of parents ($n = 66$) reported that their child saw someone from the diagnostic team within 1 month. A smaller number ($n = 59$; 29.50%) reported that that contact came within 3-6 months, and an even smaller number ($n = 14$; 7%) reported that the period exceeded 6 months. A substantial minority ($n = 61$; 30.50%) reported that they had no further contact with the diagnostic team after the conclusion of the diagnostic process.

Current healthcare. Most parents ($n = 130$; 65%) reported that they have no current contact with the team that diagnosed their child. Amongst those who reported still having follow-up assessments with that team, most reported seeing the same clinician(s) every 4-6 months ($n = 25$; 35.71% of the sub-sample).

Parent reports regarding current therapeutic interventions ranged widely (see Figure 17). Most commonly, children were receiving speech and language therapy (51% of the sample) and occupational therapy (28%). Of note, however, is that 41 parents (20.50%) reported that their child was not receiving any form of therapy, intervention, or medication.

A large proportion of parents ($n = 94$; 47%) reported that their child was on some form of medication. The type of medication ranged widely, and included treatments for

epilepsy (e.g., Epilim, epitec, epilizine, Rivitrol), ADD/ADHD (e.g., Concerta, Ritalin, Straterra), behaviour modification and mood stabilisation (e.g., risperidone, ethipramine, nuzak, Lexamil, Abilify, Zoloft, cetirizine, Prozac, Tegretol, Androcur, amitriptaline, seranace), and sleep regulation (Melatonin).

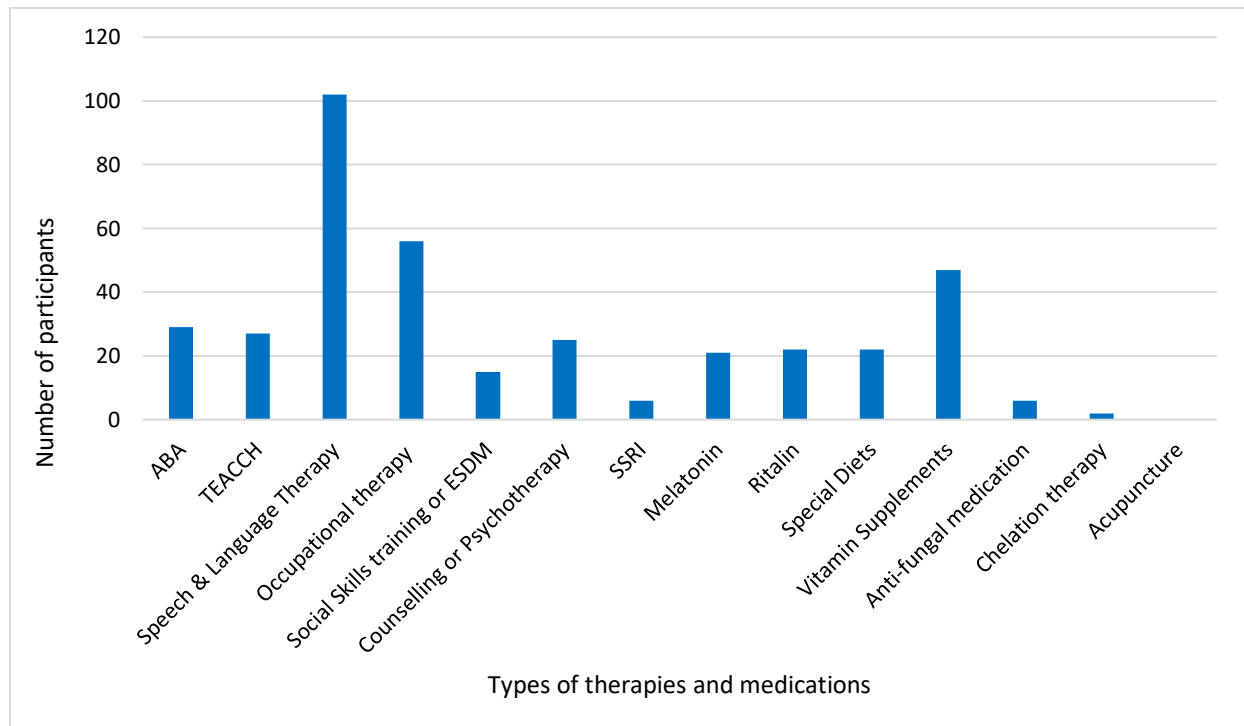


Figure 17. Parent reports regarding current therapies and medications used by their child ($N = 200$). Some parents reported that their child was receiving types of therapies not given as an option in the survey. These included cranio-sacral therapy, cognitive behavioural therapy, Son-Rise programme, special needs and autism school supports, Handle, sporting activities (e.g., swimming, cycling, yoga). ABA = Applied Behavioural Analysis; TEACCH - Treatment and Education of Autistic and Related Communication Handicapped Children; SSRI = Selective Serotonin Reuptake Inhibitor.

Most parents ($n = 115$; 57.5% of the entire sample) reported that they had private health insurance/medical aid. However, most of those individuals ($n = 75$; 65.21% of the sub-sample) reported that their health insurance/medical aid paid for little to none of the services their child was receiving, and that they had to pay out-of-pocket (in much the same way as those who had no private health insurance/medical aid). Only 11 parents (9.57% of the sub-sample) reported that their health insurance/medical aid covered all their child's required services.

Section II: Community support, educational resources, and occupational resources. Regarding *community support*, Figure 18 shows participants' responses to being questioned about various forms of community-based services and resources. Although reports indicated that most of the enquired-about services and resources were available to participants, in many cases they reported not using those services or availing themselves of those resources. Community-funded therapies, community organisations, career development, and employment assistance were endorsed as being the most notable areas of need (i.e., at least 50% of parents reported that each of these were currently unavailable and needed).

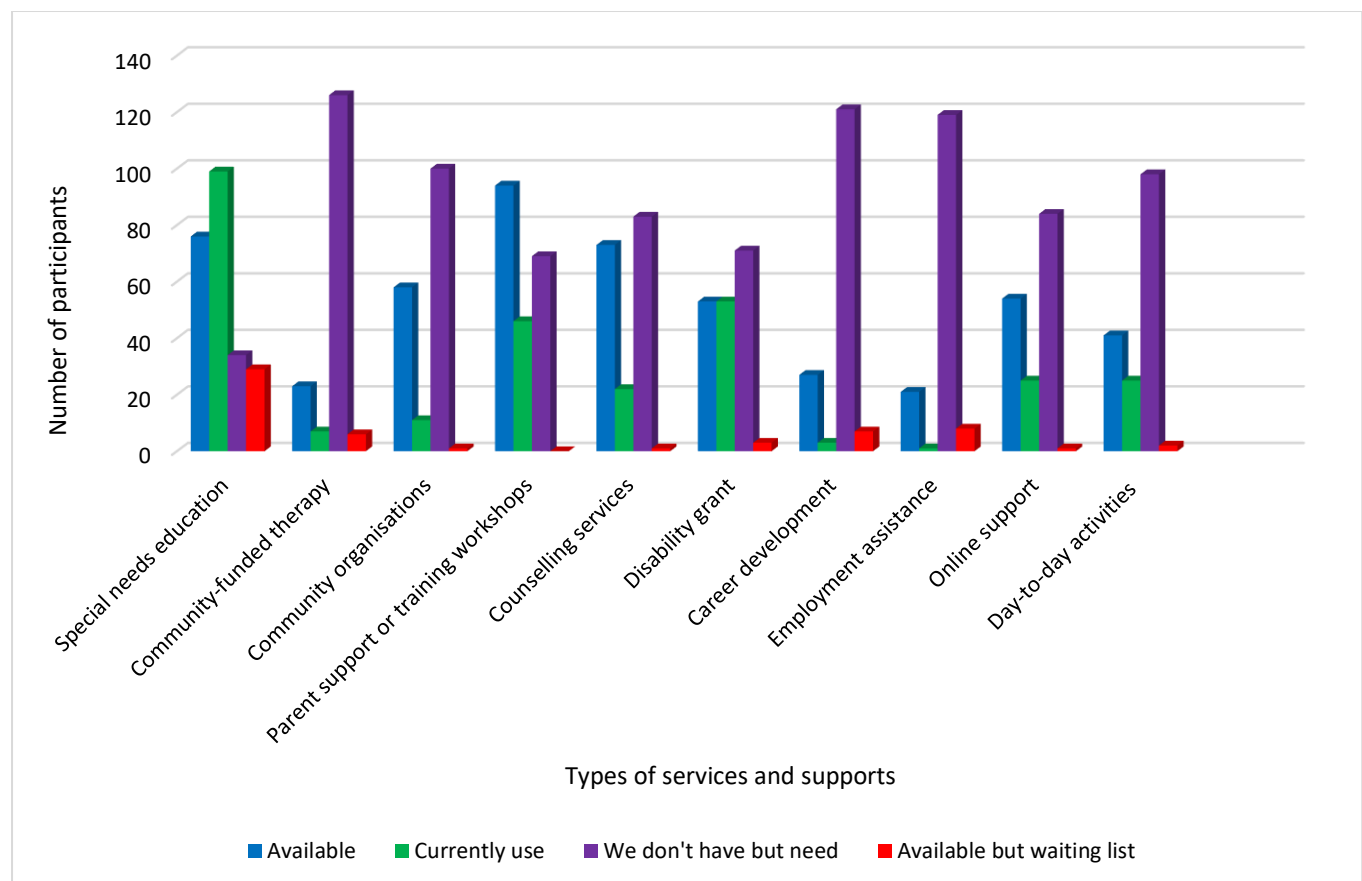


Figure 18. Parent reports regarding the availability of specific services, supports, and resources for autism-affected families within their community ($N = 200$). The category “day-to-day activities” refers to the availability of public transport services, shopping centres, babysitters, hairdressers, etc.

Most parents ($n = 132$; 66% of the sample) reported that they were not receiving a government-sponsored child dependency grant. Of those that were, most ($n = 51$; 91.07% of the sub-sample) reported receiving an amount ranging from ZAR1300-R1500.

A separate item addressed the question of why, if services are available, they are not used. As Figure 19 shows, the most frequently reported issues that affected service use were their expense (52.5%), their location (34.5%), or the length of waiting times (37%). Only 41 parents (20.50%) reported no problems with the services.

Most parents ($n = 143$; 71.5% of the 199 who responded to this question) reported that their home language was not a barrier to accessing relevant services. Of the 56 who reported that home language did present such a barrier, 28 were Xhosa first-language speakers, 20 were English first-language speakers, 4 were English-Afrikaans bilingual, 2 were Afrikaans first-language speakers, and 2 were English-other bilingual.

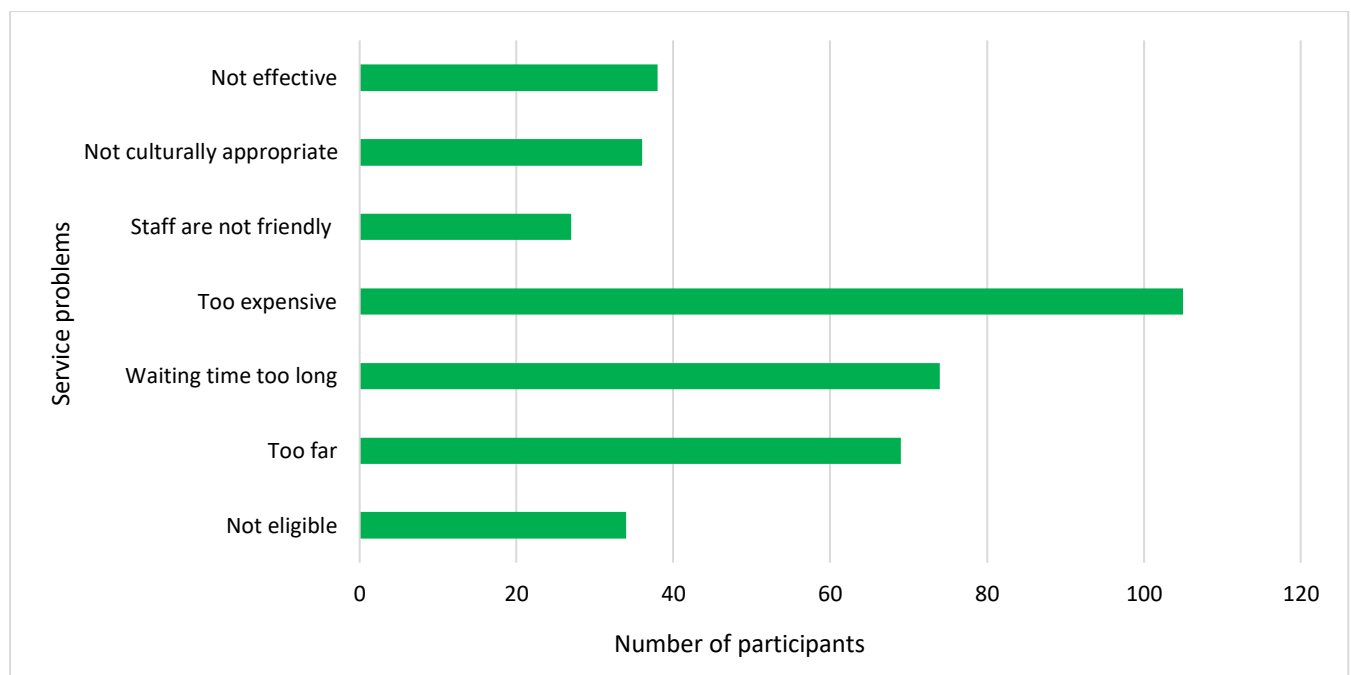


Figure 19. Parent reports regarding why they might not use services, or avail themselves of resources, that are available in their community ($N = 200$).

Regarding *educational resources*, most parents ($n = 156$; 78% of the sample) reported that their child was currently enrolled at a formal institution (e.g., school-based day-care centre, primary school, high school). For the 44 children not enrolled, reasons given included home schooling ($n = 8$), being on a waiting list ($n = 14$), being older than 18 years ($n = 15$), and “other” (e.g., suspension, informal crèche, and still looking for a school; $n = 7$).

As Figure 20 shows, substantial proportions of the children enrolled at a formal institution attended an autism-specific school ($n = 72$; 46.15% of the enrolled sub-sample) or a public school with an exclusive focus on special-needs education ($n = 37$; 23.72%). Only 3

parents (1.92%) reported that their child attended a public school and received mainstream education with no special needs supports.

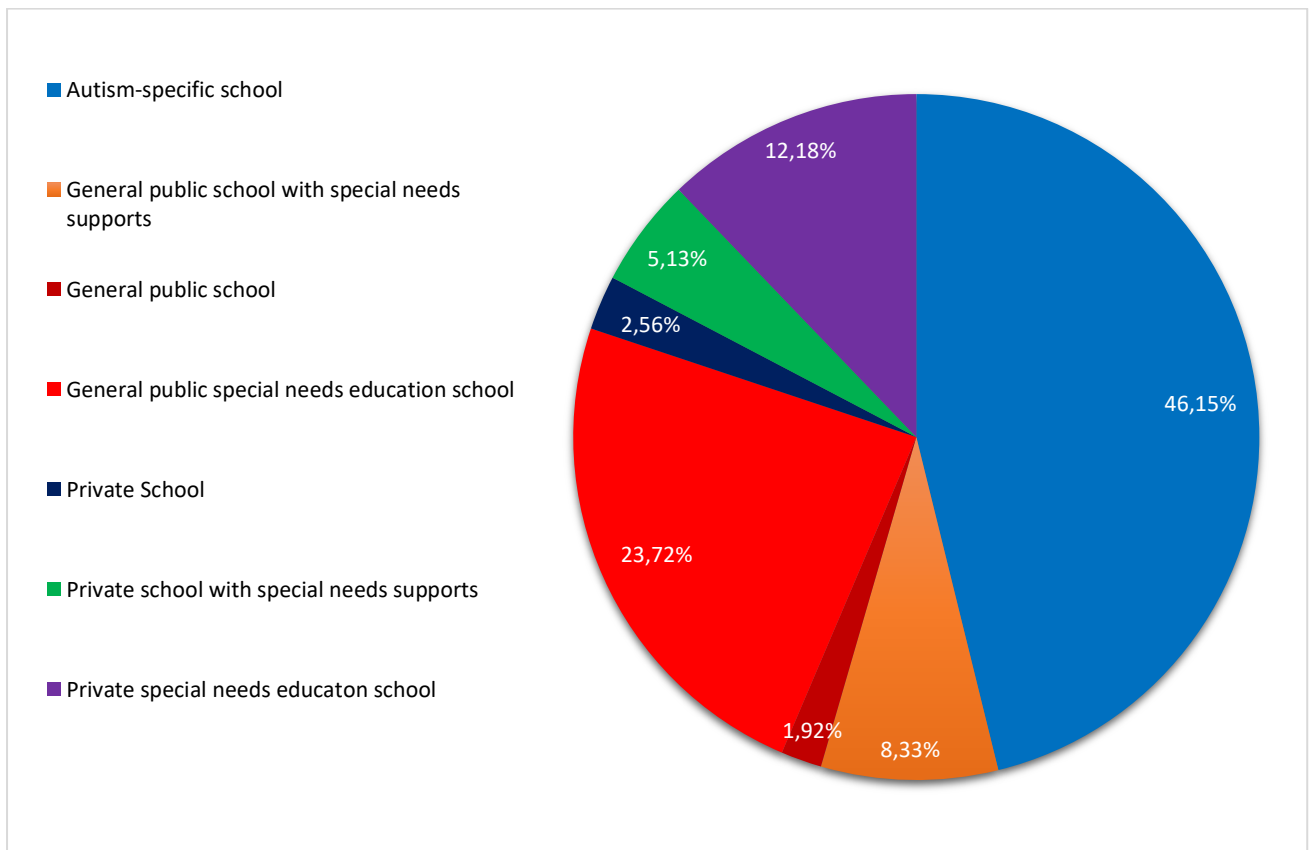


Figure 20. Parent reports regarding the type of formal educational institution their child was attending ($N = 156$). Of interest here is that a large proportion of these parents ($n = 85$; 54.49% of the enrolled sub-sample) reported that their child attended more than one school (range = 2-5 schools, mode = 2 [reported by 61 parents]).

A separate item asked parents to report on how many hours per week their child received one-on-one instruction at school. A large proportion ($n = 60$; 38.46% of the enrolled sub-sample) indicated that their child did not receive any one-on-one instruction. Of those who did receive such instruction, hours per week were as follows: ≤ 5 , $n = 41$; 5-10, $n = 24$; 11-15, $n = 9$; 16-20, $n = 7$; 21-25, $n = 3$; and ≥ 26 , $n = 11$. One parent reported not knowing how many hours of one-on-one instruction their child received per week.

Children who were enrolled at a formal educational institution reportedly had access to several different forms of intervention, and many were exposed to more than one of those (see Figure 21). As Figure 22 shows, many children were receiving social skills training ($n = 69$; 44.23% of the enrolled sub-sample) and/or PECS ($n = 64$; 41.03%). However, most parents ($n = 95$; 60.90%) reported that parent training/counselling was not available at their child's educational institution.

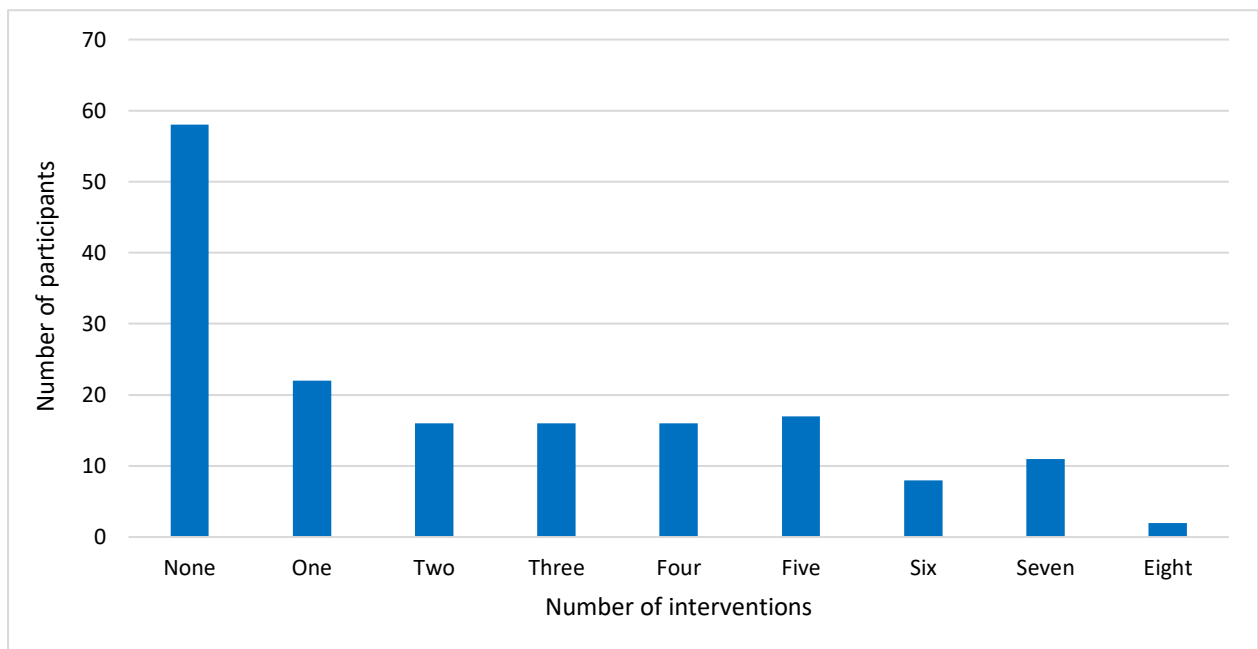


Figure 21. Parent reports regarding the total number of interventions their child was receiving at their school.

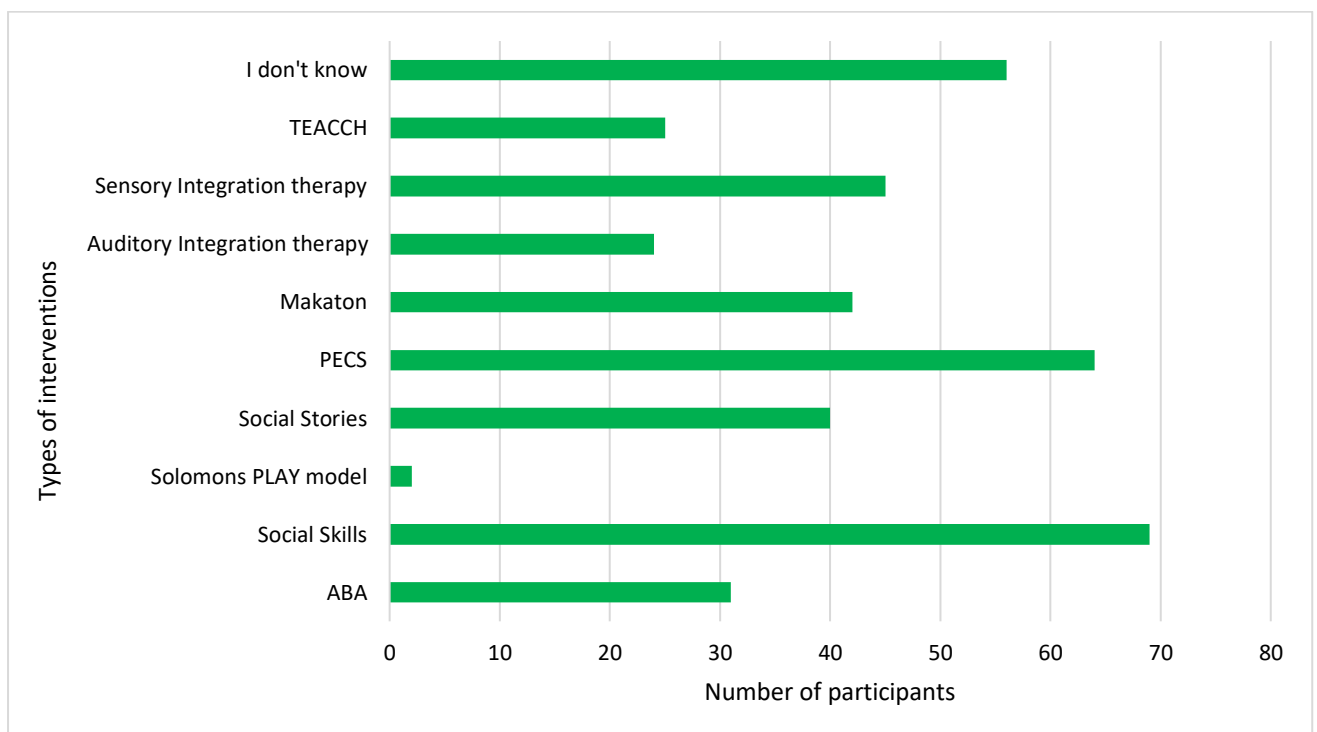


Figure 22. Parent reports regarding interventions available at their child's school/s ($N = 156$). ABA = Applied behavioural analysis; PECS = Picture exchange communication system; TEACCH = Treatment and education of autistic and related communication handicapped children.

For educational service delivery to be optimally effective, parents of a child diagnosed with ASD (or, indeed, parents of any child with special needs) must feel that they

receive regular communication from their child's school and that they are adequately informed about their child's educational program (e.g., what interventions the child is receiving, what the daily or weekly schedule entails, and how home activities can dovetail with school activities). In the enrolled sub-sample ($N = 156$), the largest proportion of parents ($n = 61$; 39.10%) reported that such communication happened on a daily basis. Thirty-nine parents (25%) reported it happened weekly. The rest reported it happened much less frequently (monthly, $n = 14$; bimonthly, $n = 2$; once a term, $n = 33$; once a year, $n = 6$; never, $n = 1$). Nonetheless, the largest proportion of parents in the enrolled sub-sample ($n = 75$; 48.08%) reported that they were "definitely" well-informed about their child's current educational programme. A substantial proportion ($n = 57$; 36.54%) felt informed "to some extent, but a significant minority ($n = 24$; 15.28%) noted that they were not informed.

Regarding *occupational resources*, the data reported here are derived from the reports of those parents who indicated that their child was older than 18 years and was employed ($n = 6$). Within that sub-sample, all parents reported that their child was working more than 10 hours per week at the time of data collection. Employment was as a waiter and pizza maker, assistant at a recycling plant, general assistant in family business, data capturer, and volunteer at an autism school ($n = 1$ each case, except for $n = 2$ for the last in the list). Five of these six parents reported feeling that their child earned less than his/her fellow employees. Only one reported that their child had received career development or job training from an NGO or government agency.

Each of these parents reported that their child's employer was aware of their child's ASD diagnosis, and only one reported that their child's co-workers did not know about the diagnosis. Three of the six parents reported that their child's employer had made ASD-related workplace adjustments for their child (e.g., sheltered placement, personal supervision).

Section III: Impact on daily living. One parent did not respond to the questions in this section, and so the data here are based on $N = 199$. Most parents ($n = 78$; 39.12% of the sample) reported spending more than 8 hours a day trying to coordinate their child's care (see Figure 23). This time was spent making appointments with healthcare professionals, driving the child to and from those appointments, school, and extracurricular activities. Unfortunately, the item asking about this information did not require the respondent to provide an estimate of exactly how many hours per week were spent engaged in such coordination. Nonetheless, it is informative that 116 parents (58%) reported that they did not have to stop working (and 107 [53.50%] reported not even having to cut down on their work hours) in order to provide appropriate care for their child and coordination of his/her daily

activities. On the other hand, half of the parents ($n = 100$) reported that they could not change jobs, even if they wanted to, because they needed the income and/or health insurance to cover the financial burden associated with their child's ASD diagnosis.

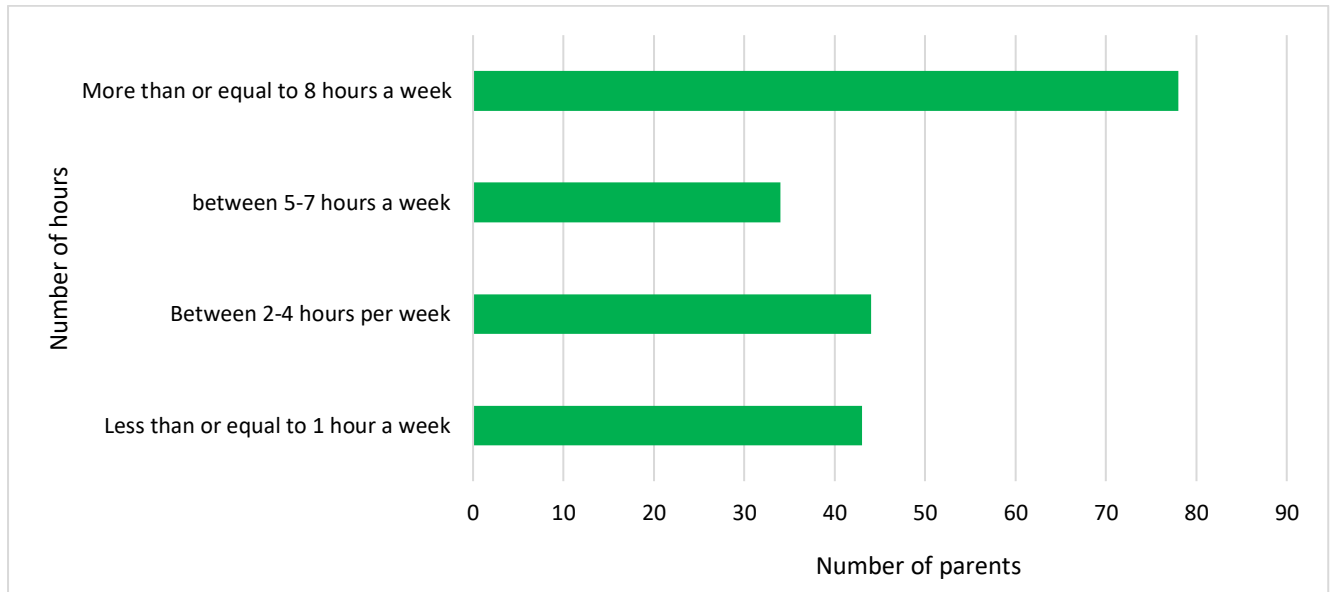


Figure 23. Parent reports regarding the number of hours per week spent coordinating their child's care ($N = 199$; one parent did not respond to this question).

Most parents ($n = 155$; 77.89%) reported that their child's ASD diagnosis had caused the family financial difficulties, with 64 (32.16%) noting difficulties "to some degree" and 91 (45.73%) noting "definite" difficulties. Unfortunately, the item asking about this information did not require the respondent to specify how those difficulties were associated with the diagnosis (e.g., whether difficulties arose because of treatment expense, limited educational or occupational opportunities, etc.).

Section IV: Pathways between SES, autism-related problem behaviours, service delivery, and parental QoL. Parents of children with ASD face many challenges, and hence their QoL is influenced by numerous factors. There are unanswered questions in the literature as to the independent and interacting roles of family SES, autism-related problem behaviours, aspects of the service delivery experience (e.g., as related to the diagnostic process, to current health care, and to educational resources), social support, and psychological distress in predicting the overall QoL of those parents. The analyses described below (path analysis, a form of structural equation modelling) attempted to answer these questions. Path Analysis allows the examination of a conceptual model, based on theory and previous findings in the literature, to determine the indirect and direct effects specific variables have on a particular outcome of interest.

Conceptual model. Figure 24 is a schematic presentation of the conceptual model that I developed and tested. Pathways within the model were constructed based on findings in the ASD literature concerning QoL and service delivery. The model contains both exogenous and endogenous variables. *Exogenous variables* are those that are taken as given because their explanation lies outside of the model. In the current conceptual model, these are parent's age, child's age, parent's occupational status, household income, parent's highest level of education, and family resources (as measured by FRS total raw score). *Endogenous variables*, in contrast, are those that are determined by the model (in other words, their explanation lies within the model). In the current conceptual model, these are autism-related problem behaviours (as measured by ABC total raw score and the VABS-II MBI total raw score), aspects of service delivery (as measured by WUN Scoping Survey scores that I created for diagnostic process, educational resources, and current healthcare; see Appendix V), psychological distress in parents (as measured by total raw scores for the CES-D, PSI-SF, and FSS), and parent's overall quality of life (QoL; as measured by WHOQOL-BREF total domain score²).

²To calculate the WHOQOL-BREF total domain score I summed the 4 derived domain scores: Physical Health (mean score of all 7 items within domain, multiplied by 4), Psychological Health (mean score of all 6 items within domain, multiplied by 4), Social Relationships (mean score of all 3 items within domain, multiplied by 4), and Environment (mean score of all 8 items within domain, multiplied by 4).

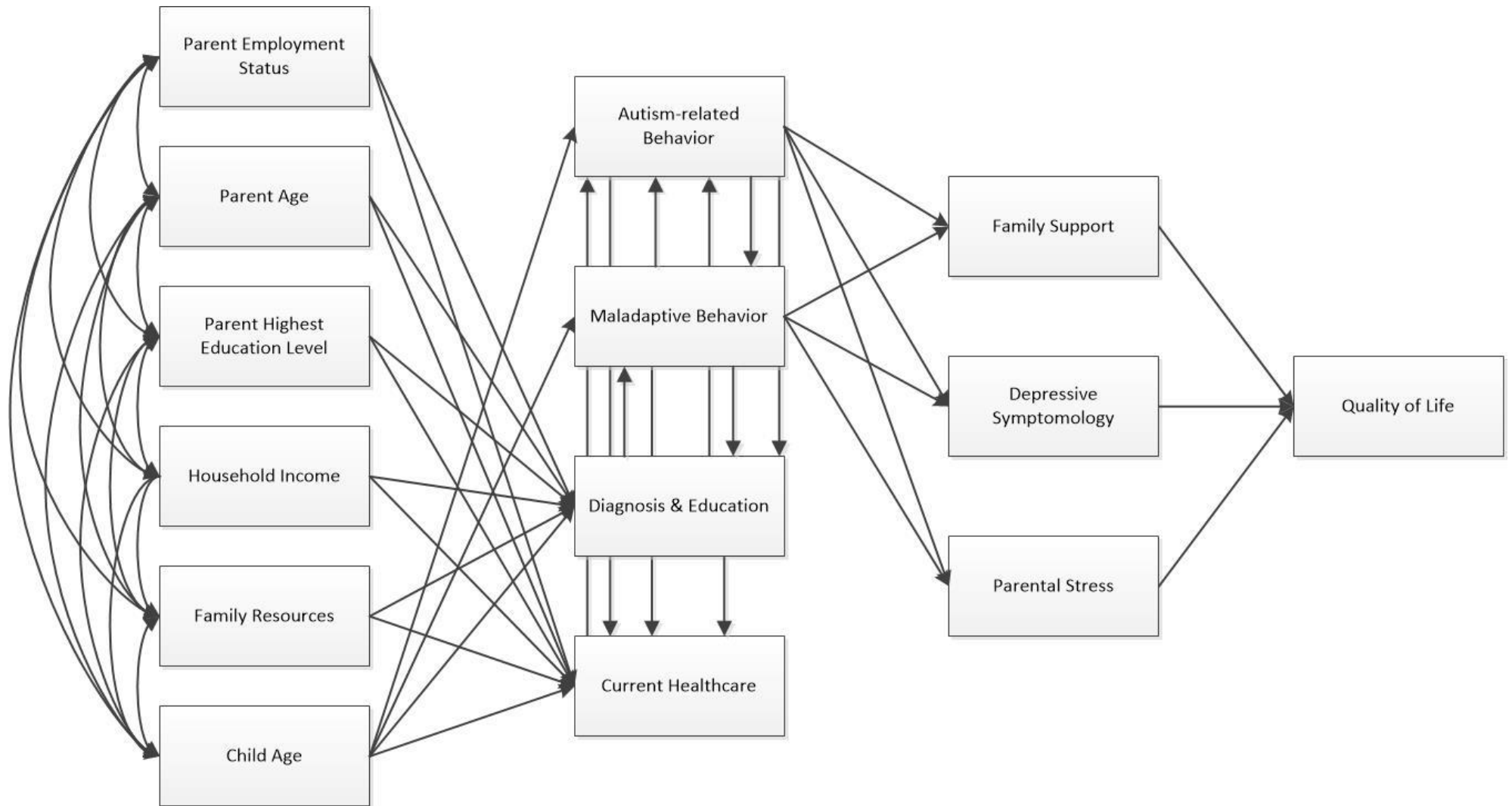


Figure 24. Path Analysis: Graphical overview of the Conceptual Model

As the Figure shows, in the conceptual model parent's overall QoL was determined as the terminal endogenous variable (i.e., the final outcome) of the psychological distress variables. In turn, psychological distress was determined by the direct and indirect contributions of several other variables (specifically, aspects of service delivery [those related to diagnosis and education, and those related to current healthcare], autism-related problem behaviours, parent's age, child's age, and SES-related variables [viz., family resources, household income, and parent's highest level of education and occupational status]). A matter of relatively minor but particular interest in this model was the influence that autism-related problem behaviours have on the relationship between service delivery and QoL.

It is useful to regard the conceptual model as being arranged into four parts. The base of the model (presented in the block of variables at the far left of Figure 24) comprises the SES-related variables, parent's age, and child's age. In this part of the model, the analysis tests the hypotheses that (a) parent's age and the SES-related variables influence the service delivery variables, and (b) child's age influences service delivery variables and autism-related problem behaviours. These hypotheses are reflected by the arrows running between the far-left block of variables and the block immediately adjacent to it.

The second part of the model (presented in the block of variables at the middle-left of Figure 24) comprises four variables that capture two different kinds of information: aspects of service delivery an ASD-diagnosed child may receive (e.g., those related to diagnosis, early interventions, education, and other forms of support), and the severity of the child's autism-related problem behaviours. In this part of the model, the analysis tests two hypotheses about determination pathways between service delivery and autism-related problem behaviours: (a) the more severe a child's problem behaviours are, the more intensive services they will require, and (b) the more services the child has received, the less severe the problem behaviours will be. Here, the model also tests the hypothesis that there will be a positive association between autism behaviour and maladaptive behaviour (i.e., that both measure the severity of autism-related problem behaviours). I based this prediction on current empirical data (recall, from Table 12 above, that they were strongly correlated) and on previous literature (other studies have used the VABS-II MBI to measure autism-related behaviours; Fulton et al., 2014). All of these hypotheses are reflected by the arrows running within the middle-left block of variables.

The third part of the part of the model (presented in the block of variables at the middle-right of Figure 24) comprises three variables that capture degree of social support available to the family and current psychological distress experienced by parents. Hence, one

set of arrows running between the second and third parts of the model tests hypotheses about determination pathways between autism-related problem behaviours and (a) parental psychological distress (viz., the more severe the autism-related problem behaviours, the more severe the parental psychological distress), and (b) family social support (viz, the more severe the autism-related problem behaviours, the more support the family would require). I based these predictions on published evidence indicating the impact autism-related problem behaviours have on parental support, stress, and depression levels (Boyd, 2002; Davis & Carter, 2008; Dempsey & Keen, 2008; Hastings, 2002; Montes & Haltermann, 2007; Phetrasuwan & Miles, 2009). Furthermore, given the two-way determination pathways between autism-related problem behaviours and service delivery, the conceptual model also tested the hypothesis that the path between service delivery and psychological distress runs via autism-related problem behaviours.

The fourth and final block of the model (presented in the single variable at the far right of the Figure 24) is comprised of the terminal variable that captures QoL in parents of children with ASD. In this part of the model, the analysis tests hypotheses about determination pathways between family social support, parental psychological distress, and overall QoL: (a) the lower the levels of support, the poorer the QoL will be, and (b) the more severe the psychological distress, the poorer the QoL will be.

Fit indices. I examined the values of four fit indices to determine the adequacy of the path analysis models: (1) the χ^2/df ratio (values between 2 and 4 indicate a good-fitting model, and values < 2 indicate an excellent model; Kline, 1998); (2) the Comparative Fit Index (CFI; values ≥ 0.90 indicate a good-fitting model, and values ≥ 0.95 indicate an excellent model; Hu & Bentler, 1999); (3) the Root Mean Square Error of Approximation (RMSEA; values ≤ 0.08 indicate a good-fitting model, and values ≤ 0.05 indicate an excellent model; Steiger, 1990); and (4) the Hoelter's Critical N index (values between 200 and 400 indicate a good-fitting model, and values > 400 indicate an excellent model). Using these four fit indices, I ran several models before obtaining the optimal (final) path analysis model. Table 13 provides information about the comparative fit indices for each of those models.

Table 13.

Path Analysis: Comparative fit indices for each model (N = 182)

Model	χ^2	df	p	χ^2/df	CFI	RMSEA	Hoelter's CN
Conceptual model	84125.59	43	< .001	1956.41	< .001	3.29	1
Model 1	104.37	57	< .001	1.83	.93	0.07	132
Model 2	98.55	52	< .001	1.90	.93	0.07	129
Model 3	38.52	35	.31	1.10	.99	0.02	235
Model 4	45.66	34	.09	1.34	.98	0.04	193
Model 5	31.17	25	.18	1.25	.99	0.04	219
Model 6	29.61	26	.28	1.14	.99	0.03	238
Model 7 (optimal)	22.24	20	.33	1.11	.99	0.03	256

Note. Given that Path Analysis requires a complete dataset on all measures, with no missing data, the current modelling used the data from 182 parents of children with ASD (i.e., the datasets of 18 parents each had at least one piece of missing data). CFI = comparative fit index; RMSEA = Root Mean Square Error Approximation; Hoelter CN = Hoelter's Critical N index, at 0.01 level.

Evaluation of the conceptual model. All the indices indicated this model (see Figure 25) was a poor fit for the data: the χ^2/df ratio was > 4 , the CFI value was < 0.90 , the RMSEA was > 0.08 , and Hoelter's Critical N value indicated that a sample of 1 would be sufficient to disconfirm the model (see Table 13).

Therefore, I examined the modification indices of the model output using the Lagrange multiplier test (Bentler, 2006). These indices indicated that the model would improve if the following pathways were added: (a) parent's highest level of education to autism behaviour, (b) household income to autism behaviour, (c) family resources to autism behaviour, and (d) parental stress to depressive symptomology. From an ecological perspective, it is quite possible that each of these three pathways could exist. The higher a parent's level of education, the more likely they are to be knowledgeable about and sensitive to problem behaviours, and hence the more likely they are to identify and describe their child's difficulties accurately. On the other hand, the higher the family income and the more resources the family has, the more likely the child will be exposed to early intervention programmes, and the more likely it will be that fewer severe autism-related problem behaviours will be identified. Finally, it is also possible that the more stressed a parent is, the more likely they will be to have more symptoms of depression.

