A retrospective case report on demographic changes of learners at a school for children with autism spectrum disorders in Gauteng Province

by

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FACULTY OF HUMANITIES

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I declare that this dissertation is my own original work. Where secondary material is used, this has been carefully acknowledged and referenced in accordance with university requirements.

I understand what plagiarism is and am aware of university policy and implications in this regard.

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ABBREVIATIONS

ASD:	Autism Spectrum Disorders
OSA:	Outisme Spektrum Afwykings
DSM-IV:	*Diagnostic and Statistical Manual of Mental Disorders (fourth edition*)
DSM-IV-TR:	*Diagnostic and Statistical Manual of Mental Disorders (fourth edition – text revision)*
DSM-5:	*Diagnostic and Statistical Manual of Mental Disorders (fifth edition)*
GDE:	Gauteng Department of Education
HIV/AIDS:	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
LSEN:	Learners with special education needs
PDD:	Pervasive developmental disorders
SES:	Socio-economic Status
USA:	United States of America
UK:	United Kingdom

ABSTRACT

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A retrospective case report on demographic changes of learners at a school for children with autism spectrum disorders in Gauteng Province

Abstract:

Limited research has been published about the demographic characteristics of children with Autism Spectrum Disorders (ASD) in South Africa. Describing the profiles of learners from a school for children with ASD may contribute knowledge to the field and build a database of South African children with ASD. A retrospective comparative research design was used, comparing the demographic characteristics of learners over two time intervals, i.e. 1992–2002 (Group 1, n=32) and 2003–2014 (Group 2, n=109). A total of 141 historical admission records in hard copy files were reviewed. In this case report the increase in the number of learners admitted at the school per year may indicate that there was an increase in the number of children diagnosed with ASD in the school's catchment area. Results indicated that there is a large male gender predisposition (8.4:1) in learners, which increased over the years. At this stage no explanation can be offered for this unexpected finding. The age of the child when parents became concerned and age at diagnosis and assessment at the school increased over the two time periods. It is concerning that ASD diagnoses in recent years among the school children were increasingly conducted by single professionals, whereas the trend in developed countries is a large and diverse multidisciplinary team. There was an increase in diversity of home languages in learners after 2002. Parental qualifications decreased, but social class increased in recent years. The low qualification of a mother was associated with an advanced age of the child at school entry. The data serves as a point of reference for future studies on the characteristics of school children with ASD in South Africa.

Keywords: Autism Spectrum Disorders, case report, characteristics, demographic, family, Gauteng Province, gender ratio, learners, special school.

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A retrospective case report on demographic changes of learners at a school for children with autism spectrum disorders in Gauteng Province

Opsomming:

In Suid-Afrika is beperkte navorsing gepubliseer oor die demografiese eienskappe van kinders met Outisme Spektrum Afwykings (OSA). Beskrywings van die profiele van leerders van 'n skool vir kinders met outisme kan bydra tot kennis in die veld en help bou aan 'n databasis van kinders in Suid-Afrika met OSA. 'n Retrospektiewe, vergelykende navorsingsontwerp is gebruik. Die demografiese eienskappe van leerders is vergelyk oor twee tyd intervalle, naamlik 1992–2002 (Groep 1, n=32) en 2003–2014 (Groep 2, n=109). 'n Totaal van 141 historiese toelatingsrekords, in harde kopie leêrs is ondersoek. In hierdie gevalle-verslag kan 'n toename in die aantal leerders wat jaarliks ingeneem is daarop dui dat daar 'n toename was in die hoeveelheid kinders wat jaarliks met OSA gediagnoseer word in die skool se opvangsgebied. Volgens die resultate is daar 'n groot manlike predisposisie (8.4:1) onder die leerders, wat oor die jare toegeneem het. Tans is daar geen verduideliking vir hierdie verrassende bevinding nie. Die ouderdom van die kind wanneer ouers begin bekommerd raak het, en die ouderdom van diagnose en assessering by die skool, het toegeneem oor die twee tydsintervalle. Dit is kommerwekkend dat die OSA diagnoses van die skool se leerders gedurende die onlangse jare toenemend deur slegs een disipline gemaak word. Die neiging in ontwikkelde lande is dat kinders deur 'n groot en diverse multi-dissiplinêre span gediagnoseer word. Na 2002 was daar 'n toename in die verskeidenheid huistale van die leerders. Gedurende die onlangse jare het kwalifikasies van die ouers afgeneem, terwyl hulle sosiale klas toegeneem het. Daar was 'n verband tussen 'n lae kwalifikasie van 'n moeder en 'n gevorderde ouderdom van die kind met skooltoelating. Die data dien as verwysingspunt vir toekomstige navorsing oor die eienskappe van skoolkinders met OSA in Suid-Afrika.

Sleutelwoorde: demografiese eienskappe, Gauteng Provinsie, gesin, geslagsverhouding, gevalle-verslag, leerders, Outisme Spektrum Afwykings, spesiale skool.

CHAPTER 1

1. INTRODUCTION

1.1. Background

The incidence of autism spectrum disorders (ASD) diagnosis has been increasing globally over the years. However, researchers are unable to agree on whether the increase in diagnosis is a consequence of improved identification, increased awareness, improved detection or a definite increase in incidence or a combination of factors (Neggers, 2014). Other possible explanations for the observed increase in ASD diagnosis may include changes in diagnostic criteria, younger age at diagnosis and milder cases of ASD (Hertz-Picciotto & Delwiche, 2009).

ASD is a new consensus description in the DSM-5 (American Psychiatric Association, 2013) where scientists agree that four previously separate disorders are, in reality, a single condition with different levels of symptom severity in two core areas of deficit. The term ASD now includes Asperger syndrome, autistic disorder (autism), pervasive developmental disorder not otherwise specified and childhood disintegrative disorder described in the previous DSM-IV-TR (American Psychiatric Association, 2000; Grandin & Panek, 2014). The two-criterion model now used for diagnosis of ASD includes, one, deficits in social communication and social interaction; and, two, restricted repetitive behaviours patterns, activities and interests (American Psychiatric Association, 2013; Grandin & Panek, 2014). In order to diagnose a child with ASD, both components have to be present. It is expected that the narrowing of diagnostic criteria will result in less children diagnosed with ASD.

Apart from the associated deficits, such as mental disability and language impairment (American Psychiatric Association, 2013), ASD may co-exist with other disorders in children, such as Fragile X syndrome, Angelman syndrome, tuberous sclerosis, epilepsy, mental disability, hearing loss, Down syndrome, fetal alcohol spectrum disorder, microcephaly, Goldenhar syndrome and hypothyroidism (Dyches, Wilder, Sudweks, Obiakor & Algozzine, 2004; Manning-Courtney et al., 2003).

The symptoms that comprise ASD can now be identified at very young ages (Sipes Matson, Worley & Koslowski, 2011). According to Baird et al. (2003), parents are able to recognise ASD features at the age of eighteen months and often raise concerns as they see their child developing in an abnormal way. Despite increasing evidence that ASD can be identified and diagnosed accurately in very young children, the age of diagnosis, on average, remains delayed (Lord et al., 2006; Sansosti, Lavik & Sansosti, 2012). Research conducted in the United States of America (USA) and the United Kingdom (UK) has documented a large gap between the age at identification and the age at which children are diagnosed with ASD (Shattuck et al., 2009). Different studies around the globe found that children with ASD are often not diagnosed until they enter school (Fountain, King & Bearman, 2011; Manning-Courtney et al., 2003; Spence, Sharifi & Wiznitzer, 2004). A number of factors have been associated with timing of identification and diagnosis of ASD in children (Mandell, Novak & Zubritsky, 2005). According to Mandell et al. (2005), only a few studies have examined factors that may delay or assist in the early identification and diagnosis of children with ASD.

Table 1.1 demonstrates the demographical and clinical characteristics associated with the timing of identification and diagnosis of children with ASD in California in 2001 (Fountain et al., 2011), Alabama, Arkansas, Arizona, Colorado, Georgia, Maryland, Missouri, Illinois, North Carolina, and New Jersey in 2002 (Shattuck et al., 2009), Pennsylvania in 2004 (Mandell et al., 2005), Japan in 2008 (Fujiwara, Okuyama & Funahashi, 2010) and New York from 2003 to 2010 (Valicenti-McDermot, Hottinger, Seijo & Schulman, 2012).

Table 1.1: Demographic and clinical factors investigated in studies about timing of identification and diagnosis of children with ASD

Factors investigated	Valicenti-McDermot et al., 2012	Fountain et al., 2011	Fujiwara et al., 2010	Shattuck et al., 2009	Mandell et al., 2005
Demographic characteristics					
Age of child at parents first concern			X		
Age of child		X			
Adopted					X
Socio-economic status		X	X		X
Prevalence of ASD in local community		X			
Maternal age	X			X	
Maternal level of education	X	X	X	X	
Clinical characteristics					
Family history of ASD	X		X		
Severity of ASD symptoms	X	X			X
Cognitive functioning of child				X	
Co-existing disorders					X

A substantial number of demographic characteristics that influence the timing of identification and diagnosis of ASD are described in Table 1.1. The five studies were carried out mainly in the USA and one in Japan, which are all developed countries (Fountain et al., 2011; Fujiwara et al., 2010; Mandell et al., 2005; Shattuck et al., 2009; Valicenti-McDermot et al., 2012). All the demographic characteristics listed in Table 1.1 were found to have a positive or negative impact on the timing of identification and diagnosis of ASD in a child.

Research in Japan indicated that delayed identification and diagnosis of ASD was associated with children who were three to five years old and in pre-school (Fujiwara et al., 2010). The delayed diagnosis may be ascribed to parents who were unable to visit health care systems offering psychiatric services because of the weak referral system between health care systems and pre-schools. Another reason for delayed diagnosis includes professionals who consider specific symptoms either imprecise or unacceptable for children of at a very young age (Fujiwara et al., 2010). Investigators in California researched the individual and community level factors influencing the age of ASD diagnosis across ten birth cohorts (Fountain et al., 2011). The results showed that, since 1992 to 2001, the age of diagnosis has declined and that the effects of individual and community level factors on the age of diagnosis were less influential than before (Fountain et al., 2011). After 1996, increasingly more children were diagnosed with ASD at three years of age (Fountain et al., 2011). This is because the age of diagnosis was less dependent on the community in which children with ASD live as the prevalence of autism increased.

Mandell et al. (2005) reported that children who were adopted received an ASD diagnosis nearly ten months later than children not adopted. The delayed ASD diagnosis in adopted children may be associated with adoptive parents attributing delayed development to early childhood experiences that may lead to temporary delays instead of a disorder associated with long-lasting delays such as ASD (Mandell et al., 2005). Children living in rural settings received a diagnosis later than children in urban settings (Mandell et al., 2005). This author also reported that children from near-poor families were diagnosed, on average, almost eleven months later than children from wealthy families. Delayed diagnosis in near-poor families and in rural settings may be ascribed to limited access to a professional who may be able to diagnose ASD early (Mandell et al., 2005). In contrast, in communities in the USA where the prevalence of ASD in children was high, children were diagnosed slightly earlier than in communities where the prevalence of children with ASD was lower (Fountain et al., 2011). This tendency may be attributed to increased awareness about ASD among physicians, teachers and parents in those communities (Mandell et al., 2005). Shattuck et al. (2009)

reported that delayed identification and diagnosis of ASD was associated with young maternal age at the birth of the child. The reason may be that young mothers may not have adequate knowledge of ASD; hence, they are unable to recognise developmental concerns (Shattuck et al., 2009). However, children with educated parents were diagnosed earlier than those whose parents had less exposure to education (Fountain et al., 2011). Educated parents have more knowledge about the characteristics of ASD and therefore are able to identify developmental concerns early. Shattuck et al. (2009) reported that delayed diagnosis were particularly associated with lower maternal education. Apart from numerous demographic factors, a few clinical factors in the child may also influence the timing of identification and diagnosis (Fountain et al., 2011; Fujiwara et al., 2010; Mandell et al., 2005; Shattuck et al., 2009; Valicenti-McDermot et al., 2012).

Clinical factors indicated in Table 1.1 refer to the observable and diagnosable characteristics of ASD. Children who have a family history of ASD are likely to be evaluated earlier (Valicenti-McDermot et al., 2012). A family history may increase parental or caregiver awareness with regard to developmental concerns and early intervention (Fujiwara et al., 2010; Valicenti-McDermot et al., 2012). Previous studies indicate that co-occurance of ASD and hearing loss is associated with delayed identification and diagnosis of ASD (Mandell et al., 2005). Children with a hearing loss were diagnosed with ASD nearly ten months later than children without hearing loss (Mandell et al., 2005). Having a hearing loss may make it more challenging for professionals to determine whether ASD is present (Mandell et al., 2005). Therefore, professionals should be observant of the possibility of ASD among children with hearing loss (Mandell et al., 2005). Individuals who had high level communication abilities were diagnosed later than individuals with low level communication abilities (Fountain et al., 2011). In contrast, Mandell et al. (2005) reported that severe and visible symptoms in children with ASD appear to elicit an early diagnosis. Except for hearing loss, it appears that children with developmental delays and co-existing disorders received a diagnosis earlier than children diagnosed with ASD only (Mandell et al., 2005; Shattuck et al., 2009; Valicenti-McDermot et al., 2012). These findings may be attributed to increased

awareness among professionals of the defined symptoms and therefore, they may request further evaluations (Mandell et al., 2005). From Table 1.1, it is clear that numerous factors are already known to contribute to early or late identification and diagnosis of ASD in children in different contexts.

Apart from the numerous factors associated with timing of identification and diagnosis of children with ASD, delayed diagnosis may have long-term consequences for the child (Mandell et al., 2005). Research in the USA suggests that late diagnosis of ASD in children may delay appropriate early intervention (Manning-Courtney et al., 2003). Early identification and diagnosis is crucial for a number of reasons as it leads to more intensive intervention, increased social acceptance, increased social support for families and professionals caring for children with ASD, and early identification may also lead to improved expectations of the prognosis for ASD (Carbone, Farley & Davis, 2010; Manning-Courtney et al., 2003).

The factors associated with the timing of identification and diagnoses of children with ASD in South Africa have not yet been described comprehensively. Furthermore, Springer, Van Toorn and Laughton (2013) stated that studies have yet to be conducted to determine whether South African children present with similar characteristics and challenges as described elsewhere.

1.2. Rationale

Children with Autism Spectrum Disorders (ASD) are highly prevalent, affecting approximately 1% of the global population (Richmond, 2011). Research on the prevalence of ASD has now been conducted in several countries around the globe such as Europe, United States of America and the Western Pacific (Elsabbagh et al., 2012). In contrast, Bakare and Munir (2011) reported that there are few published studies on autism in Africa.

The prevalence of children with ASD or what was previously described as Pervasive developmental disorders (PDD), in South Africa is unknown (Bateman, 2013; Springer,

Van Toorn, Laughton, 2013). According to Garcia (2014) the point prevalence of children diagnosed with ASD in the United States is estimated to be 1:68. These figures suggest that there could be over 270 000 people with ASD in South Africa, with an estimated 5 000 new cases per year (Springer et al., 2013). Jacklin (2006) described similar numbers indicating an 8.2% increase in the number of children presenting with ASD features attending a developmental clinic in Gauteng over the period 1996-2005. According to Springer et al. (2013) it is also not clear in South Africa whether the increase in prevalence is related to the heightened awareness of ASD among professionals and parents, or due to the broadening of the diagnostic criteria in the year 2000. Due to possible contributing factors in South Africa such as poverty, illiteracy, the high prevalence of HIV/AIDS and tuberculosis (TB); and contextual evidence lacking (Penn, 2007; Mullis et al., 2007), the prevalence of developmental disorders, such as ASD, may be even higher than in developed countries. In order to determine the future effect of a narrowing of diagnostic criteria since 2013 (American Psychiatric Association, 2013), it is important to document existing data on children with ASD in South Africa.

The prevalence of children with ASD or what was previously described as Pervasive developmental disorders (PDD), in South Africa is unknown (Bateman, 2013; Springer, Van Toorn, Laughton, 2013). According to Garcia (2014) the point prevalence of children diagnosed with ASD in the United States is estimated to be 1:68. These figures suggest that there could be over 270 000 people with ASD in South Africa, with an estimated 5 000 new cases per year (Springer et al., 2013). Jacklin (2006) described similar numbers indicating an 8.2% increase in the number of children presenting with ASD features attending a developmental clinic in Gauteng over the period 1996-2005. According to Springer et al. (2013) it is also not clear in South Africa whether the increase in prevalence is related to the heightened awareness of ASD among professionals and parents, or due to the broadening of the diagnostic criteria in the year 2000. Due to possible contributing factors in South Africa such as poverty, illiteracy, the high prevalence of HIV/AIDS and tuberculosis (TB); and contextual evidence lacking (Penn, 2007; Mullis et al., 2007), the prevalence of developmental disorders, such as ASD, may be even higher than in developed countries. In order to determine the future

effect of a narrowing of diagnostic criteria since 2013 (American Psychiatric Association, 2013), it is important to document existing data on children with ASD in South Africa.

