

Towards integrated service delivery for children with autism spectrum disorder in the Western Cape Province of South Africa

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ABSTRACT

Background

The prevalence of autism spectrum disorder (ASD) in South Africa is unknown and there is little information on the educational service needs of children with ASD in the country. There are no standardized procedures for identification, diagnosis and management of children with autism. The Western Cape is one of the better resourced provinces in the country in terms of ASD services, yet educational opportunities for these children are limited. The Western Cape was therefore used as a case study to understand the landscape of education systems for children with ASD in South Africa.

Objectives

The objectives of the study were a) to determine the number and profile of children with ASD both in and out of schools in the Western Cape, b) to examine stakeholder views, perspectives and proposed solutions to meet the educational needs of children with ASD and their families, and c) to generate suggestions to strengthen ASD systems and services.

Methods

An exploratory mixed-methods approach was used across two phases. In the first phase, quantitative provincial educational data were used to describe the profile of children with ASD in the formal public sector education system as well as those waiting for educational services. The second phase used qualitative focus groups and semi-structured individual interviews to examine the perspectives and recommendations of caregivers, service providers and government stakeholders about ASD services.

Results

A systematic database search for children with ASD in the whole provincial educational system, combined with the provincial 'waiting list' of those waiting for

school placement found very low rates of ASD (<0.1%). The majority of children with ASD (89%) were in special schools, and only 10% were in mainstream schools. All children waiting for school placement were waiting for a place at a special school. Thirty six percent (36%) of children waiting were of compulsory school-going age and 48% of all those waiting were receiving no ASD intervention while waiting. The key perspective that emerged from caregiver focus groups was that “we wait and we wait”. Caregivers expressed their frustrations with current ASD services. Service providers highlighted their limited capacity to provide services for children with ASD under a theme “we are doing the best we can to bridge the gap”, while government stakeholders acknowledged that ASD services were not prioritised because of competing demands on government resources under a theme “we are doing damage control”. Synthesis of the findings across the different phases of the study identified six key actions for service improvements.

Conclusions

Findings from this study highlighted the need for multi-stakeholder collaboration to develop and implement a strategy to strengthen ASD services for children in South Africa. Better systems for identification of children with ASD, designated early intervention programmes, ASD training for professionals and non-specialist providers, fast-tracking existing inclusive education policies, and drawing on international best practices to inform contextually relevant plans and policies were recommended. Implementation drivers, including competency drivers, organisational drivers and leadership drivers could be a way of translating the six actions identified in this study into practice.

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STYLE, ABBREVIATIONS, AND KEY TERMS

A note on spelling and style convention: UK English spelling and APA referencing has been used throughout this thesis. All references were compiled at the end of the thesis.

ABBREVIATIONS

ASD	Autism Spectrum Disorder
DBE	Department of Basic Education
DOE	Department of Education
CAMH	Child and Adolescent Mental Health
CEMIS	Centralised Education Management Information Systems
CSPID	Children with Severe and Profound Intellectual Disabilities
CST	Caregiver Skills Training
ECD	Early Childhood Development
HIC	High-Income Countries
LMIC	Low- and Middle-Income Countries
SIAS	Screening, Identification, Assessment and Support
SSA	Sub-Saharan Africa
WHO	World Health Organization
WCED	Western Cape Education Department
WCFID	Western Cape Forum for Intellectual Disability

KEY TERMS

Autism Spectrum Disorder

Education Systems

Service Delivery

Waiting List

Low- and Middle-Income Countries

CHAPTER 1: UNDERSTANDING THE LANDSCAPE OF EDUCATION SYSTEMS FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN SOUTH AFRICA

1.1 Introduction to the thesis

In health systems research, Gilson and colleagues (2017) highlighted the importance of understanding both the 'hardware' and 'software' elements of a system in order to gain a whole system understanding. 'Hardware' elements include aspects such as infrastructure, human resources and finance, while 'software' elements refer to ideas and interests, relationships and power, values and norms. In borrowing from health systems research, both these elements need to be investigated to provide a comprehensive understanding also of an educational system. Developed through a series of chapters based on quantitative and qualitative research methodology this thesis examines the education system for children with autism spectrum disorder (ASD) and their families in the Western Cape Province of South Africa. A data-informed framework could serve to inform the overarching question about what can be done to improve services for children with ASD and their families in this specific context. Whilst the focus of the thesis is on one South African province, it is envisaged that investigation of one educational system for ASD may also inform those in other South African provinces, and in other low- and middle-income countries (LMIC).

Chapter 1 begins with a description of the current landscape of education systems in South Africa, including ASD education and education policies that guide service delivery, and concludes with the purpose, aim and objectives of the study. Subsequent chapters address the study objectives by reporting the findings of studies linked to

each of three research objectives. Chapter 2 sets the ‘big picture’ scene by examining the number and profile of children with ASD in schools in the Western Cape Province. Descriptive statistics were used to describe the rates, socio-demographic, disability and education profile of children known to have ASD from among the 1.1 million children in the education system in the Western Cape Province at the time of data collection. Chapter 3 describes the profile of children with ASD who were still waiting to receive educational services in the province at the time of this study. Together, these two chapters provide the best estimate quantification of children with ASD in need of educational services and support in the province.

Having established a broad understanding of some of the ‘hardware’ needs of the ASD education system in the Western Cape Province in chapters 2 and 3, the subsequent chapters shift towards an understanding of its ‘software’ elements. Chapter 4 describes the perspectives of caregivers of children with ASD waiting for educational services. Chapters 5 and 6 respectively present the findings of two qualitative studies that investigated the perspectives of ASD service providers working in private, government and non-government sectors across the province, and the perspectives of key government stakeholders from the Departments of Education, Health and Social Development. Chapter 7 presents a summary of findings, including a synthesis across the different phases of the study, and outlines recommendations for strengthening of services for children with ASD and their families based on these findings. The chapter concludes with an acknowledgement of the limitations of the study and proposes next steps for future research and the strengthening of education system for children with ASD.

1.2 Autism Spectrum Disorder

The Diagnostic and Statistical Manual of Mental Disorder (DSM-5) defines autism spectrum disorder (ASD) as a lifelong neuro-developmental disorder that results in impaired social and occupational functioning (American Psychological Association (APA), 2013). ASD is characterised by impairment of social communication and social interaction and by restrictive and repetitive patterns of behaviours, as well as a range of co-occurring physical and mental health conditions (APA, 2013). There has been an increase in ASD awareness and identification over the past two decades (Maenner *et al.*, 2021) and an estimated 78 million individuals worldwide are thought to be living with ASD (Lord *et al.*, 2022). There are many potential factors that may have contributed to this apparent increase, including more awareness and training due to disability activism (DeVilbiss and Lee, 2014; Elsabbagh *et al.*, 2012; Orsini and Smith, 2010), the development of diagnostic instruments such as the Autism Diagnostic Interview-Revised (ADI-R) and Autism Diagnostic Observation Schedule 2nd Edition (ADOS-2), as well as socio-demographic factors such as increasing parental age (Rice *et al.*, 2012; Durkin *et al.*, 2008). Regardless of the reasons for the increased prevalence, there is consensus that, around the globe health, education and social care systems now have to meet the needs of at least 1-2% of children, adolescents and adults with ASD worldwide (Fombonne *et al.*, 2016; Lord *et al.*, 2022).

There are significant direct and indirect financial costs associated with a diagnosis of ASD (Cakir *et al.*, 2020; Horlin *et al.*, 2014). Direct costs include medical, therapeutic, special education, respite and residential care and indirect costs include loss of productivity of individuals with ASD as well as the loss of productivity of their caregivers as a result of caring for the individual (Cakir *et al.*, 2020). Combined, the estimated societal cost of caring for an individual with ASD across the lifespan is

approximately \$3.6 million in the United States of America (Cakir *et al.*, 2020). Similar societal costing for individuals with ASD in low- and middle-income countries (LMIC) is not currently available.

Early identification, diagnosis and access to behavioural and educational interventions is critical to a positive functional trajectory of the disorder and reduced costs on individuals, caregivers and society (Dawson, 2008; Rogers *et al.*, 2012; Estes *et al.*, 2015; Zwaigenbaum *et al.*, 2015; Sandbank *et al.*, 2020; Cidav *et al.*, 2013). Studies have shown that timely access to early intervention can improve outcomes by reducing some of the core features of ASD that have significant consequences for language, social and cognitive development (Vivanti and Dissanayake, 2016; Dawson, 2008).

The majority of studies on ASD come from high-income countries (HIC) and information on how individuals with ASD are identified, diagnosed and managed in low- and middle-income countries (LMIC) around the world (where the majority of individuals with ASD live) remains limited (de Vries, 2016; Abubakar *et al.* 2016; Franz *et al.*, 2017; Lord *et al.*, 2022). Access barriers for children with ASD in LMIC include poor systems for identification and diagnosis, and the lack of culturally and linguistically appropriate assessment tools for diverse populations (Franz *et al.*, 2017; Divan *et al.*, 2021; Lord *et al.*, 2022; Pillay *et al.*, 2021).

South Africa is ranked by the World Bank as an upper-middle income country and is considered to have reasonable public health data with national population surveys taking place regularly (The World Bank, 2022). Despite having a range of data on various national issues, Hall (2019) suggested that there is a lack of data on issues that relate directly to children in South Africa and that this kind of information is necessary to monitor their socio-economic and educational circumstances and needs.

An additional challenge in South Africa is the very high levels of disparity between the rich and the poor. South Africa has the world's highest Gini coefficient (The World Bank, 2022), and this economic divide often also has direct implications for health, educational and other disparities. Omotoso and Koch (2018) reported on the social determinants of health in South Africa and showed that poor health was directly linked to socio-economic inequalities relating to geographic location, access to education and employment opportunities.

There is a growing (but still limited) literature on ASD in South Africa, and to date no autism prevalence studies have been conducted in the country (Franz *et al.* 2017). Therefore, it is not known what percentage of the South African population may meet the criteria for a diagnosis of ASD or what their profile may look like in terms of socio-demographics and needs. A comprehensive scoping review of all ASD studies ever conducted in Sub-Saharan Africa before 2016 identified only 53 publications of which 28 were from South Africa (Franz *et al.* 2017). The authors identified several knowledge gaps including lack of information on screening and diagnostic procedures, professional knowledge and interventions and family perspectives on ASD. No studies up to that point had examined education systems for children with ASD in South Africa leading Franz and colleagues to suggest that there was a clear need for more research in this area.

1.3 The current landscape of education in South Africa

1.3.1 Education in South Africa

South Africa is home to about 58.78 million people of diverse cultural, ethnic, linguistic and religious backgrounds spread over nine provinces (Statistics South Africa, 2019). In 2019 there were 20 million children under the age of 18 years living in South Africa

of which 11.2 million (56%) were reported to live below the upper bound poverty line of ZAR1,268 (~US\$74.52) per month per person (Hall, 2020). Poverty and inequality are considered legacies of apartheid that influence access to services, including educational services. Since the end of apartheid in 1994 policies and legislation have been drafted to govern education in South Africa in an attempt to correct inequalities in access to education. The White Paper on “Education and Training in a Democratic South Africa: First Steps to Develop a New System” was the first post-apartheid education policy that outlined a framework of education in South Africa (Department of Education, 2001). The document recognized education as a basic human right and highlighted the government’s responsibility in protecting and advancing these rights for all citizens to be able to participate fully in society (Department of Education, 2001).

The South African Schools Act (1996) was drafted to ensure that all children have access to equal and quality education. The Act stated that it is compulsory for all children between the ages of seven and 15 years to be enrolled in a registered educational programme. The South African Schools Act (1996) was amended by the Education Laws Amendment Act, 2005 (Act 24 of 2005), which declared that schools in poverty-stricken areas would not charge schools fees, to ensure that education could be accessible to all children. The Education White Paper 6 – Special Needs Education described procedures to facilitate the inclusion of vulnerable learners and to reduce barriers to learning in order to maximize learner retention in the education system (Department of Education, 2001). Key strategies to achieving this include transformation of the existing system and developing an integrated education system that has support services, intersectoral collaboration, a flexible curriculum,

development programmes for educators, community-based support systems and funding strategies (Department of Education, 2001).

South Africa has a National Department of Basic Education (DBE) that governs all primary and secondary level education across the country. Each province in South Africa has its own Department of Education (DOE) responsible for the provision and implementation of quality education in that province. Provincial Departments of Education report to the National Department of Basic Education (DBE). The South African educational system includes ordinary/mainstream schools, full service/inclusive schools and special schools. Ordinary/mainstream schools refer to regular government-funded and private schools that offer basic primary and secondary education. Full service/Inclusive schools provide mainstream education to learners with diverse learning needs, therefore ensuring inclusion and social justice (Department of Basic Education, 2010). Special schools cater for learners with educational support needs that cannot be met in full service or mainstream educational settings and typically include children with physical and or intellectual disabilities (Department of Education, 2010). The broader educational system also includes Early Childhood Development (ECD) centers that cater for preschool age children (0-5 years) and are overseen by the Department of Social Development (Republic of South Africa, 2015).

Although the White Paper 6 prescribes that all levels of support should be offered to all children across the education system there is still a tendency to place children in the system according to their support needs (McKenzie and Dalton, 2020). Children with special needs who require minimal or no extra support typically go to

ordinary/mainstream schools, children who require moderate support go to full service/inclusive schools and children who require high levels of specialized support are placed in special schools (McKenzie and Dalton, 2020). 'Support' refers to measures that reduce intrinsic as well as extrinsic barriers to learning and include the provision of suitable physical and human resources as well as curriculum differentiation - the process of adapting teaching and assessment strategies to accommodate a range of diverse learning needs (Department of Education, 2007; Department of Basic Education, 2014). South African education policies are closely aligned with the human rights values of social inclusion. A 'universal design' framework provides strategies for inclusion by addressing barriers to learning and promoting inclusion of children with different support needs across the education system (McKenzie and Dalton, 2020). The principles of universal design for learning include a) using multiple levels of representation to present information to learners, b) providing different ways for learners to interact with learning materials and to demonstrate what they have learned, and c) using different ways to motivate learners according to their interests and contexts (McKenzie and Dalton, 2020).

The calendar year 2016 was selected as the time period for quantitative data collection for this study. This was the most recent year on which comprehensive and verified education data were available at the start of the PhD project. In 2016, there were 13,319,662 children attending 29,925 educational institutions across the country (Department of Basic Education, 2018). A total of 12,932,565 children were reported to be in ordinary/mainstream government and independent schools across the country (Department of Basic Education, 2018). A reported 22.3% of the learner population were in schools in the Kwa-Zulu Natal province, 18% in Gauteng, 15.2% in the Eastern Cape and 13.7% in Limpopo. The Mpumalanga and the Western Cape Provinces

served 8.3% and 8.6% of all learners respectively. Lower learner rates were reported in the Free State (5.3%), the Northern Cape (2.3%) and the North-West Province (6.4%) (Department of Basic Education, 2018). The majority of learners (97.1%) in South Africa were enrolled in ordinary/mainstream government or independent schools, 1.9% in early childhood development (ECD) sites and 0.9% of learners were in special schools (Department of Basic Education, 2018).

Despite having progressive inclusive education policies in place, 30.7% of children between the ages of 7-15 years were reported to be out of school in 2016 (Statistics South Africa, 2016). According to Hall (2017) the main reason for non-attendance were financial constraints, failures in learner or education systems such as poorly resourced facilities and illness and disability. Statistics South Africa (2014, p. xxiv) defined disability as *“the loss or elimination of opportunities to take part in the life of the community, equitably with others that is encountered by persons having physical, sensory, psychological, developmental, learning, neurological or other impairments, which may be permanent, temporary or episodic in nature, thereby causing activity limitations and participation restriction with the mainstream society”*. It is not clear what proportion of the children out of school cited in 2016 might have had a neurodevelopmental disability such as ASD.

1.3.2 Special education in South Africa

The special education system in South Africa is a by-product of the apartheid era where children were historically segregated on the grounds of race and disability (Department of Education, 2001). Schools for ‘White’ children with disabilities were well-resourced whereas the few schools for ‘Black’ children with disabilities were poorly resourced (Department of Education, 2001). There were also significant

disparities between urban and rural resources with a lack of provisions for children with special education needs in rural areas (Department of Education, 2007). Although much has been done to transform the racially- and ability-segregated education system and to correct the structural legacies of the past, more than half a million children with disabilities were reported to be out of schools in South Africa in 2015 (Human Rights Watch, 2015).

More recent data from the Department of Basic Education (2018) showed that 85% of schools in South Africa were ordinary/mainstream schools, and that 2% were special schools (accommodating 119,403 learners with special needs nationally). The South African Schools Act Section 12(4) stated that *“where it is reasonably practicable, learners with special educational needs should be admitted to ordinary public schools with relevant educational support”*. The Inclusive Education Policy proposed that a range of learning needs be accommodated in schools by addressing barriers to learning (Department of Basic Education, 2010). ‘Barriers to learning’ in education refer to difficulties within the education system, school or learner that obstructs access to education and learning (Department of Basic Education, 2010). These may be due to disability, poverty, inequality and social circumstances (McKenzie and Dalton, 2020). According to the Inclusive Education Policy children with disabilities should be included in mainstream schools with appropriate support in place. However, a significant portion of children with disabilities in South Africa have been reported to be out of school, in mainstream schools without appropriate support, or inappropriately placed in special schools (Hodgson, 2018).

Kahonde and colleagues (2012) argue that curriculum differentiation is fundamental to the inclusion of children with barriers to learning in the least restrictive learning

environment with their peers. The universal design for learning (UDL) framework addresses curriculum flexibility so that learners with a range of learning needs can be included in the education system (Kahonde et al., 2012). Although UDL has gained much recognition in high-income countries and higher education settings there is little information on the feasibility, acceptability and applicability of UDL in basic education in low- and middle-income countries like South Africa (Young, 2016). In exploring the applicability of UDL in special schools in low resourced areas in South Africa, Young (2016) reported that township teachers recognized the value of UDL principles. However they did not feel that it was feasible in their contexts due to limited resources, insufficient space and inappropriate buildings. Young (2016) highlighted the importance of considering a country's socioeconomic and political context when examining the applicability of inclusive education practices widely used in high income countries.

1.4 Education for children with autism spectrum disorders (ASD) in South Africa

ASD-specific education in South Africa started in the 1970's with the establishment of Vera School in 1970 and Alpha School in 1974, both in the Western Cape Province. Unica School in the Gauteng Province was established in 1974 and Quest School in the Eastern Cape in 1995. In 2005 the Johannesburg Hospital School was approached to assist with ASD education in Gauteng and since then has grown to be the largest school for children with ASD in the country. Although there are classes for children with ASD in some special schools in other provinces across the country, the majority of ASD educational services in South Africa are concentrated in three provinces (Western Cape, Gauteng and Eastern Cape).

There are also independent special needs schools (privately funded institutions of learning) and private programmes (centres providing educational or developmental services to children with ASD but not registered with the Department of Education). According to van Schalkwyk, Beyer and de Vries (2016) unregulated private ASD programmes vary in quality and do not always use evidence-based practices. Independent schools and private programmes tend to be costly and are not accessible to the majority of children with ASD in South Africa (Clasquin-Johnson and Clasquin-Johnson, 2018).

In 2016 there were 4,170 children with ASD reported to be in special schools across the country (Department of Basic Education, 2018). The majority of these children (33.1%) were in schools in the Gauteng province, 25.3% in Kwa-Zulu Natal and 18.8% in the Western Cape. These three provinces are also the largest in terms of population and combined have more than half the population of South Africa (Statistics South Africa, 2019). Lower rates were reported in Eastern Cape (7.6%), Limpopo (5.3%), Free State (3.5%), Northern Cape (3.5%), North-West (1.3%) and Mpumalanga (1.1%). At the start of this project in 2016 no reports were available on the number and profile of children with ASD in other school settings including Ordinary/Mainstream Schools or Full-service/Inclusive Schools in any South African province.

There are no policies specific to ASD education in South Africa. As a result, there are no guidelines about where children with ASD should be educated and by whom or what and how they should be taught. There is no prescribed curriculum for children with ASD in South Africa and only some of the ASD schools use Individualized Education and Development Plans (IEDPs) as a baseline for teaching. These IEDPs include learning outcomes for behaviour management, social skills, communication

skills and some functional literacy and numeracy skills. In the absence of standardized norms, children with ASD in the special education system leave school at the age of eighteen without a national certificate and poor prospects of vocation.

1.5 Autism Spectrum Disorder in the Western Cape Province

The Western Cape Province is the third largest province in South Africa in terms of population. In 2016, the year that the first phase of quantitative data collection began, there were 6.2 million people reported to be living in the province (Statistics South Africa, 2016). The majority of people in the province self-report as being 'Coloured' (49%) (Statistics South Africa, 2012). The term 'Coloured' in South Africa describes people of mixed racial ancestry from Europe, Asia and Southern Africa. Thirty three percent (33%) were self-reported as 'Black', 17% as 'White' and 1% as 'Indian/Asian' (Statistics South Africa, 2012). Afrikaans is the main language spoken in the Western Cape and is reported to be the first language of 50% of the population, followed by isiXhosa (25%) and English (20%) (Statistics South Africa, 2012). The Western Cape is often described as being one of the better resourced provinces in terms of services for children (van Schalkwyk, Beyer and de Vries, 2016). The first two Special Schools for children with ASD in South Africa started in the Western Cape in the 1970's and were the only two schools servicing the entire province for almost four decades. Over the years, the growing demand for placement at these schools called for the creation of the first informal 'ASD waiting list' in 2009. The waiting list was managed by Vera and Alpha schools in consultation with the Western Cape Education Department (WCED) until 2016, when it was taken over by the WCED. The Western Cape was the only province in South Africa with a waiting list of children with ASD awaiting educational services at the time of the research outlined in this thesis. The creation of a waiting list highlighted the growing need for educational opportunities for children

with ASD across the province. Since 2009 several new ASD units were started at special schools across the province.

The WCED also has education 'outreach teams' consisting of education psychologists, occupational therapists, speech and language therapists and learning support teachers. The purpose of these multi-disciplinary teams (MDT) is to assess children with special learning needs, including those on the ASD waiting list. The MDT assigned to children with ASD is referred to as the 'Provincial ASD Outreach Team'. The team's mandate is to determine the level of support that a child would require in the education system, to support the special schools and units catering for learners with ASD, and to conduct ASD-specific training for professionals working with children with ASD.

Despite the efforts by the WCED to coordinate ASD education services in the Western Cape, there has been an observable increase in the number of children with ASD waiting for school placement. Early educational and behavioural intervention can have positive outcomes for language development, social communication and behaviour in young children with ASD (Lord *et al.*, 2022). According to Lord *et al.*, (2022) timing is critical in addressing and modifying the different behaviours associated with ASD at the different stages of development. Being on a waiting list for an extended period and not having timely access to intervention could potentially have poor future outcomes for cognition, self-regulation and skills development in individuals with ASD (Lord *et al.*, 2022). Given the importance of early developmental intervention for children with ASD during the critical period of development as well as the human right of children with ASD to have access to education, the rapidly growing ASD waiting list had become a significant concern to professionals and families, signaling the need for

strengthening of the whole educational system for children with ASD in the province. However, no systematic data were available to outline the scale of the problem, the nature and profile of needs, or perspectives about challenges and potential solutions to the problem.

1.6 The ASD research problem

The Western Cape Education Department is challenged with providing appropriate and quality educational services and support for children with ASD and their families. The growing waiting list for children with ASD in the province therefore represents a symptom of a greater systemic problem in the WCED. At the time of this thesis there were no policies specific to ASD education in South Africa or the Western Cape. Informal comments by stakeholders concerned with the growing need for ASD services suggested that the non-attendance of school-aged children with ASD was a reflection of poor implementation of existing inclusive education policies. Apart from school-aged children, there were also unclear pathways to diagnosis and intervention for pre-school children with ASD. There was also no research to describe the current 'landscape' of needs or empirical evidence of the perspectives of key stakeholders in the province to help understand the educational needs of children with ASD and their families. In short, there were no data that could inform actions for strengthening of the whole system. For these reasons, there was a clear need to investigate 'hardware' and 'software' elements of the ASD educational system in the Western Cape Province.

1.7 Research purpose

The purpose of the study was to contribute empirical information that would substantiate the need for the development of integrated services for children with ASD and their families in the Western Cape. The notion of 'integrated services' here refers

to a collaborative and coordinated approach to service delivery that is informed by and responsive to the needs of children with ASD and their families. Service integration contributes to the fulfilment of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) that aims to “*promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity*” (United Nations, 2006, p. 4). A thorough understanding of the ‘hardware’ (quantified service demand, infrastructure and resources) and ‘software’ (ideas and interests, relationships and power, values and norms) issues restricting and facilitating integrative service delivery for children with ASD was needed to generate evidence-based, scalable and sustainable solutions to the problem.

1.8 Aim and objectives of the thesis

The overarching aims of the thesis were to describe the nature and extent of the education service needs of children with ASD in the Western Cape Province, to explore the perspectives of key stakeholders, and to generate evidence-informed recommendations to strengthen future ASD educational service delivery.

The objectives were:

- a) To determine the rates and describe the profile of children with ASD both in school and awaiting school placement in the Western Cape
- b) To examine stakeholder perspectives and proposed solutions to meet the educational needs of children with ASD and their families
- c) To generate recommendations based on the evidence that will strengthen the educational services provided to children with ASD and their families, in a sustainable and scalable way

1.9 Conceptual Framework

1.9.1 Disability Rights Framework

This thesis is positioned within a disability human rights framework (United Nations, 2006). The human rights approach to education is to ensure that every child, including those with special learning needs, has access to quality education in order to promote optimal development and dignity (UNICEF, 2007). Disability becomes a human rights issue when people with disabilities are denied equal access to opportunities like health care and education. The South African Schools Act (1996) aligns itself with disability rights by stating that every child has a right to basic education and that it is compulsory for all children between the ages of 7 and 15 years to be enrolled in a registered educational programme. The anecdotal evidence of school-going age children with ASD waiting for educational placements while not in formal education would be a contravention of their basic right to education.

1.9.2 Social Justice Theory and Social Inclusion

Rawls (1971) defined social justice as a sense of order in society that is governed by fundamental principles of justice and fairness. Social justice theory argues that all people should have equal rights and liberties and that no person in society should be denied opportunities available to others in the society (Rawls, 1971). According to the South African Schools Act (1996) each province in South Africa has responsibility for providing schooling for learners in that province and the Members of the Executive Council (MEC) are responsible for ensuring that there are enough school places for every child of compulsory school-going age.

Social inclusion is important for the well-being both of children with ASD and their families (UNICEF, 2017). According to UNICEF (2017) inclusion of children with

disabilities in quality learning requires transformation of the whole education system. This would require legislation and policy, systems for financing, administration, design, delivery and monitoring of education and schools. The South African Schools Act (1996) states that, where it is possible, learners with special educational needs should be accommodated at ordinary/mainstream public schools and should be provided with the relevant educational support services. Disability-inclusive development facilitates social inclusion of individuals with disabilities in mainstream society by including them as equal and active participants and beneficiaries in decision-making and development processes (United Nations Development Programme, 2016). This includes inclusive education, health, social, employment and other opportunities across the lifespan (United Nations Development Programme, 2016).

1.9.3. Health Disparities Research Framework

Given the complexities of ASD education in the Western Cape this study adopts a health disparities research framework (Kilbourne *et al.*, 2006). This framework is useful in gaining a comprehensive understanding of the gaps that exist in access to care for vulnerable populations and informing interventions to eliminate or reduce these disparities (Kilbourne *et al.*, 2006). The framework outlines three phases of research that align with the objectives of this study. The first quantitative phase of this study defines and describes the health disparity by presenting data on children with ASD in and out of the education system. The second qualitative phase of the study aims to develop a deeper understanding of the existing health disparities through engagement with caregivers, service providers and government stakeholders and the final phase of the study synthesizes the findings across the study to provide suggestions for reducing the disparities.

1.10 Study design

A mixed-methods research approach across two phases was used a) to describe the rates and profile of children with ASD in the province, and b) to examine stakeholder views, perspectives and proposed solutions to meet the educational needs of children with ASD and their families. According to Morgan (1998) combining the strengths of both qualitative and quantitative methods can be valuable in addressing complex issues related to health. Mixed methodology can be used to confirm or complement the result of a study (Morgan, 1998). This study uses a complementary sequenced approach (Morgan, 1998) where the finding from the first quantitative phase of the study informs and adds to the findings in the second qualitative phase to provide a more comprehensive understanding of the problem.

Both focus groups and semi-structured interviews were used in the qualitative phase of the study. Focus groups were used to explore the diverse perspectives of the service users simultaneously. Apart from being cost effective and efficient, the social nature of focus groups allows participants to “*consider and reflect upon aspects of their daily life that are usually taken for granted*” Acocella (2011, p1126). Semi-structured interviews were used to collect service provider perspectives. This allowed the participants the opportunity to share their perspectives freely and on their own terms at a time and place that was convenient for them.

The data generated in these two phases was synthesised to generate recommendations to guide service delivery in meeting the educational needs of children with ASD and their families. Table 1.1 provides a summary of the research

design across the different chapters of the thesis. Given that chapters are written as a series of papers, the relevant methodologies will be outlined in each chapter.

Table 1.1: Research design of the thesis

Overarching research question What can be done to improve services for children with ASD and their families?'						
Chapters	Chapter 2	Chapter 3	Chapter 4, 5, 6			Chapter 7
Objectives	<p>a) To perform a search for all children with a primary or secondary diagnosis of ASD attending schools in the Western Cape Province to generate a broad rate of ASD in schools</p> <p>b) To compare data on children with ASD to the population demographics of the Western Cape Province as represented by 2011 Census to ascertain the distribution of ASD across key socio-demographic and geographical variables</p> <p>c) To describe the profile of educational placement across school types of all children with ASD in the Western Cape education system</p>	<p>a) To describe the demographic, disability, referral and service provision profile of all children with ASD or suspected ASD on the ASD 'waiting list' in the Western Cape</p> <p>b) To determine how long children with ASD waited for school placement and what services were available to them while they waited</p> <p>c) To combine data on children with ASD awaiting school placement and those in schools (Chapter 2) to generate a more comprehensive profile of children with ASD in the province</p>	To examine stakeholder views, perspectives and proposed solutions to meet the educational needs of children with ASD			To synthesise recommendations for ASD service delivery in order to meet the educational needs of children with ASD and their families in a sustainable and scalable way
Fields of enquiry	Education/Health Science					
Conceptual framework	Social inclusion theory, Disability rights framework					
Methodology	Mixed Methodology					
	Non-experimental descriptive quantitative methodology			Descriptive qualitative methodology		Synthesis of findings
Method	Survey of Centralised Education Management Education System (CEMIS) data	Survey of education waiting list for children with ASD	Focus groups	Semi-structured interviews	Semi-structured interviews	
Analysis	Descriptive statistics			Qualitative thematic analysis		
Interpretation	Univariate			Inductive		

1.11 Chapter summary

This chapter presented an overall introduction to the thesis. It outlined key information about South Africa, about education systems in South Africa, and about ASD education and education policies that guide service delivery. The chapter highlighted the research gaps that led to the identification of the study problem, purpose, aim and objectives, and presented an overview of the research design for chapters to follow.

CHAPTER 2: AUTISM IN THE WESTERN CAPE PROVINCE OF SOUTH AFRICA: RATES, SOCIO-DEMOGRAPHICS, DISABILITY AND EDUCATIONAL CHARACTERISTICS IN ONE MILLION SCHOOL CHILDREN

Pillay, S., Duncan, M., and de Vries, P. J. (2021). *Autism*, 25(4): 1076-1089.
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2.1 Introduction

Autism Spectrum Disorder (ASD) is a lifelong neuro-developmental disorder characterised by persistent challenges in social communication and social interaction, as well as restricted and repetitive behaviours, interests and activities (APA, 2013). ASD results in impaired social and occupational functioning to various degrees (APA, 2013). There has been a worldwide increase in autism awareness in the past decades (Fombonne, 2018; Elsabbagh *et al.*, 2012; Wallace *et al.*, 2012) and ASD has become one of the more frequently researched developmental disorders in mental health (Matson *et al.*, 2013).

The global prevalence of ASD is estimated at 1-2% of the population (APA, 2013). Prevalence studies show increasing rates of ASD in high-income countries (HIC) around the world (Centers for Disease Control and Prevention, 2014; Baron-Cohen *et al.*, 2009), and lower (but also increasing) rates of ASD in low- and middle-income countries (LMIC) (Montiel-Nava and Peña, 2008; Paula *et al.*, 2011; Fombonne *et al.*, 2016; Dekkers *et al.*, 2015). There may be many potential reasons for the lower rates of ASD reported in LMIC to date, including lack of awareness, stigma, diagnostic overshadowing, access barriers to care, and limited research (de Vries, 2016; Franz *et al.*, 2017). De Vries argued that the lower rates in LMIC were likely attributable to

under-ascertainment rather than indicative of actual reduced rates of ASD in these parts of the world (de Vries, 2016).

Little ASD research has been performed in sub-Saharan Africa (SSA) to date (Abubakar *et al.*, 2016; de Vries, 2016; Franz *et al.*, 2017). At the time of their scoping review, Franz and colleagues pointed out that there had been no prevalence studies on ASD in SSA. In the absence of formal epidemiological studies, information systems such as those of public health or education systems may provide proxy information about whole-population profiles. However, no publications had examined either public health or educational systems data for ASD in SSA (Franz *et al.*, 2017).

South Africa is the largest country in Southern Africa with an estimated population of 58.78 million people (Statistics South Africa, 2019). An estimated 28.8% of the population are children under the age of 15 years (Statistics South Africa, 2019). Based on a 1% estimated prevalence, approximately 169,286 children under the age of 15 would be predicted to have ASD and may require health, education and other services.

The Western Cape Province in South Africa has historically been considered one of the better-resourced provinces in the country for children with ASD, with the first schools for children with ASD being established in the early 1970's in Cape Town (van Schalkwyk *et al.*, 2016). Despite having health and education systems in place, a growing number of children with ASD have not been able to be accommodated in Western Cape Education Department (WCED) schools. The creation of a 'waiting list' in 2009 signalled that the demand for school placement for children with ASD was starting to exceed the number of available school placements for these children, with potentially dire consequences for the education of children with ASD. There was

therefore an urgent need to examine the existing profile of children with ASD in the education system as a first step towards generating comprehensive, evidence-based and sustainable solutions to the growing demand for services.

2.1.1 Background to the South African educational system

South Africa has people of diverse linguistic, cultural, ethnic and religious backgrounds. In South Africa, the population is classified under five self-declared racial categories namely 'Black', 'White', 'Coloured', 'Indian or Asian' and 'Other'. 'Black' or Bantu-speaking people include Xhosa, Zulu, Basotho, Bapedi, Venda, Tswana, Tsonga, Swazi and Ndebele people. South Africans of European descent are classified as 'White'. The term 'Coloured' in South Africa describes people of mixed racial ancestry from Europe, Asia and Southern Africa. South Africans of this ethnic group identify with and prefer being referred to as 'Coloured' rather than 'Black' (De la Rey and Duncan, 2003). People from Indian or Chinese descent are classified as Asian. Given these South African contextual factors, we have therefore selected to use these terms here. The South African Constitution recognises 11 official languages that include English, Afrikaans, isiXhosa, isiZulu, Sesotho, Setswana, siSwati, Tshivenda, Sepedi, Xitsonga and isiNdebele.

There are nine provinces in South Africa (Western Cape, Eastern Cape, Northern Cape, North West, Free State, Gauteng, KwaZulu-Natal, Limpopo and Mpumalanga). The demographic composition of each province in terms of race and ethnicity, languages spoken, socio-economic status and educational attainment may vary significantly. Three provinces (Gauteng, KwaZulu-Natal and the Western Cape) contribute to nearly two-thirds of the total economy of South Africa. Over the years there has been an increase in migration of people from other provinces and other

countries to Gauteng and the Western Cape in search of better employment, healthcare and education (Statistics South Africa, 2014; Jacobs and Du Plessis, 2016).

Each of the provinces in South Africa has their own education department that oversees the implementation of the national educational policies and responds to provincial matters. Education for children with ASD in South Africa is available from public (government-funded) and independent (privately funded) schools. According to the South African Schools Act (1996) it is compulsory for all children (including children with special educational needs like ASD) between the ages of 7 and 15 years to attend school. In practice, children with and without special educational needs typically enter the education system in the year that they turn 7 years and exit at 18 years. The South African educational system includes Ordinary/Mainstream Schools (low level support for learners), Full Service/Inclusive Schools (moderate levels of support) and Special Schools (high levels of specialized support). Early childhood development (ECD) or pre-school programmes are not compulsory and are offered at only a few government-funded schools. Other specialized educational institutions include training centres, schools of skills, specialized schools and hospital schools.

South Africa has a complex history marked by apartheid, a legacy of which is inequality in the education system, particularly in the special needs sector (Department of Education, 2001). Special Schools during the apartheid era were classified according to two criteria - race and disability, and schools for White children were well resourced, while those for Black children were poorly resourced. Furthermore children with disabilities experienced barriers to accessing education as there were only a few Special Schools and these schools maintained rigid criteria for admission that allowed

only children with a particular disability to go to a specific school (Department of Education, 2001).

