FINAL REPORT

on

AUTISM SPECTRUM DISORDERS BASE LINE SURVEY IN THE LUBOMBO REGION OF ESWATINI

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Contents

Acronyms

ASD	:	Autism Spectrum Disorder
WHO	:	World Health Organization
SDGs	:	Sustainable Development Goals
CSO	:	Central Statistics Office
UNICEF	:	United Nations Children Education Fund
ECCD	:	Early Childhood Care and Development
DPMO	:	Deputy Prime Minister’s Office
FGDs	:	Focus Group Discussions
RAs	:	Research Assistants
RHMs	:	Research Assistants
ESNDPA	:	Eswatini National Disability Plan of Action
UNFPA	:	United Nations Population Fund
KIs	:	Key Informant Interviews

Introduction and Rationale

The prevalence of autism spectrum disorder (ASD) is on the rise. The World Health Organization (WHO, 2019) statistics reflect that one in 160 children has an autism spectrum disorder while Mash and Wolfe (2005) reported that four in 10000 children has an autism spectrum disorder. The increase in prevalence could be attributed to the recent expansive definition assumed by ASD which is inclusive of a range of neuropsychological conditions with wide-ranging degrees of impairment. Autism Society of Alabama (ASA) (2016) defines ASD as a complex developmental disability characterized by deficits in communication, social interaction and repetitive patterns in specific behaviours. These deficits adversely affect people with autism's daily interaction with other people and their environment while simultaneously increasing their vulnerability to a wide range of life-threatening experiences.

It is worth noting that the effects of autism on individuals are not similar. Some people with ASD are able to live independently, while others require lifelong support due to severe disabilities brought about by ASD (WHO, 2019). This scenario underscores the spectrum nature of ASD, as implied by the name, due to the differences in characteristics and severity of symptoms for each individual with ASD as stated by Bishop (2012). As a result, each individual with ASD is unique, with different combinations of characteristics and differing severity of symptoms, hence there are people who are higher and those who are lower on the spectrum, as reflected in the figure below.

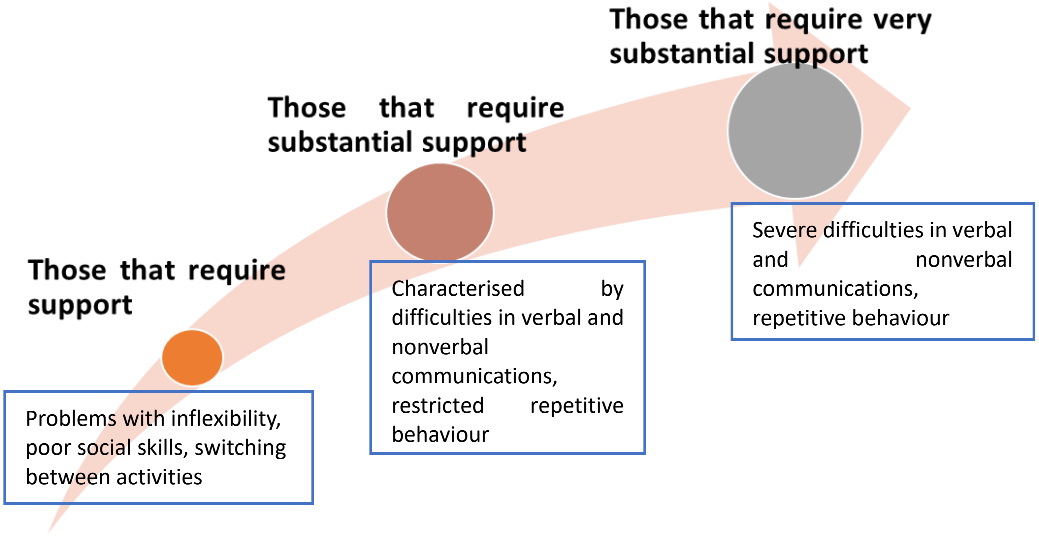

Figure 1: Autism Spectrum Disorder Categories

According to Bishop (2012), males are four times more frequently affected by ASD compared to females, while there is no difference in prevalence according to social class. The understanding of the causes of this sex differential of ASD frequency might be linked to the understanding of the specific cause of ASD which, however, is not one but multiple possible causes (Mash and Wolfe, 2005). These possible causes include biological neurological factors, genetic factors and environmental factors among others (WHO, 2019). The absence of a specific cause of ASD, the spectrum nature of the disorder, and the clustering nature of symptoms implies the need for specific tailored interventions to help improve the quality of life for people with ASD and their caregivers. Interventions should improve the lives of the most vulnerable populations, and, according to ESNDPA (2018) people affected by ASD are part of the most vulnerable population in a society.

As a form of disability, people with ASD also exist in Eswatini however the prevalence of the condition is not known, and neither are the life conditions and experiences of people with ASD and their caregivers known. In Eswatini people living with disability are estimated to comprise 16.8 percent of the national population, but the breakdown of these disabilities does not specifically spell out ASD (Mavundla, 2015). Despite the minimal data and information about people with ASD in the country, institutions, like schools and health facilities, are mainstreaming children with ASD. This practice presents a challenge for the institutions given that the service providers and the infrastructure are not adequately skilled adapted to cater to the needs of these children (Thwala, 2018). Sixty percent of children who visit the public hospitals in Eswatini are reported to be reflecting symptoms of autism, while the is no national documentation of autism in the country further states Thwala (2018). This scenario is typical of other African countries, and it is mainly due to the fact that the country is still at the awareness stage regarding autism programming.

Given the above scenario, it is extremely challenging for the country to provide the required care and support to people with ASD and their families to address the disability-related Sustainable Development Goals (SDGs). The Ministry of Health reported that it has provisions for providing ASD-related services and interventions, yet most health professionals are thought to face challenges in accurately diagnosing children with ASD. Furthermore, health facilities designated to provide ASD services to children with ASD are also reported not to be child friendly, and they lack vital equipment and skilled professionals required to serve the unique support needs of children with ASD.

The other multiplier effects of the absence of information on people with ASD in the country include inadequate human resources to provide appropriate care and support to people with ASD; exclusion from other basic services, including education; and generalized stigma of both the individual and the family. Taking into consideration that people with ASD reside in communities, there is also inadequate community level ASD-related intervention targeting people with ASD and their caregivers.

It is against this background that the country conducted a baseline survey of ASD in the Lubombo region. The Lubombo region contributes a quarter of the total number of people living with disabilities in the country and together with Shiselweni region[1], the Lubombo region has the worst national development indicators including the worst food security and employment rates[2]. The national disability policy prioritizes mainstreaming disability issues across all development

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[1] DPMO (2013).

[2] VAC (2018).

programmes of government as its main objective. In order to do this, the first step is the collection and analysis of accurate and relevant data[3]. In addition to facilitating the mainstreaming of disability, the output of the survey will also facilitate the improvement of the quality of life for people with ASD in the region and the country as a whole, which is a further objective of the national disability policy[4].

Study Conceptual Framework

The study utilized a conceptual framework to establish the baseline on people with ASD in the Lubombo region. The study addressed three main components which, when combined, depicted the overall status of ASD in the Lubombo region. These components are the: Social Environment; Physical and Institutional Environment; and Economic Environment. The different components are explained below.

Social environment

For this study, the social environment was limited to only individuals and families. As such the study looked at the knowledge, attitudes, practices, experiences and beliefs of people about ASD. It included surveying people with ASD and their caregivers, as well as surveying the general population. This study component facilitated the understanding of people's level of knowledge on ASD; the experiences of people with ASD in their families, schools and health facilities; the experiences of caregivers of people with ASD and the attitude of the general population towards people with ASD. The study of attitude towards people with ASD is very critical given that people without disabilities interact with people who have autism, and that the attitudes of the former determine their behaviour towards people with autism (Hanel and Shah, 2020; Cage, Monaco and Newell, 2018). In this component the study also explored the existing beliefs of the general population on ASD in relation to causes, treatments, prognosis and expectations.

Physical and Institutional Environment

In this study component, the institutions that provide health and education services to people with ASD were studied. These institutions were schools, ECCD centres and health facilities. They were studied in terms of the infrastructure, the policies and practices as related to providing services to people with ASD. The level of training and extent of experience of education and healthcare professionals in dealing with individuals with autism was also probed. Given that research has supported the idea that institutions' practices are influenced by the attitudes of the individuals in the institutions, attitudes were also assessed. For the people working in ECCD centres in particular, their attitudes and knowledge is critical in understanding the impact of early ASD interventions (Liu, 2016).

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[3] DPMO and UNICEF (2017).

[4] DPMO and UNICEF (2017).

Economic Environment

Research has supported the claim that people with disability are most likely to live in poverty. In fact, in Eswatini, 83.7 percent of people living with disabilities are reportedly economically inactive (DPMO and UNICEF 2017). Given that unemployment is a proxy indicator for poverty, the economic inactivity of people with disabilities can also be a poverty proxy indicator for people with disabilities. As such, the focus of this study will be on occupation, skills, education and income of people with ASD and their families and caregivers.

Study Objectives and Study Questions

The baseline survey is intended to obtain reliable and relevant data on the status of Autism Spectrum Disorder and its related indicators in the Lubombo region. The data will be utilized to inform programmatic interventions and policy formulation on ASD in the country.

Study Objectives

The specific objectives of the survey were to:

- Ascertain the level of Awareness and Knowledge about ASD in the Lubombo Region
- Assess the Accessibility of Basic Services by People with ASD *(suspected/confirmed)* in the Lubombo region

Study Questions

The main study question was to ascertain what the life situation, knowledge and conditions of people living with ASD and their families, including their caregivers, is in the Lubombo region of Eswatini. This main question was guided by a series of sub questions which included questions on the knowledge levels of ASD in the region, service utilization barriers, the experiences of families of people with ASD among others.

Methodology

Study Design

The study utilized a cross-sectional mixed-method survey design where qualitative and quantitative data were integrated. The data were collected from individuals residing in the Lubombo region, institutions working on ASD-related matters in the country, including schools, early childhood development centres and health care facilities, and households with people/children with ASD in the Lubombo region.

Sampling

Both probability and non-probability sampling techniques were utilized to select individuals and institutions that responded to the survey questionnaire. Stratified convenience sampling was used to select the general population living in Lubombo that participated in the study. A snowball sampling technique was used to identify and selected care givers of people with ASD in the region.

A statistical formula was utilized to determine the total number of respondents for each respondent category where probability sampling was used. The institution sampling margin of error was set at 10 percent, while that of the individuals was set at 5 percent. The confidence interval for sampling and analysis was set at 95 percent. In each of the selected institutions, purposive sampling was utilized to identify the specific respondent for the questionnaire.

Key informants from institutions working on issues of ASD were purposively selected with the assistance of Autism Eswatini, while convenience sampling was used for selecting individuals with ASD to participate in the study. The selection criteria for the latter were the ability of the individual to listen and respond to questions, and this was ascertained through engaging with the guardian and the person with ASD.

Data collection methodologies

Qualitative data was collected through Focus Group Discussions (FGDs) with care givers of people with ASD; and semi-structured key informant interviews. The quantitative data were collected through an electronic data collection system from the general population, teachers, health care providers, caregivers of people with ASD and people with ASD.

Data management and Analysis

The data management process for the study data was characterized by six main steps which were: Development of data dictionary; Development of data entry screen; Data entry; Data file backup procedure; Exportation of data; and Codebook development. The study data were analysed through STATA 16 and the qualitative data was analysed in NVIVO through the discourse analysis technique.