Figure 25 also shows that several pathways within the model were not statistically significant. Hence, I removed some of those pathways to obtain better goodness-of-fit indices and strengthen the model. A description and rationale for which were removed, and which were retained follows.

First, I removed the pathway between parent's occupational status and the current healthcare aspect of service delivery ($p = .522$), but retained the two related paths (viz., that between parent's occupational status and the diagnosis and education aspect of service delivery, and that between the two aspects of service delivery). It is plausible that parental occupational status would impact the first stage of service delivery (diagnosis and education), which would then in turn impact subsequent stages of service delivery (including current healthcare).

Second, within the middle-left block of the model I removed all pathways emanating from autism behaviour and running directly to aspects of service delivery ($p = 1.00$ for that involving diagnosis and education; $p = .963$ for that involving current healthcare). However, I retained the pathway running from autism behaviour to maladaptive behaviour because, given the observation of a strong correlation between the measures used to score these constructs (ABC and VABS-II MBI scores), it is plausible that parental reports on generally problematic behaviour (as captured by the VABS-II MBI) would capture and encompass their reports on autism-related problem behaviours. Hence, the pathways between (a) maladaptive behaviour and diagnosis and education, and (b) maladaptive behaviour and current healthcare, which were retained in the model, served as a sufficient test of hypotheses about how parental experiences of problematic behaviour (including that related to autism specifically) affected their service delivery experiences.

Third, and for similar reasons as described immediately above, I removed the pathways emanating from autism behaviour and running to (a) parental stress ($p = .868$), and (b) depressive symptomology ($p = .948$), but retained the pathways emanating from maladaptive behaviour and running to parental stress and to depressive symptomology.

Fourth, I made a set of removal and retention decisions based on a desire to test one of the major hypotheses contained within the conceptual model: that the more severe the autism-related behaviours the child displays, the more services they will require. Hence, I removed the pathways emanating from service delivery and running to problem behaviors: (a) diagnosis and education to autism behaviour ($p = .001$), (b) diagnosis and education to maladaptive behaviour ($p = .507$), (c) current healthcare to autism behaviour ($p = .481$), and (d) current healthcare to maladaptive behaviour ($p = .797$). However, I retained the pathway emanating from diagnosis and education and running to current healthcare (i.e., the path testing the hypothesis that more services engaged during the early stages of the process will lead to fewer intervention demands later on).

After completing all these removal and retention steps, I specified the remaining pathways and re-ran the model.

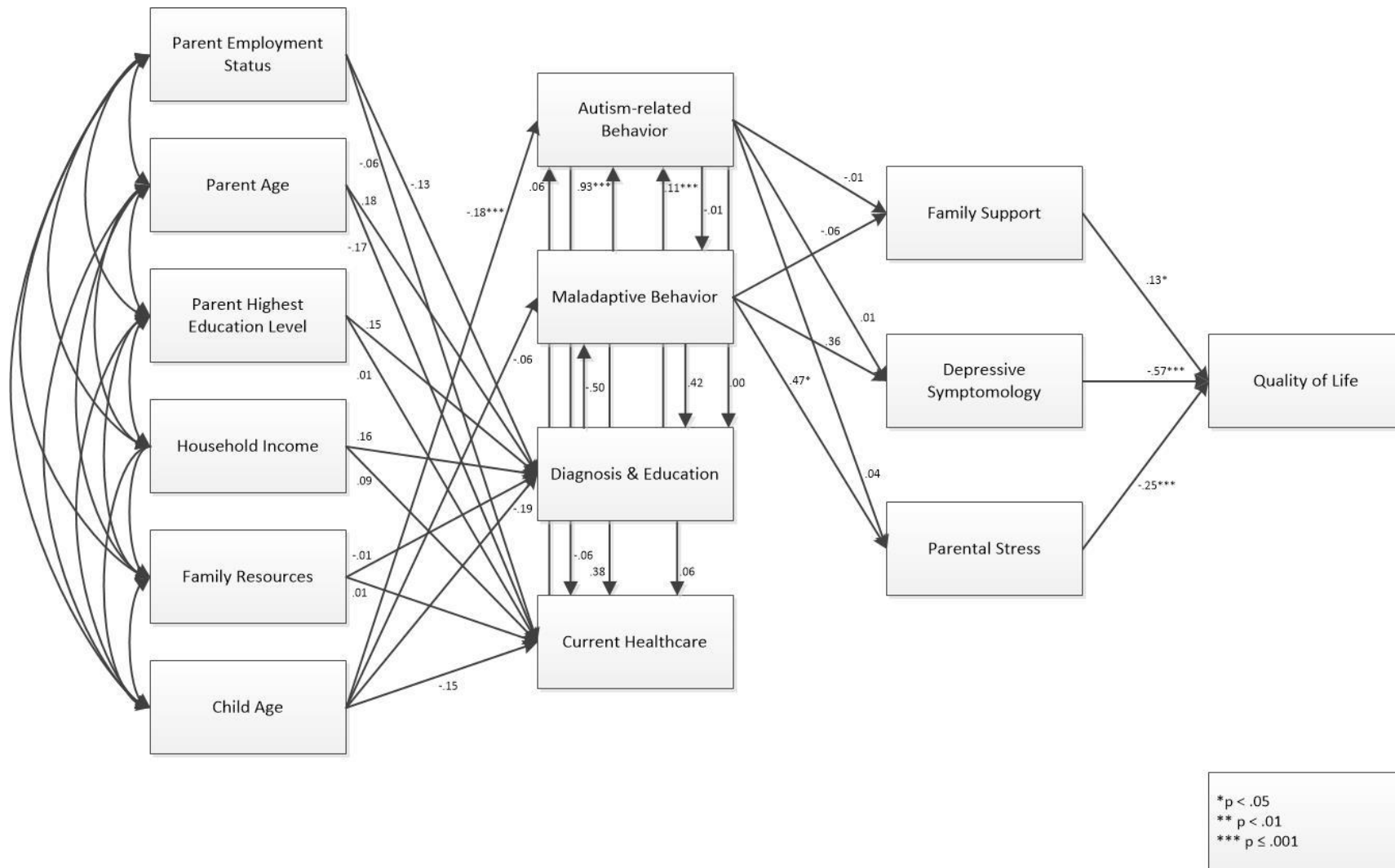


Figure 25. Path Analysis: examining the pathways between child's age, ASD severity, family SES, service delivery experiences, parent's psychological distress, and parental QoL (Conceptual model).

Evaluation of Model 1. There was significant improvement over the conceptual model in goodness-of-fit indices: the χ^2/df ratio was excellent (< 2), and the CFI and RMSEA values were good ($> .90$ and $< .08$, respectively). However, Hoelter's Critical N value indicated that a sample of 132 (i.e., a number smaller than the actual sample size) would be sufficient to disconfirm the model (see Table 13).

Moreover, the model still contained several pathways that were not statistically significant (see Figure 26 in Appendix W1). Hence, I removed some of those pathways to obtain better goodness-of-fit indices and strengthen the model. A description and rationale for which were removed, and which were retained follows.

First, I removed the pathway between child's age and autism behaviour ($p = .195$). I then added a pathway between child's age and current healthcare. This pathway makes theoretical sense because the age of the child might determine the types of healthcare s/he accesses (e.g., whereas a younger child may receive numerous [and more intense] interventions, an older child may use relatively fewer such services).

Second, I removed pathways between the diagnosis and education aspect of service delivery and (a) parent's age ($p = .484$), and (b) maladaptive behaviour ($p = .303$). Third, I removed all the pathways emanating from family resources (e.g., those going toward autism behaviour and the two aspects of service delivery; all $ps > .789$) because these were not statistically significant in both the conceptual model and the current model, suggesting the measure was not adding any value.

After completing all these removal and retention steps, I specified the remaining pathways and re-ran the model.

Evaluation of Model 2. The goodness-of-fit indices were similar to those of Model 1: the χ^2/df ratio was excellent (< 2), and the CFI and RMSEA values were good ($> .90$ and $< .08$, respectively). However, Hoelter's Critical N value now indicated that a sample of 129 (i.e., still a number smaller than the actual sample size) would be sufficient to disconfirm the model (see Table 13).

Moreover, the model still contained several pathways that were not statistically significant (see Figure 27 in Appendix W2). Hence, I removed some of those pathways to obtain better goodness-of-fit indices and strengthen the model. A description and rationale for which were removed, and which were retained follows.

First, I removed all pathways running into family support (e.g., those going from autism behaviour and maladaptive behaviour to family support; all $ps > .500$) because these

were not statistically significant in both the previous models and the current model, suggesting the measure was not adding any value.

Second, I removed all pathways emanating from parent's age (all $ps > .117$) because these were not statistically significant in both the previous models and the current model, suggesting the measure was not adding any value.

Third, I removed the pathway between household income and current healthcare ($p = .111$) but retained the pathway between household income and diagnosis and education. It is plausible that a family's financial means has a primary influence at the initial stage of services (i.e., those with more means are more likely to seek and receive early diagnosis and intervention, and to be able to place their child in a school that provides autism-specific care and education). This level of early engagement with service delivery options is then likely to influence subsequent stages (e.g., current healthcare).

After completing all these removal and retention steps, I specified the remaining pathways and re-ran the model.

Evaluation of Model 3. The goodness-of-fit indices were superior to those of Model 2: the χ^2/df ratio was excellent (< 2), as were the CFI and RMSEA values ($> .95$ and $< .05$, respectively). Of importance here is that Hoelter's Critical N value was now also good and indicated that a sample of 235 (i.e., a number greater than actual sample size) would be required to disconfirm the model (see Table 13).

Although these statistics were promising, there was still a major theoretical issue within the model that needed addressing: the pathway between parent's highest level of education and autism behaviour (see Figure 28 in Appendix W3). Although this pathway (which suggested a negative correlation between the two variables) was not specified by the conceptual model, subsequent model iterations requested that it be inserted. A possible explanation for why this pathway might need to be specified relates to the nature of the service delivery questions used during data collection. Although those questions were quite thorough, they may have lacked in not producing a separate outcome variable focusing purely on interventions. Such a variable might have intervened between parent education and autism behaviour (e.g., it might have shown that those with higher levels of education might have accessed early intervention options and might therefore report significant fewer problem behaviours as the child grows older) and thus explained their relation more clearly.

To address the questions surrounding the requested presence of this pathway, I introduced alternative pathways into the model. First, instead of a pathway running directly from parent's highest level of education to autism behaviour, I added a pathway from

parent's highest level of education to diagnosis and education, and then another from diagnosis and education to autism behaviour. This set of pathways sought to test the hypotheses that (a) the better educated a parent is, the sooner they will seek diagnosis and education (with interventions), and then (b) the earlier the intervention, the fewer autism-related behaviour problems will be reported at a later age.

After completing all these removal and retention steps, I specified the remaining pathways and re-ran the model, attempting primarily to explain the requested pathway between parent's highest level of education and ABC.

Evaluation of Model 4. The goodness-of-fit indices were similar to those of Model 3: the χ^2/df ratio remained excellent (< 2), as did the CFI and RMSEA values ($> .95$ and $< .05$, respectively). However, Hoelter's Critical N value was now not as high as the previous model, indicating that a sample of 193 (i.e., smaller than was indicated in the previous model, but still greater than the actual sample size) would be sufficient to disconfirm the model (see Table 13).

However, this model did not resolve the theoretical issue described above. Moreover, it contained some pathways that, although significant and meaningful in previous models, were now not significant (see Figure 29 in Appendix W4). Hence, I removed some of those pathways to strengthen the model. A description and rationale for which were removed, and which were retained follows.

First, I removed the newly-inserted pathways (viz., from parent's highest level of education to diagnosis and education, and from diagnosis and education to autism behaviour; $p = .321$ and $.673$, respectively) – it appeared they did not add any value to the model. In fact, adding them to the model made two formerly significant and meaningful pathways non-significant: (a) parent's occupational status to diagnosis and education ($p = .154$), and (b) household income to diagnosis and education ($p = .101$).

In a different attempt to address the problem of the requested presence of the pathway running from parent's highest level of education to autism behaviour, I simply removed the autism behaviour variable from the model. I retained the pathway running from parent's highest level of education to diagnosis and education, and added a pathway running from diagnosis and education to maladaptive behaviour. Given the observed correlation between ABC and VABS-II MBI scores, it is plausible that the same relation exists between diagnosis and education and maladaptive behaviour as I speculated might exist between diagnosis and education and autism behaviour. Furthermore, given that the maladaptive behaviour variable (as measured by the VABS-II MBI scores) measures overall problem behaviours (including

autism-related problem behaviours), it is possible that excluding autism behaviour variable (as measured by the ABC scores) from the model would have no serious consequences for its comprehensiveness.

After completing all these removal and retention steps, I specified the remaining pathways and re-ran the model, again attempting primarily to explain the requested pathway between parent's highest level of education and autism behaviour.

Evaluation of Model 5. The goodness-of-fit indices were similar to those of Model 4: the χ^2/df ratio remained excellent (< 2), as did the CFI and RMSEA values ($> .95$ and $< .05$, respectively). However, the value of Hoelter's Critical N value was now higher than that of the previous model, indicating that a sample of 219 (i.e., a number quite a bit larger than the actual sample size) would be sufficient to disconfirm the model (see Table 13).

However, this model did not resolve the theoretical issue described above. Moreover, it contained some pathways that, although significant and meaningful in previous models, were now not significant (see Figure 30 in Appendix W5). Hence, I removed some of those pathways to strengthen the model. A description and rationale for which were removed, and which were retained follows.

First, I removed the newly-inserted pathways (viz., from parent's highest level of education to diagnosis and education, and from diagnosis and education to maladaptive behaviour; $p = .321$ and $.113$, respectively) – it appeared they did not add any value to the model. In fact, in an identical manner to Model 4, adding them to the model made two formerly significant and meaningful pathways non-significant: (a) parent's occupational status to diagnosis and education ($p = .154$), and (b) household income to diagnosis and education ($p = .101$).

Second, and in response to the findings reported in the previous paragraph, I added a pathway running directly from parent's highest level of education to maladaptive behaviour. (A similar pathway, running directly from parent's highest level of education to autism behaviour, was present in Model 3 and was significant but given the theoretical issue being grappled with I attempted to adjust the model, as described above. However, these adjustments weakened the model, resulting in several statistically non-significant pathways. Hence, I introduced a similar pathway to the model.)

After completing all these removal and retention steps, I specified the remaining pathways and re-ran the model.

Evaluation of Model 6. The goodness-of-fit indices were better than those of Model 5: While the χ^2/df ratio and the CFI and RMSEA values remained excellent (< 2 , $> .95$, and $< .05$, respectively), the value of Hoelter's Critical N was higher, at 238 (see Table 13).

Overall, this was a very strong model. Only one pathway, that between parent's occupational status and diagnosis and education ($p = .070$), was of questionable significance (see Figure 31 in Appendix W6). Given the possibility that parent's occupational status has an indirect (i.e., via household income) influence on diagnosis and education, I removed parent's occupational status from the model and retained the direct pathway running from household income to diagnosis and education.

Of further note here is that the modification indices requested a direct pathway running from household income to depressive symptomology. This pathway is plausible: a wealth of literature indicates that lower levels of household income are significantly associated with higher incidence of mental health issues, particularly anxiety and depression (see e.g., Hamad et al., 2008; Santiago et al., 2011). Although the requested pathway proposes that poverty causes mental illness, it also suggests that household income is *associated* with depressive symptomology, which is entirely plausible given theory and extant research. That is, the contextual factors associated with lower income and poverty, and for which household income is a proxy variable, are plausibly correlated with a higher incidence of various mental health conditions. If we accept this line of argument, then the question remains how we specify that path. One option is to specify it as a direct path (as are all other paths in the model). This will directly indicate the relationship between household income and depressive symptomology. The risk here is that it can all too easily be misinterpreted as implying that household income is a determinant of depression. Another, more robust way is to link these two variables as correlated errors, that is, by indicating that there is a link, but as it is not germane to the overall model (e.g., a correlation that does not merit explanation within the model itself). Such a link acknowledges the theory and research on the link between the two but specifies it in a manner that does not compel direct explanation given the specific focus of this model on service delivery and quality of life in parents of children diagnosed with ASD.

After completing all these removal and retention steps, I specified the remaining pathways and re-ran the model.

Evaluation of Model 7 (optimal model). Removal of the abovementioned pathway and inclusion of the correlated error between household income and depressive symptomology resulted in a good strong model (see Figure 32). The χ^2/df ratio and the CFI

and RMSEA values remained excellent (< 2 , $> .95$, and $< .05$, respectively), and the value of Hoelter's Critical N was 256 (see Table 13).

Statistical analysis confirmed that the inclusion of the correlated error resulted in a significant improvement on the model. The Likelihood Ratio Test (see Brown, 2006) examines the difference between the model without the correlated error and the model with correlated error as follows: χ^2 difference = $27.8 - 22.4 = 5.4$; df difference = $21 - 20 = 1$. The critical value of χ^2 for $p = .05$ and $df = 1$ is 3.84. The χ^2 difference value exceeds this critical value, and hence one can conclude that adding the path indicating this correlated error significantly improved the model.

In this model, all the pathways are significant at $p < .05$ level, with one exception. The pathway between current healthcare and depressive symptomology, which throughout the modelling process was not statistically significant, trended toward significance in this model with $p < .10$.

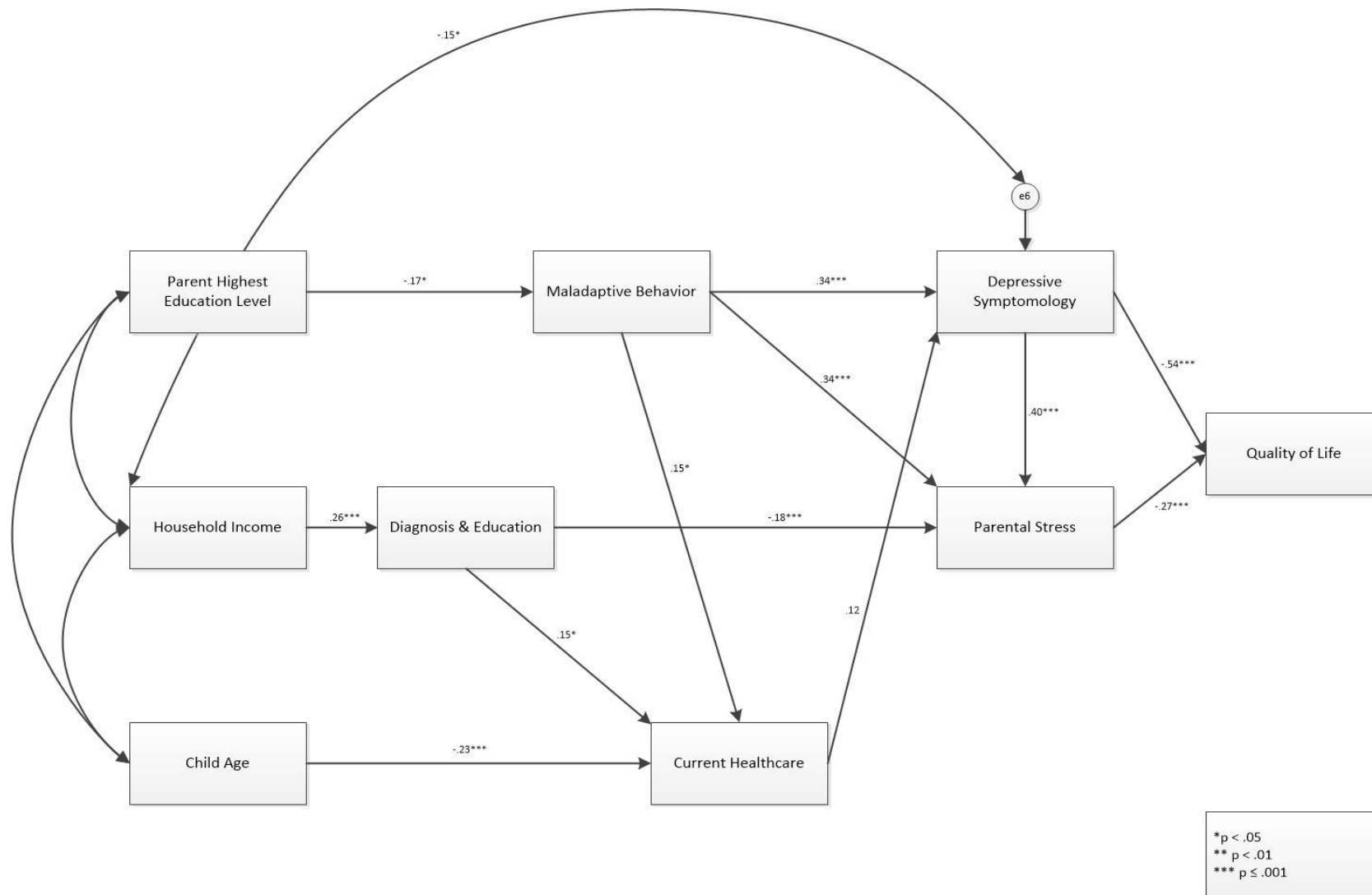


Figure 32. Path Analysis: Examining the pathways between child's age, ASD severity, family SES, service delivery experiences, parent's psychological distress, and parental QoL (Model 7: Optimal Model).

Discussion

Although numerous published studies focus on individual aspects of service delivery and psychological distress in parents of children with ASD, few published studies have comprehensively assessed multiple aspects of either service delivery or quality of life (QoL) in that population. The novelty of the current study is that it analyses data from both (a) measures that capture multiple aspects of service delivery, and (b) measures that capture multiple aspects of QoL (including psychological distress and social support). To add to this novelty, I examined associations between the experience of service delivery and current QoL in parents of children with ASD.

Another aspect of the novelty of the current study is that my sample was drawn from the South African population. As noted in Chapter 3, few studies of service delivery and QoL in ASD emerge from low- and middle-income countries (LAMICs). The lack of research on what services are (and are not) available, and the impact it may have on QoL, may have a serious detrimental impact on the lives of children with ASD and their families. For instance, without knowing what types services are lacking, and without robust characterizations of the efficiency with which existing services are provided, governmental and other policy makers can implement no changes to ensure optimal service delivery to children with ASD and their families.

To fill the abovementioned gaps in the literature and to fulfil the attendant promises of novelty, I gathered self-reports from South African parents of children with ASD ($N = 200$). I measured overall QoL quantitatively by using a comprehensive standardized instrument (the WHOQOL-BREF) as well as brief standardized tools focused on stress, depression, and social support (PSI-SF, CES-D, and FSS, respectively). I used a 75-item survey instrument to measure multiple aspects of service delivery (including healthcare system, community support, educational resources, and occupational resources; impact on daily living). Analyses proceeded across four discrete steps. First, I completed descriptive analyses for the child and parent sociodemographic data. Second, I completed similarly detailed descriptive analyses for each of the child behavioural variables (ABC and VABS-II MBI), the family resources and support variables (FRS and FSS, respectively), and the parent psychological distress and QoL variables. Third, I determined the strength of bivariate associations between all the outcome variables (child behaviour, family resources and support, parent psychological distress, and parent QoL). This was an important step as it indicated which variables may have important roles to play in the final path analysis model. Fourth, I completed descriptive analyses for the

parental service delivery data. Finally, I used path analysis to examine the role SES, autism-related problem behaviours, and aspects of service delivery have in predicting the QoL of parents of children with ASD. What follows is a summary of the results from each analytic step, as well as an account of how these results compare to those from previously published studies.

Who Were the Participants?

Parents ranged in age from 24 to 69 years. Most reported having English as a home language ($n = 114$), although a significant minority were isiXhosa speakers ($n = 41$). Most had completed at least some tertiary education (mothers, $n = 115$; fathers, $n = 109$), with only a small proportion having completed fewer than 8 years of formal schooling (i.e., having not entered high school at all).

Occupational status varied widely. Using the 9-category Hollingshead scale, the largest proportion of mothers were classed as homemakers whereas the largest proportion of fathers were classed as “administrative personnel, managers, or minor professionals.” Household income also ranged widely. For instance, while many parents ($n = 42$) reported an income in the highest bracket ($> \text{ZAR}526\,000$), a similar number ($n = 36$; 18%) reported an income in the lowest possible bracket ($\text{ZAR }0\text{--}35\,000$). Recent census data suggest that the diversity of the sample’s occupational status and household income is representative of current South African economic conditions (De Wet, 2012).

Many published studies in the ASD literature do not provide detailed biographic or financial data regarding their parent samples (in fact, some provide no such data at all). However, with regard to age and education, the profile of the current sample is similar to that of ASD-parent samples reported on by Crane et al. (2016), Goin-Kochel et al. (2006), Mandell et al. (2005), Siklos and Kerns (2006), and Valicenti-McDermott et al. (2012). (To my knowledge, these are the only studies in the literature on service delivery in ASD to report on these variables.) Across those studies, the mean age of parents ranged from 37.8–43.4 years (actual range = 23–70), and the mean years of education ranged from 14.8–15.3 years (actual range [11–20] reported only by Siklos and Kerns, 2006). These values are all similar to those for the current sample. Of note, however, is that the South African sample of parents of autistic children recently reported on by Alhazmi et al. (2018) was younger ($M = 32.9 \pm 7.8$ years) but of similar education level (18 of 26 had attended high school, at least) as the current sample.

Regarding household income, few studies in this literature report on it. However, the current sample and that of Alhazmi et al. (2018) encompassed a much more diverse range of socioeconomic backgrounds than samples used in studies emerging from outside South Africa (see, e.g., Mandell et al., 2005).

Regarding the child sample (age range 3-28 years), most participants were male ($n = 175$). This sex differential is consistent with recent findings regarding autism prevalence in the general population (Werling, 2016; Werling & Geschwind, 2013). Unsurprisingly given the language characteristics of the parent sample, most children spoke English as a home language ($n = 137$), although a significant minority were isiXhosa speakers ($n = 40$). Most were born in South Africa ($n = 192$). Moreover, most had at least one sibling ($n = 97$), and most were either the first- or second-born child in the family.

Regarding the age at which an ASD diagnosis was made, parent reports indicated that most children in the sample ($n = 115$) had received an ASD diagnosis before the age of 3 years. Furthermore, the great majority ($n = 177$) had been diagnosed by the age of 6 years. These data are consistent with most recent research studies in this field, which suggest that an ASD diagnosis is usually made between the ages of 3 and 6/7 years (i.e., the upper limit is typically the age at which school entry happens; Brett et al., 2016; Mandell et al., 2005; Valicenti-McDermott et al., 2012). However, it is important to note that few of these studies were conducted in LAMICs, and no South African study has focused on this aspect of the epidemiology of ASD. Nevertheless, it is encouraging to note that many of the participants in the current study received a diagnosis at an early age, which allows for implementation of early interventions with the aim of improving later outcomes (Yates & Couteur, 2016).

In comparison to the adult sample reported on in Chapter 3, the current sample of children were diagnosed at an earlier age. Whereas most adults in Study 1 ($n = 11$ of 15; 73%) reported being diagnosed after age 10, most children in the current sample ($n = 115$; 58%) were reportedly diagnosed before age 3. Although the difference in sample sizes (and the very small size of the adult sample) makes interpretation of this comparison risky, one might draw the tentative conclusion that the between-cohort difference in age of diagnosis indicates improvement in South African diagnostic services.

Parent reports also indicated that a substantial minority of children in the sample ($n = 59$; 29.5%) had been diagnosed with an intellectual disability (ID). Of note, however, is that I obtained no independent verification of that diagnosis or of details regarding its severity. Regarding the prevalence of ID in ASD, there are no large-scale epidemiological studies of nationally representative samples. In published literature on service delivery and QoL in

ASD, many studies do report on the prevalence of intellectual disability. However, the findings range from parent self-report to standardized assessment, with the reported disability ranging from severe to mild (see, e.g., see Brett et al., 2016; Cederlund et al., 2008; Crane et al., 2016; Mansell & Morris, 2004; Wiggins et al., 2006).

What Did Parents Report about Their Child's Autism-Related Problem Behaviours and Their Own Quality of Life?

Autism-related problem behaviors. Parent reports on the Autism Behavior Checklist (ABC) suggested that the severity of autism-specific problem behaviours in the sample of children ranged from borderline ($n = 31$) through mild ($n = 51$) to moderate-severe ($n = 110$). Reports on the Vinelands Adaptive Behavior Scale (VABS) were consistent with those on the ABC; they too suggested clinically significant levels of problem behaviours (across both internalizing and externalizing domains) in most children.

Psychological distress. Parent reports on the Parenting Stress Index-Short Form (PSI-SF) suggested almost three-quarters of the sample were experiencing clinically significant levels of stress related to managing and interacting with the child and fulfilling parental duties. This finding is, broadly speaking, consistent with previously published findings in suggesting that parents of autistic children tend to experience high levels of life stress (see, e.g., Davis & Carter, 2008; Phetrasuwan & Miles, 2009). For instance, Ingersoll and Hambrick (2011) also used the Parenting Stress Index and reported that, among their sample of 149 parents of children with ASD, 85% indicated they were experiencing clinically significant stress levels.

Similarly, parent reports on the Center for Epidemiological Studies-Depression Scale (CES-D) suggested that more than half of the sample were experiencing clinically significant levels of depression. Again, this finding is consistent with previously published findings in the ASD literature (see, e.g., Bitsika & Sharpley, 2004; Boyd, 2002; Sharpley et al., 1997). For instance, Ingersoll and Hambrick (2011) found that 55.7% of their sample reported a clinically significant CES-D score.

Quality of life. Parent reports on the WHOQOL-BREF suggested that approximately one-third of the sample were experiencing significantly poor quality of life. This finding is consistent with other studies of QoL in parents of children with ASD that used the same comprehensive measure (see, e.g., Dardas & Ahmed, 2014; Shu, 2009; Tung et al., 2014). For instance, Mugno et al. (2007) reported that parents of children diagnosed with Pervasive Developmental Disorder (PDD) had significantly lower WHOQOL-BREF scores in the

domains of physical health, social relationship, and psychological health than parents of children with mental handicap (MH) and cerebral palsy (CP).

Recently, Alhazmi et al. (2018) administered the WHOQOL-BREF to a South African sample of parents of children with ASD and parents of typically developing children ($n = 26$ each). Their results indicated that the former reported significantly poorer QoL across all four domains. As was the case in the current sample, their lowest reported QoL domain score was that related to environment domain ($M = 39.8 \pm 18.2$). This result stands in contrast to the other four studies mentioned above, which were conducted in Taiwan (Tung et al., 2014 and Shu, 2009), Jordan (Dardas & Ahmed, 2014), and Italy (Mugno et al., 2007). This piece of data suggests that aside from the daily ASD challenges faced by South African families, many are markedly impacted by the poor quality of their housing and living situations. I explore this theme further in Chapter 5.

Bivariate correlations. Analyses indicated statistically significant bivariate correlations between almost all outcomes under consideration.

First, regarding parent reports about child behaviour, those who endorsed more autism-related behaviours (as measured by the ABC) also endorsed more general problem behaviours (as measured by the VABS-II MBI). Somewhat surprisingly given the frequent use of the VABS-II in the autism literature, no published study has, to my knowledge, examined its association with the ABC. My finding of a positive association between the two therefore offers reassurance about the appropriateness of using the VABS-II to capture reports on problem behaviour in children with autism.

Second, scores on the child behaviour measures (ABC, VABS-II) were significantly positively correlated with those on the parent psychological distress measures (PSI-SF, CES-D). In other words, parents who reported more (autism-related) problem behaviours in their children also reported higher personal levels of stress and depression. Although few previously published papers examine this association, the current finding is consistent with the general trend in the literature. For instance, Ingersoll and Hambrick (2010) found significant positive associations between PSI-SF and ABC scores, and between CES-D and ABC scores (see also Dempsey & Keen, 2008; Miranda et al., 2019). However, McStay et al. (2013) found that once parent-reported child QoL and general problem behaviours (e.g., hyperactivity) were controlled for by the analyses, there was no significant association between parental stress and the severity of the child's autism-related behaviours. This finding suggests that if parents perceive their child as having a higher QoL, then the problem

behaviours do not appear to have a negative impact on parental stress. Future research might pursue these mediating/moderating avenues further.

Third, and unsurprisingly, analyses detected a significant positive association between parental stress and parental depression. This finding is consistent with a large clinical literature that extends well beyond the bounds of ASD samples (see, e.g., Andersson & Hildingsson, 2016; Kerstis et al., 2016; Saisto et al., 2007).

Fourth, analyses detected a significant negative correlation between parental stress/depression and parent QoL/ support. Parents who reported higher levels of stress and depression typically reported poorer QoL and lower levels of social support. This finding is consistent with those reported in numerous previously published studies (see, e.g., Davis & Carter, 2008; Hastings et al., 2005; Ingersoll & Hambrick, 2010; Johnson et al., 2011; Lee et al., 2009; McStay et al., 2013; Phetrasuwan & Miles, 2009; Sawyer et al., 2010). Of note here is that all of these studies (including this one) are correlational and cross-sectional, and that therefore none allows strict causal inference. Hence, although one might assume that individuals with less social support become more likely to experience depression and then become more likely to have a poorer QoL, one cannot rule out the possibility that the causal chain runs in the opposite direction.

What Did Parents Report about Their Experience with ASD Service Delivery?

Healthcare system. The biggest section of the WUN Scoping Survey consisted of questions focused on parents' contact with the healthcare system before, during, and after their child's diagnostic process. Most parents reported that this process was lengthy and included multiple sessions and several referrals.

Pre-diagnosis. Most parents reported that, if they had not already noticed behavioural and/or developmental difficulties in their child themselves, either a professional (e.g., pediatrician) or a family member (e.g., grandparent) noticed these things before the child was aged 4 years. Once identified, the largest proportion of parents reported that they took their child to a healthcare professional (e.g., pediatrician, psychologist) within 1 month, although a significant minority waited longer than a year. Furthermore, parents reported that, although they received numerous referrals (e.g., to speech or occupational therapists) and underwent several evaluations following those initial consultations, in most cases ASD was not even noted as a possible diagnosis. Relatedly, many parents noted that at this stage of the process they had inadequate knowledge regarding future diagnostic developments (e.g., how much

the assessment would cost and how long the process would last, what types of assessments would be conducted and by whom they could be conducted).

Early (i.e., < 2 years) identification of behavioural and/or developmental difficulties but subsequent delays in obtaining evaluation by an appropriate professional is commonly reported in the ASD literature (see, e.g., Crane et al., 2016; Howlin & Asgharian, 1999; Ozonoff et al., 2009; Siklos & Kerns, 2007; Young et al., 2003; Wiggins et al., 2006). Numerous previous studies describe observations consistent with those reported here, noting that children often do not receive an ASD diagnosis at initial evaluation, but instead receive multiple referrals and evaluations before being diagnosed appropriately (see, e.g., Crane et al., 2016; Goin-Kochel et al., 2006; Moh & Magiati, 2012; Siklos & Kerns, 2007). This pattern is problematic given that research indicates greater parental satisfaction and less parental stress when the diagnostic process is completed quickly and involves fewer professional consultations (Brogan & Knussen, 2003; Goin-Kochel et al., 2006; Mansell & Morris, 2004).

Diagnostic process: Assessment. Recent clinical guidelines (e.g., see, Falkmer et al., 2013; Randall et al., 2018) suggest that the gold standard for an ASD diagnostic assessment is the inclusion of both a behavioural evaluation (preferably the Autism Diagnostic Observation Schedule [ADOS-2; Lord et al., 2012]) and a parent clinical interview (preferably the Autism Diagnostic Interview [ADI; Rutter et al., 2003]). Other frequently-included core elements of the assessment are cognitive testing, speech and language evaluation, and physical examination (National Institute for Health and Care Excellence [NICE], 2014).

In the current sample, almost half of the parents reported that their child's ASD diagnostic assessment process included all five core elements and more than half reported attending more than one diagnostic session. Hearteningly, the two most commonly reported elements of the diagnostic assessment were a behavioural evaluation and a clinical interview. Interestingly, a small proportion of the parents reported receiving a genetic analysis during the diagnostic assessment. Although such analysis is not a common diagnostic measure, the provision of genetic samples by children in the current study likely reflects the rapid growth of research into the genetics of ASD (see, e.g., Arnett et al., 2019; Woodbury-Smith & Scherer, 2018).

Although almost half the sample reported consulting a specialist (e.g., pediatrician, neurologist, pediatric neurologist) to complete the diagnostic assessment, only 35% reported consulting a multidisciplinary team of professionals. Although many clinicians do try to

operate in multidisciplinary teams when diagnosing ASD (see, e.g., Taylor et al., 2016), the current finding regarding a minority of children actually being diagnosed by such a team is consistent with previous reports in the literature (see, e.g., Siklos & Kerns, 2006; Strunk et al., 2017).

Diagnostic process: Feedback. Most parents reported receiving in-person feedback (typically in a session that lasted < 45 mins) and a comprehensible written report on the same day as the diagnostic assessment finished. These reports are consistent with those provided by parents who participated in previous ASD studies (see, e.g., Abbott et al., 2012; Crane et al., 2016). Also consistent with previous studies was the current finding that most parents received multiple post-diagnostic referrals to, for instance, special needs education, speech therapy, and occupational therapy (see, e.g., Siklos & Kerns, 2007; but see Osborne & Reid, 2008, for a contrasting finding).

One finding in this section stood out as being quite different from previous reports in the ASD literature. At the end of the diagnostic process, most parents ($n = 107$ and 160 , respectively, out of 200) reported (a) being satisfied with the whole diagnostic process, and (b) that the health professional had answered their ASD-related questions adequately. In contrast, Goin-Kochel et al. (2006) reported that 40% of their sample of parents were dissatisfied with the diagnostic process. This between-study difference might be accounted for by the reported associations between, on the one hand, parental satisfaction with the process and, on the other, length of the diagnostic process, number of professionals consulted, and severity of the child's ASD symptoms (Crane et al., 2016; Osborne & Reed, 2008; Siklos & Kerns, 2007).

Current healthcare. Most parents (more than three-quarters of respondents) reported that their child was currently receiving some form of therapy, intervention, or medication to address autism-related problem behaviours. The form of treatment varied widely, although many children were reportedly receiving speech and language therapy and occupational therapy and many were prescribed anti-convulsants, stimulants, behaviour and mood stabilisers, and hypnotics.

This variation in treatment approaches is consistent with reports in the ASD literature. Approaches range from alternative therapies such as music therapy and equine therapy (see, e.g., Kertesz, 2015; Reschke-Hernandez, 2011), to evidence-based programs such as social skills training, PECS, and cognitive-behavioural therapy (for a review, see Wong et al., 2015). Also consistent with the current findings are those by Green et al. (2005), who indicated that speech therapy was the most commonly reported intervention in their sample

($N = 552$ parents of children with autism, most from the United States). Furthermore, more than half of that sample reported their child was prescribed multiple forms of pharmacological treatment, incorporating all of the medications listed by the current sample.

Community support, educational resources, and occupational resources.

Questions in this section of the WUN Scoping Survey focused on gathering information regarding (a) types of services that were lacking in the respondent's community, (b) services provided by the child's school or other educational institution, and (c) workplace accommodations provided by the child's employer.

Community support. Most parents (almost 80% of the sample) reported that important services (e.g., community-funded therapies, relevant community organisations, career development, and employment assistance) were lacking in their community, or that services were available but difficult to access (e.g., because of expense, location, or length of waiting times).

The ASD literature contains few studies that focus on whether specific community supports are available to families and what barriers to access might exist. The small number of studies that do contain such a focus present reports consistent with those detailed here (e.g., a need for employment assistance and career development for adolescents and young adults with ASD; Taylor et al., 2012; Wilczynski et al., 2013). This theme is addressed further in Chapter 5.

Educational resources. Most parents (almost 70% of those whose child was currently enrolled at a formal institution) reported that their child was attending an autism-specific school or a public school with an exclusive focus on special-needs education. Of that sub-sample of parents, most reported that their child was receiving at least one school-based intervention (most commonly, social skills training and/or PECS) even though they themselves were receiving no parent training/counselling at the school. Encouragingly, a large proportion of parents reported daily communication with the school and felt that they were well-informed about their child's current educational programme.

Numerous studies examine types of school-based interventions available to ASD children. Reports indicate that a wide variety of programmes are implemented, including social skills training, social stories, sensory integration, and cognitive-behavioural modification (see, e.g., Hess et al., 2008; Machalicek et al., 2007). There is, however, a glaring lack of research on the relative efficacy of such interventions, regardless of whether they are implemented in schools or elsewhere (Bellini et al., 2007; Kasari & Smith, 2013; Tanner et al., 2015).

Occupational resources. Six parents in the current sample reported that their child was aged > 18 years and was employed outside the home (e.g., as a waiter and pizza maker, assistant at a recycling plant, general assistant in family business, data capturer, and volunteer at an autism school). Although all parents reported their child was working more than 10 hours per week at the time of data collection, most indicated that s/he earned less than his/her fellow employees. This reported feeling of relative under-payment (perhaps because of the stigma associated with an ASD diagnosis) is consistent with findings reported in Study 1 (Chapter 3) of this dissertation and in the adult ASD literature (e.g., Cimera & Cowan, 2009; Hendricks, 2010).

All parents in this small sub-sample reported that their child's employer was aware of his/her ASD diagnosis. However, only three of the six reported that the employer had made ASD-related workplace adjustments (e.g., sheltered placement, personal supervision). This lack of supportive and appropriately adjusted work environments echoes similar findings reported in Chapter 3 and in previously published literature (for a review, see Hendricks, 2010).

Impact on daily living. The two major findings here were related to caregiving time and financial expenditure. Regarding the first of those, a large proportion of parents (almost 40% of the sample) reported spending more than 8 hours a week trying to coordinate their child's care (e.g., making appointments with healthcare professionals, driving the child to and from those appointments, and to and from school and extracurricular activities). Despite this intense time commitment, more than half the parents reported that they did not stop working or cut down on their hours of work. These sorts of reports are consistent with previous findings in the ASD literature (e.g., Jarbrink et al., 2003; Sawyer et al., 2010).

Regarding financial expenditure and its impact on daily living, most parents (89% of the sample) reported experiencing economic challenges. For instance, although most reported having private medical insurance/medical aid, it tended to cover little to none of the services their child was receiving (i.e., they had to pay out-of-pocket for most services). For families without private medical insurance/aid, the government disability or child dependency grant they received ranged from ZAR1300-1500 (equivalent to US\$88-102) per month. Recent studies suggest that this amount of money will cover barely any ASD-related costs. For instance, Horlin et al. (2014) found that mean estimated cost per annum for a child with ASD in Australia is AUD\$34 900 (equivalent to US\$23 865). Similarly, Lavelle et al. (2014) reported that ASD-related costs in a US sample of affected children amounted to \$17 081 per annum.

