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Providing early detection and early intervention for autism spectrum disorder in South Africa: stakeholder perspectives from the Western Cape province

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Abstract

We set out to examine key stakeholder perspectives on early detection and intervention for autism spectrum disorder (ASD) in South Africa. Early detection and intervention improves child and family outcomes and lessens long-term costs. We focused on stakeholders in the Western Cape province, one of the better-resourced in terms of healthcare. Eight senior management level stakeholders, two each from government's Health, Education, and Social Development, and the non-profit sector were identified using purposive sampling. In-depth interviews focused on key implementation-related themes. The National Integrated Early Childhood Development Policy was the most relevant to early detection and intervention. This policy, however, is not ASD specific. This lack of specificity is in keeping with an emerging theme: ASD was only seen within the context of other developmental disabilities, particularly by Health and Social Development. Specific ASD early detection and intervention may not currently align with Health and Social Development departmental goals. These departments are primarily responsible for identifying and providing services and financial support to young children with ASD. Increased ASD knowledge and local South African statistics on prevalence, burden and associated costs may alter this approach. At this time, ASD early intervention may be more closely aligned with Education department goals.

Objective

Many more children are now surviving the first five years of life globally, and particularly in low- and middle-income countries, as a result of effective communicable disease interventions (Engle et al., 2007). There has therefore been a recent shift in the focus of health systems from the “surviving” focus of the United Nations Millennium Development Goals (United Nations, 2015) to include an overt focus on “thriving” in the Sustainable Development Goals (United Nations, 2017) and to address morbidity associated with

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developmental disabilities of surviving children, including those with autism spectrum disorder (ASD).

In 2014, the World Health Organization adopted a resolution calling for “comprehensive and coordinated effort for the management of ASD” (World Health Organization, 2013). This resolution, supported by all member states, including South Africa, calls for the development, strengthening and implementation of national policies which align with the needs of persons with ASD and with evidence and best practice. Policies are important because they reflect commitment from government, provide a mandate to support funding and help identify those who are accountable to provide services (Shatkin & Belfer, 2004). The policies most relevant to the management of ASD are likely to be found in the child and adolescent mental health policy repository. However, there is a lack of policy development and implementation for child and adolescent mental health in low- and middle-income countries, including South Africa (Mokitimi, Schneider & de Vries, 2018). Mokitimi and colleagues recently examined the state of child and adolescent mental health policy development and implementation and found that, in spite of a national policy, no South African province had a child and adolescent mental health policy or implementation plan to support the national policy (Mokitimi et al., 2018).

ASD is now thought to be a prevalent condition, with the latest US Center for Disease Control and Prevention estimate being 1 in 59 children in the United States (Baio et al., 2018). The global prevalence of ASD is estimated between 1 and 2%. There is, however, an absence of population-based prevalence studies and early intervention studies for ASD in sub-Saharan Africa, but there is no reason to believe that rates in sub-Saharan Africa and South Africa would be any less than elsewhere (Franz, Chambers, von Isenburg, & de Vries, 2017). Early detection and early intervention for ASD and related disabilities is crucial for a range of reasons. Firstly, between birth and 6 years of age the brain is primed to develop social and language skills (Courchesne, Campbell, & Solso, 2011; Dawson, 2008; Lewis et al., 2014). Teaching social and language skills when the brain normally expects to acquire these skills is associated with more rapid and sustained responses than if skills are taught at a later age (Huttenlocher, 2002). Secondly, early detection and intervention provide a key opportunity to empower parents and caregivers for lifelong advocacy and support of their children (Rogers, Dawson & Vismara, 2012). Thirdly, early detection can ensure monitoring and early intervention for the range of comorbidities, such as ADHD, language and sleep disorders, and secondary deficits, such as stigma, associated with ASD (Bauman, 2010; Kang-Yi et al., 2018). High quality, intensive, early intervention results in both positive gains in child cognitive, social, language and adaptive behaviours as well as decreases in the long-term costs of special education, sheltered living and supported employment (Cidav et al., 2017; Dawson et al., 2010; Estes et al., 2015). The promising outcomes of early ASD intervention therefore have clear policy implications (Cidav et al., 2017).

International ASD advocacy organisations such as Autism Speaks, and professional bodies such as the American Academy of Pediatrics advocate for universal screening for ASD given that children who receive universal screening are on average diagnosed earlier and thus receive services at an earlier age (Miller et al., 2011). This finding is especially important for sectors of the population affected by health disparities, such as families with low socio-

economic situations and families from previously disadvantaged communities who tend to be diagnosed and access services significantly later (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Some of the increase in the most recent ASD prevalence estimate from the US Center for Disease Control and Prevention (from 1 in 68 to the most recent estimate of 1 in 59) may be related to improved ASD detection in populations affected by disparities due to increased universal ASD screening and more effective community outreach (Centers for Disease Control and Prevention, 2018). In the United Kingdom, the National Screening Committee does not recommend universal screening for ASD in children under 5 years of age (Allaby & Sharma, 2011). Instead, they recommend assessment of children who present with parental concerns, suggesting a “secondary screening” approach. Interestingly, the median age of ASD diagnosis in the United Kingdom is 55 months, with only 10% of children being identified before 3 years of age. This is a statistic that has remained static for the past decade (Brett, Warnell, McConachie, & Parr, 2016).

According to the World Bank Group, South Africa has the greatest income inequality in the world (World Bank Group, 2017). This severe economic inequality extends into the health sector, manifesting as stark health disparities (Mayosi & Benatar, 2014). In a South African retrospective case review, Springer and colleagues noted racial variation in expressive language ability at diagnosis in a cohort of 58 children with ASD who attended a public tertiary developmental paediatric clinic in the Western Cape over a two-year period. Ninety four per cent of black African children were non-verbal at presentation (94%), compared to children of mixed ancestry (77%) and Caucasian children (42%). The authors noted that racial variation in verbal ability at diagnosis was likely due to socio-economic factors acting as barriers to care (Springer, van Toorn, Laughton, & Kidd, 2013). This suggests that in an effort to decrease health disparities, ASD screening in South Africa should prioritise outreach to disadvantaged communities and should consider universal screening in these community settings.

The use of standardised ASD screening and diagnostic tools is well-established in high-income countries (Lord, Rutter, & Le Couteur, 1994; Lord et al., 2012; Robins et al., 2014; Scott, Baron-Cohen, Bolton, & Brayne, 2002). However, very little work has been done in this area on the African continent, and access to standardised and validated tools for ASD screening and diagnosis in young children, although critically important, is extremely limited (de Vries, 2016; Franz et al., 2017). Work in this area has started (e.g. Chambers et al., 2017; Harrison, Zimak, Sheinkopf, Manji, & Morrow, 2014; Kakooza-Mwesige et al., 2014; Smith, Malcolm-Smith, & de Vries, 2017), but significant challenges exist in relation to translation, validation and the cost of training on existing tools (Abubakar, Ssewanyana, de Vries, & Newton, 2016; de Vries, 2016; Durkin et al., 2015). In addition, while initial screening with, for example, the M-CHAT (Kleinman et al., 2008) can be quickly completed by the parent, follow-up questions of failed items using the M-CHAT-R/F (Robins et al., 2014) are typically completed by a medical doctor and can take as much as 30 minutes of a doctor’s time. While this second step in screening is critical to clarify parental concerns and to improve the screening tools’ positive predictive value (Campbell et al., 2018), this two-stage screening may complicate the use of screening tools like the M-CHAT in low-resource community settings where access to specialist care is so limited. No other culturally appropriate screening and/or diagnostic tools with good psychometric properties have to

date been developed that might facilitate early detection, but such approaches are a high priority (de Vries 2016; Durkin et al., 2015).