Ethical considerations

The study had no invasive and medical procedures. However, it adhered to the following ethical procedures: Informed all respondents on the study objectives; sought informed consent prior to data collection; ensured that all respondents were interviewed in a private space and that all respondents were treated with dignity; ensured that the rights of all respondents were respected during data collection; all Research Assistants adhered to a professional code of conduct; and clear message was communicated to respondents on the benefits associated with providing information for the study.

Limitations of the study

This study did not involve every household in the Lubombo region but only focused on households known by the Rural Health Motivators (RHMs) of the region to have an ASD case. Furthermore, households that were also identified through interacting with other households were not visited due to resource constraints, while also taking into account that knowledge of the term "autism" was limited across all population categories including the Rural Health Motivators and the general population. Hence, the identified households might be the worst-case scenarios. Other households with ASD cases might have been missed due to the limited understanding of ASD as a term. Furthermore, understanding of what autism is and what it is not, was found by the study to be unclear to many, health professional included. The lack of a common diagnostic framework, and a generalized limitation in understanding what autism is therefore complicated the findings of this study. As a result, the results of the study cannot be generalized to the whole region but their value is that they can be used as a starting point for understanding ASD in the region and the country as a whole. Additional unexpected value is found in the uncovering and description of the extent of the lack of understanding, lack of awareness and education, and lack of common diagnostic tools for identifying autism.

Findings

Introduction to Findings and description of approach

The findings are presented by the specific study objectives and their related sub-objectives. The implications of the results gained from application of these tools is explored in the discussion section, in line with the conceptual framework and as per the main study question and sub-questions. While the findings simply present the results of the surveys and interviews, the discussions present the results and implications through the economic environment; the institutional environment and the social environment.

Survey respondents

General Population

A total of 311 people participated in the survey which translates to 81 percent of the sample size. Females accounted for 76% of the respondents. The youngest was 19 years with the eldest respondent being 76 years. The average age of the respondents was 36 years and almost a third (30%) of the respondents reported to have never heard of autism. Women were more likely to have heard of autism than men, with 72% of women having heard of it versus 64% of men. The general population respondents were asked mainly on their knowledge, attitudes and myths related to ASD, and only those who had heard of it continued with the survey.

Knowledge on ASD

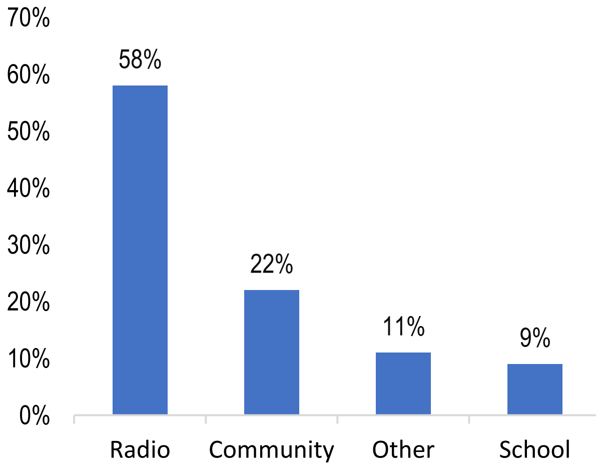

Figure 2: sources where respondents first heard of ASD.

The majority of respondents, 58 percent, said they first heard about autism via the radio. The other two main sources of autism awareness were from other community members (22%) and from schools (9%).

The general population showed a reasonably high ability to identify common autism symptoms and behaviours, as shown in the table below. Furthermore, more than half of the respondents agree that ASD cannot be cured.

Table 1: Statements of Symptoms respondents agreed with.

Key Symptoms of ASD	% in agreement
People with ASD are slow in doing things	91%
People with ASD are prone to straying	85%
People with ASD are easily upset by changes to routine	80%
People with ASD lack a sense of danger	77%
People with ASD sometimes display obsessive behavior	73%
Children with ASD do not play with others	68%
People with ASD sometimes cannot talk to others	68%
People with ASD can become upset by certain sounds	66%
People with ASD do not respond to their name	64%
People with ASD have unusual body movements	63%
Children with ASD do not show interest in other children	61%
Children with ASD do not enjoy playing	55%
People with ASD do not use eye contact	55%
Children with ASD do not grow physically	50%
People with ASD are unable to talk	46%

However, despite high ability of identifying ASD symptoms, beliefs about the causes of autism were very scattered.

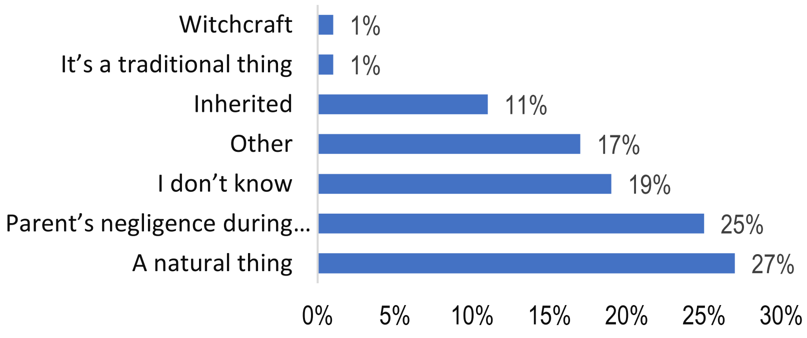

Figure 3: Respondents beliefs on causes of ASD.

Of the 17% of respondents who said that they thought autism was caused by "other" factors, most cited various stressful events and abuses of the mother during pregnancy, or neglect of the child at an early age, or likewise complications during birth of the child as the cause of autism.

A third of respondents said they thought that autism was preventable, but nearly half (48%) answered that they didn't think it was preventable. When asked if there was medication to treat autism, the answers were again scattered. Two in five (42%) agreed that there were no medications available to treat autism. But one quarter (24%) of respondents thought that there were medications available. A large proportion of the general public (33%) said they did not know if there were medications to help treat autism.

People’s attitudes on ASD

Attitudes about ASD were assessed by presenting the respondents with a statement, then offering a variety of responses along a Lickert scale (Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, Strongly Disagree). In general, attitudes about autism were quite scattered, and there was very little clear consensus or strong unanimous attitudes on most questions. Some exceptions, however, were on the emotional and financial implications of autism. 69% agreed or strongly agreed that people with autism were a financial burden, with another 61% agreeing or strongly agreeing that people with autism were an emotional burden. The full results are presented in the table.

Table 2: Linkert scale showing attitudes of respondents.

Attitude Statements	Strongly Agree (1)	Agree (2)	Neither (3)	Disagree (4)	Strongly Disagree (5)	Scale
Children with autism should be mainstreamed	12%	29%	4%	26%	13%	2.5
Mainstreaming children with autism with other children pose a safety risk to children without autism in the classroom	17%	37%	7%	30%	17%	3.2
I would be comfortable with having a friend with autism	23%	57%	4%	10%	6%	2.2
I would be uncomfortable hugging a person with autism	12%	37%	6%	32%	13%	2.9
A person with autism is an emotional burden	26%	35%	16%	21%	3%	2.4
I would be comfortable with sitting in the same room with a person with autism	20%	63%	2%	11%	4%	2.2
A person with autism is a financial burden to their family	28%	41%	11%	17%	2%	2.3
people with autism should not have children	26%	22%	10%	35%	8%	2.8
people with autism should be institutionalized/isolated for the safety of others.	9%	20%	7%	43%	21%	3.5
I would be comfortable with sitting next to a person with autism on a bus	21%	61%	1%	12%	4%	2.2
Students with autism are a distraction in class	24%	37%	11%	24%	4%	2.8
People with autism lack respect (Spoilt brats)	13%	21%	13%	32%	14%	2.9

In general, attitudes towards autism were not extreme on any particular front. With regards to education questions, the average attitude was that children with autism were a distraction in class (61% agreed or strongly agreed). On the question of whether children with ASD should be mainstreamed or not, the average attitude was neutral but it was tending slightly towards a feeling that children with ASD should not be mainstreamed, with the raw numbers showing that fifty-five percent did not think that children with autism should be mainstreamed. Likewise, while the average attitude was neutral on the statement that children with ASD pose a safety risk to other children, the average attitude fell on the tending slight agreement side. In fact, more than half (54%) agree that children with ASD posed a safety risk to the other children in the classroom.

A wide dispersion of opinions was found on the questions of whether children with ASD were spoiled and lack respect and also whether people with ASD should have children, but the more extreme feelings at both ends of the scale balanced out and so the average attitudes for both were neutral.

Sixty-five percent of respondents did not think that people with ASD should be institutionalized or isolated. Significantly, more than a quarter (28%) of respondents agreed or strongly agreed that people with autism should be isolated. However, just as significantly, a large proportion of respondents strongly disagreed with this (21%), and an additional 43% percent simply “disagreed” with isolation.

The vast majority of respondents, 83%, said they would be comfortable sitting in the same room as a person with autism, and 83% said the same about being on a bus with a person with autism. The attitudes about being in the same space as a person with autism were solidly that people feel comfortable with this. However, 50% said that they would be uncomfortable hugging a person with autism, indicating that while proximity to a person with autism does not appear to be a problem for most people, but physical touch is something that would make them uncomfortable.

General population: Beliefs about autism

Table 3: Respondents beliefs about ASD.

Beliefs Statements	Agree	Disagree	Don’t know
ASD happens in poor families	13%	85%	2%
Children with ASD need special education	79%	18%	2%
Children with ASD have intellectual disability	71%	23%	5%
Autism is a frowned-upon condition	72%	21%	6%
Autism is epilepsy	29%	57%	15%
Autism is preventable	30%	50%	21%
Autism is caused by parents’ negligence	50%	38%	12%
People with ASD need to be isolated	21%	77%	2%
Autism exists only in childhood	12%	78%	10%

CAREGIVERS

Of the 240 expected households reported by the RHMs to have at least one individual with ASD, only 2 percent did not have an ASD case in the home. The caregiver survey represented an investigation of the autism situation at a household level, but also, importantly, it probed the experiences of those who are working with ASD on a daily basis. These people are ideally situated to describe the various environments as they relate to autism, especially the social and economic environments.

A total of 201 caregivers who had heard of autism and were the primary caregiver for someone with ASD completed the survey. 91 percent of the caregivers were female, and the average age was 49 years. On average, each household had about 7 family members residing in the household, with an average total of 4 children per household. The average monthly household income was E874.00. The vast majority (88%) of the households that participated in the survey had only one person with ASD, while 10 percent of the households had two people with ASD and 2.5 percent of the households had 3 household members with ASD. In total, from the 209 households, there were 231 people with ASD. Sixty-nine percent of the people with ASD were under the age of 18 and 31% were adults, as shown in the figure below. A total of 74 percent of the people with ASD were of school going age (counted as 2 – 19), but less than half (46%) of those of school going age were actually in school.

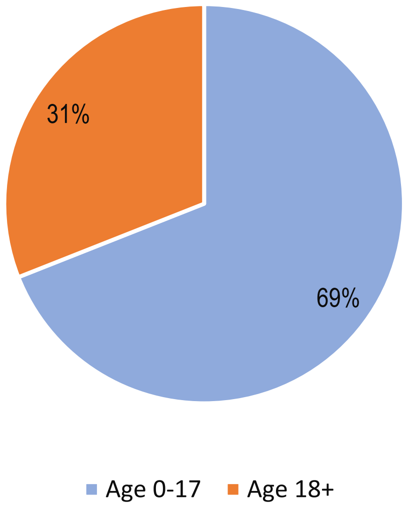

Figure 4: Age distribution for people with ASD.

Only half (50%) of the caregivers said the people with ASD in their care had been professionally diagnosed. The average age at diagnosis was lower for those professionally diagnosed compared those who were not diagnosed by professional health care workers, at 3 and 4 years of age respectively. The overall median age of diagnosis was at the age of 3 years old. Fifteen percent of people with ASD were on medication.