These parent reports about the financial burden they were experiencing are consistent with current literature on the high costs associated with an ASD-diagnosed child (e.g., Jarbrink et al., 2003; Liptak et al., 2006; Sharpe & Baker, 2007). Of interest here is the study by Wang et al. (2012), which noted that in the United States parents with private health insurance incur huge treatment costs relative to those who receive government support. Similar to the case in South Africa, this suggests that private health insurers have some way to go before their coverage of autism-related treatments and interventions is adequate.

Were There Pathways Between SES, Autism-related Problem Behaviours, Service Delivery, and Parental QoL?

The path analysis attempted to answer the questions regarding the interacting roles of family socioeconomic status, autism-related problem behaviours, aspects of the service delivery experience (e.g., as related to the diagnostic process, to current health care, and to educational resources), social support, and psychological distress in predicting overall parental QoL. Hence, the basic conceptual model set out to test four main hypotheses: (1) parent's age and the SES-related variables will directly influence the service delivery variables, while child's age will directly influence service delivery variables and autism-related problem behaviours; (2) there will be a bi-directional link between autism-related problem behaviours and aspects of service delivery; (3) autism-related problem behaviours will directly influence both parent psychological distress and levels of family support; and (4) parent psychological distress and family support will both directly influence overall parental QoL.

Although that conceptual model was not a good fit for the data, several iterations of modified models generated a final, good-fitting model. The direct pathways in that final model indicated the following:

- (a) the lower the parent's education level, the more autism-related problem behaviours were reported;
- (b) higher household income was associated with better diagnostic and educational services;
- (c) child's age was negatively associated with current healthcare services (i.e., the younger the child, the more services they were receiving);
- (d) a higher number of autism-related problem behaviours was associated with receiving more healthcare-related services;

- (e) better prior experience with diagnostic and educational services was associated with receiving more healthcare-related services currently;
- (f) a higher number of autism-related problem behaviours was associated with a higher degree of parental stress and depression;
- (g) better prior experience with diagnostic and educational services was associated with lower levels of parental stress;
- (h) better current experience with healthcare-related services was associated with lower levels of parental depression;
- (i) in parents, higher levels of stress were associated with higher levels of depression, and higher stress and depression levels were associated with poorer overall QoL.

Point (a) above bears some comment. Although the direct pathway indicated there might be interpreted as suggesting that parents with lower levels of education have children with more severe autism-related problem behaviours, it is unlikely that the real-life situation is as straightforward. For instance, there might be an uncaptured intervening pathway showing that parents with higher levels of education are more likely to seek and to access effective interventions sooner, and that therefore their children are less likely to evince severe behavioural problems later on. It is similarly plausible that parents with higher levels of education are more likely to be well-informed about autism-related problem behaviours and so might be better able to place their child's difficulties in that context. Although the service delivery survey was thorough, it did not generate an outcome variable focusing purely on such possible intervening pathways.

In summary, then, the final model indicates that socioeconomic variables (e.g., parent's highest level of education, household income), autism-related problem behaviours, and aspects of service delivery all play a role in the quality of life experienced by parents of children with autism.

To my knowledge, this is the first study in the ASD literature to simultaneously examine the influence of all those factors on overall, comprehensively-measured parental QoL. The two most similarly designed studies have found similar results, however. Hsiao (2016) found, using structural equation modelling and a US sample of 429 parents of children with ASD, that self-reported parental stress, child behaviours, and medical and neighbour support all influenced parental mental health-related QoL. Similarly, Zaidman-Zait et al. (2014) found, using path analysis and a Canadian sample of 184 mothers of young (< 6 years) children with ASD, a bidirectional relationship between parenting distress and child behaviours 12 months post-diagnosis.

Limitations and Directions for Future Research

I acknowledge three major limitations of the current study design. First, use of the Autism Behavior Checklist (ABC) as the sole measure autism severity was not ideal. Typically, research studies use more detailed measures (e.g., the Autism Diagnostic Observation Schedule [ADOS] or the Childhood Autism Rating Scale [CARS]) for the purpose of measuring the severity of ASD-related behaviours. However, even without the ABC my battery was already lengthy (approximately 1.5 hrs), and I did not want to increase participant burden by adding either the ADOS, which has an administration time of 45-60 mins and requires direct assessment of the child, or the CARS, which although it has a much shorter administration time is ideally completed only after direct observation of the child.

Second, the sample included only a small number of parents with an adult ASD child, and so it is difficult to draw firm conclusions about the experiences of such families. It may have been useful, for interest, to get parental perspective on the availability of post-school services (e.g., job training, workplace accommodations, individualized supportive employment spaces). Despite exhaustive efforts, I was not able to recruit many parents who had a child older than 18 years. One reason for this is that my main avenues for recruitment were schools and support groups for parents with young children.

Third, the sample was not geographically diverse. Most parents lived in the Western Cape which, as is noted in Chapter 3, is a province that is relatively well-resourced in terms of healthcare-related service delivery and autism-specific supports. Parents living in rural provinces, such as the Eastern Cape or Limpopo, are likely to have fewer services available to them and to have had different experiences of service delivery. Future research should therefore recruit a more nationally representative sample in order to explore regional differences in service delivery experience and QoL.

Summary, Conclusions, and Future Directions

The primary aim of this study was to investigate, using a large and demographically diverse South African sample, (1) the services and supports previously and currently received by children with ASD and their parents, (2) the QoL of parents of children with ASD, and (3) the strength of association between service delivery experiences and parents' QoL. The novelty of the current study is not only that it provides comprehensive information on service delivery and QoL in parents of children with ASD from a low- and middle-income country, but also in that it directly explores associations between parent socioeconomic status, child

age, autism-related problem behaviours, aspects of service delivery, parent psychological distress, and overall parent QoL.

The study's descriptive findings suggest that South African parents of children with ASD report clinically significant autism-related child problem behaviours and experience relatively high levels of psychological distress. Moreover, autism-related problem behaviours were associated with higher psychological distress and poorer QoL. Poorer QoL was also associated with higher levels of depression and stress and lower levels of social support. These findings suggest possible targets for intervention that have as their purpose improving QoL in these parents.

The second set of findings suggested that South African parents of children with ASD face numerous challenges related to various aspects of service delivery and that these have negative effects on their daily lives. In brief, these challenges include diagnosis delays; multiple referrals and evaluations; a limited range of available and appropriate interventions and therapies both in the general community and in the child's school; financial burdens associated with interventions and therapies; a lack of employment training, supported employment programs, and career development for young adolescents with ASD.

The third set of findings (path analysis) suggested various interacting factors (both direct and indirect) influence overall parental QoL. These factors include parent's highest level of education, household income, child's age, child's autism-related problem behaviours, aspects of service delivery (e.g., experience with process of diagnostic assessment), and parent psychological distress. These findings point to the importance of considering all variables that may possibly impact on QoL when trying to better understand, and improve, wellbeing in parents of children with ASD.

The significance of the current study is that its large overall sample size and comprehensive measures (a larger sample and a more detailed set of measures than used in previously published and unpublished LAMIC studies) provides novel insight that complements and enriches the extant ASD literature. For instance, the findings indicate that if specific areas of need (e.g., improved access to appropriate and effective services) are addressed then parents of children with ASD will have better QoL, and that multiple interacting factors (aspects of both the parent's and the child's life) have a role in determining overall parental QoL. With these sorts of data-driven directions in hand, targeted interventions and supports can be implemented to help improve and optimise the daily functioning of parents of children with ASD.

CHAPTER 5: Study 3 – Service Delivery Experiences in Parents of Children with ASD: Thematic analysis

Abstract

Introduction. Previously published studies, as well as the results presented in Chapter 4 of this dissertation, suggest that service delivery to families affected by ASD is limited in several aspects and plagued by numerous difficulties. Of particular importance are findings from the Chapter 4 path analyses suggesting that a lack of services impacts negatively on parental psychological functioning and overall QoL. However, no previous study provides a rich, in-depth description of service delivery experiences among affected families who reside in a low- and middle-income country (LAMIC) such as South Africa. Such an investigation is worthwhile given that those families, relative to their counterparts from high-income countries, are likely carrying additional health, environmental, and infrastructural burdens.

Objectives. The study set out to examine service delivery experiences among a sample of South African parents of children with ASD.

Methods. Thirty-three such parents participated. They were spread across 6 focus groups. Each group discussed their service delivery experiences and the impact these had on their daily lives. Each discussion was audiotaped and transcribed. I used thematic analysis to identify key elements of the discussion.

Results. The analysis identified seven key themes: (1) long delays before appropriate diagnosis, poor post-diagnostic support; (2) lack of ASD knowledge among healthcare professionals, long delays between appointments at government facilities, need for translators when dealing with healthcare professionals; (3) high cost of interventions, need for parent-focused training so that they might provide auxiliary home-based therapeutic support; (4) long waiting lists to be enrolled in a school with even minimal autism-specific supports, poor ASD understanding among school staff; (5) lack of services and information available to young autistic adults post-school; (6) financial impact of an ASD diagnosis, post-diagnostic parental need for emotional support; and (7) lack of ASD awareness in their community.

Conclusions. The findings presented here, along with those from Chapter 4, constitute the first attempt to comprehensively describe the service delivery experiences of LAMIC parents of children with ASD. The value of this study is that it allows policymakers to understand problematic aspects of service delivery and to thereafter design targeted programmes that might optimize the daily functioning of children with ASD and their families.

Introduction

The results of Study 2, as described in Chapter 4 of the dissertation, suggest that service delivery experiences (i.e., characteristics of interactions with healthcare, educational, and other community institutions) have a significant influence on quality of life in parents of children with autism spectrum disorder (ASD). This study uses a qualitative approach to complement and enrich Study 2's quantitative findings regarding service delivery experiences. Together, these studies allow for a detailed understanding of the ways in which shortfalls in service delivery have substantial and wide-ranging effects on the lives of South African parents of children with ASD.

As noted in detail in Chapter 4, current literature on service delivery to children with ASD and their families is lacking in two major aspects. First, most studies focus on specific services (e.g., those related to the diagnostic process, or to educational resources; Brett et al., 2016; Crane et al., 2016; Dymond et al., 2007; Goin-Kochel et al., 2006; Jarbrink et al., 2003; Karst & Van Hecke, 2012; Mandell et al., 2005; Osborne & Reed, 2008; Renty & Roeyers, 2006; Shattuck & Grosse, 2007; Wiggins et al., 2006). Few attempt to deliver a comprehensive and holistic understanding of ways in service delivery experiences, generally and across domains, might influence the lives of ASD-affected families. Second, most studies emerge from high-income countries (HICs) of the global north (e.g., Brett et al., 2016; Crane et al., 2016; Dymond et al., 2007; Mandell et al., 2005; Renty & Roeyers, 2006). Few emerge from low- or middle-income countries (LAMICs) like South Africa. These limitations in the ASD literature on service delivery mean that (a) there is not enough comprehensive information regarding what services are (and are not) available to children with autism and their families; (b) service providers lack knowledge about which services work, which need improvement, and which need to be made more available/accessible to community members; and (c) medical professionals, clinicians, teachers, and other relevant stakeholders have little understanding of how inadequacies in their service delivery impact on daily difficulties faced by ASD-affected families.

Of course, this lack of information, knowledge, and understanding may be magnified in LAMICs such as South Africa given the additional socioeconomic, health, and infrastructural burdens that families face in such settings. In fact, only a few published studies of service delivery to ASD-affected families focus on LAMIC samples (see, e.g., e.g., Bakare et al., 2015; Bakare, Agomoh, et al., 2009; Bakare, Ebigbo, et al., 2009; Franz et al., 2017; Igwe et al., 2011; Stewart & Lee, 2017), with an even smaller minority focusing on South

African samples. However, few published peer-reviewed articles, unpublished findings from Master's theses and non-governmental organization (NGO) reports indicate numerous problematic issues with ASD services in South Africa. Shortfalls include limited financial resources in the public health sector, limited ASD knowledge among healthcare professionals, disproportionate development of ASD services in relation to the growing need for services, as well as the prioritizing of healthcare services for individuals with infectious diseases such as HIV (see e.g., Balfour, 2007; Hutton et al., 2016; Jacklin, 2006; Mubaiwa, 2008; Solidarity Helping Hand, 2011; Swanepoel, 2003).

The current study. There are no published studies providing a comprehensive examination of multiple aspects of service delivery to families of children with ASD. The primary aim of the study described in this chapter is to explore, using qualitative data collection methods and analyses, the service delivery experiences of a diverse group of South African parents of children with ASD. Hence, this study's findings complement those of Study 2 (described in Chapter 4). The significance and novelty of this research is that it addresses, in an in-depth and comprehensive manner, a major gap in the literature on service delivery experiences in relatively resource-poor LAMICs in the global south. With a detailed understanding of the shortfalls of service delivery in such a context, one may approach government and other policymakers with information regarding essential service delivery areas that might require improvement. This will, in turn, assist efforts to improve the lives of ASD-diagnosed children and their families.

Methods

Research Design and Setting

This qualitative study used descriptive and exploratory methods, namely, thematic analysis of focus-group data, to examine service delivery experiences of parents of children with ASD. All of the group sessions were held in private rooms in two locations affiliated with the University of Cape Town (UCT).

Participants

Thirty-three current caregivers of a child (< 18 years) diagnosed with ASD participated. Most ($n = 31$; 94% of the sample) were biological parents of the child; the other two were a grandparent and an older sister. For the sake of brevity, I hereafter refer to the group generally as "parents." All parents had participated in Study 2, and so their initial recruitment is described in Chapter 4. Prior to their participation in Study 2 they consented to be contacted to participate in the focus groups that were the core of this study.

Materials and Procedure

I planned to run 6 focus groups (four for English-speaking participants, two for isiXhosa speakers), each comprising 5-6 participants. At the conclusion of the Study 2 procedures, I began telephoning prospective participants from the pool who had consented to be contacted. Those who agreed to participate were offered a choice of either two or four groups to join, depending on their home language. I tried to match, as far as logistically possible, the child's age within each group.

Five of the six focus groups were held at Red Cross War Memorial Children's Hospital. The other was held in the UCT Department of Psychology. All sessions were audio recorded, and each lasted approximately 90 minutes. I co-facilitated the four English groups with a fellow Psychology graduate student. Two other graduate students took notes that served as back-up to the audio files. I co-facilitated the two isiXhosa groups with a native isiXhosa speaking woman who, at that point, had 10 years of experience doing English-isiXhosa translation work, including for research studies conducted within the UCT Department of Psychology. I introduced questions and other material to the participants, and she translated the information for them. She then also translated their responses for me so that I could take notes to back up the audio files.

Before the discussion began, I read a scripted introduction that reminded participants about the purpose of and ground rules for the focus group:

Good morning everyone, thank you so much for coming and for taking part in this focus group. Today's focus group will focus on the services provided (and those not available) to families with children on the spectrum. Before we start, I just want to set some ground rules. First, there are no right or wrong answers to the focus group questions. Any opinion you have is important. We want to hear many different viewpoints and would like to hear from everyone. We hope you can be honest even when your responses may not be in agreement with the rest of the group. In respect for each other, we ask that only one individual speak at a time in the group and that responses made by all participants be kept confidential. We also ask that even if you do not agree with what someone else says to please allow them to say what they want without interruption thereby allowing each person to speak freely and openly about their opinions.

Then followed an opening question/prompt designed to start a free-flowing spontaneous discussion:

So to start us off I would like to ask, “What do you think of the services available in South Africa for children with autism (e.g. interventions, therapies, support groups, medical support)?”

I introduced the primary topic of the focus group in this general way to see what sorts of concerns would arise spontaneously. In cases where the discussion did not address certain topics/issues, or when there was a divergence from focus, I provided specific questions/prompts (see Appendix X) to ensure all key topics of interest were addressed in the group’s discussion. These 6 open-ended questions/prompts, which focused on problems, concerns, and frustrations with current services, and impact of poor service delivery (or poor-quality services) on various aspects of their lives, also allowed participants to share more detailed personal information concerning their service delivery experiences related to caring for an autistic child.

Data Management and Analyses

The audio recordings of focus-group conversations provided all the textual data that were eventually analyzed. With help from same group of colleagues who were involved in the focus groups, I transcribed the audio recording from each focus group into a separate MSWord document. I then collated those documents and used thematic analysis (Boyatzis, 1998) to describe the themes that developed regarding service delivery and the impact it has on the lives of ASD-affected South African families.

Like Study 1, I chose to use thematic analysis in Study 3 as it allows for close examination of the interview transcripts to identify patterns of themes that arose within the interviews. Furthermore, given that thematic analysis is not tied to a specific theory like other more complex types of qualitative analysis and is simple to use for novice qualitative researchers, I opted to use this method to provide detailed and complex characterisation of the data.

I took an interpretive epistemological stance when conducting the current research; this approach allowed for the collection of data first and then determining theories (the themes from the interviews) based on the observed data. Thus, a theoretical sampling strategy was used as the participants were selected based on the phenomenon being studied (e.g., autism and the services provided to autistic adults). For the analyses of the data, I used

inductive reasoning as I derived broad based themes based on specific observations and comments made by the participants during the interview.

Reflexivity. As noted in Chapter 3, reflexivity is a critical part of qualitative research. It is important to consider the impact of the researcher's subjective life experiences when conducting qualitative research (Boonzaier & Shefer, 2006). In other words, the researcher must continually reflect on how his/her life experiences and values influence the study (methodological choices, data collection instruments and procedures, etc.) and its findings.

Ways in which researchers might achieve reflexivity vary substantially but generally include reflecting on the nature of the research being conducted, the sociopolitical environment in which it is being conducted, and the socially-determined hierarchical power relations between researcher and participants (Eatough, 2012; Pillow 2003). In this study, I had to examine (a) my reason for selecting the research topic, (b) the relationship between researcher and participants, and (c) the influence my own impressions, feelings, and preconceptions may have had on the research during data collection and write-up.

First, my subjective experience indubitably influenced my research topic. This aspect of reflexivity holds true for this study as it does for the study documented in Chapter 3. Given that I have been working with children with ASD since 2008, I have first-hand experience of the negative service delivery experiences of parents of children with ASD. Therefore, my subjective experiences with parents of children with ASD influenced my current research direction in terms of directing me toward a need for in-depth examination of service delivery interactions in this population.

Second, regarding the relationship between researcher and participant, I had to consider the fact that some participants were from low-SES communities, had a different home language to mine, and may have been hesitant to share their negative perspectives with me given our cultural differences and the possibility of perceiving me as an authority figure in the healthcare field. To address these issues, I involved a translator with the same home language and cultural background to ensure the participants felt comfortable sharing their service delivery experiences.

Third, throughout the study I continually attempted to reflect on my own impressions, feelings, and preconceptions given that prior to conducting the study I had heard only negative comments about ASD service delivery in South Africa. For instance, this preconception had a negative influence on the development of my focus group questions, as well as the direction in which I steered the focus group discussions. That is to say, my initially drafted questions typically focused only on negative aspects of service delivery, and

this might have had a particular influence on the focus group's direction. Therefore, to ensure my qualitative data collection was not overly biased by these personal preconceptions, I ensured that I consulted closely with my supervisors when creating the focus group questions and ensured that I accommodated their critical feedback.

Ethical Considerations

I obtained ethical approval from the University of Cape Town Department of Psychology's Research Ethics Committee before commencing data collection (see Appendix K).

Consent, privacy and confidentiality. All participants provided informed consent for participation. The consent forms assured participants of the confidentiality of their data and of their participation. Furthermore, at the start of every focus group, participants were informed of the importance of keeping the information heard during the session confidential and private (see introduction script in Materials and Procedure section). Importantly, the information received from the study participants is stored securely; only researchers involved directly in the project, and certain University officials, can view the information. During the focus groups, participants were informed regarding the confidentiality of the information shared by other participants.

Risks and benefits. Participants were exposed to minimal physical, social, and psychological risks. They were not asked to perform any potentially harmful tasks. The only possible risk was that the participants felt uncomfortable, became distressed from some of the discussion, or became fatigued during the focus group sessions. In such instances, they were encouraged to take breaks. If a participant had become noticeably distressed or troubled during the sessions, I would have determined whether a suitable referral (e.g., counselling or social work) was required. However, no such instances occurred during the focus groups. Participants were also informed that they could withdraw from the study at any time, with no penalty and with no effect upon clinical or other services being delivered (or potentially being delivered) to them.

A direct benefit from participation in this research was the provision of an open, safe environment where participants were given a voice and listened to with respect. An indirect benefit is a greater understanding of the services provided (and those not provided) to individuals with ASD and their families, as well as the impact aspects of service delivery have on the QoL of individuals with ASD and on their families. These findings will help provide key information regarding the shortfalls and limitations of the services provided and

will help improve future services for individuals with ASD, which may in turn aid in improving the quality of life of individuals with ASD and their families.

At the conclusion of the study write-up, I provided general feedback to all participants in the form of a basic report on the findings.

Costs and compensation. Participants did not incur any costs for participating in the study. Those who completed the study procedures at the research laboratory were reimbursed ZAR100 (at the time of the study, approximately US\$9.46) to cover their travel costs.

Results and Discussion

To avoid repetition and to enable a better narrative flow between data and interpretation, I present the results and discussion of the findings together here.

Because of the way in which participants were assigned to, or chose, different focus groups, as well as the fact that availability and attendance was influenced by their own schedules (e.g., some parents either cancelled attendance or simply did not show up at the scheduled time), the sample size per focus group varied. Nonetheless, each of the six groups contained between 4 and 7 participants.

Table 14 presents the sample demographic characteristics. The overall parent age range was 26–53 years, and the overall child age range was 4–15 years. Most parents were biological mothers. Most had completed at least some high school, and a large proportion had also completed some tertiary education. Employment type ranged widely, from administrative personnel, managers, and minor professionals to homemakers. Unsurprisingly, then, household income also ranged widely. For instance, the average annual income for one focus group was reportedly > ZAR500 000 with a standard deviation of > ZAR390 000, whereas the same statistic for another group was < ZAR25 000 (*SD* < ZAR30 000).

Regarding race/ethnicity, Groups 1–4 (the English-language groups) consisted of white and Coloured participants, whereas the isiXhosa-language groups consisted of black African participants only. As noted in Study 1 and Study 2, we include descriptive racial data here because the legacy of South Africa's apartheid policies continues to permeate many aspects of life in this country. Under apartheid (i.e., pre-1994, when many of the current participants were children) White people had easier access to higher-quality healthcare and had fewer stress-provoking experiences of oppression and discrimination. Although legislated racial segregation has not existed for more than 25 years, these disparities are, to at least some degree, still present because of historically-engineered imbalances in economic power.

Table 14.
Sample Sociodemographic Characteristics (N = 33)

Variable	Sample (N = 33)	Focus Group Number					
		1 (n = 4)	2 (n = 7)	3 (n = 5)	4 (n = 6)	5 (n = 6)	6 (n = 5)
Parent sex (F:M)	31:2	4:0	6:1	5:0	5:1	6:0	5:0
Parent age (yrs; M (SD))	37.48 (7.62)	38.00 (6.55)	38.00 (6.20)	39.00 (3.80)	44.00 (9.20)	34.66 (5.80)	29.40 (5.90)
HLOE (yrs)							
≥ 13:8–12:1–7	13:19:1	2:2:0	6:1:0	2:3:0	2:4:0	0:6:0	1:3:1
Parent home language							
Eng:Afr:Xh	20:2:11	4:0:0	6:1:0	5:0:0	5:1:0	0:0:6	0:0:5
Parent employment ^a							
1	2	0	2	0	0	0	0
2	6	2	1	2	1	0	0
3	3	1	1	1	0	0	0
4	2	0	1	0	0	0	1
5	3	0	0	0	2	0	1
6	1	0	0	0	1	0	0
7	2	0	0	0	0	2	0
8	4	0	1	0	1	0	2
9	10	1	1	2	1	4	1
Annual household income							
M	202 453.10 ^b	242 750.00	527 285.70	120 400.00	167 300.00 ^b	43 625.00	23 250.00
SD	271 415.70 ^b	168 364.90	389 935.70	97 002.80	184 707.10 ^b	48 725.96	29 440.10
Child age (yrs; M (SD))	8.06 (3.46)	7.00 (1.50)	7.90 (3.90)	10.60 (3.60)	11.00 (3.60)	5.30 (1.20)	5.80 (1.10)
Child sex (F:M)	4:29	0:4	1:6	1:4	0:6	1:5	1:4

Note. HLOE = highest level of education, with ≥ 13 indicating at least some tertiary education completed, 8–12 at least some high school completed, and 1–7 at least some primary school completed. For home language, Eng = English, Afr = Afrikaans, Xh = isiXhosa. Note that Group 2 and Group 4, which were among those designated as catering for home-language English speakers, contained parents who reported being first-language Afrikaans but English-fluent. ^aCoded using the Hollingshead occupational index, where 1 = higher executives, major professionals; 2 = administrative personnel, managers, minor professionals; 3 = business managers of medium-sized businesses and other professions; 4 = clerical and sales, technicians, small businesses; 5 = skilled manual labour; 6 = semi-skilled labour; 7 = unskilled labour; 8 = student/disabled/no occupation; 9 = homemaker. ^bData from one participant missing (one parent did not know what the household income was).

Themes.

Analyses suggested that seven major themes emerged from the focus group discussions. To be classed as a “major theme,” a particular thread of discussion had to be raised or endorsed by at least five parents across the six different focus groups. The themes were: (1) ASD diagnostic process, (2) overall contact with healthcare professionals in regard to the ASD-diagnosed child, (3) education-related costs and resources for the child, (4) ASD-targeted interventions—costs and parent training, (5) transitional services available to ASD-diagnosed young adults post-schooling, (6) impact of the child’s ASD diagnosis on everyday family life, and (7) increasing ASD awareness.

Below, I discuss each theme individually. For each, I provide quoted examples of what parents said to develop the theme. Appendix Y provides additional parent quotes related to each theme. To provide detailed examples of what the participants said and still maintain their privacy and confidentiality, each participant was given a pseudonym. Participants **GR1**, **AP1**, **KM1**, **FT1**, **HB1**, **RF1**, and **PL1** were from focus group 1; **BF2**, **CY2**, **DR2**, **EF2**, and **JL2** from focus group 2; **HJ3**, **LW3**, **XV3**, **MF3**, and **NT3** from focus group 3; **HC4**, **GX4**, **VT4**, and **GY4** from focus group 4; **LDX1**, **TRX1**, **UDX1**, **DSX1**, and **YSX1** from isiXhosa focus group 1; and **ESX2**, **YAX2**, **NXX2**, **LPX2**, and **EQX2** from isiXhosa focus group 2.

Theme 1. ASD diagnostic process. One of the most prominent themes to emerge was that parents faced a long and difficult process obtaining their child’s ASD diagnosis and then received little post-diagnostic support. Several reported that the diagnostic process encompassed multiple referrals to different healthcare professionals, sometimes over a period of years, and several appointments with each of those professionals.

***AP1:** Eventually 3 years down the line, they didn’t diagnose him at that point because he was only a year and a few months old, so they had to wait until he was 3 and we had to see a lot of private specialists.*

***CY2:** We also went through the whole private doctors and OT’s, and in fact it was just a money-making thing (or scheme), and nobody could, like say what the problem was and, they kept saying he failed this and he failed that but in the meantime they didn’t really, I feel they never really did what they were supposed to do. He couldn’t speak at all. Uhm, and then we, went to a private GP, and we asked him to refer us to [government hospital] because it was now becoming financially difficult and it was*

just too much for us, and, we just wanted to go another route, so just to get a, like a referral opinion because we've seen so many specialists and OT's and that. And then when we got to [government hospital], he went to the developmental clinic, and [pause], I won't say it's pathetic [cold laugh], it's just, because you have to wait so LONG, I think that's really sad. And, but because it's a free service you kind of weigh your options, you take off one day and, you decide 'Okay, what are you going to do?' Pay ZAR600 and get no results or, sit for the day and, maybe get results or you know, it's a free process. It was a long process and it took, for me, it was a quicker process than the private process.

Many parents reported that their child received various other diagnoses (e.g., ADHD) before professionals concluded on an ASD diagnosis.

MF3: *Um, and actually I was told by my mother that my son was autistic when he was 3. And he had his official diagnosis when he was 7. I went through educational psychologists, paediatricians, um this system for just over 6 months, um and eventually I went to a paediatric neurologist in [private hospital] and she looked at me and said he's ADHD. And then a year later I was back again and "oh no he's ADHD but he's also on the spectrum." Um so it was a very drawn out, incredibly expensive procedure that medical aids don't cover.*

Many parents noted a lack of empathy and support from the healthcare professionals in the final diagnostic feedback meeting.

PL1: *... [s]ays PDD-NOS and I thought what is that and I mean it was a completely cold, unemotional, almost like this is "duh" sort of diagnosis, off you go, no support, no nothing. And for me I think the biggest challenge was the trauma it places on the family.*

FT1: *I can understand you saying now about like going, the holding the person's hand once you're given the diagnosis because when I took [child's name] to be diagnosed, by a very well-known doctor, she did not even look [parents' names] in the face, she did not even attempt to communicate with [child's name]... I walked out of there and [parent name] and I said, we are never coming back here.*

Several parents also noted a lack of professional guidance and support post-diagnosis. For instance, many reported feeling overwhelmed after the diagnosis was given and expressed a need for information regarding post-diagnostic resources and support available in the country.

FT1: ... is that when your child is diagnosed, at that point, you're actually not given the ... you're not given the direction [agreement from three other focus-group participants], you're not told what resources are available, and quite frankly after 12 years, I still don't know what resources are available. You are not told what resources are available, um, they will refer you to a specialist, another specialist, and you land up going from one specialist to another specialist, you're kind of left in the dark and you feel like you are swimming upstream and getting nowhere.

GR1: You don't get that at the specialist that diagnosed your child's office, why not? Why are those pamphlets and booklets not at his office so that he can give me one and say you know what [mom's name] I know this is bad news, take these home and when you've got time, whatever. Or here is the website's number, or the name, where you can go and get information because parent education while you wait or while, you know; you're hoping for winning the lottery, um it goes a long way in educating your child.... It is a frustrating road and it would be nice if services were readily available but in the meantime, we can get parents educated in what to do and what not to do because the outcomes is 100% what you are saying, the outcome can be very different if your child receives intervention, even if it's just behaviour intervention.

Relatedly, many parents expressed a need for better post-diagnostic advice and guidance, noting that they were typically only given further referrals that resulted in marked expenses, medication prescriptions without further explanation, or references to books or movies without further elaboration.

GR1: I was slapped in the hand the title of 2 books, not even the actual books, just the title of the books that I had to go and buy on [online shopping site] and a prescription. That was the full extent after somebody had just shred... absolutely

gutted our entire family, that was all I got, I have never been back to see him, he has never seen my child again, and that was our diagnostic experience.

AP1: *When my first-born was diagnosed, one of my cousins who is a doctor, he is a specialist anaesthetist, he found a specialist in autism, who came from Scotland, he put us into contact with her. At that point I was also told your child is autistic, watch this movie called Temple Grandin. I was like Oh, ok, what is that movie.... watch Temple Grandin – that was my son’s diagnosis, go watch Temple Grandin.*

As noted in Chapter 4, such problematic diagnostic processes are reported commonly in the ASD literature (see, e.g., Howlin & Asgharian, 1999; Ozonoff et al., 2009; Young et al., 2003; Wiggins et al., 2006). Parents often report multiple referrals and evaluations, and lengthy and time-consuming assessments, before finally receiving the ASD diagnosis (Crane et al., 2016; Siklos & Kerns, 2007). Exposure to this type of process is associated with negative parental outcomes. For instance, Goin-Kochel et al. (2006) found that parents reported greater satisfaction with the diagnostic process when their child saw fewer professionals and received their diagnosis more quickly and at a younger age. Similarly, the descriptive data and path analysis reported in Chapter 4 indicated that better diagnostic services were associated with lower levels of psychological distress and better overall QoL in parents of children with ASD.

Focus groups also discussed various other important issues regarding the diagnostic process (e.g., problems with screening tools, misleading diagnostic information on the Internet, the need for sensory issues to be part of the diagnostic criteria³), but none of these was discussed in enough depth or by enough parents to meet the threshold for a major theme.

Theme 2: Overall contact with healthcare professionals in regard to ASD-diagnosed child. A related and similarly prominent theme to emerge was that there was a lack of ASD knowledge among healthcare professionals (in both private and public settings), long delays between appointments and while waiting in line to see a healthcare professional in government hospitals and clinics, and the need for translators when dealing with healthcare professionals.

³The parent who raised this issue had a child who was diagnosed before the publication of the DSM-5 ASD diagnostic criteria.

Several parents expressed the need for healthcare professionals who assessed or treated autistic children to develop a better understanding of what ASD is and how ASD-related behaviours and symptomatology tend to manifest. Some noted the need for professionals to adapt therapies and interventions for an ASD child rather than applying therapies used for neurotypical children.

CY2: *I find that the old-school doctors that are professionals, that have private practices, I find that they have very little knowledge about this because, I used to do research from the time I heard the word, I never knew it ... So I think that the old-school doctors need to be, it needs to be really, put out there. There needs to be more awareness of it.*

LW3: *All you want to do is help your child. I feel that I can actually educate those people by now by all the reading I had to do just to educate myself because I feel that you can't turn to anybody really that understands what's going on and the problem I find is autism is so broad ... Do you also find that there aren't really psychologists that's available that knows how to treat kids on the spectrum?*

UDX1: *Even if you go to the clinics there, there are some nurses who are lost and don't even know what you're talking about when talking about autism ... There is a scale there and our child will go on the scale and [the] woman who is there will be shouting because the child doesn't want to stand on the scale. When I try to explain that my child has autism and she should try to be more gentle, she doesn't understand and says that she will end with me as if it's my fault.*

DSX1: *Yes, she is telling the truth. She goes to her clinic in her area and I attend a different clinic, still the same story, my child won't stand still on the scale and the nurse will shout "you don't know to discipline your children blah blah" and starts saying a lot of things, and when I try to explain to her that my child has autism, she'll be like what is autism? "This child is 6 years of age" and look she started comparing them to children that [are] 3 years of age and this obviously doesn't feel nice as a parent. [All the other mothers agree.]*

LW3: *I can't just go to anybody and say explain this to you, I need you to explain these things. So they, the thing with psychologists or psychiatrists, they, the therapy that give is based on what they would give a normal child. Not taking into account that he thinks differently, this means something different to him than it would another kid*

FT1: *I want [to] find psychologists who have got non-neurotypical kids.*

Families from low-income settings, in particular, reported long waiting times at hospitals and clinics, with appointments therefore sometimes taking up a whole workday and thereby costing the family a day of income. They also noted that long waiting times can lead to an increase in problematic ASD behaviours, making medical appointment days very challenging for parents.

MF3: *Because trying to get through the [government hospital] system, to even get an appointment with a pediatric neurologist was like a 6-month waiting period ... and waiting for 6 months saying well he might be and he might need this and he might need that is 6 months too late as far as I was concerned.*

DR2: *And once again if you go to somewhere like [government hospital] you would go and sit the whole day. He had to go for an ECG, he can't, yeah, he can't sit the whole day.*

TRX1: *it would be easier if they didn't make wait 3-5 hours and they treated your child like they had the flu, And it would be easier if they could give you your medicine and give your folder and then you go instead of waiting for 6 hours and irritating everybody. [Other mothers agree.]*

The long delays between appointments (sometimes amounting to months at a time) were noted to limit the efficacy of therapies and, in turn, to lead to poorer overall outcomes for the child.

LPX2: *[W]hen I come back mine has forgotten the doctors and you see its difficult for them to do the things they did before, even teaching things or*

touching, how mine becomes after waiting for such a long time coming after a month becomes upset and angry.

EQX2: *So maybe if they were to ... be able to see them maybe twice a month maybe even three times a month. The thing of once a month is such a long time.... [B]ecause sometimes there they give us things to teach the child, things like mine teaching how to use the toilet as mine does not want to go to the toilet it, he is very stubborn, stubborn. So now I think it going to be possible to be done if I was going there a week and skip the other week. At least I think and thought if I was to go two to three times I would not mind, because it's important for my child do you understand that I will also be encouraged, and I will understand that there is a problem ... the child and I will be happy if that could happen [chuckle]*

Several isiXhosa speakers reported needing trained translators available during medical appointments to ensure they fully understood all the information provided. Without translations, some parents felt that they were not able to retain all the important information.

ESX2: *I can say I don't understand what they say as what is written in the book it's in English and in isiXhosa yes the problem when you get here in hospital, they speak English.*

LDX1: *I wish there was someone on the side to help translate and when I get back home they ask me what was I told ... and I end up giving them a minimized explanation but if there was someone who spoke Xhosa [another mother asks if the doctor speaks Xhosa or English] but he tries to explain to me and I understand a little bit but if someone were to explain it would be better.*

UDX1: *What the lady is saying is true because maybe you aren't available to go with and your mother is an elderly person and they won't understand what is being said. And at least if someone can explain.... And maybe you're at work and they are not used to your mother and she comes to Red Cross, she won't understand and when you ask her what was said at the hospital, she will say no, she didn't hear anything there.*

Several previously-published studies have also noted that medical professionals often lack adequate ASD knowledge and that there is an urgent need for many to receive further training in the wide range of behaviours and symptoms present in ASD (see, e.g., Atun-Einy & Ben-Sasson, 2018; Hutton et al., 2016; Rahbar et al., 2011; Rhoades et al., 2007). As the parents noted here, the level of knowledge evinced by their practitioners provides an important backdrop to their overall experience of contact with healthcare systems. Results from the path analysis reported in Chapter 4 suggest that better such experiences are, in turn, associated with lower levels of psychological distress and better overall QoL in parents of children with ASD. Therefore, addressing the healthcare-related problems that focus-group parent noted may, ultimately, improve their overall QoL.

Focus groups also discussed two other important issues regarding contact with healthcare professionals: the way in which staff in government hospitals and clinics treat parents, and the fear parents have when asking medical professionals questions. However, none of these was discussed in enough depth or by enough parents to meet the threshold for a major theme.

Theme 3: Education-related costs and resources for the ASD-diagnosed child.

Another prominent theme to emerge was that there were long waiting lists to be enrolled in a school with even minimal autism-specific supports (a consequence, in some cases, of a simple lack of appropriate schooling options), that many school staff had poor understanding of ASD and its associated behaviors (and that, therefore, staff required more and better ASD-specific training and knowledge), and that poorer families struggled with school-related transportation issues. Within this major educational theme, however, was a thread of discussion that noted positive aspects of schooling supports within the community.

First, several parents reported enduring a very long process before being able to enrol their child in an appropriate school. Autism-specific schools were reported to have the longest waiting lists.

EF2: *We were on the waiting list for [government autism school's name] since he was 3-and-a-half years, he had his observation last year [current age 9 years; comments from the group: "Shoh, that's such a long wait!"]*.

AP1: *At that point I started immediately to look for a school because I knew that it wasn't going to be easy. I went around to every special needs school, schools for children with Down syndrome, everywhere, wherever there was an autism unit, to find*

placement for my eldest son. I wasn't happy with, um, the resources that they were given, and a lot of the people weren't equipped to work with autistic children, they were just thrown in the mix because that's the only place they had available, so I started my battle to get my son into [school name] school. I would phone every week and I would persist, and I would ask, please put my son's name on the list, but they wanted a referral from a neurologist, so we went to a neurologist and got a referral. Then they said we need more, so we went to an autism specialist, and we got [specialist name], autism specialist. So, we got her also to write a referral and eventually after a 2.5 years wait, [child's name] got into the school and then [second child's name] waited for about almost 4 years and then he got into [school name].

KM1: *And being government schools you have to sit and wait until they have space for you, which eventually your child turns 10, 11 and maybe then starts schooling, because the waiting list is that long, every other 2 years you go for screening, assessment whatever and it takes a year for everything.*

LDX1: *He is going to be 8 years old this year and he hasn't found a school till this day.*

Numerous parents also reported not knowing where to place their children or how to determine which schools or crèches were suitable for their child. For instance, some parents noted that certain schools considered their child either too advanced (verbal and cognitive ability) or not advanced enough (poor verbal and cognitive ability) for the school, which made finding an appropriate school difficult.

FT1: *And there aren't suitable schools, there aren't, because you have that problem, you're either too good or you're not bad enough.*

GR1: *There is already a shortage of these schools, there are a lot of special needs schools in South Africa, loads but unfortunately very few of them are specialised for autism. And autism again - specialised. There are some special needs schools that don't actually cater for autistic kids and will actually tell you, sorry we don't take autistic kids because their teachers don't know how to deal with them, so the few autistic schools that there are, why, why are they not being preserved?*

KM1: *She went for screening at [autism school], [autism school] says she is not autistic enough, so I said ok, so what is she now? So they said but we can't have her here because of this and that and the other thing because other autistic children does this and she doesn't. So I said now where am I supposed to take her now?*

UDX1: *The crèches in the township are not fit to teach our kids because the teachers there will teach only the kids that are able to follow what is being said by them and not for our kids.*

HC4: *There is no place that understands autism, like schools, like autism schools there are none but there are schools for special needs.... If we could [have] autistic schools because we have none in our townships.*

Another major education- related concern was the need for school staff to have more formal ASD-related training and a better understanding of how autistic behavior might manifest within the school structure. Several parents reported that, many times, even autism-specific or special needs schools did not display a comprehensive understanding of the wide spectrum of behaviours associated with autism, and that this made their everyday interactions with the schools challenging. For instance, **AP1** reported on the lack of understanding of the tone and pitch differences in ASD children:

Now that my son is in [school name] there are so many underlying issues and things.... we've been kicked out of the school because my sons were too loud. They autistic children, it's an autistic school, so I don't understand why it's an issue, because for 3 years it wasn't an issue.... I just heard from the therapist, you're not allowed on the school property anymore, you have to wait outside in the park, which I took great offence to."