The Western Cape Province, the focus of this study, had the fourth largest population in South Africa with a total of 5,822,734 people reported at the last Census in 2011, of which 1,378,126 (23.6%) were between the ages of 5-19 years (Statistics South Africa, 2012). In terms of self-classified racial/ethnic grouping, the population demographics (Statistics South Africa, 2012) showed that the majority of the province was Coloured (48.78%) followed by Black (32.85%), White (15.72%), Asian/Indian (1.04%) and Other/Unspecified (1.61%). The most frequently spoken languages in the Western Cape Province were Afrikaans (49.7%), Xhosa (24.7%) and English (20.2%) (Statistics South Africa, 2012).

As shown in figure 2.1, the Western Cape Education Department (WCED) currently has eight educational districts defined by municipal boundaries, four urban, based in the City of Cape Town (Metro North, Metro East, Metro South and Metro Central) and four rural (West Coast, Cape Winelands, Eden and Central Karoo, and Overberg).

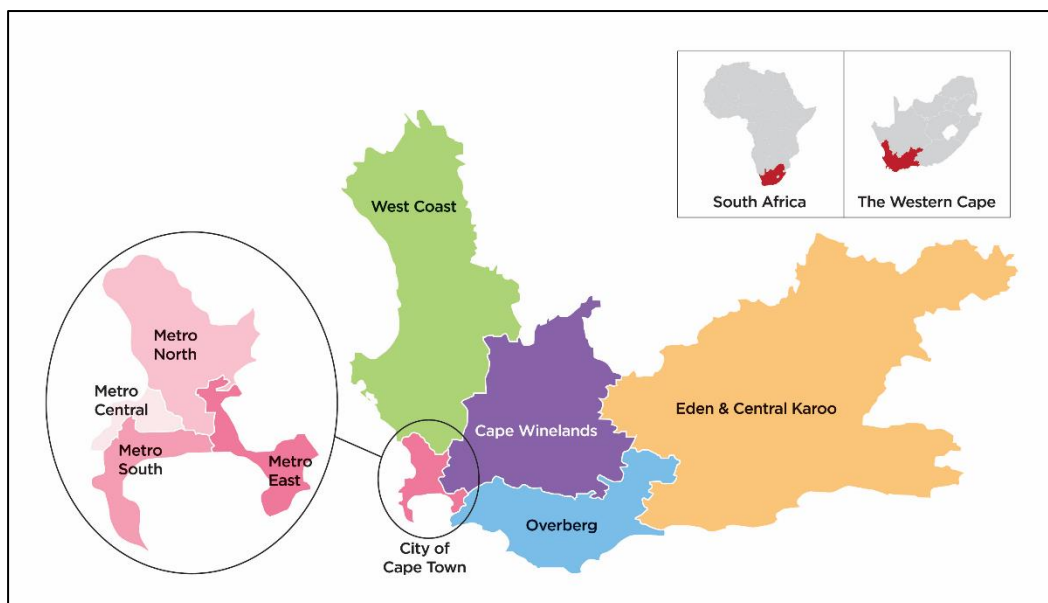


Figure 2.1: The Western Cape Province Educational Districts

2.1.2 Pathways to diagnosis and school placement for children with ASD or suspected ASD in the Western Cape

Figure 2.2 shows the pathways to diagnosis and school placement for children with ASD in the WCED.

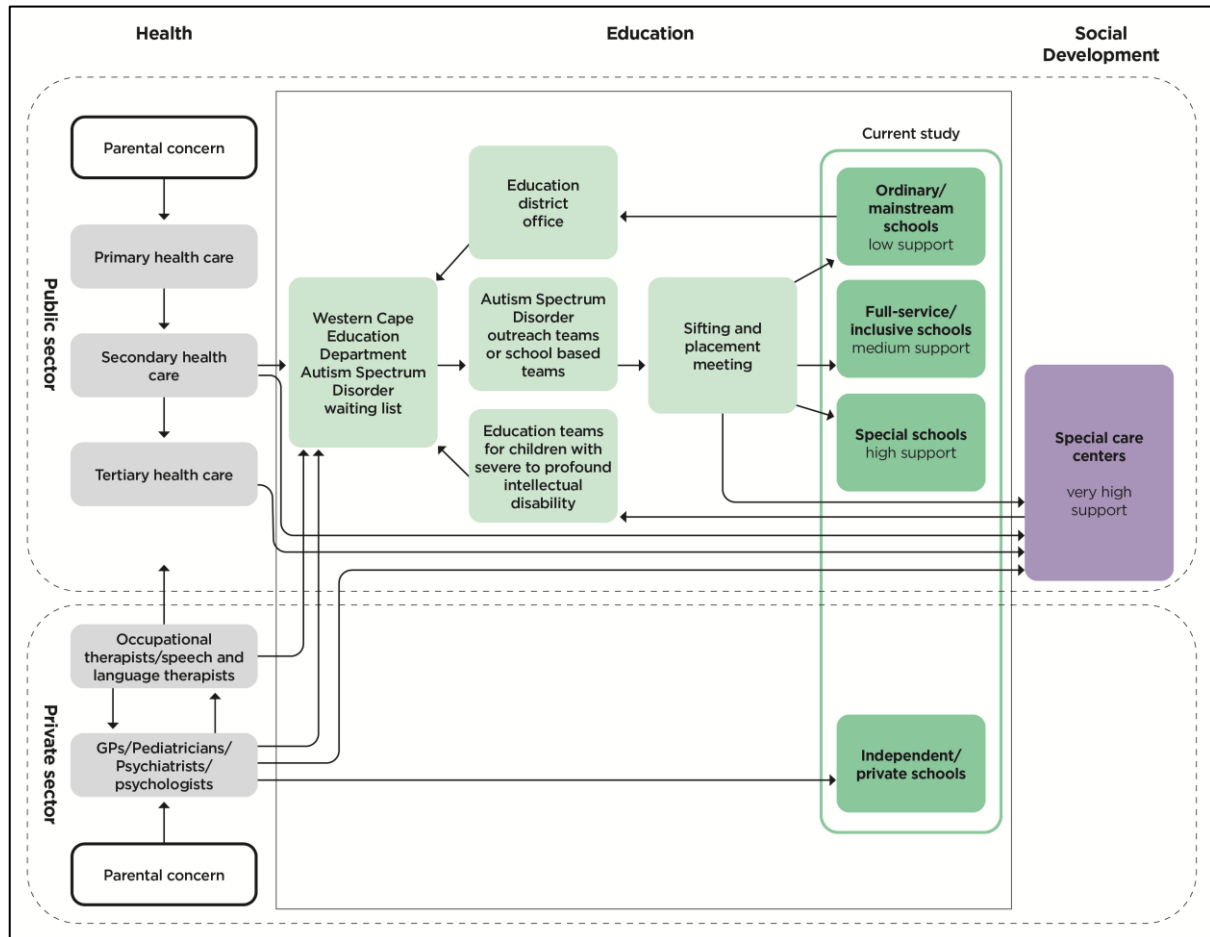


Figure 2.2: Pathways to diagnosis and school placement for children with ASD or suspected ASD in the Western Cape

No routine or ‘well child’ screening takes place in the Western Cape or any other South African province. Referral pathways are therefore triggered by parental concern. As outlined earlier, the country has a two-tier healthcare system with public (government-funded) and private (health insurance-funded) healthcare. In the public sector, concerned parents seek help from primary care community health clinics, where they are typically assessed by nurses or medical officers (non-specialist medical doctors). From here they are referred to secondary care services where they are typically

assessed by general pediatricians. If diagnosed with ASD, children are then referred to the WCED ASD waiting list for school placement. Where diagnosis is complex or unclear, children are referred to tertiary care services for multidisciplinary specialist assessment by developmental pediatricians, child and adolescent psychiatrists, and/or clinical psychologists.

In the private sector, concerned parents go directly to general practitioners, pediatricians or other medical specialists for diagnostic evaluation, or may seek evaluation from clinical psychologists, speech and language therapists or occupational therapists. Once diagnosed with ASD, a child is referred to either the ASD waiting list (for access to government-funded schools) or to independent/private schools (for privately funded education). Children with complex or unclear profiles can be referred to the tertiary services in the public sector as outlined above.

There are no standardized pathways or protocols for assessment of ASD in the Western Cape (or other South African provinces) either in the public or private sector. Given the cultural and linguistic heterogeneity in the country, diagnostic assessments are made using a range of potential tools including the Childhood Rating Scale (Schopler *et al.*, 2010), DSM-5-TR criteria (APA, 2022) and, in a few settings, the ADOS-2 (Lord *et al.*, 2012). No diagnostic tools have been validated for use in South Africa, and most tools are only available in English.

The WCED ASD waiting list is the centralized referral point for all children in the province who are thought to require special educational services. Once the child's information is captured on the waiting list, the information is sent to one of the schools

in the eight educational districts closest to where the child lives. Multi-disciplinary ASD outreach teams consisting of psychologists, occupational therapists, speech and language therapists and learning support teachers then invite the child to the school for an observation and assessment period (typically 1-2 weeks) where the diagnosis of ASD is confirmed, if required, and where standardized and non-standardized assessments are conducted to determine the level of support that the child may require in the education system. These assessments, almost without exception, are completed in English. The case is then presented at a 'sifting and placement meeting' where a decision about school placement is made and signed off by the Director of Specialized Education. The child is then referred to either an Ordinary/Mainstream School, Full Service/Inclusive School, Special School or Special Care Centre depending on their support needs.

Children with ASD who can cope academically and socially at Ordinary/Mainstream Schools typically go directly to these schools and may therefore not be referred to the WCED ASD waiting list. Children with ASD who are already in Ordinary/Mainstream Schools but are struggling in that setting, are identified by psychologists from the education district offices and referred to the ASD waiting list where they follow the same process for assessment and placement as outlined. In 2010 the Western Cape Forum for Intellectual Disability sought litigation against the South African Government for excluding children with severe to profound intellectual disabilities from education (McKenzie *et al.*, 2017). One of the outcomes of the court case was that education teams for Children with Severe and Profound Intellectual Disabilities (CSPID) were created to support Special Care Centres run by non-government organizations but overseen by the Department of Social Development. These teams identify children in

these Special Care Centres with ASD or suspected ASD who may be better placed in a different school setting and refer these children to the ASD waiting list.

The WCED has a database of all children in schools in the province. The centralised education management information system (CEMIS) is used for registration and tracking of all children in the education system. CEMIS forms are completed by caregivers and school officials when a child enters the education system. Among other data captured, CEMIS documents whether children have a primary or secondary diagnosis of ASD or other neurodevelopmental disorders. This information along with other socio-demographic information is used to calculate the 'weighting' of each child in the education system which informs the amount of resources that a school receives for each child. The CEMIS database should therefore include data on all school-going children in the province with ASD.

2.1.3 The current study

Given the absence of any formal epidemiological data on ASD in South Africa as highlighted above, we set out to:

- a) Perform a search for all children with a primary or secondary diagnosis of ASD attending schools in the Western Cape Province to generate a broad rate of ASD in schools
- b) Compare data on children with ASD to the population demographics of the Western Cape Province as represented by 2011 Census to ascertain the distribution of ASD across key socio-demographic and geographical variables
- c) Describe the profile of educational placement across school types of all children with ASD in the Western Cape education system

We predicted that:

1. the rate of children with known ASD in the education system would be lower than global estimates, set at a conservative 1% prevalence
2. there would be an under-representation of children with ASD from previously disadvantaged communities, given the complex legacy of apartheid
3. there would be an over-representation of children with ASD in special educational settings, given historical practices in the education system

2.2 Methods

A quantitative non-experimental design was used to provide descriptions of the population of children with ASD in the Western Cape Education Department (WCED).

2.2.1 The primary data source

The centralised education management information system (CEMIS), the official system for registration and tracking of all children in the education system in the Western Cape Province, was used as primary data source. All data in the CEMIS database on 27 June 2016 were included. Caseness was defined as all children registered on CEMIS with a primary or secondary diagnosis of ASD on 27 June 2016. This included ordinary/mainstream schools, full-service/inclusive schools, special schools and independent/private schools. Data on special care centres, under the jurisdiction of the Department of Social Development, is not included in CEMIS.

2.2.2 Data extraction

The dataset, in Excel format, was an anonymized list with the CEMIS number of each child serving as a study code. Three main domains of data were extracted from the

CEMIS database – demographic, disability, and educational information. The variables extracted are shown in table 2.1.

Table 2.1: Domains and variables extracted from CEMIS

Demographic information	Disability information	Educational information
1. Total number of children with ASD in schools 2. Age and sex of children with ASD 3. Race/Ethnicity of children with ASD 4. Home language 5. Number of children with ASD in schools from 2012 to 2016	1. Main disability 2. Secondary disability #1 3. Secondary disability #2 4. Secondary disability #3	1. Education district 2. Type of School (mainstream/inclusive/special) 3. Funding of school (government or private)

2.2.3 Data analysis

Descriptive statistics were used to summarise the data with means and standard deviations for continuous variables, and proportion for categorical variables. Independent sample t-tests were used to compare the age and increase in ASD prevalence between male and female children. Chi-square tests were used to compare race, home language and educational district between the CEMIS data and the Western Cape population statistics. All analyses were conducted on SPSS Version 25, with the threshold for statistical significance set at 0.05.

2.2.4 Research Ethics

This study complied with the World Medical Association Declaration of Helsinki (2013). Ethics approval was obtained from the University of Cape Town Human Research

Ethics Committee (HREC 072/2016) as well as the Western Cape Department of Education (Reference: 20150727-1712).

2.3 Results

Results are presented based on the three main domains outlined in Table 2.1.

2.3.1 Demographic Information

2.3.1.1 Total number of children with ASD attending schools in the Western Cape in 2016

In June 2016 there was a total population of 1,154,353 children attending 2,150 educational institutions across the eight educational districts in the Western Cape Province (Department of Basic Education, 2018). A total of 940 cases of ASD were reported on CEMIS, representing 0.08% of the school-going population in the province.

2.3.1.2 Age and sex distribution of children with ASD

The age distribution of children with ASD in this study is shown in figure 2.3.

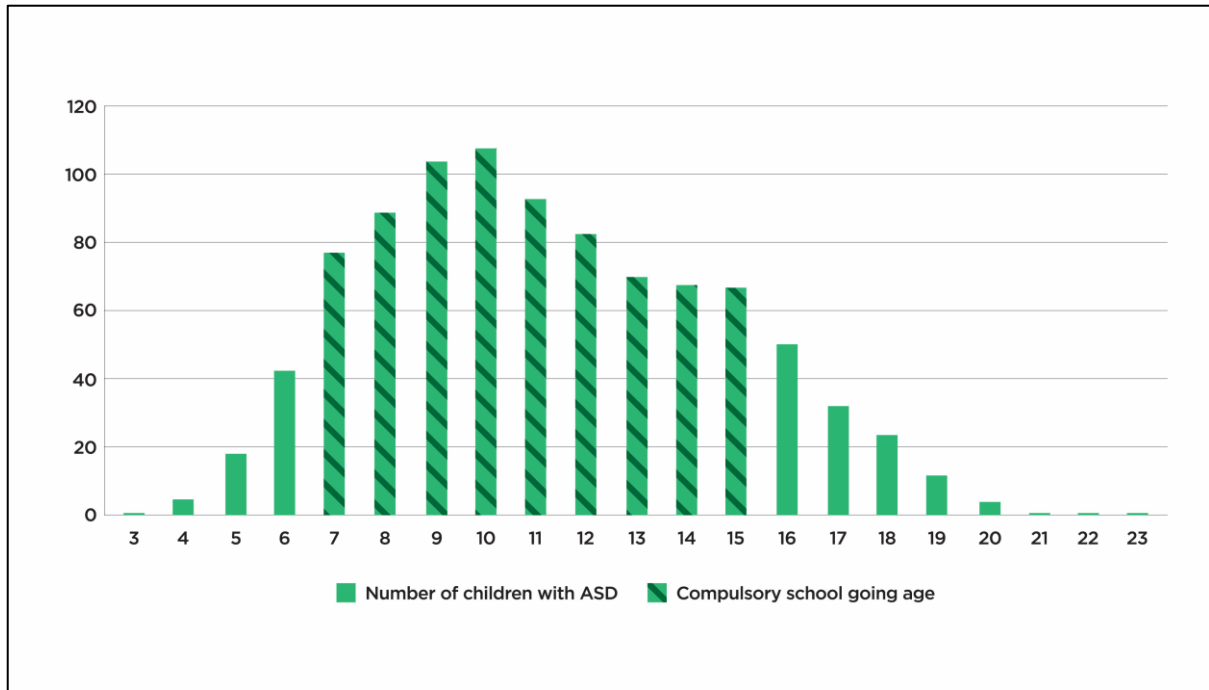


Figure 2.3: Age distribution of children with ASD on the WCED Centralised Education Management Information System (CEMIS)

The majority of children with ASD (84%) were of compulsory school-going age (7 to 15 years), but the database also identified individuals with ASD that were younger and older. The youngest child on CEMIS was 3 years old and the oldest student was 23 years. The largest age band of children with ASD on CEMIS were the 9–10-year-old group.

A total of 795 boys with ASD and 145 girls with ASD were reported with a male to female ratio of 5.5:1. Overall there was no significant difference in age between male and female children ($M = 10.5$, $SD = 3.3$ vs $F = 10.9$, $SD = 3.9$, $p = 0.195$).

2.3.1.3 ASD rates by self-reported race/ethnicity

The majority of the children with ASD on CEMIS were self-classified as Coloured (42%), followed by White (33%) and Black (22%). Indian children accounted for 1% of the sample and 2% were reported to be of Other/Unspecified races. Table 2 shows a summary of expected *versus* observed number of children with ASD across the self-

reported racial/ethnicity groups. As shown in table 2.2, there was a significant difference in the racial composition of the CEMIS ASD children compared to the Western Cape Province population demographics. A significantly higher proportion of children with ASD were from the White racial group, and a significantly lower proportion were from the Coloured and Black racial groups ($\chi^2(df = 4) = 215.69, p < 0.001$).

Table 2.2: Racial/ethnicity comparison of children with ASD on CEMIS with the Western Cape Province population demographics

Self-declared Race/ethnicity	ASD observed on CEMIS		ASD expected based on CENSUS 2011		Residual
	N (observed)	% (observed)	N (expected)	% (expected)	
Coloured	395	42%	458.7	50%	-63.7
White	306	33%	147.6	15%	+158.4
Black	206	22%	308.3	32%	-102.3
Asian/Indian	14	1%	9.4	1%	+4.6
Other	19	2%	16	2%	+3
Total	940	100%	940	100%	

Residual = N observed – N expected cases

2.3.1.4 Gender and self-reported race/ethnicity of children with ASD

The gender and self-reported race/ethnicity of children with ASD is shown in table 2.3. CEMIS data showed that the male: female ratio for Coloured children was 7:1, Black children 4.4:1, White children 4.7:1, and Indian children 2.5:1. The chi-square test indicated that the association between gender and self-reported race/ethnicity approached significance (chi-square = 8.404, $p = 0.079$). This trend in significance is attributable to the fact that the proportion of males who self-reported as Coloured was higher than the proportion of females who self-reported as Coloured.

Table 2.3: Gender and self-reported racial/ethnicity comparison of children with ASD on CEMIS

Self-reported race/ethnicity	Male		Female		Total
Coloured	346	(43%)	49	(34%)	395
White	253	(32%)	53	(36%)	306
Black	168	(21%)	38	(26%)	206
Asian/Indian	10	(1%)	4	(3%)	14
Other	18	(2%)	1	(1%)	19
Total	795		145		940

2.3.1.5 The home language of children with ASD

The self-reported home language of the majority of the children with ASD on CEMIS was English (61%), followed by Afrikaans (22%), Xhosa (15%) and Other (2%). Other languages were reported to be spoken by 2% of the ASD population on CEMIS and included other South African official languages (Sotho, Swati, Tswana, Venda and Zulu), French and German. Table 2.4 shows the percentage of ASD children by home language. There was a significant difference in the composition of home language spoken between CEMIS ASD children compared to the Western Cape Province population demographics ($\chi^2(df = 8) = 941.16, p < 0.001$). A significantly higher proportion of children with ASD were reported to speak English, and a significantly lower proportion reportedly spoke Afrikaans and isiXhosa.

Table 2.4: Home language of ASD school-going population

Home language	ASD observed on CEMIS		ASD expected based on the 2011 Census		Residual
	N (observed)	% (observed)	N (expected)	% (expected)	
English	569	61%	191.8	20.2%	+377.2
Afrikaans	205	22%	471.9	49.7%	-266.9
isiXhosa	143	15%	234.5	24.7%	-91.5
isiZulu	2	0%	3.8	0.4%	-1.8
Sesotho	1	0%	10.4	1.1%	-9.4
Setswana	1	0%	3.8	0.4%	-2.8
siSwati	1	0%	0.9	0.1%	0.1
Tshivenda	1	0%	0.9	0.1%	0.1
Unspecified	1	0%	-	0%	-
Other	16	2%	20.9	2.2%	-4.9
Total	940	100%	938.9*		-

Residual = N observed – N expected cases

*The home language of 1 child on CEMIS was classified as Unspecified which is not a category in the 2011 Census.

2.3.1.6 Rates of children with ASD diagnosis between 2012 and 2016

As shown in figure 2.4, there was a steady increase in the number of children with an ASD diagnosis from 2012 to 2016. A total increase of 76.03% was observed over the period, with an average annual increase of 15.18%. Over the 4-year period, the percentage increase in ASD prevalence was slightly higher for males (76.67%) compared to females (72.62%). However, the increase in rates of ASD did not differ significantly between male and female children ($p = 0.691$).

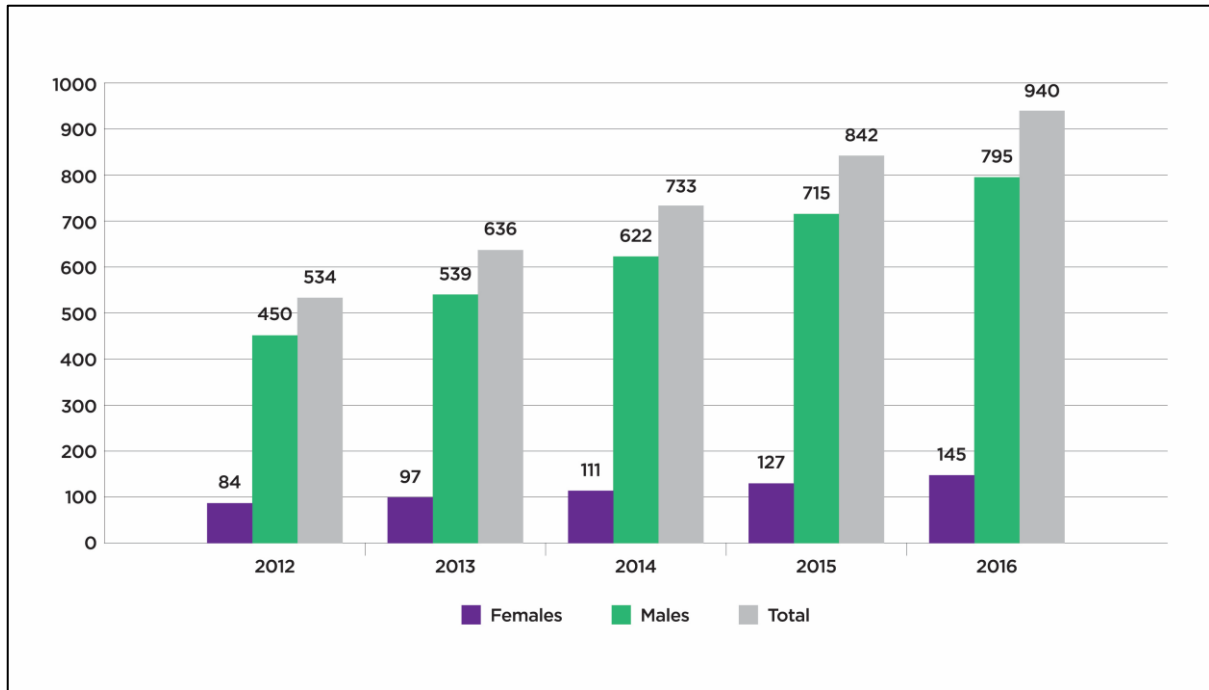


Figure 2.4: Comparison of ASD rates on CEMIS between 2012 and 2016

2.3.2 Disability Information

ASD was reported to be the primary disorder of 884 of the 940 identified children with ASD (94%). Other disability categories included hearing impairment, visual impairment, physical impairment, intellectual impairment, behavioural disorders, epilepsy and attention-deficit/hyperactivity disorder (ADHD). Table 2.5. shows a summary of disability information of the sample. Intellectual disability was reported in 22.2% of the ASD group (n = 209). Intellectual disability was further categorised as mild/moderate/severe intellectual disability. Severe intellectual disability was reported in 20.5% of the ASD group, and mild/moderate intellectual disability in 1.7% of the group. Specific learning disorders were reported in 2.9% (n = 27) and ADHD in 2.6% (n= 25). Other co-occurring disorders were reported at very low rates.

Table 2.5: Primary and secondary disabilities of ASD school-going population

	Disability	Primary disability	Secondary disability 1	Secondary disability 2	Secondary disability 3
1	Anxiety disorder	-	1	-	-
2	Attention-deficit/hyperactivity disorder	3	19	2	1
3	Autism spectrum disorder	884	45	2	1
4	Behavioural disorder	-	-	2	-
5	Blind/partially sighted	16	-	-	-
6	Cerebral Palsy	1	1	1	-
7	Deaf/hard of hearing	4	1	-	-
8	Epilepsy	-	5	1	1
9	Intellectual disability	20	184	3	2
10	Physical disability	2	3	1	-
11	Specific learning disorder	9	15	3	-
12	Other	-	1	-	-
13	None/not allocated	1	665	925	935
TOTAL		940	940	940	940

2.3.3 Educational Information

2.3.3.1 Distribution of children with ASD across education districts

The distribution of children with ASD across the Western Cape Province is shown in table 2.6. The majority (83%) of children with ASD attended schools in the City of Cape Town metropole (Metro Central, Metro East, Metro North or Metro South), and only a small proportion was reported in surrounding areas (Cape Winelands, Eden and Central Karoo, Overberg, and West Coast). The Metro Central district had the highest number of children with ASD (33% of the ASD population) distributed across 10 different schools. This district includes two special schools exclusively for children with

ASD. The Metro East district had the second highest proportion of children with ASD (27%) distributed across 17 schools, while 15% of all children with ASD were in Metro North district across 25 schools. The Overberg (1%, 4 schools) and West Coast (2%, 5 schools) has the lowest reported proportion of ASD. The distribution of ASD children across the districts was significantly different compared to the distribution of children in the Western Cape Province according to Statistics South Africa 2016 ($\chi^2(df = 7) = 472.3, p < 0.001$). A significantly higher proportion of ASD children went to school in the Metro Central and East districts, and a significantly lower proportion went to school in the Cape Winelands and Metro South districts. The other districts (Eden and Central Karoo, Metro North, Overberg and West Coast) had a lower proportion of children but the difference was not statistically significant.

Table 2.6: Distribution of children with ASD across the different school districts

School district	ASD observed on CEMIS		ASD expected (based on SA Stats 2016)		Residual
	N (observed)	% (observed)	N (expected)	% (expected)	
Cape Winelands	58	6.2%	133.6	14.2%	-75.6
Eden and Central Karoo	61	6.5%	107.3	11.4%	-46.3
Metro Central	309	32.9%	132.7	14.1%	+176.3
Metro East	255	27.1%	140.2	14.9%	+114.8
Metro North	144	15.3%	180.7	19.2%	-36.7
Metro South	80	8.5%	152.4	16.2%	-72.4
Overberg	10	1.1%	37.6	4.0%	-27.6
West Coast	23	2.4%	55.5	5.9%	-32.5
Total	940	100%	940	100%	-

Residual = N observed – N expected cases

2.3.3.2 Distribution of children with ASD across different school types in the Western Cape Province

The majority of the children with ASD (89%) were reported to be in special schools, 10% were in ordinary/mainstream schools and 1% in other educational institutions (including training centres, school of skills, specialized schools and hospital schools).

2.3.3.3 Government-funded versus privately funded schools

Out of the 940 children with ASD on CEMIS 81% attended government-funded schools and 19% attended privately funded schools. The largest number of privately funded schools with the most children with ASD was in the Metro North district where 15 schools supported 11% of children with ASD on CEMIS. There were 4 privately funded schools in the Overberg district that supported 1% of children with ASD, and no government-funded schools. The West Coast supported 2% of children with ASD on CEMIS. All were in government-funded schools and none in privately funded schools. The other districts (Cape Winelands, Eden and Central Karoo, Metro Central, Metro East and Metro South) had a higher ratio of children in government-funded schools than privately funded schools.

2.4 Discussion

In the absence of formal epidemiological studies of ASD in South Africa, we set out to identify educational information systems that could provide proxy information about the numbers, distribution and profile of school-aged children with ASD in South Africa. We selected the Western Cape Province and used the CEMIS information system to examine all school-going children in the province in 2016. We were interested to determine how many children with ASD would be in Western Cape schools compared to a conservative 1% global estimate. We then compared the identified children with

ASD with the population demographics of the Western Cape Province based on the last Census data to see if there were any differences between expectations and the observations made in this study.

In 2016 there were 1,154,353 children attending schools in the Western Cape. Based on a conservative estimate rate of 1%, we expected to identify 11,544 children with ASD in WCED schools. We observed significantly lower rates of ASD than expected with only 0.08% (n = 940; 1 in 1,131) children in Western Cape schools known to have ASD. The majority of children with ASD on CEMIS were of compulsory school-going age (7 to 15 years), and a small proportion were younger or older than these legal requirements. The male: female ratio of 5.5 to 1 was in line with international findings (Maenner *et al.*, 2020). As predicted, we observed race/ethnicity and language discrepancies in the CEMIS sample compared to the population demographic of the Western Cape Province. Self-reported race/ethnicity and language showed that there were fewer Coloured and Black children, and fewer Afrikaans and isiXhosa-speaking children than expected. ASD was found to be the primary disorder in the majority of the children and rates of reported co-occurring conditions were low. There was a disproportionate distribution of children with ASD across the educational system, both in terms of geography (83% of children attended school in the City of Cape Town), and in terms of type of school (89% were in Special Schools). We observed a 76.03% increase in the number of children with ASD in the schooling system over the 4 year period between 2012 and 2016.

There are various possible reasons for the low rates of ASD observed in the education system. The first could be due to diagnostic overshadowing. ASD is known to co-occur

with intellectual disability in at least 30% of cases if not more (CDC, 2014). Only 22.2% of the children with ASD had co-occurring intellectual disability of which most of the children were reported to have had severe intellectual disability. This suggests that many children with mild/moderate intellectual disability were probably not identified as having co-occurring ASD. This is an important consideration for future empirical evaluations. A second potential reason for the low numbers of ASD could be the methodology for data collection. CEMIS forms are completed by parents and caregivers and the information does not require verification by a medical practitioner or psychologist. Limited understanding of the disorder or unwillingness to disclose a diagnosis of ASD for various reasons would influence how the forms are completed. It may be very informative to perform a study to compare data on CEMIS forms with detailed neurodevelopmental evaluation of school-aged children. A third reason could be that the low rates were essentially a reflection of the existing capacity for children with ASD in the schooling system given that, at the time of the study, there was a large database of children with ASD waiting for school placement in the Western Cape Province (Pillay *et al.*, 2022). Understanding the profile of this population of children is a focus of this study that will be discussed in chapter 3.

One of the core principles for ASD intervention is early intervention (Estes *et al.*, 2015; Dawson, 2008). However, only a small number of children with ASD on CEMIS were 5 years or younger. This is a reflection of the legal school-going age in South Africa (7 years) and of the fact that only a few government-funded schools offer early childhood development (ECD) or pre-school services. Private schools have greater flexibility to admit children with and without ASD at a younger age. The research evidence is clear that, if untreated, ASD is associated with reduced educational success, difficulties with

attaining employment and negative economic consequences for a country (Munir *et al.*, 2016). Our observations therefore raise significant concern about the current compulsory school-going age of 7 years, and about the very limited opportunities for early intervention through government-funded ECD or pre-school services. The majority of children with ASD in the Western Cape Province come from families who cannot afford private services and are therefore unable to access early intervention during this critical developmental period.

The male to female ratio for White children (4.7:1) and Black children (4.4:1) with ASD in schools in the province was consistent with the 4-5:1 ratio reported in international data (CDC, 2014). Interestingly, a much higher male/female ratio was found in Coloured children (7:1). Studies show that ASD may present differently in girls compared to boys, and that girls may be better at masking some of the features of ASD (Duvekot *et al.*, 2017; Hiller *et al.*, 2016). Further investigation would be required to determine whether masking or other socio-cultural factors explain the lower rates of Coloured girls with ASD identified in the Western Cape Province.

As predicted from the legacy of apartheid, our observations showed racial/ethnicity disparities in children with ASD in the schooling system. Only Asian/Indian children showed a ratio proportionate to expectation. Coloured and Black children were under-represented, and White children were over-represented in comparison to population expectation (Statistics South Africa, 2012). Our findings are similar to previous South African reports that showed, in particular, an under-identification of ASD in Black children reporting to tertiary healthcare services in the Western Cape Province. (Springer *et al.*, 2013). Springer and colleagues attributed this observation to a

combination of socio-economic factors, accessibility of services, and differences in help-seeking behaviours. Given the vast socio-cultural differences between the South African population and the populations of other countries such as the USA, it may be difficult to make any direct comparisons. However, the pattern of under-representation in our findings are also in line with reports from the USA where White children were 30% more likely to be identified with ASD than Black children (CDC, 2014; Durkin *et al.*, 2010; Imm, White and Durkin, 2019). Durkin and colleagues proposed that the lower reporting of Black children with ASD between 2012 and 2014 was associated with racial disparities in access to health services and on the exclusive reliance on educational records to identify ASD in Black children (Imm, White and Durkin, 2019). We propose that in South Africa and other sub-Saharan African countries, there is a complex combination of historical legacies and a range of ongoing barriers to care and education (including the stigma associated with ASD in African cultures) that continues to prevent the timely and accurate identification of children with ASD (Tilahun *et al.*, 2016; Guler *et al.*, 2018; Chambers *et al.*, 2017). These factors continue to prevent the majority of our children from accessing appropriate educational services.

The majority of the Western Cape Province is Afrikaans-speaking, yet English was reported to be the home language of majority of the ASD population in schools. A possible reason for this could be that the language of instruction in most of the schools for children with ASD is English. Aguilar and colleagues (2016) highlighted the importance of considering the child's language preference and the medium of instruction when developing Individualised Education Plans (IEPs) for children who are exposed to multiple languages across home and school settings. In a culturally diverse country such as South Africa, children with ASD being educated almost

exclusively in English may have significant implications when these children have to function within family and community settings.

There were much lower rates of co-occurring physical and mental health conditions in children with ASD in schools in the Western Cape Province than expected from international literature that has shown co-occurring conditions to be the norm rather than the exception in ASD (Soke *et al.*, 2018; Levy *et al.*, 2010). Diagnostic substitution and diagnostic overshadowing is possible in an educational setting. However, given that the rates of ASD and all co-occurring conditions were low, we propose that the most likely explanation for our observations was under-identification and under-reporting of all disability categories, more than diagnostic substitution or overshadowing. A combination of educational as well as health records could provide a more comprehensive picture of children with ASD in the province. However, it remains of significant concern that for many children with ASD in the Western Cape Province, their schools may not have an accurate profile of their physical health and neurodevelopmental needs.

Most of the children with ASD in the Western Cape Province were accommodated in Special Schools and a large proportion of them attended schools for children who have severe intellectual impairment. Very low rates of mild/moderate intellectual disability was found (1.7%) suggesting that there may be more diagnostic overshadowing in the mild/moderate intellectual disability group than the severe intellectual disability group. Baio *et al.* (2018) reported that 44% of children with ASD fell in the average to above average intellectual functioning range. Our findings suggest that there could be a significant proportion of children with ASD in mainstream schools who are not yet

identified. There may also be a significant proportion of children with ASD in special schools whose needs may potentially be better met in mainstream school settings with appropriate supports in place.

The majority of children with ASD were reported to be attending schools in the City of Cape Town with only 17% of them in schools in the districts of the province. Based on Census data, approximately 63% of Western Cape Province residents lived in the Cape Town metropolitan area at the time of our data extraction. As shown in our findings, there was therefore a clear under-representation of children with ASD in the districts of the province. From our data it was clear that the majority of ASD school placements were available in the metropolitan areas. In particular, all ASD-specific schools were based in the City of Cape Town. International data suggest that children with ASD living in rural areas are often diagnosed later and have limited services available to them and their families (Mandell, 2005). Our findings therefore raise the question about the appropriateness of access to ASD educational resources in rural parts of the province.

The majority of children with ASD in the Western Cape Province attend government-funded schools. In a study that compared the differences between autism specific government-funded and privately-funded schools in the Gauteng province, Erasmus *et al.* (2019) found that autism-specific government-funded schools were cheaper, offered more therapies and made a more significant contribution to the education of children with ASD. However the private schools admitted children as young as 2.5 years (Erasmus *et al.*, 2019). Private schools are generally more expensive and not accessible to the majority of the population of the Western Cape Province.