Comments on people with ASD received by their caregivers

Most caregivers (58%) reported receiving comments from other people about the people with ASD under their guardianship. The majority of these comments were negative, in fact, sixty-one percent of those who had received comments reported that the comments were of a negative nature. Most of the negative comments recalled were to call the person “crazy” or spoiled, or to say they were not well taken care of or not groomed well. A number of caregivers mentioned that others call the person with ASD names, or say they are mentally disabled, or point out that they are otherwise disabled.

Some examples of the neutral comments received mentioned that the child had grown, or they expressed worry about the individuals with ASD straying, or they consisted of advice to take the person to get help from traditionalists. One of the mixed comments received said “pity about a beautiful girl who can’t speak”. Only one in five (19%) reported that the comments were positive. Some of the positive comments recalled said that the child was good at looking after livestock, was respectful, “he is a good boy” or to say that “we care for your child” or to note that the child was loved.

Knowledge on ASD

Table 4: Caregivers: Symptoms of ASD

Key Symptoms of ASD statements	% in agreement
Children with ASD do not enjoy playing	92%
Interacts with toys and objects in one way	84%
Children with ASD do not show interest in other children	82%
People with ASD do not use eye contact	81%
People with ASD can become upset by certain sounds	81%
People with ASD don’t grow up physically	79%
People with ASD are prone to straying	75%
People with ASD do not respond to their name	73%
People with ASD have unusual body movements	71%
Children with ASD do not play with others	68%
People with ASD are hyper active	64%
People with ASD are unable to talk	61%
People with ASD lack a sense of danger	61%
People with ASD display obsessive behavior	60%
People with ASD are easily upset by changes to routine	58%
People with ASD sometimes cannot talk to others	54%
People with ASD are slow in doing things	39%

In addition to the above, caregivers for people with ASD also frequently stated that people with ASD only eats particular foods, or they limit the foods they eat, or they have a big appetite. The next most common cluster of symptoms noted was forgetfulness, poor concentration, and slow learning. Also noted several times by the caregivers was that the people with ASD in their care have a violent temper and are easily angered, and break things. A few were said to engage in self-harm, often by biting hands or their own lips and tongue. Three caregivers looking after 4 individuals with ASD specifically mentioned the people with ASD under their care are obsessed with fire, with two children having burnt down their homestead in the past and another one very nearly doing so, with the caregiver living in constant fear of the fire obsession.

About 10% of caregivers noted physical symptoms and immaturities. A lack of toilet training and requiring diapers long past the normal age was frequently mentioned. Additional physical symptoms cited, but only by a few caregivers, were inability to walk, “half the body works” said one comment, falling a lot, fits and epilepsy, and hearing impairments. Another common comment made by a few caregivers was that the children with ASD enjoy and prefer playing with much younger children than them. On the positive side, a few caregivers noted that the ASD individual laughed easily.

Etiology of Autism

When care givers were asked about the causes of ASD, their responses covered a variety of responses. The figure below presents the caregivers’ beliefs on what causes ASD.

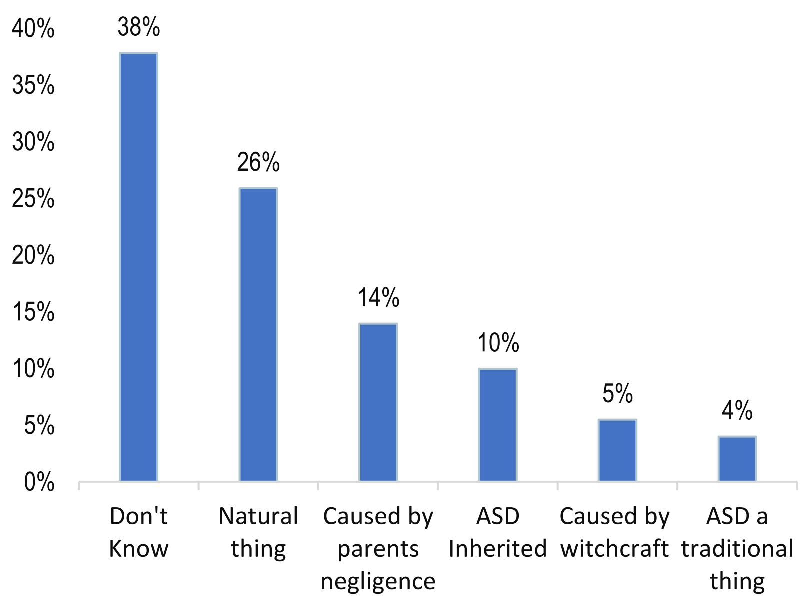

Figure 5: Caregivers: causes of ASD.

When further asked about the causes of ASD for those who said there were “other” causes, the majority of the answers mentioned abuse and stresses during pregnancy, a difficult labour, or very early childhood trauma of both emotional and physical types.

When asked about the services that are required by someone with ASD, a majority of the caregivers mentioned therapeutic services as reflected by the figure below. The majority of the services that were offered were reported by the caregivers to be provided at health facilities. In other words, where services are offered, they are typically available at health care facilities.

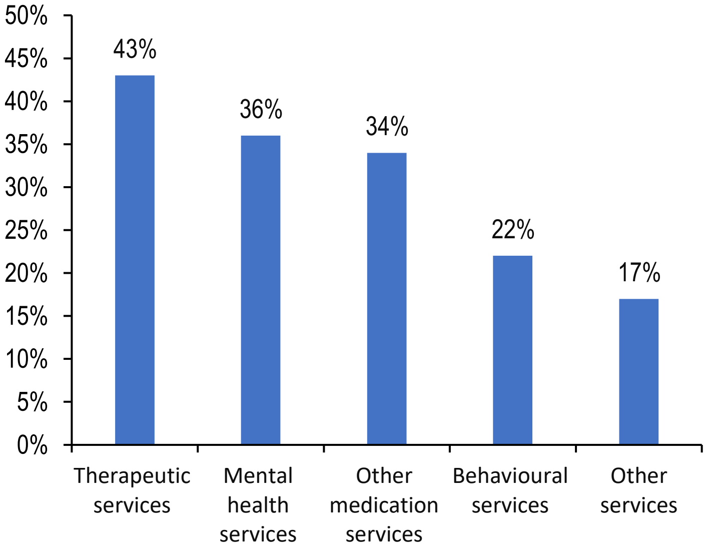

Figure 6: Caregivers: services required by person with ASD.

Caregivers went on to report that they cannot access the services they need due to different reasons which are listed below.

The overwhelming majority (92%) of those who were accessing services said services were friendly. This is to be interpreted as meaning that caregivers thought the attitudes of the service providers were friendly, not that the infrastructure or facilities or services on offer were friendly to people with ASD or other special needs.

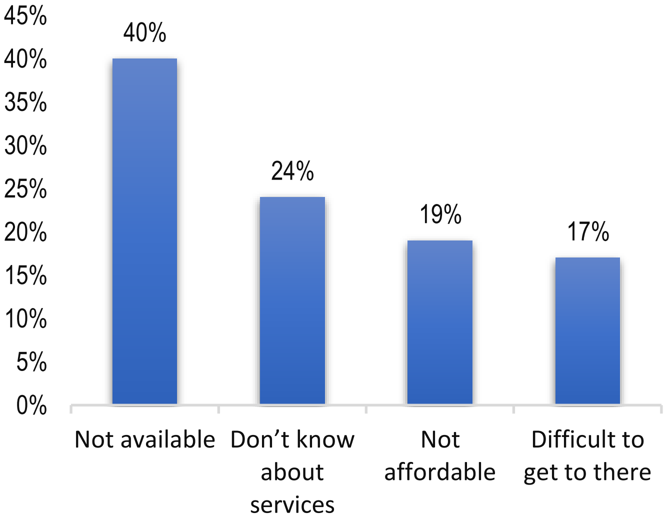

Figure 7: Caregivers: why services are not accessed.

On the matter of other supports, only 11% said they had other interventions in their community, most of these were in the form of education from NGOs, or food parcels. One individual specifically mentioned the existence of an ASD support group. Three other mentioned additional supports from government or Bucopho (a wheelchair was acquired).

Experiences of Violence by children or people with ASD

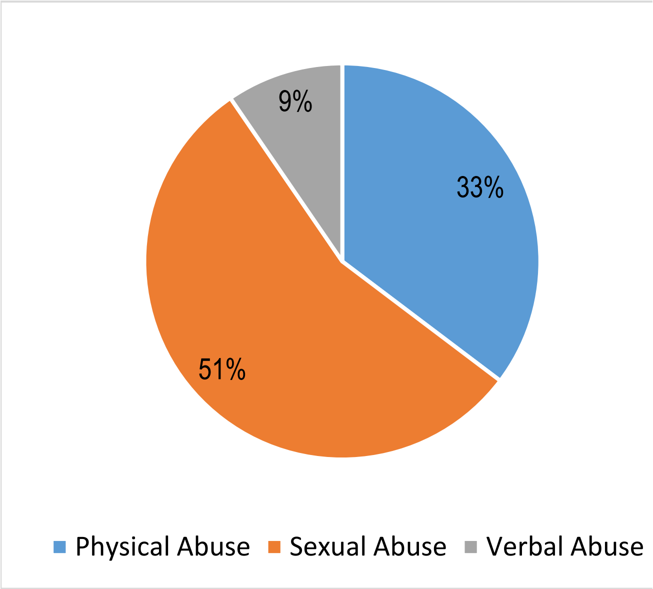

Figure 8: Caregivers: experience with abuse.

Different forms of violence experienced by children and people with ASD were asked from the caregivers. These forms of violence include; verbal violence; physical violence; sexual violence.

A total of 85 percent of the sexual abuse cases experienced by the people with ASD were reported to the police, and 15 percent of the cases were reported to the offender's family. Overall, 5 perpetrators (38% of all incidents) were reportedly punished for their sexual offences against people with ASD. Nearly a quarter of the sexual violence cases (23%) against people with ASD were reported to have "died a natural death" and only one sexual violence case against people with ASD is currently being worked. 1 case was discussed by families, 1 case saw the perpetrator not punished, and in 1 case the perpetrator fled to South Africa. There was no answer about what happened to the perpetrator from one of the 13 respondents.

The caregiver's experience

Caregivers were asked about what challenges they faced personally in their caregiving. Answers were coded and assigned into categories. By far the most frequent challenge cited was a lack of finances, mentioned by 22% of respondents. Most of these challenges specifically mentioned a lack of food, both in the context of poverty, and in the context of the specific food needs of people with autism. To a slightly lesser degree, a lack of clothing, and general poverty and lack of resources was frequently cited.

The second most common challenge was diet, which included not just picky eating, but also a lack of food. Diet issues were cited by 11% of respondents. The third most commonly mentioned challenge was the fact that the ASD individual needed full time care or a lot of attention, this was cited by one in ten. A few (1%) went on to say this impacted their ability to work for a living. Another one in ten (10%) said the biggest challenges revolved around medical issues. This included access to medical services, including transport to clinics, and it also included challenges due to acute or persistent illnesses, as well as problems accessing or taking medication.