LW3: *I found the teachers at (school name) are not, not all of them are really equipped to deal with the kids either. [Another mom: "I fully agree with you."] Yes it's a wonderful school, but there are teachers that shouldn't be [teaching] the special needs kids.*

MF3: *Grade 2 started a rather severe downhill decline where his teacher turned around and said to me, oh no he couldn't possibly be on the autistic spectrum, because he doesn't react when I move a poster from one side of the room to the other. I looked at her and said, so the thing is, the paediatric neurologist who diagnosed him then was wrong. And she looks at me and she says, "Oh was it an official diagnosis?". ... From a service point of view, it would be very helpful if special needs teachers understood that they were teaching special needs children.*

DR2: *I think this is the biggest problem, is, teachers and social workers are not taught that this is autism, this is what, these are the signs to look at, your child is badly behaved, your child is naughty, he's having meltdowns because you let him away with stuff.*

CY2: *And you go to a school and you want to place your child in the school and you've got to tell this teacher, "Well my son's got autism or my daughter's got autism." And they're like "Oh what's that?" You're a teacher, you've studied, and you're telling me you don't know this word autism? Me, a parent that's never studied, I can tell you what it means. It shouldn't be like that.*

Parents from poorer socioeconomic backgrounds reported that transport to and from schools was problematic. They raised issues concerning the expense of transport, a lack of buses for certain areas, long waiting times and distances travelled, a lack of understanding of ASD behavioural difficulties associated with changes in a routine (e.g., inconsistent pick-up times, changes in pick-up points).

GY4: *They making you stand for an hour and the drivers going be late, and this child is going to perform, and he's shouting and screaming and tapping ... you think they know they have routine.*

ESX2: *You see now the child will even wet themselves because he is not able to say 'I want to go to the toilet,' he's not able because the bus is taking long and it's going to different places.*

YAX2: *My problem is transportation the school transport leaves very early. We are not near the road so the child needs to wake up very early. For example, now that it's raining its wet and the place that we need to wait is bare and it will rain for about 5 min without a place to take shelter, the rain just pours on you. The child will drive by bus and they wet. This does not make me feel well by the time you staying at home your mind is thinking that my child is wet maybe they have fever. Almost twice a week he is not able to go to school to show that he gets fever, even if it does not rain it's cold that does not sit well with me and does not make me feel well a lot.*

NXX2: *You see if [special needs school] has their own autism bus, they should tell us because this thing it's going to be hard, because they have to drive around picking [all children, not just autistic children] up everywhere ... [names five different townships] ... it's this mix everyone you see (especially all of us) everyone in the same bus ... it goes to all the areas, if we wait for the autism bus it picks up everyone because its only 1 bus for autism.*

Even outside of these transport-related issues, several parents reported incurring large financial expenses associated with their child's education (at government and private schools as well as autism-specific and general special needs schools).

DR2: *[Finding an appropriate school is] very expensive. Very, very expensive.*

AP1: *And at the moment [government school name] is an affordable school because it's not as expensive as the other schools but with the increases and the resources that are thinning out, because like our sons used to have yoga, eurhythmic & judo every single week and now it's every second term. So the resources are also becoming more and more scarce because they cannot afford these things and finance is a big question because obviously they are retrenching people because they don't have money which means the parents need to pay more money and we are paying about ZAR1180 per child at the moment and I have 2 there, so if it goes up anymore, it could be a down payment on a car.*

GR1: *There's loads and loads... even some of the best schools, private schools, some of those, we have done the math, there's no freaking way that you can charge that amount of money.*

CY2: *So all the private schooling that's helping these kids are so expensive that the kids that are unfortunately living in like poverty and that, they just stuck with this disability and I find it's really, I find that's really sad, whereas the government could do a lot more knowing that Johannesburg is supposed to be like a, capital city, with the best facilities and the best resources and that.*

MF3: *And I am now paying a small fortune to have my child educated in a way that he can actually absorb.*

Despite the many concerns parents had about educational costs and resources, a strong sub-theme emerged regarding positive aspects of the schooling system (e.g., inclusive schooling, where autistic children have the opportunity to interact with children with other developmental disorders and challenges; multi-disciplinary schools that offer access to various forms of health support, such as speech therapy, occupational therapy, and psychotherapy).

HB1: *The other thing I wouldn't change is inclusive schooling, like [school name] and things like that, I know there's the white paper and all that sort of thing. But I really think ... I mean for one for [child's name] to actually be at a school with other children who tick the same way he does. You know maybe he will strike up a friendship with one of them and that, I mean would be amazing. He's not going to be the odd kid out, he's going to be the group down there that plays Star Wars all day. Because there are 25 of them or 30 of them, I mean that's awesome.*

RF1: *School primary ... my daughter's there and they are, their whole philosophy, because it's an inclusive school, their whole philosophy is acceptance of people with differences. Even their big, grand school play was all about that. And it was, it's just remarkable, and they just bond with children that are, that have got different issues.... [t]he inclusive schools are fantastic, they are mainstream*

schools but they ... [a]nd there, they write their exams in a separate room which is slightly quieter.

JL2: *And it was fine, it was great, he was having it fine. Getting on with all the other kids, it was a small class of 8 students, and they have OT and they have speech therapy etc. etc. And I thought this is great.*

CY2: *But if I can say one thing the school ... So you can go with a peaceful mind to work, you can come home, you can miss them, you can enjoy, they don't maybe talk about their day but you just got this peace that your child is safe, they're, getting their therapies on time, you don't have to run around for them and confuse him on what's happening.*

Although the parent reports presented in Chapter 4 were consistent with the current narratives in describing positive aspects of educational settings, previously published ASD literature discusses problems with educational costs, resources, and teachers' knowledge of ASD far more frequently (see, e.g., Barned et al., 2011; Stoner et al., 2005). For instance, Montes and Halterman (2009) reported higher levels of dissatisfaction with educational resources for parents of children with ASD in comparison to children with general special needs. This focus on poorly-resourced educational settings is justified to at least some degree, because, as indicated in the Chapter 4 path analysis, better educational services are associated with lower levels of psychological distress and better overall QoL in parents of children with ASD.

Within the focus groups, parents also discussed various other important issues regarding educational costs and resources (e.g., the lack of facilitators for children in the classroom, teachers and other school staff commenting on the need for medication, the lack of money and funding for schools). None of these was discussed in enough depth or by enough parents to meet the threshold for a major theme, however.

Theme 4: ASD-targeted interventions—costs and parent training. A less prominent but still important theme related to two practical considerations surrounding interventions: their cost, and the need for parents to receive training so that they might provide auxiliary home-based therapeutic support.

FT1: *He went with a facilitator which literally took my entire salary every month and my husband's medically boarded, so I said I'm sorry but this has to stop, he can't keep going to a mainstream school.... And facilitation costs a fortune [lots of agreement from other parents], it's ridiculously expensive. Crazy.... [F]acilitation plus speech therapy, plus OT plus the psychologist took my entire salary [agreement from others].*

GR1: *I know of people that have bonded their homes to pay for their children's [others agree].... [T]he problem is, the treatment for autism is not covered by medical aids and that is a major problem as well because all the other conditions are, are covered by medical aids and stuff but autism isn't [agreement from others] ... the amount of money that medical aids pay out on prescription drugs, it's astounding but then you ask them to pay that couple of Rand for your weekly session, no no no, we can't do that, it's not part of our ... that is also another problem.*

HB1: *All the therapies. People spend a fortune getting DNA profiling ... and millions of blood tests and this and this and this to tell you things about your child that actually you see every day. So I mean ... and people spend an absolute fortune on it. I mean I have a friend who has said look, if you want to throw your money down the drain, do this but I have done it and it's a complete waste of money. I said well thank you then I obviously won't go down that road.*

Several parents felt it would have been beneficial for them to receive some intervention-related training (and for that training to be reasonably priced), or for healthcare professionals to better explain therapies to parents so that there would be better continuity across settings and, potentially, greater improvement in outcomes. Some parents reported having received such training and noted the benefits it had for their child.

HB1: *What would also be nice is if there was a ... parent education that there would be some sort of allowance for a parent to work part-time to be able to facilitate your programme with their child. That there would be some sort of government financial support or something so that if you are a parent of a child on the spectrum, you can actually then be trained to be your child's carer until such point as they can join formal education.... But if there are no schools for them to go to, that there's some*

system in place that parents can stay at home in the meantime. Or even as parents, I mean the amount I know now I think of how much work I could do with other people's children until such time. You know just for 3 or 4 hours in the morning—give the parent a break because of what I've learnt in my experiences with my child.

FT1: *When I went for the facilitation training, I was the only parent there, OK. And it just so happened that the guy who was giving the training happened to be my son's child psychologist ... and not enough parents are aware of the fact that you can actually go and do facilitation training. And that it isn't just for a facilitator, you can learn how to train, how to work with your kids yourself. Because I was desperate!*

ESX2: *I don't want to lie the way they do things at the speech, for I wish there was another way of showing me how to pronounce or say words, but this thing that he needs to learn to point at things to me it seems like it's the very thing that makes him 'dom' [dumb, stupid].*

These parent reports are consistent with previously published literature in suggesting that ASD-targeted interventions and therapies present an enormous financial burden for many families (see, e.g., Jarbrink et al., 2003; Liptak et al., 2006; Sharpe & Baker, 2007). What appears to be necessary are more parent-assisted therapies and interventions (for a review, see McConachie & Diggle, 2007). For instance, Tonge et al. (2014) compared the effectiveness of a parent education and counselling (PEAC) intervention, a parent education and behaviour management (PEBM) intervention, and no intervention. Each group consisted of 35 parent-child dyads, with the children (age range 2.5 – 5 years) all diagnosed with pervasive developmental disorder (PDD). Outcome variables were derived from scales measuring the child's adaptive behaviour, emotional and autism behaviours and symptoms, and cognitive and language development. The observed data suggested that children in the PEBM group showed marked improvement in adaptive functioning, behaviour, and communication in comparison to the PEAC and control groups. This pattern was particularly true for children with greater communication delays. Wider application of such interventions might ensure that more children receive effective support at an earlier age.

Focus groups also discussed three other important issues regarding interventions: the wide range of interventions available (this was primarily raised by higher-income parents), the need for more interventions to be made available (this was primarily raised by lower-

income parents), and the wide range of prescribed medications and potential over-medication of the child. However, none of these was discussed in enough depth or by enough parents to meet the threshold for a major theme.

Theme 5: Transitional services available to ASD-diagnosed young adults post-schooling. Several parents complained about the lack of services and information available to young adults after they leave the schooling system. This was a clear concern that left many parents, especially those whose children were approaching school-leaving age, feeling uncertain. Some were also concerned about what would happen if their child was unable to obtain steady employment and a stable income.

NT3: *There where I see the system is lacking because there is nothing for them when they leave school, there is nothing.... So you try this workshop, no, don't want to go there because somebody confronted about something and put them on the spot like oh you haven't performed well enough, ooh, self-esteem, shut down, go off, don't go back. So no they sit at home and they depressed, frustrated, angry.... So it's all those issues become unemployable as it is and yet there's nowhere for them to go off the streets where I think even parents would be prepared to pay somebody to take them. There are a couple of places like [name of support place] and places like [name of support workplace] but they difficult to get into, there's a waiting list, and then they get into there and then they don't like it and then there's, there's not much else to go to and then it becomes now what parents going to do, where do they stay, where do they live for the rest of their life, till they 60 or 70 or till they die, I don't know.*

MF3: *[A]nd who takes care of them when you gone.*

FT1: *That's my main concern that these little NGOs that have sprung up, that's where [child's name] is at the moment. She is now focussing on, her main focus is what happens to these kids when they leave special schooling. It's all fine and well to have services up until school level, what happens to them afterwards? Especially your high-end functioning kids. What happens to them? Society won't take them because they're not normal, uhm ... what do you do with them? Where do they go? You can't stick them in workshops for the rest of their life packing boxes and whatever. I am not saying it's a bad job, don't get me wrong, but, there are kids out there, I mean like my child, and I've seen it in the home, where there is a child who is, well he's not a child,*

he's 23, incredibly high-end functioning kid. What do you do with him? Where do you put him? Where does he go to work?

GX4: *[A]nd what [school name] is also doing at the moment, when, when your child is like 14 or 15, in the week they start taking these kids to these places and they go work there for an hour or two, just to prepare themselves when they 18. You know, things like that.*

CY2: *But if he wants to go further and study, then you know he, obviously, I don't know what these facilities, if they accept kids like that, which is also another thing, because you don't know if your kid will, be able to get into, a good university or technikon or whatever Are there facilities for these kids that, you know, they can learn to become something, or, is it just going to be a sake of like, workshops where they go and learn to use things and make things with their hands and that. And, so far nobody's come up with anything that we know about, and I know we think in long term but you got to, today you've got to plan for your kid's future so that you know he's going to be well looked after, because these kids actually need our attention 24/7, you can't leave them alone for one second, and, it's difficult because you've got to work, you've got to have your house life in order, and what if you got other kids as well then you've got to make time for everybody.*

UDX1: *Our biggest fear is what will happen when they grow up? Or in case as a mother you get in to an accident... there is no one else to look after him or who understands him.*

LDX1: *Some others are like my child who has autism will grow up one day and what will happen to him/her because, I even say that I wish, and I've never seen an elderly person saying they have autism but my mother says there has been a person who works at the department of autism and has seen them, but I wish I could see them with other people and for me to ask them ... and my child will have to grow and maybe work and how or what will happen to his life.*

There is little research in the ASD literature on services available to young adolescents in transition from school to secured employment and independence. The few

studies that do address this topic suggest there is an ever-increasing need for such transitional support services (Shattuck et al., 2011; Taylor & Seltzer, 2011; Taylor et al., 2012).

Moreover, one study suggests that young adults who receive early support and services (e.g., vocational training) secure better employment in comparison to those who received support later (Cimera et al., 2013). Therefore, the current concerns surrounding the lack of post-schooling information and services are consistent with what is reported in the literature and represent a marked area of need.

Focus groups also discussed two other important issues related to this theme. These were (1) the types of workshops, employment, and housing available to adults with ASD, and (2) the expenses parents or family members incur when the autistic adult takes up that offer of housing or workshop employment. However, neither of these was discussed in enough depth or by enough parents to meet the threshold for a major theme.

Theme 6: Impact of the child's ASD diagnosis on everyday family life. Many focus-group discussions centred around the strain a child's autism diagnosis places on the family's financial wellbeing, and on post-diagnostic parental need for emotional support through ASD support groups. Although this theme was not directly related to service delivery experiences, parents often traced a line between financial consequences and quality of everyday living, and between available finances and quality of services they were able to obtain.

Many parents noted that therapies and interventions were expensive and that further financial burdens were incurred due to the necessity of buying specialized equipment or other child-related supplies (e.g., diapers for an older child that is still not potty trained). Twinned with this was a need to cut down on working hours (or to leave their jobs altogether) in order to have more time to care for the child.

XV3: *I gave up my job a year ago and have been at home for a year now and I just decided to do it to be a more hands-on mom with [child's name] and it's worked out quite well for him. You know I mean I'm a bit straddled at the moment because I'm going a bit off my rocker but I'm trying to keep busy with things, you know.*

MF3: *Well mom pays for everything, so um, so... ja, um, the fact that it's all private, all the stuff that's actually available and relatively easy to come by is all private. Um, and the thing is, when, if you got an appointment with a pediatric neurologist you literally have to take a whole day off because you have got to get to the other side of*

the world, you've got to wait there, and invariably they run late and then you go in and you've had the appointment and now you've got to take the child back to school or you can't take the child back to school because it's too late ... and my leave days are used up by doctors, school, teachers meetings, that's how I take my leave.

AP1: *Which cost an arm and a leg and because there was no day care facility that would take my child, because he was non-verbal, he was severely developmentally delayed. I had to go leave my job and stay at home which meant we couldn't really afford all of the speech therapies and all of those other things that we needed, so it was a catch-22 situation where either I go to work and put my child with someone who isn't equipped to help him, or, I go for training myself, stay at home, but we can't afford the therapies and things. So it was a terrible time to go through, knowing that there was a price tag on the health that your child is going to receive and if you don't have money that he won't have the opportunities that he deserves to have.*

KM1: *Um I stopped working, stayed at home because she was non-verbal... I mean to pay almost R1500 every month, me not working, daddy working alone, um we have another baby, which [child's name] is not potty trained, it's all that you have to take into consideration. Buying nappies, doing this, everything is too expensive.*

NXX2: *I had to stop my studies and leave everything behind. I could not find school and studies and it was the stop of my future completely.*

LPX2: *When you stop working you still need to spend money for your child going all over the place, you depended on the grant that is only R1400, and you not working and the child is still on nappies do you understand that nappies how expensive they are?*

Several participants noted that, because parents with an autistic child face many daily stressors and challenges that negatively impact their quality of life, they need and seek out sources of emotional support (e.g., from fellow parents or others who understand their situation). Parents from high-middle SES as well as low-SES communities both discussed this need. For instance, some from the former group reported:

GR1: *You're 100% right, parents need to form support groups In the end I think the biggest support lies with parents, parents have to support one another and share. And if you're not on [social media] really really really get onto [social media], there are incredible support groups on [social media], really ... even if you just join under an alias name if you want your privacy But um, really there are volumes and volumes of information and understanding and it's people that have walked the same journey.*

PL1: *So I come home and I can actually see it now, my son is 13, my daughter struggles with him, there's no support because now she has a brother who has this, and he has it so she almost tries to grow protective to some extent. You as a couple also go through it at home, blame, kind of what went wrong? Why us? What did we do? You go through that whole process, there is no one to support you with that, you're literally just the two of you, um you don't where to go, who to speak to. And even if you have a lot of money often maybe you Google stuff and go onto the Internet and you're able to pay for these things but you rather want to hear from the mouth of people that actually experienced it because often sometimes these people they give you this one story, this one tells you this, that one this, you get all this conflicting messaging. So where do I go now? What do I do? And so there's no [support].*

VT4: *Support groups are hugely beneficial ... it's a way to make friends within that school community.*

DR2: *I do feel that who do you call on. Who do you pick up the phone and say, "Hold on a second, my son's having serious meltdowns, he's going through a difficult time. I need help."*

MF3: *What I think would actually be a lot more useful is to actually have specific support groups for parents in a specific area There's no like, you know what guys, I don't want to have a workshop I want to have a coffee day, 2 hours where we can sit and cry if that's what you feel like you need to do. That would actually make life a lot more bearable I think because also you get to feed off what other people are doing But that information that you gain from other parents, I find that it is actually more valuable than what you get from professionals [other comments of agreement]*

because they all there waiting for the check, and they going, ja well this is what you need to know. No it's not, I know that already. Or, it's not relevant for my child. I don't want to know about that, I need to know about how do you manage with your child who is going through puberty who actually isn't ready for it because I've got the same problem.

Parents from lower-SES communities expressed similar feelings, but also noted the need for more support (particularly in the area of counselling) given the daily stressors (e.g., the limited services available in their neighbourhoods, and the costs of accessing those services) they faced.

YAX2: *Our support group is far from us you see [township name] meets there, all of it. I am not sure whether its Site C or the rest of [township name] that meets there. I am not sure because I stay in [township name] but others stay in [another township name] yoh its big. And then the place its full but if [township name] people had their own place to meet and [township name] people also you see If we could have our own person where we meet. You see if we were to have smaller gatherings and have own person looking after us ...*

TRX1: *We don't even have counselling we just have support groups and no ask how you feel.... Even at [special needs school].*

ESX2: *I think you need go through counselling continuously it's not easy, you need someone to talk to we really desire it.*

LDX1: *And worse in support groups, let us say in [township name] and the taxi costs R20, I wish the people from [two township names] could be looked after as well. Like maybe they get given R30 so that they can make it to the support group. And those support groups aren't always helpful because they maybe only six people but if ended up filling them and maybe we could get government officials to come listen to our qualms and show him that we have children and then maybe they could help us.*

As noted earlier in this section (Theme 4, particularly) and in Chapter 4, participants in the current studies indicated that the ASD diagnosis has enormous financial implications

for parents and families. Expenses related to, for example, interventions, therapies, special schooling, and transport to and from medical appointments and other activities negatively impact the family's day-to-day functioning. This result is consistent with numerous reports in previously published ASD literature (see, e.g., Jarbrink et al., 2003; Liptak et al., 2006; Sharpe & Baker, 2007; Wang et al., 2012). Current suggestions that there is an urgent need for better emotional support for parent's post-diagnosis is also consistent with previous reports (see, e.g., Banach et al., 2010; Law et al., 2003). Given the negative association between service delivery experiences and parental psychological distress and QoL in the path analysis (Chapter 4), services focused on providing additional emotional support might be a crucial factor in helping to alleviate psychological distress and, in turn, improve parental QoL.

Focus groups also discussed three other important issues related to this theme: (1) the need for services (perhaps based at hospitals, clinics, or schools) that could help parents from low-SES communities to toilet train their child, (2) general transportation problems (e.g., a child with ASD needing to sit in a specific seat in the taxi to avoid a meltdown), and (3) the need for better housing for children with ASD (specifically, houses with fenced-in yards, flushing toilets, and safety measures against flooding and fires). However, none of these was discussed in enough depth or by enough parents to meet the threshold for a major theme.

Theme 7: Increasing ASD awareness. A prominent concern for many parents was the lack of ASD awareness in their community. Many reported that this lack of awareness, which might be regarded as a passive ignorance, sometimes bridged over into active stigmatizing of the affected child (see similar reports in Chapter 3). Hence, participants felt that more awareness could lead to greater acceptance, and that that would have a positive practical impact on their quality of life (e.g., they would feel less trepidation when going shopping with their child or when meeting with friends and family).

CY2: So I just feel the awareness should be, put out there a lot more, like cancer, and AIDS and all of those things, it's a disability. It doesn't have to be a disability, but we'll call it a disability for our kids so that, we can all, like she said, even us adults, we don't know if we've got it, because when we were kids that was never a thing.

FT1: It's a lack of awareness ... [P]eople have no idea what autism actually is. People need to be educated as to exactly what autism is.

KM1: *Even certain areas that we live in, like the area that I live in, people don't even know the word autism so if you tell them she was diagnosed, it's like oh my word, they start panicking out and that its contagious and why do you bring your child out here and stuff like that.*

GR1: *There is stigma, there is stigma attached to autism because many years ago, unfortunately, there was still a train of thought that it was something that the parent did that caused it and we're talking back in the day of Dr Asperger, in those days it was actually a believed that a cold mother a frigid mother.... Because, I'm not saying, I mean I really, I've never come across anybody that's said to me, so what did you do wrong but I think there is still a bit of stigma attached but by the same token, this is embarrassing to say, but this is my position ... before my kids were diagnosed autism, I didn't know what the hell it was.... Awareness, parent awareness, that is something you have to do.... [W]e had, we had family that had said our children are autistic because we atheists and I said, and I said to her, you know what I said to her; so what about all the Christian children.... She was dumbstruck.*

LPX2: *A lot of people do not know about it, a the child will just cry in the mall and close his ears, people will comment and at how naughty is this child [others comment "they will say you do not discipline your child , you do not give hidings"] the child will pour Coke on you and looks at the Coke and get absolutely hysterical, in your mind you just want to buy basics but his mind is on Coke near the till and everyone is looking at you, because their child does not do that.*

UDX1: *It's hard to explain when your child has autism because when you try to explain, they will start telling you about a cousin's child when they can't speak can still behave and when I try to explain that no, it's not that he can't behave it's just that he has autism. They will be like no it's your fault and the whole community will agree to that, it's hard even. Like even when I go to the bus there will be a girl eating chips next to me and my child will just grab the chips and I will reprimand him, and he listens to me when I reprimand him and she says, no there's no problem he can have the chips and when he sees someone else with a vetkoek, he does the same thing and grabs it, then the same girl who said he can have it starts saying, what's up with*

this child who has no respect? He just did the same thing to me with my chips. So it's hard to explain and it is difficult.

Several parents, particularly those from low-SES communities, made specific recommendations about how local and national governmental and non-governmental bodies might go about raising autism awareness. These recommendations included a central online data point where parents could go to read about the manifestation of autistic symptoms, common co-morbidities, and local resources; documentaries and television shows broadcast on government television channels (i.e., freely available channels); and public service announcements broadcast widely over different forms of media.

LDX1: *It would be nice if the government would make a documentary or a show on TV that shows everyone that there is such a thing as autism in South Africa and they behave in this manner.... So that it will quickly educate people because you could be giving out pamphlets and no one will read them.... So, I hope they will make a documentary or a radio show that will play so that people will be able to relate with our children.*

YSX1: *I think TV advertisement it can be much better if they do a documentary but on one person and they visit the house and then they can see it's not just one child there are many in South Africa. So I think it would be better if they watching TV.*

MF3: *[A]t the community health clinics they have a continuous loop of educational videos going. I ... just a thought that, that would be ... instead of always TB, HIV, maybe include in that something on autism, act out a few scenarios.*

GR1: *We need a central data system with training, with courses, that's updated.... And we don't have to reinvent the wheel, that's why we have got [local NGO], we need to get in touch with them to say, can you please give us an updated database with training and put us on a mailing list to get this information, so that we don't miss out on it.*

Globally, raising awareness and encouraging acceptance of autism is one of the primary aims of many NGOs and support groups (see, e.g., Autism Act (NI), 2011;

Combating Autism Act, 2006; Dillenburger et al., 2013). There are, however, questions as to whether campaigns led by these bodies have been effective and whether the focus of the awareness campaigns are beneficial for ASD-diagnosed individuals (e.g., campaigns that frame all aspects of autism as negative and as deficits rather than providing information for optimising autism might do more harm than good in some ways). The data reported here suggest that, in the experience of our participants, South African NGOs and support groups have not succeeded in their aims of increasing autism awareness and de-stigmatizing ASD and thereby ensuring that affected children receive the best possible support and achieve the best possible outcomes.

Limitations

The current study has two prominent limitations that might affect the external validity of its findings. First, despite the fact that all of the Study 2 participants were invited to join the Study 3 focus groups, no parent in any of those groups had an adult child with ASD. Hence, it was not possible to address issues specific to adults with ASD (e.g., post-school services) in any sort of detail, even when parents anticipated that their children would be faced with those issues eventually. To obtain an in-depth and better understanding of what services are (and are not) available to adults with ASD, and how that (lack of) availability affects the family, future research studies must recruit parents of adult children with ASD.

Second, most of the questions posed to the parents during the focus group sessions asked them to reflect on service delivery challenges, shortfalls, or negative experiences; only two of the 10 questions asked about positive service delivery experiences. As noted in the reflexivity section of this chapter, this bias toward negativity might be attributed to my previous interactions and experiences in the field and with families of children with ASD. Hence, the current data might not be an accurate account of when, how, and where parents experienced effective and efficient service delivery with regard to their autistic child. Future research should include more questions framed positively (e.g., “What has worked well in service delivery?”) so that a bias toward negativity is avoided.

Summary and Conclusion

This qualitative study, with data derived from 33 parents of ASD children assigned to 6 separate focus groups, highlighted seven prominent themes characterising problematic aspects of ASD-associated service delivery within South Africa. The themes revolved around service delivery challenges related to the diagnostic process, contact with healthcare professionals, educational resources, interventions, post-school services, impact on daily

living, and ASD awareness and support (i.e., in numerous major facets of service delivery). Parents indicated that these challenges have a negative impact on their families, generally, as well as on their ability to provide their children with optimal support and care, specifically. Given that the path analyses described in Chapter 4 demonstrated a significant association between poor service delivery experiences and poor QoL, targeted improvements at multiple service delivery levels are essential to help improve the daily functioning of parents with ASD-diagnosed children (and, thereby, of ASD-affected families as a whole).

CHAPTER 6: General Discussion

The current dissertation had two specific aims. The first was to describe the services available to individuals diagnosed with autism spectrum disorder (ASD). The second was to examine the impact service delivery experiences have on quality of life (QoL) in adults with ASD and in parents of children with ASD. I investigated these aims across three studies, each written up in a separate chapter. In Study 1, I collected and analysed quantitative and qualitative data from a sample of adults with ASD ($N = 15$). In Study 2, I collected and analysed quantitative data from a large sample of parents of children with ASD ($N = 200$). In Study 3, I collected and analysed qualitative data from a smaller sample of parents of children with ASD ($N = 33$).

The central rationale underlying the current investigations is rooted in the heterogeneity of the ASD phenotype. Diagnosed individuals present with a range of complex behavioural, cognitive, and emotional challenges. This varied presentation requires a range of carefully-considered and appropriately-tailored services and resources. When such services are delivered efficiently and effectively, they may aid in improving the everyday functioning and overall QoL of both the diagnosed individual and his/her family.

However, the current literature on service delivery to ASD samples, and service delivery experiences of ASD-affected individuals and families, is limited. For instance, there is a lack of comprehensive examination of service delivery availability and experiences. Most studies tend to focus on discrete services (e.g., those related to the diagnostic process, or to educational resources), rather than focusing more broadly and holistically. Because individuals with ASD typically require several different kinds of services across different stages of development and within different domains of functioning, any study that focuses on only one kind of service is problematic as it, for instance, ignores interrelations between service delivery experiences.

Similarly, there is little comprehensive and holistic research examining QoL of ASD-affected individuals and families. Although several studies examine individual aspects of QoL (e.g., depression, anxiety, stress, social support), few use comprehensive measures of the construct. This approach is also problematic because literature suggests that ASD individuals and their families face numerous sources of psychological distress; focusing on only one aspect does not allow for a complete understanding of their struggles or of how different sources of distress might interact. Without such an understanding, it is difficult to

determine which particular aspects affect overall QoL negatively and which might therefore require more urgent support and intervention.

Furthermore, almost all of the extant literature on service delivery experiences or QoL in ASD individuals or in ASD-affected families emerges from high-income countries (HICs) of the global north and hence is focused on samples resident in those countries. These studies do not, therefore, describe or consider the additional infrastructural, healthcare, and environmental burdens facing families from low- and middle-income countries (LAMICs), and how those might affect service delivery experiences or parental QoL. If policymakers are serious about implementing change and optimising services across the globe, such description, consideration, and investigation is essential.

Given this background and the clearly identified knowledge gaps, the specific aims of the current dissertation were to examine, using South African samples, (1) psychological distress and overall QoL in adults with ASD, (2) services available to, and service delivery experiences of, adults with ASD, (3) psychological distress and overall QoL in parents of children with ASD, (4) service delivery experiences of parents of children with ASD, and (5) relations between parental socioeconomic status (SES), parental psychological distress, child ASD severity, and service delivery experiences, and the influence of all those factors (independently and collectively) on parental QoL. The novelty of the studies contained within the dissertation is threefold: First, I used comprehensive measures of both service delivery and QoL; second, I sampled participants (both ASD-diagnosed adults and parents of ASD-diagnosed children) from a LAMIC population that featured varying levels of SES; and, third, one of the studies uses path analysis to examine direct, indirect, and interacting influences of SES, ASD severity, aspects of service delivery, and psychological distress on parental QoL.

Study 1

A key aspect of this study's novelty was that, unlike most published studies in this field, it examined multiple aspects of service delivery and psychological distress in adults with ASD. Previously published service delivery studies have tended to focus predominantly on employment and independent living, with a lack of focus on other aspects (see, e.g., Howlin et al., 2005; Shattuck et al., 2011). Similarly, previously published QoL studies have tended to examine individual aspects of psychological distress, such as anxiety and depression, rather than using comprehensive measures of the construct (see, e.g., WHO, 1998). Indeed, only 5 prior studies used the same widely accepted and comprehensive

measure of QoL (the WHOQOL-BREF) as I did here (Jennes-Coussens et al., 2006; Kamio et al., 2012; McConachie et al., 2018; Saldana et al., 2009; Renty & Roeyers, 2006). All four of those studies reported relatively poor QoL in adults with ASD, particularly in the domain labelled social relationships.

The first set of findings indicated that South African adults with ASD reported relatively high levels of psychological distress (stress, depression, and anxiety) and lower levels of perceived support, both of which were independently and significantly associated with poorer QoL. High levels of psychological distress, poor QoL, and an association between perceived social support and QoL has been reported previously in the literature (Ghaziuddin et al., 2002; Gillott & Standen, 2007; Sterling et al., 2007; Stewart et al., 2006; Renty & Roeyers, 2006a).

This first set of findings from the current study illustrates two important aspects of the psychological functioning adults with ASD. The first is that adults with ASD appear to face numerous everyday challenges that can affect their daily functioning. Hence, future research should explore their emotional functioning, particularly with regard to social relations. The second is that one way to improve the overall QoL of adults with autism is to develop directed supportive interventions and therapies that focus on decreasing their levels of psychological distress (e.g., by using cognitive-behavioral frameworks) and increasing their levels of perceived social support (e.g., by assisting them to obtain better assistance from their immediate families and surrounding communities).

The second set of findings indicated that South African adults with ASD report several challenges related to service delivery. Both qualitative and quantitative data sources suggested that these challenges included (a) a lack of understanding of ASD by medical professionals which led to incorrect and delayed diagnoses, multiple referrals, and numerous (sometimes incorrect) medication prescriptions, (b) a limited range of available and appropriate interventions and therapies, (c) financial burdens associated with interventions and therapies, (d) limited one-on-one instruction and other appropriate interventions at schools, (e) a lack of employment training, supported employment programs, workplace adjustments, and career development, and (f) ASD-associated stigma within the medical field, workplace, and daily activities. These findings are consistent with previously published studies focusing on service delivery in adults with ASD (see e.g., Cimera & Cowan, 2009; Crane et al., 2016; Gantman et al., 2012; Hendricks, 2010; Hillier et al., 2007a; Howlin et al., 2005; Laugeson et al., 2015; Lorenc et al., 2017; McVey et al., 2016; Nicolaidis et al., 2015;

Obeid et al., 2015; Sharpe & Baker, 2007; Shattuck et al., 2012; Sheinin, 2006; Taylor et al., 2012).

Amongst this wealth of negative qualitative reports were two positive statements regarding service delivery. First, several respondents noted that ASD-specific support groups had a positive impact in the community. Second, some respondents indicated that their employers had made physical adjustments to their workplaces so as to accommodate sensory challenges.

Relevance of the findings. This is the first study to comprehensively examine the psychological functioning and QoL of South African adults with ASD. These findings, although they must be cast as preliminary in nature, indicate that autistic adults from a low-to middle-income country (South Africa) experience psychological distress and relatively poor quality of life. Although these observations are similar to those described in previously published reports from high-income countries, families in LAMICs experience additional burdens (e.g., higher levels of poverty, less reliable access to adequate healthcare) that may impact their psychological functioning and quality of life; hence, research from HICs is not entirely comparable. Therefore, when examining psychological functioning and QoL of adults with ASD who reside in a LAMIC, factors such as the quality of service delivery and level of SES are essential to consider.

Taking this fact into account, the second novel aspect of the current study was a comprehensive examination of service delivery experiences in adults with ASD. The current data, indicating multiple challenges regarding service delivery, were also consistent with previous findings emerging from HICs. This consistency suggests that regardless of the a country's income status, ASD-related service delivery is problematic globally. With specific regard to South Africa, again no study has examined what services are (and are not) provided to adults with ASD. And given the reported psychological distress and lower levels of QoL, lack of research focusing on services that may provide the required support to elevate such distress is concerning.

Importantly, the second novel aspect of the study, with a focus on service delivery, suggests there is a marked overall need for better and more appropriate services for autistic adults in South Africa. The fact that multiple problematic aspects of service delivery were noted bears a marked similarity to previously published reports, but it was notable that in the current study (unlike in previous studies) adults with ASD reported a dislike for applied behavioural analysis (ABA) as an intervention and questioned its appropriateness for ASD

individuals. They advocated for the consideration of other approaches, such as forms of cognitive behavioural therapy.

Thus, the importance of such comprehensive examinations into psychological distress, QoL, and aspects of service delivery in adults with ASD was three-fold. First, areas of psychological distress and poor QoL were identified and those that are supportive and beneficial recognized. Second, the major shortfalls as well as the beneficial aspects of service delivery were elucidated. And third, with such comprehensive knowledge, policy makers and service delivery providers can identify shortfalls and implement directed change in the areas that most require it. Therefore, if appropriate services are made more readily available and if the required support is provided, it is possible that autistic adults in this country will experience improved mental health and better overall quality of life.

An interesting aside here relates to a particular language issue. Qualitative observations during interactions with the adult participants on topics of psychological functioning and service delivery made it clear that they preferred identity-first terms (i.e., *ASD adults*) rather than person-first terms (i.e., *adults with ASD*). This identity-first versus person-first dichotomy is a topic of serious debate within the field. For instance, text on an autism advocacy page (Autistic Self Advocacy Network [ASAN]; <https://autisticadvocacy.org/about-asan/identity-first-language/>) noted the preference for terminology such as “autistic” or “autistic individual” by individuals formally diagnosed with the disorder because autism is an inherent part of their identity. However, the same page noted that parents of children with ASD and healthcare professionals often use the terms such as “child with autism” because they want to emphasize that the humanity of the diagnosed individual supersedes any medical identifier.

A recent review article by Botha (2021) noted that although there is no clear consensus in the literature regarding the preferred use of language by autistic individuals, the use of specific person-first language (e.g., *person with autism*) was regarded as the least preferred and most offensive when addressing autistic individuals. The review also highlighted a study by Bury et al. (2020), which noted that whereas “autistic person” was reported as being the most preferred term by autistic individuals themselves, the term “on the spectrum” was regarded as the least polarizing.

Study 2 and Study 3

Study 2 investigated the same research questions as Study 1 but used data from parents of ASD-diagnosed children. Again, I adopted a more holistic approach to questions around service delivery experiences than prior studies had done. Previously published ASD literature on service delivery to children has tended to focus on individual aspects such as the diagnostic process (see, e.g., Brett et al., 2016; Dymond et al., 2007; Jarbrink et al., 2003; Karst & Van Hecke, 2012; Mandell et al., 2005; Renty & Roeyers, 2006b; Shattuck & Grosse, 2007). For instance, some findings note that parents experience a long diagnostic process with multiple appointments and referrals, poor communication between caregiver and professionals, and the lack of feedback post diagnosis (see, e.g., Crane et al., 2016; Daley, 2004; Goin-Kochel et al., 2006; Osborne & Reed, 2008; Siklos & Kerns, 2006; Young et al., 2003; Wiggins et al., 2006; Young et al., 2003). I gathered comprehensive information regarding multiple aspects of service delivery using a similar instrument to that employed in Study 1. Adopting such an approach allowed inferences about the multiple different and interlocking aspects of service delivery that might require improvement to ensure children with ASD receive appropriate and optimal care from as early an age as possible.

Similar to the research on service delivery to ASD-diagnosed children, previously published studies on the QoL of parents in ASD-affected families is limited by a lack of comprehensive all-inclusive measures and a predominant focus on residents of HICs (see, e.g., Davis & Carter, 2008; Lee et al., 2008; Mungo et al., 2007; Shu, 2009). Within that limited literature, extant studies report high levels of depression and stress, and poor overall QoL, in parents of children with ASD (e.g., Abbeduto et al., 2004; Boyd, 2002; Dardas & Ahmed, 2014; Montes & Halterman, 2007; Mugno et al., 2007; Saldana et al., 2009; Shu, 2009; Tung et al., 2014); associations between parental psychological distress and child ASD severity (e.g., Ingersoll & Hambrick, 2010; Miranda et al., 2019); and significant associations between elevated parental psychological distress and negative service delivery experiences involving, for instance, the diagnostic process (Brogan & Knussen, 2003; Goin-Kochel et al., 2006; Mansell & Morris, 2004). However, no previous study in this literature examines, simultaneously, associations between family SES, child ASD severity, service delivery experiences, and parental psychological distress and QoL.

Study 2's preliminary analyses indicated that South African parents of children with ASD report (a) clinically significant autism-related child problem behaviours, (b) relatively high levels of psychological distress, and (c) poor QoL. These analyses also detected

significant positive associations between severity of autism-related problem behaviours, higher psychological distress (more depression and more stress), and poorer QoL. Poorer QoL was also associated with lower levels of social support. Then, the path analysis that formed the centrepiece of Study 2 indicated that both direct and indirect factors (viz., parent's highest level of education, household income, child's age, child's autism-related problem behaviours, specific aspects of service delivery [e.g., experience with process of diagnostic assessment], and parental psychological distress) all had a significant impact on parental QoL, either independently or in interaction. This finding is especially important because it suggests that clinicians, policymakers, and other interested stakeholders must consider all possible potentially influencing factors when investigating the QoL of parents in ASD-affected families. With such consideration, and with a better understanding of the impact these factors can have on the daily functioning of ASD-diagnosed individuals and their families, interventions and therapies can be tailored and appropriately directed toward improving and optimising overall QoL.

Regarding service delivery experiences, quantitative data from Study 2 and qualitative data from Study 3 were consistent in suggesting that South African parents of children with ASD face numerous challenges. These challenges are related to (a) the diagnostic process (e.g., long delays in receiving a diagnosis, poor post-diagnostic support); (b) other contact with healthcare professionals (e.g., multiple referrals and evaluations sandwiched between long inter-appointment delays, lack of ASD knowledge among those professionals); (c) educational costs and resources (e.g., long waiting lists, high costs associated with special schooling, lack of ASD knowledge in schools, a limited range of available and appropriate school-based interventions and therapies); (d) interventions (e.g., limited range, high costs, need for parent training); (e) post-school transitional services (e.g., a lack of employment training, supported employment programs, and career development for young adults with ASD); (f) impact on everyday life (involving financial costs, especially); and (g) a general need for more awareness and community support. Participants reported that these challenges have significant negative effects on their daily lives.

These findings regarding service delivery experiences of parents in ASD-affected families were consistent with the qualitative reports gathered from adults with ASD in Study 1. It is particularly notable that, across studies, participants indicated that ASD presents a massive financial burden, one that stretches from the initial diagnostic processes, through interventions, therapies, and schooling, and into post-school transitional services. Similarly, most participants appeared frustrated by the lack of ASD-specific knowledge among

healthcare professionals. Such negative experiences related to service delivery have been documented previously in both the adult and child ASD literature (see, e.g., Atun-Einy & Ben-Sasson, 2018; Hutton et al., 2016; Jarbrink et al., 2003; Liptak et al., 2006; Rahbar et al., 2011; Rhoades et al., 2007; Sharpe & Baker, 2007; Sheinin, 2006; Wang et al., 2012).

Relevance of the findings. No previous study has comprehensively examined psychological distress, QoL, and aspects of service delivery in South African ASD children and their families. Previous studies, most of which have emerged from high-income countries of the global north, have reported that ASD individuals and their families experience psychological distress, poor quality of life, and numerous service delivery challenges. This study replicated those findings but went beyond them in examining interactions between sociodemographic factors, ASD-related behaviours, service delivery, psychological functioning, and overall quality of life in ASD children and their families. This is the first time such a comprehensive investigation has been attempted and completed. As noted above with reference to Study 1, an additional note of import is that this comprehensive investigation was undertaken in a LAMIC. Because LAMIC-residing families of children with ASD are likely to face additional burdens that might further impact psychological functioning and access to services, direct comparisons with international literature are unwise.