2.5 Limitations of the study

We acknowledge a number of limitations to the study. First, the CEMIS database was an educational database with data completed by schools and families, rather than by healthcare professionals with expertise in ASD. Stigma or fear from parents and caregivers may have prevented them from disclosing ASD or other diagnoses. However, the database included all children in schools in the Western Cape Province in 2016, and thus provides the most comprehensive summary of ASD in any sub-Saharan African school system to date. Second, only children in schools were included. At the time of the study, we were aware of a growing database of children with ASD waiting to get into schools (See Chapter 3). It would therefore be important also to seek access to these numbers in order to augment the findings presented here. Third, we acknowledge that no formal evaluations or standardised questionnaires were administered as part of this study. As outlined, there are at present no standardised procedures to diagnosis for ASD in South Africa. An ideal future study could therefore use a rigorous design to include gold standard measures such as has been done in large-scale epidemiological investigations of ASD in schools. However, to date, no ASD rating scales, questionnaires or diagnostic instruments have been validated or developed for use in our multilingual and multicultural setting. Whilst efforts are ongoing to develop such tools, we believe that the findings presented here provide an important 'bird's eye view' of the profile and needs of children with ASD in schools in the Western Cape Province. Finally, given the complexity of data extraction, cleaning and approvals, the dataset for this study was from 2016, and we acknowledge that some positive progress may have been achieved in the WCED since those data were collected.

2.6 Conclusion

Findings suggest that the overall rates of known ASD in schools in the Western Cape Province were more than 10 times lower than expected. Most of the children attended Special Schools in the City of Cape Town and there was a disproportionate representation of race/ethnicity and home language with the majority of the children being White and from English-speaking homes. Therefore, efforts need to be made to identify children with ASD in the broader educational system to ensure a more racially/ethnically and geographic representation of ASD in WCED schools. Better profiling of children with ASD is necessary to understand and meet the diverse needs of this group of children. The historic practice of placing children with special needs almost exclusively in Special Schools should be re-evaluated and all types of school placement for children with ASD in the country should be considered. The legal school going age of 7 years is a barrier to early intervention with major implications for children with ASD, their families and society as a whole.

Although the rates of ASD in the education system was relatively low, this number has almost doubled since 2012 with an average rate of increase of 15.18% per annum. At the time this study was conducted, we were also aware of the growing database for children with ASD waiting for school placement. We propose an investigation of this database to get a more comprehensive picture of ASD in the province.

There are no policies in place at a national or provincial level that governs how children with ASD are admitted into the education system, and the type of education that they receive. Policies can however be developed once more is known about the ASD situation. We therefore propose engagement with stakeholders including families of

children with ASD, service providers and government representatives as a first step towards policy development.

This study raised important questions about the education of children with ASD in the Western Cape Province that may have implications also for the rest of South Africa and could inform future research to improve education systems for children with ASD in South Africa.

2.7 Chapter summary

The prevalence of autism spectrum disorder (ASD) in South Africa is unknown and to date very little research has been performed within school systems that could inform the rates, distribution and profile of needs of children with ASD in education. Here we performed a comprehensive database search of all children with ASD in the formal education system in the Western Cape Province of South Africa and compared the findings to population demographic expectations of the province. From a population of 1,154,353 children attending schools in the province a total of 940 children with a diagnosis of ASD were identified, representing a rate of 0.08%. The male: female ratio was 5.5:1. There was a significant difference in the self-reported racial and language composition of the ASD sample compared to the Western Cape demographics where a higher proportion of children with ASD were from White racial groups and English-speaking homes. Eighty nine percent (89%) of children with ASD were in Special Schools and only 10% were in Ordinary/Mainstream Schools. Most of the children (83%) attended schools in the City of Cape Town and only 17% in rural areas. Co-occurring intellectual disability was reported in 22.2% of the population, ADHD in 2.6% and epilepsy in 0.7%.

Data showed a 76.03% increase in ASD in schools between 2012 and 2016, with an average increase of 15.18% per year. Findings suggested an under-representation of ASD in schools and an under-identification of co-occurring conditions. Results indicate that, despite being one of the better-resourced provinces in South Africa, the Western Cape is not equipped to identify and meet the culturally and linguistically diverse needs of its communities. We propose strengthening of educational systems for children with ASD in the Western Cape, and similar investigations in other South African provinces. In the next chapter we examine the WCED waiting list data on children with ASD or suspected ASD not in schools in the province at the time and combine the data on children with ASD in schools and those waiting for schools to generate a more comprehensive picture of ASD in the province.

CHAPTER 3: WHO'S WAITING FOR A SCHOOL? RATES, SOCIO- DEMOGRAPHICS, DISABILITY AND REFERRAL PROFILE OF CHILDREN WITH AUTISM SPECTRUM DISORDER AWAITING SCHOOL PLACEMENT IN THE WESTERN CAPE PROVINCE OF SOUTH AFRICA

Pillay, S. Duncan, M., and de Vries, P. J. (2022). *Autism*, 26(7): 1849-1863.
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3.1 Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder that affects 1-2% of the world's population (Fombonne *et al.*, 2016). There are significant medical, educational and long-term care costs associated with having a child with ASD (Horlin *et al.*, 2014; Cidav *et al.*, 2017) and families of children with ASD often experience more stress compared to families of children with other diagnoses in accessing services (Hayes and Watson, 2013; Rivard *et al.*, 2014). The burden on parents and caregivers of navigating diagnostic and intervention systems and securing services to promote optimal development, including educational services, is widely reported (Lai and Weiss, 2017; Connolly and Gersch, 2013; Hoefman *et al.*, 2014).

Research has shown that timely diagnosis and access to early behavioural and educational intervention has positive outcomes for individuals with ASD (Dawson, 2008; Rogers *et al.*, 2012; Estes *et al.*, 2015; Sandbank *et al.*, 2020). Interventions suited to the needs of children with ASD are therefore in high demand but, even in high-income countries, access to services for individuals with ASD is variable (Elsabbagh *et al.*, 2012; WHO, 2013). There have, for instance, been reports of long waiting times for diagnostic, early intervention and educational services in many parts

of the world including the United Kingdom (Karim *et al.*, 2014; Galliver *et al.*, 2017), Ireland (Connolly and Gersch, 2013) and the United States (Gordon-Lipkin *et al.*, 2016).

Acknowledging that diagnostic and interventional systems and services are highly diverse around the world, the majority of research on autism comes from high-income countries (Tekola, *et al.*, 2016; Franz *et al.*, 2017). At the time of their comprehensive scoping review of autism research in Sub-Saharan Africa (SSA), Franz and colleagues observed that no studies had been conducted on educational services anywhere in SSA. Given the fundamental role of education and educational systems to support the development of children with autism, we performed a systematic database search of all children with ASD attending schools in the Western Cape, one of the nine provinces in South Africa (See Chapter 2; Pillay *et al.*, 2021). The Centralised Educational Management Information System (CEMIS) informed rates, socio-demographics, disability and educational profiles of all children in the formal schooling system in the province.

There were 1,154,353 children attending schools in the Western Cape Province in 2016 (the year of their study) and that only 940 of them (0.08%) were known to have a diagnosis of ASD (Pillay, Duncan and de Vries, 2021). Most of the children diagnosed with ASD attended special schools (89%) and only 10% were in mainstream schools offering inclusive education. In comparison to census data, there was a disproportionate number of children who attended school in urban areas versus rural areas (83% vs 17%). In addition, data reflected a disproportionate representation of children with ASD in terms of race/ethnicity and home language compared to the

population demographics of the Western Cape. More children with ASD were reported to be from white racial groups and English-speaking homes despite there being more people who self-report as being 'Coloured' and Afrikaans-speaking in the province. We attributed the low rate of ASD, at least in part, to poor identification and reporting of ASD, and to the limited and rather fixed capacity of schools to accommodate these children in either the special or mainstream education system (Pillay, Duncan and de Vries, 2021).

One of the key challenges raised in Chapter 2 was the absence of a clear and consistent pathway to care from parental concern to diagnosis and school placement (Pillay, Duncan and de Vries, 2021). Figure 3.1 (a modified version of Figure 2.2) shows that children with ASD or suspected ASD can be identified in primary (community level), secondary (district level) or tertiary (specialist level) system by healthcare providers and/or interventionists and then be referred to a 'waiting list' in the Education system where they are assessed by educational teams to determine the level of educational support required before being placed at a school. Due to the extensiveness of the list, children are referred as soon as a diagnosis of ASD is suspected and long before they are of compulsory school going age as a measure to secure a better chance for school placement. A formal diagnosis of ASD is often confirmed by the time the child is of school going age. The findings presented in Chapter 2 included data only on those already in school (government-funded or private) as reflected by the Western Cape Education Department (WCED) Centralised Education Management Information System (CEMIS) database. No data were therefore available to children awaiting placement in an educational setting. In South Africa it is compulsory for all children with or without disabilities to be enrolled in a

formal educational between the ages of 7-15 years (Department of Education, 2001). However, more than 500,000 school-aged children with disabilities were previously reported to be out of school in South Africa (Department of Basic Education, 2015). We were therefore concerned that there may also be school-aged children with ASD out of school without any appropriate educational or other interventional provisions.

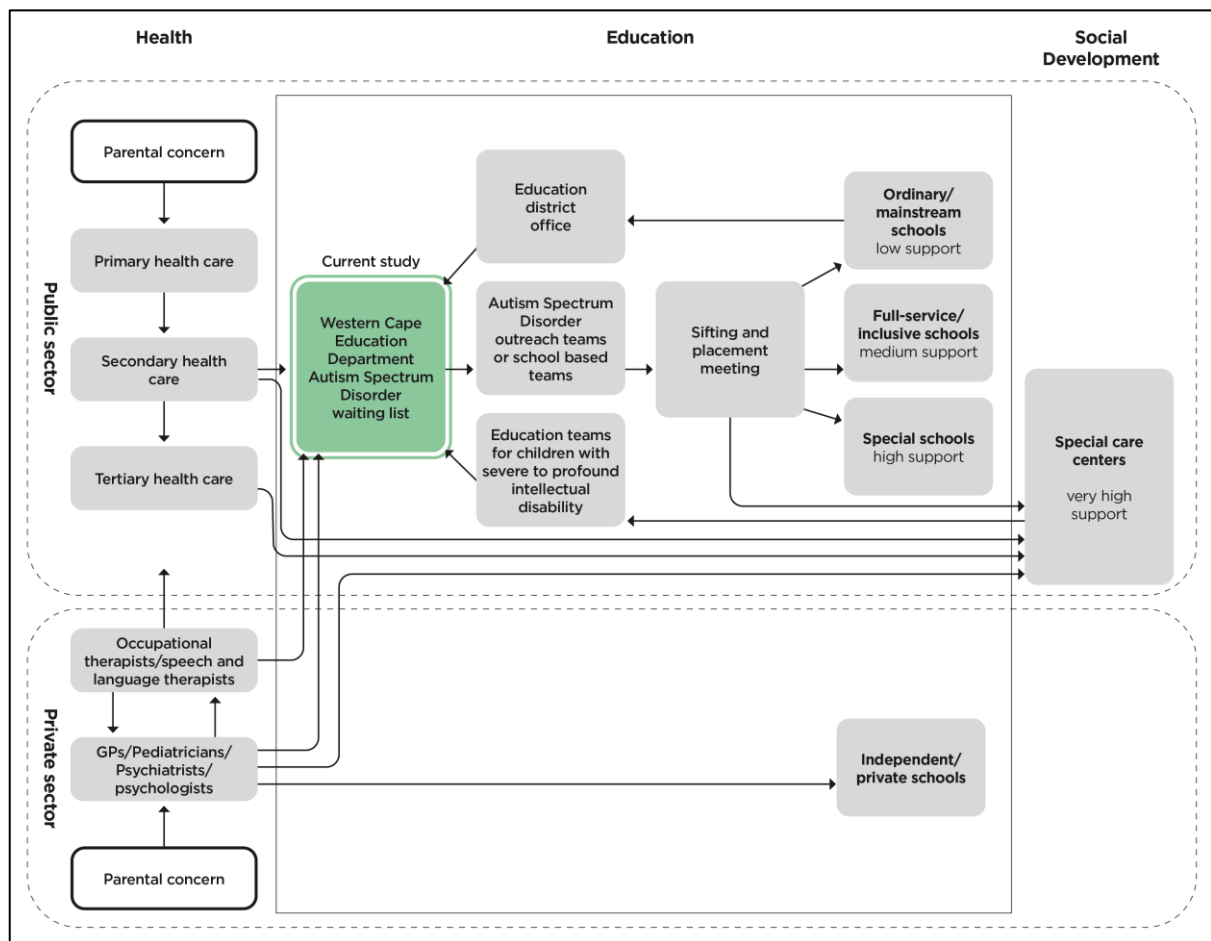


Figure 3.1: Referral pathway for children with ASD in the Western Cape

3.1.1 The ASD ‘waiting list’

When one of the ASD special schools in the Western Cape reached its capacity in 2009, the school leadership team created an informal ASD ‘waiting list’ to keep track of children with ASD seeking school placement. In 2011, management of and

responsibility for the waiting list was taken over by the Western Cape Education Department (WCED). The first author worked as an occupational therapist for the WCED and was involved in the management of the waiting list at since it was first developed in 2009. The waiting list typically included information only on children waiting for special educational placements. Special schools in South Africa accommodate children with moderate to severe intellectual disabilities who require high levels of functional and/or communication support (Department of Education, 2007). Children with ASD who were thought to be suitable for ordinary mainstream education were generally not referred to the waiting list. The National Policy for Screening, Identification, Assessment and Support (SIAS) requires all children seeking special school placement to be assessed by educational teams to ratify the admission and to ensure that the child receive appropriate educational support (Department of Education, 2014). Children were added to the list whenever referrals were received, and their names were removed once the child was placed in a school. Waiting list data included demographic information about the children (including information about their age, sex, home language, country of family origin and where they reside), diagnostic information (including family history of ASD and co-occurring conditions), reason for referral and referral source, and information about their service provisions. In addition, data on length of waiting and interventions received while waiting was also collected. Although the rudimentary waiting list was first created in 2009 the most consistent format was from 2011 therefore we were able to examine the rate of increase in the waiting list between 2011 and 2016.

In this chapter, the findings from Chapter 2 are extended by examining the rates, socio-demographic and other characteristics of children awaiting school placement

(i.e. those on the 'waiting list'). It was anticipated that the combination of 'waiting list' and in-school data would provide a more comprehensive profile of children with autism requiring educational and related interventional services in the Western Cape Province. A data-informed understanding of the service needs and resources available to children with ASD and their families could support strengthening and quality improvements of educational services in the Western Cape Province and could identify key lessons of relevance to the rest of South Africa and other low/middle-income countries. South Africa, like many other African countries is culturally and linguistically diverse with different racial and ethnic groups and language compositions as well as varying degrees of health, education and other resources in each of the nine provinces in the country. Therefore the profile of the Western Cape may have resonance to other parts of South Africa or other African countries.

The study therefore set out to:

- a) describe the demographic, disability, referral and service provision profile of all children with ASD or suspected ASD on the ASD 'waiting list' in the Western Cape
- b) determine how long children with ASD waited for school placement and what services were available to them while they waited
- c) combine data on children with ASD awaiting school placement and those in schools (Chapter 2) to generate a more comprehensive profile of children with ASD in the province

It was predicted that:

- a) there would be many children on the waiting list waiting for specialist ASD services across age, sex, language and urban/rural areas of the province

b) a significant number of children on the waiting list would not be receiving any education or other interventions while they waited, even though some may be of legal school-going age

c) even combining the number of children on the waiting list with those in school would yield rates lower than a conservative global ASD estimate of 1%

d) the language and urban/rural profile of all children with ASD known to the WCED would be disproportionate in relation to population-based expectations

3.2 Methods

3.2.1 Study design and participants

A descriptive quantitative design was used to analyse the demographic, diagnostic, referral and educational service needs profile of children on the WCED ASD waiting list. All participants on the WCED waiting list were included.

3.2.2 Data sources and extraction

The WCED ASD waiting list on 27 June 2016 was used as data source for the study. This cut-off was intentionally selected to coincide with the data period used in the previous chapter for children with ASD in school, to ensure that similar data fields could be combined. All available information on children with ASD on the waiting list was analysed. The ASD waiting list captured information about the child (name, date of birth and contact information), the referral process (the date that the referral was received and information about the referral agent), and about educational service provisions (including if the child was receiving any educational or therapeutic support while waiting for ASD special school placement). The list was anonymised, all contact information (phone numbers, email addresses and residential addresses) was removed and study codes were assigned to each child. A data extraction sheet was

constructed for variables of interest and relevant data were extracted from referral forms and supporting medical/educational/therapy reports to align the ASD waiting list as close as possible to WCED CEMIS data as used in the previous chapter. Waiting list data on race and ethnicity was not available. The variables of interest on the WCED ASD waiting list are presented in Table 3.1.

Table 3.1: Variables of interest on the WCED ASD waiting list (the * indicates data fields that were identical to data extracted in Chapter 2).

Demographic Information	Disability Information	Referral Information	Service Provisions
Total number of children waiting for schools*	Family history of ASD	Reason for referral	Intervention received
Sex of children waiting for schools*			
Age of children waiting for schools*			Waiting period
Home language*	Co-occurring conditions*	Referral source	Rate of increase in the number of referrals from 2012-2016*
Country of family descent (3)			
Geographic distribution*			

3.2.3 Data analysis

3.2.3.1 Waiting list data

Given that the profile and needs of pre-school aged children may differ from those of school-going age, the waiting list data were divided into preschool age children (0-6 years) and school-aged children (7-17 years). Data from the waiting list were extracted and summarised in three groups (pre-school age; school-going age; all children on the

waiting list). Descriptive statistics were used to summarise the data with means and standard deviations for continuous variables, and proportion for categorical variables.

3.2.3.2 Combining waiting list and CEMIS data

Waiting list data and the CEMIS data extracted by Pillay, Duncan and de Vries (2021) were combined for all variables of interest where common data fields were available between the two data sets. This allowed the opportunity to show the total number of cases of ASD known to the Western Cape Education Department (WCED). Data for two variables (self-reported home language and geographic distribution) were compared to the population demographics for the province based on the Western Cape Census for 2011. Using SPSS version 25, chi-squared tests were performed to compare observed versus expected numbers for these two variables with the threshold for statistical significance set at 0.05.

3.2.4 Ethical approvals

Ethics approval was obtained from the University of Cape Town Human Research Ethics Committee (HREC 072/2016) as well as the Western Cape Department of Education (reference: 20150727-1712).

3.2.5 Community involvement

No individuals with ASD or their families were directly involved in this study. Overall study design was guided by consultation with a broad range of stakeholder groups including representatives from the Department of Education, Department of Health and Department of Social Development.

3.3 Results

3.3.1 Demographic Information

Table 3.2 shows the demographic characteristic (total number, sex, home language, country of family origin and geographic distribution) of pre-school age, school-going age and all children on the waiting list.

Table 3.2: Demographic characteristics of pre-school age, school-going age and all children on the waiting list

Demographic characteristics		Pre-school age children (n=478)	School-going age (n=266)	Total number on the waiting list (n=744)
Sex	Male	397 (83%)	224 (84%)	621 (83%)
	Female	81 (17%)	42 (16%)	123 (17%)
	Male: Female ratio	5:1	5:1	5:1
Home language	Afrikaans	62 (13%)	29 (11%)	91 (12%)
	English	268 (56%)	121 (45%)	389 (52%)
	IsiXhosa	103 (21%)	87 (33%)	190 (26%)
	Other	32 (7%)	27 (10%)	59 (8%)
	Unknown	13 (3%)	2 (1%)	15 (2%)
Country of family origin	South Africa	432 (90%)	235 (88.3%)	667 (90%)
	Other countries	27 (6%)	22 (8.3%)	48 (6.5%)
	Unspecified	19 (4%)	9 (3.4%)	29 (3.5%)
Geographic distribution	Urban	430 (90%)	235 (88%)	665 (89%)
	Rural	48 (10%)	31 (12%)	79 (11%)

3.3.1.1 Total number and age of children on the ASD on the waiting list

On 27 June 2016 there were 744 children with confirmed or suspected diagnosis of ASD on the WCED ASD waiting list. The ages of children on the waiting list ranged

from 1 to 17 years old with a median age of 5 years. A total of 64% (n=478) of children were younger than the compulsory school-going age (0-6 years), 36% (n=265) were of compulsory school-going age (7-15 years), and 1 child was older than the compulsory school-going age (> 15 years).

3.3.1.2 Sex of children with ASD on the waiting list

A total of 83% (n=621) were males and 17% (n=123) were female. Similar male:female ratios were observed for pre-school age, school-going age and the total number of children with ASD. Table 3.2 shows the number, percentage and male:female ratios for pre-school age, school-going age and total reported children on the waiting list.

3.3.1.3 Home language

A total of 17 different home languages were reported on the waiting list. The majority of the children (90%) came from homes that used languages typically spoken in the Western Cape including English (52%; n = 389), IsiXhosa (26%; n = 190) and Afrikaans (12%; n = 91). Other South African languages included IsiZulu (0.6%; n = 5), Setswana (0.5%; n = 4), Xitsonga (0.2%; n = 2) and Sesotho (0.1%; n = 1). Six percent (6%) of children had non-South African home languages (Arabic = 4, Bengali = 1, Chewa = 2, French = 17, Kirundi = 1, Lingala = 1, Portuguese = 4, Shona = 7, Somali = 6 and Kiswahili = 4). Home language was not reported in 2% of the children. Table 3.2 shows self-reported home language of pre-school age, school-going age and total number of children on the waiting list for the three main languages spoken in the Western Cape.

3.3.1.4 Countries of family descent

Families of children on the ASD waiting list who were of South African descent represented 90% (n = 667) of the sample. Six percent (6%; n = 48) of families originated from other countries. In four percent (4%) of the sample the country of family descent was not specified. Of the children whose families originated from other countries, the majority were from other African countries (The Democratic Republic of the Congo = 18, Zimbabwe = 10, Somalia = 6, Libya = 5, Angola = 2, Burundi = 2, Ethiopia = 1, Malawi = 1, Mali = 1 and Nigeria = 1). Only one family was from outside Africa (Bangladesh). Table 3.2 shows the country of family descent of preschool, school going aged and total number of children with ASD.

3.3.1.5 Geographic distribution

The majority of children referred to the waiting list (89%) lived in urban areas and 11% were from rural areas. Table 3.2 shows the urban and rural distribution of pre-school, school-going aged and total number of children on the ASD waiting list.

3.3.2 Disability information

3.3.2.1 Family history of ASD

A family history of ASD was reported in 3.6% (n = 27) of the total number of children on the waiting list. Having a sibling with ASD was reported in 2.4% (n = 18) of the cases and having a cousin with ASD was reported in 0.9% (n = 7) of the cases. Family history was indicated but not specified in 2 cases.

3.3.2.2 Co-occurring conditions

Table 3.3 shows the co-occurring conditions reported in pre-school age, school-going age and the total number of children on the ASD waiting list. A total of 11% (n = 84) of children were reported to have co-occurring health conditions of which 3% (n = 25)

had epilepsy, 3% (n = 23) attention deficit/hyperactivity disorder (ADHD) and 1% (n = 8) cerebral palsy. Other conditions were reported in 4% (n = 28) of children and included cardiac conditions, congenital brain conditions, Down Syndrome, Foetal Alcohol Spectrum Disorder, hearing impairment, Human Immunodeficiency Virus (HIV), musculoskeletal conditions, Sotos Syndrome, tuberculosis, Tuberos Sclerosis Complex (TSC), and visual impairment.

Table 3.3: Co-occurring conditions of children with ASD on the waiting list

Co-occurring condition	Pre-school age (0-6 years)	School-going age (7-17 years)	Total number on waiting list (n=744)
Epilepsy	14	11	25
Attention deficit/hyperactivity disorder (ADHD)	6	17	23
Cerebral palsy	1	7	8
Congenital or acquired brain conditions	3	2	5
Visual impairment	2	2	4
Hearing impairment	2	2	4
Foetal Alcohol Spectrum Disorder (FASD)	2	2	4
Human Immunodeficiency Virus (HIV)	0	4	4
Tuberous Sclerosis Complex (TSC)	2	0	2
Down Syndrome	1	0	1
Sotos Syndrome	0	1	1
Musculoskeletal conditions	0	1	1
Tuberculosis	1	0	1
Cardiac conditions	1	0	1

*A single child on the waiting list may present with more than one co-occurring conditions

3.3.3 Referral information

Referral information (reason for referral, referral agency and referring professional) of pre-school age, school-going age and all children on the waiting list is shown in table 3.4.

Table 3.4: Reason for referral, referral agency and referring professional of pre-school age, school-going age and all children on the waiting list

Referral information		Preschool age children (n=478)	School going age children (n=266)	Total number on the waiting list (n=744)
Reason for referral	School placement	343 (72%)	199 (75%)	542 (73%)
	Confirmation of diagnosis	132 (27%)	60 (22%)	192 (26%)
	Diagnostic evaluation	3 (1%)	7 (3%)	10 (1%)
Referral agency	Department of Health	325 (68%)	162 (61%)	487 (65%)
	Department of Education	7 (1.4%)	30 (11%)	37 (5%)
	Department of Social Development	0 (0%)	1 (<1%)	1 (<1%)
	Private Practitioners	143 (30%)	72 (27%)	215 (30%)
	Unspecified	3 (0.6%)	1 (<1%)	4 (<1%)
Referring professional	Medical practitioners	419 (88%)	187 (70%)	606 (81%)
	Psychologists	26 (5%)	39 (15%)	65 (9%)
	Occupational therapists	11 (2%)	5 (6%)	26 (3%)
	Speech and language therapist	13 (3%)	9 (3%)	22 (3%)
	School officials	4 (<1%)	7 (3%)	11 (1%)
	Nurses	0 (0%)	1 (<1%)	1 (<1%)
	Day care facilitators	0 (0%)	1 (<1%)	1 (<1%)
	Unspecified	5 (1%)	7 (3%)	12 (2%)

3.3.3.1 Reason for referral

Reason for referral for 73% (n = 542) of children to the ASD waiting list was for school placement, 26% (n = 192) for confirmation of diagnosis, and 1% (n = 10) for diagnostic evaluation. Table 3.4 shows the reason for referral of pre-school age children, school-going age children and total number of children on the waiting list.

3.3.3.2 Referral agency

The majority of all the referrals were from service providers in the Department of Health (65%; n = 487), 29% (n = 215) from private practitioners, 5% (n = 37) from the Department of Education, and fewer than 1% were from the Department of Social Development or privately funded ASD centres. Four referral agents did not indicate their institution. Table 3.4 shows the referral agents for pre-school age children, school-going age children and total number of children on the waiting list.

3.3.3.3 Referring professional

The majority of referrals (81%, n = 606) were made by medical practitioners, 9% (n = 65) by psychologists, 3% (n = 26) by occupational therapists, 3% (n = 22) by speech and language therapists, 1% (n = 11) by school officials and fewer than 1% (n = 1) by nurses and day care facilitators (n = 1). Two percent (2%, n = 12) of referral agents did not specify their profession. Table 3.4 shows the referring professional for pre-school age, school-going age and total number on the waiting list.

3.3.4 Information about service provisions

3.3.4.1 Enrolment in other educational or interventional programmes

Almost half of children on the ASD waiting list, (48%; n = 356) were reported to be at home and were not receiving any education or intervention. This was the case for 53%

in the pre-school age group, and 38% in the compulsory school-going age group (see table 3.5).

A total of 33% of children on the waiting list were enrolled in early childhood development programmes, seven percent (7%) in mainstream schools, three percent (3%) attended privately funded ASD programmes, two percent (2%) were in special care or stimulation centres, one percent (1%) were in other non-ASD special schools, and fewer than one percent were home-schooled. Services received was not specified in six percent (6%) of children. Table 3.5 shows the educational or other intervention programmes for the pre-school age, school-going age and total number of children on the waiting list.

Table 3.5: Enrolment in other educational intervention programmes

Enrolment	Pre-school age (0-6 years)	School-going age (7-17 years)	Total number on waiting list
No intervention	255 (53%)	101 (38%)	356 (48%)
ECD programme	179 (37%)	64 (24%)	243 (33%)
Mainstream school	12 (2.5%)	40 (15%)	52 (7%)
Private ASD centre	5 (1%)	17 (6%)	22 (3%)
Special care centre	9 (2%)	4 (1.5%)	13 (2%)
Special school	1 (<1%)	10 (4%)	11 (1%)
Home-schooled	1 (<1%)	1 (<1%)	2 (<1%)
Unknown	16 (3%)	29 (11%)	45 (6%)
Total	478 (100%)	266 (100%)	744 (100%)

ECD = early childhood development

3.3.4.2 Waiting period

A total of 48% (n = 357) of children on the waiting list had been waiting for services for less than a year, 26% (n = 192) for more than a year, 19% (n = 142) for more than two years, and 7% (n = 53) for more than three years. Table 3.6 shows the waiting period for pre-school age, school-going age and total number on the waiting list.

Table 3.6: Waiting period for pre-school age, school-going age and total number on the waiting list

Waiting period	Pre-school age (0-6 years)	School-going age (7-17 years)	Total number on the waiting list
Less than 1 year	278 (58%)	79 (30%)	357 (48%)
More than 1 year	125 (26%)	67 (25%)	192 (26%)
More than 2 years	62 (13%)	80 (30%)	142 (19%)
More than 3 years	13 (3%)	40 (15%)	53 (7%)
Total	478 (100%)	266 (100%)	744 (100%)

3.3.4.3 Rate of increase in the number of referrals

There was a 276% increase in the total number of children with ASD or suspected ASD referred to the ASD waiting list between 2011 and 2016. Figure 3.2 shows the rate of increase in the number of referrals over the five-year period.

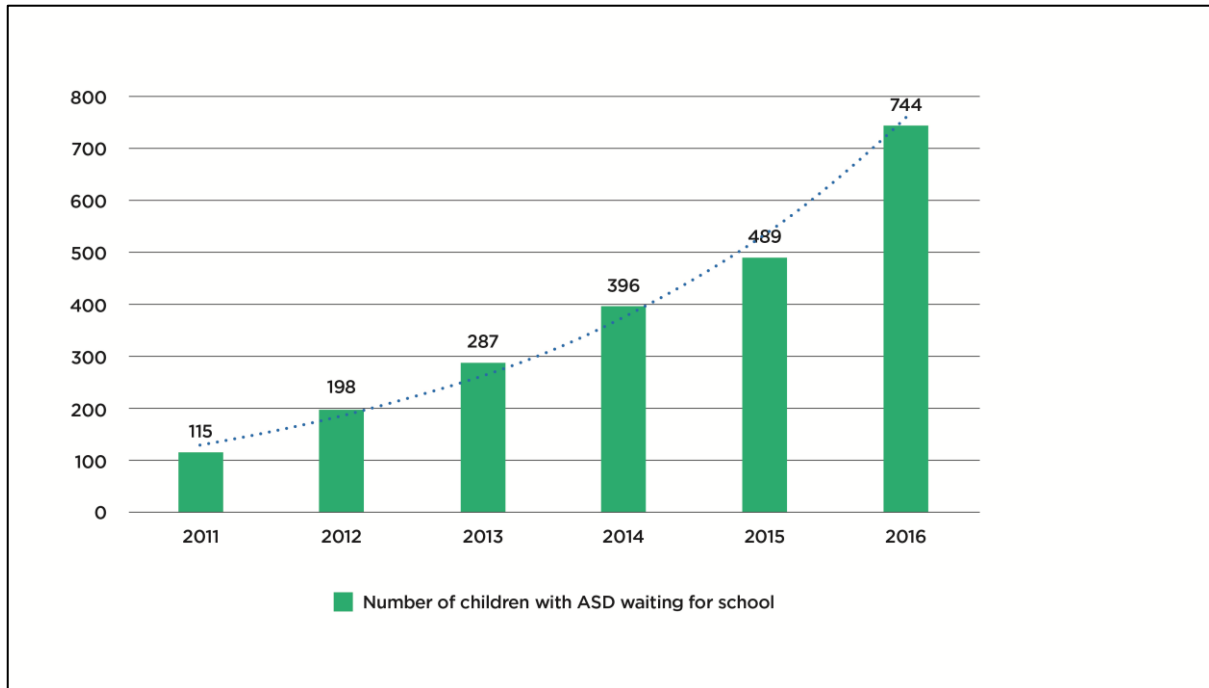


Figure 3.2: Number of children referred to the ASD waiting list between 2011 and 2016

3.3.5 Total number of children with ASD known to the Western Cape Education Department

Combining the findings of Pillay, Duncan and de Vries (2021) and this study, in June 2016 there were 1,684 children with a known diagnosis of ASD in the Western Cape (940 children with ASD in schools; 744 on the waiting list). These included 1,416 boys and 268 girls with a male: female ratio of 5:1. The age range of reported cases of children and young adult students with ASD in the Western Cape was 1-23 years. Figure 3.3 shows the age distribution of those with ASD in schools, waiting for schools and the total number of reported cases of ASD.

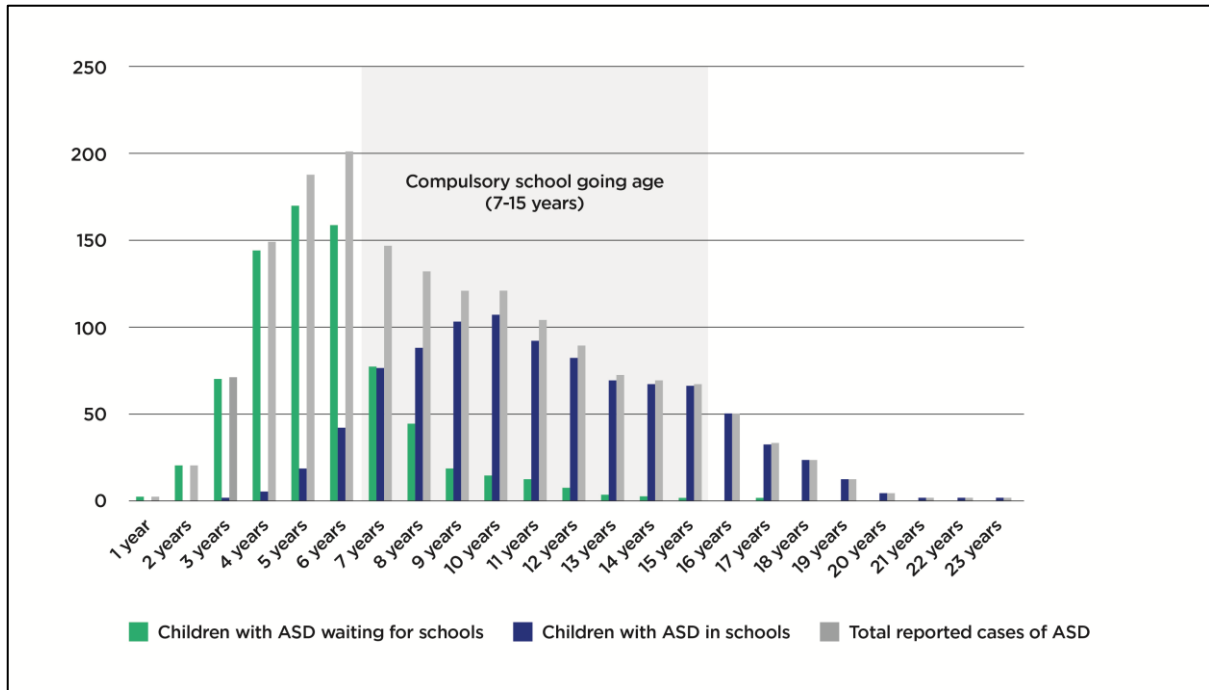


Figure 3.3: Age distribution of children and young adults with ASD waiting for school, in school and the total number of reported cases of ASD in the Western Cape

3.3.5.1 Home language of the total sample of children with ASD

We combined the data on self-reported home language for all children on the ASD on waiting list and those in schools for the three main languages spoken in the Western Cape (English, Afrikaans and IsiXhosa). A total of 57% of the children known with ASD came from homes that spoke English, 20% from homes that spoke IsiXhosa and 18% from Afrikaans-speaking homes. Table 3.7. shows the observed vs expected rates for home language in children with ASD in the Western Cape. Chi-square analyses revealed that observed and expected values differed significantly for English, Afrikaans and isiXhosa speaking children. The observed value was significantly higher than the expected for English speaking children, and significantly lower than expected for Afrikaans and isiXhosa speaking children. The observed and expected values did not differ significantly for other/unspecified speaking children.

Table 3.7: Observed versus expected rates of self-reported home language for children with ASD in the Western Cape

Self-reported home language	Total ASD observed		ASD expected based on 2011 Census				
	N (observed)	% (observed)	N (expected)	% (expected)	Residual	χ^2	P
English	958	57%	340.2	20.2%	+617.8	470.67	<.001
Afrikaans	296	18%	835.3	49.6%	-539.3	367.62	<.001
IsiXhosa	333	20%	415.9	24.7%	-82.9	10.49	.001
Other/ Unspecified	97	5%	92.6	5.5%	+4.4	0.41	.519
Total	1684	100%	1684	100%		560.39	<.001

3.3.5.2 Urban and rural distribution of the total sample of children with ASD

Table 3.8. shows the observed vs expected number of children with ASD living in urban and rural areas. The majority, 86% (n = 1453) of the children known with ASD in the Western Cape lived in urban areas, and 14% (n = 231) in rural areas. Chi-square analysis revealed that observed and expected values differed significantly for children from rural vs urban areas. The observed value was significantly higher than the expected children from urban areas, and significantly lower than expected for children from rural areas.

