

Learners in autism-specific schools and their families in South Africa

by

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In fulfilment of the requirements for the degree
PhD Speech-Language Pathology

In the Department of Speech-Language Pathology and Audiology

Faculty of Humanities

University of Pretoria

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December 2018

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Acknowledgements

Jesus Christ our Saviour: Phil 4:13 “I can do all things through Christ who strengthens me.”

Prof. Alta Kritzinger: Thank you for your on-going assistance, motivation and support throughout my study. To me you are an inspirational supervisor to me and I greatly appreciate your effort and guidance immensely!

Dr. Jeannie van der Linde: Thank you for your guidance, support and motivation as co-supervisor throughout the study. I appreciate it that I could always rely on your assistance.

Principals of the schools: Thank you for providing me with the opportunity to conduct the research at your schools and always being helpful. Your support is greatly appreciated.

Caregivers: Thank you for your willingness to participate in the study.

Dr. Dion van Zijl: Thank you for all your help regarding the statistical measurements. You enriched my view on statistics – I greatly appreciate your time, effort and support.

Dr. Elsie Naudé: Thank you for your assistance with the language and grammar aspects of the articles and thesis.

Family: Thank you for all your help, love, and motivation throughout the past three years. You provided me with a wonderful support system during my studies. I appreciate all of you!

Research outputs

The thesis is based on the following articles which were submitted for publication to international and national accredited peer-reviewed journals:

1. Erasmus, S., Kritzinger, A., & van der Linde, J. (2018). Onset of intervention for learners in autism-specific government-funded schools in South Africa. *International Journal of Disability, Development and Education* (In press).
2. Erasmus, S., Kritzinger, A., & van der Linde, J. (2018). Families raising children attending autism-specific government-funded schools in South Africa. *Journal of Family Studies* (Submitted).
3. Erasmus, S., Kritzinger, A., & van der Linde, J. (2018). Profiles of public and private autism-specific schools in Gauteng. *South African Journal of Childhood Education* (Accepted).

Abstract

Limited research is available on learners with autism spectrum disorder (ASD), their families, and their schools in low to middle income countries. The main aim of the current research was to describe the demographics of learners with ASD, their families, and their schools, in South Africa (SA), from the perspective of caregivers and school principals.

A quantitative survey design was used for three separate studies. Participants were caregivers of learners attending autism-specific public and autism-specific private schools in SA, and the relevant school principals. Data were collected by means of self-completed questionnaires.

In Study 1 learners were identified late which set a trajectory of late intervention. Underlying factors leading to late identification appear to be unfamiliarity with ASD, limited services and schools for children with ASD. Late speech and language emergence were cited by most parents as the reason why they became concerned about the child. Speech-language therapists (SLTs) should raise awareness about the early signs of ASD and advocate early communication intervention.

Certain socio-demographic characteristics of the families in Study 2 closely reflected the characteristics of the national majority of families in SA. Families live on a relatively low monthly household income and spend a significant amount of their income on educational and therapeutic services. There should ideally be more financial support for families of learners with ASD.

In Gauteng, Study 3 showed that autism-specific public schools make a significant contribution to educating learners with ASD, compared to autism-specific private schools. However, learners were missing out on early intervention. There is a need for more educational services accommodating learners with ASD in the whole of SA.

The studies provided a large body of data on learners attending autism-specific schools in SA. Future conducive research should focus on other contextual factors affecting early intervention.

Keywords

Autism spectrum disorder
Autism-specific schools
Demographic characteristics
Early Intervention
Families
Financial costs
Inclusive Education
Learners
South Africa

List of abbreviations

The following abbreviations were used in the thesis:

ASA	Autism South Africa
ASD	Autism spectrum disorder
ASHA	American Speech-Language-Hearing Association
DBST	District-Based Support Team
DoE	Department of Education
DSM-IV TR	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revised
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
ECE	Early childhood education
ECDOE	Eastern Cape Department of Education
GDE	Gauteng Department of Education
HICs	High-income countries
ICF-CY	International Classification of Functioning, Disability and Health, Children and Youth Version
ICD-11	International Statistical Classification of Diseases and Health Problems, Eleventh Revision
IE	Inclusive education
IEP	Individualized education program
LMICs	Low and middle income countries
LSEN	Learners with special educational needs
OR	Odds ratio
SA	South Africa
SASLHA	South African Speech-Language-Hearing Association
SBST	School-Based Support Team
SD	Standard Deviation
SPSS	Statistical Package for the Social Sciences
UK	United Kingdom
US	United States
WCED	Western Cape Education Department
WHO	World Health Organisation

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Declaration

UNIVERSITY OF PRETORIA
FACULTY OF HUMANITIES
RESEARCH PROPOSAL & ETHICS COMMITTEE

DECLARATION

Full name : Sumarí Erasmus

Student Number : 28024967

Degree/Certification: PhD Speech-Language Pathology

Title of thesis:

Learners in autism-specific schools and their families in South Africa

I declare that this thesis is my own original work. Where secondary material was 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.



17 December 2018

SIGNATURE

DATE

Chapter 1

Introduction

1.1 Introduction

This chapter aims to demonstrate the relevance of the study by discussing pertinent literature pertaining to learners with ASD, their families, and their education. A shortened introduction provides an overview of the three research articles. The problem statement, rationale, and research questions are described. Terminology used in the thesis is explained.

1.2 Background

Research has indicated that learners with ASD who receive early intervention during the pre-school years, show improved developmental outcomes and educational success (Zwaigenbaum et al., 2015). SLTs have an important role to play in early intervention as they are involved in assessment, intervention, determining school readiness and school placement of pre-schoolers with ASD and in counselling their families (American Speech-Language-Hearing Association [ASHA], 2008; Shipley & McAfee, 2015). Studies conducted on families of children with ASD in high income countries (HICs), found many demographic factors affecting the timing of early intervention (Daniels & Mandell, 2014; Fountain, King, & Bearman, 2011; Mandell, Novak, & Zubritsky, 2005; Rosenberg, Kaufmann, Law, & Law, 2011; Shattuck et al., 2009). However, limited research is available on the demographics of learners with ASD, their families, and their schools, in low and middle income countries (LMICs), such as SA. Research conducted in SA has mostly concentrated on viewing ASD from a medical perspective (Molteno, Molteno, Finchilescu, & Dawes, 2001; Springer, van Toorn, Laughton, & Kidd, 2013), and involved medical treatment (Grinker et al., 2012; Travis & Geiger, 2010) and the quality of life of families raising children with ASD (Greeff & van der Walt, 2010; Schlebusch, Samuels, & Dada, 2016, 2017; Schlebusch & Samuels, 2018). Education of learners with ASD in SA appears to be a neglected research area (Clasquin-Johnson & Clasquin-Johnson, 2018). There is a need to appraise ASD from a broader perspective in SA by focusing on learners with ASD attending schools, and their families.

1.3 Applicability of the International Classification of Functioning, Disability and Health Child and Youth Version (ICF-CY) for children with ASD

Children and adults classified within the diagnostic category of ASD are characterized by diverse communication, behavioural, social, and educational challenges which need to be organised within a framework. This methodical approach will assist the understanding of this complex condition (Castro, Ferreira, Dababnah, & Pinto, 2013). The ICF-CY provides a comprehensive framework that addresses the need to view ASD from a broader perspective, by outlining functioning and contextual factors influencing everyday life outcomes (Bölte et al., 2018; Gan, Tung, Yeh, & Wang, 2013; World Health Organisation [WHO], 2007). Researchers and professionals have reported that there are also some challenges related to the application of the ICF-CY for daily use, since it is very comprehensive and time-consuming (Selb et al., 2015). To ensure that the ICF-CY is practical for clinical use, the ICF Brief Core Set for ASD, and the age-appropriate core sets were developed (Bölte et al., 2014; Mahdi et al., 2018). The three age-appropriate core sets included a preschool version (0-5-year-old children), a school-aged version (6-16-year-old children) and an older adolescent and adult version (>17-year-old individuals) (Bölte et al., 2014; Mahdi et al., 2018). Furthermore, research confirmed the value of using the ICF-CY as a framework for individuals with ASD (Aljunied & Frederickson, 2014; Bölte et al., 2018; Di Rizze, Rosenbaum, & Zwaigenbaum, 2012; Gan et al., 2013). Multiple studies have highlighted the impact of the social environment on the health and everyday life outcomes of individuals with ASD (Bölte et al., 2014; Castro et al., 2013). A few studies have investigated the value of the ICF-CY framework for preschool children with ASD (Di Rezze et al., 2012; Gan et al., 2013). In a web-based survey conducted in Canada, the applicability of the ICF-CY framework to categorize the severity of impairments in the functioning of pre-school children with ASD was positively appraised (Di Rezze et al., 2012). A study from Taiwan developed an ICF-CY-based questionnaire which reflected the functional profile of preschool children with ASD (Gan et al., 2013). However, there appears to be limited research on the utility of the ICF-CY framework for school-aged children with ASD (Aljunied & Frederickson, 2014). Given the reported increase in prevalence of children with ASD in many countries (Baxter et al., 2015; Idring et al., 2015; Richmond, 2011) the potential use of the ICF-CY in children with ASD is expanding.

The intention of the present study was not to focus on the 'Functioning and Disability' domain of the ICF-CY, but to rather concentrate on documenting some of the 'Contextual factors' of learners with ASD, their families, and their schools in SA. Unique SA-specific features may be revealed in the study, that can add to the local and global knowledge base concerning ASD. Recognizing that contextual factors influence the functioning of learners with ASD can potentially improve the outcomes of early intervention. The diagram presented in Figure 1 may be helpful to clarify the scope of the study and the specific contextual factors which will be described.

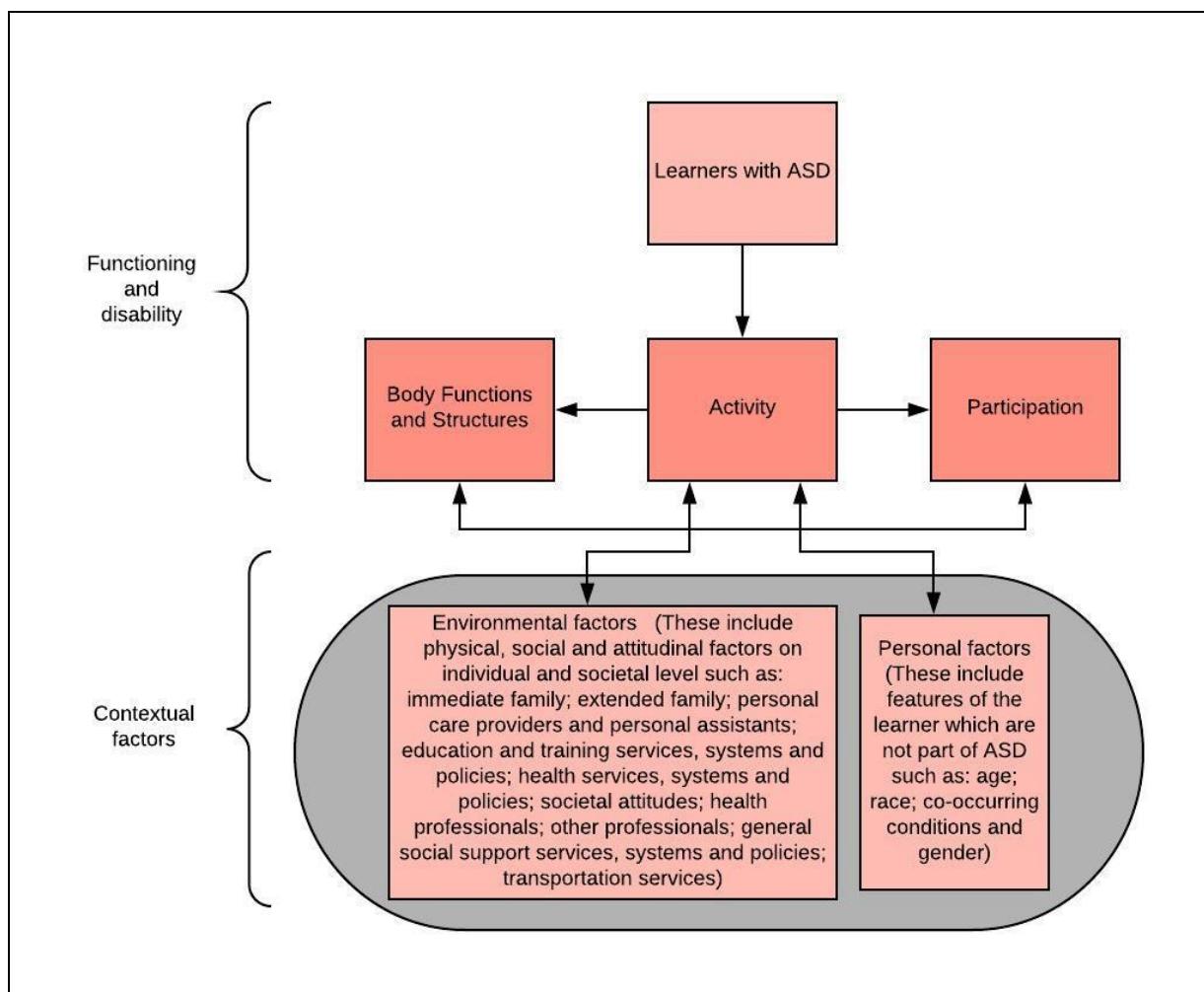


Figure 1 The scope of the study using the ICF-CY (Based on the WHO, 2007)

1.4 Contextual factors influencing functional and meaningful outcomes of ASD intervention

A number of contextual factors are currently known to contribute to the functional and meaningful outcomes of early intervention for preschoolers with ASD (Fountain

et al., 2011; Kirby, Baranek, & Fox., 2016). If children with ASD are to benefit from effective early intervention, it is essential that ASD be identified and diagnosed at an early age. Despite evidence that some symptoms of ASD are present early in life (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Goin-Kochel & Myers, 2005), most children in HICs as well as LMICs only receive an ASD diagnosis between the age of three and five years (Bello-Mojeed, Omigbodun, Bakare, & Adewuya, 2017; Goin-Kochel & Myers, 2005; Latif & Williams, 2007; Mandell et al., 2009; Samms-Vaughan, 2014; Van Biljon, Kritzinger, & Geertsema, 2015). However, most caregivers report that they became concerned about their child's development during the first two years of life, but waited almost three years to obtain an ASD diagnosis following their first visit to a professional (Siklos & Kerns, 2007). The reason for the delayed age of ASD diagnosis, may be limited awareness of early ASD symptoms among caregivers and professionals (Daniels & Mandell, 2014), or limited access to health services in LMICs, such as SA (Petersen & Lund, 2011). Furthermore, caregivers may lack knowledge about typical developmental milestones in young children, and therefore be unable to recognise developmental concerns at an early age. Late identification, and/or a long interval between the first concerns and diagnosis, have a negative impact on the effectiveness of early intervention for the child with ASD (Mansell & Morris, 2004).

Certain contextual characteristics have consistently emerged as factors affecting age of ASD diagnosis (Brett, Warnell, McConachie, & Parr, 2016; Daniels & Mandell, 2014; Fountain et al., 2011). A number of studies have associated the following environmental and personal factors with late ASD diagnosis: African-American race (in the United States [US]), immigrant status of a mother, later age of parental concern, presence of hearing impairment overlapping with ASD, co-occurring neurologic and psychiatric conditions in the child, and a greater number of professionals seen prior to an ASD diagnosis (Brett et al., 2016; Daniels & Mandell, 2014; Fountain et al., 2011). ASD diagnosis tended to be indicated as "late" when it was made by a greater number of professionals and after numerous consultations, as opposed to consulting a single specialist in ASD (Coo et al., 2012). This may be due to limited appropriate specialists available to make an ASD diagnosis, lack of knowledge of ASD symptoms amongst professionals, or not referring the child to professionals who are trained to diagnose children with ASD. Furthermore, a later

diagnosis could also point to the number of challenges families experience in accessing diagnostic services. Factors accelerating early ASD diagnosis included speech and language regression before the age of three because parents became concerned about their child's unusual development (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Another factor associated with early ASD diagnosis is when children receive speciality referrals, such as being referred from early intervention programmes as opposed to referrals from other parents, physicians, or schools (Juneja, Mukherjee, & Sharma, 2005). A possible explanation might be the advanced knowledge of the specialists involved, which enabled them to make a referral to a professional for an earlier ASD diagnosis. It is important to note that factors linked to delayed identification and diagnosis of ASD can be modified or can be targeted for improved management where the ultimate goal is early identification. Understanding the specific factors related to delayed identification and diagnosis of ASD among learners in SA, may lead to effective modifications.

Apart from the factors affecting age of identification/diagnosis and intervention, other contextual factors may also influence the functional and meaningful outcomes of early intervention, such as the substantial lifetime costs which are mostly borne by the families of children with ASD (Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014). The areas of expense for families raising children with ASD include childcare, disability-related intervention services, education, home improvement, hospitals, medical insurance payments, prescription medication, physicians, transport to school, and intervention services (Horlin et al., 2014; Järbrink, 2007; Parish, Thomas, Williams, & Crossman, 2015; Sharpe & Baker, 2011). These expenses are usually long-term and vary according to the life stage needs of the child (Ganz, 2007). Currently, only families in HICs receive financial support from the government (Autism Awareness Australia, n.d.; Autism Speaks, n.d.; The National Autistic Society, n.d.), but in LMICs limited financial assistance is provided to families by the local governments (Charles, 2014). Therefore, families in LMICs usually care for and support their child with ASD themselves (de Vries, 2016).

Studies regarding the costs incurred by families raising children with ASD have mostly been conducted in HICs (Buescher, Cidav, Knapp, & Mandell, 2014; Ganz, 2007; Horlin et al., 2014; Olivier & Ah Hing, 2009; Sharpe & Baker, 2011). Limited

research has been conducted on the financial costs faced by families raising children with ASD in LMICs, such as SA (Clasquin-Johnson & Clasquin-Johnson, 2018; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012). Even though there has been an increase in support for families of children with ASD in SA (Chambers et al., 2017; Grinker et al., 2012; Malcolm-Smith, Hoogenhout, Ing, Thomas, & de Vries, 2013), families still experience significant barriers to accessing diagnostic, intervention, and educational services (de Vries, 2016; Malcolm-Smith et al., 2013). One example of such a barrier is the fact that cost-free disability-related intervention services are scarce in SA and those that are available are often heavily overburdened, particularly at government level (Grinker et al., 2012). As a result families raising children with ASD are often obliged to resort to expensive private disability-related intervention services for their child (Saloojee, Phohole, Saloojee, & IJsselmuiden, 2006). Although some SA families of children with ASD belong to private medical insurance schemes, not all the long-term costs of disability-related intervention services are covered since they are too expensive (Saloojee et al., 2006). Consequently, families have to cover the cost of intervention services themselves. Expenses linked to having a child with ASD, however, are not limited to the cost of interventions only (Sharpe & Baker, 2011).

Families raising children with ASD face significant education-related costs (Clasquin-Johnson & Clasquin-Johnson, 2018; Järbrink, 2007). The development of education in SA initially followed the same trend of inclusive education as in most other countries where learners who experience barriers to learning, including learners with ASD, are included in mainstream classrooms (Department of Education [DoE], 2001; Engelbrecht, 2006; Jones & Frederickson, 2010; Waddington & Reed, 2017). However, it appears that learners with ASD are still being segregated from typically developing peers both in public and private special schools in SA (DoE, 2015; Pillay, Duncan, & de Vries, 2017). A possible explanation might be that learners with ASD present with unique challenges in adjusting to mainstream settings without appropriate support as their behaviours are often noticeably different from those of typically developing children (Majoko, 2017; Makin, 2017; Marsh, Spagnol, Grove, & Eapen, 2017; Whitman, 2004). Another reason might be that learners with ASD are diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) severity levels, with each level requiring a different level of

support (American Psychiatric Association [APA], 2013). There are also many contextual factors which hamper inclusive education efforts in SA, such as providing education to a large number of children vulnerable to learning breakdown, poverty, limited financial resources, lack of teacher capacity, and the negative attitudes of school communities towards diversity (Donohue & Bornman, 2014; Muthukrishna & Schoeman, 2000). Public education in HICs is generally funded by the state, local, or federal government (Department of Education, Employment and Workplace Relations, 2011; United States [US] Department of Education, 2011). In LMICs such as SA, however, public (government-funded) schools are only partially subsidised by the government and caregivers are still required to pay school fees (Dass & Rinquest, 2017). These schools are often over capacity (Grinker et al., 2012) and out of reach due to the poor public transport system in SA (Harris et al., 2011). Caregivers are often forced to either enrol their child in a private school, which is very expensive (Kiru & Cooc, 2017), or pay excessively for private transport for their child to get to school (Goudge, Gilson, Russell, Gumedze, & Mills, 2009). Moreover, children with ASD require additional dedicated childcare, which is often costly and sometimes needed for a longer period than in the case of a typically developing child, as they cannot be left unsupervised (Sharpe & Baker, 2011). Not all parents or parent substitutes, however, can afford a paid caregiver (Sharpe & Baker, 2011). They are often either unemployed or do not work full-time as they have to take care of their child (Ganz, 2007). It is thus evident that families raising children with ASD require financial support in caring for their child (Järbrink, 2007).

1.5 Problem statement and rationale

The persistent deficits in social communication and lesser recognised language disorders are not only the hallmark of ASD but also the core role and responsibility of SLTs (Roth & Worthington, 2016). SLTs have an important role to play in the screening, diagnosis, and treatment of ASD (ASHA, 2016). It is important for SLTs to view ASD from a broader perspective using the ICF-CY to understand which contextual factors are influencing the child's functioning and service delivery. It is well known that early identification and diagnosis of ASD are not only important but also possible (Kleinman et al., 2008; Mandell et al., 2005). Early identification precedes early diagnosis and intervention, and is critical for improving

developmental outcomes for children with ASD by capitalising on the sensitive period for language and cognitive development during preschool years (Mazurek et al., 2014). Researchers in HICs have found that there are a number of contextual factors which contribute to functional and meaningful outcomes of early ASD intervention (Fountain et al., 2011, Kirby et al., 2016). However, little evidence is available regarding the contextual factors which may influence the functioning of children with ASD in LMICs, such as SA (Bakare & Munir, 2011). This is sufficient justification for undertaking to describe the contextual factors which may influence the functional and meaningful outcomes of early intervention for learners with ASD in SA. The following research questions were posed:

Study1:

- What are the demographic characteristics and what is typical in the early management of learners attending the six autism-specific government-funded schools in SA?

Study 2:

- What are the socio-demographic characteristics of, and financial costs encountered by families whose children attend the six autism-specific government-funded schools in SA?

Study 3:

- How do the profiles and learners of two autism-specific public schools compare with two autism-specific private schools in South Gauteng Province?

1.6 Terminology

This section clarifies the relevant terminology as used in the thesis in hand.

Autism spectrum disorder

The terms autism spectrum disorder (ASD) and autism are often used interchangeably (Caronna, Milunsky, & Tager-Flusberg, 2008). In the thesis, the term ASD is preferred. The DSM-5 and the International Classification of Diseases, 11th revision (ICD-11) provide criteria for the diagnosis of ASD (APA, 2013; WHO, 2018). An ASD diagnosis requires three deficits in social interaction and social

communication and at least two symptoms in the category of restricted interests and repetitive behaviours (APA, 2013). Furthermore, the symptoms should be present during the early developmental period, must cause clinically significant impairment in social, occupational, or other areas of functioning, and are not better explained by an intellectual impairment or global developmental delay (APA, 2013). Also, it is important to specify whether the ASD is accompanied with, or occurs without, an intellectual impairment, language disorder, a medical or genetic condition or an environmental factor, and with catatonia. Lastly, the level of severity of symptoms should also be specified as this determines the degree of supportive care needed by the child with ASD (APA, 2013).

Autism-specific schools

The term “autism-specific schools” is used interchangeably with “special schools for children with ASD” in SA (Autism South Africa, n.d.; DoE, 2015). Autism-specific schools in this context refer to schools accommodating learners who have a primary diagnosis of ASD. The autism-specific schools do not fit in the inclusive education model but are supported by the DoE, despite an inclusive education policy adopted by the same department (DoE, 2001, 2015). At the time of data collection, there were only ix autism-specific public schools across SA.

Barriers to learning

The term “barriers to learning” refers to any difficulties that arise within the education system, the learning site, and/or within the learner him/herself which prevent access to learning and development (DoE, 2014).

Caregiver

A caregiver is an individual such as a mother, father, family member, or guardian who takes care of a child with any impairment and helps him/her with activities of daily living (Revenson et al., 2016).

Demographic characteristics

“Demographics” is defined as information about the characteristics of a population (Lee & Schuele, 2010). The demographic characteristics, also described as contextual factors in the ICF-CY, referred to in this study included socio-economic

characteristics (family income, parental education, therapy and education expenses, medical insurance scheme, transportation, home ownership status, social assistance grants) and relevant characteristics of the child and the caregivers (age, gender, race, nationality, birth order of the child, age at ASD identification and diagnosis, primary language spoken at home, marital status of the mother, immigration status of the mother, family structure).

Early intervention

The specific multidisciplinary services rendered to 1) an infant and toddler with a disability, or at risk for developmental delays, and 2) their family, from birth to three years (ASHA, 2008), constitute early intervention. SLTs play a major role in early identification and intervention for your children with ASD.

Inclusive education in SA

Inclusive education is a system where the diverse needs of all learners are addressed by reducing the barriers to and within the learning environment (DoE, 2001). Key education legislation and policies introduced since 1994 simultaneously abolished discrimination, and introduced inclusive education (DoE, 1995, 1996, 1997, 2010a, 2010b, 2014). However, there are many barriers obstructing the successful implementation of inclusive education in SA (Donohue & Bornman, 2014; Engelbrecht, 2006). The aim of the inclusive education legislation and policies is to include learners who experience barriers to learning, in mainstream (inclusive) schools.

Matric

In SA, matric (senior certificate) is a term commonly used to refer to the final year (grade 12) of high school and the qualification received upon graduating from high school (Umalusi, n.d.).

Autism-specific public and autism-specific private schools in SA

Public schools (government-funded schools) in SA are managed by the government and also receive funding from the government budget (Dass & Rinquest, 2017). In addition to the subsidy received from the government, public schools may supplement their funding by charging monthly school fees. For the purpose of this

study, the terms ‘public’ and ‘government-funded’ are used interchangeably. Independent schools, on the other hand, are privately managed and are therefore referred to as ‘private schools’. The terms independent and private schools are often used interchangeably. For the purpose of this study we prefer the term private schools. The autism-specific private schools receive their funding mainly from monthly school fees paid by parents, financial endowments, and fundraising initiatives (Dass & Rinquest, 2017).

Segregated placement in SA

During the years of apartheid in SA (1948-1994) learners who experienced barriers to learning were segregated twice according to their disability and race (Donohue & Bornman, 2014; Engelbrecht, 2006). White learners who experienced barriers to learning generally received high-quality special education with adequate resources and well-trained teachers. In contrast, Black, Indian, and Coloured children were educated in separate facilities from White learners and often received relatively low-quality education from poorly trained teachers (DoE, 2001).

1.7 Summary

This chapter provided an introduction to the three studies on the topic of learners in autism-specific and private schools and their families in SA. A discussion of the ICF-CY and contextual factors influencing functional and meaningful outcomes of ASD intervention was presented. The dimensions of the research were discussed in terms of the problem statement, rationale, and research questions. Lastly, the terminology and abbreviations used in the thesis were clarified.

Chapter 2

Method

2.1 Introduction

In this chapter, an overview is provided of the methods used in the three different studies which were written as three separate articles. The methods are described more extensively than in the articles, where journal specifications did not allow for comprehensive descriptions of approaches and methods used. The aims and sub-aims of the three research studies are outlined, as well as the research designs and ethical considerations. Aspects relating to the participants (the research context, recruitment of participants, selection criteria and description of participants) and to the material used in the studies (letters and survey questionnaires) are described. Lastly, the methods with regard to data collection and analysis are outlined.

2.2 Research aims

Main aim: To describe the demographics of learners with ASD, their families, and schools in SA from the perspective of caregivers and school principals.

To meet the main aim, three sub-aims were proposed, each constituted a separate research study for submission to an accredited peer-reviewed journal upon completion:

Study 1: The aim of the first study was to describe the demographic characteristics and typical early management of learners attending the six autism-specific government-funded schools in SA.

Study 2: The aim of the second study was to examine the socio-demographic characteristics of and financial costs encountered by families whose children attend the six autism-specific government-funded schools in SA.

Study 3: The aim for the third study was to compare the profiles and learners of two autism-specific public and two autism-specific private schools in South Gauteng Province.

2.3 Research studies

The three studies are outlined in Table 2.1 according to the titles, objectives, journals of publication and thesis chapter.

Table 2.1 Studies one, two and three - topic, aims, journal and thesis chapter

Study	1	2	3
Title	Onset of intervention for learners in autism-specific government-funded schools in South Africa	Families raising children with autism in autism-specific government-funded schools in South Africa	Profiles of public and private autism-specific schools in Gauteng
Aim	To describe the demographic characteristics and typical early management of learners attending the six autism-specific government-funded schools in SA	To examine the socio-demographic characteristics of and financial costs encountered by families whose children attend the six autism-specific government-funded schools in SA	To compare the profiles and learners of two autism-specific public and two autism-specific private schools in South Gauteng Province.
Journal	International Journal of Disability, Development and Education	Journal of Family Studies	South African Journal of Childhood Education
Publication status	Accepted	Submitted	Accepted
Chapter in thesis	3	4	5

2.4 Research methods

2.4.1 Research design

A quantitative survey design was employed for all three studies. Survey approaches are often used to publish articles in professional journals (Nelson, 2016). Survey research also involves collecting information about demographics, opinions, and reportable characteristics of the population of interest (Trochim, Donnelly, & Arora, 2015). Survey research was used in all three studies as the researcher wanted to reflect the opinions and experiences of caregivers and principals who are closely involved with learners with ASD in schools in SA. The suitability of the survey design approach selected for the three studies is further elucidated.

2.4.2 Studies 1 and 2

The research design selected for Studies 1 and 2 was a quantitative, cross-sectional, epidemiological survey which represents one of the categories of non-experimental research (Nelson, 2016). The nature of cross-sectional, epidemiological survey research is to examine the relationship between a health-related condition and other variables in a defined population at a single point in time (Abramson & Abramson, 2008; Miettinen & Karp, 2012). The aim of Study 1 was to describe the demographic characteristics and typical early management of learners attending the six autism-specific government-funded schools in SA from a caregiver perspective, and the aim of Study 2 was to examine the socio-demographic characteristics of, and financial costs encountered by families whose children attend the six autism-specific government-funded schools in SA. Data for both Study 1 and Study 2 were collected over a three month period. In both Study 1 and Study 2 the researcher was able to determine the relationship between the different variables included in the survey completed by the caregivers of learners with ASD. Furthermore, the principles of epidemiological research were used in Study 1 and Study 2 since the researcher included all six autism-specific public schools in the studies. It appeared that the population of learners with ASD in SA is mostly represented in public schools.

2.4.3 Study 3

A quantitative, cross-sectional, comparative, survey design was employed for Study 3. The nature of comparative research is to identify, analyse, and explain the similarities and differences between social entities (Leedy & Ormrod, 2016). The aim of Study 3 was to compare the profiles and learners of two autism-specific public and two autism-specific private schools in South Gauteng Province. Caregivers were asked to provide information regarding the demographics and characteristics of the learners attending the schools to establish comparisons between the profiles of the different types of autism-specific schools. Furthermore, school principals were asked to give their opinions regarding autism-specific and mainstream schooling, as there appears to be a gap between policy and implementation of inclusive education in SA. In this study, the researcher was able to identify, analyse, and explain the differences and similarities between the two autism-specific public and two autism-specific private schools.

2.5 Ethical considerations

The research project was approved by the Faculty of Humanities' Research Ethics Committee at the University of Pretoria (see Appendix A).

Permission to conduct research was obtained from:

1. Departments of Education

As per DoE regulations for conducting research the researcher requested and obtained permission from the Gauteng Department of Education (GDE), Eastern Cape Department of Education (ECDOE), and the Western Cape Department of Education (WCED) to conduct the research at the six autism-specific public schools (see Appendix B).

2. Schools

Written permission to conduct research at the schools was requested (see Appendix C) and obtained (see Appendix D) from each of the school principals of the six autism-specific public and the two autism-specific private schools.

The researcher acted responsibly towards the participants in the research project and reported the findings honestly and accurately (Strydom, 2011a). The guiding ethical principles as they were applied in the current study are listed and discussed in Table 2.2.

Table 2.2 Ethical principles applied in the research study

Principle	Application to study
<i>Avoidance of harm: Research involving human subjects is based on the principle that it should be conducted in a way that minimises harm or risk (Leedy & Ormrod, 2016).</i>	Participants in the study were school principals and caregivers who provided information by completing a survey questionnaire. There was no direct contact with the learners with ASD as the caregivers were the units of analysis. No caregiver or school principal was exposed to any risks during the study. Furthermore, school principals and caregivers did not receive any direct benefits as a result of the study. However, upon publication of the articles, the PDF manuscript will be emailed to the participating schools.
<i>Voluntary participation: Participation should at all times be voluntary, and no one should be forced to participate in a project (Leedy & Ormrod, 2016).</i>	The target populations were caregivers of learners with ASD and school principals of autism-specific schools. A flyer was distributed to all the caregivers of learners attending the autism-specific schools (Studies 1, 2, and 3). The purpose of the flyer was to solicit caregivers to participate in the study and to inform them about the importance of research on the demographic characteristics of children with ASD in SA. The flyer was printed on bright yellow A5 paper to attract the caregivers' attention (see Appendix E). Advertising the research is necessary as the researcher experienced in previous research endeavours that caregivers have limited interest in participating in research (Van Biljon et al., 2015). A follow-up card (see Appendix J) was sent to all the caregivers in the autism-specific schools thanking those who participated in the study and reminding those who would still like to participate to return the completed informed consent form and the survey questionnaire. However, no caregiver was forced or compelled to participate in the research project. The consent letters stated that caregivers may withdraw from the study at any time, without any adverse consequences.
<i>Informed consent: Respect for persons requires that participants be given the opportunity to choose what shall or shall not happen to them (Leedy & Ormrod, 2016).</i>	The researcher provided the school principals and the caregivers of all the learners in the autism-specific schools with an informed consent letter (see Appendix C and G). School principals and caregivers then gave informed consent to participate in the research study.
<i>Integrity – avoiding deception of participants: Deception refers to misleading participants, deliberately misrepresenting facts or withholding information from participants (Strydom, 2011a)</i>	No caregiver or school principal was misled regarding the research project. An information brochure was given to the caregivers and school principals that explained all the details and processes of the research study (Appendix C and G). The researcher also hosted an information session and presented the proposed research to the caregivers. Caregivers who had questions regarding the research were able to raise their queries during the information sessions and via email/telephone.
<i>Anonymity and confidentiality: Information collected during a research study is confidential and should be provided anonymously in reporting to ensure the privacy of the participants (Nelson, 2016).</i>	Only the researcher and promoters had access to the raw data obtained from the survey questionnaire completed by the caregivers (Appendix H) and the school principals (Appendix I). The names of the schools, school principals, and caregivers were not disclosed in the research project or articles submitted to scientific journals.
<i>Actions and competence of the researcher: Researchers are ethically obliged to ensure that they are competent, honest, and adequately</i>	The researcher is a qualified SLT and has completed a master's degree in the same field of interest. The researcher is furthermore familiar with the context and is collaborating with other experts in the field.

