

## **AUTISM SPECTRUM DISORDER IN ZIMBABWE: A BRIEF REVIEW OF TRENDS, CONDITIONS, CHALLENGES, AND INTERVENTION PRACTICES**

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### **Abstract**

*The prevalence of Autism Spectrum Disorder (ASD) in Zimbabwe is largely unknown owing to limited research in this area. Unlike in developed countries, many individuals with ASD do not get the correct diagnosis early enough to promote timely interventions. Tracking data on the population and characteristics of people with ASD is important for resource and interventions planning purposes. Paucity of research in this area makes it difficult to determine the challenges faced by people with ASD and efficacy of practices used to address challenges faced by this group of people. This paper presents a brief review of literature concerning trends and challenges faced by people with ASD in Zimbabwe. Challenges faced and intervention services available are discussed. Suggestions for research and practice are provided.*

**Key words:** *Autism Spectrum Disorder, Behaviour, Interventions, Zimbabwe, Special Education*

### **Introduction**

Autism Spectrum Disorder is a neurodevelopmental disorder characterized by impaired social interaction, verbal, and non-verbal communication, restricted and repetitive behaviours, and sensitivity to sensory stimulation (Happé, 1994; Fuentes, Bakare, Munir, Aguayo, Gaddour, & Oner, 2012). There is not complete knowledge regarding its causes, but a large section of research suggests genetic and environmental factors, and complications or infections during pregnancy as leading causes (Matsuzaki, Iwata, Manabe, & Mori, 2012). Typically, symptoms begin to appear at 6 – 18 months that include failure to respond to names, avoiding eye contact, lack of joint attention, and repetitive behaviours such as rocking or arm flapping (Buckley, 2005). Although various instruments for diagnosis of ASD and related mental disorders exist, parents usually notice symptoms before formal diagnosis. Utilization of formal diagnostic methods, however, provides reliable means to facilitate assessment of the disorders, as well as provision of necessary information on the relative strengths and weaknesses of the child (Brantani et al., 2013).

Although symptoms may vary across individuals, ASD is usually associated with social skills and verbal and non-verbal communication deficits (Matsuzaki et al., 2012). Children with ASD may engage in problem behaviours as a means of communicating their needs, which may present challenges to educators and other learners in an instructional environment, family members, and other caregivers (Neitzel, 2010). Exhibited problem behaviours may include refusal to requests, socially inappropriate actions, and self-stimulatory behaviours (e.g. rocking, hand flicking). Severe challenging behaviours may include self-injurious behaviour (SIBs) which can result in physical harm to self or other people if left untreated (Duerden., 2012). Such behaviours often exist on a continuum ranging from less severe (e.g., head rubbing, finger sucking, and nail biting) to extremely severe (e.g., eye poking, chronic rumination, and head banging). Lack of understanding of underlying causes of the behaviours can result in caregivers using ineffective or harmful approaches to address the behaviours (Manente, Maraventano, LaRue, Delmolino, & Sloan, 2010). In developing countries, such behaviours may go untreated or result in caregivers using punitive methods due to lack of knowledge of research-based methods to address them (Chitiyo, Hughes, Changara, Chitiyo, & Montgomery, 2017).

Application of some research-based procedures may require training so that caregivers can correctly administer the interventions in ways that do not pose harm to clients.

Existing research indicates that ASD has no boundaries and occurs in all parts of the world and in all races, societies, and different types of families (Autism Society of America, 2007). Although there is a large body of research on ASD in developed countries like the USA, there is not as extensive research in developing countries, especially in Sub-Saharan Africa (Ametepee & Chitiyo, 2009). A few studies have documented the existence of ASD on the African continent (Akande, 1999; Lotter, 1978, Mankoski et al., 2006; Mooney, 1992) but the prevalence rates and living conditions are, to a large extent still unknown. Understanding the prevalence and challenges faced by people with ASD on the continent is important as it serves as a precursor for the development of appropriate strategies to address the challenges. A major challenge associated with accumulating such information, however, lies in the significant differences in cultural, societal, and political approaches to disability in different African countries. A continent-wide approach to understand the conditions may conceal important information regarding the cultures and approaches to disability in the different countries.

Zimbabwe, like many other African countries, has been affected by ASD. In order to unravel the current state of affairs regarding the condition in Zimbabwe, we conducted a review of existing literature. The purpose of this review is to assess research on prevalence of ASD in Zimbabwe, the challenges faced by people with ASD, as well as to assess the availability of intervention services.