Table 3.8: Observed versus expected rates of children with ASD living in urban and rural areas in the Western Cape

District	Total ASD observed in WC		Total ASD Expected on 2011 census		Residual	χ^2	P
	N (observed)	% (observed)	N (expected)	% (expected)			
Urban	1453	86%	1081.1	64.2%	+371.9		
Rural	231	14%	602.9	35.8%	-371.9		
Total	1684	100%	1684	100%		209.35	<.001

3.3.5.3 Overall rate of increase in the reported cases of ASD in the Western Cape between 2012 and 2016

Figure 3.4 shows the rate of increase in the number of reported cases of ASD in the Western Cape between 2012 and 2016. There was a 76% increase in the number of children with ASD in schools in the province, a 276% increase in the number of children with ASD waiting for schools and a 230% increase in the total number of reported cases of ASD in the Western Cape.

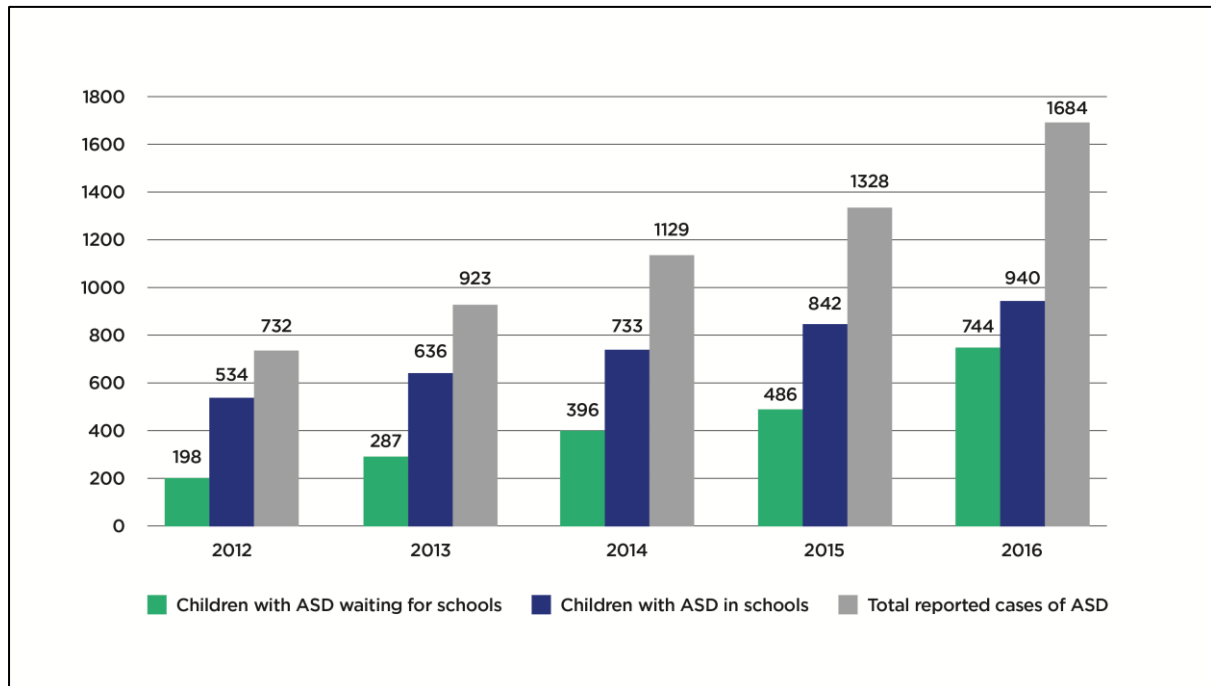


Figure 3.4: Rate of increase in reported ASD cases between 2012 and 2016

3.4 Discussion

This chapter examined the demographic, disability, referral and service provision profile of children with ASD or suspected ASD who were waiting for special education services in the Western Cape Province of South Africa. Findings from this chapter was combined with the findings from the previous chapter which examined the cohort of children with ASD already in schools in the province over the same period. The expectation was that a) there would be children on the waiting list waiting for specialist ASD services across age, sex, language and urban/rural areas of the province, b) an under identification of children with ASD compared to conservative global ASD estimate of 1%, c) a number of children on the waiting list would not be receiving any education or other interventions while they waited, even though some may be of legal school-going age, and d) a disproportionate representation of language and urban/rural profile of all children with ASD known to the WCED in relation to population-based expectations.

In June 2016 there was a total of 744 children with a confirmed or suspected diagnosis of ASD waiting for educational service in the Western Cape. Their ages ranged from 1-17 years and, similar to international findings, there were 5 times more boys than girls (Maenner *et al.*, 2020). The demographic, disability and referral profiles across the two groups were similar. High numbers of both pre-school age children (64%) and school-age children (36%) were on the waiting list and as predicted, a number of children (53%) between the ages of 0-6 years (pre-school age) and 38% between the age of 7-17 years (school-going age) were reported to be at home and not receiving any intervention while they waited for schools. More than half the children on the database had been waiting for services for more than a year.

The majority of the children (52%) were reported to be from English speaking homes and living in urban areas (89%). There was low reporting of co-occurring conditions and a family history of ASD was reported in 3.6% of the children. The referral profile showed that most of children (81%) were referred to the waiting list by medical practitioners based in the government-funded Department of Health (65%).

The combined data of individuals with ASD already in the education system (see Chapter 2) and children with ASD or suspected ASD waiting for school placement in this study showed a total of 1,684 known cases of ASD in individuals between the ages of 1-23 years in the Western Cape. Even in the absence of Census data for the exact period and age group, the total population of children and young adults between the ages of 0-24 years in the province in 2016 was 2,612,760 (Statistics South Africa, 2016), suggesting that all the children identified in our study represented less than 0.1% of the population at the time. As predicted, this was significantly lower than international findings that ASD affects 1-2% of the population (Fombonne *et al.*, 2016). Similar to findings in Chapter 2 there was a disproportionate representation of known children with ASD in terms of home language and geographic distribution compared to the population demographics of the Western Cape. We observed a 76% increase in the number of children with ASD in schools in the Western Cape over a five-year period. Data from this phase of the study showed a 276% increase in children waiting for schools and a 230% increase in the total number of known children with ASD in the Western Cape for the same period.

There are various possible reasons for the low numbers of children with ASD in the Western Cape as pointed out in Chapter 2, including under-identification and reporting

of children as well as stigma and parental reluctance to disclose a diagnosis of ASD. According to Divan *et al.* (2021), social context and family experience of ASD are key barriers to identification, diagnosis and care for children with ASD in LMIC. In their conceptual framework for understanding cultural and contextual factors on ASD across the globe, de Leeuw *et al.* (2020) described the cultural (norms, attitudes, beliefs and stigma) and contextual factors (availability, acceptability, accessibility, and affordability of services) that influence ASD screening, identification and diagnosis. A higher proportion of children both in and out of the education system in the Western Cape may have undiagnosed ASD. Chapter 2 suggested a more than ten-fold under-identification and/or reporting of children with ASD in the province. Data from this phase of the study support these findings. However, a 276% increase in the number of children waiting for school placement over a 5-year period is evidence of a rapidly increasing need that would require a highly responsive system to meet this need.

Thirty six percent (36%) of children waiting for educational services were of compulsory school-going age. The South African Schools Act (1996) states that every child, with or without disabilities has a right to free, basic education and it is compulsory for all children to be enrolled in a registered educational programme in the year that they turn 7 years until the age of 15 years (Department of Education, 2001). Children with ASD of compulsory school-going age having to wait for educational services is an infringement of their constitutional rights to education, and this could potentially have serious legal consequences for the South African Government. In 2010, the Western Cape Forum for Intellectual Disability (WCFID) resorted to legal action against the South African Government for not providing children with severe and profound intellectual disabilities (CSPID) with educational opportunities (McKenzie *et*

al., 2017). The High Court ruled in favour of the WCFID and the affidavit that followed outlined stakeholder responsibilities, clear guidelines for action as well as time frames for implementation (McKenzie *et al.*, 2017). Similarly in Canada, parent advocate groups resorting to litigation against policy makers resulted in coordinated service delivery action for children with ASD (Shepherd and Waddell, 2015).

ASD can be reliably diagnosed as early as 18 months (Baron-Cohen *et al.*, 1996; Baird *et al.*, 2000). Children with suspected ASD were referred to the ASD waiting list as early as one year of age, possibly as a precautionary measure for a better chance of school placement when the child is of compulsory school-going age. Having already been identified as at risk of having a developmental disorder, these children are ideally placed for early intervention initiatives. In 2014 a policy statement on early childhood programmes by the Deaf Federation of South Africa recommended quality early childhood programmes for deaf and hearing-impaired children from birth up to the age of seven years as a means for increasing inclusion for these children (Parliamentary Monitoring Group, 2018). Similar policy action for children with ASD would serve to meet the critical need for early intervention for children with ASD and their families.

More than half the children on the ASD waiting list had been waiting for service for more than a year and 48% of all children on the waiting list were reported to be at home and not receiving any educational or specialised intervention. In South Africa there are no government-funded early intervention programmes available for children with ASD, and the majority of families who need intervention cannot afford private services. Taking into account the importance of early intervention, there has been growing support for the use of caregiver-mediated and non-specialist interventions in

low-resourced environments where specialist services are not always feasible or accessible (Divan *et al.*, 2015; de Vries, 2016; Guler *et al.*, 2018; Schlebusch *et al.*, 2020). Therefore initiatives to link parents and caregivers of children awaiting educational placements to these types of interventions, would seem an ideal and urgent next step for government agencies.

Generally younger (pre-school) children are referred to the ASD waiting list. However, school going age children are sometimes referred when their current schools (ordinary/mainstream schools or full service/inclusive schools) are no longer able to accommodate them for various reasons. A total of 7% of children on the waiting list were reported to be in ordinary mainstream schools at the time and were waiting for special school placements to become available. According to Lilley (2015) more children with ASD in the general schooling system are moving to special education because of poor inclusion of these children. Chapter 2 showed that 89% of children with ASD in schools were in the special education system (Pillay, Duncan and de Vries, 2021). The South African Schools Act Section 12(4) states, *“where it is reasonably practicable, learners with special educational needs should be admitted to ordinary public schools with relevant educational support”*. Placement in least restrict learning environments such as mainstream schools has significant benefits for individuals with ASD including improved communication, social skills, academic achievement and better prospects of employment (Bolourian *et al.*, 2020). Children with ASD should be able to access all types of schools in the province to develop to their full potential. Inclusion of children with ASD in mainstream schools can be facilitated through changes in teacher attitude, training and support from school

management and support services as well as collaboration with families (Sanahuja Gavaldà and Qinyi, 2012).

Chapter 2 highlighted the low reporting of co-occurring conditions in the school going population of children with ASD. Similarly in this chapter, co-occurring conditions were reported in only 11% of children on the ASD waiting list. An understanding of co-occurring conditions are important for identifying appropriate services and interventions for these children (Soke *et al.*, 2018). Children with co-occurring conditions may experience additional barriers in finding the right educational setting to meet their specific needs. Furthermore special schools have rigid acceptance criteria where only children with a specific diagnosis can go to a particular school (Department of Education, 2007). Most of the existing ASD schools and units in the Western Cape are not equipped with the skills and resources to accommodate children with co-occurring physical or sensory impairments. Few of the ASD units attached to special schools have nursing staff to support children with medical conditions and those who may require medication during the school day. According to the Policy on Screening, Identification, Assessment and Support (SIAS), the Department of Education is required to collaborate with the Department of Health to remove health-related barriers and improve access to education for all school aged children (Department of Education, 2014).

Most of the referrals to the ASD waiting list (89%) were for special schools in the City of Cape Town. When combined with findings of the previous chapter on children with ASD in schools (Pillay, Duncan and de Vries, 2021), there was a clear over-representation of children with ASD in urban areas compared to the population profile

of the Western Cape. A possible reason for the low number of referrals in rural areas could be that the ASD Special School and units are mostly situated in the City of Cape Town and professionals may not refer children who live in rural areas where services are scarce. Children who live in rural areas suffer greater exclusion as schools in some rural areas are few or non-existent, lack qualified professional staff and basic resources (Du Plessis and Mestry, 2019). Information about where the children live and what services are available in the area is important for planning and resource provisions to ensure equitable access to education for all children.

A total of 17 different home languages were reported to be spoken by families on the waiting list. We combined the finding on self-reported home language in children with ASD waiting for schools (this chapter) and children with ASD in schools (Chapter 2) for the three languages typically spoken in the Western Cape (Afrikaans, English and IsiXhosa). These findings were similar to Chapter 2, where there was disproportionate representation of children with ASD compared to the population demographics of the province with more children reported to be from English-speaking homes even though the Western Cape is predominately Afrikaans-speaking. One possible reason for the over reporting of English first language could be that the medium of instruction at the majority of schools for children with ASD in the Western Cape is English (Pillay, Duncan and de Vries, 2021) and families could be reporting English for a better chance of getting into a particular school. The Constitution of South Africa (1996), Section 29(2) recognises the importance of cultural diversity and states that all learners have a right to basic education in their language of choice where it is reasonably practicable. However, in a country where there are 11 official languages, this presents as a challenge and most schools choose either English or Afrikaans as a main language of

instruction. Studies have shown that children with ASD demonstrate better comprehension, more play and fewer challenging behaviours when instructed in their home language (Lang *et al.*, 2011; Lim and Charlop, 2018), therefore policy review of home language medium of instruction at schools for children with ASD could have positive benefits for these children.

The Constitution of the Republic of South Africa, (Act 108 of 1996), Section 29(1) states that every South African citizen as well as non-citizen has the right to basic education. A total of 6% of the children on the ASD waiting list were from other African countries and one Asian country. Over the last few decades, South Africa has had an influx of immigrants from Zimbabwe, the Democratic Republic of the Congo, Nigeria, Somalia, Bangladesh, China, India and Pakistan (Rule, 2018). Studies show that immigrant families experience more barriers in accessing services for their children with ASD (Karim *et al.*, 2020). South Africa is already a racially/ethnically diverse nation and in light of the changing demographics of the country due to increased migration, education systems should be strengthened to accommodate a range of diverse needs of all children and their families.

The referral profile of children on the waiting list supports the observation in Chapter 2 of a lack of a clear and consistent referral pathway for children with ASD in the province. Although the majority of the referrals to the ASD waiting list came from medical practitioners and from the Department of Health, children were identified and referred to the waiting list by different professionals in different sectors and 26% of children were referred to the educational sector for a confirmation of diagnosis from educational psychologists as a primary reason for referral. A standardised pathway

could serve to streamline the process and clearly define the different government departments roles and responsibilities in relation to children with ASD and their families as well as to determine resource allocation to services. Clear actions need to be agreed upon to improve identification and access to appropriate education for all children with ASD in the province.

3.5 Limitations of the study

A number of limitations are acknowledged. This study highlights the unmet needs of children with ASD in the Western Cape Province in 2016 and the finding of this study may not be generalised in other parts of the country. However the Western Cape is one of the better resourced provinces in South Africa for children with ASD and their families. It is the only province in the country with a comprehensive waiting list for children with ASD awaiting school placement. It can be assumed that unmet educational needs of children with ASD in other parts of the country may be even greater. Secondary data from the WCED waiting list and referral forms as well as the findings from Pillay, Duncan and de Vries (2021) education database search was used to create the dataset for this study, and the accuracy of the information could not be verified. However this was the first systematic evaluation of the waiting list and combined with the findings of Pillay and colleagues (2021) is to the best of the researcher's knowledge the most comprehensive study of children with ASD in a South African education system. Ideally the children should have been assessed to confirm the diagnosis of ASD, however the lack of culturally and linguistically appropriate assessment tools for the diverse South African population poses as a challenge for large-scale assessment. It is also acknowledged that data from 2016 were used in this study, some positive change may have occurred since those data were collected.

3.6 Lessons beyond the Western Cape Province of South Africa

The initial creation of the waiting list was a symptom of an under-capacitated service platform and despite being an obscure data source the waiting list analysis revealed multi-layered insights that could be relevant to similar low-income contexts. The list served as an instrument for measuring the supply and demand for ASD services for children and their families in the Western Cape and this baseline measurement is the first steps to understanding and improving services. Monitoring and identifying the needs of children with ASD may have potential benefits in other provinces in South Africa as well as other LMIC where information about children with ASD and their service needs are limited or non-existent. The waiting list analysis emphasised language and geographic barriers to accessing services and these are challenges seen in both HIC and LMIC around the world. Disability services in many parts of the world still focus primarily on physical or sensory disabilities instead of neurodevelopmental conditions and there is an overemphasis on 'special school' placement as opposed to inclusion of children with diverse learning needs. The human rights issue of access to education for all children with and without disabilities is a concern in the Western Cape, South Africa, Sub-Saharan Africa as well as many other LMIC around the world.

3.7 Conclusions

The Western Cape Province of South Africa has seen a significant increase in the number of referrals for ASD specific education since the first ASD waiting list started in 2009. Despite being of compulsory school-going age, many children wait long periods of time for educational services. Having already been identified as having ASD or suspected ASD, these children should receive access to early intervention programmes. The over-subscription of special schools for the majority of children with

ASD in Western Cape is concerning. A range of appropriate of educational opportunities should be explored however in order for this to be successful education systems need to be strengthened. We propose engagement with stakeholders from the different government departments, ASD service providers as well as families of children with ASD to explore their perceptions of current ASD services and their suggestions for improving services in order and to generate contextually appropriate and participatory guidelines for next steps.

3.8 Chapter Summary

This chapter examined the demographic, disability, referral and service needs profile of children with ASD waiting for school placement in the Western Cape Province of South Africa and combined the findings of the previous chapter on children with ASD attending schools in the province over the same period of time (Chapter 2). In June 2016 there were 744 children with ASD or suspected ASD waiting for an appropriate school placement, 478 children were pre-school age and 266 children were school-going age. Fifty three percent (53%) of pre-school age children and 38% of school going age children were reported to be at home and receiving no educational or other intervention while they waited for a school. More than half the children on the waiting list had been waiting for services for more than a year.

The combined data on children with ASD in school and waiting for schools showed a total of 1684 known children with ASD in the Western Cape in June 2016, representing less than 0.1% of the childhood population in the province. Results highlight the need for education systems strengthening to accommodate all children with ASD in appropriate educational settings from early as possible. We propose multi-stakeholder engagement to develop contextually appropriate policies, best practice guidelines and

actions for the education of children with ASD in South Africa. In the next chapter we explore the perceptions of caregivers of children with ASD waiting for educational services in the Western Cape and their recommendations for service improvements.

CHAPTER 4: “WE WAIT AND WE WAIT” - CAREGIVER PERSPECTIVES OF AUTISM SPECTRUM DISORDER SERVICES IN THE WESTERN CAPE PROVINCE OF SOUTH AFRICA

4.1 Introduction

The *Lancet* Commission on the future of care and clinical research (Lord *et al.*, 2022) highlighted the global importance of autism spectrum disorder (ASD) and the profound impact of ASD on the individuals and their families. Caring for a child with ASD poses a number of unique challenges due to the nature of impairments, activity limitations, participation restrictions and co-occurring health conditions associated with the diagnosis (DePape and Lindsay 2015; Tint and Weiss, 2016). The impact of the functional, social and emotional demands of caring for a child with ASD on caregiver wellbeing has been widely reported (Rivard *et al.*, 2014; Tint and Weiss, 2016; Valicenti-McDermott *et al.*, 2015). Caring for a child with ASD is often associated with higher levels of stress compared to caring for typically developing children or children with other developmental disabilities (Estes *et al.*, 2009; Hayes and Watson, 2013). Furthermore, the challenges of securing appropriate health and education services for their children with ASD contribute to negative caregiver wellbeing including poor physical and psychological health, as well as financial stressors (DePape and Lindsay, 2015).

Studies have shown that timely access to diagnostic and appropriate early intervention services have positive developmental and long-term outcomes for children with ASD (Zwaigenbaum *et al.*, 2015; Clark *et al.*, 2018). However, Young *et al.*, (2019) reported that caregivers of children with ASD often experience numerous challenges in

navigating systems to secure services for their children including long waiting times, confusing processes, lack of longitudinal support and financial constraints. Young and colleagues argued that, even in well-resourced countries such as the USA or the United Kingdom, fragmented diagnostic and intervention service systems are challenging for caregivers to navigate (Young *et al.*, 2019).

In low-resource settings such as remote rural areas and peri-urban informal human settlements there are even fewer opportunities for health and other professional support services due to structural barriers resulting in an even greater burden of care on caregivers (Adujna *et al.*, 2020; Viljoen *et al.*, 2021; Singh *et al.*, 2019; Antezana *et al.*, 2017). Despite being one of the better resourced countries for children with ASD in sub-Saharan Africa, as highlighted in Chapters 2 and 3 the pathway to services from parental concern to diagnosis and school placement for children with ASD in South Africa was inconsistent and confusing. Based on an analysis of the waiting list of all children with ASD seeking special school placement in the Western Cape Province of South Africa as outlined in Chapter 3, many children wait long periods of time for educational services. At the time of our study, we identified a total of 744 known children with ASD who were waiting for schools in province of which 89% were reported to be living in urban areas and 11% in rural areas. Fifty two percent (52%) of these children had been waiting for services for more than a year and 48% were reported to be at home and not receiving any intervention while waiting for schools to become available (Pillay, Duncan and de Vries, 2022).

Given the fundamental importance of parents and caregivers in the lives of children with ASD and related disabilities, and given the concerning findings reported in Chapters 2 and 3 (Pillay, Duncan and de Vries, 2021; Pillay, Duncan and de Vries,

2022), we therefore set out to explore the perspectives of caregivers of children with ASD who were waiting for educational services in the Western Cape about their children's needs, their views of existing ASD services, and their suggestions for service improvements. Although numerous studies have reported on caregiver experiences of ASD, the majority to date have been from high-income countries (Schlebusch *et al.*, 2017). As a result, there is a lack of information on parental experiences and perspectives about access to ASD support and services in low- and middle-income countries (Paula *et al.*, 2020). In their scoping review of all ASD studies conducted in sub-Saharan Africa (SSA), Franz and colleagues (2017) found only eight published studies on family perspectives of ASD in SSA of which seven were from South Africa and one from Kenya. South African studies explored caregiver experiences of having a child with ASD, getting a diagnosis, perceptions around knowledge and attitudes of service providers and available support services (Alli, Abdoola and Mupawose, 2015; Du Toit and Kok, 1999; Fewster and Gurayah, 2015; Mitchell and Holdt, 2014; Oliver and Hing, 2009). Other studies reported on factors associated with resilience in families of children with ASD (Greeff and van der Walt, 2010; Kapp and Brown, 2011; Olivier and Hing, 2009). To date, there has been no systematic exploration of perspectives of caregivers of children with ASD waiting for educational services in the Western Cape Province. Findings from this study could serve to inform ASD service strengthening and policy review in the Western Cape, South Africa and potentially in other similar contexts. In line with the Lancet Commission recommendations to prioritize research that could improve the quality of life of individuals with autism and their families (Lord *et al.*, 2022), the aim of this study was to explore the perspectives of caregivers of children with autism waiting for

educational services to inform future service strengthening, delivery and policy review in the Western Cape Province of South Africa, and other similar contexts.

4.2 Methods

A pragmatic qualitative design (Major and Savin Baden, 2013) was used to identify the perspectives of caregivers about their experiences of services for their children with ASD in the province. This design provided the researcher with a practical and sensible way to answer the research question through the focus group discussions. As outlined by Sandolowski (2000, p.335) a pragmatic design allows for 'basic and fundamental qualitative descriptions' of facts and feelings to emerge in the everyday language. The focus group method was selected to gather data because of its heuristic value in generating descriptive data simultaneously and efficiently from people with diverse perspectives in a short period of time (Acocella, 2012). Despite these benefits, Acocella (2012) also highlights potential cognitive and communicative risks of focus groups relating to how participants attribute meaning to the discussion, how they retrieve and organise information and how they form judgements. To address these risks, Acocella (2012) suggests a) that the moderator should encourage participants to clarify the meaning assigned to different terms and expressions that they use and b) participants should be encouraged to write short notes on themes covered which can be read and discussed later if the participant did not have the opportunity to express their thoughts due to the speed of the discussion or if they did not feel comfortable expressing them freely. According to Babbie and Mouton (2014) ideal number in a focus group range between 5 to 10 participants in order to generate rich discussions in which the voices of everyone can be heard.

4.2.1 Participants and procedures

Purposeful sampling was used to recruit caregivers through referral agents such as medical doctors, speech and language therapists, occupational therapists and other professionals who regularly referred children to the ASD waiting list and through ASD schools in the City of Cape Town where children with ASD were awaiting school placement. Participants were contacted either telephonically or by email by the lead researcher requesting their participation in the study. The inclusion criteria were: a) caregivers of children with a confirmed diagnosis of ASD, b) caregivers of children who have been on the waiting list for more than 6 month, c) caregivers of children waiting for school placement across the different urban and peri-urban school districts, d) caregivers who were able and willing to travel to the focus group venue on the given date and e) caregivers who provided written consent to participating in the study.

Acocella (2012) suggested that a balance between homogeneity and heterogeneity in participants ensures a range of diverse perspectives to emerge. Sampling variation was achieved by including male and female caregivers of different ages, race, socio-economic backgrounds, educational levels and geospatial location. Race remains an important proxy for access to services firstly due to the lingering impact of apartheid policies in South Africa that geographically segregated people of different race and language groups experience (Shahaboonin et al., 2023; Turok et al., 2017) and secondly, due to the role that access to interventions in first language plays in promoting uptake of services (Van den Berg, 2016).

4.2.2 Data collection

The two focus groups were conducted in English by the lead researcher. An interview guide with key probes were used to answer the two main research questions: 1) what do participants think of current ASD services in the Western Cape, and 2) what would

they suggest to improve service delivery. Focus groups were terminated when the researcher and participants felt that saturation had been reached evidenced by participants indicating that all their views had been sufficiently aired. Focus groups were audio-recorded and handwritten notes were taken by the lead researcher.

4.2.3 Data analysis

The audio-recorded focus groups were transcribed verbatim by a professional transcriber and checked for accuracy by the lead researcher before being imported into NVivo12 software for data storage and management. Data analysis followed the six stages of thematic analysis outlined by Braun and Clarke (2006). The first step involved becoming familiar with the data followed by generating initial codes, generating themes, reviewing the themes, defining and naming the themes and finally producing the final write up (Braun and Clarke, 2006). First level analysis was done by the lead researcher and consensus on emerging themes was reached through discussion with the research team which included an experienced qualitative researcher.

4.2.4 Scientific rigor

Rigor was achieved by adhering to measures for ensuring the quality of qualitative research described by Creswell (2014). Credibility was achieved by the lead researcher's prolonged engagement and persistent observation in the field and by purposeful variation sampling of caregivers with prolonged exposure to the challenges of caring for a child with ASD. Data triangulation was used to ensure confirmability by using data from different sources namely transcribed interviews, the researcher's field notes and literature. The focus groups were professionally transcribed and checked for accuracy by the lead researcher to ensure reliability. All three researchers were involved in various phases of data analysis to ensure rigor.

4.2.5 Ethical approval

Ethical approval was granted by the University of Cape Town Human Research Ethics Committee (HREC 072/2016) as well as the Western Cape Department of Education (reference: 20150727-1712).

4.3 Results

4.3.1 Participants and participant characteristics

The participant characteristics are shown in table 4.1. More than 30 caregivers of the 744 children who were waiting for services at the time were contacted telephonically. Twelve caregivers indicated that they were interested in participating and completed the informed consent forms. However, two of the participants did not attend on the day, therefore two focus groups with 4 and 6 participants, respectively, were held on two separate days. Audio-recording yielded a total of 2 hours 36 minutes of data.

Table 4.1: Participant characteristics

Participant ID	Caregiver description	Race and ethnicity	Occupation	Child's age	Waiting period
P1	Grandmother	Coloured	Retired	9 years	1 year 10 months
P2	Father	Black	Technical work	7 years	2 years
P3	Mother	Coloured	Professional	5-year-old twins	1 year 9 months
P4	Father	Coloured	Professional	5 years	2 years
P5	Mother	Indian	Unemployed	8 years	7 months
P6	Father	Coloured	Sales	6 years	1 year 6 months
P7	Mother	White	Clerical work	9 years	2 years 10 months
P8	Father	Black	Law enforcement	9 years	3 year 2 months
P9	Father	Coloured	Technical work	5-year-old twins	1 year 10 months
P10	Mother	Coloured	Clerical work	4 years	2 years 8 months

4.3.2 Thematic analysis findings

The theme, categories, sub-categories and description of sub-categories are presented in table 4.2. below.

Table 4.2: Theme, categories, sub-categories and description of sub-categories

Theme		
“We wait and we wait”: ASD services are inadequate		
Category	Sub-category	Description of codes (meaning units) in each sub-category
1. The costs of waiting	Socio-emotional costs	Personal and social challenges while waiting for school placement
	Financial costs	Monetary implications of caring for a child with ASD waiting for school placement
	Time costs	Time implications of having a child with ASD on a waiting list
2. Barriers while waiting	Attitudinal barriers	Perceived attitude of service providers towards caregivers
	Structural barriers	Organizational and systemic obstructions
	Process barriers	Procedural/transactional hurdles
	Communication barriers	Obstacles encountered during the transmission of information between caregivers and service providers
3. Expecting action	Attitudinal expectations	Better service provider /user interactions
	Service expectations	Desired resources, systems and structures
	Policy expectations	Anticipated benchmarks for adequate services

The main theme that emerged from the study, “*We wait and we wait*” described caregiver perceptions that ASD service in the province were falling short of meeting the needs of their children. Perceptions about waiting, barriers and service expectations were captured in three categories, each with 3-4 sub-categories (see table 4.2). The first category, *the cost of waiting* described the socio-emotional, financial and time costs of having a child with ASD wait for services. The second category, *barriers while waiting* described the perceived attitudinal, structural, process and communication barriers that caregivers of children with ASD experienced while navigating systems to secure services for their child. The final category, *expecting action* described expectations of caregivers in terms of attitudinal, service and policy

expectations. A summary of the theme, categories, sub-categories and description of sub-categories are presented in table 4.2 and are described in the next section with illustrating quotes.

4.3.2.1 Category 1: The cost of waiting

This category describes the socio-emotional, financial and time costs associated with having a child with ASD, in particular the costs that are exacerbated by being on a waiting list for a protracted period of time.

Socio-emotional costs

The costs of caring for a child with ASD were associated with negative social attitudes towards the beneficence of the caregiver and misunderstanding of the child's behaviour:

"[ASD children] were screaming from eight till twelve o' clock. And there's a block of flats next door, those people came with their cameras to take photos... and saying 'what are you doing with these children?' They [ASD children] were scratching on the walls and the doors and they were throwing everything around and oh, it was dramatic... I mean, society out there is cruel. Even your own family at times, you know, they just categorise your kid as being naughty or spoilt, or that kind of thing" (P3)

The absence of a school placement was perceived to impact on the social and worker roles of caregivers:

"He [child] doesn't have routine, he doesn't sleep at night... all we want is just to get our lives to get back to normal now. Because he's at home 24/7, my husband is working from home now, because there's no one to look after [child]. So if he can also just go to school you know, my husband can also go and work

again, get a workshop, or do something but now he's stuck there in this situation, with [child], because [child] cannot be sorted out" (P7)

Emotional costs of waiting for school placement pertained to parental frustration and frequent disappointment with unmet expectations:

"But [child] must be in a school, I cannot take it anymore... why must they [ASD school] say there's children before him. I want him in. I want him to be settled, he's growing up" (P1)

"It's very emotional. Every year they [ASD school] would phone me for something; they will say, come in for this, come in for that. I would be at work, I would be crying, I'm so happy, and then they shoot us down, every year..." (P7)

Financial costs

The additional financial burden of meeting the special care and education needs of a child with ASD during the waiting period pertained to the lack of accessible and affordable public services, and costly private services such as early intervention programmes, speech therapy and occupational therapy to ensure that their children had a better chance of getting accepted at a school:

"I call it the rich people's disability, because if you are not rich, you can't have autism, because you can't afford it" (P3)

"There are private schools out there, that either cost an arm and a leg, or their therapy does" (P2)

“We decided, alright, we’re going to do it out of our own pocket, we’re not going to wait...even if it cost us everything that we own; we’re just going to start, so that will make it easier for them to maybe get into a school...” (P9)

Time costs

Concerns about the long waiting period for ASD educational services and the consequences thereof on future outcomes for the child was raised:

“Time is moving on...if there’s no support in this now, it’s scary to think of their future” (P5)

“...these kids need to operate in a world without their parents eventually and if you take time away from them in their young days, it screws with their development” (P2)

Some caregivers felt that a proactive approach to seeking interim services for their children was necessary however being proactive had a knock-on effect on their time use. They identified challenges of balancing their work responsibilities and the needs of their child with ASD:

“And now you’re waiting and you’re waiting and you’re waiting, so you need to do something about it, you need to start somewhere” (P9)

“...and difficult, because you, as the parent, needs to work, but you also need to sacrifice that time to take your child to that speech therapy lesson” (P10)

4.3.2.2 Category 2: Barriers while waiting

A range of attitudinal, structural, process and communication barriers that caregivers experienced in seeking services for their children with ASD were identified.

Attitudinal barriers

Caregivers perceived service providers as being indifferent about the scale and urgency of the problem and experienced their lack of sensitivity in sharing of information about the diagnosis as barriers to coping with the challenges of waiting for a school placement for their child with ASD:

“So I get that we’ve got a system for this, but I just feel like somebody else over there, just feels like his problem’s bigger when he goes home from work, and they forget everything about what we still have to go through...” (P7)

“...but that initial point of contact...I think that knowledge is heavily lacking, and you as a parent, because you’re concerned, you research it yourself, and when you try and point out...in the sense that the attitude is, we’re the professionals, and there’s no real listening. We hear you, but we aren’t listening to what you are saying” (P6)

“I wasn’t there when my kid was diagnosed, but what I heard from my wife was, the doctor diagnosed our kid and then made an appointment with [another service] ... and there, they hand you fliers, you know. It’s a new thing for us, as parent also, when you know there’s something wrong with your kid, this autism thing is new, and just to give you a bunch of fliers to read through, you know, it’s just not on, really” (P4)

Structural barriers

With the lack of appropriate state funded special school placement, caregivers expressed concerns that children with ASD were being denied the fundamental right

to education because the necessary resources and infrastructure (universally designed physical resources, special educators etc.) were not available:

“...government schools take them [children without special education needs] at six, which is so to say they must. And it’s their right. Now what about my child’s rights? He should be going to a school” (P5)

When trying to find alternative educational and stimulation programmes (private schools, mainstream schools or crèches) perceptions of children being excluded from services due to the severity of ASD was also raised:

“...they would literally give me an interview first...they want to see if they can cope with this, because they don’t want a bad name for themselves...definitely picking, because if you’ve got a bad case, they won’t want to touch it and if it’s a mild case, they will be like, no, no, he fits in perfectly” (P2)

Process barriers

Some of the caregivers expressed uncertainty about the processes and protocols for accessing support for their child:

“If autism is this condition, where they need special attention, how does this special attention come to them, what does one do?” (P9)

Other caregivers expressed frustrations with inconsistent service pathways and repetitive processes:

“Every time you go in, you see a different doctor, and then it’s almost like starting again...you think you’re taking two steps forward, but you’re actually taking two steps back, because now you’re explaining the whole thing

again...so every six months you go through the same thing, it's like déjà vu going back, and that to me is very frustrating" (P5)

"They give you multiple people to see, like a social worker, everybody, they say contact this person...you get to this person, and this person is going to send you to another person... and we're still running around...It's like someone's passing the buck, for lack of a system, you know, just keep passing names on. There's nobody you can go to... There's no one person you can go see. No one will take that responsibility, to be the representative for you" (P2)

Communication barriers

Perceptions about the lack of communication from service providers once the child has been placed on the ASD education waiting list was raised. Caregivers expressed concerns that not knowing where the child was on the waiting list posed challenges for future planning. In the absence of any clear information about waiting times, some caregivers questioned the actual existence of the ASD waiting list:

"I gave them the forms, everything that I got. When I went again, they said no he is on a waiting list. Since then, nothing...My expectation was that now that he is diagnosed, there will be something, there will be some communication, which I will receive to follow some steps. But nothing!" (P8)

"Education services just put [child] on the list. Beyond that, it was a black hole. So, you don't really know, there's no real knowing... it's not getting answers, and not getting channelled to the right points...its blind, you don't know whereabouts on the list...you never can know, is it going to be one year, two years, ten years...I don't think anybody has answers..." (P6)

“Is there a list? I asked them where is this list, can I see it?” (P7)

4.3.2.3 Category 3: Expecting action

This category described caregiver expectations for action including attitudinal, service and policy recommendations.