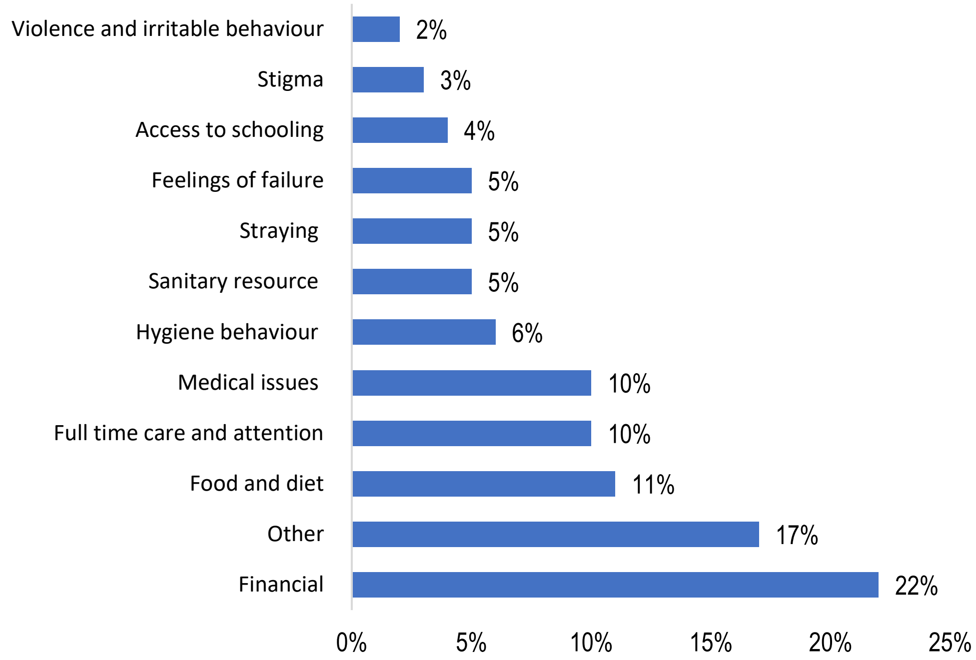

Figure 9: Challenges faced by caregivers.

Hygiene behaviour (6%) and sanitary resources (5%) were the next most common challenges. It was frequently mentioned that girls and women on their periods were particularly difficult to keep clean, partly due to poor hygiene behaviour, but also due to lack of menstrual materials. The lack of toilet training was an issue for a number of respondents, and often the problem was compounded by the fact that the ASD individual must wear diapers long past the age where diapers are usually worn, and diapers are expensive. Lack of toilet training was also cited as a reason keeping one child out of school. 5% mentioned straying as a big problem, while 4% said access to schooling was among their biggest challenge. Reasons for the child with autism not going to school further included the need for special education but this not being accessible, distance to schools, and a lack of birth certificates.

Frustration and personal feeling of failure (5%) Disobedience of the ASD (4%), stigma (3%), and violence or damaging things or irritable behaviour (2%) were the next most common challenges. 56% of caregivers agreed that it causes a lot of stress to have to care for an ASD individual.

School from the caregivers’ perspective

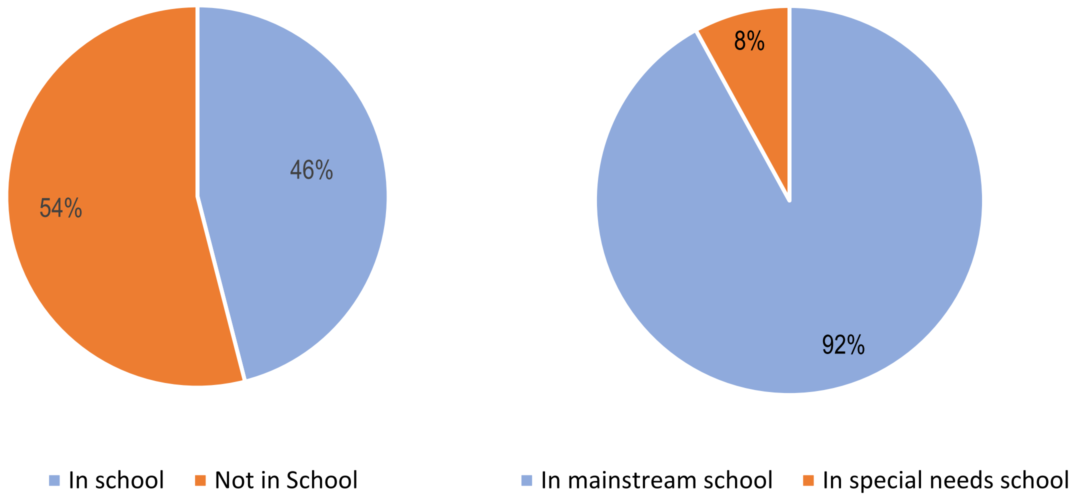

Figure 10: Caregivers: School going age persons with ASD and types of schooling they receive.

Of the 73 children in school, 85% of them travel there by foot. Two thirds (66%) were said to be performing poorly at school, but more than a quarter said the child’s performance is average (23%) or good (4%). 54% say comments from teachers are positive, while 24% say they get negative comments, or neutral comments (24%) from teachers. Caregivers expressed a positive degree of confidence in their child’s safety at school, and schools were on average rated safer than being in the community, or travelling to and from school.

THE INSTITUTIONS

A total of 110 institutions responded to the survey questions. Majority of these institutions were the primary schools from the Ubombo regions. Figure 3 presents the achievements of the survey from the targeted number of institutions by type of institution. Only 53% of the targeted health institutions were visited and 72 percent of the targeted high schools were reached as well. A total of 73 percent of the targeted Early Childhood Care and Development Centers (ECCD) were reached. This was mainly due to a closure of some of the ECCD institutions while 96 percent of the targeted primary schools were reached.

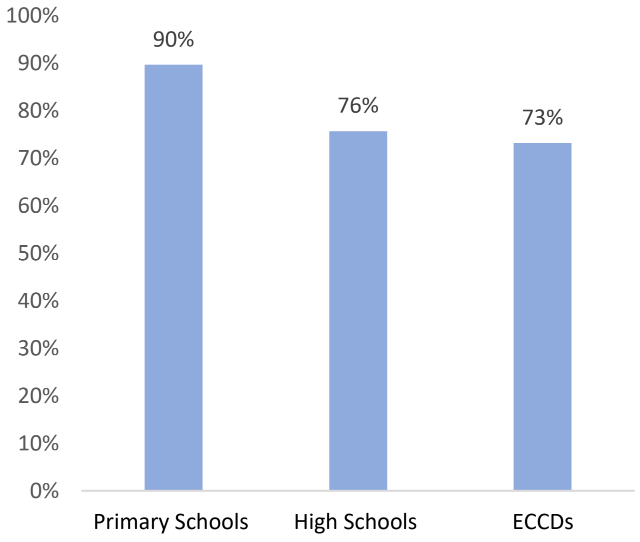

Figure 11: Institutions covered in the survey.

Health Facilities survey results

A total of 53 percent of the targeted health care professionals based at health institutions in the Lubombo region were interviewed. Three quarters (76%) were female and one quarter (24%) half were male. The median age was 39 years old. Only one, a male, had never heard of autism.

The brief demographics of the respondents show that 65% have university degrees, while 30% have a tertiary certificate or college diploma, and 6% have a high school diploma (completed high school). The mean average number of years working on the job was 7, but the range for this was high, with many respondents having fewer than five years' experience, distorted by a few respondents who had more than 20 years' experience. The bar graph below presents this distribution.

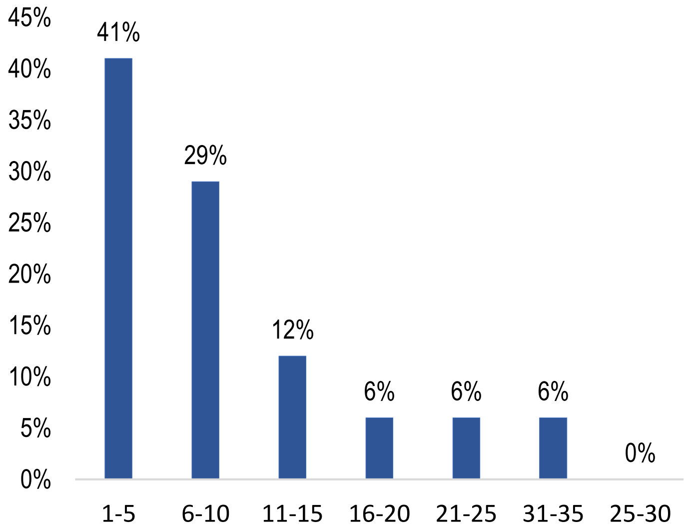

Figure 12: Experience working in health facilities in years.

Awareness and knowledge

Almost half of the respondents (47%) said they first heard about autism in an educational setting, while 29% said they first heard of it in a medical setting. Eighteen percent first heard of autism via the radio.

The average number of years' experience working specifically with autism was low, with a mean of only 4 years per health care respondent.

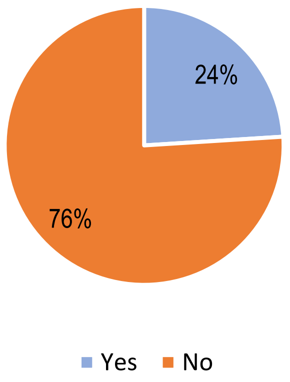

Figure 13: Health workers who have worked with people with ASD

Table 5: Healthcare workers: Knowledge on ASD.

Knowledge on ASD statements	Percentage in agreement
A child with autism does better with visual than auditory input	82%
Children with autism usually grow up to be adults with schizophrenia.	65%
Changing the diet of a child with autism will make a difference in their outcome	53%
Children with autism do not show social attachments, even to parents	47%
Autism occurs in less than 10% of the population	76%
Boys are most likely to have autism compared to girls	76%
Children with ASD have intellectual disability	47%
Autism is curable if diagnosed early and the appropriate intervention is provided	59%
Autism is a psychological problem	82%

Attitudes towards care and education

Attitudes towards autism and beliefs about rights to access services from health care professionals were assessed on a Lickert scale (Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, Strongly Disagree). This format allows for attitudes to be aggregated, so that a mean average attitude on each question can be ascertained.

Table 6: Table showing health worker attitudes towards autism service provision.

Attitude Statement	SA (1)	A (2)	N (3)	D (4)	SDA (5)	Lickert Scale	Outcome
All Health facilities need to have someone who can be able to provide services to people with disabilities including ASD.	82%	18%	0%	0%	0%	1.2	Strong agreement
Government funding should be made available to facilitate staff employment in health facilities to meet the needs of people with ASD	76%	24%	0%	0%	0%	1.2	Strong agreement
The MoH has done enough for ensuring access to services for people with ASD.	6%	0%	12%	35%	47%	4.2	Strong disagreement
The government should allocate more resources for the provision of services for children with special needs.	76%	24%	0%	0%	0%	1.2	Strong agreement
Parents are responsible for obtaining services for their own children with special needs.	12%	41%	12%	35%	0%	2.7	Neutral, tending agreement
I feel equipped to handle/provide services to children/ people with ASD	18%	18%	6%	18%	41%	3.5	Disagreement
I am interested in attending training in the area of providing services to people with ASD	82%	18%	0%	0%	0%	1.2	Strong agreement
If adequately trained, I am willing to provide services to people with ASD	88%	12%	0%	0%	0%	1.1	Strong agreement
I see the need to implement changes in the health facilities to ensure access to services for people with ASD	65%	35%	0%	0%	0%	1.3	Strong agreement
I want to make a difference in the service provision for people with ASD	82%	18%	0%	0%	0%	1.2	Strong agreement

Highlights from the respondents' answers on the attitudes assessments show that most staff have a very high willingness to provide a high level of service to people with autism. There was also unanimity on wanting to receive training on autism, which was probably partly driven by the general feeling of currently not being equipped: only 36 percent of respondents thought they were currently equipped to handle children and adults with ASD.