Principle	Application to study
<p><i>skilled to undertake the proposed investigation (Strydom, 2011a).</i></p>	
<p><i>Publication of the findings: The findings of the study must be introduced to the reading public in a written form otherwise even a highly scientific investigation will mean very little and will not be viewed as research.</i></p> <p><i>The written report leaves a body of evidence that can be used by future researchers (Strydom, 2011a)</i></p>	<p>The researcher published the findings of the study as articles in three peer-reviewed journals and sent the articles to participating schools. One of the journals, <i>International Journal of Disability, Development and Education</i>, is listed on the Institute of Scientific Information (ISI) database with an impact factor of 0.947.</p>
<p><i>Appropriate storage of data: Data collected in research studies should be safeguarded and stored appropriately (Strydom, 2011a)</i></p>	<p>The policy of University of Pretoria's Policy for the Preservation and Retention of Research Data (Crewe, 2007) states that data collected should be stored electronically, as well as in hard copy for fifteen years. Therefore, the researcher will ensure that the data be stored in hard copy and electronically for fifteen years in the Department of Speech-Language Pathology and Audiology. Furthermore, the researcher submitted an electronic and hard copy of the thesis to the GDE, ECDOE and the WCED upon completion of the investigation.</p>

2.6 Research context

Although there are no official statistics available on how many learners with ASD are being accommodated in autism-specific and mainstream schools in SA, it appears that the majority of school-going aged children with ASD are accommodated in autism-specific schools (Evans, 2016). These schools are therefore described as “population-rich settings” ($n=823$) (see Table 2.3) (Evans, 2016). Prior to data collection, the researcher consulted Autism South Africa (ASA) and requested a list of all the autism-specific public and private schools in Gauteng Province. The director of ASA helped the researcher identify the autism-specific public and autism-specific private schools in SA.

2.6.1 Studies 1 and 2

At the time of data collection, there were only six autism-specific public schools in SA (February 2017 – April 2017). All six autism-specific schools were approached to participate in the research study, and all agreed to participate. Only three of the nine provinces provide limited autism-specific public educational services since the schools are situated in urban settings within Gauteng, Western Cape, and Eastern Cape Provinces (ASA, n.d.).

2.6.1 Study 3

Only autism-specific schools which have existed for more than ten years in the Gauteng Province were chosen for the study because they have accumulated experience and are seen as resource centres for training and research (ASA, n.d.). At the time of data collection, there were three autism-specific private and three autism-specific public schools in Gauteng Province, but only two autism-specific private and two autism-specific public schools existing for more than ten years. The autism-specific private and autism-specific public schools were also chosen to match their founding dates [autism-specific public school 1 (1973) and 2 (2004); autism-specific private school 3 (1975) and 4 (2006)] in order to make comparisons. Table 2.3 provides information regarding the province where each school is located, type of school, setting, when the school was established, number of teachers in the schools, and the number and age ranges of learners in the schools.

Table 2.3 Characteristics of participating autism-specific schools (n=8)

School	1	2	3	4	5	6	7	8
Province	Western Cape	Gauteng	Western Cape	Eastern Cape	Gauteng	Gauteng	Gauteng	Gauteng
Type of School	Public (government-funded)						Private	
Setting	Urban areas							
Date when schools was established	1968	1973	1974	1995	2004	2016	1975	2006
Number of teachers in the schools	23	14	14	14	45	9	2	5
Number of learners in the school at the time of data collection	118	116	97	79	350	63	12	41
Age range of learners in the schools	6-18	3-18	4-18	6-18	3-21	6-18	2-11	3-10

As can be seen in Table 2.3 only three out of nine provinces provide limited autism-specific public educational services, as these schools are only situated in the urban areas within the Gauteng, Western Cape, and Eastern Cape Provinces only. Learners from rural areas appear to be excluded from public education in SA, although some schools provide hostel facilities. Four of the autism-specific schools were established between 1968 and 1975, while the other four schools were only established a few decades later. There are a number of reasons why only a few schools were established for learners with ASD. Firstly, during the late 1960's-1970's professionals and caregivers in SA had limited knowledge about ASD. Only caregivers and professionals who knew about ASD referred children to the autism-specific schools. A second reason might be that the increase in ASD diagnosis was only observed from the 1980s. Before that time, ASD was a rare condition. A third explanation might be that the early established schools met only the capacity needs of White¹ children with ASD, as Black² children were not allowed in those schools at that time. New schools were only established in the democratic era (after 1994). Lastly, some children never received an ASD diagnosis during this time because of the limited awareness and were placed in typically developing mainstream schools or schools for learners with special educational needs (LSEN).

¹ According to Statistics South Africa people describe themselves in the census in terms of five racial population groups. The categories were Black, White, Coloured, Indian and Asian (Statistics South Africa, 2011).

² According to Statistics South Africa people describe themselves in the census in terms of five racial population groups. The categories were Black, White, Coloured, Indian and Asian (Statistics South Africa, 2011).

2.7 Participants

The participants for Studies 1 and 2 were the same and consisted of caregivers of learners with ASD attending the six autism-specific public schools in SA. The participants for Study 3 consisted of caregivers of learners attending two autism-specific public and two autism-specific private schools in South Gauteng Province, as well as the principals of the schools. The sampling method, selection criteria, sample size, and participant description are presented in the following sections.

2.7.1 Recruitment of participants

Studies 1 and 2: In epidemiological survey research it is important to include as many members of the predefined population as possible (Abramson & Abramson, 2008; Miettinen & Karp, 2012). The predefined target population for Studies 1 and 2 consisted of all the caregivers of learners with ASD attending the six autism-specific public schools in SA. Different methods were used to involve a sufficient number of respondents in the research project. The researcher visited all six autism-specific schools and distributed a flyer to each of the 823 (total number of learners in autism-specific public schools in SA from February - April 2017) caregivers wherein they were invited to an information session where the researcher explained the purpose and value of the research project. At the information session, caregivers were invited to participate in the research project. Those who were willing to participate were given a survey packet (hand-delivered cover letter, information brochure and consent form and a self-administered, paper-based survey questionnaire). Caregivers were asked to complete the consent form and the self-administered survey questionnaire at their earliest convenience and to return it to the learner's teacher. Survey packages were distributed to all caregivers who were unable to attend the information session by placing the survey package in the learner's school bag. Therefore, all caregivers had an equal opportunity to participate in the study. In order to increase the return rate of the survey, teachers were asked to remind caregivers to return the questionnaires and consent forms. In addition, a follow-up card was distributed to the caregivers to remind them to return the survey questionnaire and consent form by a certain date. After considerable efforts to introduce the study to prospective participants, the return rate was still disappointingly low. All survey questionnaires and consent forms which were returned by the caregivers were included in the study. Therefore, non-probability, purposive sampling

appears to be the most appropriate sampling technique to describe the recruitment process (Leedy & Ormrod, 2016).

Study 3: The target population for Study 3 consisted of all the caregivers of learners attending two autism-specific public and two autism-specific private schools in Gauteng Province, as well as the school principals of the schools. Similar methods as in Study 1 and Study 2 were followed to recruit the participants and to increase the return rate of the survey package.

2.7.2 Selection criteria

The researcher was interested in obtaining information on the demographics of learners with ASD, their families, and their schools in SA. Therefore, caregiver and school principals were considered data-rich sources. The following sections discuss the justification of the selection criteria.

2.7.2.1 Selection criteria for caregivers

The selection criteria for the caregivers in all three studies were: 1) caregiver of 2) a learner diagnosed with ASD, 3) attending an autism-specific school.

Firstly, caregivers were the selected respondents. However, the respondents were not necessarily the primary caregivers of the learners but were asked to think about the learner with ASD and his/her family when completing the survey. The respondents in Study 1, 2 and 3 were one of the following: a mother, father, family member or guardian. Chapter 3, 4 and 5 provide a detailed description of the selection criteria for the respondents.

Secondly, confirmation of the ASD diagnosis of the learner was based on parental report and the school's admission criteria. All the autism-specific schools require that learners be diagnosed with ASD according to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition Text Revised (DSM-IV TR) (APA, 2000) or DSM-5 (APA, 2013) before they can be admitted to the schools.

Lastly, the caregivers had to be caring for a learner attending one of the autism-specific schools.

2.7.2.2 Selection criteria for school principals

The selection criterion for the school principals in Study 3 was that they had to be a principal of an autism-specific public or autism-specific private school in South Gauteng Province. Chapter 5 provides a detailed description of selection criteria for the school principals.

2.7.3 Sample size

Studies 1 and 2: Caregivers ($n=234$) of learners attending the six autism-specific public schools in SA acted as participants in the studies. The majority of the participants in Studies 1 and 2 were mothers (85.0%) who were unmarried³ (55.1%). The expected response rate in survey research is known to be 30% or less (Delport & Roesteburg, 2011), as was seen in Studies 1 and 2 where a 28.4% (234/823) response rate was achieved. Lack of response to a survey questionnaire by potential participants is referred to as non-response rate (Leedy & Ormrod, 2016). Since the non-response rate was high, the participants who returned the survey questionnaire may not necessarily represent the original selected sample (Leedy & Ormrod, 2016). Very few returned questionnaires were incomplete, which could indicate that respondents felt confident to provide information about the learners. Although there can be no generalisation beyond the sample, some of the results reflected the larger demographics of the country, thereby indicating some significance of the findings for SA.

Study 3: The sample size in this study consisted of 126 caregivers of learners attending the two autism-specific public and 24 caregivers of learners attending the two autism-specific private schools in South Gauteng Province. The non-response rate in this study was also high, as 27.7% (150/541) caregivers responded to the study. The majority of the respondents in the autism-specific public (86.5%) and autism-specific private (79.2%) schools were also mothers. Apart from the caregivers, four school principals also acted as participants in the study. All four of the principals returned the survey questionnaire.

³ Mothers who were unmarried were never married, divorced or widowed.

2.7.4 Participant description

Table 1 in chapter 3, Table 1 in chapter 4 and Table 1 and Table 2 in chapter 5 provide a detailed description of the participants.

2.8 Survey material

2.8.1 Format of survey questionnaires

Self-administered survey questionnaires were preferred to interview type of surveys because of the large sample size required and the wide geographical area covered. Also, a self-administered survey questionnaire was considered more suitable to reach the participants who would otherwise be difficult to reach. Furthermore, the self-administered survey questionnaires offered anonymity, and the respondents could complete the survey questionnaire at a convenient time and could check their personal records for information about the learners. Lastly, paper-based surveys were preferred to internet surveys. The reason was twofold: 1) 64.8% of the SA population does not have access to the internet (Statistics South Africa, 2011), and 2) the length of the survey would have been compromised given the suggested briefness of internet surveys.

The known disadvantages of using survey design were the potential low response rate from caregivers with low literacy levels and that the queries of the caregivers or school principals could not receive attention (Leedy & Ormrod, 2016). Another disadvantage of self-administered surveys is that the memories of school principals or caregivers for certain events are often distortions of what had happened (Leedy & Ormrod, 2016).

Since both survey questionnaires used were to be self-completed by the caregivers or school principals, it was important that these survey questionnaires be easy to understand and straightforward to complete (Blair, Czaja, & Blair, 2013). Both survey questionnaires were designed in such a way as to improve the response rate by ensuring that the survey questionnaire was distributed to caregivers in the middle of the term, and the format was user-friendly, avoiding measurement errors by keeping the wording, organisation, and visual appearance simple (Blair et al., 2013; Leedy & Ormrod, 2016). The survey questionnaires were printed on A4 paper and stapled together, questions relating to the same content were

grouped together, specific instructions were included where necessary, answer categories were vertically listed in table format, and the cover letter which was glued to the front of the envelope contained the university's letterhead and was designed in such a way as to create a professional and positive first impression (see Appendix F).

2.8.1.1 Survey questionnaires completed by the caregivers in Study 1, 2 and 3

There were no available standardised survey questionnaires for measuring the demographic characteristics and typical early management of learners attending the six autism-specific government-funded schools in SA nor for measuring the socio-demographic characteristics of and financial costs encountered by families whose children attend the six autism-specific government-funded schools in SA. Therefore, a survey questionnaire had to be designed to address the first two sub-aims of the study and a section of the third sub-aim of the study.

The undertaking of designing the survey questionnaire was preceded by a thorough review of the literature reporting on the demographic characteristics, early management of ASD, socio-demographics and financial costs of families with learners with ASD (Amr et al., 2012; Becerra et al., 2017; Christensen et al., 2016; Mandell et al., 2005; Mandell et al., 2009; Musa, 2016; Riya et al., 2014; Springer et al., 2013; Van Biljon et al., 2015). After reviewing the literature, the researcher subsequently designed a survey questionnaire, ensuring that the content covered all the facets of the three sub-aims and therefore addressing content validity (Delport & Roestenburg, 2011). In addition, experts in the field were consulted to review the preliminary survey questionnaire whereafter feedback was used to improve its validity (Delport & Roestenburg, 2011). Furthermore, face validity was addressed by ensuring that the wording of the questions elicits the appropriate information, asking questions which the respondents know, using terminology which the respondents were familiar with and including several types of questions (Trochim et al., 2015). The survey questionnaire included different types of questions such as yes/no and categorical responses (Trochim et al., 2015).

The content of the survey questionnaire (see Appendix H) used for the three sub-aims consisted of two sub-sections. Section A focused on demographic information and typical early management of ASD in the learner and included questions about gender, age, population group, gestational age, co-occurring health conditions, speech-language

developmental history, age when caregivers became concerned about their child's development, reasons why caregivers became concerned, what caregivers thought the cause or problem was, first professional consulted regarding concern, age when child was first assessed by a professional, age at ASD diagnosis, professional involved in ASD diagnosis, age when child was admitted to an autism-specific school, medication history, and transportation used to get to school. Section B focused on socio-demographic characteristics of families and costs to families and included questions on nationality, population group, who the primary caregiver was, the highest qualification of the mother, father, and primary caregiver, marital status of the mother, number of people living in the household, type of dwelling, siblings with ASD, transport used to get to school from parent's home, distance from parent's home to child's school, medical health scheme, therapy costs, monthly household income, school bursary, and social grant.

After the survey questionnaire had been designed the reliability was increased by conducting a pilot study in one of the autism-specific schools (Delport & Roestenburg, 2011). Section 2.9.1 provides a detailed description of the pilot study. Furthermore, the split-half reliability technique was also used to establish the reliability of the survey questionnaire in the Statistical Package for the Social Sciences (SPSS). Questions related to the same content in section A and B were grouped together and then divided into two halves to determine the extent to which scores on these two halves were consistent with one another. A high-reliability coefficient ($r = .803$), was calculated indicating a highly reliable survey questionnaire (Delport & Roestenburg, 2011). The survey questionnaire proved to be valid and reliable since the researcher was able to obtain the information needed to address the first two sub-aims and a section of the third sub-aim of the study.

2.8.1.2 Survey questionnaires completed by the school principals in Study 3

There were no available standardised survey questionnaires for measuring the profiles of autism-specific schools. Consequently, a survey questionnaire had to be designed to address a section of the third sub-aim of the study.

Prior to designing the survey questionnaire, a comprehensive literature review was conducted on studies reporting on the profiles of autism-specific schools (Amr et al., 2012; Musa, 2016; Riya et al., 2014; Van Biljon et al., 2015). Subsequently, the researcher designed a survey questionnaire and ensured that the content of the questionnaire covered

all the facets of the third aim, thus addressing content validity (Delport & Roestenburg, 2011). School principals familiar with the field of ASD were consulted to determine the face and content validity of the questionnaire whereafter recommendations were used to improve the validity (Delport & Roestenburg, 2011). The different types of questions included questions with yes/no and categorical responses (Trochim et al., 2015).

The survey questionnaire (see Appendix I) included questions about the history of the school, the structure of the school, teacher-learner ratio in the school, current therapeutic services offered by the school, admission criteria of the school, whether or not the school received subsidy from government, number of learners paying tuition fees, number of children on the waiting list of the school, policy on medication, school's needs, and the school principals' opinion on autism-specific schools and inclusive school settings. The survey questionnaire proved to be valid since the researcher was able to obtain the information needed to address the third sub-aim of the study.

2.9 Procedures

2.9.1 Pilot study

A pilot study with a clear list of aims and objectives can improve the success and effectiveness of the main investigation (Strydom, 2011b). Therefore, permission was requested and obtained from the school principal of one autism-specific school to conduct a pilot study. The two survey questionnaires were pretested by distributing them to fifteen caregivers of learners attending the school and the school principal (as applicable). Pilot participants were asked to complete the survey questionnaires and to indicate which questions were difficult to answer. No amendments were made to the pilot questionnaire completed by the school principal. Minor amendments were made to the caregiver questionnaire by refining the wording, reordering the questions, and adding alternative responses to the questions. The aims, procedures, results, and recommendations of the pilot study are described in Table 2.4.

Table 2.4 Aims, procedure, results, and recommendations of the pilot study

Aims	Procedures	Results	Modifications
To identify wrong answers (i.e. questions were answered inconsistently or inaccurately)	The returned survey questionnaires were reviewed for wrong or inconsistent information provided.	Q42b. The type of therapy and amount was identified as potentially problematic since the nature of the respondents' answers varied.	Q42b. was split up into two separate questions (Q42b. and Q42c.). Q42b. asked caregivers about the extracurricular therapies their child received which were not covered by the school fees, and Q42c. then asked about the amount per month charged for each type of therapy.
To identify inappropriate wording of questions (i.e. questions were interpreted incorrectly).	Questions to which caregivers provided irrelevant answers were also reformulated to ensure that the caregivers understand it correctly.	Four of the fifteen respondents who returned questionnaires indicated that they had difficulty understanding Q5b.	Reformulated Q5b by adding vertical response categories from which respondents could choose.
To evaluate the data collection procedures	The school principal, teachers, and caregivers were asked to provide suggestions on how to improve the response rate of the caregivers in the main investigation.	Feedback from the school principal, teachers, and caregivers advised the researcher to thank families and remind those families who still wanted to participate to return the completed informed consent form and survey questionnaire.	A follow-up card (thanking the families who participated and reminding those who still wanted to participate to please return the completed informed consent form and survey questionnaire) was included in the main investigation. Teachers also requested the caregivers to return the survey questionnaires by writing a letter in the learner's homework book.
To determine if there were sufficient response categories for all the questions	The responses to the different questions were critically evaluated to determine whether there were sufficient response categories for each question.	Q17. <i>Occupation of the professional who made the diagnosis</i> was identified as not having enough response categories. Q28. <i>Type of transport used to get to school</i> was identified as not having adequate response categories Q39. <i>Type of housing</i> was identified as not having sufficient response categories.	The response options for Q17 (professional who made the diagnosis) was increased to allow for seven different professional categories. For Q28 (transport used to get to school), the response options were also increased to six different transport categories. The response options for Q39 (type of housing for the household) was increased to eight categories.

In conclusion, the findings of the pilot study provided valuable recommendations to improve content and face validity that increased the rigorousness of the three studies. These recommendations were incorporated, and amendments were made to the survey questionnaire before data collection for the three studies commenced.

2.9.2 Data collection procedures for the main investigation

This section provides a detailed description of the data collection procedures which were followed in the study. After the researcher obtained permission from the Departmental Research Committee of the Faculty of Humanities' Research Ethics Committee at the University of Pretoria and the GDE, ECDOE and WCED, the researcher followed the following steps:

- The researcher met with the school principals and gave them the survey questionnaire about the school-specific information to complete.
- Specific dates were also discussed with the school principals of the autism-specific schools to host a caregiver information session.
- The researcher invited the caregivers to an information session by distributing a flyer to the teachers of learners at the individual schools.
- The teachers were asked to glue the flyer in the homework books of the learners.
- The researcher hosted the caregiver information session and informed caregivers about the nature of the study.
- Caregivers who had queries were able to raise them after the information session, and the researcher answered their questions.
- After the information session, the researcher distributed survey packages to the caregivers and encouraged them to participate in the study.
- Caregivers who gave consent were asked to complete the survey questionnaire and informed consent form.
- The caregivers could complete the self-administered survey questionnaire at their convenience.
- After the caregivers had completed the survey questionnaire, the researcher collected them from the schools.

- Caregivers who did not attend the parent information session were approached at the schools' coffee shops and were given the information brochure, an informed consent form, and a survey questionnaire to complete.
- The researcher also obtained the class lists and was able to give the teachers enough survey packages for all the learners in each class, which the teachers then put in their schoolbags.
- The researcher collected all the completed informed consent forms and survey questionnaires.
- A follow-up card (thanking caregivers who participated in the study and reminding those who still wanted to participate) was couriered to the autism-specific schools and teachers then distributed the cards to all the learners in their classes.
- An extension proved to be fruitful as more caregivers completed and returned the questionnaire.
- After receiving the survey questionnaires back from the caregivers and school principals, the researcher captured, recorded, and analysed the data electronically.
- The researcher completed the research project and submitted the three articles about the research project to the following three journals: *International Journal of Disability, Development and Education*, *Journal of Family Studies*, and the *South African Journal of Childhood Education*.
- After completion of the research, the researcher thanked the caregivers, principals and teachers, provided them with copies of the articles, and gave them feedback on the results.
- The researcher also contacted the WCED, ECDOE and GDE and gave them electronic and hard copies of the three articles.

2.9.3 Data preparation and data analysis procedures

Each returned survey questionnaire received a unique identification number to ensure anonymity of the participants. After that, the data were captured into Microsoft Excel spreadsheets. Data were verified by comparing the data in the Excel spreadsheets to information contained in the original questionnaires.

Studies 1 and 2: A total of 234 (28.4%) survey questionnaires were returned by caregivers. All returned questionnaires were included in the study. More than 10% of the values were missing for two questions (Q7 and Q22). These two questions were excluded from data

analyses. The statistical software package IBM SPSS for Windows version 24 was used to analyse data for Studies 1 and 2. Descriptive statistics were used to describe the characteristics of the participants and to provide summaries about the continuous and categorical variables investigated (Pallant, 2013). The Pearson Chi-Square Test for independence was used to explore the statistical relationship between categorical variables (Pallant, 2013). Underlying linear relationships between continuous variables were determined using Pearson Correlation Coefficient (Pallant, 2013). P-values <0.05 were accepted as statistically significant. Additional odds ratios (OR) were computed in Study 1 to determine associations between continuous variables which were significantly associated ($p<0.05$) with age of parental concern (Pallant, 2013).

Study 3: A total of 150 (27.7%) survey questionnaires were returned by the caregivers and four (4) by the school principals. Fewer survey questionnaires were returned than in Study 1 and Study 2. This may be because there were fewer caregivers who participated in Study 3 than in Study 1 and Study 2 since only schools in the South Gauteng region were selected. Data analyses for the survey questionnaire returned by the caregivers were performed using the statistical software package IBM SPSS for Windows version 24. Means, SD and percentages (%) were used to describe the data. Fisher's Exact Probability Test (for small samples) was used to determine the existence of significant differences amongst different variables between the autism-specific public and private schools. P-values <0.05 were accepted as statistically significant. Since the sample size of the survey questionnaire completed by the school principals in Study 3 was too small, the data were not statistically analysed for group differences, and the differences between the two autism-specific public and two autism-specific private schools in South Gauteng Province were simply described in the research article.

2.9.4 Validity and reliability

In order to ensure that Studies 1, 2 and 3 generated accurate and valid findings of the demographics of learners with ASD, their families, and their schools in SA from the perspective of caregivers and school principals, careful consideration was given to the validity and reliability of the study. Validity and reliability were addressed in all sections of this chapter and were regarded as central to the integrity of the studies undertaken.

2.10 Summary

The three studies were completed and submitted for publication to international and national accredited peer-reviewed journals. The first article is currently in press, the second article was submitted, and the third article accepted for publication. They are included as chapters three, four, and five of the thesis. The format of each of the articles appears as per editorial requirements of the three journals.

Chapter 3

Onset of intervention for learners in autism-specific government-funded schools in South Africa

This article was accepted by an international peer-reviewed journal, the Journal of Disability, Development and Education (2017 Impact Factor 0.947). The format of the article is that of the journal and differs from the rest of the thesis.

Onset of intervention for learners in autism-specific government-funded schools in South Africa

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Abstract

Late identification of children with ASD remains a concern. Due to limited research in low and middle-income countries (LMICs) such as South Africa (SA), the early management of autism spectrum disorder (ASD) should be further explored. The aim was to describe the demographic characteristics and typical early management of learners attending the six autism-specific government-funded schools in SA. Participants included 234 (28.4% of total approached) caregivers of children with ASD enrolled at the only six autism-specific government-funded schools in SA. Data were collected from parent-completed questionnaires. The majority of caregivers became concerned about their child's development on average at 25.2 months, but only a few (3.8%) thought it was ASD. Late identification was significantly associated with the respondent, nationality, qualification of the father and qualification of the mother. It appears that late identification sets a trajectory of late intervention. Factors underlying the trajectory appear to be unfamiliarity with ASD, and limited services and schools for children with ASD. Public awareness should focus on early symptoms associated with ASD risk to expedite early intervention.

Keywords: Autism spectrum disorder; demographic characteristics; families; government-funded schools; identification; intervention; late onset; learners; South Africa

With the growing concern over the increased prevalence together with greater awareness, much effort has been directed towards early identification of autism spectrum disorder (ASD) (Wiggins, Baio, & Rice, 2006). A growing body of evidence suggests that early identification and diagnosis of ASD is not only important but also possible (Kleinman et al., 2008; Mandell, Novak, & Zubritsky, 2005). In a retrospective study researchers were able to recognise early ASD features in children between the ages of 8-10 months, who were later diagnosed with ASD, utilising data from home video recordings (Werner, Dawson, Osterling, & Dinno, 2000). Similarly, in a prospective, longitudinal study the emergence of early behavioural signs of ASD was evident by 12 months of age (Ozonoff et al., 2010). In the United States (US) ASD can now be diagnosed reliably between the age of 8-14 months (Chawarska, Klin, Paul, Macari, & Volkmar., 2009; Guthrie, Swineford, Nottke, & Wetherby, 2013). In contrast, research in SA (SA) revealed late diagnosis of ASD (Van Biljon, Kritinger & Geertsema, 2015). A retrospective study conducted in a single school in SA found that the mean age of diagnosis in children with ASD was 76.1 months (Van Biljon et al., 2015). Late diagnosis was also revealed in a survey of 1047 caregivers of children with ASD in the United Kingdom (UK) where the mean age of ASD diagnosis was 89 months (Crane, Chester, Goddard, Henry & Hill, 2016). Early identification precedes early diagnosis and intervention and is critical for improving developmental outcomes for children with ASD by capitalising on the sensitive period for language and cognitive development during preschool years (Mazurek et al., 2014).

Background

Certain demographic characteristics and early management factors are often associated with age of identification and diagnosis (Brett, Warnell, McConachie, & Parr, 2016). It appears that factors

linked to delayed identification and diagnosis of ASD can be modified or can be targeted for improved management where the ultimate goal is early identification.

A systematic review revealed that a number of diverse child, family and community level factors are associated with late ASD diagnosis: African-American race, immigrant status of mother, later parental concern, presence of hearing impairment, co-occurring neurologic and psychiatric conditions in the child, greater number of professionals seen prior to ASD diagnosis, and when an ASD diagnosis was made by a team of professionals in schools (personal communication with the principal; Daniels & Mandell, 2014). Factors associated with early ASD diagnosis included speech and language regression before three years and when the child was referred from hospitals or speciality centres to a service provider for intervention, while no associations between age of diagnosis and gender were found (Daniels & Mandell, 2014).

Due to contradictory findings regarding the age of identification as well as limited research in low and middle-income countries such as SA, the demographic characteristics, early management of ASD and the age at which caregivers became concerned about their children's development should be explored (Springer, Vaughn, Laughton, & Kidd, 2013; Van Biljon et al., 2015). Such research may help South Africans understand children with ASD and their families better, identify possible demographic risk factors, promote early identification and diagnosis, identify parental needs, and plan educational support and appropriate services to learners (Musa & Fakher, 2016; Riya et al., 2014). Therefore the study aimed at describing the demographic characteristics and typical early management of learners attending the six autism-specific government-funded schools in SA.

Method

Setting

At the time of data collection, there were only six autism-specific government-funded schools, situated in urban areas, in SA. The learners attending the schools ranged between the ages of 3 and 21. Since the schools are only situated in three provinces, namely Gauteng, Western Cape, and

Eastern Cape Provinces, the other six provinces in SA were excluded from the study. Independent schools were excluded from the study as they are not all ASD specific. The learner admission requirements for all six schools were twofold: the child had to be diagnosed with ASD and caregivers had to work or live in the school's catchment area. All these schools have long waiting lists, and a child might not be admitted to the school directly. On average the distance which learners had to travel from home to school was 16.4 kilometres (km). After school admission, multi-disciplinary teams assess the child to determine the current level of performance and to prioritise educational needs.

Participants

The autism-specific government-funded schools in SA provide access to the largest population of school-going children with the disorder in SA and are therefore population-rich (Autism South Africa (ASA), 2016). The potential participants were all the caregivers of learners attending the participating schools. Non-probability, purposive sampling was used to select the caregivers. Of the total number of 823 self-completion questionnaires that were distributed to all children attending the autism-specific schools, 234 (28.4%) were returned after having been completed by the mothers (85.0%), fathers (11.1%), family members (3.4%) and guardians (0.5%). The caregivers were not necessarily the primary caregivers of the learners. The response rate was not as high as desired. The highest response rate (58.3%) was from a recently established school in a township. Although it is acknowledged that there can be no generalisation beyond the study sample, the study may serve to build an understanding of the demographic characteristics and early management of children with ASD in SA. The majority (85.0%) of the caregivers were mothers. Eighty-eight percent were South African, and 11.5% were from other countries within Africa and the UK. Both mothers (44.4%) and fathers (36.3%) had an educational level of either diploma or degree or postgraduate qualification.

Data gathering and data management

Prior to the main investigation, a pilot study was conducted in one of the autism-specific schools to establish the validity and reliability of the questionnaire. Completed questionnaires of fifteen caregivers were selected and were reviewed. After completing the pilot study, minor amendments were made to the questionnaire. The extensive questionnaire distributed to the caregivers was adapted from questionnaires used in other studies (Amr et al., 2012; Becerra et al., 2014; Musa & Fakher, 2016; Riya et al., 2014; Springer et al., 2013; Van Biljon et al., 2015). Questions about gender, population group, home language/s, perinatal history, co-morbidities, medication, speech and language development, age at ASD identification and diagnosis, and intervention services consulted were included. Based on the information obtained from the questionnaire, a structured electronic checklist, with relevant information to be captured from the questionnaire was designed. Completed questionnaires without any missing information were used for analysis. The data were captured into IBM SPSS (Version 22) (IBM Corp, 2013) in order to facilitate analysis. Basic means, frequencies, standard deviations and descriptive tables were constructed to investigate and describe the distribution of the data. Non-parametric tests were used to explore associations and correlations between variables. Only characteristics which were significantly associated ($p<0.05$) with age of parental concern were included in the second phase of the statistical analysis. As the data (first professional contact regarding concern) were too many to be added into the odds assessment in the categories allied health professionals ($n=128$), government primary healthcare clinic ($n=32$), general practitioner ($n=28$), and specialist professional ($n=18$), they were recategorised into two groups, namely specialist professional and allied health professional, governmental health clinic, and general practitioner. The descriptives in the odds assessment provided insightful results for the reference group.

Ethical considerations

We obtained written permission from the University of Pretoria (GW20160702HS), the Gauteng Department of Basic Education (D2016/268), Western Cape Department of Education, Eastern Cape Department of Education, and the principals of the autism-specific government-funded schools. Informed consent was obtained from caregivers of the children attending each school at the time of data collection.

Results and discussion

Learner characteristics

The demographic characteristics of the learners ($n=234$) attending the autism-specific government-funded schools are provided in Table 1.

Table 1. Demographic characteristics of learners attending autism-specific government-funded schools ($n = 234$)

Characteristic	Category	Frequency (n)	Percentage (%)
1.1 Gender	Male	201	85.9%
	Female	33	14.1%
	Male-to-female ratio	6.1:1	
1.2 Age of child (mean age in years = 9.88) (SD = 6.2)	<4 years	10	4.3%
	5-9 years	123	52.6%
	>10 years	101	43.1%
1.3 Population group distribution	Black	182	77.8%
	Coloured	33	14.1%
	White	14	6.0%
	Asian/Indian	5	2.1%
1.4 Primary language at home	English	140	59.8%
	Other (Afrikaans, isiNdebele, isiXhosa, isiZulu, Sesotho sa leboa, Sesotho, Setswana, siSwati, Xitsonga, Shona or French)	94	40.2%
1.5 Term pregnancy	Full term	190	81.2%
	Preterm	44	18.8%
1.6 Birth order of the child	1 st child	108	46.2%
	2 nd child	63	26.9%
	3 rd child	39	16.7%
	4 th -7th child	15	10.2
1.7 Siblings diagnosed with ASD	Yes	21	8.9%

As can be seen in Table 1 (1.1), the predominant gender of the sample was male. The male-to-female ratio was 6.1:1. The gender disparity in this study was considerably higher than that reported by

Fombonne (2009) in an epidemiologic study conducted in fifteen high-and-middle-income countries (UK, Denmark, US, Japan, Sweden, Ireland, Germany, Canada, France, Indonesia, Portugal, Finland, Iceland, Israel and Norway), where the male-to-female ratio was 4.2:1. The male bias could simply reflect the difficulty of diagnosing ASD in females (New, Triebwasser, & Charney, 2008). Evidence suggested that the clinical presentation of ASD is different in males than in females, although available findings are inconsistent (Rivet & Matson, 2011). Females may have more social difficulties and are less able to perform social play and imaginative social play than males (Attwood, 2007; Holtman, Bolte, & Poustka., 2007). Also, some females who present with the relevant symptoms tend to be diagnosed with other disorders such as social phobia or borderline personality disorder, instead of ASD (Van Wijngaarden-Cremers, 2017). These differences could lead to delayed or even missed diagnosis of ASD in females (Van Wijngaarden-Cremers, 2017).

The mean age of the learners in the six autism-specific schools was 9.8 years. More than half (52.6%) of the learners were between the ages of 5-9 years. The other half of the learners were >10 years (43.1%) and only 4.3 % were younger than four years. A possible explanation why more learners were between the ages of 5-9 years and older than >10 years may be because according to the South African Schools Act (Department of Education [DoE], 1996) children between the ages of seven and fifteen are compelled to attend schools.

The population groups and home languages spoken represent the cultural and linguistically diverse profile of the learners in the schools. The results indicated that while the majority (77.8%) of learners belonged to the black population group, 59.8% of the learners' primary language at home was specified as English and not an African language. Possible explanations may be that English is more frequently spoken by families in urban areas (Spaull, 2013) and to assist their children with ASD to learn the Language of Teaching and Learning (LoLT) used in the schools (personal communication with the teachers). However, the primary languages of 40% of the learners were Afrikaans, French, isiNdebele, isiXhosa, isiZulu, Sesotho sa leboa, Sesotho, Setswana, Shona,

siSwati, Xitsonga. It therefore appears that the language diversity in SA limits first-language education for learners with ASD in the same measure as for learners without ASD (see e.g. Foley, 2008).

Most (81.2%) learners were full-term infants, with 18.8% born preterm. The preterm birth rate from our study is approximately 4% higher than the 14.17% national preterm birth rate reported in SA (Pattinson, 2013). The findings from the current study corresponded with the results from a population-based study conducted in Denmark between 1980 and 2009 (Atladóttir, Schendel, Hendriksen, Hjort, & Parner, 2016). The researchers found that across all birth year cohorts, the risk of being diagnosed with ASD increased with lower gestational age, although the overall risk for ASD from preterm births had decreased across the years as more children with ASD were born full term (Atladóttir et al., 2016).

Forty-two percent of children from a clinical sample in California were first-born (Fountain, King, & Bearman, 2011). Similarly, 46.2% of learners in the current study were first-born and therefore agree with results from other studies which found that there is an increased risk for ASD if the child was a first-born (Fountain et al., 2011; Gardener, Spiegelman, & Buka, 2009).

Twenty-one of the caregivers in this study indicated that they had more than one child diagnosed with ASD. Fewer families reported having another child with ASD than in a longitudinal study conducted in twelve international network sites by the Baby Siblings Research Consortium (BSRC) (Ozonoff et al., 2011). These researchers indicated that the chances of families with one or more child on the spectrum having another sibling with ASD are about 20% (Ozonoff et al., 2011). It remains important that families be counselled about the genetic risk of having another child with ASD.

To conclude, it appears that most of the learners were males from black, English speaking families and were first-born, full-term infants.

Early management of ASD

The early management of learners ($n=234$) attending the autism-specific government-funded schools is provided in Table 2.