Attitudinal expectations

Caregivers advocated for more ASD awareness and inclusion of children with special needs in mainstream society. They felt that service providers could adopt a more empathetic approach when dealing with families of children with ASD:

“Less exclusion. I just feel that special needs shouldn’t be isolated to special needs. It should be implemented through all schools, everyone should be aware, it shouldn’t just be a day or five days of activism or whatever the case may be. It’s part of life...so develop more awareness” (P2)

“Maybe it should be more than just a knowledge test for those people that want to go into that field of work, more than just a knowledge test, maybe, a test of empathy, put them under pressure, you know and see how well they cope. But these guys, they write test, pass, fine, go get a degree” (P4)

Service expectations

Caregivers expressed three clear service expectations - regular updates and communication from the education sector about the waiting process, more special schools for children with ASD, and family support:

“I think that we should be updated...I think more could be done to try and proactively calculate where a child fits in, in terms of the school years. I mean,

I don't think anyone can and it shouldn't be where, it's like you're number fifty on the list and you're number twenty-five, but if he's on a...you know, family by family basis, we see your child potentially being in the school in two years, or one year, or five years... you're better prepared to go the two years" (P6)

"I would want to see more special needs schools...Like McDonald's, there's one in every area" (P2)

"...support...as a family. Especially when you have other kids, then your concentration can't only be on the one, because then it's like you're kind of lacking with the other two" (P5)

"My wife is still in denial. She can't work with my child...we need, as parents, some support groups" (P8)

Policy expectations

Caregivers felt that it was the government's responsibility to provide services for children with ASD and that the education sector should be putting plans in place to make more services available to children with ASD and their families:

"The government in Western Cape is failing us, because there's not many schools that can cater for a child with autism...as a parent you can't walk to the government and tell them because it doesn't have the weight. The Department of Education, they have a list of [children with] autism, which is growing, they could have taken the list and said, we have this challenge with autism; there are not enough schools for them, so can't you help us?" (P8)

“...there’s no central ownership or going forward for the next five years, ten years, we see a trend growth of so many children needing, and how many more, potentially, and we only have so many spaces and we need to grow at a certain rate...I don’t think that they have a picture of how big the problem really is, population wise, and that could obviously make it difficult to plan in such a manner, but maybe some studies like these, and maybe a census would help towards quantifying it, firstly, then it could be quiet easy to place people in a more...’we’ll have a placement for him in two years, or one year’ because then you know you can plan for it” (P6)

“I think all other countries are aware of the spectrum. And they have those conferences. They have the support on that end. I don’t think our government is aware of everything that should be happening” (P10)

Table 4.3. provides a summary of the eight key recommendations made by the participants to improve service delivery for children with ASD and their families and will be discussed in more detail in the next section.

Table 4.3: Summary of key recommendations for service improvements made by caregivers of children waiting for ASD educational services

Caregiver recommendations	
1	More ASD awareness and better inclusion of children with ASD in mainstream schools
2	Service providers should adopt a more empathic approach when dealing with families of children with ASD
3	Better communication and updates regarding the waiting process
4	Provision of more infrastructure to accommodate children with ASD in the education system
5	Provide support for families of children waiting for educational services
6	Government should take responsibility for providing services for children with ASD
7	There should be research to quantify the problem and inform planning
8	Learning from international examples of good practice

4.4 Discussion

This chapter explored the perspectives of caregivers of children with ASD who were waiting for special education services in the Western Cape Province about current services and their suggestions for improved service delivery. Caregivers expressed a high level of dissatisfaction with existing education and other service systems due to the unmet needs of their children. Importantly, findings from the caregiver focus groups also identified a clear list of recommendations for action which will be incorporated into the discussion.

According to Connolly and Gersch (2013) caregivers of children with ASD find the time ‘waiting’ to be the most stressful part of seeking services for their children. Caregivers in this study express concerns about the socio-emotional, financial and time ‘cost’ associated with waiting for services. Caregivers of children with ASD often experience significant financial strain as a result of having to care for the child with ASD (Tint and Weiss, 2016; DePape and Lindsay, 2015). In this study, caregivers referred to ASD

as the “*rich people’s disability*” due to the high financial costs of private services in the absence of government funded service. Buescher *et al.*, (2014) estimated the national lifetime cost of caring for an individual with ASD and accompanying intellectual impairment to be £1.5 million in the United Kingdom and \$2.4 million in the United States (Buescher *et al.*, 2014). These costs were significantly higher in early childhood and involved mostly non-medical expenses like special education and early intervention services (Buescher *et al.*, 2014).

There have been numerous reports on the financial challenges that caregivers of children with ASD experience in high income countries (Jones *et al.*, 2017; Horlin *et al.*, 2014; DePape and Lindsay, 2015) and it can be assumed that the financial burden on caregivers in low- and middle-income countries would be greater by far. An autoethnographic reflection of the cost of raising a child with ASD in South Africa describes ASD interventions in the country as being financially unsustainable (Clasquin-Johnson and Clasquin-Johnson, 2018). Apart from the high out of pocket expenses that caregivers of children with ASD experience studies show that caregivers experience further loss of income due to reduced productivity of having to take the children to therapy appointments or in some instances caregivers had to leave their employment to take care of their child (Paula, 2020; Buescher *et al.*, 2014). With limited opportunities for government funded education, some families resort to expensive private sector education. Clasquin-Johnson and Clasquin-Johnson (2018) suggested that ASD should not be a burden that families have to deal with alone and that government should take responsibility for the education of children with ASD.

Concerns around children with ASD missing out on intervention during the critical period of development while waiting for schools were raised. Early intervention has

been shown to have positive developmental and future outcomes for children with ASD (Zwaigenbaum *et al.*, 2015). Evidence based interventions such as speech therapy, occupational therapy and naturalistic developmental behavioural interventions are often recommended however, the majority of the families who need the services in South Africa cannot afford private sector rates (Van Schalkwyk, Beyer and de Vries, 2016). There is therefore a need for cost effective and sustainable early intervention for children with ASD waiting for educational services in South Africa.

Caregiver-mediated and non-specialist led interventions are suggested for children with ASD in low resource settings where there is a lack of specialized services (de Vries, 2016). In light of the growing burden of disease and limited public health sector resources in South Africa the National Mental Health Policy Framework and Strategic Plan (2013-2020) and the Framework and Strategy for Disability and Rehabilitation Services in South Africa (2015-2020) supports task-shifting of interventions to community health and rehabilitation workers in order to reduce the service gap and deliver treatment and support to people with disabilities in their communities (Academy of Science of South Africa, 2021). Including ASD competences in the skills set of community health and rehabilitation workers will go a long way towards making basic task-shifted help available in homes of families with children with ASD during the critical period of development.

Caregivers highlighted various systems barriers that they experienced in seeking services for their children with ASD. Findings from this study were consistent with studies from high- and low-income countries that caregivers find navigating systems to secure services for their children with ASD stressful due to systems barriers (De Pape and Lindsay, 2015; Paula *et al.*, 2020; Rutherford *et al.*, 2018; Tekola *et al.*,

2016; Young *et al.*, 2019). Chapters 2 and 3 (Pillay, Duncan and de Vries, 2021; Pillay, Duncan and de Vries, 2022) described the pathway to care for children with ASD in the Western Cape Province as being complicated and lengthy with children moving between the different government departments and services. In a study that examined challenges and barriers to care for families of children with ASD in six Latin American countries, Paula *et al.*, (2020) report that Brazilian caregivers experienced more frustration with waiting lists and obtaining information about processes than the other Latin American countries in the study and attributed this to a lack of human and financial resources as well as unequal distribution of resources in the country.

According to Young *et al.*, (2019) caregivers in Canada found navigating post-diagnostic service systems overwhelming and frustrating. They referenced studies by Braiden and colleagues (2010) where caregivers described the time between diagnosis and accessing services as “a void”. Similarly in this study, caregivers referred to the lack of communication once the child is on the ASD waiting list as being a “*black hole*”. Caregivers felt that better communication about the waiting list process and regular updates could help them prepare better. Young and colleagues (2019) suggested that a self-tracking tool, similar to an immunization card, could be a useful strategy to help caregivers navigate service systems. The Pediatric Developmental Passport was created in collaboration with caregivers of children with ASD in Canada and was used to track ASD services and to share information between health, education and other stakeholders (Young *et al.*, 2019). Pilot studies showed that this digital tool was an effective, low-cost mechanism to empower caregivers to navigate service systems (Young *et al.*, 2019). A similar system for the South African context could help families of children with ASD to navigate systems, avoid having to repeat

information every time they see a new service provider, receive updates as well as hold government departments accountable for providing services on time.

Although their study dealt with a waiting list for diagnostic services and not school placement, recommendations by Connolly and Gersch (2013) may have some relevance for ASD services in low- and middle-income countries like South Africa. The authors suggested that caregivers should receive information packs including information on ASD and the referral process as soon as possible, that information and support groups should be available from service providers, and that 'mentors' should be appointed to support caregivers (Connolly and Gersch, 2013). Participants in our study felt that there was a need for more caregiver support and that only receiving information booklets post diagnosis was not enough. Therefore, having support systems in place like designated mentors, caregiver support groups and short training courses held by multi-disciplinary educational outreach teams or speech and occupational therapy students as part of their in-service training may be more valuable. Furthermore, using technology like cellular phone applications to provide information and short training courses could provide a platform for caregivers to help make the waiting bearable. Kumm and colleagues (2022) pointed out that affordable, accessible and culturally and contextually appropriate technology could be a way of providing ASD support and services for people living in LMIC where services are scarce (Kumm, Viljoen and de Vries, 2022).

Basic education is a fundamental human right for all children including children with disabilities. Education systems being unable to provide timely access to education is a contravention of this right. Caregivers in this South African study felt that it was the government's responsibility to provide education for their children and that the

government should be more proactive in planning and creating more educational opportunities for children with ASD. In Chapter 3, we reported a 76% increase in the number of children with ASD in schools and a 276% increase in the number of children with ASD waiting for schools in the Western Cape (Pillay, Duncan and de Vries, 2022). Therefore, both immediate and long-term plans for education of children with ASD should be prioritized.

In South Africa, the majority of children with ASD are in the state funded special education system and only a few children with ASD go to ordinary mainstream schools (Pillay, Duncan and de Vries, 2021). There are few schools that accommodate children with ASD and the limited capacity in these schools result in long waiting times. Similarly, studies from Ethiopia showed that 75% of caregivers reported unmet needs around educational provisions for their child with ASD that included shortage of schools and problems with accessing education (Tekola *et al.*, 2016).

Some of the caregivers in this study felt that there should be more infrastructure to accommodate children with ASD in the education system and others felt that ASD awareness and inclusion in mainstream education should be prioritised. In Chapter 3 we proposed that education systems in South Africa should be strengthened to accommodate children with ASD in a range of appropriate education setting and not only in special schools (Pillay, Duncan and de Vries, 2022). The Education Department's responsibility to all children in South Africa begins in the year that they turn 7 years old and prior to that, children are enrolled in non-compulsory pre-schools or Early Childhood Development (ECD) programmes overseen by the Department of Social Development. Children with ASD are often excluded from these programmes due to a lack of educator knowledge and training to accommodate these children.

Chapter 3 highlighted that 48% of children on the ASD education waiting list were reported to be at home and not receiving any intervention while they waited for schools. ECD educator training to facilitate inclusion of children with ASD in at these centers could fill the gap in providing developmental intervention to children with ASD before they are of compulsory school-going age.

Finally, given the adversities that caregivers of children with ASD experience and the negative wellbeing effects it has on them (Rivard *et al.*, 2014; Tint and Weiss, 2016; Valicenti-McDermott *et al.*, 2015) caregivers in this study expressed the need for family support. Many individuals with ASD will be dependent on caregivers for care and support throughout the lifespan, therefore importance of seeking approaches to improve the wellbeing and quality of life of caregivers of children with ASD should be a priority (Schlebusch *et al.*, 2017). There has been a growing evidence-base for the use of acceptance and commitment therapy in reducing stress in caregivers of children with various conditions including ASD (Byrne *et al.*, 2021; Juvin *et al.*, 2022) even in LMIC such as South Africa (Schlebusch *et al.*, 2022). Mindfulness-based approaches for caregivers of children with ASD waiting for services could provide valuable coping and stress reducing strategies for these caregivers. Culture, language and other social determinants of health will have to be factored into the design of appropriate support (Fong and Lee, 2017; Papoudi *et al.*, 2021; Ault, 2021).

4.5 Limitations of the study

Firstly, this study reflects the views of only ten caregivers of children waiting for ASD services in the Western Cape. However, efforts to recruit participants of different race and ethnicity, socio-economic and professional groups was made to ensure diverse perspectives. Secondly, only caregivers of children with ASD living in the City of Cape

Town were recruited for convenience purposes and the study therefore may not reflect the views of caregivers of children waiting for ASD services in rural areas. We presume that caregivers of children with ASD in rural areas may experience even more challenges to access support and services for their children, but that the fundamental observations made by urban-based caregivers may still be applicable. Similarly, we appreciate that these data were from South African caregivers, and that findings in other sub-Saharan African or other LMIC may be different. However, the themes identified here may provide a helpful framework for further studies of caregivers in other contexts and countries. In addition, the perspectives of ASD service providers and of government stakeholders will be very important to inform a multi-level understanding of the complexities of ASD educational service provision.

4.6 Conclusion

Caregivers of children with ASD waiting for educational services in the Western Cape Province of South Africa expressed dissatisfaction with the void created by inadequate services. They wait as it were in a 'black hole' due to difficulties with obtaining information about processes, navigating complex service systems, accessing practical guidance and support and - most importantly - securing clarity on when and where a school placement for their child with ASD is likely to occur. Furthermore, the emotional wellbeing needs of caregivers of children with ASD waiting for educational services was raised. Efforts to find novel and innovative solutions to providing services and support to children with ASD waiting for educational services and their caregivers should be prioritised.

4.7 Chapter summary

Caregivers of children with ASD face significant challenges in navigating systems to secure services for their children with ASD. Here we performed a qualitative study using focus groups to collect data on the perspectives of caregivers of children with ASD waiting for school placement about current ASD services and their suggestions for service delivery improvements. The main theme that emerged was 'We wait and we wait'. Caregivers expressed high levels of frustration with existing ASD educational and other services in the Western Cape Province of South Africa. Perspectives about services were captured under three categories.

The first category, 'The costs of waiting' described the socio-emotional, financial and time costs associated with having a child with ASD wait for educational services. The second category 'Barriers while waiting' described the attitudinal, structural, process and communication barriers experienced by caregivers while seeking services for their children. The final category 'Expecting action' described attitudinal, service and policy expectations that caregivers felt could improve service delivery. Caregivers provided ten recommendations for ASD system and service improvements.

CHAPTER 5: “WE ARE DOING THE BEST WE CAN TO BRIDGE THE GAP” - SERVICE PROVIDER PERSPECTIVES OF EDUCATIONAL SERVICES FOR AUTISM SPECTRUM DISORDER IN SOUTH AFRICA

Pillay, S. Duncan, M., and de Vries, P. J. (2022). *Frontiers in Psychiatry*, 13: 907093
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5.1 Introduction

Autism Spectrum Disorder (ASD) is a complex developmental disorder that affects 1-2% of the world's population at varying degrees and is characterised by a range of impairments in the areas of social communication, learning and behaviour (APA, 2013). The quality of life of many individuals with ASD and their families are significantly impacted by these impairments (Jones *et al.*, 2017; Schlebusch *et al.*, 2017; Vasilopoulou and Nisbet, 2016) and individuals with ASD may require services across the lifespan to minimize and manage some of the core features of ASD and co-occurring conditions (Cidav *et al.*, 2013; Turcotte *et al.*, 2016).

High-income countries (HIC) are typically better resourced to meet the needs of individuals with ASD and their families. However, even in some HIC there have been reports on challenges in service delivery, most notably in the areas of access to early diagnostic evaluations (Kanne and Bishop, 2021), policy implications for early intervention and support for school-aged children with ASD (Shepherd and Waddell, 2015), and inclusion and employment of individuals with ASD (McCall, 2017).

Olusanya *et al.* (2018, 2020) reported that 95% of all children with developmental disabilities including ASD live in low-or middle-income countries (LMIC), yet there is little information on how they are identified, evaluated, treated and educated (Abubakar *et al.*, 2016; de Vries, 2016; Franz *et al.*, 2017; Tekola *et al.*, 2016). In a

scoping review of all autism research in sub-Saharan Africa, Franz and colleagues identified that less than 1% of the world's autism research had taken place in Africa, and that no studies had examined health or education systems for children with autism (Franz *et al.*, 2017).

South Africa has a population of 58.8 million people of diverse cultural and socio-economic backgrounds (Statistics South Africa, 2019). It is an upper-middle income country with the highest Gini co-efficient indicating vast socio-economic disparities between rich and poor (Sulla and Zikhali, 2018). High Gini co-efficient is characteristic of many LMIC, including India and most Latin-American countries (World Population Review, 2022). South Africa therefore has a socio-economic profile that is very representative of the needs of the majority of the world's population.

Vast disparities across social class and racial lines exist in access to public health and education services due, amongst others, to the socio-political legacy of apartheid (Mayosi and Benatar, 2014; Omotoso and Koch, 2018; Veriava, 2019). In South Africa, children with disabilities including those diagnosed with ASD are most at risk of not having their health, social and educational needs met due to reliance on state-funded services used by the majority of the population (Department of Education, 2001). The South African special education sector is a product of the apartheid era where children were historically classified according to race and disability (Department of Education, 2001) and children with specific disabilities could only be enrolled at the few available schools allocated to the disability. Although there have been efforts to correct these legacies of apartheid, in 2016 there were 119,403 children with disabilities attending 455 schools across the country (Department of Basic Education, 2018) and an estimated 597,953 children with disabilities reported to be out of schools (Hodgson, 2018). The limited state-funded services for children with special education needs in

South Africa therefore tend to be oversubscribed resulting in long periods of waiting for access.

In Chapter 2 we set out to identify all school-aged children with a diagnosis of ASD in the Western Cape Education Department database. Out of more than 1 million children, only 940 children with a diagnosis of ASD were identified, representing a rate of 0.08%. Based on a conservative ASD prevalence at 1%, the finding suggested a more than 10-fold under-identification of ASD in schools in the Western Cape Province (Pillay, Duncan and de Vries, 2021). Apart from the low numbers, we also identified very low rates of co-occurring diagnoses in the sample, complex and confusing pathways to diagnosis and treatment, and, surprisingly, found that 89% of children with an ASD diagnosis were in special educational placements (Pillay, Duncan and de Vries, 2021). Next we proceeded to search for those children waiting for a school placement in the province, and identified 744 children, with 266 (36%) of them being of legal school-going age, but not in education (Pillay, Duncan and de Vries, 2022). Fifty two percent (52%) of children had been waiting for schools for more than a year (Pillay, Duncan and de Vries, 2022). To compound the emerging picture of ASD in the province, we found a 76% increase in children with ASD in school between 2012 and 2016 (Pillay, Duncan and de Vries, 2021) and a 276% increase in children on the 'waiting list' for the same period (Pillay, Duncan and de Vries, 2022). The findings from these earlier studies made it clear that, even in one of the better-resourced provinces of South Africa, the educational system was not able to meet the needs of children with ASD and their families.

In health systems research, Gilson and colleagues (Sheikh *et al.*, 2011) pointed to the importance of understanding any given system in a 'whole-system' way, including the

'hardware' elements (e.g. human resources, infrastructure, financing), the 'software' elements (e.g. ideas and interests, relationships and power, values and norms), and the interaction between these hardware and software elements. Applying the whole-system concept to the educational system in the Western Cape Province of South Africa, and in the context of the previous work in Chapters 2 and 3 on hardware elements, we recognised the importance of exploring also the software elements in the education system in order to generate strategies that may support strengthening of the system. In Chapter 2 and 3, examination of the hardware elements of the education system reported the rates, demographic, disability and educational profile of children with ASD both in schools and those waiting for schools in the province (Pillay, Duncan and de Vries, 2021; Pillay, Duncan and de Vries, 2022). These data provided a starting point for understanding the landscape of ASD education in the Western Cape and we proposed that engagement with stakeholders would be necessary next steps for developing a more comprehensive picture of the ASD situation in the province.

In an effort to complement the 'hardware' findings (Chapter 2 and 3), we therefore set out to examine the 'social' elements of the system by seeking the perspectives of service providers, a key stakeholder group, in the Western Cape Province. Our overarching aim was to describe their views of existing services for children with ASD in the Western Cape, and their recommendations for improvements to existing service systems.

5.2 Methods

5.2.1 Design

A qualitative pragmatic research methodology (Major and Savin Baden, 2013) was used to collect descriptive data arising from the realities faced by ASD service providers.

5.2.2 Participants and procedures

Purposive and snowball sampling was used to identify and recruit a broad range of service providers from the government, private and voluntary sectors. To be eligible, potential participants had to have first-hand experience of delivering ASD educational services, and knowledge of the waiting list for these services in the Western Cape Province. Participants were invited by email or telephonically to participate. Written informed consent was obtained from all participants.

5.2.3 Data collection

Individual semi-structured interviews of approximately 45–60 minutes were conducted by the lead author. Interviews were conducted in English and were digitally recorded. The interview guide included broad, open-ended questions around service provider perspectives of existing services in the province and their proposed solutions to improve ASD service delivery. Clarification probes were used to ensure the following research questions were being answered: “what do service providers think about the current unmet education needs of children with ASD in the Western Cape Province and what recommendations do they have for addressing these needs?” The interview was terminated when the interviewer and interviewee felt that data saturation was reached.

5.2.4 Data analysis

Audio-recorded interviews yielded 7 hours and 30 minutes of data that were transcribed verbatim by the first author into textual form for thematic analysis (Babbie and Mouton, 2014). NVivo version 12 was used for data storage, management and first-level inductive coding to identify units of meaning expressed by the service providers. Second-level coding of inductively identified codes was done manually and involved grouping codes into sub-categories and categories of meaning from which an overarching theme emerged. Thematic synthesis described by Thomas and Harden (2008) was used where the lead researcher identified the sub-categories, categories, and theme and consensus was reached through discussions with the second author, an experienced qualitative researcher. All proposed subcategories, categories and themes were then presented to the third author for discussion until consensus was reached.

5.2.5 Scientific rigor

The creditability and transferability of the data (Lincoln and Guba, 1999) were enhanced by the lead researcher's prolonged engagement and participant observation in the field that enabled the pertinent use of probes during the data gathering interviews. Participants verified the accuracy of the information reflected in the findings through a rigorous process of member checking (Creswell, 2014). Rigor was also enhanced through data triangulation from different sources namely interviews, researcher field notes and document reviews.

5.2.6 Ethical approval

Ethical approval was granted by the University of Cape Town Human Research Ethics Committee (HREC 072/2016) as well as the Western Cape Department of Education (reference: 20150727-1712).

5.2.7 Community participation

No individuals with ASD or their family members were directly involved in this study, but service providers who work with individuals with ASD and their families were involved.

5.3 Results

5.3.1 Demographic characteristics of participants

The characteristics of included participants are shown in table 5.1. A total of ten participants across different professional groups, sectors, departments and base for work (urban/rural) were included.

Table 5.1: Participant characteristics

Participant Number	Service provider	Sector	Urban/Rural
P1	Medical doctor	Health	Urban
P2	Special school principal	Education	Urban
P3	Special school deputy principal	Education	Urban
P4	Occupational therapist	Education	Rural
P5	Educational psychologist	Education	Urban/Rural
P6	Educator	NGO	Urban/Rural
P7	Parent advocate	NGO	Urban
P8	ASD educational consultant	Private	Urban/Rural
P9	Medical doctor	Health	Urban
P10	Psychologist	Education	Urban/Rural

NGO = non-government organisation

5.3.2 Thematic analysis

Table 5.2. provides a summary of the main theme, categories and sub-categories identified in analysis. The overarching theme that emerged in answering the research questions was “*we are doing the best we can to bridge the gap*”. The theme reflected service providers’ awareness of the discrepancies that exist between the scope and nature of the ASD educational service demands and their capacity (either individually or collectively) to meet these demands. Providers expressed perspectives about the scope and nature of ASD service needs in three discreet capacity-related categories: 1) *bridging the gap across the spectrum and lifespan*, 2) *gaps to bridge*, and 3) *building bridges*. The first category captured provider perspectives of service-related factors inherent in the ASD diagnosis and intervention. That is, providers acknowledged the wide-ranging, lifelong and changing needs of children with ASD and their families. The second category summarised service provider views of the range of structural constraints that limited their capacity to meet service needs. The third category captured provider perspectives on potential actions to ‘build bridges’ that might reduce the demand-capacity divide.

The theme, categories and sub-categories as presented in Table 5.2 will next be discussed with representative quotes.

Table 5.2: Summary of main theme, categories and sub-categories

Theme	Categories	Sub-categories	Description of codes that constituted the sub-category
We're doing the best we can to bridge the gap	Bridging the gap across the spectrum and lifespan	Lifespan factors	The lifespan needs of persons with ASD
		Disability factors	How the diagnostic label of ASD can be a barrier to services
		Curriculum factors	The fit between the learning potential and educational needs of each child with ASD and what they are being taught
		Policy factors	Participant views on the regulatory, policy and political factors influencing ASD services in the province
	The gaps to bridge	Resource constraints	The challenges in human and infrastructural resources
		Contextual constraints	Issues of litigation arising from unmet service needs, equity of access and the burden of public health care
		Competence constraints	The perceived competencies and skill set of decision-makers, policymakers and planners
	Building bridges	Leadership	The importance of leadership to address the challenges in ASD education
		Capacity building	Recommended actions that would strengthen the range and quality of resources
		Co-ordination	System efficiency through managed interagency collaboration
		Innovation	Novel actions for improved service delivery

5.3.2.1 Category 1: Bridging the gap across the spectrum and lifespan

Service providers spoke about the need for ASD services to be available to individuals with all levels of severity of ASD throughout the different stages of their life. Four sub-categories emerged: lifespan factors, disability factors, curriculum factors, and policy factors.

Lifespan factors

Given the lifespan implications of the diagnosis, service providers felt that the right type of service was essential to support the individual with ASD across the different stages of life and that these services were generally lacking:

“That’s what we need, cradle to grave provision...And I do think it would be great if the Western Cape could do that...if it was possible” (P8)

Disability factors

This sub-category contained perspectives about the diagnosis of autism acting as an inherent barrier to service access and inclusion:

“If I didn’t know you were autistic, I might still provide services for you, but now, oh but you come with that label, oh you’re ASD, sorry then you fall into that stream...You see, and for me, that is then a disservice to the child” (P9)

“The question was asked to me by somebody yesterday, about, why is autism so fearful? Everybody cringes when they hear you have to take learners with autism, why can’t they just go to other schools?” (P2)

Service providers stressed the right to participation in education for all children with ASD regardless of the severity of disability. Some expressed concern that ASD children presenting high levels of needs were denied access to educational services because of the amount of individualised functional support that they require. These children are referred to ‘special care centres’ (centres for children with severe-to-profound intellectual disability and associated ASD) where the education-related intervention that they receive is not always optimal:

“...but the special care centres can’t necessarily cater for our children with autism, who are very busy, and they don’t present the same as the other children at the special care centres. The disability is just so different. So what happens to those children who can’t be supported in an autism school, and needs even higher level of support?” (P5)

Curriculum factors

The quality of education for children with ASD was a big concern with some service providers feeling that the curriculum did not prepare young adults with ASD for vocation after school:

“... where we are focusing on skills, we’re focusing on really mundane skills... And I think situations where our teenagers and our young adults being taught, for example, to put windscreen wipers into boxes... that’s not a career” (P7)

The need for differentiation of the mainstream curriculum to accommodate and optimally support the learning potential of all children with ASD according to their developmental needs was stressed:

“I think that there might be a lot of children who are in autism schools, the traditional autism schools, who could potentially find a home in mainstream schools, if there was the willingness to say ‘you know what? This child is not going to be attending English, it’s going to go to Maths, and then he’s going to sit in his or her own little space for the next hour’. I don’t know, I mean obviously there are massive kind of logistical requirements, and you’ve got a schooling system already under strain...” (P10)

Policy and political factors

This sub-category included perspectives on the moral and legislative right to education for all children irrespective of ability:

“Sorry, I take the extreme view, every child has a right to education in the constitution, and they should all be in school, and I know they’re not...Everybody else can fight for their piece of cake, but we need to say, if we’re not looking after the most needy citizens, then what are we as a society?”

(P8)

Concerns were raised that ignorance about the diagnosis and its service requirements rendered policy-makers ineffective. Service providers felt that government stakeholders and policy-makers did not have a good understanding of the ASD situation in the province and that people who did know (such as service providers, individuals with ASD and their families) were not included in policy decision-making processes, leading to ‘knee-jerk’ short-term rather than strategic long-term actions:

“I think they just don’t know. Honestly, my opinion is that the policy makers and even some of the people who are writing the adapted curriculums have never set foot in a classroom. Some of the people who are even writing the SIAS document, for example, which I think is a brilliant document, have never stepped into a classroom. And you can’t... you can’t do this... you can’t make decisions for the people on the ground if you’ve never been on the ground” (P7)*

*Policy on Screening, Identification, Assessment and Support (SIAS) provides a framework for standardised procedures to facilitate the inclusion of children who require additional support in schools.

“...they [policy makers] are reactionary. I understand why, I understand the pressures that they experience and they have to endure, but they have knee-jerk reactions all the time” (P3)

Perspectives on policy compliance and the political agenda behind policy development and implementation were raised. Service providers felt that the lack of transparency around the ASD waiting list had unfortunate consequences for the children with ASD:

“I call it a political game as well...we can't get away from it...I'm not saying the one is better than the other [political party], but it's politics. And unfortunately, the children suffer. And once again it comes back to my point of, I question, is it in the best interest of the children?” (P3)

“I suspect that it had become something that would potentially be politically very, very uncomfortable, were it to arrive in the public domain; that in reality, that we were able somehow to generate a list of children who weren't in schools for autism, versus available proper spaces, it would look like a disaster.” (P10)

5.3.2.2 Category 2: Gaps to bridge

The second category described resource, contextual and competence constraints that were creating service gaps that needed to be bridged in order for ASD services in the Western Cape to meet current and future needs.

Resource constraints

Resource constraints referred to challenges in human and infrastructural resources, and the impact thereof on a) service provider well-being, and b) the ability of the education system to provide critical early intervention services.

With the growing demand for ASD educational services, service providers felt the current infrastructure was not keeping up with the need for customised physical space:

“I don’t see any significant moves, plans, to provide that infrastructure. And when I talk infrastructure, I mean the hard buildings, people, you know, not just a programme, but the physical facilities to provide in this growing need, that is just getting more and more. You know, we’re already battling with a backlog, we’re sitting with this backlog...But it’s not just trying to catch up, we have to provide for the ever growing number” (P9)

Human resources including people with the necessary skills and willingness to work with children with ASD was seen as a major gap that needs to be bridged:

“I think what we’re lacking is people. People qualified to work in it, and not just people qualified, people passionate about working in it. And I think this isn’t a field to go into for a nine to five job. You go into this field, it’s hard work, the kids do have their challenges, and as gorgeous as they are, they aren’t without tough days, and what we’re lacking is people who want to work with that. So, for me, that’s the biggest resource we’re missing, is people. People motivated to work in the field” (P7)

In the absence of appropriate and adequate resources, it was felt that the increasing pressures put on existing ASD schools by the education department to place more children in a classroom to alleviate the waiting list would have negative consequences on the quality of education and on the mental health of the staff:

“I’m concerned about the quality of education that we’re going to deliver from here on in. I’m very concerned about that because our staff members will be burnt out.” (P3)

Participants were of the opinion that resource constraints also contributed to the constant delays in establishing essential early intervention programmes. With the pressures that the education department faced in providing education for school-aged children with ASD, early intervention programmes were being neglected:

“I think [it] is absolutely heart-breaking, never mind heart-breaking, it’s also a human right being denied, in my opinion, that’s early intervention... it’s not available, because they need to deal with the waiting list.” (P8)

“I think the communication support for children, knowing that there’s some critical windows, in young lives. And I’m talking about the two to four / five age group, that missing period of communication support.” (P10)

Contextual constraints

The context within which the growing ASD waiting list exists was highlighted. Service providers acknowledged that education for children with ASD was only one of the public health challenges that the education department was faced with:

“But I think people are working hard, and I think one shouldn’t underestimate the amount of work that the Education Department must be looking at, and even Early Childhood Development. Because remember, we’re just looking at autism. We have huge numbers... I have children with cerebral palsy and other special needs, who are also struggling to get services” (P1)

Some service providers indicated that the waiting list was a useful tool for monitoring the need for services “*it is a fair system*” (P3) while others questioned its purpose:

“I think that initial idea with the waiting list, was... it was meant well, but it turned out to be a disaster. I think there exists, quite a huge misunderstanding, a lack of knowledge, regarding the... what is the waiting list? Waiting for what? Waiting for placement? Waiting for assessment? Waiting for a chair? What are we waiting for? And to me, it is sad... as much as I understand the need, that, we have to put people on a list to get the services to them, I disagree with them having to be on a list, especially the numbers that we’re talking about...” (P10)

Concerns about children on the waiting list not receiving any intervention while they wait for a placement at a school was raised:

“And that confusion, I think, contributes to part of the problem. Some think, no they are being serviced somewhere, so they’re okay. And then, yet there are others that are also on the waiting list, but they’re sitting in the home, so they’re out of school, and nothing happens with them, for years on end” (P9)

Service providers felt that children from lower-income homes with parents who did not complain or who were foreign nationals were more at a disadvantage:

“I think there’s been a huge move of people into the Western Cape. And wherever you see immigrant groups, large numbers of children from the DRC, there’s been children from Somalia, and they are all trying to access services. These children are born in this country, so it’s not a case that they’ve come from other places to access services, they were born here, but they are needing*

services and education. So I think we are having to extend the number... or increase the number of... or capacity of autism units” (P1)

**DRC – Democratic Republic of Congo*

Competency constraints

Participants attributed the current situation in service delivery to lack of capacity rooted in ignorance, denial and poor planning. The competence of decision makers in assessing the urgency of the ASD situation, strategic planning and taking action to manage the situation in the province was raised:

“No, there’s a better word - ignorance. It’s a pervasive ignorance in the society, about the need and the problem that we’re facing. So yes, you know, speaking of other things, country-wide, everything on the news at the moment, is mismanagement, poor planning, but for me it’s poor planning of Eskom, poor planning of resources... but for me, it’s less... it’s not just poor planning, it is a not knowing, it wasn’t even aware of this coming” (P10)*

**South African electricity utility company*

Service providers raised concerns that government stakeholders were not doing enough to manage the situation despite warnings from service providers. One service provider explained:

“So I don’t know whether anybody could foresee it, but those that do...in the last six years, the same noises have been made, but I don’t see a balancing. The writing was on the wall, people have been putting these things in meetings and in presentations and saying, listen, wake up, there’s something coming, and I didn’t see the counter to that.” (P10)

Service providers felt that decision-makers did not acknowledge the urgency of the ASD situation. The increasing number of children being diagnosed with ASD that would require services was not taken into consideration for future planning:

“... well maybe it’s living in denial, maybe it’s just simply saying, can’t deal with that now, got other crisis to deal with, fighting fires within the moment, but not making long term plans.... I don’t think there’s enough future planning, projections made, and strategic planning towards those projections.” (P9)

Service providers felt that there was no clear sense of who ‘owned’ the problem and who accepted accountability and responsibility. Instead, there was a tendency to shift responsibility and not generate solutions to the problem:

“... who’s problem is it? Is it the country’s problem? Is it that community’s problem? Is it a social...you know, is it a worldwide problem? Is it the government’s problem? Who’s problem is this? And if we’re now particularly talking about autism, autism is on the rise, who’s problem is it? And can we shrug shoulders and say, well it’s not my problem, you know, I’m doing this kind of work, that’s your problem, find help for it...So we all sort of put these little blinkers on, and I know I’m making a sweeping statement, but it is easier, than to then live in the denial, and say, you know what? I’m doing the best I can, just to get my yard clean, and leave that one with the problem, to deal with their problem. Yet that person, has questions, has need for support, where... who’s door, do they knock on to? I don’t know, I don’t have that answer. It’s a philosophical one.” (P10)

5.3.2.3 Category 3: Building bridges

The third category described service provider acknowledgement of the efforts made by the current leadership and their suggestions for improved ASD service delivery in three sub-categories: capacity-building, co-ordination and innovation.