Likewise, all respondents agreed that government funding should be made available to facilitate employment of staff in health facilities to meet the needs of people with ASD, with 76percent feeling strongly that this should be the case. There was also agreement that the Ministry of Health (MOH) could be doing more to ensure people with autism had access to services.

The survey asked the health care professionals to identify what they thought were challenges for those with autism, as well as the gaps and needs in service provision. Two thirds (65%) said that stigma and discrimination are challenges, while another 25 percent say an absence of medications are a challenge. Half of the respondents (53%) identified additional challenges. Some of these are expressed in the table below:

Table 7: Additional challenges for people with ASD as identified by health care workers.

Facilities are usually busy and they need a lot of intervention which they don't get due to limited time constraints
Identification and provision of the necessary health needs not identified in time
Lack of trained people to help them with their needs. There are no local preschools that accommodate them
Parents hide their children due to lack of knowledge
Parents of children living with autism are alone no one has taken time to equip them about conditions of their children and their needs
The hospital isn't equipped to handle or identify them so it impossible to give the special treatment they deserve
They are not diagnosed on time
They cannot express clearly what their problem is
We may see them around the community, but they don't come to the facility

Likewise, the health care professionals were asked to identify the institutional shortcomings in providing services. The most frequently mentioned barrier to service provision was that staff were not trained in identifying autism, nor in medical problems that are common with autism, nor are they trained in dealing with ASD individuals. While some resource shortcomings were mentioned, such as specific rooms and lack of medical interventions, by far the most common shortcoming for institutions was the human capacity, namely, the appropriate and adequate training of staff.

Table 8: Health Care Centers Institutional challenges identified by health care workers.

"Staff is not well equipped in how to handle people with special needs
we do not have proper room to have counselling or do assessment"
Cannot interact with the child especially if they are deaf
Communication is a huge challenge because in most cases, they can't speak properly
Community is not aware about ASD we need to be sensitized
Hospital doesn't have speech therapist patients need to be referred to Mbabane and that is expensive
we also need to have reception that accommodates children with special needs
I'm not trained and I don't know where to refer clients
Lack of knowledge about ASD
Not knowing what to do
Provision of the services they need (lack of)
Stuff shortage, leading to take poor service delivery
There is no enough training or knowledge pertaining ASD hence the need of a refresher course
They may not understand or sometimes even speak to you as a service provider
We are adequately trained to provide services for special needs clients
We need a wellness program that is caring for the carers which include therapy, I need to offload and distress some of the issues I deal with
You cannot give the proper care and service needed by the person because they don't give attention too
inadequate training on ASD, could lead to misdiagnosis
not knowing how to handle or service them

The health care workers were asked about their beliefs on ASD. This was undertaken through a set of ASD-related questions with agree, disagree and don't know response options. The responses of the health care workers and their varying percentages are presented in the table below.

Table 9: Healthcare workers: Beliefs about autism

Belief Statements	Agree	Disagree	Don't know
ASD happens in poor families	0%	100%	0%
Children with ASD need special education	76%	24%	0%
Children with ASD have intellectual disability	47%	53%	0%
Autism is a frowned-upon condition	76%	12%	12%
Autism is epilepsy	12%	88%	0%
Autism is preventable	29%	35%	35%
Autism is caused by parents' negligence	18%	76%	6%
People with ASD need to be isolated	6%	94%	0%
Autism exists only in childhood	18%	76%	6%

Recommendations from healthcare professionals

The major needs that patients have, as identified by healthcare workers, are mostly for counselling and similar psychological supports, with a smaller minority mentioning the need for general medical services, physiotherapy and medications. Some mentioned the need for healthcare workers to be trained in ASD in order to be able diagnose. Additional innovative answers include the need for therapies such as behavioural intervention therapies, speech therapy, and artistic therapies. Although not specifically a health care need, some mentioned the need for general awareness of autism.

When asked for their recommendations, health care workers most frequently said that they themselves need to be trained on ASD. Correctly recognising and identifying the needs of people with ASD, and their families or caregivers was frequently mentioned as an existing gap in the system, and therefore a barrier to appropriate service provision. Some said that facilities need at least one person trained in this regard. There were several comments to the effect that appropriate referrals and referral networks could be strengthened if the primary healthcare staff were better trained on all aspects of autism. The health care workers also frequently mentioned the need for raising general awareness about ASD, with a dominating expectation being that if healthcare workers are trained, then they in turn can raise awareness and sensitize communities about ASD. Decentralizing services was also a recommendation.

Table 10: Selected healthcare workers recommendations.

Capacity building for facilities
Decentralization of services
Every clinic should have a Psyche Nurse, and every nurse be trained on taking care of people with ASD
Government should assist with under-staffed facilities, and all facilities need at least one trained person on the subject.
Have tickets or some form of identity for people with ASD for efficient assistance
Health workers and support staff needs to be sensitized and trained on ASD everyone needs to know about it.
MOH should have an initiative about ASD and implement a policy about ASD
Ensure an all-inclusive health care system
Proper training for clinic stuff on early childhood education and ASD.
Raise awareness on ASD for us as health care workers because we do not know anything about ASD.
Sensitization in community in order to understand then identify the need.

Educational Institutions survey results

The Institutions Survey asked educators at Early Childhood Care and Development Centers, primary schools, and high schools to respond to 60 questions about their experiences with children with autism in educational settings. This survey looked at the levels of knowledge about autism of the education providers. It further assessed the general understanding of these institution about the inclusive education standards of the country. On the social environment, the survey assessed the attitudes towards provision of services for Children with ASD and went further to probe personal beliefs about autism. On the institutional environment, it looked at the interest levels, and their perceived efficacy. Several open-ended questions also formed part of this survey, and these were necessary in order to provide the educators with the opportunity to speak freely about their personal experiences in case the closed survey questions did not anticipate these experiences.

ASD awareness and Knowledge

The demographics show that 76 percent of respondents were female. 40 percent held a bachelor's degree or master's degree, and 44% had a college diploma. The median number of years of experience in an educational setting was 8 years, and the mean was 10 years, indicating that these are generally quite experienced teachers who took part in this survey. A quarter (24%) had more than 15 years teaching experience. The vast majority (76%) indicated that they had worked with special needs children, with half having 1-2 years of this experience, and 24 percent with 5 years' or more experience, and 13% having 8 years or more experience in working with special needs children. Significantly, every single educator approached for an interview had heard of autism.

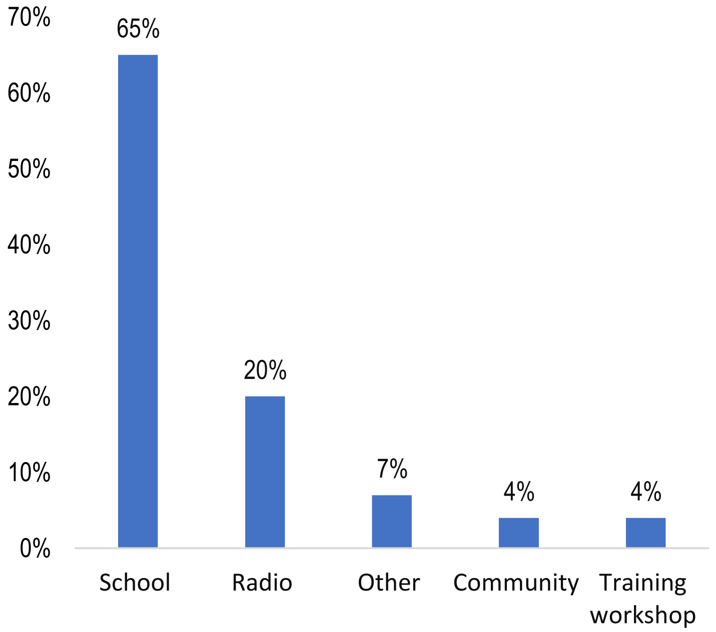

Figure 14: Sources of information where educators first heard of ASD.

The majority (65%) said they first heard of autism at school. Radio was the next most common source where the respondents first heard of autism (20%) as presented in the figure below.

The educators were asked about their knowledge levels on ASD. This was undertaken through a set of ASD-related questions with a true and false response. The responses of the educators and their varying percentages are presented in the table below.

Table 11: Educators: ASD knowledge

Educators: ASD knowledge	% in agreement
Children with ASD are better visual learners than auditory learners	84%
Autism is a psychological problem	76%
With proper treatment, most children with autism outgrow autism	73%
Autism is curable if diagnosed early and appropriate interventions provided	69%
Children with ASD have intellectual disability	73%
Boys are more likely to have autism compared to girls	67%
Autism occurs in less than 10% of the population	71%
Children with ASD become schizophrenic adults	65%
Changing the diet of a child with ASD makes a difference in outcome	62%
Children with ASD do not show social attachments, even to parents	58%

Attitudes towards provision of education services for children with ASD

There was a consensus among educators on some of the actions that needs to be implemented regarding the education of children with ASD. There was strong agreement among the interviewed educators that government should increase funds to cater for children with ASD in schools; that all preschools need to have special education teachers and therapists; and that more resources should be allocated by government to cater for needs of children with ASD.

Table 12: Linkert scale table on attitudes towards provision of education for children with ASD.

	SA (1)	A (2)	N (3)	D (4)	SDA (5)	Linkert Scale	Result
Government funding should be made available to facilitate staff employment in preschools to meet the needs of these children.	80%	20%	0%	0%	0%	1.2	Strong agreement
All preschools should have special education teachers and therapists to provide services to children with special needs attending class there.	65%	31%	0%	2%	2%	1.4	Strong agreement
The government should allocate more resources for the provision of services for children with special needs.	71%	27%	0%	0%	2%	1.4	Strong agreement
All schools and preschools should allow children requiring special education to attend their classes while waiting placement	31%	47%	4%	15%	4%	2.1	Agreement
Children with special needs should be integrated into mainstream school	35%	33%	5%	22%	5%	2.3	Agreement
Parents are responsible for obtaining services for their own children with special needs.	11%	36%	9%	40%	4%	2.9	Neutral
Parents should help bear the cost of services within the preschool.	16%	22%	11%	40%	11%	3.1	Neutral
Preschools should allow parents of children with special needs in the classroom	15%	27%	4%	36%	18%	3.2	Neutral
There is adequate provision of services of children with special needs in schools and preschools in Eswatini	0%	5%	0%	44%	51%	4.4	Strong disagreement

The average attitude was neutral regarding parents' responsibility for ensuring that their children with special needs have access to services; parents to bear the costs of special needs services at preschool level; and it was neutral when it came to the question of whether preschools should allow the parents of children with ASD inside the classrooms.

The educators disagreed with the statement that there is adequate provision of services to children with special needs in the education sector of Eswatini.

Perceived efficacy and Belief about ASD among the educators

The educators were asked about their abilities and willingness to educate children with ASD. The educators reported very high levels of willingness and interest in educating children with ASD, and also in themselves being further trained.

However, there was ambivalence about feeling equipped to handle children with special needs, and also about having "therapists or parents" present in classes to assist. For the latter, it could be that the teachers are in favour of having qualified professionals to assist, but not in favour of having unqualified and possibly judgmental and untrained parents present. The results of some of the qualitative answers seem to indicate that this is the case, however, the quantitative survey question did not make this distinction between qualified professionals and unqualified parents, hence a possible reason for the average attitude being one of ambivalence.

Table 13: Linkert scale table on efficacy among educators.