Table 2. Early management of learners ($n=234$) attending the autism-specific government-funded schools

Characteristic	Category	Frequency (n)	Mean (SD)	Median	Percentage (%)
2.1 Age (months) when caregivers became concerned about child's development	<47 months	217	25.21 (13.4)	24	92.7%
	>48 months	17			7.3%
2.2 Reason why caregivers became concerned about the child's development	Delayed speech and language	136			58.1%
	Developmental delay	51			21.8%
	No response to name	44			18.8%
	No social interaction with peers	2			0.9%
	Atypical behaviour	1			0.4%
2.3 What caregivers thought was the problem or cause	Developmental causes	164			70.1%
	No idea	45			19.2%
	ASD	9			3.8%
	Medical causes	7			3.0%
	Mental difficulties	6			2.6%
	Environmental causes	3			1.3%
2.4 First professional contact regarding concern	Allied health professionals	128			54.7%
	Government primary healthcare clinic	32			13.7%
	General practitioner	28			12.0%
	None	28			12.0%
	Specialist professional, such as a developmental paediatrician, paediatric neurologist or a child psychiatrist	18			7.6%
2.5 Age (months) when child was first assessed by a professional	<47 months	183	34.75 (16.9)		78.2%
	>48 months	51			21.8%
2.6 Age (months) when child was diagnosed with ASD	<47 months	128	46.69 (22.3)		54.7%
	>48 months	106			45.3%
2.7 Professional involved with ASD diagnosis	Paediatric neurologist	97			41.5%
	Multi-disciplinary team	82			35.0%
	Child psychiatrist	54			23.1%
	Developmental paediatrician	1			0.4%
2.8 Age (years) when child was admitted to	<3.9 years	18	6.80 (6.1)	6	7.7%

autism-specific school	>4.0 years	216	92.3%
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Eighty-five percent of the caregivers were mothers who became concerned about their child's development on average at 25.2 months. Studies of parental concerns about children who were later diagnosed with ASD have indicated that caregivers were able to recognise atypical development between the ages of 8 and 12 months (Werner et al., 2000; Young, Brewer, & Pattison, 2003). Significant, positive associations were found between the following variables and age when caregivers became concerned about their child's development: respondent (*p-value* = <0.000), nationality (*p-value* = <0.002), qualification of the father (*p-value* = <0.027) and qualification of the mother (*p-value* = <0.016). The results show that delayed age at parental concern was most likely associated with the respondent being the father, family-caregiver or guardian, being a South-African citizen, and having a lower level of parental education. Therefore, it appears that the lower level of education, the later the father, family-caregiver or guardian became concerned about their child's development. Generally, higher maternal education appears to be associated with more knowledge about child development (Chawarska et al., 2007; Herlihey, Knoch, Vibert & Vein, 2015). In our study, it appears that South African caregivers became concerned about their child's development later than caregivers from countries within and outside of Africa. A possible reason why caregivers from Africa became concerned about their child's development earlier than South African caregivers might be that the majority of children with ASD from countries in Africa do not have access to specialised education services (Thomas, Badoe, & Owusu, 2015) and caregivers are therefore compelled to do more research about their child's development in order to find specialised education for them. The delayed age at parental concern could also be due to the limited access to health services in SA (Petersen & Lund, 2011). It further appears from our results that caregivers may lack knowledge about typical developmental milestones in young children and therefore were unable to recognise developmental concerns at an early age. The result has further implications for policy in basic education, social development, and health departments in SA. The findings emphasise the

importance of supporting and empowering caregivers using targeted awareness and early identification programmes for infants and young children with special needs.

Children with late language emergence (LLE) usually have an age-appropriate understanding of language and no other delays in the cognitive and motor domains but have limited spoken vocabulary at 24 months (Owens, 2016). In contrast, infants and young children with ASD show many difficulties, in particular, lack of social interaction, limited orientation to child-directed speech, restricted and repetitive behaviours and interests (Webb & Jones, 2009). The main reason why caregivers became concerned about their child's development was delayed speech and language (58.1%) and not about early ASD symptoms. The findings show that LLE in their children raised the alarm for caregivers (on average at 25.2 months), close to the age at which LLE is recognised as a missed language learning milestone. The current results are in agreement with those from other studies which also found that the most common parental concern in the case of children with ASD was LLE (De Giacomo & Fombonne, 1998; Herlihy et al., 2015; Kozlowski, Matson, Horovitz, Worley, Neal, 2011). It appears that caregivers in our study were unaware of early symptoms of ASD, which is confirmed by the findings of the later age at parental concern.

Once the caregivers became concerned about their child's development, less than 4% suspected the cause to be ASD. Seventy percent of the caregivers thought that their child's atypical behaviour was caused by developmental conditions such as hearing impairment, visual impairment, LLE, developmental delay, or attention-deficit-hyperactivity-disorder (ADHD). As mentioned earlier, the majority (85.0%) of the caregivers were mothers, and 87.2% of them thought the atypical behaviour was caused by developmental conditions. The results from our study indicate that caregivers were unfamiliar with ASD, which symptoms can already be identified during late infancy as indicated by Ozonoff et al. (2000) and Werner et al. (2010).

As seen in Table 2 (2.4) the majority (54.7%) of caregivers first consulted allied health professionals regarding their concerns. Furthermore, these caregivers became concerned about their

child's LLE on average at age 25.2 months, contrasting sharply with the few caregivers (7.7%) who first consulted specialist professionals (developmental paediatrician, paediatric neurologist or child psychiatrist) at an earlier age of 19.1 months. The fact that allied health professionals, such as speech-language therapists and occupational therapists, were consulted first could indicate that caregivers did not know whom to consult when they first suspected that their child had developmental delays or that their child had a serious developmental condition which warranted specialised attention from the beginning. The result could also mean that there is a shortage of specialist professionals in SA. Therefore, caregivers sought help from the allied health professionals providing intervention for developmental delays first instead of professionals specialising in ASD diagnosis. Our results do not correspond with results from a study conducted in a clinic in the UK where general practitioners were the first to be consulted by caregivers of children with ASD (Giacomo & Fombonne, 1998). This may be due to differences in the structure of health services differs between the two countries. In the UK the first health service contact is the general practitioner ("Autism spectrum disorder", 2016) and not the allied health professionals, whereas in SA it seems that the allied health professionals in the private sector are contacted first (Fewster & Gurayah, 2015).

The mean age of first assessment by a professional was 34.75 months, almost a year later than when the caregivers became first concerned about their child's development. The results show that most learners assessed were surprisingly younger than the age of 48 months at first assessment reported for the large metropolitan area of Atlanta (Wiggins et al., 2006). Significant, positive associations were found between age at assessment and the following variables: age at parental concern ($r = .563$; $p\text{-value} = <0.000$), age at diagnosis ($r = .584$; $p\text{-value} = <0.000$) and age at admission to the autism-specific school ($r = .210$; $p\text{-value} = <0.001$). The results show that the later caregivers became concerned, the later the age at first assessment, the age of ASD diagnosis and age at admission to the autism-specific school. Therefore, although caregivers were concerned about their

child's development at 25.2 months already, they consulted a professional about their concern only after some time had passed (on average at 34.7 months of age) and children only received the ASD diagnosis much later (on average at 46.6 months of age) and were also admitted to the autism-specific schools even later (on average 6.8 years). The slow trajectory of delayed intervention may indicate the lack of parental awareness of ASD and limited services available to accelerate the process of admitting a child to an appropriate school in SA. Furthermore, the results reflect the situation approximately eight years ago in SA, as the mean age of the participants in our study was 9.8 years. Increased public awareness may be shown in future studies as there is now increased coverage of ASD in mass media in SA (ASA, 2016.).

The average age at diagnosis in middle-income countries such as Colombia, India, Jamaica, Jordan, and Mexico is 45-57 months (Samms-Vaughan, 2014). Our results correspond with the age of diagnosis reported by Samms-Vaughan (2014) since the mean age at diagnosis was 46.6 months. However, the age of diagnosis in our study is earlier than the age of diagnosis (56.0 months) reported by Springer et al. (2013) in a tertiary hospital developmental clinic in the Western Cape Province of SA over a two-year period (2008-2010). Possible explanations for the earlier age at diagnosis in the current study might be increased awareness of ASD among caregivers and professionals as well as the implementation of effective screening tools.

More (41.5%) learners were diagnosed by paediatric neurologists and fewer by child psychiatrists, developmental paediatricians, and multidisciplinary teams. The results differ from those reported at a Child Neuropsychiatry Clinic in Sweden where comprehensive clinical assessments were primarily conducted by multidisciplinary teams which included a psychologist, psychiatrist, neurologist, speech-language therapist and professionals who are qualified to diagnose ASD (Anderson, Gillberg, & Miniscalco, 2013). This dissimilarity is to be expected due to the difference in both the demographics and the health systems of the two countries involved. In SA the public primary health care system is often inaccessible and overburdened (Petersen & Lund, 2011) and there

are only ten central hospitals operating on a national level who provide specialised services, such as paediatric clinics, on a national basis (Department of Health, 2015).

Most (93.1%) of the learners were admitted to school >4.0 years. Significant, positive associations were found when further exploring the underlying linear relationship between age at school admission and the following: age at parental concern ($r = .197$; $p\text{-value} = <0.000$); age at first assessment ($r = .210$; $p\text{-value} = <0.001$); and age at diagnosis ($r = .239$; $p\text{-value} = <0.000$). The later the age at parental concern, the later the age at first assessment, age at ASD diagnosis and age at autism-specific school admission. According to the South African Schools Act (DoE, 1996) governing bodies of schools for learners with special educational needs (LSEN) may develop their own admission policies. The governing bodies of the six autism-specific schools where the research was conducted developed an admission policy specifying that learners may be admitted throughout the year. As learners leave classes, openings become available, and these may be filled with other learners of the same level of functionality. It appears that late identification by caregivers set a trajectory of late intervention for the learners. A possible explanation why the learners were not admitted earlier once they are diagnosed may be that there are only a few schools that can accommodate them. These schools are often inaccessible to rural communities or overstretched. There is a need to establish more schools accommodating children with ASD to allow for inclusive education in SA and to relieve the pressure on the existing ones.

Table 3. Selected autistic characteristics of learners attending autism-specific government-funded schools (n = 234)

Characteristic	Category	Frequency (n)	Mean (SD)	Median	Percentage (%)
3.1 Co-occurring conditions	None	167			71.4%
	ADHD	40			17.1%
	Epilepsy	19			8.1%
	Other neurological conditions	8			3.4%
3.2 Medication history	Currently on medication	125			53.4%
	No medication	109			46.6%
3.3 Type of medication	Medication for poor attention	110			47.0%
	Medication to treat Epilepsy	10			4.3%

3.4 Speech-language developmental history	Other medications (e.g. for asthma or flu)	3			1.3%
	Medications to treat anxiety	2			0.9%
	Verbal	148			63.3%
	Age of first words <47 months	92	36.82 (26.8)	26	39.3%
	Age of first words >48 months	56			24.0%
	Non-verbal	86			36.7%
	Speech and language regression	94			40.2%
	Speech and language regressions started at <47months	79	33.18 (17.2)	30	33.4%
	Speech and language regression started >48 months	16			6.8%

As seen in Table 3 (3.1) seventy-one percent of the learners did not have any co-occurring conditions, however almost 30% of the learners had comorbid neurologic conditions which included ADHD, Epilepsy, Tourette syndrome, and visual impairments. Fewer learners from our study had co-occurring conditions than in the study by Springer et al. (2013) who found that 43% of the children with ASD in the tertiary hospital clinic had co-occurring conditions. A possible explanation why fewer learners from our study had co-occurring conditions than reported by Springer et al. (2013) may be because the data were collected at different sites. Springer et al. (2013) collected the data in a tertiary hospital clinic in the Western Cape Province and our data was collected at autism-specific schools. Children with co-occurring conditions such as intellectual disability may not always comply with the schools' admission criteria and therefore not be admitted in the schools (personal communication with principals). The current findings highlight the need for further investigation of associated conditions with an ASD diagnosis. Furthermore, it is also possible that in younger children other symptoms or disorders may be masking or obscuring core symptoms of ASD, thereby delaying a diagnosis of ASD (Levy et al., 2010).

As further indicated in Table 3 (3.2) more than half (53.4%) of the learners in our study were on medication. Although only 17.1% of the learners had been diagnosed with ADHD as well as ASD,

47.0% of the learners received medication, such as Risperdal, Concerta and Ritalin, typically prescribed to treat poor attention (Damian, Gharaie, Sabzali, Darabi, & Javadi, 2017). Therefore some learners in our study received medication to improve their attention, even though they were not diagnosed with ADHD as well. A number of studies have found that tantrums and aggressive and self-injurious behaviours in children with ASD decreased with ADHD medication (McCracken et al., 2002; LeClerc & Easly, 2015; Sharma & Shaw, 2012; Troost et al., 2005).

The mean age when learners said their first words was 36.82 months, much later than typically developing children who are usually able to say their first words at age twelve months and when LLE is identified (Paul, Norbury, & Gosse, 2017; Owens 2016). Twenty-eight percent of the learners at the time of data collection were non-verbal, and 40.1% had experienced speech and language regression. Our results correspond with results from a population-based study which reported that 40% of children with ASD experience regressed speech and language (Hansen et al., 2008). Regressed speech and language usually occurs at 19-21 months and is considered a ‘red flag’ for ASD (Webb & Jones, 2009).

In summary, it may appear that differences reported represent unique South African characteristics of learners in autism-specific government-funded schools.

Associated odds of single factors predisposing delayed age of parental concern

Odds for the reference group (>48 months) was calculated for all factors associated with age of parental concern. Only one factor was significant and is reported on.

The odds of caregivers becoming concerned late (>48 months) was higher ($r = 5.0$; $p\text{-value} = <0.005$) when the first professional contacted regarding the caregivers concern was a specialist professional (developmental paediatrician, paediatric neurologist or a child psychiatrist) than when it was an allied health professional, a governmental clinic, or a general practitioner ($r = 0.8$). The finding that allied health professionals were consulted first is in agreement with research by Self,

Coufal and Parham (2010) in the US who found that children suspected of ASD are usually referred to speech-language therapists and other allied health professionals after screening. This could mean that they are known to be knowledgeable on ASD as many allied health professionals are trained to identify ASD and contribute to the diagnosis (Self et al., 2010). The odds are in agreement with the earlier reported finding that most caregivers in the study did not link LLE with ASD or recognise the early symptoms of ASD in their children. Furthermore, some caregivers might have suspected ASD but did not know whom to consult first regarding their concern or they did not suspect a serious developmental condition and therefore did not consult a specialist first. Therefore, caregivers sought assistance from allied health professionals providing intervention for developmental delays first instead of professionals specialising in ASD diagnosis.

Limitations

The researchers relied solely on data obtained from the questionnaires completed by the caregivers of the learners in the autism-specific schools. The data from the questionnaires were not validated against direct contact or interviews with the caregivers. Also, the response rate was low and further research using another data collection method than a survey is required to confirm the findings. The survey provides a baseline for further studies. Another limitation was the purposive sampling method due to the small number of completed questionnaires which were returned.

Recommendations and future research

The data obtained in this study can be used as a baseline for similar studies about learners with ASD in autism-specific government-funded schools in order for changes in increasing public awareness of ASD and accessing early intervention to be tracked. It could be helpful to conduct a study similar to the descriptive survey conducted in various autism-specific organisations within Canada and the US (Mercer, Creighton, Holden, & Lewis, 2006), where caregivers were asked specifically about their

beliefs concerning the cause of their child's ASD. Among the forty-one caregivers who completed the survey, genetic influences (90.2%), perinatal factors (68.3%), diet (51.2%), prenatal factors (43.9%) and vaccines (40.0%) were implicated as possible causes of the ASD in their child (Mercer, et al., 2006). The research is important in order to systemise local priorities for timely diagnosis and to provide targeted support. Furthermore the research may inform public awareness campaigns on ASD and its causes, support ASD training for allied health professionals, aid in planning for educational and therapeutic services, assist in measuring the efficacy of early identification and intervention programs and identifying possible contributing factors associated with trends in age at parental concern that could be modifiable. Future research should also be conducted on the emotional and attitudinal responses of caregivers following an ASD diagnosis.

Conclusion

This article revealed the complexity of factors contributing to delayed age of diagnosis and intervention of children with ASD in SA. Factors associated with delayed diagnosis and treatment for children with autism may be context-specific but appears to be a complex issue described by authors across the globe (Becerra et al., 2014; Daniels & Mandell, 2014; Fountain et al., 2011; Mandell et al., 2005). Decreasing the age of identification and diagnosis are essential steps towards improving access to early intervention. The current findings indicate that caregivers became concerned about their child's development at the advanced age of 25.2 months and the main reason for concern was their child's delayed speech and language development. Also, the results show that delayed age at parental concern may be attributed to the respondent being the father, family-caregiver or guardian, being a South-African citizen, and having a lower level of parental education. Furthermore, caregivers consulted a professional about their concern only after some time had passed (on average at 34.7 months) and this led to the learner being diagnosed (on average at 46.6 months) and admitted to the autism-specific school (on average at 6.8 years) much later. It appears that more learners are

diagnosed by single professionals instead of being diagnosed by multi-disciplinary teams. In our study, it appears that two underlying factors may improve early intervention for children with ASD, greater public awareness of ASD and many more facilities for families to have their children assessed, diagnosed and admitted to a school. The current findings highlight the need for further investigation of associated conditions with an ASD diagnosis in SA. Furthermore, it is also possible that in younger children other symptoms or disorders may be masking or obscuring core symptoms of ASD, thereby delaying a diagnosis of ASD. More than half of the learners were receiving medication to treat their challenging behaviours. Also, the findings indicate that there is a need to establish more government-funded early intervention and educational opportunities for children with ASD in all South African provinces to relieve the pressure on the existing ones and to ensure that these schools are accessible for families of learners with ASD.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This research was supported by the University of Pretoria Postgraduate Bursary.

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References

- Amr, M., Ali, W. B., Hablas, H., Raddad, D., El-Mehesh, F., El-Gilany, A.H., ...Al-Shamy, H. (2012). Sociodemographic factors in Arab children with autism spectrum disorders. *Pan African Medical Journal*, 13(65), 1-11.
- Anderson, G.N., Gilberg, C. & Miniscalco, C. (2013). Autism in Preschoolers: does individual clinician's first visit diagnosis agree with final comprehensive diagnosis? *The Scientific World Journal*, 2013, 1-7.
- Atladóttir, H.Ó., Schendel, D.E., Henriksen, T.B., Hjort, L., & Parner, E.T. (2016). Gestational age and autism spectrum disorder: trends in risk over time. *Autism Research*, 9(2), 224-231.
- Attwood, T. (2007). *The complete guide to asperger's syndrome*. London, United Kingdom: Jessica Kingsley Publishers.

- Autism South Africa. (2016). *Autism government funded schools*. Retrieved from <http://aut2know.co.za/>
- Autism spectrum disorder. (2016, January, 06). Retrieved from <https://www.nhs.uk/conditions/autism/diagnosis/>
- Becerra, T.A., Von Ehrenstein, O.S., Heck, J.E., Olsen, J., Arah, O.A., Jeste, S.S., ...Ritz, B. (2014). Autism spectrum disorders and race, ethnicity, and nativity: a population-based study. *Pediatrics*, 134(1), e63–e71.
- Brett, D., Warnell, F., McConachie, H., & Parr, J.R. (2016). Factors affecting age at ASD diagnosis in the UK: no evidence that diagnosis age has decreased between 2004 and 2014. *Journal of Autism and Developmental Disorders*, 46(6), 1974-1984.
- Crane, L., Chester, J.W., Goddard, L., Henry, L.A., & Hill, E. (2016). Experiences of autism diagnosis: a survey of over 100 parents in the United Kingdom. *Autism*, 20(2), 153-162.
- Chawarska, K., Klin, A., Paul, R., Macari, S., & Volkmar, F. (2009). A prospective study of toddlers with ASD: short-term diagnostic and cognitive outcomes. *Journal of Child Psychology and Psychiatry*, 50(10), 1235-1245.
- Damian, G.F., Gharaie, J.M., Sabzali, P., Darabi, F., Javadi, H.S.P.(2017). Comparison of risperidone and melatonin effects in methylphenidate treated children with attention deficit hyperactivity disorder for treatment of sleep disorders. *Journal of Sleep Disorders and Therapy*, 6(4), 273-278.
- Daniels, A.M., & Mandell, D.S. (2014). Explaining differences in age at autism spectrum disorder diagnosis: a critical review. *Autism*, 18(5), 583-597.
- De Giacomo, A., & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *European Child and Adolescent Psychiatry*, 7(3), 131-136.
- Department of Education (DoE). (1996). *South African schools act, act 84 of 1996*. Pretoria, South Africa: Department of Education.
- Department of Health (DoE). (2015). *Management and governance of public sector hospitals under the national health insurance*. Pretoria, South Africa: Department of Health.
- Fewster, D., & Gurayah, T. (2015). First port of call: facing the parents of autism spectrum disorder. *South African Family Practice*, 57(1), 31-34.
- Fountain, C., King, M.D., & Bearman, P.S. (2011). Age of diagnosis for autism: Individual and community factors across 10 birth cohorts. *Journal of Epidemiology & Community Health* 65(6):503-510.
- Foley, A. (2008). Foley, A. (2008, February 29). *Mother-tongue educationin South Africa*. Paper presented at PanSALB miniconference, Collosseum Hotel, Pretoria.
- Fombonne, E. (2009). Epidemiology of autistic disorder and pervasive developmental disorders. *Pediatric Research*, 65(6):591-598.
- Gardener, H., Spiegelman, D., & Buka, S.L. (2011). Perinatal and neonatal risk factors for autism: a comprehensive meta-analysis. *Pediatrics*, 128(2), 344-355.
- Guthrie, W., Swineford, L.B., Nottke, C., & Wetherby, A.M. (2013). Early diagnosis of autism spectrum disorder: stability and change in clinical diagnosis and symptom presentation. *Journal of Child Psychology and Psychiatry*, 54(5), 582-590.
- Hansen, R. L., Ozonoff, S., & Krakowiak, P., Angkustsiri, K., Jones, C., Deprey, L.J., ...Hertz-Pannier, I. (2008). Regression in autism: prevalence and associated factors in the CHARGE study. *Ambulatory Pediatrics*, 8(1), 25-31.
- Herlihy, L., Knoch, K., Vibert, B., & Fein, D. (2015). Parents' first concerns about toddlers with autism spectrum disorder: effect of sibling status. *Autism*, 19(1), 20–28.
- Holtman, M., Bolte, S., & Poustka, F. (2007). Autism spectrum disorders: sex differences in autistic behaviour domains and coexisting psychopathology. *Developmental Medicine and Child Neurology*, 49(5), 361–366.

- Kleinman, J.M., Robins, D.L., Ventola, P.E., Pandey, J., Boorstein, H.C., Esser, E.L., Wilson, L.B., ...Fein, D. (2008). The modified checklist for autism in toddlers: a follow-up study investigating the early detection of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38(5), 827-839.
- Kozlowski, A.M., Matson, J.L., Horovitz, M., Worley, J.A., & Neal, D. (2011). Parents' first concerns of their child's development in toddlers with autism spectrum disorders. *Developmental Neurorehabilitation*, 14(2), 72-78.
- LeClerc, S., & Easly, D. (2015). Pharmacological therapies for autism spectrum disorder: a review. *Pharmacy and Therapeutics*, 40(6), 389-397.
- Levy, S.E., Giarelli, E., Lee, L.C., Schieve, L.A., Kirby, R.S., Cunniff, C., ...Rice, C.E. (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental and Behavioral Pediatrics* 31(4), 267-275.
- 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.
- Mazurek, M.O., Handen, B.L., Wodka, E.L., Nowinski, L., Butter, E., & Engelhardt, C.R. (2014). Age at first autism spectrum diagnosis: the role of birth cohort, demographic factors, and clinical features. *Journal of Developmental and Behavioral Pediatrics*, 35(9), 561-569.
- Mercer, L., Creighton, S., Holden, J.J.A., & Lewis, M.E.S. (2006). Parental perspectives on the causes of an autism spectrum disorder in their children. *Journal of Genetic Counseling*, 15(1), 41-50.
- McCracken, J.T., McGough, J.H., Shah, B., Cronin, P., Hong, D., Aman, H.G., ...McMahon, D. (2002). Risperidone in children with autism and serious behavioral problems. *New England Journal of Medicine*, 347(5), 314-321.
- Musa, M.M., & Fakher, M.Y. (2016). Sociodemographic correlates of autism spectrum disorders in children: Study in Autism Center\ThiQar health office\Iraq. *Global Journal of Multidisciplinary Studies*, 4(7), 100-107.
- New, A.S., Triebwasser, J., & Charney, D.S. (2008). The case for shifting borderline personality disorder to Axis I. *Biological Psychiatry*, 64(8), 653-659.
- Owens, R. E., Jr. (2016). *Language development: an introduction*. (9th ed.). Boston, United States: Pearson.
- Ozonoff, S., Iosif, A.M., Baguio, F., Cook, I.C., Hill, M.M., Hutman, T., ...Young, G.S. (2010). A prospective study of the emergence of early behavioral signs of autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 49(3), 256-266.
- Pattinson, R.C. (2013). *Saving babies 2010-2011: Eighth report on perinatal care in South Africa*. Pretoria, South Africa: Tshepesa Press.
- Paul, R., Norbury, C., & Gosse, C. (2017). *Language disorders from infancy through adolescence: assessment & intervention* (5th ed.). Missouri, Untied States: Elsevier.
- Petersen, I., & Lund, C. (2011). Mental health service delivery in South Africa from 2000 to 2010: one step forward, one step back. *South African Medical Journal*, 101(10), 751-757.
- Riya, S., Begum, M., Begum, N., Majid, F., Jahan, S., & Rahman, A. (2014). Maternal risk factors associated with autistic children. *Anwer Khan Modern Medical College Journal*, 5(2), 14-17.
- Rivet, T.T., & Matson, J.L. (2011). Review of gender differences in core symptomatology in autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(3), 957-976.
- Samms-Vaughan, M.E., (2014). The status of early identification and early intervention in autism spectrum disorders in lower- and middle-income countries. *International Journal of Speech-Language Pathology*, 16(1), 30-35.
- Self, T.L., Coufal, K., & Parham, D.F. (2010). Allied healthcare providers' role in screening for autism spectrum disorders. *Journal of Allied Health* 39(3), 165-174.

- Sharma, M.A., & Shaw, S.R. (2012). Efficacy of risperidone in managing maladaptive behaviors for children with autistic spectrum disorder: a meta-analysis. *Journal of Pediatric Health Care*, 26(4), 291-299.
- Spaull, N. (2013). Poverty & Privilege: primary school inequality in South Africa. *International Journal of Educational Development*, 33(5), 436-447.
- Springer, P.E., Van Toorn, R., Laughton, B., & Kidd, M. (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.
- Thomas, P.D., Badoe, E.V., & Owusu, N.K. (2015). Family perspectives of autism spectrum disorder in urban Ghana. *Journal of the International Child Neurology Association*, 1(1), 1-7.
- Troost, P.W., Lahius, B.E., Steenhuis, M., Ketelaars, C.E.J., Buitelaar, J.K., Van Engeland, ... Hoekstra, P.J. (2005). Long-term effects of risperidone in children with autism spectrum disorders: a placebo discontinuation study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44(11), 1137-1144.
- Van Biljon, S., Kritzinger, A., & Geertsema, S. (2015). A retrospective case report on demographic changes of learners at a school for children with autism spectrum disorder in the Gauteng Province. *South African Journal of Childhood Education*, 5(1), 42–61.
- Van Wijngaarden-Cremers P. (2017). Autism in girls and women. In Barahona Corrêa B., & van der Gaag RJ. (Eds.), *Autism spectrum disorders in adults* (pp. 193-202). Cham, Switzerland: Springer.
- Webb, S.J., & Jones, E.J. (2009). Early identification of autism: early characteristics, onset of symptoms, and diagnostic stability. *Infants & Young Children*, 22(2), 100-118.
- Werner, E., Dawson, G., Osterling, J., & Dinno, N. (2000). Brief report: Recognition of autism spectrum disorder before one year of age: a retrospective study based on home videotapes. *Journal of Autism and Developmental Disorders*, 30(2), 157-162.
- 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.
- Young, R.L., Brewer, N., & Pattison, C. (2003). Parental identification of early behavioural abnormalities in children with autistic disorder. *Autism*, 7(2), 125-143.

Chapter 4
Families raising children attending autism-specific government-funded schools in South Africa

This article was submitted to an international peer-reviewed journal, the Journal of Family Studies. The format of the article is that of the journal and differs from the rest of the thesis.

Families raising children attending autism-specific government-funded schools in South Africa

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Abstract

Limited research is available about the financial costs incurred by families of children with ASD in low-and-middle-income countries (LMICs). This article describes socio-demographic characteristics of and financial costs encountered by families whose children attend autism-specific government-funded schools in South Africa (SA). Survey questionnaires were completed by 234 caregivers (representing 28.4% of the caregivers involved in the six autism-specific schools around the country). The distribution of population group, nationality, household size, marital status, and average combined monthly household income closely reflect the national majority of families in SA. Families are living on a relatively low monthly household income and spending a significant amount on school fees, transportation, medical insurance payments, and extracurricular therapeutic services. Monthly social assistance government grants were accessed by 46.6% of families only and 57% do not own their own dwelling. Certain factors were associated with higher monthly income: higher qualification of the father and mother, school fees, medical insurance scheme payments and extracurricular therapy services. Key differences between our data and data from other LMICs are that our sample showed higher monthly household income, lower parental education, and more single mothers. LMICs families receive limited social assistance grants from governments. Country-specific research on families of children with ASD is needed.

Keywords: autism spectrum disorder; families; financial costs; government-funded schools; raising children; South Africa

Introduction

An ASD diagnosis is usually associated with significant lifetime costs which are mostly borne by the families of children with ASD (Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014). Families are typically required to care for and support their child with ASD themselves (de Vries, 2016) as the child requires intensive intervention, specialised educational services, and continuous lifelong support (Parish, Thomas, Williams, & Crossman, 2015). Most studies about costs of families raising children with ASD have been conducted in high-income countries [HICs] (Buescher, Cidav, Knapp, & Mandell, 2014; Ganz, 2007; Horlin et al., 2014; Olivier & Ah Hing, 2009; Sharpe & Baker, 2011). However, research remains critically lacking in LMICs, such as SA (Clasquin-Johnson & Clasquin-Johnson, 2018; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012). Despite increased efforts to improve local capacity to support families of children with ASD in SA (Chambers et al., 2017; Grinker et al., 2012; Smith, Malcolm-Smith, & de Vries, 2016), families still experience challenges in accessing diagnostic, intervention, and educational services (de Vries, 2016; Malcolm-Smith, Hoogenhout, Ing, Thomas, & de Vries, 2013). For example, cost-free disability-related intervention services in SA are often heavily overburdened and scarce, especially at state level (Grinker et al., 2012). Families are therefore often compelled to resort to expensive private disability-related intervention services for their child with ASD (Saloojee, Phohole, Saloojee, & IJsselmuiden, 2006). Even though some South African families of children with ASD belong to private medical insurance schemes, the schemes do not cover long-term costs of disability-related intervention services as these amenities are too expensive (Saloojee et al., 2006). Consequently, families need to bear the cost of intervention services themselves. The responses to intervention varies widely and it is not yet

possible to predict which children will benefit from which intervention (Becerra et al., 2017). Parents are using numerous alternative approaches to treat the core symptoms of ASD such as buying costly foods or dietary supplements and prescriptions for psychotropic medication (Sharpe & Baker, 2011). Expenditure associated with having a child with ASD, however, is not limited to the cost of interventions (Sharpe & Baker, 2011).

Families raising children with ASD have significant costs related to the education of the child (Järbrink, 2007). Children with ASD are either placed in mainstream schools or schools for special educational needs (Frederickson & Jones, 2010; Jäbrink, 2007; Waddington & Reed, 2017). Although there are no official statistics available in SA, it appears that the majority of children with ASD are being placed in autism-specific government-funded (public) schools (Autism South Africa, n.d.; Pillay, Duncan, & de Vries, 2017). In HICs public education is funded by the state, local or federal government (United States [US] Department of Education, 2011; Department of Education, Employment and Workplace Relations, 2011). However, in LMICs, such as SA, government-funded schools are only partially subsidized by the government and caregivers are still obligated to pay school fees (Dass & Rinquest, 2017). These schools are often overstretched (Grinker et al., 2012) and inaccessible due to the poor public transport system in SA (Harris et al., 2011). Parents are often compelled to either enrol their child in independent (private) schools, which is extremely expensive (Kiru & Cooc, 2017) or pay excessively for private transport for their child to get to school (Goudge, Gilson, Russell, Gumede, & Mills, 2009). Furthermore, children with ASD also require dedicated childcare, which is often costly and sometimes needed for a more extended period than in the case of a typically developing child, as they cannot be left unsupervised (Sharpe & Baker, 2011). However, not all parents can afford a paid caregiver (Sharpe & Baker, 2011). They are often either unemployed themselves or do not work full-time as they have to take care of their child (Ganz, 2007). Therefore it is evident that families raising children with ASD require financial support in caring for their child (Järbrink, 2007). It appears that currently, only families in HICs receive financial support from the

government (Autism Awareness Australia, n.d.; Autism Speaks, n.d.; The National Autistic Society, n.d.), but limited financial assistance is provided to families from LMICs by the government (Charles, 2014).

The family systems approach and the International Classification of Functioning, Disability and Health Child and Youth Version (ICF-CY) draws attention to a more holistic view of families raising children with ASD (Horlin et al., 2014; World Health Organization [WHO], 2007). Research confirmed the value of using the family systems approach (Alli, Abdoola, & Mupawose, 2015; Cridland, Jones, Magee, & Caputi, 2014) and the ICF-CY (Aljunied & Frederickson, 2014; Bölte et al., 2018) as a framework for children with ASD. The family systems approach stresses that the individual cannot be viewed in isolation but rather as part of their family, as the family is seen as a unit (Mirsalimi, Perleberg, Stoval, & Kaslowi, 2003). Families of children with ASD have various expenditure associated costs which have a significant influence on the entire family (Horlin et al., 2014). Similar to the family systems approach, the ICF-CY also states that the child should be seen in the context of the family system (WHO, 2007). There are various environmental factors within the ICF-CY related to the family which influence the everyday life outcome of individuals with ASD (Bölte et al., 2014; Castro, Ferreira, Dababnah, & Pinto, 2013; WHO, 2007). Although a few studies have focused on the value of the ICF-CY framework for preschool children with ASD (Di Rezze et al., 2012; Gan, Tung, Yeh, & Wang, 2013), limited research has focused on the environmental factors component of the ICF-CY influencing the outcomes of school-aged children with ASD (Aljunied & Frederickson, 2014). In addition, there is a paucity of information in LMICs, such as SA, on the financial difficulties experienced by families of children with ASD. The research may increase the understanding of the financial impact of ASD on the family, inform support services for these families, improve the allocation of therapeutic and educational resources to those affected by ASD, inform action in comparable countries, and assist to target medical insurance policies that affect

access to and cost of ASD related services (Durkin et al., 2010; Horlin et al., 2014). Therefore research regarding the families who are affected by ASD is essential.

Goals of the study

The aim of the study was to describe the socio-demographic characteristics of and financial costs encountered by families whose children attend autism-specific government-funded schools in SA.

Methods

Settings of participating schools

There were only six autism-specific government-funded schools in SA during the time of data collection. The researchers included all six schools, all of which were situated in urban areas. Only three out of nine provinces provide limited autism-specific government-funded educational services, since the schools are located in urban areas within the Gauteng, Western Cape, and Eastern Cape Provinces only. Independent schools are not all autism-specific and were therefore excluded from the study. Participating schools only admit children who have been diagnosed with ASD and whose parents reside or work in the school's catchment area. Once admitted, multi-disciplinary teams assess the learner to establish the current level of performance and to identify educational needs. The age of the learners in the schools ranged from 3 to 21 years (mean age = 9.8 years), and the total number of children in all six schools was 823.

Participants

There are no official statistics available on the prevalence of ASD among children in LMICs, including SA (Bakare & Munir, 2011). Therefore, it was postulated that the selected schools accommodate the largest total of school-going children with ASD and are therefore described as "population-rich" research settings. Potential participants included all the caregivers of learners attending the six autism-specific government-funded schools in SA. Two hundred and thirty-four caregivers participated in the study. The majority of the caregivers were mothers (85.0%) with the

remainder 15% consisting of fathers, other family members, and guardians. Not all the caregivers were necessarily the primary caregivers of the learners. Forty-four percent ($n = 104$) of the mothers and thirty-six percent ($n = 85$) of the fathers had a diploma, degree, or postgraduate qualification.