### **Methodology**

An electronic literature search using ERIC, PyschINFOR, and PsychARTICLES databases was conducted. Search terms consisting of *autism\**, *special education*, and *Zimbabwe* were used. The initial abstracts search consisting of only *autis\** and *Zimbabwe* yielded only a single article. A separate search of the abstracts using all three search terms yielded 19 articles. The search was extended to include literature on Special Education in Zimbabwe since most services for autism are offered through special education facilities. No restrictions were placed regarding literature sources. The different literature sources reviewed included peer reviewed journal articles, book chapters, conference reports, and newspaper articles. Following identification of the literature, a narrative analysis was conducted. The narrative analysis focused on the prevalence of autism in Zimbabwe, identification and assessment options available, challenges faced, and available services for individuals with Autism.

### **Prevalence of ASD in Zimbabwe**

Although a lot of research on characteristics and behavioural interventions for ASD and related mental disabilities is done in developed countries, not much is known nor has been researched about the conditions in Zimbabwe. As of 2017, there were no statistics on the population of children affected by ASD in Zimbabwe. The Psychological Services, Special Needs, and Learner Welfare Department, an organ of the Ministry of Education, Sports, and Culture is responsible for the compilation of national statistics on the state of disability in Zimbabwe. The most recent report (Ministry of Primary and Secondary Education, 2017) contains statistics regarding the population of school age children with different types of disabilities (e.g. visual, physical, and hearing impairment, intellectual disabilities, and learning disabilities), but does not contain specific statistics regarding ASD. Part of the lack in statistics on ASD stems from the absence of reliable diagnostic systems and lack of awareness of ASD amongst practitioners and families (Chitiyo et al., 2017). The crucial importance of keeping track of such data lies on the fact that children with ASD can

present unique challenges that warrant specialized interventions to address their unique skills deficits (Dente & Coles, 2012).

There is a possibility that a large population of children in Zimbabwe has ASD, (Chitiyo et al., 2017). A study by Khan and Hombarume (1996) found that 18 children with intellectual disability displayed behaviours that are usually exhibited by children with ASD, suggesting that the condition is prevalent. However, as a result of lack of formal and comprehensive diagnostic measures, the condition is not diagnosed. Diagnosis of ASD is difficult since it does not involve medical tests (e.g. blood examinations). Although parents can trace symptoms of autism in their children if they possess necessary knowledge about the symptoms, a formal and more reliable diagnosis can only be offered by a trained and experienced professional (e.g. medical doctors, psychologists). However, regardless of services offered by medical practitioners, populations in remote areas often fail to access medical services due to cost and long distances, making it almost impossible to get diagnosis (Deluca, Tramontano, & Kett, 2014).

Furthermore, collection of data on ASD and other developmental disabilities may be difficult given the obsolete nature of data collection systems in state hospitals, health institutions, and public schools, as well as lack of expertise and research based diagnostic systems (Ministry of Health and Child Welfare, 2011). A few years ago, the Ministry of Health and Child welfare adopted an E-Health strategy to enhance adoption of ICTs in the health sector, an initiative which was set to improve collection of data on health (Ministry of Health and Child Welfare, 2011). However, the strategy has yet to culminate tangible benefits as far as data collection for autism is concerned.

### **Challenges faced by people with ASD in Zimbabwe**

Individuals living with ASD and other developmental disabilities in Zimbabwe face acute problems that often go unattended (Majoko, 2015; Mugweni & Dakwa, 2013). Although there is legislation and policies meant to protect the rights of individuals with disabilities in Zimbabwe (i.e., National Disability Act and Zimbabwe's Special Education Policy), these policies are not comprehensively implemented (Lang & Charowa, 2007). The ignorance towards the welfare of individuals with disabilities, coupled with lack of implementation of disability legislation makes communities turn a blind eye on such populations, and they do not treat these people with the importance they otherwise deserve (UNICEF, 2013). As such, the welfare of individuals with disabilities, including those with ASD, in Zimbabwe has been primarily the responsibility of religious organizations and non-governmental organizations.