There is a pressing need to identify, develop, implement, and evaluate evidence-based early interventions that range from low- to high-intensity (de Vries 2016), with an emphasis on making low-intensity parent education and training available to all affected families. Examples of low-intensity parent/caregiver education and training, and caregiver coaching studies currently underway or recently completed in South Africa include the World Health Organization Caregiver Skills Training Programme (Hamdani et al., 2017) which targets developmental disabilities more broadly, EarlyBird/EarlyBird Plus, which is an ASD parent education and training programme (Dawson-Squibb, Davids, & de Vries, 2018), and Early Start Denver Model caregiver coaching (Franz et al., 2018a; 2018b). The Early Start Denver Model is one of the naturalistic developmental behavioural early interventions, which are a type of empirically based early ASD intervention method that are derived from the principles of applied behavior analysis and developmental science and target key behaviors that promote language development, such as joint attention. (Dawson et al., 2010; Schreibman et al., 2015). Given the scarcity of specialist service providers in most low- and middle-income countries, it is unlikely that sufficient highly trained therapists will ever be available to provide intervention directly to the children who need it (de Vries, 2016). For this reason, involving parents and caregivers of young children with ASD in treatment delivery is a potentially powerful mechanism to deliver early intervention in low-resource settings. There is consensus that parent/caregiver education and skills training should be an essential component after an ASD diagnosis. This recommendation is clearly articulated in the World Health Organization Resolution on ASD (2014) and their mental health Gap Action Programme (mhGAP) for developmental disabilities including ASD (World Health Organization, 2015).

The Western Cape province is recognised as one of the better-resourced in terms of healthcare in South Africa. However, even in the Western Cape, access to early ASD detection and intervention services is extremely limited for the majority of the population. If ASD is suspected, a child would be evaluated in a primary care setting and referred to a neuro-developmental clinic affiliated with a tertiary hospital for a formal diagnosis. This process typically takes 9 to 18 months, but may be longer. Following a diagnosis of ASD, children would be referred for therapy and the child's name would be placed on the Western Cape Education Department's provincial ASD waiting list for school placement. Therapy programmes differ widely across the province, but generally families may receive a short period of "specialised" block therapy or may be seen once every four to six weeks by an occupational or speech therapist for a 30-minute session, with the burden of ongoing care falling to the parents or caregivers (Van Schalkwyk, Beyer, & de Vries, 2016). In 2016, 940 children with ASD were in Special Education Schools in the Western Cape, and 744 children were waiting for placement, of which 646 were younger than 7 years of age (Pillay, Duncan, & de Vries, 2017). The catchment area for this waiting list is supposed to be the entire Western Cape province. This is, however, highly dependent on the availability of professionals to identify and refer children to the waiting list for school placement. In a recent review of children on the ASD waiting list, the majority of provincial districts were represented. There was a 276% increase in the number of children with ASD on the waiting

list between 2012 and 2016, and it is highly likely that this increasing trend will continue (Pillay et al., 2017). There is currently no published information from other provinces on early detection and intervention approaches or on provincial waiting lists for ASD schooling. South Africa has nine ASD specific schools, but these typically do not provide early detection and intervention services, given that the legal school-going age is 7 years old in South Africa. Six of the ASD-specific schools are in the Western Cape, two are in Gauteng, and one is the Eastern Cape. Given the small number of schools in the context of a population of 52 million people, clearly many children with ASD are unable to attend these facilities (Van Schalkwyk et al., 2016). Services are available in the private sector, but are expensive, vary in quality, and it is not known to what extent these services are evidence-based. (Guler, de Vries, Seris, Shabalala, & Franz, 2017). The bulk of additional supports and services to children and families who live with ASD in South Africa are provided by non-profit organisations (NPOs) which are a significant part of the ASD treatment landscape and provide a range of services, with a prominent focus on applied behavioural analysis (ABA), which applies the psychological principles of learning theory in a systematic way to change/teach behaviours; treatment and education of autistic and communication-related handicapped children (TEACCH), which provides tools and strategies for teachers to use in the classroom); Picture Exchange Communication System (PECS), a form of augmentative and alternative communication; and Makaton, a language programme that uses signs and symbols to help communication (Van Schalkwyk et al., 2016).

ASD is fast becoming a very significant public health concern in South Africa. The system, as it stands, is clearly not able to provide adequate care for young children with ASD and their families. In line with the 2014 World Health Organization resolution calling for “comprehensive and coordinated effort for the management of ASD” (World Health Organization, 2013), which South Africa supported, and as a priority step towards understanding relevant national policies and developing a sustainable model of early ASD detection and intervention in South Africa, we set out to engage with key stakeholders in Health, Education, Social Development, and the non-profit sector in the Western Cape province to explore (1) the policy environment relevant to young children with developmental disabilities such as ASD, (2) the practicality of providing early ASD detection and intervention, (3) whether early intervention could be integrated into existing platforms of care, and (4) how early ASD intervention could become a sustainable approach.

Method

Study participants and procedures

Participants were eight senior management level stakeholders, two each from the Department of Health (DoH), Department of Education (DoE), Department of Social Development (DSD), and the non-profit sector (NPOs). Purposive sampling was used to identify and recruit these participants because they had portfolios that included young children in the Western Cape with ASD, and would be able to address policy and capacity for early ASD detection and intervention. Data collection was completed between July and November 2016 in Cape Town. The Human Research Ethics Council (HREC) of the University of Cape Town (UCT) and the Institutional Review Board (IRB) of Duke

University approved the study (UCT HREC 039/2015 and Duke IRB Pro00064533). Written informed consent was obtained from all participants.

Interview guide

The principal investigator of the study, in collaboration with other study team members, developed the guide. The domains of inquiry were informed by three implementation research outcome categories described by Proctor et al. (2011), including appropriateness, feasibility, and sustainability of early detection and intervention approaches.

Data collection

Individual interviews were conducted by a local interviewer who had clinical experience in ASD and in qualitative methodology. Individual interviews lasted 60 to 90 minutes, were conducted in English in private office settings, and were digitally audio recorded. A semi-structured interview guide included broad opening questions and follow-up probes. Interviews terminated once the interviewer and interviewee felt that all elements of the interview guide had been discussed.

Data analysis

Audio recordings of the interviews were transcribed verbatim, and cross-checked by two members of the research team. Narrative memos were written to organise transcript content, to make connections across transcripts, and to achieve insights into the data. Transcribed data were analysed utilising content analysis, which involved systematically reducing textual forms of qualitative data into emergent sub-themes under the four predefined, a priori categories, thus representing a combination of an inductive and deductive approach (Elo & Kyngäs, 2008). A deductive content analysis approach was also used to identify any additional emerging themes from the data. Rigour of the study was ensured through reflective journaling, peer debrief, and member checking to ensure transcription accuracy.