South Africa has a multicultural and multilingual population in which eleven official languages and a variety of unofficial languages and dialects are spoken by its citizens (Pascoe & Norman, 2011). Consequently, children with ASD and their families are from different cultural and linguistic backgrounds and need specialised education and speech-language therapy that closely match their experiences.

Springer et al. (2013) described the demographics, history, clinical features, co-morbidity and diagnostic characteristics of children with ASD from Tygerberg Hospital's developmental paediatric clinic in the Western Cape Province. This descriptive study involved a retrospective review of medical records over two years. Although the majority of children were from South African mixed ancestry, the overall study sample was diverse (Springer et al., 2013). The male to female ratio was 3.8:1, which is less than the gender disparity reported by an epidemiological study by Fombonne (2005) in fourteen countries (UK, Denmark, USA, Japan, Sweden, Ireland, Germany, Canada, France, Indonesia, Norway, Finland, Iceland and Israel). This author reported on an estimated high male to female ratio of approximately 4.3:1. A study in Atlanta, in the USA, found that the median age at assessment for children with ASD was forty eight months (Wiggins, Baio & Rice, 2006). In contrast, Springer et al. (2013) found that the median age at assessment in the Western Cape was fifty six months. The age at assessment in the Western Cape appears to be significantly later than in the USA.

As reported earlier, research conducted in the USA and UK has documented a gap between the age at which children are identified, and the age at which they are diagnosed (Shattuck et al., 2009). Osterling and Dawson (1994) suggested that middle class parents in Washington DC were able to recognise ASD features already at the age of eighteen months, based on their home video recordings of their children's development. Impairments in both joint and social attention behaviours are said

characterised children with ASD by one year of age (Osterling & Dawson, 1994). Therefore, it is clear that children with ASD features can be identified very early in life, yet the average age of diagnosis appears to be much later. Springer et al. (2013) reported that the median age of children at ASD diagnosis in their study in the Western Cape Provence was forty two months, similar to that of children attending a tertiary developmental clinic in Singapore (Lian & Ho, 2012). Different researchers around the globe reported that children with ASD have often not been diagnosed until they have entered school (Fountain et al., 2011; Manning-Courtney et al., 2003; Spence et al., 2004). Despite increasing evidence that ASD can be identified and diagnosed accurately in very young children, the age of diagnosis on average, remains delayed (Lord et al., 2006; Sansosti et al., 2012). The most important consequences of delayed diagnosis of ASD in children may imply missed early intervention opportunities during the period of high neuroplasticity (Manning-Courtney et al., 2003). Delayed diagnosis may also occur when children present with mild degrees of ASD which may not be easily identifiable (Manning-Courtney et al., 2003).

Springer et al. (2013) suggested that it appears that non-verbal children were referred without hesitation to health professionals to determine whether there was hearing loss, but children that were verbal and presented with mild degrees of ASD were not referred or were overlooked. These authors reported that children from the black African group of participants had the highest percentage of non-verbal children. The ethnic groups in this study were representative of the demographic profiles of people living in the hospital drainage area in Tygerberg. There were 72.4% of children in the study by Springer et al. (2013) who were non-verbal which suggests a high percentage of children with intellectual disability. Statistics SA (2011) estimated that 79.2% of the South African population is black Africans. This may explain the high percentage of black African children presenting with ASD symptoms. Springer et al. (2013) reported that only 6.9% of the children with ASD in the study were immigrants. The results from Springer et al. (2013) do not correspond with Beccerra et al. (2014) who reported that children with ASD who were black and born in foreign countries were at high risk for impaired expressive language abilities. The reason may be because immigrant parents

were unable to access and receive an appropriate diagnosis and treatment for their children (Beccerra et al., 2014). Apart from intellectual disabilities, Springer et al. (2013) described some children in their study as having complex ASD.

According to Springer et al. (2013), complex ASD refers to dysmorphic features and/or microcephaly being present, and indicates some change in the early morphogenesis of the child (Springer et al., 2013). A higher rate of macrocephaly (12.1%) compared to the general population (<3%), was reported by Springer et al. (2013). Macrocephaly has been reported to be present in 5% to 15% of children with ASD (Fombonne et al., 1999). The results by Fombonne et al. (1999) corresponded with Springer et al. (2013) who reported that 7% of the children studied had microcephaly and one child was diagnosed with Rett syndrome. Miles et al. (2005) stated that 20% to 30% of children with ASD present with complex ASD, and have a poor prognosis. Springer et al. (2013) furthermore reported that 40% of children in their study fulfilled the criteria for complex ASD. The high figures reported may be due to the referral pattern of the developmental clinic that included children who were young and had severe language delays (Springer et al., 2013). Some children with ASD may also have co-morbid conditions. Bolton et al. (2011) reported that epilepsy is prevalent in 5% to 40% of children with ASD. Their results are similar to those of Springer et al. (2013) who reported that 10.3% of the children with ASD in their study presented with epilepsy.

In conclusion, important differences were highlighted in the Western Cape Provence study by Springer et al. (2013). The authors report a slightly higher prevalence of male to female ratio, an older age at assessment, higher percentage of non-verbal children from black African ethnicity groups and a high prevalence of complex ASD than studies elsewhere. Therefore, it could be that a unique profile of children with ASD in South Africa is emerging. More locally relevant data needs to be added to further investigate the nature and extent of these apparent differences. Enriched information about the demographic profiles of children with ASD in South Africa may lead to increased awareness amongst professionals and caregivers that may in turn lead to earlier identification, diagnosis and intervention.

1.3. Research question

In South Africa research has yet to be published to strengthen the evidence of small studies already conducted locally. Therefore, the researcher aimed to answer the following research question: *Has the demographic profile of children with ASD attending a special school in Gauteng changed over the past two decades, and if so can factors be identified that have contributed to the change?*

CHAPTER 2

2. METHODOLOGY

The research methodology describes the process that was followed in order to determine whether the profile of learners with ASD in a special school has changed over two time intervals.

2.1 Aim of the study

The aim of the study was to compare the learner and family characteristics of children diagnosed with ASD attending a special school in the Gauteng Province, between 1992–2002 (Group 1) and 2003–2014 (Group 2).

The results of the study were compiled and described in the article titled "A retrospective case report on demographic changes of learners at a school for children with autism spectrum disorders in Gauteng Province" (Chapter 3) and accepted for publication in the *South African Journal of Childhood Education*, on 26 April 2015.

2.2 Research design

A quantitative descriptive research design was selected for the study. Leedy and Ormrod (2010) reported that the characteristics of descriptive quantitative research designs entail either exploring possible affiliations among two or more phenomena or establishing the characteristics of an identified phenomenon. A quantitative research approach was appropriate since numerical data and statistical procedures were used to analyse and draw conclusions from the data (Leedy & Ormrod, 2005). Data collection included reviewing the historical school admission records of the participants who attended the special school between 1992 and 2014. Therefore, the research was retrospective.

McKenna, Hasson and Keeney (2010) stated that a retrospective survey design refers to a researcher exploring a current phenomenon by seeking information from

individuals' histories. A retrospective survey design aims to examine the possible factors that might be associated with the outcome (McKenna et al., 2010). Retrospective research studies are conducted on a smaller scale and less time is needed to complete the research. Disadvantages include that the researcher needs to rely on the accurate record-keeping of others and small scaled some key statistics can often not be measured (Mckenna et al., 2010). In this case, the researcher had to rely on only old school admission records from one special school. Furthermore, the research study was a case report.

De Vos, Strydom, Fouché and Delport (2002) describe a case report as a detailed report of an individual. This case report endeavoured to provide a detailed description of an individual case, in this instance highlighting the unique features of learners in a school for children with ASD. Lastly, the research incorporated a comparative component.

According to Leedy and Ormrod (2010), a comparative research design is used to determine whether there is a possible relationship between pre-existing conditions or characteristics. The researcher gathered data regarding different pre-existing variables for the two groups of participants selected for the study and made a comparison over two historical time periods (Leedy & Ormrod, 2010). The objective data collected in the study provided statistical information regarding the significant differences and similarities of the learners at a school for children with ASD in Gauteng over a period of twenty two years.

2.3. Ethical considerations

The researcher obtained ethical clearance (see Appendix A) from the Faculty of Humanities' Research Ethics Committee at the University of Pretoria.

The researcher has to act responsibly towards the participants in the research project, and report the findings honestly and accurately (De Vos, Strydom, Schulze & Patel, 2011). The following ethical rules were followed:

- ***Permission to conduct research***

  The researcher obtained permission from the two following institutions:

  1. *School*

     The researcher provided the principal of the school with information on the prospective research study (see Appendix C). Thereafter, the researcher obtained written permission from the principal to conduct the research study at a school for children with ASD (see Appendix D). Furthermore, the principal gave permission that the researcher may view the records, but that the records of the learners may not be removed from the school premises. Permission was granted to view records of learners who have left the school without consent from the parents. Consent was obtained from parents of the participants currently attending the school (see Appendix E).

  2. *Gauteng Department of Education (GDE)*

     After obtaining ethical clearance, the researcher obtained permission from the GDE to conduct the research in a public school (see Appendix B).

- ***Voluntary participation***

  Rubin and Babbie (2005) acknowledge the importance that participation in research should be voluntary at all times. No participant should be forced or coerced to participate in a research project. The consent letters stated that participants may withdraw from the study at any time, without any adverse consequences for the participants.

- ***Confidentiality***

  Only the researcher and supervisors had access to the data obtained from the school files. The names of the parents and participants were not disclosed in the research project.

- ***Storage of data***

  The policy of University of Pretoria's states that data collected should be stored electronically, as well as in hard copy for 15 years. The GDE Director of Knowledge Management and Research requested that an electronic and hardcopy of the research report were to be submitted upon completion of the research investigation. Therefore, the data collected in the study was safely stored electronically and in hardcopy.

2.4. Setting

The special school was established in 1973 with less than thirty learners. Since the 1970's, the special school had to increase the number of learners admitted annually as there was an increase in children with ASD that needed special education. The researcher selected this specific special school and hoped to obtain information rich data from the school admission records over the past twenty two years. Furthermore, this case report was considered an exploratory study which could be a foundation for future studies, where the data can be compared with different special schools across South Africa. The school is situated in an urban area and currently accommodates 111 learners between the ages of three and eighteen years (personal communication with school principal). Parents apply to the school for admission by completing an application form. The application form is then paper screened by the school assessment team to determine whether the child is a candidate for the school. Usually the child already has a diagnosis of ASD and is then assessed by the school's multi-disciplinary team to determine in which phase the child should be placed. The team includes a speech-language therapist, occupational therapist, clinical psychologist and sometimes a psychiatrist, who conducts approximately three weekly assessments. Children who do not have an ASD diagnosis are referred to health professionals, or assessed and diagnosed by the multi-disciplinary team. There is a long waiting list at the school and a child may not be admitted directly. In such a case, the child is referred to a nearby school for children with special needs until there is an opening. Children are placed into a

specific phase according to their age and level of functionality, once they are admitted. The five educational phases are reception, foundation, intermediate, senior and school leaving phase. Each phase has two classes, one for children with high functioning ASD and one for children with low functioning ASD.

2.5. Participants

The target population of the research investigation was all the learners who were admitted in the special school for learners with ASD from 1992–2014. Participants were assigned to two groups according to the time interval that they were admitted to the school, Group 1 (n=32), and Group 2 (n=109). Since 1992–2014, a total of 397 children had been admitted at the school. The researcher reviewed 141 complete historical records in paper-based files of the total number of 397 children who were admitted in the school. The available historical school admission records included those from the archive and the records of the current learners whose parents completed a consent form. Many records of past learners were lost, but available files contained the complete information required for the study.

2.5.1 Sampling procedures

Convenience sampling was used to select participants for this study. The researcher selected convenience sampling as there was a limited number of historical school admission records available at the special school and only a small number of participants could be recruited to participate in the study. The researcher selected all the historical school admission records that were complete and the school admission records of the current learners whose parents gave permission. There were 397 historical school admission records, but only ninety files were complete. The ninety historical school admission records and the fifty one current school admission records were reviewed by the researcher. A total of 141 or 35.52% of the files could be accessed.

It is of critical concern that the sample population should present with demographic characteristics representative of children with ASD, to allow the accurate generalisation

of the characteristics (Bless, Higson-Smith & Kagee, 2006). Therefore, the inclusion criteria were as follows:

- The participants currently attending the special school for children with ASD whose parents completed the consent forms and the past learner records were included in the research study.
- The parents of the participants who agreed to the files of their children being accessed in the research study had to have a child with a confirmed diagnosis of ASD. The historical school admission records and current school admission records contained various reports from professionals who made the ASD diagnosis or saw the child for therapy.
- Participants had to be admitted to the special school for children with ASD between the years 1992 and 2014. No other records before 1992 were available in the archive as the special school only archives the school admission records of school leavers for the last seven years.
- Participants of all ages and gender were included.

2.5.2. Description of the participants

General participant characteristics are depicted in Figure 2.1 and Figure 2.2.

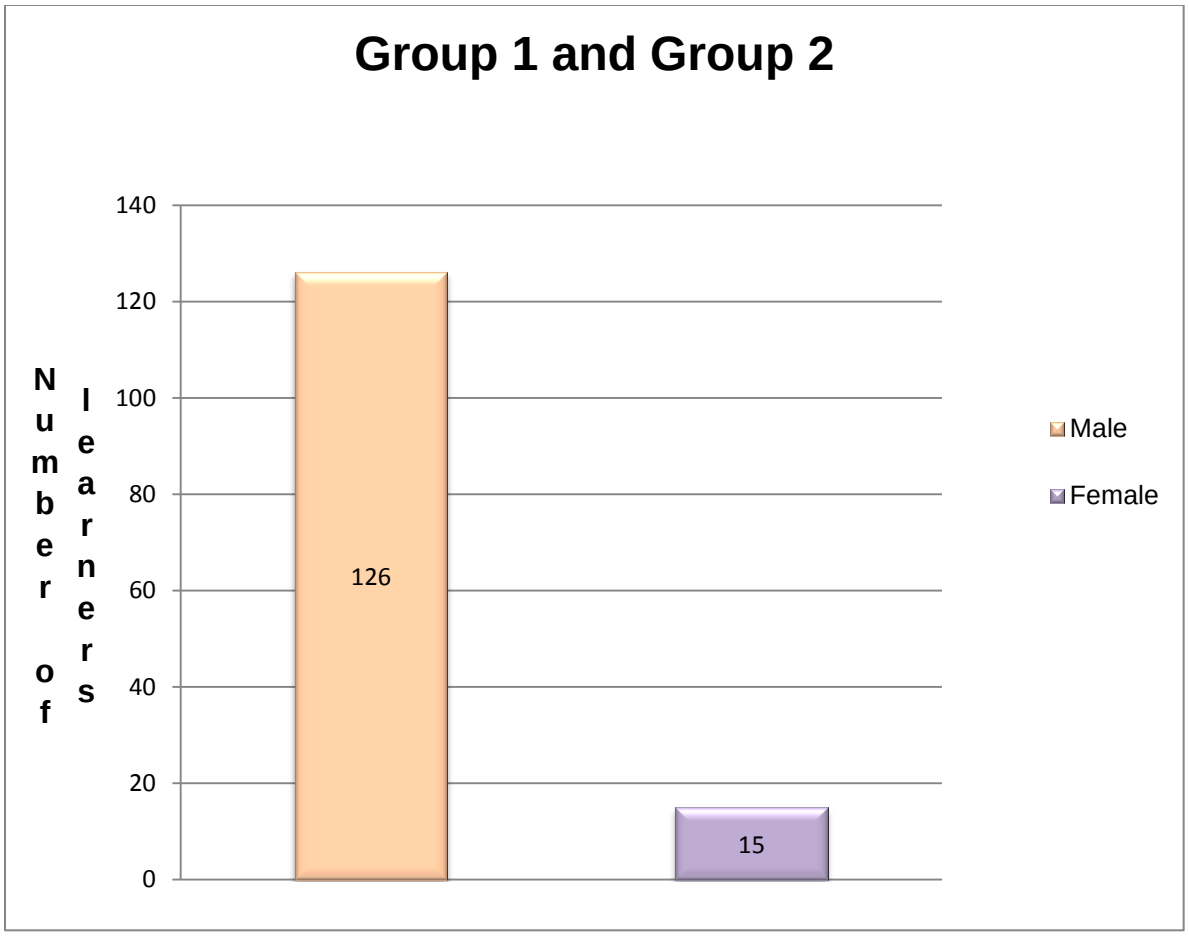

Figure 2.1: Gender of learners in the combined sample 1992–2014 (n=141)

Figure 2.1 reflects the prevailing gender of the sample as male. The male to female ratio in the study sample was surprisingly 8.4:1. Upon further investigation, the school principal confirmed the finding and added that the current male bias is even larger, with a ratio of 11.7:1. The gender disparity in the study was considerably higher than that reported by Fombonne (2005) in the epidemiologic study conducted in fourteen developed countries where the male to female ratio in children with ASD was 4.3:1. Researchers offer different reasons as to why more boys than girls are diagnosed with ASD. The male bias could merely reflect the difficulty of diagnosing ASD in females (New, Triebwasser & Charney, 2008). However, classic autism would not be overlooked in females and Asperger syndrome may present as other conditions, for example, borderline personality disorder (New et al., 2008) or anorexia (Treasure, 2007). Both anorexia and borderline personality disorder occur more in females and includes

excessively controlling people or the environment and a degree of self-centredness (New et al., 2008; Treasure, 2007), thereby demonstrating similar features found in ASD. Stanford (2003) added that there is a substantial gender gap in the referral and diagnosis of Asperger syndrome as the male to female ratio is 10:1. Asperger syndrome might be underdiagnosed in females if they present with imitation skills or are interested to learn to adapt socially which permits them to present as normal (Holliday Willey, 1999). Young girls with Asperger syndrome find it easier to form friendships than young boys, as females present with more social intuition (Sansone & Sansone, 2008).