Data collection tools and procedures

Before data collection ethical approval for the study was obtained from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria (GW20160702HS), Departments of Education (D2016/268) in the three provinces approved the research study, as well as the principals of the autism-specific government-funded schools. Data collection material included a comprehensive survey questionnaire used to obtain socio-demographic information from the caregivers and the financial costs related to raising children with ASD. The researchers reviewed survey research about socio-demographic characteristics and financial costs of families raising children with ASD in order to develop a comprehensive survey questionnaire (Cidav, Marcus, & Mandell, 2011; Horlin et al., 2014; Knapp, Romeo, & Beecham, 2009; Meral & Cawkaytar, 2012; Parish et al., 2015; Sharpe & Baker, 2007; Thomas, Badoe, & Owusu, 2015). The survey questionnaire included questions about primary caregiver, nationality, population group, highest qualifications of the mother and of the father, marital status of the mother, average monthly household income, number of people living in the household, type of dwelling, whether or not the family belonged to medical insurance, if the family received a social assistance government grant or a school bursary, and particulars regarding school and therapy related costs. Self-administered, paper-based surveys were preferred to internet surveys. The reason was two-fold: 1) 64.8% of the SA population does not have access to the internet (Statistics South Africa, 2011) and 2) the length of the survey would have been compromised given the suggested briefness of internet surveys.

Caregivers of children with ASD attending the schools were invited to attend an information session at their child's school and the researcher explained to the nature of the study. The caregivers

were asked to complete the consent form and the self-administered survey questionnaire at their earliest convenience and to return it to the learner's teacher. Survey packages were distributed to all caregivers who were unable to attend the information session by placing the survey package in the child's school bag. A follow-up card was also distributed to the caregivers reminding them to return the survey questionnaire and consent form by a certain date. After considerable efforts to introduce the study to caregivers, the return rate was still low. We received 234/823 (28.4 %) self-completed survey questionnaires back from the respondents. The data was extracted from the survey questionnaires and captured into IBM SPSS (Version 24) (IBM Corp, 2018) to facilitate analysis. To determine the existence of significant associations amongst certain variables, non-parametric tests were used, with a significance level of $p < 0.05$.

Results and Discussion

Socio-demographic characteristics of families

Table 1 presents data on the socio-demographic characteristics of study participants.

Table 1 Socio-demographics of families raising children attending autism-specific government-funded schools (n = 234)

Characteristic	Category	Frequency (n)	Percentage (%)
1.1 Respondent	Mother	199	85.0%
	Father	26	11.1%
	Family member	8	3.4%
	Guardian	1	0.5%
1.2 Nationality	South African	207	88.5%
	Africa (Zimbabwe, Mozambique, Malawi, Democratic Republic of Congo, Zambia, Nigeria, Ethiopia)	26	11.1%
	Outside Africa (United Kingdom)	1	0.4%
1.3 Population group	Black	183	78.2%
	Coloured	30	12.8%
	White	16	6.8%
	Asian/Indian	3	2.2%
1.4 Primary caregiver	Mother only	98	41.9%
	Both parents	88	37.6%
	Extended family members	33	14.10%
	Nanny only	8	3.4%
	Father only	7	3.0%
1.5 Highest qualification of primary caregiver	Gr12 (senior school certificate)	96	41.0%
	Diploma / degree / postgraduate qualification	86	36.7%
	<Gr12 (senior school certificate)	30	12.8%
	unknown / deceased / no formal schooling	22	9.5%
1.6 Highest	Diploma / degree / postgraduate	85	36.3%

	qualification		
father	Gr 12 (senior school certificate)	69	29.5%
	unknown / no formal schooling	50	21.4%
	< Gr12 (senior school certificate)	30	12.8%
1.7 Marital status of the mother	Single / divorced / widowed / separated	129	55.1%
	Married	105	44.9%
1.8 Highest qualification of mother	Diploma / degree / postgraduate qualification	104	44.4%
	Gr 12 (senior school certificate)	99	42.3%
	<Gr12 (senior school certificate)	21	9.0%
	Unknown / deceased / no formal schooling	10	4.3%
1.9 Number of people living in the household	2-4	119	51.7%
	>5	113	48.3%
1.10 Type of dwelling	Own my own house/ apartment in a residential area	100	42.7%
	Renting a house/apartment	64	27.4%
	I stay with others	55	23.5%
	Living in informal dwelling	15	6.4%

As can be seen in Table 1 (1.1), eighty-five percent of the respondents were mothers, and fifteen percent were the father, family caregiver, or guardian. Mothers as respondents appear to be characteristic of family-related surveys in autism studies, both in LMICs and HICs. In a study conducted in Northern India in autism-specific schools and organizations, 75% of the respondents were mothers (Tripathi, 2015). Furthermore, a survey conducted in the Pennsylvania, US, reported that 86% of the respondents were the mothers of children with ASD (Mandell & Salzer, 2007).

In our study, the majority of caregivers were black (78.2%). The different population groups in the study do not only represent the demographic profile of families raising children with ASD in the autism-specific government-funded schools in SA, but also closely resembles the distribution of population groups in SA (Statistics South Africa, 2015). Eighty percent of the South African population is black, 10.4% white, 7.3% colored, and 2.3% Indian or Asian (Statistics South Africa, 2015). It should be noted that the prevalence rate of ASD in children among population groups in LMICs, such as SA, have not yet been established (Elsabbagh et al., 2012). Although the association between population group and ASD is unconfirmed and conflicting (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004), some studies conducted in HICs reported that the prevalence rate of ASD was higher among children from the white population groups than children from other

population groups (Jo et al., 2015; Mandell et al., 2009). For example, in a population-based study from 2009-2010 by the National Center for Health Statistics (NSCH) in the US eighty percent of the of the total sample of children with ASD were from non-Hispanic-white population groups, while the other 19.7% were non-Hispanic-Black (7.6%) or Hispanic-any-race (9.3%) (Jo et al., 2015). Families are living on a relatively low monthly household income and spending a significant amount on school fees, transportation, medical insurance payments, and extracurricular therapeutic services. Monthly social assistance government grants were accessed by 46.6% of families only and 57% do not own their own dwelling.

Although the majority of caregivers in the current study were South African (88.5%), a small percentage of the caregivers indicated that they had immigrated to SA from countries within (11.1%) and outside of Africa (0.4%). The nationality distribution of permanent residents in our study is similar to the information reported by Statistics South Africa where leading sending countries of migrants were within Africa (Statistics South Africa, 2013). However, our results differ from a study conducted in a tertiary hospital developmental clinic in the Western Cape Province of SA over a two-year period (2008-2010) where 6.9% of the families were foreign-born migrants (Springer, van Toorn, Laughton, & Kidd, 2013). Possible explanations may be the scarcity of specialized education services in Africa and an increase in immigration to SA over the past decade (Springer et al., 2013; Statistics South Africa, 2013; Thomas et al., 2015). The prevalence rate of ASD in children of foreign-born migrants in SA has not yet been determined (Elsabbagh et al., 2012). However, some studies conducted in LMICs and HICs revealed increased prevalence rates or increased risk of ASD in children of foreign-born migrants compared to children born in native families (Barnevik-Olsson, Gillberg, & Fernell, 2010; Becerra et al., 2017; van der Ven, Termorshuizen & Laan, 2013). A birth-cohort study (1999-2003) from Sweden reported an ASD prevalence rate of four times higher in the Somali population than that of the non-Somali population (Barnevik-Olsson et al., 2010). Meanwhile, in another population-based cohort study (1998-2007) conducted in the Netherlands, children of

foreign-born migrants were at lower risk of ASD than children of Dutch-born parents (van der Ven et al., 2013).

The results showed that only forty-four percent of the mothers and thirty-six percent of the fathers had a diploma, degree, or postgraduate qualification. The post-secondary education attainment level from our study is higher than the national post-secondary attainment level (9.1%) reported in SA (Statistics South Africa, 2016). It appears that in recent years there was an increase in the education level of South Africans. It also appears that caregivers in our study had a lower post-secondary attainment level than caregivers of children with ASD in other countries. An Iranian study conducted in autism-specific schools and mother and child clinics reported that 51% of the parents attended university (Samadi, Mahmoodizadeh, & Samuels, 2012). In addition, another study by an agency offering specialized disability services in Canada, a HIC, found that forty-nine percent of mothers and fifty-six percent of fathers had post-high school education or university degrees (Rivard et al., 2014).

A large percentage of caregivers from our study reported that they were unmarried (55.1%) which suggests that children were often being raised by a single parent, usually a mother (85.0%), with little indication of live-in fathers. The percentage of mothers who indicated that they were unmarried in our study is in close agreement with the national status of unmarried mothers (48.4%) reported in SA (Statistics South Africa, 2015). Single parenthood reported in our study may indicate a need for additional support when raising a child with ASD. Contrary to our findings, fewer parents raising children with ASD were unmarried in other studies conducted in LMICs and HICs. Samadi et al. (2012), for example, reported ninety-three percent of parents were married. Furthermore, a university-based research study at multiple sites across North America also found that 93% of the parents of children with ASD were married (Kanne & Mazurek, 2010).

Approximately half of the caregivers indicated that between two and four people were living in their household (51.7%). The total number of people living in the households includes the children

with ASD, their caregivers, and other family members. Our results are similar to the average household size (3.30) in South Africa (Statistics South Africa, 2015). There is a dearth of research on the household composition of families raising children with ASD in LMICs and HICs (Schlebusch, Dada, & Samuels, 2017). Most studies conducted in HICs only report on the number of children with ASD or other disabilities living in the household, and not on the total number of people (Bromley, Hare, Davison, & Emerson, 2004, Jo et al., 2015; Parish et al., 2015). Furthermore, the smaller household size reported in our study may be related to the single parenthood reported earlier and the fact that caregivers indicated that they were renting a house or apartment, living with others, or living in informal housing.

In our study, more than half (57.3%) of the caregivers indicated that they were unable to own a house or an apartment and were either renting a property (27.4%), living with others (23.45), or living in informal housing (6.4%). Fewer families in our study were living in formal dwellings, such as houses and apartments, compared to the 80% of South African households living in formal housing (Statistics South Africa, 2015). However, it should also be noted that there was a general decline in homeownership in SA over the past decade (Statistics South Africa, 2015). Factors which might have contributed to the decline include the National Credit Control Act and the economic crisis in the country (Republic of South Africa, 2006; Statistics South Africa, 2015). Minimal research has been conducted in LMICs and HICs on how children with disabilities, such as ASD, influence household financial decisions, such as owning a house (Bogan & Fernandez, 2017; Schlebusch et al., 2017). However, results from our study are in agreement with a literature review indicating that US families raising children with disabilities, such as ASD, are often not in the financial position to own a house due to their economic circumstances (Park, Turnbull, & Turnbull, 2002).

Financial costs incurred by families

Table 2 reports on information regarding the financial costs encountered by families whose children attend the six autism-specific government-funded (public) schools in SA, and significant associations were noted. Basic frequencies, means, standard deviations (SD) and percentages for the financial costs incurred by the families in the study are also presented in Table 2. The exchange rate as reported in the table and text below was 1 US Dollar (\$) = 11.95 South African Rand (R) on the 7th of February 2018.

Table 2 Financial costs incurred by families raising children attending autism-specific government-funded schools (n = 234)

Characteristic	Category	Frequency (n)	Mean (SD)	Percentage (%)
2.1 Unreimbursed out-of-pocket expenditures				
2.1.1 Monthly school fees for the child	\$41.9-\$122.1 (R500-R1459)	88	\$81.5 (84.2)	37.6%
	\$0-\$41.8 (R0-R499)	79		33.7%
	>\$122.2 (>R1450)	67		28.1%
2.1.2 Transport used to get to the child's school from parent's home	Private transport	151		64.5%
	School bus	56		23.9%
	Public transport	27		11.6%
2.1.3 Distance (km) from parent's home to child's school	<15km	132	16.4 (12.7) km	56.4%
	>16km	102		43.6%
2.1.4 Family belonging to medical insurance	No	132		56.4%
	Yes	102		43.6%
2.2 Intervention currently utilized				
2.2.1 Number of children in the school receiving extracurricular therapies	Child receiving extra therapy	78		32.5%
2.2.2 Therapy services excluded from school fees	Speech-Language Therapy	27		34.6%
	Occupational Therapy	20		25.6%
	Psychiatry services	9		11.5%
	Music therapy	8		10.3%
	Applied Behavior Analysis	3		3.9%
	Physiotherapy	3		3.8%
	Floor Time Therapy	2		2.6%
	Hippo therapy or therapeutic riding	2		2.6%
	Psychology services	2		2.5%
	Aqua therapy	1		1.3%
	Dietary information sessions	1		1.3%
2.2.3 Amount spent on extracurricular therapy	\$1-\$167.3 (R1-R1999)	55	\$81.9 (84.9)	70.5%
	\$167.4-\$251.0 (R2000-)	20		25.6%

services per month	2999)				
	>\$251.1 (>R3000)	3			3.9%
<i>2.3 Financial resources</i>					
2.3.1 Combined monthly household income	\$133.8- (R1600-R12799)	\$1071.1 64	70	\$903.7(612.3)	29.9%
	\$1-\$133.7 (R1-R1599)				27.3%
	\$1071.2-\$2142.2 (R12800-R25599)		56		24.0%
	>\$2142.3 (>R25600)		29		12.4%
	No income		15		6.4%
2.3.2 Family receiving school bursary	No	109			91.9%
	Yes	19			8.1%
2.3.3 Family receiving a social assistance grant from South African Social Security Agency the (SASSA)	No	125			53.4%
	Yes	109			46.6%
2.3.4 Type of social assistance grant	Disability grant	69			63.3%
	Care dependency grant	35			32.1%
	Child support grant	5			4.6%
2.3.5 Social assistance grant amount family receives	\$125.5-\$138.9 (R1499- R1660)	102		\$124.1(30.7)	93.6%
	\$31.7-\$125.4 (R380 – R1499)	7			6.4%

The average combined monthly household income for families in our study was \$903.7/R10799. More than half (53.9%) of the caregivers fell in the middle-income category (\$133.8-\$2142.1/R1600-R25599), according to Statistics South Africa (2011). The families' combined average monthly household income (\$903.7/R10799.2) is in close agreement with the average household income (\$963.5/R11514) in SA (Statistics South Africa, 2015). Furthermore, our results indicate that most of the caregivers were living above the poverty threshold in SA (R441 per month) (Statistics South Africa, 2015). Findings from our study differ from survey research conducted in Turkey, a LMIC (Meral & Cavkaytar, 2012). In that study, 31.7% of the families raising children with ASD fell in the low-income category (901-1500 Turkish Lira [TL]) and 59.7% of the families were living below the poverty threshold (2000 TL) (Chandran, 2016; Meral & Cavkaytar, 2012). However, our results are in agreement with a case study conducted by the Institute for Democracy and Economic Affairs (IDEAS) Autism Centre in Malaysia (Chandran, 2016). The study found that most of the families fell in the middle-income category (3961-8319 Malaysian Ringgit [RM]) and were, therefore, living above the national poverty threshold of RM800 (Chandran, 2016).

As can be seen in Table 2 (2.1.1-2.2.3) there are many expenses related to the care and support of a child with ASD. When considering the average monthly amount spent on school fees and extracurricular therapy services (\$163.4/R1952.6) in relation to the caregivers' combined average monthly household income (\$903.7/R10799.2), caregivers spend almost 20% of their income on the school fees and therapy services. Therefore, the caregivers are left with a relatively small amount (\$740.3/R8846.5) to cover other expenditures such as housing, water, electricity, transport, food, medical health and other expenses. Limited research has been conducted on the costs related to ASD in LMICs (Clasquin-Johnson & Clasquin-Johnson, 2018). However, our results are in close agreement with studies conducted in HICs which reported that ASD is associated with a substantial loss of household income (Meral & Cavkaytar, 2012; Montes & Halterman, 2008; Parish et al., 2015; Sharpe & Baker, 2011). Malaysian families reported that they were spending on average 13% of their monthly household income on school fees and therapeutic services (Chandran, 2016).

Table 2 (2.3.2 – 2.3.5) shows that only a few families raising children attending autism-specific government-funded (public) schools in South Africa are receiving some financial support from the government in the form of school subsidy (8.1%) and social assistance government grants (46.6%) (\$124.1/R1483.5) to alleviate the high financial burden associated with ASD. The results from our study are in close agreement with the percentage (45.5%) of South Africans receiving at least one type of social assistance government grant (Statistics South Africa, 2015). One of the reasons why some households (53.4%) were not receiving social assistance government grants for their children is because they did not meet the minimum requirements which include having a combined family monthly income of less than \$1029.2/R12300 (Statistics South Africa, 2015). Our results show that 63.6% of the families were earning less than \$1071.1/R12799. Furthermore, some families do not receive social assistance government grants because the majority of children with ASD have no physical disabilities and therefore present as typically developing children (Charles, 2014). Another possible reason may be that families do not know where to find information about the

social assistance government grants (personal communication with school principals, February 21, 2016) or because they were foreign-born migrants. Only South African citizens, permanent residents or refugees living in SA at the time of application may apply for social assistance government grants (Charles, 2014). To date, only a handful of studies in HICs have examined the financial support needs of parents raising children with ASD (Hartley & Schultz, 2015). The US federal and state government provides a range of financial resources for individuals with ASD which include the Medicaid Home and Community Based Services (HCBS) waivers, Social Security Income (SSI), and Social Security Disability Insurance (SSDI) (Autism Speaks, n.d.). In the UK the government offers a range of benefits for families raising children with ASD (The National Autistic Society, n.d.). These benefits include disability living allowances, carer allowances, child tax credit, housing benefits, and income benefits (The National Autistic Society, n.d.). Lastly, in Australia families of children with ASD are supported at both state and federal government level through Helping Children With Autism (HCWA) funding, National Disability Insurance Scheme (NDIS), Medicare, Centrelink and other government subsidized services (Autism Awareness Australia, n.d.).

Furthermore, significant associations were found between the following variables and monthly household income: qualification of the father (*p-value* = <0.001), qualification of the mother (*p-value* = <0.001), marital status of the mother (*p-value* = <0.001), school fees (*p-value* = <0.001), school bursaries (*p-value* = <0.001), medical insurance schemes (*p-value* = <0.001) and extracurricular therapy services (*p-value* = <0.004). The results show that the higher the monthly household income, the higher the qualification of the father and mother, the school fees, the medical insurance scheme payments and the extracurricular therapy services. These associations show the factors that were likely to have lessened the financial hardships of the sample. For a significant proportion of the sample, a number of factors could have contributed to hardships. Sixty-three percent of the father and 55.6% of the mothers had no tertiary education, 55.1% were unmarried and/or single parents and only 42.7% were homeowners.

Limitations

Some limitations should be noted. Firstly, the researchers depended exclusively on information obtained from the survey questionnaires completed by the caregivers of the children in the autism-specific schools. Secondly, the information from the survey questionnaires was not verified with the parents through interviews. Thirdly, the response rate from the caregivers was not as high as was hoped. Lastly, since the participating schools were government-funded and situated in urban areas only, many children with ASD from independent schools and rural areas were excluded from the study. If all families raising children with ASD in SA were included in the study, the socio-demographic profile might have differed, for example, families from rural areas are generally poorer, and the richer families' children could have been attending independent schools.

Recommendations and future research

Survey research should be conducted on a large scale in LMICs on how best to support families financially by asking them to report on their needs. Now that the socio-demographics of families with children in government-funded autism-specific schools are known and it has transpired that they are similar in some ways to the characteristics of average families in SA, a comparison with families in independent schools may inform us more about the diversity of learners with ASD in SA. Furthermore, there is a need for professionals to consider charging reduced fees for therapies in LMICs families who could not otherwise obtain financial assistance. Another study should investigate the financial challenges which affect families in other LMICs. Lastly, future research in other LMICs should also investigate the family-related factors influencing everyday life outcomes of children with ASD. Further research is required to understand more about the large number of single mothers in our study.

Conclusion

In the current study, it was found that an ASD diagnosis has a significant financial impact on the entire family. This finding points to the importance of using the family systems approach and the ICF-CY as two functional frameworks when working with families of children with ASD. Various professionals are directly involved in the identification, diagnosis, and treatment of ASD (American Speech-Language-Hearing Association [ASHA], 2016). It is important for them to understand the effect on the family of having a child with ASD and the influence of the specific family-related environmental factors on the child's everyday life outcomes. Although the return rate was low, the results closely reflect the characteristics of the majority of families in South Africa with reference to the population group, nationality, household size, marital status, and average combined monthly household income. It is encouraging to see that families from the black population groups now have better access to autism-specific schools for their children than in the past when they were excluded from the schools (Van Biljon et al., 2015). Furthermore, the findings differ to a certain extent from data obtained in other LMICs, showing the diversity of average families with children with ASD in these countries and the need for context-specific research. The study also adds to the growing body of evidence that the societal costs of ASD are exceptionally high (Sharpe & Baker, 2011). Specifically, the study contributed to a better understanding of the factors which might be associated with higher monthly household income. Families in our study were receiving a relatively average monthly household income but had to spend a significant amount of money on monthly school fees, transportation to school and back, medical insurance payments, and extracurricular therapeutic services. Therefore, families raising children with ASD experience a high financial burden and require additional financial support from the government. However, it is difficult to identify how the government may be financially supporting families of children with ASD as there is limited data available. Policies and social assistance government grants should be reformed to alleviate the high financial burden for families raising children with ASD as these families have more expenses than

families raising children with other disabilities (Sharpe & Baker, 2011). The current findings, therefore, highlight the need for LMICs to make the provincial departments of education and national government aware of the needs of families with children with ASD in their schools.

Funding

This work was supported by the University of Pretoria Postgraduate Scholarship.

Compliance with Ethical Standards

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethical approval for the study was provided by the University of Pretoria.

Informed Consent

Informed consent was obtained from all individual participants included in the study.

Conflict of interest

No potential conflict of interest was reported by the authors.

References

- Alli, A., Abdoola, S., & Mupawose, A. (2015). Parents' journey into the world of autism. *South African Journal of Child Health*, 9(3), 81-84.
- Aljunied, M., & Frederickson, N. (2014). Utility of the international classification of functioning, disability and health (ICF) for educational psychologists' work. *Educational Psychology in Practice*, 30(4), 380-392.
- American Speech-Language-Hearing Association [ASHA]. (2016). *Scope of practice in speech-language pathology*. Retrieved from <https://www.asha.org/policy>.
- Autism Awareness Australia. (n.d.). *Financial support*. Retrieved from <http://www.autismawareness.com.au/financial-support/>
- Autism South Africa. (n.d.). *Autism government funded schools*. Retrieved from <http://aut2know.co.za/>
- Autism Speaks. (n.d.). *Financial assistance*. Retrieved from <https://www.autismspeaks.org/family-services/financial-assistance>

- Barnevik-Olsson, M., Gillberg, C., & Fernald, E. (2010). Prevalence of autism in children of Somali origin living in Stockholm: brief report of an at-risk population. *Developmental Medicine & Child Neurology*, 52(12), 1167-1168.
- Becerra, T.A., Massolo, M.L., Yau, V.M., Owen-Smith, A.A., Lynch, F.L., Crawford, P.M., ... Croen, L.A. (2017). A survey of parents with children on the autism spectrum: Experience with services and treatments. *The Permanente Journal*, 21(16), 16-009.
- Bogan, V.L., & Fernandez, J.M. (2017). How children with mental disabilities affect household investment decisions. *American Economic Review: Papers & Proceedings*, 107(5), 536-540.
- Bölte, S., de Schipper, E., Robinson, J.E., Wong, V.C., Selb, M., Singhal, N., ... Zwaigenbaum, L., (2014). Classification of functioning and impairment: the development of ICF core sets for autism spectrum disorder. *Autism Research*, 7(1), 167-172.
- Bölte, S., Mahdi, S., de Vries, P.J., Granlund, M., Robison, J.E., Shulman, C.,...Selb, M. (2018). The Gestalt of functioning in autism spectrum disorder: Results of the international conference to develop final consensus International Classification of Functioning, Disability and Health core sets. *Autism*. <https://doi.org/10.1177/1362361318755522>
- Bromley, J., Hare, D.J., Davison, K., & Emerson, E. Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, 8(4), 409-423.
- Buescher, A.V., Cidav, Z., Knapp, M., & Mandell, D.S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *Journal of the American Medical Association*, 168(8), 721-728.
- Castro, S., Ferreira, T., Dababnah, S., & Pinto, A.I. (2013). Linking autism measures with the ICF-CY: Functionality beyond the borders of diagnosis and interrater agreement issues. *Developmental Neurorehabilitation*, 16(5), 321-331.
- Chandran, S. (2016). *Financial burden of living with autism: A case study of parents of at IDEAS Autism Centre*. Retrieved from <http://www.ideas.org.my/>
- Chambers, N., Wetherby, A.M., Stronach, S.T., Njongwe, N., Kauchali, S., & Grinker, R.R. (2017). Early detection of autism spectrum disorders in young isiZulu-speaking children in South Africa. *Autism*, 21(5), 518-526.
- Charles, L. (2014, October 22). Access to social grants for people with autism. *Berea mail*. Retrieved from <https://bereamail.co.za/44892/access-to-social-grants-for-people-with-autism/>.
- Christensen, D.L., Bilder, D.A., Zahorodny, W., Pettygrove, S., Durkin, M.S., Fitzgerald, R.T.,...Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among 4-year-old children in the autism and developmental disabilities monitoring network. *Journal of Developmental and Behavioural Pediatrics*, 37(1), 1-8.
- Cidav, Z., Marcus, S., & Mandell, D.S. (2011). Implications of childhood autism for parental employment and earnings. *Pediatrics*, 129(4), 617-623.
- Clasquin-Johnson, M.G., & Clasquin-Johnson, M. (2018). "How deep are your pockets?" Autoethnographic reflections on the cost of raising a child with autism. *African Journal of Disability*, 7(0), 1-8.
- Cridland, E.K., Jones, S.C., Magee, C., & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism*, 18(3), 213-222.
- Dass, S., & Rinquest, A. (2017). School fees. In F. Veriava (Ed.), *Basic education rights handbook* (142-158). Johannesburg, South Africa: Section 27.
- Department of Education, Employment and Workplace Relations. (2011). *Review of funding for schooling – final report*. Canberra: Department of Education, Employment and Workplace Relations.

- Di Rezze, B., Rosenbaum, P., & Zwaigenbaum, L. (2012). What attributes determine severity of function in autism? A web-based survey of stakeholders. *Focus on Autism and Other Developmental Disabilities*, 27(1), 139–41.
- De Vries, P.J. (2016). Thinking globally to meet the needs: autism spectrum disorders in Africa and other low-resource environments. *Current Opinion in Neurology*, 29(2), 130-136.
- Divan, G., Vajaratkar, V., Desai, M.U., Strik-Lievers, L., & Patel, V. (2012). Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. *Autism Research*, 5(3), 190-200.
- Durkin, M.S., Maenner, M.J., Newschaffer, C.J., Lee, L.C., Cunniff, C.M., Daniels J.L., ...Kirby, S.R., Schieve, L.A. (2008). Advanced parental age and the risk of autism spectrum disorder. *American Journal of Epidemiology*, 168(11), 1268-1276.
- Dyches, T.T., Wilder, L.K., Sudweeks, R.R., Objakor, E.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., ... Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research*, 5(3), 160-179.
- Frederickson, N., & Jones, A. (2010). Inclusive provision options for pupils on the autistic spectrum. *Journal of Research in Special Educational Needs*, 10(2), 63-73.
- Gan, S.M., Tung, L.C., Yeh, C.H., & Wang, C.H. (2013). ICF-CY based assessment tool for children with autism. *Disability and Rehabilitation* 35(8), 678–685.
- Ganz, M.L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics & Adolescent Medicine*, 161(4), 343-349.
- Grinker, R.R., Chambers, N., Njongwe, N., Langman, A.E., Guthrie, W., Stronach, S., ...Wetherby, A.M. (2012). “Communities” in community engagement: Lessons learned from autism research in South Korea and South Africa. *Autism Research*, 5(3), 201-210.
- Goudge, J., Gilson, L., Russell, S.J., Gumede, T., & Mills, A. (2009). Affordability, availability and acceptability barriers to health care for the chronically ill: Longitudinal case studies from South Africa. *BMC Health Services Research*, 9(1), 75-93.
- Harris, B., Goudge, J., Ataguba, J.E., McIntyre, D, Nxumalo, N., Jikwana, S., ...Chersich, M. (2011). Inequities in access to health care in South Africa. *Journal of Public Health Policy*, 32(1), 102-123.
- Hartley, S.L., & Schultz, H.M. (2015). Support needs of fathers and mothers of children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(6), 1636-1648.
- Horlin, C., Falkmer, M., Parsons, R., Albrecht, M.A., & Falkmer, T. (2014). The cost of autism spectrum disorders. *PLOS ONE*, 9(9). <https://doi.org/10.1371/journal.pone.0106552>.
- Jäbrink, K. (2007). The economic consequences of autistic spectrum disorder among children in a Swedish municipality. *Autism*, 11(5), 453-463.
- Jo, H., Schieve, L.A., Rice, C.E., Yeargin-Allsopp, M., Tian, L.H., Blumberg, S.J., ...Boyle, C.A. (2015). Age at autism spectrum disorder (ASD) diagnosis by race, ethnicity, and primary household language among children with special health care needs, United States, 2009-2010. *Maternal Child Health Journal*, 19(8), 1387-1697.
- Kanne, S.M., & Mazurek, M.O. (2011). Aggression in children and adolescents with ASD: Prevalence and risk factors. *Journal of Autism and Developmental Disorders*, 41(7), 926-937.
- Knapp, M., Romeo, R., & Beecham, J. (2009). Economic cost of autism in the UK. *Autism*, 13(3), 317-336.
- Kiru, E., & Cooc, N. (2017) A comparative analysis of access to education for students with disabilities in Brazil, Canada, and South Africa. *Journal of International and Special Needs Education, in Press*. <https://doi.org/10.9782/16-00024R4>

- Malcolm-Smith, S., Hoogenhout, M., Ing, N., Thomas, K.G., & de Vries, P. (2013). Autism spectrum disorders – global challenges and local opportunities. *Journal of Child & Adolescent Mental Health*, 25(1), 1-5.
- Mandell, D.S., & Salzer, M.S. (2007). Who joins support groups among parents of children with autism? *Autism: The International Journal of Research and Practice*, 11(2), 111–122.
- Mandell, D.S., Wiggins, L.D., Carpenter, L.A., Daniels, J., DiGuiseppi, C., Durkin, M.S., ...Kirby, R.S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99(3), 493–498.
- Meral, B.F., & Cavkaytar, A. (2012). A study on social support perception of parents who have children with autism. *International Journal on New Trends in Education and Their Implications*, 3(3), 124-135.
- Mirsalimi, H., Perleberg, S.H., Stoval, E., & Kaslow, N.J. (2003). Family psychotherapy. In B.I. Weiner (Ed.), *Handbook of Psychology* (pp. 225-233). Hoboken, New Jersey: John Wiley & Sons.
- Molteno, G., Molteno, C.D., Finchilescu, G., & Dawes, A.R.L. (2010). Behavioural and emotional problems in children with intellectual disability attending special schools in Cape Town, South Africa. *Journal of Intellectual Disability Research*, 45(6), 515-520.
- Montes, G., & Halterman, J.S. (2008). Association of childhood autism spectrum disorders and loss of family income. *Pediatrics*, 121(4), 821-826.
- Republic of South Africa (RSA). (2006). *National Credit Act* (Report No. 28619). Pretoria: Government Printer.
- Olivier, M.A., & Ah Hing, A.D. (2009). Autistic spectrum disorder (ASD): Parental challenges and strategies. *Vulnerable Children and Youth Studies*, 4(1), 58-66.
- Ouellette-Kuntz, H., Coo, H., Lam, M., Breitenbach, M. M., Hennessey, P. E., Jackman, P. D., ...Chung, A. M. (2014). The changing prevalence of autism in three regions of Canada. *Journal of Autism and Developmental Disorders*, 44(1), 120–136.
- Parish, S.L., Thomas, K.C., Williams, C.S., & Crossman, M.K. (2015). Autism and families' financial burden: The association with health insurance coverage. *American Journal of Intellectual Developmental Disabilities*, 120(2), 166-175.
- Park, J., Turnbull, H., & Turnbull, R. (2002). Impacts of poverty on the quality of life in families of children with disabilities. *Exceptional Children*, 68(2), 151-170.
- Pillay, S., Duncan, M., & de Vries, P. (2017). *How many children with autism spectrum disorder (ASD) are there in South African schools: A systematic database search for known cases of ASD in the Western Cape Province*. Poster presented at the 2017 Africa Regional International Meeting for Autism Research, Stellenbosch, South Africa.
- Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(7), 1609-1620.
- Samadi, S.A., Mahmoodizadeh, A., & McConkey, R. (2012). A national study of the prevalence of autism among five-year-old children in Iran. *Autism*, 16(1), 5-14.
- Saloojee, G., Phohole, M., Saloojee, C., & IJsselmuiden, C. (2006). Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child: Care, Health and Development*, 33(3), 230-235.
- Schlebusch, L., Dada, S., & Samuels, A.E. (2017). Family quality of life of South African families raising children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(7), 1966-1977.
- Sharpe, D.L., & Baker, D.L. (2007). Financial issues associated with having a child with autism. *Journal of Family and Economic Issues*, 28(2), 247-264.

- Sharpe, D.L., & Baker, D.L. (2011). The financial side of autism: Private and public costs. In M.R. Mohammadi (Ed.), *A comprehensive book on autism spectrum disorders* (pp. 275-296). Rijeka, Croatia: InTech.
- Smith, L., Malcolm-Smith, S., & de Vries, P. J. (2016). Translation and cultural appropriateness of the Autism Diagnostic Observation Schedule-2 in Afrikaans. *Autism*, 21(5), 552-563.
- Springer, P. E., van Toorn, R., Laughton, B., & Kidd, M. (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.
- Statistics South Africa. (2011). *Census 2011*. Retrieved from <http://www.statssa.gov.za/publications/p03014/p030142016>
- Statistics South Africa. (2013). *Documented immigrants in South Africa 2013*. Retrieved from www.statssa.gov.za/publications/P03514/P035142013.pdf
- Statistics South Africa. (2015). *Living conditions of households in South Africa 2015*. Retrieved from <http://www.statssa.gov.za/publications/P0310/P03102014.pdf>
- Statistics South Africa. (2015). *GHS Series Volume VII Housing from a human settlement perspective*. Retrieved from www.statssa.gov.za/publications/Report-03-18-06/Report-03-18-062014.pdf
- Statistics South Africa. (2016). *Education Series Volume III Educational Enrolment and Achievement 2016*. Retrieved from www.statssa.gov.za/publications/Report%2092-01-03/Report%2092-01-032016.pdf
- The National Autistic Society. (n.d.). *Benefits for autistic children*. Retrieved from <http://www.autism.org.uk/about/benefits-care/benefits/children.aspx>
- Thomas, P.D., Badoe, E.V., & Owusu, N.M.V. (2015). Family perspectives of autism spectrum disorders in urban Ghana. *Journal of the International Child Neurology Association*, 1(1), 1-7.
- Tripathi, N. (2015). Parenting style and parents' level of stress having children with autism spectrum disorder (CWAS): A study based on Northern India. *Journal of Neuropsychiatry*, 5(1), 42-49.
- United States Department of Education. (2011). *Ensuring equal access to high-quality education*. Washington, DC: Office for Civil Rights.
- Van Biljon, S., Kritzinger, A., & Geertsema, S. (2015). A retrospective case report on demographic changes of learners at a school for children with autism spectrum disorder in the Gauteng Province. *South African Journal of Childhood Education*, 5(1), 42-61.
- Van der Ven, E., Termorshuizen, F., Laan, W., Breetvelt, E.J., van Os, J., & Selten, J.P. (2012). An incidence study of diagnosed autism-spectrum disorders among immigrants to the Netherlands. *Acta Psychiatrica Scandinavica*, 128(1), 54-60.
- Waddington, E.M., & Reed, P. (2017). Comparison of the effects of mainstream and special school placements on national curriculum outcomes in children with ASD: An archive-based analysis. *Journal of Research in Special Educational Needs*, 17(2), 132-142.
- World Health Organization (WHO). (2007). *International classification of functioning, disability and health: children and youth version: ICF-CY*. Geneva, Switzerland: WHO.