Leadership

Despite the numerous challenges alluded to in the preceding categories, service providers felt that the public sector services in the Western Cape Province were taking the lead and doing much better than the rest of the country in terms of ASD service delivery:

“Contrary to popular belief, the Western Cape is streets ahead of the rest of the country, and for many reasons. And the first reason is, the coordinated way in which things are done. There is a consolidated database (waiting list), which is maintained very efficiently, extremely efficiently, with all sorts of information about each child in that database. It’s a tracking mechanism for where a child is, what happens to the child, etc., etc. It is a fair system...Fair in the sense that you obviously have to look at children first, who are school going age, those children need to be prioritised, it is first come first serve, it’s not about financial status, socio-economic structure, culture doesn’t play a role” (P3)

Capacity-building

The expertise and experience necessary for working with children with ASD was raised. Service providers felt that increasing the competence in school staff would result in improved inclusion of children with ASD in the educational system:

“The biggest shift they [teachers] need to make, is to know that in this class, you need to prepare a child for life, and not teaching math and literacy. And that’s a teacher thing. Teachers are born and trained to teach math and literacy. And to make that shift, to helping you to wipe your nose, is also part of learning and getting you ready...So don’t feel like you’re not doing your work when you’re not teaching, you’re playing all day...” (P4)

Participants proposed that the multidisciplinary educational outreach teams that were appointed by the Western Cape Education Department mainly to support to the ASD schools and units across the province could support children with ASD in mainstream schools as well and advocate for better inclusion of these children in the broader education system:

“There needs to be a service like the outreach, but it’s not just for special schools, not just for screening. It should be, here we’ve got a service, a referral is your service, we’ll come and help this teacher to include this child in her class. And that’s what I was doing for nearly two years, and it works. But you’ve got to get the staff trained, you’ve got to get them on the same page, they’re going to accept this child. And it’s a whole school issue, it’s whole school philosophy.” (P9)

The provision of essential home programmes, early intervention services and family support programmes could assist in bridging the service gap while children with ASD wait for school placement:

“I think if we could have more home programme type things, like they have here at [an ASD school], that would maybe be useful. So then while children are

waiting on the waiting list, they at least have some intervention in the meantime as well, or some extra support...If it was an ideal world also supporting the whole family, because often I think parents struggle, the siblings struggle, so the whole family could be supported. That would be ideal” (P5)

Planning and Coordination

Participants advocated for long-term planning of sustainable solutions that ensured coordinated intersectoral actions to provide educational opportunities for children with ASD:

“In the Western Cape, our biggest drawback is planning. I think we are all doers. It feels like everyone wants to jump in and do, and I’m not a planner, that’s maybe why it’s frustrating for me as well, I’m also a doer, I see the problem, I want to fix it. But we need to take a step back, because especially, I’ve looked on the waiting list yesterday, especially with the young ones coming, that are identified, is someone planning for what’s coming? Is someone looking at what is on their way? Or are we just trying to figure out what to do with the ones that we have now?” (P4)

“Research has shown, where the best services across the world is rendered, is where you have very close inter-departmental collaboration. And that is, I think, one of the reasons why we struggle, it is almost non-existent.” (P3)

Innovation

Participants advocated for innovation that would design contextually-relevant educational opportunities for every child with ASD to be among their typically-

developing peers. They felt that innovative ideas could emerge from inter-professional collaboration in the design of early intervention packages drawing on international best practice examples:

“If it’s an ideal world, I’d like to have a child in a school...and the neurotypical children need to learn about how to engage with an autistic child. However, there are those children that need, and if you’re asking ideal world, then I’m saying there must be way more facilities. Not only big schools with three hundred of these children together; smaller, small facilities with fifty children in, ten classes of five each, you know.” (P9)

Service providers acknowledged that ASD is a particularly challenging condition to manage and by drawing on the experiences of other countries, the Western Cape could develop a contextually relevant model for ASD service delivery as one service provider explained:

“I think, with intelligent people who know the landscape, to craft something that is necessarily pragmatic. There are going to be disappointments, it’s an incredibly challenging condition, that the most developed countries in the world don’t get right. But what are the core things that we can draw in, and build on.... let’s make a concerted effort, to go look at international trends of developed countries, where they have trialled, and tried, and tested, and what is working and what does not work.” (P10)

5.3.2.4 Recommendations from participants for service strengthening of ASD education in the Western Cape

Table 5.3 shows a summary of the ten key recommendations made by participants for service strengthening of ASD education in the province. Narrative comments on these will be incorporated into the discussion.

Table 5.3: Participant recommendations for service strengthening of ASD education in the Western Cape

Service provider recommendations	
1	Introduce early intervention and support to children younger than compulsory school going age on the waiting list
2	Support children and their families at home or in the community long before children require formal education
3	Rethink inclusive education so that the majority of children with ASD may not require special school placements
4	Change the stigma and perception about autism in mainstream education at primary, secondary and tertiary level
5	Develop training programmes for educators to enhance their skills to work with learners/students with ASD
6	Rethink curricula for children with ASD to be flexible, based on the needs of individual learners/students, and, where appropriate, focus on a meaningful range of life skills
7	Include users/carers and people with ASD into policymaking, curriculum development and training at all levels
8	Balance the need for more special educational provisions and improved access to mainstream settings for children with ASD
9	Avoid 'knee-jerk' responses to service needs by development of long-term, integrated policies, plans and actions
10	Learn from international best practice examples to develop contextually appropriate solutions to meet the educational needs of children with ASD in South Africa

5.4 Discussion

The purpose of this phase of the study was to examine 'software' elements of ASD educational services in the Western Cape Province of South Africa that might, firstly, complement the 'hardware' data reported to date, and secondly, inform systems

strengthening through service re-organisation, policy review and development of best practices in ASD services. Earlier studies of the hardware of ASD educational services in the Western Cape Province of South Africa identified a range of structural challenges – low identification rates of ASD, low identification of co-occurring diagnoses, complicated and inconsistent pathways to diagnoses and, concerningly, an observation that 89% of all children in school with a known diagnosis of ASD were in special school settings (Pillay, Duncan and de Vries, 2021). In addition, we identified a large ‘waiting list’ of children in need of special educational ASD placements, more than a quarter of which were of legal school-going age (Pillay, Duncan and de Vries, 2022).

Using qualitative data from ten diverse ASD experts in the province, the findings suggested that participants perceived ASD services in the Western Cape as doing ‘the best we can to bridge the gap’ despite the complexities of ASD population needs and prevailing contextual circumstances. However, in spite of doing ‘the best we can’, the majority of participants expressed significant concern about various hardware (e.g. limited human resources, infrastructure, training) and software (e.g. lack of priority of ASD and other disabilities, knee-jerk responses, ignoring early intervention) elements and made a number of recommendations to strengthen education services in the province.

Participants acknowledged the complexity of the ASD spectrum that inherently poses unique service delivery challenges. Vohra and colleagues (2014) concurred that individuals with ASD experience more barriers in accessing services compared to individuals with other developmental disabilities or mental health conditions. Lai and Weiss (2017) argued that the variable and lifelong nature of ASD makes planning for

services challenging, pointing out that individuals with ASD have normative age-dependent service needs, including timely access to identification and diagnostic services, early intervention, school services, after-school and adult services. The participants in this study felt that all levels of services for individuals with ASD were lacking in the Western Cape.

Services providers pointed out that children were on a waiting list but that there were no systems in place to provide intervention or support for these children and their families while they waited. Studies have shown that early identification, diagnosis and intervention is essential for minimizing some of the core features of ASD and thereby positively influencing the functional trajectory of the disorder throughout schooling into adulthood (Vivanti and Dissanayake, 2016; Dawson, 2008). The lack of early intervention services during the critical period of development has significant consequences for language, social and cognitive development with more financial costs relating to long term care and poor prospects of employment (Cidav *et al.*, 2013). A waiting list initiative to find and intervene in young children with ASD could be a very powerful strategy for improved future outcomes.

Service providers suggested that young children with ASD should receive services either at their homes or an interim place should be provided for them to receive developmentally appropriate stimulation. There is growing evidence internationally on the effectiveness of caregiver mediated interventions (Kasari *et al.*, 2010; Naveed *et al.*, 2019; Rogers *et al.*, 2012; Wetherby *et al.*, 2018). In a study from the Western Cape of South Africa, Guler *et al.* (2018) suggested that contextually relevant and sustainable caregiver-led interventions could bridge the service gap in low-income countries where intensive early intervention programmes are not financially accessible

to the majority of the population. Furthermore, de Vries (2016) argued that caregiver-led interventions such as naturalistic developmental behavioural interventions (NDBIs) would be ideal for LMIC contexts where the need is far greater than the number of 'expert' service providers available to deliver interventions. Therefore, foregrounding policy initiatives and service efforts that target early intervention will contribute to bridging the current education service gap in the long-term.

Apart from the need for early action, the ASD diagnosis also influences access to development opportunities throughout the lifespan. Critical to these opportunities is the mainstream participation and inclusion of people with disability in learning environments. Hehir *et al.* (2016) reported on the short- and long-term benefits of inclusive education for people with disabilities including improved social and cognitive development as well as better opportunities for further education and employment. In the study by Pillay, Duncan and de Vries (2021) 89% of the school-going population of children with ASD in the Western Cape attended schools for children with special educational needs and only 10% were in ordinary mainstream schools. An important perspective held by the service providers that a significant proportion of children with ASD in special schools could potentially be better placed in mainstream education supports the need for action to identify and shift children with ASD in special schools to mainstream schools. This however, would require advocacy and training to facilitate successful inclusion of these children in mainstream schools.

Service providers felt that a label of ASD was associated with 'fear' in educators and poor inclusion of children with ASD in mainstream schools. Nah and Tan (2021) reported that caregivers seeking mainstream education services for their children with ASD in Singapore were hesitant to disclose the diagnosis of ASD due to fear of stigma

and perceived negative attitudes of educators. Studies have shown that mainstream educators tend to have negative perceptions of teaching children with ASD due to lack of competence in managing social, communication and behavioural issues associated with ASD (Hayes, 2014). According to Simpson *et al.* (2011), a diagnosis of ASD warrants highly qualified educators with sound knowledge of evidence-based practices. They suggested that higher education institutions like universities and educator training colleges should work collaboratively with schools to improve the scope of training programmes to prepare educators for working with children with ASD (Simpson *et al.* 2011).

A diagnosis of ASD also warrants curriculum content that is shaped by knowledge of the educational needs of this population (Sanahuja Gavaldà and Qinyi, 2012; Simpson *et al.*, 2011). Service providers in the current study expressed concerns that the skills taught to children with ASD in special schools were 'mundane' and not optimal for development of their full potential. ASD special schools in the Western Cape do not follow a prescribed curriculum, only some of the schools work with individualized education and development plans (IEDPs) and children leave school at the age of eighteen without a national certificate and with limited vocational opportunities. In South Africa there are no policies specific to what children with ASD should learn, how they are taught and where they should be educated. Service providers felt that those responsible for developing special needs education policies and curricula had little or no knowledge of ASD and that the people with the necessary educational expertise and experience were not consulted. In Canada, after decades of conflict with policy makers, parent groups, with the help of researchers were able to influence policy, improve service delivery including customised programmes for their children with ASD (Shepherd and Waddell, 2015). The participants in this study advocated for

differentiation of the curriculum, taking into account the heterogeneity of ASD. The development of a customised and national qualification aligned curriculum for learners with ASD would go a long way towards addressing the current service gaps identified in this study.

Taking into consideration the many contextual constraints that service providers described, participants acknowledged the need for an appropriate range of infrastructure and resources to provide educational opportunities for every child with ASD according to their profile of needs. At the time of this research, the Western Cape was the only province in South Africa that had a list of children with ASD waiting for a place to become available in a special school. Although the waiting list has been contentious as outlined in comments from participants, others remarked that the waiting list itself was an important resource for identifying infrastructure and service gaps. Information about the number of children waiting, their ages and other socio-cultural factors could serve to inform future planning.

Service providers felt that the lack human and infrastructural resources, compounded by the lack of competence in decision makers could negatively impact educator wellbeing. With special schools under pressure from decision-makers to admit more children with ASD in a class as a means to alleviate the waiting list, service providers expressed concerns that educators would experience 'burn out'. Brunsting *et al.* (2014) raised similar concerns about the well-being demands placed on ASD educators in specialised education settings. They argue that having more children with ASD in a class can lead to educator burn out despite educator's having the knowledge and skills to work with children with ASD. Mrstik *et al.* (2019) reported that retention of educators of children with ASD in the special education sector was a major problem

in the United States as well as other countries around the world resulting in a shortage of special educators. In a phenomenological study on the lived experience of educating students with ASD, educators reported that high workloads coupled with poor support from administrators was a major source of stress in educators (Mrstik *et al.*, 2019).

While some service providers felt that more special schools should be provided for children with ASD others felt that greater efforts should be made to ensure successful inclusion of children with ASD in existing mainstream schools. In a study that explored the challenges and facilitators of mainstreaming children with ASD, Lindsay *et al.* (2013) adopted the Lipsky and Gartner (1997) model to inform their analysis. The model identified both human and financial resources as essential elements for inclusion (Lipsky and Gartner, 1997). Similarly, Simpson *et al.* (2011) argued for the benefits of allocating resources to address the increasing prevalence of ASD in contemporary societies, pointing out that policymakers should make financial resources available for professional development programmes and other resources that would allow mainstream classrooms to become more conducive to learning for children with ASD. The Western Cape is relatively well-resourced in comparison to other provinces (with two of the five ASD specific special schools in South Africa and several satellite ASD unit classes attached to special schools across the province), however some of the service providers felt that taking into consideration the increasing number of children being identified with ASD and the significant backlog of children already waiting for ASD educational services in the province, a range of appropriate educational opportunities for children with ASD should be explored and supported in order to bridge the service gap.

Service providers also commented on the need to learn from international good practice in order to develop contextually relevant local innovations to ‘build the bridges’ between the current and future service landscape for children with ASD in the province. Service providers felt that greater efforts should be made for long-term planning rather than ‘knee-jerk’ or reactionary decision-making. Lessons from policymakers in Canada has shown that rushed decision-making due to political pressures resulted in poor outcomes for children with ASD and a more proactive rather than reactive approach was prescribed (Shepherd and Waddell, 2015). Stronger intersectoral and inter-professional collaboration was advocated. Service providers felt that where collaboration between the different stakeholder groups was happening there was progress therefore calling for larger scale collaborative efforts. According to Cloet *et al.* (2019), collaboration is key to meeting the diverse needs of children with ASD. Finally, service providers suggested that aligning with international ASD best practice frameworks and drawing on key concepts could support the development of contextually relevant policies and practices for the South African context.

5.5 Limitations of the study

A range of limitations are acknowledged in this qualitative study. First, this study was conducted in one better resourced province in South Africa, and in one sub-Saharan African country. Caution should therefore be taken to generalise findings to other provinces and other LMIC. However, the high level of concern expressed about ASD education in this South African province suggests that even greater challenges may present in other South African provinces and in other LMIC. Second, the interviews were conducted by the lead author only. However, all the authors were involved in developing the interview schedule and analysing the data. Third, results reflected the perspectives of a small group of ASD service providers and findings may therefore not

be easily generalisable. However, the participants represented a broad range of perspectives, and many years of collective expertise and experience of the educational system in the province. Findings are therefore likely to be a fair representation of the state of education systems in the Western Cape. Fourth, data were collected in 2018, and there may have been some 'hardware' and 'software' improvements since the study. However, no major changes have been observed by the authors since the data collection for this study. More research would be necessary to determine the extent to which these improvements have impacted service delivery for children with ASD and their families. Fifth, the study focused on perspectives of service providers. It will also be important to incorporate the views of caregivers of children with ASD, and of government stakeholders in order to ensure a multi-level evaluation of the ASD educational landscape in the province.

5.6 Conclusion

Despite the many complex challenges of delivering educational services to children with ASD and their families in the Western Cape Province of South Africa, the overarching message from participants was that everyone was doing the best they could. Service providers felt that services could improve if collaborative efforts were made by different stakeholder groups to understand and strengthen education systems. Educator training to facilitate inclusive education for children with ASD in the greater education system, parent-mediated early intervention, and intersectoral and inter-professional collaboration were identified as areas that could bridge the service gap. Drawing on international frameworks to develop contextually appropriate ASD policies and best practice for South Africa were recommended.

5.7 Chapter Summary

The South African education system is increasingly unable to meet the growing needs of children with autism spectrum disorder (ASD). Recent studies in the Western Cape, one of the better resourced provinces in South Africa, showed that the pathway to care for children with ASD was an inconsistent and lengthy process, and that many children with ASD waited for extended periods to get access to an appropriate school placement. It is therefore clear that scalable and sustainable solutions are required to improve access to appropriate education for children with ASD. Here we performed a qualitative study using thematic analysis of ten multi-sectorial ASD service providers in the Western Cape Province to examine provider perspectives and proposed solutions to meet the educational needs of children with ASD. Provider perspectives were grouped in three categories: 'bridging the gap across the spectrum and lifespan', 'gaps to bridge', and 'building bridges'.

The first category captured provider perspectives of the service-related needs inherent to a diagnosis of ASD. The second category summarised service provider views of the challenges associated with providing services to children with ASD and the third category captured provider perspectives on potential actions to improve ASD education services delivery in the province. The overarching theme that emerged was 'We're doing the best we can to bridge the gap'. Participants provided ten key recommendations for service strengthening that may lead to contextually relevant innovations to meet the educational needs of children with ASD in the province. Findings from this study has direct relevance to other South African provinces and may have relevance to improve pathways and reduce service delivery gaps also in other low- and middle-income countries. In the next chapter we report on key

government stakeholder perspectives of ASD services in the Western Cape and their suggestions for improved service delivery.

CHAPTER 6: “WE ARE DOING DAMAGE CONTROL” - GOVERNMENT STAKEHOLDER PERSPECTIVES OF EDUCATIONAL AND OTHER SERVICES FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN SOUTH AFRICA

Pillay, S., Duncan, M., and de Vries, P. J. (2022). *Autism*, online early
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6.1 Introduction

Although South Africa is classified as an upper-middle income country (World Bank, 2022) more than half of the population live below the upper-bound poverty line (currently ZAR1227/USD87 per person per month) (Sulla and Zikhali, 2018). With one of the highest Gini coefficients globally, the economic divide between rich and poor in South Africa is starkly visible in the unmet health and social needs of a large percentage of the population. Disparities in access to housing, sanitation, nutrition and education services between rich and poor are attributed to a growing quadruple public health burden of disease (maternal, newborn and child health; HIV/AIDS and tuberculosis; non-communicable diseases; and violence and injury) intersecting with inadequate human and infrastructure resources (Bradshaw *et al.*, 2019; Sulla and Zikhali, 2018).

Education is fundamental for the social and economic growth and development of nations (Shrivastava and Shrivastava, 2014; United Nations General Assembly, 2015). Development in the South African education system requires the complex socio-economic legacies of the apartheid era that excluded children from ‘non-White’ racial groups and children with disabilities from appropriate educational settings to be addressed (Engelbrecht, 2020; Bornman and Donohue, 2014). In correcting the

injustices of the past, the education system is working towards the full participation in education for all children including those with diverse learning needs (Department of Education, 2001; Department of Education, 2007; Department of Education, 2014). To ensure equity and social justice for all citizens, including those with disability, the post-apartheid South African education system adopted national policies that align with the 1989 United Nations Convention on the Rights of the Child (Article 23) and the 2006 Convention on the Rights of Persons with Disabilities (Article 24) (United Nations General Assembly, 1989; United Nations, 2006). The main components of these policies are that every child irrespective of ability has the right to an inclusive education system, the right to accessible education, and the right to individualised support (Hodgson, 2018).

Well-developed policies provide a framework for service delivery and monitoring, including the government's commitment to and accountability for funding and resource allocation to enable implementation (Mokitimi *et al.*, 2018). Education policy enactment in South Africa has been problematic due to contextual factors, policy weaknesses and poor guidelines for implementation (Engelbrecht, 2020). Policy aligned education for children with disability is inadequate and specific policies for children with diverse learning needs such as those with autism spectrum disorder (ASD) have not yet been developed. For example, an estimated 597,953 South African children with disabilities were reported to be out of school (Department of Basic Education, 2015). While it is unknown how many of these children have ASD, there are no ASD specific policies or guidelines for service delivery including ASD education services in any Sub-Saharan African country (de Vries, 2016).

With an estimated 78 million people with ASD worldwide, ASD is rapidly becoming a global public health concern due to the significant impact of the diagnosis on individuals, families and society (Lord *et al.*, 2022). The burden of disease and associated socio-economic costs of ASD is widely reported particularly in low- and middle-income countries (LMIC) (WHO, 2014; Baxter *et al.*, 2015; Leigh and Du, 2015; Clasquin-Johnson, 2018) and the majority of people with ASD do not have access to services (Lord *et al.*, 2022). In South Africa, there is an urgent need for attention to policy design and implementation (de Vries 2016; Franz *et al.*, 2017; Franz *et al.*, 2018; Pillay *et al.*, 2021; Pillay *et al.*, 2022). In 2014 the World Health Assembly resolution WHA67.8, '*Comprehensive and coordinated efforts for management of autism spectrum disorder*' called for government actions to improve the quality of life of individuals with ASD and their families (WHO, 2014). It urged governments to develop new ASD policies or update existing policies that are aligned with the WHA67.8 and to have multi-sectorial strategies for implementation of these policies (WHO, 2014). Despite the adoption of this resolution, information on ASD in South Africa and other LMIC remains limited (de Vries, 2016; Tekola *et al.*, 2016; Bakare *et al.*, 2019) and there is no strategic plan for identification, management and education of children with ASD in South Africa.

The *Lancet* Commission on the future of care and clinical research in autism (Lord *et al.*, 2022) found that ASD knowledge at government and policy development levels is generally poor. ASD services are not prioritised in some LMIC due to other competing socio-economic and public health challenges that these governments are faced with (Hahler and Elsabbagh, 2015). Franz and colleagues (2018) interviewed senior management level government stakeholders in the Western Cape to examine their

perspectives on early detection and intervention for children with ASD in South Africa. They found that most of the government stakeholders acknowledged that ASD was an area of growing concern, however early detection and intervention was not supported by policy, goals and values of all government departments. They suggested that more local information on ASD was necessary for better management and support for these children (Franz et al., 2018).

In Chapter 2 we identified poor systems for identification and reporting of children with ASD in South Africa, a lack of essential early intervention programmes, and education system failure to accommodate children with ASD in appropriate educational settings (Pillay, Duncan and de Vries, 2021). In Chapter 3 we found a total of 744 children with ASD or suspected ASD were reported to be waiting for special school placement over the same period of which 36% (n=265) were of compulsory school-going age (Pillay, Duncan and de Vries, 2022). Children with ASD being out of school is an infringement of their constitutional rights. Acknowledging the complexities associated with disability education, a whole-system understanding of why this rights violation is happening is indicated.

In health systems research, Gilson and colleagues (2017) recognise governance as a complex process with multiple layers that influence decision making, policy enactment and service delivery. Therefore an understanding of the 'hardware' (e.g. finances, resources and infrastructure) and 'software' (e.g. values, norms and relationships) elements of a system is necessary for 'whole-systems' understanding (Gilson *et al.*, 2017). Examination of the 'hardware' of education systems for children with ASD in the Western Cape, showed that the referral pathway for children with ASD from

parental concern to accessing educational services required navigation across complicated inter-governmental service systems (Pillay, Duncan and de Vries, 2021). Therefore it would be important to explore and understand education services for children with ASD not only through an educational lens but through a broader inter-governmental perspective. This study therefore set out to build on findings from Franz and colleagues (2018) on government stakeholder perspectives of ASD related services by exploring the perspectives of key government stakeholders on current ASD educational and other services in the Western Cape and potential solutions to meeting the educational needs of children with ASD and their families.

6.2 Methods

6.2.1 Design

A pragmatic qualitative research methodology (Major and Savin-Baden, 2013) was used to collect and explore government stakeholders perspectives of ASD services in the Western Cape. A pragmatic research approach allowed the researcher to use interviewing as the most sensible and practical method available in order to answer the research question. Instead of having thick descriptions (as in ethnography), theory development (grounded theory) or interpretive understanding of experience (phenomenology), the researcher aimed to discover and understand the perspectives of the people involved by providing “basic and fundamental qualitative description” of facts and feelings in the everyday language of the participants, as interpreted by the researcher (Sandelowski, 2000, p. 335).

6.2.2 Participants and procedures

Senior-level provincial government stakeholders including directors and managers were identified and recruited through purposive and snowballing sampling. As a first

step, government stakeholders known to the research team were approached and recruited. Participants were then asked to recommend additional names for participation in the study and those individuals were subsequently approached directly. A total of six representatives participated in the study, two from each of the following public sector departments in the province: the Western Cape Education Department (WCED), Department of Health (DoH), and the Department of Social Development (DSD). Selection criteria included a) knowledge about ASD services and practical experience of working with ASD at various governance and policy levels, including service planning and interdepartmental coordination of services, and b) willingness to participate in the study. Participants were recruited telephonically or via email by the lead author and written informed consent to be interviewed was obtained. To ensure anonymity, a summary of the participant characteristics is not provided here.

6.2.3 Data collection

Six individual semi-structured interviews of approximately 40-60 minutes each were conducted by the first author and were digitally recorded. A literature review informed the development of the interview guide which included broad, open-ended questions and clarification probes to ensure the following research questions were being answered: “What do government stakeholders think about the current educational services and services in general for children with ASD in the Western Cape Province?” and “What do they propose for improved service delivery?”. The interviews were conducted in English and were terminated when the interviewer and interviewee felt that saturation was reached.

6.2.4 Data analysis

A total of 5 hours and 30 minutes of data was yielded from the audio recorded interviews and was transcribed verbatim. NVivo version 12 was used for data storage, management and first-level inductive coding to identify units of meaning expressed by participants. Second-level coding of inductively identified codes was done manually as described by Major and Savin-Baden (2013) and involved grouping codes into sub-categories and categories of meaning from which an overarching theme emerged.

6.2.5 Scientific rigour

The four criteria for ensuring scientific rigour in qualitative studies were applied (Lincoln and Guba, 1999). Credibility was enhanced by the lead researcher's prolonged engagement as a therapeutic service provider in the field and familiarity with the ASD landscape in the province. This immersed positioning contributed to the development of the interview guide and the use of appropriate probes during the interviews. Researcher bias arising from immersive positioning was managed through clarifying biases with the research team and in so doing, bracketing assumptions about ASD services in the province (Bless, Higson-Smith and Sithole, 2013). Dependability was achieved by keeping an audit trail of the data collection and analysis processes and maintaining sustained reflexivity with the research team. The codes, sub-categories, categories and theme, were agreed upon by the research team. Data triangulation involved collecting data from various sources, namely the interviews, the lead author researcher field notes and document reviews. Transferability involved the use of purposive and snowball sampling to collect a diverse range of perspectives of senior government stakeholders, thereby increasing the likelihood that the findings can be broadly generalised as representative of the perspectives held by current

government officials at a particular point in time in the development of education services in a particular governance context.

6.2.6 Ethical approval

Ethical approval was obtained from the University of Cape Town Human Research Ethics Committee (HREC 072/2016) as well as the Western Cape Department of Education (reference: 20150727-1712).

6.2.7 Community involvement

No individuals with ASD or their family members were directly involved in this study. Six government stakeholders with ASD experience at various governance and policy levels were involved. Participants were not asked to disclose whether they had ASD or had family members with autism.

6.3 Results

Table 6.1. provides a summary of the main theme, categories and sub-categories identified in analysis. The overarching theme "*We are doing damage control*" reflected government stakeholders' perspectives that ASD services are falling between the 'cracks' created by competing societal demands on government resources and systems. At best public sector departments were utilising available capacity in siloes to do damage control by 'stop-gapping' the emergent service needs of the ASD population in a reactive manner. As summarised in table 6.1, participants expressed perspectives about current ASD services in three categories, each comprised of three sub-categories: 1) *A cracked society*, 2) *Siloed service systems*, and 3) *Gap-filling strategies*.

In the first category, stakeholders identified contextual, governance and ideological factors as playing a role in the State's responsiveness to the service needs of specific populations such as children with ASD. The second category summarised participants' views of the bureaucratic, knowledge and resource barriers that obstruct proactive responsiveness by government departments to specific service demands, and in so doing, creating siloes in service delivery. The third category included perspectives on potential actions to 'filling gaps' that may lead to improved service delivery for children with ASD and their families.

The theme, categories and sub-categories and descriptions of sub-categories will be discussed in the next section. Given space limitations, a limited number of representative quotes are provided here per subcategory.

Table 6.1: Summary of theme, categories, sub-categories and description of sub-categories

Overarching Theme “We are doing damage control”		
Category	Sub-category	Description of codes as meaning units in sub-category
A cracked society	Contextual factors	Aspects of the South African society that place demands on government resources and departmental service systems
	Governance factors	Perspectives on departmental responsibility and accountability for ASD services
	Ideological factors	Ideals and values informing how government stakeholders engage with societal needs
Siloed service systems	Bureaucratic barriers	Procedural obstructions at the expense of efficiency and common sense
	Knowledge barriers	Knowledge limitations about the ASD waiting list and service needs of children with ASD across government departments
	Resource barriers	Resource restrictions preventing service organizations from functioning effectively
Gap-filling strategies	Structural strategies	Arrangement of and relations between the parts or elements of the complex whole of the ASD service delivery system
	Direct intervention strategies	Practical actions, steps and service-orientated approaches
	Political strategies	Ways of navigating power dynamics between different entities

6.3.1.1 Category 1: A cracked society

This category describes the external, societal factors affecting government departments’ ability to provide services for children with ASD and their families. Here we present the sub-categories pertaining to external influences that included contextual, governance and ideological factors with representative quotes.

Contextual factors

Participants were of the opinion that socio-political circumstances of the country contributed to inefficiency (qualitatively described as ‘cracked’) in state departments thus restricting their ability to be proactive in planning and delivering appropriate ASD

services. With government departments under pressure to meet a range of public health and social needs, the importance of contextualising the ASD situation within a larger systemic problem was raised:

“you’ve got life-threatening illnesses, you’ve got emergencies, you’ve got trauma, you’ve got violence, you’ve got a range of issues, public health issues, that we need to respond to, and we need to try to get to everybody, to have a response for everything. And it’s that context, where we find ourselves now...”
(P6)

Governance factors

Participants noted that ASD service inefficiencies and ‘cracks’ were created by lack of clarity as to the departmental ownership and responsibility for the ASD situation. Participants felt that the urgency of providing services for children with ASD was not a priority for all government departments with the Education Department being under more pressure than the health and social development departments because of the ASD education waiting list:

“...the only department under pressure at the moment is Education, because of the waiting list and it can be proven.” (P1)

With government being unable to provide services for children with special education needs in rural areas and informal human settlements, unregulated services by lay providers are ‘mushrooming’ in the form of daycare centres where the educational needs of children with ASD are not being optimally met. Participants noted that the support provided to these centres by the Department of Social Development was a short-term solution to a problem that required much more thought:

“...but it still doesn’t mean that the school is a formal school... So I think, I think is a half-baked service...It’s a plaster that’s been put on a sore, because it is one department taking up another department’s responsibility... I think we’re really trying to heal something by quick fixes, and not thinking it through. (P4)

Ideological factors

This sub-category contained participants’ views about the ideals and values informing how government stakeholders engage with societal needs. Participants felt that because ASD only affected a small percentage of society, the issues that people with ASD and their families experience do not receive due attention from government:

“You know, you can have community activism and you can have a swell of people talking about autism, etc., but I don’t think it’s the kind of issue that... because the numbers are so small and it doesn’t affect a large spectrum of society, it’s not the kind of issue that probably normally ends up in the general public domain...and I think, people, from politicians to government people, generally respond in terms of a big societal burden, and autism is probably not one of them yet.” (P6)

6.3.1.2 Category 2: Siloed service systems

This category addressed intra-departmental fragmentation associated with the lack of clarity about the role of different stakeholders, poor sharing of information between education, health and social development, and limited decision-making capacity. It described the internal departmental bureaucratic, knowledge and resource barriers that pose challenges for each of the government departments in meeting the needs of children with ASD and their families. These intra-departmental ‘cracks’ were viewed

as a contributing factor to siloed service delivery leading to poor inter-departmental collaboration.

Bureaucratic barriers

Stakeholders expressed frustration with the bureaucratic barriers that influence access to information and service delivery within and between government departments. Participants acknowledged that large government departments with hierarchical structures and protocols in place posed challenges for effective decision-making and action:

“...If you look at [government departments], they’re such big organisations... You need to go through three hundred channels to get a budget. You need to go through three hundred channels to do an intervention. So for me it is a pure bureaucratic structure.” (P5)

Knowledge barriers

Government stakeholders felt that varying degrees of knowledge about the ASD service related challenges in the province contributed to systemic dysfunction. For example health and social development government departments not having access to the Education Department’s ASD waiting list information meant that they were not aware of the extent of the situation. The lack of information about the prevalence of ASD posed challenges for planning and resource allocation:

“...there’s a large unmet need that we don’t actually know about, and if we don’t know about it, we can’t plan for it. So from a resource and planning perspective, that’s actually quite an important challenge for us. It’s important for us to know what’s that burden of disease out there, that we need to be planning for, what’s

the gap from what we have, and from that burden is, and how can we close that gap.” (P6)

Participants felt that not knowing how to categorise and capture a diagnosis of ASD under existing government frameworks has resulted in a lack of a clearly defined focus on service delivery for these children:

“But I think the one part of all of the services being rendered to children in general, that when you do have children with specific special needs, which is not always captured very well within a government perspective. So that, it is as if the main focus would be just children in general, but forgetting, now suddenly when you get an autistic child that needs services, or a child with any other pathology, then what now?...they will say, sorry, we don’t deal with this...” (P5)

Resource barriers

The need for more physical and human resources were highlighted. Participants felt that the lack of ASD services was a direct consequence of limited financial resources available to government departments to provide services for children with ASD:

“There isn’t a lot [money] going around. The country is going through a little bit of a fiscal problem at the moment. So whatever resources we have, we use it, you know, and we want to place all the children. So that’s our long term goal.” (P2)

Participants felt that ASD was an expensive diagnosis to manage and children from poorer families and rural areas were more likely to have poor access to services:

“A child with autism in an impoverished or poor family, is compoundedly marginalised. Because it is an expensive disability, when you are rehabilitating, when you are intervening, you know, in terms of what they need.” (P1)

The lack of human resources in the form of professional and academic leadership to articulate and create knowledge and awareness about the ASD situation was highlighted:

“I think our biggest gap is professional leadership. I think academic leadership, professional leadership, I think university leadership. And when you have a problem like this then you have a serious knowledge problem and a serious advocacy problem, because academics who are researching in the field, should make a case for autism.” (P2)

6.3.1.3 Category 3: Gap-filling strategies

This category describes potential actions to fill the service gaps caused by ‘societal cracks’ and ‘siloes service systems’. Structural strategies, direct intervention strategies and political strategies were identified by government stakeholders as areas to improve services for children with ASD and their families.

Structural strategies

Having structures in place for government departments to work collaboratively at various levels was proposed. Participants highlighted the need for a collective government strategy for addressing the service needs of children with ASD:

“...And I suppose it’s not only something that you can put in front of education’s door. I think that we as government, collectively have to take responsibility for it, because if the child is identified early through the health system, what are we

doing to notify the rest of the departments, in a seamless way, that the child gets picked up and seen.” (P4)

Direct intervention strategies

Despite the numerous challenges that government departments face, participants felt that efforts to impact and improve the lives of the children with ASD and their families should not be disregarded:

“There are all sorts of things, and you know, it becomes overwhelming, and then you’ve got to take a step back and say, well we’re assisting this one child, and that makes an impact on somebody’s life, and somebody’s family, and somebody, you know...” (P1)

In discussing strategies to support children with ASD and their families, some participants felt that there should be intervention for children waiting for education services and others felt that children with ASD should be allowed into the education system from an earlier age. Where services were being offered, participants suggested that government departments should not duplicate services:

“...if we start at three, the way we start with the deaf, there I feel we’re making a dent... it’s amazing to see how they catch up and how they can compare to their counterparts in mainstream...With deaf education, there is no waiting list at all. So if a deaf child comes into the system, he is taken in immediately.’ (P3)

The provision of more infrastructure or repurposing of existing infrastructure to accommodate children with ASD in the education system was proposed. Mainstream inclusion of children with special education needs, including ASD was advocated:

“I still think there is not that buy-in with mainstreaming children...You’ve got the right to education, no matter what kind of child you are, or what kind of issues you have” (P5)

Participants were of the opinion that the service gap could be reduced if more financial resources were available:

“...the only way that we are going to solve the waiting list is more resources. More Rands and Cents and there is less Rands and Cents”. (P2)

Political strategies

Participants felt that finding solutions to the current situation with ASD services would require active participation from higher authorities like national policy makers and political figures:

“I’ve been part of activism for different causes, and it generally always worked...But unless you can involve the decision-makers, unless you’re actually going to get active participation from decision-makers, you’re not going to get very far very quickly.” (P6)

One participant referred to litigation against the South African Government for denying children with severe and profound intellectual disability the Right to Education (Western Cape Forum for Intellectual Disability vs Government of the Republic of South Africa) and stated that there have been positive gains in service delivery in response to the court order:

“I think, as much as we are often complaining, I think the court order brought us to a focus point, where we had to improve services, even though it’s not the

children you are seeing. But it's the children that's more profound and severe, but that's including those with autistic symptoms.” (P4)

Participants felt that a 'Whole-of-Society Approach' could improve collaborative efforts between government departments and break down bureaucratic barriers:

“Whole-of-Society Approach is aimed at trying to reduce bureaucratic obstacles that we tend to find with their collaborative efforts between government departments, and its working well, where we have piloted. We're starting to find people who don't normally talk to each other...people at the operational level, that they wouldn't necessarily normally engage with each other and are able to resolve a whole host of issues.” (P6)

6.3.1.4 Summary of key recommendations from participants for strengthening ASD services

Table 6.2. shows a summary of the ten key strategies for ASD service strengthening in the Western Cape which will be incorporated into the discussion.

