

Key Stakeholder Perspectives on the Feasibility of
Implementing Early Childhood Autism Spectrum Disorder (ASD) Interventions in South
Africa

by

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Thesis submitted in partial fulfillment of
the requirements for the degree of
Master of Science in the Duke Global Health Institute
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ABSTRACT

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Abstract

Background: Autism spectrum disorder (ASD) is a major public health challenge worldwide. Early intensive intervention services have been shown to reduce core ASD symptomatology, but there are many barriers to implementing these services in low resource settings. Training caregivers to deliver intensive early ASD intervention may help to overcome many of the implementation barriers, but there is limited research about the feasibility of delivering a caregiver-mediated early ASD intervention in low resource settings and the compatibility of such interventions with existing platforms of care. Study Aims: This study explored key stakeholder perspectives on the feasibility of implementing early ASD intervention services in the Western Cape Province of South Africa. Methods: Eight in-depth interviews with District and Provincial representatives from the Department of Health, the Department of Education, the Department of Social Development, and two non-governmental organizations were conducted. Results: Stakeholders identified 20 current policies relevant to ASD in South Africa, future directions for ASD policy, and perceived barriers to ASD early intervention services. All participants reported a strong desire for early intervention services and identified key potential facilitators to early intervention. Conclusion: Caregiver mediated early ASD intervention may address barriers to ASD services in the Western. This study identified perceived barriers to such interventions as well as facilitators to delivering a caregiver

mediated intervention. Adaptions of caregiver-mediated early ASD interventions in the Western Cape must be affordable, simplified to be delivered by paraprofessionals, and adapted to include local cultural components such as language.

Dedication

To my parents Abayomi and Olufunke Adewumi, who encourage me to accomplish my dreams and who continue to see possibilities where I see roadblocks. To my sister and brother Teniope Adewumi- Gunn and Cameron Gunn, my mentors, my supporters, and my constant voices of wisdom. To the students of Classroom 8 at the University of Pittsburgh's Center for Autism and Developmental Disorders, who inspired me to ask the bigger questions.

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1. Introduction

Autism Spectrum Disorder (ASD) is a lifelong condition that is characterized by social communication deficits as well as restrictive repetitive patterns of behavior or interests (American Psychiatric Association, 2014). ASD is a major public health challenge worldwide (Centers for Disease Control and Prevention, 2014; de Vries, 2016; Khan et al., 2012; World Health Organization, 2013). In the United States, approximately one in 68 children have been identified with ASD according to estimates from the Centers for Disease Control and Prevention's' Autism and Developmental Disabilities Monitoring Network (Centers for Disease Control and Prevention, 2014).

Data on the global prevalence of ASD are mostly limited to epidemiologic studies conducted in the "global North" (e.g., North America, Europe and Japan), where less than 10% of the world's children live (Elsabbagh et al., 2012). As a result, very large disparities in global knowledge of this disorder and its effect on children and families exist (Abubakar, Ssewanyana, de Vries, & Newton, 2016; Franz, Chambers, von Isenburg, & de Vries, 2017).

ASD can be reliably diagnosed by two years of age (Lord et al., 2006). However, even in highly resourced settings, the average age of diagnosis is far later. For example, in the United States the average age of diagnosis is four years of age (Centers for Disease Control and Prevention, 2014).

ASD is beginning to gain international attention. In 2014 the World Health Organization adopted a resolution on “Comprehensive and Coordinated Effort for the Management of Autism Spectrum Disorders,” urging member states to have in place a clear set of actions to facilitate comprehensive inter-sectoral responses to the needs of individuals with ASD and their families by 2020 (World Health Organization, 2014). However, there is limited data ASD in low and middle income countries that could serve to inform the development and delivery of ASD services in low and middle (Khan et al., 2012).

1.1 Societal Impact of ASD

ASD represents a significant financial burden for both families and societies as a whole. For example, ASD is estimated to cost the United States \$35 billion a year (Ganz, 2007). It is related to higher healthcare, non-health care, and education costs (Lavelle et al., 2014). Direct medical costs in the first 5 years of life average around \$35,000 per person (Ganz, 2007). Direct, nonmedical costs such as childcare and special education in the first 7 years of life cost an average of about \$11,000 (Ganz, 2007). School services are the largest contributor to ASD related cost because of the high costs of special education services required (Lavelle et al., 2014). The high costs continue well into adulthood (Ganz, 2007).

1.2 Early intervention for ASD

Early intervention for ASD is the provision of psychosocial and behavioral treatments that target ASD symptomology for toddlers and young children with an ASD diagnosis (Wallace et al., 2012). It has been identified as the most effective strategy for improving functioning for children with ASD from diagnosis to 5 years of age (Dawson et al., 2010). Though early intervention services may vary in content and intensity, early intensive intervention has been shown to improve outcomes in cognitive function, decrease the severity of core ASD symptoms, and improve adaptive behavior and language (Estes et al., 2015; Vismara, Colombi, & Rogers, 2009). Early intensive behavioral interventions have also been shown to (1) foster independence and (2) be cost effective (Byford et al., 2015; Piccininni, Bisnaire, & Penner, 2017).

1.3 Global Perspective on ASD intervention

There is limited knowledge about ASD intervention services in low and middle income countries. Furthermore, there are often a myriad of issues affecting the delivery of and access to early ASD intervention services (Abubakar et al., 2016; Franz et al., 2017). Problems such as a lack of ASD early intervention policy, a lack of ASD services, a lack of trained professionals, financial constraints, and social stigma can act as barriers to accessing care (Abubakar et al., 2016; Bakare & Munir, 2011). Non-specialist training, a possibly a cost-effective approach, has been identified as a possible means of addressing some of these barriers (Khan et al., 2012; Patel, Goel, & Desai, 2009; Reichow,

Servili, Yasamy, Barbui, & Saxena, 2013).

A systematic review exploring non-specialist interventions for children with intellectual disabilities found only seven interventions set in LMICs, two of which were random control trials that studied the delivery of a caregiver mediated early intervention.

