

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

Sumari Erasmus<sup>1</sup>, Alta Kritzinger<sup>1</sup> and Jeannie van der Linde<sup>1</sup>

<sup>1</sup>Department of Speech-Language Pathology and Audiology, University of Pretoria, Lynnwood Road, Hatfield, South Africa

\*Corresponding author: Sumari Erasmus:sumari.erasmus01@gmail.com

**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 autism spectrum disorder (ASD) diagnosis is usually associated with significant lifetime costs which are mostly borne by the families of children with ASD (Horlin, Falkmer, Parson, 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, specialized 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 low-and-middle-income countries (LMICs), such as South Africa (SA) (Clasquin-Johnson & Clasquin-Johnson, 2018; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012).

ASD research in South Africa indicated a need to translate screening tools in local languages (Chambers et al., 2017), difficulties to accommodate regional language variations when preparing interview questions for parents of children undergoing the ADOS-2 evaluation (Smith et al., 2016) and how to engage local communities in ASD research (Grinker et al., 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, 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

## FAMILIES RAISING CHILDREN WITH AUTISM

bear the cost of intervention services themselves. The responses to intervention vary 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; Järbrink, 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

## FAMILIES RAISING CHILDREN WITH AUTISM

(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). 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 and their families in SA. There are various contextual 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, 2012; 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

## FAMILIES RAISING CHILDREN WITH AUTISM

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 learners 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). Children with ASD diagnosed with ASD in SA are mostly placed in autism-specific schools. 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"

## FAMILIES RAISING CHILDREN WITH AUTISM

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 & Cavkaytar, 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

## FAMILIES RAISING CHILDREN WITH AUTISM

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 brevity 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. A plausible explanation of why the response rate was so low might be as a result of the low literacy levels of the caregivers. The data was extracted from the survey questionnaires and captured into Excel spreadsheets which were exported to IBM SPSS (Version 24) (IBM Corp, 2018) to facilitate analysis. Data were verified by comparing the data in the Excel spreadsheets to the information contained in the original survey questionnaires. 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.

## FAMILIES RAISING CHILDREN WITH AUTISM

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

<b>Characteristic</b>	<b>Category</b>	<b>Frequency (n)</b>	<b>Percentage (%)</b>
<b>1.1 Respondent</b>	Mother	199	85.0%
	Father	26	11.1%
	Family member	8	3.4%
	Guardian	1	0.5%
<b>1.2 Nationality</b>	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%
<b>1.3 Population group</b>	Black	183	78.2%
	Coloured	30	12.8%
	White	16	6.8%
	Asian/Indian	3	2.2%
<b>1.4 Primary caregiver</b>	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%
<b>1.5 Highest qualification of primary caregiver</b>	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%
<b>1.6 Highest qualification of father</b>	Diploma / degree / postgraduate qualification	85	36.3%
	Gr 12 (senior school certificate)	69	29.5%
	unknown / no formal schooling	50	21.4%
	< Gr12 (senior school certificate)	30	12.8%
<b>1.7 Marital status of the mother</b>	Single / divorced / widowed / separated	129	55.1%
	Married	105	44.9%
<b>1.8 Highest qualification of mother</b>	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%
<b>1.9 Number of people living in the household</b>	2-4	119	51.7%
	>5	113	48.3%
<b>1.10 Type of dwelling</b>	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%



## FAMILIES RAISING CHILDREN WITH AUTISM

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 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, has 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.

## FAMILIES RAISING CHILDREN WITH AUTISM

As displayed in Table 1 (1.3), the majority of caregivers in the current study were South African (88.5%), however, 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).

As reported in Table 1 (1.7) 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

## FAMILIES RAISING CHILDREN WITH AUTISM

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 was higher than the national status of unmarried mothers (48.4%) reported in SA (Statistics South Africa, 2015). However, future research is needed to determine the marital status of mothers of children with ASD, other disabilities and those without disabilities. 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).

As noted in Table 1 (1.9) 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 households includes 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

## FAMILIES RAISING CHILDREN WITH AUTISM

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 do not 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 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 enforcement of 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 family's financial position (Park, Turnbull, & Turnbull, 2002). The limited home ownership of the families participating in the study (42.7%) may be the strongest evidence of their financial hardship.

In summary, by using the ICF-CY and the family systems approach as frameworks the researchers were able to document the socio-demographic characteristics of families raising children attending autism-specific schools. This enabled the researchers to obtain a more holistic view of the families' socio-demographics characteristics.

