CAREGIVERS' EXPERIENCES OF SERVICE PROVISION FOR THEIR CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER

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DECLARATION

I, **Jennifer Hooper**, declare that this research report is my own, unaided work. It is being submitted for the degree of Master of Science in Occupational Therapy in the University of the Witwatersrand, Johannesburg.

It has not been submitted before for any degree or examination at this or any other University.

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Jennifer Hooper

Signed on the ____ day of ____________ 2009

For John, my family and friends,

who supported me throughout this process.

PRESENTATIONS ARISING FROM THIS STUDY

1. Hooper, J.J **Caregivers' experiences of service provision for their children diagnosed with Autism Spectrum Disorders.** OTASA Congress. Port Elizabeth: Unpublished, June 2009.

2. Hooper, J.J **Caregivers' experiences of service provision for their children diagnosed with Autism Spectrum Disorders.** University of the Witwatersrand School of Therapeutic Sciences Research Day. Johannesburg: Unpublished, August 2009.

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ABSTRACT

An increase in the prevalence of ASD has led to increased demands on service provision.

This questionnaire-based, descriptive study aimed to explore service use and experiences of health and education service delivery by caregivers and their children with ASD in Johannesburg. The sample size was 39. Comparisons were drawn between the experiences of the participants accessing the private and public service sectors.

Children were diagnosed at an average age of 4 years; 2 years after the first symptoms were noted by their caregivers. Families accessed a mean of 3 institutions and 6 professionals in seeking diagnosis and treatment. No specific referral patterns could be established. Challenges to service access identified by caregivers included: logistical problems, lack of professional knowledge and experience, poor parental coping and insight, and lack of community support. Solutions identified by the caregivers included: marketing, training, better referral procedures, and establishment of educational facilities.

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NOMENCLATURE

AD – Autistic Disorder
ADHD – Attention Deficit Hyperactivity Disorder
AS – Asperger’s Syndrome
ASD – Autistic Spectrum Disorder
OT – Occupational Therapy
PDD – Pervasive Developmental Disorder
PDD-NOS – Pervasive Developmental Disorder - Not Otherwise Specified

Definitions:

The key terms used in this research were defined as follows:

Caregiver: refers to the parent, foster parent, or legal guardian that tends to the needs of the child with ASD.[1] Caregivers included in this study resided in Johannesburg, South Africa, and thus described their experiences from a South African perspective.

Experiences: refers to the series of events or occurrences encountered by the caregivers in accessing services.[1] These experiences included those related to seeking professional help, finding a diagnosis, the referral process, and the use of health and educational services. Positive and negative experiences were described relating to the factors challenging access and the factors facilitating access to appropriate services.

Service Provision: refers to the provision of health care and education specifically for children (under 18 years) presenting with ASD and their families. Both the public and private service sectors were included.

Autistic Disorder: “characterised by sustained impairment in comprehending and responding to social cues, aberrant language development and usage, and restricted, stereotypical patterns.”[2] **p1191**

Asperger's Syndrome: "condition in which the child is markedly impaired in social relatedness and shows repetitive and stereotyped patterns of behaviour without a delay in language development…the child's cognitive abilities and adaptive skills are normal". [2]**p1191**

Dosage: "the giving of a therapeutic agent in a prescribed amount" [3] Taken to mean the prescribed frequency of therapy as a means of intervention.

CHAPTER 1: INTRODUCTION

"When the paediatrician told Marissa that her beautiful son Sean was autistic, her heart sank to the floor. It took days for Marissa and her husband, John, to confront the diagnosis and to realise its dramatic implications for their beloved, bright-eyed two-year old child and for their own life together. When they did, and after they had done some research on autism and autistic spectrum disorders the weight in their hearts did not lighten. The information about ASD they gleaned from books and from the Internet was overwhelming, with many different points of view and treatment options. They had to learn a whole new vocabulary just to understand what was going on with Sean, and in the midst of their grief at the diagnosis, they found this very hard to do. Most disturbing of all, they weren't sure they were getting the right advice on how to treat their son…The first specialist whom Marissa and John consulted told the couple that Sean would probably never be able to relate to other people's feelings or to think creatively. The best they could expect was for Sean to learn to behave in socially acceptable ways through treatment approaches that focused on his symptoms and behaviour…In the face of this advice, the couple felt hopeless and helpless. They believed that their son had more potential than that, and they wanted him to want to relate to them and to think for himself." (Greenspan & Wieder, 2006, p ix)[4]

This story relays a common tale of parents' experiences of learning the news of their child's diagnosis of Autistic Spectrum Disorder. It illustrates parents' desperation and struggle to find appropriate help. And once help is found, the parents' experience of disillusionment and mistrust of professionals who cannot offer help that will enable their child to communicate with his family, and live an independent life.

This study explored the experiences of South African caregivers of service provision for their children with Autism Spectrum Disorder.

Some ambiguity exists in the literature regarding the terms Pervasive Developmental Disorders and Autistic Spectrum Disorders. [5-7]

The DSM-IV TR (2000) and the ICD-10 describe Pervasive Developmental Disorders (PDD'S) as a range of neuro-psychiatric, developmental disorders, in which deficits present on a continuum of severity.[2,8,9] Disorders included in the range of PDD's include: Autistic Disorder (AD), Rett's Syndrome, Childhood Disintegrative Disorders, Asperger's Syndrome (AS) and Pervasive Developmental Disorder not otherwise specified (PDD-NOS).[2,9,10]

The term "Autistic Spectrum Disorders" (ASD) was introduced in the 1990's, and is used widely by researchers and clinicians. While this term continues to be defined inconsistently by different researchers, it is commonly used to describe a spectrum of disorders including Autistic Disorder (AD), Asperger's Syndrome (AS) and Pervasive Disorder-Not Otherwise Specified (PDD-NOS). Rett's Disorder, and Childhood Disintegrative Disorder are thus excluded from this Spectrum of Disorders.[5-7] For the purposes of this study, the term ASD was adopted, and the sample selected according to this definition.

Children diagnosed with ASD present with deficits in reciprocal social interaction and communication and present with restricted and repetitive behaviours and interests. These symptoms may be of varying severity.[5-7,10] Disturbances in sensory and perceptual processing are also characteristic in ASD. These deficits impact on development and affect adaptive functioning throughout the lifespan.[9,11]

The prevalence of ASD has increased almost 25-fold since the late 1980's, with current estimates in the region of 1 in 160.[7,12-17] Controversy is noted in epidemiological literature with some claiming that the increase in prevalence is largely due to the increase in awareness of ASD and in the clarification of diagnostic criteria, while others claim that this increase in prevalence must also reflect a change in risk largely related to environmental factors.[7,12,14,16] Four times as many boys are affected as girls. No significant correlation with racial, ethnic, intellectual or socioeconomic background has been established.[11,15,17] Life expectancy is not usually affected by ASD, although functional prognosis is diverse.[11]

The significant increase in the prevalence of ASD impacts on the demand for health services. Medical expenditure research describes an increased number of professionals and health services accessed, longer consultation times, and greater health costs for children with autism spectrum disorders compared to other children. [18] Health costs and intervention requirements, together with the increased numbers of children presenting with ASDs, present significant demands on service delivery, accessibility and quality.

A variety of interventions are used nationally and internationally in the remediation or containment of symptoms of ASD.[19] Many of these interventions lack empirical support. There is also limited research that explores caregivers' decision to pursue some treatments, despite the lack of evidence of these treatments' efficacy.[19] Inadequate interventions and poor outcomes contribute to poor compliance to treatment, and feed into the cycle of caregiver hopelessness and helplessness, in the face of their child's diverse functional problems and poor prognosis.

1.1 Statement of the Problem

Health service provision for children with ASD in South Africa faces many challenges. There is a paucity of published South African research into epidemiological trends and the use and effectiveness of different interventions in ASD. Service provision in Gauteng, in both the public and private health and education sectors is not centralised, and specialized services are compromised by poor knowledge, skill and experience of health care professionals as well as limited networking between various professionals and services. There is a need for the development of holistic multidisciplinary services and resources, taking into account the unique South African setting and the needs of the caregivers and children with ASD.

1.2 Justification for the study

Autism South Africa, in conjunction with the multi-disciplinary paediatric team at the Children's Memorial Institute, instigated the formation of Autism Johannesburg, a parent-professional committee in February 2007. The purpose of this committee was to: assess the needs of caregivers, families, children and professionals involved in the field of PDD's; co-ordinate the development of comprehensive services and pooling of resources; and to establish support networks between professionals, families and service providers in Johannesburg.

This research aimed to explore the utilization of services by children with ASDs and their families in the Johannesburg Metropolitan Region. The challenges the caregivers faced in accessing effective and efficient assessment and treatment were to be documented together with their suggestions for improving service access and delivery. This information could assist South African health and education facilities as well as organisations such as Autism Johannesburg and Autism South Africa, in the development of an appropriate service delivery model aiming to improve the quality and effectiveness of service provision for children with ASD and their families. This information could also be used to motivate for funding and resources.

1.3 Purpose of the study

A great need exists in South Africa and Johannesburg in particular, for the development of appropriate services to meet the needs of children presenting with ASD, as well as the needs of their caregivers. The information gathered in this study could be used to inform service provision and motivate for more appropriate, cost-effective and efficient service development. Research findings could also be used in lobbying for funds and resources within the public and private sectors.

1.4 Aim of the Study

This study aimed to explore caregivers' perceptions and experiences of service provision for their children with ASD in Johannesburg, South Africa.

1.5 Objectives of the Study

1.5.1 To investigate patterns of use of health and education services by caregivers and their children presenting with ASDs.

1.5.2 To compare the patterns of service use in the private and public sectors.

1.5.3 To identify the perceived barriers impacting on service delivery and access.

1.5.4 To identify the factors perceived to be facilitating better service delivery and access.

1.6 Organisation of the research report

This study and its findings are organised into 7 chapters and discussed as follows:

Chapter	**Content**
Chapter 1	The **Introduction** outlines the background to this study including: the statement of the problem, justification of the study, purpose of the study, research aims and objectives.
Chapter 2	The **Review of the Literature** defines and describes key concepts, and critically evaluates current research in the field of ASD with particular reference to service provision and access.
Chapter 3	This chapter describes the **Development of the Research Instrument.** The contents and piloting of the self-reporting questionnaire that was designed for this study, together with the establishment of validity and reliability, are discussed.
Chapter 4	The **Research Methodology** describes the research procedure, including the: research design, sampling, ethical considerations, measurement techniques, data collection procedure, and data analysis.
Chapter 5	The **Results** chapter presents the findings of the study. The demographics of the sample is described followed by the findings relating to the research objectives.
Chapter 6	The **Discussion** chapter positions the findings of this study in the context of the available literature, interprets the possible reasons for these findings, and discusses their significance in the South African context. The ASD Service Delivery Model is presented as a summary of the findings and recommendations of this study.
Chapter 7	The **Conclusion** summarises the key findings of the study. The implications for practice are discussed and recommendations for further research are made.

CHAPTER 2: REVIEW OF THE LITERATURE

2.1 Introduction

This chapter defines and describes the key concepts discussed in the literature that underpin this study. These include the clinical presentation of ASD, its aetiology, course, prognosis and prevalence. The role of the caregiver and the family in caring for the child with ASD in facilitating development is highlighted, justifying the use of a caregiver survey in this study.

Descriptive studies and systematic reviews were critically reviewed and used to inform the research methodology as described in chapter 3 and 4, and discuss and analyse the findings of this study in chapter 6.

The bodies of literature reviewed included: prevalence; burden of care; service use; assessment, intervention and management of ASD; education; and medical expenditure research. A scarcity of accessible, published South African literature pertaining to ASD was found. While unpublished conference papers and generic South African research relating to disability, health and education services and legislature were reviewed, the bulk of the research reviewed consisted of systematic reviews and descriptive studies carried out internationally.

2.2 Definitions and Perspectives of Autistic Spectrum Disorders

Leo Kanner first described “infantile autism” in his classic paper “Autistic Disturbances of Affective Contact” in 1943. Classification of autism has evolved substantially since this time. Until the 1980’s, the diagnosis of typical autism was largely guided by the Kanner or Rutter descriptions of autism. These descriptions excluded any child with intellectual impairment from being described as autistic.[20,21] Kanner suggested that many children were being misdiagnosed as having mental retardation or childhood schizophrenia and that, as such, Autism was likely to be more prevalent than it seemed.[20,21]

Autism first became a diagnostic entity when the DSM-III was published in 1980.[21] According to the DSM-III, Autism was classified as one of a group of conditions then termed Pervasive Developmental Disorders (PDD).[21] These criteria and classifications evolved with the revision of the DSM, and finally with the alignment of the DSM-IV and the ICD-10.[21]

Currently, DSM-IV and ICD-10 criteria are the most commonly accepted and widely used criteria for diagnosis. These criteria included a broader range of signs and symptoms such as intellectual impairments and various social impairments. There was an acknowledgement that autistic traits and autism are commonly associated with other conditions, particularly psychiatric diagnoses. In addition, criteria were extended to cover different classifications of ASD or PDD including: classical Autism or Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).[21-23] The DSM IV-TR included further revisions of the criteria.[8]

The term "Autistic Spectrum Disorders" (ASD), introduced in the 1990's, is commonly used to refer to a spectrum of disorders including Autistic Disorder (AD), Asperger's Syndrome (AS) and Pervasive Disorder-Not Otherwise Specified (PDD-NOS).[5-7] These three diagnoses will be defined further.

2.2.1 Autistic Disorder

AD is characterized by a triad of key impairments. These include: impairments in socialization, impairments in language and communication; and the presence of restricted patterns of behaviour and/or interests.[2,8] Baron-Cohen described an impairment in "theory of mind" as responsible for the lack of flexible social interaction, poor communicative abilities and lack of empathy.[24] Sensory and perceptual processing problems, behavioural disturbances including hyperkinesias, and mood and affect instability are also characteristically present.[2,25]

The age of the child, and the severity of involvement impacts on the presentation of these impairments.

- **Impairment in socialisation**

Poor social interaction and limited awareness of others and their needs and feelings persists throughout life, and limits the ability to form and maintain appropriate relationships. Social interaction is compromised by limited shared attention and poor non-verbal communication including poor eye contact, poor use and understanding of facial expression and gesturing etc. Poor judgement of social context leads to inadequate selection and display of appropriate social behaviour. Spontaneity and social and emotional reciprocity is restricted, and individuals with ASD appear to prefer to be alone.[2,8,24,25]

- **Impairment in communication**

The presentation of communication deficits varies greatly. Both verbal and non-verbal communication is affected. The intonation, pitch, rate and rhythm of speech may be impaired. Echolalic speech, which has no communicative value or relevance to the social context, may be present. Grammatical errors in language use are common, and speech tends to be repetitive and stereotyped. Receptive language and comprehension are also impaired. Pragmatic language is poor with literal use and understanding of language and limited understanding of abstract language such as irony or humour.[2,8,25]

- **Disturbance in behaviour**

Individuals with ASD commonly present with a variety of behavioural problems including: impulsivity, inattention, hyperactivity, aggression, self-injurious behaviours, temper tantrums, strange eating behaviours, and moodiness.[2,8] They tend to be rigid, intolerant and resistant to change. Changes to routines and environment, and unpredictability tend to precipitate tantrums. A restricted range of interests, with obsession for one particular topic or object, is characteristic. Play tends to be concrete, with some exploration of the sensory qualities of objects, and manipulation of objects to cause an effect, rather than constructive or imaginative. Stereotyped, repetitive movements (e.g. flicking fingers, banging head, rocking) may be present.[2,8,25]

- **Sensory and perceptual processing difficulties**

Inadequate sensory processing related to abnormal sensory thresholds, leads to either over or under-reaction to sensory stimuli. Sensory modulation difficulties are also characteristic, impairing the child's ability to focus their attention on the task at hand and prevent distraction by irrelevant stimuli. Sensory seeking and sensory avoidant behaviours may be noted.[2,25,26]

2.2.2 Asperger's Syndrome

AS is characterised by dysfunction in two key areas: usually socialization and restricted patterns of interests.[2,27] Classically, AS is not characterized by marked cognitive or language impairments, and verbal intelligence quotients tend to higher than performance (non-verbal) intelligence quotients.[28] Motor and other developmental milestones may be achieved age-appropriately. Precocious vocabulary and particular interest in, and knowledge on certain topics may give the impression that the child is developmentally advanced.[2,27] This has implications for diagnosis.

2.2.3 Pervasive Developmental Disorder-Not Otherwise Specified

PDD-NOS is characterized by impairments in socialization and one other area: either impairment in communication; or presentation of a restricted pattern of behaviour or interests.[2,27,29]

2.3 Aetiology of ASD

While the aetiology of ASD is not comprehensively understood, the early explanations of the effect of "emotionally unresponsive" or "refrigerator mothering" in causing ASD have been disproved, and the biological aetiology of ASD increasingly described.[2] ASD is described as a complex disorder with varying neurobiological anomalies impacting on the brain and cognition in particular[7]. It is thought that the variation in aetiology may indicate that different subgroups of ASD may have different aetiologies and thus, may respond better to different interventions.[7]

Abnormalities in brain connectivity have been demonstrated in studies linking genetic and neurobiological causes of ASD. The abnormal action of genes related to synapse formation and plasticity has been noted. This appears to play a role in compromising neurological development by impairing the process of myelination and dendrite and synapse growth, resulting in inadequate selective pruning and elimination of dendritic connections relative to experience and learning[7,25]. Accelerated head circumference growth at about 12 months of age in children later diagnosed with ASD has been associated with brain overgrowth. This overgrowth is largely noted in the temporal, parietal and occipital lobes, and has been attributed to increases in neuronal and non-neuronal cell growth, with decreased apoptosis.[2]

Neuro-imaging studies note increased cell density and reduced neuron size in characteristic areas in the brain including the: amygdala, cerebellum, right somatosensory cortex, orbitofrontal cortex, and cingulate gyri. Functional changes in the cerebral cortex are also noted.[25,30] These neuro-imaging studies have largely been conducted on adolescents and adults presenting with ASD, and findings have been criticised for not being representative of the developmental trajectory of ASD. Instead, these findings are reflective of the person’s present brain structure influenced by compensatory development and treatment effects.[7]

Changes in the neurochemistry of synapses have also been described. Elevated serotonin levels and hypothalamic-pituitary-adrenal axis dysfunction with consequent abnormalities in neuroendrocrine functioning, have been noted.[25]

The effects of genetic abnormalities are not only limited to neurological systems. They may also influence the immune and gastro-intestinal (GIT) systems. This may explain the abnormal findings in immune and GIT systems in a subgroup of children presenting with ASD. Other findings regarding the role of non-allergic food sensitivities, GIT dysfunction and immune dysfunction in causing ASD symptoms are inconsistent.[7]

Diet and vaccinations have not been scientifically proven to cause, prevent or cure autism, contrary to popular belief.[7,25]

2.4 Co-morbid conditions

Conditions such as Cognitive Impairment, Epilepsy, Attention Deficit Hyperactivity Disorder (ADHD), Affective disorders, Anxiety disorders, Tourette's Syndrome and various other neuropsychiatric disorders have been commonly associated with ASD.[25] The prevalence rates of co-morbid conditions range between 0 and 16% , with a mean of 6% in children presenting with ASD.[21] Prevalence rates of epilepsy range from 5 to 40 % in people presenting with ASD, with onset usually in early adolescence.[7,21,31] Epilepsy is commonly associated with cognitive impairment and as such, cognitive impairment is predictive of co-morbid epilepsy.[21] Co-morbidity may complicate the diagnosis of ASD.

The DSM-IV TR criteria describe ASD as a "pre-emptive" diagnosis, and comorbid diagnoses of conditions such as ADHD and Tourette's Syndrome cannot be made.[7,8] Despite this, the full criteria for these various co-morbid conditions are often met, and lead to significant functional impairment. As such, clinicians commonly diagnose these co-morbid conditions despite the recommendations made in the DSM-IV TR.[7]

Sadock et al noted that 70% to 75% of children with AD have a low Intelligence Quotient (IQ). 30% function in the mild to moderate category, and 45% to 50% in the moderate to severe category, with approximately 20% to 25% presenting with normal IQ.[2] Incongruence is noted in the verbal and non-verbal IQ scores achieved by younger children with ASD and low IQ. Verbal skills tend to be poorer than non-verbal skills. Verbal IQ tends to improve with age and may exceed performance IQ in adolescence and early adulthood.[31]

The symptoms of other psychiatric disorders such as anxiety, depression, oppositional behaviour, poor attention, and compulsive behaviours, have also been associated with ASD and make differential diagnosis in higher-functioning individuals difficult, and the diagnosis of ASD is often missed. Where a diagnosis of ASD is confirmed, it is sometimes unclear as to whether the symptoms of other psychiatric diagnoses are severe enough to warrant a second diagnosis, or whether these symptoms are simply a function of the diagnosis of ASD.[21]

The patterns of co-morbidity appear to be different in AD when compared to AS. AS is more commonly associated with psychosis, bipolar disorder, depression, anxiety and obsessive-compulsive disorder.[28]

2.5 Course

ASDs are present at birth and progress and change throughout the lifespan, impacting different individuals differently and resulting in varying functional impairment.[9,10,32]
Many parents note symptoms in early infancy, but early diagnosis is complex. In 25% of cases, parents report normal development in the first one to two years of life. Thereafter the child appears to lose previously acquired language and some regression and deviance in development, consistent with a diagnosis of autistic disorder, is noted.[2,8] During school-going age and adolescence, some improvement, particularly in social functioning, is common, although in some cases, adolescence triggers significant regression.[8]
The impairment in adaptive functioning limits the ability to acquire functional behaviour and ultimately compromises independent functioning. Few adults with ASD (5-15%) will develop social and adaptive skills and go on to live and work independently, while the majority (60%) will continue to require some level of care or supervision throughout the lifespan.[9,10,25,32-34]
Stereotypical behaviours tend to improve with age and intervention, while impairments in social skills and communication tend to persist into adulthood, even in higher-functioning, more independent individuals.[33]

AS is also characterized by early onset. But early diagnosis is often complicated by the presence of good verbal skills. Children are commonly misdiagnosed and their behaviour attributed to stubbornness or behaviour problems.[8] Motor delays and clumsiness often become apparent in school-going children.[28] Adolescents may show interest in forming social relationships and may learn to apply social and verbal rules and routines in order to adapt and function more independently. They tend to form relationships with people much older or much younger than themselves due to residual social inadequacies. Individuals with AS may be able to maintain gainful employment and lead reasonably independent lives. In some cases, special interests and skills may provide the foundation for career selection. Despite having a much better prognosis than adults presenting with AD, adults with AS tend to continue to struggle with social interaction, demonstrating poor empathy and often being quite shy and uncomfortable in social contexts.[8,28]

2.6 Prognosis

Prognosis has been shown in the literature, to be most influenced by intellectual ability and the ability to communicate using speech.[8,25,31,32] Language acquisition before the age of six years, an IQ score of above 50, and having a special skill, constitute good prognostic indicators.[21,33]

Follow up studies indicated that 75% of people with AD have poor outcomes, with only 25 % of cases having a good prognosis.[21] Most are able to build a few friendships, but few marry or maintain close relationships. Most people presenting with AD and an IQ below 70, are unable to lead independent adult lives. People presenting with AD and a normal range IQ exhibit a level of independence, but may still require support in finding and maintaining employment and accommodation independently. These individuals tend to continue to display poor communication and social interaction skills, and tend to follow rigid routines of activities and have a limited range of interests.[8,31]

Comparing outcome studies from the pre 1980's to more recent studies: overall language skills, independence and employment outcomes have improved in the adult population presenting with ASD. This may reflect the results of earlier detection and early, more comprehensive, intervention .[21]

People presenting with AS tend to have better overall prognoses. Many are able to live independently, and maintain gainful employment.[8,28]

2.7 Prevalence

An increase in the prevalence of ASD has been noted since the 1980's. There is much controversy in the literature regarding this rise in prevalence. Some argue that the change in diagnostic criteria and improvement in diagnostic practices, improved awareness of ASD, improved referral practices and methodological errors in studies, play a significant role in the increased prevalence rates.[35] Others note that once these other explanations for the rise in prevalence have been controlled for, an increase in prevalence is still noted. They explain that this may be linked to the role of environmental factors in the aetiology of the condition.[21,36]

Both primary and secondary (or associated) diagnoses are not commonly taken into account when calculating prevalence. This implies that should a child be diagnosed with more than one condition, only the primary diagnosis will be considered in calculating prevalence. Consequently, a corresponding decrease in the prevalence of other disorders like cognitive impairment and global developmental delay has been noted.[21-23]

Fombonne reviewed 21 epidemiological studies from 1987 to 2003, carried out in 13 different countries. Subjects ranged from birth to adulthood, with a median age of 8 years. The prevalence of ASD varied between 2.5 in 10 000 to 30.8 in 10 000 in these studies. Fombonne related the incongruence between findings to methodological differences in case finding, population sampling, and diagnostic procedures.[20,21] Other reviews have also highlighted the effect of methodological problems such as case finding methods, single source ascertainment, the size and nature of the study populations, and power determination on the varying incidence and prevalence rates reported in epidemiological studies.[22,23] The varying ages of the study participants is also problematic as the number of diagnoses made varies with age. Thus prevalence is affected by the age groups included in the particular study.[22,23]

Fombonne noted better case finding methods and more precise diagnostics in the three most recent studies reviewed. The average prevalence rate reported by these studies was 60/10000.[20,21,25] This is supported by a more recent study conducted by the Center for Disease Control and Prevention (CDC) on 8yr old children living in 14 sites in US and reported in

2007. They reported an average prevalence of 1 in 150 presenting with ASD.[37,38] Considering prevalence of other developmental disorders, CDC concluded that ASD is therefore the second most common developmental disorder after intellectual disability in the US.[37]

There continues to be poor agreement around prevalence rates of the various subtypes of PDD.[8,20,21,39] The ratio of children presenting with AD, to children presenting with AS is reported to be about 4:1.[20,40,41].

Male-to female ratio is relatively consistent in the literature. Studies report a mean ratio of 4.3:1.[2,8,21,25,31] This ratio has been shown to increase within the higher functioning ASD group to 10:1. This implies that females presenting with ASD tend to be lower functioning.[8]

No socio-economic differences in prevalence have been reported in epidemiological studies.[2,8,21,25]

No published South African epidemiological studies were found. Jacklin presented findings based on a ten year review of clinic records, at the World Autism Congress in 2006.[17] While prevalence could not be determined in her study, Jacklin reported a six-fold increase in cases of ASD presenting at the clinic between 1996 and 2005. Increases in the number of cases between 2004 and 2005 however, were attributed to greater community awareness of services provided by the clinic.[17]

The rising prevalence of ASD has increased the demand on service provision. In California, the Department of developmental services has documented a 97% increase in the number of people with ASD utilizing services between 1998 and 2002. This is the result of better identification and diagnosis of higher functioning children with ASD. There was a 20 fold increase in the number of children with ASD catered for in schools.[39]

2.8 The role of the family in managing the child with ASD

Up until the 1960's, parenting style was thought to cause ASD. It was thought then, that parents should undergo therapy as a means of treating dysfunction in the children.[38] As previously discussed, this has been disproved, shifting the focus away from psychodynamic models of causality and the parenting style or personality traits of parents of children with ASD. The stress, challenges and burden of care parents of children with ASD endure, in comparison with other parents, has now become the focus of research, emphasising the need for supportive therapy for the parent and family.[38]

The caregiver and families' role in caring for the child and managing the child's interventions is also significant. The dynamic systems and ecological systems models, adopted from the late 1980's, describe children as an integrated part of the family system. Child development is thus impacted significantly by the family context.[38,42]

While ASD results in developmental delays and deviance throughout the lifespan, the outcomes and quality of their occupational performance is not predetermined. Family dynamics and experiences have a significant impact on the vulnerability and resilience of children, and thus on the functional outcomes and disability of the child.[42]

The family is responsible for organising and enabling the child's daily occupations, shaping the child's earliest occupational contexts; selecting and managing the child's activities and daily routine; and facilitating exposure to learning opportunities.[42] The family's socio-economic status influences the type, variety and quality of activities, performance contexts (school, home, social) and resources. The family also plays a primary role in the child's social learning and development, in bonding and in modelling relationships, interaction and emotional responsiveness. This is particularly significant in a child with ASD in which social development is impaired.[42]

In considering the family as a system, the impact of the child with special needs on the caregiver and the family is also significant.[42-45] Factors impacting on the family or caregiver's ability to cope with a child with special needs includes: the age of the child, abilities and behaviour of the child; the type and severity of disability; the caregiver's motivation and skill in managing the child's disability; care giving demands and the caregiver's perception of the parenting role; caregiver's coping skills and the family structure and cohesiveness.[42,45]

Many studies have explored the health and coping of caregivers of children with disabilities and chronic health conditions.[42-45] Caregivers of children with ASD are most severely impacted due to the severity of the disorder and the demands on care giving. ASD impairments in verbal communication, human relationships and disparity in cognitive functioning, have been identified as the most stressful child characteristics impacting on care giving. The role of parenting takes on new significance for a parent in the face of prolonged functional impairment and possible life-long dependence of the child on the parent. The parent-child relationship is also primarily compromised by the child's inability to bond and form relationships with the primary caregiver. Heightened parental stress in caregivers of children with ASD commonly results in depression, marital discord and decreased marital intimacy, social isolation, feelings of incompetence and low self esteem.[43]

Research has identified moderators of parental stress. These include: family-centred interventions, social supports (support groups, parental counselling), facilitation of adaptive coping skills, education and skills development.[42,43,45] While this research has been conducted internationally, it is assumed that it remains relevant in the South African context.

2.9 Service needs

The family-centred approach, which is favoured in the management of childhood conditions, considers both the needs of the child with ASD as well as their caregivers and family. A few international surveys have explored the needs of children and adults with ASD and their caregivers in the interests of developing appropriate, context-specific services.[19,32,46] The most significant needs identified included: the need for effective communication; the meeting of social and emotional needs; the need for suitable work and recreational facilities and activities; the need for a safe, caring place of residence; the need for advocacy for holistic management and co-ordination of comprehensive services; and the need for adequate health and educational services.[32,43]

These surveys were conducted in first world countries where a variety of ASD-specific services were at least available, even though they may not have been centralised or comprehensive. Methods of data collection were largely internet or mailed surveys. While these methods drew large samples with adequate statistical power, this methodology was biased against educational level or level of literacy, socio-economic status and geographical location. These factors impact on the generalisability of the research findings across different population groups and contexts.

The prioritisation and significance of the needs of SA caregivers and their children may be impacted by the unique South African context, where the variety and accessibility of health and education services is limited. Culture, socio-economic status and educational level impact on the patterns of health care access and the needs expressed. There is also a significant difference in service provision in the public and private sectors. Knowledge and appreciation of these specific needs is fundamental in the development of sustainable, appropriate and accessible services that will effectively meet these needs.

2.9.1 Changing caregiver needs in the cycle of acceptance

Nuutila and Salantera explored the experiences of care, described by caregivers of children with long-term illness. They described the experiences in terms of a process of learning that caregivers went through in learning to meet, and care for their children's needs.[47] The relationship between caregivers and health care practitioners, together with the transfer of information and mutual trust between them, was correlated with the caregiver's ability to cope in each phase of the process.

Nuutila et al showed that in the first, diagnostic phase, parents tended to feel uncertain, confused and emotional. Trust of the professional was based on the caregiver's perceptions of the adequacy of the professional's qualifications to care for their child. The importance of the professional's empathy and respect in communication with the caregiver was highlighted. The relationship was primarily dependent, with the flow of information tending to be "unidirectional". Caregivers needed to receive simple, concrete information from the professional on the child's condition and the necessary treatment. Practical advice on how to care for the child was also required by the caregivers.[47]

The second phase was described as "learning the home care". Caregivers continued to experience uncertainty and fear, and tended to be focused on coping on a day-to-day basis. The need for information was guided by arising situations and experiences. The flow of information tended to be more two-way, with caregivers describing their experiences and professionals acknowledging appropriate caregiver problem solving, and supplementing their experiences with other ideas and solutions. Caregiver's highlighted the need for affirmation and the need to be able to contact professionals easily. Mutual trust, based on a long-term relationship and good communication, needed to be developed at this phase. The need for professionals to have a good understanding of the client, family, lifestyle and living environment was highlighted. Professionals also needed to acknowledge the caregiver's abilities and skills.[47]

The third phase was described as "successful coping". During this phase, caregivers were seen to be more confident and competent in caring for their children. The focus of care shifted to facilitating the caregiver's planning for the future. Support was also required in negotiating new hurdles encountered as the child moved through different developmental stages. Caregivers in this study explained that equality and mutual trust in this phase were often compromised by inadequate professional expertise in managing their children's conditions, and by professionals' mistrust of caregivers' abilities to care for their children.[47]

These phases have important implications for the design of service provision models, both internationally, where this research was conducted, and locally.

2.10 Service utilization

People with ASDs are a particularly challenging population to service. The increasing prevalence of ASD widely shown in both local and international research, presents an increased demand on services.[12-17] The development of services has not been proportional to the growing demands for services for people with ASD in South Africa.[17]

Service eligibility regulations, political advocacy, rising public and professional awareness, and wider media coverage of ASD and the interventions available for the management of ASD, have further increased demands on service provision.[22,48] In South Africa, the provision of services is complicated by the lack of resources. High mortality rates relating to infectious disease lead to preferential service provision for these conditions, to the detriment of the management of neuro-developmental conditions and disabilities like ASD.[33]

2.10.1 Referral process or introduction into services

In literature reviewed by Howlin et al, parents or primary caregivers were usually the first to note unusual behaviour or atypical development within the child's first year of life.[41] In Howlin's survey (n=770), caregivers of children later diagnosed with AD had noted symptoms of atypical development within the first 18months of life.[31,41] Symptoms were noted slightly later, at an average age of 30 months, in children later diagnosed with AS.[41]

The most common concerns noted by caregivers initially, were: the child's delayed development of language and reciprocal communication; atypical social interaction; strange behaviours including eating, toileting and tantrums; and the lack of imaginative play.[31,41]

Caregivers of children later diagnosed with AS noted similar initial concerns, but tended to emphasize the atypical social development and presence of general behavioural problems.[41]

Neither the caregivers of children later diagnosed with AD, nor those of the children later diagnosed with AS, noted stereotypical or repetitive behaviours as problematic in early life.[41] Howlin et al reported that repetitive stereotypical behaviours were first noted when the child was about three to four years old.[31,41] This is particularly pertinent as it may complicate and delay diagnosis, since the presence of stereotypical and repetitive behaviours is one of the diagnostic criteria for ASD.

On average, caregiver's first sought professional advice regarding their child, later diagnosed with AD, when the child was 2.05 years old, approximately 7 months after atypical development or behaviour was noted. Caregivers of children later diagnosed with AS, first sought help when their child was about 3.49 years old, an average of 1 year and 1 month, after atypical development or behaviour was noted.[41] These delays in seeking help may impede diagnosis and delay the commencement of intervention.

2.10.2 Professionals consulted

Most children were seen by at least three different professionals before a diagnosis of ASD was made, resulting in significant caregiver dissatisfaction and frustration with the diagnostic process.[29,41] Caregivers of children diagnosed with AS were often more frustrated than caregivers of children diagnosed with AD, due to the increased number of professionals consulted and longer delay in diagnosis.[41]

Howlin reported that the first professional most commonly consulted was the GP or a "health visitor".[41] At this initial consultation, less that 10% of the children were diagnosed. Approximately 50% of the children were referred on for further investigation. About 10% of the caregivers were told to return only if the problems persisted, and around 27% of caregivers of children later diagnosed with ASD, were told not to worry, since no significant problems were evident.[41]

Subsequent to the initial consult, caregivers generally went on to consult with specialists - most commonly: Paediatricians; Child Psychiatrists or Psychologists. Many families also reported seeing a multidisciplinary team for assessment.[41]

2.10.3 Diagnosis

Accurate and efficient diagnosis facilitates appropriate and timely commencement of intervention working towards better long term outcomes. Early intervention may work to alter the child's developmental trajectory and improve functional behaviour. It may also help to prevent secondary impairments including behavioural problems, and improve adaptive functioning.[7]

In reality, early diagnosis, appropriate referral and early, effective intervention is uncommon, complicated by the complex presentation of ASD, diverse diagnostic criteria, as well as the incapacity of service systems to provide the appropriate services as required. [40]

The process of diagnosis

The diagnosis of ASD is complex and requires specialist skill and experience since clinical observation of behaviour is used to guide the diagnosis of ASDs, rather than clinical testing or medical measures.[27] Diagnosis must be made based on the presence of specific symptoms, and distinguished from other differential diagnoses including intellectual impairment, sensory impairments and other developmental and psychiatric diagnoses with similar presentations.[31] Diagnosis is complicated by the fact that ASD affects children differently at different ages, producing different combinations of symptoms, and varying presentations and levels of severity.[7,27]

Best practice assessment should be carried out by a multidisciplinary team. The assessment should include a comprehensive interview and a clinical examination.[21] Due to the variation in aetiology, no comprehensive protocol for aetiological investigation has been determined and clinical evaluation needs to be guided by a full history and clinical examination.[7]

The literature describes evaluation guidelines which may be helpful in confirming a diagnosis of ASD. A full history should be taken, including information regarding: pregnancy; birth; developmental history; presence, absence or regression in developmental milestones; age of perceived onset of symptoms; general health including sleeping and eating habits; family history particularly of neurodevelopmental disorders; and current level of functioning.[21] Clinical examination should include: a physical examination and growth measurement (particularly head circumference), a neurological examination, skin examination and a hearing test. If abnormal neurological findings are made, an EEG and MRI Scan should be done. If a regression or loss of language abilities was noted, a sleep deprived EEG is required. Laboratory testing for Fragile X syndrome and chromosomal analysis is also recommended.[21] Cognitive and developmental assessments are useful.[31] From these guidelines, the complexity of the diagnostic process becomes apparent. Several professionals and multiple appointments may be needed to carry out these assessments. The costs of these tests are also considerable.