Prior to and post the colonial era, disability has either been denigrated or associated with misfortune, warranting spiritual mediation (Stone & Butera, 2012). The plight of individuals with disabilities is often worsened by the general notion that disability is equated to physical impairment. In some cultural models pertaining to causes of disability in Africa, populations with mental disabilities are generally not considered disabled; rather, they were often perceived as outcasts under a spell for some bad deeds, or victims of witchcraft performed on them by other people (Stone & Butera, 2012). Consequently, people with mental disabilities were often denied certain rights available to typical populations. This and other problems present acute challenges to people with disabilities, including ASD, thereby negatively impacting their quality of life.

### **Absence of interventions services and facilities**

Children with ASD and other developmental disabilities may fail to benefit from general curriculum, thereby creating a need for special education services (Majoko, 2015; Mugweni & Dakwa, 2013). Special education classes are created to enable provision of services that are tailor made to meet the special needs of such children. Although most schools in Zimbabwe's urban centers have special education classes, they are either inadequate to meet the rising numbers of children needing the services, or they lack the necessary resources to facilitate learning (Majoko, 2016; Mugweni & Dakwa, 2013). Although no formal records exist, most schools in rural areas and other small towns do not have such facilities at all (Deluca, Tramontano, & Kett, 2014). Limited government spending on special education can partly be attributed to the limited supply of special education facilities in Zimbabwean schools (Chitiyo, Hughes, Changara, Chitiyo, & Montgomery, 2017).

**Lack of professional development.** One of the key factors regarded as crucial for the success of students with ASD is the availability of highly qualified educators. Zimbabwe has an acute shortage of specially trained personnel in special education (Chitiyo et al., 2017; Deluca et al., 2014). Most special education teachers either lack effective training on the most appropriate interventions to address skills deficits of children with ASD, or lack necessary resources to use in their classrooms. In a survey by Deluca et al. (2014), around 80% of teachers in Mashonaland province reported not having attained appropriate pre-service training in special needs education. Limited initiatives and programs to foster teacher development in special needs education, compounded by limited government funding largely explain lack of appropriate teacher training. Several other factors hindering effective delivery of special education services in Zimbabwe include lack of assistive devices, societal attitudes towards disability, and shortage of personnel with expertise to train teachers in special needs education (Chitiyo et al., 2017). This assertion is consistent with the findings of Deluca et al. (2010) in which 98.5% of head teachers, 93.3% of teachers, and 89.4% of caregivers surveyed in four school districts in Mashonaland West reported lack of assistive devices and fear of abuse as major barriers inhibiting inclusion of students with disabilities into mainstream education. As pointed out earlier, unique needs of children with ASD may warrant specialized training to address such needs.

**Limited access to employment.** Since most children with ASD may not benefit from general education curriculum, they may not possess the necessary skills for employment when they transition into adulthood (Hendricks, 2010). The USA provides a model for evidence in this regard; In 2009, people with ASD aged 16 to 65 were more than twice less likely to get employed relative to typical people without disabilities (Bureau of Labor Statistics, 2017). On average, young adults with ASD and employed earned about 15% less than similar age counterparts with disabilities (Bureau of Labor Statistics, 2017). Given the industrial structure of the USA, which is more likely to have job opportunities for people with disabilities, these findings suggest even lower rates for populations with ASD in Zimbabwe and other developing countries. Hendricks (2010) posited that regardless of their level of education, people with ASD were less likely to be employed or faced common employment related challenges. Lack of employment amongst people with ASD results in even more complicated problems like lack of access to decent accommodation and other basic life amenities. To date, no statistics regarding the extent to which populations with ASD are affected by such inconveniences in Zimbabwe.

**Lack of identification and diagnostic systems.** Although parents can detect symptoms for ASD in their kids by mere inspection of their daily behaviours, most parents lack the precise knowledge on the signs and symptoms of ASD. As a result, most cases go undetected for a long time. Absence of reliable diagnosis at

early ages often result in symptoms and behavioural problems worsening at later ages, as well as difficulty for clients to respond to interventions (Hume, Bellini, & Pratt, 2005). In a study to investigate the efficacy of autistic diagnostic services in Zimbabwe (Chitiyo et al., 2017), five parents of children with ASD reported the processes of accessing services as difficult and the diagnosis outcomes as often inaccurate. Given lack of adequate knowledge about and access to diagnostic services, there is a possibility of misdiagnosis or cases going for long without being detected.