The age distribution of the participants is presented in Figure 2.2.

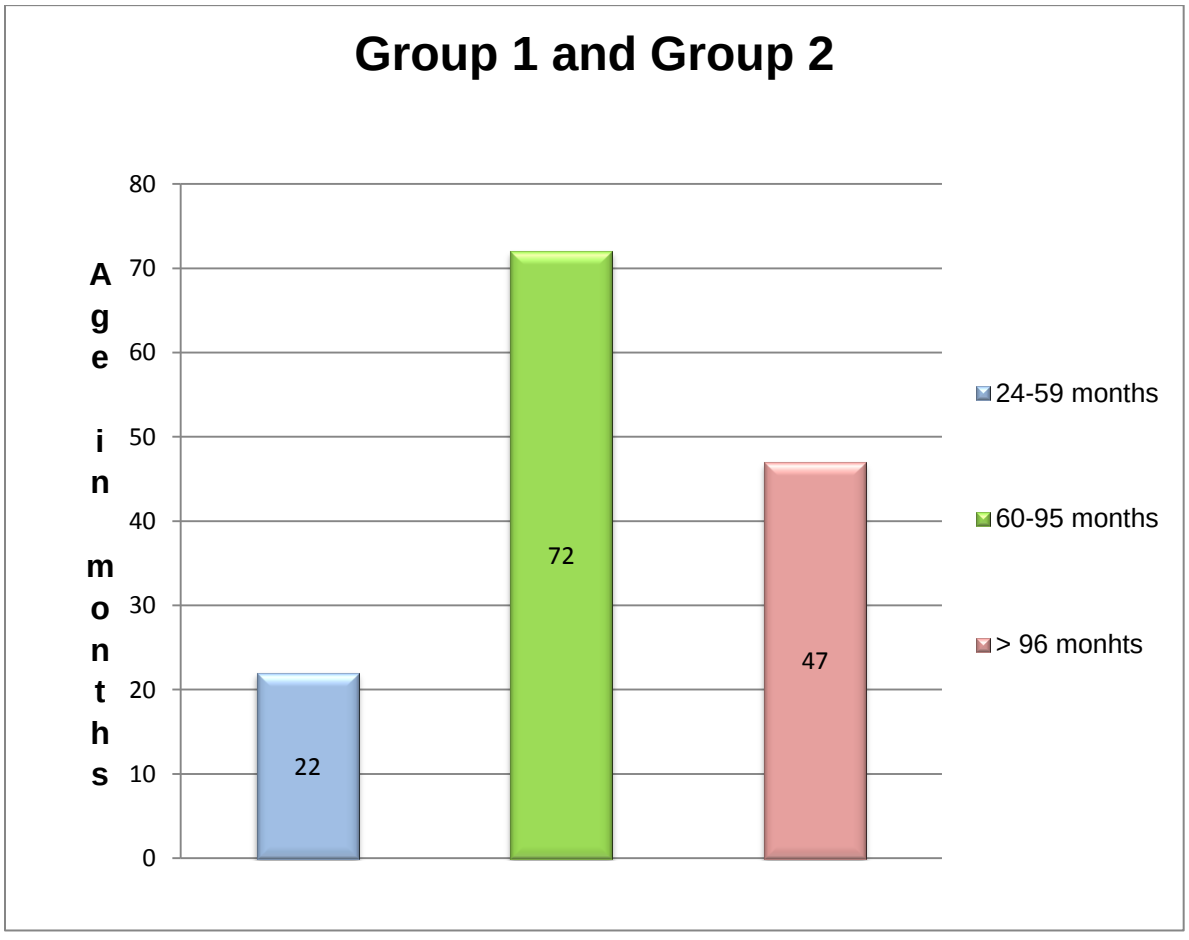

Figure 2.2: Age (in months) of learners in the combined sample (1992–2014) when admitted at special school (n=141)

Figure 2.2 show that most children in the combined sample entered school between 6;0 to 7;9 years of age, with some as late as nine years. One of the main reasons why children might have been admitted so late was that the school was unable to accommodate more learners and had reached its full capacity; therefore, participants had to wait until there was an opening before they could be admitted.

2.6 Material and apparatus

The following material and apparatus were used for data collection.

2.6.1 Material

- *Checklist*

  According to Delport and Roestenburg (2011), a criteria or merit checklist lists a series of characteristics that are either present or absent in the participants observed in a study. The researcher ensured that the dimensions of observation in the checklist were comprehensive and not overlapping (Delport & Roestenburg, 2011). The researcher drafted a structured checklist (see Appendix F) which was derived from a questionnaire formulated by the special school for children with ASD and found in the learner records. Parents of the participants completed the questionnaire before admission at the school. As parents are familiar with the characteristics, difficulties and needs of their children, the questionnaires may be viewed as reliable. After the parents of the participants provided consent to view the school admission records, the researcher studied the files and completed the structured checklist.

- *Validity and reliability*

  According to Delport and Roestenburg (2011), face validity refers to the applicability of the instrument administered or completed by the researcher. The sub-sections in the checklist were extensive and the information obtained correlated with the aim of the study. Lastly, the structured checklist was user-friendly and ensured that the information obtained was valid and reliable. The structured checklist was not a standardised instrument; however, a pilot study was conducted to determine if the instrument truly collects the characteristics being investigated (King & Bearman,

2011). The researcher completed the same structured checklist for every participant in the study. The structured checklist was stable and consistent, and therefore reliable (Kumar, 2005).

The checklist consisted of two sub-sections with a total of 21 questions. Each section of the checklist included aspects of the main aim. Section A focussed on questions about learner characteristics. The questions included:

- What age was the child when parents became concerned about the child's development?
- Reasons why parents became concerned about child's development and what type of school was the child in before admission to special school?
- What was the age of participant when diagnosed with ASD, according to the DSM-IV or DSM-IV-TR?
- What was the participant's diagnosis according to the DSM-IV or DMS-IV-TR?
- What was the occupation of professional involved with ASD diagnosis?
- What was the occupation of person involved with referral to the special school?
- At what age was the participant at team assessment at special school?
- What age was the participant when admitted at special school?
- What is the participant's home language?
- What is the participant's gender?
- Was the participant the first born?
- What was the speech-language developmental history of the participant?
- In which province did the participant live?

Section B focussed on family characteristics of the learners. Here the questions included:

- Did the participant have siblings or was he/she a single child?
- Was there a family history of disabilities or conditions?
- What was the father's age when child was conceived?

- What were the father's qualifications?
- What was the marital status of the mother?
- What was the mother's age when child was conceived?
- What were the mother's qualifications?

It was hoped that demographical data collected in section A and B added knowledge about the characteristics of children with ASD in South Africa.

2.6.2 Apparatus

The researcher used an ACER laptop, which was password protected, to capture the data obtained from the questionnaires into the structured checklist. This process of manually capturing the data enabled the researcher to record data directly into an Excel spread sheet instead of recording it on paper. Furthermore, the researcher was able to directly review information obtained from the checklist and create changes effortlessly.

2.7 Development of the checklist

Strydom (2011) notes that it is important for a researcher to have thorough background knowledge on a research topic at hand. Prior to the main investigation the first author visited the special school and reviewed five historical school admission records. The admission records included a questionnaire completed by the parents, reports from various professionals and information about the learner's school progress. During the child's assessment and interview with the parents missing information were obtained and supplemented to the questionnaire. Based on the information obtained from the parent questionnaire the researchers were able to formulate an electronic structured checklist. Relevant information was electronically captured from the parent questionnaire. Adjustments could be made to the checklist and the Microsoft 2010 EXCEL spreadsheet to accommodate as many variables as possible.

2.8 Data collection

2.8.1 Data collection procedures

The data collection procedures which were followed in the study are discussed in-depth below.

The researcher obtained ethical clearance from the Research Ethics Committee of the Faculty of Humanities (University of Pretoria), and the GDE, prior to the data collection procedures:

- The special school for children with ASD were contacted to commence with the study.
- Specific dates were discussed and confirmed with the principal of the special school.
- The researcher distributed the informed consent forms to the teachers at the special school.
- The teachers and teacher assistants placed the consent forms in the backpacks of the learners for the parents to complete.
- The informed consent forms were also emailed to the parents of learners.
- The researcher collected the completed informed consent forms.
- Records of current learners whose parents did not complete the consent forms and the 256 files that were incomplete or unavailable were not included in the study.
- The researcher compiled a list of the participants whose parents gave consent and who met the selection criteria.
- The researcher selected five files to improve the development of the checklist.
- After the five files were reviewed and the data captured, improvements were made to the checklist.
- The researcher commenced with the main investigation.
- The 90 historical and 51 current school admission records, with a total of 141, were reviewed by the researcher.
- The researcher captured, recorded and analysed the data electronically.
- The researcher completed the research project and submitted an article about the research project to the South African Journal of Childhood Education.

- The principal of the school scheduled a time for the researcher to present the results to the staff at the school.
- The researcher scheduled an appointment with the principal of the special school for children with ASD and the Gauteng Department of Education and provided them with a copy of the completed research project.

2.8.2 Procedures for Data Processing and Analyses

The researcher analysed the raw data from the structured checklist. The data was captured on Microsoft 2010 EXCEL spreadsheets. A data dictionary (see appendix G) was compiled to map variables and coding procedures, such as the age in months when parents became concerned about the child's development, reasons why parents became concerned about the child's development, type of school before admission at special school, age when participant was diagnosed with ASD according to the DSM-IV or DSM-IV-TR, participant's diagnosis according to DSM-IV or DSM-IV-TR, occupation of the professional/person involved with the diagnosis and referral to the special school, age of participant at assessment and admittance at the special school, home language, gender, speech developmental history, province, number of siblings, family history of disabilities or conditions, father's and mother's age when participant was conceived, father's and mother's qualifications, father's and mother's social class according to occupation and marital status of the mother. The data was captured into IBM SPSS (Version 22) to facilitate analysis.

Basic frequency and descriptive tables were constructed to investigate and describe distribution of the data. These results were presented in tabular and graphical format to aid interpretation.

Non-parametric tests were used to identify differences between groups and explore underlying relationships amongst variables. The Pearson chi-square test of independence was employed to compare differences between study groups pertaining more specifically to learner and family characteristics. Pearson correlation coefficients were calculated to further explore underlying linear relationships between selective

variables. These Pearson correlation coefficients were calculated primarily due to traditional chi-square analysis not taking natural ordering of certain variables into account (Howell, 2010).

The main aim of the statistical data analysis was firstly to present a profile of learners, and secondly, to identify variables that explain the variation between the two groups. From these profiles and variables, some generalisations could be presented. The researcher discussed the identified differences and similarities and established conclusions based on the results. Furthermore, the researcher explored alternative explanations which could help to identify, describe and explain the results obtained in the study. The conclusions are discussed after the results section.

CHAPTER 3

A retrospective case report on demographic changes of learners at a school for children with autism spectrum disorders in Gauteng Province

This is the article submitted to *South African Journal of Childhood Education (SAJCE)* and was accepted for publication on 26 April 2015. The editing and style are according to the journal specifications and differ from the dissertation.

Abstract

Limited research has been published about the demographic characteristics of children with Autism Spectrum Disorders (ASD) in South Africa. Describing the profiles of learners from a school for children ASD may contribute local knowledge to the field. A retrospective comparative design was used, comparing the demographic characteristics of learners over two time intervals, i.e.1992–2002 (Group 1, n=32) and 2003–2014 (Group 2, n=109). A total of 141 historical admission records in paper-based files were reviewed. Results indicated that there is a large male gender bias (8.4:1) in learners, which increased over the years. The age of the child when parents became concerned and age at diagnosis and assessment at school increased over the two time periods. There was an increase in diversity of home languages in learners after 2002. Parental qualifications decreased, but social class improved in recent years. The low qualification of a mother was associated with an advanced age of the child at school entry. The data serves as a point of reference for future studies about the characteristics of school children with ASD in South Africa.

Keywords: Autism Spectrum Disorders, demographic characteristics, family, Gauteng, gender ratio, learners, special school, case report

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Introduction

Children with Autism Spectrum Disorders (ASD) are highly prevalent, affecting approximately 1% of the global population (Richmond, 2011). Research on the prevalence of ASD has now been conducted in several countries around the globe such as Europe, United States of America and the Western Pacific (Elsabbagh et al., 2012). In contrast, Bakare and Munir (2011) reported that there are few published studies on autism in Africa.

The prevalence of children with ASD or what was previously described as Pervasive developmental disorders (PDD), in South Africa is unknown (Bateman, 2013; Springer, Van Toorn, Laughton, 2013). According to Garcia (2014) the point prevalence of children diagnosed with ASD in the United States is estimated to be 1:68. These figures suggest that there could be over 270 000 people with ASD in South Africa, with an estimated 5 000 new cases per year (Springer et al., 2013). Jacklin (2006) described similar numbers indicating an 8.2% increase in the number of children presenting with ASD features attending a developmental clinic in Gauteng over the period 1996-2005. According to Springer et al. (2013) it is also not clear in South Africa whether the increase in prevalence is related to the heightened awareness of ASD among professionals and parents, or due to the broadening of the diagnostic criteria in the year 2000. Due to possible contributing factors in South Africa such as poverty, illiteracy, the high prevalence of HIV/AIDS and tuberculosis (TB); and contextual evidence lacking (Penn, 2007; Mullis et al., 2007), the prevalence of developmental disorders, such as ASD, may be even higher than in developed countries. In order to determine the future effect of a narrowing of diagnostic criteria since 2013 (American Psychiatric Association, 2013), it is important to document existing data on children with ASD in South Africa.

According to Mubaiwa (2008) children with ASD and their families often face challenges related to management and diagnosis in South Africa. Limited provision of special needs services in formal education, as well as insufficient material resources in the educational setting in South Africa pose significant challenges that result in children not receiving the education they need (Pascoe & Norman, 2011). There are only nine dedicated public schools in South Africa for children with ASD, while an estimated 135 000 children with ASD are not receiving

the specialised education they need (Bateman, 2013). The few public schools that accommodate children with ASD are overstretched and tend to be inaccessible to the majority of children who need them (Mubaiwa et al., 2012). Public transport is generally inaccessible to children with special needs, preventing them from accessing special schools (Department of Education, 2001). These public special schools are mostly situated in urban areas, which is a further disadvantage for children from rural areas. In effect, more children may either be home schooled or placed in a typical nursery or primary school. Apart from challenges related to the accessibility to special schools, the language diversity in South Africa limits first language education for all.

In South Africa research has yet to be published to strengthen the evidence of small studies already conducted locally. Therefore, the researchers aimed to answer the following research question: Has the demographic profile of children with ASD attending a special school in Gauteng changed over the past two decades, and if so can factors be identified that have contributed to the change?

Methodology

Aim of the study

The aim of the study was to compare the learner and family characteristics of children diagnosed with ASD attending a special school in the Gauteng Province, between 1992–2002 (Group 1) and 2003–2014 (Group 2). The learners constituted the units of analysis.

Research design

A retrospective comparative design was used, comparing the demographic characteristics of learners over the two time intervals. The study is a case report as only one school was investigated.

Ethical considerations

Written permission was obtained from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria (s28024967); the Gauteng Department of Education (D2014/268), the principal of the special school for learners with ASD and informed consent was obtained from parents of the participants currently attending the school.