Results

A summary of inductive and deductive themes and sub-themes is presented in Box 1. Sub-themes that emerged under the main themes are presented with representative quotes under each main theme. An additional theme (ASD seen within the context of other developmental disabilities) was identified and will be discussed with representative quotes.

Theme 1: Policy environment

Sub-themes within this category included the ideas that most stakeholders identified ASD as an area of concern, DSD was identified as the department responsible for managing young children with ASD, current policies related to ASD were described by stakeholders, and future directions in policy and service delivery for ASD early detection and intervention were provided.

Subtheme 1.1: Most, but not all participants identified ASD as an increasing area of concern—Participants across sectors reported that NPOs are at the forefront of

ASD service provision in South Africa and are acutely aware of the needs and vulnerability to abuse of young children with ASD.

When you look at where I'm working in Khayelitsha, Du Noon, Joe Slovo, there are children being locked up. They [are] being chained to tables because they run away, because they have challenging behaviour. If they get water they are lucky. And I think the stigma of the community as well. It is seen as a curse and it's not only in the African cultures, in the coloured community as well.

Participants from the DoE commented on the tremendous growth in the Western Cape Education Department's provincial ASD waiting list for school placement:

The enquiries come daily. The waiting lists are growing daily. I don't think there's another sector growing as quickly as the ASD sector.

Participants from both the DoE and DSD noted that attention to ASD is increasing at a national level. A DSD representative remarked:

There is a national task team comprised of the parents of children with autism advising the DSD national minister. It's high on the agenda of the national minister.

Interestingly, although the DoH is currently primarily responsible for identifying and providing clinical intervention services for young children with ASD, DoH representatives only saw ASD as a priority within the context of future developmental screening that could be incorporated into the "First 1 000 Days" campaign of the Western Cape DoH:

I wouldn't say autism per se. But what has been seen as an important area is, for example, the "First 1 000 days of life", from conception up until two years. So I guess autism can be seen within that context.

Subtheme 1.2: The Department of Social Development (DSD) is seen as responsible for management of young children with ASD—DSD was identified by all participants as being responsible for the management and education of all children younger than 5 years of age, with the DoE collaborating with DSD on curriculum development for early childhood development (ECD) settings.

ECD would be the responsibility of DSD. We [are] talking crèches, preschools and the general provision for children in that age group. There is a section in the DoE that is responsible for ECD. Although DoE is expected to provide education for children from the age of 7 years, which is the age of compulsory school going, we also provide grade R, which is 5 to 6 year olds. So, our responsibility for providing education programmes actually starts at grade R. DSD is responsible for the age group younger than 5, but because they don't have any expertise around education programmes, the person in DoE would assist them in developing those.

Subtheme 1.3: ASD-relevant policies cross multiple sectors—All the national and regional acts and policies relevant to the management of children with ASD reported by participants are included in Table 1.

Two Acts were noted by participants: The Mental Health Care Act of 2002, which enshrined the human rights of people living with mental health disorders (South African Government, 2002) and the Children's Act of 2005, which gave effect to rights of children as contained in the Constitution (South African Government, 2006). Nine national policies were noted by participants: The DoE Education White Paper 6 of 2001 provided a framework for inclusive education and training, detailed a funding strategy, and listed key steps to operationalise this system in South Africa (Department of Education, 2001). The DoE Policy on Screening, Identification, Assessment and Support of 2014 provided a framework to identify, assess and provide programmes for all learners who require additional support to enhance their inclusion in school (Department of Basic Education, 2014). The DoE and DoH Integrated School Health Policy of 2012 aimed to strengthen existing school health services (Department of Basic Education, 2014). The DoH Policy Guidelines of Child and Adolescent Mental Health of 2008 served as a framework for establishing mental health services for children and adolescents at national, provincial and local levels within primary health care (Department of Basic Education, 2012). The DoH Strategic Plan for Maternal, Newborn, Child and Women's Health and Nutrition in South Africa of 2012 outlined interventions to strengthen the health system and improve the functioning of primary healthcare services and the district health system (Department of Health, 2012). The DSD White Paper on the Rights of Persons with Disabilities of 2015 (Department of Social Development, 2015b) updated the 1997 White Paper on an Integrated National Disability Strategy with obligations from the United Nations Convention on the Rights of Persons with Disabilities and the Continental Plan of Action for the African Decade of Persons with Disabilities, both of which South Africa has signed. The DSD White Paper on Families of 2012 aimed to mainstream family issues into government-wide, policy-making initiatives in order to foster positive family well-being and overall socio-economic development in the country (Department of Social Development, 2015b). The DSD National Integrated Early Childhood Development Policy of 2015 asserted the commitment of the South African government to provide a comprehensive package of ECD services to all young children by 2030. This policy is described in further detail in the next paragraph (Department of Social Development, 2015a). The DSD Framework for Social Welfare Services of 2013 sought to facilitate the implementation of a comprehensive, integrated, rights-based, well-resourced and quality developmental social welfare service (Department of Social Development, 2013). The DSD Integrated Service Delivery Model of 2005 aimed to provide a comprehensive national framework that set out social services which formed the basis for norms and standards for service delivery (Department of Social Development, 2005). Two Western Cape provincial policies were noted: Western Cape DoH Healthcare 2030: the Road to Wellness Policy of 2014 set out the vision guiding the Western Cape DoH to 2030, and presented a strategic framework and a set of planning parameters and tools that would be incrementally applied (Western Cape Department of Health, 2014). Western Cape DoH Post-Natal Care Policy of 2016 aimed to promote wellness for mothers and their babies in the immediate postnatal period and beyond (Western Cape Department of Health, 2016). One Cape Town City Policy was identified by participants: The Policy on Vulnerable Groups of 2013 aimed to articulate specific interventions to meet the needs of vulnerable groups (Western Cape Department of Health, 2016).

The most relevant policy for ASD early detection and intervention identified by participants was the National Integrated Early Childhood Development Policy developed by DSD in 2015 (Department of Social Development, 2015a). The policy acknowledges the importance of the early years for human development and the need to invest resources to support and promote optimal early child development. The National Integrated Early Childhood Development Policy covers from conception until the year before the calendar year the child turns seven, the age of compulsory schooling. The policy asserts the commitment of the South African government to provide a comprehensive package of ECD services to all young children by 2030. Importantly, the policy prioritises vulnerable children, including children with disabilities, to ensure equitable access to ECD services. It acknowledges that ECD should be “[r]ooted in prevention, early screening and intervention, appropriate support, and early learning and development opportunities”.

Subtheme 1.4: Future directions for ASD early detection and intervention policy and service delivery—

Participants highlighted the need for societal shifts in understanding the importance of early intervention. Although the benefits of early intervention were recognised, structural barriers, such as the age of formal schooling, were identified:

Participant If you can start off as soon as they’ve been identified, maybe some of them can be mainstreamed after a few years. But there is a law that says all school-going children must be in a school. We have to give preference to them.