Delay in Diagnosis

With the revision of diagnostic criteria in the DSM-IV TR and the ICD-10, as well as the emergence of standardized diagnostic tools such as the Checklist for Autism in Toddlers (CHAT), the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule-Generic (ADOS-G), expert clinicians are now able to reliably and accurately diagnose ASD in children as young as two to three years old.[21,29,49] And yet, research shows that children are only diagnosed at around 4 years old, 2 years after their parents have begun seeking help.[29]

Studies exploring the differences in diagnosing AD and AS, found that a diagnosis of AD was typically confirmed between the ages of 3 and 5.5 years, more than three years after the first symptoms were noted by parents. AS was diagnosed between 7 and 11 years, five to eight years after caregiver's first noted their concerns.[2,8,27,31,41]
In approximately 4% of participants in Howlin's study (30 cases), an accurate diagnosis was not reached until after 20 years of age.[41]

The delay in diagnosis causes significant distress for families and delays the commencement of early, effective intervention.[29] Early intervention has been shown to improve cognitive, linguistic, social, and self-help skills, and minimize the emergence of maladaptive behavioural patterns. Early intervention together with education on the diagnosis and associated counselling, works to empower parents with more effective management techniques and coping strategies and offer them support. If diagnosis is delayed, the commencement of early intervention is delayed and the families' distress in the face of limited support is also exacerbated. The informed placement of children in appropriate schooling is also compromised.[7,29,41]

Considering the possible genetic causes of ASD, a delay in the diagnosis of one child may delay genetic counselling guiding family planning or compromise the identification of the condition in siblings with broader phenotypes and more subtle presentations.[41,7,48]

The reasons for the delay in diagnosis are extensively documented in the literature.

Shattuck and others noted that diagnoses can be given by various professionals (e.g. psychiatrist, psychologist, and educationalist); within varying service sectors (e.g. public, private, education) and for different purposes (e.g. placement, eligibility, schooling, and treatment planning).[48] The criteria for diagnosing generally vary across these different contexts, leading to multiple diagnostic evaluations with varying conclusions. The various professionals were also noted to disagree about criteria for diagnoses and use the diagnostic terms differently.[41] These factors compromise the efficiency of the diagnostic process and lead to confusion and increased financial strain on families.[48] Logistically, the increased demand on services has led to longer waiting lists particularly for specialty diagnostic centres. This also delays the diagnostic process further.

A Multidisciplinary Consensus Panel, made up of various health care professionals, parent organizations and clinical researchers, drawn from the American Academies of Neurology, Paediatrics and Child and Adolescent Psychiatry, noted several other factors impacting on early detection and diagnosis. They criticized existing screening tools, explaining that few of these tools had been tested on the general population, and that they tended to have poor sensitivity, implying that not all cases are detected by these tools. The variability in the nature and timing of early signs indicative of the presence of autism in different children and the limitations in knowledge and skill in the interpretation of these diverse signs, further compromise the reliability and validity of these tools in detecting ASD.[29] The panel recommended that critical ages for detection be identified to address this limitation. They emphasized the importance of the developmental appropriateness of these tools, together with the need to make tools adaptable to individuals with varying developmental trajectories and impairments including cognitive, emotional and motivational limitations.[29]

Another possible reason for the delay in diagnosis is the practitioner's caution in labelling a child with ASD, considering the implications of this diagnosis in terms of prognosis and the need for lifetime care and dependence on caregivers. Bax explains that this is a daunting task for a health care practitioner, particularly if there is some doubt concerning the accuracy of this complex diagnosis.[50]

Disparity in the timing of diagnosis

Children with more significant impairments tend to be diagnosed earlier than children with more subtle presentations. This is noted in the longer delays in diagnosis experienced by children later diagnosed with higher functioning AD and AS. The caregivers of these children reported that their concerns were dismissed as anxieties, and that their children tended to be diagnosed with behavioural problems relating to poor parenting styles or given an alternative diagnosis such as: ADD, emotional or behavioural disorders, rather than a diagnosis of ASD.[41]

Disparity in the timing of diagnosis was correlated with race and ethnicity in a number of US studies.[48] This disparity may reflect the cultural insensitivity of the screening tools, and/or insensitivity of professionals who struggle to communicate with caregivers of diverse cultures, and thus misinterpret the caregivers' presentation of symptoms, and perspectives of treatment and treatment outcomes.

There was also some evidence to suggest that not all areas, and not all population groups, were equally serviced, with the result that marginalized groups of people needed to travel long distances to seek help. This added to the delay in obtaining a diagnosis as well as commencing appropriate intervention.[48]

In some states in the US and in Australia, eligibility for services and funding of services is based on diagnosis. In cases where a diagnosis is not clear or where a diagnosis of ASD would allow access to better intervention or more comprehensive funding, diagnosis may be biased. Standardized functional measures have been introduced in an attempt to control this bias, by taking the emphasis off diagnosis and ensuring that clients' specific intervention needs are catered for.[48]

Caregiver experiences of the diagnostic process

Ruble et al explored caregivers' experiences of the diagnostic process. Parents generally reported that they were unable to access appropriate services in their own communities, and needed to seek help elsewhere. They also reported that they rarely encountered trained, expert professionals. In addition, resources were seldom given to parents to assist in explaining the diagnosis or the prognosis.[27]

Professionals giving the diagnosis.

Children are commonly diagnosed by specialists. In Goin-Kochel et al's study, paediatric neurologists and developmental paediatricians made the diagnosis most commonly, followed by psychologists, then psychiatrists, then teams of professionals, and in a few cases, other professionals such as the GP or school personnel.[51]

2.10.4 Services accessed

"Where there is no cure, there are 1000 treatments" Donald Cohen in Goin-Kochel et al, 2007, p195.[51]

Given the heterogeneity of the condition in terms of severity and presentation; the number of neurological systems involved; and the co-morbidities associated, research has struggled to isolate and prove the specific aetiology of ASD. Several causal factors including genetic susceptibility and environmental influence affect the expression and severity of the condition, and impact on the effectiveness of intervention strategies. Consequently, no single medical treatment or form of prevention is currently available or suitable for all people with ASD. Instead of targeting the cause of the condition, treatment aims to minimise core deficits and improve functional independence. A comprehensive, holistic and individualised, interdisciplinary intervention constitutes best management for ASD.[10,11,25,37,38]

Interventions that have been advocated include: behaviour modification, cognitive-behavioural interventions, speech and language therapy, auditory integration training, facilitated communication approaches, sign language training, visual imaging/ Picture Exchange Communication System (PECS), pharmacotherapy, vitamins, enzymes or hormones, metabolic interventions, psychotherapy or counselling, family support, dietary intervention, music therapy, physiotherapy, occupational therapy, sensory integration, sacro-cranial therapy, social skills training, structured, specialised educational programmes, respite care, residential care and vocational skills training.[11,19,27,32]

Despite the wide use and advocacy of various other interventions, many of these approaches lack rigorous scientific support. Researching the effectiveness of intervention is complicated by the difficulty in isolating the effect of one type of intervention where the child is receiving multiple therapies and treatments.[11,19]

Little research is available explaining the reasons behind caregiver's selection of intervention strategies given the relative dearth of information on treatment efficacy.[19,51]

Ruble et al summarised the key intervention outcomes and practice guidelines for the management of ASD, from a variety of sources including: the National Research Council, and The National Early Childhood Technical Assistance Center sponsored Forum on ASDs.[27] These guiding principles include:

- There are no recognized cures for ASD.
- Treatment is not universal. Different interventions work differently for different children.

- Early and intensive intervention is best.
- Family-centred models of service provision are preferable.
- Assessment information should be used to guide individualized intervention.
- Comprehensive education strategies are important. These should include a variety of therapeutic and educational strategies including behavioural approaches and structured, supportive teaching environments.
- Intervention should be directed towards treatment outcomes and progress should be monitored.
- Key areas of intervention should include: imitation, engagement, initiative, communication, play, social interaction skills, adaptation to transitions and generalization of skills to other contexts.
- Practical and proactive management of problem behaviours should be carried out.
- Opportunities for peer interaction should be created.
- "Consistency between service providers" should be striven for.[27]

While these guiding principles are based on international research, they are not context-dependent and as such, are universal and applicable to the South African context.

2.10.5 Number and type of services used

Research shows that children and their families often began accessing services and started with intervention programmes before a diagnosis of ASD had been confirmed, when the child was, on average, 3 years old.[27]

It is widely documented in the literature that children with ASD, and their families, commonly access multiple services, delivered by a variety of agencies, institutions and professionals.[18,40,51,52] And yet, evidence of the effectiveness of polytherapy or cost implications of polytherapy, is sparse.[52]

Three surveys that investigated the services used by ASD children and their families were reviewed. These studies used large samples sizes (383 to 552 caregivers), and thus the results seemed credible, with broad representation. These studies found that families and children were currently accessing between four and seven different treatments concurrently, and had tried a total of seven to nine therapies during the child's lifespan.[19,40,51] These services included: medical services, biomedical services, speech and language therapy, occupational therapy, behaviour intervention, respite care, social skills therapy, family counselling and case management.[40] Kohler et al established that the participants in their study accessed an average of four different types of institutions, seeing more than seven different professionals.[52]

In several studies, factors impacting on the number and type of professionals seen were identified. Age, and the nature and severity of the presenting dysfunction impacted significantly on the number and variety of services accessed. Children diagnosed with severe AD tend to use more treatments in comparison with children diagnosed with Asperger's Syndrome. Younger children typically received a wider range of services than older children. Family-related services were accessed less as the children aged.[19,40,51,52]

In terms of the types of interventions used: children diagnosed with Asperger's Syndrome had generally tried more drug treatments than children presenting with AD or PDD-NOS. Children presenting with AD and PDD-NOS tended to have tried more behavioural, educational and alternative therapies.[19,40,51] The use of medication increased with age, such that adolescents used pharmacotherapy most commonly. Younger children tended to make use of more diet, behavioural, educational and alternative treatments and therapies. This showed that caregivers tended to exhaust all possible non-pharmacological treatments before resorting to the use of medication. These findings may also reflect that many of the currently available behavioural, educational and alternative interventions were not available or widely used when the older subjects in the studies were younger.[51]

Green et al explored the popularity of use of different types of interventions. "Standard therapies" was the most frequently used category of intervention. Skills-based interventions and medication were also commonly used. Detoxification treatments were rarely used (less than 10% of the sample).[19]

Little evidence could be found in the literature pertaining to the reasons for the selection and discontinuation of interventions. It is also unclear as to how long interventions were used for, before being discontinued.[19]

2.10.5.1 Treatment options

The goals of treatment in managing ASD focus on improving communication and social skills, and reducing disruptive behaviour in order to facilitate better integration into the community and more independent living skills.[2]

Research describes a combination of behavioural interventions and structured educational programmes as the treatment of choice in achieving these goals. However, there are many different interventions and therapies available to manage the symptoms of ASD.[2]

Behavioural intervention

Behavioural intervention is favoured in the literature as one of the most widely researched and used modes of intervention. These methods of intervention which target social and functional communication skills are a priority in early intervention.[7] Interventions such as: Treatment and Education of Autistic and related Communication Handicapped Children (TEACH), and Applied Behaviour Analysis (ABA) are intensive, time-consuming interventions, requiring skilled practitioners and specialist facilities, and the commitment of parents and families to carry these programmes over to the home environment.[33] These services are offered by a few special schools in South Africa, and as such are largely inaccessible to the majority of individuals presenting with ASD.[33]

Medication

Presently, there are no proven medical interventions that treat the cause or reduce the core symptoms of ASD. The variation in the aetiology and presentation of ASD in different subgroups complicates the testing of psychopharmacological treatments. The poor quality of medication trials has also been highlighted. Few randomised control trials have been performed, with open-label studies and case reports being commonly used to demonstrate efficacy of treatments.[7]

Some medications have been shown to be effective in managing the secondary symptoms of ASD such as disturbances in behaviour, as a last resort, or in conjunction with other behavioural strategies.[7,27]

Neuroleptics, e.g. Risperidone, have been demonstrated to be useful in containing aggression, impulsivity and stereotypical behaviour.[7,29] Side effects may include sedative and cognitive effects, weight gain with increased appetite and drooling.

Selective Serotonin Reuptake Inhibitors have been shown to be helpful in treating adults by reducing repetitive behaviours, aggression and maladaptive behaviour with few side-effects. Little response is noted in children, and the significant risks in treating children with these drugs discourage use.[7,29]

Ritalin is commonly prescribed to treat hyperactivity and impulsivity, but may cause irritability, dysphoria and increase repetitive behaviours.[7,29]

Anticonvulsants have been used to stabilise mood and contain impulsivity and aggression however limited controlled trials have been carried out on the use of these drugs in ASD. Gastrointestinal Peptide Secretin has consistently failed to show efficacy.[29] Other treatments including diet eliminations, vitamins, immune system steroids and anti-fungal agents have not been rigorously tested or proven.[7]

Ruble et al found that 45% of the children in their study were treated with medication for emotional, behavioural or mental health problems. In their sample of 113, 29.2% used miscellaneous medications; 25.7% took antidepressants; 21.2% took anti-psychotics; 11.5% took stimulants; and less than 10% took anticonvulsants, anti-hypertensives, sedatives, or mood stabilisers.[27]

Occupational Therapy

By definition, occupational therapy aims to improve the adaptive functioning of the child with ASD. Occupational therapy strives to improve the child’s independence in self care, play, work and leisure activities, thereby improving quality of life through meaningful participation in activities of daily living. The family and physical context is also explored and managed in order to support the child's functioning and the quality of life of the whole family.[23] Watling et al in surveyed OT's working with children with ASD in the USA.[23] They found that the occupational therapists largely applied the sensory integration and skills building approaches in treating children with ASD. Occupational therapy sessions tended to be direct, individual sessions, focusing on improving self regulation and sensory processing, praxis, language and communication, oral motor control, feeding and social interaction.[23]

Education

Academic learning is important to the child's development, but social and emotional well being, participation in school and recreational activities and effective integration into the social school environment are key to ensuring that the child with ASD has a sense of belonging and is acknowledged and esteemed.[29]

Delay in diagnosis may lead to placement in inappropriate schooling, selection or application of ineffective teaching strategies and inadequate learning. This may result in secondary complications like poor self esteem, educational failure, depression, rejection by peers, and harsh discipline, which increase vulnerability to other psychiatric conditions and emotional difficulties in adulthood.[41]

School placement should therefore be carefully considered, taking into account the child's characteristics, the programme content and the presentation and support services available, in order to ensure optimal student outcomes concerning, academic achievement, emotional stability, and social integration.[39]

Education principles have been debated and changed over the years. In Canada, prior to the 1980's, children with ASD were placed in small, special classes together with other children with varying diagnoses. These schools were traditionally located away from the children's residential community.[29] Post 1980, inclusion policies aimed to deinstitutionalise children by including them in public schools on part-time or full-time programmes. This policy made the development of specific Individual Education Plans (IEPs) compulsory for each learner, in consultation with their parents, and taking into account individual learning needs and styles.[29,36]

Ruble et al found that 86% of the children in their study were in “public school programmes attending general education classrooms”[27] and 6% of the children attended private schools or were home-schooled.[27] 92.8% of children followed an Individualized Educational Programme (IEP), 48.4% of these included a behaviour plan, and 25.8% received extended school year services Caregivers did not report significant satisfaction with the child’s education programme and they rarely found the educators to be well-trained in the latest methods of educating children with ASD.[27]

White et al explored the relationship between child characteristics, educational placement and patterns of school-based service use. They found that children with AD, with significant impairment in cognitive ability and communication skills tended to be in special education classes part or full-time, while children with PDD-NOS and AS or higher functioning children with AD tended to be in mainstream (inclusive) classes.[39] They found that there was insignificant movement between different types of schools such that children that started school at a special school, tended to remain in the special school for example. Communication skills seemed to be the biggest indicator for the use of special services within the school context.[39] The most frequently used services were school-based speech therapy and occupational therapy. There was minimal use of school-based social skills services, despite clinically proven impact of social skills on the academic progress of children with ASD.[39]

Better outcomes have been noted in children who have been exposed to highly structured, routinised teaching environments, which nurture the children’s strengths and compensate for their deficits.[25] Their diverse needs are best met by increasing the teacher to pupil ratio, and instituting a multidisciplinary approach. Collaboration between professionals, teachers and parents is fundamental in ensuring effective comprehensive service, with ongoing support, information sharing and problem solving between team members.[39] A minimum of 25 hours of specialised educational input is recommended at a preschool level.[36] Goals should be set and progress measured accordingly.[39] Teacher aides may also be used to facilitate the implementation of IEPs. The design and implementation of IEPs with children with ASDs is difficult. It is therefore recommended that teachers receive additional training in the use of evidence-based methods of education and the management of behaviour to ensure adequate knowledge and skill in implementation of these programmes in order to maximise the programmes' outcomes.

Evidence-based outcomes related to inclusive education are contradictory. No significant differences in learner outcomes in inclusive versus segregated classrooms have been proven.[39] Some studies have shown that inclusive education promotes contact with typically developing peers. But, children with ASD are generally poorly accepted by these peers and few actually form friendships with these peers. Thus the opportunity for social skills development is limited rather than facilitated by the peers.[39]

In inclusive classrooms, teachers may not be able to accommodate the special needs of learners with ASD. In turn, teachers' focus on the special needs learners may compromise the education of other learners. Children with ASD may find it difficult to follow changing schedules, or challenging curricula in a mainstream school. They may struggle to keep up with their peers, resulting in greater dependence on facilitators, and further compromising independence.[39] The discrepancy between cognitive capacity and the level of functional independence in activities of daily living was found to be larger in children attending mainstream schooling, than children attending special schools. It was deduced that placement in regular mainstream education may widen the gap between capacity and functional skill due to the lack of focus on basic social and life skills in mainstream school programmes. This is in contrast with special schooling, where learning of these skills may be a focus of the educational programme. This leads to a widening in the developmental gap between children with ASD and their typically developing peers with age.[39]

Education in the South African setting

Since 1994, educational policies have undergone a radical change in South Africa. White Paper 6 of 2001 introduced policy to build an inclusive education and training system as a means of eradicating exclusion based on race and disability, and ensuring adequate learning opportunities and resources for all.[53] No studies could be found on the impact of this policy on the placement and teaching of the ASD cohort of children in South Africa currently..

Disparities in service provision for different racial groups and children with and without special needs continue to exist in South Africa. The White Paper outlined the current profile and distribution of special schools and those accessing them.[53] Gauteng has the largest number of special schools (96) in the country. According to census information, Gauteng's disabled population constitutes 17.14% of the country's disabled population, but 25.26% of the country's special schools. The disparity between needs and service provision resulted from the allocation of resources according to race in the apartheid era. This resulted in learners needing to travel long distances to attend residential special schools in provinces other than their residential provinces, where no facilities were accessible to them.[53]

While no studies pertaining to the education of children with ASD in South Africa could be accessed, some literature regarding access to educational facilities for children with disabilities in Soweto, Johannesburg, was found. Saloojee et al (2007) noted that in Orange Farm, Johannesburg, only 44% of disabled children between the ages of 7 and 15 years, were attending school. Of the group attending school, 55% were attending mainstream schooling and 45% attended special schooling, training centres or day-care centres. A large proportion of the children were not attending school, despite the children's rights to attend school being entwined in the constitution. Of the children presenting with motor disability, 42% were not attending school and 44% of children with intellectual disabilities were not attending school.[54]

2.10.6 Frequency of services accessed.

The large number of interventions accessed by children and their caregivers has been explored in detail. However the cost and the challenges experienced in accessing these different services cannot be fully understood without determining the frequency with which these different services are accessed.

Ruble et al surveyed a sample of 113 caregivers regarding their use of various interventions. They explored the type and dosage of interventions accessed, and the cost incurred in accessing the various treatments or therapies. Limitations of this study include: the small sample size and exclusive inclusion of therapies or interventions accessed in the last 6 months only. This introduced variability in results related to the age of the child and the severity of their clinical presentations, and failed to account for therapies previously used.[27]

Despite these limitations, the following findings are interesting in the context of this study: The majority of the sample (62.8%) had used pharmacotherapy in the previous 6 months. Caregivers reported that they consulted with a doctor in order to review the child's medication, an average of three times a year. They travelled an average of 75 miles to get to these follow up appointments.[27] Approximately 36% of caregivers received parental counselling or training. They attended these sessions an average of 7.7 times in 6 months (slightly more frequently than once a month).[27] About 42% of children attended individual therapy sessions. These sessions were generally attended two to three times weekly.[27] In-home behaviour therapy was accessed by 22% of subjects, an average of three times a week.[27] The majority of subjects (63%) attended both speech therapy and occupational therapy. Speech and language therapy was attended by 76% of the children. The average frequency of attendance was twice weekly. Occupational therapy services were accessed by 68% of the sample. They attended sessions once a week on average.[27]

Some caregivers (27%) consulted with case managers. These consultations were held once or twice a month, on average.[27] 29% of families made use of respite care services, on average twice a month. Only 6% of children had received in-patient psychiatric or residential care in the previous 6 months. The admissions were an average of 47 days or approximately 7 weeks in duration.[27] Other interventions were accessed by 12% of the sample. These interventions included: reading and comprehension tutoring, vision therapy, hippotherapy, biomedical interventions, recreational therapy, community coaching, and physical therapy.[27]

2.10.7 Outcomes of intervention

Language ability is the most recognized predictor of adult outcomes. Adaptive functioning may be a more accurate predictor of outcomes, however it is poorly researched and documented.[29]

There are many different intervention approaches described in the literature. Characteristics of programmes with good outcomes include: adequate time spent in intervention (mostly >20 hours per week); individualized, focused programmes targeting specific and individual language, communication, social skills, play, cognition, and independence skills; specific, well planned and co-ordinated instruction and service provision.[23] Specific models of intervention have been shown to be more useful than an eclectic assortment of teaching or therapeutic techniques.[29] Parental counselling, behavioural interventions, sensory integration, social skills training, speech and language therapy, medication, family support and an individualised, structured and specialised education programme have been shown to be effective in managing ASD.[25] Respite care was found to be most effective in reducing parenting and financial stress.[52]

Caregiver perceptions of outcomes

In Ruble et al's study, the total number of services, type of services, and dosage of therapy had no significant impact on caregivers' perceptions of the efficacy of treatment or treatment outcomes.[52]

Caregivers rated in-home behaviour therapy as the most effective intervention, followed by medication.[52] Parents of younger children reported more satisfaction with services than parents of older children. This could reflect that service providers are not catering well for the specific needs of older children and thus service provision is not as effective or meaningful. Alternatively this could reflect parents' burnout, or the waning sense of satisfaction over time, which could be related to the realization and acceptance of the child's diminishing progress and likely future prognosis.[52]

Services prioritized by caregivers in Ruble et al's study included: social skills, speech and language therapy, behaviour management, respite care, in-home therapeutic support, occupational therapy, counselling, case-management.[52]

2.10.8 Cost of intervention

"..children who have autism have a substantial burden of medical illness as manifest in health-related activities and expenses." Liptak et al p 876 [18]

Research has shown that the cost of services is affected by the complexity of the disorder, the diversity of functional impairments and the number of co-morbidities. These factors influence the number of professionals consulted, the duration of professional care (throughout the lifespan), the medication prescribed, assistive devices provided, as well as the dependence on social supports.[18,55,56] Given the complexity of ASD and the multitude of services accessed by caregivers and their children diagnosed with ASD, the financial burden on caregivers as well as health, education, and social services is noteworthy.

Landrigen et al estimated a lifetime cost of $1 680 000 for people diagnosed with ASD, while Jarbrink and Knapp estimated the lifetime cost in excess of 12 400 000 pounds. These calculations incorporated the costs of "living support and day activities". Information on medical expenditure was sparse and prevented accurate estimates of lifetime medical expenditure. Consequently, medical expenditure was not incorporated into these lifetime cost estimates.[18,55]

Liptak et al analysed the data from three national surveys: The Medical Expenditure Panel Survey (MEPS); The National Ambulatory Medical Care Survey (NAMCS); and The National Hospital Ambulatory Care Survey (NHAMCS), in order to determine relative medical utilization and health-care expenditure of caregivers and their children with ASD in USA.[18]

The Medical Expenditure Panel Survey (MEPS) found that the children with ASD were more likely to have private insurance. Most (98%) of the children with ASD followed a specialized education programme, similar to 73% of children diagnosed with cognitive impairment. This finding was significantly different from normal children or children diagnosed with depression.[18]

Collectively, these surveys reported that the average annual medical expenditure of a typically developing child was estimated at $ 860, and $3860 for a child with cognitive impairment, compared to a child with ASD, where cost was estimated at $ 6 132.[18] Children with ASD generally attended more outpatient and physician visits and were prescribed more medications, than other children.[18]

Children diagnosed with ASD averaged 42 outpatient visits per year, at a cost of $3 992 (equal to 65% of their annual medical expenditure). In comparison, other children had an average of 3.3 outpatient visits annually, at a cost of $355. Children with ASD consulted the physician for at least 32minutes, 8 times a year, spending $869 on these visits, while children in general consult with Physicians for 15.8 minutes, twice a year at a cost of $200 annually. 24% of children with ASD were found to be taking psychotherapeutic medications (most commonly risperidone). They were prescribed an average of 21.8 medications and refills, at a cost of $971 annually, compared to other children who averaged 2.1 prescribed medications at a cost of $77 per year. General out-of-pocket medical expenditure for children with ASD was calculated at $613, while other children spent $193 on out-of-pocket expenses annually. In addition, children with ASD commonly accessed some form of home health care at a cost of $2 239 per year.[18]

A large portion of children with ASD (92% in Liptak et al's study) require specialized schooling and individual education plans. It was noted that children with ASD missed, on average, 25 days of school per year related to their condition.[18] The Special Education Expenditure Project conducted by the American Institutes for Research for the U.S. Department of Education, documented the mean annual education expenditure in 1999-2000. They reported that the average cost per pupil diagnosed with ASD, per year for standard education was $1 230. In addition, special education and related services cost an average of $11 543 per pupil per year. These costs were compared to those for a child with cognitive impairment, where standard education cost an average of $1 093 per child annually, and $8 153 per year for special education and related services.[18]

Ruble et al found that 21% of participants had publicly-funded health insurance, 76% had private insurance, and 2% of participants had no insurance.[27] The study noted that different resources covered different types of services. Medication tended to be funded by medical aids. Parent counselling and training, and individual therapy for the child, were largely paid for by the parents themselves. School fees tended to cover school-based services such as occupational therapy and speech and language therapy. In-home behaviour therapy was generally funded by particular funding agencies according to eligibility criteria. Case management and respite care were covered by medical aid schemes most commonly and then by funding agencies. Funding agencies tended to cover treatments with highly rated outcomes, including behaviour therapy and respite care.[27]

2.10.9 The South African Healthcare System

The National Health Act [61 of 2003] implemented a new health system in South Africa, eradicating racially biased service provision and decentralizing health care, emphasizing easy access to primary health care for all.[57]

Despite the new policy, change in the health system has been slow and many disparities in service provision still exist. Two distinct health systems exist currently: a private and a public health system, however the implementation of a national health insurance is being considered in order to unify these two systems.[58]

The private sector serves a mere 16% of the population who has access to private medical aids. Medical aid fees are split between the employer and the employee. Medical aid schemes vary according to individual preference and means. Medical aids rarely cover all medical expenses and members are forced to cover additional costs of health care and medication. While the cost of private health care is considerable, service is generally of a high quality.[57,58]

The remaining 84% of the population is served by the public sector health system. A small percentage of this group also accesses private health care according to their means. Public health care is funded by the government at a national and provincial level. Public health care is free for pregnant women, children under the age of 6 years old, and people with disabilities. Otherwise, public health services are billed for according to a sliding scale relative to the means of the patient. The quality of public health care varies according to location, and human and non-human resources. Urban, tertiary facilities tend to offer better service than rural, district facilities.[57,58]

2.11 Factors impacting on service delivery and access

Children with ASD have such different presentations, associated conditions and developmental trajectories that their service needs and response to interventions vary significantly. The management of ASD thus requires comprehensive, intensive, specific treatment, including a variety of medical, therapeutic and supportive interventions. This presents a significant challenge to service provision, policy and funding schemes. Given the depth and breadth of services required by this group and the relative costs involved, rationalization of spending and service provision becomes vital. However, there is inadequate evidence describing the specific needs or justifying which services or combinations of interventions will facilitate the achievement of intervention outcomes and meet the needs of different groups of children. This makes it difficult to justify the allocation of public resources for such intensive intervention and compromises the provision of equitable, affordable and effective services.[48]

Shattuck et al described barriers to the provision of specific, intensive intervention including early intervention and special education, based on the Individuals with Disabilities Education Act.[48] The high cost of services, and the questionable legal responsibility for the provision and funding of these services were identified as key challenges. Dispute has arisen over the type of

intervention that should be made available, the intensity, length and frequency of sessions and the context in which intervention should take place.[48] Considering the available budget, the cost of such programmes is high and relatively unequal for differing diagnoses. The cost for a full-time, intensive intervention programme per child per year is approximately $40 000. The average amount spent on the special education of children with ASD is $18 790, while expenditure on a child not receiving special education is about $6 556.[48]
Law discussed some of the challenges experienced in Canada, in the provision of occupational therapy services, and services in general throughout the child's lifespan. She notes the shortage of experienced occupational therapists, with post-graduate training as a barrier to effective service provision. It is also noted that occupational therapy is seen as a non-essential service, and as such, funding of this service is limited. Due to the impairment in adaptive functioning, children with ASD experience difficulties in adapting to transitions between the different developmental stages. Funding schemes tend to focus on popular behavioural interventions for the younger child, rather than funding eclectic treatment approaches, which address differing needs encountered at the different stages of development. As the child ages, case management also shifts between different service sectors. At each shift, funding problems and long waiting lists hamper effective, efficient intervention.[23]

Law discussed some of the challenges caregivers identified. The caregivers noted that they had limited awareness and knowledge of the kind of services that would be most appropriate for their child and family, and that they had struggled to find experienced professionals who were able to provide the necessary services. The quality and quantity of available services was also concerning to them.[23]

Research conducted in the U.S.A. by Thomas et al (n=383), explored the impact of family characteristics on the use of autism-related services.[40] The study showed that services were accessed differently by different groups. Racial and ethnic minority families, low parental education and living in a non-metropolitan area, were the factors associated with limited service access. These groups tended to access less services and different types of services compared to other groups. Differences were attributed to a lower socio-economic status, disparity in service sectors providing services, and cultural factors. Access to services was compromised by the shortage of outreach services to outlying areas. Inadequate sensitivity to cultural diversity and religious belief, and discrimination in the practice of service providers, client-professional relationship, and assessment and treatment procedures, were associated with low service use by caregivers of minority groups, who reported mistrust of professionals and service providers. Stigma was also described as a barrier to service access in these groups.[40]

Higher family income was associated with increased service use. Caregivers with a higher level of education showed a greater cognizance of their needs and rights and were more aware of the services and resources available to them. They were thus empowered to advocate successfully and demand better service delivery.[40]

Research has also shown that caregivers were less likely to report difficulties in accessing appropriate services for their children with ASD, when they were covered by public and private insurance.[40]

The study also noted that child characteristics including age, and severity of impairment, impacted patterns of service use. Caregivers of younger children, with greater functional impairment, and who experienced greater stress, tended to access more services, more urgently. The most common services accessed by these caregivers included medication and respite care. Families with more than one child with special needs tended to access fewer services and express greater discontentment with service access than others. These families identified the need to develop policy, practice and family interventions to overcome their barriers to service access.[40]

Some methodological limitations were noted in this study. The sample was recruited from ASD-related health and education service registries. Thus people with limited resources and no access to a service network were not represented in the study. Volunteer bias also plays a role. The participants may have had different characteristics in terms of energy, time, motivation and stress, when compared with families who opted not to participate. These factors may have distorted service use findings and underestimated barriers to care.[40]

Saloojee et al conducted a community-based study, exploring prevalence of disability and use of services in Orange Farm, Johannesburg. While children presenting with emotional and behavioural problems including autism, were excluded from this study, the findings describe key factors impacting on health, social and educational service provision in general in the semi-urban South African context.

The study found limited service use by the disabled population. Only 44% of school-going aged children with disabilities were attending school; 26% of children who required rehabilitation services were actually accessing rehabilitation services; and of the 78% of children found to qualify for social grants, only 45% were actually receiving grants.[54] Saloojee et al (2007) reported these caregivers' reasons for not accessing services in Johannesburg. These reasons included: financial constraints; poor awareness of available services and rights to health, educational and social services; and bureaucratic obstacles including lack of information, limited empathy of service providers and inadequate implementation of policy, as the major reasons for poor service access.[54]

Further, this study noted limited collaboration between the departments of health, education and social welfare relating to the management of disability. Saloojee et al explained that this lead to fragmentation in service provision and exacerbated poor awareness and use of available services in the community.[54]

The inadequacy of public health services is acknowledged in the government document outlining the policy guidelines for child and adolescent mental health.[59]. Inaccessibility of services, particularly in rural and poor areas; the limited number of appropriate mental health service facilities; and the limited expertise and availability of trained professionals, especially at a primary level, are described.[59] While strategies have been determined to address these inadequacies, studies demonstrate that transformation of service provision remains elusive in South Africa.[59]

2.12 Improving service delivery and effectiveness of intervention

Ruble et al made the following recommendations to facilitate improvement in service provision.[27]

- There is a significant need for more co-ordination and consistency between service providers including therapists and educators.
- Schools need to provide training and support to caregivers.
- Parents need more access to speech and language therapy outside school system.
- Funding should cover parent counselling and training as a standard intervention.
- Individual therapy is vital and should also be funded adequately.
- More families need funded access to respite care.
- In-home behaviour therapy is subjectively viewed by parents as a helpful but very costly intervention. Lobbying for greater funding for this intervention would be helpful.
- More information should be made available about case management and in-patient hospitalization or residential placement. Only once caregivers have been adequately exposed to these interventions and their benefits, can the need for these services be ascertained.
- Delays in diagnosis need to be addressed in order to maximize the effects of early intervention.
- It is important to describe the lack of services and trained professionals, in an attempt to lobby for better service provision.

Saloojee et al emphasised the need for a comprehensive response to the needs of caregivers and their children with disabilities. They suggested the development of outreach services, projects and community-based rehabilitation. The need for the establishment of support networks for caregivers and increased education of caregivers on disabilities and the available services was also emphasised.[54]

2.13 Summary

In summary, the literature reviewed described a 25 fold increase in the prevalence of ASD since the 1980's, such that currently, 1 in 160 children present with ASD. While better awareness of ASD and improved diagnostics have been associated with this rise in prevalence, some assert that there is increased risk due to environmental factors.
ASD is thus the second most common developmental disorder in the USA. This has important implications for service demand and gives justification for service provision and budget resources.

Due to the complexity and heterogeneity of the condition in terms of severity and presentation and the associated co-morbidities, research has struggled to isolate and prove the specific aetiology of ASD. This makes the diagnosis and treatment of ASD very complex. Clinical skill and expertise are required to reach the correct diagnosis efficiently through clinical evaluation. Delays in diagnosis are common, affected by several factors including: the complexity of the condition; inadequate screening tools; poor skill and expertise of professionals; and poor referral procedures. The delay in diagnosis impedes early intervention which can be detrimental to treatment outcomes.

There is no single cure or treatment to address the causes of ASD. Instead, treatment aims to minimise core deficits and improve functional independence. A comprehensive, holistic and individualised, interdisciplinary intervention constitutes best management for ASD. As such, children with ASD and their families consult up to nine different professionals, trying various different types of intervention, regardless of their evidence-base. Since many of these interventions are time-intensive, long-term interventions, the health costs incurred for the family as well as the state are considerable. Special schooling and educational programmes also need to be individually formulated and supported by skilled teaching and therapeutic input, which is resource-intensive.

The stress, challenges and burden of care caregivers of children with ASD endure, in comparison with other parents, is also significant. Family dynamics and experiences have a significant impact on the vulnerability and resilience of children, and thus on the functional outcomes and disability of the child with ASD. This highlights the importance of adopting a family-centred approach whereby the need for supportive therapy for the family is balanced with the needs of the child with ASD, in order to reach optimal treatment outcomes.