Chapter 5

Profiles of public and private autism-specific schools in Gauteng

This article was accepted in a local peer-reviewed journal, the Journal of South African Journal of Childhood Education. The format of the article is that of the journal and differs from the rest of the thesis.

Profiles of public and private autism-specific schools in Gauteng

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Profiles of public and private autism-specific schools in Gauteng

Abstract

Despite inclusive education (IE) policies and legislation being introduced in South Africa (SA), learners with autism spectrum disorder (ASD) are still placed in autism-specific *public* and *private* schools. Limited data is available on who makes use of the two different types of schools. Results may provide information on the profiles and education of learners with ASD in Gauteng schools. Two survey questionnaires were used to collect data from four principals of two *public* and two *private* schools and 150 caregivers of learners attending the participating schools. Results showed that due to their size *public* schools make a significant contribution to the education of learners with ASD in Gauteng, compared to *private* schools. *Public* schools offered more therapy services than the *private* schools, despite lower fees than *private* schools. Significantly more Black learners attend *public* schools than *private* schools. Regardless of the differences in population groups across the participating schools, the mean age when caregivers became concerned about their child's development was similar across the two types of schools. Learners enrolled at the *private* schools were diagnosed with ASD earlier than learners enrolled at the *public* schools. Also, they commenced school earlier than the learners in the *public* schools. Lastly, three of the four principals expressed a preference that learners with ASD be placed in autism-specific schools. The results highlight the need to raise awareness of ASD symptoms among parents with young children in all communities and to determine the barriers that hinder IE for learners with ASD in SA.

Introduction

In SA, educational placement for learners with ASD is a pertinent topic in light of the IE policy recommending that all learners should be educated in the least restrictive environment (Department of Education [DoE] 2001). The current state of education in SA could be attributed to the legacy of apartheid education policies (1948-1994) (Engelbrecht 2006:254). During the 46 years

of apartheid, learners with disabilities were segregated twice according to their population group and disability (Donohue & Bornman 2014:2; Engelbrecht 2006:254). Under apartheid, White learners who experienced barriers to learning received high-quality special education with adequate resources and well-trained teachers. In contrast, Black, Indian and Coloured children were educated in separate facilities from White learners and received relatively low-quality education from poorly trained teachers (DoE 2001). The Bill of Rights, included in the Constitution of the Republic of South Africa (Act No. 108 of 1996), declares that all South African citizens have the right to basic education, regardless of the barriers to learning. Key education legislation and policies introduced since 1994 simultaneously abolished discrimination and introduced IE (DoE 1995; DoE 1996; DoE 1997; DoE 2010a; DoE 2010b; DoE 2014). IE is a system where the diverse needs of all learners are addressed by reducing the barriers to and within the learning environment (DoE 2001). Therefore, the intention was to follow the same trend of IE as in most other countries where learners who experience barriers are included in mainstream classes (DoE 2001; Engelbrecht 2006:260; Jones & Frederickson 2010:1102; Waddington & Reed 2017:139).

Barriers to the effective implementation of IE include a lack of teacher capacity, limited financial resources, poverty, as well as the negative attitudes towards disability in general (Bornman & Rose 2010:7; Engelbrecht 2006:255). These barriers may contribute to certain discomfort about the concept of inclusion in SA (Donohue & Bornman 2014:3). Furthermore, although the IE policy in SA (DoE 2001) recommends that learners with barriers to learning, should be included in mainstream schooling, learners with ASD are still being segregated in *public*, and *private* special schools (DoE 2015; Pillay, Duncan & De Vries 2017; Statistics South Africa 2014). One of the reasons may be because learners with ASD experience increased difficulty adapting to mainstream school settings since their behaviour is often noticeably different from that of typically developing children (Whitman 2004). Another reason may be that the three levels of severity of ASD, as described by the Diagnostic and Statistical Manual of Mental Disorder Fifth Edition (DSM-5), may differ significantly and therefore require various levels of support (American Psychiatric Association [APA] 2013). For example, a learner with ASD with a severity level of three requires 'very substantial support' (APA). These learners require very substantial support with social communication skills as they have severe deficits in verbal and nonverbal communication. Furthermore, they require very substantial support in their restricted and repetitive behaviours as they may experience consistent difficulty in coping with changes and inflexible behaviour (APA). Whereas a learner with ASD with level two severity requires considerable support since they present with marked deficits in verbal and nonverbal social communication and difficulty in coping with changes as their restricted and repetitive behaviour interfere with their functioning in various

contexts (APA). Lastly, a learner with ASD with a severity level of one only requires minimal support. Should the learner not receive the necessary support, deficits in social communication may cause significant impairments while inflexibility of behaviour may also cause interference with functioning in one or more contexts (APA). It is therefore important to ensure that learners with ASD are placed in a school meeting their support needs.

Currently, there are only a few autism-specific *public* schools in SA. Over the past two years, however, the Gauteng Department of Education (GDE) has opened 18 new ASD classroom units in schools for learners with special educational needs [LSEN] (Evans 2016) to reduce extensive waiting lists (Clasquin-Johnson & Clasquin-Johnson 2018:4). It therefore appears that the GDE is perpetuating segregated placement for learners with ASD even though legislation and policy recommend inclusion in mainstream schools (DoE 2001; Evans). According to Clasquin-Johnson and Clasquin-Johnson (2018:4), there are still many learners with ASD who are not benefitting from early childhood education (ECE) (age birth-to-nine years) as they are waiting for school placement. Also, the ECE sector does not have the capacity for early screening and intervention as personnel are either under- or un-qualified (Human Sciences Research Council [HSRC] 2009). A further disadvantage of the autism-specific *public* schools is that they are largely limited to the urban middle-to-high income communities (Autism South Africa [ASA] nd.), thereby excluding children with ASD from rural areas (Saloojee, Phohole, Saloojee & Ijsselmuiden 2006:233). As a consequence, there has been an increase in home-schooling children with ASD (Nhlapo 2018) as well as an increase in *private* schools accommodating learners with ASD and other developmental disabilities (ASA nd.). While *private* schools are more costly than *public* schools, they provide an educational solution for families with limited options due to the lack of space in autism-specific *public* schools in SA. However, limited research has been conducted on the profiles of autism-specific schools and their learners in SA. When investigating learners with ASD in SA, it is clear that both *public* and *private* special schools should be considered. Results may provide information on the education of learners with ASD in Gauteng Province schools. The researchers expect that the comparison will reveal critical differences between the two types of schools, but also similarities. Due to limited space in autism-specific *public* schools and minimal progress in the implementation of IE for learners with ASD, there may also be similarities in learner profiles across the different types of schools. By investigating the two types of South African schools, the study may also provide a description of the diversity of learners with ASD and their families across the socioeconomic spectrum. Data may be used by education planners, therapists, psychologists and future researchers.

Theoretical framework

The current study was entrenched in Bronfenbrenner's eco-systematic theory and the International Classification of Functioning, Disability and Health – Child and Youth Version (ICF-CY) as it draws attention to a more holistic view of the profiles and learners of autism-specific schools (Bronfenbrenner 1994; World Health Organisation [WHO] 2007). Research confirmed the value of using Bronfenbrenner's ecological theory (Eriksson & Ghazinour 2018) and the ICF-CY (Aljunied & Frederickson 2014:382). Bronfenbrenner's theory focuses on the individual and contextual systems and the interdependent relations between the two systems (Bronfenbrenner 1994). There are various contextual factors influencing the development of learners attending autism-specific schools (WHO 2007). Similar to the Bronfenbrenner theory, the ICF-CY also states that the child should be seen in the context of the environment (WHO 2007). There are various environmental factors within the ICF-CY related to the child, family and school which influence the everyday life outcomes of individuals with ASD (Bölte et al. 2014:2). Although a few studies have focussed on the value of the ICF-CY (Di Rezze et al. 2012:40; Gan, Tung, Yeh & Wang 2013:679), limited research has focused on the environmental factors component of the ICF-CY influencing the outcomes of school-aged children with ASD (Aljunied & Frederickson 2014:382). Therefore research regarding the profiles and learners of autism-specific schools is essential.

Research methods

Aim and design

A quantitative, cross-sectional, comparative research design was used to compare the profiles and learners of two autism-specific *public* with two autism-specific *private* schools in South Gauteng Province.

Setting

Although there are no official statistics available on how many learners with ASD are being accommodated for in autism-specific and mainstream schools, it appears that the majority of school-going-age children with ASD are accommodated in autism-specific schools (Evans 2016). These schools are therefore described as “population-rich settings” (Evans). Before the data collection, the researcher consulted ASA and requested a list of all the autism-specific *public* (government-funded) and *private* (independent) schools in Gauteng Province. Only autism-specific schools which existed for more than ten years in the province were selected for the study, because they have accumulated experience and are regarded as resource centres for training and research (ASA n.d). At the time of

data collection, there were three autism-specific *private* and three autism-specific *public* schools in Gauteng Province, but only two autism-specific *private* and two autism-specific *public* schools existing for more than ten years. The autism-specific *private* and *public* schools were also chosen according to approximate their founding dates [autism-specific *public* school 1 (1973) and 2 (2004); autism-specific *private* school 3 (1975) and 4 (2006)] in order to make comparisons.

Participants

The participants in the study included four principals of the autism-specific *public* and *private* schools, and 150 caregivers of learners attending the participating schools. Purposive sampling was employed to select the participants as only principals and caregivers who completed informed consent forms and a questionnaire could participate (Leedy & Ormod, 2016).

All four participating principals were female, SA citizens with a post-secondary attainment level of either a degree, or a postgraduate teaching qualification. All four principals had more than 25 years teaching experience. The majority of the 150 caregivers in both the autism-specific *public* (86.5%) and *private* (79.2%) schools were mothers. Furthermore, 50.8% of the mothers in the autism-specific *public* schools and 83.3% of the mothers in the autism-specific *private* schools had a post-secondary attainment level of either a diploma or a degree, or a postgraduate qualification.

Data collection

Different questionnaires were distributed to the principals and the caregivers. The first questionnaire was completed by the four principal and the second questionnaire was distributed to the caregivers of the 541 learners attending the four designated autism-specific schools. Different methods were used to establish the reliability and validity of the two questionnaires. First, the researchers reviewed literature and subsequently designed a survey questionnaire, ensuring that the content covered all the facets of the aims and therefore addressing content validity (Delport & Roestenburg 2011). In addition, experts in the field were consulted to review the preliminary survey questionnaire where after feedback was used to improve its validity (Delport & Roestenburg 2011). Furthermore, face validity was addressed by ensuring that the wording of the questions elicits the appropriate information, asking questions which the respondents know, using terminology which the respondents were familiar with and including several types of questions (Trochim, Donnelly & Arora 2015). Lastly, the researchers conducted a pilot study in a autism-specific school. Fifteen caregivers and one principal completed and returned the pilot questionnaires, and the necessary changes were made.

The survey questionnaire included different types of questions such as yes/no and categorical responses (Trochim et al. 2015). The questionnaire to the principals focussed on information about the school and included questions about when the school was established, age ranges of the learners, admission criteria of the school, school fees, therapeutic services offered by the school, number of learners the school can accommodate, number of learners currently attending the school, number of names on the waiting list, teacher-learner ratio, and the principal's preference regarding IE and autism-specific education. The caregiver survey included questions about gender, population group, age of child when parent became concerned about development, age when diagnosed and when admitted to school. We received the self-completed questionnaires back from the four principals and a total of 150 (27.2%) questionnaires from caregivers. A possible explanation why the response rate was so low might be the low literacy levels of the caregivers and that the queries of the caregivers or principals could not receive attention. The caregivers in the study were either a mother, father, family member, or guardian who taking care of a child with ASD and helping him/her with activities of daily living. Caregiver questionnaires were assigned to one of two groups according to the type of school the learner was attending: Group 1 (public) ($n=126$) and Group 2 (private) ($n=24$).

Data analysis

Comparisons between the two autism-specific *public* and two autism-specific *private* schools were descriptive in nature (questionnaire for principals). Data from the caregiver questionnaire was captured electronically and exported to IBM SPSS (Version 22) (IBM Corp 2013) for further analysis. Non-parametric tests, using a significance level of $p<0.05$, were used to explore the existence of significant differences amongst different variables.

Ethical considerations

Ethical clearance was obtained from the University of Pretoria (GW20160702HS) and written permission from the Gauteng Department of Basic Education (D2016/268), and the principals of the autism-specific *public* and *private* schools. Informed consent was obtained from principals and the caregivers of learners attending the schools during 2017. The researchers maintained anonymity and confidentiality of the participants and their schools throughout the research process.

Results

The results are presented according to the study objectives. Firstly, differences and similarities in the profiles of the participating autism-specific schools are depicted in Table 1. Secondly, the profiles of

learners, with specific reference to the early management of ASD, in Group 1 and Group 2 are explained.

Profiles of participating autism-specific schools

Table 1 presents the comparison between two autism-specific *public* and two autism-specific *private* schools in Gauteng.

Table 1: Profiles of the participating autism-specific schools

Schools	1	2	3	4
	<i>Public</i>		<i>Private</i>	
1.1 Date when schools were established	1973	2004	1975	2006
1.2 Age ranges of learners in the schools	3-18	3-21	3-10	2-11
1.3 Admission requirements of the schools	Child had to be diagnosed with ASD and caregivers had to be working or living in the school's catchment area		Child had to be diagnosed with ASD No limitations on where family lives	
1.4 Monthly school fees	Mean South African Rand (R) value = R1185.4 (Standard Deviation [SD] = R1193)		Mean R value = R4731.2 (SD= R1404.1)	
1.5 Therapy services included in school fees	Speech-language therapy, occupational therapy, psychology services and music therapy	Speech-language therapy, occupational therapy, psychology services, hippotherapy, and music therapy	Speech-language therapy, occupational therapy, and Floortime therapy	Speech-language therapy (in groups) and occupational therapy (in groups)
1.6 Number of learners the schools can accommodate	116	350	30	45
1.7 Number of learners in the schools at the time of data collection	116	350	12	41
1.8 Number of names on the waiting list of the schools	16	16	0	0
1.9 Number of teachers in the schools	14	45	2	5
1.10 Teacher-learner ratio	1:7	1:7.5	1:6	1:8.2
1.11 Gender of learners in schools	Male	89 (88.1%)	23 (92.0%)	14 (93.3%)
	Female	12 (11.9%)	2 (8.0%)	1 (5.7%)
	Male-to-female ratio	7.4:1	11.5:1	14.0:1
1.12 Population distribution of learners in the schools	Black	98 (97.1%)	15 (65.2%)	7 (46.8%)
	White	1 (0.99%)	7 (30.4%)	5 (33.3%)
	Asian/Indian	1 (0.99%)	1 (0.4%)	2 (13.3%)
	Coloured	1 (0.99%)	0 (0.0%)	1 (6.6%)
				0 (0.0%)

As can be seen in Table 1 (see section 1.1) two of the autism-specific schools (*public* school 1 and *private* school 4) were established during the apartheid era (1948-1994), and the other two autism-specific schools after the democratic change of government in SA. During the 1970's children with disabilities were entirely excluded from the mainstream education system worldwide (Inclusion BC 2014). The change towards IE in high-income countries (HICs) began in the late 1980s (Inclusion BC 2014). Whereas in low-and-middle income countries (LMICs), such as SA, the transformation to IE only began in the early 2000s when IE policies were formulated and implemented (DoE 1995; DoE

1996; DoE 1997; DoE 2010a; DoE 2010b; DoE 2014; Margia, McConkey & Myezwa 2014; United Nations Educational, Scientific and Cultural Organization [UNESCO] 1994). Our results show that even though legislation and policies stipulate that learners with disabilities, such as ASD, should be included in mainstream schools, the DoE is still establishing autism-specific schools, therefore, perpetuating the IE legislation and policies (Evans 2016). Although there are no official statistics in SA, it appears that children with ASD are still placed in *public*, and *private* special educational needs schools rather than in mainstream schools (ASA n.d; DoE 2015; Pillay et al. 2017). Therefore, our results are in agreement with a systematic database study conducted in the Western Cape Province by Pillay et al (2017) who found that of the 940 children with ASD enrolled in schools in that province, approximately 90% attended special education needs schools and only 10% were attending mainstream schools. A possible explanation might be that the educational implications of ASD are extensive and encompass many challenges for learners in mainstream schools. This also seems to be the trend in other countries such as Australia, United Kingdom (UK) and United States (US) (Humphrey 2008:132; Roberts & Simpson 2016:1093; Simpson, de Boer-Ott & Smith-Myles 2003:130).

The autism-specific *public* schools accommodate very young and older learners (3-21 years), whereas the autism-specific *private* schools mostly accommodate learners only until the age of ten-to-eleven years (see section 1.2 of Table 1). Although the SA Schools Act (DoE 1996) compels children between the ages of seven and fifteen to attend school, it appears that the autism-specific *private* schools do not accommodate learners older than 11 years. Therefore, learners attending the autism-specific *private* schools are often compelled to transition to other *private* special education needs schools or mainstream schools when they reach the school's age limit. Evidence suggests that learners with ASD experience significant and unique challenges in adjusting to new educational settings (Adreon & Durocher 2007:271; Cheak-Zamora, Teti & First 2015:557; Marsh, Spagnol, Grove & Eapen 2017:194). The learners experience enhanced anxiety levels when transitioning between schools which may be due to difficulty in dealing with new social situations due to social communication and social interaction impairments, problems with adjusting to the new environment as well as responses to new sensory experiences (Hannah & Topping 2012:207). To prevent unnecessary changes, it is imperative that educational services accommodate learners with ASD who are older than 11 years.

In both the autism-specific *public* and *private* schools, the children are screened and assessed by the school's multidisciplinary team to determine whether they are candidates for the school. Firstly, the admission criteria in both the autism-specific *public* and *private* schools required candidates to be diagnosed with ASD by a professional such as a child psychiatrist, developmental

paediatrician or child neurologist. Secondly, in the autism-specific *public* schools, caregivers had to be working or living in the school's catchment area, whereas in the autism-specific *private* schools there were no limitations on where the family lives. Therefore, admission is determined by the caregivers' ability to pay the high monthly school fees. The admission criteria for autism-specific *private* schools differ from that of the autism-specific *public* schools as they are not accountable to the GDE in this regard (Dass & Rinquest 2017).

The results show that the monthly school fees in autism-specific *private* schools were significantly higher (*p-value* = <0.001), far more than double the amount than that of autism-specific *public* schools (see section 1.4 of Table 1). A possible explanation may be that some *private* schools do not receive any subsidy from the government (Dass & Rinquest 2017). Furthermore, they are allowed to determine their school fees and rely on parents to pay these fees, endowments from the public and fundraising to cover their costs (Dass & Rinquest 2017). Our results are in agreement with a study conducted in Sweden who found that families raising children with ASD have significant costs related to their education (Järbrink 2007:102).

Statistically significant differences were found when comparing the therapy services included in the school fees of the autism-specific *public* and *private* schools (*p-value* = <0.001). The results showed that even though the school fees in autism-specific *private* schools are higher than that of the autism-specific *public* schools, they offer fewer therapies which are included in the school fees. A reason could be that the allied health professionals, which include speech-language therapists, occupational therapists, and psychologists, are employed by the GDE (Dass & Rinquest 2017). Therefore, the autism-specific *public* schools can offer a wider variety of therapeutic services. This may also be because allied health professionals usually work in private practice in SA and only offer their services at the autism-specific *private* schools, but are not employed by the school. According to the principals, the therapeutic services included in the autism-specific *private* schools' fees are usually limited to a few days per week or therapy is provided in groups. Learners requiring individualised therapy receive additional intervention either at school or in private practice, but caregivers are responsible for the costs. Future research is needed to determine the effectiveness of group therapy compared to individualised therapy for learners with ASD.

As can be seen in Table 1 (see section 1.6-1.8) the autism-specific *public* schools can accommodate more learners than the autism-specific *private* schools. This is due to the autism-specific *public* schools having bigger buildings, since the autism-specific *private* schools usually renovate houses which become school buildings. Although the autism-specific *public* schools can accommodate more learners these schools are often overstretched (ASA, n.d.). Both of the autism-specific *public* schools reported that at the time of data collection they had 16 names on the waiting

list. The waiting lists could have been longer if the GDE did not open units for ASD in LSEN schools. On the contrary, the autism-specific *private* schools were able to accommodate a few more learners and were not over-capacity. The study by Pillay et al. (2017) also reported on the consolidated waiting list for children with ASD in the Western Cape Province. Therefore, although there were not as many names on the waiting list in Gauteng Province as in the Western Cape Province reported by Pillay et al. (2017), there is a need to establish more educational services across SA to accommodate learners with ASD and to relieve the pressure on the existing schools and to reduce the teacher-learner ratios.

As was to be expected there were more teachers in the autism-specific *public* schools than in the autism-specific *private* schools (see section 1.9 of Table 1). The teacher-learner ratio in both the autism-specific *public* and *private* schools were approximately the same (*p-value* = <0.910), ranging from 1:7-1:8.2. The teacher-learner ratio in autism-specific schools is lower than in mainstream schools because it has been widely reported that teaching one learner with ASD equals teaching six neurotypically developing learners (Clasquin-Johnson & Clasquin-Johnson 2018:3).

Although no statistically significant differences were found when comparing the gender of the learners in the autism-specific *public* and *private* schools (*p-value* = <0.739), the majority of learners in the sample were males (see section 1.11 of Table 1). The findings show that the male-to-female ratio in the autism-specific *public* schools (6.8:1) and autism-specific *private* schools (8.0:1) did not differ greatly. However, the gender inequality in our study was higher than that reported in a population-based cohort study (2001-2011) conducted in Stockholm, Sweden, where the male-to-female ratio was 4:1 (Idring et al. 2014:1769). Male dominance may merely reflect the difficulty of diagnosing ASD in females (New, Triebwasser & Charney 2008:654). Some variability in the ratio can be attributed to the clinical presentation of ASD, which is different in males in comparison to females, although available findings are inconsistent (Rivet & Matson, 2011:966). Females with an ASD diagnosis and high intelligence quotient (IQ) are perceived as being more social and have higher language abilities (Halladay et al. 2015:2). Therefore the presentation of their symptoms may be misinterpreted, and an accurate diagnosis might be delayed (Halladay et al.).

The majority of learners in both the autism-specific *public* (89.7%) and *private* (62.5%) schools were Black, which is consistent with the racial demographics in SA (Statistics South Africa 2011). The results also show that significantly more (*p-value* = <0.001) learners in the autism-specific *private* schools were White (25.0%) and Asian/Indian (12.5%) than in the *public* schools (White = 6.4%; Asian/Indian = 1.5%). A possible explanation why more White, Indian and Asian learners were able to attend the autism-specific *private* schools might be because they were able to

afford the higher school fees. According to Statistics South Africa (2011) families from White, Indian and Asian population groups earn a higher average income than Black families.

Profiles of learners attending the autism-specific schools

Table 2 show the differences and similarities in the profiles of learners, with specific reference to the early management of ASD, for Group 1 ($n=126$) and Group 2 ($n=24$).

Table 2: Profiles of learners in Group 1 ($n=126$) and Group 2 ($n=24$)

Characteristic	Category	Frequency (n) and percentages (%)		Significance p-value
		Group 1	Group 2	
2.1 Age (months) when caregivers became concerned about child's development	<47 months	120 (95.2%)	24 (100.0%)	0.590
	>48 months	6 (4.8%)	0 (0.0%)	
	Mean age (in months)	26.2 (SD = 10.0)	26.3 (SD = 15.2)	
2.2 Age (months) when child was diagnosed with ASD	<47 months	76 (60.3%)	17 (70.8%)	0.368
	>48 months	50 (39.7%)	7 (29.2%)	
	Mean age (in months)	47.9 (SD = 25.2)	42.7 (SD = 10.7)	
2.3 Age (years) when child was admitted to autism-specific school	<3.9 years	12 (9.5%)	7 (29.2%)	0.015*
	>4.0 years	114 (90.5%)	17 (70.8%)	
	Mean age (in years)	5.7 (SD = 1.9)	4.1 (SD = 1.1)	

* Statistically significant association ($p < 0.05$)

Results in Table 2 (see section 2.1) indicate that the mean age (in months) when caregivers became concerned about their child's development in the autism-specific *public* and *private* schools were similar ($p\text{-value} = < 0.590$). The greater standard deviation in the autism-specific *private* schools indicates that some caregivers became concerned about their child's development earlier than caregivers in autism-specific *public* schools. Furthermore, the differences in the post-secondary education attainment level of the mothers (Group 1 = 83.3%; Group 2 = 50.8%) might have had an influence on the age when mothers became concerned. US studies found that higher educational levels are associated with earlier age of identification (Fountain, King & Bearman, 2011:505; Goin-Kochel & Myers 2005:441). Despite the differences in population groups, all caregivers in our study became concerned about their child's development later than in other studies (Werner, Dawson, Osterling & Dinno 2000:158; Young, Brewer & Pattinson 2003:134). Studies on parental concerns about children who were later diagnosed with ASD have shown that caregivers from Australia and the US were able to recognise atypical development between the ages of 8 and 12 months (Werner et al.; Young et al.). Our results show that caregivers may have limited knowledge about typical developmental milestones in young children and as a result were unable to identify developmental concerns at an early age (8-12 months). The findings also highlight the importance of supporting all caregivers by coordinated awareness raising and introducing early identification and intervention programmes for infants and young children with special needs.

No statistically significant differences were noted between the autism-specific *public* (on average 47.9 months) and *private* schools (on average 42.7 months) when considering the age of ASD diagnosis, but the mean age at diagnosis was later than in other studies conducted in SA (*p-value* = < 0.368) (Springer, Van Toorn, Laughton & Kidd 2013:95). Results from our study are in close agreement with the age of ASD diagnosis (45-47 months) in LMICs such as Colombia, India, Jamaica, Jordan and Mexico (Samms-Vaughan 2014:30). A population-based study in the US found that ASD can now be reliably diagnosed on average at the age of 15-24 months (Guthrie, Swineford, Nottke, & Wetherby 2013:589). A possible explanation why learners in our study were diagnosed later could relate to delayed parental concerns about their child's development. Caregivers might have limited knowledge of typical developmental milestones, limited awareness of developmental disorders such as ASD, and limited access to diagnostic services.

Although no statistically significant differences were found between the age when caregivers became concerned about their child's development and the mean age of ASD diagnosis, the results in Table 2 (section 2.3) indicated that significantly more (*p-value* = < 0.015) children in the autism-specific *private* schools (29.2%) were admitted to school before the age of 3.9 years than in the autism-specific *public* schools (9.5%). Therefore learners in the autism-specific *private* schools started attending school earlier than learners in the autism-specific *public* schools. The earlier age at school admission in autism-specific *private* schools may relate to no waiting lists and because the admission criteria of the *private* schools stipulate that they already accommodate children with ASD from the age of two-to-three years. Furthermore, it could be that caregivers of learners in the autism-specific *private* schools were able to afford the high monthly school fees and therefore enrol their child in autism-specific *private* schools without having to wait for placement. Evidence suggests that early intervention for children with ASD are predictors of success in intervention (Corsello 2005:81). It is therefore important that children with ASD are enrolled in ECE and early intervention programs as early as possible (Peters-Sheffer, Didden, Korzilius & Matson 2012:1770). If children are to benefit from early childhood education and early intervention, it is essential that ASD is identified and diagnosed at an early age.

Principals' preferences toward the inclusion of learners with ASD in mainstream schools

Of the four schools, only one principal indicated that she preferred that learners with ASD be included in mainstream schools. This principal was of the opinion that learners with ASD will benefit from socially interacting with their typically developing peers, and show improved behaviour and academic performance (Kasari & Rotherham-Fuller 2007). In contrast, the other three principals preferred that learners with ASD be placed in separate autism-specific schools. Reasons given

included that teachers are currently not adequately trained to support learners with ASD in typical classrooms and these learners often experience difficulty adapting in mainstream schools because they present with significant challenges in behaviour, social interaction, and communication. The principals reported that there is an overall lack of support and training for teachers working with learners with ASD in mainstream schools and that there are many challenges related to IE policy implementation. Furthermore, learners with ASD often experience difficulty in adapting to mainstream schools because their behaviour is markedly different from that of typically developing peers. Also, learners with ASD may show particular interaction challenges in the classroom and a lack of theory of mind which may include low tolerance of their peer group, little or no empathy for others and dislike taking turns (Lamers & Hall 2003:94). Learners with ASD often present with communication challenges which are amplified in the classroom. The communication challenges include limited conversational skills, lack of communicative intent and limited understanding of the attempts of others (Lord 2000:393). Lastly, behavioural challenges displayed by learners with ASD are sometimes even more severe in the classroom than at home (Lord & Corsello 2014:96). Behavioural problems often include difficulties with the rigidity of thought, pretend play, repetitive play patterns, and understanding the cause and effect of their behaviour (Lord & Corsello). Our results are in agreement with early studies conducted before the full IE implementation in the US which found that principals prefer that learners with ASD be placed schools for special education needs instead of mainstream schools (Cook, Semmel & Gerber 1999:206; Praisner 2003:141). Our findings are in support of a study from SA that reported that there are many barriers related to the inclusion of learners with disabilities in mainstream schools. The preferences of principals from mainstream schools and other autism-specific schools toward IE of learners with ASD should be investigated further in SA, as such research may help identify factors that contribute the successful inclusion of learners with ASD and point to the support needs of all stakeholders. A recent study in Australia found that successful inclusion of learners with ASD is possible if all stakeholders receive adequate training, structural support, resources, and funding from the government and if a collaborative approached is followed in the education process (Roberts & Simpson 2016:1084).

Limitations of the study

The study is subject to a few limitations. Firstly, the researchers relied solely on information obtained from the questionnaires completed by the caregivers of the learners in autism-specific *public* and *private* schools. Although data obtained from the questionnaires were not confirmed with the caregivers and principals through interviews, it should be noted that self-completed questionnaires are less biased than interviews. Furthermore, the participating schools were situated in urban Gauteng

areas only, and therefore only a small sample was recruited for the study. Lastly, there was a low response rate from caregivers.

Implications or recommendations

Data obtained from this study can be used as reference for future studies to track changes in ASD education trends in SA or similar countries. Such research may improve early ASD management, determine how many children with ASD are in the mainstream and special educational needs schools, and identify how to better support learners, caregivers, teachers and principals in autism-specific schools. Also, homeschooling for learners with ASD should be further investigated. It is important to promote targeted awareness about ASD among the general public by developing on-going ASD information training programmes. The successful inclusion of learners with ASD and principals' preferences toward the inclusion of learners with ASD in mainstream schools should be investigated further in SA. It is essential that autism-specific *public* and *private schools* provide full-service and mainstream schools with training and resources so that learners with ASD receive quality education. If older children are accommodated and school fees are reduced, more families will be able to afford to pay the school fees. Lastly, more educational services accommodating learners with ASD should be established in SA to relieve the pressure on the existing schools and to accommodate other children with ASD who are not receiving the ongoing specialised education they need.

Conclusion

In this article, we focussed on comparing the differences between autism-specific *public* and *private* schools. It is evident that the autism-specific *public* schools make by far the greatest contribution to education learners with ASD. Our results support the recent progress report on the Implementation of WP6 which indicated that some children with disabilities, including ASD, are not receiving the specialised education they need (DoE 2015). Consequently, there is a need to establish more educational services accommodating learners with ASD in SA, but this does not necessarily imply segregated placement. Instead, learners with ASD should be placed in schools according to their level of severity and therefore meeting their educational needs. Overall, it is encouraging to note that both the *public* and *private* autism-specific schools in SA are now providing education to racially diverse children in SA. As a result of limited space in autism-specific *public* schools and minimal progress in IE for learners with ASD, some similarities were also found in the learner profiles across the different types of schools than differences. The results indicated that children in both *public* and *private* autism-specific schools were not benefitting from ECE. It appears that late identification sets a

trajectory of late intervention. Therefore, if children are to benefit from ECE, it is essential that children with ASD are identified and diagnosed earlier than indicated in our study. Factors underlying the trajectory may be that caregivers were unfamiliar with early ASD symptoms, and the fact that there are limited diagnostic services and schools for children with ASD. It is important to focus on creating awareness about ASD among the general public by developing systematic training programmes. Lastly, the findings showed that principals preferred that learners with ASD should be placed in separate autism-specific schools rather than being included in mainstream schools. The current findings, therefore, highlight the need to determine the barriers that hinder IE of learners with ASD in SA.

Acknowledgements

Competing interests

The authors declare that they have no financial or personal relationships which may have inappropriately influenced them in writing this article.

Authors' contribution

S.E. was the primary author; compiled the complete document based on doctoral degree research. A.K. was the supervisor; provided continuous input and internal review of this article. J.VDL. was the co-supervisor; provided continuous input and internal review of this article.

References

- Adreon, D. & Durocher, J.S., 2007, 'Evaluating the college transition needs of individuals with high-functioning autism spectrum disorders', *Intervention in School and Clinic* 42(5):271-279.
- Aljunied, M. & Frederickson, N., 2014, 'Utility of the international classification of functioning, disability and health (ICF) for educational psychologists' work', *Educational Psychology in Practice* 30(4), 380-392.
- American Psychiatric Association, 2013, *Diagnostic and statistical manual of mental disorders (DSM-5®)*, Washington, DC: American Psychiatric Association.
- Autism South Africa n.d., *Autism government funded schools*, viewed 27 May 2016, from <http://aut2know.co.za/>
- Bornman, J. & Rose, J., 2010, *Believe that all can achieve*, Pretoria, Van Schaik.
- Bölte, S., de Schipper, E., Robinson, J.E., Wong, V.C.N., Selb, M., Singhal, N., et al., 2014, 'Classification of functioning and impairment: the development of ICF core sets for autism spectrum disorder', *Autism Research*, 7(1): 167-172.
- Cheak-Zamora, N.C., Teti, M. & First, J., 2015, 'Transitions are scary for our kids, and they're scary for us': Family member and youth perspective on the challenges of transitioning to adulthood with autism. *Journal of Applied Research and Intellectual Disabilities* 28(6): 548-560.
- Clasquin-Johnson, M.G. & Clasquin-Johnson, M., 2018, 'How deep are your pockets? Autoethnographic reflections on the cost of raising a child with autism', *African Journal of Disability* 7(0): 1-8.

- Cook, B.G., Semmel, M.I. & Gerber, M.M., 1999, 'Attitudes of principals and special education teachers toward the inclusion of student with mild disabilities', *Remedial and Special Education* 20(4): 199-207.
- Corsello, C.M., 2005, 'Early intervention in autism', *Infants & Young Children* 18(2): 74-85.
- Dass, S., & Rinquest, A., 2017, 'School fees', in F. Veriava (ed.), *Basic education rights handbook*, pp. 140-159, Johannesburg, South Africa: Section 27.
- Delpot, 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. Fouché, & C.S.L. Delpot (Eds.), *Research at grass roots. For the social sciences and human service professions*, 4th edn., Pretoria: Van Schaik Publishers.
- Department of Education, 1995, *White Paper on Education and Training*, Pretoria: Government Printer.
- Department of Education, 1996, *South African Schools Act, Act 84 of 1996*, Pretoria: Government Printer.
- Department of Education, 1997, *Integrated National Disability Strategy*, Pretoria: Government Printer.
- Department of Education, 2001, *Education white paper 6. Special Needs Education: Building an inclusive education and training system*, Pretoria: Government Printer.
- Department of Education, 2010a, *Guidelines for full service/inclusive schools* Pretoria: Government Printer.
- Department of Education, 2010b, *Guidelines for inclusive teaching and learning*, Pretoria: Government Printer.
- Department of Education, 2014, *Policy on screening, identification, assessment and support (SIAS)*, Pretoria: Government Printer.
- Department of Education, 2015, *Report on the implementation of education white paper 6 on inclusive education*, Pretoria: Government Printer.
- Donohue, D. & Bornman, J., 2014, 'The challenges of realising inclusive education in South Africa', *South African Journal of Education* 32(2): 1-14.
- Engelbrecht, P., 2006, 'The implementation of inclusive education in South Africa after ten years of democracy', *European Journal of Psychology of Education* 21(3): 253-264.
- Eriksson, M. & Ghazinour, M., 2018, 'Different uses of Bronfenbrenner's ecological theory in public health research: what is their value for guiding public mental health policy and practice?', *Social Theory & Health* 16(4):414-433.
- Evans, J., 2016, 'Gauteng rolling out schools for autistic children', *News 24*, viewed 12 May 2016, from <https://www.news24.com/SouthAfrica/News/gauteng-rolling-out-schools-for-autistic-children-20160512>.
- Fountain, C., King, M.D. & Bearman, P.S., 2011, 'Age of diagnosis for autism: Individual and community factors across 10 birth cohorts', *Journal of Epidemiology & Community Health* 65(6):503-510.
- Gan, S.M., Tung, L.C., Yeh, C.H. & Wang, C.H., 2013, 'ICF-CY based assessment tool for children with autism', *Disability and Rehabilitation* 35(8): 678–685.
- Goin-Kochel, R.P. & Myers, B.J., 2005, 'Parental report of early autistic symptoms: Differences in ages of detection and frequencies of characteristics among three autism spectrum disorders', *Journal on Developmental Disabilities* 11(2): 21-39.
- Guthrie, W., Swineford, L. B., Nottke, C. & Wetherby, A. M., 2013, 'Early diagnosis of autism spectrum disorder: Stability and change in clinical diagnosis and symptom presentation', *Journal of Child Psychology and Psychiatry* 54(5): 582-590.
- Hannah, E. & Topping, K.J., 2012, 'Anxiety levels in students with autism spectrum disorder making the transition from primary to secondary school', *Education and Training in Autism and Developmental Disabilities* 47(2): 198-209.