Interviewer So if a three-year-old has been on the waiting list for a year and an eight-year-old comes on the waiting list, you have to pick the eight-year-old over the three-year-old?

Participant Yes. And that three-year-old then has to wait until they are school-going age.

A need for future integrated policy and services was also identified.

One of the issues we have in the health system is the silos and people not working in an integrated way. So it’s part of our Healthcare 2030 strategy. It is part of really transforming the health system. We are looking more closely at how we can integrate services.

Screening by front-line providers was identified as an important future direction:

We are trying to get our generalists to have some basic skills or at least a high level of suspicion that something is wrong and be able to refer appropriately to specialists who can then diagnose, come up with a treatment plan and that treatment can be implemented back in primary healthcare.

Theme 2: Practicality of providing early ASD detection and intervention

A number of sub-themes relating to practical issues of providing early ASD detection and intervention were raised by participants, including strategies to incorporate child development screening and early intervention into routine care, identifying sectors that already provide outreach, and identifying who within the existing system could train caregivers in early ASD intervention.

Subtheme 2.1: Incorporate general child development screening and early intervention into routine care—DoH representatives suggested that screening could be integrated into routine contact within the healthcare system:

Our utilisation rate for primary health care for under 5 years is usually very high. On average, we will see kids up to seven times a year. If there's one age group that has many touch points with the health services, I would say it's that under 5 years.

Screening could also occur in early childhood development centres:

Our ECDs, our daycare [centre]s, that's where you can catch it. It can be integrated into the ECD so that the early intervention programmes can kick in.

Collaboration between sectors would be needed to link detection to intervention:

Because it is normally identified in the preschool years. I think the main responsibility would not be the education department. I would see that as a DoH responsibility. And handing over to DSD to provide support. We are trying not to work in silos. When we work separately, we could be missing valuable opportunities to provide early intervention which would lessen the impact of disability on a child.

Subtheme 2.2: Health, education, and non-profit sectors are already providing outreach—Outreach is provided by DoH community health workers and the DoE multidisciplinary outreach team. Evidence-based early ASD intervention is implemented in naturalistic community settings, including the child's home environment (Schreibman et al., 2015), therefore understanding which sector provides community-based outreach could help to build an intervention approach that is sustainable.

Community health workers go to early childhood development centres to screen children. It is largely around immunisations and general developmental milestones and that sort of thing. In school we also do screening for eyes, ears, malnutrition.

In terms of the multidisciplinary outreach teams:

We have 71 special schools. Twenty-four of them are resourced to do outreach. It's very much part of how we envision the special school being a resource to other schools. We are trying to build an inclusive education system which has a continuum of support.

While DoE provides outreach for young children with other developmental disabilities, for example cochlear implants, no such service exists for young children with ASD. But this type of outreach model suggests DoE may have the capacity to extend a similar outreach approach to young children with ASD:

For children who have cochlear implants it is really important that language stimulation happens as young as possible. So our school that specialises in dealing with these children, have "hot seats" where children come in for two weeks with their parents and get parent guidance. From the age of 2 years, maybe a bit younger, until the time they get admitted to the school.

NPOs, often but not always supported financially by DSD, provide parent support groups and provider training.

Support groups are a way of getting parents together in a safe non-judgmental environment. They then know each other and they support each other on WhatsApp.

One example of provider trainings described by a NPO participant included the following: *Part of the outreach is the road trip programme. We take all our services, we try and do as many home visits and run workshops for professionals and parents.*

Subtheme 2.3: Options of whom could train parents/caregivers in early ASD intervention—NPOs are contracted by DSD to provide parent support for children with developmental disabilities. NPOs already provide parent/caregiver support and training.

It's one of our programme areas to support parents of children with disabilities. Our community team is led by social workers. Our ECD programme has a parent training component.

The DoE multidisciplinary ASD outreach teams were identified as an existing structural system that could provide caregiver training:

Our multidisciplinary outreach teams are based at some of our special schools. Usually a psychologist, an occupational therapist, a speech therapist, and special education teacher. I think those are the people who would probably be best suited [to training caregivers].

Within the DoH, community health workers were identified as a potential group. However, significant limitations in current capacity of this work force were noted:

The current cadre of community health workers do not have the skills nor the competencies to be able to do this. Also, they have a lot on their plate. So, we as a government are working towards increasing the numbers, the skills and the competencies. We have to understand that they are lay people so it does take them a while. It takes a while to build them up such that they are able to provide the service. But if there were additional resources, you could choose a smaller cadre and they could be specialised.

Lastly, parents of children with ASD were suggested by participants as potential caregiver trainers:

I think someone who had been through it. So a parent. I think it is very valuable because a lot of the time, the parents express the challenges that no one else understands. They have the empathy. They have the solutions. They have had to cope.

Theme 3: Integration of early intervention into existing platforms of care

Integration was reported to depend on how compatible caregiver training was with existing services. NPOs are already working with parents, therefore caregiver training was reported to be highly compatible with their existing services:

We used to run a parent champion programme. We trained 350 parents across all provinces last year for the national DSD on disability rights, awareness, sensitisation, and setting up groups and how to support parents and refer parents to DSD and other organisations.

DoE participants reported that caregiver training could be compatible with special schools and their outreach programme:

It would be part of the resource function of certain special schools. Resource coupled with outreach. It can definitely be part of that.

DoH community health workers could also provide this service:

I would imagine that it would be a home- and community-based care platform done by community health workers. The biggest issue is the capacity and looking at how we can maximise that. And what kind of skills and competencies you need.

Theme 4: Sustainability of training parents/caregivers in early ASD intervention

Two factors were identified as affecting sustainability of this intervention approach: how early intervention fitted with departmental goals and culture, and whether departments were willing to provide financial investment in such an approach.

Subtheme 4.1: Early intervention caregiver training fits with multiple departmental goals and culture—DSD participants reported that building local parent support structures is core to the DSD mission, suggesting that early intervention parent/caregiver training may be a sustainable approach for this sector:

Our programme focus is to promote the rights, well-being, and socio-economic empowerment of persons with disabilities and their families and their caregivers.

Parent/caregiver coaching would also fit with DoE outreach programmes if provided with extra support:

I think if we were given extra resources, it is something that we could certainly do. It would be in our interest to provide it. One of the responsibilities of our special schools is an outreach function and if we gave extra resources, it would fit into what they currently are doing.

With shifting departmental priorities, caregiver coaching could fit with DoH agenda:

We are kind of moving away from the “survive”, you know the kids are alive. We’ve made sure they have all the immunisations. Our HIV programme is one of the best and we have reduced the infant mortality rate. Okay, the survive component is done now. But how do we get these kids to thrive? How do we get them to more? So that’s definitely what we’re working on in the province.

Subtheme 4.2: Financial investment in the training in early intervention would be required—Participants felt strongly that a motivation would need to be provided to the national DoE to provide funding for early intervention services:

There is an interest from the national DoE in the growing incidence of ASD, and if this is one of the ways that we could lessen the level of support that is needed by the time the child comes into our formal schooling system, then that is something that could certainly be considered. It is certainly something that if we felt strongly enough about, we could motivate to the national department.