There was a paucity of South African research found discussing the epidemiology of ASD and the use and efficacy of different interventions in SA. Generic health, education, and social research described some of the challenges caregivers of disabled children faced. These included: financial constraints; poor awareness of available services and rights to health, educational and social services; and bureaucratic obstacles including lack of information, limited empathy of service providers and inadequate implementation of policy. However, there is limited information on the challenges faced by caregivers of children with ASD specifically in South Africa. This information would be helpful in identifying weaknesses in service delivery and access, and suggesting solutions to facilitate better management of the complex condition that is ASD.

CHAPTER 3:
DEVELOPMENT OF THE RESEARCH INSTRUMENT

3.1 Introduction

The purpose of this study was to explore caregiver's perceptions and experiences of service provision within the Johannesburg Metropolitan Region, for their children diagnosed with ASD. To achieve this, the study focused on three key issues pertaining to service provision. These included: the patterns of use of health and education services; the factors compromising service access and use; and the factors that facilitate better service provision. The experiences of service provision in the private and public sectors were then compared.

An appropriate questionnaire that collected data specific to the study objectives and was suitable for the South African context, could not be found in the literature. A questionnaire therefore had to be specifically designed for the purpose of this study, and its reliability and validity tested.

Consequently, this research study consisted of two parts:

1. The design and piloting of the research instrument – a self-reported questionnaire.
2. A descriptive and analytical study pertaining to the research objectives.

This chapter will discuss the development and piloting of the self-reporting questionnaire used for data collection. Validity and reliability of the questionnaire will be outlined. Part two, the research method utilized in the descriptive and analytical study, will be described in Chapter 4.

3.2 Identifying the need for the research instrument

Several questionnaires utilized in international research, exploring caregivers' service use for their children with ASD, were critically reviewed.[19,27,32,46] None of these questionnaires had been used in South Africa. Many of the interventions described in these questionnaires are not widely available in South Africa. In addition, educational policies and the design and implementation of educational programmes in South Africa are not comparable with those used internationally. The health systems, health insurance and structure of service delivery also differ. It was thus decided that a questionnaire be specifically developed to gather the relevant information to meet the research objectives laid out in Chapter 1, and ensure relevance to the South African context.

3.3 Identifying the purpose of the research instrument and the most suitable study population

The purpose of the research instrument was to gather both quantitative and qualitative data that would describe the use of services by caregiver's of children with ASD in both the private and public health and education settings in Johannesburg, and give insight into their experiences of these services and the challenges they experienced in accessing help. It was envisaged that this information could be used to identify shortfalls and strengths in current service provision and ultimately make recommendations on how to improve service delivery.

The South African population is diverse in terms of its demographic characteristics. Historically, characteristics such as race, socio-economic status and educational level, have influenced the individual's access to services. It was thus important that the diversity of the South African population be represented in the study, as far as possible. The content and format of the research instrument needed to be designed to enable participation of subjects of varying literacy and educational levels, socio-economic status, language and race. It was decided that a single measurement tool be developed and used to ensure validity and reliability of the information gathered. However, the administration of the tool needed to be adjusted according to the profile of the participant. As such, the questionnaire was self-administered by able participants, and a face-to-face interview was used to fill out the questionnaire with participants who were unable to complete the questionnaire independently.

3.4 Defining the underlying constructs

Once the research objectives had been set, a consistency matrix was drawn up to define and describe the constructs that arose from the objectives. (See Appendix A) In defining these constructs, factors were identified that needed to be measured by the research instrument. Existing research that explored service use and experiences of caregivers and children with ASD in accessing services was used to inform the definition of constructs.[19,27,32] Clinical experience in the South African public health and special education facilities serving caregivers and their children with ASD was also used to ensure that the description of constructs and factors was appropriate to the South African context.

3.5 Formatting of the questionnaire

The research aims and questions were determined by reviewing the existing literature and taking into account clinical experience. It was decided that a questionnaire would be the most suitable research tool to generate the relevant information to answer the research questions, as it could be used to generate both qualitative and quantitative data, and was a relatively inexpensive method of data collection.[60] A self-administered questionnaire was preferable as the participants could fill out the questionnaire at their convenience, anonymity was preserved and interviewer bias prevented. Follow up systems had to be in place to ensure return of the questionnaire. To ensure a racially and socio-economically diverse sample, "face-to-face administration" of the questionnaire was necessary to facilitate participation of "hard-to-reach populations"[60], and the participation of respondents who were illiterate.

The questionnaire was formatted such that each question was followed by answer options. Participants were required to tick the options they felt best applied to their situation. This design was used in order to speed up response time. Likert scales were used in the questions pertaining to the use of, effectiveness of, and need for various interventions. No open ended questions requiring paragraph answers were included initially.

3.6 Development of items making up the questionnaire

The research instrument was developed by formulating specific questions that would operationalize the constructs. Questionnaire 1 was thus developed. (See Appendix B)

Questionnaire 1 consisted of 37 questions, which were divided into two sections.

Section A consisted of 11, quantitative questions about the caregiver and the family. These questions included:

- Relationship of the caregiver to the child
- Caregiver age and gender
- Family composition
- Location and type of housing
- Level of education
- Income.

This section was included in order to establish basic demographic details of the sample. It was hoped that a diverse sample could be included in the study so that the impact of various demographic factors, including socio-economic status and educational level, on service use could be explored.

Section B consisted of 26 questions concerning the child presenting with ASD.
These questions included:

- Child's age and gender
- Age at which the child was diagnosed
- Child's diagnosis and co-morbid diagnoses
- Time taken to get a diagnosis
- Professional who made the diagnosis
- Number and type of professionals consulted
- Caregiver's understanding of the term "ASD"
- How caregiver found out more about ASD

- Institutions accessed
- Specific treatments that have been used and their effectiveness
- Treatments that caregivers would like to access
- Medications and supplements the child takes
- Cost and affordability of treatments
- Educational facilities accessed and needed
- Services child or family needs
- General quality of life of the family.

The questions in Section B were important in extracting the information pertaining to the research objectives concerning patterns of service use, and the needs of caregivers and their children presenting with ASD. It was hoped that challenges in service provision could be identified through comparison of the services used and needed, to the services that were not available to caregivers and their families.

3.7 Content Validity

The purpose of this study was largely descriptive. It was thus appropriate to establish content and construct validity of the research instrument to be used in the study.[60]

Three methods were used in establishing content validity of the questionnaire.
These were:

i) Reviewing of existing literature on the subject matter.
ii) Reviewing of existing questionnaires exploring similar constructs.
iii) Review of the questionnaire by an expert panel.[60]

The questions and answer options laid out in Questionnaire 1 were developed based on the available literature and clinical experience paying particular attention to ensuring that the questions comprehensively reflected and operationalized the constructs.

After Questionnaire 1 had been drafted, it was reviewed by an expert panel.[60] The questionnaire was sent to each expert for independent review. Thereafter, meetings were scheduled with each expert to discuss feedback on the questionnaire and recommended revisions.

The expert panel was made up of five professionals with expertise in the field of ASD and/or Research. This panel included:

1. A Neuro-developmental paediatrician with more than 10 years clinical experience in the management of children with ASD, and research and post-graduate teaching experience.
2. The principal of an autism-specific Special School, with more than 10 years experience in special education.
3. A sensory integration-trained occupational therapist with experience in treating children with ASD and with research experience in the field of ASD.
4. An experienced physiotherapist with research experience including research into the experiences of caregivers of children presenting with cerebral palsy.
5. An experienced occupational therapist with expertise in the field of psychiatry and research.

The practitioners were asked to review the clarity, relevance and significance of the questions and the answer options, in an attempt to ensure validity and focus the questionnaire on the appropriate content, eliminating unnecessary and inappropriate detail.

The research experts were asked to review the format and design of the questionnaire and discuss the implementation of the questionnaire on the intended population.

A statistician was also consulted to review the format of the questionnaire for the purposes of data capturing and analysis.

Two child psychiatrists and one child psychologist who work in the field of ASD were contacted to participate in the expert panel and review the questionnaire. However, they were unavailable to meet with the researcher and review the questionnaire within the time limits of this process. The omission of this professional perspective may have influenced the inclusion and exclusion of content in the questionnaire, which may have impacted on the relevance of the questionnaire.

3.8 Feedback from the expert panel

The panel expressed concern that the questionnaire was too lengthy and covered too many topics too broadly. The content of the questionnaire was revised in an attempt to simplify, shorten and focus the questionnaire, and discard irrelevant questions. One of the initial objectives regarding reviewing of the needs of the caregivers was eliminated and it was decided that the questionnaire focus on the patterns of service use and the caregiver's experiences of service access. All questions regarding the needs of caregivers were thus removed from the questionnaire. Question 17, which asked caregivers to tick the specific treatments or therapies they had used, and then rate their efficacy, was removed from the questionnaire, in an effort to focus the questionnaire more on the process of service access and the general experience of the process of service provision rather than reviewing specific treatments and treatment efficacy. It was also felt that the format and content of this particular question was inaccessible and inappropriate to some of the intended participants. Quality of life questions were also removed in an effort to focus the questionnaire.

Some debate was held with the panel regarding the implementation of Questionnaire 1, and the intended study population. The instructions on how to fill out the questionnaire were revised to ensure that they were comprehensive and clear so that the questionnaire could be successfully self administered by able participants. Participants who were unable to fill out the questionnaire independently would be interviewed by the researcher and/or a translator.

3.9 Development of Questionnaire 2

All answer options were tabulated and coded for data analysis purposes, according to the statistician's recommendations. Questions and answers were edited to ensure that appropriate nominal and ordinal data could be generated easily from the questionnaire. Some questions and answers were revised and clarified to reduce ambiguity and ensure intelligibility. Some questions were split into multiple questions for ease of understanding and accurate response.

The 26-item “Household Economic and Social Status Index” (HESSI) (Barbarin et al, 1995) was included in the questionnaire as a tool to measure socio-economic status. The HESSI has been standardised for the black urban population in South Africa.

Questionnaire 2 was drafted. (See Appendix C) The questions were reorganized and regrouped into eight sections instead of two sections. This provided for better categorization of questions into themes which correlated with the research objectives, and followed the timeline of service access. This made the content easier to follow.

The sections were as follows:

- Section A: “You and Your family”, consisting of 10 questions.
- Section B: “Child who has been diagnosed with ASD”, consisting of 2 questions.
- Section C: “Early Signs”, consisting of 5 questions.
- Section D: “Looking for help”, consisting of 2 questions.
- Section E: “Getting a Diagnosis”, consisting of 13 questions.
- Section F: “Finding more information about ASD”, consisting of 1 question.
- Section G: “Starting intervention after diagnosis”, consisting of 5 questions.
- Section H: “How is your child doing at present”, consisting of 9 questions.

Open-ended, qualitative questions were included to ensure depth of information and prevent prompting of some information by answer options. Three open-ended questions regarding early birth and medical history, and the first signs and symptoms noted, were included in Section C, with a view to gaining a detailed description of the early history which may have impacted on how many services were accessed and the timing of this service access. Two open-ended questions were included in Section E, to enquire about: the challenges and supports caregivers had experienced in seeking help for their children. An open-ended question was also included in Section G about the child’s early school history.

Questions in Section E were adapted to ask caregivers to identify the sequence in which they consulted different institutions and practitioners. These responses could later be ranked, and a process of referral interpreted.

A more direct question was included in Section E regarding challenges caregivers had experienced in accessing service, a topic which had not been well explored in Questionnaire 1.

Section H was included to ascertain the child's level of functioning in daily activities as well as the child's level of speech and communication. It was discussed that the level of functioning and severity of impairment may impact on the number and type of services accessed as well as the age at which children began accessing services.

3.10 Construct Validity

Convergent construct validity was ensured by including both quantitative and qualitative questions that explored the same factor. In some cases, an open-ended question was asked near the beginning of the questionnaire, while another question relating to the same topic was asked later in the questionnaire, this time giving answer options that could be selected and prioritized. These two answers were compared to determine whether the questions were understood by the participants and whether their answers were reliable and valid. This gave some level of convergent construct validity and internal consistency. No statistical measures of validity were calculated however due to the nature of data compared.

3.11 Piloting of Questionnaire 2

Questionnaire 2 was then tested in a pilot study. Four caregivers of children attending an ASD outpatient clinic were recruited to participate in the pilot study. Questionnaire 2 was administered by means of a face-to-face interview. The purpose of the pilot study was to identify: any difficulties experienced in the administration of the questionnaire; irrelevant or inappropriate content; and ambiguity of instructions, questions or answer options.

The questionnaire took a long time to administer and the interviews lasted between 60 and 90 minutes. The participants gave very positive feedback on the content of the questionnaire and the research in general. Caregivers did not report discomfort with the time taken to complete the questionnaire. This may have been influenced by the fact that the questionnaire was filled out directly after their appointment with the therapist, and thus caregivers were not expected to make an additional appointment to fill out the questionnaire.

3.12 Development of the final Questionnaire 3

Given the time it took to administer the questionnaire, the questionnaire was edited further to reduce the content, and Questionnaire 3 was developed. (See Appendix D)

It was decided that the HESSI would be excluded. Instead, 7 questions were added to Section A of the questionnaire to ensure that adequate demographic information was collected in the absence of the HESSI. These questions included: household occupancy, marital status, educational level, occupation, income and medical aid.

The open-ended questions regarding birth and medical history in Section C, and school history, in Section G, were removed from the questionnaire as these questions were time consuming and yielded superfluous information, which had been covered in other questions.

The answer options to Question 23, in Section D of Questionnaire 2 were reformulated and coded for easier data analysis. Question 24, in Section D of Questionnaire 2 was also reformulated to include the sequence in which institutions were accessed, so that the pattern of referral could be established during analysis. Question 27 of Section E in Questionnaire 2 was re-categorised and moved to Section D in Questionnaire 3, to improve the flow of questioning.

Questions 22, 23, 24 and 29 of Questionnaire 2 were removed from Section E, as the responses to these questions in the pilot study did not add value.

Section G of Questionnaire 2 was completely revised as the questions did not yield adequate information to meet the research objectives. Items from Ruble et al's (2004) questionnaire were adapted and included in this section.[27] Section G in Questionnaire 3 consisted of 35 questions. Services were broadly categorised into: medical; residential care; counselling and support; speech therapy and occupational therapy. Questions explored the use of services; frequency of access and cost. Caregivers were also asked to select and prioritise the services they required greater access to.

It was decided that the research title needed to be changed at this point, in line with the changes to the questionnaire and the research objectives. (See Appendix D) The new title, "Caregivers' experiences of service provision for their children with Autism Spectrum Disorder" was used in Questionnaire 3.

The final draft of the Questionnaire was reviewed by the research experts and no further changes were made. Questionnaire 3 was thus accepted as the research instrument. (See Appendix E).

3.13 Description of the final measurement tool (Questionnaire 3)

Clear, simple instructions on how to fill out the questionnaire preceded the questionnaire. The questionnaire consisted of 78 questions formulated as open and closed-ended questions.[46,61] The closed ended questions gave answer options to be ticked, or requested participants to rank or sequence options. These options were coded for data analysis. Space was left for participants (or the interviewer) to write short paragraphs in response to the open-ended questions.

The questions were categorized and divided into 8 sections in order to facilitate logical flow of questioning and for purposes of data analysis. The first two sections comprised demographic questions including: race and ethnicity; family dynamics; educational level; socioeconomic status; income sources; health care systems accessed; and child characteristics. The remaining sections explored the themes: early signs and symptoms; seeking professional help; process of diagnosis; seeking information on ASD; and treatment accessed.

3.14 Conclusion

This chapter described the development of the research instrument. Revisions to the questionnaire were made in order to ensure content validity based on an expert review and a pilot study. The final draft of the questionnaire was then drawn up to be used in data collection. The research method used in the study will be discussed in chapter 4.

CHAPTER 4: RESEARCH METHODOLOGY

4.1 Introduction

This chapter describes the research design and procedure using the questionnaire (as described in Chapter 3) as a measurement tool to collect data for analysis to meet the three objectives of this study:

- To investigate patterns of use of health and education services by caregivers and their children presenting with ASDs.
- To compare the patterns of service use in the private and public sectors
- To identify the perceived barriers impacting on service delivery and access.
- To identify the factors perceived to be facilitating better service delivery and access.

The study population is also described in this chapter, together with the sampling procedure, sample size and response rate. The ethical considerations taken into account in this study are highlighted. A summary of the coding and analysis of the data concludes this section.

4.2 Research Design

This was a cross-sectional, questionnaire-based study that utilized a descriptive research design in order to explore and describe caregiver's experiences of service provision for their children diagnosed with ASD in the Johannesburg Metropolitan regions.[46,60,61]

The sample was divided into two groups which were described and compared using a non-experimental design. Group A consisted of participants who accessed private sector health and education services largely, while Group B consisted of participants who accessed public sector health and education services.

Questions laid out in the questionnaire were used to extract both quantitative and qualitative data.

4.2.1 Study Population

The study population was made up of caregivers of children who present with ASD, and who live in Johannesburg. These caregivers included: mothers, fathers, grandmothers, and legal guardians or adoptive parents.

4.2.2 Sampling procedure

Non-probability, convenience sampling was used in this study. Participants were recruited according to the inclusion criteria stated below, at the ASD outpatient clinic at Chris Hani Baragwanath Hospital; school parents' meetings; and by means of a letter sent home from school with their children. All caregivers who met the inclusion criteria, and who agreed to participate, were included in the study. The sample was recruited such that equal numbers of caregivers accessing public health and/or educational services, as caregivers accessing private health and/or educational services for their children with ASD were recruited.

Inclusion Criteria:

- Caregivers of children (0-18 years) who had been diagnosed with an ASD or who were accessing services based on a working diagnosis of ASD.
- Caregivers were defined as the biological parents, legal guardians or primary caregivers of the child with ASD.

Exclusion criteria:

- Caregivers of children residing in children's homes, where background information was not available.
- There was no caregiver age, gender, cultural or socio-economic exclusion criterion.

4.2.3 Sample size

Clinicians working at the ASD outpatient clinic at Chris Hani Baragwanath Hospital and Charlotte Maxeke Johannesburg Academic Hospital were approached to invite all suitable caregivers to participate in the study. Approximately 109 caregivers were approached: in person at the Chris Hani Baragwanath Hospital out-patient clinic; at parent meetings; or via written letter sent home from school with their child, to participate in the study. No suitable caregivers were referred from Charlotte Maxeke Johannesburg Academic Hospital during the period of data collection however.

A sample size of 30 was chosen according to the recognized minimum requirements of sample size for a correlation study, and taking into account the limited availability or accessibility of the sample population.[60,62]

4.3 Ethical considerations

Ethical clearance to carry out this study was granted by the University of the Witwatersrand Ethics Committee for Research on Human Subjects (Ethical Clearance number: M070432/ R14/49). A copy of the Ethical clearance certificate is included in Appendix F. The Research Protocol was also approved by the University of the Witwatersrand.

Permission was requested from, and granted by the hospital superintendents of Charlotte Maxeke Johannesburg Academic Hospital, and Chris Hani Baragwanath Hospital to carry out the study at the hospital outpatient clinic. (See Appendix G) Permission was also granted by the school principals to address the parents at parent's meetings; and to send a letter home (see Appendix H) with each child who has been diagnosed with ASD, to invite their caregivers to participate in the study.

Caregivers were given an information sheet (Appendix I) outlining the study and the expectations of participants. They were also informed of their rights to refuse to participate or withdraw from the study at any time. Consent to participate in the study was implied through the participants' completion of the questionnaire.[46,61]

Confidentiality and anonymity were maintained by excluding participant's names and contact details from the questionnaire. Participants were assigned codes for reference and contact purposes for use by the researcher only.

The completion of the questionnaire was time intensive. For this reason, specific interview appointments were made with caregivers who required assistance in filling out the questionnaire, either before or after their outpatient appointments or in the afternoons when caregivers fetched their children from school. Some caregivers elected to take the questionnaire home to complete in their spare time.

4.4 Measurement Techniques, Collecting and Recording Data

4.4.1 Measurement tool

The research instrument consisted of a self-administered questionnaire which was developed by the researcher. (See Appendix D) The development of this questionnaire, together with its content and format as well as its validity and reliability testing, are described in detail in Chapter 3.

4.4.2 Research Procedure

Data was collected at the following sites:

- Chris Hani Baragwanath Hospital: ASD Outpatient Clinic, Speech Therapy and Audiology Department, Soweto.
- Children's Disability Centre, Children's Memorial Institute, Braamfontein.
- The Key School, Parktown.
- Bellavista School, Birdhaven.
- Little Stars Early Intervention Centre, Highlands North.

Data was collected during a six week period, from the beginning of May to mid-June 2008. The data collection procedure varied slightly between the schools and out-patient clinic, and is described below.

Out-patient clinics

Information sheets (see Appendix I) were distributed to all caregivers in the waiting room at the ASD outpatient clinic at Chris Hani Baragwanath Hospital. A translator was used to explain the information sheet to the non-English speaking caregivers and answer any questions the caregivers had. The caregivers who elected to participate were then handed a questionnaire to fill out. In some instances, where participants were illiterate or unable to complete the questionnaire independently, the researcher completed the questionnaire by interviewing the participant individually. Alternatively, the researcher ran small groups, going through each question, step-by-step with the group, allowing participants to fill in their own forms. The researcher clarified any questions and assisted individuals where necessary. A translator was available to assist where necessary.

Schools for learners with special needs

The information sheet together with a questionnaire (appendix) was distributed to all the caregivers of children diagnosed with ASD who attended the particular school.
Caregivers were asked to return the completed or blank questionnaires to the school with their child. Where possible, and in particular where caregivers were illiterate or needed assistance in filling out the questionnaires, appointments were arranged for the caregiver to meet the researcher in order to fill out the questionnaire by interview. Translators were used where necessary.

Translation and assistance aimed to prevent exclusion of participants of varying race, culture or educational level, and thus preserve some ecological validity.

Critique of the research procedure

A combination of data collection methods was chosen in order to lower costs, improve efficiency of data collection and improve the quality of the data collected.[60] However, bias may have been introduced through the use of a variety of data collection methods.

The administration of the questionnaire through face-to-face interviews with groups and individuals was useful in collecting data from illiterate and hard-to-reach participants. More complex questions could be explained and clarified to ensure that questions were appropriately understood and comprehensively answered. A translator was also used to ensure that participants understood the questions. However the interviewer and translator could have been a source of bias, as participants may have altered information given in order to seek the interviewer's approval. The interviewer's own opinions may also bias the recording of information. The interviewer attempted to control for this bias by recording the participant's exact words and reading the answers back to the participant to ensure that they were correctly recorded. Differences between the participant and the interviewer's age and culture may have also biased the responses. Lack of anonymity was controlled for by not recording any personal details and by assigning participant codes.

The self-administration of the questionnaire was beneficial, particularly given the length of the questionnaire, in that it allowed participants to complete the questionnaire at their convenience with no time constraints. Since no personal contact was made with the researcher, respondent anonymity was maintained and interviewer bias was eliminated. However, response rate was compromised by this method and repeated follow ups needed to be made in order to ensure the return of completed questionnaires. This may have introduced volunteer bias.

This method also required good participant literacy, and was biased against participants whose first language was not English (the language used in the questionnaire). It was also found that some questions were misinterpreted by participants and some questions were omitted, which compromised the quality of the data collected. It may have been useful to ask participants to include a telephone number with their returned questionnaire so that the researcher could contact them in the case of incorrectly interpreted questions or incomplete answers.

4.5 Data Analysis

4.5.1 Quantitative Data

Responses to the closed-ended questions were coded, organized according to the construct the question operationalised and tabulated for statistical analysis. Descriptive statistics were used to describe the sample using calculations of frequency, and measures of central tendency(mean) and variability (standard deviations).[60]

The responses to question 33 and 69, regarding the ranking of the top five challenges and prioritization of services needed respectively, were weighted, and ranked to obtain an overall rank for each item. Where a caregiver had ranked an item as the most significant challenge, a weighted score of 5 was recorded for that item. The second most significant challenge scored 4, the third most significant challenge scored 3, the fourth most significant challenge scored 2 and the fifth most significant challenge scored 1. The scores for each item were then added. The items were then arranged in descending order of score, such that the item with the largest score was deemed the most significant challenge. This enabled the researcher to discern the most common challenges faced. Service needs were interpreted in the same way.

Cross tabulation (Chi square and Fischer's Exact Coefficients) was used to test for interdependence of outcomes for the variables of public and private groups. p-values were calculated and interpreted in order to determine statistical significance of findings.

4.5.2 Qualitative Data

Responses to the open-ended questions were analysed qualitatively. Inductive codes were developed by the researcher in analyzing the responses to questions 22 and 27, and considering the literature on these subjects. Priori codes were established from the literature and were used to generate the answer options given in question 33 (closed-ended questions) that related to question 26 (open-ended question). These same codes were used to categorise the responses to question 26 regarding challenges to service access.

The findings of the data analysis will be presented in Chapter 5: Results, and discussed in Chapter 6: Discussion.

4.6 Conclusion

This chapter has outlined the design and method used to gather and analyse data. The following chapter will describe in detail the findings of the study. The research method, limitations and bias will be critiqued in the discussion chapter.

CHAPTER 5: RESULTS

5.1 Introduction

The purpose of this study was to explore caregiver's perceptions and experiences of service provision within the Johannesburg Metropolitan Region, for their children diagnosed with ASD. To achieve this aim a self reporting questionnaire was designed by the researcher. The validity and reliability of the questionnaire was examined and tested in a pilot study and adjustments made to the questionnaire accordingly (see Chapter 3). The questionnaire was used to collect the data as described in Chapter 4.

The questionnaire employed two types of research, descriptive and qualitative. The results of the quantitative data collected in the descriptive study, pertaining to the demographics of the sample, the patterns of service use and barriers to service provision, will be described first. Results are presented for the total sample as well as separately for Group A (participants accessing private sector services) and Group B (participants accessing public sector services). Fisher exact or chi-squared significance values (p-values) are indicated for each variable, comparing Group A and Group B. Findings were described as "significant" where the p-value was less than or equal to 0.05.
Subsequently, the results of the qualitative study, pertaining to the barriers to, and facilitators of service delivery and access, will be discussed.

5.2 Description of the sample

Of the 109 caregivers, 41 caregivers volunteered to participate in the study, generating a response rate of 37.6%. This response rate is comparable with an acceptable response rate of 30% as described in the research literature.[61]

Two completed questionnaires were excluded from the study. One, because the child resided in a children's home, and thus did not meet the inclusion criteria, and the other because 20 out of the 78 questions were omitted. This left a sample size (n) of 39. The sample of 39 was further divided into:

- **Group A:** consisting of 21 participants accessing private health and educational facilities
- **Group B:** consisting of 18 participants accessing public health and educational facilities.

This division was made as these groups presented with different demographic profiles, and varying experiences of service provision in the private and public sectors.

5.2.1 Characteristics of the Caregivers and Families

The majority of the caregivers (89.7%), who made up the sample, were the biological mothers of the children presenting with ASD while fathers and grandmothers made up 7.7% and 2.6% of the rest of the sample respectively. The mean age of all the participants was 36.84 years and the range was 25-75years of age. No significant difference was found in the age of the caregivers in Group A versus Group B.

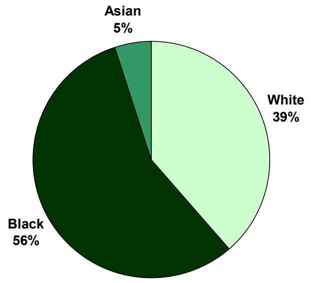
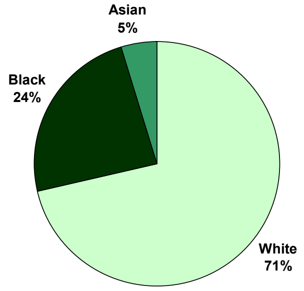
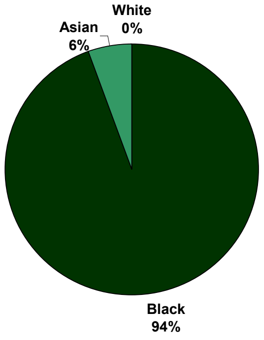
Total Sample	Group A	Group B
		

Figure 5. 1 Population groups

Participants of varying race groups were included in this study. A significant difference (p=0.00) was noted between Group A and Group B. Group A consisted largely (71%) of white participants, while Group B consisted of non-white participants only (100%).

Table 5. 1 Marital status

Marital status	Total sample % (Frequency)	Group A % (Freq)	Group B % (Freq)	p-value
Married	53.9% (21)	80.9% (17)	22.2% (4)	0.00*
Not married but living with a partner	10.3% (4)	0% (0)	22.2% (4)	
Never married, not living with a partner	25.7% (10)	9.5% (2)	44.4% (8)	
Separated/divorced	5.1% (2)	9.5% (2)	0% (0)	
Widowed	5.1% (2)	0% (0)	11.1% (2)	

More than half the participants were married. A significant difference (p=0.00) was found between Groups A and B, with the majority (80.9%) of participants in Group A being married, while more than half (55.5%) of Group B were not married nor living with a partner. This has implications for family support.

Table 5. 2 Household occupants

	Age Range	Total Sample		Group A		Group B		p-value
		Mean (SD)	**Range**	**Mean (SD)**	**Range**	**Mean (SD)**	**Range**	
Total number of occupants		5.19(2.21)	2;13	4.38(0.97)	3;7	6(2.89)	2;13	0.03*
Family composition (Total number of household occupants divided per age group)	>18 yrs	2.78(1.58)	1;9	2.1(0.54)	1;4	3.69(2.02)	2;9	0.01*
	6 – 18 yrs	1.38(1.11)	0;4	1.43(1.12)	0;4	1.31(1.14)	0;4	0.76
	<6 yrs	1(0.85)	0;4	0.90(0.77)	0;2	1.13(0.96)	0;4	0.46

A mean number of 5.19 people were found to be living in the participants' households. Household occupancy was significantly different (p=0.03) in Group A and B. Group A was more homogeneous (SD=0.97) with a mean number of occupants of 4.38; the Group B participants had a mean occupancy of 6. In terms of age distribution of the occupants, the only significant difference (p=0.01) was that more adults lived in the Group B households (x=3.69) in comparison with Group A (x=2.1). Most households included children.

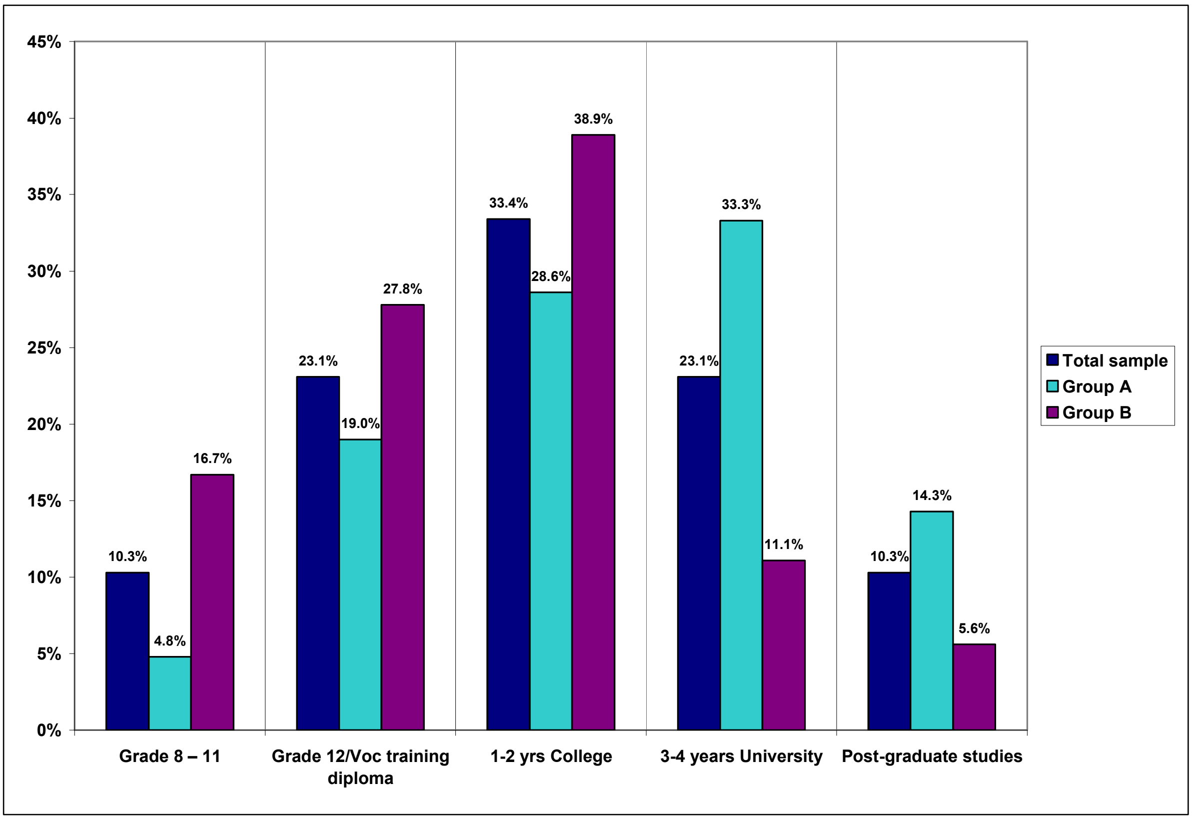


Figure 5. 2 Educational Level of the sample

The total sample was evenly distributed with 33.4% of participants' highest level of education being Grade 8 to Grade 12; 33.4% of participants with a highest level of education of a 1-2 year diploma or college course and 33.4% of participants with a highest level of education of an undergraduate or post-graduate university degree..

No significant difference (p=0.39) was noted in the educational profiles of Group A and B. From the graph, the largest proportion (33.3%) of the Group A participants had completed three to four years of university, while the largest proportion (38.9%) of Group B had completed a one to two year diploma or college course.

The majority of the sample (89.7%), with an educational level of Grade 12 or tertiary education was at least literate. Only four participants (10.3%) had a highest level of education of Grade 8 to Grade 11. These participants required assistance in completing the questionnaire due to poor literacy.

Table 5. 3 Employment and Income demographics

Caregiver Characteristics	Description	Total sample % (Freq)	Group A % (Freq)	Group B % (Freq)	p-value
Employment	Full time	43.6% (17)	38.1% (8)	50% (9)	0.33
	Part-time	23.1% (9)	33.3% (7)	11.1% (2)	
	Piece work	2.5% (1)	0% (0)	5.6% (1)	
	Unemployed	30.8% (12)	28.6% (6)	33.3% (6)	
Type of income	Salary/wages	89.7% (35)	100% (21)	77.8% (14)	0.00 *
	Caregiver grant (pension)	2.6% (1)	0% (0)	5.6% (1)	
	Child support grant	5.1% (2)	0% (0)	11.1% (2)	
	Care dependency grant	15.4% (6)	0% (0)	33.3% (6)	

Results were similar (p=0.33) for both the groups for the time caregivers spend at work: Two thirds of the sample (66.7%) worked full-time or part-time; while a third (30.8%) of caregivers were not currently employed.

A significant difference (p=0.00) was noted between the two groups' sources of income. Group A derived their income from salaries only (100%), while a large proportion (77.8%) of Group B derived their income from salary/wages, and 50% of the group received grants. It was noted that two participants from the public sample received income from salary/wages as well as income from public grants, and one participant received two grants – a pension together with a Child Disability Grant.

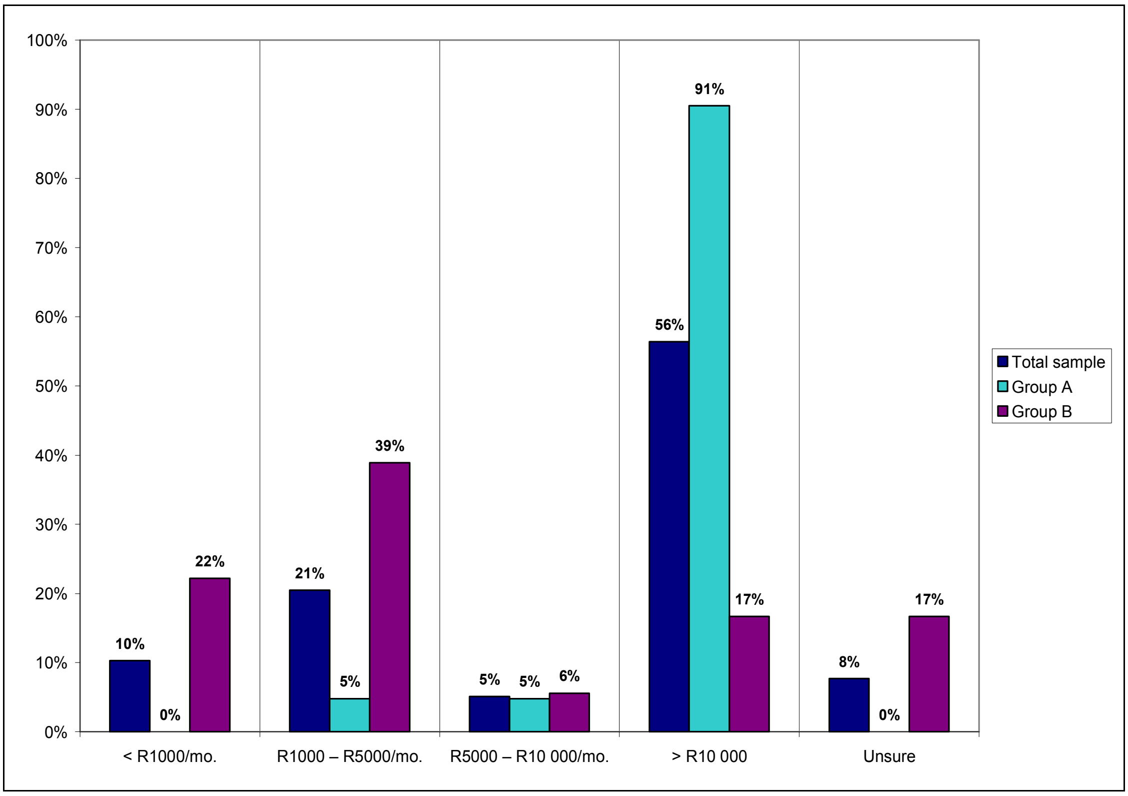


Figure 5. 3 Income of the sample

The difference in socioeconomic status and income bracket of the two groups was significant (p=0.00). The majority (91%) of Group A earned a gross monthly income of more than R10 000/month, while the majority (61%) of Group B earned a gross monthly income of less than R5000/month.