- Halladay, A. K., Bishop, S., Constantino, J. N., Daniels, A. M., Koenig, K., Palmer, K., et al., 2015, 'Sex and gender differences in autism spectrum disorder: Summarizing evidence gaps and identifying emerging areas of priority', *Molecular Autism* 6(36): 1-5.
- Human Sciences Research Council, 2009, *Western Cape department of social development 2009: audit of early childhood development facility quality*, South Africa, Human Sciences Research Council.
- Humphrey, N., 2008, 'Including pupils with autistic spectrum disorders in mainstream schools', *Support for Learning* 23(1): 41-47.
- Idring, S., Lundberg, M., Sturm, H., Dalman, C., Gumpert, C., Rai, D., et al., 2015, 'Changes in prevalence of autism spectrum disorders in 2001-2011: Findings from the Stockholm youth cohort', *Journal of Autism and Developmental Disorders* 45(6): 1766-1773.
- Inclusion BC, 2014, *A parent's handbook on inclusive education*, 5th edn., British Columbia, Inclusion BC.
- Jäbrink, K., 2007, 'The economic consequences of autistic spectrum disorder among children in a Swedish municipality', *Autism* 11(5): 453-463.
- Jones, A.P. & Frederickson, N., 2010, 'Multi-informant predictors of social inclusion for students with autism spectrum disorders attending mainstream school', *Journal of Autism and Developmental Disorders* 40(9): 1094-1103.
- Kasari, C. & Rotheram-Fuller, E., 2007, 'Peer relationships of children with autism: challenges and interventions', in E. Hollander & E. Anagnostou, E. (eds), *Clinical manual for the treatment of autism*, pp 235-258, American Psychiatric Publishing: Arlington, Virginia.
- Lamers, K. & Hall, L.J., 2003, 'The response of children with autism to preferred prosody during instruction', *Focus on Autism and Other Developmental Disabilities* 18(2): 93-102.
- Leedy, P.D. & Ormrod, J.E., 2016, *Practical research: Planning and design*, 11th edn., New Jersey, Pearson Educational International and Prentice Hall.
- Lord, C., 2000, 'Commentary: Achievements and future directions for intervention research in communication and autism spectrum disorders', *Journal of Autism and Developmental Disorders* 30(5): 393-398.
- Lord, C. & Corsello, C., 2014, 'Diagnostic instruments in autism spectrum disorders', in F.R. Volkmar, R. Paul, A. Klin & D. Cohen (eds.), *Handbook of autism and pervasive developmental disorders*, 3rd edn., pp. 730-771, New Jersey, Hoboken, John Wiley & Sons Inc.
- Marsh, A., Spagnol, V., Grove, R. & Eapen, V., 2017, 'Transition to school for children with autism spectrum disorder: a systematic review', *World Journal of Psychiatry* 7(3): 184-196.
- Margia, L., McConkey, L. & Myezwa, H., 2014, 'Introduction', in L. Margia, L. McConkey & H. Myezwa (eds.), *Inclusive education in low-income countries: a resource book for teacher educators, trainers and community development workers*, pp. 2-11, Cape Town, South Africa, Atlas Alliance and Disability Innovations Africa.
- 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.
- Nhlapo, Z., 2018, 'Why homeschooling is becoming more of an option for South Africans', *Huffington post*, viewed 27 June 2018, from https://www.huffingtonpost.co.za/2018/01/25/why-homeschooling-is-becoming-more-of-an-option-for-south-africans_a_23343216/
- Pillay, S., Duncan, M. & De Vries, P., 2017, 'How many children with autism spectrum disorder (ASD) are there in South African schools: A systematic database search for known cases of ASD in the Western Cape Province', poster presented at the 2017 Africa Regional International Meeting for Autism Research, Stellenbosch, 7-9th September.

- Peters-Scheffer, N., Didden, R., Korzilius, H. & Matson, J., 2012, 'Cost comparison of early intensive behavioral intervention and treatment as usual for children with autism spectrum disorder in the Netherlands', *Research in Developmental Disabilities* 33(6): 1763-1772.
- Praisner, C.L., 2003, 'Attitudes of elementary school principals towards the inclusion of students with disabilities', *Exceptional Children* 69(2): 135-145.
- Rivet, T.T. & Matson, J.L., 2011, 'Review of gender differences in core symptomatology in autism spectrum disorders', *Research in Autism Spectrum Disorders* 5(3): 957-976.
- Roberts, J. & Simpson, K., 2016, 'A review of research into stakeholders perspectives on inclusion of students with autism in mainstream schools', *International Journal of Inclusive Education* 20(10): 1084-1096.
- Saloojee, G., Phohole, M., Saloojee, C. & IJsselmuiden, C., 2006, 'Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township', *Child: Care, Health and Development* 33(3), 230-235.
- Samms-Vaughan, M.E., 2014, 'The status of early identification and early intervention in autism spectrum disorders in lower- and middle-income countries', *International Journal of Speech-Language Pathology* 16(1): 30-35.
- Simpson, R.L., de Boer-Ott, S.R. & Smith-Myles, B., 2003, 'Inclusion of learners with autism spectrum disorders in general education settings', *Topics in Language Disorders* 23(2): 116-133.
- Springer, P.E., Van Toorn, R., Laughton, B. & Kidd, M., 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.
- Statistics South Africa, 2011, 'Census 2011', viewed 2 April 2018, from <http://www.statssa.gov.za/publications/p03014/p030142016>
- Statistics South Africa, 2014, 'Census 2011: Profiles of persons with disabilities in South Africa' viewed 10 June 2018, from <http://www.statssa.gov.za/?p=3180>
- Trochim, W., Donnelly, J.P. & Arora, K., 2015, 'Research methods: The essential knowledge base', 2nd edn., Boston, Massachusetts: Cengage Learning.
- UNESCO, 1994, 'The Salamanca statement and framework for action on special needs education', Paris, UNESCO.
- Waddington, E.M. & Reed, P., 2017, 'Comparison of the effects of mainstream and special school placements on outcomes in children with ASD: An archive-based analysis', *Journal of Research in Special Educational Needs* 17(2): 132-142.
- Werner, E., Dawson, G., Osterling, J. & Dinno, N., 2000, 'Recognition of autism spectrum disorder before one year of age: A retrospective study based on home videotapes', *Journal of Autism and Developmental Disorders* 30(2): 157-162.
- Whitman, T.L., 2004, *The development of autism: A self-regulatory perspective*, London, United Kingdom, Jessica Kingsley Publishers.
- World Health Organization (WHO), 2007, 'International classification of functioning, disability and health: children and youth version: ICF-CY', Geneva, Switzerland, World Health Organization.
- Young, R. L., Brewer, N. & Pattison, C., 2003, 'Parental identification of early behavioural abnormalities in children with autistic disorder', *Autism* 7(2): 125-143.

CHAPTER 6

GENERAL DISCUSSION, IMPLICATIONS AND CONCLUSION

6.1 Introduction

The purpose of this PhD research project was to describe the demographics of learners with ASD, their families, and some of their schools in SA from the perspective of caregivers and school principals. This was achieved through three studies 1) describing the demographic characteristics and typical early management of learners attending the six autism-specific government-funded schools in SA; 2) examining the socio-demographic characteristics of and financial costs encountered by families whose children attend the six autism-specific government-funded schools in SA; and 3) comparing the profiles of two autism-specific public and two autism-specific private schools in South Gauteng Province. Limited research is available on the contextual factors of the ICF-CY pertaining to children and youth with ASD in LMICs (de Schipper et al., 2015). It is important for SLTs to document the contextual factors of learners with ASD and their families as these factors may influence their everyday life outcomes and decision making. Since contextual factors for learners with ASD and their families differ for different income groups and across countries, this study contributed to knowledge concerning LMICs, in particular SA. The studies made a unique contribution to knowledge about learners with ASD who were mostly educated in autism-specific schools, in contrast to the widely accepted trend of inclusive education for learners with this condition. It is expected that the inclusive education policy of the SA DoE will be implemented in the future, marking this study as a reference for upcoming studies about the education of learners with ASD in SA.

The major findings of the three studies are summarized in this chapter and the theoretical and clinical implications are indicated. The implications of each study will be linked to recent literature to reflect the consequences of the research and to describe the contribution of the study to the field of ASD research and education in SA and possibly in a broader context. Lastly, the research will be critically evaluated and a final conclusion is drawn. The major findings and implications of the studies are discussed in section 6.2.

6.2 Study 1: Demographic characteristics and typical early management of learners attending the six autism-specific government-funded schools in SA – theoretical and clinical implications

The adverse impact of contextual factors, which include demographic factors, on the early management of learners attending autism specific schools in SA was confirmed in the current study. The majority of caregivers were mothers (85.0%) who became concerned about their child's development at the average age of 25.2 months, but only a few (3.8%) caregivers considered ASD as a possible cause. Demographic factors which were significantly associated with delayed age at parental concern (>48 months) included the respondent being the father, family-caregiver, or guardian, being a South African citizen, and having a lower level of parental education. The last two findings are in accordance with previous research which also confirmed that ethnicity and lower level of parental education may contribute to the delayed age at parental concern (Werner, Dawson, Osterling, & Dinno, 2000; Young, Brewer, & Pattison, 2003; Zablotsky et al., 2017). Research conducted in HICs and LMICs on whether the respondents' specific relationship to the child with ASD is associated with the age at parental concern could not be found. The results of this study are in agreement with well-known research findings that mothers' higher level of education is associated with better outcomes for children in general (Carneiro, Meghir, & Parey, 2013).

Furthermore, the results indicated that the child's age at parental concern influenced the age at the first assessment (on average 34.75 months), the age of ASD diagnosis (on average 46.6 months) and age at admission to the autism-specific school (6.8 years). The slow trajectory of delayed intervention may point to the limited awareness of ASD amongst caregivers and professionals, poverty, and the limited healthcare and educational services available for children with ASD in SA. One of the reasons why caregivers became concerned about their children's development was late speech and language emergence. The results are in agreement with studies conducted in HICs and LMICs, which found that although ASD can be identified early in life, early intervention is still mostly delayed (Bello-Mojeed et al., 2017; Goin-Kochel & Meyers, 2005; Latif & Williams, 2007; Mandell et al., 2009; Samms-Vaughan, 2014; Van Biljon et al., 2015). Therefore, it is important for SLTs to establish and advance early ASD intervention services in the communities where they are working (South African Speech-Language Hearing Association [SASLHA], 2017). Moreover,

SLTs should raise awareness of the early signs of ASD and advocate early intervention for children with ASD (SASLHA, 2017).

Lastly, the odds of caregivers becoming concerned late (>48 months) was higher when the first professional contacted regarding the caregiver's concern, was a specialist professional (developmental paediatrician, paediatric neurologist or a child psychiatrist), than when it was an allied health professional, a governmental clinic, or a general practitioner. Possible explanations include that there is a shortage of specialist professionals in SA, and caregivers ultimately do not have access to early diagnostic services. The majority of early diagnostic services are situated in urban areas and there is thus a need to establish early communication intervention services in rural communities in SA (SASLHA, 2017). A further finding was that in most instances allied health professionals were consulted first. The finding is in agreement with research in the US, which found that children suspected of ASD are usually referred to SLTs by allied health professionals after screening (Self, Coufal, & Parham, 2010). This could indicate that these health professionals are known to be knowledgeable about ASD as many allied health professionals are trained to identify ASD and are involved in the diagnosis (Self et al., 2010). SLTs should create opportunities for knowledge and skills sharing among allied health professionals in order to promote early communication intervention services for children with ASD (SASLHA, 2017). Early communication intervention, with an emphasis on an SLT approach, should be an essential component of every department, hospital, clinic, or practice providing services to young children with ASD (SASLHA, 2017).

This study provided foundational research which should be built upon in future studies. The data obtained can be used to systemise local priorities, such as early intervention programmes, for timely diagnosis and to provide targeted support for all caregivers, especially for mothers in SA. Research has shown that mothers of children with ASD are usually responsible for taking care of their children and typically spend more time with them (Boyd, 2002). Therefore, if mothers are educated about early ASD symptoms the age of identification and diagnosis may be lowered. Lastly, the study adds knowledge about best practice in the diagnosis of ASD. It is important that young infants and toddlers should be screened for atypical behaviours (Huerta & Lord, 2013). Should the screening indicate cause for concern the child should be referred for formal diagnostic assessment. Furthermore, it is important to include standardized assessments for cognitive,

developmental, and language areas. These tests should provide in-depth information of children's overall level of ability and functioning and may help the clinician to make a diagnosis (Huerta & Lord, 2013). It is also important that caregivers of children with ASD are actively involved in the early intervention process as they are usually involved in the intervention process as co-therapists and should help set goals for their child's treatment (Zwaigenbaum et al., 2015). It is important to consider developmental factors throughout the entire diagnostic process (Huerta & Lord, 2013). Research evidence suggest that nonverbal cognitive skills at age two can predict the verbal ability at age five (Huerta & Lord, 2013). Likewise, repetitive behaviour and poor adaptive skills at age two can predict more behavioural difficulties in older children diagnosed with ASD (Huerta & Lord, 2013). Lastly, it is important to determine the socio-economic characteristics of the family as this may present barriers to service provision and influence participation in intervention (Zwaigenbaum et al., 2015)

6.2 Study 2: Socio-demographic characteristics of and financial costs encountered by families whose children attend the six autism-specific government-funded schools in SA – theoretical and clinical implications

There is a need for a more holistic view of families raising school-aged children with ASD (Aljunied & Frederickson, 2014). In the second study, the family systems approach and the ICF-CY were used as frameworks to view families raising children with ASD from a broader perspective (Horlin et al., 2014; WHO, 2007). The study focused on describing environmental factors, such as socio-demographic characteristics of and financial costs encountered by families whose children attend autism-specific government-funded schools in SA.

Given the high non-response rate of the survey questionnaire and the subsequent limited generalizability of the results, unexpected similarities were found between the demographic profiles of the families of children with ASD in the schools, and the characteristics of the national majority of families in SA (Statistics South Africa, 2015). The majority of caregivers were Black, followed by White, Coloured, and Asian caregivers in similar distributions as in the population demographics in SA (Statistics South Africa, 2015). It is a positive observation that families from the Black population group now have better access to autism-specific schools for their children since they were excluded from these schools in the past (Van Biljon et al., 2015). Lastly, almost 50% of the mothers in the study indicated that they

were unmarried. Although we are cautious to generalise, the results may, to some extent, be seen as representative of SA mothers as reported by Statistics South Africa (2015).

The present study also confirmed existing evidence (Sharpe & Baker, 2011) that the societal costs of raising a child with ASD are exceptionally high. Families in the study were receiving a monthly household income that could be classified as "average" in the SA context but had to spend a significant amount of money on monthly school fees, transportation to and from school, medical insurance payments, and extracurricular therapeutic services. Furthermore, significant associations were found between the following variables and monthly household income: qualification of the father, qualification of the mother, marital status of the mother, school fees, school bursaries, and medical insurance schemes payments. The findings indicate that the higher the monthly household income, the higher the qualification of the father and mother, the school fees, the medical insurance scheme payments and the extracurricular therapy services. Therefore, all families of school-aged children with ASD experience a high financial burden and require extra financial support from the government. It is not clear, however, how the government is financially supporting families of children with ASD as there are limited data available. A few important differences were found between the data in this study and research from other LMICs. The sample showed higher monthly household income, lower parental education and more single mothers than in other LMICs (Chandran, 2016; Meral & Cavkaytar, 2012; Rivard, Terroux, Parent-Boursier, & Mercier, 2014; Samadi, Mahmoodizadeh, & McConkey, 2012). The differences may indicate the diversity of average families with children with ASD in these countries and the need for context-specific research. This study increased the understanding of the financial impact of ASD on the entire family. This finding implies that it is important for SLTs to broaden their perspective by using the family systems approach and the ICF-CY as two functional frameworks when working with families of children with ASD. Since there is limited research available about the contextual factors of the ICF-CY for children with ASD in LMICs (de Schipper et al., 2015), the research may contribute to the ICF-CY Core set of contextual factors for ASD in LMICs. Future research should focus on linking the contextual factors to the ICF core sets for ASD in LMICs. Various professionals, such as SLTs, are directly involved in the identification, diagnosis, and treatment of ASD (ASHA, 2016). It is therefore imperative for them to understand the financial implications on the family of a child with ASD, and the influence of the specific contextual factors related to the family on the child's everyday life outcomes.

In conclusion, the findings of the study imply that there should be a greater emphasis on finding ways to support families of children with ASD in LMICs financially. Furthermore, there is a need for professionals in private practice, such as SLTs, to find ways to charge reduced rates for therapies in LMICs families who could not otherwise obtain financial support.

6.3 Study 3: Profiles of two autism-specific public and two autism-specific private schools in South Gauteng Province – theoretical and clinical implications

Educational placement for learners with ASD in SA is a pertinent topic in light of the inclusive education policy which recommends that all learners should be educated in the least restrictive environment (DoE, 2001). In HICs countries such as Australia, the UK, and the US the trend seems to be that learners with ASD are placed in mainstream schools. However, there are many factors influencing inclusive education in mainstream schools (Humphrey, 2008; Roberts & Simpson, 2016; Simpson, de Boer-Ott, & Smith-Myles, 2003). Although legislation and policies in SA stipulate that learners with disabilities, such as ASD, should be included in mainstream schools, the DoE is still establishing autism-specific schools, thereby contradicting the inclusive education legislation and policies (Evans, 2016). Learners with ASD are still placed in autism-specific public and autism-specific private schools, but limited research is available regarding placement of children in the two different types of schools (Pillay et al., 2017). This was therefore sufficient justification for undertaking to describe the profiles of two autism-specific public and two autism-specific private schools.

The study demonstrated that although similarities prevail, the critical differences between the two types of schools, are consequential. The two autism-specific public schools make an enormous contribution to the education of learners with ASD in Gauteng Province as they are able to accommodate many more learners than the two autism-specific private schools. Autism-specific public schools have the capacity for more learners than the autism-specific private schools as they have bigger buildings. The autism-specific public schools are often overstretched, however, and have long waiting lists. Consequently, there is a need to establish more educational services accommodating learners with ASD in SA, especially in rural areas, but this does not necessarily imply segregated placement. Instead, learners with ASD should be placed in schools according to their severity levels and therefore meeting their educational needs. In addition, the autism-specific public schools are able to

accommodate young and older learners (3-21 years), whereas the autism-specific private schools do not accommodate learners older than 11 years. Therefore the autism-specific private schools are unable to provide the learners with ASD with uninterrupted education in one facility, from basic education up until twelfth grade (senior certificate). Furthermore, the autism-specific public schools offer a wider variety of therapy services than the autism-specific private schools. Many learners still require additional individualised therapy, which includes speech-language therapy, either at school or in private practice, but caregivers are responsible for the costs. Also, the autism-specific public schools offer more therapy services than the autism-specific private schools, despite the lower fees than private schools. The results indicated that the monthly school fees in autism-specific private schools (on average R4731.2) were significantly higher than that of the autism-specific public schools (on average R1185.4). SLTs and other organizations should advocate for the families they serve by disseminating information about the need for services and lobbying governmental and non-governmental agencies to provide financial assistance.

When considering the population group, significantly more Black learners were attending the autism-specific public schools than the autism-specific private schools. A possible explanation may be that the majority of the population in South Gauteng Province is also Black (Statistics South Africa, 2015). Although there were more teachers in the autism-specific public schools, the teacher-learner ratio in the autism-specific public and autism-specific private schools were more or less the same. Furthermore, the male-to-female ratio in the autism-specific public and autism-specific private schools did not differ greatly. All caregivers in the autism-specific public and autism-specific private schools became concerned about their child's development later (autism-specific public 26.2 months, private schools 26.3 months) than in other studies (Young, Brewer & Pattinson 2003). Similar to Study 1, it appears that late identification set a trajectory of late intervention for learners in both the autism-specific public and the autism-specific private schools. The later the caregiver became concerned about the child's development, the later the learner was diagnosed with ASD and enrolled in an autism-specific school. Learners enrolled at the autism-specific private schools were diagnosed with ASD earlier (on average at 42.7 months) than learners enrolled at the autism-specific public schools (on average at 47.9 months). A reason why the learners in the autism-specific private schools were diagnosed earlier might be that the caregivers had better access to diagnostic services since they earned a higher income. Also, the learners from autism-specific private schools commenced

school earlier (on average at 4.1 years) than the learners in the public schools (on average at 5.7 years). The findings indicate that caregivers may have limited knowledge about typical developmental milestones in young children and therefore were unable to identify developmental concerns at an early age (8-12 months). The results highlight the role of SLTs in autism-specific schools as they should support all caregivers by coordinating awareness programmes focussing on early ASD markers which include reduced levels of social attention and social communication; increased repetitive behaviour; abnormal body movements and motor development; temperamental profile; and atypical trajectory of early language and nonverbal development (Zwaigenbaum et al., 2015). The SLTs should also provide early communication intervention to the preschool learners. Furthermore, if children are to benefit from early childhood education (ECE), it is essential that children with ASD are identified and diagnosed earlier than indicated in this study. SLTs should also share their knowledge about early ASD symptoms with ECE teachers, enabling them to identify the symptoms in the classroom setting.

Lastly, three of the four principals expressed a preference for having learners with ASD placed in autism-specific schools. The principals stated that there is an overall lack of support and training for teachers working with learners with ASD in mainstream schools in SA and that there are many challenges related to the inclusive education policy implementation. It is evident that there is a need for additional support at school level which may include school and district support structures such as the School-Based Support Teams (SBST) and District-Based Support Teams (DBST). In addition, there is a paucity of research on the best education model for learners with ASD. Also, teachers should receive extensive training so that they have the necessary skills to teach learners with ASD.

In summary, the data obtained from this study indicate that there is a need to establish how many children with ASD are in the mainstream and special educational needs schools, and to identify how to better support these learners, caregivers, teachers, and principals in autism-specific schools. Furthermore, there should be a greater emphasis on identifying the barriers that prevent inclusive education for learners with ASD in SA.

6.4 Contribution of the studies to the field of speech-language pathology

Learners with ASD are known for their diversity in symptoms and severity of condition, and experience significant challenges in behaviour, social interaction, and communication

(Castro et al., 2013). They often require intensive intervention, specialised educational services, and continuous lifelong support (Parish et al., 2015). There is a large body of literature providing evidence that ASD is influencing the everyday life outcomes of children (Lord, 2000) and their families. Consequently, there is a need for SLTs to use the ICF-CY as a holistic framework to guide their assessment and service provision for learners with ASD and their families. The ICF-CY does not only provide a holistic perspective but is also detailed and in-depth. The ICF Brief Core Set for ASD and the age-appropriate core sets for ASD describe the symptoms of ASD very carefully and provide SLTs with a database that can be used for assessment and intervention. The findings of all three studies also provide further evidence that contextual factors of learners with ASD should be documented during the assessment and intervention process. Although caregivers and significant others are encouraged to be involved in the intervention, SLTs typically guide the final decision regarding intervention goals (McCormack, McLeod, Harrison, & McAllister, 2010).

6.5 Critical evaluation of the study

The strengths and limitations of the research study critically reviewed in the subsequent section. The critical analysis assisted in identifying research problems for future investigations.

6.5.1 Strengths of the studies

- Using a self-administered survey questionnaire enabled the researcher to distribute the questionnaire to a large sample and to cover a wide geographical area. The researcher was also able to reach participants who would otherwise be difficult to contact if an internet survey questionnaire was used since more than 64.8% of the SA population does not have access to the internet (Statistics South Africa, 2011). Despite a high non-response rate, the survey questionnaire reflected the opinions and experiences of a large number ($n=258$) of caregivers and principals who are closely involved with learners with ASD in schools in SA.
- Since early intervention for learners with ASD in SA is lacking (Springer et al., 2015; Van Biljon et al., 2015; Van Biljon & Kritzinger, 2017), the data obtained from Study 1 can be used to support and empower caregivers using targeted awareness and early identification programmes for infants and young children with ASD. The data may expedite timely ASD diagnosis in children and identify possible risk factors which can be modified.

- Study 2 was underpinned by the family systems approach and the ICF-CY to view families raising children with ASD from a broader perspective. This allowed the researcher to conduct family-focused ASD research of school-aged children that not only add knowledge about the financial impact of ASD on families of children with ASD but also information on the socio-demographic characteristics influencing everyday life outcomes. This study contributed important information about the socio-demographic characteristics and financial impact of ASD diagnosis on the entire family.
- The research adds knowledge to the field regarding the demographic and contextual characteristics of learners in urban areas of South Africa, a LMIC. The data obtained from Study 3 will help researchers understand differences in cultural contexts among the various service models for children with disabilities, and is especially important in helping LMICs refine and enhance the services they provide, particularly to the most vulnerable families.
- Limited research is available regarding the educational placement of learners with ASD (DoE, 2001). The data obtained from Study 3 support the recent progress report on the *Implementation of Education White Paper Six on Inclusive Education* (DoE, 2015) which indicated that there is minimal progress in inclusive education for learners with ASD. This study, therefore, provides clear and important implications for public policy in LMICs, like SA.

6.5.2 Limitations of the studies

- Data for all three studies were collected from families and principals closely involved with learners with ASD in schools in SA. The researcher did not include any principals or families of children with ASD from mainstream schools or those who make use of homeschooling. Therefore, it is important to note that there can be no generalisation beyond the sample since the families from mainstream schools might show different results.
- In epidemiological survey research, it is important to include as many members of the predefined population as possible (Abramson & Abramson, 2008; Miettinen & Karp, 2012). The target population was caregivers of learners in autism-specific public and autism-specific private schools and the researcher was able to include all the target schools. However, only 234 (28.4%) caregivers in Studies 1 and 2 and 150 (27.2%)

caregivers in Study 3 participated in the study. If the sample size had been larger, the sample would have been more representative.

- The survey questionnaire was only available in English and not translated into any of the other official South African languages. If the questionnaire was translated into other official South African languages more participants might have participated in the research.
- Another limitation is that all the information obtained from the survey questionnaires was respondent-reported. The researcher did not verify the information obtained from the survey questionnaire with the caregivers through interviews.
- Some questions in the survey questionnaire completed by the caregivers were retrospective. Since the average age of the learners was 9.8 years the memories of caregivers for certain events could have been distortions of what had happened (Leedy & Ormrod, 2016). However, since the respondents were able to check their personal records in their own time when completing the survey questionnaire they could have reported the facts accurately most of the time (Delport & Roestenburg, 2011).
- In Study 3 data were collected from two autism-specific public and two autism-specific private schools in South Gauteng Province only, which may limit generalizability to other local schools.
- No information was available regarding the level of ASD severity of the learners in Study 3. Knowing the severity levels of the learners would have been useful in understanding how representative each sample was, and how severity affected the family's financial burden, as well as the choice of public or private school.

6.6 Recommendations for future research

The following recommendations for future research were made:

- The data obtained in this study can be used as a baseline for epidemiological studies in LMICs about learners with ASD in autism-specific public schools in order to track changes in increasing public awareness of ASD and accessing early intervention. Interventions to increase public awareness of the early signs of ASD and best practices in early ASD management should first be implemented before baseline data can be used to determine progress.
- The response rate of the survey research design was low and may always be low, as it is an inherent limitation of the method (Leedy & Ormrod, 2016). Alternative methods of

data collection could be used to obtain data from families of children with ASD such as travelling to families' homes and collecting the questionnaire by interview, offering incentives for survey completion, or giving families the option of filling out the survey as an interview in the school setting. The research bias may be increased with such additional methods of data collection.

- Exploring the emotional and attitudinal responses of caregivers following an ASD diagnosis fell beyond the scope of this study. Investigating these responses might indicate additional psycho-social support needed by families raising children with ASD.
- Future research should investigate how the autism-specific schools operate, the curricula they are following, and the progress of learners in the schools.
- To date, limited research has focused on the environmental factors of the ICF-CY framework influencing the outcomes of school-aged children in LMICs (Aljunied & Frederickson, 2014). In addition, only a few studies in LMICs have confirmed the value of using the family systems approach as a framework for children with ASD (Schlebusch et al., 2017). Future research in LMICs is warranted to allow for more in-depth as well as a holistic view of families raising school-aged children with ASD within the context of theoretical frameworks.
- This study focused on the impact of environmental factors which included the socio-demographic characteristics and financial costs of families whose children attended autism-specific public schools in SA. Future research should be conducted on a larger scale in LMICs on how best to support families financially by reporting their needs. Further studies could investigate the financial challenges which affect families in other LMICs.
- There is no information available regarding learners with ASD and their families in rural areas. This sample did not include families from rural areas, families of children not attending schools, or illiterate families. It is therefore imperative for future research to focus on learners with ASD and their families in rural areas as this may help researchers understand how these learners and families are affected by ASD as their economic circumstances are likely to be worse than the families who participated in this study.
- In SA, educational placement for learners with ASD is a pertinent topic in light of the inclusive education policy recommending that all learners should be educated in the least restrictive environment (DoE, 2001). Therefore, the successful inclusion of learners

with ASD and teacher preferences toward the inclusion of learners with ASD in mainstream schools should be investigated further in SA and similar countries.

- Limited research is available on the education of learners with ASD in SA. The data obtained from this study can be used as a reference for future studies to track changes in ASD education trends, especially inclusive education, in SA and other LMICs.
- To date, there is a paucity of information regarding the process of transitioning from school to adult life for learners with ASD (Marsh et al., 2017). Research could reveal the needs related to transitioning into adulthood for learners with ASD and their families in LMICs.
- Future research is needed to obtain information on the factors influencing educational placement for learners with ASD in LMICs. Obtaining more information regarding this topic will assist all stakeholders in making more appropriate decisions for educational placement of learners with ASD.

6.7 General conclusions

SLTs have an important role to play in early intervention service delivery for children with ASD and their families (Zwaigenbaum et al., 2015). With an emphasis on communication, language learning, and language as the prerequisite of academic learning, they are involved in a) screening, evaluation and assessment; b) planning and implementation of intervention; c) consultation with and education of team members, which include other allied health professionals, teachers and families; c) transition planning; and d) creating awareness of early intervention (ASHA, 2006, 2008). However, the current human resource capacity of SLTs is severely limited in SA (Kathard et al., 2011). SLTs are grossly underrepresented in public special schools, such as autism-specific schools, across the country (Kathard et al., 2011). The majority of school-aged learners in SA receive therapy from SLTs in private practice and only families who can afford the therapy are benefitting from it (Clasquin-Johnson & Clasquin-Johnson, 2018; Kathard et al., 2011). It is evident that there is a need for allied health professionals, including SLTs, families and teachers to follow an educational team approach when working with learners with ASD in SA. The educational team should develop an individualised educational plan (IEP) in collaboration with the learner's caregivers to ensure that their specific educational needs are addressed and that they receive the best possible services within the school (Odom, Collet-Klingenber, Rogers, & Hatton, 2010). It is important for the educational team to use the ICF-CY as a

framework when developing an IEP for a learner with ASD, as the framework provides important information regarding the functioning and disability and the contextual factors influencing the learner's everyday life outcomes (Aljunied & Frederickson, 2014, Odom et al., 2010; WHO, 2007). Documenting the contextual factors of the ICF-CY may support early intervention planning for learners with ASD (Castro et al., 2013) and their families and point to disparities in access to services (Hopfe, Prodinger, Bickenbach, & Stucki, 2018). Strong evidence indicates that early intervention is critical for improving developmental outcomes for children with ASD by capitalising on the sensitive period for language and cognitive development during preschool years (Mazurek et al., 2014).

Overall the three studies provided a large volume of data on learners attending autism-specific schools in SA. The first study contributed important information on the demographic characteristics and typical early management of learners attending autism-specific schools in SA. Although the sample was not representative, the results provide the first data on the advanced age of diagnosis and school entry of the cohort of learners currently in autism-specific schools in SA. In the second study, the researcher confirmed the high societal costs associated with raising a child with ASD. The third study provided insightful information on the similarities and differences between the two types of schools in South Gauteng Province but also highlighted the need to raise awareness of ASD symptoms among parents with young children in all communities. Another contribution of the third study is that it provided information on the barriers that hinder inclusive education for learners with ASD in SA. Furthermore, the three studies provided evidence that there is a need for more research regarding the contextual factors influencing the timing of early intervention for learners with ASD and their families in SA and other LMICs. Young children and learners with ASD are the shared responsibility of their families, teachers, SLTs and many other professionals, and they deserve our best efforts.

References

- Abramson, J., & Abramson, H. (2008). *Research methods in community medicine: Surveys, epidemiological research, programme evaluation, clinical trials* (6th ed.). Chichester, England: John Wiley & Sons, Ltd.
- Aljunied, M., & Frederickson, N. (2014). Utility of the international classification of functioning, disability and health (ICF) for educational psychologists' work. *Educational Psychology in Practice*, 30(4), 380-392.
- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: American Psychiatric Association.
- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.
- American Speech-Language-Hearing Association [ASHA]. (2006). *Guidelines for Speech-Language Pathologists in Diagnosis, Assessment, and Treatment of Autism Spectrum Disorders Across the Life Span*. Retrieved from <https://www.asha.org/policy>
- American Speech-Language-Hearing Association [ASHA]. (2008). *Core knowledge and skills in early intervention*. Retrieved from <https://www.asha.org/policy>
- American Speech-Language-Hearing Association [ASHA]. (2016). Scope of practice in speech-language pathology. Retrieved from <https://www.asha.org/policy>
- Amr, M., Ali, W.B., Hablas, H., Raddad, D., El-Mehesh, F., El-Gilany, A.H.,...Al-Shamy, H. (2012). Sociodemographic factors in Arab children with autism spectrum disorders. *Pan African Medical Journal*, 13(65). Retrieved September 1, 2018, from <https://www.ajol.info/index.php/pamj/article/view/86994/76771>
- Autism Awareness Australia. (n.d.). *Financial support*. Retrieved from <http://www.autismawareness.com.au/financial-support/>
- Autism South Africa. (n.d.). *Autism government funded schools*. Retrieved from <http://aut2know.co.za/>
- Autism Speaks. (n.d.). *Financial assistance*. Retrieved from <https://www.autismspeaks.org/family-services/financial-assistance>
- Baghdadli, A., Picot, M.C., Pascal, C., Pry, R., & Aussilloux, C. (2003). Relationship between age of recognition of first disturbances and severity in young children with autism. *European Child & Adolescent Psychiatry*, 12(3), 122-127.