	SA (1)	A (2)	N(3)	D(4)	SDA (5)	Scale
I feel equipped to handle children with special needs	13%	33%	9%	36%	9%	3.0
I am interested in attending training in the area of childhood developmental and behavioral disorders.	69%	27%	2%	2%	0%	1.4
If adequately trained, I am willing to have children with special needs in my class.	67%	33%	0%	0%	0%	1.3
I am keen to be a partner in the classroom management of children with special needs	44%	56%	0%	0%	0%	1.6
I am happy to have parents or therapists sit in as helpers	20%	38%	2%	31%	9%	2.7
I see the need to implement changes in the classroom to accommodate a child with special needs.	44%	51%	0%	5%	0%	1.7
I want to make a difference in the education of children with special needs	60%	40%	0%	0%	0%	1.4

Experiences and challenges of children with ASD

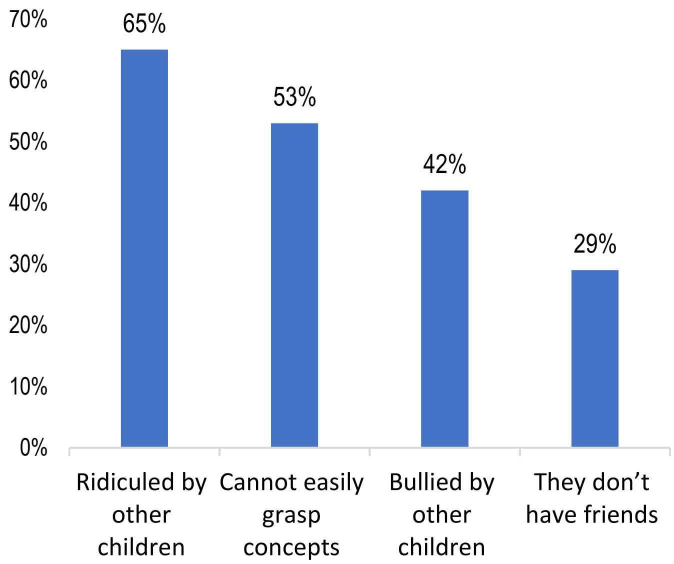

Figure 15: Educators: challenges of children with ASD.

When asked what challenges Children with ASD in the school experience, the responses presented in Figure 15 were provided.

Additional challenges cited by the respondents include a lack of facilities or learning materials, and failure of others (including teachers) to be sympathetic and understanding about ASD. Other challenges mentioned were teachers having a bad attitude and calling the Children with ASD names (general stigmatization), parents not welcoming advice on their children, and ASD individuals not feeling comfortable being around other children. Some comments also mentioned that Children with ASD were sometimes left out both socially and academically.

Experiences and challenges of teachers in teaching children with ASD

Educators were asked to provide a short word describing their experience with Children with ASD. The answers were assigned a positive, neutral, mixed, or negative rating. Thirty seven percent of the respondents from the education sector reported an overall negative experience in teaching children with ASD. Nearly half (47%) described their experience as mixed or neutral, while 16% reported an overall positive experience.

When the educators who mentioned they have negative experiences with teaching children with ASD were asked about the negative experiences, the main source of the negative experiences was mainly the attention required by the children with ASD and the pace of the student in grasping some concepts in class as compared to the other students. A significant proportion of the educators also highlighted that the behaviour of the child with ASD was also the source of the negative experience. To note though was that only 13 percent of the educators reported that their own lack of skills for teaching children with ASD was the main cause of the biggest challenges they face in the classroom.

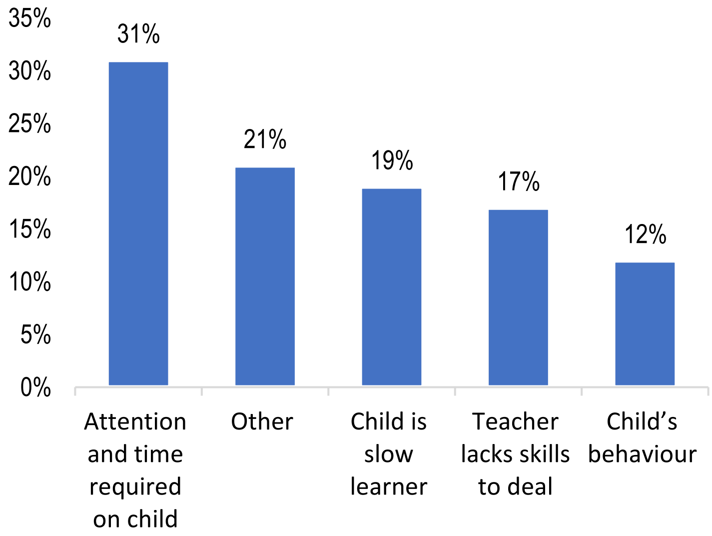

Figure 16: Educators: challenges in teaching children with ASD.

Of the "other" category, the lack of materials and communication problems with the ASD child were the most mentioned challenges. Also of significance was that teachers frequently said they lacked the skills to identify autism (this was coded as "teacher lacks skills to deal").

Providing clarity on their experiences of teaching children with ASD, educators included the phrases presented in the table below.

Table 14: One word sum up of educators' experiences in working with children with ASD.

Words defining educators' experiences of teaching children with ASD
Challenging
Amazing
Tough
Hectic
Handful
Great
Good
Strenuous
Difficult
Tough
Educational
Frustrating
Taxing
Tricky

The negative experiences of educators teaching children with ASD emanated from the reasons stated in the table below.

Table 15: Challenges Faced by Teachers of people with ASD

Challenges faced by the teachers
He couldn't stay in one place for long period of time
Want attention where else you are faced with other 40 children in the class room
Lomunye umtfwana ufundza at a lower level yet sokhululile so ukhandza kutsi bayamhleka and sokhandza kutsi uyabashaya sekuba nabo bullying
You need to repeat yourself over and over again
Lack social interaction
I can't finish work on time and attend to other kids because I have to take extra care on the child
We can't interact and she doesn’t want change or noise she easily gets agitated
Sometimes she acts like a child who disrespect, she talks anyhow
Lacking Knowledge
They are very slow when writing which then eats up time for the others
I have to take them to toilet if need be, spend most of my time on that particular child than the entire class
They don't concentrate and they need more attention yet the groups we have are large
Need extra attention need to be patient: Administration does not help us much with such cases visual aids
I didn't have the material to help her
They need constant assistance so you need another teacher to work hand in hand
At times you do not know how to handle the child especially when you don't have the know how
The pace of learners is not the same they cannot progress at the same rate as other children so that delays me
Sometimes, they get hyperactive and end up disturbing the class
Have to devise special programme so as to get desired results
It is frustrating to see that the child is struggling and have no way to help

Knowledge of Inclusive education standards

The majority of the educators (76%) stated that they believe their school is an inclusive school. Where educators said their schools were not inclusive, the main reasons for this were the lack of infrastructure to accommodate special needs (62%), followed by a lack of teacher training on special needs (46%).

When asked about the standards of inclusive education, not all educators were aware of the standards, and among those that were aware, none of them knew all the standards. The figure below presents the percentages of educators who were aware of each of the specific inclusive education standards.

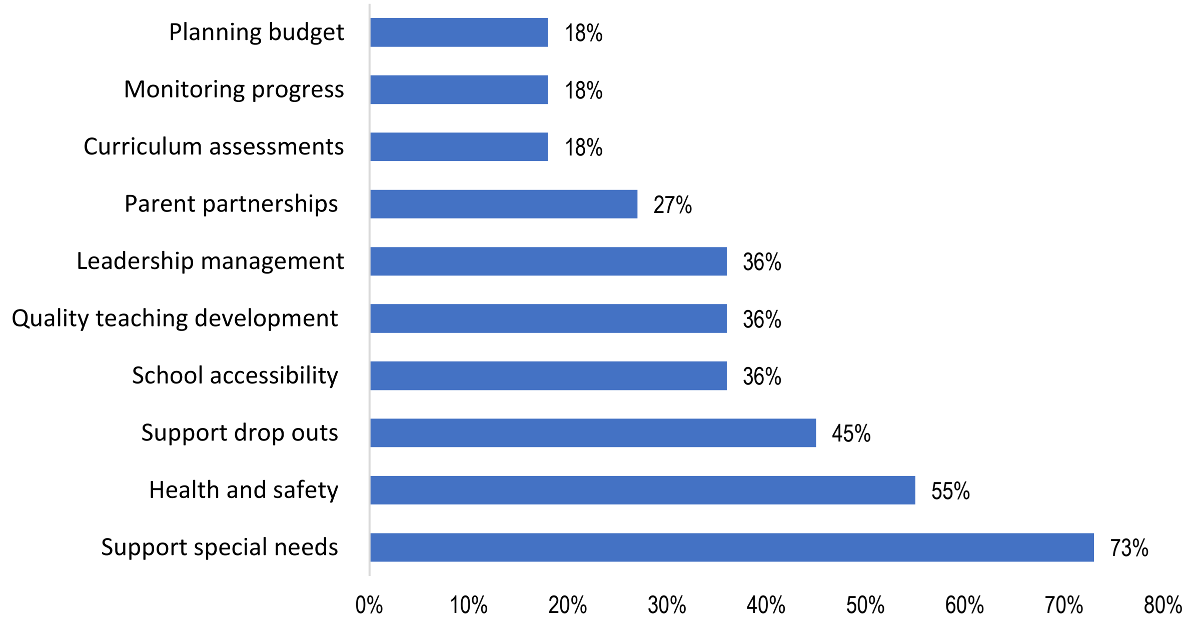

Figure 17: Educators' awareness on inclusive education standards.

Educators: Beliefs about autism

When asked what could be done to improve the situation in education with regards to accommodating and supporting both the children with ASD and the teachers, a large proportion of the responses were recommendations to train teachers. The specific kind of training desired was to be better equipped with skills to deal with the children who have ASD, but also to better understand the condition, and importantly, training to be able to recognize it in the first place. A number of teachers indicated that knowing a child had ASD earlier rather than later was key to their effectiveness in managing the classroom.

Table 16: **Educators: Beliefs about autism**

Belief statement	Agree	Disagree	Don't know
ASD happens in poor families	7%	91%	2%
Children with ASD need special education	91%	9%	0%
Children with ASD have intellectual disability	67%	27%	5%
Autism is a frowned-upon condition	82%	11%	7%
Autism is epilepsy	7%	80%	13%
Autism is preventable	15%	60%	25%
Autism is caused by parents' negligence	20%	69%	11%
People with ASD need to be isolated	2%	98%	0%
Autism exists only in childhood	7%	85%	7%

The next most common suggestion from the educators was to raise awareness in general about autism, and in so doing address stigma. Twenty percent recommended that there be more investment in infrastructure, facilities and resources to deal with special needs children. Fifteen percent recommended specially trained teachers or having teaching assistants in the classroom to help teachers cope. Significantly, 11% of the recommendations were to educate and train parents on autism.

Individuals with ASD survey results

The survey-based interview with individuals with autism was necessarily short, consisting of only 15 questions. There was a wide range of engagement encountered, with some individuals clearly understanding and quickly responding to the questions, while others had difficulty responding, or they repeated stories and answers.

The gender distribution was weighted slightly towards more females (52%). The age range ran from the youngest at 11 years old, to the oldest at 67 years old. The average age was 25.

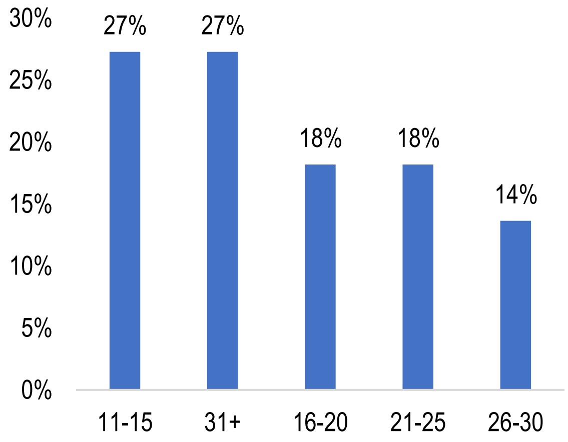

Figure 18: Distribution of ages of people with ASD.