Table 5. 4 Resources used by caregivers

Resources	Description	Total sample % (Frequency)	Group A % (Freq)	Group B % (Freq)	p-value
Transport used	Public transport	33.3% (13)	4.8% (1)	66.7% (12)	0.00*
	Private transport	66.7% (26)	95.2% (20)	33.3% (6)	
Health benefits/ system	No Medical Aid	41% (16)	9.5% (2)	77.8% (14)	0.00*
	Comprehensive Medical Aid Scheme	48.7% (19)	71.4% (15)	22.2% (4)	
	Hospital plan – medical aid	10.3% (4)	19.0% (4)	0% (0)	

As expected, transport used varied significantly (p=0.00) between the two groups. The majority (95.2%) of Group A made use of private transport; while the majority (66.7%) of Group B utilized public transport.

Use of medical aid also varied significantly (p=0.00) between the groups: with the majority (90.4%) of Group A having access to medical aid, either comprehensive or hospital plans, while most (77.8%) of Group B did not have medical aid. In the South African context medical aid usually determines whether an individual will need to access public sector health care or can afford to access private sector health care.

5.2.2 Characteristics of the children presenting with ASD

5.2.2.1 Demographics

The questionnaire explored the characteristics of the children who present with ASD briefly. No significant difference was noted between the children in Group A and B.

The mean age of the children was 6.9 years, with those in Group A being slightly older with a mean age of 7.9 years, while the mean age of the children in Group B was 5.67 years. This reflects the norm for the samples of preschool age children attending the outpatient clinic and the primary school age children attending the special schools that were included in the study.

The ratio of male:female for the children was 6.8:1, with 87.2% of the children being male and 12.8% being female.

5.2.2.2 Functioning in Occupational Performance and Communication

The questionnaire attempted to discern the children's approximate level of functioning in two of the most problematic aspects of functioning impacted by ASD: speech and communication; and adaptive functioning. Scores for independence in performance of personal management tasks were weighted, added and averaged to attain a score for adaptive/independent functioning for each child.

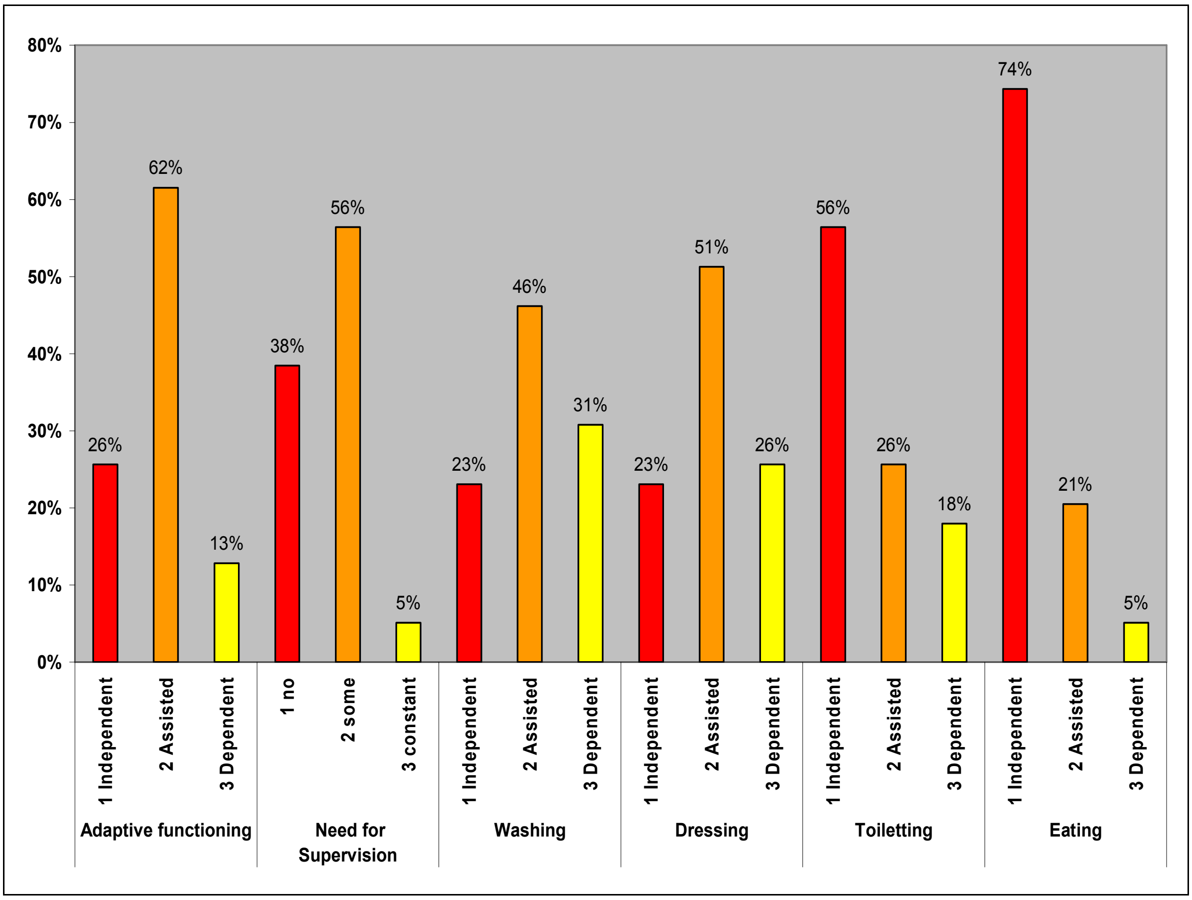


Figure 5. 4 Level of adaptive functioning

The majority (62%) of the children performed tasks with assistance, showing moderate impairment in functioning.

The children largely (56%) required “some” supervision. Scores for performance in washing were the lowest with 46.15% of the children requiring assistance with bathing/washing. The children were largely (56%) independent in toileting and eating. There was no significant difference (p=0.19) between Group A and B in adaptive functioning.

The communication abilities of the children were described according to the complexity of speech, expression of needs and the ability to be understood by others.

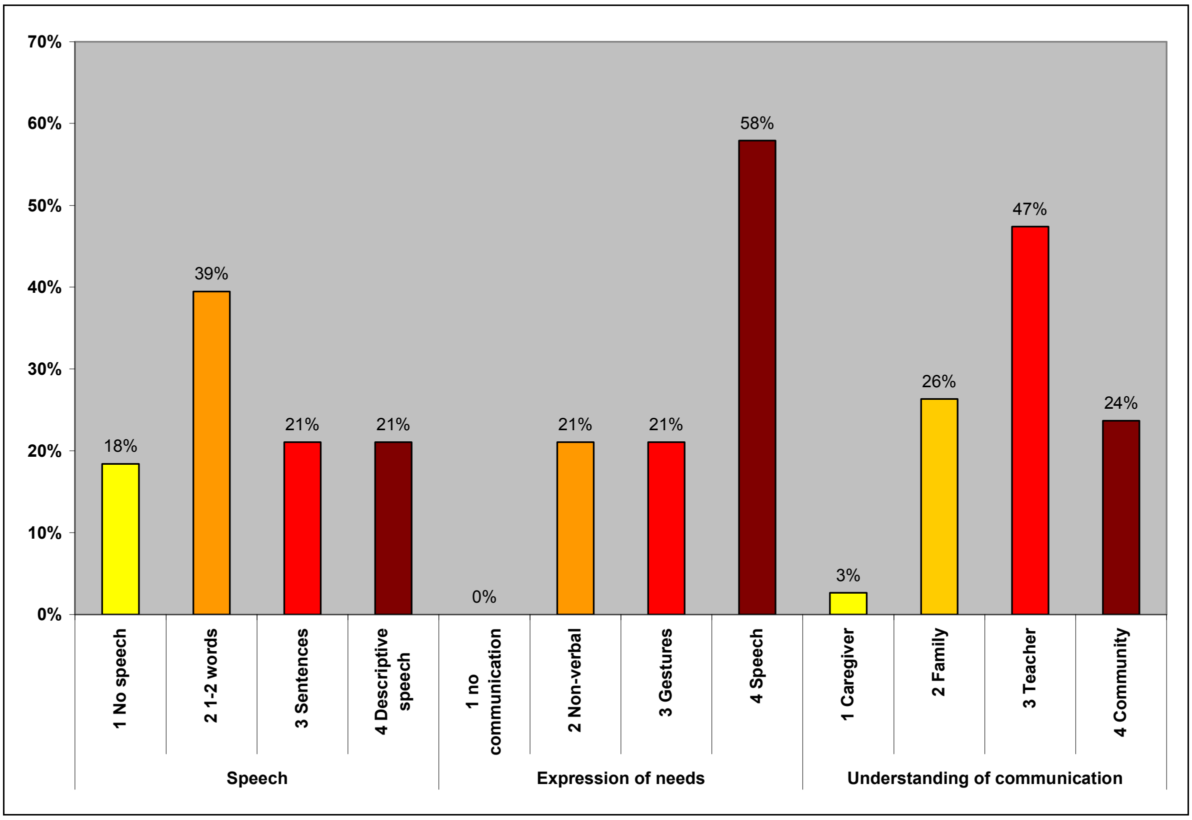


Figure 5. 5 Communicative abilities

Most of the children (81.7%) presented with some speech, with the largest proportion of these children (39%) using one to two word phrases, with a limited vocabulary. All (100%) of the children were attempting to express their needs, with the majority (58%) of the children expressing their needs verbally rather than non-verbally. Intelligibility of speech and communication tended to be limited to people who knew the child well including the caregiver, family and teacher (47%) and not by the general community.

5.3 Investigation of patterns of service use

5.3.1 Referral process and first point of contact

The primary caregiver was usually (74.4%) the first person to note dysfunction in their child, with health care professionals first noting symptoms in only 7.6% of cases. Signs of dysfunction first became obvious in the child at a mean age of 1.97 years. No significant difference (p=0.33) was noted in this variable between the groups.

Table 5. 5 Initial signs of atypical development

Symptoms	Examples of observations with Percentage (Frequency)
General Developmental	• Delay in achieving milestones 20.51%(8) • Low muscle tone 2.56% (1)
Speech	• Poor speech development 48.71% (19) • Regression in speech 20.51% (8) • Deviance in speech 5.13% (2) (learns speech in language different from vernacular; echolalic) • Poor gesturing 7.69% (3)
Sensory	• Sensory sensitivities -total 20.51%(8) ○ Auditory 10.25%(4) ○ Tactile 10.25%(4) • Appeared deaf at times 10.25%(4) • Fussy eater 12.82%(5) • Stereotypical behaviours 7.69% (3) • Poor calming 2.56% (1) • Sensory seeking behaviour ○ Poor awareness and fear of danger 7.69% (3) ○ Plays rough 2.56% (1) ○ Hyperactive/uncontained 17.94% (7)
Routine	• Excessive sleeping 2.56% (1) • Not sleeping 10.25% (4)
Social Interaction	• Poor response to cuddling 2.56%(1) • Poor social interaction 35.90%(14) (withdrawn, shying away from people, playing alone) • No social smile 2.56% (1) • Poor coping in public situations 5.13% (2) • Poor eye contact 5.13% (2)
Behavioural	• Tantrums and screaming 23.08%(9) • Anxious/fearful/insecure 7.69% (3) • Hyperactive/uncontained 17.94% (7)
Understanding/ Cognition	• Obsessive interests 2.56% (1) • Not playing appropriately with toys 7.69% (3) • Poor awareness and fear of danger 7.69% (3)
Concentration	• Inattentive 2.56% (1) • Poor concentration 5.13% (2)
Other	• Fits 2.56% (1)

The most common, initial abnormal/atypical signs caregivers observed were: poor speech development (48.71%), poor social interaction (35.9%) and behavioural problems such as excessive tantrums and screaming (23.08%). Other signs that caregivers noted are listed and categorized above. The findings will be discussed in more detail in the discussion chapter.

Cognitive impairment, poor adaptation to routine and the presence of stereotypical behaviours were rarely (<10%) noted initially.

Table 5.6 lists the institutions that were accessed first, and Table 5.7, the professionals at these institutions that were consulted first, after the initial signs of abnormal development had been noted by the caregiver.

Table 5. 6 First institution accessed after problem was noted

Institution consulted first	Total sample % (freq)	Group A % (freq)	Group B % (freq)	p-value
Government clinic	20.51% (8)	4.76% (1)	38.8% (7)	0.01 *
Government hospital	7.69% (3)	0% (0)	16.67% (3)	
Private clinic/hospital	12.82% (5)	19.04% (4)	5.5% (1)	
Private practice	48.71% (19)	66.67% (14)	27.7% (5)	
School/Crèche	5.13 % (2)	4.76% (1)	5.5% (1)	
Traditional Healer	5.13% (2)	4.76% (1)	5.5% (1)	

The first institution accessed by caregivers in seeking help for their child was most commonly a private practice (48.7%). A significant difference (p=0.01) was found between the institutions accessed first by Group A and B, with Group A tending to access private practices first (66.7%), and 38.8% of Group B accessing government clinics first. However, a substantial percentage (27.7%) of Group B accessed private practices first.

Referral sequence was explored further. As can be seen in Figure 5.6 below, no common pattern of referral could be established from the data in either group.

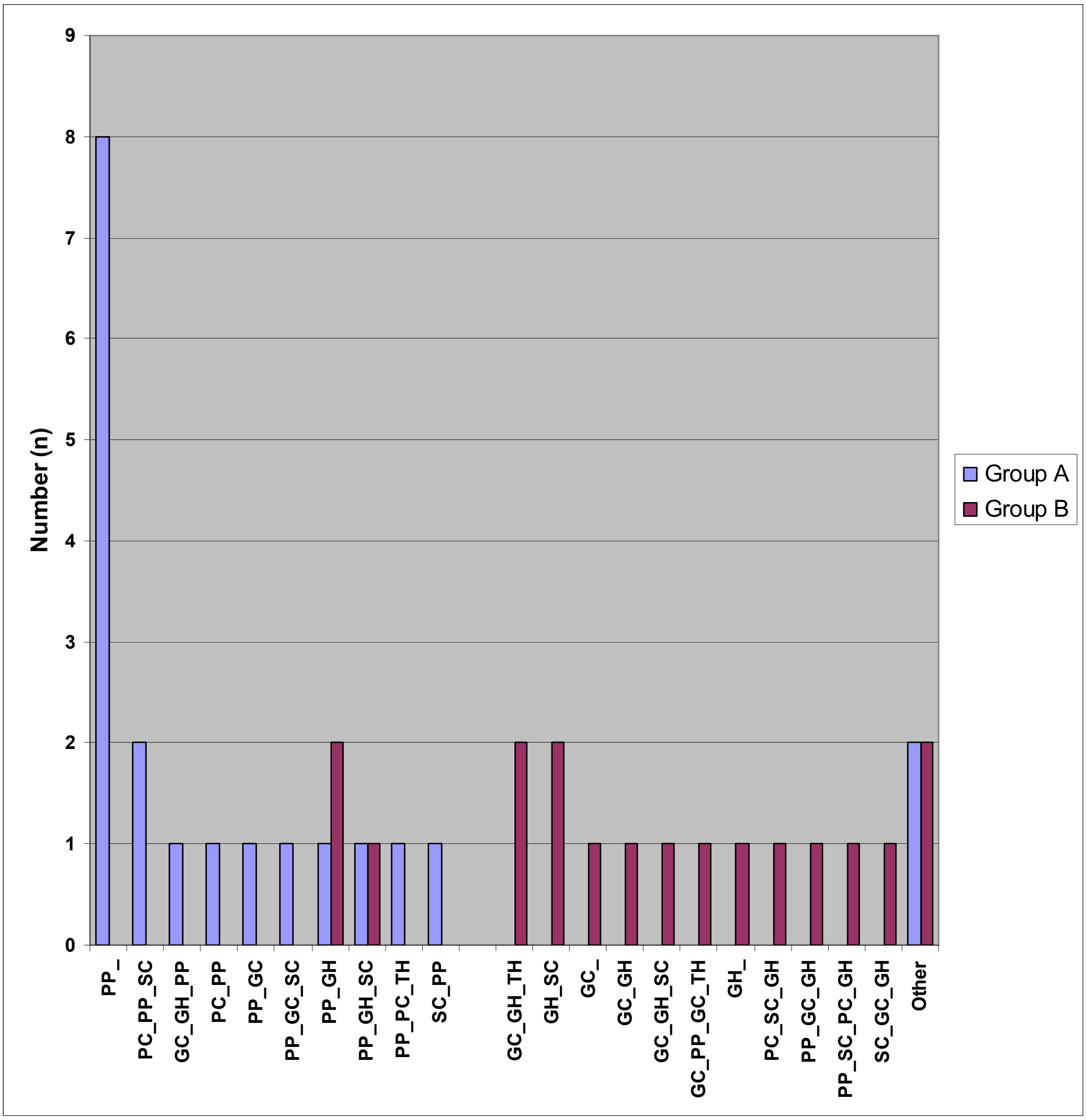


Figure 5. 6 Sequence of referral between institutions

Key:
PP = Private Practice
PC = Private Clinic
SC = School
GC = Government Clinic
GH = Government Hospital
TH = Traditional Healer

The x-axis presents the different sequences of services accessed by the caregivers.

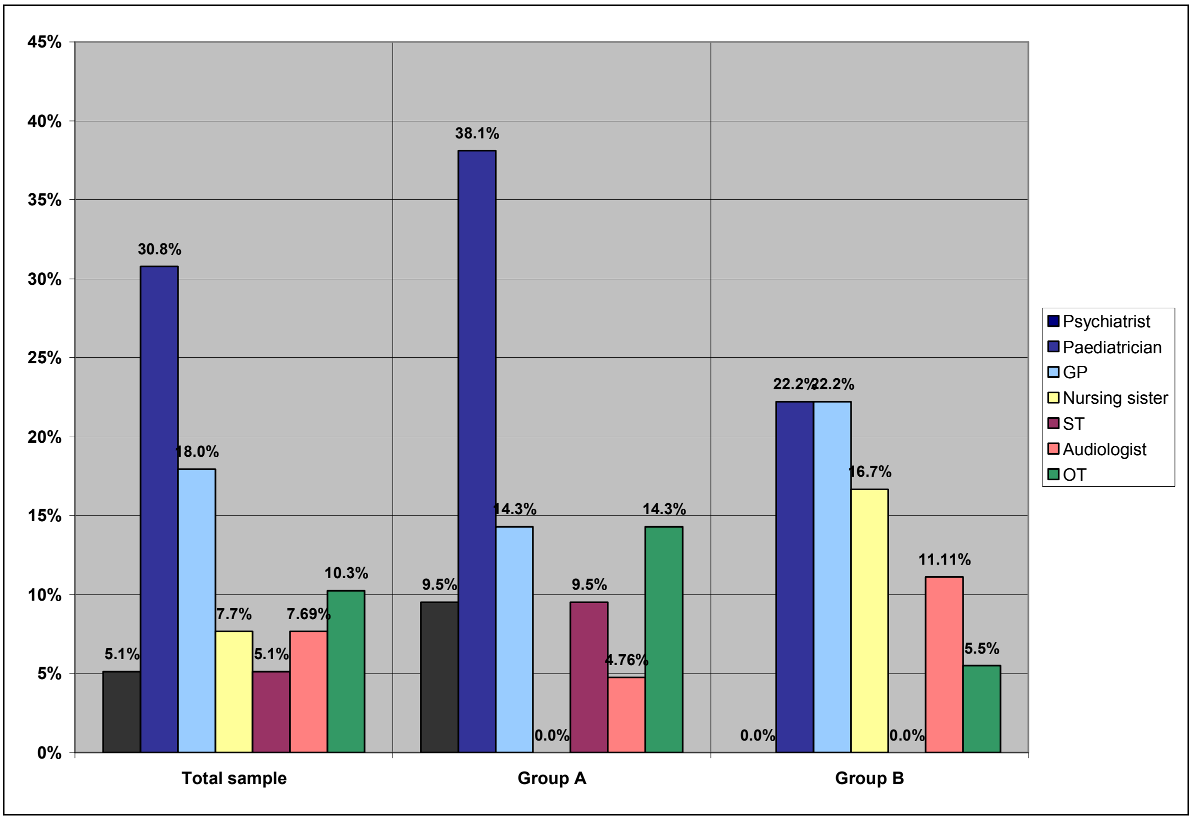


Figure 5. 7 Professionals consulted first after atypical development was noted

The paediatrician was the health professional most commonly (30.8%) consulted first, followed by the general practitioner (GP) (18%) and then the occupational therapist (OT) (10.3%). Group A largely (38.8%) consulted with a paediatrician first. Group B first consulted with the paediatrician (22.2%), general practitioner (22.2%) or nursing sister (16.7%) most commonly.

5.3.2 The process of diagnosing ASD

The questionnaire investigated the process of diagnosis. The information gathered described: the diagnoses the children were given; the time taken to diagnose ASD; the way in which diagnosis was discussed with the caregivers; and the support caregivers received in accepting the diagnosis.

5.3.2.1 Diagnosis given

Caregivers were asked what their child's diagnosis was and if any co-morbid diagnoses had been made. The results are described in Figure 5.8 and Table 5.7 respectively.

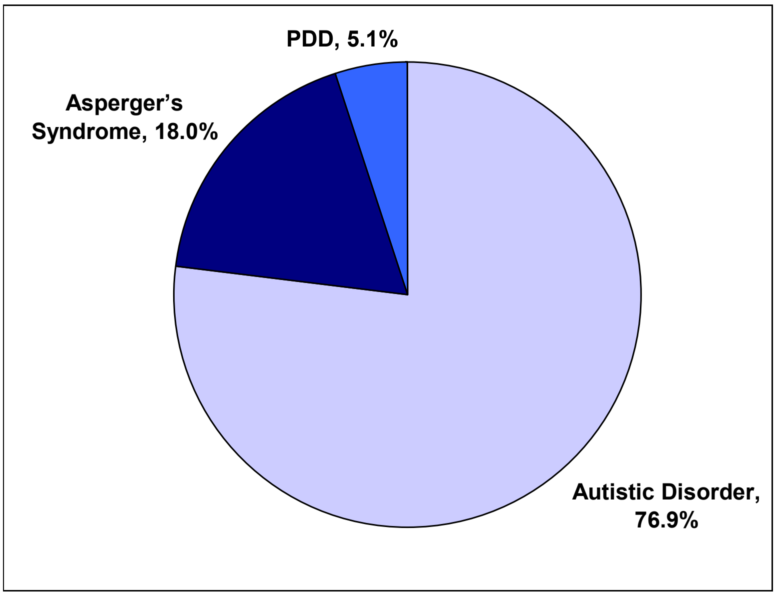


Figure 5. 8 Diagnoses of children

The majority (76.9%) of the participants' children were diagnosed with Autistic Disorder (AD). The ratio of Autistic Disorder to Asperger's Syndrome was 4.3:1. Six of the seven children presenting with Asperger's Syndrome were accessing private sector, remedial educational facilities.

Table 5. 7 Co-morbid Conditions

Co-morbid Conditions	Percentage	Frequency
Epilepsy	15.4%	6
ADD	5.1%	2
ADHD	33.3%	13
Other	5.1%	2

Co-morbid conditions were present in 59% of the children. ADHD was the most commonly (33.3%) presenting co-morbid condition.

5.3.2.2 Time taken to diagnose ASD

The age of the children at diagnosis varied between 1 year and 11years of age. The mean age of the children at diagnosis was 4 years. The participants reported a mean time of 2.03 years taken to confirm a diagnosis. This represents the difference in years, between the child's age when the first signs were noted, and the child's age at diagnosis. No significant difference was noted between Group A and B.

Table 5. 8 Time taken to diagnose comparing Aspergers Group with Autistic Group

		Total	**AS**	**AD**	**p-value**
First noted something wrong	Mean	1.97yrs	2.45 yrs	1.86 yrs	0.27
	Range	[0;4]	[1;4]	[0;3.5]	
	Standard deviation	0.939	1.22	0.85	
Age at diagnosis	Mean	4	6.41yrs	3.43yrs	0.03*
	Range	[1;11]	[3.42;11]	[1;9]	
	Standard Deviation	2.10	2.67	1.49	
Time taken to confirm a diagnosis of ASD	Mean	2.03 yrs	3.95yrs	1.57yrs	0.01*
	Range	[0;8]	[1.42;7]	[0;8]	
	Standard Deviation	1.86	1.72	1.59	

Caregivers noted symptoms in their children with AD or AS at a similar age (p=0.27). Children were significantly (p=0.03) older when diagnosed with AS (6 years 5 months), compared to children diagnosed with AD (3 years 5 months). Caregivers also reported significantly (p=0.01) longer time frames in awaiting diagnosis of children with AS (3 years 11 months) compared to children with AD (1 year 7 months).

5.3.2.3 How diagnosis was discussed with caregivers

The participants were asked how they were given the diagnosis of ASD for their child, and if they were referred for counselling or to a support group to assist them in coming to terms with the diagnosis.

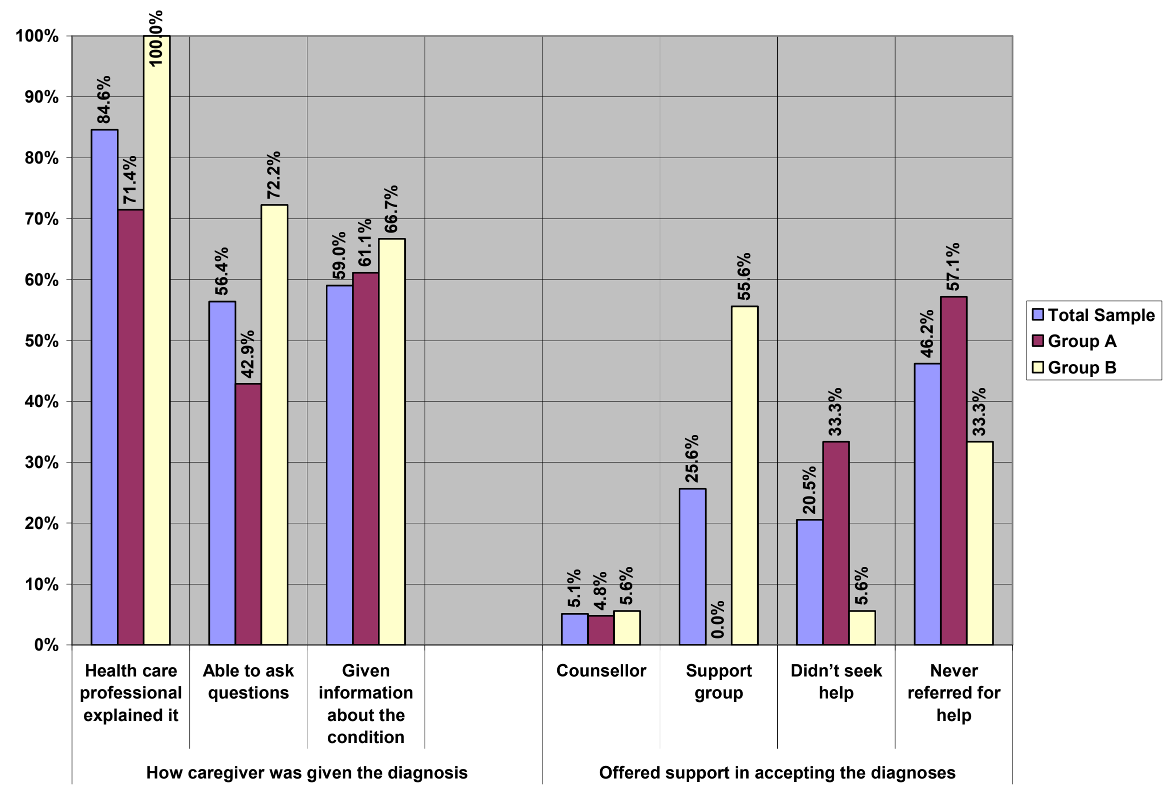


Figure 5. 9 Description of how diagnosis was given

Most (84.6%) of the participants were given the diagnosis by a health care professional. A large proportion (56.4%) of participants felt that they were able to ask questions about the diagnosis, with 59 % of participants explaining that they were given adequate information on the condition.

The majority (66.7%) of the participants received no further support in accepting and understanding the diagnosis. 20.51% of the participants were referred for counselling or support, but did not access it due to work-related time constraints or personal preference, while 46.15% of the participants were never referred for support.

One participant from each group (5.1% of total sample) had accessed a counsellor. The 10 participants (25.6%) who reported that they accessed caregiver support groups were all Group B participants. This comprised 55.6% of the Group B sample. None of the Group A participants was referred to a caregiver support group.

5.3.3 The services children and caregivers accessed

This section explores the access of health and education services by the caregivers and their children. The number and type of health institutions accessed is discussed first. This is followed by the number and type of professionals consulted, and the type of educational facilities that were accessed. The access to private and public sector institutions and professionals is described. The frequency of service access is presented last. Comparisons between Group A and B patterns of service use are drawn.

5.3.3.1 Institutions accessed

Caregivers and their children had accessed on average, 2.5 different types of institutions (range: [1;5]). No significant difference (p=0.12) was noted between Group A and B in the number of different institutions they accessed.

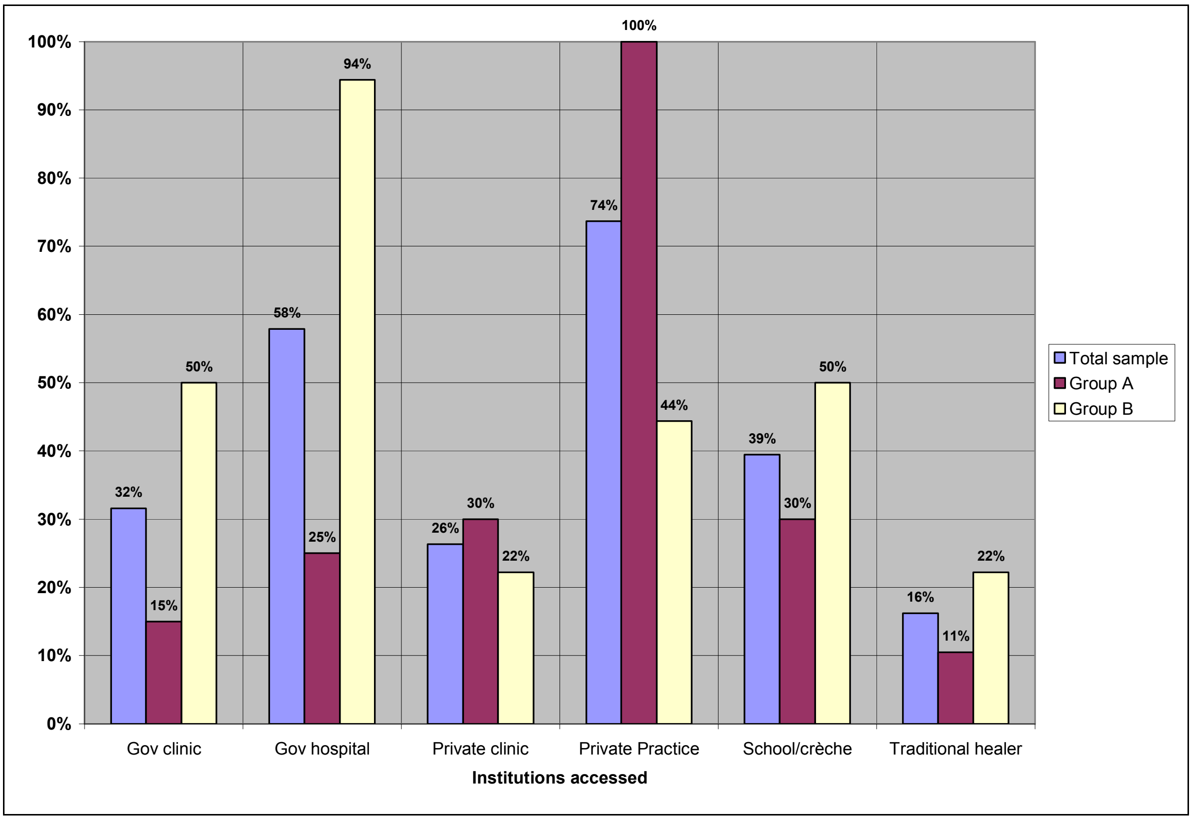


Figure 5. 10 Institutions accessed

Private practices were most frequently accessed. A significant difference was noted between Group A and B’s access of government clinics (p=0.02), government hospitals (p=0.00) and private practices (p=0.00). Government clinics and hospitals were largely accessed by the Group B, with 100% of the Group A accessing private practices and only 44.44% of the Group B accessing the private practices. Access of private clinics, schools and traditional healers was similar in both groups.

5.3.3.2 Professionals consulted

Participants were asked which professionals they had consulted and in which sector these professionals worked (Table 5.9). The frequency of professionals consulted is represented for the total sample as well as for Group A and B.

The mean number of professionals consulted by participants and their children presenting with ASD, was 6.25. No significant difference (p=0.96) in the number of professionals consulted by Group A and Group B participants was noted.

Table 5. 9 Private and public sector professionals consulted

Professionals consulted in private and public sectors	**Total sample**	**Group A**	**Group B**	**p-value**
Psychiatrist	41.1% (16)	38.1% (8)	44.4% (8)	0.11
Private sector	15.4% (6)	23.81 (5)	5.56 (1)	
Public sector	25.6% (10)	14.29 (3)	38.89 (7)	
None	59% (23)	61.90 (13)	55.56 (10)	
Paediatrician	84.6% (33)	90.5% (19)	77.8%(14)	0.00 *
Private sector	56.4% (22)	80.95 (17)	27.78 (5)	
Public sector	28.2% (11)	9.52 (2)	50.00 (9)	
None	15.4% (6)	9.52 (2)	22.22 (4)	
Neurologist	51.3% (20)	57.1% (12)	44.4% (8)	0.02 *
Private sector	25.6% (10)	42.86 (9)	5.56 (1)	
Public sector	25.6% (10)	14.29 (3)	38.89 (7)	
None	48.7% (19)	42.86 (9)	55.56 (10)	
GP	41% (16)	38.1% (8)	44.4% (8)	0.47
Private sector	30.8% (12)	33.33 (7)	27.78 (5)	
Public sector	10.3% (4)	4.76 (1)	16.67 (3)	
None	59% (23)	61.90 (13)	55.56 (10)	
Nursing Sister	18% (7)	14.3% (3)	22.2% (4)	0.38
Private sector	2.6% (1)	4.76 (1)	0 (0)	
Public sector	15. 4% (6)	9.52 (2)	22.22 (4)	
None	82.1% (32)	85.17 (18)	77.78 (14)	

Professionals consulted in private and public sectors	**Total sample**	**Group A**	**Group B**	**p-value**
Speech Therapist	92.4% (36)	90.5% (19)	94.4%(17)	0.00 *
Private sector	56.4% (22)	85.71 (18)	22.22 (4)	
Public sector	35.9% (14)	4.76 (1)	72.22 (13)	
Both	2.6% (1)	4.76 (1)	0 (0)	
None	5.1% (2)	4.76 (1)	5.56 (1)	
Audiologist	71.8% (28)	66.7% (14)	77.8%(14)	0.00 *
Private sector	35.9% (14)	57.14 (12)	11.11 (2)	
Public sector	35.9% (14)	9.52 (2)	66.67 (12)	
None	28.2% (11)	33.33 (7)	22.22 (4)	
Occupational Therapist	71.8% (28)	81% (17)	61.1%(11)	0.00 *
Private sector	48.7% (19)	76.19 (16)	16.67 (3)	
Public sector	23.1% (9)	4.76 (1)	44.44 (8)	
None	28.2% (11)	19.05 (4)	38.89 (7)	
Physiotherapist	28.2% (11)	47.6% (10)	5.6% (1)	0.01 *
Private sector	20.5% (8)	38.10 (8)	0 (0)	
Public sector	7.7% (3)	9.52 (2)	5.56 (1)	
None	71.8% (28)	52.38 (11)	94.44 (17)	
Psychologist	41.1% (16)	47.6% (10)	33.3% (6)	0.32
Private sector	28.2% (11)	38.10 (8)	16.67 (3)	
Public sector	12.8% (5)	9.52 (2)	16.67 (3)	
None	59% (23)	52.38 (11)	66.67 (12)	
Social Worker	13.2% (5)	9.5% (2)	16.7% (3)	0.78
Private sector	5.1% (2)	5.00 (1)	5.56 (1)	
Public sector	7.7% (3)	5.00 (1)	11.11 (2)	
None	84.6% (33)	90.00 (18)	83.33 (15)	
Remedial Th.	15.8% (6)	23.8% (5)	5.6% (1)	0.22
Private sector	10.3% (4)	15.00 (3)	5.6 (1)	
Public sector	5.1% (2)	10.00 (2)	0.00 (0)	
None	82.1% (32)	75.00 (15)	94.44 (17)	
Dietician	44.7% (17)	23.8% (5)	66.7%(12)	0.01 *
Private sector	17.9% (7)	20.00 (4)	16.67 (3)	
Public sector	25.6% (10)	5.00 (1)	50.00 (9)	
None	53.8% (21)	75.00 (15)	33.33 (6)	
Counsellor	5.3% (2)	9.5% (2)	0% (0)	0.39
Private sector	2.6% (1)	5.00 (1)	0 (0)	
Public sector	2.6% (1)	5.00 (1)	0 (0)	
None	92.3% (36)	90.00 (18)	100 (18)	
Traditional Healer	15.8% (6)	14.3% (3)	16.7% (3)	0.54
Private sector	12.8% (5)	10.00 (2)	16.67 (3)	
Public sector	2.6% (1)	5.00 (1)	0 (0)	
None	82.1% (32)	85.00 (17)	83.33 (15)	

The most commonly consulted professionals (consulted by more than 50% of participants) were the: speech therapist (92.4%), paediatrician (84.6%), audiologist (71.8%), occupational therapist (71.8%), and neurologist (51.3%). The least commonly consulted professionals (less than 50% of participants accessing this service) were the: counsellor (5.3%), social worker (13.2%), remedial therapist (15.8%), traditional healer (15.8%), nursing sister (18%), physiotherapist (28.2%), psychiatrist (41.1%), GP (41%), psychologist (41.1%), and the dietician (44.7%).