Setting

The special school is the largest public school for children with ASD in Gauteng Province and was established in 1973. The school is situated in an urban area and currently accommodates 111 learners between the ages three and 18 years (personal communication with school principal). Parents apply to the school for admission by completing an application form which is paper screened by the school assessment team to determine whether the child is a candidate for the school. Usually the child already has a diagnosis of ASD and is then assessed by the school's multidisciplinary team to determine in which phase the child should be placed. The team includes a speech-language therapist, occupational therapist, psychologist and sometimes a psychiatrist, who conducts approximately three weekly assessments. Children who do not have an ASD diagnosis are referred, or assessed and diagnosed by the multi-disciplinary team. There is a long waiting list at the school and a child may not be admitted directly. In such a case the child is referred to a school for children with special needs until there is an opening. Once admitted the child is placed into a specific phase according to age and level of functionality. The five phases are reception, foundation, intermediate, senior and school leaving. Each phase has two classes, one for high functioning children and one for low functioning children.

Participants

The target population of the investigation were all the learners admitted in the school from 1992-2014. Participants had to comply with the following inclusion criteria: diagnosed with ASD according to the DSM-IV (American Psychiatric Association, 1994) or DSM-IV-TR (American Psychiatric Association, 2000) and admitted at the school between 1992-2014. The first author reviewed 141 (35.5%) complete historical records in paper-based files of the total number of 397 children who were admitted in the school 1992-2014. Participants were assigned to two groups

according to the time interval that they were admitted to, Group 1 (n=32) and Group 2 (n=109). The available historical school admission records included those from the archive and the records of the current learners whose parents completed consent forms. Many records of past learners were lost, but available files contained the complete information required for the study. Convenience sampling was therefore used.

Description of the participants

General participant characteristics are depicted in Table 3.1

Table 3.1: General participant characteristics (n=141)

Characteristics	Categories	Frequency	(%)
3.1.1. AGE (MONTHS) AT SCHOOL ADMISSION (mean age = 49.5 months) (p-value = >0.235)	24-59 months	22	15.6%
	60-95 months	72	51.1%
	> 96 months	47	33.3%
	TOTAL	141	100%
3.1.2. GENDER (p-value = >0.298)	Female	15	10.6%
	Male	126	89.4%
	TOTAL	141	100

According to Table 3.1 nr 3.1.2 the prevailing gender of the sample was male. The male to female ratio in the study sample was 8.4:1. Upon further investigation the school principal confirmed the finding and added that the current male bias is even larger, with an 11.7:1 ratio. The gender disparity in our study was considerably higher than that reported by Fombonne (2005) in the epidemiologic study conducted in 14 developed countries (UK, Denmark, USA, Japan, Sweden, Ireland, Germany, Canada, France, Indonesia, Finland, Iceland, Israel and Norway) where the male to female ratio in children with ASD was 4.3:1. The male bias could merely reflect the difficulty of diagnosing ASD in females (New, Triebwasser, Charney, 2008). While classic autism would not be overlooked in females, Asperger syndrome may present as other conditions e.g. borderline personality disorder (New et al., 2008) or anorexia (Treasure, 2007). Both anorexia and borderline personality disorder includes excessively controlling people

or the environment and a degree of self-centredness (New et al., 2008; Treasure, 2007). Furthermore, Asperger syndrome might be underdiagnosed in females if they present with imitation skills or are interested to learn to adapt socially which permit them to present as normal (Holliday Willey, 1999).

Most children in the combined sample entered school between 6;0 to 7;9 years of age, with some as late as nine years. One of the reasons why children might have been admitted so late was that the school was unable to accommodate more learners and had reached its full capacity; therefore participants had to wait until there was an opening before they could be admitted.

Data gathering and data handling

The admission records included a questionnaire completed by the parents, reports from various professionals and information about the learner's school progress. During the child's assessment and interview with the parents missing information were obtained and supplemented to the questionnaire. Based on the information obtained from the parent questionnaire the researchers were able to formulate an electronic structured checklist. Relevant information was electronically captured from the parent questionnaire. To facilitate analysis the data was captured into IBM SPSS (Version 22). A data dictionary was compiled to map variables and code procedures.

Data analysis

Basic means, frequency and descriptive tables were constructed to investigate and describe distribution of the data. These results were presented in tabular and graphical format to aid interpretation. Nonparametric tests were used to identify differences between groups and explore underlying relationships amongst variables. The Pearson chi-square test of independence was employed to compare differences between study groups pertaining more specifically to learner and family characteristics of the learner. To further explore underlying linear relationships between selective variables Pearson correlation coefficients were calculated. This was done primarily due to traditional chi-square analysis not taking natural ordering of certain variables

into account (Howell, 2010). Generally, the main aim of the statistical data analysis was to first present a profile of learners and their families, and secondly to identify variables that explain the variation between the two groups. From the statistical analysis some generalisations could be presented.

Results and Discussion

Learner characteristics

Learner characteristics of the participants of Group 1 and Group 2 are illustrated in Table 3.2.

Table 3.2: Comparison of participant profiles between Group 1 (n=32) and Group 2 (n=109)

Characteristics of Participants	Categories	Frequency		(%)	
		Group 1	Group 2	Group 1	Group 2
3.2.1. AGE (MONTHS) WHEN PARENTS BECAME CONCERNED ABOUT CHILD'S DEVELOPMENT (Group 1 mean age = 48.8 months and Group 2 mean age = 52.3 months) (p-value = >0.599)	24-35months	3	6	9.4%	5.5%
	36-47 months	15	45	46.9%	41.3%
	48-59 months	6	19	18.8%	17.4%
	60-71 months	7	26	21.9%	23.9%
	> 72 months	1	13	3.1%	11.9%
	TOTAL	32	109	100%	100%
3.2.2. REASON WHY PARENTS BECAME CONCERNED ABOUT CHILD'S DEVELOPMENT (p-value = >0.705)	Delayed speech development	20	72	62.5%	66.1%
	Autistic behaviour	8	18	25.0%	16.5%
	Suspected hearing loss	1	2	3.1%	1.8%
	Speech regressed	3	15	9.4%	13.8%
	Struggling to cope academically at school	0	2	0.0%	1.8%
	TOTAL	32	109	100%	100%
3.2.3. TYPE OF DAYCARE BEFORE ADMISSION AT SPECIAL SCHOOL (p-value = >0.000)	Mother	20	19	62.5%	17.4%
	Special school	8	41	25.0%	37.6%
	Typical nursery school	3	35	9.4%	32.1%
	Typical primary school	1	11	3.1%	10.1%
	Day care centre	0	3	0.0%	2.8%
	TOTAL	32	109	100%	100%
3.2.4. AGE (MONTHS) WHEN PARTICIPANT WAS DIAGNOSED WITH ASD (DSM-IV OR DSM-IV®) (Group 1 mean age = 78.5 months and Group 2 mean age = 73.7 months)	24-59 months	4	25	12.5%	20.6%
	60-95 months	17	49	53.1%	45.0%
	> 96 months	11	35	34.4%	32.6%
	TOTAL	32	109	100%	100%

(p-value = >0.427)					
3.2.5. PARTICIPANT'S DIAGNOSIS ACCORDING TO DSM-IV® (p-value = >0.914)	Autism	28	96	87.5%	88.1%
	PDD	2	8	6.3%	7.3%
	Asperger syndrome	2	5	6.3%	4.6%
	TOTAL	32	109	100%	100%
3.2.6. OCCUPATION OF PROFESSIONAL INVOLVED IN ASD DIAGNOSIS (p-value = >0.228)	Child psychiatrist	11	30	34.4%	27.5%
	Speech-language therapist, occupational therapist, psychologist, child psychiatrist	11	28	34.4%	25.7%
	Paediatric Neurologist	9	29	28.1%	26.6%
	Paediatrician	1	14	3.1%	12.8%
	Neurologist	0	8	0.0%	7.3%
	TOTAL			100%	100%
3.2.7. OCCUPATION OF PERSON INVOLVED WITH REFERRAL TO THE SPECIAL SCHOOL (p-value = >0.107)	Parents	5	8	15.6%	7.3%
	Neurologist/ Paediatric neurologist/ Paediatrician/ Child psychiatrist/ Speech-Language therapist/ Occupational therapist/ Social worker/ General medical practitioner	22	66	68.8%	60.6%
	School support team	5	35	15.6%	32.1%
	TOTAL	32	109	100%	100%
3.2.8. AGE (MONTHS) OF PARTICIPANT AT TEAM ASSESSMENT AT SPECIAL SCHOOL (Group 1 mean age = 65.3 months and Group 2 mean age = 75.2 months) (p-value = >0.034)	24-59 months	11	23	34.4%	21.1%
	60-95 months	17	47	53.1%	43.1%
	> 96 months	4	39	12.5%	35.8%
	TOTAL	32	109	100%	100%
3.2.9. AGE (MONTHS) OF PARTICIPANT WHEN ADMITTED AT SPECIAL SCHOOL (Group 1 mean age = 72.2 months and Group 2 mean age = 78.4 months) (p-value = >0.235)	24-59 months	7	15	21.9%	13.8%
	60-95 months	18	54	56.3%	49.5%
	> 96 months	7	40	21.9%	36.7%
	TOTAL	32	109	100%	100%
3.2.10. HOME LANGUAGE (p-value = >0.122)	Afrikaans/English	26	69	81.3%	63.3%
	Other South African Languages: Tshivenda, isiZulu, Sesotho, Setswana, isiXhosa, Xitsonga	5	38	15.6%	34.9%
	Other (French, Malayalam, Ibo)	1	2	3.1%	1.8%
	TOTAL	32	109	100%	100%
3.2.11. GENDER (p-value = >0.298)	Female	5	10	15.6%	9.2%
	Male	27	99	84.4%	90.8%

	TOTAL	32	109	100%	100%
3.2.12. FIRST BORN (p-value = >0.862 for first born) (p-value = >0.480 for first born gender)	Yes	15	53	46.9%	48.6%
	No	17	56	53.1%	51.4%
	TOTAL	32	109	100%	100%
	Female	19	57	59.4%	52.3%
	Male	13	52	40.6%	47.7%
	TOTAL	32	109	100%	100%
3.2.13. SPEECH-LANGUAGE DEVELOPMENTAL HISTORY (p-value = >0.577 for verbal/ non-verbal) (p-value = >0.223 for regressed speech)	Non-verbal	6	16	18.8%	14.7%
	Verbal	26	93	81.3%	85.3%
	TOTAL	32	109	100%	100%
	No speech regression	18	48	56.3%	44.0%
	Speech regressed	14	61	43.8%	56.0%
	TOTAL	32	109	100%	100%
3.2.14. PROVINCE (p-value = >0.276)	Gauteng	24	91	75.0%	83.5%
	Other provinces (Mpumalanga, Limpopo, Western Cape, KwaZulu Natal, Northern Cape, Free State, North West)	8	18	25.0%	16.5%
	TOTAL	32	109	100%	100%

No statistical significant differences were observed when considering the age of identification of ASD symptoms between Group 1 and Group 2 (p-value = >0.599). Results in Table 3.2 nr 3.2.1 show that the mean age when parents became concerned about the development of the participant in Group 1 was 48.8 months and 52.3 months in Group 2. The majority of children in both groups (Group 1 – 46.9% and Group 2 – 41.3%), were identified by their parents between 36-47 months. Some children were identified as late as >72 months. Other studies of parental concerns indicate that the majority recognised atypical development by their child's second birthday (Baghdadli et al., 2003; Chakrabarti, 2009; Chavarska, Klin, Paul & Volkmar; 2007, De Giacomo & Fombonne, 1998; Young, Brewer, Pattison, 2003). The age at identification of ASD symptoms by parents in our cohort even differed from the age of toddlers at the State Diagnostic and Counselling Center in Iceland where parents had developmental concerns about their children before age 3 (Jónsdóttir et al., 2011). The results indicate that after 2002 participants were identified later. It appears that parents in our study may have been unaware that their child had a developmental delay and therefore unable to identify the developmental concerns early.

There were no statistical significant differences found between the groups regarding the reason why parents became concerned about the development of the participant (p-value =

>0.705). The main concern in Group 1 (62.5%) and Group 2 (66.1%) was delayed speech in the child. After 2002 more parents became concerned about their child's speech and language development than autistic behaviour. Our results correspond with De Giacomo and Fombonne (1998) who also reported that the most common parental concern was delayed speech and language development (74.4%). In our study only 25.0% of the parents in Group 1 and 16.5% of the parents in Group 2 became concerned about the presence of ASD characteristics. The failure to recognise ASD symptoms in their child is confirmed by the result about the advanced age of identification of the child. It appears that many parents in the sample were unfamiliar with ASD before their child was diagnosed. Another reason why parents became concerned was because they suspected that their child had a hearing loss (Group1 - 3.1% and Group 2 - 1.8%). Some parents reported that their child had regressed speech and that was why they became concerned (Group 1 - 9.4% and Group 2 - 13.8%). Lastly, parents seldom became concerned when their child was struggling at school (Group 1 - 0.0% and Group 2 - 1.8%).

Statistical significant differences were noted in Table 3.2 nr 3.2.3 when considering the type of day-care before being admitted at the special school (p-value = >0.000). The majority of participants in Group 1 (62.5%) stayed with their mothers before being admitted at the special school. In contrast, only 17.4% of participants in Group 2 stayed with their mothers before being admitted at the school. The result indicated that after 2002 more children went to typical nursery schools rather than staying at home with their mothers. This may be because fewer mothers stayed at home after 2002 and had to work to earn an income.

No statistical significant differences were noted when considering the age at ASD diagnosis (p-value = >0.427). The mean age at diagnosis of ASD in Group 1 was 78.5 months and 73.7 months in Group 2. According to the results the majority of participants in Group 1 (53.1%) and Group 2 (45.0%) received an ASD diagnosis at age 60-95 months. Some children were diagnosed with ASD as late as >96months. After 2002 the age of diagnosis for participants in the sample decreased slightly. Results in our study are different from the findings of a population-based study from 13 sites in the United States which revealed that the median age of ASD diagnosis was 68.4 months (Shattuck et al., 2009). Furthermore, the age of ASD diagnosis differs from the study by Springer et al. (2013) in the Western Province where the mean age at

ASD diagnosis was 42 months. Possible explanations for the late age of diagnosis might be because of limited awareness of developmental disorders such as autism, limited services and schools available in South Africa for children, and limited space in designated schools.

The entire sample of participants was described according to the features listed on the DSM-IV (American Psychiatric Association, 1994) and DSM-IV-TR (American Psychiatric Association, 2000). No statistical significant differences were observed when considering the type of ASD diagnosis between Group 1 and Group 2 (p-value = >0.914). The majority of participants (Group 1 – 87.5% and Group 2 – 88.1%) were classified as having autism. It appears that the two different editions of the classification system used to diagnose the participants, did not result in a difference in the type of ASD in the participants. The result may also indicate that the admission criteria at the school stayed consistent over the 22 years.

There were no statistical significant differences observed between the two groups when considering the occupation of the professional who made the ASD diagnosis (p-value = <0.228). Fewer participants in Group 1 (3.1%) than in Group 2 (12.8%) were diagnosed by a paediatrician. The results indicated that after 2002 more participants were diagnosed by paediatricians and fewer by child psychiatrists, paediatric neurologists and multidisciplinary teams. The reason why more diagnoses were made by paediatricians could be due to increased awareness of ASD among paediatricians and an increase in paediatricians practicing in the city where the school is located. The results differ from a study conducted at a Child Neuropsychiatry Clinic in Sweden by Anderson, Gilberg and Miniscalco (2013) who reported that comprehensive clinical assessments were primarily conducted by a multidisciplinary team that included a psychologist, neurologist, psychiatrist, speech-language therapist, or other professionals who diagnose children with ASD. In our study there appears to be a move away from team-based diagnostic assessments, implying that the assessments may not be as comprehensive as described in the literature.

No statistical significant differences were observed when considering the profession of the person who made the referral to the special school (p-value = >0.228). More participants in Group 1 (68.8%) than in Group 2 (60.6%) were referred to the special school by neurologists,

paediatric neurologists, paediatricians, child psychiatrists, speech-language therapists, occupational therapists, psychologists, social workers and general medical practitioners. The results in Table 3.2 nr 3.2.7 indicated that participants who were referred to the school after 2002 were referred less by professionals and more by school support teams. School support teams were only instituted since 2001 by the Department of Education and are perhaps now functioning more than in the past (Department of Education, 2001). Some of the professionals who referred the participants to the special school were the same as those who made the ASD diagnosis. The reason why more participants were referred to the special school by health professionals might be as a result of their increased awareness of ASD symptoms and where the special school is situated.