## FAMILIES RAISING CHILDREN WITH AUTISM

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

Characteristic	Category	Frequency (n)	Mean (SD)	Percentage (%)
<b>2.1 Unreimbursed out-of-pocket expenditures</b>				
<b>2.1.1 Monthly school fees for the child</b>	\$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%
<b>2.1.2 Transport used to get to the child's school from parent's home</b>	Private transport	151	16.4 (12.7) km	64.5%
	School bus	56		23.9%
	Public transport	27		11.6%
<b>2.1.3 Distance (km) from parent's home to child's school</b>	<15km	132	16.4 (12.7) km	56.4%
	>16km	102		43.6%
<b>2.1.4 Family belonging to medical insurance</b>	No	132		56.4%
	Yes	102		43.6%
<b>2.2 Intervention currently utilized</b>				
<b>2.2.1 Number of children in the school receiving extracurricular therapies</b>	Child receiving extra therapy	78		32.5%
<b>2.2.2 Therapy services excluded from school fees</b>	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%
<b>2.2.3 Amount spent on extracurricular therapy services per month</b>	\$1-\$167.3 (R1-R1999)	55	\$81.9 (84.9)	70.5%
	\$167.4-\$251.0 (R2000-2999)	20		25.6%
	>\$251.1 (>R3000)	3		3.9%
<b>2.3 Financial resources</b>				
<b>2.3.1 Combined monthly household income</b>	\$133.8- \$1071.1 (R1600-R12799)	70	\$903.7(612.3)	29.9%
	\$1-\$133.7 (R1-R1599)	64		27.3%
	\$1071.2-\$2142.2 (R12800-R25599)	56		24.0%
	>\$2142.3 (>R25600)	29		12.4%
	No income	15		6.4%
<b>2.3.2 Family receiving school bursary</b>	No	109		91.9%
	Yes	19		8.1%
<b>2.3.3 Family receiving a social assistance grant from South African Social Security Agency the (SASSA)</b>	No	125		53.4%
	Yes	109		46.6%
<b>2.3.4 Type of social assistance grant</b>	Disability grant	69		63.3%
	Care dependency grant	35		32.1%
	Child support grant	5		4.6%
<b>2.3.5 Social assistance grant amount family receives</b>	\$125.5-\$138.9 (R1499-R1660)	102	\$124.1(30.7)	93.6%
	\$31.7-\$125.4 (R380 - R1499)	7		6.4%

## FAMILIES RAISING CHILDREN WITH AUTISM

### *Financial costs incurred by families*

Table 2 reports on information regarding the financial costs incurred by families raising children attending autism-specific government-funded (public) schools, 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 7<sup>th</sup> of February 2018.

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

## FAMILIES RAISING CHILDREN WITH AUTISM

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

## FAMILIES RAISING CHILDREN WITH AUTISM

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 ( $p\text{-value} = <0.001$ ), qualification of the mother ( $p\text{-value} = <0.001$ ), marital status of the mother ( $p\text{-value} = <0.001$ ), school fees ( $p\text{-value} = <0.001$ ), school bursaries ( $p\text{-value} = <0.001$ ), medical insurance schemes ( $p\text{-value} = <0.001$ ) and extracurricular therapy services ( $p\text{-value} = <0.0004$ ). 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.

In conclusion, it is evident that families raising children attending autism-specific schools have significant financial expenses which have an influence on the whole family. Therefore, using the ICF-CY and the family systems approach as frameworks assisted the researchers to better understand the significant financial impact of an ASD diagnosis on the entire family.



### **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. Therefore, it is important to note that there can be no generalisation beyond the sample since the families from independent schools were not included in the sample. Fourthly, the survey questionnaire was only available in English and not translated into any of the other official South African languages. If the survey questionnaire was translated into other official South African languages more participants might have participated in the research. 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. Another study could compare the health and educational related costs of learners with ASD to learners with other disabilities than ASD and learners without disabilities. Furthermore, there is a need for professionals to consider charging reduced fees for therapies in LMICs families who could not

## FAMILIES RAISING CHILDREN WITH AUTISM

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 contextual 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, Kritzinger & Geertsema, 2015). Furthermore, the findings differ to a certain extent from data obtained in other LMICs, showing how average families with children with ASD across these countries may differ, 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

## FAMILIES RAISING CHILDREN WITH AUTISM

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.

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### **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.

#### **Disclosure statement**

No potential conflict of interest was reported by the authors.

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## FAMILIES RAISING CHILDREN WITH AUTISM

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