1.4 Caregiver-Mediated ASD Intervention

Caregiver-mediated ASD intervention is a method in which caregivers are included in psychosocial interventions that intend to reduce core ASD symptomology and improve social communication, attention, and language (Divan et al., 2015). This intervention method involves providing caregivers with the skill sets and strategies to better support their children early in life (Oono, Honey, & McConachie, 2013).

Caregiver-mediated intervention also allows children to learn within in their own family environment and allows families to gain consistency in managing ASD symptoms and behavioral challenges (Oono et al., 2013).

Studies have shown that caregiver-mediated early intervention results in positive outcomes for both the parent and the child. It has been linked to improvements in verbal and nonverbal communication skills, gains in imitation and play skills, and an overall maintenance of learned skills (Kasari et al., 2014; Vismara et al., 2009). Furthermore, research has shown that children are better able to demonstrate and maintain treatment skills with caregiver-mediated ASD intervention (Sally J. Rogers et al., 2012; Vismara et

al., 2009). Parents also report high levels of satisfaction with short term, low intensity intervention programs (Carter et al., 2011; Sally. J. Rogers et al., 2014).

Though caregiver training methods vary, they generally involve professionals such as therapists delivering interventions to caregivers that range from 5 to 52 hours a week (Reichow et al., 2013).

Caregiver-mediated interventions can be used in both high and low resource settings. Research has found that parent involvement in interventions, such as parent coaching, that focuses on parental responsivity and individualized intervention contributed to successful reduction of ASD symptomology and equips caregivers with a sense of self-confidence (Wallace et al., 2012).

A caregiver-mediated early intervention method may be particularly advantageous in low-resource settings because parents are a widely available and affordable human resource (Divan et al., 2015). Studies that have attempted to adapt such interventions to low resource settings such as making the intervention short term and low intensity have shown that adapted caregiver-mediated interventions may also reduce core ASD symptomology (Estes et al., 2015; Rahman et al., 2016). Language, other communication modalities, joint attention outcomes, and maintenance of learned skills in low resource settings have been observed to be similar to outcomes in high income settings (Kasari et al., 2014; Reichow et al., 2013). This indicates that change may be made in core ASD symptomology for children with ASD with brief but targeted intervention adapted to

low resource settings (Kasari et al., 2014). This research indicates that caregiver-mediated early ASD intervention may be an effective means of addressing the burden of ASD in low resource settings.

1.5 ASD in South Africa

South Africa is a middle-income country that is marked by significant economic and social inequities. With a GINI coefficient of .68, a measure of income inequality, South Africa ranks among the countries with the highest income inequality (Mayosi & Benatar, 2014). With limited measurement and diagnostic, little is known about the burden of ASD in South Africa (deVries & Bölte, 2016).

In the healthcare system, about 84% of the South African population receives care from the national public health sector while only 30% of the country's medical doctors work in this sector (Mayosi & Benatar, 2014). The private health sector has an annual per capita expenditure that is almost 10 times greater than the public health sector (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009). Current ASD services provided in South Africa vary amongst the private and public sector. There are limited ASD services offered within the public sector. This limits children to low intensity interventions such as one 30-minute visit to a speech or occupational therapist per month. Within the private sector, ASD services vary in quality. There is often limited guarantee that interventions found in the private sector are evidence based. Children suspected of having ASD in the Western Cape Province in South Africa often receive

their evaluations in primary care clinics prior to referral to neurodevelopmental clinics for official diagnosis. Children are then added to the waiting list for special education services from the Department of Education. In the Western Cape Province, there are currently over 500 children on the ASD waiting list, resulting in a minimum three year wait to enter ASD-specific schools. Children in South Africa are not required to enter school until they are 7 years old and there are no government preschool programs. Although South Africa signed the World Health Assembly's resolution on the "Comprehensive and Coordinated Effort for the Management of Autism Spectrum Disorders," children under the age of 7 with ASD still do not have access to educational programming (van Schalkwyk, Beyer, & de Vries, 2016).

1.6 Programs and policy examples in South Africa

South African nongovernmental and governmental departments in the Western Cape Province have attempted to create policy and programming to address gaps in healthcare provision for children with disabilities for example the Universal Referral Pathway (URP) for the Western Cape (Western Cape Department of Social Development, 2015). In addition, early identification and intervention services that raise awareness around the importance of healthy development in a child's first 1000 days of life are emerging as a priority in the Western Cape (Western Cape Government, 2016).

The Universal Referral Pathway (URP) for the Western Cape is a draft protocol created by the Department of the Premier, the Department of Social Development, and a

non-governmental organization (Uhambo Foundation) to set guidelines and assign responsibilities for the care of children with disabilities to various governmental departments, non-governmental organizations (NGOs), and other institutions. The URP hopes to ensure that organizations are held accountable for their assigned responsibilities. It also intends to reduce the duplication of disability services delivered by organizations. The URP maps the responsibilities of the Department of Social Development, the Department of Health, the Department of Education, and disability organizations. According to the URP: (1) the Department of Social Development is responsible for the development and maintenance of rehabilitation facilities, the delivery of social welfare services, the development and implementation of policy, and referral of children at risk; (2) the Department of Health is responsible for the prevention of disability, early detection, therapeutic services, community support and rehabilitation services, the provision of assistive devices, and referral of children at risk; (3) the Department of Education is responsible for the provision of education services, skills and development of training of children with disabilities, and the referral of at risk children; and (4) the responsibilities of disability specific NGOs are support services and disability education, specialized services such as assessment and intervention, child and family counseling, economic empowerment, advocacy, and referral of cases of at risk children (Western Cape Department of Social Development, 2015).

The First Thousand Days of Life Campaign was launched in 2016 by the Department of Health and Department of Social Development in the Western Cape Province. This campaign adapted the global nutrition program, 1000 Days, to meet the needs of mothers and children in the Western Cape from conception onward. It is a part of the Province's commitment to raise awareness around the importance of healthy development in a child's first 1000 days of life. Their goals are to promote the development of children's brains, fuel physical growth, strengthen immune systems, improve school readiness, and reduce the likelihood of chronic diseases in the future. This initiative intends to take care of both the mother and the child by encouraging play, encouraging love and attention, providing support services to mothers, and providing health and nutrition information (Western Cape Government, 2016). Though ASD is not specifically mentioned in the First Thousand Days of Life Program, it is an important program for the ASD community because of its early interaction with children at an age pertinent to early ASD intervention.