Statistical significant differences were noted between Group 1 and Group 2 when considering the age at assessment at the special school (p-value = >0.034). The mean age of assessment at the special school in Group 1 was 65.3 months and 75.2 months in Group 2. Furthermore proportional differences were noted between Group 1 (12.5%) and Group 2 (35.8%) at age of assessment (>95 months) at the school. The result indicated that participants assessed after 2002 were on average older, and much older than children in developed countries. Our results are in sharp contrast with a study in Atlanta, which reports that the median age at assessment for children with ASD was 48 months (Wiggins, Biao, Rice, 2006). Nor do the results from our study correspond with the study by Springer et al. (2013) who found that the median age at assessment in the study was 56 months. Different factors could have contributed to an increase in age of assessment, such as a long waiting list at the school.

The South African Schools Act (Department of Education, 1996) allows the School Governing Body of learners with special education need (LSEN) schools to develop their own Admission Policies. The Governing Body of the school where the research was conducted, developed an own admission policy which stipulates that learners may be admitted throughout the year and may also be admitted for a trial period of a few months. As learners leave classes an opening becomes available and the opening may be filled with another learner of that age and functionality. No statistical significant differences were noted between Group 1 and Group 2 at age of admittance at the special school (p-value = >0.235). More participants in Group 1 (21.9%)

and Group 2 (36.7%) were admitted at the school at the advanced age of >96 months. While not significant, when further exploring the underlying linear relationship of age of participant at school admittance, a similar trend (as with age at assessment) was observed. Similar to the result about the age of assessment at the school, children admitted after 2002 were on average older than before 2002. As reported by Bateman (2013) there are only nine dedicated public schools in South Africa for children with ASD, therefore children with ASD might not be admitted early as the few schools that can accommodate them are either overstretched or inaccessible. The late concern about the child's development by parents appears to have a knock-on effect on the child's age at diagnosis, assessment and admission to the school.

Although no statistical significant differences were found when comparing the home language of participants between Group 1 and Group 2 (p-value = >0.122), proportional differences were noted when considering the African languages spoken by the participants in Group 1 (15.6%) and Group 2 (34.9%). Furthermore, results indicated that more participants in Group 1 (81.3%) and fewer in Group 2 (63.3%) spoke Afrikaans and English at home. The results showed a change in the profile of the school after 2002; more participants were from African language speaking families, with a decrease in participants with Afrikaans/English as home language. There was an increase in African language speaking children in the school which most probably reflects the democratic change in the country. It is positive to see that the school is now providing education to the diversity of children in South Africa. The home languages spoken represent the demographic profile of the participants in the special school. The changes across the two periods appear to relate to environmental changes, in particular political changes in the country.

No statistical significant differences were found when considering the gender of the participants in Group 1 and Group 2 (p-value = >0.298). The prevailing gender of Group 1 (84.4%) and Group 2 (90.8%) were males, as already indicated in Table 3.1 as a salient characteristic of the study sample. However, upon further analysis the results indicated that the male to female gender ratio in the study was 5.4:1 in Group 1 and 9.9:1 in Group 2. Over the two periods the gender bias increased. The male gender bias is much higher than reported in a tertiary hospital developmental clinic in the Western Cape Province (3.8:1) by Springer et al. (2013) and

in a tertiary hospital clinic in KwaZulu-Natal (2.8:1) by Mubaiwa et al. (2012). The large gender bias in the sample cannot be explained and further research is required to investigate the reasons why the school has had more boys than girls over the years.

No statistical significant differences were noted between the groups when considering whether the participant was the first born (p-value = >0.862). According to Fountain et al. (2011) 42% of children with ASD, from a clinical sample in California, were first born. In contrast, our results indicated that that more participants from both groups (Group 1 - 53.1% and Group 2 – 51.4%) were first born. Furthermore, no statistical significant differences were noted regarding the gender of the first born (p-value = >0.480). More participants in Group 1 (59.4%) than in Group 2 (52.3%) were first born females. Similar trends were observed between both groups when considering being the first born and the gender of the first born. The results indicated that the first born and the gender of the first born in the sample stayed the same over 22 years.

Table 3.2 nr 3.2.13 shows some aspects of the speech-language developmental history of the participants. No significant differences were noted with participants being verbal (p-value = >0.577) or having had regressed speech (p-value = >0.223) upon admission at the school. The majority of participants in Group 1 (81.3%) and Group 2 (85.3%) were primarily verbal, and 43.8% of Group 1 and 56.0% of Group 2 had regressed speech. The results indicated that the majority of participants were verbal when they entered school over the 22 year period, but more participants after 2002 had regressed speech. Our results differ with that of Springer et al. (2013) where 72.4% of the preschool participants in the Western Cape were non-verbal and 17.2% had regressed speech. However, results from our study correspond with an on-going population-based case-control study in California by Hansen, Ozonoff and Krakowiak (2008) who reported that up to 40% of children with ASD experience regressed speech.

The province of residence between Group 1 and Group 2 were very similar, hence, no significant differences were noted (p-value = >0.276). The majority of participants in Group 1 (75.0%) and Group 2 (83.5%) resided in the Gauteng province. According to the results in Table 3.2 nr 3.2.14 after 2002 more participants resided in the Gauteng Province than in the other provinces in South Africa. The Census of 2011 indicated that 12.2 million people reside in the

Gauteng Province (Statistics South Africa, 2011). Since 2001 there has been a 6.4% increase in the population in the Gauteng Province. This is consistent with our finding where the majority of both groups resided in the Gauteng province. A global increase in children diagnosed with ASD, the establishment of schools in other provinces and a population increase in the school's feeder province might be some of the reasons for the increase in participants who resided in the Gauteng Province.

In summary, it appears that many of the learner characteristics of the participants remained stable over the 22 years reported in the study, although the school increased the number of intake per year. The advanced age of participants at the diagnosis of ASD, type of ASD diagnosis, male dominance of participants, gender of the participants who were first born in their families, verbal communication of the participants and the residence in Gauteng province remained the same. Important differences between the two periods can be seen in the type of school before admission at the special school, increased age when assessed at the school, diversity of home languages and age of school entry after 2002. During the later time interval, fewer participants stayed at home with their mothers and were assessed and admitted later at the school. Lastly, the participants represented a great diversity in home languages in recent years.

Family characteristics of the learners

The family characteristics of the learners are illustrated in Table 3.3

Table 3.3: Comparison of family characteristics between Group 1 (n=32) and Group 2 (n=109)

Characteristics of the participant's family	Categories	Frequency		(%)	
		Group 1	Group 2	Group 1	Group 2
3.3.1. NUMBER OF CHILDREN IN FAMILY (p-value = >0.545)	Single child	6	26	18.8%	23.9%
	Siblings	26	83	81.3%	76.1%
	TOTAL	32	109	100%	100%
3.3.2. FAMILY HISTORY OF DISABILITIES OR CONDITIONS (p-value = >0.466)	Yes	4	9	12.5%	8.3%
	No	28	100	87.5%	91.7%
	TOTAL	32	109	100%	100%
3.3.3. FATHER'S AGE (YEARS) WHEN CHILD WAS CONCEIVED	20-29	15	35	46.9%	32.1%
	30-34	7	36	21.9%	33.0%
	35-39	8	30	25.0%	27.5%

(Group 1 mean age = 30.7 years Group 2 mean age = 32.1 years) (p-value = >0.452)	40-50	2	8	6.3%	7.3%
	TOTAL	32	109	100%	100%
3.3.4. FATHER'S QUALIFICATIONS (17 missing values - *dead, not involved) (p-value = >0.963)	GR 9/10	1	2	3.7%	2.1%
	Matric	9	37	33.3%	38.1%
	Degree	12	38	44.4%	39.2%
	Diploma/certificate	3	11	11.1%	11.3%
	Postgraduate	2	9	7.4%	9.3%
	TOTAL	27	97	100%	100%
3.3.5. FATHER'S SOCIAL CLASS ACCORDING TO OCCUPATION (17 missing values - *dead, not involved) (p-value = >0.266)	A/B	15	41	55.6%	42.3%
	C	11	43	40.7%	44.3%
	D/E	1	13	3.7%	13.4%
	TOTAL	27	97	100%	100%
3.3.6. MARITAL STATUS OF MOTHER (p-value = >0.420)	Single	6	28	18.8%	25.7%
	Married	26	81	81.3%	74.3%
	TOTAL	32	109	100%	100%
3.3.7. MOTHER'S AGE WHEN CHILD WAS CONCEIVED (Group 1 mean age = 28.2 years Group 2 mean age = 28.8 years) (p-value = >0.420)	20-29	20	57	62.5%	52.3%
	30-34	9	37	28.1%	33.9%
	35-39	1	15	3.1%	13.8%
	40-50	2	0	6.3%	0.0%
	TOTAL	32	109	100%	100%
3.3.8. MOTHER'S QUALIFICATIONS (1 missing value - *dead, not involved) (p-value = .>0.401)	GR 9/10	1	1	3.1%	0.9%
	Matric	17	45	53.1%	41.7%
	Diploma/Certificate	10	34	31.3%	31.5%
	Degree	4	23	12.5%	21.3%
	Postgraduate	0	5	0.0%	4.6%
	TOTAL	32	108	100%	100%
3.3.9. MOTHER'S SOCIAL CLASS ACCORDING TO OCCUPATION (1 missing value - *dead, not involved -) (p-value = >0.041)	A/B	4	29	12.5%	26.9%
	C	9	41	28.1%	38.0%
	D/E	19	38	59.4%	35.2%
	TOTAL	32	109	100%	100%

Results in Table 3.3 nr 3.3.1 shows that no statistical significant differences were noted between Group 1 and Group 2 when considering whether the participant had siblings or was a single child (p-value = >0.545). The majority of participants in Group 1 (81.3%) and Group 2 (76.1%) had siblings. The results on the number of children in the families therefore stayed the same over 22 years. According to Ozonoff et al. (2011) having an older biological sibling with ASD increases the recurrence rate of ASD. The results may indicate that parents were not aware of the risk of ASD recurrence in siblings and therefore did not halt reproduction after diagnosis of their affected first born child (Ozonoff et al., 2011). As already indicated, most parents in our sample did not recognise ASD symptoms in their child before diagnosis.

No statistical significant differences were observed with the family history of disabilities or conditions (p-value = <0.466) between Group 1 and Group 2. There were a few participants in Group 1 (12.5%) and Group 2 (8.3%) who reported a family history of disabilities or conditions, such as psychological disorders, language disorders, ASD and epilepsy. After 2002 fewer families reported histories of disabilities or conditions. Our results do not agree with the South African study by Springer et al. (2013) who found that 34.4% of the participants had a family history of conditions or disabilities.

No statistical significant differences were found when considering the age of the father when child was conceived between Group 1 and Group 2 (p-value = >0.452). The mean age of the father when child was conceived in Group 1 was 30.7 years and 32.1 years in Group 2.

Although no statistically significant differences were found (p-value = >0.963) regarding the qualifications of the fathers, as 44.4% of the fathers in Group 1 and 39.2% of the fathers in Group 2 had a degree. The results showed that after 2002 fewer fathers obtained a degree. Fountain et al. (2011) stated that children with more educated parents are diagnosed earlier with ASD. An increased awareness of different help-seeking strategies, developmental delays and improved ability to gain early access to professionals can be ascribed to parents being educated (Laughton et al., 2010).

Social class was determined by grading the occupation of the participants' parents by using the National Readership Survey 'ABC1' demographic profiling system, also known as the social grade definitions (http://www.businessballs.com). Although no statistically significant differences were observed (p-value = >0.266), more fathers in Group 1 (55.6%) than in Group 2 (42.3%) were from social class A (upper class, i.e. high managerial, administrative or professional) or B (middle class, i.e. intermediate managerial, administrative or professional) families. The results in Table 3.3 nr 3.3.5 show that after 2002 fewer fathers were from social class A (upper class)/ B (middle class) and more were from social class C (lower middle class or skilled manual workers) or D (working class) or E (unemployed). A study conducted by Fountain et al. (2011) investigated individual and community level factors associated with ASD

in children across 10 birth cohorts in California. The researchers found that children from high socio-economic status (SES) were diagnosed earlier than children from low SES (Fountain et al., 2011). Our results do not correspond with Fountain et al. (2011) as the age at diagnosis of ASD was not early, and after 2002 there was an increase in fathers who were from social class D (working class) and E (unemployed).

The marital status of the mothers of the participants in Group 1 (81.3%) and Group 2 (74.3%) were primarily married, therefore no statistically significant differences were noted (p-value = >0.420). The results indicated that after 2002 fewer mothers were married. The results suggest that more learners in recent years were being raised by a single parent, usually a mother.

According to the results a statistically significant difference between Group 1 and Group 2 were noted when considering the age of the mother when child was conceived (p-value = >0.019). The mean age of the mother when child was conceived in Group 1 was 28.2 years and 28.8 years in Group 2. Furthermore, results indicated that less participants in Group 1 (3.1%) than in Group 2 (13.8%) had mothers who were 35-50 years at the time when they were conceived. A recent cohort study conducted by Durkin et al. (2008) in the United States found that the odds of developing ASD was significantly reduced for parental age <20 and increased for maternal age >35. The results in our study suggest that after 2002 mothers were on average older and therefore might be at risk of having children with ASD.

Although no statistically significant differences were observed with the qualification of the mother (p-value = <0.401), an educational level of senior school certificate (matric) was documented in 53.1% of mothers in Group 1 and 41.7% of mothers in Group 2. Upon further analysis of the underlying linear relationship of the qualification of the mother and the year the child was admitted, statistical significant differences were noted (p-value = <0.059). The results showed that after 2002 fewer mothers obtained their senior school certificate (matric) and that the qualification of the mother had an influence on the year the participant was admitted at the school. The father's educational level was also lower during this time period.

More mothers in Group 1 (59.4%) and Group 2 (35.2%) were from social class D (working class) or E (unemployed) families. According to the results there was a statistical significant difference when considering the social class of the mother. After 2002 more mothers were from social classes A (upper middle class) or B (middle class) and C (lower class/skilled working class). Although the social class of the mothers were relatively high, the participants were not diagnosed earlier. Therefore our results do not agree with Fountain et al. (2011) who found that children from high socio-economic status (SES) were diagnosed earlier, than children from low SES. When considering the mothers' lower educational level after 2002 than before, the result of an increase in social class in mothers after 2002 appears to be surprising. Further research is required to explain the result.

In summary, it appears that many of the family characteristics of the learners remained stable over the 22 years reported in the study. Having a sibling or being the only child and having family history of conditions or disabilities remained the same. Important differences between the two periods can be seen in the qualification the mother obtained and the year child was admitted at the special school, the age of the mother at birth of the participant and the social class of the mother according to her occupation. During the later time interval mothers were older at the birth of the participant and more mothers were from the upper middle class or middle class, yet less educated. Lastly, the low qualification of the mother seems to have an influence on the advanced age when the child was admitted at the school.

Conclusion

The following critical evaluation remarks on the research process can be stated: The researchers chose a retrospective comparative design, comparing the demographic characteristics of learners over the two time intervals. By using this design, the researchers were able to add local knowledge about the demographic characteristics of children with ASD in South Africa. The study limitations should be mentioned. First, the researchers collected all the data from only one school in the Gauteng Province, which limits generalisability to other locales. Only 35% of the population of learners educated over 22 years at the special school could be sampled. The researchers relied solely on secondary data from the historical school admission records. Data was therefore abstracted from historical admission records which were not validated against

direct contact and observations. Finally, data on some variables were missing for a portion of the sample.

In conclusion, in this case report the increase in the number of learners admitted at the school per year indicated that there was an increase in the number of children diagnosed with ASD in South Africa. It is concerning that ASD diagnoses in recent years among the school children were increasingly conducted by single professionals, whereas the trend in developed countries is a large and diverse multidisciplinary team. The great variety of home languages spoken by the learners in the second time period reflects the increased cultural diversity in the school. It is positive to see that the school is now providing education to children with ASD from many different backgrounds in South Africa. The data serves as a point of reference for future studies on the characteristics of school children with ASD in South Africa.

CHAPTER 4

4. ADDITIONAL DISCUSSION AND CONCLUSION

4.1 Discussion of results

This was the first known study to describe the changed demographic profile of children with ASD attending a special school in Gauteng Province, South Africa. There was an increase in learners admitted to the school over the two time periods of the study period. Furthermore, the study identified important factors that have contributed to the changed demographic profiles of the learners with ASD over two time periods. The type of day-care before admission at the special school, increased age when assessed at the school, increased diversity of home languages and increased age of school entry after 2002 were factors that changed significantly over the two time periods.

The results of the family characteristics of the learners indicated that the qualification of the mother, the year that the child was admitted at the special school, the age of the mother at birth of the participant and the social class of the mother (according to her occupation) contributed to change over the two time periods.

One factor that remains surprising and unexplained is the male bias in the study sample. The male bias in participants increased over the two time periods. The male bias (8.4:1) in the study was also considerably higher than that reported by Fombonne (2005) in the epidemiologic study conducted in fourteen developed countries (UK, Denmark, USA, Japan, Sweden, Ireland, Germany, Canada, France, Indonesia, Finland, Iceland, Israel and Norway) where the average male to female ratio in children with ASD was 4.3:1.