43percent of the respondents were able to answer the question “at what age were you diagnosed with autism”? The youngest age of diagnosis given was 1 year old, while the oldest was 13. The median age was an autism diagnosis at 5 years old. When asked who had given the diagnosis, 35percent were unable to say whom. 26percent said they were diagnosed by a health professional, and 30% said they were diagnosed by their parents.

Education demographics

Fewer than half the number of respondents (39%) were of school-going age (19 and younger). Of the school-going age group, 66percent said they were in school, meaning that 33percent of school-going aged people with autism in this survey were not in school. Of all respondents, 17percent said they had never been to school. One said they had gained a primary certificate, while the vast majority (87%) said their education level was at Grade 6 or below.

Emotional experiences

Several questions in this survey probed the lived experience of people with ASD. This was done in order to understand how ASD individuals view their own lives, and their general emotional outlook. In general, the responses received to this portion of the survey were mostly on the positive side. When asked if they feel they have enough support to live their lives, 87 percent responded affirmatively. More than half (57%) agreed that they were able to be themselves around other people, while only 35 percent said they felt they could not be themselves around others. Slightly more than half (52%) said they had friends, while 48percent said they did not have friends.

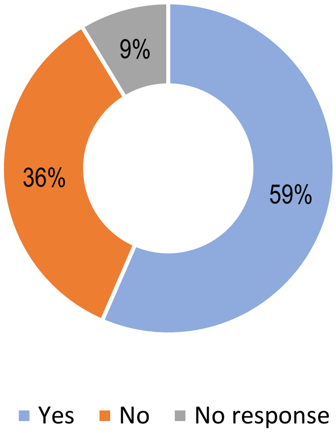

Figure 19: Individual with ASD's ability to be themselves around other people.

Safety and abuse

When asked if they feel safe at school and in the community, more than two thirds (70%) said that they did, although 17 percent said they did not. Those who said they did not feel safe were asked what they were scared of. About half were able to reply to this, saying they are scared of being kidnapped, or that they are scared and feel they need their mother near them at all times.

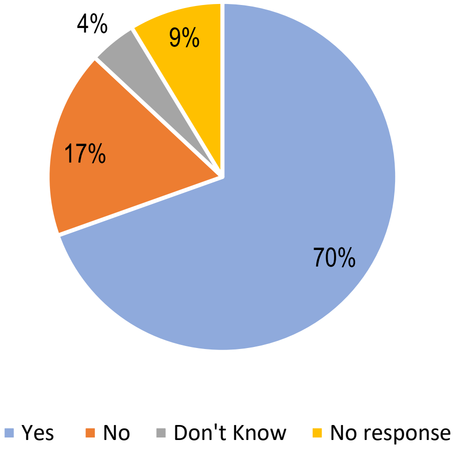

Figure 20: Individuals with ASD: Whether they feel safe.

When asked about whether they had ever been treated in a way that upset them ("Has someone ever done something to you that you did not like?") 30percent responded that they had experienced this. 11percent specifically mentioned incidents of violence (being stoned, being beaten), while 6percent mentioned verbal emotional abuse (the use of discriminatory words). 6percent also mentioned not being provided with "bread and meat". Slightly more than half (52%) said they had been tested for HIV. One individual volunteered that they had HIV and not ASD.

Perceived needs and shortcomings

In terms of services from health facilities, 78 percent of respondents said they were able to obtain the services they need. When probed about what services are needed, the most common response was that some form of medication was needed, cited by a third of respondents. Others said they needed to be treated when sick or when they have flu. One mentioned needing vaccination for her child, and another said she needed treatment for menstrual pains.

The respondents were given an opportunity to express what needs they had that are not always being met. The answers received were varied, but the majority of the responses received related to medical needs. About two thirds of the respondents provided an answer to the question, of those two thirds, 38 percent mentioned medical requirements such as the need for medication, medical supplies. Transports to hospital was also cited as a need, as was money and clothes. 17 percent said they needed food. Nine percent said they needed business support.

Table 17: Individuals with ASD: Needs.

Perceived Needs for people with ASD by people with ASD	Unmet needs for people with ASD by people with ASD
Food	Transport to go to the hospital
To be treated for menstrual pains	Tablets/ pills
To get injection	Food
When I have flu	Tablets
Pills	Money
supply of medication on time	Adequate medical supply
Vaccination for my baby	To be healed
Medication	Business (self-employment)
to get proper medication from the hospital	Food and clothes
Medication when sick	Business support
Cards	Injection
Physiotherapy	

Qualitative Findings

These findings were derived from the FGDs with the caregivers of people with ASD and the key informant drawn from institutions reported to be working on ASD related issues in the country. These qualitative findings also support the quantitative survey findings. As such the qualitative aspect of the study allowed for issues to be probed in greater depth, to yield a more comprehensive understanding of the problems, needs and emotional demands brought about by ASD. Critical to note here is that through some referrals from some parents and other stakeholders the study identified an organization that has been working on ASD related issues in the country for the past 13 years whose views are also incorporated in the findings.

Language and terminology

The researchers noted that there is some cultural unease around use of the very word “autism”. People tended to avoid using the word at all, preferring to use different terms or euphemisms.

Autism Eswatini confirmed the general unease, advising that “in Eswatini it is very offensive for the parents to call their children autistic, even worse is calling them ‘autistics’. Further advice from AE was to avoid using the terms “non-autistic” and “an ASD”. The preferred manner was to say “a person with ASD” or “a person with autism” in cases where the word “autism or autistic” is to be used.

Through the FGDs and KIIs it also became evident that there are additional problems with language use and the characterization of autism, and of ASD treatment therapies, as they relate to mental health. The following terminologies, while all interconnected and oftentimes difficult to separate from one another, are nevertheless all loaded with their own associations depending on the professional or context, or even the international context in which they are used: mental disorder; psychological disorder; developmental disorder/delay; psycho-social support; counselling; mental health; mental illness; psychological condition; psychological help; behavioural interventions; behavioural therapy; social support; therapy.

It would be prudent to engage various organizations working with people with ASD (Health, NGOs, Education, government and the academic sector) to develop a common understanding about how each one of these terms relate to autism and what they mean in autism in Eswatini context. This common language is essential not only to avoid unintended offence, but to improve communication and messaging between those working to improve the lives of people with autism. Additionally, having common accepted and agreed-upon language terms is important when it comes to education of the general public about autism. Widely accepted and consistently used terms that the public can be educated to use will play a critical role in addressing stigma and the verbal abuse that exists around autism.

Knowledge of ASD

The engagement with FGD participants and the Key informants on the knowledge on ASD reflected that in as much as there are commonalities on the knowledge of ASD symptoms among the respondents, contradictions were also observed. These contradictions mainly involved the physical manifestations of autism, and the understanding of autism as it relates to psychology.

Contradictions on understanding of ASD

Amongst all respondents, in both the caregiver FGDs and the institutional KIIS, there was a lack of common agreement and understanding on the physical symptoms of autism or indeed whether autism even has obvious physical symptoms. There was a general lack of consensus across all surveys and interviews on the degree to which autism is understood as psychological, the degree to which it is understood as emotional, and the degree to which it is understood as having physical and physique manifestations.

In the institutional interviews some were of the view that one of the key symptoms is the physical structure of the individual. In fact, this was a view that was also commonly but not universally expressed in the survey answers from the general population and the caregivers. For example, in one of the institutional interviews, a respondent stated that in people with autism their heads are not proportional to their bodies, while on the opposite side some respondents argued that symptoms of ASD do not involve physical appearance of the individual. One of the key informants stated that:

"Then another notable thing is their appearance, at times even if that person is chubby, you find that the head is so tiny. Eehh! … they are quite a lot I can't exhaust them" - Key informant respondent.

While another respondent stated that:
"…because it has nothing to do with persons physique. In some instances, it varies with the degrees of the conditions. In some cases, it is mild and is able to go to school, but is a slow learner" - Key informant respondent.

Among the FGD respondents some of the participants also mentioned that physical features of an individual can help you see whether someone has ASD. To this effect, one FGD participant when asked about the symptoms of ASD stated that:
"I am not sure but I once asked someone that how does you see a person with autism? He said their eyes are different, they are like this (Making gestures) they are like Chinese eyes" - FGD participant.

But in contradiction to this, a key informant stated that:

"Basically, autism leans towards mental illness more than the physical aspect" - Key informant respondent.

Another pointed out the lack of physical visibility of autism:

"It's basically a mental disability and bare it in mind that it's a spectrum… [T]here is a need… to acknowledge the fact that not all disabilities are visible" - Key informant respondent.

An FGD respondent agreed that autism " *is a disability that cannot be seen by naked eyes"* - FGD participant.

A different FGD participant noted that there was a general view about autism being physical and emotional- "*they mix it with physical and emotional disability"* - FGD participant.

Commonalities on understanding of ASD
Despite the contradictions, in general the symptoms of ASD were common among the survey key informants. One of the areas of commonality was that people with ASD have poor communication and social skills while they also have repetitive behaviours. To this effect one respondent stated that:
"…yes, you cannot generalize it, but then there are those symptoms that are core such as poor communication, poor social skills and repetitive behaviors" - Key informant respondent.

While other respondents stated that:

"…ok, actually they are very varied, it's quite a lot of them but then we are guided by a criteria called the diagnostic criteria which is poor communication skills, poor social skills and in addition to that they may have stereotype behaviors or repetitive behaviors. So, it's called ASD because

within the spectrum, there's varied symptoms so one individual may not be similar to another" - Key informant Interview respondent.

Among the FGD participants there were also some that stated the issues of behaviours and communication as the key symptoms of ASD. One of the FGD participants said:

"I know those who take time to respond when talking to them (utfuka lite). Some it's like they are far away with thoughts, you see by their reaction when talking to them, they want you to say one and the same thing for a long time and its where they pickup" - FGD participant.

Bias towards health needs as main needs of people with ASD

There was consensus among the key informants on the needs of people with ASD. In fact, this can be summarised by stating that their needs are not as different from other people, namely they need to be able to access services like health, therapies and education, as well as normal social services like access to birth certificates. However, the identification of these needs was biased towards health needs with the claim that meeting the health needs will automatically address or assist in meet the other needs. This was stated by some of the respondents with one specifically stating that:

"It's more into health my brother, the others follow and in fact we cannot begin to discuss other needs without addressing the health needs of people with ASD. In order for a person to be more productive, that person must be in good health. So yes, economically you can't expect a person who is not healthy to be economically active. Address the health needs first and all the other needs will be synchronized" - Key informant interview.

Echoing the above response, another respondent singled out "mental health" as the key health need for people with ASD. The respondent specifically stated that:

"First, it's the mental health, the children need to be identified in the earliest possible stage for a prompt response to reduce the harshness of the condition… The other needs such as social and economically, I can't address, I insist on the health needs." - Key informant respondent.

The main reasons for not meeting the needs of people with ASD was stated by the respondents a lack of awareness on the needs and existing treatments (such as speech therapy), and the unavailability of services in other parts of the country and such services only being available in the Manzini and Mbabane corridor.

However, these responses in favour of the broad category of "health" can also be interpreted to mean that medical fundamentals must first be in place before support services can kick in, and such medical fundamentals include the proper, early and correct diagnosis of autism. Correct and early diagnosis is a critical part of health needs.