1.7 Aims of the study

Limited ASD services combined with large economic and health disparities result in significant barriers to ASD care in South Africa. Caregiver-mediated early ASD intervention may provide a care modality to address some of these barriers. Although there has been recognition of the importance of making low-intensity interventions such

as caregiver-mediated interventions available to all families, important questions remain around which group of providers within the existing healthcare, education, or NGO sector could deliver a these interventions (de Vries, 2016). Given the gap in research and the potential for caregiver-mediated early ASD intervention, this study aims to explore the key stakeholder's perspectives on the feasibility of delivering such an intervention in South Africa, specifically the Western Cape Province.

2. Methods

2.1 Setting

The study took place in Cape Town, South Africa. Cape Town, the second largest city in South Africa, is the capital of the Western Cape, one of the country's nine provinces. There are approximately 56 million people in South Africa, 3.7 million of whom live in Cape Town. Cape Town has a racially diverse population, with 42% Coloured, 39% Black African, and 17 % White. Over a third of Cape Town's inhabitants live below the poverty line, 4% do not have access to electricity, and 9% do not have access to sanitation. The unemployment rate is currently 24% (Africa, 2012). There are 11 official languages spoken in South Africa with the most frequently spoken languages in the Western Cape being Afrikaans (46%), isiXhosa (24%), and English (20%) (Africa, 2012).

2.2 Participants

This study utilized purposive sampling to identify and recruit key stakeholders. Stakeholders were determined to be professionals that could speak on the ASD policy environment in the Western Cape. Purposive sampling is the identification and selection of research participants who are well-informed on the phenomenon of interest (Palinkas et al., 2015). Participants included 8 key informants from the Department of Health (n=2), Department of Education (n=2), Department of Social Development (n=2), and two Non-Governmental Organizations that work with children with ASD in the Western

Cape (Autism Western Cape and Uhmabo). The Department of Health, Department of Education, and Department of Social Development each recommended one senior official from the district level and one from the provincial level.

2.3 Procedures

All study procedures were approved by the ethical review boards at Duke University and the University of Cape Town (Duke IRB Pro00064533 and UCT HREC 039/2015). Additional permission was required for the Department of Health. The project was registered on the South African National Health Research Database for each Department of Health participant. The registration required the name, credential, and geographic area of each participant. One participant required additional permission from members of their hospital institution. Confirmation of approval was received electronically. Prior to data collection, the research was explained to each participant by a research assistant and the participants signed an informed consent form. The interviews were captured on a handheld recording device.

The individual interviews were held in a small private office located at the Western Cape Department of Child and Adolescent Psychiatry. Each interview was conducted by one member of the South African research team. All interviews were conducted in English. They lasted between 30 minutes and 1 hour. All interviews were recorded for future transcription. All participants received ZAR100, as a 'thank you' and to cover travel expenses.

The interview guide consisted of 10 questions, with follow-up probes, that explored key stakeholder perceptions of the feasibility of delivering a caregiver mediated early autism intervention. Four questions assessed the policy environment surrounding ASD in the Western Cape Province, three were intended to address the practicality of delivering an early caregiver mediated autism intervention, one question assessed the possibility of integrating early caregiver mediated autism intervention into existing services, and two questions addressed the expansion and sustainability of early caregiver mediated autism services. Please see appendix for interview guide.

2.4 Analysis

Audiotapes of the interviews were transcribed verbatim, as Word documents, and cross-checked by two other members of the research team for transcription accuracy. Transcribed data were then analyzed utilizing content analysis (Patton, 2002). Content analysis involves systematically reducing textual forms of qualitative data into themes (Patton, 2002). All data were read and coded utilizing preliminary structural codes based on the interview guide, which were developed by the author. Next, the graduate student read the transcripts and the author and principal investigator met to review and reach consensus on a codebook comprised of the a priori structural codes for themes and subthemes. The two coders then re-read the transcripts and each identified and coded additional emergent themes to inform an updated codebook. Representative quotes for a priori and emergent themes were identified by both coders. Thematic

analysis was an iterative process that included (re)reading, coding, displaying the data as matrices, and reducing the coded data into themes.

3. Results

The analysis of the data resulted in three categories, each with related themes and subthemes (See Table 1 and 2 below). Participants described existing policies, plans and programs relevant to child development and mental health, perceived barriers to providing early intervention services for ASD, their interest in early intervention services, and potential facilitators of caregiver mediated early autism intervention in South Africa.

Table 1 Identified components of the policy environment

Components of the policy environment identified	Title
Policies	*Children’s Act
	Child and Adolescent Mental Health Act
	Integrated Management of Chronic Disease
	Maternal Child and Women’s Health Policy
	*Mental Healthcare Act
	*Draft National Early Childhood Development Policy
	*Orphans and Vulnerable Children’s (OVC) Policy

	Prevention of and Treatment for Substance Abuse Act
	Postnatal Care Policy
	SIAS: Screening, Identification, Assessment, Support
	White Paper
	White Paper 6. Subtitle: Special Needs Education Building an Inclusive Education and Training Systems
	White Paper Pillar 2 on Services to People at Risk of Compounded Marginalization
Plans	Adult Pack (Practical Approach Care Kit)
	Child PACK (Practical Approach Care Kit) (Draft)
	Healthcare 2030
	Uniform Referral Pathway
Programs	First Thousand Days of Life
	Integrated School Health Program
	Road to Health

*Most frequently mentioned policies

Existing policies, plans, and programs

Participants listed 20 South African policies, plans, and programs that were relevant to ASD. Policies were nationally developed courses of action, plans were operational documents that aimed to drive the implementation of policy or become policies, and programs were a planned series of events or future events.