The research question on whether the demographic profile of children with ASD attending the special school changed over the past two decades could therefore be answered. Certain characteristics of the participants and their families remained the same, while many changes took place over the two time periods.

Apart from the findings of the study, the advantages and disadvantages of a retrospective study should also be mentioned. According to Leedy and Ormrod (2010), there are a number of advantages associated with retrospective research studies, such as studies can be conducted on a small scale, multiple outcomes can be analysed and the study is normally less time consuming than prospective research studies. The researcher reviewed 141 complete historical admission records, and was able to collect all the data needed for the research from the special school within a reasonable amount of time. Furthermore, it was possible to analyse key learner and family characteristics of the learners from the two time intervals.

However, the disadvantages to retrospective research studies should also be noted. There may be significant biases which may influence the selection process, some statistics are immeasurable and the researcher solely relies on the accurate record-keeping of others (Leedy & Ormrod, 2010). Since convenience sampling was chosen as the sampling method, there might have been significant bias, as the sample was not representative of the ASD population in special schools in South Africa. The total number of files included in the study was too few; therefore random selection of the records could not take place. Additionally, the researcher relied solely on the information within the historical admission records, which limited the data obtained.

4.2 Clinical and future research implications

Limited research has been published about the demographic characteristics of children with ASD in South Africa. Describing the profiles of learners from a school for children with ASD has contributed to local knowledge in the field. The clinical implications of the study are discussed according to the results:

- The results indicated that no statistical significant differences were observed when considering the age of identification of developmental concerns between Group 1 and Group 2. The results indicated that, after 2002, participants were identified slightly, but not significantly later. The majority of children over the two groups were identified after four years, which indicates late identification and past the ideal age

for effective early intervention. Although no statistical differences were noted when considering the age of identification of developmental concern, a replication of this type of analysis in special schools for children with ASD across South Africa would tell us if the age of identification of developmental concerns are typical. Fountain et al. (2011) reported that the increased public awareness of ASD has an influence on increased and earlier diagnosis. Raising public awareness of the early symptoms of ASD factor in infants and toddlers in South Africa may therefore assist to identify children with ASD earlier than in the present study. Despite increasing evidence that ASD can be identified and diagnosed accurately in very young children, the age of diagnosis on average, remains delayed (Lord et al., 2006; Sansosti et al., 2012). The most important consequences of delayed diagnosis of ASD in children may imply missed early intervention opportunities during the period of high neuroplasticity (Manning-Courtney et al., 2003). Delayed diagnosis may also result when children present with mild degrees of ASD which may not be easily identifiable (Manning-Courtney et al., 2003). The late identification of the participants' ASD symptoms in this study meant that the age of an ASD diagnosis was even later.

- The mean age at diagnosis of ASD in Group 1 was 78.5 months and 73.7 months in Group 2. No statistical significant differences were noted when considering the age at ASD diagnosis. According to the results the majority of participants in Group 1 and Group 2 combined received an ASD diagnosis at age 60 to 95 months. Some children were diagnosed with ASD as late as >96 months. After 2002, the age of diagnosis for participants in the sample decreased slightly, but remained unacceptably high. Results in the present study are different from the findings of a population-based study from thirteen sites in the USA which revealed that the median age of ASD diagnosis was 68.4 months (Shattuck et al., 2009). Furthermore, the age of ASD diagnosis differs from the study by Springer et al. (2013) in the Western Cape Province where the mean age at ASD diagnosis was 42 months. Possible explanations for the late age of diagnosis might be because of limited awareness of developmental disorders such as autism and limited services and schools available in South Africa for children. The factors contributing to late diagnosis of ASD in South Africa should be investigated in the future so that targeted

community interventions can be implemented to lower the age of diagnosis in children with ASD.

- There were no statistical significant differences found between the groups regarding the reason as to why parents became concerned about the development of the participant. Results showed that the main concern in both groups was delayed speech in the child. The current results correspond with De Giacomo and Fombonne (1998) who also reported that the most common parental concern was delayed speech and language development (74.4%). The clinical implication of the finding is that speech-language therapists are key role players in early intervention service provision to families with young children with ASD.
- The entire sample of participants was described according to the features listed on the DSM-IV (American Psychiatric Association, 1994) and DSM-IV-TR (American Psychiatric Association, 2000). No statistical significant differences were observed when considering the type of ASD diagnosis between Group 1 and Group 2. The majority of participants in both groups were classified as having autism. Not many learners were diagnosed with PDD or Asperger syndrome. It appears that the two different editions of the classification system used to diagnose the participants did not result in a difference in the type of ASD diagnosis in the participants. Children with Asperger syndrome are considered high functioning, and may be included in mainstream education. Children with PDD may have been considered too low functioning for academic education (American Psychiatric Association, 2013). The result may also indicate that the admission criteria at the school stayed consistent over the 22 years. In future, research should be conducted to determine the influence of the changed diagnostic criteria of the DSM-5 (American Psychiatric Association, 2013) on children with ASD across South Africa.
- When considering the occupation of the professional who made the ASD diagnosis, no statistical significant differences were observed between the two time periods. The results indicated that after 2002, more participants were diagnosed by paediatricians only and fewer by child psychiatrists, paediatric neurologists and multi-disciplinary teams. The results differ from a study conducted at a Child Neuropsychiatry Clinic in Sweden by Anderson et al. (2013). These authors reported

that comprehensive clinical assessments were primarily conducted by a multi-disciplinary team that included a psychologist, neurologist, psychiatrist, speech-language therapist, or other professionals who diagnose children with ASD. Future research should investigate whether children are diagnosed with ASD more by single professionals than by multi-disciplinary teams in South Africa. Extensive assessments which include genetic analysis are currently recommended before the diagnosis of ASD is reached in Canada (Anagnostou et al., 2014). Although genetic analysis is not feasible for every child with ASD in South Africa, multi-disciplinary assessments including speech-language and audiological assessments are strongly recommended.

- More participants in Group 1 than in Group 2 were referred to the special school by neurologists, paediatric neurologists, paediatricians, child psychiatrists, speech-language therapists, occupational therapists, psychologists, social workers and general medical practitioners. The results indicated that participants who were referred to the school after 2002 were referred less by professionals and more by school support teams. The reason why more participants were referred to the special school by health professionals might because this school is one of the few schools in the Gauteng Province that provide special needs education for children with ASD. The reasons why fewer participants in Group 2 were referred to this specific special school by health professionals should be determined, and whether this trend can be observed in other schools for children with ASD as well. Such data may point out targeted awareness-raising among professionals who may contribute to early identification and diagnosis of children with ASD in South Africa.
- The mean age of assessment at the special school in Group 1 was 65.3 months and 75.2 months in Group 2. The increase in age is concerning, as opportunities for timely educational and therapeutic intervention for learners in the school are decreasing. The results indicated that participants assessed after 2002 were on average older, and much older than children in developed countries. The current results are in contrast with a study in Atlanta, USA, which found that the median age at assessment for children with ASD was 48 months (Wiggins et al., 2006). The present results also differ from the study by Springer et al. (2013) in the Western

Cape Province. These authors found that the median age at assessment in the study was 56 months. Different factors could have contributed to an increase in age of assessment, such as a long waiting list at the school. However, these factors have not yet been established in South Africa and should be determined with future research.

- More participants in Group 1 and Group 2 were admitted to the special school at the advanced age of >96 months. While not significant, when further exploring the underlying linear relationship of age of participants at school admittance, a similar trend (as with age at assessment) was observed. Similar to the result about the age of assessment at the school, children admitted after 2002 were, on average, older than before 2002. As reported by Bateman (2013), there are only nine dedicated public schools in South Africa for children with ASD. Therefore, children with ASD might not be admitted early as the few schools that can accommodate them are either overstretched or inaccessible. Establishing more special schools for children with ASD in South Africa may relieve the pressure on the few existing special schools for children with ASD.
- Although no statistical significant differences were found when comparing the home language of participants between Group 1 and Group 2, proportional differences were noted when considering the African languages spoken by the participants in Group 1 and Group 2. Furthermore, results indicated that more participants in Group 1 and fewer participants in Group 2 spoke Afrikaans and English at home. The results showed a change in the profile of the community after 2002; more participants were from African language speaking families, with a decrease in participants with Afrikaans/English as home language. There was an increase in African speaking children in the school which reflects the democratic change in the country. It is positive to see that the school is now providing education to the diversity of children in South Africa. The home languages spoken represent the demographic profile of the participants in the special school. The changes across the two periods appear to relate to environmental changes and, in particular, political changes in the country. Future research should be conducted in special schools across South Africa to determine the home languages spoken by children with ASD,

and to determine whether more children with ASD are Afrikaans, English or speakers of an African language.

- The prevailing gender of Group 1 and Group 2 were males. The male gender bias is much higher than reported in a tertiary hospital developmental clinic in the Western Cape Province (3.8:1) by Springer et al. (2013) and in a tertiary hospital clinic in Kwa-Zulu Natal Province (2.8:1) by Mubaiwa et al. (2012). The two studies appear to be the only studies which reported on the gender ratio of children with ASD in South Africa. The large gender bias in the sample cannot be explained and further research is required to investigate the reasons why the special school has had increasingly more boys than girls over the years.
- Fountain et al. (2011) reported that 42% of children with ASD, from a clinical sample in California, were first born. In contrast, our results indicated that that more participants from both groups were first born. Furthermore, more participants in Group 1 than in Group 2 were first born females. Similar trends were observed between both groups when considering being the first born and the gender of the first born. The results indicated that the first born and the gender of the first born in the sample stayed the same over twenty two years. Future research should be conducted to determine if our results regarding first born and gender of the first born are similar to children with ASD in other special schools across South Africa, in order to understand if there is a trend in the family composition of children with ASD. Another aspect of family composition involved the number of siblings that the participants had.
- The majority of participants in Group 1 (81.3%) and Group 2 (76.1%) had siblings. The results on the number of siblings in the families, therefore, stayed the same over 22 years. According to Ozonoff et al. (2011), having an older biological sibling with ASD increases the recurrence rate of ASD. Since most of the participants had siblings, it is clear that the parents were not aware of the risk of recurrence rate of ASD in siblings and, therefore, did not halt reproduction after diagnosis of their affected first born (Ozonoff et al., 2011). Parents with a child with ASD should be counselled by health professionals about the risk of recurrence rate of ASD in siblings.

- Some aspects of the speech-language developmental history of the participants were investigated in the study. The results indicated that the majority of participants were verbal when they entered school over the twenty two year period, but more participants after 2002 had regressed speech. Our results differ with that reported by Springer et al. (2013) where a very high number (72.4%) of pre-school participants in the Western Cape Province were non-verbal and 17.2% had regressed speech. However, results from our study correspond with an on-going, population-based case-control study in California by Hansen et al. (2008) which reported that up to 40% of children with ASD experienced regressed speech. Future research should investigate in-depth aspects of the speech-language developmental history of children with ASD in South Africa.
- There were a few participants in both groups who reported a family history of disabilities or conditions, such as psychological disorders, language disorders, ASD and epilepsy. After 2002, fewer families had histories of disabilities or conditions. The present results stand in contrast with the South African study by Springer et al. (2013) who found that 34.4% of the participants had a family history of conditions or disabilities. Further research should be conducted to determine if our results regarding family history of disabilities or associated conditions are representative of children with ASD across South Africa.
- When considering the age of the father at the birth of participants between Group 1 and Group 2, no statistical significant differences were found. The mean age of the father at birth of the participant in Group 1 was 30.7 years and 32.1 years in Group 2. The age of the father at birth of the child with ASD should be investigated in larger studies in the future to determine if our results are representative of fathers with children with ASD. The mean age of mothers at the birth of the participants also did not change significantly over the two time periods.
- The mean age of the mother at birth of the participant in Group 1 was 28.2 years and 28.8 years in Group 2. Furthermore, results indicated that less participants in Group 1 than in Group 2 had mothers who were 35 to 50 years at the time of their birth. A recent cohort study conducted by Durkin et al. (2008) in the USA found that the odds of developing ASD were significantly reduced for parental age <20 and

increased for maternal age >35. The results in our study suggest that after 2002, mothers were, on average, older and, therefore, might be at risk for having children with ASD. Shattuck et al. (2009) reported that delayed identification and diagnosis of ASD was associated with younger maternal age at the birth of the child. The reason may be that younger mothers may not have adequate knowledge of ASD; hence they are unable to recognise developmental concerns (Shattuck et al., 2009). Future research in South Africa should determine whether our results regarding the age of the mother at birth of children with ASD are similar to mothers with children diagnosed with other developmental disabilities.

- When considering the qualifications of the father, our results showed that, after 2002, fewer fathers obtained a degree. Fountain et al. (2011) stated that children with more educated parents are diagnosed earlier with ASD. An increased awareness of different help-seeking strategies, developmental delays and improved ability to gain early access to professionals can be ascribed to parents being educated (Laughton et al., 2010). In the future, the qualifications of fathers with children with ASD should be researched in South Africa to determine whether our results are representative. Based on many results of the present study, a recurring recommendation is raising awareness among the public of the early symptoms of ASD in a child. However, this should be done with caution so as not to alarm the general public. A similar downward trend in mothers' qualifications was observed.
- The results showed that, after 2002, fewer mothers obtained their senior school certificate (Matric) and that the qualification of the mother has an influence on the year the participant was admitted to the school. Shattuck et al. (2009) noted that delayed diagnosis was particularly associated with lower maternal education. In the future, the qualification of the mother of children with ASD in South Africa should be investigated.
- The results show that after 2002, fewer fathers were from social A (upper class) or B (middle class) and more were from social class C (lower middle class or skilled manual workers) or D (working class) or E (unemployed). A study conducted by Fountain et al. (2011) investigated individual and community level factors associated with ASD in children across ten birth cohorts in California. The researchers found

that children from a high socio-economic status (SES) were diagnosed earlier than children from a low SES (Fountain et al. 2011). Our results do not correspond with Fountain et al. (2011) as the age at diagnosis of ASD was not early, even though the fathers were from A or B social classes.

- According to the results, there was a statistically significant difference when considering the social class of the mother. The findings related to the social class of the mother were similar to that of the father where after 2002, fewer mothers and fathers were from social A (upper class) or B (middle class). However, with regard to the lower social class, the results differed as more fathers were from social class C (lower middle class or skilled manual workers), D (working class) or E (unemployed) and more mothers from social class C (lower class/skilled working class). Although the social class of the mothers was relatively high, the participants were not diagnosed earlier. Therefore, our results do not correlate with Fountain et al. (2011) who found that children from a high SES were diagnosed earlier, than children from a low SES. Further research should be conducted regarding the characteristics of social class of mothers and fathers of children with ASD.
- The marital status of the mothers of the participants in both groups was primarily married. The results indicated that after 2002, fewer mothers were married. The results suggest that more learners are being raised by a single parent, usually a single mother in recent years. Marital status of parents with children with ASD in South Africa should be investigated in future research. Single parentship may indicate a need for additional support when a child has ASD.

4.3 Strengths and limitations of the study

4.3.1 Strengths of the study

- The researcher chose a retrospective comparative design, comparing the demographic characteristics of learners and their families over the two time intervals. By using this design, the researcher was able to add knowledge about the demographic characteristics of children in South Africa with ASD in a single case report.

- Some results in the present study differed from similar studies in developed countries, and revealed a unique situation in South Africa, which warrants detailed further investigation. The most important unique characteristic was the large male gender bias. Other characteristics, which differ from children with ASD in developed countries, warrant direct action. These challenging characteristics include the late age of identification, diagnosis, assessment and school admission of the participants in the study.
- Limited research has been published about the demographic characteristics of children with ASD in South Africa. Therefore, the researcher was able to contribute baseline data for future research.

4.3.2 Limitations of the study

- All the data used for the research study was collected from only one school in the Gauteng Province, which limits generalisability of the results to other locales.
- The researcher relied solely on secondary data from the school's historical admission records. Therefore, data was abstracted from historical admission records which were not validated against direct contact and observations.
- A limitation was the convenience sampling technique due to the small number of complete school records. Randomised selection of records would have assured a representative sample of the school population over the years.
- Data on some variables was missing for a portion of the sample, but did not have an influence on the statistical analysis and results.
- Only 141 participants were selected for the study. A larger number of participants would have increased the representativeness of the sample. As a result of missing files and a number of parents not providing informed consent, the sample was small.