Advocacy to national government on behalf of the children served by DoH was raised as a method to increase financial investment:

We have to persuade them. I think the best we can do as clinicians is speak up on behalf of children and try and constantly make the noise that they need to hear. To me this is an advocacy issue. Start teaming up and saying together as a collective. If we all speak the same way, people will hear the same kind of message coming through.

DSD representatives stated that DSD would invest if it was accredited training:

Definitely. Not only parents, but our social worker, the professionals. It's a need. If I can take it to my seniors and say it's an accredited programme, they won't hesitate to look for funds. The training must not only focus on empowerment. It must also focus on the professionals working with the parent so that they can better understand and advise the parents.

Emerging theme: ASD is only thought of in the context of other developmental disabilities, rather than as a “named” disability

An emerging theme from stakeholder discussions was that ASD was typically only seen within the context of other developmental disabilities. This was most clearly articulated from DoH and DSD participants, as well as the NPO that provided more generic disability services. This finding is interesting because DoH and DSD are the sectors primarily responsible for the age group of children who would benefit from specific early ASD detection and intervention.

A DoH stakeholder noted that ASD was typically seen within the context of disabilities more broadly, not as a specific disability:

There's a specific project looking at people with disabilities which includes children. Autism isn't mentioned in particular at the moment. It just says “children with disabilities”. There might be a need to lift autism out more specifically or at least talk about the top five or top ten disabilities by age group. I'm not seeing clear articulation of autism jumping out as something specific yet.

A DSD respondent noted that they had a broad approach to disabilities:

In the disability programme, especially for DSD, our policies are more generic. They don't go deep into the specific disabilities. They will say “disability”, but they're referring across disability. So you won't find a policy that will zoom straight to autism, it will say disability.

The NPO respondent who provided more general disability services reported:

We support children of all disabilities of which one sector...is ASD. We would never develop a policy specifically for autism. Everything that we do relates to the support of children and towards inclusion, irrespective of where they are and what their additional needs are.

It is possible that ASD is only seen within other disabilities more broadly due to limited ASD knowledge and a lack of local ASD statistics. A DoH respondent noted:

Participant In the big scheme of things autism is a very small burden in terms of the population. Where we are looking at is what is the burden of disease and how can we provide services for everybody. As part of the First Thousand Days, developmental screening is one of the key pillars. What is the burden of autism? How many kids have autism in our province?

Interviewer That is a difficult question to answer because the research has not been done. There is the view that autism targets all population groups equally around the world. So we looking at about 1 in 68 children.

Participant 1 in 68? Really it's that high?

Interviewer It's that high, yes.

Participant Oh really? I wouldn't have thought 1 in 68! Really!

Discussion

In this paper we set out to examine stakeholder perspectives about early detection and early intervention, particularly caregiver education and training and caregiver coaching, for ASD in South Africa, as well as the policy environment supporting these activities. A summary of the key take-home points are presented in Box 2. Given that no similar work had been performed anywhere in South Africa, we started with multi-sector stakeholders in the Western Cape province, as it is thought of as relatively well-resourced in comparison to other South African provinces. Eight senior management level stakeholders, two each from the departments of Health, Social Development, Education, and the non-profit sector participated in in-depth interviews with a focus on key implementation-related themes.

The National Integrated Early Childhood Development Policy from DSD (Department of Social Development, 2015a), although not ASD specific, was identified by participants as the most relevant policy currently in place to guide early detection and intervention practice. The policy acknowledges the importance of early detection and early intervention and calls for the public provision of inclusive ECD services to “ensure participation of all children with disabilities to their full potential”. This policy provides a framework to guide the provision of comprehensive, inter-sectorial services for young children with disabilities, including ASD, and their families, in line with the Sustainable Development Goals, particularly goal 4 (United Nations, 2017). However, while the policy provides clear goals, the mechanism by which inter-sectorial collaboration could be facilitated for the provision of early detection and early intervention, of any disability, including ASD, is not clearly operationalised and policy implementation has not yet begun. Barriers to policy

implementation may include stakeholder concerns about the feasibility and sustainability of policies, a lack of health-system readiness for evidence-based practice, lack of health-system human and financial resources, and lack of financial support to implement the policy (Schneider et al., 2016). The absence of a specific ASD policy was in keeping with a theme that emerged from the data, that ASD was only seen and thought of within the context of other developmental disabilities, and not as a “stand-alone” developmental disability, particularly by DoH and DSD, who are primarily responsible for identifying and providing services and financial support to young children with ASD in South Africa.

With respect to providing early ASD detection, participants suggested that screening could be integrated into routine DoH primary care visits and/or outreach to ECD centres. While stakeholders provided information on an existing system of care in which early ASD screening could be integrated, as previously noted, access to standardised and validated tools for ASD screening and diagnosis in young children in South Africa’s multicultural, multilingual society is extremely limited (Chambers et al., 2017; de Vries, 2016; Franz et al., 2017; Smith et al., 2017). In addition, secondary screening and further diagnostic work currently requires highly qualified, specialist providers (Campbell et al., 2018), who are not located in primary healthcare clinics or ECD centres. This suggests that alongside efforts to identify and build a sustainable early ASD screening system, work on translation and validation of screening and diagnostic tools needs to occur (de Vries, 2016; Franz et al., 2017) as well as efforts towards open-access screening and diagnostic tools and technologies that could help facilitate cost-effective services in low-resource settings (de Vries, 2016; Durkin et al., 2015).

Linking early ASD detection with early intervention would require collaboration between sectors, notably the DoH and the DSD. As described previously, DoH and DSD key district- and provincial-level stakeholders noted that ASD was seen within the context of other developmental disabilities, and not as a “stand-alone” developmental disability, suggesting that specific ASD detection and intervention may not match up with departmental goals and culture. Increased ASD knowledge among these stakeholders as well as availability of local South African statistics on ASD prevalence, burden and associated costs may alter this approach.

Participants reported that parent/caregiver coaching, which aims to equip parents and caregivers with the skills to engage with their children from the earliest days of detection, could be integrated into existing platforms within DoH, DoE and the non-profit sector that already provide outreach and parent/caregiver support. Given that DoH and DSD see ASD only within the context of other developmental disabilities at present, the World Health Organization Caregiver Skills Training Programme for children with autism and other developmental disabilities which takes a universal approach to developmental disabilities (Hamdani et al., 2017) may “fit” the current system in South Africa as a first step for families of children with potential developmental disabilities. Work is currently underway to pilot the World Health Organization Caregiver Skills Training Programme in South Africa. Findings from a pilot study of EarlyBird/EarlyBird plus (Dawson-Squibb et al., 2018), an ASD-specific parent education and training group programme developed in the United Kingdom, showed positive initial results, with next steps requiring consideration of a range

of implementation factors. Evidence-based early ASD interventions, which fall within the category of naturalistic developmental behavioural interventions (Schreibman et al., 2015), offer ASD-specific intervention strategies. These types of interventions could be included in the services provided by the DoE's multidisciplinary ASD outreach teams or DoE schools who provide ECD services, as stakeholders identified this as an existing structural system that could provide caregiver training. Various types of service providers, including parents of children with ASD, were identified as potential candidates for training as caregiver coaches. This suggests that early ASD detection and early intervention could be practical and sustainable within the existing system of care, particularly with additional financial support. However, barriers related to capacity and competency of non-specialist workers, particularly in the DoH, were noted.