- Bakare, M.O., & Munir, K.M. (2011). Autism spectrum disorder (ASD) in Africa: A perspective. *African Journal of Psychiatry*, 14(3), 208-210.
- Baxter, A.J., Brugha, T.S., Erskine H.E., Scheurer, R.W., Vos, T., & Scott, J.G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, 45(3), 601–613.
- Becerra, T.A., Massolo, M.L., Yau, V.M., Owen-Smith, A.A., Lynch, F.L., Crawford, P.M.,... & Croen, L.A. (2017). A survey of parents with children on the autism spectrum: Experience with services and treatments. *The Permanente Journal*, 21. <https://doi.org/10.7812/TPP/16-009>
- Bello-Mojeed, M.A., Omigbodun, O.O., Bakare, M.O., & Adewuya, A.O. (2017). Pattern of impairments and late diagnosis of autism spectrum disorder among a sub-Saharan African clinical population of children in Nigeria. *Global Mental Health (Cambridge)*, 4, 1-9.
- Blair, J., Czaja, R.F., & Blair, E.A. (2013). *Designing surveys: A guide to decisions and procedures* (3rd ed.). Thousand Oaks, California: SAGE Publications Inc.
- Bölte, S., de Schipper, E., Robinson, J.E., Wong, V.C.N., Selb, M., Singhal, N., ...Zwaigenbaum, L., (2014). Classification of functioning and impairment: the development of ICF core sets for autism spectrum disorder. *Autism Research*, 7(1), 167-172.
- Bölte, S., Mahdi, S., de Vries, P.J., Granlund, M., Robison, J.E., Shulman, C.,...Selb, M. (2018). The Gestalt of functioning in autism spectrum disorder: Results of the international conference to develop final consensus international classification of functioning, disability and Health core sets. *Autism*. <https://doi.org/10.1177/136236131875522>
- Boyd, B.A. (2002). Examining the relationship between stress and lack of social support for mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 17(4), 208-215.
- Brett, D., Warnell, F., McConachie, H., & Parr, J.R. (2016). Factors affecting age at ASD diagnosis in the UK: No evidence that diagnosis age has decreased between 2004 and 2014. *Journal of Autism and Developmental Disorders*, 46(6), 1974-1984.
- Buescher, A.V., Cidav, Z., Knapp, M., & Mandell, D.S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *Journal of the American Medical Association*, 168(8), 721-728.

- Carneiro, P., Meghir, C., & Parey, M. (2013). Maternal education, home environments and the development of children and adolescents. *Journal of European Economic Association*, 11(1), 123-160.
- Caronna, E.B., Milunsky, J.M., & Tager-Flusberg, H. (2008). Autism spectrum disorders: Clinical and research frontiers. *Archives of Disease in Childhood*, 93(6), 518-523.
- Castro, S., Ferreira, T., Dababnah, S., & Pinto, A.I. (2013). Linking autism measures with the ICF-CY: Functionality beyond the borders of diagnosis and interrater agreement issues. *Developmental Neurorehabilitation*, 16(5), 321-331.
- Chambers, N., Wetherby, A.M., Stronach, S.T., Njongwe, N., Kauchali, S., & Grinker, R.R. (2017). Early detection of autism spectrum disorders in young isiZulu-speaking children in South Africa. *Autism*, 21(5), 518-526.
- Chandran, S. (2016). *Financial burden of living with autism: A case study of parents of at IDEAS Autism Centre*. Retrieved from <http://www.ideas.org.my/>
- Charles, L. (2014, October 22). Access to social grants for people with autism. *Berea mail*. Retrieved from <https://bereamail.co.za/44892/access-to-social-grants-for-people-with-autism/>.
- Christensen, D.L., Bilder, DA., Zahorodny, W., Pettygrove, S., Durkin, M.S., Fitzgerald, R.T.,...Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among 4-year-old children in the autism and developmental disabilities monitoring network. *Journal of Developmental and Behavioural Pediatrics*, 37(1), 1-8.
- Clasquin-Johnson, M.G. & Clasquin-Johnson, M. (2018). How deep are your pockets? Autoethnographic reflections on the cost of raising a child with autism. *African Journal of Disability*, 7, 1-8.
- Coo, H., Ouellette-Kuntz, H., Lam, M., Yu, C.T., Dewey, D., Bernier, F.P., ...Holden, J.J. (2012). Correlates of age at diagnosis of autism spectrum disorders in six Canadian regions. *Chronic Diseases and Injuries in Canada*, 32(2), 90-100.
- Crewe, R.M. (2007). *Policy for the preservation and retention of research data*. Retrieved from https://www.up.ac.za/media/.../preservation_and_retention_of_research_data.pdf
- Daniels, A.M., & Mandell, D.S. (2014). Explaining differences in age at autism spectrum disorder diagnosis: A critical review. *Autism*, 18(5), 583-597.
- Dass, S., & Rinquest, A. (2017). School Fees. In F. Veriava (Ed.), *Basic education rights handbook* (pp.142-158). Johannesburg, South Africa: Section 27.

- De Schipper, E., Lundequist, A., Wilteus, A.L., Coghill, D., de Vries, P.J., Granlund, M., ...Bölte, S. (2015). A comprehensive scoping review of ability and disability in ADHD using the international classification of functioning, disability and health-children and youth version (ICF-CY). *European Child & Adolescent Psychiatry*, 24(8), 859-872.
- De Vries, P.J. (2016). Thinking globally to meet local needs: autism spectrum disorders in Africa and other low-resource environments. *Current Opinion in Neurology*, 29(2), 130-136.
- 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. Fouché, & C.S.L. Delport (Eds.), *Research at grass roots. For the social sciences and human service professions* (4th ed.). Pretoria: Van Schaik Publishers.
- Department of Education (DoE). (1995). *White paper on education and training*. Pretoria, South Africa: Government Printer.
- Department of Education (DoE). (1996). *South African schools act, act 84 of 1996*. Pretoria, South Africa: Government Printer.
- Department of Education (DoE). (1997). *Integrated national disability strategy*. Pretoria, South Africa: Government Printer.
- Department of Education (DoE). (2001). *Education white paper 6 special needs education: Building an inclusive education and training system*. Pretoria, South Africa: Government Printer.
- Department of Education (DoE). (2010a). *Guidelines for full service/inclusive schools*. Pretoria, South Africa: Government Printer.
- Department of Education (DoE). (2010b). *Guidelines for inclusive teaching and learning*. Pretoria, South Africa: Government Printer.
- Department of Education (DoE). (2014). *Policy on screening, identification, assessment and support (SIAS)*. Pretoria, South Africa: Government Printer.
- Department of Education (DoE). (2015). *Report on the implementation of education white paper 6 on inclusive education*. Pretoria, South Africa: Government Printer.
- Department of Education, Employment and Workplace Relations. (2011). *Review of funding for schooling – final report*. Canberra, Australia: Department of Education, Employment and Workplace Relations.

- Di Rezze, B., Rosenbaum, P., & Zwaigenbaum, L. (2012). What attributes determine severity of function in autism? A web-based survey of stakeholders. *Focus on Autism and Other Developmental Disabilities*, 27(1), 139–41.
- Divan, G., Vajaratkar, V., Desai, M.U., Strik-Lievers, L., & Patel, V. (2012). Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. *Autism Research*, 5(3), 190-200.
- Donohue, D., & Bornman, J. (2014). The challenges of realising inclusive education in South Africa. *South African Journal of Education*, 32(2), 1-14.
- Engelbrecht, P. (2006). The implementation of inclusive education in South Africa after ten years of democracy. *European Journal of Psychology of Education* , 21(3), 253-264.
- Evans, J. (2016, May 12). Gauteng rolling out schools for autistic children. *News 24*. Retrieved from <https://www.news24.com/SouthAfrica/News/gauteng-rolling-out-schools-for-autistic-children-20160512>.
- Fountain, C., King, M.D., & Bearman, P.S. (2011). Age of diagnosis for autism: Individual and community factors across 10 birth cohorts. *Journal of Epidemiology & Community Health*, 65(6), 503-510.
- Gan, S.M., Tung, L.C., Yeh, C.H., & Wang, C.H. (2013). ICF-CY based assessment tool for children with autism. *Disability and Rehabilitation* 35(8), 678–685.
- Ganz, M.L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics & Adolescent Medicine*, 161(4), 343-349.
- Goin-Kochel, R.P. & Myers, B.J. (2005). Parental report of early autistic symptoms: Differences in ages of detection and frequencies of characteristics among three autism spectrum disorders. *Journal on Developmental Disabilities*, 11(2), 21–39.
- Goudge, J., Gilson, L., Russell, S.J., Gumede, T., & Mills, A. (2009). Affordability, availability and acceptability barriers to health care for the chronically ill: Longitudinal case studies from South Africa. *BMC Health Services Research*, 9(1), 75-93.
- Greeff, A.P., & van der Walt, K.J. (2010). Resilience in families with an autistic child. *Education and Training in Autism and Developmental Disabilities*, 45(3), 347-355.
- Grinker, R.R., Chambers, N., Njongwe, N., Langman, A.E., Guthrie, W., Stronach, S.,...Wetherby, A.M. (2012). “Communities” in community engagement: Lessons learned from autism research in South Korea and South Africa. *Autism Research*, 5(3), 201-210.

- Harris, B., Goudge, J., Ataguba, J.E., McIntyre, D., Nxumalo, N., Jikwana, S.,...Chersich, M. (2011). Inequities in access to health care in South Africa. *Journal of Public Health Policy*, 32(1), S102-S123.
- Hopfe, M., Prodinger, B., & Bickenbach, J.E., & Stucki, G. (2018). Optimizing health system response to patient's needs: an argument for the importance of functioning information. *Disability Rehabilitation*, 40(9), 2325-2330.
- Horlin, C., Falkmer, M., Parsons, R., Albrecht, M.A., & Falkmer, T. (2014). The cost of autism spectrum disorders. *PLOS ONE*, 9(9). <https://doi.org/10.1371/journal.pone.0106552>.
- Huerta, M., & Lord, C. (2013). Diagnostic evaluation of autism spectrum disorders. *Pediatric Clinics of North America*, 59(1), 103-111.
- Humphrey, N. (2008). Including pupils with autistic spectrum disorders in mainstream schools. *Support for Learning*, 23(1), 41-47.
- Idring, S., Lundberg, M., Sturm, H., Dalman, C., Gumpert, C., Rai, D.,...Magnusson, C. (2015). Changes in prevalence of autism spectrum disorders in 2001-2011: Findings from the Stockholm youth cohort. *Journal of Autism and Developmental Disorders*, 45(6), 1766-1773.
- Jäbrink, K. (2007). The economic consequences of autistic spectrum disorder among children in a Swedish municipality. *Autism*, 11(5), 453-463.
- Jones, A.P. & Frederickson, N. (2010). Multi-informant predictors of social inclusion for students with autism spectrum disorders attending mainstream schools. *Journal of Autism and Developmental Disorders*, 40(9), 1094–1103.
- Juneja, M., Mukherjee, S.B., & Sharma, S. (2005). A descriptive hospital based study of children with autism. *Indian Pediatrics*, 42(5), 453-458.
- Kathard, H., Ramma, L., Pascoe, M., Jordaan, H., Moonsamy, S., Wium, A., ...Khan, N.B. (2011). How can speech language therapists and audiologists enhance language and literacy outcomes in South Africa? (And why we urgently need to). *South African Journal of Communication Disorders*, 58(2), 59-71.
- Kirby, A.V., Baranek, G.T., & Fox L. (2016). Longitudinal predictors of outcomes for adults with autism spectrum disorder: Systematic review. *Occupation, Participation and Health*, 36(2), 55–64.
- Kiru, E., & Cooc, N. (2017). A comparative analysis of access to education for students with disabilities in Brazil, Canada, and South Africa. *Journal of International and Special Needs Education*. Advance online publication. <https://doi.org/10.9782/16-00024R4>

- Kleinman, J.M., Robins, D.L., Ventola, P.E., Pandey, J., Boorstein, H.C., Esser, E.L.,...Fein, D. (2008). The modified checklist for autism in toddlers: A follow-up study investigating the early detection of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38(5), 827-839.
- Latif, A.H.A., & Williams, W.R. (2007). Diagnosis trends in autistic spectrum disorders in the South Wales valleys. *Autism*, 11(6), 479-487.
- Lee, M., & Schuele, C. (2010). Demographics. In N.J. Salkind (Ed.), *Encyclopedia of research design* (pp. 347-347). Thousand Oaks, California: SAGE Publications Inc.
- Leedy, P.D., & Ormrod, J.E. (2016). *Practical research: Planning and design* (11th ed.). New Jersey: Pearson Educational International and Prentice Hall.
- Lord, C. (2000). Commentary: Achievements and future directions for intervention research in communication and autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 30(5), 393-398.
- Mahdi, S., Viljoen, M., Yee, T., Selb, M., Singhal, N., Almodayfer, O.,...Bölte, S. (2018). An international qualitative study of functioning in autism spectrum disorder using the world health organization international classification of functioning, disability and health framework. *Autism Research*, 11(3), 463-475.
- Majoko, T. (2017). Practices that support the inclusion of children with autism spectrum disorder in mainstream early childhood education in Zimbabwe. *Sage Open*, 7(3). <https://doi.org/10.1177/2158244017730387>
- Makin, C. (2017). The primary-to-secondary school transition for children on the autism spectrum: A multi-informant mixed-methods study. *Autism & Developmental Language Impairments*, 2. <https://doi.org/10.1177/2396941516684834>
- Malcolm-Smith, S., Hoogenhout, M., Ing, N., Thomas, K.G., & de Vries, P. (2013). Autism spectrum disorders – global challenges and local opportunities. *Journal of Child & Adolescent Mental Health*, 25(1), 1-5.
- Mandell, D.S., Listerud, J., Levy, S.E., & Pinto-Martin, J.A. (2002). Race differences in the age at diagnosis among medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41 (12), 1447-1453.
- 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.

- Mandell, D.S., Wiggins, L.D., Carpenter, L.A., Daniels, J., DiGuiseppi, C., Durkin, M.S.,...Kirby, R.S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99(3), 493-498.
- Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism*, 8(4), 387-407.
- Marsh, A., Spagnol, V., Grove, R., & Eapen, V. (2017). Transition to school for children with autism spectrum disorder: A systematic review. *World Journal of Psychiatry*, 7(3), 184-196.
- Mazurek, M.O., Handen, B.L., Wodka, E.L., Nowinski, L., Butter, E., & Engelhardt, C.R. (2014). Age at first autism spectrum diagnosis: The role of birth cohort, demographic factors, and clinical features. *Journal of Developmental and Behavioral Pediatrics*, 35(9), 561-569.
- McCormack, J., McLeod, S., Harrison, L.J., & McAllister, L. (2010). The impact of speech impairment in early childhood: Investigating parents' and speech-language pathologists' perspectives using the ICF-CY. *Journal of Communication Disorders*, 43(5), 378-396.
- Meral, B.F., & Cavkaytar, A. (2012). A study on social support perception of parents who have children with autism. *International Journal on New Trends in Education and Their Implications*, 3(3), 124-135.
- Miettinen, O.S., & Karp, I. (2012). *Epidemiological research: An introduction*. Dordrecht, Netherlands: Springer.
- Molteno, G., Molteno, C.D., Finchilescu, G., & Dawes, A.R.L. (2001). Behavioural and emotional problems in children with intellectual disability attending special schools in Cape Town, South Africa. *Journal of Intellectual Disability Research*, 45(6), 515-520.
- Musa, M.Y.F.H.M. (2016). Sociodemographic correlates of autism spectrum disorders in children: Study in Autism Center|ThiQar health office\Iraq. *Global Journal of Multidisciplinary Studies*, 5(5), 99-102.
- Muthukrishna, N., & Schoeman, M. (2000). From "special needs" to "quality education for all": A participatory, problem-centred approach to policy development in South Africa. *International Journal of Inclusive Education*, 4(4), 315–335.
- Nelson, L. (2016). *Research in communication sciences and disorders: Methods for systematic inquiry*. San Diego, California: Plural Publishing Inc.

- Odom, S.L., Collet-Klingenber, L., Rogers, S.J., & Hatton, D.D. (2010). Evidence-based practices in interventions for children with autism spectrum disorders. *Preventing School Failure: Alternative Education for Children and Youth*, 54(4), 275-282.
- Olivier, M.A., & Ah Hing, A.D. (2009). Autistic spectrum disorder (ASD): Parental challenges and strategies. *Vulnerable Children and Youth Studies*, 4(1), 58-66.
- Pallant, J. (2013). *SPSS survival manual* (5th ed.). Crows Nest, Australia: Allen & Unwin.
- Parish, S.L., Thomas, K.C., Williams, C.S., & Crossman, M.K. (2015). Autism and families' financial burden: The association with health insurance coverage. *American Journal of Intellectual Developmental Disabilities*, 120(2), 166-175.
- Petersen, I., & Lund, C. (2011). Mental health service delivery in South Africa from 2000 to 2010: One step forward, one step back. *South African Medical Journal*, 101(10), 751-757.
- Pillay, S., Duncan, M., & de Vries, P. (2017, September). *How many children with autism spectrum disorder (ASD) are there in South African schools: A systematic database search for known cases of ASD in the Western Cape Province*. Poster presented at the 2017 Africa Regional International Meeting for Autism Research, Stellenbosch, South Africa. Retrieved from https://www.researchgate.net/publication/319620840_How_many_children_with_Autism_Spectrum_Disorder_are_there_in_South_African_Schools_A_systematic_database_search_for_known_cases_of_ASD_in_the_Western_Cape
- Revenson, T., Griva, K., Luszczynska, A., Morrison, V., Panagopoulou, E., Vilchinsky, N.,...Hagedoorn, M. (2016). *Caregiving in the illness context*. Basingstoke, United Kingdom: Palgrave Macmillan.
- Richmond, A. (2011). Autism spectrum disorder: A global perspective. *Perspectives on Global Issues in Communication Sciences and Related Disorders*, 1(2), 39-46.
- Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(7), 1609-1620.
- Riya, S., Begum, M., Begum, N., Majid, F., Jahan, S., & Rahman, A. (2014). Maternal risk factors associated with autistic children. *Anwer Khan Modern Medical College Journal*, 5(2), 14–17.
- Roberts, J., & Simpson, K. (2016). A review of research into stakeholders perspectives on inclusion of students with autism in mainstream schools. *International Journal of Inclusive Education*, 20(10), 1084-1096.

- Rosenberg, R.E., Kaufmann, W.E., Law, J.K., & Law, P.A. (2011). Parent report of community psychiatric comorbid diagnoses in autism spectrum disorders. *Autism Research and Treatment, 2011*. <http://dx.doi.org/10.1155/2011/405849>
- Roth, F.P., & Worthington, C.K. (2016). *Treatment resource manual for speech-language pathology* (5th ed.). Clifton Park, New York: Cengage Learning.
- Saloojee, G., Phohole, M., Saloojee, C. & IJsselmuiden, C. (2006). Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child: Care, Health and Development, 33*(3), 230-235.
- Samadi, S.A., Mahmoodizadeh, A., & McConkey, R. (2012). A national study of the prevalence of autism among five-year-old children in Iran. *Autism, 16*(1), 5-14.
- Samms-Vaughan, M.E. (2014). The status of early identification and early intervention in autism spectrum disorders in lower-and middle-income countries. *International Journal of Speech-Language Pathology, 16*(1), 30-35.
- Schlebusch, L., & Dada, S. (2018). Positive and negative cognitive appraisal of the impact of children with autism spectrum disorder on the family. *Research in Autism Spectrum Disorders, 51*, 86-93.
- Schlebusch, L., Dada, S., & Samuels, A.E. (2017). Family quality of life of South African families raising children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(7), 1966-1977.
- Schlebusch, L., Samuels, A.E., & Dada, S. (2016). South African families raising children with autism spectrum disorders: Relationship between family routines, cognitive appraisal and family quality of life. *Journal of Intellectual Disability Research, 60*(5), 412-423.
- Selb, M., Escorpizo, R., Kostanjsek, N., Stucki, G., Üstün, B., & Cieza, A. (2015). A guide on how to develop an International Classification of Functioning, Disability and Health Core Set. *European Journal of Physical and Rehabilitation Medicine, 51*(1), 105–117.
- Self, T.L., Coufal, K., & Parham, D.F. (2010). Allied healthcare providers' role in screening for autism spectrum disorders. *Journal of Allied Health, 39*(3), 165-174.
- Sharpe, D.L., & Baker, D.L. (2011). The financial side of autism: private and public costs. In M.R. Mohammadi (Ed.), *A comprehensive book on autism spectrum disorders* (pp. 275-296). Rijeka, Croatia: InTech.
- Shattuck, P.T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D.S., Wiggins, L., ...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*, 48(5), 474-483.
- Shipley, K.G., & McAfee, J.G. (2015). *Assessment in speech-language pathology* (5th ed.). Boston, Massachusetts: Cengage Learning.
- Siklos, S., & Kerns, K.A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities*, 28(1), 9-22.
- Simpson, R.L., de Boer-Ott, S.R., & Smith-Myles, B. (2003). Inclusion of learners with autism spectrum disorders in general education settings. *Topics in Language Disorders*, 23(2), 116-133.
- South African Speech-Language Hearing Association (SASLHA). (2017). *Practice guidelines for audiologists and speech-language therapists in early communication intervention*. Retrieved from https://www.saslha.co.za/Content/Documents/Guidelines_for_Early_Communication_Intervention_2017.pdf
- Springer, P. E., van Toorn, R., Laughton, B., & Kidd, M. (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.
- Statistics South Africa. (2011). *Census 2011*. Retrieved from <http://www.statssa.gov.za/publications/p03014/p030142016>
- Statistics South Africa. (2015). *GHS Series Volume VII Housing from a human settlement perspective*. Retrieved from www.statssa.gov.za/publications/Report-03-18-06/Report-03-18-062014.pdf.
- Strydom, H. (2011a). Ethical aspects of research in the social sciences and human service professions. In A.S. De Vos, H. Strydom, C.B. Fouché, & C.S.L. Delport (Eds.), *Research at grass roots. For the social sciences and human service professions* (4th ed.) (pp.113-130). Pretoria, South Africa: Van Schaik Publishers.
- Strydom, H. (2011b). The pilot study in the quantitative paradigm. In A.S. De Vos, H. Strydom, C.B. Fouché, & C.S.L. Delport (Eds.), *Research at grass roots. For the social sciences and human service professions* (4th ed.) (pp. 236-247). Pretoria, South Africa: Van Schaik Publishers.
- The National Autistic Society. (n.d.). Benefits for autistic children. Retrieved from <http://www.autism.org.uk/about/benefits-care/benefits/children.aspx>

- Travis, J., & Geiger, M. (2010). The effectiveness of the picture exchange communication system (PECS) for children with autism spectrum disorder (ASD): A South African pilot study. *Child Language Teaching and Therapy*, 26(1), 39-59.
- Trochim, W., Donnelly, J.P., & Arora, K. (2015). *Research methods: The essential knowledge base* (2nd ed.). Boston, Massachusetts: Cengage Learning.
- Umalusi. (n.d.). *Certification and verification*. Retrieved from <https://www.umalusi.org.za/services.php?cat=Certification%20and%20Verification>
- United States Department of Education. (2011). *Ensuring equal access to high-quality education*. Washington, DC: Office for Civil Rights.
- Van Biljon, S., & Kritzinger, A. (2017). Early identification of learners with autism spectrum disorder: Drawing on developmental histories. *Early Child Development and Care*. Advance online publication. <http://dx.doi.org/10.1080/03004430.2017.1301934>
- Van Biljon, S., Kritzinger, A., & Geertsema, S. (2015). A retrospective case report on demographic changes of learners at a school for children with autism spectrum disorder in the Gauteng Province. *South African Journal of Childhood Education*, 5(1), 42–61.
- Waddington, E.M., & Reed, P. (2017). Comparison of the effects of mainstream and special school placements on national curriculum outcomes in children with autism spectrum disorder: An archive-based analysis. *Journal of Research in Special Educational Needs*, 17(2), 132-142.
- Werner, E., Dawson, G., Osterling, J., & Dinno, N. (2000). Brief report: Recognition of autism spectrum disorder before one year of age: A retrospective study based on home videotapes. *Journal of Autism and Developmental Disorders*, 30(2), 157-162.
- Whitman, T.L. (2004). *The development of autism: A self-regulatory perspective*. London, United Kingdom: Jessica Kingsley Publishers.
- World Health Organization (WHO). (2007). *International classification of functioning, disability and health: children and youth version: ICF-CY*. Geneva, Switzerland: World Health Organization.
- World Health Organization (WHO). (2018). *International classification of diseases and related health problems* (11th Revision). Geneva, Switzerland: World Health Organization.
- Young, R. L., Brewer, N., & Pattison, C. (2003). Parental identification of early behavioural abnormalities in children with autistic disorder. *Autism*, 7(2), 125-143.

- Zablotsky, B., Colpe, L.J., Pringle, B.A., Kogan, M.D., Rice, C., & Blumberg, S.J. (2017). Age of parental concern, diagnosis, and service initiation among children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities*, 122(1), 49-61.
- Zwaigenbaum, L., Bauman, M.L., Choueiri, R., Kasari, C., Carter, A., Granpeesheh, D.,...Natowicz, M.R. (2015). Early intervention for children with autism spectrum disorder under 3 years of age: Recommendations for practice and research. *Pediatrics*, 136(1), S60-S81.

Appendices

Appendix A) Ethical clearance certificate



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

8 August 2016

Dear Prof Vinck

Project: Demographics of learners with autism spectrum disorder,
their families and schools in South Africa
Researcher: S van Biljon
Supervisor: Prof A Kritzinger
Department: Speech-Language Pathology and Audiology
Reference: 28024967 (GW20160702HS)

Thank you for the application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** on 28 July 2016, conditional to written permission being granted by:

- The Department of Education

Please note that data collection may not commence prior to the above permissions being submitted as request and subject to final approval by this Committee. To facilitate the administrative process, please respond to Ms Tracey Andrew at tracey.andrew@up.ac.za or Room HB 7-27, at your earliest possible convenience.

Sincerely

Prof Maxi Schoeman
Deputy Dean: Postgraduate Studies and Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:tracey.andrew@up.ac.za

Kindly note that your original signed approval certificate will be sent to your supervisor via the Head of Department. Please liaise with your supervisor.

Research Ethics Committee Members: Prof MME Schoeman (Deputy Dean); Prof KL Harris; Dr L Blokland; Dr R Fasselt; Ms KT Govinder; Dr E Johnson; Dr C Panebianco; Dr C Puttergill; Dr D Reyburn; Prof GM Spies; Prof E Taljard; Ms B Tsebe; Dr E van der Klashorst; Mr V Sithole

Appendix B) Letter of Approval from DoE



For administrative use:
Reference no. D2017 / 321 A
Enquiries: Diane Bunting 011 843 6503

GAUTENG PROVINCE
EDUCATION
REPUBLIC OF SOUTH AFRICA

GDE AMENDED RESEARCH APPROVAL LETTER

Date:	6 October 2016
Validity of Research Approval:	6 February 2017 to 30 September 2017
Previous GDE Research Approval letter reference number	D2017 / 240 dated 24 August 2016
Name of Researcher:	Van Biljon S.
Address of Researcher:	141 Panorama Drive; 1 Eagle Rock Estate; Constantia Kloof; 1709
Telephone / Fax Number/s:	072 151 4353
Email address:	sumsievb@gmail.com
Research Topic:	Demographics of learners with Autism Spectrum Disorder, their families and schools in South Africa
Number and type of schools:	THREE LSEN Schools
District/s/HO	Gauteng East; Gauteng North and Tshwane South

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. A separate copy of this letter must be presented to the Principal, SGB and the relevant District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted. However participation is VOLUNTARY.

The following conditions apply to GDE research. The researcher has agreed to and 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:

CONDITIONS FOR CONDUCTING RESEARCH IN GDE

1. The District/Head Office Senior Manager/s concerned, the Principal/s and the chairperson/s of the School Governing Body (SGB) must be presented with a copy of this letter.

Julie
2016/10/07

1

Making education a societal priority

Office of the Director: Education Research and Knowledge Management ER&KM)

2. The Researcher will make every effort to obtain the goodwill and co-operation of the GDE District officials, principals, SGBs, teachers, parents and learners involved. Participation is voluntary and additional remuneration will not be paid;
3. Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal and/or Director must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.
4. Research may only commence from the second week of February and must be concluded by the end of the THIRD quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.
5. Items 3 and 4 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.
6. It is the researcher's responsibility to obtain written consent from the SGB/s; principal/s, educator/s, parents and learners, as applicable, before commencing with research.
7. The researcher is responsible for supplying and utilizing his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institution/s, staff and/or the office/s visited for supplying such resources.
8. The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research title, report or summary.
9. On completion of the study the researcher must supply the Director: Education Research and Knowledge Management, with electronic copies of the Research Report, Thesis, Dissertation as well as a Research Summary (on the GDE Summary template). Failure to submit your Research Report, Thesis, Dissertation and Research Summary on completion of your studies / project – a month after graduation or project completion - may result in permission being withheld from you and your Supervisor in future.
10. The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned;
11. Should the researcher have been involved with research at a school and/or a district/head office level, the Director/s and school/s concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

Dr David Makhado

Director: Education Research and Knowledge Management

DATE: 2016/10/07



STRATEGIC PLANNING POLICY RESEARCH AND SECRETARIAT SERVICES

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Date: 14 September 2016

Sumari Van Biljon

141 PanorM Drive

1 Eagles Rock Estate

Constantia Kloof

1709

Dear Ms Van Biljon

PERMISSION TO UNDERTAKE A DOCTORAL STUDY: DEMOGRAPHICS OF LEARNERS WITH AUTISM SPECTRUM DISORDER, THEIR FAMILIES AND SCHOOLS IN SOUTH AFRICA

1. Thank you for your application to conduct research.
2. Your application to conduct the above mentioned research at the 6 Autism specific government funded schools of the Eastern Cape Department of Education (ECDoE) is hereby approved based on the following conditions:
 - a. there will be no financial implications for the Department;
 - b. institutions and respondents must not be identifiable in any way from the results of the investigation;
 - c. you present a copy of the written approval letter of the Eastern Cape Department of Education (ECDoE) to the Cluster and District Directors before any research is undertaken at any institutions within that particular district;
 - d. you will make all the arrangements concerning your research;
 - e. the research may not be conducted during official contact time, as educators' programmes should not be interrupted;

building blocks for growth

Page 1 of 2



Ikamva eliqaqambileyo!

- f. should you wish to extend the period of research after approval has been granted, an application to do this must be directed to Chief Director: Strategic Management Monitoring and Evaluation;
 - g. the research may not be conducted during the fourth school term, except in cases where a special well motivated request is received;
 - h. your research will be limited to those schools or institutions for which approval has been granted, should changes be effected written permission must be obtained from the Chief Director: Strategic Management Monitoring and Evaluation;
 - i. you present the Department with a copy of your final paper/report/dissertation/thesis free of charge in hard copy and electronic format. This must be accompanied by a separate synopsis (maximum 2 – 3 typed pages) of the most important findings and recommendations if it does not already contain a synopsis.
 - j. you present the findings to the Research Committee and/or Senior Management of the Department when and/or where necessary.
 - k. you are requested to provide the above to the Chief Director: Strategic Management Monitoring and Evaluation upon completion of your research.

 - l. you comply with all the requirements as completed in the Terms and Conditions to conduct Research in the ECDoE document duly completed by you.

 - m. you comply with your ethical undertaking (commitment form).
 - n. you get consent from the parents of the learners involved.
 - o. you submit on a six monthly basis, from the date of permission of the research, concise reports to the Chief Director: Strategic Management Monitoring and Evaluation.
3. The Department reserves a right to withdraw the permission should there not be compliance to the approval letter and contract signed in the Terms and Conditions to conduct Research in the ECDoE.
4. The Department will publish the completed Research on its website.
5. The Department wishes you well in your undertaking. You can contact the Director, Ms. NY Kanjana on the numbers indicated in the letterhead or email nykanjana@live.co.za should you need any assistance.



NY KANJANA

DIRECTOR: STRATEGIC PLANNING POLICY RESEARCH & SECRETARIAT SERVICES

FOR SUPERINTENDENT-GENERAL: EDUCATION



REFERENCE: 20160804 –2962
ENQUIRIES: Dr A T Wyngaard

Ms Sumari Van Biljon
141 Panorama Drive
1 Eagles Rock Estate
Constantia Kloof
7800

Dear Ms Sumari Van Biljon

RESEARCH PROPOSAL: DEMOGRAPHIC CHARACTERISTICS OF LEARNERS THEIR FAMILIES AND AUTISM SPECIFIC SCHOOLS IN SOUTH AFRICA

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

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **08 August 2016 till 30 June 2017**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Dr A.T Wyngaard at the contact numbers above quoting the reference number?
8. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

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

We wish you success in your research.

Kind regards.
Signed: Dr Audrey T Wyngaard
Directorate: Research
DATE: 04 August 2016

Appendix C) Request for permission to conduct research at schools



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Speech-Language Pathology and Audiology

August 2016

REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT YOUR SCHOOL

Dear Principal

I am conducting research for a PhD degree in Speech-Language Pathology, at the Department of Speech-Language Pathology and Audiology at the University of Pretoria. The letter is to request written permission to conduct research titled: "**Demographics of learners with autism spectrum disorder, their families and schools in South Africa**".

In South Africa we do not yet know enough about the learners with ASD. A large study about learners with ASD in South Africa is undertaken. The purpose of the research is to describe the demographic characteristics of children with ASD in South Africa. I intend to include six autism-specific government funded schools and two independent autism-specific schools in South Africa for the study. All parents of learners with ASD are encouraged to participate in the study. I require information about the learners, their families, and the autism-specific schools.

Similar research conducted worldwide have helped countries understand children with ASD and their families better and to plan and implement educational support and appropriate services to learners. Knowledge of factors associated with late identification, diagnosis and admission to schools may be obtained from the study.

WHO ARE THE PARTICIPANTS FOR THIS STUDY?

The inclusion criteria for the participants are as follows:

1. The parent/main caregiver must have a child diagnosed with ASD.
2. The child should be a current learner at the school.
3. Principal of the school.

WHAT WILL THE PARTICIPANTS HAVE TO DO?

Parents will be given a flyer to invite them to participate in the research. The parents who are willing to partake in the study will be asked to complete a self-administered questionnaire and an informed consent form. The completed questionnaire should be returned on a specific date determined by the researcher. To complete the questionnaire will take approximately 15 minutes of their time. The principals of the autism-specific schools who grant the researcher permission to conduct the research at the school will also be asked to complete a questionnaire requiring school-specific information. The principals will be asked to grant the researcher written permission and informed consent.

WHAT WILL BE EXPECTED OF THE SCHOOL?

Upon the favourable permission of the school the following will be expected:

1. To allow me to distribute a flyer and invite parents to an information session at the school.
2. To allow me to give parents informed consent brochures to complete.
3. To provide parents who did not attend the information session and would still like to be part of the research project, an information brochure and consent form.

Speech-Language Pathology and Audiology
Building Room 2-11
University of Pretoria
Private Bag X20, Hatfield 0028
Republic of South Africa

Tel: 012 420 2949

Fax: 012 420 3517

Email: alta.kritzinger@up.ac.za

www.up.ac.za

4. To allow the researcher to give parents who have given their consent a questionnaire to complete.
5. To safely keep the completed questionnaires for the researcher to collect at a prearranged date.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

1. The study was approved by the Faculty of Humanities' Research Ethics Committee at the University of Pretoria.
2. The departments of Education (Western Cape Department of Education [WCED], Eastern Cape Department of Education [ECDOE] and Gauteng Department of Education [GDE]) gave permission for the study to be conducted.

CONFIDENTIALITY AND ANONYMITY

All information obtained from the questionnaire will be reported on anonymously as there will be no names or learners or schools on the questionnaires. I intend to write three articles and a thesis about the information obtained from the questionnaire. No school specific information will be given.

DATA STORAGE

According to the University of Pretoria's policy, data must be securely stored for a minimum of 15 years.

WILL YOU HAVE ACCESS TO THE RESEARCH RESULTS?

Upon completion of the research projects an electronic and hard copy of the research report will be submitted to the WCED, GDE and ECDOE.

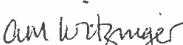
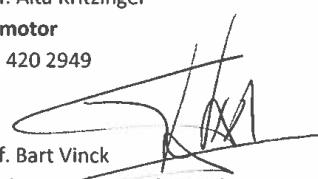
I am happy to share the results from this study with you. If you are interested to receive a free copy of the results, please inform me. Alternatively, you are welcome to arrange for a feedback session in the form of a presentation.

Should you require any further information please contact me or my promotor.