Hence, the relevance of the novel findings for ASD individuals living in a relatively resource-poor low-to middle-income country is clear in multiple levels. First, it is apparent that South African parents of children with ASD experience high levels of psychological distress and report relatively poor QoL. Interestingly, compared to HICs, one of the lowest reported domains of QoL was that of the environment – this piece of data provides further evidence for the additional burdens and lower resources that families from LAMICs might face. Second, the numerous service delivery challenges faced by South African ASD individuals and their families show where shortfalls and deficits are present in the healthcare systems with which they have had, and continue to have, contact. In this regard, most of the current findings were consistent with those from previously published studies. However, additional problematic aspects that were perhaps more specific to lower-income settings were notable. These included issues such as accessing appropriate housing for children with ASD, transport to and from services and schools, and accessing healthcare and support in the individuals home language. In other words, although ASD-related service delivery is problematic globally, families from LAMICs face additional challenges that cannot be ignored. Again, despite the fact that valuable research regarding service delivery in ASD has

emerged from HICs, it is clear that such findings are not completely comparable or applicable to LAMICs.

Additionally, the interactive and complex nature of the interactions between all factors (sociodemographics, ASD-related behaviours, service delivery, psychological functioning, and overall QoL) in families of children with ASD, as demonstrated by the current data, show the need to for researchers, clinicians, service delivery providers, and policy makers to consider all these factors – not only when interpreting data or helping individuals patients/families, but when trying to make ground-level changes. With such comprehensive information in hand, policymakers and healthcare professionals can make some fundamental changes; they can implement targeted improvements and supports and attempt to address shortfalls with the overall aim of improving psychological functioning and quality of life in ASD individuals and their families.

Major Limitations of the Research Program

The write-up of each individual study concluded with an acknowledgement of methodological and other limitations. Rather than summarizing all of those limitations here, I offer a perspective on three major limitations that cut across the three studies and so affect the overall conclusions that might be drawn from this dissertation.

First, data were collected from, and about, a relatively small number of adults with ASD. This limitation is particularly pertinent when one considers the individual aims of each study. For instance, a primary aim of Study 1 was to obtain a rich dataset reflecting relations between psychological distress, QoL, and service delivery experiences among South African adults with ASD. The fact that only 15 individuals participated, with only 3 of those completing the qualitative portion of the study, means that great care has to be taken when drawing inferences from their reports. Similarly, a primary aim of Study 2 was to describe relations between various individual difference factors (e.g., ASD severity, family SES, service delivery experiences, psychological distress) and overall QoL among parents of children with ASD. The small number of adult children among that sample ($n = 18$ of 200) meant it would have been futile to, for instance, explore cohort effects or to include child's age as a variable in the path analysis. Moreover, given the challenges noted by the adults with ASD in Study 1, it would have been complementary and useful for Study 2 to obtain more detailed information from the parent's perspective regarding the availability of post-school services for young adults with ASD. As noted in the Study 1 Limitations sub-section, the lack of a large sample of adults with ASD was due to resistance amongst the target population

rather than to poor recruitment effort. Nonetheless, future studies should attempt to address the limitations outlined here, and to thereby deliver novel research outcomes, by focusing more intensely on this difficult-to-recruit ASD sub-population

A second limitation of the research program, also related to sample characteristics, is its lack of geographical diversity. In all three studies, most participants were residents of urban areas within the Western Cape province of South Africa. Hence, they lived in communities that were relatively well-resourced in terms of, for instance, medical professionals and facilities, schools, and support groups. It is certainly possible (and perhaps even probable) that residents of other, more rural provinces such as the Eastern Cape or Limpopo would have had different service delivery experiences, higher levels of psychological distress, and more exposure to poverty and environmental trauma, all leading to an overall poorer QoL. Hence, it is important that future studies in LAMICs and rural under-served populations recruit more geographically diverse, socioeconomically variable, and nationally representative samples in order to not only explore possible regional differences in service delivery experience and QoL, but also to ensure that research does not replicate clinical service delivery in under-serving certain segments of society.

A third limitation of the research program was that I did not use the gold standard ASD diagnostic and severity measure, the Autism Diagnostic Observation Schedule (ADOS-2; Lord et al., 2012) in Study 2. Instead, Study 2 used the Autism Behavior Checklist (ABC; Krug et al., 1978) as a measure of ASD severity, with the Maladaptive Behavior Index of the Vineland Adaptive Behavior Scale (VABS-II) as an additional measure of general and ASD-related problem behaviours. I made the methodological decision to use those measures rather than the ADOS-2 because the latter is relatively more time-consuming and effortful and so, given the already lengthy battery, it was not plausible to complete an ADOS-2 on all 200 children in the sample. Additionally, given that the ADOS-2 is not officially back-translated into Afrikaans and isiXhosa, by using this measure I would not be able to assess many participants in my sample thereby leading to a smaller sample size that would not be representative of an ASD South African sample. Nonetheless, because the ADOS-2 is the instrument used most frequently to capture data concerning the severity of ASD-related problem behaviours and symptoms, future studies attempting to replicate the current findings should use that instrument.

Overall Summary and Conclusion

This dissertation provides significant and novel insight into service delivery experiences and quality of life in autism-affected families who are resident in a low- and middle-income country. Across three studies, I used comprehensive service delivery and QoL measures, and mixed quantitative-qualitative data collection methods and analyses, to investigate multiple aspects of the constructs of interest. Data regarding service delivery experiences of adults with ASD, and of parents of children with ASD, and how these impact on the daily life of affected individuals and families, are important in that they suggest that families who receive adequate and appropriate services have less psychological distress, feel better supported, and have better QoL. Hence, the strongest implication and relevance of the research program's findings is that researchers, clinicians, policymakers, and others who design ASD-relevant treatment and intervention programs must (a) consider the multiple factors that influence QoL in affected individuals and families and (b) address the significant service delivery challenges faced by individuals with ASD and their families if they are to enhance the daily lives of members of these groups.

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Follow-Up Study More than 5 Years after Original Diagnosis

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APPENDIX A: DEMOGRAPHIC QUESTIONNAIRE ADULTS WITH ASD

Participant no.: _____ Date: _____

DEMOGRAPHIC QUESTIONNAIRE

Adults's Information:

1. Name: _____
2. Age: _____
3. Date of Birth (dd/mm/yy): _____
4. Sex (circle one): Male Female
5. Ethnicity: White Black Indian Coloured Asian
 Other If other please specify: _____
6. Home Language: _____
7. Handedness (circle one): Left Right Ambidextrous
8. Number of siblings: _____
9. Number of **older** siblings: _____
10. Marital status: Single Married Divorced Widow
11. Have you ever experienced a head injury? (e.g., being hit on the head with an object and losing consciousness as a result)
 YES NO
 If yes, please give details:

12. Have you ever experienced any of the following medical conditions:
 a. Neurological problems YES NO
 If yes, please specify:

b. Depression	YES	NO

If yes, please specify:

c. Memory problems	YES	NO

If yes, please specify:

d. Problems with your vision	YES	NO

If yes, please specify:

e. Problems with your hearing	YES	NO

If yes, please specify:

f. Are you currently taking any prescription medication?	YES	NO

If yes, what medication(s)?

11. Have you ever been diagnosed with a social disorder such as conduct disorder or oppositional defiant disorder (ODD)?

YES	NO

If yes, please specify:

12. Have you ever had a communication disorder? (For example: Having problems with understanding or producing speech, slow vocabulary development, difficulties recalling words or problems with producing sentences appropriate for his/her age.)

YES

NO

If yes, please specify:

13. Have you ever been diagnosed with a pervasive developmental disorder such as autism, Asperger's syndrome, Rett's disorder or childhood disintegrative disorder?

YES

NO

If yes, please specify:

14. Have you ever experienced learning difficulties such as dyslexia or attention-deficit / hyperactivity disorder (ADD/ ADHD)?

YES

NO

If yes, please specify:

1. What is the total yearly income of the household in which you live? (Tick the appropriate block):

[NOTE: This should be total household income, not personal income.]

0-35000: _____ 36000-75000: _____ 76000-125000: _____ 126000-175000: _____

176000-225000: _____ 226000-275000: _____ 276000-325000: _____ 326000-375000: _____

376000-425000: _____ 426000-475000: _____ 476000-525000: _____ more than
526000: _____

2. Highest level of education reached (please circle appropriate number).

1) 0 years (No Grades / Standards) 1.

= Never went to school

2) 1-6 years (Grades 1-6 / Sub A-Std 4) 2.

= Didn't complete primary school

3) 7 years (Grade 7 / Std 5) 3.

= Completed primary school

4) 8-11 years (Grades 8-11 / Stds 6-9) 4.

= Some secondary education

(didn't complete high school)

5. 12 years (Grade 12 / Std 10) 5.

= Completed high school

6. 13+ years = Tertiary education 6.

Completed university / technikon / college

7. Don't know

7.

3. Employment: (Please circle appropriate number)

1. Higher executives, major professionals, owners of large businesses 1.

2. Business managers of medium sized businesses, lesser professions (e.g. nurses, opticians, pharmacists, social workers, teachers) 2.

3. Administrative personnel, managers, minor professionals, owners / proprietors of small businesses (e.g. bakery, car dealership, engraving business, plumbing business, florist, decorator, actor, reporter, travel agent) 3.

4. Clerical and sales, technicians, small businesses (e.g. bank teller, bookkeeper, clerk, draftsperson, timekeeper, secretary) 4.

5. Skilled manual – usually having had training (e.g. baker, barber, chef, electrician, fireman, machinist, mechanic, painter, welder, police, plumber, electrician) 5.

6. Semi-skilled (e.g. hospital aide, painter, bartender, bus driver, cook, garage guard, checker, waiter, machine operator)

7. Unskilled (e.g. attendant, janitor, construction helper,
unspecified labour, porter, unemployed) 6.

8. Homemaker

9. Student, disabled, no occupation

7.

8.

9.

4. Material and financial resources (please circle appropriate number).

Which of the following items, in working order, does your household have?

Items	Yes	No
1. A refrigerator or freezer	1.	1.
2. A vacuum cleaner or polisher	2.	2.
3. A television	3.	3.
4. A hi-fi or music center (radio excluded)	4.	4.
5. A microwave oven	5.	5.

6. A washing machine	6.	6.

7. A video cassette recorder or dvd player	7.	7.

Which of the following do you have in your home?

Items	Yes	No
1. Running water	1.	1.
2. A domestic servant	2.	2.
3. At least one car	3.	3.
4. A flush toilet	4.	4.
5. A built-in kitchen sink	5.	5.
6. An electric stove or hotplate	6.	6.
7. A working telephone	7.	7.

Do you personally do any of the following?

Items	Yes	No
1. Shop at supermarkets	1.	1.
2. Use any financial services such as a bank account, ATM card or credit card	2.	2.
3. Have an account or credit card at a retail store	3.	3.

APPENDIX B: DEPRESSION SCREENING (CED-S)



Depression Screening

Center for Epidemiologic Studies Depression (CES-D)

Scale Description:

The following scale was developed by the Center for Epidemiologic Studies (Radloff, 1977). The scale has been found reliable ($\alpha > .85$) in previous research (Hann et. al., 1999). A Spanish version of this scale is also available.

Scale items:

Below is a list of some ways you may have felt or behaved. Please indicate how often you have felt this way during the last week by checking the appropriate space. Please only provide one answer to each question.

	During the past week:	<i>Rarely</i> or none of the time (less than 1 day)	<i>Some</i> or a little of the time (1-2 days)	<i>Occasionally</i> or a moderate amount of time (3-4 days)	<i>Most</i> or all of the time (5-7 days)
1.	I was bothered by things that usually don't bother me.				
2.	I did not feel like eating; my appetite was poor.				
3.	I felt that I could not shake off the blues even with help from my family or friends.				
4.	I felt I was just as good as other people.				
5.	I had trouble keeping my mind on what I was doing.				
6.	I felt depressed.				
7.	I felt that everything I did was an effort.				
8.	I felt hopeful about the future.				
9.	I thought my life had been a failure.				
10.	I felt fearful.				
11.	My sleep was restless.				
12.	I was happy.				
13.	I talked less than usual.				
14.	I felt lonely.				
15.	People were unfriendly.				
16.	I enjoyed life.				
17.	I had crying spells.				
18.	I felt sad.				
19.	I felt that people disliked me.				
20.	I could not get going.				

Scoring:	Rarely (Less than 1 day)	Some (1-2 days)	Occasionally (3-4 days)	Most (5-7 days)
Questions 4, 8, 12, and 16	3	2	1	0
All other questions	0	1	2	3

The score is the sum of the 20 questions. Possible range is 0-60. If more than four questions are missing answers, do not score the CES-D questionnaire. A score of 16 points or more is considered depressed.

References:

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APPENDIX C: BECK ANXIETY INVENTORY (BAI)

Beck Anxiety Inventory 1

Beck Anxiety Inventory

Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past month, including today, by circling the number in the corresponding space in the column next to each symptom.

	Not At All	Mildly but it didn't bother me much.	Moderately - it wasn't pleasant at times	Severely – it bothered me a lot
Numbness or tingling	0	1	2	3
Feeling hot	0	1	2	3
Wobbliness in legs	0	1	2	3
Unable to relax	0	1	2	3
Fear of worst happening	0	1	2	3
Dizzy or lightheaded	0	1	2	3
Heart pounding/racing	0	1	2	3
Unsteady	0	1	2	3
Terrified or afraid	0	1	2	3
Nervous	0	1	2	3
Feeling of choking	0	1	2	3
Hands trembling	0	1	2	3
Shaky / unsteady	0	1	2	3
Fear of losing control	0	1	2	3
Difficulty in breathing	0	1	2	3
Fear of dying	0	1	2	3
Scared	0	1	2	3
Indigestion	0	1	2	3
Faint / lightheaded	0	1	2	3
Face flushed	0	1	2	3
Hot/cold sweats	0	1	2	3
Column Sum				

Scoring - Sum each column. Then sum the column totals to achieve a grand score. Write that score here _____.

Interpretation

A grand sum between 0 – 21 indicates very low anxiety. That is usually a good thing. However, it is possible that you might be unrealistic in either your assessment which would be denial or that you have learned to “mask” the symptoms commonly associated with anxiety. Too little “anxiety” could indicate that you are detached from yourself, others, or your environment.

A grand sum between 22 – 35 indicates moderate anxiety. Your body is trying to tell you something. Look for patterns as to when and why you experience the symptoms described above. For example, if it occurs prior to public speaking and your job requires a lot of presentations you may want to find ways to calm yourself before speaking or let others do some of the presentations. You may have some conflict issues that need to be resolved. Clearly, it is not “panic” time but you want to find ways to manage the stress you feel.

A grand sum that exceeds 36 is a potential cause for concern. Again, look for patterns or times when you tend to feel the symptoms you have circled. Persistent and high anxiety is not a sign of personal weakness or failure. It is, however, something that needs to be proactively treated or there could be significant impacts to you mentally and physically. You may want to consult a physician or counselor if the feelings persist.

APPENDIX D: PERCEIVED STRESS SCALE (PSS)

Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.

Name _____ Date _____

Age _____ Gender (Circle): M F Other _____

0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?.....	0	1	2	3	4
2. In the last month, how often have you felt that you were unable to control the important things in your life?.....	0	1	2	3	4
3. In the last month, how often have you felt nervous and "stressed"?	0	1	2	3	4
4. In the last month, how often have you felt confident about your ability to handle your personal problems?.....	0	1	2	3	4
5. In the last month, how often have you felt that things were going your way?.....	0	1	2	3	4
6. In the last month, how often have you found that you could not cope with all the things that you had to do?	0	1	2	3	4
7. In the last month, how often have you been able to control irritations in your life?	0	1	2	3	4
8. In the last month, how often have you felt that you were on top of things?.....	0	1	2	3	4
9. In the last month, how often have you been angered because of things that were outside of your control?	0	1	2	3	4
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?.....	0	1	2	3	4

Please feel free to use the *Perceived Stress Scale* for your research. The PSS Manual is in the process of development, please let us know if you are interested in contributing.

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References

The PSS Scale is reprinted with permission of the American Sociological Association, from Cohen, S., Kamarck, T., and Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 386-396.

APPENDIX E: INTERPERSONAL SUPPORT EVALUATION LIST (ISEL)

Scale:

INSTRUCTIONS: This scale is made up of a list of statements each of which may or may not be true about you. For each statement check "definitely true" if you are sure it is true about you and "probably true" if you think it is true but are not absolutely certain. Similarly, you should check "definitely false" if you are sure the statement is false and "probably false" if you think it is false but are not absolutely certain.

1. There are several people that I trust to help solve my problems.
☐ definitely true (3) ☐ definitely false (0)
☐ probably true (2) ☐ probably false (1)
2. If I needed help fixing an appliance or repairing my car, there is someone who would help me.
☐ definitely true (3) ☐ definitely false (0)
☐ probably true (2) ☐ probably false (1)
3. Most of my friends are more interesting than I am.
☐ definitely true (3) ☐ definitely false (0)
☐ probably true (2) ☐ probably false (1)
4. There is someone who takes pride in my accomplishments.
☐ definitely true (3) ☐ definitely false (0)
☐ probably true (2) ☐ probably false (1)
5. When I feel lonely, there are several people I can talk to.
☐ definitely true (3) ☐ definitely false (0)
☐ probably true (2) ☐ probably false (1)
6. There is no one that I feel comfortable talking about intimate personal problems.
☐ definitely true (3) ☐ definitely false (0)
☐ probably true (2) ☐ probably false (1)
7. I often meet or talk with family or friends.
☐ definitely true (3) ☐ definitely false (0)
☐ probably true (2) ☐ probably false (1)
8. Most people I know think highly of me.
☐ definitely true (3) ☐ definitely false (0)
☐ probably true (2) ☐ probably false (1)
9. If I needed a ride to the airport very early in the morning, I would have a hard time finding someone to take me.
☐ definitely true (3) ☐ definitely false (0)
☐ probably true (2) ☐ probably false (1)

10. I feel like I'm not always included by my circle of friends.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
11. There really is no one who can give me an objective view of how I'm handling my problems.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
12. There are several different people I enjoy spending time with.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
13. I think that my friends feel that I'm not very good at helping them solve their problems.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
14. If I were sick and needed someone (friend, family member, or acquaintance) to take me to the doctor, I would have trouble finding someone.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
15. If I wanted to go on a trip for a day (e.g., to the mountains, beach, or country), I would have a hard time finding someone to go with me.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
16. If I needed a place to stay for a week because of an emergency (for example, water or electricity out in my apartment or house), I could easily find someone who would put me up.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
17. I feel that there is no one I can share my most private worries and fears with.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
18. If I were sick, I could easily find someone to help me with my daily chores.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
19. There is someone I can turn to for advice about handling problems with my family.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
20. I am as good at doing things as most other people are.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)

21. If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
22. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
23. If I needed an emergency loan of \$100, there is someone (friend, relative, or acquaintance) I could get it from.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
24. In general, people do not have much confidence in me.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
25. Most people I know do not enjoy the same things that I do.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
26. There is someone I could turn to for advice about making career plans or changing my job.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
27. I don't often get invited to do things with others.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
28. Most of my friends are more successful at making changes in their lives than I am.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
29. If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my house or apartment (the plants, pets, garden, etc.).
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
30. There really is no one I can trust to give me good financial advice.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
31. If I wanted to have lunch with someone, I could easily find someone to join me.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)



32. I am more satisfied with my life than most people are with theirs.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
33. If I was stranded 10 miles from home, there is someone I could call who would come and get me.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
34. No one I know would throw a birthday party for me.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
35. It would me difficult to find someone who would lend me their car for a few hours.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
36. If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
37. I am closer to my friends than most other people are to theirs.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
38. There is at least one person I know whose advice I really trust.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
39. If I needed some help in moving to a new house or apartment, I would have a hard time finding someone to help me.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)
40. I have a hard time keeping pace with my friends.
 ____definitely true (3) ____definitely false (0)
 ____probably true (2) ____probably false (1)

Scoring:

Items 3, 6, 9, 10, 11, 13, 14, 15, 17, 24, 25, 27, 28, 29, 30, 34, 35, 36, 39, and 40 are reverse scored.

Items 1, 6, 11, 17, 19, 22, 26, 30, 36, and 38 make up the Appraisal Support Subscale

Items 2, 9, 14, 16, 18, 23, 29, 33, 35, and 39 make up the Tangible Support Subscale

Items 3, 4, 8, 13, 20, 24, 28, 32, 37, and 40 make up the Self-Esteem Support Subscale

Items 5, 7, 10, 12, 15, 21, 25, 27, 31, and 34 make up the Belonging Support Subscale.

All scores are kept continuous.

APPENDIX F: WORLD HEALTH ORGANISATION QUALITY OF LIFE SCALE (WHOQOL-BREF)

MSA/MNH/PSF/97.6
Page 16

I.D. number

ABOUT YOU

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your **gender**?

Male Female

What is your **date of birth**?

____ / ____ / ____
Day / Month / Year

What is the highest **education** you received?

None at all
Primary school
Secondary school
Tertiary

What is your **marital status**?

Single Separated
Married Divorced
Living as married Widowed

Are you currently **ill**? Yes No

If something is wrong with your health what do you think it is? _____ illness/ problem

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks**. For example, thinking about the last two weeks, a question might ask:

	Not at all	Not much	Moderately	A great deal	Completely
	1	2	3	4	5
Do you get the kind of support from others that you need?					

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

	Not at all	Not much	Moderately	A great deal	Completely
	1	2	3	4	5
Do you get the kind of support from others that you need?					

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither	Good	Very good

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				poor nor good		
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form?.....

How long did it take to fill this form out?.....

Do you have any comments about the assessment?

.....
.....

THANK YOU FOR YOUR HELP

APPENDIX G: WUN SCOPING SURVEY ADULTS WITH AUTISM

Version 3 as of May 8 2013

WUN SCOPING SURVEY OF ASC SUPPORT AND RESOURCES

Part I: Social-Demographic and Clinical Characteristics

Background Information of Primary Caregiver

1. What is your age?
2. What is your ethnicity?
[Categories according to your country]
3. How long have you lived in [the country]?
4. What is your highest completed level of education
[Categories according to your country]
5. What is your annual household income?
[Categories according to your country]
6. How many children do you have?
7. How many children diagnosed with ASC do you have?

Part II: Healthcare System

1. At what age did you receive a diagnosis?
.....
2. Did you receive any interventions or therapies as a child?
a. If yes, what type of interventions or therapies

.....
.....
.....

Current Health Care

1. What types of behavioral and medical treatments and therapies are you currently receiving? (Check all the apply)
☐ Applied Behavioral Analysis (ABA) program
☐ TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children)
☐ Speech and language therapy (SLT)
☐ Counseling and psychotherapy
☐ SSRI (selective serotonin reuptake inhibitors)
☐ Melatonin
☐ Special diets, such as gluten-free diets
☐ Vitamin supplements
☐ Anti-fungal medication
☐ Chelation therapy (e.g., remove mercury from the body)
☐ Acupuncture
☐ Other, please specify _____

Version 3 as of May 8 2013

☐ No, I am currently not receiving any treatment

3. Do you have health insurance? [country specific*]

☐ Yes ☐ No

4. Does your health insurance offer benefits or cover services that meet your needs?
[country specific*]

☐ All ☐ Most ☐ Some ☐ Little ☐ Never

Part III. Social Support and Education Resources

Social Support

1. Among the following social services, which of them (1) do you know are available in your city/ town, (2) do you currently use, and (3) do you need? Please tick (V) accordingly.

	Available in my city/ town	I currently Use	I don't have but do need
Special education			
Community- funded therapy			
Community organizations			
Parent support or training workshops			
Counseling services			
Disability living allowance			
Career development?			
Employment assistance?			
Online support			
Day-to-day activities*			
Other, specify			

* "Day-to-day activities" include transportation, domestic help, hairdressing, etc

2. If you have difficulties with obtaining autism-related services, what are the reasons?

☐ I am not eligible ☐ Service is too far to use
☐ Waiting time is too long ☐ Service is too expensive, not affordable
☐ Service staff are not friendly
☐ Service is not culturally appropriate
☐ Services are not effective ☐ I do not have any difficulties
☐ Other, Please specify

Education

1. What type of school did you attend?

☐ General public school
☐ Private School
☐ General public school with special needs supports
☐ Private school with special needs supports
☐ Public special-needs education school
☐ Private special-needs education school
☐ Autism –Specific school
☐ Home-schooled

2. How many hours per week did you have one-to-one instruction class at school?

Version 3 as of May 8 2013

- ☐ Equal to or less than 5 hours a week
☐ Between 5 to 10 hours a week
☐ Between 11 to 15 hours a week
☐ Between 16 to 20 hours a week
☐ Between 21 to 25 hours a week
☐ Equal to or more than 26 hours a week
☐ My child does not receive one-to-one instruction at school

3. What types of intervention programs did you use when you were at school? (Check all that apply)

- ☐ Applied Behavioral Analysis (ABA) ☐ Social skills training
☐ Solomon's PLAY model ☐ Social stories
☐ Auditory integration training
☐ Sensory Integration Therapy ☐ TEACCH
☐ Other, please specify _____
☐ I don't know

Employment Sector

1. Are you currently employed?
- ☐ Yes, employed with regular salary
☐ Yes, but works voluntarily without salary
☐ No, not employed at present.
☐ No, not currently employed, but have been looking for a job for _____ months _____ years
2. Have you received career development or job training from an NGO or government agency?
- ☐ Yes ☐ No

If you are NOT employed please skip questions 2-6 to the next section, part IV

3. What is your job? _____
4. How many hours per week do you work?
- ☐ Less than 5 hours a week
☐ 6-9 hours a week
☐ 10 or more hours a week
5. Does your employer know of your condition?
- ☐ Yes ☐ No
- IF YES, has the employer made any adjustments for you?
- ☐ Yes ☐ No
6. Do your coworkers know of your condition?
- ☐ Yes ☐ No
7. In your opinion, are you making as much money as other employees in a similar position?
- ☐ Yes, you are making the equivalent amount of money as other employees
☐ No, you are making less than other employees

Version 3 as of May 8 2013

8. Does your work place receive supports for individuals with autism? (Check all that apply)
- ☐ From government ☐ From local NGO ☐ From company
- ☐ No, no support at all ☐ I don't know

Part IV. Social and Economic Costs

Impact on the Family

- Do you feel that you are able to access relevant services based on the language you speak?
☐ Yes ☐ No
- How much government allowance do you currently receive per month?
[Categories according to your country or numerical value]
- Based on the therapies and treatments used as a result of your diagnosis, how much did you have to pay out of pocket for the following services during the past 12 months?

	Cost [Local Currency]	Percentages of Insurance or Government Coverage (%, 100% = full coverage)
Medical services and medication		%
Behavioral Therapies (ABA, TEEACH, etc)		%
Occupational Therapy		%
Speech and language therapy		%
Education		%
Other, Please Specify _____		%

☐ None, I have not used any medical or other treatment services

- Has your diagnosis of autism created financial problems for you?
☐ Yes definitely ☐ Yes to some degree
☐ Only a little ☐ Never
- Have you ever cut down on the hours you work because of your diagnosis?
☐ Yes ☐ No

Any other comments/ thoughts on your services? Please use the space below to elaborate.

Thank you very much for your participation in the survey. The survey findings will be available at xxx in xxx. We are planning to conduct individual life-story interviews with parents of children with autism to hear about their experiences of living with the condition. If you'd like to share your stories, please contact us at xxx.

APPENDIX H: ADAPTATIONS TO THE WUN SCOPING SURVEY

Several questions were removed edited from the original WUN Scoping Survey to create the adapted WUN Scoping Survey for adults with ASD. For all the questions applying to children, the word child was removed, and the question was framed to address the adult.

For instance:

Has your child's diagnosis of autism created financial problems for your family?
 ___ Yes definitely ___ Yes to some degree
 ___ Only a little ___ Never

Was changed to:

Has your diagnosis of autism created financial problems for you?
 ___ Yes definitely ___ Yes to some degree
 ___ Only a little ___ Never

The following questions were removed from each section:

BACKGROUND INFORMATION

1. Removed section on background information of child given the survey is about the adult and not their children

DIAGNOSIS

1. Diagnostic assessment section was edited and the only questions that remained included:
 - a. At what age did you receive a diagnosis?
 - b. Did you receive any interventions or therapies as a child?
 - i. If yes, what type of interventions or therapies

 - c. Are you currently receiving any interventions or therapies?
 Yes ____
 No ____

CURRENT HEALTHCARE

1. In the current healthcare section, the following questions were removed:
 - a. Does your child still have follow-up appointments with the assessment team?
 ___ Yes ___ No
 IF YES, how often are the appointments? Every ..
 ___ 1-3 months
 ___ 4-6 months
 ___ 7-9 months
 ___ 10-12 months
 ___ if more than 12 months, please specify ____

- b. Is your child on any medications?

☐ Yes ☐ No

If yes, please specify what medications and the dose your child takes per day

- c. How do you pay for the services your child receives?

EDUCATION

The following questions were removed:

1. Does your child currently attend school?

☐ Yes ☐ No

If not, please state why?

2. Has your child changed schools before

☐ Yes ☐ No

If yes,

2.1. How many schools has he/she attended? _____

2.2. How long did he/she attend each school (in months and years)

3. In what grade is your child currently?

1. After diagnosis, how long did it take before your child was accepted into an intervention/ educational program at school?

☐ Within 2 weeks* ☐ Less than 1 month ☐ 1 to 3 months
☐ 4 to 6 months ☐ 7 to 9 months ☐ 10 to 12 months

If more than 12 months please specify _____

Not in intervention ☐

2. Are parent counseling and/or training included in your child's intervention program/ education?

☐ Yes ☐ No

3. How often do you communicate with your child's school?

☐ Daily ☐ Weekly ☐ Monthly ☐ Bimonthly ☐ Per Term
☐ Once a year ☐ Never

4. Do you feel that you are well-informed about your child's current education/ program?

☐ Yes definitely ☐ Yes to some extent ☐ No

IMPACT ON FAMILY

The following questions were removed as they related to a child rather than the adult themselves.

1. How many hours per week do you or other family members spend arranging or coordinating your child's care (including transportation)?
☐ Less than or equal to 1 hour a week
☐ Between 2 to 4 hours a week
☐ Between 5 to 7 hours a week
☐ More than or equal to 8 hours a week
2. Have you or other family members stopped working because of your child's diagnosis? ☐ Yes ☐ No
3. Have you or other family members avoided changing jobs because of your child?
☐ Yes ☐ No

APPENDIX I: OPEN ENDED QUESTIONS ADULTS WITH ASD

1. What do you think of the services available in South Africa for autistic adults (e.g. interventions, therapies, support groups, medical support)?
2. What are your main concerns and frustrations with the available services?
3. What challenges have you faced when trying to obtain interventions/therapies or other services (e.g., support groups, medical support etc.)?
4. With regards to employment, have you ever faced any obstacles in obtaining employment, related either to your autism or others' perspectives of ASD?
5. Have you ever had any challenges in the work environment at your company (due to autism or others' perspectives of ASD)?
6. What would you want changed about your work environment or the support you receive at work?
7. What would you NOT want changed about your work environment or the support you receive at work?
8. What would you want changed regarding the service system in SA?
9. What wouldn't you change regarding the services in SA?
10. Do you feel that the service delivery system affects your everyday life?
 - a. And if yes, in what way does it?

APPENDIX J: CONSENT FORM ADULTS WITH ASD

Consent Form: Adults with ASD

Principal Researchers:

Dr. Kevin G. F Thomas

Associate Professor

Department of Psychology

University of Cape Town

021-650-4608

Natalia Ing

Doctoral candidate

Department of Psychology

University of Cape Town

071-689-5843

Dr Susan Malcolm-Smith

Senior Lecturer

Department of Psychology

University of Cape Town

021-650-4605

1. Invitation and Purpose

You are invited to take part in a research study about the services provided to adults with autism as well as the impact service delivery may have on the quality of life of adults with autism. I am a researcher from the Department of Psychology at the University of Cape Town. The study aims to obtain a greater understanding of the services provided (and those not provided) to adults with Autism Spectrum Disorder (ASD) as well as the impact aspects of service delivery have on the quality of life of adults with autism. This study will help provide key information regarding the shortfalls and limitations of the services provided and will help improve future services for individuals with autism which may in turn aid in improving the quality of life of adults with autism. Approximately 50 adults with ASD will participate in this study.

2. Procedures

If you decide to take part in this study, we will ask you to complete a series of questionnaires and surveys relating to service delivery and quality of life. This first session will last between 60-90 minutes. You may withdraw from the session at any time if you feel uncomfortable. You

have the option of participating in the second session involving focus groups with 4 other adults to discuss various topics concerning service delivery and quality of life in adults with autism. You do not have to participate in the second session, this participation is optional even if you are participating in the first session.

3. **Risks, Discomforts & Inconveniences**

If you decide to take part in this study you will be exposed to no physical, social, or psychological risk. You will not be asked to perform any potentially harmful tasks. You will be able to withdraw from the study at any time, with no penalty and with no effect upon clinical or other services being delivered (or potentially being delivered).

4. **Benefits**

Although there are no direct benefits by participating in this study, the information from this study may help improve our understanding of what services are (and are not) provided to ASD individuals and their families. This information may also provide us with a better understanding of the quality of life of adults with autism as well as the possible impact service delivery may have on the quality of life of with autism within South Africa. This study also aims to provide information to help lobby for better service provision for the ASD community.

5. **Privacy and Confidentiality**

Information collected during each session will be stored in locked filing cabinets or in computers with security passwords. Only certain people have the right to review these research records. These people include the researchers for this study and certain University of Cape Town officials.

6. **Money Matters**

Participants will not incur any costs when participating in this study. A small compensation of R100 will be provided to all participants for participation within the study.

7. **Questions**

If you have questions or concerns about the study please contact the principal investigator Kevin G. F. Thomas, PhD: (office) 021-650-4608 (email) Kevin.Thomas@uct.ac.za, Susan Malcolm-Smith, PhD: (office) 021-650-4605 (email) susanmalcolmsmith@gmail.com or Natalia M. Ing (cell) 071-689-5843 (email) Natalia.Ing@uct.ac.za.

Consent Form

The study has been explained to me, and my questions have been answered.

I understand that participation in this study is voluntary, and that I may withdraw at any point.

I understand that I will not be identified except by an initial, and that this anonymity will be maintained throughout the study and when the research is published.

I consent to participate in this study.

Participant's name _____

Signature of parent _____

Date _____

I have explained the study to the participant, and in my opinion s/he understands that participation is voluntary and is able to give informed consent.

Researcher _____

Signature _____

Date _____

Use of Samples/Data for Future Research

With your permission, we would like to store the unused parts of your tests for use in future research. This is your choice entirely and you are free to say no and you will still be able to take part in the study. Please check the boxes that apply to your choice:

I do not want my samples to be used for any future research. ____

You may use my samples for any future research. ____

Please indicate below if you would like to be notified of future research projects conducted by our research group:

_____ (initial) Yes, I would like to be added to your research participation pool and be notified of research projects in which I might participate in the future.

Would you like to participate in a focus group with 4 other parents?

YES

NO

Method of contact:

Phone number: _____

Cell phone number: _____

E-mail address: _____

Mailing address: _____

APPENDIX K: DEPARTMENTAL ETHICS APPROVAL



UNIVERSITY OF CAPE TOWN

FACULTY OF HUMANITIES

DC: HUM /

PROPOSAL APPROVAL FORM

DOCTORATE (A research proposal must accompany this form)	RESEARCH MASTERS (A research proposal must accompany this form)	C/W MASTERS

SECTION A: (To be completed by candidate)

Please complete this form and return it to the Faculty Office once you have obtained the signatures of the supervisor(s) and Head of Department.

Surname	ING				First Name(s)	NATALIA
Title	Mr.	Ms.	Mrs.	(Miss)	Student No	INGNAT001
Address	25 Mitchells Way Edgemead					
Telephone(Home)				Work/Cell	071 689 5843	

Note: Your UCT Email address is the default email address for all official communication – make sure that you access it regularly.

Department	Psychology
Title of Dissertation:	Service Delivery and its Implications for Quality of Life in ASD

Qualifications held			
Degree/Diploma	Major(s) & Subjects	Month/Year awarded	University
Masters in Psychological Research	Neuropsychology	2011	UCT
Honours in Psych		2008	UCT
BA in humanities	Psych + Sociology	2007	Stellenbosch

Signature Removed

Signature of candidate: _____ Date: 05/06/13

SECTION B:

	Name	Signature	Date
Supervisor	Karen Thomas	Signature Removed	5/8/13
Co-supervisor (if applicable)	Susan Hordern	Signature Removed	7/8/13
HOD	M. Solms	Signature Removed	12/8/13
Deputy-Dean: Research			
Ethics approval obtained where applicable	on behalf of Departmental Ethics Committee	Signature Removed	8/8/13

August 8, 2013

DEPARTMENT OF PSYCHOLOGY REPORT OF THESIS COMMITTEE

Student Name: NATASHA LING

Student #: 115040001

Degree: PhD

Title (as proposed): SERVICE DELIVERY AND ITS IMPLICATIONS
FOR QUALITY OF LIFE IN ASD

Supervisor: KEVIN THUMAI

Co-supervisor: DR. SHARON SMITH

Committee members: CATHY WARD
ROBERT NICHOLS
NORWELLA SINGELA

WE

1. Approve the proposal, and recommend that the student continue with the research.
2. Approve the proposal, and recommend that the student may continue with the research. However, we recommend that change(s), as noted below, be incorporated in the research, to the satisfaction of the supervisor.
3. Approve the proposal in terms of its ethical implications. If necessary, explanatory notes appear below.
4. Find the proposal unsatisfactory, for the reason(s) listed below. The student is hereby requested to re-present the proposal to a departmental thesis committee by _____.

NOTES:

- ① Please guidelines to emerge as from groups
- ① Screen adults for comprehension - study needs to be replicable
- ② Consider a deeper developmental theoretical approach instead of the breadth
- ③ Avoid duplication of questions across instruments; post-test employment
- ④ Consent forms: add recording and signature line for focus groups, simplify consent for adult ASD participants and build a consent form for their guardians
- ⑤ Include discussion of available future

APPENDIX L: TABLE CONTAINING WHOQOL-BREF Z SCORE NORMATIVE DATA ADULTS WITH ASD

Table 4.

The WHOQOL-BREF Z-Score normative data: Adults with ASD (N = 15)

Participants	Physical Domain Z- Score	Physical Domain (M)	Psychological Domain Z- Score	Psychological Domain (M)	Social Relationship Domain Z-Score	Social Relationship Domain (M)	Environment Domain Z- Score	Environment Domain (M)
1	-0,75	77.5	-1,81	71.1	-1,50	76.8	0,18	72.7
2	-0,95	83.6	-0,06	74.3	-0,08	61.8	0,50	77.2
3	-2,54	80.3	-1,13	73.6	-1,08	74.8	0,13	73.4
4	-1,61	84.3	-0,61	73.4	-1,35	72.1	-1,80	72.9
5	-2,06	77.5	-0,82	71.1	-2,36	76.8	-2,00	72.7
6	-1,40	84.3	-1,43	73.4	-2,76	72.1	-0,03	72.9
7	-0,30	88.7	0,74	74.3	-0,36	61.8	0,50	77.2
8	-1,49	80.3	-0,30	73.6	-1,41	74.8	1,13	73.4
9	-0,32	84.3	0,00	73.4	-0,64	72.1	-0,21	72.9
10	-2,70	83.6	-0,85	74.3	-0,36	61.8	0,03	77.2
11	-0,19	78	0,55	71.7	-0,14	69.2	0,42	72
12	-1,53	83.6	-1,64	74.3	-1,22	61.8	-1,86	77.2
13	-2,04	84.3	-1,83	73.4	-1,35	72.1	-2,33	72.9
14	-1,04	77.5	0,66	71.1	-1,50	76.8	-1,01	72.7
15	0,22	83.6	0,34	74.3	-0,93	61.8	0,26	77.2

APPENDIX M: DEMOGRAPHIC QUESTIONNAIRE PARENTS OF CHILDREN WITH ASD

Participant no.: _____ Date: _____

DEMOGRAPHIC QUESTIONNAIRE

Child's Information:

12. Name: _____

13. Age: _____

14. Date of Birth (dd/mm/yy): _____

15. Sex (circle one): Male Female

16. Ethnicity: White Black Indian Coloured Asian

Other If other please specify: _____

17. Home Language: _____

18. Handedness (circle one): Left Right Ambidextrous

19. Number of siblings (brothers and sisters): _____

20. Number of **older** siblings (brothers and sisters): _____

21. Has your child ever experienced a head injury? (e.g., being hit on the head with an object and losing consciousness as a result)

YES

NO

If yes, please give details:

12. Has your child ever experienced any of the following medical conditions:

a. Depression

YES

NO

If yes, please specify:

g. Memory problems	YES	NO
If yes, please specify:		

h. Problems with their vision	YES	NO
If yes, please specify:		

i. Problems with their hearing	YES	NO
If yes, please specify:		

j. Is he/she currently taking any prescription medication?	YES	NO
If yes, what medication(s)?		

11. Has your child ever been diagnosed with a social disorder such as conduct disorder or oppositional defiant disorder (ODD)?	YES	NO

If yes, please specify:

12. Has your child ever had a communication disorder? (For example: Having problems with understanding or producing speech, slow vocabulary development, difficulties recalling words or problems with producing sentences appropriate for his/her age.)

YES	NO

If yes, please specify:

13. Has your child ever been diagnosed with a pervasive developmental disorder such as autism, Asperger's syndrome, Rett's disorder or childhood disintegrative disorder?

YES

NO

If yes, please specify:

14. Has your child ever experienced learning difficulties such as dyslexia or attention-deficit / hyperactivity disorder (ADD/ ADHD)?

YES

NO

If yes, please specify:

Participant's Information:

22. Name: _____

23. Age: _____

24. Date of Birth (dd/mm/yy): _____

25. Sex (circle one): Male Female

26. Ethnicity: White Black Indian Coloured Asian

Other If other please specify: _____

27. Home Language: _____

28. Relationship to child (circle one): Biological parent Caregiver Adoptive parent

Stepparent Guardian Foster parent

1. What is the total yearly income of the household in which you live? (Tick the appropriate block):

[NOTE: This should be total household income, not personal income.]

0-35000: _____ 36000-75000: _____ 76000-125000: _____ 126000-

175000: _____

176000-225000:_____ 226000-275000:_____ 276000-325000:_____ 326000-375000:_____

376000-425000:_____ 426000-475000:_____ 476000-525000:_____ more than 526000:_____

2. Highest level of education reached for mother and father (please circle appropriate number).

	Mother	Father
1) 0 years (No Grades / Standards) = Never went to school	1.	1.
2) 1-6 years (Grades 1-6 / Sub A-Std 4) = Didn't complete primary school	2.	2.
3) 7 years (Grade 7 / Std 5) = Completed primary school	3.	3.
4) 8-11 years (Grades 8-11 / Stds 6-9) = Some secondary education (didn't complete high school)	4.	4.
5. 12 years (Grade 12 / Std 10) = Completed high school	5.	5.