Of these policies, three were from the Department of Education, eight were from the Department of Health, eight were from the Department of Social Development, and

one was not department specific. The Mental Healthcare Act was the most cited policy (n=3) written by the Department of Health. This document was enacted in 2002 to provide mental health care, rehabilitation, and treatment to people with mental health illnesses. The Children's Act was the most commonly cited policy written by the Department of Social Development, followed by the Orphans and Vulnerable Children's Policy (OVC), draft National Early Childhood Development Policy. The Children's Act of 2005 was enacted to ensure that the State respects, protects, promotes, and fulfills the rights of children. It also outlines the principles related to the care and protection of children in South Africa. The Orphans and Vulnerable Children's Policy protects the rights of orphans and other children that have been made vulnerable because of HIV/AIDS. This policy was created by the government to restore dignity to children and ensure their wellbeing. The draft National Early Childhood Development Policy was created in 2015 by the government to show its commitment to guaranteeing the universal availability of and equitable access to early childhood services. Finally, the Uniform Referral Pathway (URP) for South Africa was the most cited plan developed by the Department of Social Development (n=2). The (URP) is a protocol created by the Departments of Social Development, the Department of the Premier, and Uhambo (a local NGO) to set guidelines and assign responsibilities for the care of children with disabilities to various government departments and NGOs. The South African White Paper, the most commonly cited policy (n=4), was the only policy that was not specific to a sector. This document

represents the commitment of the South African government to provide quality and affordable health services to all citizens of the South Africa.

Interestingly, only one participant cited South Africa’s Child and Adolescent Mental Health Act and no participants cited the National Mental Health Policy.

Table 2 Identified Themes and Subthemes

Categories	Themes	Subthemes
Barriers to ASD services	Financial constraints	Economic burden on caregivers
		Lack of government funding
	Resources constraints	Lack of ASD skilled professionals
		Education level of service providers
		Structural barriers to education services
	Awareness	Lack of knowledge
		Abuse
	Stigma	Family
		Community
		Society
Interest in early intervention		
Facilitators to early ASD services	Collaboration	
	Partnerships	
	Maintain key components of current services	Outreach services delivered in home language
		Parent psychosocial support

Barriers

Potential barriers to caregiver mediated early autism intervention included financial constraints, resource constraints, lack of ASD awareness, and stigma.

Financial constraints

Participants cited financial constraints as a significant barrier to ASD services.

Financial constraints identified were: (1) the economic burden on caregivers due to poverty and the out-of-pocket expense of services, and (2) a lack of government funding for ASD services.

One participant explained the difficulty of providing for a child with ASD within families from “very disadvantaged backgrounds” who can “barely put food on the table,” and were “living in shacks.” She illustrates the additional economic burden on families when she says:

“There are other organizations, who we don’t work with...we don’t agree with the way they’re doing things and the money ... their people are taking out extra bonds on their houses and all that sort of thing and we feel that...to charge, 10 to 12 thousand rand a month, it’s a lot of money for anybody and so we don’t have much collaboration with them, for those reasons. Because we don’t charge for anything.not to judge other organizations but, how can, it’s almost like how do they sleep at night charging these parents who are already stressed for cash, cause there’s so much they’ve got to deal with and medications, extra services, extra interventions and all that.”

Participants also cited inadequate government funding as “always a problem.”

For example, high costs of transportation and accommodation on organizations limited ASD outreach to underserved communities. In addition, one participant reported a lack of government recognition of their need for more staff:

“They know our organization, they know how hard we work, and that we need more staff and they give us the same amount that they gave last year. So, they’re not recognizing that there needs to be more people.”

Participants reported that the Department of Health is “under serious financial constraints” and “it’s likely to be like that and get worse over the next 5 to 7 years.”

Resource constraints

Participants reported significant resource constraints as an additional barrier to ASD services. These constraints included (1) a lack of skilled professionals, (2) low education levels of service providers, and (3) structural barriers to education services.

ASD was noted to “not be important enough” to include in professional training. As a result, service providers “don’t know how to work with autistic children” because it is “very specialized.” The lack of skilled professionals was also raised as an issue that prevented the delivery of ASD services. The education system was reported not to have the “man power” to give the necessary attention to children with ASD. The “skills” are not there to handle students with ASD “the way they need to be handled.”

The low education level of paraprofessionals combined with their workload was reported to limit their ability to adequately deliver ASD specific services, as described in this quote:

“Obviously, the current cadre of community health workers do not have the skills nor the competences to be able to do this thing and also they have a lot on their plate... the people there... as you can imagine are lay people, so it takes them a while to kind of learn the material. If you are a clinician... you’re in school for like 5 or a minimum of 4 years... Some of them don’t even have a matric (secondary school degree). We have to understand that it is lay people so it does take them a while too and we’ve learned that we must take it slowly.”

Structural barriers to education were reported by participants. ASD was noted to be the “fastest growing disability sector” in the Western Cape Province. The length of the waitlist to enter specialized schools was reported to be “getting too long,” with a participant expressing that she received multiple inquiries daily.

“There’s not a day that I open my emails and do not have three, four inquiries, new inquiries daily.”

The “very few autism schools in the Western Cape,” and the “waiting list of about 800 kids,” result in children having to “wait for 3 years for their observation.”

“Yeah, one of the things is advocating for children who would have been denied access to schools. Because there are very few autism schools in the Western Cape. They’ve got a waiting list of about 800 kids. And many of them after that, they wait for 3 years for their observation, and some of them are just told that they’re either too high functioning or low functioning. “

Lack of ASD awareness

A lack of ASD knowledge and a lack of skills to manage challenging behavior among parents and the community at large was reported. This knowledge included a lack of understanding of the abilities of children with developmental disabilities including ASD.

“Parents don’t understand that their children can learn, they don’t turn up... for training on how to do Early Child Development until they understand their children can learn. There’s been a fundamental shift in turn up now that we run the community dialogues first, because parents understanding that their children can learn is the vital part.”

Abuse also emerged as a subtheme in the context of parents’ inability to manage challenging behaviors. One participant explained that the “parents didn’t mean to abuse

him,” however they “just didn’t know what to do.” Stories of abuse emerged from an inability to handle “challenging behavior” such as “screaming and shouting,” aggression, and “running into the street.” One example is illustrated below:

“But you can’t still have a child being tied to a chair. At one point he was, before they removed him, they left him out in the sun with a bowl of water and a few toys and a little bit of food... and tied up to something. So, it was almost, it was almost like they left the dog... the dog... in the yard.”

Stigma

Stigma was also reported by multiple participants as a barrier to ASD services.