Group B tended to make use of public sector professionals while Group A tended to access private sector professionals. However, this was not the rule, there were Group B participants accessing private sector professionals and Group A participants accessing public sector professionals. Significant differences between Group A and B are highlighted in the table.

5.3.3.3 Educational facilities accessed

Caregivers were asked to indicate which of the different types of educational facilities their child had attended in the past, or were currently attending.

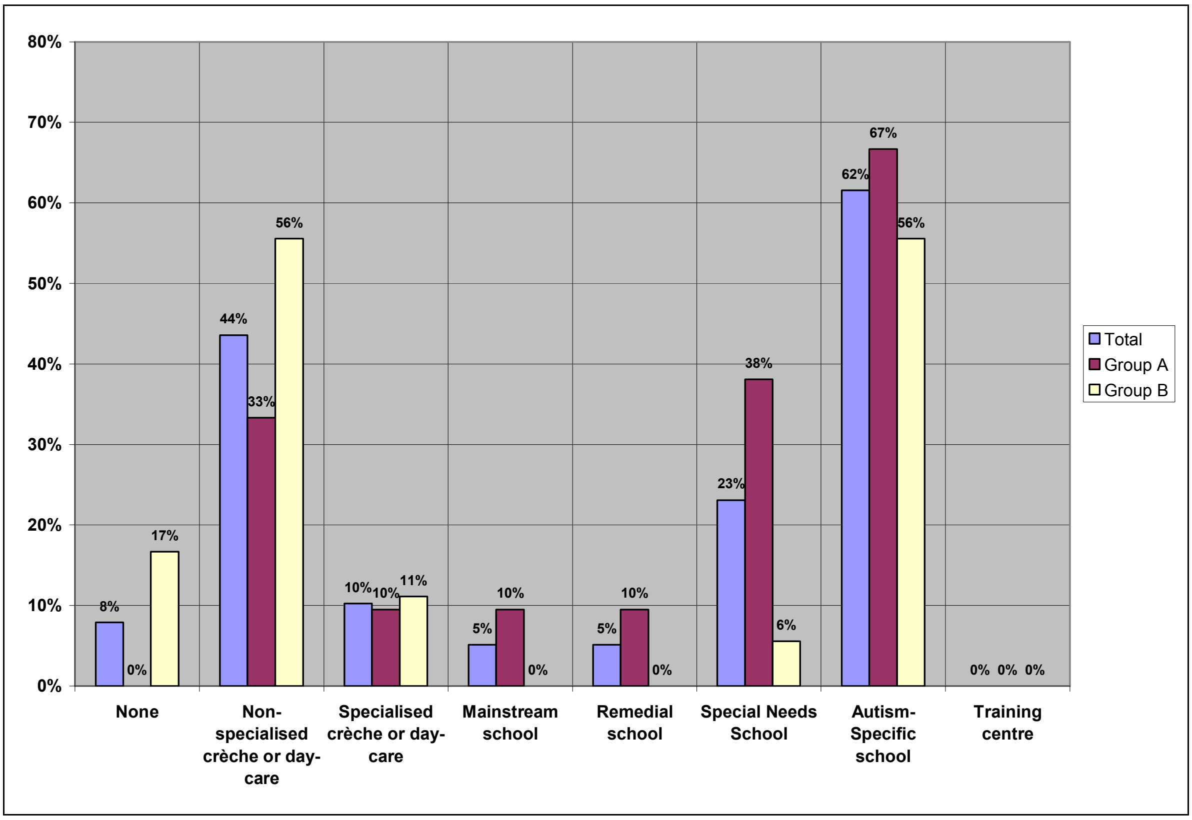


Figure 5. 11 Educational facilities accessed

The most commonly attended educational facilities were: Autism-Specific Schools (62%), non-specialised crèche or day care facilities (44%); and special needs schools (23%). Few children attended: specialised crèches (10%); mainstream schools (5%); and remedial schools (5%), while no children in this sample attended a training centre. A difference (p=0.05) between Group A and B was calculated in the pattern and number of children attending the various types of educational facilities.

Most caregivers (97.2%) paid their children's school fees in a personal capacity. Monthly fees varied greatly (SD= R2338.08; Range [R0;R10 000]). In the private sector, fees were an average of R4160 per month, compared to R432 per month in the public sector.

5.3.3.4 The frequency of services accessed

Caregivers were asked how frequently they accessed five common services. These included: medical intervention (largely consultation with a doctor for the review of medication); counselling; speech therapy; occupational therapy and care-giving services.

Table 5. 10 Frequency (Dosage) of services accessed

	Mean frequency of consult Total Sample		**Group A**	**Group B**	**p-value**
Medication		4.22visits/yr	3.43 visits/yr	5.18visits/yr	0.28
Counselling/ support		9 visits total	20 visits total 2 go frequently	3.5 visits total 1 goes frequently	
Speech therapy	Daily	10.53% (4)	19.05% (4)	0% (0)	0.00*
	>1/wk	13.16% (5)	19.05% (4)	5.56% (1)	
	Weekly	44.74% (17)	47.62% (10)	38.89% (7)	
	Monthly	18.42% (7)	0% (0)	38.89% (7)	
	Occasional	7.89% (3)	14.29% (3)	0% (0)	
	Not currently	5.26% (2)	0% (0)	11.11% (2)	
Occ. Therapy	Daily	9.38% (3)	14.29% (3)	0% (0)	0.04*
	>1/wk	12.50% (4)	19.04% (4)	0% (0)	
	Weekly	53.13% (17)	42.86% (9)	44.44% (8)	
	Monthly	12.50% (4)	0% (0)	16.67% (3)	
	Not Currently	12.50% (4)	9.52% (2)	11.11% (2)	
Carer	Daily	53.84% (21)	38.1% (8)	38.89% (7)	0.04*
	Weekly	38.46% (15)	0% (0)	11.11% (2)	
	Monthly	5.12% (2)	0% (0)	11.11% (2)	
	Occasionally	5.12%% (2)	19.04% (4)	0% (0)	
		10.26% (4)			

Doctors were consulted by 48.72% of the participants to review their children's medication. Children consulted with a doctor on average 4.22 times per year.

Counselling or support services were accessed by 51.28% of the participants, with 38.1% of Group A and 72.2% of Group B accessing these services. Consultations were irregular and depended on caregiver availability, need and the availability of services. No trends in dosage could be established.

The majority of participants (97.4%) accessed speech therapy services, with 55.3% of children attending group sessions while 97.4% attended individual therapy sessions. Occupational therapy services were accessed by 82.1% of participants with 46.8% attending group sessions and 93.8% attending individual sessions. These results do not correlate directly with the results presented in Table 5.9 indicating some inconsistency in the participant's responses to the two sets of questions.

Speech therapy and occupational therapy sessions were attended weekly by 44.74% and 53.13% of participants respectively. A significant difference (p=0.00 and p=0.04 respectively) was noted between Group A and B, with Group A attending therapy more regularly than Group B.

The service of carers was used by 53.8% of participants, with 38.5% making use of these services daily.

5.4 Factors compromising service delivery and access

5.4.1 Quantitative results

Participants were asked to identify the challenges they faced in seeking a diagnosis and treatment for their child with ASD. These results are presented in Table 5.11. Priori codes/themes were established from the literature and were used to generate the answer options given in question 33 (closed-ended questions) that related to question 26 (open-ended question). These same codes were used to categorise the responses to question 26 regarding challenges to service access and delivery. The results have been categorised and colour-coded according to these priori codes/themes.
They include:

- Logistical barriers
- Professional-related factors
- Caregiver-related factors
- Family and Community-related factors

Table 5. 11 Challenges faced by caregivers and their children in accessing services

	Yes it's a problem % (freq)	**No it's not a problem %(freq)**	**Group A Yes – problem % (freq)**	**Group B Yes-problem % (freq)**	**p-value Group A vs. B**
Location of the service.	43.59 (17)	56.41 (22)	42.86 (9)	44.44 (8)	0.92
There are very few appropriate health services available.	56.41 (22)	43.59 (17)	61.90 (13)	50.00 (9)	0.46
There are very few appropriate schools available.	87.18 (34)	12.82 (5)	100.00 (21)	72.22 (13)	0.01*
Finding affordable, appropriate child minding services.	43.59 (17)	56.41 (22)	28.57 (6)	61.11 (11)	0.04*
Cost of transport.	46.15 (18)	56.41 (22)	38.10 (8)	55.56 (10)	0.28
Cost of consultations.	38.46 (15)	61.54 (24)	47.62 (10)	27.78 (5)	0.20
Too many different appointments.	56.41 (22)	43.59 (17)	52.38 (11)	61.11 (11)	0.58
Long waiting lists for appointments.	38.46 (15)	61.54 (24)	47.62 (10)	27.78 (5)	0.20
Too much time off work.	33.33 (13)	66.67 (26)	28.57 (6)	38.89 (7)	0.50
Waiting in long queues.	25.64 (10)	74.36 (29)	19.05 (4)	33.33 (6)	0.31
The professionals didn't seem to know or understand what was wrong with my child.	58.97 (23)	41.03 (16)	66.67 (14)	50.00 (9)	0.29
Different professionals told me different things.	53.85 (21)	46.15 (18)	71.43 (15)	33.33 (6)	0.02*
The teachers or school have limited understanding of ASD and how to educate my child.	48.72 (19)	51.28 (20)	47.62 (10)	50.00 (9)	0.88
	Yes it's a problem % (freq)	**No it's not a problem %(freq)**	**Group A Yes – problem % (freq)**	**Group B Yes-problem % (freq)**	**p-value Group A vs. B**
I didn't understand what to do or know where to go.	56.41 (22)	43.59 (17)	66.67 (14)	44.44 (8)	0.16
I didn't think that there was anything wrong.	28.21 (11)	71.79 (28)	14.29 (3)	44.44 (8)	0.04*

I didn't think that it was that important.	20.51 (8)	79.49 (31)	19.05 (4)	22.22 (4)	0.81
I felt embarrassed and hid my child away from the community.	17.95 (7)	82.05 (32)	14.29 (3)	33.33 (6)	0.16
We missed lots of appointments.	5.26 (2)	94.74 (36)	5.00 (1)	5.56 (1)	0.94
My family put a lot of pressure on me.	17.95 (7)	82.05 (32)	14.29 (3)	22.22 (4)	0.52
My family did not understand and didn't help to support me and the child.	46.15 (18)	53.85 (21)	38.10 (8)	55.56 (10)	0.28
The community/my friends did not understand and didn't help to support me.	35.90 (14)	64.10 (25)	9.52 (2)	66.67 (12)	0.00*
Other. Please Specify.	10.25 (4)				

Significant differences (p-values; and values >60%) are highlighted in the relevant colour. Options marked by more than 50% of the participants as a challenge are highlighted in yellow.

Logistical Barriers

The most common challenge (87.18%) identified by the participants, was the limited availability of appropriate schooling. Limited availability of appropriate health services was reported by 56.41% of the participants. 56.41% of participants also noted the large number of different appointments as a challenge. Location of the services was found to impact on accessibility of services by 43.59% of the participants. Consequently, cost of transport incurred in accessing appointments was identified as a challenge for 46.15% of the participants.

Significant differences in challenges experienced by Group A and B were noted and are highlighted in the table. 61.11% of Group B reported difficulty finding appropriate, affordable child-minding services, compared to 28.57% of Group A.

Cost of consultations was not identified by Group B as a challenge, while 47.62% of the Group A found costs of consultations a challenge.

Only 33.33% of the participants cited time off work as a challenge. This should be taken into consideration together with the demographic profile of the participants which stated that 43.6% of participants work full-time.

Long waiting lists and delays between appointments was identified by 38.46% of the participants as a challenge. 27.78% of Group B noted this as a challenge, compared to 47.62% of Group A.

Waiting in queues was not perceived as a noteworthy problem by 74.36% of the participants.

Professional Related factors

Participants emphasized their concern with the skill and knowledge of the professionals they had come into contact with, in both the open and closed ended questions. 58.97% of participants felt that "*the professionals didn't seem to know or understand what was wrong with their child*". 53.85% complained that different professionals told them different things concerning diagnosis and treatment of their child. 48.72% of participants explained that the teachers in schools had a limited understanding of ASD and how to educate children with ASD.

Caregiver related factors

Participants noted poor awareness and knowledge of ASD and the suitable services available as their biggest challenge, with 56.41% of participants confirming that "*they did not understand what to do or where to go*" to seek help. They claimed good insight into the existence of problems (71.79%) and appropriate compliance with appointments (94.74%).

Community/family related factors

While social pressure and lack of support were not perceived as problematic for the majority of participants, a large proportion (55.56%) of Group B participants noted that their family did not understand and did not help to support the caregiver and the child, and 66.67% of Group B explained that the community did not understand and support the caregiver and the child. The latter was significantly different (p=0.00) to Group A, where only 9.52% of participants noted the lack of support and understanding of the community as a challenge.

Once participants had identified which items had posed a challenge for them, they were asked to identify the top 5, most significant challenges they faced and prioritize them. These items were then weighted and ranked to establish the order of challenges. This is represented in Table 5.12.

Table 5. 12 Prioritization of challenges

Rank	**Total order**	**Weight-ed score**	**Group A: order**		**Group B: order**	
1	33.3 There are very few appropriate schools available	97	33.3. There are very few appropriate schools available	73	33.3. There are very few appropriate schools available	24
2	33.2 There are very few appropriate health services available	43	33.2. There are very few appropriate health services available	30	33.4. Finding affordable, appropriate child minding services	22
3	33.1 Location of the service	41	33.1. Location of the service	29	33.11. The professionals didn’t seem to know or understand what was wrong with my child.	16
4	33.12 Different professionals told me different things.	40	33.12. Different professionals told me different things.	28	33.5. Cost of transport	14
5	33.11 The professionals didn’t seem to know or understand what was wrong with my child.	37	33.14. I didn’t understand what to do or know where to go	25	33.2. There are very few appropriate health services available	13
					33.13. The teachers or school have limited understanding of ASD and how to educate my child.	13

Accessibility and availability of appropriate educational and health services were identified as the most significant challenges by the participants. The location of services was also deemed a challenge, as participants explained that they needed to travel long distances to access services due to the limited number of schools and health centres offering appropriate, specialized services.

Professional-related factors such as conflicting professional opinions and diagnoses, and poor professional awareness and knowledge of ASD and the management thereof were rated as the fourth and fifth most significant challenges.

The ranking of challenges by Group A and B were compared. Both groups identified the limited availability of appropriate schooling as the most significant challenge. This is despite the fact that the majority of participants (61.54%) have placed their children in autism-specific schooling.

Both Group A and B ranked accessibility and availability challenges in the top five challenges. Group A identified the limited accessibility of health services and the location of services as challenging, while Group B identified limited availability of appropriate child minding services, cost of transport (also related to location of the services) and limited availability of health services.

In terms of professional-related factors, Group A ranked conflicting professional opinions in the top five challenges, while Group B identified the professionals' limited knowledge and awareness of ASD as problematic.

Group A also identified their own limited understanding of the condition and where to seek help as a significant challenge. This theme was re-iterated by Group A's suggestions to improve community awareness of ASD and the available health and education services in the open-ended questions.

5.4.2 Qualitative results

Caregivers were asked what the greatest challenges they faced were in finding out what was wrong with their child, and then, in trying to seek help.

The caregivers' responses to the open-ended question were analysed qualitatively and are listed and categorized according to priori themes as in the previous section. These responses will be discussed in more detail in the discussion chapter.

Table 5. 13 Perceived barriers to service access

Priori Themes	Categories	Quotations
Logistical Barriers	Time, Financial issues and excessive costs incurred	"…long delays between appointments and report back."
		"No money."
		"I am not working…I find it difficult to find a school for my son…he needs to go to Unica which is very expensive for me."
		"The fees – I could not afford." (consultations and schools)
		"The financial implication of having a child with ASD is huge. It has set the family back so much."
		"The costs to see all the doctors and the cost for special education and treatment…"
		"Finance is difficult – education. Private schools are expensive to get better quality. Transport costs R400-R500 monthly. Spend a lot on clothing because child is active and wears and breaks clothing. Grant is not enough money."
		"…problem I have is that the child's mom and myself and myself are working and find it difficult or sometimes impossible to practice with him all that we have learned from the therapy sessions."
		"I was told about the support group, but I could not attend because of work."
	Accessibility and availability of services	"Distance to travel because I wanted to ensure he could get the best help and treatment."
		"Schools are not in our area, can't find help close to our area."
		"We have found that there are not many schools that offer the same support that he received on a primary school level. We have decided to home school him… But what about parents who are in the same position but do not have the means by which to give their children high school education with support!"
		"Trying to source the appropriate ECD service for my son."

Priori Themes	Categories	Quotations
Professional related factors	Diagnosis - Delay in diagnosis - Misdiagnosis - Consult multiple professionals to obtain diagnosis	“Seeing all these people and nobody was able to put the pieces together.”
		“Finding a correct assessment, there were so many theories and diagnoses.”
		“Information given was sometimes contradictory. No one could honestly say what the problem was.”
		“His language was very strong, his memory excellent, so one would at first believe that the other problems were minor. He was labelled ADD, a day dreamer, emotional etc. But none of the labels explained everything.”
		“Trying to get help seemed impossible because I heard different versions of what could be wrong with him.”
		“No one could give a definite diagnosis, some said epilepsy, others said this is just the way he was born.”
		“I don’t know because even now I’m not sure that diagnosis is complete. The reason I am saying this is because one practitioner is saying that my child has ASD, the other one is saying he is suffering from ADHD, whereas another is saying there is nothing wrong with my child. I don’t know what to believe anymore.”
		“…referred child to a psychiatrist for a diagnosis. This was after 2 – 2,5 years of therapy.”
		“Asperger’s Diagnosis came after speech and OT.”
		“The different health care practitioners I consulted said that there was nothing wrong with my child. They said he is too young and will outgrow this at some stage.”
		“There was sometimes false hope given by incorrect diagnosis, i.e. it was something an operation could fix.”
		“…first we were told it was a communication disorder, but then later we were told it was Autism.”
		“…everyone kept telling me that there was nothing wrong with her.”
		“Speech therapist rejected possibility of Autism.”
		“My biggest challenge was when my child was being misdiagnosed. I was so frustrated I took him to a public hospital I could not believe so I had to go to private psychiatrist to a second opinion.”
		“She (psychologist) misdiagnosed his problems and just said he was hyperactive.”
		“I was one of the lucky ones to get a diagnosis. These days the top professionals are not diagnosing correctly.”
		“…no one could help, see him and send him on”
	Skill / knowledge - Health professionals - Educationalists	“Nobody knew what was wrong.”
		“…the biggest challenge to getting a diagnosis was that people who didn’t deal with Autism didn’t know that Autism can manifest itself as high functioning. Because my daughter was able to do some advanced things like puzzles and naming all the shapes, autism wasn’t considered.”
		“Person making the diagnosis had no knowledge of Autism to pursue educational or medical interventions options.”
		“Most of the practitioners didn’t know exactly what was wrong with my child.”
		“Lack of knowledge.”

		“Doctors couldn’t tell me what was wrong, family didn’t know what was wrong, lots of confusion, offering ideas of what was wrong. Couldn’t find doctor to tell me what was wrong, keep searching.”
		“Carers don’t care, just have to look after him by yourself. No support.”
		“Helpers at school have limited knowledge about ASD and don’t’ know how to handle the children. Sometimes the helpers are just working for money and do not care about the children.”
		“School did not acknowledge a problem”
		“…he attended a ECD centre close to home but they couldn’t deal with his problems, but provided love and a safe environment for him.”
		“I mentioned Autism to Doctor, then not sure if doctor was objective about assessment, (child) might be different from what I had read about.”
	Mistrust Contradiction/ conflicting opinions	“Medication – don’t support – got frustrated because it didn’t help.”
		“Stopped the treatment, didn’t like the changes in the child you know.”
		“Contradictory information given.”
		“Disagreement with doctors regarding queried over-medication”
		“…one faces a lot of problems as these children approach puberty…There is no visible support out there.”
	Poor long-term planning and management	“…where to go from there (diagnosis). No support leaving the family in fear.”
		“After that (diagnosis) we were alone with no help.”
		“Developmental specialist told us our child’s diagnosis, and added that my child had no future.”
		“A neuro-developmental paediatrician: she just said my child has a PDD/ASD most probably Asperger’s, and then she gave us a booklet from ASA and the sent us on our way.”
		“We as parents of an Autistic child spend our lives worrying about what will happen to our son when we die. What are the adult care facilities like? Are they going to improve? How much will it cost? Will he be well looked after? Will he be happy? Will his special talents be nurtured?”
		Poor awareness of what services and resources are available to children with ASD and their families – so couldn’t refer appropriately or discuss treatment options available or guide caregiver in selecting appropriate treatment option.
	Referral - Professionals have limited insight into available services	Poor knowledge of who to refer to, to get a diagnosis.
		“We were not given any guidance to what behavioural intervention programmes were available.”
		“No one was sure where I should take her.”

Priori Themes	Categories	Quotations
Caregiver related factors	Awareness and knowledge	"Not knowing where to go for specific help."
		"It was the first time I hear about Autism, it was a big shock. I did not know that my son was Autistic because his brother is also a late talker. I had hope that he was going to be also fine."
		"CT scan and audiology tests normal – difficult to understand what is wrong, expecting to see damage or abnormal test results, confusing."
		"I didn't know what was wrong or what Autism is."
	Coping and insight	Emotional Reaction: "It was frustrating not knowing what was wrong with my son."
	Burden of care	"Very distressed to hear about problem…expected him to be independent and now he will lean on me for a long time. Feel very depressed."
Social/ Community related factors	Stigma - Lack of understanding	"Difficult…throwing tantrums at the mall, community doesn't understand, blame mom who doesn't discipline."
		"…the people they don't accept the child with Autism."
		"To make my family understand that my child is autistic not spoilt."
	Lack of support	"…father of my child doesn't support me at all. So that didn't give me strength to face the problem."

5.5 Factors which did or would facilitate good service delivery and access.

Inductive codes were developed by the researcher in analyzing the responses to questions 22 and 27, and considering the literature on these subjects.

Participants were asked what factors assisted them, or would have assisted them in finding out what was wrong with their child and in getting the necessary help. The participants' answers to this open-ended question were categorized according to emerging themes and further divided into categories. They are listed below.

Table 5. 14 Factors facilitating service delivery and access

Priori Themes	Categories	Quotations
Service Provision	Need a comprehensive treatment approach and greater variety of services	“A more comprehensive approach to treatment.” *involving a multidisciplinary team who is skilled and informed*
		“There needs to be a team of professionals giving PDD or ASD diagnosis who actually have experience in the area and are properly trained both on a medical and educational intervention. As far as I know, such people…do not exist in Johannesburg.”
		“A great need exists in South Africa for services for parents of special needs children.”
	Centralising services	“Need a central location where you can get help.”
	Government support	“Would appreciate government subsidy for families to help bear costs of caring for child with special needs. Help is available but very expensive, over and above medical aid cover. Approved private schools should be subsidised as no access to state remedial (2 year waiting list).”
		“…if government can start to recognise Autism as a disability and to incorporate Autism classes in mainstream schools because that will make more people to be aware of these condition.”
	Need for appropriate schooling	“High school education with support.”
		“We feel that he now needs to move to a new environment where he can be stimulated more. He seems to have outgrown his present school.”
		“We can notice the child developments since he has attended…school. Especially in speech.”
		“Since being at his school he has progressed in leaps and bounds.”
	Referral	“Paediatrician/neurologist could have pointed us in the right direction – school/therapists.”
		“It would have helped if we were referred to a paediatrician at an early age.”
		“I think had I gone to the Neurologist first. Parents need to know that once the neurologist had given the diagnosis, only then should all else follow.”
	Diagnosis	“”My boy got the right diagnosis when he was 2.5 years old which was still relatively early, but he probably would have made much progress if the right diagnosis was made at 18 months when we first sought help.”
		“Seeing the correct people.”
	Intervention	Children need more regular therapy
		“…once a week session with an occupational therapist for two consecutive months.”
		“What help me is Speech Therapy.”
		“Hospital helped with medication.”
		“Accept and gave the child treatment and follow instructions …child improving each day.”

Priori Themes	**Categories**	**Quotations**
Health Care Professionals and Teachers	Need for informed and experienced specialists	"Going to a child psychiatrist that specialises in ADD and Autism."
		"More awareness among teachers and supervisors at school, and various therapists etc. that child may present at – speech, OT etc."
		"If GP's and paediatricians and day care mothers knew the symptoms of Autism and/or if they could just direct you to the right centre for help."
		"Neurologist…directed us to the right school."
		"Doctor whose brother had been diagnosed with ASD, referred to ASA and the conference."
		"After seeing the Prof,…that's when I knew he was Autistic."
		"If practitioners had knowledge of these disorders."
	Need for informed teachers	"Teachers should know more nowadays. More pupils than before have problems and teachers are under-educated in this regard."
		"I think the teachers should be more informed of the condition and picking it up."
	Support -Doctors -Therapists -School	"People and doctors were supportive."
		"Coming to (school), the teachers support."
		"Getting support from therapists in order to understand and deal with it."
		"The school my child was attending offered all the support I needed."
	Training	"Big need for training. Mother to train as teacher, at least she has understanding of children with ASD and invested interest in helping the children."
		"Hold workshops for doctors, teachers and day care mothers."
		"Need to bring local teachers for training."
Marketing and Awareness	Distribution of information	"To see more out there. In USA and Europe it is publicized more. Better access to info."
		"I read about Autism – some idea of what it is….Still read how to deal with him."
		"Need more information in the media, TV programmes, magazines."
		"I listened to a programme on Autism on radio…and I immediately knew I have to have him assessed, specifically for Autism."
		"I read the book "Out-of-sync Child" which lead me to OT."
		"Finding information on the internet, find out your child is not the only child with this problem…watched programmes on TV – gave ideas, watched and learned."
	Content	Need more literature on different professions and services they offer.
		"It would be nice if there was some information on the latest advances made in media; research e.g. creation of a drug to assist digestion of peptides; what is being done about MMR vaccine."
		Own research on the internet – find out about available interventions
	Specialist directory	"there should be more literature on OT and the difference, and perhaps an easily accessible directory on specialists, what they do and how they can help."
		"Having a directory of special need facilities/centres/practices etc for different needs would be very useful."

Priori Themes	**Categories**	**Quotations**
Caregivers	Awareness	“Knowing where to go from the start would have helped.”
		“…asking around to find the best well-known person and not going to the normal GP and medical staff who has absolutely no experience in this field.”
		“Knowing where to go – there are a few doctors (GP’s) who understand Autism.”
	Resources	“We are in a very fortunate position to provide for our son, whatever or whenever the need arises.”
		“If I had medical aid, I think I could have helped him quicker when I first noticed the symptoms.”
	Education - Empowering parents	“Language Workshops (education) helped; self esteem workshop;…; learning to accept child and not get upset with him because he had his own way of thinking.”
		“Working at the school helped to learn skills and teach the children.”
		More info on how to encourage him because he gets bored easily and is not easily stimulate.”
		Learning how to teach or help the child.
Social/ Community	Family support and	“…family supported me and gave me strength.”
		“Staying with cousin. Cousin helps me with the baby, I can’t manage on my own.”
	Parent support groups	“…meeting other parents – seeing you are not alone.”
		“To speak with the problem of my son.”
		“…by coming to support group, that help me much.”
		“The parent support group (weekly in the beginning).”

5.6 Summary of Findings

In conclusion, the following key findings were made:

5.6.1 Patterns of service use:

- Long delays in diagnosis were found, with children with ASD being diagnosed at an average of four years of age, 2 years after their caregivers had noted abnormal development and begun seeking help. These time frames were not dissimilar to international research.
- 41% of participants reported that they did not receive adequate explanation and information when they were given the diagnosis.
- 46.2% of participants were never referred for support or counselling in accepting the diagnosis of their child.

- Caregivers accessed on average two to three different institutions and an average of 6 different types of professionals, irrespective of the sector of service they had access to.
- Dosage or frequency of sessions attended varied, corresponding to the type of service offered (i.e. medical, vs. therapeutic, vs. counselling) and the sector in which these services offered, with the private group accessing therapy more frequently than the public group.
- Children with AS were diagnosed later (at age 6 years 5months) than children with AD (at age 3 years 5months) and their caregivers often struggled more with finding appropriate services.
- In the public sector, health services are financed by department of health, while department of education subsidises education costs and caregivers have to pay part of the fee. Transport costs are substantial due to services being located outside of communities.
- In the private sector, medical aids covered some of the medical expenses, with caregivers paying residual medical expenses and covering expensive private school fees.
- Counselling and support services were usually paid for the caregivers.

5.6.2 Factors compromising service delivery

The key factors impacting on service delivery that were identified included:

- Limited availability and accessibility of appropriate schools and health care facilities.
- Location of few services far away from where caregivers lived, incurring substantial transport costs.
- Sizeable medical expenses.
- The professionals and teachers’ limited skill and knowledge of ASD.
- Conflicting professional opinions.
- Limited community awareness of ASD and the available of services.
- Some limitations in family and community support relating to poor insight into ASD and the child’s presenting behaviour.

5.6.3 Factors facilitating service delivery

Caregivers went on to identify factors they felt would facilitate better service delivery. These included:

- More schools, particularly high schools and specialised crèches, need to be set up.
- Comprehensive, specialised assessment and intervention units need to be established and publicised.
- Training and workshops need to be offered on two levels for health care professionals and teachers.
- Basic awareness needs to be created amongst the practitioners who are the first point of contact for caregivers, enabling them to recognise the need for referral, and the knowledge of appropriate services to refer these caregivers onto.
- Professionals involved in diagnosing and intervening with children with ASD and their caregivers, need to be appropriately specialised and experienced.
- Consultation with multidisciplinary teams may work to reduce the number of different appointments children need to attend, whilst facilitating case discussion and better, more holistic management of cases.
- Marketing and publicity is critically important to improve awareness of ASD in the community. This will improve caregiver's insight and assist them in finding the appropriate help. It will also help to reduce stigma and improve the supportive environment for caregivers of children with ASD.
- Support and education of caregivers as part of the intervention process is important in equipping them to manage their children with ASD and empowering them to cope.

It is important to note that these findings reflect the perceptions and experiences of the caregivers. These findings will be rationalised and critically discussed in Chapter 6.

CHAPTER 6: DISCUSSION

6.1 Introduction

The purpose of this study was to explore caregivers' perceptions and experiences of service provision within the Johannesburg Metropolitan Region, SA, for children diagnosed with ASD. The findings of the study that were presented in chapter five, are discussed in this chapter according to the research objectives laid out in chapter one. The findings were analysed and compared to the trends discussed in the literature. Reasons underlying the findings are explored and contextualised in the South African setting. A discussion of the limitations of the study concludes this chapter.

A sample of 39 caregivers of varying race, socio-economic status and educational level, who accessed both private and public sector services were included in this study. This was done to ensure representation of the South African population in the sample. This sample size was small in comparison to the larger international studies, and thus findings cannot be credibly generalised to other contexts. This sample was drawn from a "serviced population", i.e. caregivers and children already accessing health and education services. It is likely that the needs and experiences of caregivers who do not have access to adequate health and education services are thus underestimated by this study.

Despite these factors, the study results generated similar findings to the large international studies. The descriptive research design worked to generate descriptive information discussing the experiences of caregivers in Johannesburg, a unique South African context.

6.2 The sample

6.2.1 The caregivers

A sample size of 39 was obtained in this study. While this sample was small, it included caregivers with a range of racial, socio-economic, educational and social demographic characteristics. The sample was relatively homogeneous in terms of age and gender. The majority were the biological mothers of the children, and the average age was 36.8 years with a range of 25 to 75 years. The gender bias was expected, since mothers are commonly the primary caregiver.

Significant differences in race, socio-economic status (SES), income brackets and source of income, marital status, medical aid and transport, were noted between the caregivers accessing private and public sector health and educational services. For this reason, the sample was segregated into Group A (private sector group) and Group B (public sector group). Comparisons were drawn to establish whether Group A and B's experiences of service provision and patterns of service use were similar or different.

Table 6. 1 Comparison of Group A and B's mean demographic information

Group A (private sector group)		**Group B (public sector group)**	
	Mean		**Mean**
White participants	71%	Black participants	94%
Married and living within nuclear families	80.9%	Not married, nor living with a partner, living with extended family with complex social dynamics	55.5%
Highest level of education: Tertiary (university)	33.3%	Highest level of education: Grade 12/ completed additional courses or diploma's	38.9%
Income bracket of >R10 000 per month	91%	Income bracket of >R5000 per month	61%
Medical aid benefits	71.4%	No medical aid benefits	77.8%
Utilising private transport	95.2%	Utilising public transport.	66.7%

Table 6.1 is a summary of the main demographic differences summarised from the results. The comparison shows that residual disparities in race, socio-economic status, education and social or family dynamics still exist in post-apartheid South Africa. Similar to Shattuck et al's findings in the USA, there was some evidence to suggest that different population groups are not equally serviced[48], with the result that marginalized groups of people travel long distances to seek help, and differences in the frequency and quality of service provision in the public and private sectors are evident.

The above demographic factors also influence the caregivers' ability to meet their needs. Group B's needs tended to be more basic (meeting physiological, security, love and esteem needs) while Group A's basic needs were largely met and they tended to focus on the need for quality of life, and realising the child's potential. This impacted on the caregivers' perceptions and expectations of service provision. Group A focused on the quality and effectiveness of service provision, while Group B focused on the quantity and accessibility of services and the social (inadequate paternal and family support) and physical environmental (financial and geographical) difficulties they faced.

Some similarities were noted in the two groups' experiences of service provision however. No significant difference was noted in the mean children's age at diagnosis or in the mean number of professionals consulted, for example. The referral procedures were also not clear in either group. These similarities may reflect the influence of the complexity of the ASD condition rather than caregiver- or service sector-related factors on experiences of service provision.

6.2.2. The children presenting with ASD

Analysis of the characteristics of the children with ASD in this study, found no significant difference between the children in Group A and B. Hence, these attributes were consistent with those characteristic of ASD rather than being influenced by demographic factors such race, educational level of the caregiver or SES.

The ratio of boys to girls in this study was: 6,8:1. This ratio supports the literature that shows that more males present with ASD than females, although it is higher than the mean ratio of 4,3:1 described in the literature.[2,8,21,25,31] The disparity in ratios is likely to be due to the small sample size in this study.

The children came from a variety of racial and socio-economic groups supporting the literature which states that the prevalence of ASD is not affected by socio-economic differences.[2,8,21,25] No significant difference in the severity of presentation was noted between the groups either. Thus severity does not appear to be linked to either racial group or socio-economic status.

From the literature, the age of the child, and the nature and severity of the presenting dysfunction, impacted significantly on the number and variety of services accessed.[19,40,51,52] The sampling procedure and data collection sites (schools and early intervention hospital clinics) limited the age range of the children in this study to 2 to 14 years, with a mean age of 6,9 years. The caregivers commented on their concerns for the future regarding schooling in particular, reporting that professionals tended to focus on diagnosis and early intervention rather, with limited long-term planning or discussion of what caregivers could expect in the future. However actual experiences of caregivers of adolescents with ASDs are under-represented in this study. Hence, the study findings are representative of services provided for children under the age of 14 years.