4.4 Conclusion

In conclusion, Mubaiwa (2008) stated that children with ASD and their families often face challenges related to management and diagnosis in South Africa. The same

challenges are also faced by families elsewhere. Despite increasing evidence that ASD can be identified and diagnosed accurately in young children, the age of diagnosis on average, remains delayed (Lord et al., 2006; Sansosti et al., 2012). The most important consequences of delayed diagnosis of ASD in children may imply missed early intervention opportunities during the period of high neuroplasticity (Manning-Courtney et al., 2003). The limited provision of special needs services in formal education, as well as the insufficient material resources in the educational setting in South Africa, pose significant challenges that result in children not receiving the education they need (Pascoe & Norman, 2011). There are only nine dedicated public schools in South Africa for children with ASD, which means that an estimated 135 000 children with ASD are not receiving the specialised education they need (Bateman, 2013). These public special schools are mostly situated in urban areas, which is a further disadvantage for children in rural areas. In effect, more children from rural areas may either be home-schooled or placed in a typical nursery or primary school than those in cities (Attwood, 2006). Therefore, the children are not prepared for the specialised school setting and unable to reach their full potential. Therefore, the special school selected in this study is an extremely valuable educational asset in Gauteng to parents of children with ASD.

5. REFERENCES

Anagnostou, E., Zwaigenbaum, L., Szatmari, P., Fombonne, E., Bridget, A., Fernandez, B., Woodbury-Smith, M., Brian, J., Bryson, S., Smith, I.M., Drmic, I., Buchanan, J.A., Roberts, W., & Sherer, S.W. (2014). Autism spectrum disorder: Advances in evidence-based practice. *Canadian Medical Association Journal*, 1-11. DOI:10.1503.

Anderson, G.N., Gilberg, C., & Miniscalco, C. (2013). Autism in pre-schoolers: Does individual clinician's first visit diagnosis agree with final comprehensive diagnosis? *The Scientific World Journal 2013*, 1-7. doi:10.1155/2013/716267.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders: DSM-IV*. Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental Disorders: DSM-IV-TR*. Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Washington, DC: American Psychiatric Association.

Attwood, T. 2006. The Complete Guide to Asperger's Syndrome. London, UK: Jessica Kingsley Publishers.

Baghdadli, A., Pico, M.C., Pascal, C., Pry, R., & Aussiloux, C. (2003). Relationship between age of recognition of first disturbances and severity in young children with autism. *European Child and Adolescent Psychiatry 12*(3),122-127.

Baird, G., Cass, H., & Slonims, V. (2003). Diagnosis of autism. *British Medical Journal, (327),*488-493.

Bakare, M.O., & Munir, K.M. (2011). Autism spectrum disorders (ASD) in Africa: A perspective. *African Journal of Psychiatry 14*(3),208-210.

Bateman, C. (2013). Autism – mitigating a global epidemic. *The South African Medical Journal 103*(5),276-277.

Beccerra, T.A., von Erhenstein, O.S., Heck, J.E., Olsen, J., Onyebuchi, A.A, Shafali, S.E., Roderiquez, M., & Ritz, B. (2014). Autism spectrum disorders and race, ethnicity, and nativity: A Population-Based Study. *Journal of Pediatrics 134*(1), 63-71.

Bello, S.C. (2007). Autism and environmental influences: A review and commentary. *Reviews on Environmental Health, 22*(2),139-156.

Bless, C., Higson-Smith, C., & Kagee, A. (2006). Fundamentals of social research methods: An African perspective. Cape Town, South Africa: Juta.

Bolton, P.F., Carcani-Rathwell, I., Hutton, J., Goode, S., Howlin, P., & Rutter, M. (2011). Epilepsy in autism: Features and correlates. *The British Journal of Psychiatry 198*(4),289-294.

Business balls demographics classification glossaries. (2014). Available from http://www.businessballs.com/demographicsclassificationn.html (accessed on 10 October 2014).

Carbone, P.S., Farley, M., & Davis, T. (2010). Primary care for children with autism. *American Academy of Family Physicians, 81*(4),453-460.

Chakrabarti, S. (2009). Early identification of autism. *Indian Pediatrics 46*(5),412-414.

Chavarska, K., Klin, A., Paul, R., & Volkmar, F. (2007). Autism spectrum disorder in the second year: Stability and change in syndrome expression. *Journal of Child Psychology and Psychiatry 48*(2),128-138.

Corsello, C. M. (2005). Early intervention in autism. *Infants & Young Children, 18*(2),74-85.

De Giacomo, A., & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *European Child and Adolescent Psychiatry 7*(3),131-136.

De Vos, A.S., Strydom, H., Fouche, C.B., & Delport, C.S.L. (2002). *Research at grass roots. For the social sciences and human service professions* (2nd ed.). Pretoria: Van Schaik Publishers.

De Vos, A.S., Strydom, H., Schulze, S., & Patel, L. (2011). The sciences and the professions. In A. S. De Vos, H. Strydom, C. B. Fouche & C. S. L. Delport (Eds.). *Research at grass roots. For the social sciences and human service professions* (4th ed.). Pretoria: Van Schaik Publishers.

Delport, C.S.L., & Roestenburg, W.J.H. (2011). Quantitative data-collection methods: questionnaires, checklists, structured observation and structured interview schedules. In A.S. De Vos, H. Strydom, C.B. Fouche & C.S.L. Delport (Eds.). *Research at grass roots. For the social sciences and human service professions* (4th ed.). Pretoria: Van Schaik Publishers.

Durkin, M.S., Maenner, M.J., Newschaffer, C.J., Lee, L.C, Cunniff, C.M., Daniels J.L., Kirby, S.R., L, Leavitt., Miller, L., Zahorodny, W., & Schieve, L.A. (2008). Advanced parental age and the risk of autism spectrum disorder. *American Journal Epidemiology 168*(11),1268-1276.

Dyches, T.T., Wilder, L.K., Sudweks, R.R., Obiakor, F.E., & Algozzine, B. (2004). Multicultural issues in Autism. *Journal of Autism and Developmental disorders, 34*(2),211-222.

Elsabbagh, M., Divan, G., Koh, Y., Kim, Y., Kauchali, S., Marcín, C., Montiel-Nava, C., Patel, V., Paula, C.S., Wang, C., Yasamay, M.T., & Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research 5*(3),160-179.

Fountain, C., King, M.D., & Bearman, S.B. (2011). Age of diagnosis for autism individual and community factors across 10 birth cohorts. *Journal of Epidemiology & Community Health 65*(6),503-510.

Fombonne, E., Roge, B., Claverie, J., Courty, S., & Fremolle, J. (1999). Microcephaly and macrocephaly in autism. *Journal of Autism and Developmental Disorders 29*(2),113-199.

Fombonne, E. (2005). Epidemiology of autistic disorder and pervasive developmental disorders. *Journal of Clinical Psychiatry 66*(10),2-8.

Fujiwara, T., Okuyama, M., & Funahashi, K. (2011). Factors influencing time lag between first parental concern and first visit to child psychiatric services in children with autism spectrum disorders in Japan. *Research in Autism Spectrum Disorders 5*(1),584-591.

Garcia, T. (2014). *Child life specialists' reflections of children with autism in the healthcare setting*. Unpublished Masters Dissertation: Mills College, San Francisco.

Grandin, T., & Panek, R. (2014). *The Autistic Brain: Exploring the Strengths of a Different Kind of Mind*. London, UK: Rider Books.

Hansen, R.L., Ozonoff, S., & Krakowiak, P. (2008). Regression in autism: Prevalence and associated factors in the CHARGE study. *Ambulatory Pediatrics Journal 8(*1), 25-31.

Hertz-Picciotto, I., & Delwiche, L. (2009). The Rise in Autism and the Role of Age at Diagnosis. *Journal of Epidemiology (Cambridge, Mass.) 20*(1),84-90.

Holliday Willey, L. (1999). *Pretending to be normal: Living with Asperger's syndrome*. London, UK: Jessica Kingsley Publishers.

Howell, D.C. (2010). *Statistical methods for psychology*. Belmont, CA: Cengage Learning.

IBM Corp. (2013). IBM SPSS Statistics for Windows, Version 22.0. Armork, NY: IBM Corp.

Jacklin, L. (2006). The changing profile of autism in a clinic for children with developmental delay: A ten year survey. Paper presented at Autism Safari 2006: 2nd World Autism Congress & Exhibition, Cape Town.

Jónsdóttir, S.L., Saemundsen, E., Antonsdóttir, I.S., Sigurdardóttir, S., & Ólason, D. (2011). Children diagnosed with autism spectrum disorder before or after the age of 6 years. *Research in Autism Spectrum Disorders 5*(1),175-184.

King, M.D., & Bearman, P.S. (2011). Socioeconomic status and the increased prevalence of autism in California. *American Sociological Association, 76*(2),320-346.

Kumar, R. (2005). *Research methodology. A step-by-step guide for beginners*. (2nd ed.). London: SAGE.

Laughton, B., Springer, P.E., Grove, D., Seedat, S., Cornell, M., Kidd, M, Madhi, S.A., & Cotton, M.F. (2010). Longitudinal developmental profile of children from low socio-economic circumstances in Cape Town, using the 1996 Griffiths Mental Developmental Scales. *South African Journal of Child Health 4*(4),106-111.

Leedy, P.D., & Ormrod, J.E. (2005). *Practical research: Planning and design* (8th ed.). New Jersey: Pearson Educational International and Prentice Hall.

Leedy, P.D., & Ormrod, J.E. (2010). *Practical research: Planning and design* (9thed.). New Jersey: Pearson Educational International and Prentice Hall.

Lian, W.B., & Ho, S.K. (2012). Profile of children diagnosed with autistic spectrum disorder managed at a tertiary child development unit. *Singapore Medical Journal 53*(12),106-111.

Lord, C., Risi, S., DiLavore, P. S., Schulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of General Psychiatry, 63*(6),694-701.

Mandell, D.S., Novak, M.M., & Zubritsky, C.D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116*(6), 1480-1486.

Manning-Courtney, P., Brown, J., Molloy, C.A., Reinhold, J., Murray, D., Sorensen-Burnworth, R., Messerschmidt, T., & Kent, B. (2003). Diagnosis and treatment of autism spectrum disorders. *Current Problems in Pediatric and Adolescent Health Care, 33*(9),283-304.

Marillyn, J., Wood, J., & Ross-Kerr, C. (2011). *Basic steps in planning nursing research*. *From question to proposal* (7th ed.). Canada: Jones and Bartlett Publishers.

McKenna, H., Hasson, F., & Keeney, S. (2010). In K. Gerrish, & A. Lacey (Eds.). *The Research Process in Nursing* (6th ed.). United Kingdom: Blackwell Publishing Ltd.

Miles, J.H., Takahashi, T.N., Bagby, S., Sahota, P.K., Vaslow, D.F., Wang, C.H., Hillman, R.E., & Farmer, J.E. (2005). Essential versus complex autism: Definition of fundamental prognostic subtypes. *American Journal of Medical Genetics 135A*(2),171-180.

Mubaiwa, L. (2008). Autism: Understanding basic concepts. *South African Journal of Child Health 2*(1),6-7.

Mubaiwa, L., Aziz, L., Govender, R., & Govender, V. (2012). Pervasive developmental disorders: Clinical characteristics and outcome in African children. *Journal of Developmental Medicine & Child Neurology 54*(suppl4),151.

Mullis, I.V.S., O'Martin, M., Kennedy, A.M., & Foy, P. (2007). *IEA's progress in international reading literacy study in primary schools in 40 countries*. Chestnut Hill, MA: TIMSS & PIRLS International Study Centre, Boston College.

Neggers, Y.H. (2014). Increasing Prevalence, Changes in Diagnostic Criteria, and Nutritional Risk Factors for Autism Spectrum Disorders. *International Journal of Scholarly Research Notice Nutrition 2014.* doi:10.1155/2014/514026.

New, A.S., Triebwasser, J., & Charney, D.S. (2008). The case for shifting borderline personality disorder to Axis I. *Biological Psychiatry Journal 64*(8),653-659.

Nordin, V., & Gilberg, C. (1998). The long-term course of autistic disorders: Update on follow-up studies. *Acta Psychiatrica Scandinavica, 97*(2),99-108.

Osterling, J., & Dawson G. (1994). Early recognition of children with autism: A study of first birthday home video tapes. *Journal of Autism and Developmental Disorders* 24(3),247-59.

Ozonoff, S., Young, G.S., Carter, A., Messinger, D., Yirmiya, N., Zwaigenbaum, L., & Stone, W.L. (2011). Recurrence risk for autism spectrum disorders: A baby sibling research consortium study. *Journal of Pediatrics 128*(3),488-495.

Pascoe, M., & Norman, V. (2011). Contextually-relevant resources in speech-language therapy and audiology in South Africa: Are there any? *South African Journal of Communication Disorders 58*(1),2-5.

Penn, C. (2007). 'Don't give me the theory, just tell me what to do in therapy!' The slippery slope challenge for the South African professions of speech-language

pathology and audiology. *South African Journal of Communication Disorders 54*, 13-17.

Richmond, A.S. (2011). Autism spectrum disorder: A global perspective. *Perspectives on Global Issues in Communication Sciences and Related Disorders 1*(2),39-46.

Rubin, A., & Babbie, E. (2005). *Research methods for social work* (5th ed.). Australia: Thomson: Brooks Cole.

Sansone, R.A., Sansone, L.A. (2008). Bully Victims: Psychological and Somatic Aftermaths. *Journal of Psychiatry (Edgmont) 5*(6),62-64.

Sansosti, F.J., Lavik, K.B., & Sansosti, J.M. (2012). Family experiences through the autism diagnostic process. *Focus on Autism and Other Developmental Disabilities, 27*(2),81-92.

Shattuck, P.T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D.S., Wiggins, L., Lee, L., Rice, C., Giarelli, E., Kirby, R., Baio, J., Pinto-martin, J., & Cuniff, C. (2009). Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *Journal of the American Academy of Child and Adolescent Psychiatry 45*(5),474-483.

Sipes, M., Matson J.L., Worley, J.A., & Koslowski, A.M. (2011). Gender differences in symptoms of autism spectrum disorders in toddlers. *Research in Autism Spectrum Disorders 5*(4),1265-1470.

South Africa. Department of Education. (1996). *South African Schools Act 84 of 1996.* Pretoria, South Africa: Department of Education.

South Africa. Department of Education. (2001). *Education White Paper 6. Special Needs Education: Building an inclusive education and training system.* Pretoria, South Africa: Department of Education.

Spence, S. J., Sharifi, P., & Wiznitzer, M. (2004). Autism spectrum disorder: Screening, diagnosis, and medical evaluation. *Seminars in Pediatric Neurology, 11*(3),186-195.

Springer, P.E., Van Toorn, R., & Laughton B. (2013). Characteristics of children with pervasive developmental disorders attending a developmental clinic in the Western Cape Province, South Africa. *South African Journal of Child Health 7*(3),95-99.

Stanford, A. (2003). *Asperger Syndrome & Long-Term Relationships*. London: Jessica Kingsley Publishers.

Statistics South Africa. (2011). Census 2011. Retrieved from

http://www.statssa.gov.za/publications/p03014/p030142011 (accessed on 15 September 2014).

Strydom, H. (2011). The pilot study in the quantitative paradigm. In A. S. De Vos, H. Strydom, C.B., Fouche, & C.S.L. Delport (Eds.). *Research at grass roots. For the social sciences and human service professions* (4th ed.). Pretoria: Van Schaik Publishers.

Treasure, J.L. (2007). Getting beneath the phenotype of anorexia nervosa: The search for viable endophenotypes and genotypes. *Canadian Journal of Psychiatry 52*(4),212-219.

Valicenti-McDermott, M., Hottinger, K., Seijo, R., & Schulman, L. (2012). Age of diagnosis of autism spectrum disorders. *The Journal of Pediatrics, 161*(3),554-556.

Wiggins, L.D., Biao, J., & Rice, C. (2006). Examination of time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Journal of Developmental and Behavioral Pediatrics 27*(2),S79-S87.

Wing, L., Gould J., & Gillberg, C. (2011). Autism spectrum disorders in the DSM-V: Better or worse than the DSM-IV?. *Research in Developmental Disabilities 32*(2), 768-773.

Young, R.L., Brewer, N., & Pattison, C. (2003). Parental identification of early behavioural abnormalities in children with autistic disorder. *Autism 7*(2),125-143.