Types of stigma reported were (1) societal perceptions of ASD (2) community stigma and (3) familial stigma. ASD was reported to viewed by society as “a swear word, almost. Say the word autism and the eyes goes up.” This perception of disability was noted to negatively impact the interest of individuals to take jobs in the disability sector.

“Because of the stigma associated with disability, for a lot of [service providers] at a lot of centers, particularly low resource centers... who are not themselves parents, they have this job it’s the lowest of the low. It’s the job that you take when you can’t find a cleaner job. Because disability is the lowest thing to do.”

Children with ASD were reportedly viewed as “demons” or having a “curse” among “the African cultures and the colored community.” As a result, one participant noted, people “don’t think of the children as human beings.” In addition, children with ASD, were considered “rude” because they “do not greet.”

There was also a reported need to address the rejection of families with children with ASD. Such families are often “ostracized, judged and avoided.” The stigma of having a disability was said to be “difficult for parents.”

“There’s a huge need for educating the public and also to help them accept and show acceptance of the children and of the family. Cause the whole family becomes isolated.”

Interest in early intervention

Participants reported both an interest in and a need for early intervention services. Early intervention training was seen as a way to begin to address disability.

“It’s a need, it’s a need, we would invest in that. We would scrape together funds for the training... If there’s a training, and it’s an accredited training. We would invest in that. What it is, to empower, even myself. Because disability is so prominent, it’s complicated. I don’t know everything, but given the opportunity of a training program, I would receive with both hands.”

Early intervention was also mentioned as a way to address the length of the school waiting list. These services were believed to increase the “success rate” of learners later in life with a hope that the learners could be “mainstreamed after a few years.”

“This is what excites me quite a bit, of this possibility of early intervention. Because I heard from many sources that when there’s intervention from the time of diagnosis which is plus minus two until 5, the child presents very differently than at age 6, and that’s exciting because, otherwise were wiping up a dripping tap, as the Education Department who gets to see this child at 6 or 7. When so much could have been done during intervening periods.”

One participant reported an interest in early intervention services to broaden the services that could be offered to families.

“I would say an early intervention program would really do the thing... to get, parents involved and to do home visits, rather than interact with a child in a school, that they have a link with the school and they do early intervention programs also at home.”

Facilitators to caregiver-mediated intervention

Potential facilitators to caregiver mediated early autism intervention included collaboration between sectors (for example between Health and Social Development), partnerships with outside organizations, and maintaining key components of current services.

Collaboration

A move toward collaboration among sectors was reported by all participants as important to ASD service delivery. The need for collaboration is illustrated below:

“A problem that we’ve got in the disability sector is that a lot of organizations don’t collaborate because everybody’s scrambling for funding. And the autism community is very fractured. And so there’s more of a need to work together because we’re all trying to do the same thing and that’s to help children... I think there just needs to be, for everyone, a policy of more collaboration and pooling resources rather than just not wanting to work together and share resources.”

Important aspects of collaboration mentioned were the need for “formal collaboration” among “all three departments” and “pooling funds.” Collaboration also emerged to delivery early intervention services.

“When we work separately in silos we could be missing valuable opportunities to provide early intervention which would lessen the impact of a particular disability on a child...So yah, I look forward to collaborating with other government departments.”

Nesting ASD services within the First Thousand Days of Life Program was also suggested as a possible means of reaching children with developmental disabilities.

“If you looked at what the gaps were, you can have the conversation to say, ‘okay these are gaps at the moment.’ ‘What would suit your needs in terms of filling that gap?’ ‘How can we contribute?’ Providing a more general package and autism becomes a key component of that or you will partner with people to say we will do the autism bit will you do that whatever else... and if you can make it look a bit like what First Thousand Days is trying to do, you know if you try and align the threads for instance it would help because then we can use that kind of common framework to say ‘we see you sitting there’. That would be your roll.”

Lastly, collaborations between the Department of Health and Department of Education was identified as a way to link schools with health care providers.

“One of the areas of collaboration is with the Department of Education and trying to work closer with them. With their school psychologists, around how we can collaboratively work together because we also have doctors that do outreach into schools and things like that.”

Partnerships

Potential partners for collaboration mentioned by participants included churches, other departments, and NGOs. South African churches were cited as a possible platform for providing support services such as “psychosocial support” and parent support. Churches were reported as appropriate to provide this service because the “majority of South Africans belong to some kind of church.”

NGOs were also mentioned as potential partners for collaboration. One participant reported that NGOs could bridge the gap in ASD services because they could “go into the home” to “train the parents.”

“And what we haven’t mentioned so far is NGOs. Because they often provide support to that age group. And so we do have partnerships with certain NGOs and I think that, that could be strengthened. So, you asked about who would train the parents, NGOs can also play a very important role there. Because often the NGOs in the past were started to raise funds, to provide schooling for children with special education needs or barriers to learning but now government is taking that over. And so maybe the space they need to move into, increasingly, is that null to 5 [years of age].”

Maintain key components of current services

Though participants noted the importance of delivering outreach in the child’s in the home and in the home language, only two reported providing outreach services in the home language. Subsequently, only two participants noted delivering home based outreach. Even given the many barriers to outreach services, psychosocial support was also found to be a key (though often limited) components of current and future services in South Africa. Services were identified by as most beneficial to families when they were provided “in their home” and “in their own language.”

“We’ve also identified that if training doesn’t happen in the home language, it actually is severely compromised. So, we have facilitators who are Afrikaans speaking, isiXhosa speaking, and Zulu speaking, and we working very hard at increasing the number of local first language speakers who deliver the program.”

Parent support services were identified by almost all participants as an important area of outreach. These services focused on “counseling,” “helping parents with ways on how to interact with their children,” “promoting interaction and communication,” and “parent support groups.” Participants noted that in the Western Cape Province health has moved beyond survival and should now incorporate psychosocial support for both parents and children.

“How do we support parents to be able to be better parents so that we know that they can create an environment where the kids can thrive? So, we’re moving away from the ‘survive’, the kids are alive. We’ve made sure that all the immunizations and our HIV program is one of the best and we reduced the infant mortality rate. The survive component is done now. But how do we get these kids to thrive? How do we get them to more? What’s the point if you have these kids that are alive but don’t have good psychosocial support and parents? Such that they can actually be the best that they can be and be able to be meaningful members of society. So, that’s definitely what we’re working on in the Province.”