We acknowledge that the perspectives of study participants may not be representative of the views and priorities of key stakeholders in the departments of Health, Education, Social Development, and the non-profit sector in other provinces or at a national level, given that we focused on the Western Cape. However, many of the findings were very consistent across respondents, suggesting that there may be significant similarities in stakeholder perspectives in other South African provinces. This requires examination in future studies. We also acknowledge the small sample size as a potential study limitation. However, specific efforts were made to identify and recruit a diverse range of key participants, through purposive sampling, who could speak to ASD policy and capacity for early detection and early intervention in the Western Cape. In addition, findings from qualitative analysis were highly consistent and reached data "saturation".

Conclusions

Given that ASD is emerging as a growing public health concern in South Africa, a national inter-sectorial strategy, led by a technical coordinating body at national and provincial level, is needed to bring all sectors together and operationalise the provision of effective early detection and early intervention services, as mandated by the National Integrated Early Childhood Development Policy. Societal and governmental recognition of the importance of both early detection and early intervention for ASD is of utmost importance and in keeping with United Nations sustainable development goals (United Nations, 2017). Securing political and financial support for the development and implementation of effective programmes will require increased public awareness of the value of early detection and early intervention as well as increased advocacy from caregivers, clinicians and policy makers, to extend services to include these young children and their families. Significant challenges exist in providing screening and diagnostic tools to South Africa's multicultural, multilingual communities. It is key that work in this area continues to grow and develop. In terms of early intervention, caregiver-led interventions that address developmental disabilities more broadly may currently be a better "fit" with DoH and DSD departmental orientation and systems of care, while ASD-specific interventions may match more closely with the DoE.

References

- Abubakar A, Ssewanyana D, de Vries PJ, & Newton CR (2016). Autism spectrum disorders in sub-Saharan Africa. *The Lancet. Psychiatry*, 3(9), 800–802. 10.1016/S2215-0366(16)30138-9 [PubMed: 27568261]
- Allaby M, & Sharma M (2011). Screening for autism spectrum disorders in children below the age of 5 years. A draft report for the UK National Screening Committee. Solutions for Public Health Retrieved from http://www.legacyscreening.phe.org.uk/policydb_download.php?doc=170
- Baio J, Wiggins L, Christensen DL, Maenner M, Daniels J, Warren Z, ... Dowling NF (2018). Prevalence of autism spectrum disorder among children aged 8 years – Autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *Morbidity and Mortality Weekly Report – Surveillance Summaries*, 67(6), 1–23. 10.15585/mmwr.ss6706a1
- Bauman ML (2010). Medical comorbidities in autism: Challenges to diagnosis and treatment. *Neurotherapeutics: the Journal of the American Society for Experimental NeuroTherapeutics*, 7(3), 320–327. 10.1016/j.nurt.2010.06.001 [PubMed: 20643385]
- Brett D, Warnell F, McConachie H, & Parr JR (2016). Factors affecting age at ASD diagnosis in UK: No evidence that diagnosis age has decreased between 2004 and 2014. *Journal of Autism and Developmental Disorders*, 46(6), 1974–1984. 10.1007/s10803-016-2716-6 [PubMed: 27032954]
- Campbell K, Carpenter KLH, Espinosa S, Hashemi J, Qiu Q, Tepper M, ... Dawson G (2018). Use of a digital M-CHAT-R/F to improve quality of screening for autism. *The Journal of Pediatrics*, 183, 133–139. 10.1016/j.jpeds.2017.01.021
- Centers for Disease Control and Prevention. (2018). Autism prevalence slightly higher in CDC's ADDM Network Retrieved from <https://www.cdc.gov/media/releases/2018/p0426-autism-prevalence.html>
- Chambers NJ, Wetherby AM, Stronach ST, Njongwe N, Kauchali S, & Grinker RR (2017). Early detection of autism spectrum disorder in young isiZulu-speaking children in South Africa. *Autism*, 21(5), 518–526. 10.1177/1362361316651196 [PubMed: 27335105]
- Cidav Z, Munson J, Estes A, Dawson G, Rogers S, & Mandell D (2017). Cost offset associated with Early Start Denver Model for children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 56(9), 777–783. 10.1016/j.jaac.2017.06.007 [PubMed: 28838582]
- City of Cape Town. (2013). Policy on vulnerable groups Retrieved from [http://resource.capetown.gov.za/documentcentre/Documents/Bylaws%20and%20policies/Vulnerable%20Groups%20\(Policy%20number%2012399A\)%20approved%20on%2004%20December%202013.pdf](http://resource.capetown.gov.za/documentcentre/Documents/Bylaws%20and%20policies/Vulnerable%20Groups%20(Policy%20number%2012399A)%20approved%20on%2004%20December%202013.pdf)
- Courchesne E, Campbell K, & Solso S (2011). Brain growth across the life span in autism: Age-specific changes in anatomical pathology. *Brain Research*, 1380, 138–145. 10.1016/j.brainres.2010.09.101 [PubMed: 20920490]
- Dawson G (2008). Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. *Development and Psychopathology*, 20(3), 775–803. 10.1017/S0954579408000370 [PubMed: 18606031]
- Dawson G, Rogers S, Munson J, Smith M, Winter J, Greenson J, ... Varley J (2010). Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model. *Pediatrics*, 125(1), e17–e23. 10.1542/peds.2009-0958 [PubMed: 19948568]
- Dawson-Squibb J-J, Davids EL, & de Vries PJ (2018). Scoping the evidence for EarlyBird and EarlyBird Plus, two United Kingdom-developed parent education training programmes for autism spectrum disorder. *Autism [online]*. 10.1177/1362361318760295
- Department of Basic Education. (2012). Integrated school health policy Retrieved from <http://serve.mg.co.za/content/documents/2017/06/14/integratedschoolhealthpolicydbeanddoh.pdf>
- Department of Basic Education. (2014). Policy on screening, identification, assessment and support Retrieved from <https://www.education.gov.za/Portals/0/Documents/Policies/SIAS%20Final%2019%20December%202014.pdf?ver=2015-02-24-131207-203>
- Department of Education. (2001). White Paper 6: Special needs education building an inclusive education and training system Retrieved from <https://wcedonline.westerncape.gov.za/Specialised-ed/documents/WP6.pdf>