No further analysis of the patterns of service use relative to the age of the children was carried out for this report.

Children with various functional levels (indicator of severity) were included in the study. The data demonstrated the defined presentation of ASD. Children presented with varying levels of functioning in the different self care activities. Generally, the children presented with limitations in adaptive functioning and required at least some supervision and assistance in self care activities. The children tended to be more independent in toileting and eating. These tasks involved meeting basic physiological needs and thus may be more intrinsically motivating for the children resulting in greater participation, practice and thus performance in these tasks. Dysfunction in speech and communication was noted. The children largely used one to two word phrases to communicate their basic needs, and were not usually easily understood by strangers, indicating that their communication may not be easily understood or interpreted, without a good understanding of the child and his/her abilities and habits. These presentations are characteristic of ASD.

Overall, the majority of the children presented with a moderate functional level, and moderate impairments in speech and communication, with few children presenting with very low and very high functional levels. This may have biased results, emphasising the experiences of caregivers of children with moderate levels of function. Due to the large differences in the number of children in each functional group (low, moderate and high functioning), together with the fact that the functional measure does not have proven reliability or validity in determining the level of severity of the ASD, the patterns of service use were not analysed relative to the various functional levels.

6.3 Patterns of service use

This study supported the literature, noting an increased number of professionals consulted and services accessed, with delays in diagnosis, inappropriate referral, multiple interventions and excessive costs incurred. Three key phenomena emerged, presenting possible reasons for these findings:

1. The complexity and heterogeneity of the condition in terms of aetiology, severity, presentation of key symptoms over time, and the associated co-morbidities, complicates diagnosis and effective intervention. Best practice involves consultation with a skilled multidisciplinary team, and various time-intensive, costly, long-term interventions are commonly indicated.
2. The inadequacy and inefficiency of service provision due to: rising prevalence which is disproportional to the development of services; poor referral systems; inadequate screening tools; inexperienced and under-qualified professionals. This leads to limited availability of services, unnecessary duplication of appointments, escalating costs, frustration and mistrust of service providers.
3. Caregiver factors such as educational level, racial group, socio-economic status and social supports influence the service sector which is accessed, determine the needs of the caregivers and influence the caregivers' perceptions of their experiences of services.

6.3.1 Initial presentation of signs and symptoms of ASD

Similarly to the literature reviewed, the study revealed that the caregivers were generally the first to notice dysfunction in their child.[41] Caregivers first noted signs and symptoms earlier in children later diagnosed with AD (by 22 months), than children later diagnosed with AS (by 29 months).

The discrepancy between the ages at which symptoms are noted related to the severity of presentation, as described in the literature. Symptoms are noted earlier in lower functioning children with AD, when compared to higher functioning children presenting with AS.[41] As might be expected, co-morbidity also plays a role in the age at which first signs are noted. Co-morbid conditions may be diagnosed earlier and result in early introduction into the healthcare systems where further diagnosis of ASD may be made in the younger child.

Like Howlin et al's study, the most common symptoms noted initially were poor social interaction and poor speech development. Delay in achieving developmental milestones, regression in speech development, sensory sensitivities, and behavioural problems including tantrums and screaming were the next most common symptoms, followed by hyperactive behaviour.[41]

Similar to Howlin et al's study, 20.5% of the caregivers in this study reported that their children were developing age-appropriately up to a point. They then noted regression in language and social development in particular, which evoked concern.[41] This presentation may affect the age at which the first signs were noted and help was sought. The sudden onset of dysfunction may also have made the diagnosis of ASD more difficult for caregivers to accept (than for those caregivers who had noted that something was wrong with their child early in the child's development), leading to mistrust and caregivers searching for second opinions.

In this study, stereotypical and repetitive behaviours were seldom noted initially. Howlin et al explained that these behaviours are commonly first noticed when the child is older, at the age of three to fours years.[41] Taking into account the DSM-IV criteria, which are used routinely by psychiatrists to diagnose ASD, the absence of these stereotypical, repetitive behaviours may negate a diagnosis of ASD.[8] This could imply then, that a diagnosis could only be made when these behaviours appear – i.e. after three to four years of age, two years after the first symptoms were noted.

6.3.2 Referral process

There was a delay between the time that caregivers noticed abnormal development in their child, and the time at which they sought help. They explained that did not know where to take their children to be assessed and diagnosed, and then following diagnosis, what intervention they should access and where it could be accessed. This relates to the limited community awareness and understanding of what ASD is, how ASD presents, what services are available for children with ASD and their families, and how to access these services. Caregivers thus depend on health professionals and educationalists to refer them to the appropriate services.

The first point of contact is significant in determining the referral process and directing the caregiver and child through the appropriate channels of assessment in order to obtain an appropriate diagnosis. In the South African public health setting, policy dictates that patients first present their ailments and concerns to the nursing staff and general practitioners at the local clinics. Should consultation with specialists be required, these practitioners would then refer onto the secondary health care level (regional or district hospitals) and then onto the tertiary level (academic and tertiary hospitals) for more specialist assessment and intervention.[63] Similarly in the private health care setting, the medical aid uses funding policy to encourage clients to see a general medical practitioner first, who should then refer to a specialist if the need arises.

It is thus important that the general practitioner working in the primary public health care setting, and the practitioner working in general private practice, is able to detect deviance and delay in development, and have some level of insight into possible causes and conditions, and the respective protocols for referral and management of these conditions, in order to refer on appropriately and timeously.

The first institution most commonly accessed (48.7%) by the study participants was private practice. A significant difference (p=0.01) was noted between Group A (private sector group) and Group B (public sector group), in keeping with their socio-economic differences and the type of health setting accessed. Such that, the mostly white, private Group A (largely with medical aid benefits) participants commonly (66.7%) accessed private practices first, while the mostly black, public Group B participants (largely without medical aid and depending on government health services) commonly (38.8%) accessed government clinics first, with 27.7% of the public group accessing services outside of their usual health systems in private practices.

While Howlin et al's study found that caregivers most commonly consulted with a GP first, followed by the paediatrician, this study found that the paediatrician was consulted first most commonly (30.8%), followed by the GP (18%) and the OT (10.3%).[41] This pattern was generally consistent between Group A and B. Group A consulted with the paediatrician most commonly (38.1%), followed by the GP(14.29%) and the OT (14.29%); while Group B consulted the paediatrician (22.2%) or the GP (22.2%) most commonly, followed by the nursing sister (16.7%) and the audiologist (11.1%). This may depend on the availability or accessibility of the respective professionals and established referral patterns. The presenting problems, and trustworthiness of particular professionals, may also play a role in the choice of the professional from whom help was first sought.

Analysing the initial consultations of Group B further, may suggest that those caregivers accessing private practices first, tended to consult with paediatricians, while those accessing clinics first consulted with GP's. Caregivers accessing clinics first should not have been able to see paediatricians first in accordance with policies regarding levels of care, and were thus possibly accessing nursing staff and GP's primarily.[63]

It was unclear from this study which professional gave the diagnosis. From the data collection process, it was also apparent that a few of the participants were unsure as to which kinds of professionals they had consulted due to limited medical knowledge, and this may have compromised the accuracy of the study findings.

The sequence of referral following the initial consultation was difficult to analyse statistically. There did not appear to be any clear, common referral procedure in either group with participants accessing a variety of different combinations and sequences of professionals and institutions. In addition, the time lapse between when symptoms were first noted and when a diagnosis was confirmed, was on average 2 years. It is thus plausible that caregivers and children were not appropriately and efficiently referred, assessed and diagnosed.

From the open-ended questions, caregivers complained that the health care professionals and teachers were unable to refer them to the correct service providers. Caregivers felt that these referral problems emanated from the professionals' poor knowledge of the condition and poor awareness of the most effective interventions available and the location of these available services. Delays in referral may also have been exacerbated by the caregivers' cycle of grieving and acceptance. Consequently, caregivers visited numerous services and professionals, searching for the appropriate assessment and diagnosis. This in turn delayed the diagnostic process and compromised the commencement of early intervention. In addition, it left the caregivers feeling frustrated, disillusioned about health and educational services, unsupported and disempowered.

6.3.3 Process of diagnosis of ASD

According to literature, the diagnosis of ASD is commonly a complicated, difficult, time consuming process.[21,41,48] Given the poor prognosis of this condition, the weight and implications of such a diagnosis are significant, and diagnosis may be made cautiously, at the expense of efficiency.

In the literature, the age of the child, and the severity of the presentation were shown to impact on the timing of diagnosis.[41] The severity of presentation and the prevalence of ASD have been associated with gender, such that more males are affected than females, but the females that do present with ASD tend to be lower functioning.[8]

The children in this study had a mean age of 6 years and 11months old. The ratio of males to females was 6.8:1 compared to the documented 4.3:1 ratio.[8,21,31] The ratio of children presenting with AD to children presenting with AS was 4.3:1 compared to the reported ratio of 4:1.[20,40,41] Co-morbidities were noted in 59% of the study population which is slightly elevated in comparison with international data (6-49%).[21,27] ADHD was the most common co-morbid diagnosis (33.3%), despite the fact that the DSM-IV TR criteria state that ADHD is a differential diagnosis to ASD, and that although high levels of activity and inattention are frequently noted in ASD, an additional diagnosis of ADHD cannot be made in the presence of a diagnosis of ASD.[8] While the gender and diagnostic profile of the children in this study was comparable with that in other studies, it may have been biased by the sampling procedure and the small sample size, and can thus not be taken as being representative of the profile of children with ASD in the general South African population.

This study found similar trends and delays in diagnosis to those reported in the literature. Like other studies, the children in the study were diagnosed at an average age of 4 years, 2 years after the caregivers first noted signs and symptoms.[41] Very little difference (p=0.7) was noted between Group A and B in this regard. The average age at diagnosis in Group B (public sector) was 3 years 11months, while Group A (private sector) children were diagnosed slightly later at 4 years 2months. This may be affected by the level of involvement of the MDT which seemed to differ between the two groups. Also, Group A included a larger proportion of higher functioning children, who tend to be diagnosed later.[41] This may account for the slight difference in the age at diagnosis.

Dysfunction is more marked and thus easier to identify earlier in the development of children presenting with AD compared to children presenting with AS. This is reflected in the average age of diagnosis for the different types of ASD.[41] In this study, the difference in the time frames for diagnosis of the different types of ASD was significant (p=0.03) but not as extreme as in Howlin et al's sample. Children with AD were diagnosed by the age of 3 years and 5 months (compared to 4 years and three months[41]), 1 year and 7 months after first signs were noted. Children with AS were diagnosed at the age of 6 years and 5 months (compared to 11 years[41]), about 4 years and 11 months after initial symptoms were noted. The caregivers in Howlin et al's study tended to note symptoms slightly earlier than the caregivers in this study.[41] This may relate to poor community awareness of ASD in SA.

The caregivers of the children presenting with AS expressed significant frustration with misdiagnosis and conflicting professional opinions. They described the limited experience and knowledge of health care professionals and educationalists regarding ASD and its various levels of presentation, as a significant barrier to appropriate service provision, and a cause for mistrust of health care providers.

This finding highlights the complexity of diagnosis with higher functioning children, when distinguishing features between various differential diagnoses become more difficult to identify.[21,41,48] The need for specialised, experienced professional services is emphasised. These higher functioning children tend to have a better prognosis in the long term, and have the potential to lead fairly independent lives and maintain some gainful employment. Appropriate early intervention based on an accurate diagnosis is crucial in order to facilitate functionality and assist in preventing secondary co-morbidity such as depression and anxiety, which are common in the higher functioning adolescent and young adult presenting with ASD.[21]

The diagnosis of ASD is potentially devastating news to break, considering the pervasive effect on the child's functioning and prognosis. It implies the need for lifetime care and dependence on caregivers. Bax explains that this is a daunting task for a health care practitioner, and may make the practitioner over-cautious in giving the diagnosis, particularly if there is some doubt concerning the accuracy of the diagnosis. This may lead to further delay in diagnosis, while practitioners continue to observe a child over multiple sessions to ensure correct diagnosis.[50] Bax challenges this cautiousness noting that he had experienced caregivers' gratitude and relief in learning what was wrong with their child, following their experience of multiple referrals and lack of diagnosis. He reported that children who are diagnosed early can be accepted and understood better by their community from early on, while children, who are not diagnosed until later, tend to be alienated by their community, who do not understand their behaviour and therefore do not make allowances for them. [50]

A diagnosis of ASD constitutes "bad news". Caregivers are likely to experience difficulty in adjusting to the news and accepting the implications the diagnosis has for the child and for the family. The need to provide support and educate caregivers regarding the condition thus forms an important part of the health care practitioner's role in diagnosing ASD, as highlighted by Nuutila et al.[47] While the majority of participants in this study (56.4%) felt they were able to ask questions about the diagnosis and (59%) were given adequate information on the condition and how it would impact on their child's future, more than 30% of caregivers, didn't feel they were adequately informed. Some of the caregivers explained that they were simply given the diagnosis with a brief description of what it was, and told that their child would never be independent or achieve anything, before the session was terminated without further support. This finding mirrored Ruble et al's finding that resources were rarely given to caregivers to assist in explaining the diagnosis or prognosis of their child.[27]

The majority of participants (66.7%) in this study received no support in accepting and understanding the diagnosis, largely because they were never referred for this support, or in some cases, due to work-related time constraints which prevented them from attending such appointments. A small proportion (20.5%) of the public group participants were referred to caregiver support groups which they found very helpful. No private group participants were referred to a support group by the diagnosing practitioner.

These findings demonstrate poor quality of service provision, with disregard of best practice principles advocating adequate discussion of the condition with the caregiver, appropriate long-term planning and provision of caregiver support. This practice may compromise the achievement of optimal outcomes for the child.[47] Considering the vast body of literature exploring parental stress related to the diagnostic process, and then the significant burden of care experienced by caregivers in caring for a child with ASD[43-45], this result is concerning. This lack of support and the limited information given to the caregiver tends to disempower them and leave them feeling hopeless and helpless. The principles of: providing support and adequate information; and building a trusting permanent relationship with clients and their families during the diagnostic phase[47], are disregarded. The foundations for the initiation of appropriate management are thus already compromised.

6.3.4 Services accessed by caregivers and their children

Caregivers described accessibility and availability of services as significantly challenging. In particular, limited availability of appropriate schooling and health care services; excessive costs of consultations and transport to access services; and the large number of different appointments were emphasised. These challenges emerged from the tendency to access multiple services from a variety of different service providers in order to address the wide range of child and family needs, which is common in relation to ASD. The limited number of available and accessible services as well as inefficient, unequal service provision also impacted on these experiences.

6.3.4.1 Number and type of services accessed

On average, two to three different institutions were accessed by caregivers and their children, which is less than the average of 4 institutions accessed by participants in Kohler's study.[52] While all of the Group A (private sector) participants had accessed private practices and the majority of Group B (public sector) participants (94%) had accessed government hospitals, some (25%) Group A participants had accessed public hospital services, and a large portion (44%) of Group B participants had accessed private practice services. Thus some flexibility in service sector access was noted. This may have been driven by the search for appropriately experienced professionals and services that could provide a diagnosis and direct caregivers to appropriate intervention, irrespective of the service sector the professional served in, or the SES of the caregiver. This finding is similar to Jacklin's finding that a large proportion (58% of the total number of clients with ASD accessing the clinic) of Group A families were accessing state run services with a "perceived greater skill level".[17]

The mean number of professionals consulted by the caregivers and their children was 6.25. This was comparable to international research which reported averages of four to nine different types of treatment accessed.[19,40,51,52] There was no significant ($p=0.96$) difference between Group A and B in this regard. This finding relates to the pervasive nature of the condition and the need to consult with a variety of different professionals in order to meet the diverse needs of the child and the family.

The most commonly consulted professionals in this study were the paediatrician, neurologist, speech therapist, audiologist and occupational therapist. The least commonly consulted professionals were the: psychiatrist, GP, nursing sister, physiotherapist, social worker, remedial therapist, dietician, counsellor and traditional healer. The reason for the limited use of these services was not determined by the study. Many of these professionals may be able to offer valuable input or useful services to children with ASD. It is possible, based on the perceptions of the caregivers, that either: these professionals are not routinely referred children with ASD; or these services are not widely available; or these services are not deemed appropriate by caregivers either due to the caregiver's limited insight, mistrust of the professionals or stigma.

Therapy was accessed more frequently by this sample than in Ruble et al's study. This result may be biased by the clinic and school-based sample, where therapy services are easily accessible. The majority of the sample (97.4%) accessed speech therapy (compared to 76% in Ruble's sample[27]), with 55.3% accessing group sessions and 97.4% accessing individual sessions. Occupational therapy was accessed by 82.1% of the sample (compared to 68% of Ruble's sample[27]), with 46.9% accessing group sessions and 93.8% accessing individual sessions. These statistics show that while individual therapy was favoured in managing ASD in this study, many children accessed both individual and group sessions. Respite care was accessed by 7.9% of the sample, where 29% of Ruble's sample accessed respite care. The access of respite in this study seems inflated since respite care in Johannesburg is extremely rare. The use of carers however, was common (53.8%). None of this study's participants reported accessing in-patient care for diagnostic or intervention purposes, nor did they place their children in residential care. While this may have been affected by sampling biases, it may also reflect under-utilisation of these services or a differing trend in service use in this context compared to international studies.

As seen in the access of institutions, Group A participants tended to access private sector services while Group B participants accessed public sector services. However, similarly, mixed sector service use was apparent.

The use of different types of interventions (e.g. ABA, PECS, SI etc) offered by these different professionals was not explored in this study, as caregivers interviewed in the piloting process showed little insight into the type of intervention being accessed. They showed better insight into the type of professional offering the service, and hence the questionnaire was adapted accordingly and in contrast with international studies which explored the specific type of intervention utilised.

6.3.4.2 Frequency of services accessed

The frequency of intervention sessions, or dosage of intervention, may impact on the efficacy of the intervention in attaining treatment outcomes. Dosage is closely related to the type of intervention and the mechanism of treatment effect.

However, frequency of intervention increases the financial and care burden for caregivers. Many caregivers highlighted the financial burden imposed by multiple appointments carrying excessive medical and transport costs. Time was another challenge. The attendance of numerous appointments resulted in excessive time off work, and many caregivers reported being unable to work due to the burden of care (30.8% unemployed). Those caregivers that were employed found it difficult to implement recommendations and home programmes prescribed by the professionals due to time constraints.

In this study, caregivers consulted the doctor on average, every 3 months. This was comparable to Ruble et al's study which reported average consultation every 4 months.[27] Counselling services were accessed by few caregivers in this study and tended to be accessed erratically or once-off, rather than regular, long term access to therapy. It was thus difficult to establish frequency of access. Speech therapy and occupational therapy services were accessed on average once weekly, compared to the twice weekly average in Ruble et al's study.[27] A significant difference was noted in the access of speech therapy (p=0.01) and occupational therapy (p=0.04) services within the private and public sectors, with Group A accessing therapy more frequently than Group B. Respite care is not widely available in Johannesburg, and so caregivers were asked the extent to which they used carers to assist in caring for their children. The service of carers was used daily by 38.5% of the caregivers. These carers included privately paid caregivers and family members assisting with child care. Despite the high level of use of carers, caregivers noted difficulty in finding carers that were trained adequately to understand and care for their children, and reported high turnover rates of carers.

The sample was partly drawn from autism-specific schools. Thus findings regarding the placement of children with ASD are unlikely to be representative of the general population of children presenting with ASD, of which many may not be placed in these schools. It is interesting to note that even though the majority (85%) of children in the sample were attending an autism-specific or special needs school, caregivers identified the limited number and accessibility of appropriate schooling as the most significant challenge they faced. This perception may be influenced by caregiver's lack of acceptance of their child's educational limitations and prognosis. However, cost of education, location (often a far distance from home) and poor training and knowledge of the teachers at the schools were some of the factors identified by caregivers as challenging. Caregivers explained that few specialised educational and crèche facilities were available before the child was of school-going age, and most (43.6%) children attended mainstream day care centres if they attended crèche at all. Caregivers explained that they had struggled to find appropriate schooling for their children and that this had resulted in the children attending a variety of different schools before an appropriate school was found. Caregivers also expressed concern about where to send their child for high school education since there seemed to be very few accessible and appropriate secondary education facilities.

6.3.4.3 Cost of health and educational services.

While the exact cost of the services was not established in this study, caregivers were asked who covered the cost of services, what the costs of educational services were, and whether they perceived the costs of health and education services to be affordable or not.

The experience of cost was different for Group A and B participants. The impact of SES, geographic location and service sector accessed, played a role in these findings.

Group B reported that their medical expenses were largely covered by the department of health. The South African Constitution guarantees children with disabilities, the right to health and education services. As such, free health care is provided for children under the age of six years, and children and adults with disabilities at state institutions.[54,57]

Caregivers in Group B identified transport costs and elevated costs of special education in comparison to mainstream education as their most significant costs. Educational services cost these participants on average, R432 a month. Many of the Group B participants were unemployed (33.3%) or earning less than R5000/month (61.1%) with 77.8% earning a salary or wages and 44.4% dependent on social grants (less than R1000/month). The cost of education and transport enabling access to health services were thus a significant burden for them in addition to general expenses.

Group A largely (71.54%) belonged to comprehensive medical aid schemes. These schemes covered some of the medical expenses but caregivers did report having to pay residual costs. Therapy services were usually funded through school fees which were paid by caregivers. Education costs were on average, R4160 a month for special education and related services, compared to the $11543 per annum paid in the US for special education and related services (this translates broadly to R7 695/month). While this discrepancy in cost may relate to difference in the socio-economics of the countries, depth of service provision in national and international schools also varies.

Despite the fact that Group A reported an average income of more than R10 000/household per month (90.5%), much higher than Group B, they still highlighted costs of consultation and education as a burden for the family.

6.4 Factors impacting on service delivery and access

The challenges identified by the caregivers were categorised into four key themes. These included:

- Logistical barriers, which related to the demographics of the group and the limited availability and accessibility of services.
- Professional-related factors, which included inadequacy in the expertise and experience of professionals which led to poor service provision.
- Caregiver-related factors, associated with limited medical insight, burden of care, poor coping and acceptance.
- Family and Community-related factors, linked to limited community awareness of ASD, stigma and poor social support.

6.4.1 Perceived barriers impacting on service provision

The international studies reviewed concerning barriers to service provision were largely written from the perspective of the service providers or funding agencies rather than that of the consumer. These articles identified the costs and complexities of holistic, multidisciplinary health care and educational service provision, with a view to informing the rationalisation of the depth and breadth of service provision, and the eligibility of autistic individuals compared to other individuals (with different diagnoses and needs) for funding of such services.[40,48]

This study established the caregiver's perspectives of service provision. These views may have been influenced by the caregivers' exposure to services, insight into their children's conditions and awareness of available services. The clinic-based and school-based sampling used may have biased the factors identified, as these subjects had at least succeeded in obtaining services for their children. It is thus likely that service needs and barriers may be underestimated in this study.

The key challenges experienced by the caregivers included: logistical barriers; inadequate professional expertise and efficiency of service provision; and limited awareness and knowledge of available services. This finding mirrored South African and international findings.[23,54] Saloojee et al's study explored the unmet service needs of disabled children in a peri-urban South African population. Unlike this study, Saloojee et al used a community-based sample, and found significant numbers of disabled children and caregivers who did not have access to health and education services at all. The main reasons Saloojee et al identified for poor utilization of services included: "lack of money, poor awareness and knowledge about the right to health care and available services, and bureaucratic obstacles".[54] Despite the difference in research sample, and sampling technique, this study reported similar caregiver views even once services had been accessed, indicating that these factors continued to play a role in the access of services even after the initiation of services.

International studies also reported similar barriers to service provision to those identified in this study. This suggests that problems experienced in providing services and accessing service for children with ASD throughout the world, and in different service sectors, are impacted significantly by the complexity of the condition itself. The limited evidence-base for treatment options; and the effect of models of service provision and the context in which services are provided, may also play a complementary role.

Group A: The private sector group

Group A was 71.4% white, 23.8% black and 4.8% Asian. They tended to have an income greater than R10 000/month and belonged to medical aid schemes. Their children attended private schooling and they largely made use of private health care based in private practices. Thomas et al (2007) established that caregivers with higher incomes tended to have access to greater numbers of services[40]. This was not noted in this study where no significant difference was noted between Group A and B in the numbers of professionals and institutions accessed. The difference in service access appeared to be more in terms of the frequency of services accessed. Caregivers in Group A appeared more critical of the quality of services than Group B. Therefore, even though the quality and frequency of public services may have been poorer than the private sector services, the perceptions of Group A and B caregivers of the quality of services were fairly similar.

Even though most of the caregivers in Group A had access to medical aid and private sector services, they reported considerable difficulty finding, accessing and affording appropriate services. This may suggest that there are insufficient available and accessible services.

Caregivers in Group A unanimously reported that were few appropriate schools available in Johannesburg. Pretoria, Cape Town and Durban each have one resourced and staffed Autism-Specific Government School. Johannesburg schooling for children with ASD consists largely of small, expensive, private Autism-Specific schools, general special needs and remedial schools, and only one, comparatively under-resourced government school with Autism-Specific classes. The costs and logistics of building and resourcing highly specialised, easily accessible schooling for children with ASD in Johannesburg is a controversial expectation, in the face of other pressing societal needs. However, given that Johannesburg is the most economically active city with one of the largest populations in SA, service provision should at least be in line with other major city centres if not more expansive than the other cities.

A large proportion (61.9%) noted that there were few available appropriate health services, reporting that they had to travel fair distances to access services as they were not available in their immediate communities.

A lack of appropriate child minding services did not seem to provide as much of a challenge for this group as it did for Group B. However, this view may be affected by the fact that all children were attending school during the day, and (61.9%) of these caregivers only worked part-time or not at all and would thus be available to care for their children after school. A further 38.1% made use of daily carers, which seemed to meet the respective needs.

Caregivers in Group A noted that the medical aid would cover some of the medical expenses incurred. Therapy services were billed as part of their school fees, which complicates claiming from medical aids for these services. Counselling and residual costs not covered by the medical aid were for their expense. Different to Group B, and international findings, they found the costs of consultations (which exceeded medical aid rates and cover) and the cost of school fees, a burden. Some (38%) also reported transport costs to access health and educational services challenging, given the location of these services relative to their residential address.

Similar to Thomas et al's findings, Group A did show some greater cognisance of their needs and rights to appropriate service delivery, and they complained significantly of poor quality of service delivery.[40] The majority (76.2%) of this group had a level of education higher than grade 12, i.e. they had some college or university level education. This may account for the better knowledge of their rights.

The group described numerous experiences of poor professional skill in assessing and accurately diagnosing, and referring their children to appropriate services. Conflicting professional opinions challenged more than 70% of caregivers, while poor professional awareness and knowledge of ASD posed a challenge to 66.7% of the caregivers. This group also found the large number of appointments, and the delays between appointments due to long waiting lists, frustrating. This may point to the overburdening of the few available services, which is compromising the efficiency of their service provision.

Despite the fact that all the children in this sample were attending autism-specific or special needs schools, 47% of the sample highlighted the poor knowledge and awareness of teachers as problematic.

Caregivers in this group also reported significant anxiety around their own limited knowledge of ASD and awareness of what services were available to them, but did not report as much denial of the problem as was noted in Group B. Only 14.3% explained that they didn't perceive anything to be wrong with their child.
Of the caregivers in Group A, 80.9% were married. Research into burden of care describes extreme stress placed on a marriage by the birth of a child with ASD, which leads to high levels of divorce in these families.[43] This was not reflected in this sample. In terms of household composition, the Group A families tended to be nuclear families with two caregivers and on average two children. Some (38%) of these caregivers had received counselling on hearing the diagnosis of their child, but none of the caregivers belonged to or had accessed support groups despite the tremendous stress they were under. Some caregivers (38%) reported poor support and understanding of the child by the family, and only 9.5% noted antagonism from the community. While lack of general community involvement may explain the limited perception of community stigma and lack of support in this group, the lack of general awareness around ASD appeared to impact on the perceptions of their close friends and families, who continue to blame parenting for the child's behaviour.

Group B: The public sector group

Findings suggest that the quality of service provision may not have been of paramount importance to this Group. This group of caregivers' identified of the location of the service, the number of appropriate schools and health services available, finding affordable and appropriate child minding facilities, too much time off work and too many different appointments as significant challenges, where long waiting lists and queues were not viewed as significant.

The high patient numbers, with limited staffing and resources in state services compromise the depth and breadth of service delivery, and it is unlikely that services are provided as frequently as they should be. Thus the fact that caregivers did not perceive long waiting lists and queues challenging, contradicts the reality of long waiting lists, queues and delays experienced commonly in the public sector hospitals and schools. Possible factors playing a role in this finding, other than the difference in priority of needs, is the relative complacency of the participants who may have become accustomed to this level of service provision and therefore do not view it as out of the ordinary or noteworthy.

Cost was a significant challenge for the majority of the caregivers. However, what cost was incurred was different in the two groups. Group B, who mostly utilised free, state health services, struggled to afford transport costs and school fees, while the cost of consultation was not a problem. This finding was similar to Saloojee et al's findings.[54] Cost was exacerbated by the large number of appointments (related to the complex assessment and intervention needs of children with ASD) that had been scheduled for caregivers, at the larger hospitals, which tended to be a substantial distance away from where the families lived. This may have also produced the perception that infrequent therapy or consultation was not a challenge for this Group. Lack of knowledge of the frequency of sessions required to produce good treatment outcomes results in acceptance of the scheduling of follow up appointments monthly or delaying appointments based on availability, unless there is a medical crisis. Less frequent sessions are also more affordable. On the contrary the more informed and resourced Group A caregivers may have higher demands on frequency and quality of service provision.

An interesting finding was that only one caregiver admitted to missing appointments. This could of course be related to insight and truthfulness. However, it could also demonstrate the desperation of caregivers in finding help for their children and their using all the opportunities available to them. This may reverse the basic needs balance, and illustrate that having a child with ASD presents challenges at least as significant as the caregivers other needs and problems.

The cultural and social differences noted between the two groups may also have impacted on their perceptions of the barriers to service provision. Over half (55%) of caregivers in Group B were not married, nor living with a partner. This has implications for financial and emotional support in raising a child with ASD. An analysis of the household composition showed that the Group B caregivers tended to live in households together with three or more adults and two or more children. Many of these caregivers reported that the other adult family members and friends assisted in child minding. However, a higher percentage of caregivers (66.7%) than in Group A, noted that close friends and family often did not understand the child and his/her condition, and at times, blamed the caregiver for poor parenting, alienating the caregiver rather than supporting them. This may also be related to the general level of education and awareness of these communities regarding ASD, particularly in the context of traditional beliefs. Caregivers in this group also noted that paid carers were often poorly equipped to care for their children and often unsympathetic to their children or the caregiver's situation, reporting that carers simply "worked for the money" without empathy or skill.

Thomas et al suggested that the educational level affected the caregiver's cognisance of needs and rights, and awareness of available services and also empowered people to demand better quality of service provision.[40] The educational level of Group B was quite diverse. While 44% had a highest educational level of Grade 12 or less, 55% reported having college diplomas, or university degrees. This group identified both professional inadequacies and personal inadequacies in knowledge and awareness of ASD and the available services. Half the group noted that health care professionals and teachers showed a limited understanding of their child and what was wrong with the child. Only 33% noted conflicting professionals' opinions as problematic. This was significantly different to Group A (p=0.02). This may have been influenced by the greater level of multidisciplinary work found in public sector service provision than in private sector services. A large proportion (44%) of this group reported that they didn't understand what to do or where to go to help their children which was similar to the Group A, reflecting a generic limitation in community awareness. An equal proportion

(44%) noted that they didn't believe that there was anything wrong. This was significantly different to Group A. (p=0.04) Education, insight (related to stages of acceptance), level of empowerment and the significance of family and community views are factors which may play a role here.

6.4.2 Factors facilitating service provision

While few caregivers reported positive experiences of service provision and access of services for their children, they had many suggestions and recommendations to facilitate improvement of service provision and access, and the general management of the ASD situation in South Africa.

In response to the challenges caregivers experienced in locating and accessing appropriate services, they highlighted the need for the development of a greater number and variety of services. They advocated the need for a more comprehensive treatment approach where a team of professionals could provide for the child's needs holistically rather than referring children to numerous institutions and professionals for a variety of services. This would help to reduce the number of appointments and might improve the efficacy of intervention.

Caregivers emphasised the need for the setting up of a greater number of schools in their home communities which would help to limit the transport costs incurred in accessing these schools. They also claimed that the presence of such services may help to facilitate awareness of ASD in the communities. Crèche and high school facilities appear to be the most limited, leaving the caregivers with few options beside home schooling or early termination of schooling. These schools need to be developed to offer specialist support in educating children with ASD.

Caregivers noted that the experience and expertise of individual health care practitioners and service providers had made the difference in arriving at an appropriate diagnosis. Many complaints of misdiagnosis, conflicting diagnoses, and mistrust of doctors' opinions due to their inadequate knowledge and experience were fielded. They called for training of the general practitioners, teachers, day care mothers, nurses and therapists who tended to be the first point of contact, to make them aware of the condition ASD, and enable them to make informed choices as to where and how to refer these children on to specialised services. This recommendation is supported by Mubaiwa who suggested the need for inclusion of adequate training in neurodevelopmental conditions at an undergraduate level for medical and allied health practitioners and community health care workers.[33] Caregivers highlighted the need for expert training and specialisation of professionals in the field. They also called for exploration of different intervention techniques available abroad and the implementation of these interventions in the South African context.

Caregivers pointed out the inefficiency of the referral procedure and the importance of referring to the correct practitioner early on. The caregivers recommended that, besides improving awareness and knowledge of professionals, a specialist directory of experts in the field should be compiled to direct both professionals and caregivers to the correct service providers.

Caregivers noted that therapy, medication and appropriate schooling have improved their children's functionality significantly, so access to regular services must be maintained and made available to all, regardless of their means.

Caregivers did find, to a certain extent, that having access to medical aid helped to support access to services and gave them greater opportunities to access treatment. However, they did note that living costs, educational costs and medical costs together, placed a significant burden on caregivers and families. They felt that government should get involved in subsidising certain schools and services in line with international governments.

The need for marketing and public awareness also came through strongly. Caregivers noted the important role reading books, searching on the internet, watching programmes on television etc. had played in developing their insight into their child's problems. They recommended that information needs to be made more widely available and publicised more openly to facilitate awareness and knowledge in the general community. This would help to break the stigma and misconceptions surrounding the behaviour of children with ASD, and possibly improve the level of support and understanding of caregivers by their families and communities. While caregivers found general information available on what ASD, they would like more access to information on the different professions and what services they can provide, and the latest advances made in research into different interventions. Again the need for setting up a specialist directory, which could be easily accessed by both caregivers and professionals was emphasised. This would help to facilitate better networking and more efficient referral to and between professionals.

Caregivers commented on their appreciation of education sessions and workshops held by professionals for caregivers. They found that discussing their experiences with professionals and learning techniques empowered them to understand their children and care for them better. They still asked for more of this kind of input.

Caregivers who had attended support groups and found counsel with supportive doctors, therapists and teachers, found these services helpful. Support groups helped them to speak about and share their experiences with people who understood them. These groups helped to create a feeling of universality where the caregivers felt they were not alone. Shared problem solving and networking were other benefits of these groups.

6.5 Limitations of the study

Limitations to the study include the following:

- *Non-response bias:* The response rate was compromised by the length of the questionnaire which affected the time the survey took to complete. The use of indirect data collection methods for example email and hand outs given to all pupils at the special schools also compromised the number of questionnaires that were completed and returned.[60]
- *Inaccuracy of responses:* response bias was introduced in that caregivers struggled to remember some details of their service use and the problems that they encountered, resulting in inaccurate or incomplete responses at times. Some questions were answered incorrectly, due to the caregiver's misinterpretation of the question. Attempts

were made to limit this through the piloting process and in the use of face-to-face interviews where the interviewer could ensure that the questions were well understood.[60]

- *Sampling:* This study's sample was drawn from clinics and schools, where caregivers and children were already accessing services, and thus their views may underestimate true barriers to service provision and access. A community-based sample may have been able to give more generalised views of barriers to access to care, by representing those who had not been able to access any care. However, the difficulty in locating these participants would have presented significant challenges to the use of this type of sampling for this study. Especially, considering the difficulty in finding and classifying children in the community, who have not accessed services and as yet, do not have a diagnosis of ASD.

6.6 Summary of key findings

The limitations of service provision, found in this study, were summarised and are represented graphically on the left hand side of Figure 6.1 below. The caregivers' suggestions for improving service provision, together with best-practice principles from the literature, were used to propose a more appropriate service delivery model (represented on the right hand side of Figure 6.1). It is predicted that poorer long-term outcomes related to the key challenges experienced in service provision currently, could be averted, and the scale tipped in favour of better long-term outcomes through better management of both the caregiver and the client. Research, policy, marketing and community awareness of ASD, and training of service providers may play a role in effecting this change.