4. Discussion

This study provides insight into the perspectives of key stakeholders on implementing early ASD interventions in South Africa. Stakeholders identified 20 existing policies, plans, and programs relevant to their sectors. Of these policies, the Mental Healthcare Act (2002), the Children's Act (2005), the Orphans and Vulnerable Children's Policy (2005), and the draft National Early Childhood Development policy (2005) were most often cited as relevant to the ASD sector. Interestingly, important policies that would appear to be relevant to the ASD community such as the Child and Adolescent Mental Health Act and the Mental Health Policy were neglected. Only one participant mentioned the Child and Adolescent Mental Health Act, which was implemented by the South African government to establish a framework for an inter-sectoral approach to mental health services for children and adolescents. The Child and Adolescent Mental Health Act also highlights the importance of addressing mental health from conception to nine years of age. Though the policy was not mentioned in conversations about the Thousand Days Program, it appears to align similarly with the intentions of the program. Furthermore, no participants mentioned the Mental Health Policy in interviews specifically focused around mental health. This underrepresentation of the Child and Adolescent Mental Health Act and the Mental Health Policy may suggest that there is some disconnect between existing policies and knowledge about said policies.

This gap in policy knowledge highlights the importance of not just policy enactment but policy implementation. For example, there is an identified need for increased ASD awareness in South Africa. As mentioned, South Africa signed the World Health Organization's resolution on the "Comprehensive and Coordinated Effort for the Management of Autism Spectrum Disorders," suggesting its commitment to addressing barriers to ASD services (van Schalkwyk et al., 2016). This document urges member states to have clear, inter-sectoral policies that address the burden of ASD as well as raise awareness about ASD by 2020. However, there are currently no ASD specific policies in South Africa. Data from this study suggests that if South Africa was to produce an ASD specific policy, the enactment of ASD policy will not be enough, there is also a need for a concerted effort to ensure that key political stakeholders are aware of and implementing any policies put in place.

The Uniform Referral Pathway (URP) for the Western Cape (2014) was the most mentioned plans. The URP was suggested to help facilitate inter-sectoral and inter-organizational collaboration. This protocol provides a holistic approach to the care of children with disabilities by outlining the roles of responsibilities of various governmental and nongovernmental organizations.

The most mentioned program was the First Thousand Days of Life Program. The First Thousand Days of Life, developed by the Department of Health, was noted as an example of a collaborative program in which early ASD intervention services could be

nested. Returning briefly to conversation about policy, the Child and Adolescent Mental Health Act outlines a framework that intends to address mental health from conception to nine years of age. Given this framework and the data from this study, nesting early ASD detection and intervention into an existing program such as the First Thousand Days of Life may serve to facilitate inter-sectoral collaboration as well as provide mental health care access to children from conception forward.

Perceived barriers to early ASD intervention services in the Western Cape Province were financial constraints, resource constraints, a lack of ASD awareness, and stigma. Understaffing and the limited education level of paraprofessionals (e.g. community health workers) were important resource constraints mentioned. In addition, stakeholders identified the length of the waiting list to enter ASD schools as a barrier. Even with the perceived barriers noted, all participants reported a strong interest in early ASD intervention services. Caregiver-mediated early ASD intervention can be a possible means of delivering early intervention services in the Western Cape by addressing resource constraints such as the identified lack of skilled professionals. As previously mentioned, parents are an abundant human resource. Caregiver-mediated interventions have also been shown to improve parent confidence in themselves as well as improve dyadic engagement.

The identification of the limited education level of paraprofessional service providers indicates that a caregiver mediated intervention in this setting must be simple

and easy for paraprofessionals to understand and deliver. Furthermore, the identification of a lack of government funding and the economic burden on caregiver indicates that any adaption of a caregiver mediated intervention must pay careful attention to ensure that the intervention is made cheap and affordable.

Possible facilitators of delivering early ASD intervention services were formal collaboration among sectors, partnerships with community stakeholders, and maintaining key components of current services.

Though there are limited outreach services being provided, services delivered in the family's home language and parent psychosocial support were highlighted by the Department of Health and Department of Education as key components of current ASD services to maintain. This indicates that a caregiver-mediated ASD intervention adapted to this setting should be adapted to be delivered in the home language of the child. This may prove to be challenging because of the many languages spoken in South Africa, comprising of both South Africa languages and the languages of neighboring countries. Nonetheless, the outreach components of language, home delivery, and parent psychosocial support were identified as integral parts of early intervention delivery in the Western Cape.

4.1 Implications for policy and practice

This study has important implications for future policy and practice in South Africa. Policies can serve as a roadmap for program implementation. They are an

“identification of commitment from government systems, a means of developing accountability, and a bridge to an increase in access to services” (Shatkin & Belfer, 2004). However, once in place it is important to ensure that policies are properly implemented and consistently assessed for quality. This study highlighted an interesting gap in knowledge about policies relating to the ASD community in the Western Cape. Though participants listed 20 policies, plans, and programs that they perceived to be important to children with ASD in their sector, there remained some gaps in knowledge about ASD policy.

Furthermore, this study highlighted the desire for early ASD intervention services in the Western Cape Province. The development of ASD specific policy must incorporate early intervention service provision. To facilitate this, formal collaboration that can be integrated into policy may be necessary. An example of a documented inter-sectoral formal collaboration is the Uniform Referral Pathway (URP) for the Western Cape. This protocol provides guidelines and assigns the responsibilities of sectors that deliver services to children with disabilities. The URP can serve as a template for the creation of formal collaboration (Western Cape Department of Social Development, 2015). Importantly, early ASD identification and intervention could be nested in an existing program such as the First Thousand Days, which works to develop healthy children by providing support services to families from conception onward (Western Cape Government, 2016).