6. APPENDICES

A) Ethical Clearance –

Faculty of Humanities, University of Pretoria

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

23 October 2013

Dear Prof Kritzinger

Project:	**Identification and diagnosis of Autism Spectrum Disorders: a retrospective case report from a school for children with autism in South African**
Researcher:	**S van Biljon**
Supervisor:	**Prof A Kritzinger**
Department:	**Communication Pathology**
Reference number:	**28024967**

Thank you for your response to the Committee's letter of 9 October 2013.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 23 October 2013. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof. Sakhela Buhlungu
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: sakhela.buhlungu@up.ac.za

Research Ethics Committee Members: Dr L Blokland; Prof S Buhlungu (Chair); Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris; Ms H Klopper; Prof A Mlambo; Dr C Panebianco-Warrens; Prof GM Spies; Prof E Taljard ; Dr FG Wolmarans; Dr P Wood

B) GDE –

Letter of Approval

GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

For administrative use:
Reference no: D2014/268

GDE RESEARCH APPROVAL LETTER

Date:	22 October 2014
Validity of Research Approval:	10 February to 3 October 2014
Name of Researcher:	Van Biljon S.
Address of Researcher:	141 Panorama Drive
	1 Eagles Rock Estate
	Constantia Kloof
	1709
Telephone Number:	011 675 3310 / 072 151 4353
Email address:	sumsievb@gmail.com
Research Topic:	Identification and diagnosis of Autism Spectrum Disorder: A retrospective case report from a school for children with Autism in South Africa
Number and type of schools:	ONE LSEN school
District/s/HO	Tshwane East

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

2013/10/23

The following conditions apply to GDE research. The researcher may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

1

Making education a societal priority

Office of the Director: Knowledge Management and Research
9th Floor, 111 Commissioner Street, Johannesburg, 2001
P.O. Box 7710, Johannesburg, 2000 Tel: (011) 355 0506
Email: David.Makhado@gauteng.gov.za
Website: www.education.gpg.gov.za

C) Consent letter to participate in research study at special school:

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Department of Communication Pathology
Faculty of Humanities

28 February 2013

Dr C Lombaard
The Principal: UNICA School
Cecilia Road
Ashlea Gardens
Pretoria
0081

Dear Dr Lombaard

Consent to participate in a research study

As per requirements of my degree in MCommunication Pathology (Speech-Language Pathology) it is expected of me to complete a research project. The research project is titled: "*Identification and diagnosis of Autism Spectrum Disorders: A retrospective case report from a school for children with autism in South Africa*"

Autism Spectrum Disorders (ASDs) are often not diagnosed in children until years after the onset of symptoms (Spence, Sharifi & Wiznitzer, 2004). According to different authors, children in the recent past may not have received an ASD diagnosis until they entered school (Fountain, King & Bearman, 2011; Spence, et al., 2004). However, symptoms of the classical form of ASD, autistic disorder, may be reliably diagnosed by the age of three years (Goin-Kochel, Mackintosh & Myers, 2006). Furthermore, children with Asperger disorder appear to be diagnosed on average at 6.1 years, and those with pervasive developmental disorder not otherwise specified (PDD-NOS), at 3.6 years (Goin-Kochel, Makintosh & Myers, 2006).

There are numerous contributing factors which may influence the late identification of ASD. Fountain et al. (2011) found community-related factors as well as factors on an individual level contributing to the late identification and diagnosis of ASDs in the USA. However, limited research has been conducted about the topic in South Africa. The results of the proposed study may contribute to a better understanding of aspects influencing the age of identification and diagnosis in a specific school over time.

For this reason I would like to obtain permission to conduct research at UNICA School. I would like to study all available school record files of children (past and present learners) with an ASDs diagnosis. The study is retrospective in nature so that possible patterns and factors in the age of identification and diagnosis may be found.

Communication Pathology Building Room 2-11
University of Pretoria
Private Bag X28, Hatfield 0028
Republic of South Africa

Tel: 012 420 2949
Fax: 012 420 3517

Email address alta.kritzinger@up.ac.za
www.up.ac.za

If you give consent that past school records may be used, parents of current children in the school will be approached to provide informed consent that their children's files may be studied. It may be possible that missing information may have to be obtained directly from the parents via a short interview. If parents are contacted to obtain missing information, they will be approached and interviewed in a sensitive manner. As a speech-language therapist I have had training in counselling parents whose children have communication disorders.

No risks are involved to participate in the study. The parents may withdraw from the study without negative consequences, at any time if they do not want to participate any longer. Information obtained through the research project will be treated as confidential and the data will be destroyed should the parents withdraw. The name of your school, parents and participants will not be disclosed in the research report. Upon completion of the research project an electronic and hard copy of the research report will be submitted to the Gauteng Department of Education and school. According to the University of Pretoria's policy, data must be securely stored for a minimum of 15 years. The data collected in the study will be stored in hardcopy and electronically.

It will be appreciated if you can provide us with a letter of your decision. If you give permission, I will proceed to obtain permission from the Gauteng Department of Education to conduct the research. The research project will also not commence unless ethical clearance is obtained from the University of Pretoria. Should you require any further information please feel free to contact me or my supervisors.

Yours sincerely

Sumari van Biljon
Student
072 151 4353

Prof. Alta Kritzinger
Supervisor
012 420 2949

Mrs. Salomé Geertsema
Co-Supervisor
012 420 3614

Prof. Bart Vinck
Head: Department of Communication Pathology

D) Written permission from principal:

UNICA SCHOOL FOR CHILDREN WITH AUTISM

P.O. BOX 35182, MENLO PARK, 0102
CECILIA ROAD, NEW HOPE CAMPUS, ASHLEY GARDENS
TEL: 012 460 6539 / 012 346 1103
FAX: 012 460 6324
HOSTEL: 012 329 0647

REG NO: GDE 211177 TS D4

PRINCIPAL: DR J.C. LOMBARD **DEPUTY: J. PERUMAL**

29 April 2013

Dear Me. Van Biljon/Prof Kritzinger

Re: Study at Unica School

I herewith acknowledge receipt of your letter requesting consent to participate in a research study at Unica School titled *"factors influencing the timing of identification and diagnosis of Autism Spectrum Disorders in children in a South African school*".

We will make learner's school records available to you, but said records may not be removed from our premises. We also grant permission to Ms Van Biljon to view records of learners who have left the school, without consent from the parents provided that confidentiality will be honoured at all times.

We will require consent forms from parents who currently have learners in the school as well as appropriate documentation from GDE and the University of Pretoria.

Yours sincerely

DR J.C. LOMBARD
Principal

E) Parent consent letter:

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Department of Communication Pathology
Faculty of Humanities

28 February 2013

Dear Parents

Consent to participate in research study

As per requirements of my degree in MCommunication Pathology (Speech-Language Pathology) it is expected of me to complete a research project. The research project is titled: "*Identification and diagnosis of Autism Spectrum Disorders: A retrospective case report from a school for children with autism in South Africa*"

Autism Spectrum Disorders (ASDs) are often not diagnosed in children until years after the onset of symptoms (Spence, Sharifi & Wiznitzer, 2004). According to different authors, children in the recent past may not have received an ASD diagnosis until they entered school (Fountain, King & Bearman, 2011; Spence, et al., 2004). However, symptoms of the classical form of ASD, autistic disorder, may be reliably diagnosed by the age of three years (Goin-Kochel, Mackintosh & Myers, 2006). Furthermore, children with Asperger disorder appear to be diagnosed on average at 6.1 years, and those with pervasive developmental disorder not otherwise specified (PDD-NOS), at 3.6 years (Goin-Kochel, Makintosh & Myers, 2006).

There are numerous contributing factors which may influence the late identification of ASD. Fountain et al. (2011) found community-related factors as well as factors on an individual level contributing to the late identification of ASDs in the USA. However, limited research has been conducted about the topic in South Africa. The results of the proposed study may contribute to a better understanding of aspects influencing the age of identification and diagnosis in a specific school over time. The results may assist to find quicker ways of identifying and diagnosing children with ASD.

For this reason I would like to obtain permission to allow me to study your child's school record file. The study is retrospective in nature so that possible patterns in the age of identification and diagnosis may be found. It may be possible that missing information may have to be obtained directly from you via a short interview. If you are contacted to obtain missing information, you will be approached and interviewed in a sensitive manner. As a speech-language therapist I have had training in counselling parents whose children have communication disorders.

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University of Pretoria
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Tel: 012 420 2949
Fax: 012 420 3517

Email address alta.kritzinger@up.ac.za
www.up.ac.za

No risks are involved to participate in the study. You may withdraw from the study without negative consequences, at any time if you do not want to participate any longer. Information obtained through the research project will be treated as confidential and the data will be destroyed should you withdraw. The names of the participants of the school will not be disclosed in the research report. Upon completion of the research project an electronic and hard copy of the research report will be submitted to the Gauteng Department of Education and UNICA School. According to the University of Pretoria's policy, data must be securely stored for a minimum of 15 years. The data collected in the study will be stored in hardcopy and electronically.

If you are willing to participate in the research study, please sign the attached consent form. I will proceed to obtain permission from the Gauteng Department of Education to conduct the research. I have already obtained ethical clearance from the University of Pretoria. Should you require any further information please feel free to contact me or my supervisors.

Yours sincerely

Sumari van Biljon
Student
072 151 4353

Prof. Alta Kritzinger
Supervisor
012 420 2949

Mrs Salomé Geertsema
Co-Supervisor
012 420 3614

Prof. Bart Vinck
Head of Department: Communication Pathology
University of Pretoria

CONSENT FORM

Herewith I _____ (parent / caregiver) give consent for _____ (child's name) file to be studied by the researcher in the research study titled: ***"Identification and diagnosis of Autism Spectrum Disorders: A retrospective case report from a school for children with autism in South Africa"***

I understand the procedures as explained in the letter and I am aware that I may withdraw from the research study at any time.

_____
Signature

F) Data Collection Checklist

A retrospective case report on demographic changes of learners at a school for children with autism spectrum disorders in Gauteng Province

Please answer all the following questions. Indicate your answer with **X** or follow alternative instructions.

Number [ ][ ](will be completed by researcher)

Section A: Learner characteristics

Characteristics of Participants	Categories	Please indicate answer with X
1. AGE (MONTHS) WHEN PARENTS BECAME CONCERNED ABOUT CHILD'S DEVELOPMENT	24-35months	
	36-47 months	
	48-59 months	
	60-71 months	
	> 72 months	
2. REASON WHY PARENTS BECAME CONCERNED ABOUT CHILD'S DEVELOPMENT	Delayed speech development	
	Autistic behaviour	
	Suspected hearing loss	
	Speech regressed	
	Struggling to cope academically at school	
7. TYPE OF SCHOOL BEFORE ADMISSION AT SPECIAL SCHOOL	Mother	
	Special school	
	Typical nursery school	
	Typical primary school	
	Day care centre	
8. AGE (MONTHS) WHEN CHILD WAS DIAGNOSED WITH ASD (DSM-IV OR DSM-IV®)	24-59 months	
	60-95 months	
	> 96 months	
5. CHILD'S DIAGNOSIS ACCORDING TO DSM-IV DSM-IV®	Autism	
	PDD	
	Asperger's	
6. OCCUPATION OF PROFESSIONAL INVOLVED IN ASD DIAGNOSIS	Child psychiatrist	
	Speech-language therapist, occupation therapist, psychologist, child	

	psychiatrist	
	Paediatric Neurologist	
	Paediatrician	
	Neurologist	
9. OCCUPATION OF PERSON INVOLVED WITH REFERRAL TO THE SPECIAL SCHOOL	Parents	
	Neurologist/ Paediatric neurologist/ Paediatrician/ Child psychiatrist/ Speech-Language therapist/ Occupational therapist/ Social worker/ General medical practitioner	
	School support team	
10. AGE (MONTHS) OF CHILD AT TEAM ASSESSMENT AT SPECIAL SCHOOL	24-59 months	
	60-95 months	
	> 96 months	
11. AGE (MONTHS) OF CHILD WHEN ADMITTED AT SPECIAL SCHOOL	24-59 months	
	60-95 months	
	> 96 months	
12. HOME LANGUAGE	Afrikaans/English	
	Other South African Languages: Tshivenda, isiZulu, Sesotho, Setswana, isiXhosa, Xitsonga	
	Other (French, Malayalam, Ibo)	
13. GENDER OF CHILD	Female	
	Male	
14. FIRST BORN	Yes	
	No	
15. SPEECH-LANGUAGE DEVELOPMENTAL HISTORY	Child is non-verbal	
	Child is verbal	
	Child had no speech regression	
	Child had regressed speech	
16. PROVINCE CHILD RESIDES	Gauteng	
	Other provinces (Mpumalanga, Limpopo, Western Cape, KwaZulu Natal, Northern Cape, Free State, North West)	

Section B: family characteristics of the learners

Characteristics of the participant's family Participant	Categories	Please indicate answer with X
1. SIBLINGS OR SINGLE CHILD	Single child	
	Siblings	
2. FAMILY HISTORY OF DISABILITIES OR CONDITIONS	Yes	
	No	
3. FATHER'S AGE (YEARS) WHEN CHILD WAS CONCEIVED	20-29	
	30-34	
	35-39	
	40-50	
4. FATHER'S QUALIFICATIONS	GR 9/10	
	Matric	
	Degree	
	Diploma/certificate	
	Post graduate	
5. MARITAL STATUS OF MOTHER	Single	
	Married	
6. MOTHER'S AGE WHEN CHILD WAS CONCEIVED	20-29	
	30-34	
	35-39	
	40-50	
7. MOTHER'S QUALIFICATIONS	GR 9/10	
	Matric	
	Diploma/Certificate	
	Degree	
	Post graduate	

G) Data Dictionary

Section A: Learner characteristics

Characteristics of Participants	Categories	Code
1. AGE (MONTHS) WHEN PARENTS BECAME CONCERNED ABOUT CHILD'S DEVELOPMENT	24-35months	1
	36-47 months	2
	48-59 months	3
	60-71 months	4
	> 72 months	5
2. REASON WHY PARENTS BECAME CONCERNED ABOUT CHILD'S DEVELOPMENT	Delayed speech development	1
	Autistic behaviour	2
	Suspected hearing loss	3
	Speech regressed	4
	Struggling to cope academically at school	5
3. TYPE OF SCHOOL BEFORE ADMISSION AT SPECIAL SCHOOL	Mother	1
	Special school	2
	Typical nursery school	3
	Typical primary school	4
	Day care centre	5
4. AGE (MONTHS) WHEN CHILD WAS DIAGNOSED WITH ASD (DSM-IV OR DSM-IV®)	24-59 months	1
	60-95 months	2
	> 96 months	3
7. CHILD'S DIAGNOSIS ACCORDING TO DSM-IV DSM-IV-TR	Autism	1
	PDD	2
	Asperger's	3
8. OCCUPATION OF PROFESSIONAL INVOLVED IN ASD DIAGNOSIS	Child psychiatrist	1
	Speech-language therapist, occupation therapist, psychologist, child psychiatrist	2
	Paediatric Neurologist	3
	Paediatrician	4
	Neurologist	5
5. OCCUPATION OF PERSON INVOLVED WITH REFERRAL TO THE SPECIAL SCHOOL	Parents	1
	Neurologist/ Paediatric	2

	neurologist/ Paediatrician/ Child psychiatrist/ Speech-Language therapist/ Occupational therapist/ Social worker/ General medical practitioner	
	School support team	3
6. AGE (MONTHS) OF CHILD AT TEAM ASSESSMENT AT SPECIAL SCHOOL	24-59 months	1
	60-95 months	2
	> 96 months	3
7. AGE (MONTHS) OF CHILD WHEN ADMITTED AT SPECIAL SCHOOL	24-59 months	1
	60-95 months	2
	> 96 months	3
8. HOME LANGUAGE	Afrikaans/English	1
	Other South African Languages: Tshivenda, isiZulu, Sesotho, Setswana, isiXhosa, Xitsonga	2
	Other (French, Malayalam, Ibo)	3
9. GENDER OF CHILD	Female	1
	Male	2
10. FIRST BORN	Yes	1
	No	2
11. SPEECH-LANGUAGE DEVELOPMENTAL HISTORY	Child is non-verbal	1
	Child is verbal	2
	Child had no speech regression	3
	Child had regressed speech	4
12. PROVINCE CHILD RESIDES	Gauteng	1
	Other provinces (Mpumalanga, Limpopo, Western Cape, KwaZulu Natal, Northern Cape, Free State, North West)	2

Section B: family characteristics of the learners

Characteristics of the participant's family Participant	Categories	Code
1. SIBLINGS OR SINGLE CHILD	Single child	1
	Siblings	2

2. FAMILY HISTORY OF DISABILITIES OR CONDITIONS	Yes	1
	No	2
3. FATHER'S AGE (YEARS) WHEN CHILD WAS CONCEIVED	20-29	1
	30-34	2
	35-39	3
	40-50	4
4. FATHER'S QUALIFICATIONS	GR 9/10	1
	Matric	2
	Degree	3
	Diploma/certificate	4
	Post graduate	5
5. MARITAL STATUS OF MOTHER	Single	1
	Married	2
6. MOTHER'S AGE WHEN CHILD WAS CONCEIVED	20-29	1
	30-34	2
	35-39	3
	40-50	4
7. MOTHER'S QUALIFICATIONS	GR 9/10	1
	Matric	2
	Diploma/Certificate	3
	Degree	4
	Post graduate	5