- Department of Health. (2008). Policy guidelines on child and adolescent mental health Retrieved from <file:///C:/Users/lf29/AppData/Local/Temp/Policy%20Guidelines%20on%20Child%20and%20Adolescent%20Mental%20Health.pdf>
- Department of Health. (2012). Strategic plan for maternal, new-born, child and women's health and nutrition in South Africa Retrieved from <https://extranet.who.int/nutrition/gina/sites/default/files/ZAF%202012%20MNCWHstratplan.pdf>
- Department of Social Development. (2005). Integrated service delivery model Retrieved from http://www.dsd.gov.za/index2.php?option=com_docman&task=docview&gid=%20%0B515&Itemid=39
- Department of Social Development. (2012). White paper on families in South Africa Retrieved from http://www.dsd.gov.za/index.php?option=comdocman&task=cat_view&gid=33&Itemid=39
- Department of Social Development. (2013). Framework for social welfare services Retrieved from http://www.dsd.gov.za/index2.php?option=com_docman&task=doc_view&gid=%20%0B515&Itemid=39
- Department of Social Development. (2015a). National Integrated Early Childhood Development Policy Retrieved from <https://www.gov.za/sites/default/files/National%20Integrated%20ECD%20Policy%20%28web%20Version%20-%20Final%29%2001%2008%202016a.pdf>
- Department of Social Development. (2015b). White paper on the rights of persons with disabilities Retrieved from https://www.gov.za/sites/www.gov.za/files/39792_gon230.pdf
- de Vries PJ (2016). Thinking globally to meet local needs: Autism spectrum disorders in Africa and other low resource environments. *Current Opinion in Neurology*, 29(2), 130–136. 10.1097/WCO.000000000000297 [PubMed: 26886354]
- Durkin MS, Elsabbagh M, Barbaro J, Gladstone M, Happe F, Hoekstra RA, ... Shih A (2015). Autism screening and diagnosis in low resource settings: Challenges and opportunities to enhance research and services worldwide. *Autism Research*, 8(5), 473–476. 10.1002/aur.1575 [PubMed: 26437907]
- Elo S, & Kyngäs H (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. 10.1111/j.1365-2648.2007.04569.x [PubMed: 18352969]
- Engle PL, Black MM, Behrman JR, Cabral de Mello M, Gertler PJ, Kapiriri L, ... Young ME (2007). Strategies to avoid the loss of developmental potential in more than 200 million children in the developing world. *Lancet*, 369(9557), 229–242. 10.1016/S0140-6736(07)60112-3 [PubMed: 17240290]
- Estes A, Munson J, Rogers SJ, Greenson J, Winter J, & Dawson G (2015). Long-term outcomes of early intervention in 6-year-old children with autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 54(7), 580–587. 10.1016/j.jaac.2015.04.005 [PubMed: 26088663]
- Franz L, Chambers N, von Isenburg M, & de Vries PJ (2017). Autism spectrum disorder in sub-Saharan Africa: A comprehensive scoping review. *Autism Research*, 10(5), 723–749. 10.1002/aur.1766 [PubMed: 28266791]
- Franz L, Guler J, Adewumi K, Seris N, Shabalala N, Viljoen M, ... & de Vries PJ (2018a). The contextual and policy landscape for caregiver-mediated early intervention in South Africa Poster presented at the INSAR Annual Meeting, Rotterdam, Netherlands.
- Franz L, Ramseur K, Guler J, Shabalala N, Seris N, Dawson G, & de Vries PJ (2018b). Implementing ESDM in Africa – Is caregiver coaching acceptable in South Africa and which joint activity routines can we target? Poster presented at the INSAR Annual Meeting, Rotterdam, Netherlands.
- Guler J, de Vries PJ, Seris N, Shabalala N, & Franz L (2017). The importance of context in early autism intervention: A qualitative South African study. *Autism* [online]. 10.1177/1362361317716604
- Hamdani SU, Akhtar P, Zill-e-Huma, Nazir H, Minhas FA, Sikander S, ... Rahman A (2017). WHO parents skills training (PST) programme for children with developmental disorders and delays delivered by family volunteers in rural Pakistan: Study protocol for effectiveness implementation hybrid cluster randomized controlled trial. *Global Mental Health* (Cambridge, England), 4, e11 10.1017/gmh.2017.7
- Harrison AJ, Zimak EH, Sheinkopf SJ, Manji KP, & Morrow EM (2014). Observation-centred approach to ASD assessment in Tanzania. *Intellectual and Developmental Disabilities*, 52(5), 330–347. 10.1352/1934-9556-52.5.330 [PubMed: 25247726]

- Huttenlocher P (2002). *Neural plasticity: The effects of environment on the development of cerebral cortex* Cambridge, Massachusetts: Harvard University Press.
- Kakooza-Mwesige A, Ssebyala K, Karamagi C, Kiguli S, Smith K, Anderson MC, ... Grether JK (2014). Adaptation of the “ten questions” to screen for autism and other neurodevelopmental disorders in Uganda. *Autism*, 18(4), 447–457. 10.1177/1362361313475848 [PubMed: 23536263]
- Kang-Yi CD, Grinker RR, Beidas R, Agha A, Russell R, & Shah SB, ... Mandell DS (2018). Influence of community-level cultural beliefs about autism on families’ and professionals’ care for children. *Transcultural Psychiatry*, 55(5), 623–647. 10.1177/1363461518779831 [PubMed: 29972327]
- Kleinman JM, Robins DL, Ventola PE, Pandey J, Boorstein HC, Esser EL, ... Fein D (2008). The modified checklist for autism in toddlers: A follow-up study investigating the early detection of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38(5), 827–839. 10.1007/s10803-007-0450-9 [PubMed: 17882539]
- Lewis JD, Evans AC, Pruett JR, Botteron K, Zwaigenbaum Z, Estes A, ... Piven J (2014). Network inefficiencies in autism spectrum disorder at 24 months. *Translational Psychiatry*, 4(5), e388 10.1038/tp.2014.24 [PubMed: 24802306]
- Lord C, Rutter M, DiLavore PC, Risi S, Gotham K, & Bishop S (2012). *Autism diagnostic observation schedule (2nd edn)*. Torrance: Western Psychological Services.
- Lord C, Rutter M, & Le Couteur A (1994). Autism diagnostic interview-revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24(5), 659–685. 10.1007/BF02172145 [PubMed: 7814313]
- Mandell DS, Listerud J, Levy SE, & Pinto-Martin JA (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41(12), 1447–1453. 10.1097/00004583-200212000-00016 [PubMed: 12447031]
- Mayosi BM, & Benatar SR (2014). Health and health care in South Africa: 20 years after Mandela. *The New England Journal of Medicine*, 371(14), 1344–1353. 10.1056/NEJMs1405012 [PubMed: 25265493]
- Miller JS, Gabrielsen T, Villalobos M, Alleman R, Wahmhoff N, Carbone PS, & Segura B (2011). The each child study: Systematic screening for autism spectrum disorders in a pediatric setting. *Pediatrics*, 127(5), 866–871. 10.1542/peds.2010-0136 [PubMed: 21482605]
- Mokitimi S, Schneider M, & de Vries PJ (2018). Child and adolescent mental health policy in South Africa: History, current policy development and implementation, and policy analysis. *International Journal of Mental Health Systems*, 12(1), 36–51. 10.1186/s13033-018-0213-3 [PubMed: 29983735]
- Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, ... Hensley M (2011). Outcomes for implementation research: Conceptual distinctions, measurement challenges, and research agenda. *Administration and Policy in Mental Health*, 38(2), 65–76. 10.1007/s10488-010-0319-7 [PubMed: 20957426]
- Pillay S, Duncan M, & de Vries PJ (2017). How many children with autism spectrum disorder are there in South African schools? A systematic database search for known cases of ASD in the Western Cape Poster presented at the Regional IMFAR SA-ACAPAP.
- Rogers SJ, Dawson G, & Vismara LA (2012). *An early start for your child with autism: Using everyday activities to help kids connect, communicate, and learn* New York: Guilford Press.
- Robins DL, Casagrande K, Barton M, Chen CM, Dumont-Mathieu T, & Fein D (2014). Validation of the modified checklist for Autism in toddlers, revised with follow-up (M-CHAT-R/F). *Pediatrics*, 133(1), 37–45. 10.1542/peds.2013-1813 [PubMed: 24366990]
- Schneider M, Baron E, Breuer E, Docrat S, Honikman S, & Kagee A, ... Lund C (2016). Integrating mental health into South Africa’s health system: Current status and way forward. *South African Health Review*, 2016(1): 153–163.
- Schreibman L, Dawson G, Stahmer AC, Landa R, Rogers SJ, Mcgee GG, ... Halladay A (2015). Naturalistic developmental behavioral interventions: Empirically validated treatments for autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(8), 2411–2428. 10.1007/s10803-015-2407-8 [PubMed: 25737021]