**Societal discrimination.** People with disabilities often face discrimination in various spheres of life including participation in societal activities and employment (UNICEF, 2013). Due to lack of effective social skill repertoires, children with ASD often face challenges in engaging in social interactions with same age peers or other people in general. Consequently, such children are likely to be victims of bullying and isolation from typical, same age peers in schools and inclusive education settings. In a study to investigate the experiences of children with ASD in USA public schools, Zablotsky, Bradshaw, Anderson, and Law (2014) found out that children with autism attending a public school in a general education classroom were more likely to be bullied relative to those in special education classes. Vulnerability to physical and sexual abuse and bullying inherent in high functioning autism may lead to emotional stress, which ultimately correlates with suicidal ideation for this population (Richa, Fahed, Khoury, & Mishara, 2014). Zimbabwe currently does not have documented investigation in this regard to assess the experiences of children with autism in elementary and secondary school.

As a result of the negative societal attitude towards disability, families of children with ASD may withdraw their children from school or never send them in fear of discrimination or abuse. Gona, Newton, Rimba, Mapeenzi, ...& Abubakar (2016) investigated challenges faced by parents of children with ASD in Kenya. Parents of children with ASD participating in the study reported being blamed for their children's behaviours, on the supposition that they had bad parenting skills. Society's misconception and failure to understand ASD as a developmental disorder is a factor that hinders a societal approach to addressing the challenges faced by children with the condition and their families.

### **Service facilities for children with ASD in Zimbabwe**

The provision of services for students with disabilities including ASD in Zimbabwe is primarily the responsibility of the Ministry of Primary and Secondary Education. The ministry is also responsible for the coalition of data on population of children with special needs enrolled in various institutional settings, including special schools, residential facilities, and resource rooms, among others (Peresuh & Barcham, 1998). Through the Ministry of Primary and Secondary Education, the government of Zimbabwe institutes a special education policy whose prime goals include early detection, intervention, and prevention of handicap, integration of children with special education needs into mainstream classes, development of local training facilities, and development of resource centers for integration (UNICEF, 2013). The population of schools with special education facilities in Zimbabwe has grown steadily over the last three decades (Mugweni & Dakwa, 2013). However, most schools with such facilities are faced with numerous challenges that negate inclusion of children with ASD. Some of the special education classes are under-resourced (i.e. lacking equipment for use with children with special needs), or they lack teachers with specialized training in special education (Chitiyo et al., 2016). Often, children with disabilities are turned away from schools because teachers perceive themselves as being untrained to teach such children (Mutepfa, Mpofu, & Chataika, 2007). There are a few publicly identifiable non-governmental organizations specifically aimed at addressing the needs of children with ASD. These include St. Giles Medical Rehabilitation Center, Jairos Jiri Foundation,

Autism Trust, and Ronald Trust for Cerebral Palsy and Autism Children in Zimbabwe. St. Giles Medical Rehabilitation Center and Jairos Jiri Foundation have extensive provision of services ranging from physiotherapy, occupational therapy, speech and language therapy, and psychological counselling. However, the organizations' capacities to provide services are limited given the growing population of children in need of services (Ncube & Hlatywayo, 2014). Furthermore, most of the organizations report a lot of other challenges, including dilapidating infrastructure, lack of rehabilitative equipment, and lack of personnel etc. (Muranda, 2015).

### **Recommendations: Need for applied behaviour interventions in Zimbabwe**

Like many other African countries, Zimbabwe has not drawn lessons regarding interventions for ASD from developed countries with extensive interventions research. Although some special needs care organizations use standard procedures to address challenging behaviours (e.g. St. Giles, Jairos Jiri), there is limited utilization of research to guide practice by practitioners (Chitiyo et al., 2017). The USA represents a model with an extensive research on interventions for ASD and related mental disabilities to support adoption and utilization of evidence-based practices. Use of interventions not supported by research can be discredited for unwarranted expectations about treatment results and misplaced confidence on otherwise ineffective and potentially harmful interventions.

Research on basic principles for early interventions suggests several guiding principles to facilitate learning and skills acquisition by children with autism (Lindgren & Doobay, 2011). For instance, interventions targeted at early ages as soon as symptoms of ASD begin to appear are likely to be more effective than interventions administered as symptoms become more pronounced (Hume et al., 2005). Additional aspects of effective intervention include one to one teaching platforms, ongoing data collection of a child's performance to track progress, incorporation of higher degrees of structure like routine schedules, and use of multiple environmental elements to promote generalization of taught skills (Mosier, 2011).