6. 13+ years = Tertiary education	6.	6.
Completed university / technikon / college		

7. Don't know	7.	7.

3. Parental employment: (Please circle appropriate number)

	Mother	Father
1. Higher executives, major professionals (Doctor, Lawyer, accountant) , owners of large businesses	1.	1.
2. Business managers of medium sized businesses, other professions (e.g. nurses, opticians, pharmacists, social workers, teachers)	2.	2.
3. Administrative personnel, managers, minor professionals, owners / proprietors of small businesses (e.g. bakery, car dealership, engraving business, plumbing business, florist, decorator, actor, reporter, travel agent)	3.	3.
4. Clerical and sales, technicians, small businesses (e.g. bank teller, bookkeeper, clerk, draftsman, timekeeper, secretary)		
5. Skilled manual – usually having had training	4.	4.

(e.g. baker, barber, chef, electrician, fireman, machinist, mechanic, painter, welder, police, plumber, electrician)	5.	5.
6. Semi-skilled (e.g. hospital aide, painter, bartender, bus driver, cook, garage guard, checker, waiter, machine operator)		
7. Unskilled (e.g. attendant, janitor, construction helper, unspecified labour, porter, unemployed)	6.	6.
8. Homemaker		
9. Student, disabled, no occupation	7.	7.
	8.	8.
	9.	9.

4. Material and financial resources (please circle appropriate number).

Which of the following items, in working order, does your household have?

Items	Yes	No
1. A refrigerator or freezer	1.	1.
2. A vacuum cleaner or polisher	2.	2.

3. A television	3.	3.
4. A hi-fi or music center (radio excluded)	4.	4.
5. A microwave oven	5.	5.
6. A washing machine	6.	6.
7. A video cassette recorder or dvd player	7.	7.

Which of the following do you have in your home?

Items	Yes	No
1. Running water	1.	1.
2. A domestic servant	2.	2.
3. At least one car	3.	3.
4. A flush toilet	4.	4.
5. A built-in kitchen sink	5.	5.

6. An electric stove or hotplate	6.	6.

7. A working telephone	7.	7.

Do you personally do any of the following?

Items	Yes	No
1. Shop at supermarkets	1.	1.
2. Use any financial services such as a bank account, ATM card or credit card	2.	2.
3. Have an account or credit card at a retail store	3.	3.

APPENDIX N: VINELAND ADAPTIVE BEHAVIOR SCALE MALADAPTIVE BEHAVIOR INDEX (VABS-II MBI)

Problem Behaviors Part 1

Response Options: 2 = Often, 1 = Sometimes, 0 = Never

Section A				Circle "2" if You Have a Question
Start Ages 3+	1	Is overly dependent (that is, clings to caregiver, teacher, brother, or sister).	0 1 2	?
	2	Avoids others and prefers to be alone.	0 1 2	?
	3	Has eating difficulties (for example, eats too fast or too slowly, hoards food, overeats, refuses to eat, etc.).	0 1 2	?
	4	Has sleep difficulties (for example, sleepwalks, has frequent nightmares, sleeps significantly more or less than typical for his or her age).	0 1 2	?
	5	Refuses to go to school or work because of fear, feelings of rejection or isolation, etc.	0 1 2	?
	6	Is overly anxious or nervous.	0 1 2	?
	7	Cries or laughs too easily.	0 1 2	?
	8	Has poor eye contact (that is, does not look at or face others when speaking or spoken to).	0 1 2	?
	9	Is sad for no clear reason.	0 1 2	?
	10	Avoids social interaction.	0 1 2	?
	11	Lacks energy or interest in life.	0 1 2	?

Section B				Circle "2" if You Have a Question
Start Ages 3+	1	Is impulsive (that is, acts without thinking).	0 1 2	?
	2	Has temper tantrums.	0 1 2	?
	3	Intentionally disobeys and defies those in authority.	0 1 2	?
	4	Taunts, teases, or bullies.	0 1 2	?
	5	Is inconsiderate or insensitive to others.	0 1 2	?
	6	Lies, cheats, or steals.	0 1 2	?
	7	Is physically aggressive (for example, hits, kicks, bites, etc.).	0 1 2	?
	8	Is stubborn or sullen.	0 1 2	?
	9	Says embarrassing things or asks embarrassing questions in public (for example, "You're fat," or "What's that big red thing on your nose?").	0 1 2	?
	10	Behaves inappropriately at the urging of others.	0 1 2	?

Section C				Circle "2" if You Have a Question
Start Ages 3+	1	Sucks thumb or fingers.	0 1 2	?
	2	Wets bed or must wear diapers at night.	0 1 2	?
	3	Acts overly familiar with strangers (for example, holds hands, hugs, sits on lap, etc.).	0 1 2	?
	4	Bites fingernails.	0 1 2	?
	5	Has tics (that is, involuntary blinking, twitching, head shaking, etc.).	0 1 2	?

Problem Behaviors Part 1, continued

Response Options: 2 = Often, 1 = Sometimes, 0 = Never

Section C, continued

		0	1	2	Circle "1" If You Have a Question
6	Grinds teeth during the day or night.	0	1	2	?
7	Has a hard time paying attention.	0	1	2	?
8	Is more active or restless than others of same age.	0	1	2	?
9	Uses school or work property (for example, telephone, Internet access, office supplies, etc.) for unapproved personal purposes.	0	1	2	?
10	Swears.	0	1	2	?
11	Runs away (that is, is missing for 24 hours or longer).	0	1	2	?
12	Is truant from school or work.	0	1	2	?
13	Ignores or doesn't pay attention to others around him or her.	0	1	2	?
14	Uses money or gifts to "buy" affection.	0	1	2	?
15	Uses alcohol or illegal drugs during the school or work day.	0	1	2	?

Problem Behaviors Part 2

Response Options: 2 = Often, 1 = Sometimes, 0 = Never, S = Severe, M = Moderate

Section D

Start Ages		0	1	2	S	M	Circle "1" If You Have a Question
3+	1 Engages in inappropriate sexual behavior (for example, exposes self, masturbates in public, makes improper sexual advances, etc.).	0	1	2	S	M	?
	2 Is obsessed with objects or activities (for example, constantly repeats words or phrases, is preoccupied with mechanical objects, etc.).	0	1	2	S	M	?
	3 Expresses thoughts that do not make sense (for example, talks about hearing voices, seems delusional, etc.).	0	1	2	S	M	?
	4 Has strange habits or ways (for example, makes repetitive noises, odd hand movements, etc.).	0	1	2	S	M	?
	5 Consistently prefers objects to people (for example, pays more attention to objects than to people, etc.).	0	1	2	S	M	?
	6 Displays behaviors that cause injury to self (for example, bangs head, hits or bites self, tears at skin, etc.).	0	1	2	S	M	?
	7 Destroys own or another's possessions on purpose.	0	1	2	S	M	?
	8 Uses bizarre speech (for example, has conversations with self in public, speaks in phrases or sentences that have no meaning, repeats same word or phrase over and over, etc.).	0	1	2	S	M	?
	9 Is unaware of what is happening around him or her (for example, seems to be in a "fog," stares blankly, etc.).	0	1	2	S	M	?
	10 Rocks back and forth repeatedly.	0	1	2	S	M	?
	11 Is unusually fearful of ordinary sounds, objects, or situations.	0	1	2	S	M	?
	12 Remembers odd information in detail years later.	0	1	2	S	M	?
	13 Is unable to complete a normal school or work day because of chronic pain or fatigue.	0	1	2	S	M	?
	14 Is unable to complete a normal school or work day because of psychological symptoms.	0	1	2	S	M	?

APPENDIX O: AUTISM BEHAVIOR CHECKLIST (ABC)

Autism Behavior Checklist

From Krug, Arick, and Almond (1978)

Patient _____

Birth Date: _____

Examiner _____

Test Date _____

Circle the number for those items most accurately describing the child:

1	Whirls self for long periods of time (spins self around for long periods of time)			4		
2	Learns a simple task but "forgets" quickly					2
3	Frequently does not attend to social/environmental cues		4			
4	Does not follow simple commands (sit down, come here, stand up) given once				1	
5	Does not use toys appropriately (spins wheels, etc.)			2		
6	Poor use of visual discrimination when learning (fixates on parts of objects such as size, color, position...)	2				
7	Lacks a social smile (may smile out-of-context)		2			
8	Exhibits pronoun reversal (you for I...)				3	
9	Insists on keeping certain objects with him/herself			3		
10	Seems not to hear (despite normal hearing tests)	3				
11	Speech is atonal and arrhythmic				4	
12	Rocks self for long periods of time			4		
13	Does not (or did not as a baby) reach out when reached for		2			
14	Strong reactions to minor changes in routine/environment					3
15	Does not respond to own name when called out among two or more other names				2	
16	Lunges and darts about, interrupted by spinning, toe walking, hand flapping...			4		
17	Not responsive to other people's facial expressions or feelings		3			
18	Seldom uses "yes" or "I"				2	
19	Has special abilities in one area – seems to rule out mental retardation					4
20	Does not follow simple prepositional commands (e.g., "put the ball in the box")				1	
21	Sometimes shows no "startle response" to a loud noise	3				
22	Flaps hands (or other self-stimulating behavior)			4		
23	Severe temper tantrums and/or frequent minor tantrums					3
24	Actively avoids eye contact		4			
25	Resists being touched or held		4			
26	Sometimes, painful stimuli (cuts, injections, bruises) evoke no reaction	3				
27	Is (or was as a baby) stiff and hard to hold		3			
28	Is flaccid (doesn't cling) when held in arms		2			
29	Gets desired objects by gesturing				2	
30	Walks on toes			2		
31	Hurts others by biting, hitting, kicking...					2
32	Repeats phrases over and over again				3	
33	Does not imitate other children at play		3			
34	Often will not blink when a bright light is directed toward eyes	1				
35	Hurts self by biting hand, banging head...			2		
36	Does not wait for needs to be met (wants things immediately)					2
37	Cannot point to more than five named objects					1

Autism Behavior Checklist

From Krug, Arick, and Almond (1978)

Patient _____

Birth Date: _____

Examiner _____

Test Date _____

38	Has not developed any friendships		4			
39	Covers ears at many sounds	4				
40	Twirls, spins, and bangs objects a lot			4		
41	Difficulties with toilet training					1
42	Uses 5 or less words per day spontaneously to communicate wants or needs				2	
43	Often frightened or very anxious		3			
44	Squints, frowns, or covers eyes when in the presence of natural light	3				
45	Does not dress self without frequent help					1
46	Repeats sounds or word over and over again				3	
47	"Looks through" people		4			
48	Echoes questions or statements made by other people				4	
49	Frequently unaware of surroundings and may be oblivious to dangerous situations					2
50	Prefers to manipulate and be occupied with inanimate objects					4
51	Will feel, smell, or taste objects in the environment			3		
52	Frequently has no visual reaction to a "new" person	3				
53	Gets involved in complicated "rituals" such as lining things up...			4		
54	Is very destructive (toys and household items are quickly broken)			2		
55	A developmental delay was identified at or before 30 months of age					1
56	Uses at least 15 but less than 30 spontaneous phrases daily to communicate				3	
57	Stares into space for long periods of time		4			
Totals:						

Overall Total: _____

Comments:

APPENDIX P: PARENTING STRESS INDEX (PSI)

PSI

The questions below ask you to mark an answer which best describes your feelings. While you may not find an answer which exactly states your feelings, please mark the answer which comes closest to describing how you feel. YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Please mark the degree to which you agree or disagree with the following statements by filling in the number which best matches how you feel. If you are not sure, please fill in #3.

	1 Strongly Agree	2 Agree	3 Not Sure	4 Disagree	5 Strongly Disagree
Example:	1	3	4	5	I enjoy going to the movies. (If you sometimes enjoy going to the movies, you would fill in #2.)
1. I often have the feeling that I cannot handle things very well.	1	2	3	4	5
2. I find myself giving up more of my life to meet my child's needs than I ever expected.	1	2	3	4	5
3. I feel trapped by my responsibilities as a parent.	1	2	3	4	5
4. Since having my child I have been unable to try new and different things.	1	2	3	4	5
5. Since having my child I feel that I am almost never able to do things that I like to do.	1	2	3	4	5
6. I am unhappy with the last purchase of clothing I made for myself.	1	2	3	4	5
7. There are quite a few things that bother me about my life.	1	2	3	4	5
8. Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend).	1	2	3	4	5
9. I feel alone and without friends.	1	2	3	4	5
10. When I go to a party I usually expect not to enjoy myself.	1	2	3	4	5

	1 Strongly Agree	2 Agree	3 Not Sure	4 Disagree	5 Strongly Disagree
11. I am not as interested in people as I used to be.				1	2 3 4 5
12. I don't enjoy things as I used to.				1	2 3 4 5
13. My child rarely does things for me that make me feel good.				1	2 3 4 5
14. Most times I feel that my child likes me and wants to be close to me.				1	2 3 4 5
15. My child smiles at me much less than I expected.				1	2 3 4 5
16. When I do things for my child, I get the feeling that my efforts are not appreciated very much.				1	2 3 4 5
17. When playing, my child doesn't often giggle or laugh.				1	2 3 4 5
18. My child doesn't seem to learn as much as most children.				1	2 3 4 5
19. My child doesn't seem to smile as much as most children.				1	2 3 4 5
20. My child is not able to do as much as I expected.				1	2 3 4 5
21. It takes a long time and it is really hard for my child to get used to new things.				1	2 3 4 5
22. I feel that I am:				1	2 3 4 5
1. a very good parent.					
2. a better than average parent.					
3. an average parent.					
4. a person who has some trouble being a parent.					
5. not very good at being a parent.					
23. I expected to have closer and warmer feelings for my child than I do and this bothers me.				1	2 3 4 5
24. Sometimes my child does things that bother me just to be mean.				1	2 3 4 5
25. My child seems to cry more often than most children.				1	2 3 4 5
26. My child generally wakes up in a bad mood.				1	2 3 4 5
27. I feel that my child is very moody and easily upset.				1	2 3 4 5
28. My child does a few things that bother me a great deal.				1	2 3 4 5
29. My child reacts very strongly when something happens that my child doesn't like.				1	2 3 4 5
30. My child gets upset easily over the smallest thing				1	2 3 4 5
31. My child's sleeping and eating schedule was much harder to establish than I expected.				1	2 3 4 5
32. I have found that getting my child to do something is:				1	2 3 4 5
1. much harder than I expected.					
2. somewhat harder than I expected.					
3. about as hard as I expected.					
4. somewhat harder than I expected.					
5. much easier than I expected.					

	1	2	3	4	5
	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
33. Think carefully and count the number of things which your child does that bothers you. For example: refuses to listen, cries, interrupts, fights, whines, etc. Please fill in the number that includes the number of things you counted:	1	2	3	4	5
1. 1-3					
2. 4-5					
3. 6-7					
4. 8-9					
5. 10+					
34. There are some things my child does that really bother me a lot.	1	2	3	4	5
35. My child turned out to be more of a problem than I expected.	1	2	3	4	5
36. My child makes more demands on me than most children.	1	2	3	4	5

APPENDIX Q: FAMILY RESOURCE SCALE (FRS)

Participant Enrolment Number:							
Date:							

FAMILY RESOURCE SCALE

For each response write the number response that best describes how well the needs are met on a consistent basis in your family (that is, month-in and month-out). Eg: 1. Food for 2 meals a day: 3

NA= Does not apply

1= Not at all adequate

2= Seldom adequate

3= Sometimes adequate

4= Usually adequate

5= Almost always adequate

1. Food for 2 meals a day : _____
2. House or apartment: _____
3. Money to buy necessities: _____
4. Enough clothes for your family: _____
5. Heat for your house or apartment: _____
6. Indoor plumbing/water: _____
7. Money to pay monthly bills: _____
8. Good job for yourself or spouse: _____
9. Medical care for your family: _____
10. Public assistance(SSI, AFDC, Medicaid. Etc: _____
11. Dependable transportation (own transport or provided by others): _____
12. Time to get enough sleep/rest: _____

Participant Enrolment Number:							
Date:							

13. Furniture for your home or apartment: _____
14. Time to be by yourself: _____
15. Time for family to be together: _____
16. Time to be with children: _____
17. Time to be with spouse or close friend: _____
18. Telephone or access to phone: _____
19. Babysitting for your child(ren): _____
20. Child care/day care for your child(ren): _____
21. Money to buy special equipment/supplies for child(ren): _____
22. Dental care for your family: _____
23. Someone to talk to: _____
24. Time to socialize: _____
25. Time to keep in shape and looking nice: _____
26. Toys for your child(ren): _____
27. Money to buy things for self: _____
28. Money for family entertainment: _____
29. Money to save: _____
30. Travel/vacation: _____

THANK YOU

APPENDIX R: FAMILY SUPPORT SCALE (FSS)

Participant Enrolment Number:							
Date:							

FAMILY SUPPORT SCALE

Instructions: We are going to present you with a list of people and groups that often are helpful to members of a family raising a child. Please choose one of the numbers on the card to describe how helpful sources have been to your family during the past 3 – 6 months. If a source of help has not been available to your family during this period, check the not available response.

For example, if your parents were not helpful to your family during the past 3 – 6 months, choose (1) - “Not at all helpful”. If they were sometimes helpful, choose (2) – “Sometimes helpful”. Choose (3) if they were generally helpful, (4) if very helpful, (5) if extremely helpful. If your parents are no longer living, choose (0) which tells me they were not available during this time period.

		0 Not available	1 Not at all helpful	2 Sometimes helpful	3 Generally helpful	4 Very helpful	5 Extremely helpful
1	Your parents						
2	Your spouse or partner's parents						
3	Your relatives/kin (other you're your parents)						
4	Your spouse or partner's relatives/kin						
5	Spouse or partner						
6	Your friends						
7	Your spouse or partner's friends						
8	Your own children						
9	Other parents						
10	Co-workers						
11	Parent groups						
12	Social groups/clubs						
13	Church members/minister						
14	Your family or child's physician						
15	Early childhood intervention programs						
16	School/day care centre						
17	Professional helpers(social, worker,therapist,teacher, etc)						
18	Professional agencies(public health, social services,mental health, etc)						

APPENDIX S: WUN SCOPING SURVEY PARENTS OF CHILDREN WITH ASD

Part I: Social-Demographic and Clinical Characteristics

Background Information of Primary Caregiver

1. What is your age? _____
2. What is your ethnicity?
 _____ White _____ Black _____ Coloured _____ Indian _____ Asian
 _____ Other
3. How long have you lived in South Africa? _____
4. How many children do you have? _____
5. How many children diagnosed with Autism Spectrum Disorder (ASD) do you have?

*If more than one child, please complete the following survey based on the **first** child diagnosed with Autism Spectrum Disorder.

Background Information of Child

1. Year of Birth _____
2. Gender
 ___ Male ___ Female
3. Was your child born outside of South Africa?
 ___ Yes ___ No
4. How old was your child when first diagnosed with an Autism Spectrum Disorder?
 ___ 1 year old ___ 2 years old ___ 3 years old
 ___ 4 years old ___ 5 years old ___ 6 years old
 ___ Older than 6 years, please specify exact age _____

5. Has your child ever been diagnosed with an intellectual disability?

☐ Yes ☐ No

- a. If yes, which range below is applicable?

☐ Mild ☐ Moderate ☐ Severe ☐ Learning Difficulty ☐ Don't know/Not given

6. Besides autism, does your child have any other clinical diagnoses, chronic illnesses or disabilities (e.g., ADHD, Epilepsy)?

☐ Yes ☐ No

IF YES, please specify _____

- 6.1. Is your child receiving treatment for this illness/other clinical diagnosis or disability?

☐ Yes ☐ No

If yes, please specify _____

- 6.2. Is your child currently on any medication for this illness/other clinical diagnosis or disability?

☐ Yes ☐ No

If yes, please specify _____

- 6.3. How much do you spend a month on this illness/other clinical diagnosis or disability?

7. Is your child currently in school?

☐ Yes, Part-Time ☐ Yes, Full Time ☐ No, they are not in school

8. If your child is over 18, are they currently employed?

☐ Yes ☐ No

Part II: Healthcare System

Before the diagnostic Assessment

1. At what age was your child when you started thinking that his/her behavior or development was different to other children his/her age?
Age _____ Years _____ Months

2. Which professional first alerted you to your child's symptoms?
 ___ Teacher ___ Nurse ___ Pediatrician ___ Dentist
 ___ Specialist Doctor ___ General doctor ___ Psychologist
 ___ Other, please state _____

3. How long did it take for you to bring your child to the doctor from when you first observed the symptoms?
 ___ Within a month ___ 2 -3 months ___ 4-5 months
 ___ 6-7 months ___ 8-9 months ___ 10-11 months
 ___ 12 months

If more than 12 months, please specify years/months _____

4. Which healthcare professionals did you go to first to write a referral for diagnosis or who did you see/ consult before the diagnosis?
 ___ Nurse ___ Pediatrician ___ General doctor (GP) ___
 Psychologist ___ Other, please state _____

5. Did the healthcare professional(s) you first consulted mention autism spectrum conditions at all as a possible diagnosis for your child in your first contact with services?
 ___ Yes ___ No

6. Did the healthcare professional provide/refer you to any services for the child (i.e. pre-school, speech and language therapy, others) while you waited to be seen for the diagnosis?
 ___ Yes ___ No

If YES, what services did they refer you for: _____

7. How long did you have to wait between obtaining a referral and going to the diagnostic assessment?
 _____ Months _____ Weeks

8. What happened between obtaining a referral and the diagnostic assessment?

a. Who were you first referred to? _____

b. After the first referral, were you referred to another professional

___ Yes ___ No

If yes, please specify all the professional referrals you received:

c. How many referrals did you receive before going to the diagnostic assessment?

9. Prior to the diagnostic assessment, did you know how much the assessment would cost?

___ Yes ___ No

10. Prior to the diagnostic assessment, did you know how long you would have to wait to get an assessment?

___ Yes ___ No

11. Prior to the diagnostic assessment, did you know the name of the clinician who would see your child for the diagnostic assessment?

___ Yes ___ No

12. Prior to the diagnostic assessment, did you know the title/profession of the clinician who would see your child for the diagnostic assessment?

___ Yes ___ No

13. Prior to the diagnostic assessment, did you know how long the assessment process would last?

___ Yes ___ No

14. Prior to the diagnostic assessment, did you know what types of assessment would be conducted?

___ Yes ___ No

15. Prior to the diagnostic assessment, did you know the number of appointments the assessment would take?

___ Yes ___ No

During the Diagnostic Assessment

1. Which healthcare professionals were present during the assessment? (Check all that all apply)

☐ Medical doctor ☐ Specialist Doctor ☐ Psychologist
☐ Psychiatrist ☐ Speech Therapist ☐ Occupational Therapist
☐ Nurse

☐ I didn't know who they were

☐ They told me who they were, but I don't remember anymore.

☐ Other, please specify _____

2. Were you able to observe the child during the assessment?

☐ Yes ☐ No

3. What did the assessment comprise of? (Check all that apply)

☐ Family history ☐ Observation of the child's behavior
☐ Cognitive assessment ☐ Assessment of child's speech/ language
☐ Physical assessment ☐ Blood and urine test
☐ MRI scan ☐ DNA analysis
☐ Therapy needs assessment ☐ Family needs assessment
☐ Other, please specify _____
☐ I don't know

4. Did you attend more than one appointment during the assessment process?

☐ Yes ☐ No

If yes,

- 4.1. Please specify how many appointments you attended during the assessment process?

- 4.2. How long did each appointment take?

5. How long did the whole assessment process take (this may be over one or several appointments)?

- ☐ Less than 1 hour in total for all assessment appointments
☐ 1 hour to 2 hours in total
☐ 3 hours to 4 hours in total
☐ 5 hours

If more than 5 hours, please specify _____

Receiving the Diagnosis of Autism Spectrum Disorder

- k. How long did it take until you received the diagnosis?
- ☐ I was informed of the diagnosis of Autism Spectrum Disorder on the same day of the assessment
☐ Within a week ☐ 2-3 weeks ☐ 4-5 weeks
☐ 6-7 weeks If more than 7 weeks please specify how long _____
- l. After the assessment, did you receive a written report of the assessment?
- ☐ Yes, I received it and understood the assessment findings and diagnosis
☐ Yes, I received it but I only understood some of the assessment outcome findings
☐ Yes, I received it but I did not understand most of it
☐ No, I did not receive the report of the assessment
- m. After the completion of the assessment, did the assessment professionals meet you in person to tell you about the diagnosis?
- ☐ Yes ☐ No
- IF YES, how long did they spend to tell you about the autism diagnosis?
- ☐ Less than 15 min
☐ 16-30min
☐ 31-45min
☐ 46-60min
☐ Over an hour, please specify how long _____
- n. What kind of services did the assessment team recommend and refer you to? (Check all that apply)
- ☐ Special education for Autism ☐ NGO supports

- ☐ Parent workshops ☐ Behavioral interventions (e.g., ABA, TEACCH)
☐ Speech therapy ☐ Occupational therapy
☐ Psychological support (counseling) ☐ Social welfare for disability
☐ Other _____ ☐ No, they did not refer any services

- o. Were you satisfied with how the assessment team answered your questions about your child's condition?
☐ Very Satisfied ☐ Satisfied ☐ Unsatisfied ☐ Very unsatisfied
- p. After your child's diagnosis, how long was it before you saw someone from the same specialist team?
☐ Within 1 month
☐ Within 3-6 months
☐ After six months, please specify how many months _____
☐ I did not see someone from the same specialist team after diagnosis
- q. How did you feel about the quality of the ASD assessment and diagnosis process?
☐ Very Satisfied ☐ Satisfied ☐ Unsatisfied ☐ Very unsatisfied

Current Health Care

1. Does your child still have follow-up appointments with the assessment team?
☐ Yes ☐ No

IF YES, how often are the appointments? Every ..

- ☐ 1-3 months
☐ 4-6 months
☐ 7-9 months
☐ 10-12 months
☐ if more than 12 months, please specify _____

2. What types of behavioral and medical treatments and therapies is your child currently receiving? (Check all the apply)
☐ Applied Behavioral Analysis (ABA) program
☐ TEACCH (Treatment and Education of Autistic and Related Communication-

Handicapped Children)

- ☐ Speech and language therapy (SLT)
☐ Occupational Therapy
☐ Social skills training or ESDM
☐ Counseling and psychotherapy, please specify _____
☐ SSRI (selective serotonin reuptake inhibitors)
☐ Melatonin
☐ Ritalin
☐ Special diets, such as gluten-free diets
☐ Vitamin supplements
☐ Anti-fungal medication
☐ Chelation therapy (e.g., remove mercury from the body)
☐ Acupuncture
☐ Other, please specify _____
☐ No, my child currently is not receiving any treatment

3. Is your child on any medications?
☐ Yes ☐ No

If yes, please specify what medications and the dose your child takes per day

4. How do you pay for the services your child receives?

5. Do you have health insurance/medical aid for your child?
☐ Yes ☐ No

6. Does your child's health insurance/medical aid offer benefits or cover services that meet [his/her] needs?
☐ All ☐ Most ☐ Some ☐ Little ☐ Never

7. Which services were you recommended that your health insurance/hospital or medical aid does not cover?

Part III. Social Support and Education Resources

Social Support

1. Among the following social services, which of them (1) do you know are available in your city/ town, (2) do you currently use, (3) do you need but don't have, and (3) are available but there is a waiting list or limited space? Please tick (V) accordingly.

	Available in my city/ town	We currently Use	We don't have but we need	Available but waiting list/limited space
Special education				
Community- funded therapy				
Community organizations				
Parent support or training workshops				
Counseling services				
Disability living allowance				
Career development for my adolescent or adult with ASD?				
Employment assistance for my adolescent or adult with ASD?				
Online support				
Day-to-day activities*				
Other, specify				

* "Day-to-day activities" include transportation, domestic help, hairdressing, etc

2. If you have difficulties with obtaining autism-related services for your child, what are the reasons?

☐ My child is not eligible ☐ Service is too far to use
☐ Waiting time is too long ☐ Service is too expensive, not affordable
☐ Service staff are not friendly
☐ Service is not culturally appropriate for my family or my child
☐ Services are not effective ☐ I do not have any difficulties
☐ Other, Please specify

Education

***For parents of adults with Autism Spectrum Disorder, 'current' education questions concern the school they attended the most**

4. Does your child currently attend school?

☐ Yes ☐ No

If not, please state why?

5. Has your child changed schools before

☐ Yes ☐ No

If yes,

5.1. How many schools has he/she attended _____

5.2. How long did he/she attend each school (in months and years)

6. In what grade is your child currently?

7. What type of school does your child go to?

☐ General public school

☐ Private School

☐ General public school with special needs supports

Please specify what special needs supports programs he/she attends at school

☐ Private school with special needs supports

Please specify what special needs supports programs he/she attends at school

☐ Public special-needs education school

☐ Private special-needs education school

☐ Autism –Specific school

☐ Home-schooled

8. After diagnosis, how long did it take before your child was accepted into an intervention/ educational program at school?

☐ Within 2 weeks* ☐ Less than 1 month ☐ 1 to 3 months

☐ 4 to 6 months ☐ 7 to 9 months ☐ 10 to 12 months

If more than 12 months please specify _____

Not in intervention ☐

9. How many hours per week does your child have one-to-one instruction class at school?

☐ Equal to or less than 5 hours a week

☐ Between 5 to 10 hours a week

☐ Between 11 to 15 hours a week

☐ Between 16 to 20 hours a week

☐ Between 21 to 25 hours a week

☐ Equal to or more than 26 hours a week (6)

☐ My child does not receive one-to-one instruction at school

10. What types of intervention programs is your child currently using in their school?

(Check all that apply)

- ☐ Applied Behavioral Analysis (ABA)

 ☐ Social skills training
☐ Solomon's PLAY model

 ☐ Social stories
☐ Picture Exchange Communication System (PECS)
☐ Makaton
☐ Auditory integration training
☐ Sensory Integration Therapy

 ☐ TEACCH
☐ Other, please specify _____
☐ I don't know

11. Are parent counseling and/or training included in your child's intervention program/ education?

- ☐ Yes ☐ No

12. How often do you communicate with your child's school?

- ☐ Daily ☐ Weekly ☐ Monthly ☐ Bimonthly ☐ Per Term
☐ Once a year ☐ Never

13. Do you feel that you are well-informed about your child's current education/ program?

- ☐ Yes definitely ☐ Yes to some extent ☐ No

Employment Sector

ONLY COMPLETE IF YOUR CHILD IS OVER 16/ 18 YEARS OLD; IF YOUR CHILD IS YOUNGER PLEASE GO TO THE NEXT SECTION, PART IV

Please complete this section with your child if appropriate

1. Is your adult child currently employed?

- ☐ Yes, employed with regular salary
☐ Yes, but works voluntarily without salary
☐ No, he/ she is not employed at present.
☐ No, my child is not currently employed, but has been looking for a job for
 _____ months _____ years

2. Has your child received career development or job training from an NGO or government agency?
☐ Yes ☐ No

If your adult child is NOT employed please skip questions 2-6 to the next section, part IV

3. What is your child's job? _____
4. How many hours per week does your child work?
☐ Less than 5 hours a week
☐ 6-9 hours a week
 If more than 10 hours a week please specify _____

5. Does your child's employer know of your child's condition?
☐ Yes ☐ No

If yes, has the employer made any adjustments for the child?

☐ Yes ☐ No

If yes, what adjustments have been made?

6. Do your child's coworkers know of his condition?
☐ Yes ☐ No
7. In your opinion, is your child making as much money as other employees in a similar position?
☐ Yes, they are making the equivalent amount of money as other employees
☐ No, they are making less than other employees
8. Does your child's work place receive supports for individuals with autism? (Check all that apply)
☐ From government ☐ From local NGO ☐ From company
☐ No, no support at all ☐ I don't know

Part IV. Social and Economic Costs

Impact on the Family

4. Do you feel that you are able to access relevant services for your child based on the language you speak?

☐ Yes ☐ No

5. How much government allowance/child care dependency grant do you currently receive per month? (If parent of an adult with ASD, do you receive an adult dependency grant?)

6. Based on the therapies and treatments used as a result of your child's diagnosis, how much did you have to pay out of pocket for the following services during the past 12 months?

	Cost [Local Currency]	Percentages of Insurance or Government Coverage (%, 100% = full coverage)
Medical services and medication		%
Behavioral Therapies (ABA, TEEACH, etc)		%
Occupational Therapy		%
Speech and language therapy		%
Education		%
Other, Please Specify _____		%

☐ None, I have not used any medical or other treatment services

7. How many hours per week do you or other family members spend arranging or coordinating your child's care (including transportation)?

☐ Less than or equal to 1 hour a week

☐ Between 2 to 4 hours a week

☐ Between 5 to 7 hours a week

☐ More than or equal to 8 hours a week

8. Has your child's diagnosis of autism created financial problems for your family?

☐ Yes definitely ☐ Yes to some degree

___ Only a little ___ Never

9. Have you or other family members stopped working because of your child's diagnosis? ___ Yes ___ No

10. Have you or other family members cut down on the hours you work because of your child's diagnosis?
___ Yes ___ No

11. Have you or other family members avoided changing jobs because of your child?
___ Yes ___ No

Any other comments/ thoughts on your child's services? Please use the space below to elaborate.

Thank you very much for your participation in the survey. The survey findings will be available at xxx in xxx. We are planning to conduct individual life-story interviews with parents of children with autism to hear about their experiences of living with the condition. If you'd like to share your stories, please contact us at xxx.

APPENDIX T: CONSENT FORM PARENTS OF CHILDREN WITH ASD

Principal Researchers:

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University of Cape Town

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13.1. Invitation and Purpose

You are invited to take part in a research study about the services provided to individuals on the autism spectrum and their families as well as the impact service delivery may have on the quality of life of the parents of autism spectrum disorder (ASD) children. I am a researcher from the Department of Psychology at the University of Cape Town. This study aims to obtain a greater understanding of the services provided (and those not provided) to individuals with autism and their families, as well as the impact aspects of service delivery have on the quality of life of individuals with autism and their families. This study will help provide key information regarding the shortfalls and limitations of the services provided and will help improve future services for individuals with autism which may in turn aid in improving the quality of life of individuals with autism and their families. Approximately 150 parents of children with autism will participate in this study.

13.2. Procedures

If you decide to take part in this study, we will ask you complete a series of questionnaires and surveys relating to service delivery and quality of life. This will last between 60-90minutes. You may withdraw from the session at any time if you feel uncomfortable. You can come in to complete the survey or you could complete an online survey that would be sent to you via

email. You have the option of participating in the second session involving focus groups with 4 other parents to discuss various topics concerning service delivery and quality of life in parents of children with autism. You do not have to participate in the second session, this participation is optional even if you are participating in the first session. If you are asked to partake in the focus group session, this session will last 90 minutes. You will be allowed to take breaks whenever requested during the sessions.

13.3. Risks, Discomforts & Inconveniences

If you decide to take part in this study you will be exposed to no physical, social, or psychological risk. You will not be asked to perform any potentially harmful tasks. You will be able to withdraw from the study at any time, with no penalty and with no effect upon clinical or other services being delivered (or potentially being delivered).

13.4. Benefits

Although there are no direct benefits by participating in this study, the information from this study may help improve our understanding of what services are (and are not) provided to individuals with autism and their families. This information may also provide us with a better understanding of the quality of life of parents with children with autism as well as the possible impact service delivery may have on the quality of life of parents of children with autism within South Africa. This study also aims to provide information to help lobby for better service provision for the autism community.

13.5. Privacy and Confidentiality

Information collected during each session will be stored in locked filing cabinets or in computers with security passwords. Only certain people have the right to review these research records. These people include the researchers for this study and certain University of Cape Town officials.

13.6. Money Matters

Participants will not incur any costs when participating in this study. A small compensation of R100 will be provided to all participants that come in to complete the survey.

7. Questions

If you have questions or concerns about the study please contact the principal investigator Susan Malcolm-Smith, PhD: (office) 021-650-4605 (email) susanmalcolmsmith@gmail.com , Kevin G. F. Thomas, PhD: (office) 021-650-4608 (email) Kevin.Thomas@uct.ac.za, or Natalia M. Ing (cell) 071-689-5843 (email) Natalia.Ing@uct.ac.za.

Consent Form

The study has been explained to me, and my questions have been answered.

I understand that participation in this study is voluntary, and that I may withdraw at any point.

I understand that I will not be identified except by an initial, and that this anonymity will be maintained throughout the study and when the research is published.

I consent to participate in the survey component of this study.

Parent's name _____

Signature of parent _____

Date _____

Please select one of the options below:

____ I would like to come in and complete the survey in person with the researcher

____ I would like to be sent a link via email to complete the survey online

Use of Samples/Data for Future Research

With your permission, we would like to store the unused parts of your tests for use in future research. This is your choice entirely and you are free to say no and you will still be able to take part in the study. Please check the boxes that apply to your choice:

I do not want my samples to be used for any future research. ____

You may use my samples for any future research. ____

Please indicate below if you would like to be notified of future research projects conducted by our research group:

_____ (initial) Yes, I would like to be added to your research participation pool and be notified of research projects in which I might participate in the future.

Would you like to partake in a focus group session with 4 other parents?

YES

NO

I consent to participate in the focus group component of this study.

Parent's name _____

Signature of parent _____

Date _____

Method of contact:

Phone number: _____

Cell phone number: _____

E-mail address: _____

Mailing address: _____

Researcher section:

I have explained the study to the participant, and in my opinion s/he understands that participation is voluntary and is able to give informed consent.

Researcher _____

Signature _____

Date _____

APPENDIX U: TABLE CONTAINING WHOQOL-BREF Z SCORE NORMATIVE DATA PARENTS OF CHILDREN WITH ASD

Table 11.

WHOQOL Z-scores Normative Data: Parents of children with ASD (N =200).