Table 6.2: Recommendations for ASD service strengthening in the Western Cape

Gap filling strategies proposed	
1	Formalising collaboration within and between government departments
2	Formulating a collective government strategy for ASD
3	Provision of intervention for children waiting for education services
4	Revisiting the compulsory school going age for children with ASD to begin school at an earlier age
5	Promoting mainstream inclusion of children with ASD
6	Avoid duplication of services between government departments
7	Creating of more infrastructure or repurposing of existing infrastructure to accommodate children with ASD in the education system
8	Making more financial resources available for ASD services
9	Getting active participation from higher authorities like national policy makers and political figures
10	Adopting a 'Whole-of-Society Approach' for ASD to break down bureaucratic barriers

6.4 Discussion

In this study we explored the perspectives of government stakeholders about ASD educational and other related services in the Western Cape Province of South Africa and sought their proposals to improve services. The overarching theme “We are doing damage control” suggested that government departments were not doing what they should be doing for children with ASD and their families. Government stakeholders felt that the challenges in service delivery for children with ASD were part of a greater ‘cracked society’ problem, in which the legacies of apartheid are being addressed through rigid bureaucratic government systems with limited budgets. Poverty, crime and the burden of other diseases outweigh the needs of children with ASD and their families. However, based on the South African government’s ratification of international disability policies, we argue that the State has a legal obligation to provide

services for children with ASD despite competing priorities. The constitutional right to inclusive education for children with ASD is an absolute human right that cannot be neglected.

Poorly developed inclusive education systems are not unique to South Africa (Hodgson, 2018; Bornman and Donohue, 2014; van Reenen and Combrinck, 2011) with Hodgson (2018) asserting that the United Nations Convention on the Rights of Persons with Disabilities (CRPD) was developed in the global context of unsatisfactory systems for inclusion of people with disabilities. The CRPD states that every person with disabilities has the right to equal opportunities, inclusion and full participation in society. South Africa signed the CRPD in 2006 which was ratified in 2007, accepting the obligations of this legally binding instrument. However, van Reenen and Combrinck (2011) argue that progress in incorporation of the principles of the CRPD in African countries, including South Africa has been slow, bordering on neglect. Ngang (2021), in examining the government's apparent disassociation from its constitutional commitments to meeting the socio-economic rights of its people including access to healthcare, social security and education argues that a human rights approach is central to socio-economic transformation in South Africa. The right to education for all children, including those with disabilities like ASD is enshrined in Section 29 of the Constitution of South Africa and government therefore has a legal obligation to provide timely access to education for these children. Ngang (2021) asserted that when government is unable to take necessary measures for socio-economic transformation, as stipulated in the Constitution, the Constitutional Court is obligated to intervene and ensure that the government takes action.

Pillay, Duncan and de Vries (2022) provided a factual reflection of the education system's failure in policy enactment. We reported that, despite having progressive national education policies in place to support the inclusion of children with disabilities in the education system, a large number of children with ASD in the Western Cape Province are either out of school, awaiting school placement or attending over-subscribed special ASD schools (Chapter 2 and 3). Hodgson (2018) described South African inclusive education policies as 'nice theories' developed by academics and activists to correct historic injustices and argues that theories alone are not enough for disability inclusive transformation. Bornman and Donohue (2014) agree that ambiguous policies born out of political reason are often passed down with little accountability for implementation.

Poor policy implementation is not exclusive to the education system. Franz and colleagues (2018) reported that even though the principles of National Integrated Early Childhood Development (ECD) Policy (Department of Social Development, 2015) supported early detection and intervention for children with ASD, there was poor implementation of these policies for children with disabilities in general. Mokitimi *et al.* (2018) found that there was concerning neglect of Child and Adolescent Mental Health (CAMH) policies despite the recognition of the associated burden of CAMH in South Africa.

Government stakeholders in this study attributed the lack of policy enactment evidenced by poor service delivery for children with ASD in part to a lack of knowledge of the extent of the ASD burden and to difficulties with capturing the diagnosis under existing government data frameworks. Franz and colleagues (2018) reported similar

difficulties with categorising the diagnosis finding that children with ASD are included under the Department of Health's data framework for intellectual disability with implication for shared funding and resource allocation. Baxter *et al.* (2015) stated that accurate epidemiological description of ASD is imperative for policy development and planning. Epidemiological studies on ASD are not feasible in low- and middle-income countries like South Africa for various reasons including a lack of culturally and linguistically appropriate assessment tools (de Vries, 2016; Smith *et al.*, 2017; Pillay, Duncan and de Vries, 2021). Despite the lack of formal epidemiological data, we however argue that there is substantial evidence of education systems failure to provide services for children with disabilities in South Africa for the government to act (Ngwena, 2013; Human Rights Watch, 2015; Hodgson, 2018).

One of the challenges in service delivery for children with ASD described in this study was the poor communication and collaboration within and between the different government departments. Orsini and Smith (2010) examined the interaction between social movements, knowledge mobilization and policy for individuals with ASD and argue that the process should not be a 'top-down' approach from government and instead be a collaborative and interactive effort between government and civil society to create knowledge. Lord *et al.* (2022) suggested that coordination between government sectors, including individuals with ASD and their families is essential for meeting the complex needs of these individuals and their families. The recurring theme of government 'silos' in South African studies (Franz *et al.*, 2018; Mokitimi *et al.*, 2018) confirms that government departments need to develop systems for working together. Having structures in place to formalise collaboration at various levels instead of working in silos and duplicating services would be in line with the WHA 67.8 resolution

(WHO, 2014) which recommends that government “*strengthen different levels of infrastructure for comprehensive management of autism spectrum disorders and other developmental disorders*” (WHO, 2014).

Government stakeholders in this study felt that the lack of finance was a significant barrier to providing services for children with ASD. Hodgson (2018) asserted that the lack of financial resources cannot be an excuse for not delivering on human rights obligations and argues that existing funds have been misused by building more special schools instead of promoting the inclusion of children with special learning needs in existing mainstream and full-service schools. The WHA 67.8 resolution recommends that governments facilitate resource mobilization especially in countries with limited resources to address the needs of individuals with ASD (WHO, 2014). According to Mayosi and Benatar (2014) there should be a shift in attitude in government to incorporate a “doing better with less” philosophy in light of the limited available resources and poor prospects of economic growth in the country.

One way of using the limited resources more economically would be to explore various educational settings for children with ASD and not rely almost exclusively on special education placements which are more costly for governments than ordinary mainstream schools (UNICEF, 2018). In 2016, the annual cost of educating a single child in the special education system in South Africa was approximately R57,000 per annum [~US\$3,983.29] which is four times more than the cost of educating a child in mainstream schools (UNICEF, 2018). Advocacy and awareness campaigns to promote ASD inclusion in mainstream schools and ECD centres as well as resource

mobilisation to strengthen these systems to accommodate children with ASD from as early as possible is recommended.

Participants in this study highlighted that the government generally responds to big societal burdens and because ASD only affected a small portion of society, the challenges that individuals with ASD and their families experience often do not receive enough attention from the state. However, participants also drew on the example of consumer led activism where caregivers of children with severe and profound intellectual disability (CSPID) sought litigation against the South African Government through the Western Cape Forum for Intellectual Disability (WCFID) for denying these children the Right to Education (Murungi, 2011). The court case forced government departments to work together to develop a strategy to meet the courts mandate and improve services for children with severe and profound intellectual disabilities (McKenzie *et al.*, 2017). Similarly, developing a strategy to meet the needs of children with ASD and their families would require active participation from authorities like national policy makers and political figures.

South Africa became a signatory to the United Nations 2030 Agenda for Sustainable Development that makes a commitment to 'leave no one behind'. The Western Cape Government's commitment to a 'Whole of Society Approach' has been operationalised by putting health and safety projects in place to improve the lives of all of its citizens (Western Cape Government, 2015). Leigh and Du (2015) predicted that by 2025 the cost of ASD on society will far exceed that of diabetes and ADHD if the numbers of ASD continue to increase as it has in the past. In light of the growing burden of ASD

similar projects for children with ASD and their families are indicated through engagement with government, civil society, private sector and media.

Government stakeholders highlighted numerous systems challenges in delivering appropriate and equitable services for children with ASD. They also provided ten gap filling strategies that, if actioned could go a long way in improving services for children with ASD and their families in the Western Cape as well as other parts of South Africa.

6.5 Limitations to the study

It is acknowledged that senior level government stakeholders from the three main government departments in a local context is by nature a small group of people. While the small sample size in the study may be seen as a limitation, it nevertheless provides a representative perspective of persons concerned with high-level governance of ASD services. Secondly, data were collected from government stakeholders only in the Western Cape and we acknowledge that their perspectives may not be representative of the situation in other South African provinces. However, given that the Western Cape is frequently cited as one of the better resourced provinces for children with ASD in South Africa, it can be assumed that the situation in some of the other provinces in the country could be far worse. Further research would be necessary to evaluate government perspectives on ASD education and clinical services in the rest of the country and other LMIC.

6.6 Relevance to other low- and middle-income countries

Even though this study explored the perspectives of government stakeholders about educational and other services for children with autism in one province of South Africa

only, we propose that our findings may have relevance for and resonance also with other LMIC contexts. Knowledge and research evidence about autism is generally very low in LMIC (Lord et al., 2022; Hahler and Elsabbagh, 2015; Franz et al., 2017) and government departments and policy makers in most LMIC do not prioritise ASD research and service delivery (Hahler and Elsabbagh, 2015). Therefore, insufficient national funds are allocated to meet the needs of children and adolescents with neurodevelopmental disabilities such as ASD in LMIC (World Health Organization, 2018). The lack of trained mental health professionals, leading to gaps in identification and support for those with autism, is another theme from our work that is very similar to the majority of other LMIC, as are the disparities in service delivery between urban and rural communities (Divan et al., 2021; Lord et al., 2022). For these reasons, we believe that many of the 'gap filling strategies' recommended by participants in this study may be of value also to other LMIC.

6.7 Conclusion

Qualitative insights into the 'software' elements of government values, norms and relationships that inform ASD service delivery in the Western Cape contributed towards a 'whole-system' understanding. Despite having progressive inclusive education policies in place, many children with ASD are out of schools. The education system's failure in policy enactment for children with ASD is concerning. Fast-tracking policy translation into practice so that all children with disabilities can be accommodated in the education system as early as possible should be a priority of government. Mobilising resources and using existing resources more optimally to create educational opportunities for children with ASD is proposed. Collaboration between government departments and other relevant stakeholder groups to develop

a collective strategy for ASD in line with the WHA67.8, '*Comprehensive and coordinated efforts for management of autism spectrum disorder*' is recommended.

6.8 Chapter summary

Autism spectrum disorder (ASD) is a growing public health concern in low- and middle-income countries (LMIC) that has prompted a World Health Organization (WHO) resolution on '*comprehensive and coordinated efforts for management of autism spectrum disorder*'. Despite being a signatory of the resolution, South Africa does not have any national policies to guide the management of ASD services. This study explored the perspectives of key government stakeholders on educational and other services for children with ASD in the Western Cape Province of South Africa and their proposed solutions to meet the needs of these children and their families. The overarching theme that emerged was "*We are doing damage control*". Government stakeholders acknowledged that ASD services were falling between the 'cracks' caused by competing societal demands on government resources. Participants shared perspectives about ASD services in three categories: *a cracked society*, *siloed service systems*, and *gap-filling strategies*. Findings from this study highlighted the need for collaborative efforts between government departments and civil society to develop a strategy for ASD in line with the WHO resolution. Multi-stakeholder engagement to break down barriers, strengthen systems and develop innovative solutions to improving services for children with ASD and their families is recommended. In the next chapter we summarise and synthesise the findings of the thesis and provide recommendations for improving services for children with ASD and their families.

CHAPTER 7: TOWARDS INTEGRATED SERVICE DELIVERY FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN THE WESTERN CAPE: SYNTHESIS OF FINDINGS, RECOMMENDATIONS AND FUTURE DIRECTIONS

7.1 Introduction

The *Lancet* Commission on the future of care and clinical research in autism (Lord *et al.*, 2022) recognised the degree to which ASD impacts individuals, families and society and called for urgent action to improve their lives. The majority of individuals with ASD live in low- and middle-income countries and do not have access to health, education and social services (Lord *et al.*, 2022). The Commission recommended that government departments and other stakeholders should address the service-related needs of persons with ASD over the next five years by a) documenting individuals with ASD through government (health, education and social) systems to determine their needs, b) adopting a personalised, stepped care model for assessment and intervention, c) providing intervention for young children with ASD and co-occurring conditions as soon as there are concerns even before a formal diagnosis is made, d) developing personalised and contextually appropriate intervention for individuals with ASD across the lifespan, e) monitoring and ensuring equitable access to services, and f) prioritising and supporting research that builds an evidence-base of interventions for ASD (Lord *et al.*, 2022).

The purpose of the study was to contribute empirical information that would substantiate the need for the development of integrated services for children with ASD and their families in the Western Cape Province of South Africa. In this final chapter the findings across all previous chapters in the thesis are summarised before

synthesising and providing a set of key recommendations informed by the evidence generated in this thesis to improve services for children with ASD and their families.

To address the overarching research question ‘What can be done to improve services for children with ASD and their families in the Western Cape?’ we conducted an examination of some of the ‘hardware’ (quantitative evidence, infrastructure, and resources) and ‘software’ (ideas and interests, relationships and power, values and norms) elements of education systems to understand the current landscape of education for children with ASD and to generate recommendations for future ASD educational services.

Examination of ‘hardware’ elements involved analysis of the WCED CEMIS database information on children with ASD already in the education system (Chapter 2) and analysis of the WCED waiting list for children with ASD waiting for educational services (Chapter 3). Chapter 2 reported on the rates, socio-demographic, disability and education profile of children with ASD in schools across the Western Cape and found very low rates of children known to have ASD in the education system and poor reporting of co-occurring physical and mental health conditions. The majority of children with ASD in schools attended special schools in urban areas and there was a discrepancy between self-reported home language and race and ethnicity compared to the population demographics of the Western Cape. Analysis of the CEMIS data on children with ASD highlighted several gaps in services including poor systems for identification and reporting of children with ASD and poor accommodation of their diverse learning needs. Chapter 3 continued with the examination of the ‘hardware’ elements and reported on the rates, socio-demographics, disability and referral profile of children with ASD waiting for school placement in the Western Cape. We found 744

children with ASD or suspected ASD who were waiting for special school placement. Thirty six percent (36%) were of compulsory school-going age and 64% were of pre-school age. More than half of children had been waiting for services for more than a year and 48% were at home at the time and receiving no intervention while they waited for services. Chapter 3 highlighted the urgent need to create educational opportunities for children with ASD from as early an age as possible rather than to wait till the 'official' or legal school-going age. Combined findings of children with ASD in school and of those waiting for schools found a very low rate of children known to have ASD in the province (0.1% versus international estimates of 1-2%). The work presented in chapters 2 and 3 represents the most comprehensive data analysis of children with ASD in an education system in South Africa to date and showed a rapidly growing need for educational and other services for children with ASD. Data also highlighted the misalignment between demographic population profiles and the actual services provided, disproportionate services in special educational environments, and lack of services to pre-schoolers.

Next, the 'software' analysis of the education system involved examination of stakeholder perspectives of current ASD services and their recommendations for service improvements. Focus groups were conducted with caregivers of children with ASD waiting for educational services (Chapter 4). Caregivers expressed high levels of dissatisfaction and frustration with existing services for children with ASD in the province and provided eight key recommendations for service improvements. These included better communication and a more empathetic approach from service providers, and the provision of support for caregivers of children with ASD waiting for services. Caregivers felt that the government should take more responsibility for ASD services and learn from international good practice examples. Chapter 5 examined

service provider perspectives of current educational services. Service providers felt that they were 'doing the best they could' in light of the limited resources that they had. Service providers recommended that children with ASD should receive support in their homes and communities while they wait for educational placements to become available. They also suggested that there should be more efforts to develop and implement a truly inclusive education system so that the majority of children with ASD may not require special school placements. Chapter 6 investigated the perspectives of key government stakeholders from the Departments of Education, Health and Social Development. Government stakeholders acknowledged that ASD services were not given enough attention due to other competing demands on government resources, and provided ten recommendations that could potentially improve services for children with ASD and their families. Government stakeholders recommended that there should be better collaboration between the different government departments in order to make resources available and develop a sustainable strategy for ASD service delivery.

7.2 Synthesis of recommendations from the thesis and six actions for ASD service improvement

In order to provide a synthesis of recommendations from the thesis, findings from all chapters were combined and integrated into key actions that may lead to service improvements and system strengthening for children with ASD in the Western Cape. Table 7.1. shows the recommendations from findings in chapters 2 and 3, and recommendations provided by stakeholder groups in chapters 4, 5 and 6. We suggest that findings point to six key implementable actions. Below we will outline the six actions and discuss how they relate to recommendations from the *Lancet* Commission Report on the future of care and clinical research in autism (Lord *et al.*, 2022).

Table 7.1: Summary of recommendations from the thesis, and six actions for ASD service improvements

CHAPTER 2 Recommendations based on findings from CEMIS analysis	CHAPTER 3 Recommendations based on findings from waiting list analysis	CHAPTER 4 Recommendations from caregivers	CHAPTER 5 Recommendations from service providers	CHAPTER 6 Recommendations from government stakeholders	Actions for ASD service improvements
Provide early intervention services for children with ASD	Develop policy for early intervention and support	Provide support for families of children waiting for educational services	Provide early intervention for children younger than compulsory school going age	Provide intervention and support for children waiting for services	ACTION 1 <i>The earlier the better:</i> Design and implement dedicated early intervention programmes using a dedicated team that includes caregivers
Accommodate children with ASD in school from a younger age	Create opportunities for caregiver/non-specialist interventions		Support children and families in homes and communities long before formal education	Revisit compulsory school-going age so children with ASD can begin school earlier	
Ensure home language medium of instruction for children with ASD	Enable home language medium of instruction		Rethink curricula to focus on a range of meaningful skills		ACTION 2 <i>The more informed the better:</i> Place an emphasis on ASD in curricula for service providers (teachers, health professionals community health workers) and local government policy makers/service system planners
Implement profiling of children with ASD in the education system for understanding of their diverse needs	Accommodate a range of diverse learning needs across the education system				
Enable inclusion in the broader education system	Ensure children of compulsory school going age are in schools	Address ASD awareness to promote better inclusion of	Rethink inclusive education so that the majority of children with ASD may not require	Make more infrastructure available or repurpose existing infrastructure to	ACTION 3 <i>The more included the better:</i>

		children with ASD in mainstream schools	special school placements	accommodate children with ASD in education	Fast-track implementation of the Education White Paper 6 on building an inclusive education and training system
			Balance the need for special education and increase access to mainstream education		
	Provide a range of educational opportunities	Provide more infrastructure to accommodate children with ASD in education	Change stigma about ASD in mainstream education	Make financial resources available to accommodate children with ASD in education	
			Train mainstream educators to enhance knowledge and skills for working with ASD		
Create identification and intervention services in rural areas	Promote equitable access to education for rural children				ACTION 4 <i>The less spatial dispersion the better:</i> Create and resource a dedicated rural inclusive ASD plan
	Promote transversal, interdepartmental collaboration to remove health and social related barriers for children with co-occurring conditions	Hold government departments accountable for providing services for children with ASD		Create structures for collaboration between government departments	ACTION 5 <i>The more integrated the better:</i> Develop trans-sectoral service planning, monitoring and evaluation systems for ASD
	Develop standardized pathway from diagnosis to care that			Formulate a collective government strategy for ASD	
				Avoid duplication of services	

	clearly define roles and responsibilities of government departments			Adopt a 'Whole-of-Society Approach'	
Develop policies to govern early educational services for children with ASD	Implement policy action to improve identification and access to appropriate early education for all children with ASD	Learn from international examples of good practice	Include users/carers/individuals with ASD in policymaking, curriculum development and skills training programmes for children with ASD	Ensure active participation from policymakers	<p>ACTION 6</p> <p><i>The more specific the better:</i></p> <p>Participatory development of integrated policies for ASD and related neurodevelopmental disabilities that include international best practices</p>
		Support research to quantify the problem and inform planning	Avoid knee-jerk responses to services, develop long term, integrated policies, plans and actions		
			Learn from international best practice examples to develop contextually appropriate solutions for SA		

7.2.1 Action 1: The earlier the better

Findings across the study highlighted the urgent need for designated early intervention programmes for children with ASD and in so doing, aligns with the Lancet Commission recommendation that children with ASD should have access to intervention as soon as there are possible signs of ASD (Lord *et al.*, 2022). The Commission states that “no one should wait for months or years to start treatment because they are unable to find an appropriate assessment” (Lord *et al.*, 2022, p. 272). Early behavioural and educational intervention during the critical period of development could have long lasting positive outcomes for individuals with ASD including increased language, social and intellectual development (Estes *et al.*, 2015; Vivanti and Dissanayake, 2016; Dawson, 2008) which could potentially lead to less reliance on the special education system and better prospects for employment and participation in society (Cidav *et al.*, 2017; Estes *et al.*, 2015; Munir *et al.*, 2016). Ideally, as a cost saving strategy, evidence-based early behavioural and educational intervention programmes should be incorporated into education systems with existing infrastructure and resources. For that to happen, the policy on compulsory school-going age for children with ASD and other neurodevelopmental disabilities in South Africa would have to be reviewed and refined. There are no policies specific to ASD education in South Africa, but there are National Early Childhood Development (ECD) Policies (Department of Social Development, 2015; Franz *et al.*, 2018). The National Integrated Early Childhood Development Policy (Department of Social Development, 2015, pp. 21,27) states that all children with disabilities have the right to quality inclusive ECD services and that government is obligated to provide these services. ECD policy implementation for children with ASD is poor as evidenced by finding in Chapter 3 that showed 53% of ECD aged children with ASD to be at home and receiving no

intervention. Until ECD and education policy implementation can be operationalised, immediate, interim actions will need to be taken to promote delivery of essential early intervention services to children with ASD in their homes and communities long before they are of compulsory school-going age.

Munir *et al.* (2016) recommended that high-intensity evidence-based interventions typical used in high-income countries such as the USA, United Kingdom and some European countries should be adapted to be more affordable in low resource settings. The stepped care model advocated in the *Lancet* Commission (Lord *et al.*, 2022) involves task-sharing where less expensive and more accessible services are provided by non-specialists and supervised by trained professionals. Such interventions could be provided in community settings, at home, in ECD centres or in school environments where pre-school facilities are available. Applying the WHO (2007) principles of task-shifting and task-sharing, community-based caregiver skills training could be provided in partnership with non-profit organisations to caregivers who are concerned about the development of their children, even before any diagnostic work-up has been done. The WHO Caregiver Skills Training Programme (CST) has been adapted for implementation in a South African low-resource context as an academic-NPO-government partnership between the Centre for Autism Research in Africa at the University of Cape Town, Autism South Africa, and the National Department of Social Development, and is currently in a scaling-up phase in two South African provinces (Free State and Limpopo). The project has shown promise in delivering culturally and contextually appropriate intervention that is affordable, sustainable and scalable (Schlebusch *et al.*, 2020; Schlebusch *et al.*, 2022). Home-based early interventions for children with ASD (and other

neurodevelopmental disorders) could be delivered by appropriately trained community rehabilitation workers (CRWs) supervised by the relevant health professionals in the specialist primary level district health teams (United Nations, 2016; Hoeft *et al.*, 2018). Such studies are underway in South Africa. The Autism Navigator® for Primary Care is an online training programme that helps caregivers and professionals recognise early signs of developmental delays. In a feasibility study, Chambers and colleagues (2018) found that the programme was appropriate for training professional such as CRWs in South Africa to recognise the early signs of ASD. In ECD or pre-school educational settings, ECD workers or teaching assistants could be trained to coach caregivers to deliver ASD evidence-informed interventions, such as the Early Start Denver Model (ESDM), currently under investigation as a cascaded task-sharing intervention as collaborative project between the Centre for Autism Research in Africa at the University of Cape Town and the Western Cape Education Department (Franz *et al.*, 2022; Makombe *et al.*, 2019).

There is a growing body of research in South Africa and internationally that shows that caregiver and non-specialist mediated early intervention programmes may be a way to bridge the service gap in low- and middle-income countries (Chambers *et al.*, 2018; Divan *et al.*, 2015; de Vries, 2016; Franz *et al.*, 2022; Guler *et al.*, 2018; Makombe *et al.*, 2019; Schlebusch *et al.*, 2020). Therefore, cost-effective training of caregivers and non-specialist service providers such as community rehabilitation workers in home-based habilitative interventions for children with ASD waiting for educational services could go a long way to meeting the needs of these children and their families. Human resource planning for community-orientated primary care within the district health system (Mash *et al.*, 2020) should ideally include community health workers who have

disability inclusion and community-based habilitation and rehabilitation competences (Ned *et al.*, 2020). ASD training should include Early Childhood Development (ECD) teachers so that children with ASD can attend and benefit from ECD centres in their communities.

7.2.2 Action 2: The more informed the better

This action proposes the development of a variety of curricula on ASD interventions that are pertinent to the role and scope of practice of various stakeholders such as caregivers, teachers, community health and rehabilitation workers, health professionals, disability inclusive policy makers, and health and education system planners. In the Western Cape knowledge and expertise in ASD education is currently concentrated in a few ASD special schools, placing increasing demands on these schools and members of ASD specialist outreach teams to educate and/or monitor the development of the majority of children with ASD. Training a broader range of staff on the heterogeneity of ASD could lead to less demand for special education placements and better inclusion of children with ASD in a range of educational settings. Likewise, carers and persons with ASD have a wealth of 'lived expertise' that could inform the development of nuanced curriculum content. ASD experts could partner with specialists in curriculum development to design content for a range of educational offerings such as short courses, a higher certificate, an undergraduate module and a postgraduate diploma for specialisation in ASD. Given the competing demands for curriculum prioritisation by other similarly urgent health conditions and disorders, the uptake of ASD curricula by training institutions (colleges, universities, government human resource in-service training units, etc.) and various qualification programmes

will require rights-based advocacy for the inclusion of disability in graduate exit competences (United Nations, 2018).

Apart from the development of ASD curricula for service providers and policy makers, there is also a need for curriculum flexibility to accommodate the diverse learning needs of individuals with ASD. The development of a flexible curriculum for learners with ASD will require better profiling of children with ASD in the education system in order to better understand and meet their diverse and constantly changing learning needs. Regular profiling and the availability of flexible and inclusive educational opportunities aligned with the principles of universal design (McKenzie and Dalton, 2020) should facilitate the movement of some children with ASD out of the special schools and into full-service/inclusive and mainstream schools. The SIAS policy advocates for curriculum differentiation in teaching and assessment that considers learners interest and abilities (Department of Basic Education, 2014). Alignment with the SIAS policy means that the curriculum in full-service and mainstream schools must develop a range of adaptive skills to promote independence in all children including those with special learning needs instead of focusing primarily on traditional academic skills of reading, writing and arithmetic. Similarly, the curriculum content and modes of delivery must be available in the home language of the learner with ASD. Studies have shown that when children with ASD are educated in their home language, there is better comprehension and less challenging behaviours (Lang *et al.*, 2011; Lim and Charlop, 2018).

7.2.3 Action 3: The more included the better

The third action supported by recommendations across the study suggested fast-tracking policy implementation to support the inclusion of children with ASD in appropriate educational settings. According to the *Lancet* Commission (Lord *et al.*, 2022) children with ASD in most high-income countries cannot be denied access to education while children with ASD in LMIC face significant barriers to education. The commission states that “*the mandate to include children with autism in schools should be a primary public policy focus*” (Lord *et al.*, 2022, p 35). It has been more than two decades since the Education White Paper 6 was published, yet progress in establishing an inclusive education and training system has been slow (Bornman and Donohue, 2014; Hodgson, 2018; van Reenen and Combrinck, 2011). Many children with disabilities including ASD are out of school in South Africa in contravention of their right to education (Department of Basic Education, 2015; Pillay, Duncan and de Vries., 2022). Findings from this thesis highlighted the need for better inclusion of children with ASD in the broader education system and less reliance on the special education system to meet the educational needs of the majority of children with ASD. For this to happen, education systems would have to be broadened by fast-tracking the implementation of the Education White Paper 6 as it pertains specifically to children with ASD and other neurodevelopmental disorders. The more attention that is placed on disability rights-based policy implementation, the better the educational and human development outcomes will be for children with ASD and their caregivers. (Bullock *et al.*, 2021). Mendoza and Heymann (2022) performed a systematic review of inclusive education interventions in low- and middle-income countries and identified teacher training, medium of instruction, curriculum flexibility, improving educational facilities, providing teaching materials and community partnership as interventions that could

support inclusion. ASD awareness campaigns for schools and communities could facilitate better inclusion of individuals with ASD in society.

7.2.4 Action 4: The less spatial dispersion the better

The *Lancet* Commission (Lord *et al.*, 2022) stated that governments should monitor and provide equitable access to services for marginalised or underserved groups. The ‘hardware’ analysis in Chapters 2 and 3 found a disproportionate representation of children with ASD in rural areas compared to the population dynamics of urban areas in the province, highlighting the need for better systems of identification and intervention for these children. Children with special educational needs in rural areas face exclusion due to limited infrastructure and human resources (Engelbrecht, 2020; Engelbrecht and Muthukrishna, 2018). Therefore, there is a need for the creation of a dedicated ASD inclusive plan that ensures equitable access to education for all children, including rural children. Educational outreach teams, especially occupational therapists and speech language therapists linked to ward-based (municipal subdivisions) primary school health outreach teams operating as part of the national district health plan towards the future National Health Insurance (Schneider *et al.*, 2018) could play an important role in delivering training and supporting the inclusion of children with ASD in existing rural schools. More research into ASD in rural areas is necessary to inform resource provisions and service delivery.

7.2.5 Action 5: The more integrated the better

This action recommends trans-sectoral service planning, monitoring and evaluation systems for ASD. Adopting a ‘whole-of-society’ approach specific to ASD through ongoing multistakeholder engagement is advocated. A “whole-of-society” approach

calls for partnership between government, private sector, academia and civil society to achieve the 2030 agenda for sustainable development (Kindornay and Kocaata, 2019). The Sustainable Development Goal 4 (“*ensure inclusive and equitable quality education and to promote lifelong learning opportunities for all*” (United Nations, n.d., p. 21) is necessary for transformation in society. The provision of equitable educational infrastructure continues to be a challenge for the South African government and the National Development Plan has outlined targets for addressing this challenge (Statistics South Africa, 2019). Multi-stakeholder partnership could generate innovative solutions to these challenges.

The *Lancet* Commission report notes that integration across systems is necessary to support individuals with ASD and their families across the different stages of development (Lord *et al.*, 2022, p 272). Chapter 2 and 3 of the thesis showed that the pathway to services and care for children with ASD in the Western Cape was a complicated and lengthy process and that caregivers often had to navigate between health, education and social development systems to secure services for their children with ASD. A standardized intersectoral ASD service pathway with corresponding algorithms and protocols from concern to diagnosis to care that clearly defines the roles and responsibilities of each government department is urgently required. Formalising collaboration between government departments and other stakeholders could help break down bureaucratic barriers and siloed government systems towards a collective strategy for ASD in South Africa. This initiative would have be included on the agenda of provincial inter-governmental forums. The Department of Provincial and Local Government guidelines on intergovernmental relations states that the different government spheres must work together by “*assisting and supporting one another*;

consulting one another on matters of common interest; co-ordinating their actions and legislation with one another and adhering to agreed procedures” (The Department of Provincial and Local Government, n.d., p.5). The document further states: *“Thus far, we are excited with the emerging realisation that national, provincial or local goals, especially in respect of improving the lives of our people, cannot be achieved by any one sphere acting alone, but by all spheres acting in unison. Accordingly, we must collectively strive to ensure that intergovernmental processes are geared towards policy implementation for the betterment of the lives of our people.”* (The Department of Provincial and Local Government, n.d., p. 2). The implementation of Action 2 in terms of raising the knowledge of local government policy makers and service planners about disability inclusive development and ASD in will provide substance to this statement.

There is a need for better collaboration between the Departments of Health and Education to remove health-related barriers for children with co-occurring conditions to improve access and retention of these children in the education system. According to the SIAS policy, the Department of Education should be working with the Department of Health to reduce health-related barriers and to facilitate access to and participation education for children with special educational needs (Department of Basic Education, 2014). Likewise, as per Action 2, collaboration between the Department of Education and Social Development is necessary to capacitate and strengthen ECD services to support the inclusion of children with ASD in these centres. Children with ASD could potentially benefit from the developmental programmes offered at these centres to develop school readiness skills that could

facilitate better transition into the education system when they are compulsory school going age.

7.2.6 Action 6: *The more specific the better*

South Africa already has comprehensive inclusive education policies in place, yet implementation into practice since the fall of apartheid has been contentious and dismally slow. Bornman and Donohue (2014) argued that the lack of clarity and guidelines for implementation is the main reason for poor policy implementation. Specific, applicable factors from extant policies have not yet been extrapolated for specific application to ASD education neither has international best practice examples been reviewed to enrich the specificity and contextual relevance of ASD services. Action 6 is supported by the *Lancet* Commission that states that “*the mandate to include children with autism in schools should be a primary public policy focus*” (Lord *et al.*, 2022, p. 305). There is a need for participatory development of integrated policies for ASD and related neurodevelopmental disabilities in South Africa to avoid temporary solutions to the problem. This process should draw on and include international best practice examples.

Implementation science could be a way of bridging the gap between education policies and practice. Implementation science provides a scientific way of translating evidence-based knowledge into real world practice (Villalobos Dintrans *et al.*, 2019). There are various implementation science frameworks that measure success and identify gaps in implementation (Villalobos Dintrans *et al.*, 2019). Fixsen *et al.* (2015, p. 1) state that “*policy, practice, and science related to implementation can be advanced more rapidly with practical ways to assess implementation*”. One such process is the use of implementation drivers that facilitate effective implementation through changes in

attitudes, behaviours and knowledge at individual and systems levels (Fixsen *et al.*, 2015). Further details will be provided about implementation drivers in the next section.

7.3 Potential implementation drivers for recommended actions

The implementation of the six actions recommended in the previous section hinges on the collective determination of interested parties. While it is beyond the scope of this thesis to describe the application of implementation science to the development of integrated service delivery needs of children with ASD, we outline three implementation drivers that could potentially lead to improved ASD service delivery outcomes. Implementation drivers are defined as *“key components of capacity and the functional infrastructure supports that enable a program’s success”* (Fixsen *et al.*, 2015, p.3). Implementation drivers include competency drivers, organizational drivers and leadership drivers (Fixsen *et al.*, 2015). Figure 7.1, adapted from Fixsen *et al.* (2015), shows how the six actions could be linked to three implementation drivers.

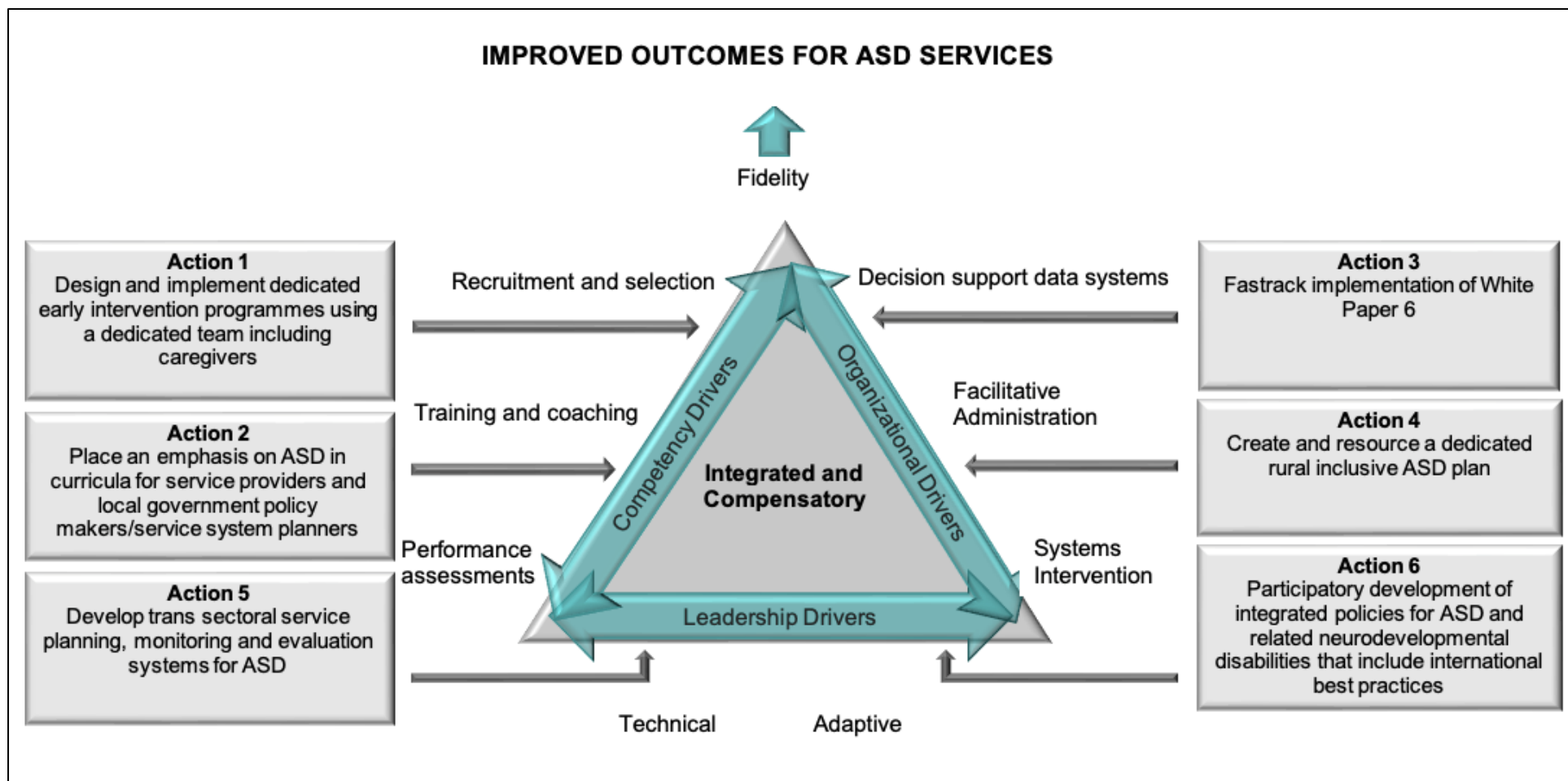


Figure 7.1: Implementation drivers for improved ASD services (Adapted from Fixsen *et al.*, 2015, p. 2).