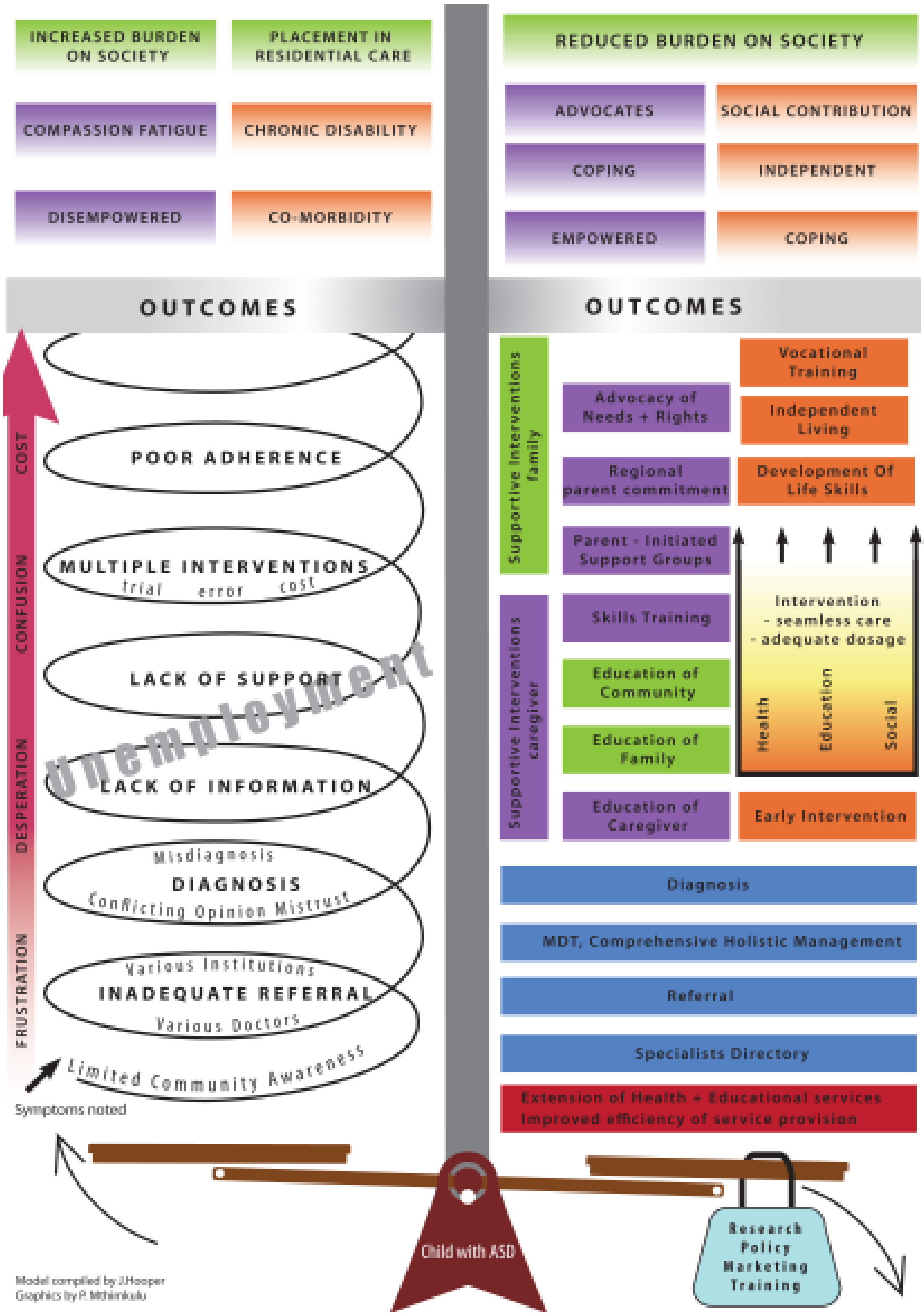


Figure 6. 1 Summary of key findings

6.6.1 Current experiences of service provision and access

(Left-hand side of Figure 6.1)

→ **Format:** This section of the model is presented as an ascending spiral, representing inefficiency and inadequacy of service provision. This leads to increasing **frustration, desperation, confusion and cost** for the caregiver, as indicated by the red arrow.

→ **"Symptoms noted":** refers to the initial signs and symptoms noted by caregivers in their children at an average age of 2 years.

→ **"Limited community awareness of ASD"** compromises the caregiver's insight into what may be wrong with the child and delays initial consultation as caregivers are uncertain as to which professional or institution they should access.

→ **"Various institutions and doctors":** Caregivers accessed 2 to 3 institutions and 6 different professionals to find the appropriate diagnosis and intervention for their child with ASD. This is influenced by the complexity of the condition, limited professional expertise and inappropriate referral.

→ This leads to numerous consultations, several **misdiagnoses and conflicting professional opinions** which lead to caregivers' **mistrust** of professionals and significant frustration.

→ This delays diagnosis further.

→ **"Diagnosis"** is commonly made late, at the age of four years, 2 years after first symptoms were noted. This impedes appropriate referral and commencement of suitable intervention, and adequate school placement.

→ **"Lack of information"**: Many caregivers explained that they did not receive adequate information from professionals on their child's diagnosis. Long-term prognosis and planning was also not well covered in consultations. This compromises the caregiver's insight and disempowers the caregiver, making it difficult for them to make informed decisions regarding intervention.

→ **"Lack of support"**: Few caregivers were referred to a support group or counselling. Of those that were referred, some caregivers were unable to attend these appointments due to work-related time constraints and financial constraints. This worsens the burden of care and compromises coping.

→ **“Multiple interventions”**: Caregivers use a **trial and error** approach, trying various interventions (despite poor evidence of efficacy) in an attempt to alleviate their child’s diverse symptoms and maximise the child’s potential. This incurs further **cost.**

→ **“Poor Adherence”:** Caregivers often abandon interventions prematurely, due to unsatisfactory outcomes and excessive cost.

→ Caregiver outcomes (purple): **“Disempowered” and “Compassion Fatigue”**

→ The continuous cycle of frustration, disillusionment, financial and emotional burden leads to compassion fatigue and burn out. The caregiver’s mental health, family relationships and resources may be jeopardised. The caregiver’s need for health and social services may present.

→ Client outcomes (orange): **“Co-morbidity” and “Chronic Disability”**

→ Inadequate intervention leads to poor treatment outcomes with chronic residual disability, increased co-morbidity and further dependence on the family and society for care.

6.6.2 Appropriate Service Delivery *(Right-hand side of Figure 6.1)*

Research has shown that with the provision of an appropriate continuum of co-ordinated and comprehensive health and educational services based on expressed needs, it is possible to achieve better outcomes and contain the burden on society.[32]

Service models should accommodate the diversity of needs, and aim to serve larger numbers of people throughout their lifespan. Services should promote the individual’s sense of purpose and value and enable them to be more independent, and play a productive role in society.[32]

→ **Format:** This section is presented as an organised procedure for service provision. Services are listed in ascending order, and represent progression through the service system in time. These services are graphically aligned with the corresponding challenges.

→ **Key:** Services and outcomes are colour-coded according to the themes identified in Chapter 5.

→ **Logistical factors**

→ **Profession/service-related factors**

→ **Caregiver-related factors**

→ **Community and Social factors**

→ **Client factors**

→ **"Extension of Health and Educational services" and "Improved efficiency of service provision"** In the developing South African economy, it is more realistic to expand available services and improve efficiency of service provision rather than creating new services. This will also be more sustainable.

→ **"Specialists Directory"** refers to the establishment of a directory of accredited practitioners and service providers specialising in the management of ASD. The directory must be well publicised and accessible to the general community as well as professionals and educationalists.

→ **"Referral":** Referral procedures in both the public and private health settings should be streamlined according to set protocols. This will reduce the number of unnecessary consultations, reduce delays in diagnosis and contain cost.

→ **"MDT, comprehensive, holistic Management"**: MDT assessment, utilising more appropriate screening tools will facilitate more timely and accurate diagnosis based on the most important presenting features (speech and social dysfunction).

→ **"Diagnosis":** Accurate, early diagnosis of ASD is critical in order to refer appropriately to **"Early Intervention"** and place children in the appropriate schooling.

→ **Intervention for the caregivers, family and community:** A family-centred treatment approach should be implemented (purple and green).

→ This should commence with **"Education of caregivers"** providing caregivers with adequate information on ASD, prognosis and long term outcomes.

→ **"Supportive interventions for caregivers"** should also follow diagnosis. Caregivers should be referred to support groups and counselling to facilitate the grieving process, acceptance and coping.

→ **“Education of family” and “Education of Community” and “Supportive Interventions for the family”:** Once caregivers have adequate insight and have come to accept the child’s condition, work should commence with their support structures including the family, followed by the community.

→ Thereafter, caregivers can begin with **“Skills training”**. This encompasses teaching caregivers skills and facilitation of caregivers’ problem solving in managing their child’s behaviour.

→ **“Regional Parent commitment” and “Advocacy of Needs and Rights”** :

→ Once caregivers feel more empowered and supported, they will be better positioned to support other caregivers of children with ASD. They may be able to take over responsibility for organising and running support groups; and/or assist in advocacy and lobbying for further improvement in service delivery and social acceptance of people with ASD. This may build sustainability of the model of service provision. It also supports better caregiver outcomes.

→ **Intervention for the client with ASD (orange)**:

→ **“Early intervention”**: leads to better treatment outcomes due to the potential for neuroplasticity in the developing brain.

→ **“Seamless health, education and social interventions”** which are evidence-based, holistic, tailored to the individual’s needs and administered at the correct dosage, will improve outcomes.

→ Long-term planning and planned service provision throughout the lifespan is important. Intervention with the adolescent and adult with ASD should include: **“Development of Life Skills”, “Vocational training”** and ongoing support, to promote **“Independent Living”** and meaningful engagement in occupational performance.

→ Outcomes for this intervention should be: **“Coping”**, greater **“Independence”**, and **“Social Contribution”**.

While the validity of this diagram still needs to be adequately researched, taking into account an audit of existing services, it may provide a preliminary structure for reorganising and streamlining service provision for clients with ASD and their families, in Johannesburg.

CHAPTER 7: CONCLUSIONS

This study aimed to investigate the utilization of health and education services by children with Autistic Spectrum Disorders and their families. Caregivers' experiences were analysed to identify the challenges the caregivers faced in accessing effective and efficient assessment and treatment. Their positive experiences and suggestions for improving service access and delivery were then explored to make recommendations on how access to, and delivery of appropriate services could be facilitated.

7.1 Summary of study findings

The caregivers in this study were generally dissatisfied with health and education services available to their children in both the public and private sectors.

In summary, this study supported the literature, noting an increased number of professionals consulted (mean of 6) and services accessed (mean of 3 institutions), with delays in diagnosis, inappropriate referral, multiple interventions and excessive costs incurred. These findings were associated with: the complexity and heterogeneity of ASD as a condition; the inadequacy and inefficiency of service provision in this context; and the demographic profiles of caregivers which influenced their needs and thus perceptions of service provision, as well as the service sector they accessed.

Differences in race, socio-economic status, education and social dynamics were noted when comparing Group A (private sector) and Group B (public sector) participants. There was some evidence in this study to suggest that the different groups were not equally serviced with differences in the frequency and quality of service provision in the public and private sectors. The needs of the two groups relative to their circumstances appeared to impact on the caregivers' perceptions and expectations of service provision, with Group A focusing on the quality and effectiveness of service provision, while Group B focused on the quantity and accessibility of services, and the social and physical environmental difficulties they faced.

Some similarities were noted in the groups' patterns of service use however, which reflected the influence of the complexity of the ASD condition rather than caregiver- or service sector-related factors on experiences of service provision.

Caregivers in both Group A and B noted several barriers to service access and delivery and described considerable frustration, desperation and burden in caring for a child with ASD and in accessing the necessary services. These challenges included: logistical barriers; lack of professional knowledge, experience and skill; poor referral systems; poor coping and insight of caregivers; and the lack of community support.

Factors identified by the caregivers, which would improve the adequacy and efficiency of services to produce better long term outcomes for the child with ASD, family, and community, included: marketing and awareness, the establishment of an accessible specialist directory, training of professionals and educators, better referral procedures, and establishment and funding of good educational facilities.

7.2 Implications for practice and further research

The prevalence of ASD in the South African context needs to be established. Only then, can the magnitude of service-related problems and the impact on society as a whole, be fully understood. Service access and delivery should be driven by the needs of the clients it serves. This research has helped to highlight some of these needs, and describe the key difficulties caregivers continue to experience in trying to access the best possible care for their children with ASD. If these problems and needs are not addressed, chronicity, lifetime dependence and caregiver burn out will result, continuing to burden families and society in general.

Practical solutions have been suggested by caregivers to facilitate the improvement of service access and delivery which would help to meet the needs of children with ASD and their families. Some of these solutions can be implemented in the short term, beginning with marketing, publicity and awareness of ASD. Others will require careful planning and research, and long-term implementation including: advocacy of children and caregivers' rights and needs, training of professionals, establishment of a specialist directory, the improvement of case-finding methods and referral systems, and the development of accessible specialist assessment and intervention units and educational centres.

Research now needs to compare these perception- and experience-based barriers and solutions with the real-life situation. An audit of the presently available services and the expertise and experience of health and education practitioners needs to be documented. This will assist in discerning which factors exist as a result of a genuine lack of appropriate and accessible services and which factors relate to poor caregiver insight fuelled by poor awareness and marketing of services which are available, but possibly underutilised.

Cost analysis would be useful in two ways. Firstly, the cost of intensive, frequent intervention with good outcomes needs to be rationalised against lifetime cost based on ineffective but equitably distributed, relatively infrequent treatment. Secondly, this cost analysis and rationalisation could assist in motivating for greater government subsidies for education for example; and for greater coverage of intervention expenses by medical insurance schemes.

Treatment outcomes and efficacy studies also need to be carried out in the South African context, taking into account our geographic context and available resources. Large scale, longitudinal research should be conducted to test the true effect of the implementation of the suggested services presented in Figure 6.1, on the outcomes for the individual with ASD, family and community. It would also be interesting to investigate if the short-term, intensive, outreach services including child and family-based interventions could produce a better outcome than the infrequent long-term interventions favoured in the public sector currently. This research could assist in the formulation of an appropriate ASD service delivery model for the South African context.

7.3 Conclusion

In conclusion, children with ASD and their families are a difficult and costly population to service adequately, particularly in the South African context where HIV/AIDS, poverty and infectious disease dominate government attention and resources. However, considering the sharp rise in the prevalence of ASD and the pervasive impact this condition has on the individual and their family, the ramifications of poor intervention outcomes in these individuals may burden society significantly. The allocation of large budgets and the development of new, first class assessment and treatment facilities may be unrealistic in the South African setting. However, the institution of assessment, intervention and educational protocols; streamlining of referral procedures; training of health and educational professionals in the management of ASD; and community ASD awareness drives, are practical suggestions which may assist in transforming existing, resourced health and educational services. This would improve the efficiency, quality and long-term outcomes of evidence-based services, thus containing the burden on South African society.

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APPENDICES

APPENDIX A: Research Consistency Matrix

Caregiver experiences of service provision for their children with Autistic Spectrum Disorder

Information regarding demographic profile of sample			
Sub Problem or Objective	**Supporting Literature**	**Proposition**	**Data Collection and Methodology**
• Representation of sample (race, SES, age) • **Caregiver factors**: age, gender, race, education, occupation, income, support • **Child factors**: age, diagnosis and comorbid diagnosis, dependence/level of care required across OPAs, level of communication • **SES=highest level of education and occupation** • Geographical location • Transport • Health system: public/private	• Gillian Saloojee • HESSI • Adult needs survey • People in context • HBS book – health seeking behaviours	• Low SES, high physical needs, less health priority-barriers to satisfying needs • High SES:11-15:sum of services, more services • High SES, 11-15: 17: 24,25 private, low SES public • High SES paying more for services 11-15: sum of cost • Significance of severity of child: more noticeable impairment, greater access to services, earlier, easier to diagnose70-77: sum of services	**Questions:** **Caregiver: Q1-17** **Child:18,19,70-77** Quantitative – Pre-determined close-ended questions Based as far as possible on Std questionnaire HESSI Additional questions – age and gender of caregiver and relationship to child Source of family income Total monthly income. Riordan : socioeconomic status

Objective 2: Investigate service utilization

Sub Problem or Objective	Supporting Literature	Proposition	Data Collection and Methodology
• What was the referral process or introduction into services – first point of contact	• Intervention studies • Best practice literature • Early intervention	Important information regarding who needs to be educated around early signs and symptoms and referral procedures linked to early intervention	o **Questions:** o 20 (who noticed 1st) o 21 Age o 22 early signs o 24 where did you go (1st option) o 25 who did you see first
• The process of diagnosing ASD	• Varying functional level related to diagnostic info		o Questions o 28,30 Diagnosis and comorbid diagnoses (severity of involvement) o 31 How told (relate to grieving cycle) o 25? Who told (?elicited from questionnaire)
• What services have caregivers/children accessed o Type o Public/private	• Decreased empirical support for treatments • Difficult to research due to complexity of condition (can't eliminate variables) • Inadequate services don't meet needs or are not effective – links to barriers!!! • Best practice=comprehensive holistic, multidisciplinary intervention • Emphasis on family therapy : locating child within family		o Questions: o 24 (type) o 25 (professionals) o 32, 47 (counselling or support) o 36,37 (home programmes) o 38,42 (medication) o 44 (in-patient/residential care) o 50, 52,53 (speech therapy) o 55, 57,58 (OT) o 60,61 (Respite care or child minding) o 64 (education) o Sum of services being accessed

• Frequency of services accessed			○ 21 vs 23. Time between notice and help ○ 23 vs 29. Time between seek help and diagnosis ○ 29 vs 35. time between diagnosis and treatment ○ Frequency of services: ○ 42. Medication review ○ 48 counselling ○ 51 speech therapy ○ 56 OT ○ 62 respite care ○ 67 other
• When did they access them ○ Age of child ○ Sequence			○ 21/23; age of child when began seeking help ○ 29. Age at diagnosis ○ 24. Sequence of services accessed ○ 25. sequence of professionals
• What were the costs involved	• decrease demand		○ sum of cost/month ○ 16, 33.5,42: transport ○ 33.6, 41, 46, 49, 54, 59, 63, 65, 68 Rx costs ○ same: who pays ○ 49,63 ?parent cost >child cost ○ Compare to income: 14, 15 ○ Compare to health system:17 ○
• What information/ resources have they accessed			○ 31, delivery of info ○ 34 type of info ○ 33.12

What services are not being accessed compared to: • prioritisation of services • services endorsed by literature Not covered adequately in questionnaire	Reference to hierarchy of needs and health seeking behaviours Intervention studies	Problem: caregivers not always adequately educated or with a good understanding of services available; seen in the pilot study. Poor insight into different disciplines and techniques cf to 1st world studies Would be better to approach by doing an audit of services available and compare to services accessed. Should have asked what is their biggest challenge or struggle and questions regarding coping currently.	○ Question ○ 69: services needed ○ 69: priorities ○ ○ ○ Which services are you and your child using? ○ Which services would you like to access but can't. ○ Why can't you access them- not available, staff shortages, too expensive, don't know about them ○ Analysis: compare services accessed to perceived needs.

Objective 3: Investigate perceived factors impacting on service delivery and access

Sub Problem or Objective	Supporting Literature	Proposition	Data Collection and Methodology

Barriers:
• Physical: accessibility due to location etc
• Availability
• Cost/affordability
• Time
• Skill or knowledge:
  ○ Professional
• Individual:
  ○ Cycle of grieving /stage of acceptance
  ○ Knowledge
  ○ Interest
  ○ needs
• Social
  ○ Community awareness and support
  ○ Family awareness and support
	• Increased incidence and prevalence leads to increased demands on service delivery: disproportional to development of service or service competence and capacity
	• ASD particularly costly due to multitude of presenting problems – see multiple professionals, access multiple services, longer consultation times
	• Pervasive throughout the lifespan therefore require services throughout lifespan:increase demand and cost
	Increase independence earlier will decrease need for services and length of service provision-decrease demand
	Impacts on service delivery, accessibility and quality
			○ Open: 26 :code thematically (below)
			○ Physical:33.1, 33.14
			○ Availability: 33.2, 33.3, 33.4, 33.8, 33.10
			○ Cost: 33.5,33.6
			○ Time: 33.7,33.8,33.9,33.10,
			○ Skill or knowledge :prof: 33.7, 33.11, 33.12,33.13
			○ Caregiver factors: 33.14,33.15,33.16,33.21, 33.19
			○ Social: 33.17, 33.18, 33.19, 33.20
			○ Open ended
			○ Closed ended
			○ Where are the services located
			○ What do they cost – transport, service
			○ Affordability?
			○ Convenience–location, time off work, time spent at hospital etc…

Supports: • Health • Social • Educational			• open ended: question 27 • closed ended: negative responses as above

APPENDIX B: Questionnaire 1

THE NEEDS OF CAREGIVERS IN RELATION TO THEIR CHILDREN DIAGNOSED WITH PERVASIVE DEVELOPMENTAL DISORDERS INCLUDING AUTISM AND ASPERGER'S SYNDROME.

Caregiver Needs Survey

Study Code:

How to fill in the survey

- Please tick the option that applies to you or your child
- Please fill in details where asked to "please specify"
- If you feel there is any other information that you feel is relevant – please feel free to write it under the "Comments" heading at the end of the questionnaire.

Interview Details:

About you (person completing the survey) and your family

1. **Your relationship to the child who has been diagnosed with a Pervasive Developmental Disorder**

   ○ Mother of the child
   ○ Father of child
   ○ Legal guardian (foster parent or adoptive parent) of the child
   ○ Grandparent of the child
   ○ Sibling of the child
   ○ Other. Please describe relationship
   ____

2. **Your Age:**_________ Years

3. **Your gender:**
○ Male ○ Female

4. **How many children do you have?**______________________________

5. **Which family members do you live with?**

Spouse	Yes	No
Partner	Y	N
Grandfather	Y	N
Grandmother	Y	N
Children	Y	N
Nieces or nephews	Y	N
Other :Please Specify___________________________	Y	N

6. **How many people live together with you and your child with PDD**?_________

7. **Where do you and your family live?**

Suburb___________________
Town____________________

8. **What type of housing do you live in?**

- ○ Informal housing
- ○ Shared room
- ○ Flat
- ○ Townhouse
- ○ House

9. **Your highest level of education is…..**

- ○ No formal schooling
- ○ Primary School OR ○ Grade_________ or Standard__________
- ○ High School
- ○ Matric or Grade 12 Certificate
- ○ Grade 12 Certificate plus additional courses
- ○ Tertiary education: Degree or Diploma

10. **The family's income per month is:**

- ○ No regular income
- ○ Under R1 000/month
- ○ R1 000 – R 5000/month
- ○ R5 000 – R10 000/month
- ○ Over R10 000/month

11. **Which Social Grant do you receive for your Child with PDD?**

- ○ Child Care Grant
- ○ Foster Care Grant
- ○ Care Dependency Grant
- ○ No grant

About your Child who has been diagnosed with a Pervasive Developmental Disorder (PDD):

1. **Your child's age:**_________ Years__________ Months

2**. Your child is:**
○ Male ○ Female

3. **How old was your child when you first noticed that something was wrong or that your child was not developing typically?**

___________ years old.

4. **Has your child been formally diagnosed with a Pervasive Developmental Disorder?**
○ Yes ○ No

5. **If the answer to question 4 is NO:**
Are you currently trying to get a diagnosis or assessment?
○ Yes ○ No

6. **If the answer to question 4 is YES:**
What is your child's diagnosis?
○ Autism
○ Asperger's Syndrome
○ Rett's Disorder
○ Childhood Disintegrative Disorder
○ Pervasive Developmental Disorder not otherwise specified
○ Another Developmental Disorder.
Please specify:____

7. **If your answer to question 4 is YES:**
How old was your child when he/she was diagnosed with PDD?
___________ years old

8. **Has your child been diagnosed with any other conditions?**

Epilepsy	Yes	No
Attention Deficit Disorder	Y	N
Attention Deficit Hyperactivity Disorder	Y	N
Cognitive Disability/ Mental Retardation	Y	N
Cerebral Palsy	Y	N
Any other neurological condition: Please specify______________________________________	Y	N
Genetic Condition Please Specify_____________________________________	Y	N
Metabolic Condition Please specify_______________________________________	Y	N

9. **Who first mentioned the "Autism" or "Pervasive Developmental Disorders" to you?**
   - ○ Specialist
   - ○ Doctor
   - ○ Therapist
   - ○ Educator
   - ○ Friend

10. **How many professionals did your child see before a diagnosis was made?**

    ____

11. **How long did it take to get a diagnosis?**
   - ○ A few days
   - ○ A few weeks
   - ○ A few months
   - ○ 1 – 2 years
   - ○ More than 2 years

12. **Who diagnosed your child with a Pervasive Developmental Disorder?**
   - ○ Psychiatrist
   - ○ Paediatrician
   - ○ General Medical Practitioner
   - ○ Psychologist
   - ○ Other

     Please specify____

13. **Do you understand what the terms "Pervasive Developmental Disorder" and "Autism" mean?**

○ Yes ○ No ○ I have some idea.

14. **How did you find out more about PDD or Autism?**
(You may tick more than one option)

   - ○ Health Care Professional explained the condition in a way that I could understand
   - ○ Health Care Professional explained the condition, but I still do not understand
   - ○ An educator explained the condition to me
   - ○ I read about PDD/Autism:
     - ○ In the press (newspapers and magazines)
     - ○ In pamphlets
     - ○ In books
     - ○ On the internet
   - ○ I heard about it from a friend or another caregiver

15. **Which health care facilities have you and/or your child used?**
(You may tick more than one option)

- ○ Government hospital
- ○ Government clinic
- ○ Out-patient Department
- ○ In-Patient Department
- ○ Private hospital or clinic
- ○ A private Practice
- ○ Other
  Please Specify:____

16. **Which Professionals have you or your child consulted with?**

- ○ Psychiatrist
- ○ Paediatrician
- ○ GP
- ○ Speech and Language Therapist
- ○ Audiologist
- ○ Occupational Therapist
- ○ Physiotherapist
- ○ Psychologist
- ○ Social Worker
- ○ Remedial Therapist
- ○ Dietician
- ○ Counsellor
- ○ Other
  Please specify:____

17. **Please tick the treatments or therapies that you, your child, or your family has used before, or is using now, and if you have found them useful. Please also indicate which treatments or therapies you would like your child to receive in the future.**

(Please note that the inclusion of a treatment in this survey should not be seen as an endorsement of that treatment)

Treatment or therapy	**Never tried**	**Using currently**	**Used in the past, but not now**	**Would like to use in the future**		**Was not very helpful**	**Was/is helpful**	**Very Helpful**
Auditory Integration Training								
Augmentative Alternative communication (AAC)								
Behaviour Modification								
Cognitive-Behaviour Therapy								
Counselling/ Psychotherapy								
Detoxification								
Dietary Intervention								
Drug or Pharmacological Treatment								
Early Intervention Programme								
Facilitated communication								
Floor Time								
Massage								
Music Therapy								
Art Therapy								
Neurofeedback (Biofeedback)								
Occupational Therapy								
PECS – Picture Exchange Communication								
Physiotherapy								
Crano-sacral therapy								
Sensory Integration								
Sign Language								
Social skills Training								
Speech and Language Therapy								
TEACCH								
Traditional Medicine or Spiritual healing								
Visual schedules								
Vitamins, enzymes or hormones								
Parent support groups								
Sibling support groups								
Parental counselling								
Family counselling								
Workshops on Autism Spectrum Disorders								

18. **Please fill in any other treatments or therapies that your child is receiving, that have not been mentioned above.**

Treatment or Therapy	**Never tried**	**Using currently**	**Used in the past, but not now**	**Would like to use in the future**	**Was not very helpful**	**Was/is helpful**	**Very Helpful**

19. **Please list any medication, vitamins, enzymes or supplements that your child is taking:**

____
____
____
____
____

20. **How much, on average does treatment or therapy cost you per month?**

____

21. **Do you find the cost of treatment…. (Tick the appropriate response)**
- ○ Affordable
- ○ A financial strain
- ○ Unable to afford

22. **Which form of education is your child currently receiving?**
- ○ No formal education
- ○ Non-specialised crèche or day care facility
- ○ Specialised crèche or day care facility
- ○ Mainstream School
- ○ Remedial class in a Mainstream School
- ○ Remedial School
- ○ Special Needs School
- ○ Training Centre
- ○ Other
  Please specify:____

23. **The educational facility is a:**
- ○ Government Facility
- ○ Private Facility
- ○ Non-profit Organisation

24. **Which form of education do you feel would best suit your child with PDD?**

○ No formal education
○ Non-specialised creche or day care facility
○ Specialised crèche or day care facility
○ Mainstream School
○ Remedial class in a Mainstream School
○ Remedial School
○ Special Needs School
○ Training Centre
○ Other
Please specify:____

25. **Please indicate which services you feel you, your child or your family needs most importantly.**

Service Needs	**Not at all important /needed**	**Somewhat important/ Needed**	**Important/ Needed**	**Very important/ Urgently needed**
Multi-disciplinary Assessment Centre				
Multi-disciplinary Treatment Facility				
Case management and co-ordination of services				
Home-based programmes				
Family Support Groups				
Sibling Support Groups				
Grandparent Support groups				
Early Intervention Programmes				
Understanding a new diagnosis of PDD or Autism Spectrum Disorder				
Workshops on Autism Spectrum Disorders/PDD				
PDD Library and Resource Centre				
Assistance in long-term planning				
Assistance in appropriate School Placement				

Service Needs	**Not at all important /needed**	**Somewhat important/ Needed**	**Important/ Needed**	**Very important/ Urgently needed**
Provision of appropriate schooling				
Residential Care Facilities				
Respite Care Facilities				
Baby-sitting services				
Home care assistance				
Support and training of child minders				
Marriage or Relationship Counselling				
Behaviour Modification or Support				
Teaching skills (Independence, life skills, community skills etc.)				
Help with Social Skills				
Help with Communication skills				
Help with transitions (Coping with adjustments and transitions into next developmental stage)				
Help with gastrointestinal problems				
Help with Sensory Integration problems				
Visual Aids				
Legal services				

26. **How would you rate your overall quality of life as it is now?**

- ○ My life is unbearable
- ○ My life is only barely adequate, there are many things to be changed
- ○ My life is pretty good most of the time, but a few things need to be improved
- ○ My life is very good, I want everything in my life to continue

Comments:

____

____

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____

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____

Thank you for taking the time to participate in this study!

APPENDIX C: Questionnaire 2

THE NEEDS OF CAREGIVERS IN RELATION TO THEIR CHILDREN DIAGNOSED WITH PERVASIVE DEVELOPMENTAL DISORDERS INCLUDING AUTISM AND ASPERGER'S SYNDROME.

Caregiver Survey

How to fill in the survey

- Please draw a cross in the box next to the option that applies best to you or your child
- You may cross more than one box.
- Please fill in details where asked to "please specify"
- Please try to answer every question.
- If there is any other information that you feel is relevant – please write it under the "Comments" heading at the end of the questionnaire.

Please note:

- Some of the information requested may be of a sensitive nature.
- Your answers will be kept anonymous and confidential.
- This information is vital in ensuring that this study reflects our diverse South African population and as such includes a variety of people from different racial groups, genders and socio-economic backgrounds.
- Your honesty and openness will assist us in understanding this topic fully.
- However, you do still have the right to refuse to answer any of the questions.

Subject Code: ____________________________
Date of interview: ____/____/2008____________
Venue: ____________________________

A. YOU AND YOUR FAMILY

2. **What is your relationship to the child who has been diagnosed with a Pervasive Developmental Disorder (PDD) / Autistic Spectrum Disorder (ASD)?**

1.1	Mother
1.2	Father
1.3	Legal guardian (foster parent or adoptive parent) of the child
1.4	Grandparent
1.5	Sibling
1.6	Other. Please describe relationship:

3. **If the caregiver is not the biological mother of the child, why is the child's mother not the primary caregiver?**

2.1	Mother died
2.2	Mother is divorced/separated
2.3	Mother works
2.4	Mother is ill
2.5	Mother is at school
2.6	Mother has absconded
2.7	Unknown
2.8	Other : Please Specify

3. **Your age:**_________ Years

4. **Your gender:**

4.1	Male
4.2	Female

5. To which group do you and your family belong?

5.1	Caucasian
5.2	Black
5.3	Coloured
5.4	Asian
5.5	Other: Specify

6. What language(s) do you speak at home?___________________________________

6. Where do the child and his/her caregiver live?
Suburb___________________
Town____________________

7. Are you working currently?

7.1	Yes - Full time
7.2	Yes - Part-time
7.3	Yes – Piece jobs
7.4	No

8. The family's average income per month is:

8.1	No regular income
8.2	Under R1 000/month
8.3	R1 000 – R 5000/month
8.4	R5 000 – R10 000/month
8.5	Over R10 000/month
8.6	I don't know

9. What does your family's income consist of?

9.1	Regular salary/wages from working
9.2	Occasional income from working
9.3	Self-employed
9.4	Pension
9.5	Child Support Grant
9.6	Care Dependency Grant
9.7	Foster Care Grant
9.8	Maintenance Grant
9.9	Other Private Sector Grant
9.10	Disability Grant
9.11	No income
9.12	Unknown
9.13	Other: Please specify.

10. What type of transport do you use?

10.1	We have no transport – we walk everywhere
10.2	We use public transport
10.3	We use private transport

B. CHILD WHO HAS BEEN DIAGNOSED WITH AN AUTISTIC SPECTRUM DISORDER (ASD):

11. Your child's age: _________ Years__________ Months

12. Your child's gender is:

12.1	Male
12.2	Female

C. EARLY SIGNS

13. Please describe any complications you experienced during pregnancy or the birth of your child.

____

____

____

____

____

14. Please describe your child's early medical history.

____

____

____

____

____

15. How old was your child when you first noticed that something was wrong or that your child was not developing as you would have expected?
_________ Years__________ Months

16. Who first noticed that something was wrong?

16.1	I can't remember
16.2	Caregiver
16.3	Family Member
16.4	Care worker
16.5	Teacher
16.6	Health Care Professional. Please specify
16.7	Other. Please specify.

17. What did you notice was wrong? ______________________________________

____

____

____

D. LOOKING FOR HELP

18. When did you first look for help?

When my child was ___________years ____________months old.

19. Where did you go to look for help? If you went to several places, please indicate the order in which you went to the different facilities.

		Sequence of visits
19.1	Government clinic	
19.2	Government Hospital	
19.3	Private Clinic/Hospital	
19.4	Private practice	
19.5	School / Crèche	
19.6	Traditional healer	
19.7	Can't remember	
19.8	Other. Please specify.	

E. GETTING A DIAGNOSIS

24. Has your child been formally diagnosed with a Pervasive Developmental Disorder or an Autistic Spectrum Disorder?

24.1	Yes
24.2	No
24.3	Currently trying to get a diagnosis or awaiting assessment
24.4	I don't know

20. What were the biggest challenges you faced in trying to find out what was wrong with your child and in then trying to get help?

____

____

____

____

____

21. What do you think did help, or would have helped you, in finding the correct diagnosis of your child's problems quickly?

____

____

____

____

22. Was it important for you to get a diagnosis for your child?

22.1	Yes, very important
22.2	Yes, somewhat important
22.3	No, not really that important

23. Why was/is it important, or not important to you that your child has the correct diagnosis?

____

____

____

25. What is your child's diagnosis?

25.1	Autism
25.2	Asperger's Syndrome
25.3	Rett's Disorder
25.4	Childhood Disintegrative Disorder
25.5	Pervasive Developmental Disorder not otherwise specified
25.6	I don't know
25.7	Other. Please specify:

26. Has your child been diagnosed with any other conditions?

26.1	Epilepsy	Yes	No
26.2	Attention Deficit Disorder	Y	N
26.3	Attention Deficit Hyperactivity Disorder	Y	N
26.4	Cerebral Palsy	Y	N
26.5	Learning Disorder	Y	N
26.6	Sensory Integration Disorder	Y	N
26.7	Communication Disorder	Y	N
26.8	Behavioural Disorder	Y	N
26.9	Not known	Y	N
26.10	Other. Please Specify	Y	N

27. In trying to find out what was wrong with your child - which health care practitioners did you or your child consult? In what order/sequence did you see them?