Participants	Physical Domain Z-Score	Physical Domain (M)	Psychological Domain Z-Score	Psychological Domain (M)	Social Relationship Domain Z-Score	Social Relationship Domain (M)	Environment Domain Z-Score	Environment Domain (M)
1	0,77	69,7	0,38	70,3	-0,78	68,6	1,14	76
2	-0,60	77,5	-0,82	71,1	-1,08	76,8	-0,02	72,7
3	-0,65	80,3	-0,30	73,6	-0,74	74,8	-0,67	73,4
4	0,19	80,3	-0,02	73,6	-0,41	74,8	-0,27	73,4
5	-0,08	78,6	0,49	73,9	-0,27	72,1	-0,37	75,5
6	-1,28	80,3	-1,13	73,6	0,26	74,8	-0,87	73,4
7	-0,89	82,6	-1,80	73,7	-0,51	74,4	-3,74	79
8	-0,44	80,3	-0,58	73,6	-0,07	74,8	-1,47	73,4
9	-0,75	84,3	0,00	73,4	-0,99	72,1	-0,91	72,9
10	-1,48	77,5	-2,55	71,1	-1,93	76,8	-0,21	72,7
11	0,24	78,6	0,76	73,9	1,05	72,1	1,32	75,5
12	-0,89	77,5	-1,56	71,1	-2,36	76,8	1,17	72,7
13	0,24	78,6	-3,54	73,9	-2,24	72,1	0,30	75,5
14	-2,12	80,3	-1,13	73,6	-1,08	74,8	-1,47	73,4
15	-1,49	80,3	-2,24	73,6	-1,08	74,8	-2,27	73,4
16	0,61	80,3	0,81	73,6	0,60	74,8	-0,67	73,4
17	1,24	80,3	1,64	73,6	0,93	74,8	0,13	73,4
18	-2,64	77,5	-2,55	71,1	-1,93	76,8	-2,20	72,7
19	-0,73	78,6	-0,85	73,9	-0,27	72,1	0,64	75,5
20	-0,02	77,5	-0,58	71,1	0,21	76,8	-0,81	72,7
21	-0,02	80,3	0,53	73,6	0,60	74,8	0,13	73,4
22	-0,60	77,5	0,66	71,1	-0,22	76,8	-0,21	72,7
23	-1,49	80,3	-1,69	73,6	-1,75	74,8	-0,47	73,4
24	-1,33	77,5	-2,30	71,1	-1,08	76,8	-2,00	72,7

25	-0,02	77,5	0,41	71,1	-0,22	76,8	0,58	72,7
26	-0,60	77,5	-1,07	71,1	-3,64	76,8	-2,60	72,7
27	-0,02	80,3	0,26	73,6	0,93	74,8	0,53	73,4
28	-0,46	77,5	0,66	71,1	0,63	76,8	0,38	72,7
29	0,40	80,3	0,81	73,6	1,27	74,8	-0,67	73,4
30	-0,23	80,3	-0,58	73,6	-1,08	74,8	-0,07	73,4
31	-0,50	70	-1,00	71,7	-0,86	69,2	-1,68	72
32	-0,75	77,5	-0,08	71,1	0,21	76,8	0,18	72,7
33	-0,89	77,5	-3,04	71,1	-0,65	76,8	-0,61	72,7
34	0,13	77,5	0,41	71,1	-1,08	76,8	1,37	72,7
35	0,27	77,5	0,66	71,1	-0,22	76,8	1,17	72,7
36	0,82	80,3	1,64	73,6	0,93	74,8	0,73	73,4
37	0,56	82,6	-1,29	73,7	-1,82	74,4	0,09	79
38	-1,33	77,5	-1,32	71,1	-0,22	76,8	-1,60	72,7
39	-0,57	83,6	0,02	69,7	-1,46	75,6	-1,91	72,7
40	-1,07	80,3	-0,58	73,6	-0,41	74,8	-0,67	73,4
41	0,19	80,3	1,09	73,6	-0,07	74,8	-1,27	73,4
42	-0,86	80,3	-1,69	73,6	0,26	74,8	-0,47	73,4
43	-0,60	77,5	-0,33	71,1	-0,65	76,8	-0,02	72,7
44	0,42	77,5	0,66	71,1	-0,22	76,8	0,78	72,7
45	-2,34	78,6	-3,81	73,9	-1,91	72,1	-1,89	75,5
46	0,61	80,3	0,26	73,6	0,26	74,8	0,53	73,4
47	-1,77	77,5	-2,80	71,1	-3,64	76,8	-2,60	72,7
48	0,93	70	0,78	71,7	0,94	69,2	-0,15	72
49	-0,57	83,6	-0,17	69,7	-0,58	75,6	-2,14	72,7
50	0,42	77,5	-0,58	71,1	0,63	76,8	-0,41	72,7
51	0,40	78,6	0,22	73,9	0,72	72,1	1,15	75,5
52	-1,07	80,3	-0,58	73,6	-0,41	74,8	-1,87	73,4
53	0,71	77,5	0,66	71,1	0,21	76,8	0,98	72,7
54	0,19	83,6	0,95	69,7	0,29	75,6	-0,02	72,7
55	0,93	70	0,78	71,7	0,58	69,2	0,42	72

56	-1,04	77,5	-2,06	71,1	-1,08	76,8	-0,41	72,7
57	0,13	77,5	0,66	71,1	-2,36	76,8	0,58	72,7
58	-0,89	88,7	-0,65	74,3	-0,35	68,1	-1,39	77,2
59	0,27	77,5	1,15	71,1	0,63	76,8	0,58	72,7
60	0,21	70	0,55	71,7	0,22	69,2	-0,34	72
61	-0,46	77,5	-1,81	71,1	-1,08	76,8	-0,21	72,7
62	-0,86	80,3	-1,97	73,6	-2,08	74,8	0,33	73,4
63	0,08	78,6	0,22	73,9	0,06	72,1	-0,54	75,5
64	-1,84	83,6	-0,54	69,7	-1,46	75,6	-2,61	72,7
65	0,93	70	1,00	71,7	0,22	69,2	0,80	72
66	-1,84	83,6	0,02	69,7	-1,46	75,6	-2,14	72,7
67	0,08	78,6	-0,58	73,9	0,06	72,1	-1,55	75,5
68	-0,89	78,6	-1,39	73,9	0,06	72,1	-1,39	75,5
69	-1,07	80,3	-1,13	73,6	-2,08	74,8	-0,47	73,4
70	0,40	80,3	0,26	73,6	-0,07	74,8	0,93	73,4
71	0,27	77,5	0,17	71,1	-1,50	76,8	-0,02	72,7
72	1,15	77,5	0,66	71,1	0,21	76,8	1,57	72,7
73	-0,73	78,6	-2,73	73,9	-1,25	72,1	-1,72	75,5
74	-1,77	77,5	-1,81	71,1	-2,79	76,8	-1,40	72,7
75	-0,24	78,6	-0,05	73,9	0,39	72,1	0,98	75,5
76	-1,04	77,5	-0,82	71,1	-1,08	76,8	0,58	72,7
77	-0,75	77,5	-1,32	71,1	-1,08	76,8	-0,61	72,7
78	-0,21	70	-0,34	71,7	-0,50	69,2	-1,68	72
79	-1,28	80,3	-1,97	73,6	-1,08	74,8	-0,87	73,4
80	0,24	78,6	0,22	73,9	0,39	72,1	-0,20	75,5
81	0,13	77,5	-1,07	71,1	0,21	76,8	-0,21	72,7
82	-0,21	70	-0,78	71,7	-0,50	69,2	-1,49	72
83	-0,46	77,5	-0,82	71,1	-0,22	76,8	-1,60	72,7
84	-0,44	80,3	0,53	73,6	1,27	74,8	-0,67	73,4
85	0,61	80,3	0,81	73,6	0,60	74,8	0,13	73,4
86	-0,46	77,5	-1,07	71,1	-1,50	76,8	-0,02	72,7

87	-1,70	80,3	-3,63	73,6	-1,08	74,8	-2,67	73,4
88	0,40	78,6	0,22	73,9	0,39	72,1	-0,37	75,5
89	-0,31	77,5	1,40	71,1	0,63	76,8	0,98	72,7
90	-1,33	83,6	0,58	69,7	-0,15	75,6	-0,96	72,7
91	0,82	80,3	-0,30	73,6	-0,07	74,8	0,73	73,4
92	0,27	77,5	0,17	71,1	-1,08	76,8	0,58	72,7
93	-0,86	80,3	0,26	73,6	-0,07	74,8	-0,07	73,4
94	-0,07	83,6	0,58	69,7	0,29	75,6	0,69	72,7
95	0,13	77,5	0,41	71,1	1,49	76,8	1,57	72,7
96	0,42	77,5	-1,07	71,1	-0,22	76,8	1,77	72,7
97	-0,31	77,5	0,66	71,1	0,21	76,8	-0,21	72,7
98	-1,91	80,3	-3,08	73,6	-1,75	74,8	-2,27	73,4
99	-0,02	80,3	0,81	73,6	-0,41	74,8	-0,67	73,4
100	1,53	74,1	1,57	69,8	0,88	70,8	1,46	76,2
101	0,56	77,5	1,40	71,1	0,21	76,8	1,77	72,7
102	0,50	70	-1,00	71,7	-0,86	69,2	-1,30	72
103	-0,31	77,5	0,41	71,1	-1,50	76,8	-0,02	72,7
104	-0,44	80,3	-0,02	73,6	-0,07	74,8	-0,47	73,4
105	0,21	70	0,33	71,7	0,58	69,2	-0,53	72
106	0,19	80,3	0,26	73,6	-0,07	74,8	0,33	73,4
107	0,71	77,5	1,65	71,1	0,63	76,8	1,17	72,7
108	-1,77	77,5	-2,80	71,1	-1,08	76,8	0,98	72,7
109	-0,16	77,5	-0,08	71,1	-0,65	76,8	-0,02	72,7
110	-1,07	80,3	-1,13	73,6	-1,08	74,8	-2,27	73,4
111	-1,37	78,6	-1,12	73,9	-0,92	72,1	-1,39	75,5
112	-0,86	80,3	-0,30	73,6	-0,07	74,8	0,13	73,4
113	-0,16	77,5	0,91	71,1	1,49	76,8	-0,21	72,7
114	-1,49	80,3	-2,24	73,6	-1,08	74,8	-1,67	73,4
115	-1,04	77,5	-1,32	71,1	0,63	76,8	-1,01	72,7
116	0,40	80,3	-1,41	73,6	-1,41	74,8	-0,27	73,4
117	-0,31	77,5	-1,07	71,1	-1,08	76,8	-1,01	72,7

118	-0,89	77,5	0,17	71,1	-1,08	76,8	-1,80	72,7
119	0,40	80,3	0,53	73,6	0,26	74,8	-0,07	73,4
120	-1,08	83,6	0,02	69,7	0,29	75,6	-2,85	72,7
121	-1,18	77,5	-0,82	71,1	-1,93	76,8	-0,81	72,7
122	-1,91	80,3	-1,13	73,6	-0,74	74,8	-1,27	73,4
123	0,56	77,5	0,41	71,1	0,21	76,8	0,78	72,7
124	0,42	77,5	-0,33	71,1	-0,65	76,8	-1,01	72,7
125	-0,16	77,5	-0,08	71,1	-0,65	76,8	-0,02	72,7
126	-1,07	80,3	-2,52	73,6	-0,41	74,8	-3,47	73,4
127	-0,89	77,5	-0,58	71,1	0,21	76,8	-0,81	72,7
128	-0,75	77,5	-1,56	71,1	-1,50	76,8	-0,41	72,7
129	0,79	70	0,55	71,7	0,58	69,2	0,04	72
130	-2,34	83,6	-0,91	69,7	-0,15	75,6	-2,61	72,7
131	-1,91	80,3	-0,02	73,6	-1,08	74,8	-3,07	73,4
132	-0,57	83,6	0,58	69,7	0,29	75,6	-2,61	72,7
133	0,40	78,6	0,76	73,9	0,88	72,1	-0,20	75,5
134	-0,86	80,3	-0,02	73,6	-0,07	74,8	-2,07	73,4
135	-0,02	80,3	-1,97	73,6	-0,41	74,8	-1,67	73,4
136	-0,02	80,3	-1,13	73,6	0,26	74,8	-1,27	73,4
137	-0,65	80,3	-0,02	73,6	-1,41	74,8	-2,47	73,4
138	-0,65	80,3	0,81	73,6	0,60	74,8	-1,07	73,4
139	-0,31	77,5	-1,32	71,1	-1,93	76,8	-1,60	72,7
140	0,40	80,3	0,26	73,6	-0,41	74,8	-2,27	73,4
141	-3,15	78,6	-3,00	73,9	-2,24	72,1	-2,57	75,5
142	-2,64	74,1	-1,02	69,8	0,88	70,8	-3,39	76,2
143	-1,49	80,3	-1,97	73,6	-1,08	74,8	-2,47	73,4
144	-2,59	83,6	0,02	69,7	0,72	75,6	-3,08	72,7
145	1,03	80,3	-0,02	73,6	-0,74	74,8	-3,47	73,4
146	-0,89	82,6	-0,28	73,7	0,37	74,4	-0,36	79
147	0,02	82,6	0,48	73,7	-0,07	74,4	-0,36	79
148	-1,37	78,6	-1,12	73,9	-0,60	72,1	-0,88	75,5

149	-1,61	84,3	-0,61	73,4	-0,29	72,1	-2,33	72,9
150	-0,86	80,3	-0,58	73,6	-1,08	74,8	-0,87	73,4
151	-0,75	77,5	-1,32	71,1	-2,79	76,8	-0,81	72,7
152	-0,23	80,3	-0,58	73,6	0,60	74,8	-0,07	73,4
153	-1,70	80,3	-2,80	73,6	-1,41	74,8	-2,87	73,4
154	-0,75	77,5	0,17	71,1	-1,08	76,8	-2,00	72,7
155	-0,31	77,5	0,17	71,1	-0,22	76,8	-0,41	72,7
156	0,71	77,5	1,15	71,1	-1,08	76,8	0,58	72,7
157	0,27	77,5	-1,56	71,1	0,63	76,8	-0,61	72,7
158	0,40	80,3	0,81	73,6	-0,07	74,8	0,53	73,4
159	0,07	70	-0,78	71,7	0,22	69,2	-1,68	72
160	-0,65	80,3	-0,02	73,6	0,26	74,8	-0,27	73,4
161	1,36	70	1,44	71,7	1,66	69,2	0,99	72
162	0,13	77,5	1,15	71,1	1,49	76,8	0,58	72,7
163	-1,70	80,3	-0,58	73,6	-1,08	74,8	-2,67	73,4
164	-1,07	80,3	-0,30	73,6	-0,07	74,8	-0,47	73,4
165	-1,28	80,3	-1,97	73,6	-1,25	74,8	-0,47	73,4
166	-1,49	80,3	-0,30	73,6	0,26	74,8	-0,07	73,4
167	0,71	77,5	0,91	71,1	-0,65	76,8	1,97	72,7
168	0,56	77,5	1,40	71,1	0,63	76,8	0,38	72,7
169	0,72	78,6	1,03	73,9	-1,25	72,1	0,14	75,5
170	0,02	82,6	0,98	73,7	1,25	74,4	0,09	79
171	0,13	77,5	0,66	71,1	0,63	76,8	-0,21	72,7
172	-1,91	80,3	-0,86	73,6	-0,41	74,8	-1,67	73,4
173	-0,57	83,6	-1,29	69,7	-2,76	75,6	-3,08	72,7
174	-0,86	80,3	0,26	73,6	-0,74	74,8	-3,27	73,4
175	-1,18	77,5	-1,32	71,1	-2,36	76,8	-2,40	72,7
176	-0,16	77,5	0,66	71,1	-0,22	76,8	-0,61	72,7
177	0,21	70	1,00	71,7	1,30	69,2	-0,53	72
178	-0,86	80,3	-0,58	73,6	-2,08	74,8	-1,47	73,4
179	-1,48	77,5	0,17	71,1	1,06	76,8	-1,80	72,7

180	0,56	78,6	0,49	73,9	0,39	72,1	0,81	75,5
181	0,56	78,6	1,03	73,9	0,39	72,1	-0,03	75,5
182	-1,07	80,3	1,09	73,6	0,26	74,8	-0,27	73,4
183	-0,89	77,5	-1,07	71,1	-1,08	76,8	-1,40	72,7
184	-0,02	77,5	0,66	71,1	-1,08	76,8	-0,81	72,7
185	-0,89	82,6	-0,53	73,7	-0,95	74,4	-3,29	79
186	-2,12	80,3	-1,69	73,6	-2,08	74,8	-2,07	73,4
187	0,64	70	0,33	71,7	0,58	69,2	-0,73	72
188	-1,21	78,6	-2,20	73,9	-2,24	72,1	-1,22	75,5
189	-1,05	78,6	0,22	73,9	-0,60	72,1	-1,72	75,5
190	0,69	83,6	0,76	69,7	-0,58	75,6	-2,85	72,7
191	0,42	77,5	1,15	71,1	0,63	76,8	0,98	72,7
192	0,27	77,5	-0,08	71,1	-0,22	76,8	1,37	72,7
193	0,44	83,6	0,95	69,7	0,72	75,6	-1,20	72,7
194	-2,85	83,6	-1,66	69,7	-1,89	75,6	-3,32	72,7
195	0,40	78,6	-0,05	73,9	0,06	72,1	-0,03	75,5
196	-1,49	80,3	-0,58	73,6	-1,41	74,8	-0,87	73,4
197	-1,91	80,3	-0,30	73,6	0,26	74,8	-1,87	73,4
198	-1,08	83,6	0,20	69,7	-1,46	75,6	-1,43	72,7
199	-0,23	80,3	1,09	73,6	0,26	74,8	-1,87	73,4
200	0,61	80,3	1,92	73,6	0,60	74,8	1,33	73,4

APPENDIX V: SCORES DERIVED FROM WUN SCOPING SURVEY FOR PATH ANALYSIS

Diagnosis and Education.

To obtain the diagnosis and education score, items within the diagnostic and education sections of the WUN Scoping Survey were rated and collated. The scores derived for each item is indicated in the brackets in blue. The items from the survey included:

16. How long did it take for you to bring your child to the doctor from when you first observed the symptoms?

___ Within a month (7)

___ 2 -3 months (6)

___ 4-5 months (5)

___ 6-7 months (4)

___ 8-9 months (3)

___ 10-11 months (2)

___ 12 months (1)

___ More than 12 months (0)

17. Did the healthcare professional(s) you first consulted mention autism spectrum conditions at all as a possible diagnosis for your child in your first contact with services?

___ Yes (1)

___ No (0)

18. Did the healthcare professional provide/refer you to any services for the child (i.e. pre-school, speech and language therapy, others) while you waited to be seen for the diagnosis?

___ Yes (1)

___ No (0)

19. How many referrals did you receive before going to the diagnostic assessment?

___ More than 1 referral (0)

___ None (1)

20. Prior to the diagnostic assessment, did you know how much the assessment would cost?

___ Yes (1)

___ No (0)

21. Prior to the diagnostic assessment, did you know how long you would have to wait to get an assessment?

___ Yes (1)

___ No (0)

22. Prior to the diagnostic assessment, did you know the name of the clinician who would see your child for the diagnostic assessment?

___ Yes (1)

___ No (0)

23. Prior to the diagnostic assessment, did you know the title/profession of the clinician who would see your child for the diagnostic assessment?

___ Yes (1)

___ No (0)

24. Prior to the diagnostic assessment, did you know how long the assessment process would last?

___ Yes (1)

___ No (0)

25. Prior to the diagnostic assessment, did you know what types of assessment would be conducted?

___ Yes (1)

___ No (0)

26. Prior to the diagnostic assessment, did you know the number of appointments the assessment would take?

___ Yes (1)

___ No (0)

27. Which healthcare professionals were present during the assessment? (Check all that all apply) [Add up the total amount of professionals consulted.]

- ☐ Medical doctor ☐ Specialist Doctor ☐ Psychologist
☐ Psychiatrist ☐ Speech Therapist ☐ Occupational Therapist
☐ Nurse ☐ I didn't know who they were
☐ They told me who they were, but I don't remember anymore.

28. Were you able to observe the child during the assessment?

- ☐ Yes (1)
☐ No (0)

29. What did the assessment comprise of? (Check all that apply) [Add up the number selected.]

- ☐ Family history ☐ Observation of the child's behavior
☐ Cognitive assessment ☐ Assessment of child's speech/ language
☐ Physical assessment ☐ Blood and urine test
☐ MRI scan ☐ DNA analysis
☐ Therapy needs assessment ☐ Family needs assessment

30. Did you attend more than one appointment during the assessment process?

- ☐ Yes (0)
☐ No (1)

31. How long did the whole assessment process take (this may be over one or several appointments)?

- ☐ Less than 1 hour in total for all assessment appointments (4)
☐ 1 hour to 2 hours in total (3)
☐ 3 hours to 4 hours in total (2)
☐ 5 hours (1)

If more than 5 hours, please specify _____ (0)

32. How long did it take until you received the diagnosis?

- ☐ I was informed of the diagnosis of Autism Spectrum Disorder on the same day of the assessment (5)

___ Within a week (4)

___ 2-3 weeks (3)

___ 4-5 weeks (2)

___ 6-7 weeks (1)

If more than 7 weeks please specify how long ____ (0)

33. After the assessment, did you receive a written report of the assessment?

34.

___ Yes, I received it and understood the assessment findings and diagnosis (3)

___ Yes, I received it but I only understood some of the assessment outcome findings (2)

___ Yes, I received it but I did not understand most of it (1)

___ No, I did not receive the report of the assessment (0)

35. After the completion of the assessment, did the assessment professionals meet you in person to tell you about the diagnosis?

___ Yes (1)

___ No (0)

IF YES, how long did they spend to tell you about the autism diagnosis?

___ Less than 15 min (0)

___ 16-30min (1)

___ 31-45min (2)

___ 46-60min (3)

___ Over an hour, please specify how long ____ (4)

36. What kind of services did the assessment team recommend and refer you to? (Check all that apply) [Add up total amount selected]

___ Special education for Autism

___ NGO supports

___ Parent workshops

___ Behavioral interventions (e.g., ABA, TEACCH)

___ Speech therapy

___ Occupational therapy

___ Psychological support (counseling)

___ Social welfare for disability

37. Were you satisfied with how the assessment team answered your questions about your child's condition?

___ Very Satisfied (3)

___ Satisfied (2)

___ Unsatisfied (1)

___ Very unsatisfied (0)

38. After your child's diagnosis, how long was it before you saw someone from the same specialist team?

___ Within 1 month (3)

___ Within 3-6 months (2)

___ After six months, please specify how many months _____ (1)

___ I did not see someone from the same specialist team after diagnosis (0)

39. How did you feel about the quality of the ASD assessment and diagnosis process?

___ Very Satisfied (3)

___ Satisfied (2)

___ Unsatisfied (1)

___ Very unsatisfied (0)

40. Does your child currently attend school?

___ Yes (1)

___ No (0)

41. Has your child changed schools before

___ Yes (0)

___ No (1)

42. After diagnosis, how long did it take before your child was accepted into an intervention/ educational program at school?

- ☐ Within 2 weeks* (7)
☐ Less than 1 month (6)
☐ 1 to 3 months (5)
☐ 4 to 6 months (4)
☐ 7 to 9 months (3)
☐ 10 to 12 months (2)
 If more than 12 months please specify _____ (1)
 Not in intervention ☐ (0)

43. How many hours per week does your child have one-to-one instruction class at school?

- ☐ Equal to or less than 5 hours a week (1)
☐ Between 5 to 10 hours a week (2)
☐ Between 11 to 15 hours a week (3)
☐ Between 16 to 20 hours a week (4)
☐ Between 21 to 25 hours a week (5)
☐ Equal to or more than 26 hours a week (6)
☐ My child does not receive one-to-one instruction at school (0) DK (0)

14. What types of intervention programs is your child currently using in their school?
 (Check all that apply) [\[Add up total amount selected\]](#)

- ☐ Applied Behavioral Analysis (ABA)
☐ Social skills training
☐ Solomon's PLAY model
☐ Social stories
☐ Picture Exchange Communication System (PECS)
☐ Makaton
☐ Auditory integration training
☐ Sensory Integration Therapy
☐ TEACCH

44. Are parent counseling and/or training included in your child's intervention program/ education?

___ Yes (1)

___ No (0)

45. How often do you communicate with your child's school?

___ Daily (6)

___ Weekly (5)

___ Monthly (4)

___ Bimonthly (3)

___ Per Term (2)

___ Once a year (1)

___ Never (0)

46. Do you feel that you are well-informed about your child's current education/ program?

___ Yes definitely (2)

___ Yes to some extent (1)

___ No (0)

Current Healthcare items

To obtain the current healthcare score, items within the healthcare section of the WUN Scoping Survey were rated and collated. The scores derived for each item is indicated in the brackets in blue. The items from the survey included:

3. Does your child still have follow-up appointments with the assessment team?

___ Yes (1)

___ No (0)

IF YES, how often are the appointments? Every ..

___ 1-3 months (4)

___ 4-6 months (3)

___ 7-9 months (2)

___10-12 months (1)

___if more than 12 months, please specify___ (0)

4. What types of behavioral and medical treatments and therapies is your child currently receiving? (Check all the apply) [Add up total amount selected]

___ Applied Behavioral Analysis (ABA) program

___ TEACCH (Treatment and Education of Autistic and Related Communication-
Handicapped Children)

___ Speech and language therapy (SLT)

___ Occupational Therapy

___ Social skills training or ESDM

___ Counseling and psychotherapy, please specify _____

___ SSRI (selective serotonin reuptake inhibitors)

___ Melatonin

___ Ritalin

___ Special diets, such as gluten-free diets

___ Vitamin supplements

___ Anti-fungal medication

___ Chelation therapy (e.g., remove mercury from the body)

___ Acupuncture

___ Other, please specify _____

___ No, my child currently is not receiving any treatment

8. Do you have health insurance/medical aid for your child?

___ Yes (1)

___ No (0)

9. Does your child's health insurance/medical aid offer benefits or cover services that meet [his/her] needs?

___ All (4)

___ Most (3)

___ Some (2)

___ Little (1)

___ Never (0)

5. If you have difficulties with obtaining autism-related services for your child, what are the reasons? [\[Add up total amount selected\]](#)

___ My child is not eligible

___ Service is too far to use

___ Waiting time is too long

___ Service is too expensive, not affordable

___ Service staff are not friendly

___ Service is not culturally appropriate for my family or my child

___ Services are not effective

APPENDIX W: PATH ANALYSIS: MODEL ITERATIONS

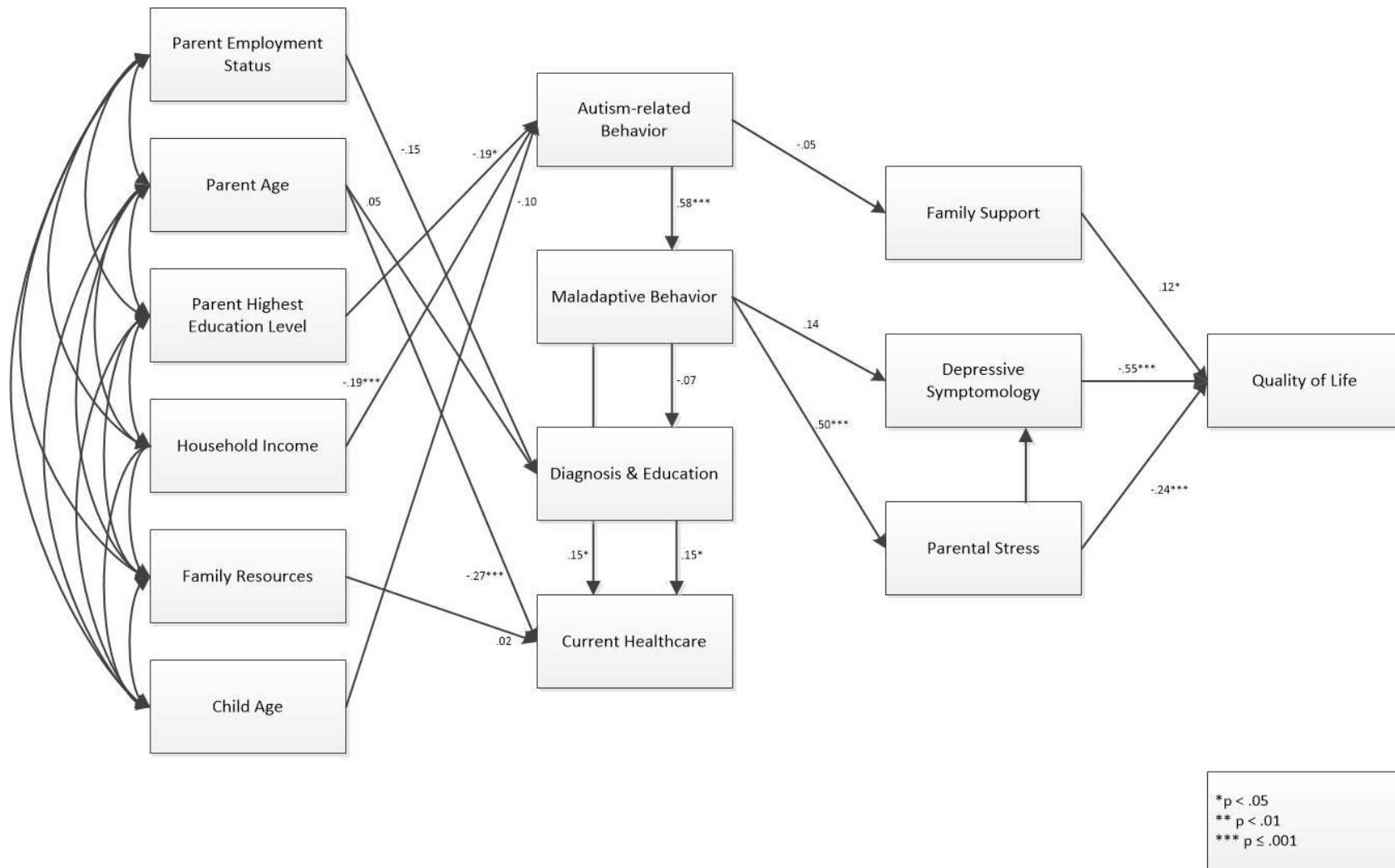


Figure 26. Path Analysis: Examining the pathways between child's age, ASD severity, family SES, service delivery experiences, parent's psychological distress, and parental QoL (Model 1).

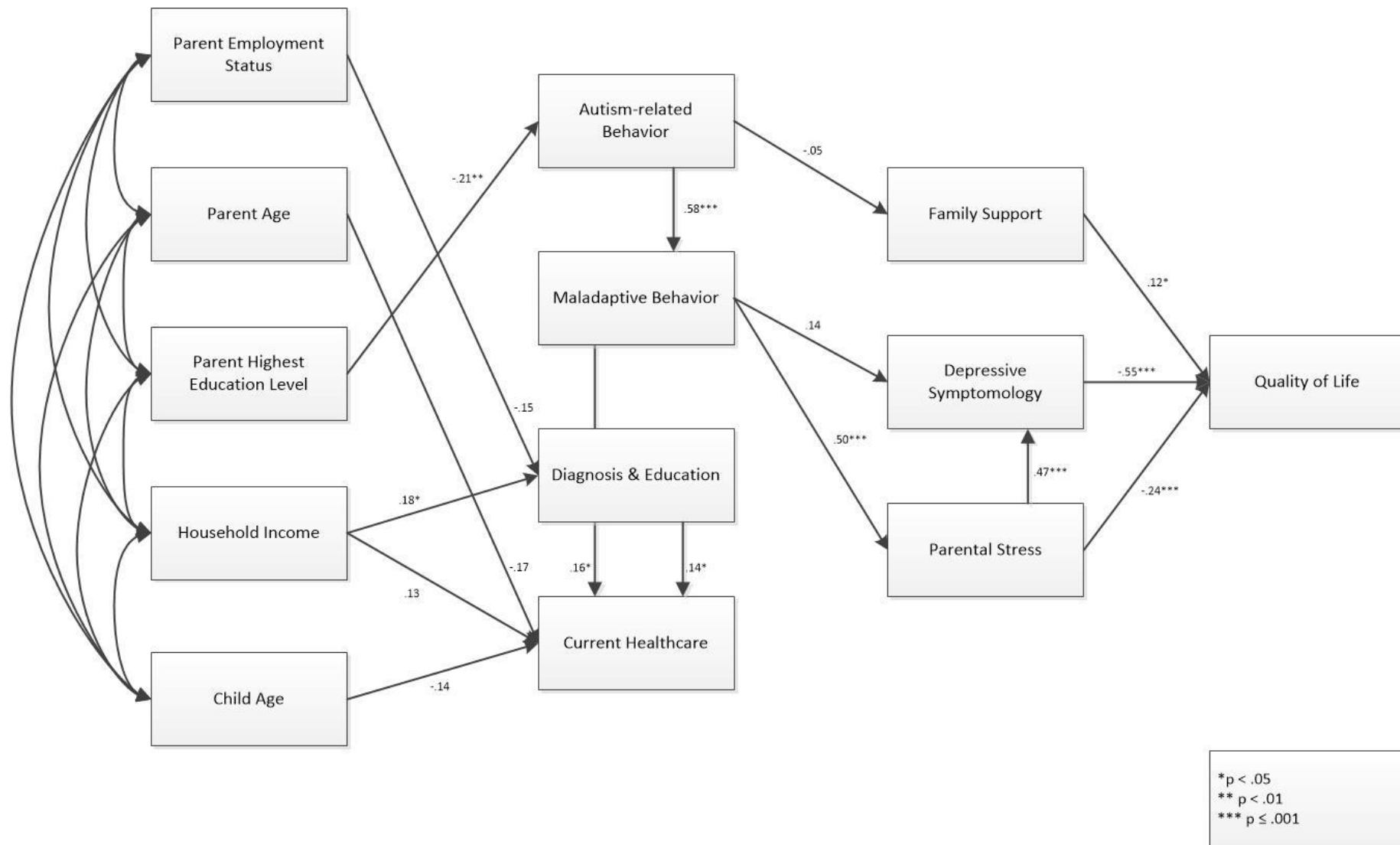


Figure 27. Path Analysis: Examining the pathways between child's age, ASD severity, family SES, service delivery experiences, parent's psychological distress, and parental QoL (Model 2).

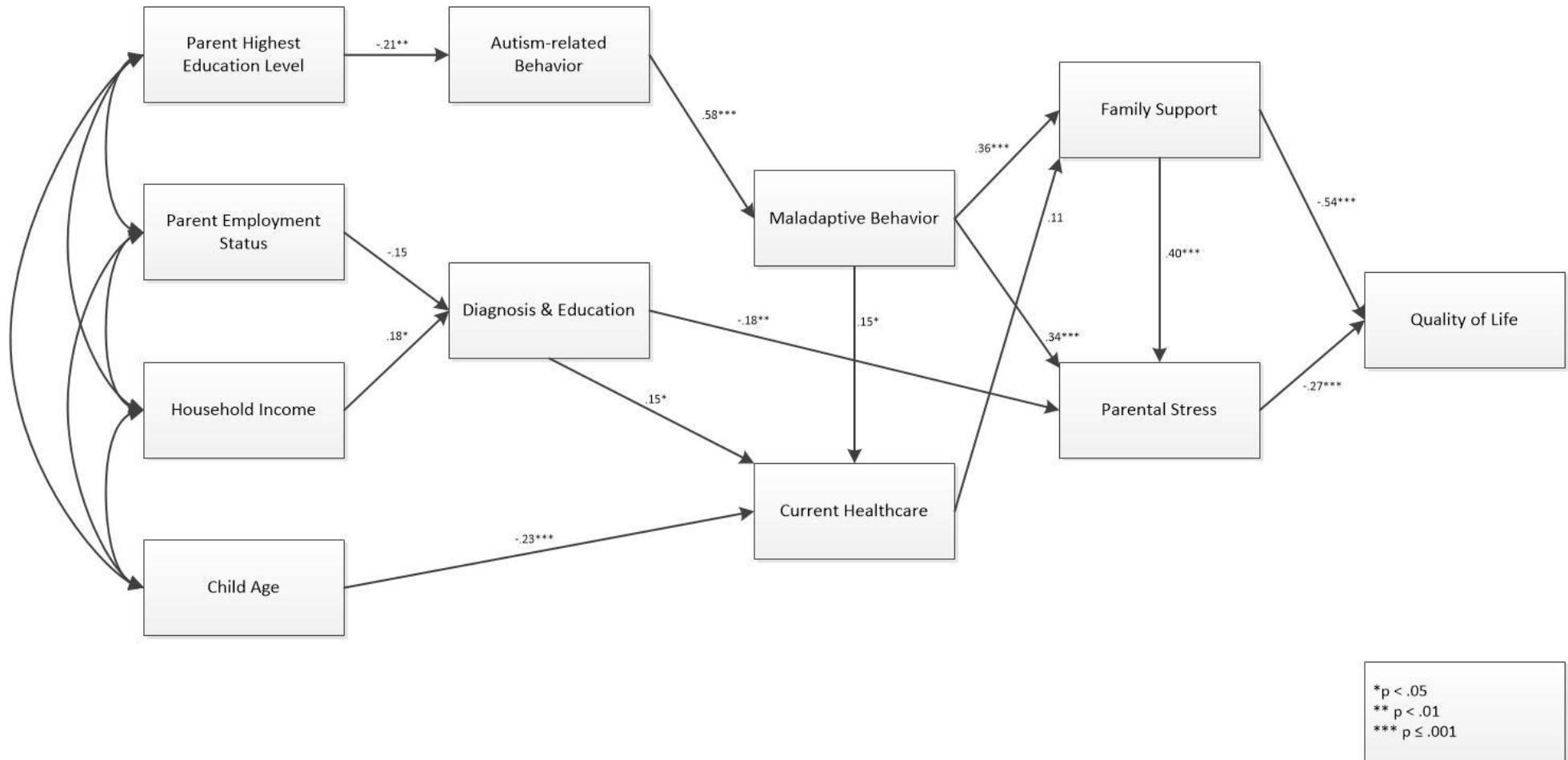


Figure 28. Path Analysis: Examining the pathways between child's age, ASD severity, family SES, service delivery experiences, parent's psychological distress, and parental QoL (Model 3).

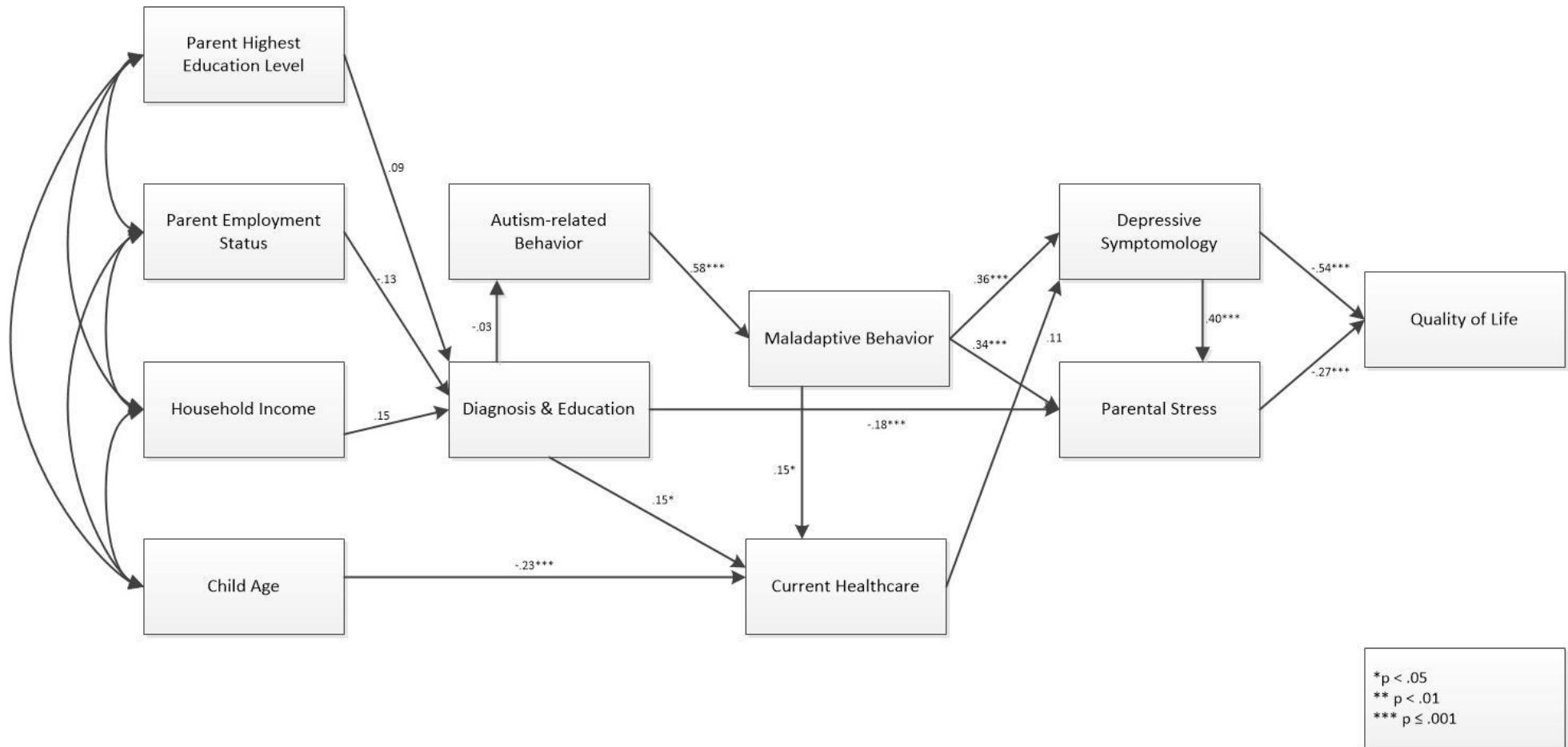


Figure 29. Path Analysis: Examining the pathways between child's age, ASD severity, family SES, service delivery experiences, parent's psychological distress, and parental QoL (Model 4).

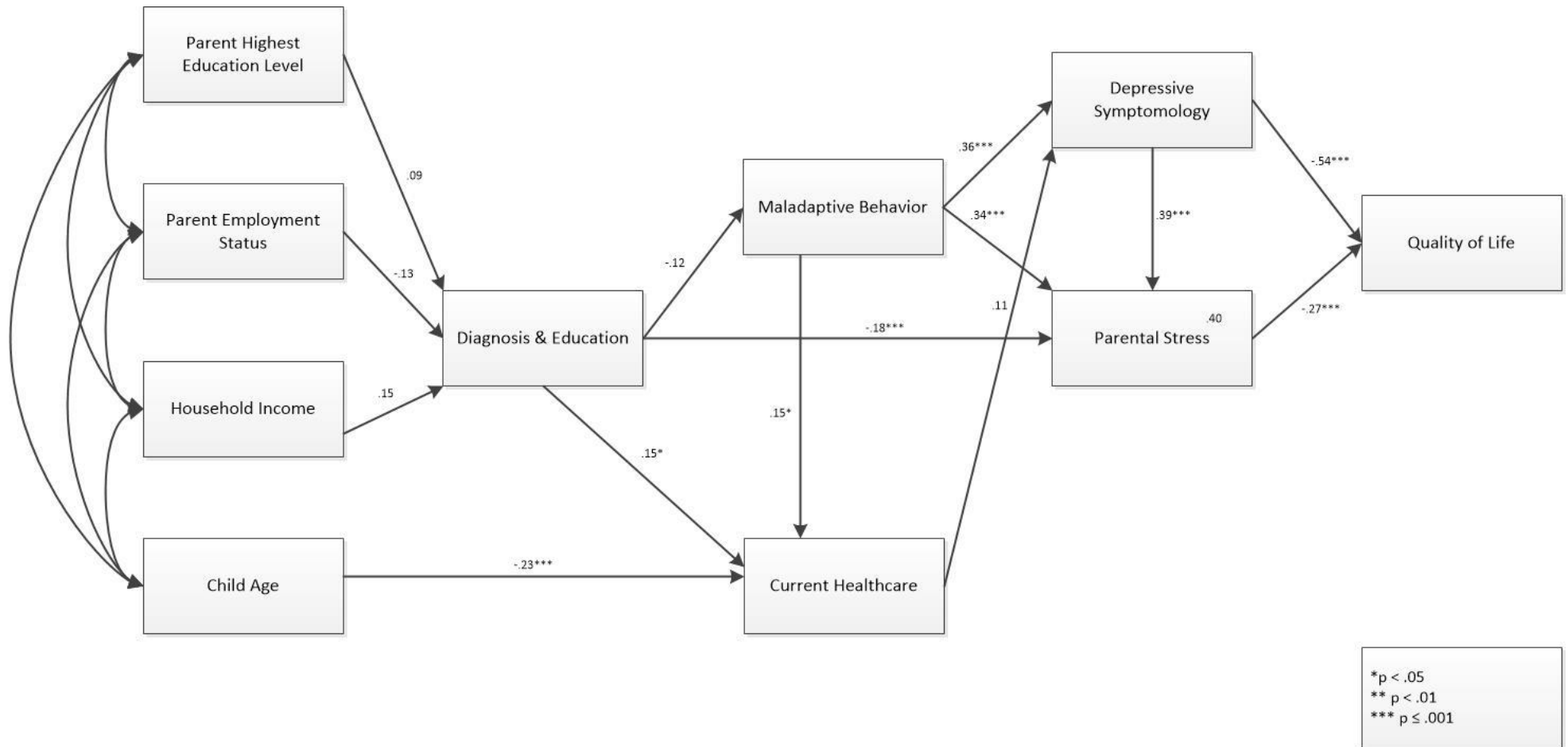


Figure 30. Path Analysis: Examining the pathways between child's age, ASD severity, family SES, service delivery experiences, parent's psychological distress, and parental QoL (Model 5).