4.2 Implications for further research

A study conducted prior to this one, explored the perspectives of caregivers of children with ASD. This study explored the perspectives of key stakeholders and identified perceived barriers to early intervention services in South Africa, an expressed interest in early ASD intervention services, and has identified possible facilitators to delivering service. Furthermore, this study identified the possibility of potentially partnering with governmental or nongovernmental organizations to deliver such services. However, more research is needed to understand questions around who would be best equipped to deliver early intervention services such as caregiver training. Identifying the specific program and group of providers within the existing Health, Educational, or Social Development Sector that could deliver a caregiver-mediated early ASD intervention will help guide intervention adaptation. Cultural adaptation of the intervention will be necessary to enhance its success in this novel environment (Divan et al., 2015; Rahman et al., 2016). Once an intervention is adapted, it must be piloted, and both qualitative and quantitative data must be collected on the pilot studies.

4.3 Study strengths and limitations

This is the first study to explore the opinions of key stakeholders in the Education, Health, Social Development, and the NGO sector in the Western Cape Province in South Africa on delivering early ASD intervention. One of the strengths of the study was the participant selection. The participants, who were purposefully

sampled held positions of leadership among the various governmental departments and NGOs and were representative of individuals who were well informed and could speak on the policy environment in South Africa.

This strength may also serve as a limitation of the study. Though every effort was made to represent the perspectives of the various sectors sampled, the small sample size may have excluded some valuable perspectives. Although we chose individuals who were in positions that were responsible for children with ASD, knowledge about ASD and contact with families affected by ASD varied among participants. This may have influenced how they responded. Subsequently, as is the nature, of qualitative research, participant responses may have influenced if they received follow up questions, diversifying the level of information received by varying participants. Furthermore, it possible that participants may have been hesitant to speak openly about institutional barriers to ASD services that may closely relate to their jobs.

5. Conclusion

This was the first study to explore key stakeholder perspectives on the implementing an early ASD intervention in the Western Cape Province of South Africa. It yielded rich qualitative data that informed on current ASD policy in the Western Cape. The study also highlighted key barriers and facilitators to ASD services that were specific to the Western Cape Province of South Africa. Policies addressing collaboration within the disability sector, such as the Uniform Referral Pathway, may be beneficial to addressing the roles of various departments in delivery and responsibility. This study also suggested that an adapted ASD intervention should adhere to the financial and resource constraints of the ASD community in the Western Cape. Caregivers are an abundant human resource that can be taught to deliver ASD intervention services to their children. However, the data from this study indicates that there are limited skilled ASD professionals in the Western Cape. There is a need to identify paraprofessionals that could work to train caregivers to deliver such interventions. Once identified, more work needs to be done to understand how such an intervention would look. With the limited time, money, and human resources in low resource settings, interventions may need to be of low intensity and low frequency to serve a wider range of families. Nesting early ASD intervention in an existing program may also prove to be beneficial to gaining access to young children as well as utilizing or strengthening existing inter-sectoral collaborations in the Western Cape.

Appendix A

MEASURES

1. Individual Interview Questions

Determining the Policy Environment

- a. Within your sector, what are the most relevant existing policies relating children with developmental disabilities such as autism?
- b. Where do you think the policy going in the area of early child development and care of children with developmental disabilities such as autism?
- c. Is autism seen as an important area of concern? If so, by whom?
- d. Who do you think is 'responsible' for children with developmental disability from birth through age 5 years?

Practicality

- e. Within your sector which providers do you think have the credentials or training to train caregivers to deliver an early autism intervention to their child?
- f. What is the availability of resources to implement services with a home-based component? Is outreach already part of your sector's service delivery spectrum?
- g. How do you think these intervention services could be nested within an early autism detection mechanism, such as routine child development screening?

Integration

- h. How compatible is training caregivers in early autism intervention with existing services you provide?

Expansion/Sustainability

- i. Would providing early autism intervention services fit with your departments/your organizations goals and culture?
- j. Would your department be willing to financially invest in the training and supervision of providers of early intervention services?

References

- Abubakar, A., Ssewanyana, D., de Vries, P. J., & Newton, C. R. (2016). Autism spectrum disorders in sub-Saharan Africa. *The Lancet Psychiatry*, 3(9), 800-802. doi:[http://dx.doi.org/10.1016/S2215-0366\(16\)30138-9](http://dx.doi.org/10.1016/S2215-0366(16)30138-9)
- Africa), S. S. (2012). *City of Cape Town – 2011 Census – Cape Town*. Retrieved from American Psychiatric Association. (2014). *Diagnostic and Statistical Manual of Mental Disorders* (Vol. 5).
- Bakare, M. O., & Munir, K. M. (2011). Autism spectrum disorders (ASD) in Africa: a perspective. *Afr J Psychiatry (Johannesbg)*, 14(3), 208-210. doi:<http://dx.doi.org/10.4314/ajpsy.v14i3.3>
- Byford, S., Cary, M., Barrett, B., Aldred, C. R., Charman, T., Howlin, P., . . . Green, J. (2015). Cost-effectiveness analysis of a communication-focused therapy for pre-school children with autism: results from a randomised controlled trial. *BMC Psychiatry*, 15(1), 316. doi:10.1186/s12888-015-0700-x
- Carter, A. S., Messinger, D. S., Stone, W. L., Celimli, S., Nahmias, A. S., & Yoder, P. (2011). A randomized controlled trial of Hanen's 'More Than Words' in toddlers with early autism symptoms. *J Child Psychol Psychiatry*, 52(7), 741-752. doi:10.1111/j.1469-7610.2011.02395.x
- Centers for Disease Control and Prevention. (2014). *Prevalence of autism spectrum disorder among children aged 8 years. Surveillance Summaries*. Retrieved from
- Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & McIntyre, D. (2009). The health and health system of South Africa: historical roots of current public health challenges. *The Lancet*, 374(9692), 817-834. doi:10.1016/S0140-6736(09)60951-X
- Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenon, J., . . . Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*, 125(1), e17-23. doi:10.1542/peds.2009-0958
- de Vries, P. J. (2016). Thinking globally to meet local needs: autism spectrum disorders in Africa and other low-resource environments. *Curr Opin Neurol*, 29(2), 130-136. doi:10.1097/wco.0000000000000297
- deVries, P. J., & Bölte, S. (2016). Measuring functional ability of autism spectrum disorder in a global context. *Developmental Medicine & Child Neurology*, 58(9), 894-895. doi:10.1111/dmcn.13203
- Divan, G., Hamdani, S. U., Vajartkar, V., Minhas, A., Taylor, C., Aldred, C., . . . Patel, V. (2015). Adapting an evidence-based intervention for autism spectrum disorder for scaling up in resource-constrained settings: the development of the PASS intervention in South Asia. 2015, 8. doi:10.3402/gha.v8.27278

- Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcin, C., . . . Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Res*, 5(3), 160-179. doi:10.1002/aur.239
- Estes, A., Munson, J., Rogers, S. J., Greenson, J., Winter, J., & Dawson, G. (2015). Long-Term Outcomes of Early Intervention in 6-Year-Old Children With Autism Spectrum Disorder. *J Am Acad Child Adolesc Psychiatry*, 54(7), 580-587. doi:10.1016/j.jaac.2015.04.005
- Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. (2017). Autism spectrum disorder in sub-saharan africa: A comprehensive scoping review. *Autism Res*. doi:10.1002/aur.1766
- Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics & Adolescent Medicine*, 161(4), 343-349. doi:10.1001/archpedi.161.4.343
- Kasari, C., Lawton, K., Shih, W., Barker, T. V., Landa, R., Lord, C., . . . Senturk, D. (2014). Caregiver-mediated intervention for low-resourced preschoolers with autism: an RCT. *Pediatrics*, 134(1), e72-e79.
- Khan, N. Z., Gallo, L. A., Arghir, A., Budisteanu, B., Budisteanu, M., Dobrescu, I., . . . Elsabbagh, M. (2012). Autism and the grand challenges in global mental health. *Autism Res*, 5(3), 156-159. doi:10.1002/aur.1239
- Lavelle, T. A., Weinstein, M. C., Newhouse, J. P., Munir, K., Kuhlthau, K. A., & Prosser, L. A. (2014). Economic burden of childhood autism spectrum disorders. *Pediatrics*, 133(3), e520-e529.
- Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 years of age. *Arch Gen Psychiatry*, 63(6), 694-701. doi:10.1001/archpsyc.63.6.694
- Mayosi, B. M., & Benatar, S. R. (2014). Health and health care in South Africa—20 years after Mandela. *New England Journal of Medicine*, 371(14), 1344-1353.
- Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Cochrane Database Syst Rev*(4), Cd009774. doi:10.1002/14651858.CD009774.pub2
- Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health*, 42(5), 533-544. doi:10.1007/s10488-013-0528-y
- Patel, V., Goel, D. S., & Desai, R. (2009). Scaling up services for mental and neurological disorders in low-resource settings. *International Health*, 1(1), 37-44. doi:<http://dx.doi.org/10.1016/j.inhe.2009.02.002>
- Patton, M. Q. (2002). Qualitative interviewing. *Qualitative research and evaluation methods*, 3, 344-347.

- Piccininni, C., Bisnaire, L., & Penner, M. (2017). Cost-effectiveness of Wait Time Reduction for Intensive Behavioral Intervention Services in Ontario, Canada. *JAMA Pediatr*, 171(1), 23-30. doi:10.1001/jamapediatrics.2016.2695
- Rahman, A., Divan, G., Hamdani, S. U., Vajaratkar, V., Taylor, C., Leadbitter, K., . . . Green, J. (2016). Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in south Asia in India and Pakistan (PASS): a randomised controlled trial. *The Lancet Psychiatry*, 3(2), 128-136. doi:10.1016/S2215-0366(15)00388-0
- Reichow, B., Servili, C., Yasamy, M. T., Barbui, C., & Saxena, S. (2013). Non-Specialist Psychosocial Interventions for Children and Adolescents with Intellectual Disability or Lower-Functioning Autism Spectrum Disorders: A Systematic Review. *PLOS Medicine*, 10(12), e1001572. doi:10.1371/journal.pmed.1001572
- Rogers, S. J., Estes, A., Lord, C., Vismara, L., Winter, J., Fitzpatrick, A., . . . Dawson, G. (2012). Effects of a Brief Early Start Denver Model (ESDM)-Based Parent Intervention on Toddlers at Risk for Autism Spectrum Disorders: A Randomized Controlled Trial. *J Am Acad Child Adolesc Psychiatry*, 51(10), 1052-1065. doi:10.1016/j.jaac.2012.08.003
- Rogers, S. J., Vismara, L., Wagner, A. L., McCormick, C., Young, G., & Ozonoff, S. (2014). Autism treatment in the first year of life: a pilot study of infant start, a parent-implemented intervention for symptomatic infants. *Journal of Autism and Developmental Disorders*, 44, 2981+.
- Shatkin, J. P., & Belfer, M. L. (2004). The Global Absence of Child and Adolescent Mental Health Policy. *Child and Adolescent Mental Health*, 9(3), 104-108. doi:10.1111/j.1475-3588.2004.00090.x
- van Schalkwyk, G., Beyer, C., & de Vries, P. (2016). South Africa and autism. . In F. V. (Ed.) (Ed.), *Encyclopedia of autism spectrum disorders*: New York: Springer.
- Vismara, L. A., Colombi, C., & Rogers, S. J. (2009). Can one hour per week of therapy lead to lasting changes in young children with autism? *Autism*, 13(1), 93-115. doi:10.1177/1362361307098516
- Wallace, S., Fein, D., Rosanoff, M., Dawson, G., Hossain, S., Brennan, L., . . . Shih, A. (2012). A global public health strategy for autism spectrum disorders. *Autism Res*, 5(3), 211-217. doi:10.1002/aur.1236
- Western Cape Department of Social Development, U. F. (2015). *Children and Youth with Disabilities at Risk, focus on family and caregiver. Phase 2: Uniform Referral Pathway Protocol for the Western Cape* Retrieved from
- Western Cape Government. (2016). First 1000 Days Campaign. *Public Information* Retrieved from <https://www.westerncape.gov.za/general-publication/first-1-000-days-campaign>

- World Health Organization. (2013). *Autism spectrum disorders & other developmental disorders: From raising awareness to building capacity: Meeting report* Retrieved from Geneva, Switzerland:
- World Health Organization. (2014). *Comprehensive and coordinated efforts for the management of autism spectrum disorders*. Retrieved from Geneva, Switzerland