Applied behaviour analysis (ABA) is the most commonly used form of interventions for ASD in USA. This is an approach to behaviour management that focuses on functions of behaviour and manipulation of environmental circumstances shaping behaviour to bring about desired behaviour change and skills acquisition (Lindgren & Doobay, 2011). Most ABA interventions are empirically supported by rigorous research, having been tested across varied simulations and populations (Lindgren & Doobay, 2011). Many studies conducted to evaluate ABA interventions on children with autism have demonstrated significant gains in academic outcomes, social and communication skills, emotional regulation, and adaptive skills (Wong, Odom, Hume, Cox, Fettig, ..., & Shultz, 2014; Tonge, Bull, Brereton, & Wilson, 2014). Often, interventions are administered by registered behaviour technicians (RBTs), professionals whose training consists of 40-hour video modules that encompass review questions and brief examinations. Upon completion of modules and additional practical training, one can be able to administer interventions.

Zimbabwe can borrow some lessons on ABA interventions for ASD from the USA model. Special education teachers, paraprofessional, families, and other direct care staff working with children with ASD can be trained in ABA basic principles. The challenge, however, is that training in ABA interventions is relatively costly. Professionals getting qualifications in the field of ABA usually have to take a series of ABA courses from accredited institutions, most of which charge higher tuition for the courses. Additionally, such individuals are also required to take part in a supervised practicum so that they gain some hands-on experience of administering the interventions (BACB, 2018). Upon completion of the practicum, the candidates are

certified to work with populations needing ABA interventions. Regardless of the high costs of attaining qualifications in ABA, various organizations usually conduct training workshops which involve training parents, caregivers, or other professionals on ABA interventions (Bearss, 2017). This model could be a best fit for Zimbabwe where majority of direct care staff are not financially capable of paying for the services. Aside from developing interventions, there is also a great need to have comprehensive identification and diagnostic frameworks in place. This requires training of professionals who work with young children on some of the diagnostic or screening tools (e.g. Modified Checklist for Autism in Toddlers) used in the context of developmental surveillance. The Modified Checklist for Autism in Toddlers (M-CHAT) is a screening tool administered to parents to assess risk of ASD. The children identified as at risk of having an ASD are then referred to pediatricians for further assessment. This will ensure that children are diagnosed early and can receive early intervention services. A number of studies suggest that children who undergo a few years of intervention make significant gains in their social, communication, and academic skills (McEachin, Smith, & Lovaas, 1993; Ozonoff, & Cathcart, 1998).

Since most interventions for children with ASD are provided in special education classes, there is a need for increased investment in the recruitment and training of teachers in this field. Although Zimbabwe has had an increasing enrollment of trainee teachers in institutions of higher education, such enrollment has perennially been limited for special needs education. Colleges offering such training can consider expanding curriculum or infusing training on inclusive education within general teacher education training. However, in the longer term, there still remains needs to focus on expanding exclusive training of special needs educators especially given the ever-increasing population of students with other types of disabilities.

Finally, more empirical research needs to be conducted regarding contextual factors interacting with provision and access of intervention services. As noted earlier, there has not been a lot of research regarding reported challenges of teaching students with ASD by both teachers and caregivers in both urban and rural areas. Understanding the challenges from the perspectives of individuals involved in direct care is important in order to get a true picture of what those factors are and how best they can be addressed given the prevailing circumstances. Other areas of research can also involve societal awareness and education of autism and capacity building for societal approach to addressing challenges faced by people with ASD.

### **Conclusion**

The lack of statistics regarding the population of people with ASD in Zimbabwe potentially implies the availability of many people with autism who do not receive any intervention services. Due to lack reliable and trustworthy diagnostic services, there is a possibility that some people do not receive the correct diagnosis regarding ASD. Diagnosis can be improved by training more healthcare workers (e.g. nurses) on assessment tools for diagnosing autism. The lack of intervention services and trained personnel in ASD limits the access of people with autism to the services that they need. Although there is an increasing availability of special education classes in Zimbabwean schools, most such classes lack the requisite resources as well as teachers that are adequately trained to deal with the skills deficits and behavioural challenges of children with autism. Since children with ASD exhibit some unique challenges both in educational or social settings, there is a need for teachers and personnel to be specially trained in applied behaviour analysis interventions that help to improve the skills needs of this population. The Zimbabwean government may need to consider investing in training of personnel in Applied Behaviour Analysis interventions in order to address the challenges faced by children with autism.

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