- Scott FJ, Baron-Cohen S, Bolton P, & Brayne C (2002). The CAST (Childhood Asperger Syndrome Test): Preliminary development of a UK screen for mainstream primary school-age children. *Autism*, 6(1), 9–31. 10.1177/1362361302006001003 [PubMed: 11918111]
- Shatkin JP, & Belfer LM (2004). The global absence of child and adolescent mental health policy. *Child and Adolescent Mental Health*, 9(3), 104–108. 10.1111/j.1475-3588.2004.00090.x
- Smith L, Malcolm-Smith S, & de Vries PJ (2017). Translation and cultural appropriateness of the Autism Diagnostic Observation Schedule-2 in Afrikaans. *Autism*, 21(5), 552–563. 10.1177/1362361316648469 [PubMed: 27231336]
- South African Government. (2002). Mental Health Care Act Retrieved from <https://www.gov.za/sites/www.gov.za/files/a17-02.pdf>
- South African Government. (2006). Children's Act Retrieved from <https://www.gov.za/sites/default/files/a38-05.pdf>
- Springer PE, van Toorn R, Laughton B, & Kidd M (2013). Characteristics of children with pervasive developmental disorders attending a developmental clinic in the Western Cape Province, South Africa. *South African Journal of Child Health*, 7(3), 95–99. 10.7196/sajch.530
- United Nations. (2015). United Nations Millennium Development Goals Retrieved from <http://www.un.org/millenniumgoals/>
- United Nations. (2017). United Nations Sustainable Development Goals Retrieved from <http://www.un.org/sustainabledevelopment/sustainable-development-goals/>
- Van Schalkwyk GI, Beyer C, & de Vries PJ (2016). South Africa and Autism. In Volkmar FR (ed.), *Encyclopedia of Autism Spectrum Disorders* (pp. 1–7). New York: Springer 10.1007/978-1-4614-6435-8_102111-1
- Western Cape Department of Health. (2014). Healthcare 2030: the road to wellness Retrieved from <http://www.westerncape.gov.za/assets/departments/health/healthcare2030.pdf>
- Western Cape Department of Health. (2016). Postnatal care policy Retrieved from https://gallery.mailchimp.com/c7b8ed60db72f069982c7e4ee/files/PostnatalCarePolicy_2016.01.pdf
- World Bank Group. (2017). GINI index (World Bank estimate) Retrieved from <https://data.worldbank.org/indicator/SI.POV.GINI/>
- World Health Organization. (2013). Comprehensive and coordinated efforts for the management of autism spectrum disorders Retrieved from http://apps.who.int/gb/ebwha/pdf_files/EB133/B133_4-en.pdf
- World Health Organization. (2015). Caregiver skills training for the management of developmental disorders Retrieved from http://www.who.int/mental_health/mhgap/evidence/child/q6/en/

Box 1:**Summary of themes and sub-themes****Policy environment**

- Most, but not all participants identified autism spectrum disorder (ASD) as an increasing area of concern
- Department of Social Development responsible for management of young children with ASD
- National Integrated Early Childhood Development Policy most relevant policy
- Future directions include recognition of the importance of early intervention, integrated policy and services, and screening

Practicality of providing early ASD detection and intervention

- Strategies to incorporate developmental screening and early intervention into routine care
- Identifying sectors already providing outreach
- Many options on who could train parents/caregivers in early ASD intervention

Integration of early intervention into existing platforms of care

- Integration depends on how compatible caregiver training is with existing services

Sustainability of training parents/caregivers in early ASD intervention

- If training fits with departmental goals and culture, approach could be sustainable
- Financial investment for training in early intervention would be required

ASD is only thought of in the context of other developmental disabilities

- Department of Health and Department of Social Development participants see ASD only within the context of other developmental disabilities

Box 2:**Key take-home points**

- There is no national autism spectrum disorder (ASD) policy, but a general policy on early detection and intervention: National Integrated Early Childhood Development Policy
- A national inter-sectorial strategy is needed to bring sectors together and operationalise early detection and early intervention services, as mandated by the National Integrated Early Childhood Development Policy
- ASD is not seen as a “stand-alone” developmental disability by Department of Health (DoH) and Department of Social Development (DSD)
- ASD-specific early detection and intervention may not match DoH and DSD goals
- Interventions with a universal approach to developmental disabilities may “fit” current DoH and DSD goals
- Increased ASD knowledge and South African statistics on prevalence, burden and cost may alter DoH and DSD approach
- ASD-specific early detection and early intervention matches Department of Education goals
- Local translation and validation of ASD screening and diagnostic tools needs to occur.

Table 1:

Acts/policies relating to children with developmental disabilities including autism spectrum disorder

Level of act/policy	Name of act/policy	Department
Acts of Parliament	Mental Healthcare Act (South African Government, 2002)	
	Children's Act (South African Government, 2006)	
National policies	Education White Paper 6: Special Needs Education Building an Inclusive Education and Training System (Department of Education, 2001)	DoE
	Policy on Screening, Identification, Assessment and Support (Department of Basic Education, 2014)	DoE
	Integrated School Health Policy (Department of Basic Education, 2012)	DoE and DoH
	Policy Guidelines of Child and Adolescent Mental Health (Department of Health, 2008)	DoH
	Strategic Plan for Maternal, New-born, Child and Women's Health and Nutrition in South Africa (Department of Health, 2012)	DoH
	White Paper on the Rights of Persons with Disabilities (Department of Social Development, 2015b)	DSD
	White Paper on Families (Department of Social Development, 2012)	DSD
	National Integrated Early Childhood Development Policy (Department of Social Development, 2015a)*	DSD
	Framework for Social Welfare Services (Department of Social Development, 2013)	DSD
Western Cape provincial policies	Integrated Service Delivery Model (Department of Social Development, 2005)	DSD
	Healthcare 2030 – The Road to Wellness (Western Cape Department of Health, 2014)	DoH
City of Cape Town policies	Postnatal Care Policy (Western Cape Department of Health, 2016)	DoH
	Policy on Vulnerable Groups (City of Cape Town, 2013)	

DoH: Department of Health; DoE: Department of Education; DSD: Department of Social Development

* Most relevant policy for ASD early detection and intervention identified by participants