Yours sincerely


 Ms. Sumari van Biljon
 Researcher
 072 151 4353


 Dr. Jeannie van der Linde
 Co-Promotor
 012 420 2948


 Prof. Alta Kritzinger
 Promotor
 012 420 2949

 Prof. Bart Vinck
 Head Department of Speech Language
 Pathology and Audiology

REPLY FORM: PERMISSION TO CONDUCT RESEARCH AT YOUR SCHOOL AND INFORMED CONSENT

I herewith give permission that Ms S van Biljon can conduct research titled: "Demographics of learners with autism spectrum disorder, their families and schools in South Africa" at the school. I also give consent to participate in the study. The researcher, Ms Sumari van Biljon, has informed me about the nature, process, risks, discomforts and benefits of the study. I am aware that the results of the study will be anonymously processed into articles and research reports. I have had the time to ask questions and have no objection to participate in the study. I hereby also give/do not give consent that the data may be used for future research

Name of Principal:.....

Signature:.....

Date:.....

Appendix D) Written permission obtained from the schools

REPLY FORM: PERMISSION TO CONDUCT RESEARCH AT YOUR SCHOOL AND INFORMED CONSENT

I herewith give permission that Ms S van Biljon can conduct research titled: "Demographics of learners with autism spectrum disorder, their families and schools in South Africa" at the school. I also give consent to participate in the study. The researcher, Ms Sumari van Biljon, has informed me about the nature, process, risks, discomforts and benefits of the study. I am aware that the results of the study will be anonymously processed into articles and research reports. I have had the time to ask questions and have no objection to participate in the study. I hereby also give/do not give consent that the data may be used for future research

Name of Principal: JENNIFER GOOS

Signature: JG

Date: 15.6.18

REPLY FORM: PERMISSION TO CONDUCT RESEARCH AT YOUR SCHOOL AND INFORMED CONSENT

I herewith give permission that Ms S van Biljon can conduct research titled: "Demographics of learners with autism spectrum disorder, their families and schools in South Africa" at the school. I also give consent to participate in the study. The researcher, Ms Sumari van Biljon, has informed me about the nature, process, risks, discomforts and benefits of the study. I am aware that the results of the study will be anonymously processed into articles and research reports. I have had the time to ask questions and have no objection to participate in the study. I hereby also give/do not give consent that the data may be used for future research

Name of Principal:.....*Ann Currie*.....

Signature:.....*Currie*.....

Date:.....*14/6/2018*.....

REPLY FORM: PERMISSION TO CONDUCT RESEARCH AT YOUR SCHOOL AND INFORMED CONSENT

I herewith give permission that Ms S van Biljon can conduct research titled: "Demographics of learners with autism spectrum disorder, their families and schools in South Africa" at the school. I also give consent to participate in the study. The researcher, Ms Sumari van Biljon, has informed me about the nature, process, risks, discomforts and benefits of the study. I am aware that the results of the study will be anonymously processed into articles and research reports. I have had the time to ask questions and have no objection to participate in the study. I hereby also give/do not give consent that the data may be used for future research

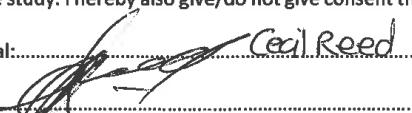
Name of Principal: *Azwindini F. Dze Zemane*

Signature: *AZedzemane*

Date:.....

REPLY FORM: PERMISSION TO CONDUCT RESEARCH AT YOUR SCHOOL AND INFORMED CONSENT

I herewith give permission that Ms S van Biljon can conduct research titled: "Demographics of learners with autism spectrum disorder, their families and schools in South Africa" at the school. I also give consent to participate in the study. The researcher, Ms Sumari van Biljon, has informed me about the nature, process, risks, discomforts and benefits of the study. I am aware that the results of the study will be anonymously processed into articles and research reports. I have had the time to ask questions and have no objection to participate in the study. I hereby also give/do not give consent that the data may be used for future research

Name of Principal:.....  *Cecil Reed*

Signature:.....

Date:..... *18/7/2018*

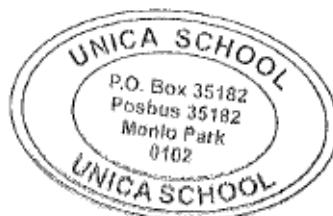
REPLY FORM: PERMISSION TO CONDUCT RESEARCH AT YOUR SCHOOL AND INFORMED CONSENT

I herewith give permission that Ms S van Biljon can conduct research titled: "Demographics of learners with autism spectrum disorder, their families and schools in South Africa" at the school. I also give consent to participate in the study. The researcher, Ms Sumari van Biljon, has informed me about the nature, process, risks, discomforts and benefits of the study. I am aware that the results of the study will be anonymously processed into articles and research reports. I have had the time to ask questions and have no objection to participate in the study. I hereby also give/do not give consent that the data may be used for future research

Name of Principal: *A.J. Deenudt*

Signature: *A.J. Deenudt*

Date: 11/09/2018



REPLY FORM: PERMISSION TO CONDUCT RESEARCH AT YOUR SCHOOL AND INFORMED CONSENT

I herewith give permission that Ms S van Biljon can conduct research titled: "Demographics of learners with autism spectrum disorder, their families and schools in South Africa" at the school. I also give consent to participate in the study. The researcher, Ms Sumari van Biljon, has informed me about the nature, process, risks, discomforts and benefits of the study. I am aware that the results of the study will be anonymously processed into articles and research reports. I have had the time to ask questions and have no objection to participate in the study. I hereby also give/do not give consent that the data may be used for future research

Name of Principal: Rachel C de Vries

Signature: R.C. de Vries

Date: 12/08/2016



REPLY FORM: PERMISSION TO CONDUCT RESEARCH AT YOUR SCHOOL AND INFORMED CONSENT

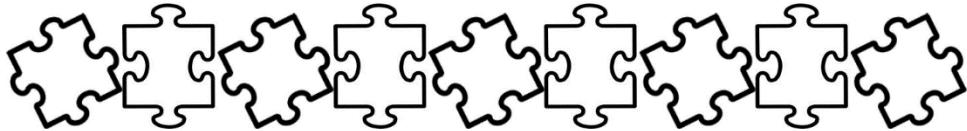
I herewith give permission that Ms S van Biljon can conduct research titled: "Demographics of learners with autism spectrum disorder, their families and schools in South Africa" at the school. I also give consent to participate in the study. The researcher, Ms Sumari van Biljon, has informed me about the nature, process, risks, discomforts and benefits of the study. I am aware that the results of the study will be anonymously processed into articles and research reports. I have had the time to ask questions and have no objection to participate in the study. I hereby also give/do not give consent that the data may be used for future research

Name of Principal: N. Keavons

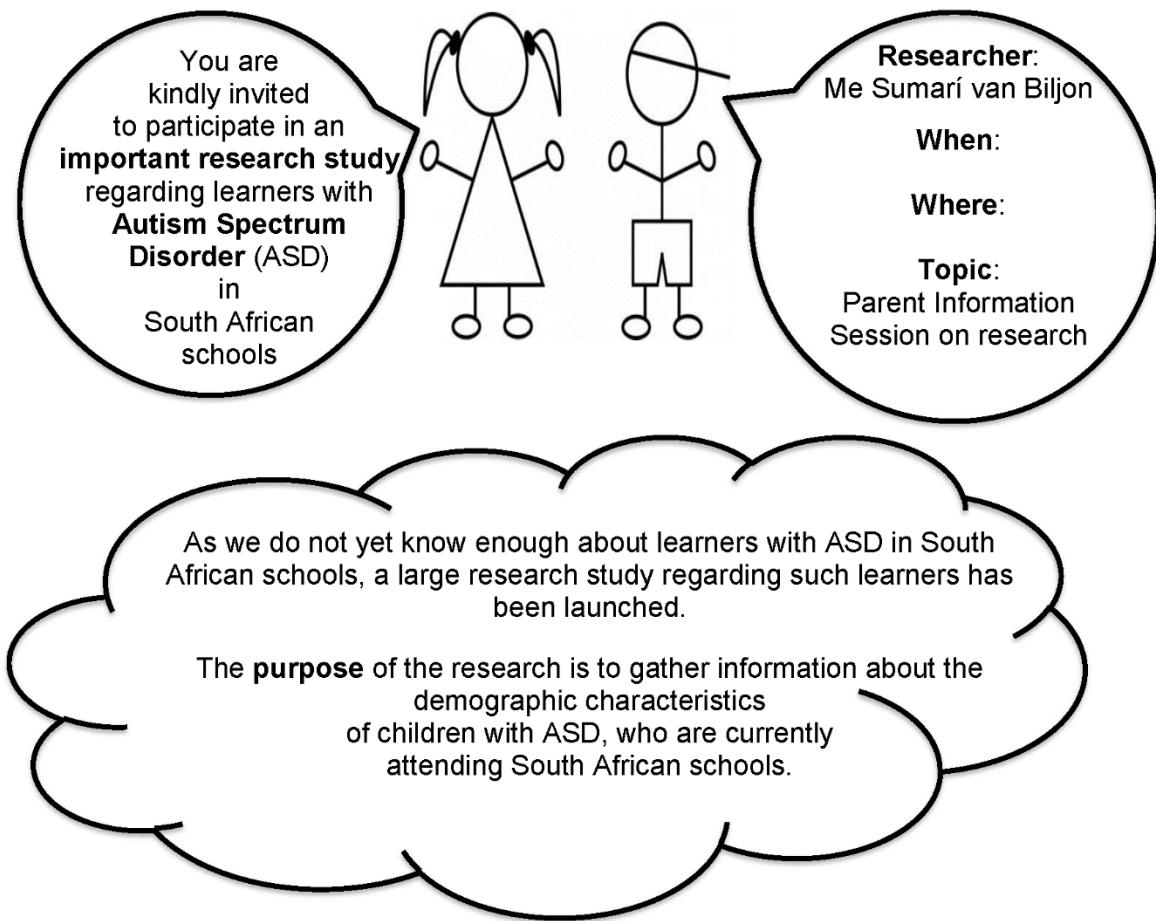
Signature: N. Keavons

Date: 07/10/2016

Appendix E) Flyer



AUTISM RESEARCH STUDY



Appendix F) Cover letter

February 2017

Invitation to participate in a research study titled:
"Demographics of learners with autism spectrum disorder,
their families and schools in South Africa"

Dear Parent

You are invited to participate in an important research study on learners with autism spectrum disorder (ASD) in South African schools.

If you are willing to participate, please complete the survey questionnaire and consent letter included in this packet. To complete the survey will require 15 minutes of your time. Please return the completed questionnaire and consent letter in the envelope provided to your child's educator as soon as possible, or at the latest Wednesday, the 8th March 2017.

Finally, please know that I understand the many demands on your time and that I truly appreciate your help. Please contact myself or my supervisor if you have any questions. I thank you for your time and hope you will consider this request favourably.

Yours sincerely



Ms. Sumari van Biljon
Researcher
072 151 4353
sumsievb@gmail.com

Appendix G) Information brochure and participant consent form



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

August 2016

Faculty of Humanities
Department of Speech-Language Pathology and Audiology

**Information brochure and participant consent for the study entitled:
"Demographics of learners with ASD, their families and autism specific schools in South Africa "**

Dear Parent

You are invited to participate in an important research study on learners with Autism Spectrum Disorder (ASD) in South African schools.

INTRODUCTION

I am conducting research for a PhD degree in Speech-Language Pathology, at the Department of Speech-Language Pathology and Audiology at the University of Pretoria. This brochure will provide information about the study. Before you agree to take part you should fully understand what the study is about. If you have any questions this information brochure does not fully explain, please do not hesitate to contact the researcher, Ms Sumari van Biljon (0721514343).

THE NATURE AND PURPOSE OF THIS STUDY

In South Africa we do not yet know enough about the learners with ASD. A large study about learners with ASD in South Africa is undertaken. The purpose of the research is to describe the demographic characteristics of families and children with ASD in South Africa. I intend to include six autism-specific government funded schools and two independent autism-specific schools in South Africa for the study. All parents of learners with ASD are encouraged to participate in the study. I require information about the learners, their families, both in government funded and independent schools.

WHO ARE THE PARTICIPANTS FOR THIS STUDY?

The more parents included in the study the more reliable the results will be. I would therefore like to include all parents of children in the school.

The inclusion criteria for the participants are as follows:

1. The parent/main caregiver must have a child diagnosed with ASD.
2. The child should be a current learner at the school.

EXPLANATION OF THE PROCEDURES

1. You will be invited to a parent information session on _____ at _____ at the school. Information will be given about the latest autism demographic characteristics in South Africa and the world.
2. At the information session you will be asked to participate in the study. Should you give consent to participate in the study you shall be asked to complete a self-administered questionnaire.
3. To complete the questionnaire will take approximately 15 minutes of your time.
4. If you are not able to attend the information session you will still be able to participate in the research.

RISK AND DISCOMFORT

Nor you or your child will be exposed to any risks during the study. The researcher will not ask any uncomfortable questions in the questionnaire.

Speech-Language Pathology and Audiology
Building Room 2-11
University of Pretoria
Private Bag X20, Hatfield 0028
Republic of South Africa

Tel: 012 420 2949

Fax: 012 420 3517

Email: alta.kritzinger@up.ac.za

www.up.ac.za

POSSIBLE BENEFITS OF THE STUDY

Parents will not receive any direct benefits as a result of the study. Yet, previous research conducted worldwide, have helped countries understand children with ASD and their families better and to plan and implement educational support and appropriate services to learners.

WHAT ARE YOUR RIGHTS AS A PARENT?

Your participation in the study is entirely voluntary. You can refuse to participate or withdraw from the study without negative consequences, at any time if you do not want to participate any longer. If you withdraw, all information collected from the questionnaire will be deleted.

INFORMATION AND CONTACT PERSON

The contact person for the study is me, Ms Sumari van Biljon. If you have any questions about the study please contact me. Alternatively you may contact my promotor.

COMPENSATION

No contribution towards your transport expenses will be given.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

1. The study was approved by the Faculty of Humanities' Research Ethics Committee at the University of Pretoria.
2. The departments of Education (Western Cape Department of Education [WCED], Eastern Cape Department of Education [ECDOE] and Gauteng Department of Education [GDE]) gave permission for the study to be conducted.

CONFIDENTIALITY AND ANONYMITY

All information obtained from the questionnaire will be reported on anonymously as there will be no names on the questionnaires. I intend to write three articles and a thesis about the information obtained from the questionnaire. No school specific information will be given.

DATA STORAGE

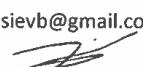
According to the University of Pretoria's policy, data must be securely stored for a minimum of 15 years.

WILL YOU HAVE ACCESS TO THE RESEARCH RESULTS?

Upon completion of the research projects an electronic and hard copy of the research report will be submitted to the WCED, GDE and ECDOE. I am happy to share the results from this study with you. If you are interested to receive a free copy of the results, please inform me. Alternatively, a parent information session can be arranged. Should you require any further information please contact me or my promotor.

Yours sincerely


Ms. Sumari van Biljon
Researcher
072 151 4353
sumsievb@gmail.com


Dr. Jeannie van der Linde
Co-Promotor
012 420 2948


Prof. Alta Kritzinger

Promotor
012 420 2949


Prof. Bart Vinck
Head Department of Speech Language
Pathology and Audiology

REPLY FORM: CONSENT TO PARTICIPATE IN THE STUDY

I herewith give consent to participate in the study titled: "Demographics of learners with ASD, their families and autism specific schools in South Africa". The researcher, Ms Sumari van Biljon, has informed me about the nature, process, risks, discomforts and benefits of the study. I am aware that the results of the study will be anonymously processed into articles and research reports. I have had the time to ask questions and have no objection to participate in the study. I hereby also give/do not give consent that the data may be used for future research.

Name:.....

Signature:.....

Date:.....

Appendix H) Survey questionnaire completed by the caregivers

Demographics of learners with autism spectrum disorder (ASD) and their families in South Africa

Thank you for participating in the research survey. I would like to ask you some questions regarding your child and your family. Please remember that answers will be kept confidential and will only be reported as a group, not as individual families. This questionnaire should be completed by the primary caregiver/parent/guardian. Please answer the questions by indicating your answer with an **X** in the shaded box or by writing your answer in the shaded space provided.

Section A: Information about your child

1. Date the questionnaire was completed:

2. What is your relationship to your child?

Mother	1
Father	2
Family Caregiver	3
Guardian	4
Other (please specify):	5

3. Child's date of birth:

4. What is the gender of your child?

Male	1
Female	2

5.a) Was your child born preterm?

Yes	1
No	2

If you answered yes to question 5.a) please answer question 5.b)

5.b) Please indicate how many weeks preterm

Preterm	1
Full term	2

6. Describe any common condition treated in the neonatal intensive care unit (NICU).

Anemia	1
Respiration problems	2
Feeding problems	3
Hypoglycemia	4
Congenital heart defects	5
Gastroschisis	6
Pneumonia	7
Jaundice	8
Intraventricular haemorrhage (IVH)	9
Retinopathy of prematurity (ROP)	10
Sepsis	11
Intrauterine growth restriction (IUGR)	12
Macrosomia	13
Other (please specify):	14

FOR OFFICE USE

School code

V1

--	--	--	--	--	--

V2

--	--

V3

--	--	--	--	--	--

V4

--	--

V5a

--	--

V5b

--	--

V6

--	--

7. What was the birth weight of your child?

<input type="text"/>	<input type="text"/>	Kilograms/grams
----------------------	----------------------	-----------------

V7

8. What is your child's birth order?

1 st born	1
2 nd born	2
3 rd born	3
4 th – 7 th born	4

V8

9. When did you become concerned about your child's development? Please give approximate age in months.

<47 months	1
>48 months	2

V9

10. Why did you become concerned about your child's development? Please explain.

Delayed speech and language	1
Developmental delay	2
Not social interacting with peers	4
No response to name	5
Atypical behaviour	6
Other (please specify):	7

V10

11. When first concerned about your child's development, what did you think was the problem or cause?

Developmental causes	1
No idea	2
ASD	5
Medical causes	6
Mental difficulties	7
Environmental causes	8
Other (please specify):	9

V11

12. What kind of support/intervention/s have you tried since you became concerned about your child's development?

Allied health professionals	1
Government primary healthcare clinic	2
General practitioner	3
None	4
Specialist professional, such as a developmental paediatrician, paediatric neurologist or a child psychiatrist	5
Other (please specify):	6

V12

13. Who was the first professional seeing your child regarding your concern?

Allied health professionals	1
Government primary healthcare clinic	2
General practitioner	3
None	4
Specialist professional, such as a developmental paediatrician, paediatric neurologist or a child psychiatrist	5
Other (please specify):	6

V13

14. What age (in months) was your child when first assessed by a professional?

<47 months	1
>48 months	2

V14

--	--

15. At what age (in months) was your child diagnosed with Autism Spectrum Disorder?

<47 months	1
>48 months	2

V15

--	--

16. What was your child's initial diagnosis according the professional?

ASD/Autism	1
Asperger syndrome	2
Pervasive Developmental Disorder	3
No diagnosis	4
Other (please specify)	5

V16

--	--

17. What was the occupation of the professional who made the diagnosis?

Paediatric Neurologist	1
Child Psychiatrist	2
Neurologist	3
Paediatrician / Developmental paediatrician	4
Multi-disciplinary team	5
Other (please specify):	6

V17

--	--

18. Does your child have any additional difficulties (such as epilepsy, cerebral palsy, ADHD, etc.)?

None	1
Epilepsy	2
ADHD	3
Delayed milestone	4
Other (please specify)	5

V18

--	--

19.a) Is your child currently on any medication?.

Yes	1
No	2

V19a

--	--

If you answered yes to question 19.a) please answer question 19.b)

19.b) Please specify the medication your child is currently taking.

None	1
Medications to treat ADHD (Risperdal, Ritalin, Concerta)	2
Medications to treat anxiety (Leximal, Abilify)	3
Other medications (Asthavent)	4
Other (please specify)	5

V19b

--	--

20. What was the age (in years) .of your child when was he/she admitted in this specific school?

Years

V20

--	--

21. How long was your child on the waiting list of the school he/she is in now?

Months

Years

V21

--	--

22. How many months/years has your child been in this school?

	Months
	Years

--	--

V23

--	--

23. How old is your child now (age in years)?

>4 years	1
5-9 years	2
>10 years	3

--	--

V24

24. According to the Employment Equity Act, to which population group does your child belong to?

Black	1
Coloured	2
White	3
Asian	4
Other (please specify):	5

V25

1	8	15	22	
2	9	16	23	
3	10	17	24	
4	11	18	25	
5	12	19	26	
6	13	20	27	
7	14	21	28	

V26

1	8	15	22	
2	9	16	23	
3	10	17	24	
4	11	18	25	
5	12	19	26	
6	13	20	27	
7	14	21	28	

26. What other languages does your child speak? Please tick more than one of the applicable

Afrikaans	1
English	2
isiNdebele	3
isiXhosa	4
isiZulu	5
Sesotho sa Leboa	6
Sesotho	7
Setswana	8
siSwati	9
Tshivenda	10
Xitsonga	11
Non-verbal	12
None	13
Other (please specify):	14

V27a

--	--

27a) Is your child verbal?

Yes	1
No	2

If you answered yes to question 27 a) please answer question 27 b) and 27 c)

27. b) If you answered yes to question 27 a), at what age (in months) did your child say his/her first words (that you could understand)?

	Months
--	--------

27. c) Did your child show speech regressions? If yes, please indicate age when speech regression started.

*Speech regression occurs when a child appears to develop language typically but then starts to lose speech, typically between the ages of 15 and 30 months.

Yes	1
No	2

27. d) If you answered yes to question 27 c), at what age (in months) did the speech regressions starts

	Months
--	--------

28. What type of transport does your child use to get to school?

Public transport (Bus taxi, train)	1
Private transport (Own car, shuttle service)	2
School bus	3
Other (please specify):	4

29. How far (in kilometres) is one journey from home to your child's school?

0-15 km	1
>16 km	2

Section B: Information about the family

30.a) Does your child have any other siblings with ASD?

Yes	1
No	2

If you answered yes to question 30 a) please answer question 30 b)

30.b) If yes, please specify the age and gender.

--

31. What are your biggest challenges (regarding your child) currently?

None	1
Social, behavioural and communication challenges (struggling to communicate, behavioural problems – tantrums, meltdown, aggression, socially inappropriate, not socializing with peers, food preferences)	2
Challenges related to self-help skills (not being able to function independently, unable to dress themselves, toilet training, bathing)	3
Other challenges (transport, finding a suitable school, future after leaving school, poor academic progress, limited awareness of ASD in community, poor attention, discipline, sleeping difficulties, finances, puberty)	
Other (please specify):	4

V27b

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V27c

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V27d

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V28

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V29

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V30a

--	--

V30b

Age	
Gender	

V31

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32. Who is the primary *caregiver of your child?

*Caregiver: An individual, such as a family member or guardian, who takes care of a child with an impairment and helps him/her with activities of daily living.

Both parents	1
Father	2
Mother	3
Grandparents	4
Extended family members	5
Guardian	6
Other (please specify):	7

V32

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33. What is the highest qualification of the father?

I don't know	1
No formal schooling	2
< Grade 12	3
Grade 12	4
Diploma	5
Degree	6
Postgraduate qualification	7

V33

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34. What is the marital status of the mother?

Single	1	Widowed	3
Married	2	Divorced / separated	4

V34

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35. What is the highest qualification of the mother?

I don't know	1
No formal schooling	2
< Grade 12	3
Grade 12	4
Diploma	5
Degree	6
Postgraduate qualification	7

V35

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36. What is the highest qualification of the primary caregiver?

I don't know	1
No formal schooling	2
< Grade 12	3
Grade 12	4
Diploma	5
Degree	6
Postgraduate qualification	7

V36

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37. What is the average monthly household income?

No income	1	R6401-R12800	7
R1-R400	2	R12801-R25600	8
R401-R800	3	R25601-R51200	9
R801-R1600	4	R51201-R102400	10
R1601-R3200	5	R102401-R204000	11
R3201-R6400	6	R204001 or more	12

V37

--	--

38. How many people are living in your household?

2-4	1
>5	2

V38

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39. Indicate the type of housing for the household:

Own my house in a residential area	1
Own a house in a complex	2
Own a flat	3
Own an informal housing	4
Renting a house/flat	5
Renting informal housing	6
I live with others	7

V39

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40. Does your family belong to a medical aid?

Yes	1
No	2

V40

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41.a) Are you receiving a grant from the South African government?

Yes	1
No	2

V41a

--	--

If you answered yes to question 41.a) please answer question 41.b) and 41.c)

41.b) Please specify the type of grant.

Disability grant	1
Care dependency grant	2
Child support grant	3

V41b

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41.c) Please specify the grant amount.

R380-R1499	1
R1450-R1660	2

V41c

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42. Is your child receiving a school bursary?

Yes	1
No	2

V42

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43.a) Does your child receive any therapy which is not included in the school fees?

Yes	1
No	2

V43a

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If you answered yes to question 43.a), please answer question 43.b) and 43.c)

43.b) Please indicate the type of therapy your child receives with a X.

Therapy services not included in school fees	Type	
Speech-Language Therapy	1	
Occupational Therapy	2	
Physiotherapy	3	
Psychiatry services	4	
Psychology services	5	
Hippotherapy	6	
Aqua therapy	7	
Music therapy	8	
Dietry information sessions	9	
Vision therapy	10	
Floor Time Therapy	11	
Applied Behaviour Analysis	12	
Pivotal Response Treatment	13	
Other (specify)	14	

V43b

1		8	
2		9	
3		10	
4		11	
5		12	
6		13	
7		14	

43.c) Please indicate the amount the therapy costs per month

Therapy services not included in school fees	Amount
Speech-Language Therapy	1
Occupational Therapy	2
Physiotherapy	3
Psychiatry services	4
Psychology services	5
Hippotherapy	6
Aqua therapy	7
Music therapy	8
Dietry information sessions	9
Vision therapy	10
Floor Time Therapy	11
Applied Behaviour Analysis	12
Pivotal Response Treatment	13
Other (specify)	14

V43c

1	8	
2	9	
3	10	
4	11	
5	12	
6	13	
7	14	

44. a) Are you a South African citizen?

Yes	1
No	2

V44a

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If you answered no to question 44 a) please answer question 44 b) and 44 c).

44.b) From which country did you immigrate?

Africa (Zimbabwe, Mozambique, Malawi, Democratic Republic of Congo, Zambia, Nigeria, Ethiopia)	1
Outside Africa	2

V44b

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44.c) How long have you been living in South Africa?

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V44bc

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45. According to the Employment Equity Act, to which population group do you as parent/primary caregiver belong to?

Black	1
Coloured	2
White	3
Asian/ Indian	4
Other (please specify):	5

V45

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46. Do you prefer autism-specific schools or would you want your child to be included in an ordinary school?

Yes, I prefer autism-specific schools	1
No, I want my child to be included in an ordinary school	2

V46

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Thank you for participating in the survey!

Appendix I) Survey questionnaire completed by the principals

Demographics of autism specific schools in South Africa

Thank you for participating in the research survey. I would like to ask you questions regarding the school. Please remember that answers will be kept confidential and only reported as a group, not as individual schools. This questionnaire should be completed by the principal of the school.

Please answer the questions by indicating your answer with **X** in a shaded box or by writing your answer in the shaded space provided.

Section A: Information about the school

1. What year was the school established?

2. Please indicate the current number of learners in the school

3. What are the ages of the learners in the school?

3.a Number of phases in the school		3.b Number of classes	3.c Age range of learners in the class	3.d Please indicate how many of the classes in each phase are low, medium or high support
Early Childhood		1		
Foundation		2		
Intermediate/ Middle		3		
Senior		4		
FET		5		
Other (please specify)		6		

4. What is the teacher learner ratio in the school?

5. What is the teacher turnover rate in the school?

6. How many teachers are in the school?

7. How many facilitators are there in a class?

8. What qualifications does a facilitator need to have?

None		1
Matric		2
Diploma in educational special needs		3
Other (please specify)		4

FOR OFFICE USE

School code

V1

V2

V3a

V3b

V3c

V3d

V4

V5

V6

V7

V8

9. a) What services do you offer at the school?

Therapy services offered at the school	
Speech-Language Therapy	1
Occupational Therapy	2
Physiotherapy	3
Psychiatry services	4
Psychology services	5
Hippotherapy	6
Aqua therapy	7
Music therapy	8
Dietry information sessions	9
Vision therapy	10
Floor Time Therapy	11
Applied Behaviour Analysis	12
Pivotal Response Treatment	13
Other (specify)	14

V9a

1		8	
2		9	
3		10	
4		11	
5		12	
6		13	
7		14	

V9b

1		8		15		22	
2		9		16		23	
3		10		17		24	
4		11		18		25	
5		12		19		26	
6		13		20		27	
7		14		21		28	

V10

--	--

V11

--	--

V12

--	--

V13a

--	--

V14

--	--

10. Does the school receive subsidy from the government?

Yes		1
No		2

11. What are your admission criteria for learners?

ASD diagnosis		1
ASD diagnosis and living in the school's catchment area		2

12. a) Does the school have a waiting list?

Yes		1
No		2

13. b) Approximately how many names are on the waiting list?

--	--	--	--	--

14. Is the learner assessed upon admission at the school?

Yes		1
No		2

15.a) Do you agree with inclusive education or do you prefer separate autism-specific schools?

Yes, I prefer autism-specific schools		1
No, I want my child to be included in an ordinary school		2

V15a

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15.b) Please explain your answer above by choosing the best possible answer/s

In inclusive schools the learners will benefit from socially interacting with their typically developing peers, and show improved behaviour and academic performance		1
There are many challenges related to the implementation of inclusive education policies in mainstream schools		2
In mainstream schools the teachers are not adequately trained to support learners with ASD in typical classrooms and these		3
In mainstream schools the learners often experience difficulty adapting in schools because they present with significant challenges in behaviour, social interaction, and communication		4

V15b

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Thank you for participating in the survey!

Appendix J) Follow-up card

Dear Parent or Caregiver

Thank you for completing the research survey on the demographics of learners with autism spectrum disorder that I recently sent you. I truly appreciate your participation in this research study.

Sincerely,

Sumari van Biljon

Doctoral Student

University of Pretoria

0721514353

sumsievb@gmail.com

If you have not had a chance to complete the survey yet, you are still welcome to do so before Friday, 24th of March. If you have any questions or need another copy of the questionnaire, please call/send a SMS to 0721514353

Appendix K) Confirmation of accepted and submitted articles in accredited peer-reviewed journals

International Journal of Disability, Development and Education

The screenshot shows the 'Manuscripts with Decisions' section of the International Journal of Disability, Development and Education's Author Dashboard. It lists two manuscripts:

Action	Status	ID	Title	Submitted	Decided
ATTE: Silanesu, Isabella	CIJD-2018-0098.R2	Onset of intervention for learners in autism-specific government-funded schools in South Africa	View Submission	03-Oct-2018	15-Oct-2018
a revision has been submitted (CIJD-2018-0098.R2)	ATTE: Silanesu, Isabella	CIJD-2018-0098.R1	Onset of intervention for learners in autism-specific government-funded schools in South Africa	06-Aug-2018	26-Sep-2018

For the first manuscript, actions listed are: Accept (15-Oct-2018) and Awaiting Production Checklist. For the second manuscript, actions listed are: Accept as it is or with minor changes to the satisfaction of the editor (26-Sep-2018).

Journal of Family Studies

The screenshot shows the 'Submitted Manuscripts' section of the Journal of Family Studies' Author Dashboard. It lists one manuscript:

Status	ID	Title	Created	Submitted
EO: Velez, Camille	RJFS-2018-0192	Families raising children attending autism-specific government-funded schools in South Africa	10-Oct-2018	10-Oct-2018

Actions listed for the manuscript are: Under Review.

South African Journal of Childhood Education



Sumari Erasmus <sumsievb@gmail.com>

SAJCE External Review Decision 691 - Revisions required

3 messages

aosis@sajce.co.za <aosis@sajce.co.za>
Reply-To: Elizabeth Henning <ehenning@uj.ac.za>
To: Ms Sumari Erasmus <sumsievb@gmail.com>
Cc: Alta Kritzinger <alta.kritzinger@up.ac.za>, Jeannie van der Linde <jeannie.vanderlinde@up.ac.za>

14 December 2018 at 14:55

Ref. No.: 691
Manuscript title: Profiles of public and private autism-specific schools in
Gauteng
Journal: South African Journal of Childhood Education

Dear Ms Sumari Erasmus

We thank you for the submission of your manuscript. The peer review process of your manuscript has now been completed and we have reached a decision regarding your submission.

At present, your manuscript requires minor revisions to address the concerns of the reviewers. Their comments are attached to the email and/or to the bottom of this letter. If not, for your convenience log onto your profile to view the reviewers' comments.

Please include with your revised submission an itemised, point-by-point response to the reviewers which details the changes made. The revised manuscript should be submitted by 21 December 2018; if you anticipate that you will be unable to meet this deadline, please notify the Editorial Office.

Below my signature, you will find steps to resubmit your revised manuscript. If you need any assistance, kindly contact the Editorial Office at submissions@sajce.co.za with any questions or concerns.

We look forward to receiving the revised manuscript.
Subject: Profiles of public and private autism-specific schools in Gauteng

This is a different kind of paper because the authors are providing profiles of two different types of autistic schools.

for a normal research project the following sub headings need to be addressed:

there should be a purpose statement - particularly for this topic it would be interesting to know why these authors find this information important to publish

there should be research aims and problem statement

an important aspect of any research project is the literature review and theoretical framework - but these sections are missing??

Open Rubric

there is no discussion on the trustworthiness of this research project -
there is no triangulation - only 2 questionnaires were given!!!

Yours sincerely,
Elizabeth Henning
Editor, SAJCE
Phone 011 559 5102
ehenning@uj.ac.za

Frequently Asked Question

How do I view the reviewer comments, after the formal peer review, if the Editor-in-Chief provided feedback regarding my article?

The editor should send you an email stating all the revisions suggested during the formal peer review process. If you are advised to download the comments via your personalised journal section, follow these steps:

- Log into your personalised journal section in the journal.
- Under your 'User Home' click on the 'Author' or 'Active' link that will direct you to your 'Active Submissions Table'.
- Under the 'Status Column', click on 'In Review: Revisions Required'. This link takes you to the overview of the peer review process.
- The review page of your article provides information and documentation under the heading 'Peer Review', and will identify files by reviewers, e.g. Reviewer B 19-123-1-RV.docx 2011-08-10. Download these documents to view the reviewer files.

Frequently Asked Question: The Editor-in-Chief has requested revisions to my article. How do I submit my revised version?

When the editor dealing with your submission chooses to ask for a revision, you will be notified by email. In the journal's personalised section your submission will move in the active table from the status 'In Review' to 'In Review: Revisions Required'.

When you prepare a revised version of your manuscript, it is essential that you carefully follow the instructions given in the editor's letter. Use the standard uploading format (as described for original submissions), but include both a clean copy of your manuscript and an annotated copy describing the changes you have made. Failure to do so will cause a delay in the review of your revision.

If references, tables, or figures are moved, added, or deleted during the revision process, renumber them to reflect such changes so that all tables, references (Vancouver Style) and figures are cited in numeric order. Images need only be uploaded if changes have been made to the figures since the previous version.

The annotated copy should have highlights on the changes (either by using the 'Track Changes' function in Word or by highlighting or underlining text) with comments in the text referring to the editor or reviewer query. Be sure when you upload your annotated version that the changes are clearly visible on the Word (.doc) file prior to resubmission.

You should create a point-by-point response letter specifying how you have addressed each of the editor's and reviewer's comments.

Using the review version of your manuscript, edit and revise your submission according to the reviewers' and editor's comments, and follow the steps:

- When you have addressed the comments and completed your revisions, log into your journals' personalised section and click on 'In Review: Revisions Required'.
- Under the 'Editor Decision', click on the bubble icon to view the editor's decision letter. If needed, you may view the original editor and reviewer comments by clicking files linked under the 'Review Round'.
- Once your revisions are correctly formatted and prepared, click on 'Browse' to begin uploading your revised manuscript from your desktop. Ensure to upload a clean, annotated and point-by-point version as part of your revised manuscript submission.

Once all three documents are uploaded, you will need to inform the editor via email of your resubmission. Click on the email icon and proceed to type and email the editor. Remember to press 'Send'.

For a video detailing the uploading of your revised manuscript see here:
https://pkp.sfu.ca/files/author_submission_status_acadiau.mp4

South African Journal of Childhood Education
<http://www.sajce.co.za>

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