		Yes	**Sequence**	**No**
27.1	Psychiatrist	**Y**		**N**
27.2	Paediatrician	**Y**		**N**
27.3	Neurologist	**Y**		**N**
27.4	GP	**Y**		**N**
27.5	Speech & Language Therapist	**Y**		**N**
27.6	Audiologist	**Y**		**N**
27.7	Occupational Therapist	**Y**		**N**
27.8	Phyisotherapist	**Y**		**N**
27.9	Psychologist	**Y**		**N**
27.10	Social Worker	**Y**		**N**
27.11	Remedial Therapist	**Y**		**N**
27.12	Dietician	**Y**		**N**
27.13	Counsellor	**Y**		**N**
27.14	Traditional Healer	**Y**		**N**
27.15	Other. Please specify	**Y**		**N**

28. How old was your child when he/she was diagnosed with PDD/ASD?

___________ years ______________months old

29. Who diagnosed your child with a Pervasive Developmental Disorder?

29.1	Psychiatrist
29.2	Paediatrician
29.3	General Medical Practitioner
29.4	Psychologist
29.5	A team of different professionals. Please list
29.6	Other. Please specify

30. Describe how you were told the diagnosis: (you can select more than one option)

30.1	A health care professional discussed it with me (and my family)
30.2	A counsellor told me
30.3	I was able to ask questions
30.4	I was given information about the condition and how it will affect my child's future.
30.5	It was written in my file but not discussed with me
30.6	I was not told anything
30.7	I can't remember
30.8	Other. Please Specify

31. Were you offered support or counselling in understanding and accepting the news of your child's diagnosis?

31.1	Yes, and then I went to see a counsellor
31.2	Yes, and I went to a support group
31.3	Yes, but I decided not to go for help
31.4	No, I was never told about counselling
31.5	Other. Please specify

32. What made it difficult to get an accurate diagnosis quickly? Please prioritise the top five reasons.

		Yes	**Top 5 reasons**	**No**
32.1	Accessibility of the service	**Y**		**N**
32.2	Cost of transport	**Y**		**N**
32.3	Cost of consultations	**Y**		**N**
32.4	Too many different appointments	**Y**		**N**
32.5	Long waiting lists for appointments	**Y**		**N**
32.6	Too much time off work	**Y**		**N**
32.7	Waiting in long queues	**Y**		**N**
32.8	The professionals didn't seem to know or understand what was wrong with my child.	**Y**		**N**
32.9	Different professionals told me different things.	**Y**		**N**
32.10	I didn't understand what to do or know where to go	**Y**		**N**
32.11	I didn't think that there was anything wrong	**Y**		**N**
32.12	I didn't think that it was that important	**Y**		**N**
32.13	My family put a lot of pressure on me	**Y**		**N**
32.14	My family did not understand and didn't help to support me and the child.	**Y**		**N**
32.15	I felt embarrassed and hid my child away from the community	**Y**		**N**
32.16	The community/my friends did not understand and didn't help to support me.	**Y**		**N**
32.17	Other. Please Specify.	**Y**		**N**

F. FINDING INFORMATION ABOUT PDD/ASD

33. How did you find out more about PDD/ASD? (You may tick more than one option)

33.1	I didn't find out more about PDD/ASD
33.2	Health Care Professional explained the condition in a way that I could understand
33.3	Health Care Professional explained the condition, but I still do not understand
33.4	An educator explained the condition to me
33.5	I read about PDD/ASD in the press (newspapers and magazines)
33.6	I read about PDD/ASD n pamphlets
33.7	I read about PDD/ASD in books
33.8	By searching on the internet
33.9	I heard about it from a friend or another caregiver
33.10	Other. Please Specify

G. STARTING INTERVENTION AFTER DIAGNOSIS

34. After your child condition was diagnosed, were you referred for therapy/treatment?

34.1	Yes
34.2	No
34.3	I don't know

35. How old was your child when he/she started therapy or treatment?

________________months __________________years old.

36. What type of treatment or therapy did you start with? (Family intervention; Health – medical/therapy; Community; Education)

Please describe:

____

____

____

____

37. Describe your child's early school history

____

____

____

____

38. What, if any, recommendations were made about what school your child should attend?

38.1	No recommendations were made
38.2	Non-specialised crèche or day care facility
38.3	Specialised crèche or day care facility
38.4	Mainstream School
38.5	Remedial class in a Mainstream School
38.6	Remedial School
38.7	Special Needs School
38.8	Autism-specific school
38.9	Training Centre
38.10	Other Please specify:

H. HOW IS YOUR CHILD DOING AT PRESENT

How would you describe your child's level of functioning?

39	**Supervision**	39.1 Needs **constant** supervision	39.2. Needs **some** supervision	39.3. Needs **no** supervision
40	**Washing**	40.1. **Can** wash himself/herself	40.2. Needs some **assistance** in washing self	40.3. **Caregiver** washes child
41	**Dressing**	41.1. **Can** dress himself/herself	41.2. Needs some **assistance** in dressing	41.3. **Caregiver** dresses child
42	**Toileting**	42.1. Child uses the toilet on his/her **own**	42.2. Needs some **assistance** in toileting	42.3. Child is still wearing **nappies**
43	**Eating**	43.1. **Can** eat and drink by himself/herself	43.2. Needs some **assistance** in feeding	43.3. **Caregiver** feeds child

How would you describe your child's current level of communication?

44	**Speech**	44.1 No speech /just noises	44.2. 1-2 words	44.3. Sentences	44.4 Descriptive speech
45	**Expression of needs**	45.1. No communication	45.2. Non verbal communication	45.3. Gestures	45.4. Speech
46	**Communication is understood by…**	46.1 Primary caregiver	46.2. Family	46.3. Teacher	46.4. General community

47. How often does your child display difficult behaviour/have tantrums?

47.1	Daily
47.2	Weekly
47.3	Monthly
47.4	From time to time
47.5	Never
47.6	I'm not sure

Comments:

____

____

____

____

____

____

Thank you for taking the time to participate in this study!

APPENDIX D: Title Change

Faculty of Health Sciences
Medical School, 7 York Road, Parktown, 2193
Fax: (011) 717-2119
Tel: (011) 717-2745

Reference: Ms Tania Van Leeve
E-mail: tania.vanleeve@wits.ac.za
24 July 2008
Person No: 0002025N
TAA

Mrs JJ Hooper
4 Lorna Street
Harmelia
Edenvale
1609
South Africa

Dear Mrs Hooper

Master of Science in Occupational Therapy: Change of title of research

I am pleased to inform you that the following change in the title of your Research Report for the degree of has been approved:

From:	**The needs of caregivers in relation to their children diagnosed with pervasive developmental disorders**
To	**Caregiver's experiences of service provision for their children diagnosed with Autism Spectrum Disorders**

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX E: Questionnaire 3

CAREGIVERS' EXPERIENCES OF SERVICE PROVISION FOR THEIR CHILDREN WITH AUTISM SPECTRUM DISORDER

Caregiver Survey

How to fill in the survey

- Please draw a cross in the box next to the option that **applies best** to you or your child
- You may cross more than one box.
- Please fill in details where asked to "please specify"
- Please try to answer every question.
- If there is any other information that you feel is relevant – please write it under the "Comments" heading at the end of the questionnaire.

Please note:

- Some of the information requested may be of a sensitive nature.
- Your answers will be kept anonymous and confidential.
- This information is vital in ensuring that this study reflects our diverse South African population and as such includes a variety of people from different racial groups, genders and socio-economic backgrounds.
- Your honesty and openness will assist us in understanding this topic fully.
- However, you do still have the right to refuse to answer any of the questions.

Subject Code: ____________________________
Date of interview:_____/____/2008____________
Venue: ____________________________

A. YOU AND YOUR FAMILY

4. **What is your relationship to the child who has been diagnosed with Autistic Spectrum Disorder (ASD)?**

1.1	Mother
1.2	Father
1.3	Legal guardian (foster parent or adoptive parent) of the child
1.4	Grandparent
1.5	Sibling
1.6	Other. Please describe relationship:

5. **If the caregiver is not the biological mother of the child, why is the child's mother not the primary caregiver?**

2.1	Mother died
2.2	Mother is divorced/separated
2.3	Mother works
2.4	Mother is ill
2.5	Mother is at school
2.6	Mother has absconded/disappeared
2.7	Unknown
2.8	Other : Please Specify

3. **Your age:**_________ Years

4. **Your gender:**

4.1	Male
4.2	Female

5. **To which group do you and your family belong?**

5.1	Caucasian/ White
5.2	Black
5.3	Mixed race/ Coloured
5.4	Asian
5.5	Other: Specify

6. What language(s) do you speak at home?___________________________________

7. Where do the child and his/her caregiver live?
Suburb___________________
Town____________________

8. How many people live in your home?___________________________________

9. How many people living at home are…
9.1 18 years and older?_____________________________
9.2 6 to 18 years old?_______________________________
9.3 Less than 6 years old?___________________________

10. What is your marital status?

10.1	Never married, not now living with a partner.
10.2	Never married, but now living with a partner.
10.3	Married, and currently living with a partner.
10.4	Married before, but not now living with a partner (e.g. divorced/separated)
10.5	Widowed

11. What is the highest level of education you have attained?

11.1	Less than Grade 5.
11.2	Grade 5 to 7
11.3	Grade 8 to 10
11.4	Grade 12/Vocational training diploma
11.5	1-2 years College/Technikon
11.6	3-4 years of University
11.7	Post-graduate studies (Masters, PhD etc)
11.8	Other. Please specify:____

12. Are you working currently?

12.1	Yes – Full time
12.2	Yes – Part-time
12.3	Yes – Piece jobs
12.4	No

13. What is your occupation?____

14. The family's average income per month is:

14.1	No regular income
14.2	Under R1 000/month
14.3	R1 000 – R 5000/month
14.4	R5 000 – R10 000/month
14.5	Over R10 000/month
14.6	I don't know

15. What does your family's income consist of?

15.1	Regular salary/wages from working
15.2	Occasional income from working
15.3	Self-employed
15.4	Pension
15.5	Child Support Grant
15.6	Care Dependency Grant
15.7	Foster Care Grant
15.8	Maintenance Grant
15.9	Other Private Sector Grant
15.10	Disability Grant
15.11	No income
15.12	Unknown
15.13	Other: Please specify.

16. What type of transport do you use?

16.1	We have no transport – we walk everywhere
16.2	We use public transport
16.3	We use private transport

17. Do you and your family belong to a medical aid?

17.1	No.
17.2	Yes, we have a hospital plan.
17.3	Yes, we have a comprehensive medical aid plan.
17.4	Other. Please specify____

B. CHILD WHO HAS BEEN DIAGNOSED WITH AUTISTIC SPECTRUM DISORDER (ASD):

18. Your child's age: _________ Years__________ Months

19. Your child's gender is:

19.1	Male
19.2	Female

C. EARLY SIGNS

20. Who first noticed that something was wrong with your child or that your child was not developing as you would have expected?

20.1	I can't remember
20.2	Caregiver / person completing the questionnaire.
20.3	Family Member
20.4	Care worker
20.5	Teacher
20.6	Health Care Professional. Please specify
20.7	Other. Please specify.

21. How old was your child when you first noticed that something was wrong

_________ Years__________ Months

22. What did you notice was wrong? ____

____

____

____

____

D. LOOKING FOR HELP

23. How long after you noticed that something was wrong with your child, did you seek help?

23.1	A few days
23.2	A few weeks
23.3	A few months
23.4	A few years

24. Where did you go to look for help? If you went to several places, please indicate the order in which you went to the different facilities using descending numbers.

		Sequence of visits
24.1	Government clinic	
24.2	Government Hospital	
24.3	Private Clinic/Hospital	
24.4	Private practice	
24.5	School / Crèche	
24.6	Traditional healer	
24.7	Can't remember	
24.8	Other. Please specify.	

25. Which health care practitioners did you or your child consult?

a. Circle **Y (yes) or N (no)** to indicate if you saw that practitioner or not.
b. Specify if it was a **private** practitioner or a practitioner working in the **public** health setting.
c. Please indicate the **sequence** you saw the practitioners in by **numbering** e.g. number the practitioner seen first with a "1".

		Yes	**Public/ Private**	**Sequence**	**No**
25.1	Psychiatrist	**Y**			**N**
25.2	Paediatrician	**Y**			**N**
25.3	Neurologist	**Y**			**N**
25.4	GP	**Y**			**N**
25.5	Nursing sister	**Y**			**N**
25.6	Speech & Language Therapist	**Y**			**N**
25.7	Audiologist	**Y**			**N**
25.8	Occupational Therapist	**Y**			**N**
25.9	Phyisotherapist	**Y**			**N**
25.10	Psychologist	**Y**			**N**
25.11	Social Worker	**Y**			**N**
25.12	Remedial Therapist	**Y**			**N**
25.13	Dietician	**Y**			**N**
25.13	Counsellor	**Y**			**N**
25.14	Traditional Healer	**Y**			**N**
25.15	Other. Please specify	**Y**			**N**

E. GETTING A DIAGNOSIS

26. What were the biggest challenges you faced in trying to find out what was wrong with your child and in then trying to get help?

____

____

____

____

____

27. What do you think did help, or would have helped you, in finding the correct diagnosis of your child's problems quickly?

____

____

____

____

____

28. What is your child's diagnosis?

28.1	Autism
28.2	Asperger's Syndrome
28.3	Rett's Disorder
28.4	Childhood Disintegrative Disorder
28.5	Pervasive Developmental Disorder not otherwise specified
28.6	My child hasn't been diagnosed yet.
28.7	I don't know
28.9	Other. Please specify:

29. If your child has been diagnosed with an Autism-Spectrum Disorder, how old was your child when he/she was diagnosed with ASD?

___________ years ______________months old

30. Has your child been diagnosed with any other conditions?

30.1	Epilepsy	Yes	No
30.2	Attention Deficit Disorder	Y	N
30.3	Attention Deficit Hyperactivity Disorder	Y	N
30.4	Cerebral Palsy	Y	N
30.5	Learning Disorder	Y	N
30.6	Sensory Integration Disorder	Y	N
30.7	Communication Disorder	Y	N
30.8	Behavioural Disorder	Y	N
30.9	Not known	Y	N
30.10	Other. Please Specify	Y	N

31. Explain how you were told what was wrong with your child.
(You may select more than one option)

31.1	A health care professional discussed it with me (and my family)
31.2	A counsellor told me
31.3	I was able to ask questions
31.4	I was given information about the condition and how it will affect my child's future.
31.5	It was written in my file but not discussed with me
31.6	I was not told anything
31.7	I can't remember
31.8	Other. Please Specify

32. Were you offered support or counselling in understanding and accepting the news of your child's diagnosis?

32.1	Yes, and then I went to see a counsellor
32.2	Yes, and I went to a support group
32.3	Yes, but I decided not to go for help
32.4	No, I was never told about counselling
32.5	Other. Please specify

33. What are your biggest challenges in accessing help for you or child?
Please prioritise the top challenges by placing the numbers 1,2,3,4,5 under the column "Top 5 Challenges", with "1" as the highest priority/ biggest challenge.

		Yes	**Top 5 challenges**	**No**
33.1	Location of the service	**Y**		**N**
33.2	There are very few appropriate health services available	**Y**		**N**
33.3	There are very few appropriate schools available	**Y**		**N**
33.4	Finding affordable, appropriate child minding services	**Y**		**N**
33.5	Cost of transport	**Y**		**N**
33.6	Cost of consultations	**Y**		**N**
33.7	Too many different appointments	**Y**		**N**
33.8	Long waiting lists for appointments	**Y**		**N**
33.9	Too much time off work	**Y**		**N**
33.10	Waiting in long queues	**Y**		**N**
33.11	The professionals didn't seem to know or understand what was wrong with my child.	**Y**		**N**
33.12	Different professionals told me different things.	**Y**		**N**
33.13	The teachers or school have limited understanding of ASD and how to educate my child.	**Y**		**N**
33.14	I didn't understand what to do or know where to go	**Y**		**N**
33.15	I didn't think that there was anything wrong	**Y**		**N**
33.16	I didn't think that it was that important	**Y**		**N**
33.17	My family put a lot of pressure on me	**Y**		**N**
33.18	My family did not understand and didn't help to support me and the child.	**Y**		**N**
33.19	I felt embarrassed and hid my child away from the community	**Y**		**N**
33.20	The community/my friends did not understand and didn't help to support me.	**Y**		**N**
33.21	We missed lots of appointments.	**Y**		**N**
33.22	Other. Please Specify.	**Y**		**N**

F. FINDING INFORMATION ABOUT ASD

34. How did you find out more about ASD? (You may tick more than one option)

34.1	I didn't find out more about ASD
34.2	Health Care Professional explained the condition in a way that I could understand
34.3	Health Care Professional explained the condition, but I still do not understand
34.4	An educator explained the condition to me
34.5	I read about ASD in the press (newspapers and magazines)
34.6	I read about ASD in pamphlets
34.7	I read about ASD in books
34.8	By searching on the internet
34.9	I heard about it from a friend or another caregiver
34.10	I was referred to an organisation or association who gave me further information
34.11	Other. Please Specify

G. TREATMENT

35. When did your child start with treatment or intervention?

35.1	Before my child was diagnosed.
35.2	A few days after diagnosis
35.3	A few months after diagnosis
35.4	A few years after diagnosis

36. Does your child have a home programme?

36.1	Yes
36.2	No

37. If yes, is your child's programme tailored to meet his/her needs?

37.1	Yes
37.2	No

Medication:

38. Does your child take any medication?

38.1	Yes
38.2	No

39. Please list all the medications, vitamins or supplements your child is taking currently

____

____

40. Please list any medications, vitamins or supplements your child has taken previously, but is no longer taking.

____

____

41. Who pays for your child's medication and the medical consultations?

41.1	We do. Our cost per month is:_____________________________________
41.2	The medical aid pays for it.
41.3	Department of Health pays for it.
41.4	Other. Please specify.____

42. How often is your child seen by a professional to check this medication?
_________times/month or ________times /year

43. How far do you travel to access this service?____________________________________

In-patient care/residential care:

44. Has your child ever received in-patient hospital or residential care?

44.1	Yes
44.2	No

45. If yes, what was the length of stay?___________ Type of facility?__________________

46. Who paid/pays for this service?

46.1	We did. The cost we covered was R__________________________________
46.2	The medical aid paid for it.
46.3	Department of Health paid for it.
46.4	Other. Please specify.____

Counselling:

47. Have you or your family ever received counselling regarding your child and your coping?

47.1	Yes
47.2	No

48. How many times have you attended counselling sessions?________________________

49. Who paid/pays for this service?

49.1	We did. The cost we covered was R___________________________________
49.2	The medical aid paid for it.
49.3	Department of Health paid for it.
49.4	Other. Please specify.____

Therapy

Speech and Language Therapy

50. Has your child ever received SPEECH AND LANGUAGE THERAPY?

50.1	Yes
50.2	No

51. How frequently did/does your child attend Speech and Language Therapy?

51.1	Daily
51.2	Weekly
51.3	Monthly
51.4	Yearly
51.5	Occasionally

52. Has your child attended group Speech and Language Therapy sessions?

52.1	Yes
52.2	No

53. Has your child attended individual Speech and Language Therapy sessions?

53.1	Yes
53.2	No

54. Who paid/pays for this service?

54.1	We did. The cost we covered was R___________________________________
54.2	The medical aid paid for it.
54.3	Department of Education paid for it.
54.4	Department of Health paid for it.
54.4	Other. Please specify.____

Occupational Therapy

55. Has your child ever received OCCUPATIONAL THERAPY?

55.1	Yes
55.2	No

56. How frequently did/does your child attend Occupational Therapy?

56.1	Daily
56.2	Weekly
56.3	Monthly
56.4	Yearly
56.5	Occasionally

57. Has your child attended group Occupational Therapy sessions?

57.1	Yes
57.2	No

58. Has your child attended individual Occupational Therapy sessions?

58.1	Yes
58.2	No

59. Who paid/pays for this service?

59.1	We did. The cost we covered was R___________________________________
59.2	The medical aid paid for it.
59.3	Department of Education paid for it.
59.4	Department of Health paid for it.
59.5	Other. Please specify.____

<u>Respite Care</u> (Respite care or child minding: to provide support to caregivers by having a person come to your home to watch your child)

60. Has your child ever received respite care?

60.1	Yes
60.2	No

61. Do you have a carer that looks after your child regularly?

61.1	Yes
61.2	No

62. How often do you make use of carers?

62.1	Daily
62.2	Weekly
62.3	Monthly
62.4	Yearly
62.5	Occasionally

63. Who paid/pays for this service?

63.1	We did. The cost we covered was R________________________________
63.2	The medical aid paid for it.
63.3	Department of Education paid for it.
63.4	Department of Health paid for it.
63.5	Other. Please specify.____

Education:

64. What educational facilities has your child attended?

64.1	None
64.2	Non-specialised crèche or day care facility
64.3	Specialised crèche or day care facility
64.4	Mainstream School
64.5	Remedial class in a Mainstream School
64.6	Remedial School
64.7	Special Needs School
64.8	Autism-specific school
64.9	Training Centre
64.10	Other Please specify:

65. What do pay for your child's education currently?

65.1	R__________________/month
65.2	I don't pay school fees, Department of Education covers the cost.
65.3	Private bursary/scholarship covers the costs
65.4	Other. Please specify.____

Other services:

66. What other services have you, your family, or your child accessed?

____
____
____
____
____

67. How frequently did/do you make use of these services?

67.1	Daily
67.2	Weekly
67.3	Monthly
67.4	Yearly
67.5	Occasionally

68. Who paid/pays for this service?

68.1	We did. The cost we covered was R__________________________________
68.2	The medical aid paid for it.
68.3	Department of Education paid for it.
68.4	Department of Health paid for it.
68.5	Other. Please specify.____

69. What services would you like to access or gain greater access to? Please prioritise from 1 to 8, with 1 being your highest priority.

		Prioritisation
69.1	Respite care/child minding: to provide support to caregivers by having a person come to your home to watch your child	
69.2	Speech and language therapy: to improve your child's communication and language skills	
69.3	Social skills therapy: to improve your child's social skills	
69.4	Occupational Therapy: to enhance your child's development and address sensory processing problems.	
69.5	Counselling : To provide emotional or other support to caregivers	
69.6	Case management: to help caregivers get and co-ordinate services across different providers	
69.7	In-home therapeutic support: to teach the child self-help skills in the home and community	
69.8	Behaviour management: to train caregivers or provide direct help using behaviour plans.	
69.9	Other. Please describe:	

H. HOW IS YOUR CHILD DOING AT PRESENT

How would you describe your child's level of functioning?
Tick one of the boxes (1, 2, or 3) for each line.

70	**Supervision**	70.1 Needs **constant** supervision	70.2. Needs **some** supervision	70.3. Needs **no** supervision
71	**Washing**	71.1. **Can** wash himself/herself	71.2. Needs some **assistance** in washing self	73.3. **Caregiver** washes child
72	**Dressing**	72.1. **Can** dress himself/herself	72.2. Needs some **assistance** in dressing	72.3. **Caregiver** dresses child
73	**Toileting**	73.1. Child uses the toilet on his/her **own**	73.2. Needs some **assistance** in toileting	73.3. Child is still wearing **nappies**
74	**Eating**	74.1. **Can** eat and drink by himself/herself	74.2. Needs some **assistance** in feeding	74.3. **Caregiver** feeds child

How would you describe your child's current level of communication?
Tick one of the boxes (1, 2, or 3) for each line.

75	**Speech**	75.1 No speech /just noises	75.2. 1-2 words	75.3. Sentences	75.4 Descriptive speech
76	**Expression of needs**	76.1. No communication	76.2. Non verbal communication	76.3. Gestures	76.4. Speech
77	**Communication is understood by…**	77.1 Primary caregiver	77.2. Family	77.3. Teacher	77.4. General community

<u>Comments or additional information:</u>

____

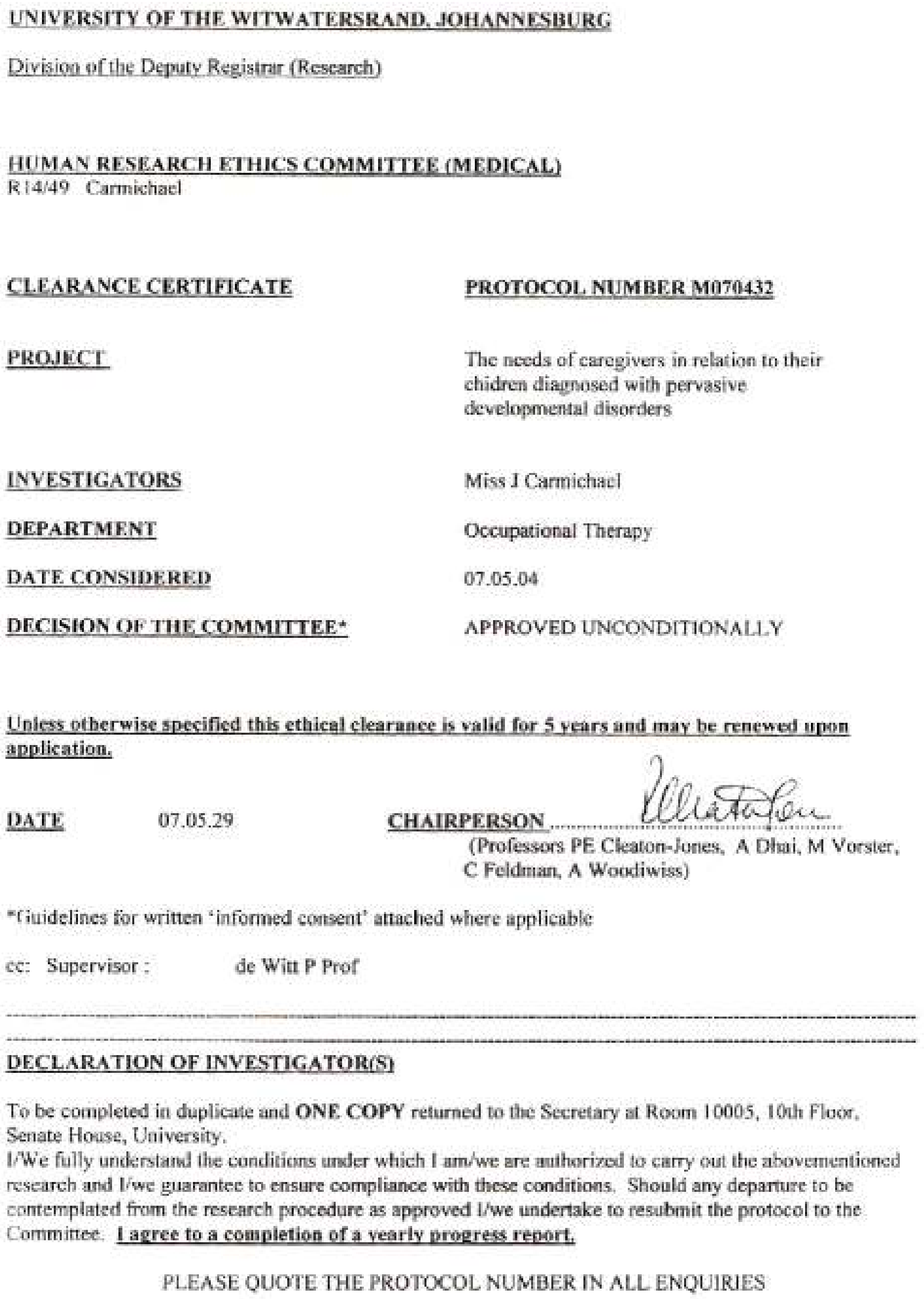
____

____

____

Thank you for taking the time to participate in this study!

APPENDIX F: Ethical Clearance Certificate



UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Carmichael

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M070432**
PROJECT	The needs of caregivers in relation to their children diagnosed with pervasive developmental disorders
INVESTIGATORS	Miss J Carmichael
DEPARTMENT	Occupational Therapy
DATE CONSIDERED	07.05.04
DECISION OF THE COMMITTEE*	APPROVED UNCONDITIONALLY

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 07.05.29 **CHAIRPERSON** ....
(Professors PE Cleaton-Jones, A Dhai, M Vorster, C Feldman, A Woodiwiss)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : de Witt P Prof

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX G: Permission letters

GAUTENG PROVINCIAL GOVERNMENT

DEPARTMENT
OF HEALTH

DATE: 04/01/2008

NAME OF RESEARCH WORKER:
Jennifer Carmichael

TITLE OF RESEARCH PROJECT:
The needs of the Caregivers in relation to their children diagnosed with Pervasive Developmental Disorders.

OBJECTIVES OF STUDY:
This study aims to explore:

- The subjective needs of the caregiver and family of the child with PDD:
- The identification and current use of services and resources by caregivers and their children diagnosed with PDD, related to demographics such as area of residence, educational level and socioeconomic status in the Johannesburg Metro Region.

METHODOLOGY:

See attached synopsis of the research protocol.

CONFIDENTIALITY OF PATIENTS MAINTAINED:

Confidentiality and anonymity will be maintained by excluding participant's names and contact details from the survey questionnaire. Participants will be assigned codes for reference and contact purposes for use by the researcher only

COSTS TO THE HOSPITAL: No financial resources required. The researcher will cover the costs of patient transport. In terms of human resources, assistance with translation would be appreciated if available. Alternatively other arrangements will be made.

APPROVAL OF HEAD OF DEPARTMENT:

APPROVAL OF CRHS OF WITS UNIVERSITY:

SUPERINTENDENT PERMISSION:

SYNOPSIS OF RESEARCH

Statement of the Problem

Specialised health and education service provision for children with Pervasive Developmental Disorders and their families, in both the public and private sectors in Gauteng, is limited. Health costs and intervention requirements, together with the increased numbers of patients presenting with autism spectrum disorders, presents significant demands on service delivery, accessibility and quality.

Services are not well co-ordinated and integrated. Specialist knowledge, skill and experience of health care professionals is inadequate and networking between various professionals and services is poor. There is a need for the development of holistic multidisciplinary services and resources, taking into account the unique South African setting and the needs of the caregivers and children with PDD.

Aim of the study

To establish the needs of caregivers and their family in relation to the child with PDD and what services are currently available to them in the Johannesburg Metro regions. Their use of these services will also be explored.

Research Methodology

This study will use a quantitative research method, utilising a non-experimental, cross-sectional research design.

Non-probability purposive sampling will be used. All caregivers of children (0-18 years) who have been diagnosed with a PDD attending paediatric out-patient and in-patient clinics and hospitals at Chris Hani Baragwanath Hospital, CMI, and Johannesburg General Hospital will be invited to participate in the study. Caregivers who are members of the Autism South Africa Association will also be invited to participate in the study.

The measurement tool to be used comprises a caregiver needs survey, which has been developed by the researcher based on available literature. The survey will need to be piloted and edited before being used in the research. The survey will be administered on the day of patient appointments, or distributed by post or email as convenient for the participant.

Data Analysis

Descriptive statistics will be used to describe, organise and summarise data gained from the Caregiver Survey. Some of the responses to the questions and statements in the questionnaires will be quantified by means of a rating scale. Other responses will be coded. Data will be compiled, converted and expressed as: frequencies, percentages and descriptions of central tendency; measures of spread and descriptions of relative position. Charts and tables will be used to represent data graphically.

Application of research findings

This research will assist in formally documenting the current needs and demands on services for children with PDD and their families. It is hoped that this information will assist health and education facilities and organisations such as "Autism-Johannesburg" (a professional-parent committee that has been set up with the aim of improving service delivery for children with PDD in Johannesburg), in appropriate service model development, and facilitate lobbying for funds and resources.

**DEPARTMENT OF
OCCUPATIONAL THERAPY**
SCHOOL OF THERAPEUTIC SCIENCES
FACULTY OF HEALTH SCIENCES

7 York Road, Parktown, 2193
Tel: 011 717-3701
Fax: 011 717-3709

13 December 2007

HEAD OF DEPARTMENT: SPEECH THERAPY AND AUDIOLOGY
Chris Hani Baragwanath Hospital

Dear Sadna,

Re: Permission to carry out Research in the Speech Therapy Department in 2008

I am currently completing my Masters Degree in Occupational Therapy at WITs University. I have completed the coursework component and now need to carry out a research project.

The title of my project is:

THE NEEDS OF CAREGIVERS IN RELATION TO THEIR CHILDREN DIAGNOSED WITH PERVASIVE DEVELOPMENTAL DISORDERS.

I have attached a summary of the research for your perusal. Ethical Clearance has already been attained and my protocol approved by WITS University.

I have requested permission to carry out this research at Chris Hani Baragwanath Hospital via the Occupational Therapy Department. Since my research will be based in the ASD service that runs in your Department, I would also like to request your permission to carry out the research.

In terms of the logistics of the research: I will need to meet with the parents of the children attending the ASD clinic in order to conduct an interview/questionnaire with them. I will undertake to cover their transport costs for the visit to the hospital. I am fully aware of the staffing pressures at the hospital. If at all possible, some assistance from your therapists or assistants in booking patients and possibly translating for parents that do not understand English or Afrikaans would really be appreciated. Having worked with these patients before, I found that a phone call from, or discussion with a familiar therapist or assistant was so much less threatening for patients. However, if this assistance is not possible, I will explore other alternatives e.g. the use of an external research assistant.

I had hoped to begin data collection in January 2008, before therapy commences and the demands on the Patients and caregivers' time increases. This will however depend on when permission is granted by the hospital to carry out the research.

Should you have any queries or concerns, please feel free to contact me.

Kind Regards

Jennifer Carmichael
Lecturer
Occupational Therapy Department
University of the Witwatersrand

Tel: 011 717 3704
Cell:082 511 4448
Fax: 011 717 3709
Email: Jennifer.Carmichael@wits.ac.za

DEPARTMENT OF
OCCUPATIONAL THERAPY
SCHOOL OF THERAPEUTIC SCIENCES
FACULTY OF HEALTH SCIENCES

7 York Road, Parktown, 2193
Tel: 011 717-3701
Fax: 011 717-3709

19 May 2008

Principal's Name
School

Dear Principal,

I, Jennifer Carmichael, am an occupational therapist currently completing my Masters degree at the University of the Witwatersrand. I am investigating the need for, experiences and costs of services utilized by caregivers and their children presenting with Autism Spectrum Disorders in Gauteng.

I would like to request your permission to invite the caregivers of children presenting with Autism-Spectrum Disorder and who attend your school, to participate in my study. This would involve serving the caregivers an information letter explaining the study and what they would need to do to participate in the study. Should they agree to participate in the study, they would then need to fill in a questionnaire and return it to me. I will cover printing costs. There will be no cost to the school.

I have included a copy of the questionnaire and the information letter for your perusal.

Should you have any further questions please don't hesitate to contact me.

Many thanks,

____

J. Carmichael
BSc (OT) Wits MSc (OT) II
Cell) 082 511 4448   W) 011 717 3724/3701
jennifer.hooper@wits.ac.za

APPENDIX H: Parent permission letter

DEPARTMENT OF
OCCUPATIONAL THERAPY
SCHOOL OF THERAPEUTIC SCIENCES
FACULTY OF HEALTH SCIENCES

7 York Road, Parktown, 2193
Tel: 011 717-3701
Fax: 011 717-3709

20 May 2008

Dear Parents,

Please read the attached information letter regarding my study.

If you would like to participate in the study, please fill in your contact details below and send this note back to school with your child. I will then contact you to schedule a time to fill out the questionnaire.

Thank you for your time.

Kind Regards,
Jennifer Carmichael
Lecturer: Occupational Therapy Department, University of the Witwatersrand
Tel: 011 717 3724 / 011 717 3701
Email: jennifer.carmichael@wits.ac.za
Cell: 082 511 4448

Reply Slip:

I, ________________________________, mother/father/caregiver of
________________________________ who attends the Children's Disability Centre, (**would like**)/(**would not like**) to participate in the study.

You (**may**)/(**may not**) contact me to set up an appointment to carry out the questionnaire.

My contact details are:
Telephone Number (Home)________________________________
Telephone Number (Work)________________________________
Cell phone number________________________________
Email address:________________________________

APPENDIX I: Information Letter

DEPARTMENT OF
OCCUPATIONAL THERAPY
SCHOOL OF THERAPEUTIC SCIENCES
FACULTY OF HEALTH SCIENCES

7 York Road, Parktown, 2193
Tel: 011 717-3701
Fax: 011 717-3709

Dear Parent,

I am Jennifer Carmichael, an Occupational Therapist completing my Masters Degree in Occupational Therapy at the University of the Witwatersrand. I wish to invite you to participate in my research into the needs of caregivers in relation to their children who have been diagnosed with Pervasive Developmental Disorders (including Autistic Spectrum Disorders, Asperger's Syndrome, Rett's Disorder, Childhood Disintegrative Disorder and Pervasive developmental disorders not otherwise specified).

Why this study?

Many parents complain that they have difficulty finding health care and educational services that meet their needs, and the needs of their children. We need research that explores the experiences of parents and their children, analyses their needs and finds out about the types of services parents think would be most useful to them. The research findings will help us to motivate for funding and development of services that are accessible to all. This will in turn help you and your child have better access to better quality services.

How to participate in this study

Participation in this study is entirely voluntary. Refusal to participate will not be held against you in any way and will not affect any treatment which you may receive.

Should you choose to participate in this study, you would be required to fill in the Caregiver Needs Survey along with the researcher. The survey takes about 30-45minutes to complete. Please know that you will remain anonymous and the confidentiality of the information you provide will be protected. The information collected in this survey will be grouped so that your individual responses will not be revealed to anyone else without your permission. Questions asked include basic demographic information, questions about the health and education services you and your child have made use of, and questions about the challenges you have experienced in accessing these services.

If you would like to find out about the results of this study, kindly give your contact details to the researcher so that the results can be sent to you. These details will only be used by the researcher and will not be included in the research report.

Supportive counselling services can be arranged for you, at your convenience, should the need arise.

Thank you for taking the time to read this letter. If you have any queries or need more information, please contact me on 011 717 3724 or 011 717 3701.

Yours faithfully

Jennifer Carmichael