7.3.1 Competency drivers

Competency drivers include the recruitment and selection of staff, training and coaching and performance assessment (Fixsen *et al.*, 2015). In supporting the implementation of Actions 1 and 2, the competency drivers point to the importance of collective deliberations about the inclusion of ASD in curricula by curriculum planners and programme convenors at institutions of tertiary education. For example, in low resource settings, a task-sharing approach may be used where intervention is delivered by skilled non-specialist practitioners (Divan *et al.*, 2021; Lord *et al.*, 2022). Cognisance of competency drivers suggests that the exit competences of graduates who will work in ASD services must include the ability to task-share and task-shift. Competency drivers can likewise be used for recruitment and selection of non-specialist practitioners such as community rehabilitation workers or classroom support facilitators, training them in evidence-based practices, coaching them to fidelity in implementation of good ASD practices, assessing their performance and getting feedback about the process from them. Similarly, for inclusion of children with ASD in the broader education system to be successful, the right educators need to be recruited and selected. Educating children with ASD requires highly qualified educators with knowledge of evidence-based practices (Simpson *et al.*, 2011). Therefore, skilled educators with the willingness to work with children with ASD and other neurodevelopmental conditions need to be recruited, selected and capacitated in accordance with competency drivers. Induction and training for new educators and continuous training for existing educators on the latest developments in ASD evidence based educational practices is necessary. Assigning skilled coaches to mentor and support educators and to practice and establish skills is essential. Coaches could include inclusive education and outreach teams and special needs educators with

knowledge and experience of working with children with ASD. Educator performance assessments should be conducted to assess the effectiveness of training and coaching in developing ASD skills and competency in order to reach fidelity.

7.3.2 Organizational drivers

Organizational drivers include decision support data systems, facilitative administrative supports and systems intervention (Fixsen *et al.*, 2015). Implementing Actions 3 and 4 from an implementation science perspective will require the collective deliberations of ASD-informed governmental policy makers and systems planners. As drivers of organizational fidelity through systems interventions, these stakeholders need access to data that support their decisions for the development of integrated ASD services. Chapters 2 and 3 highlighted the need for better systems for identification and reporting of children with ASD both in and out of the education system. The disproportionate representation of children with ASD in rural areas also points to the need for system identification and reporting to inform rural service delivery. Data are necessary for planning, implementation and monitoring of interventions (Fixsen *et al.*, 2015). One of the key recommendations of the thesis was that critical factors from existing policies need to be extrapolated for application to ASD education. Facilitative administrators could support the alignment between policies and practice by making use of available resources to support effective implementation (Fixsen *et al.*, 2015). Systems intervention involves collaboration between organisations and external systems to ensure the availability of financial and human resources (Fixsen *et al.*, 2015). Collaboration between education systems, private sector organisations and civil society could be a way of generating resources for the implementation of ASD services.

7.3.3 Leadership drivers

Implementing Actions 5 and 6 will require technical and adaptive forms of leadership (Fixsen *et al.*, 2015). Adaptive leadership at the beginning of implementation is important for facilitating change and technical leadership is required for sustaining implementation over time (Fixsen *et al.*, 2015). The ASD agenda needs visible, politically astute and vociferous public champions, albeit individuals with ASD or an influential advocacy collective such as Section 27 Catalyst for Social Justice (Section 27, 2022). Fixsen and colleagues also assert that leadership can involve more than one person. Effective technical leadership for ASD policy refinement may emerge from Action 2 initiatives with relevant role players in the Department of Provincial and Local Government. Such leadership would support the development of trans-sectoral service planning, monitoring and evaluation systems for ASD education as well as fast track implementation of education policies for equitable access to appropriate education for children with ASD.

7.4 Limitations of the study

Over and above the specific limitations indicated in chapters 2-6 we acknowledge a few overarching limitations of the thesis. Firstly, the thesis did not include the voices of individuals with ASD about their experiences of mainstream and special education systems in the Western Cape. Given that there were no perspectives of ASD services at the time we decided to start with caregivers, service providers and senior government stakeholders. We recognise that including the perspectives of individuals with ASD would have enriched the data, however this would have presented significant ethical and practical challenges in the context of a time-limited project such as this one. Including the voices of individuals with ASD is an important next step for future research. Secondly, rural voices were under-represented in the thesis. We set out to

include urban and rural representation of providers and carers in rural districts. We were able to include service providers who worked both in urban and rural areas, and they were able to provide some insight into rural service provisions. However, due to logistical challenges, we were not able to recruit service providers who worked only in rural areas or caregivers from rural communities. We acknowledge this as a weakness and future research that explores the perspectives of rural caregivers of children with ASD and of rural service providers is therefore a clear area for future research. Thirdly, this research focused primarily on public sector services for children with ASD and limited data on private sector services for children with ASD is presented in the thesis. However, given that only 19% of children with ASD have access to private sector education we felt that it would be appropriate to focus exclusively on public sector education in the context of this PhD thesis. It would be interesting to explore the perspective of individuals with ASD and their caregivers of private sector education. Finally, we acknowledge that data for this research was collected between 2016 and 2018 and there may have been positive developments in education systems for children with ASD since then. However, the demand for special educational placements for children with ASD in the province remains high as evidenced by the growing ASD waiting list.

7.5 Future directions for research

Findings from the thesis raised many potential directions for future research. Here we will briefly outline five areas that could help to strengthen services and systems for ASD in our context.

7.5.1 Large-scale prevalence studies of ASD in South Africa

Quantitative data analysis in chapters 2 and 3 found lower rates of children with ASD in the province than expected. This points to poor systems for identification and reporting of children with ASD in the education systems. Large scale prevalence studies could be helpful in identifying the true rates of ASD in the country in order to inform service needs and resource allocation. Prevalence studies would require appropriately validated screening and diagnostic tools that are acceptable and accessible, as well as culturally and linguistically appropriate to the diverse South African population. Unfortunately, there are currently no such tools available in South Africa or any African country to our knowledge, thus significantly limiting the possibility of formal prevalence studies in our context.

7.5.2 Development and validation of linguistically and culturally accepted screening and diagnostic tools for ASD

Given the absence of any standardised screening and diagnostic tools for ASD in South Africa, we recommend research on the development and validation of such tools for low-resource, contexts. As suggested by various commentators, the current 'gold standard' diagnostic tools such as the ADOS-2 and ADI-R are very expensive, require highly-skilled and trained professionals to administer, and these tools have virtually never been validated in most LMIC. The majority of children with ASD in LMIC such as in South Africa are identified in community and primary care settings and are not diagnosed by highly-qualified specialists. A set of tools that could be accessible to less specialised and community-based practitioners may be a very valuable contribution both to the ASD research community and to local clinical services in low-resource communities.

7.5.3 Creative use of 'real-world' data for ASD research

The Western Cape Education Department is the government department with the most comprehensive data on children with ASD in the province at present. Future research should aim to improve the robustness of educational data and aim to ensure that this becomes a national strategy. This could provide an immediate dataset of 'messy' real-world data that could be utilized to get a broad brushstroke sense of needs and to monitor services and systems within the Education Department. Similarly, systems to collect ASD data in other government departments, e.g. through the Department of Health during routine developmental screenings or through the Department of Social Development ECD programmes or disability grant support systems could be developed. This could contribute to the development of a centralised government database for ASD.

7.5.4 Use of technology to reach and support children and families waiting for services

This thesis highlighted the gap in services for children waiting for educational placement. Caregivers expressed the need for more information while waiting. Research that explores the development and use of technology to provide information and support to caregivers of children waiting for services is recommended. Mobile applications could provide local and relevant information on ASD services, intervention strategies and interactive support for caregivers. Further research could inform what these mobile applications should look like and how acceptable and feasible they are in the South African context.

7.5.5 Research on implementation of evidence-informed early intervention programmes that use task-sharing

Research that informs the development and validation of evidence-informed early intervention programmes that uses principles of task-sharing was recommended in the Lancet Commission (Lord *et al.*, 2022). Such studies are underway in South Africa. Franz and colleagues adapted the Community-ESDM (C-ESDM) which is an open access web-based intervention and trained non-specialist ECD teachers to deliver the early intervention to families of children waiting for school placement (Franz *et al.*, 2022). Fidelity studies on the intervention are ongoing (Franz *et al.*, 2022). Schlebusch and colleagues adapted the WHO Caregiver Skills Training Programme (CST) for implementation in a South African low-resource context and the project is currently in the scaling up phase (Schlebusch *et al.*, 2020; Schlebusch *et al.*, 2022). Research that continues to build an evidence base for early interventions that use principles of task-sharing in South Africa is recommended.

7.5.6 Integrated policy research and implementation on ASD in South Africa

There are no policies specific to the identification, monitoring and care of children with ASD in South Africa. A systematic review of international best practices for ASD could serve to inform the development of contextually relevant policies and guidelines for ASD in South Africa. In addition to international examples there is also local knowledge of what should be done as highlighted by the recommendations from the caregivers, service providers and senior government stakeholders in this study. Bringing together the different stakeholder groups could help explore the implementation of recommendations in meaningful ways. A theory of change framework that identifies priority long term goals and works backwards to identify medium- and short-term outcomes for implementation is recommended. This could support informed decision

making about strategies and actions as well as evaluate the progress of implementation (Breuer *et al.*, 2015).

7.6 Personal reflections and conclusion

I trained as an occupational therapist and have worked with children with ASD in the special education sector for more than 20 years. This was one of the main inspirations for this thesis. As a founding member of the Western Cape Provincial ASD Outreach team, I became increasingly concerned about the systemic problem being signalled by the extensive waiting list and increased demand for educational services for children with ASD in the province. I met with the Director of Inclusive and Specialised Education Support to explore the possibility of making these concerns a research agenda for my PhD. Having gained the support of the Director, I called a consultation group meeting with representatives from the Western Cape Department of Education, Department of Health, Department of Social development and private ASD practitioners. The purpose of the meeting was to generate questions, concerns and possible solutions to the waiting list problem. The key concerns that emerged from both meetings was a lack of information about the prevalence of ASD in the Western Cape and the significance of creating a profile of this population in order to understand their needs better. The importance of inter-sectoral collaboration to effectively meet the needs of children with ASD was also raised.

I acknowledge my 'positionality' in terms of my direct experience in the Western Cape ASD system and accept that this would have influenced by approach to this thesis in conscious and unconscious ways. However, throughout the process of data collection and analysis I consciously aimed to remain objective and am grateful to have had two supervisors who were able to help me remain conscious of potential biases. I do

however believe that my knowledge and experience in this sector allowed me to understand the complexities and provide a more nuanced account of the situation. I believe that this work is the most comprehensive summary of ASD in an education system in Sub-Saharan Africa to date and I sincerely hope that the findings of this thesis will be of value in providing data informed recommendations for service improvements in South Africa and other low- and middle-income countries.

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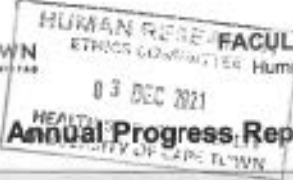
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APPENDICES

Appendix A: Human Research Ethics (HREC) Approval 2016

	<p>UNIVERSITY OF CAPE TOWN Faculty of Health Sciences Human Research Ethics Committee</p>	
		<p>Room E53-24 Old Main Building Groote Schuur Hospital Observatory 7928 Telephone (021) 406 8338 • Facsimile (021) 406 6411 Email: gsresearch.ethics@uct.ac.za Website: www.health.uct.ac.za/fhs/research/humanethics/forms</p>
<hr/>		
<p>12 February 2016</p>		
<p>HREC REF: 072/2016</p>		
<p>A/Prof E Duncan Department of Occupational Therapy F-45 OHB</p>		
<p>Dear A/Prof Duncan</p>		
<p>PROJECT TITLE: TOWARDS INTEGRATIVE SERVICE DELIVERY FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN THE WESTERN CAPE: A MIXED METHODS STUDY (PhD-candidate- S Pillay)</p>		
<p>Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.</p>		
<p>It is a pleasure to inform you that the HREC has formally approved the above-mentioned study.</p>		
<p>Approval is granted for one year until the 28th February 2017.</p>		
<p>Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period. (Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)</p>		
<p>Please quote the HREC REF in all your correspondence.</p>		
<p>We acknowledge that the following student, Sarosha Pillay will also be involved in this study.</p>		
<p>Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.</p>		
<p>Yours sincerely</p>		
<p><u>PROFESSOR M BLOCKMAN</u> <u>CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE</u> Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH HREC/REF/072/2016</p>		

Appendix B: Human Research Ethics (HREC) Approval (2022)

 UNIVERSITY OF CAPE TOWN <small>UNIBESITHI YASEMANTHAPENINGI YASEMANTHAPENINGI</small>		 FACULTY OF HEALTH SCIENCES <small>HEALTH SCIENCES FACULTY</small>	
			
FHS016: Annual Progress Report / Renewal			
HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
<input checked="" type="checkbox"/> Approved	Annual progress report	Approved until/next renewal date	30-11-2022
<input type="checkbox"/> Not approved	See attached comments		
Signature Chairperson of the HREC		Date Signed 7/12/21	
Comments to PI from the HREC			
Principal Investigator to complete the following:			
1. Protocol information			
Date (when submitting this form)	3 DECEMBER 2021		
HREC REF Number	072/2016	Current Ethics Approval was granted until	30-11-2021
Protocol title	Towards integrative service delivery for children with autistic spectrum disorders in the Western Cape: a mixed methods study		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No		
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.	n/a		
Principal investigator	Supervisor: A/Prof E M Durcan Co-supervisor: Prof P de Vries		
Department / Office Internal Mail Address	Health & Rehabilitation Sciences		
12 March 2018		Page 1 of 5	
		FHS016	
(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)			



1.1 Does this protocol receive US Federal funding?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> X No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Note: Any annual approvals for Full Committee review MUST be submitted on the monthly HREC submission dates. (Please send electronic copy for full committee review to hrec-enquiries@uct.ac.za)		
If yes in 1.2 please complete section 1.3 below for invoicing purposes		
1.3 Annual Approval for full committee review	- R 3420 (inclusive of vat)	
For invoicing purposes, please provide:		
Sponsor's name		
Contact person		
Address		
Telephone number		
Email Address		

2. List of documentation for approval

n/a

3. Protocol status (tick ✓)

<input type="checkbox"/>	Open to enrolment
<input type="checkbox"/>	Closed to enrolment (tick ✓)
<input checked="" type="checkbox"/>	Research-related activities are ongoing
<input type="checkbox"/>	Research-related activities are complete, long-term follow-up only
<input type="checkbox"/>	Research-related activities are complete, data analysis only
<input type="checkbox"/>	Main study is complete but sub-study research-related activities are ongoing
<input type="checkbox"/>	Study is closed → Please submit a Study Closure Form (FHS010)

4. Enrolment

Number of participants enrolled to date	n/a
Number of participants enrolled, since last HREC Progress report (continuing review)	n/a



Additional number of participants still required	n/a
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5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	n/a
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6. Cumulative summary of participants

Total number of participants who provided consent	26
Number of participants determined to be ineligible (i.e. after screening)	n/a
Number of participants currently active on the study	n/a
Number of participants completed study (without events leading to withdrawal)	n/a
Number of participants withdrawn at participants' request (i.e. changed their mind)	n/a
Number of participants withdrawn by PI due to toxicity or adverse events	n/a
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	n/a
Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up.	n/a
Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	n/a

7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:

During 2021 Ms Pillay presented a talk on her study at the South African Association for Child and Adolescent Psychiatry and Allied Professions (SAACAPAP) congress. Two articles were published in peer reviewed journals and another two abstracts have been accepted for potential publication in special edition journals. She has finished writing the introduction and literature review chapters of her thesis and is busy writing the final chapter after which she will apply to the doctoral board for permission to submit her thesis by publication. Ms Pillay intends to submit the thesis for examination in 2022.

8. Protocol violations and exceptions (tick ✓ all that apply)

- No prior violations or exceptions have occurred since the original approval
 Prior violations or exceptions have been reported since the last review and have already been acknowledged or approved



<input type="checkbox"/>	Unreported minor violations that have occurred since the last review, as well as significant deviations not yet reported, are attached for review
--------------------------	---

9. Amendments (tick ✓ all that apply)

<input checked="" type="checkbox"/>	No prior amendments have been made since the original approval
<input type="checkbox"/>	Prior amendments have been reported since the last review and have already been approved
<input type="checkbox"/>	New protocol changes/ amendments are requested as part of this continuing review (See note below)

Note: If new protocol changes are being requested in this review, please complete an amendment form (FHS006). Specific changes in the amended protocol and consent/assent forms must be **bolded**, *italicised* or tracked and all changes must include a rationale.

10. Adverse events

10.1 Please provide below or attach a narrative summary of serious adverse events and/ or unanticipated problems since the last progress report. Please indicate changes made to the protocol and informed consent document(s) as a result (if not already reported to the HREC). Please comment on whether causality to any study procedure or intervention could be established.

n/a

10.2 Have participants received appropriate treatment/ follow-up/ referral when indicated (e.g. in the case of abnormal or incidental clinical findings, distress or anxiety)?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input checked="" type="checkbox"/> Not applicable
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If yes, please describe:

--

11. Summary of Monitoring and Audit Activities (tick ✓)

11.1 Was this study monitored or audited by an external agency (e.g. SAHPRA, FDA)?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input checked="" type="checkbox"/> Not applicable
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11.2 Did a Data and Safety Monitoring Board publish a report?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input checked="" type="checkbox"/> Not applicable
------------------------------	-----------------------------	--

11.3 If yes, please identify the agency and attach a summary of the findings.

Agency Name	Report attached	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable
	DSMB report attached	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable



11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
If yes, please explain:	

12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:	
<input type="checkbox"/>	Increased
<input type="checkbox"/>	Decreased
<input type="checkbox"/>	Shown no change
If there has been a change, please explain:	
n/a	

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.
n/a

13. Statement of conflict of interest

Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓)	
<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
If yes, please explain and if necessary attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form FHS013):	

14. Signature

My signature certifies that the above is complete and correct.			
Signature of PI		Date	03/12/21

Appendix C: Western Cape Education Department Research Ethics Approval



Western Cape
Government
Education

Directorate: Research

awyngaard@westerncape.gov.za
Tel: +27 831 467 9372
Fax: 0865902282
Private Bag X9114, Cape Town, 8000
wced.wcap.gov.za

REFERENCE: 20150727-1712
ENQUIRIES: Dr A.T Wyngaard

Mrs Sarosha Pillay
8 Regency Close
Leopard Rock Estate
Blatteloop,
7500

Dear Mrs Sarosha Pillay

RESEARCH PROPOSAL: TOWARDS AN INTEGRATIVE SERVICE DELIVERY MODEL FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN THE WESTERN CAPE

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **23 January 2019 till 27 September 2019**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Dr A.T Wyngaard at the contact numbers above quoting the reference number?
8. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

The Director: Research Services
Western Cape Education Department
Private Bag X9114
CAPE TOWN
8000

We wish you success in your research.

Kind regards,

Signed: Dr Audrey T Wyngaard
Directorate: Research
DATE: 14 December 2018

Lower Parliament Street, Cape Town, 8001
Tel: +27 21 467 9372 Fax: 0865902282
Safe Schools: 0800 45 46 47

Private Bag X9114, Cape Town, 8000
Employment and salary enquiries: 0861 92 33 22
www.westerncape.gov.za

Appendix D: Western Cape Department of Social Development Ethics Approval



Western Cape
Government
Social Development

Research, Population and Knowledge Management

tel: +27 21 483 4512 fax: +27 21 483 5602

48 Queen Victoria Street, Cape Town, 8000

Reference: 12/1/2/4

Enquires: Clinton Daniels

Tel: 021 483 8658/483 4512

S. Pilay

8 Regency Close

Leopard Rock Estate

Platteklouf

7500

Dear Ms Pilay

RE: APPROVAL TO UNDERTAKE RESEARCH IN THE WESTERN CAPE DEPARTMENT OF SOCIAL DEVELOPMENT

1. Your request for ethical approval to undertake research in respect of 'Towards Integrated Service Delivery for children with Autism Spectrum Disorder in the Western Cape' refers.
2. It is a pleasure to inform you that your request has been approved by the Research Ethics Committee (REC) of the Department, subject to the following conditions:
 - That the Secretariat of the Research Ethics Committee be informed in writing of any changes made to your proposal after approval has been granted and be given the opportunity to respond to these changes.
 - That ethical standards and practices as contained in the Department's Research Ethics Policy be maintained throughout the research study, in particular that written informed consent be obtained from participants.
 - The confidentiality and anonymity of participants, who agree to participate in the research, should be maintained throughout the research process and should not be named in your research dissertation or any other publications that may emanate from your research.
 - The Department should have the opportunity to respond to the findings of the research. In view of this, the final draft of your research dissertation should be sent to the Secretariat of the REC for comment before further dissemination.

- That the Department be informed of any publications and presentations (at conferences and otherwise) of the research findings. This should be done in writing to the Secretary of the REC.
- Please note that the Department supports the undertaking of research in order to contribute to the development of the body of knowledge as well as the publication and dissemination of the results of research. However, the manner in which research is undertaken and the findings of research reported should not result in the stigmatisation, labelling and/or victimisation of beneficiaries of its services.
- The Department should receive a copy of the final research description and any subsequent publications resulting from the research.
- The Department should be acknowledged in all research reports and products that result from the data collected in the Department.
- Please note that the Department cannot guarantee that the intended sample size as described in your proposal will be realised.
- Logistical arrangements for the research must be made through the Office of the Chief Director, Social Welfare, Mr C. Jordan, subject to the operational requirements and service delivery priorities of the Department.
- Failure to comply with these conditions can result in the approval being revoked.
- Please provide written acceptance of these conditions and recommendations within 5 working days of the receipt of this letter.

Yours sincerely

Ms M. Johnson

Chairperson: Research Ethics Committee

Date: 14/8/18

I hereby acknowledge receipt and accept the conditions set out in this letter of approval.

Name:	SAROSHAN NULAN
Signature:	
Date:	21-08-2018
Place:	BELLVILLE

Appendix E: Informed consent form – Caregivers



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Department of Health and Rehabilitation Sciences
Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur
Hospital, Observatory 7925
Tel: +27 (021) 406 7667
Fax: +27 (021) 406 6323

INFORMED CONSENT FORM

TITLE OF THE STUDY: TOWARDS INTEGRATIVE SERVICE DELIVERY FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN THE WESTERN CAPE: A MIXED METHODS STUDY

MAIN RESEARCHERS: A/PROF EVE DUNCAN, PROF. PETRUS DE VRIES AND SAROSHA PILLAY

DATE: OCTOBER 2015

INVITATION TO PARTICIPATE

You are invited to participate in this research study because you are a parent or caregiver of a child whose name appears on the Consolidate Waiting List for school placement at a school for autism spectrum disorder in the Western Cape.

PURPOSE

This is the first phase of a larger study on services for children with autism spectrum disorder in the Western Cape. This study aims to describe the current services for children with autism and to make recommendations for future services. Your experience as a parent or caregiver of a child with autism and your feelings about autism services in the province is important in helping us understand the situation better. The information that you provide will be shared with policy makers. You will remain anonymous.

PROCEDURES

As a participant you will be required to take part in a focus group along with seven other parents of children on the waiting list. You will be required to travel at your own cost to the venue on the given date. You will be asked various questions about your experiences with the waiting list and autism services for your child. The focus group will be approximately 2 hours long and it will be audio taped. This recording will be stored in safe place and will only be available to the researcher. The recordings will be deleted once information has been analyzed.

RISK

Some of the questions that you will be asked may possibly result in you becoming emotional. The researcher will try as far as possible to ensure that you are comfortable. You are encouraged to discuss any uncomfortable feelings that you experience from participating in the focus group with the researcher. If you feel that you wish to stop taking part in the study, you are free to do so at any time. If you feel that you require additional support and counselling, you will be referred to the following people:

1. Antoinette du Preez, psychologist at Autism Western Cape. Telephone: (021) 685 9581. Email: support@awc.org.za
2. Babs Tuswa-Mapena, social worker at Autism Western Cape. Telephone: (021) 685 9581. Email: socialworker@awc.org.za
3. Cape Mental Health. 22 Ivy Street, Observatory, 7935. Telephone: (021) 447 9040. Email: info@cmh.org.za

COSTS AND FINANCIAL RISKS

You will incur travelling costs and will possibly have to take time away from work if you agree to participate in this study.

BENEFITS

There is no guarantee that your participation in this study will have any direct benefits to you or your child. However the information from the focus group could be used to understand and make suggestions for future autism services in the province that could possibly be used by policy makers.

COMPENSATION

All participants will receive R100 for their participation that could be used towards travelling costs.

ALTERNATIVES

Your participation in this study is completely voluntary and you can choose not to participate if you wish to do so.

CONFIDENTIALITY

All the information collected during the focus group will be strictly confidential. If the research is published, your name will not be used. Confidentiality will be discussed with all participants however, confidentiality cannot be guaranteed as group members may disclose what was discussed outside the research setting.

ADDITIONAL INFORMATION

You are encouraged to ask the researcher questions about the study. If you agree to participate in the study, you will be informed of the time, place and date of the focus group meeting at a later stage.

DISCLAIMER/WITHDRAWAL

Your participation in this study is voluntary and you have the right to withdraw from the study at any point and this will not affect you or your child in any way.

PARTICIPANTS RIGHTS

If you have any questions regarding your participation in the study, you can contact Sarosha Pillay by telephoning 082 706 8999 or emailing saroshapillay@gmail.com

You can also contact the following people if you have any questions, comments or complaints about the study process:

- A/Professor Marc Blockman. Human Research Ethics Committee. Old Main Building of Groote Schuur Hospital, Floor E52, Room 23, Observatory, 7925. Telephone: (021) 4066496
- A/Professor Eve Duncan. School of Health and Rehabilitation Sciences. Faculty of Health Science. University of Cape Town. Telephone: (021) 4066325. Email: eve.duncan@uct.ac.za
- Professor Petrus De Vries. Sue Struengmann Professor of Child and Adolescent Psychiatry. Division of Child and Adolescent Psychiatry. Telephone: 021 685 4103. Email: petrus.devries@uct.ac.za

CONCLUSION

By signing below you are agreeing to the following:

- | | | |
|---|-----|----|
| a) That you have read and understood the consent form | Yes | No |
| b) That you agree to participate in this study | Yes | No |
| c) That you agree to be audio taped | Yes | No |

Participant's signature

Date

Researcher's signature

Date

Appendix F: Informed consent form – Service Providers



UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences

Department of Health and Rehabilitation Sciences

Divisions of Communication Sciences and Disorders,

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur

Hospital, Observatory 7925

Tel: +27 (021) 406 7667

Fax: +27 (021) 406 6323



INFORMED CONSENT FORM

TITLE OF THE STUDY: TOWARDS INTEGRATIVE SERVICE DELIVERY FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN THE WESTERN CAPE: A MIXED METHODS APPROACH

MAIN RESEARCHERS: A/PROF EVE DUNCAN, PROF PETRUS DE VRIES AND SAROSHA PILLAY

DATE: FEBRUARY 2016

INVITATION TO PARTICIPATE

You are invited to participate in this research study because you are an ASD service provider in the Western Cape who has knowledge and experience of working with children with ASD.

PURPOSE

This is the second phase of a larger study on services for children with autism spectrum disorder in the Western Cape. This study aims to describe the current services for children with autism and to make recommendations for future services. Your knowledge and experience of autism services in the province is important in shaping our understanding of the situation and to provide valuable information that will be shared with policy makers. You will however remain anonymous.

PROCEDURES

As a participant you will be required to take part in an interview for approximately 1 hour -1hour 30 minutes. You will be asked various questions about your thoughts on the waiting list, current ASD services and suggestions for improving services. The interview will be audio taped. This recording will be stored in safe place and will only be available to the researcher. The recordings will be deleted once information has been analyzed.

RISK

Some of the questions that you may be asked may be of a sensitive nature to you. The researcher will try as far as possible to minimize your discomfort. You are encouraged to discuss any

uncomfortable feelings that you experience from participating in the interview with the researcher. If you feel that you wish to stop participating in the study, you are free to do so at any time.

COSTS AND FINANCIAL RISKS

There are no financial costs linked directly to your participation in the study. You may however be required to take time off from work in order to participate in the interview. The research will try as far as possible to arrange the interview in a time that is convenient for you. The researcher will also travel to a place that is convenient for you to conduct the interview.

BENEFITS

There is no guarantee that your participation in this study will have any direct impact on ASD services in the province. However the information from the interview could be used to understand and make suggestions for future autism services that will be presented to policy makers.

COMPENSATION

There will be no compensation for your participation in the study.

ALTERNATIVES

Your participation in this study is voluntary and you can choose not to participate if you wish to do so.

CONFIDENTIALITY

All the information collected during the interview will be strictly confidential, except if information is required by law. If the research is published, your name will not be used.

ADDITIONAL INFORMATION

You are encouraged to ask the researcher questions about the study. If you agree to participate in this phase of the study you may be approached at a later stage to participate in the final phase of the study where you will have the opportunity to hear some of the research findings including suggestions for autism services and to make comments.

DISCLAIMER/WITHDRAWAL

You have the right to withdraw from the study at any point and this will not have any impact on you in any way.

PARTICIPANTS RIGHTS

If you have any questions regarding your participation in the study, you can contact Sarosha Pillay by telephoning 082 706 8999 or emailing saroshapillay@gmail.com.

You can also contact the following people if you have any questions, comments or complaints about the study process:

- A/Professor Marc Blockman. Human Research Ethics Committee. Old Main Building of Groote Schuur Hospital, Floor E52, Room 23, Observatory, 7925. Telephone: (021) 4066496

- A/Professor Eve Duncan. School of Health and Rehabilitation Sciences. Faculty of Health Science. University of Cape Town. Telephone: (021) 4066325. Email: eve.duncan@uct.ac.za
- Professor Petrus De Vries. Sue Struengmann Professor of Child and Adolescent Psychiatry. Division of Child and Adolescent Psychiatry. Telephone: 021 685 4103. Email: petrus.devries@uct.ac.za

CONCLUSION



By signing below you are agreeing to the following:

- | | | |
|---|-----|----|
| a) That you have read and understood the consent form | Yes | No |
| b) That you agree to participate in this study | Yes | No |
| c) That you agree to be audio tape | Yes | No |

_____	_____
Participant's signature	Date

_____	_____
Researcher's signature	Date

Appendix G: Informed consent form – Government Stakeholders

	<p>UNIVERSITY OF CAPE TOWN Faculty of Health Sciences Department of Health and Rehabilitation Sciences Divisions of Communication Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy</p> <p>F45 Old Main Building, Groote Schuur Hospital, Observatory 7925 Tel: +27 (021) 406 7667 Fax: +27 (021) 406 6323</p>	
<hr/> INFORMED CONSENT FORM		
<p>TITLE OF THE STUDY: TOWARDS INTEGRATIVE SERVICE DELIVERY FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN THE WESTERN CAPE: A MIXED METHODS STUDY</p>		
<p>MAIN RESEARCHERS: A/PROF. EVE DUNCAN, PROF. PETRUS DE VRIES AND SAROSHA PILLAY</p>		
<p>DATE: FEBRUARY 2016</p>		
<p>INVITATION TO PARTICIPATE</p>		
<p>You are invited to participate in this research study because you are a role player in the Western Cape Education Department, Department of Health or the Department of Social Development.</p>		
<p>PURPOSE</p>		
<p>This is the second phase of a larger study on services for children with autism spectrum disorder in the Western Cape. This study aims to describe the current services for children with autism and to make recommendations for future services. Your knowledge and experience of services in general in the province is important in shaping our understanding of autism specific service provisions.</p>		
<p>PROCEDURES</p>		
<p>As a participant you will be required to take part in an interview for approximately 1 hour-1 hour 30 minutes. You will be asked various questions about your thoughts on the waiting list, current ASD services and suggestions for improving services. The interview will be audio taped. This recording will be stored in safe place and will only be available to the researcher. The recordings will be deleted once information has been analysed.</p>		
<p>RISK</p>		
<p>Some of the questions that you may be asked may be of a sensitive nature to you. The researcher will try as far as possible to minimize your discomfort. You are encouraged to discuss any</p>		

uncomfortable feelings that you experience from participating in the interview with the researcher. If you feel that you wish to stop taking part in the study, you are free to do so at any time.

COSTS AND FINANCIAL RISKS

There are no financial costs linked directly to your participation in the study. You may however be required to take time from work to participate in the interview. The researcher will try as far as possible to schedule the interviews at a time that is convenient for you. The researcher will travel to a place that is convenient for you to conduct the interviews.

BENEFITS

There is no guarantee that your participation in this study will have any direct impact on ASD services in the province. However the information from the interview could be used to understand and make suggestions for future autism services that will be presented to policy makers.

COMPENSATION

There will be no compensation for your participation in the study.

ALTERNATIVES

Your participation in this study is voluntary and you can choose not to participate if you wish to do so.

CONFIDENTIALITY

All the information collected during the interview will be strictly confidential, except if information is required by law. If the research is published, your name will not be used.

ADDITIONAL INFORMATION

You are encouraged to ask the researcher questions about the study.

DISCLAIMER/WITHDRAWAL

You have the right to withdraw from the study at any point and this will not have any impact on you in any way.

PARTICIPANTS RIGHTS

If you have any questions regarding your participation in the study, you can contact Sarosha Pillay by telephoning 082 706 8999 or emailing saroshapillay@gmail.com.

You can also contact the following people if you have any questions, comments or complaints about the study process:

- A/Professor Marc Blockman. Human Research Ethics Committee. Old Main Building of Groote Schuur Hospital, Floor E52, Room 23, Observatory, 7925. Telephone: (021) 4066496

- A/Professor Eve Duncan. School of Health and Rehabilitation Sciences. Faculty of Health Science. University of Cape Town. Telephone: (021) 4066325. Email: eve.duncan@uct.ac.za
- Professor Petrus De Vries. Sue Struengmann Professor of Child and Adolescent Psychiatry. Division of Child and Adolescent Psychiatry. Telephone: 021 685 4103. Email: petrus.devries@uct.ac.za

CONCLUSION

By signing below you are agreeing to the following:

- | | | |
|---|-----|----|
| a) That you have read and understood the consent form | Yes | No |
| b) That you agree to participate in this study | Yes | No |
| c) That you agree to be audio taped | Yes | No |

Participant's signature Date

Researcher's signature Date

Appendix H: Interview guide for caregiver focus groups

Focus group questions for caregivers of children on the CWL

1. When did you first think that something was different with your child and what did you do?
2. What did you think and how did you feel when you were told that your child has a diagnosis of autism?
3. Think back to when you were told that your child's name was being put on the waiting list, what did you think was going to happen at the time?
4. What has been your experience with the waiting list?
5. What steps have you taken since the diagnosis and is your child receiving any intervention currently? if so, what? If not, what would you recommend?
6. What has been your experience of ASD services in the province?
7. What suggestions could you make to improve ASD service delivery in the province?
8. Is there anything else that you would like to add?

Appendix I: Interview guide for service provider semi-structured interviews

Semi-structured interview schedule for ASD practitioners

1. What is your impression of current autism services in the Western Cape?
2. What is your biggest concern regarding ASD services in the province?
3. What are your thoughts on the waiting list?
4. What do you think are the gaps in ASD services?
5. What would you like to see in terms of ASD service delivery in the province?
6. What do you think can be done to improve ASD services in the province?
7. Is there anything further that you think is important?

Appendix J: Interview guide for government stakeholder interviews

Semi-structured interview schedule for participants from the different government sectors

1. What is your perception of existing ASD services in the province?
2. How accessible do you think are services for children with ASD and their families?
3. What do you think about the long waiting list for children with ASD in the province?
4. How do you think that this problem can be addressed?
5. How do you think the different departments can work together to meet the needs of children with ASD?
6. What do you think can be done to improve existing ASD services in the province?
7. Do you have anything further to add?