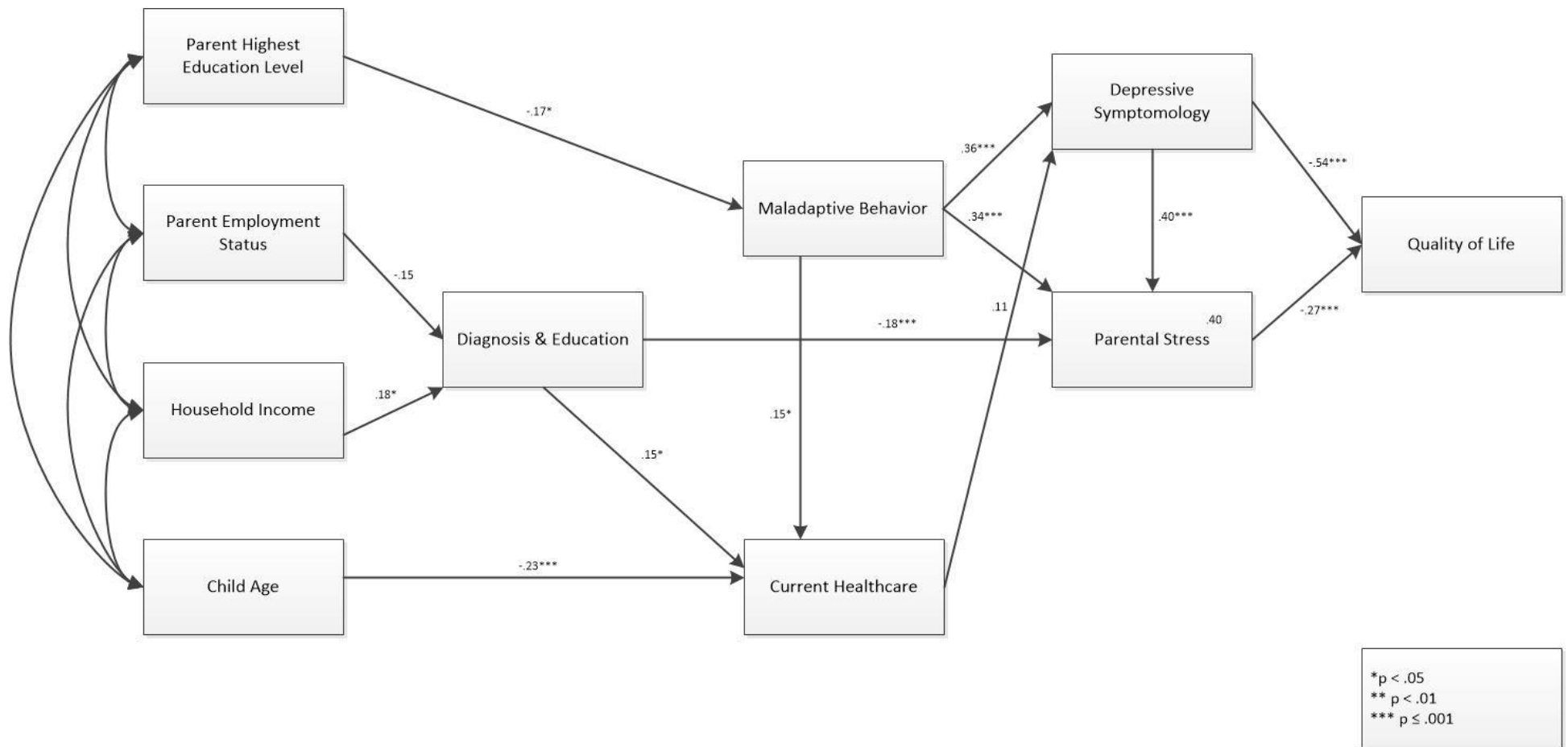


Figure 31. Path Analysis: Examining the pathways between child's age, ASD severity, family SES, service delivery experiences, parent's psychological distress, and parental QoL (Model 6).

**APPENDIX X: FOCUS GROUPS: OPEN ENDED QUESTIONS PARENTS OF
CHILDREN WITH ASD**

1. What do you think of the services available in South Africa for children with autism (e.g. interventions, therapies, support groups, medical support)?
2. What are your main concerns and frustrations with the available services?
3. What challenges have you faced when getting trying to obtain interventions/therapies or other services (e.g., support groups, medical support etc)?
4. What would you want changed regarding the service system in SA?
5. What wouldn't you change regarding the services in SA?
6. Do you feel that the service delivery system affects your everyday life?
 - a. And if yes, in what way does it?

APPENDIX Y: FOCUS GROUP DATA: ADDITIONAL PARENT QUOTES FOR EACH THEME

Theme 1. ASD diagnostic process.

Long process with multiple referrals and incorrect diagnoses.

LW: *I, gosh it probably took me 5 or 6 years for me to finally find out what is wrong with my daughter. She just didn't speak, I think she was 6 when she started speaking. I've been like you, everywhere. Educational psychologists, audiologists, psychologists, psychiatrists, it's so frustrating because all you want to do is help your little one and you do not know where to start. I did not even know what autism was and I got diagnosis from "she's just lazy", "she's naughty", "you spoiling her", all that kind of nonsense things. I was so shocked that doctors could not identify that there is something wrong with my child. If you tell a doctor my daughter is almost 6 years old and she's not speaking. Yes she can "mamma and dada" but she should be speaking. If they can't see there is something wrong then I didn't know where. I was here once to do a genetics test with doctor [name], can't remember his name. That was when my daughter was about 4 years old. I'm still waiting on the results. I never ever got the results, I just gave up. She's turning 14 this year, so it's like 10 years that I am still waiting on the results. So I thought ok, maybe it's a case of if something is wrong we will let you know, if nothing is wrong then we won't. So we just assumed nothing is wrong but that's not helping my daughter. Eventually we ended up also at [hospital name], with doctor [doctors name], but I found that everybody goes to [doctors name]. Then it's ADHD for a couple of years and then it's has anybody told you your child might be on the spectrum. ... He fits the criteria so well but the doctors won't diagnose him because he doesn't speak much. He can speak but he is an selective mute so no we can't put him in a little box because he can't answer my questions. So no, nothing can be done for him.*

PL: *We've been to I think its grade 4 and the teacher said there's something not happening there, he's struggling in the class to socially interact. We sent him on to a neurologist, we sent him to an educational psychologist which we also had to wait quite a while to get. Got the educational psychologist report and it says PDD-NOS.*

BF: *He was finally diagnosed uhm, with Autism Spectrum Disorder amongst other things about two years ago. Uh, so I suppose that would be the first thing, uhm, about getting a diagnosis, uhm. Argh we went through quite a few different private doctors, uhm, and none of them could say for sure, and eventually we ended up at [government hospital name] uhm, what is it called... Neuro development, developmental... Then we eventually ended up with a diagnosis.*

DR: *Going to uhm, various doctors, [doctors names], also having no money left, ended up at [government hospital name]. And, uhm, the, I ended up going to [doctors name] who is the head of psychology.*

MF: *Um, because those diagnostic tools of if you tick more than 17 of these 15 items you probably Aspergers, um ja ok. Yes, um that is, that is a very good indicator and it was something that gave me a lot of insight and pushed me to go and see a pediatric Neurologist and pay ZAR2500 for that appointment. Um, but the actual information about Aspergers and what it is, it's contradictory because you get there is no empathy, there is lots of empathy, there's too much empathy, they have no social skills, they are brilliant, they are not brilliant. Um, you get it's ok so I could be on the spectrum because I am that, I'm not that, I am that and I'm not that. Pick one. Its very very difficult and literally everybody who has written anything about Aspergers say something different. There's no consistency.*

GR: *Most of the kids that don't have a speech delay are misdiagnosed with ADD, from the bat. ... I think a part that's being neglected, both in diagnostics and in intervention, is sensory profiling... And its only now recently that a lot of the professionals are starting to say you know what, we need to address sensory, or do a sensory profile because that's something that's been neglected... You as a parent or as a professional have to identify the sensory issue and if you don't, the behaviour will always be there till you put an end to the sensory issues.*

Sensory problems.

HB: *Well I got a diagnosis of ADHD. ... Because my OT offered it and I said, no I don't think he's sensory, but there is also the vestibular sensory thing and I think that Marius' problem. As a child he could not walk on uneven ground, just physically incapable of it*

and he would scream and cry... I mean even now if he just stumbles, but not even close to a fall, but a bit of a stumble he completely freaks out. Ya, and I think it's that.

JL: *It's like we couldn't, use the tumble dryer. He used to stand on guard by the, where the tumble dryer was, he wouldn't let anybody use the tumble dryer. The maid used to put the vacuum on and he'd switch it off, she'd put it on and he'd switch it off. I said "Please, you only put that vacuum thing on when we leave this house to go to school in the mornings." Couldn't use the hair dryer, couldn't use the chain saw, couldn't mow the lawn, couldn't use the blender, none of that, okay. Running away with his hands over his ears, and now, he's so much better, he's like got a hair dryer he's blow drying his hair and, wanting to blend things and use the onion chopper with me you know. As long as he's involved in doing it then he'll let you use that thing.*

CY: *That's it, and his senses are bad. Well, they're very good but to me it's hectic, we can't go anywhere with him not saying "Something smells absolutely gross", and we'll be embarrassed because it will be like in a food place, and I mean, the one day he smelled something and he said "What's that smell?" And I said "Don't say that. There's people sitting around you, don't say that." And he's like "I'm going to vomit, I'm going to..." "No. Don't say that." I swear to you, I couldn't smell it, until this plate of food came past me that was on the other side, came past and I was like "What is that smell?" And when the person ate it, it was off. So he smelled this food [Dad 1 interjects "Yeah, way before it even came past him."] It has to be right down our nose, for us to smell it."*

Lack of direction and support following an ASD diagnosis.

FT: *Is that when your child is diagnosed, at that point, you're actually not given the ... you're not given the direction (Agreement from 3 other speakers), you're not told what resources are available, and quite frankly after 12 years, I still don't know what resources are available. You are not told what resources are available, um, they will refer you to a specialist, another specialist, and you land up going from one specialist to another specialist, you're kind of left in the dark and you of feel like you are swimming upstream and getting nowhere"*

GR: *The problem is that your child is diagnosed with something that is a life changing disease, not disease, sorry- disorder (Agreement by others) Not just for you but for your*

entire family, all your friends, everything. And then you have to go to war, that's...that's the heart breaking part about autism. And if you don't have money you are F*****! ... 100% and if you're a parent, you're traumatised, for God's sake, I mean you've just had this life changing discovery and, and the first person that comes out and offers you some form of light at the end of the tunnel, you grab onto it. ... So again, there's that parent gap that needs to be filled, and there needs to be services that bridges between diagnoses and placing a child. And that gap is parent and family intervention and education and that is quite missing at the moment. And it doesn't have to be a physical service, it can literally be a booklet, it can be a CD with information on. ... I had a similar experience in [name of place], we went to see this guy ... I still remember going into the spar afterwards because I was completely dumbstruck. And I was telling spar... looking for nik naks, because my son wanted nik naks and I started crying and these people just looked and I said you can look all you want, it's fine. It is horrible. And the same doctor phoned me about a year later because we've started a support group and we've started a training centre and stuff like that, he phoned me for advice, and I was like, are you kidding me, are you kidding me.... So there is definitely a big need for parents... um parent's empathy??”

HB: But I just think if there was just something that, ok if your child is diagnosed, that you could have a weekly class that you go to with your child and they say right, you can't get them into a school because they not advanced enough, but this is how you can advance them. You know, I mean there is an amazing programme, [name of programme]

KM: We didn't know what was waiting, really, we were told Autism and then it was. Because before she was diagnosed, the doctor mentioned a possible diagnosis and then I told her, they say, well they actually said now its Autism and she asked me, “hoe voel julle?” and um and I remember telling her, “Ag its niks nie” because I didn't know what it was, I didn't know what was waiting, really. Because at that time I really didn't feel sad about it because to me she was walking, she had all her fingers and all her toes and nothing was wrong with her face and... But, but I really didn't know what was waiting.

FT: I can understand you saying now about like going, the holding the persons hand once you're given the diagnosis because when I took [child's name], to be diagnosed, by a very well-known doctor [name of place], she did not even look [parent name] or I in the

face, she did not even attempt to communicate with [child's name]. I walked out of there and [parent name] and I said, we are never coming back here.

Expenses associated with and ASD diagnosis.

GR: *The problem with diagnostics, diagnostics...its specialised. Unfortunately the private... the people in private practice have a checklist and they tick it but that is not the actual diagnostic criteria, the diagnostic criteria is actually a lengthy process. If you go to the children's hospital or [name of hospital] it really is a couple of weeks process, it's a very intense thing, its interviews with parents, its observation with child etc etc if you have that specific one done in private it's about ZAR5000, Okay. [b]ut that's when you have it done at the hospital in private, if you go to these psychiatrists, they call themselves experts, sit with a checklist, you have 45 minutes and they diagnose the child. Can I be honest with you... 95% of children diagnosed with Autism is diagnosed by the parent. You then go to professional and say I suspect my child is Autistic, please confirm it and then they confirm it. But 95% of Autism is diagnosed by the parent and the reason why the parent goes to the professional is to get the piece of paper so that they can then get into schools or whatever.*

MF: *Incredibly expensive procedure that medical aids don't cover.*

LW: *I'm like you pay a fortune. I've got an appointment for him for the 2nd March, my son, just so that I can get a script for statera because nobody else wants to give me the script. I must pay ZAR850 for half an hour just for "is it working for him, how's he been coping at school. Ok we'll see you in a year's time". I feel that spending almost a thousand rand for half an hour is a hellava lot of money, it's almost a month's school fees I have to pay to a doctor just to get a script. ... [a]nd I have just been to every specialist in the province and I don't know, it is expensive.*

Theme 2: Overall contact with healthcare professionals in regard to ASD-diagnosed child.

Lack of ASD knowledge among healthcare professionals.

GR: *Somebody said to me, do you see a therapist, and I said , you know what, there isn't a therapist out there that can help me with the way I feel, or the things I deal with. Because I find everything they say patronising, I find everything that they say, like 'wow,'*

and it sounds selfish and it sounds a little bit I think, I think you know... but you get what I'm saying.

Long delays between appointments and while waiting in line to see a healthcare professional in government hospitals and clinics.

KM: *When we see the doctor which is every 9 months, you'll see the doctor. This year once and then the following year once and that is the only time that we get feedback.*

CY: *Or it's too far. Or it's time-consuming and you know, takes a lot of, it just takes a lot out of you.*

YA: *If they can change the thing of the child coming every 6 months to at least twice a month.*

The need for translators for families that do not speak English in the government hospitals.

TY: *Someone else who is xhosa would explain/translate and other people would be able to ask. But now I don't even know when they ask me.*

RA: *Even this subject of language , even if we had someone who spoke xhosa or even a doctor was xhosa but the for me on my side the white doctors have more care but if there must be a translator that would also be very helpful and not the xhosa doctors because they have attitudes.*

Expensive services

LW: *I was doing our taxes in July last year and I said to my husband, do you know how much we spend on a psychologist, just a psychologist ZAR25 000 per year. And there is still no answer so we go back to the school and speak to the school psychologist and they tell me no go back and see a psychiatrist and maybe a psychiatrist can tell us what to do.*

FT: *Services are still expensive no matter which way you look at it.*

BF: *Unless you want to spend loads and loads and loads of money for dubious outcomes, nothing's guaranteed. Uhm, yeah, so I would say that the services are, are pretty poor.*

Unfriendly government staff

GR: So, from the services, I never used government services before but from that part its yoh I don't know how other people actually survive. There is first of all, like there is no respect towards any parent... It's like you in this bracket of I don't know, like you don't deserve respect, you don't deserve any type of treatment.

MF: And you get absolutely no help, I mean social services is useless. They looked at me and said oh you white, you don't need it, and that was the end. And I was given this whole rigmoral and I was given more chasing around then you did. And also treated like dirt as if I am sitting there with my hand out because I have this I'm white and I deserve it and for me it was you know what, never mind, I will find the money somewhere else.

Theme 3: Education-related costs and resources for the ASD-diagnosed child.

Long process and waiting lists to enrol in a formal schooling institution with lack of available and appropriate schooling options.

CY: Then we applied for a school, at [school name], and we had to go on the waiting list for 2 years, which I find was really sad, because how you struggle and you know your child can't go to a normal crèche and he can't go to a normal house-sitter, nobody understands him when he's throwing his tantrums and he can't talk and, YOU'RE frustrated because you're at work and then you get these calls, "Oh, he's, breaking this or oh he's, doing this and oh..." And it's, it's kind of a lot of pressure, where you actually uhm, like me, giving up my job because now you really don't know what the heck to do anymore....And then when, eventually he was on the two-year waiting period I phoned the school, I said "Uhm, is there no way you can get like, make a plan for us and, you know this child's really now, I can't anymore." And she said "Oh but you've been placed." Then I got a notification. Nothing. I said "No, that's impossible". She tells me: "You were the last, you were number 20". So they do I think 20 every two years I think that's how it works. "But don't worry I'll put you back on the list". So I said "You want me to wait another two years? I can't anymore, not, for my sake, it's for my child's safety for his, for his uhm... Yeah, you just don't know any more what to do. And I said "You need to make another plan for me". And eventually she said "You know what, I'm going to put you number 1, let's do it like that". And she put me number 1 and, 2 weeks later I got a call to

say he can come to the school for his two-week assessment and, I tell you, I sat there when they said that, not crying because he's been like finally in a school for autistic kids but, the relieve of knowing that, you don't have to leave your job to go here to go there.

JL: *And then of course the [school's name] which is a school school. But he was, too young to go into school school. But he was on the waiting list anyway.*

DR: *After many meetings and then he went to a little creche in, in Wynberg, because we're on the waiting list at Vista Nova.*

KM: *So I said if it's going to be like and then its fine because started going around to crèches which I thought was special needs or whatever and um they said they have a waiting list that's as long as forever. So I said I can't have her at home, until the hospital say they have a school. ... And being government schools you have to sit and wait until they have space for you, which eventually your child turns 10, 11 and maybe then starts schooling, because the waiting list is that long, every other 2 years you go for screening, assessment whatever and it takes a year for everything.*

HB: *What I'm really concerned about is, I mean the key for successful intervention is early intervention, and it's just not available, when you've got to wait 4 years to get your child into a school, they are now 4 years behind.*

KM: *But I have a huge problem finding schools for her and even a crèche that's willing to take her..... I started finding crèches for her and whatever and each and every crèche would keep her for like a period and say ah no sorry we can't have her and then one day my mom actually got very fed up with the people telling us we can't have her, she's not a puppy, she's a human being and it's just that she has a condition.... but when we registered and when we had like a meeting with them, I told them everything about [child's name], because having one autistic child and having another autistic child is not the same, you going find that with the one autistic child and that with the other one.... She is in a crèche now, they called me last week, they told me. "we're sorry you're going to have to look for another place for [child's name] for next year because she doesn't nap, she is playing with the other children while they have to nap," doing this, doing that and*

whatever. And then I said I'm now very sick and tired of this, I sat there in the principal's office and I said its getting too much now.

Need for more formal ASD training for teachers and staff in formal schooling institutions.

GR: *Of course, did anyone offer to do behaviour therapy to modify the behaviour, I mean that is insane, how can that be an autism-specialised establishment, if they do not counter with the appropriate therapy to assist that child, I mean that just does my head in. ... The town that I live in has the teaching college for Western Cape, so all the teachers in the Western Cape go to that college, that's where I live right. So we've got teaching students all over the show and do you know how much time they spend on Autism- half a day (Gasps from group) half a day! And you know what, you know what's the shocking part- we have volunteered to attend the college with [doctors name] to do...um free of charge um... but we've never heard back, type of thing and that is the amount of time they spend. Because all of them that I have spoken... because I've interviewed a lot of them to try and get tutors and stuff like that and they've all said "we've heard of it, we've never heard of it" and I said but don't you do...in their 3rd year they do half the day on Autism.*

AP: *We were told that when we have school meetings, our children are no longer allowed to be in the school and have the teachers or the assistant teachers look after them, so me as a mother, I don't have a live in or an assistant or a facilitator and my husband would like to attend the meeting so what do we do with my sons and we don't have a babysitter, I'm going to have to drive to my grandmother, my mother in law and drop my kids there and be back there. It's just, they are not accommodating as they were, or as I was promised they would be when my kids started, so I don't know if it's just, things are getting difficult, that there's a huge demand for kids to be in the school, the school is under pressure and they can't handle, you know all of these, that they can't be as accommodating to individual parents or should we actually try and have schools that are accommodating and that don't make the meetings at 2-3 when people have to be at work and we have to find a babysitter but like after hours or, somehow, there's just like a lack of accommodation and consideration for parents..... So it's difficult because I mean didn't fight for all of these years to get my son into the school, relocate because they wouldn't accept people from a certain area as well, so we had to up our house and move to get into [schools name], now I'm in at [schools name] and now just all of these. I just*

don't feel at home and comfortable at the school, and I mean being an autism parent is not easy, and having two kids on the spectrum is a whole new ball game, so I mean, that's my two cents, so I don't know.

KM: *So I said, I told her, it's actually very sad because now people that's supposed to, that's trained to educate normal children, has to sit with children that they, they don't have, they don't know anything about. So she said "ya that's why they send out help, to help the teachers," so whoever is the teacher of Amy-lee, she will have a help, which government sponsors that.*

DR: *The teachers are struggling. They're, uhm, for example, [school name] where my son, my older son was and my younger son wasn't. Uhm, the teachers, uhm, I belong to an ADHD support group and, it's just, that, everybody on there is diagnosed with ADHD. You know, it's like, it's almost like a trend and then, every second kid is on Ritalin and every second kid, I'm talking about mainstream now because, the teachers don't know how to cope, they don't have the life skills, they haven't been taught the life skills how to cope. But this child actually, doesn't want, he can't sit still that, the child can rather sit on the floor and still take in the learning. The teacher that taught my younger son said "I'm the teacher. And it's my way or no way." And I said "But with a child like him, and a child like, some of the other kids, it can't be your way or no way.*

HB: *Well I've just completed by 3rd year Montessori so I'll be, if I've passed, I'll be graduating end of the year and we did no special needs, we were basically told we need to screen children. But we had no training on any special needs.*

Problematic transport to and from school.

MF: *I've got the school bus, which I'm not even going to go to because my son missed 20 % of his school year last year just from the school bus being late.*

EQ: *It should be like every place has its own school you see like in [place name] they their own school and like [another place name] they have theirs like that.*

Financial costs associated with education.

CY: *I find that autistic schools are over-priced. Especially knowing that Autism is mostly in like the poverty-stricken areas.*

KM: *We asked, if we jump out and try to go to schools, like private schools and whatever, she said that school, that will be like that much a month, I tell her are you serious, my husband's salary is not even that much a month, how can they charge that for a school?*

Positive aspects regarding the schooling system.

DR: *The teacher at creche was, this creche was ABSOLUTELY amazing. Fortunately he was verbal, uhm, they were amazing and, the teacher that taught him has actually now, gone into Autism and specialise in Autism and, they understood him.*

JL: *They actually, they're trying to, they're trying to understand and learn more about the children they deal with every day of their lives.*

Medication in the schooling structure.

LW: *Actually, when we were in Grade 2, [child's name] teacher complained that she can't cope with him, we must up the dosage. So, doctor gives me a script for a higher dosage, my husband decides, no he's not taking any medication. Two weeks later sister phones, um, do you want to repeat, the doctor actually phoned, did it, the higher dosage work? Teacher and the aid came to tell her how wonderful he is doing on it. So, meanwhile he was on no medication at all. So, it's just like, I do not know what to believe anymore.*

MF: *But what I do with [child's name] to test the medication, I put him on a placebo test at school, um, where they give him a sugar pill for a week. And only the nurse and myself know about it. And sister will phone me two days in, [child's name] teacher came to me today. She just wanted to know whether we have changed any medication because [child's name] is impossible to deal with. I'll be ok, you can put him back on the Ritalin tomorrow, its fine.*

GR: *I took him off medication when [school name] put him on Concerta, also I, I heard one of the parents saying that the child, they said was doing so well, the child wasn't on medication. And that was exactly what we did with [child's name]. We took him off the medication and they thought that he was on medication and they said he was doing well, and that is exactly what we did.*

Lack of facilitators for children in the school setting.

LW: *There are facilitators at [schools name], some people pay a facilitator to be with their child, some the government sponsor... government should get more facilitators available for children with special needs. ... But when she gave me her price, I'm like sorry R10 000 a month. I cannot afford that.*

KM: *Government pays the facilitators nothing, next to nothing. So basically, the ones that come in from government, they don't have the full experience of a facilitator of special needs, so they basically coming to intern in a sort of way.*

Theme 4: ASD-targeted interventions—costs and parent training.

Costs.

AP: *So I started doing private therapy but then could only afford once or twice a week and we carried on that way.*

MF: *[comments on facilitators] It's more than the school fees.*

Parent training.

FT: *I actually went and did a facilitation course to learn how to work with my son.*

AP: *We gave her the money, it was ZAR6000 to get the facilitators course, which was a group of printed, not even stapled, just like a stack of paper like this that she told me; read through and I will come every week at the cost of ZAR1600 to come and supervise and watch her training my son in. It went on for about 8 months like this until I thought but hold on; I don't know what I'm doing to my son. It was ABA actually, she would come and facilitate and show me how to do ABA with my son and I would feel like the worst*

mother ever because I would have to lock him in a room, and I didn't even get through the stack of paper, I just told her I did but I didn't have time, because I have an autistic child and a newborn. And after, in hindsight I now realise that we were take advantage of, and immediately when I realised that, the day I realised was the day I went for that interview with the speech therapist at [school name] to get my son for speech there because I told my husband I'm not seeing a difference, it's been 8 months with my child, I'm not confident in my training because I didn't even get any training. We paid ZAR6000, we got a pack, just a bunch of papers.

GR: *Or the training should be provided for free. The training should be provided for free.*

Types of interventions that families have made use of.

MF: *I mean when [child's name] was 2 I started telling him stories. And we had the hippy hoppy bunny stories. It was a story every single night and the main character mirrored everything [child's name] did in the day. And it was before I knew about social stories. ... I did Equion therapy. Horses. Ja, it's called hippotherapy actually. Um, there's a woman out at [suburb name] riding school, she does, and it's a combination of occupational therapy and horse riding. And, that really worked because [child's name] focuses around animals, um, so having him on a horse where he was actually focused on the horse. ... The other thing that my kids did, was um, kiddy kinetics, which is offered by [college name]. Um, where the bioknetist, biokenetics students use kids as their Guinee pigs, and that did a lot because [child's name] also had poor muscle tone, his shoulder girdle and pelvic girdle muscle tone was really weak.... its movement therapy, its kinetic movement but the biokentic students need somebody to practice on. So, it's offered at a minimal cost. ... nild therapy course ... Um, it is basically a form of teaching, for special needs kids. Um, it's mainly used with difficult dyslexia, and that kind of difficulties, um, and there is a school in [suburb name] I think, that offers nild education classes. And it's basically, it's you basic reading, writing and arithmetic, which is where my son fell down because he didn't get those basics.*

KM: *[child's name] I went for the Makaton, the school sent me because of [child's name] speech delay, and um, I went for the course at [schools name], the Makaton course, and I could only do, I went the one Saturday and they gave me the CD and I came*

home with the CD and myself and [child's name] sat in front of the TV trying to you know, do the whole sign and things, and he just didn't want to take to it. And I just gave up on it, you know I'm not going to force it on to you. ... We busy with pecs now. I've, I've got extra speech lessons with him at [school name] now. I managed to get to see [speech therapist name], she's the speech therapist. So yes, so we started with pecs yesterday, so I'm not sure if it's going to work with him, I'm not sure if [child's name] is passed that stage.

GR: *My son, we used ABA, um... we've used it because also when [child's name] was diagnosed we took him to [school name] um... with [name of principle]. The [school name] programme is really really good, it focuses mostly on ABA... But we've been using ABA throughout, it's the only scientific therapy that works and I know there's a lot of people that don't like ABA because they say it's too rigid or whatever, in actual fact I think we should just move away from ABA, the term and start calling it behaviour therapy. You know you've got unwanted behaviour, you need to replace it with wanted behaviour and this is what we have to do to get that, whether it's modelling, social stories, puppeteering, whatever the case is you know.*

HB: *That's what [therapist name] deals with the work, but he doesn't like ABA because he doesn't like the negative reinforcement that a lot of ABA uses, and some children respond brilliantly and others don't. So he does the ABA but with positive reinforcers, and it's all very very positive... But I don't know quite what they did with [child's name] at [school name] but I mean he was a different child after he went for 6 months, it was amazing.*

Need for more intervention options for families

MF: *I didn't know any of it. Um, I just followed what my own common sense told me. And when I saw that it started working with one thing, um, I started using it for more. And I just kind of built on what I did. Um, there is very little information in South Africa.*

NT: *I think the support system goes straight to medication which I don't use. I avoid it for years, don't like it. Rather go for behaviour assistance and things like that and because it won't be everything that will need medication, some will be behavioural don't need any meds...it's not the child and what is best for that child, its different to the one waiting in*

the waiting room outside even though the both Aspergers. Its different issues, one is verbal, one is nonverbal, one is too much, one is too little and they can't just one medication fits all. Yet they prescribe the same thing, Ritalin, Concerta, Stratera. It's not right.

GR: *Behavioural therapy to teach flexibility, to teach um... generalisation, to teach that their world will not come to an end if I do not cut your bread in squares instead of triangles..... the longer you wait to intervene, the more inflexible the child's brain becomes, or the less chance you'll have of effective treatment.*

Types of medications and associated problems.

MF: *I have Ritalin, stratera and risperidone, all three.*

LW: *Back to the medication story. My daughter's not on medication. Yet I feel that the Aspergers are worse, it's worse than [child's name] but [child's name] has behavioural problems at school so he gets to be on medication. Do you guys feel it's more to help the teacher cope with the kids than the benefit for the kid itself.*

NT: *They wanted him on Ritalin earlier but I never went that route because I could see he's not struggling to concentrate, its other, its other people that are annoying him, they must sort them out, not for him now to sit and, oh he's the one reacting to that, well they must stop that. He can concentrate actually, why must I medicate when some other child is misbehaving, really. So anyways he never really need that sort of, he's on risperidone for the anxiety because he does get a little uptight by those people, so that takes the edge off things, but I must say till this day, you can sort of tell when he is off it.*

Theme 5: Transitional services available to ASD-diagnosed young adults post-schooling.

Lack of appropriate information for young adolescents post school.

MF: *And who takes care of them when you gone.*

NT: *I'm looking at my daughter thinking you've got your brother and your uncle if anything happens to me because there is nobody else, my sisters in Johannesburg, I don't know if she is going to take on all my whole lot plus her brother but she hasn't come to the party much yet so there's (there's a place called ..) so they need a place where we can*

put them where somebody else looks after them that is paid for and then you work your butt off so that you got money to do this otherwise there isn't any place available, they on the street under the tree.

FT: *Yes, all the support is there, and then they leave school and then?*

KM: *What happens to the child...What happens to the gifted children? What happens? Do they go into a workshop?*

LD: *And personally, after they are 18 years of age what happens?*

YS: *Another thing honestly, I wonder when she grows up since we are old already and I wonder when she is older who will guard her? And maybe she will end up getting hurt and there will be no one to guard her and maybe when she is 18 she will find school and then it stops. And what will happen after that? Will there be anyone to guard her? Or will she be idly spending her time in the townships without any guidance?*

Expenses families face with a young adult post school

NT: *Because everything else is expensive, these homes are R10 000 a month. To keep these people with, that will take them to a workshop, and make sure they have eaten and have clean clothes and that stuff like that.*

MF: *These people haven't got jobs so it's the families to pay ... [J]a, if you've got somebody then, then it's children and then you can't give them that then without leaving them some financial support ...*

Theme 6: Impact of the child's ASD diagnosis on everyday family life.

Impact of ASD diagnosis on family finances and employment.

KM: *I'm trying to do something, I started, I left school to go study but I didn't do matric, so now afterwards I decided, no but I have to have matric because there are a lot of opportunities coming up for me and then I started doing it and then I had to leave it again because [child's name] was now at home with me and now I started doing 2 classes now up and that and so now I told now what, does it mean I have to leave the classes again now because who's going to look after [child's name]?*

AP: *She was actually the one who convinced me to leave my job and stay at home and look after my son myself because I thought I could just pay for a specialist. But at that point we didn't know any and I said to her but if I leave my job I won't be able to afford all of these things. She said no you can do it on your own, I'll train you, just give me ZAR6000 and I'll train you.*

FT: *I think that's the biggest thing, is financially.*

VT: *I think financially it's huge.*

LD: *Maybe, I'm working at night and/or my mother passes away or moves to the Eastern Cape. Those would be the reasons I end up quitting my job to look after my child. Or a school that will take them for a week and I look after them on weekends or even if that happens for a month and you look after them on your off days... although you would worry about your child's well-being. Honestly, your life will stagnate because you don't work and you're possibly just receiving the grant funding per month, or even the time you would have to yourself is taken away. Also, if you're working night shift how are you going to look after your kid. And your bosses don't understand, and you could get fired for that.*

JD: *When I was still working, I had to know to know that either myself or my mom had to be at work on those days the other would be off.*

ES: *Yes its true like for me I was thinking about stopping my work so that I can look after my child.*

YA: *I also stopped.*

LP: *So they take the one who is already off nappies. So they said we can't take him at all so he had to stay [at] home, then I thought how am I going to work, who is going to look after him. I can't, who is going to look after him if he comes back early by that maybe am in a bus or in the train, because school ends early. Other children are at school and who will taking care of him. There is no one else to look after him.*

NX: *To add it happens a lot the minute you stop working it's not easy, not all you thought it was going to be, when you stop you have hope that it's going to be easy but it's not, and you see it's not easy and you become frustrated by your child and you don't have money, do you understand that it's not easy.*

The need for emotional support

GR: *Parent support groups but look, parent support groups but you must always have an expert present because fights happen. People start fighting over opinions and bickering and that's when you need a referee or a professional person to step in. Especially when you tackle the topic of bullying! You can have online support groups and stuff like that.*

JL: *Because we want there to be more facilities and more support. ... My family's all overseas, my sister lives in America, my brother lives in Spain. So I don't really have that support. ... But uhm, there aren't a lot of facilities or support. There's no support here. People don't understand that.*

KM: *There is very little help when it comes to having an autistic child really.*

MF: *What I think would actually be a lot more useful is to actually have specific support groups for parents in a specific area. ... There's no like, you know what guys, I don't want to have a workshop I want to have a coffee day, 2 hours where we can sit and cry if that's what you feel like you need to do. That would actually make life a lot more bearable I think because also you get to feed off what other people are doing, but that information that you gain from other parents. I find that it is actually more valuable than what you get from professionals (other comments of agreement) because they all there waiting for the check, and they going, ja well this is what you need to know. No it's not, I know that already. Or, it's not relevant for my child. I don't want to know about that, I need to know about how do you manage with your child who is going through puberty who actually isn't ready for it because I've got the same problem.*

DR: *I found that educating MYSELF, REALLY, REALLY helped, and getting support. Uhm, I joined uhm, the Asperger's support group uhm, I joined a group called "Ask me,*

I'm autistic." Uhm and everybody was giving me all that support and with my sister overseas as well.

YA: *And when I just found out that my child has autism I didn't even know what was autism, I didn't know where to start and where to go, who will I talk to.*

LD: *In support groups like for people who stay far, like those who stay in [township name] but there's one support group and its in [another township name] (other mothers agree), like maybe they should use 2 taxis to get to the support group.*

YS: *And we don't always have transport, so the government officials can't come for 6 people they'll come for maybe more maybe 50.*

Better housing for families from low SES areas with an ASD child.

YA: *They could provide us with housing like with yard and that are safe (other mothers agree) like for example on cutting edge, they have houses made for them. It's housing and not flats because if I'm upstairs my child will fall on the stairs. I just want a house that has space with a yard, I don't actually mind as long as it's enough for my child to run around and not in my shack which is small and my child can't run around.*

XS: *Am talking about place to stay even when I talk to him and saying I wish that government can give us places to stay*

General transportation problems for families with an ASD child.

LD: *Also the not understanding of your child in transport.*

JD: *Mine boy, scares the drivers, sometimes he wants to sit behind the driver and the driver sees this child who is cute, that's normal and then the taxi leaves and he's fine but then there will be something that he sees on the road that makes him scream and the gives the driver a fright and then he hoots because he wasn't expecting that. When he's in the taxi, he will just want to be right by the driver or we get on the taxi and the driver is not there yet, and he is going to want to go to the front and press all the buttons are in front of the driver's seat and the taxi driver is going to get back and he will be upset with you, even though he can see you're busy reprimanding your child. So, I've decided to sit in the*

back seat now (other mothers chime in and agree) I will sit at the back and he will make a noise and even I get a fright sometimes, because there are times I'm sitting there thinking of my stresses and he screams "hoooo" and everyone in the taxi gets a fright and turns to look at me. Then I get upset because I'm wondering why he does that. I wish sometimes we take transport that knows my child's situations and so he drives carefully because he knows that my child might just randomly scream and cause him to get a shock and in turn might cause an accident, and seriously he will do that. Because sometimes my child will just scream and the driver will ask "what's wrong with your child mam, is he crazy?" So what they do is let him sit in the front and they play with him and he is so happy, and also because they're playing music and in the morning he wants to be the first one.

TY: *So when we in the taxi and we must get off, I need to tell him before that we're getting off, or I must tell him the destination like, "we aren't going to the mall, we are going to the creche today.*

The need for support around toilet training.

YA: *Oh I was going to contribute to this sisi, it's hard to take him to the toilet, I was also finding it very difficult in my situation, while I got speech therapy they told me that they can't find the school while he is still on nappies. ... It was hard with mine he did not want up to a year doing the same thing. Put him on the toilet sit and you have to jump towards him then he stops. You have to leave him there I will say stay if you do not do this you not going to stand up, I even said lastly I will do an enema to make his stools lose because if you have done that everything is going to come quickly. ... Sisi it's not an easy thing it takes time. You also need to make sure that you not going to remove him from the seat and try to leave him until he feels ashamed, he will sit doing nothing I let mine sit there until they could recognise it. ... You buy them even if it's a bucket of potty, you buy bucket or potty because I do not have a toilet close by its too far from my house, so I have bought him a potty maybe it will help to put it there, this was the advice that was given from the support group.*

ES: *The other one is afraid of falling even for doing number two.*

NX: *I would like them to offer service like potty training here in [government hospital name] unlike that they take a child away for a period of 3 months and you are only allowed to him once a week.*

Theme 7: Increasing ASD awareness.

LW: *If there was like a website, for this you go there, for that you go there.*

AP: *At that point in time there was not really a lot of, I didn't know anything about Autism. I tried to do a lot of research and I had to do a lot of convincing as well, to professionals that my son is Autistic.*

PL: *I mean he had an epileptic fit which is also part of, that comes with the territory but completely out of the blue, traumatised all of us completely, because we didn't see it coming, no one told us that's part of it. ... I think the more the awareness will be raised, we get to hear what's out there. I'd really, for me it's been a bit of a revelation over the last 2 years only. I mean we're talking he's 13, we found it when he was 6/7, so it's been a long ride.*

GR: *I think the awareness is when people, I tell people that he's on, he's on the Autism spectrum. They go "No, he's not!" You know, "don't talk rubbish, of course he's not, you can't label him". But he is and he has to be labelled because that is who he is and that he how you understand him. I don't go and tell everybody 'Yeah, you know, he's autistic.' But uhm, he had a terrible meltdown at Builder's Warehouse last week because he wanted a torch for ZAR195 and I said no and, he went ballistic. Everybody there was like "Aah aah aah!" It's fine, it's fine. I'm like. he's getting bigger now, he's getting stronger which is hard and I'm worried about that going forward, is when he has meltdowns, his safety, other people's safety. Uhm, but the awareness is so...*

JL: *Statistics are showing and we need to prepare ourselves, and prepare the rest of the world for these children, because they aren't, they are special, they are definitely special, and people don't understand them that's why they don't know how to deal with them. We need to try and see things the way they are seeing things, because they see things completely differently, and it's not necessarily a bad thing, it's just, different.*

DR: *I think there definitely is a lack of awareness.*

CY: *I just think there should be a bigger awareness, like it should be, like there should be a day for it, like there's a cancer day. Like the Autism day I think it's the 1st of April, should be a day where people, communities come together. ... So, the awareness, it is, we don't want to say it's a disability but it is a condition.... And this is the biggest problem, a lack of [another participant completes: "Awareness."]...but it's with everything.*

UT: *Have autism walk, that way you also get awareness. Raise awareness to the community, to the public.*

FT: *That type of awareness doesn't even go over into adulthood. You put your child in a special needs school, they're labelled. ... They test these kids, give them an IQ, they're now labelled as either stupid or whatever, like I say, the stigma is now attached to that child. It's horrible, but that's the way society looks at people.*

GR: *We had, we had family that had said our children are autistic because we atheists and I said, and I said to her, you know what I said to her; so what about all the Christian children...ya... she was dumbstruck.*

YS: *Not only in the Western Province only there are in other provinces more especially Eastern Cape because they have to be taught there, because they don't know this autism thing because they come with their children in Cape Town and they only know it when they get here that "oh my child has this, this disease" they say it's a disease and it can't be cured and you know old people mos... Other people at the clinic will look at me like a mother who doesn't discipline my child and when I try to explain they just glare at me in disbelief. ... There are a couple of girls who stay around my area so they ask "haibo where are you going?" and I say there's a meeting for autism for my sibling that's in my area and then they ask, "what is autism" and I explain to them.... So I have to once I meet someone and explain to them about autism they still won't understand or even try to explain.*

TY: *The other day I was watching overseas kids news and other children were been given awards and even elderly people were given awards, and some of them haven't*

learnt how to speak properly yet... I even told my mother when she came back from work after working night shift. They ended up laughing at me saying that there was no such thing and that is hurtful.

LD: *A child with autism gets restless very quickly especially if they are in one particular spot 30 minutes becomes a long period of time for them because they will just start causing chaos again and when the nurses are calling out to you and you ask if your number has been called out, no one wants to respond to you and you get laughed at (other mothers agree) that is hurtful and other parents don't realise that ... And since then I didn't ever go back because of their lack of empathy towards my child.*

NX: *It's the thing like in a mall with your child like kids with Autism they do whatever they want to do and they do not have to hide or have tact in what they want to do, if there is another child with juice they can grab it. Other parents they do not like that the child does that.*

ES: *The problem where we stay people do not understand them. Like people do not understand we have a problem like a place where we are understood and the child is understood do you understand. Like my son is being bullied by other children. To go back to the thing that I wish people could be taught about this thing so that they can understand, because people in the community they are able to work and help you, if maybe they know what's going on.*

Recommendations on how to spread awareness.

TY: *I also think that they should do campaigns in our communities that show people and educate people on autism and how to teach autistic kids and maybe other people will be interested in seeing that oh! Is this how these kids live and maybe we should treat them like this. ... They should teach people about autism and not us as parents, we know, but for the community. And like they understand when someone's deaf and you know to read their lips. They understand when someone's deaf but not with autism so, I wish they would understand and the same goes for disabled people. They relate more when they see it on television ... or if they see him at the mall, and they take a photo of that child, they'll ask why that child is like that but once they see the child on television and it was explained, everyone understood.*

JD: *Like, let's say on radio and overseas they are given programs and maybe it's just the Western Cape who have a problem with this and you can speak to [local television station] or the Western Cape Government and tell them that have these types of problems. ... Like someone who knows about being disabled or autism and is trained, like they raised awareness in the locations using, pamphlets and posters in the township everyone would know about disabled. Like I said before raise awareness, like someone from the township who is trained to teach people about autism. Who will do all these like workshops and telling people about autism because black people don't know about it.*

NX: *Some like what used to happen in the past with AIDS going to schools to teach/ awareness to people who do not know about autism.*