On these lines, one key informant gave an eloquent and insightful answer when asked "what are the nerve centres of ASD programming and why?" she stated that:

"It goes back to the medical aspect, if the individual is diagnosed, then he/she must receive the necessary assistance timeously. The assistance can be medical, therapeutic and what not. So, I strongly believe in the medical model and that it has to be intensified and must come on top of all other programs" - Key informant.

Lack of awareness on the needs as the main reason for not meeting needs

Respondents argued that one of the key reasons the needs of people with ASD are not met was because people and institutions as well as family members were not aware of the needs of people with ASD. To this effect one respondent stated that:

"One thing I can tell you is that such failure to meet their needs is not deliberate but is as a result of lack of awareness. Nobody will want to do this on purpose. This is a worldwide crisis not only in our country. The numbers are rising and you know we all have autism including yourself" - Key informant respondent.

Echoing the above respondent is another respondent who stated that:

"…so, the most affected are those that are around that person and so as an institution we are relying on them to bring the ones with ASD to the hospital unfortunately they are not psychologically prepared to do so, or maybe because of financial barriers, so we need to treat the whole family here…" - Key informant interview respondent.

The salient points being made by these two respondents is that autism is a disorder that affects not just individuals, but the caregivers, family, and communities that people with ASD are a part of. As such, all have a role to play in understanding what autism is, how to recognise it, and how to accommodate people with autism and those who are caregivers.

With reference to the health sector, one respondent also highlighted the issue of lack of awareness on the needs of people with ASD as the main reasons health needs are not met. The respondent stated that:

"…So we need to create a lot of awareness in our health care sector so that they are aware of the ASD symptoms…" Key informant interview respondent.

Lack of societal awareness and sensitization

Participants in both the key informant interviews and the focus group discussions uniformly emphasized the importance of raising awareness about autism across the board. This is seen as key to reducing stigma and abuse, and there were a number of remarks to the effects that insensitive comments and poor treatment of people was a result of ignorance about autism. Notably, the interviews supported the claim that the stigma and abuse surrounding autism is a burden not only suffered by people with autism, but by the caregivers and particularly the mothers of children with ASD.

The stigma takes on several manifestations. The idea that mothers are somehow to blame for bearing children with autism was again expressed in the focus group discussions, echoing the trend seen in the surveys. When during the FGD the question on what causes autism was asked, some of the FGD participants stated that:

"I think it's when the mother is stressed during pregnancy and negligence when delivering the child." FGD participant
While another echoed with the above statement through stating that:

"I think it's not getting all the necessary nutrients when pregnant" FGD participant.

However, there were also several comments mentioning autism as "a natural thing" or "God-given". Nevertheless, any blame on the mother, even if it is a minority view, is a cause for concern. In fact, the caregivers of people with ASD who are also parents to people with ASD are concerned about attributing autism to them as mothers of people with ASD. The care givers during their FGD stated that:

"They treat us as if it's our fault for the children to be like this" – FGD participant.

While another FGD participant stated that:

"The community assume that we are spoiling the children that's why they are behaving like this" - FGD participant.

And another participant also stated that:

"Some think there is something bad that you have done and what is happening to your child its punishment of your evil deeds, they say "it's a curse"" - FGD participant.

Stigmatization of People with ASD and their families and caregivers

The stigma towards people with ASD and their caregivers and families is apparent as reported by their caregivers. During the FGD some of the caregivers mentioned that people think people with ASD are mentally impaired, are useless and the caregivers are sometimes not afforded the same level of respect and dignity as others. Evidence to the above are the following statements by the caregivers during different FGDs.

One caregiver stated that:

"[People with ASD] are regarded as lunatic and stupid people" - FGD participant.

While another caregiver echoed by stating that:

"They think they are useless because of they are mentally disturbed" – FGD participant.

Regarding the treatment afforded to people with ASD and their caregivers, one caregiver stated that:

"I usually travel with great difficulty in buses. When we are called to meetings they are treated harshly, please treat them right" – FGD participant.

Key informant interview participants recommendations

When asked about how Autism in Eswatini can best be addressed, one of the Key Informants had a lengthy but insightful answer:

"ASD management is multifactorial or multi-disciplinary as I may say so. Within the health fraternity it starts with screening, so you need to make sure that you are able to screen and diagnose as early as possible, because the international guidelines suggest that we should at least be able to diagnose before the age of three, so that we will be able to institute therapy as soon as possible while the brain is growing. If we are able to intervene early, then we are able to come with better outcomes and the child is able to reach his/her full potential. So, we start by screening and make sure you get an early diagnostic.

So then again by taking care of an individual with ASD we need a lot of people such as pediatricians, therapists, occupational therapists sometimes even a dietician because they are choosey with food for example some consider only brown things as food, psychologists are also needed and beyond that they also have commodities' as well such as epilepsy... normally its asthma and epilepsy. [Also] others such as constipation, coughing which is something that also need to be treated. Most importantly as well is the social component of ASD because the person we are taking care of akakuboni yena as a condition, so the most affected are those that are around that person and so as an institution we are relying on them to bring the ones with ASD to the hospital unfortunately they are not psychologically prepared to do so, or maybe because of financial barriers, so we need to treat the whole family here" - Key Informant Respondent.

Other comments highlighted those services need to be more widely available, especially the ability to diagnose in the health sector in places other than Mbabane:

"Screen and diagnose as early as possible. Then provide the services all over the country even in the schools" - Key Informant Respondent.

"The services are only available in Mbabane government hospital. So, they all come to Mbabane for diagnostics still we rely on people to have picked up the symptoms because parents can't just pick their child up to Mbabane. So, we need to create a lot of awareness in our health care sector so that they are aware of the ASD symptoms" - Key Informant Respondent.

In terms of managing autism as a country, early diagnosis is said to have cost-effective benefits down the line:
"The major drawback is late diagnosis, number two, its poor social circumstances. We need to institute this measure before the age of three and by so doing you are likely to save money due to the reduction in therapy visits, you go to a normal school stream, you save more money" - Key Informant Respondent.

Other recommendations were to put the Disability Act into action. In fact, one respondent was of the view that the legal instruments to advance the state of autism support in the country were already in place, however long delays in operationalization meant they had yet to have any real effect:

“Advocating for the operationalization of the disability act which will in turn give us our budget and allocate it accordingly” - Key Informant Respondent.

The role of schools and access to education was also mentioned several times. Participants in the KIIs and FGDs were in favour of additional assistants in the classroom to help teachers cope. Most were of the view that mainstreaming is a solution, but only up to a point, and there was broad recognition that in some sever cases, special schools are required.

“Taking this initiative to do this base line survey is a sign that there is work being done and it’s a huge milestone so that we know where we are as a country and what services we have to cater for autism, so there is light at the end of the tunnel however we are still far from making sure that it is ideal, we still need to make sure that we institute all this systems and start something concrete so I have only dwell on health needs, the big issue is about school, we need special schools, when we say special schools we mean there should be therapist at that school, the teacher should be able to give adequate time to the child with special needs” - Key Informant Respondent.

Additionally, interventions that would allow people with autism to become economically self-sufficient and attain a greater degree of independence, such as tradable skills, were mentioned. Finally, the role of NGOs was mentioned as being key, with the model seeing NGOs as partners for addressing various aspects of autism in the country.

Discussions

General demographics and prevalence

The vast majority of the primary caregivers were women (88%). The caregivers, at an average age of 49, are much older than the people with ASD they are caring for (average age 15), with the mean difference being 33.8 years. Two thirds (67%) of the caregivers of people with ASD were a single generation older: 48 percent of all primary caregivers were mothers, 7 percent were fathers, 10 percent were aunts or uncles. With mothers specifically and women in general carrying the workload of caring for people with ASD in Eswatini, their ability to earn a living is compromised, and therefore efforts to address autism in the country may also be considered as efforts to address gender inequality.

Grandmothers or grandfathers were the primary caregiver in 30 percent of cases. While the weight of responsibility for care evidently falls on mothers, grandparents are also shouldering a large proportion of the workload. The implication of this is that, for a third of people with ASD, their security is especially tenuous as dependents on an older generation. These individuals can therefore be thought of as particularly vulnerable.

The sex distribution of the people with ASD in the households visited for the purposes of this study reflect that more males were reported to have ASD compared to females. In our study 58 percent of the cases of suspected autism were in males, while 42 percent were in females. Therefore, the incidence ratio of male: female in our study was 1.4:1, meaning that for every 14 males identified with autism, there were 10 females. In other words, there were 40% more males than females. Even though there were more males, the ratio was significantly lower than the rates typically reported from other countries (e.g., Bishop, 2012; King and Bearman, 2011) where the wide asymmetry in sex has been supported as far back as the 1970s (e.g., Rutter, 1978). It is likely that the much-reduced sex asymmetry in our study is due to the lack of a common diagnostic framework and lack of clarity among professionals and non-professionals alike about what constitutes autism as opposed to other disorders.

Prevalence

Given the lack of a common diagnostic framework and lack of clarity in healthcare professionals, teachers and parents about what constitutes autism, establishing a prevalence rate can only be done by basing it on the best available information. In the population we visited, there are approximately 201 total number of households with a total population of 231. The numbers show that we were referred to 201 number of households who were said to have an individual with autism. Of the households we visited, 98% confirmed a case of autism in their household, and there were 231 individuals with autism in the 201 household who completed the survey in full. Fifty percent of the cases were said to have been professionally diagnosed. If we accept that 98% of the indicated cases are indeed autism, that results to a prevalence rate of 16.4 percent which is obtained by summing the total number of people with ASD in all the households and dividing it by the total number of people in all the households (231/1407).

Further to the matter of establishing an accurate prevalence, half of all cases were said to have been professionally diagnosed; however, our study indicates that the healthcare system in the country is not adequately capacitated and professionals are not trained to make this extent of diagnoses reliably. We base this on the healthcare professionals survey as well as the key informant interviews and focus group discussions, where it was indicated that diagnostic services in the country tend to be confined to the Mbabane-Manzini corridor. In other words, diagnoses are being made, but without a common diagnostic tool adapted to the local Eswatini context, especially one that can adequately cater for differential diagnoses; and also, without the suitable knowledge base in the healthcare system, the reliability of diagnoses is in question. The research team on the ground who visited the homesteads reported seeing a very wide range of presentation of what was called autism. However, our research team was also not qualified to confirm or refute autism diagnoses. Until there is common understanding of the definition of autism in the Eswatini context, along with a suitable diagnostic framework and tools, and adequate professional training, the ability to accurately and reliably establish the prevalence of ASD in the country is not possible.

SOCIAL ENVIRONMENT

The general population survey showed that about one in three people had never heard of autism. This indicates a need for information campaigns and activities to raise general awareness at the most basic level of what autism is and how it may present. In fact, the need to raise awareness across all sectors of society was explicitly and repeatedly noted by many people across the KIIs, FGDs, and the educational and healthcare professionals' surveys.

In terms of a medium of communication, it is pertinent to point out that of those who have heard about autism in the general population, radio was typically the source (58% first heard of it via radio, followed by word-of-mouth in the community at 22%). Therefore, this is evidence that radio remains a key communication channel for information dissemination, with schools being a second institutional source of information.

Due to the fact that children with ASD are mainstreamed in the education system, this could be the reason schools were also a main source of first information about autism. Furthermore, it may be that many people have their first actual encounter with a person with autism via their connection with a school as a learner, or as a parent, or as a teacher. This sort of interaction is very different from simply hearing about ASD via a mass communications medium. The quality and depth of information that a person obtains from first-hand interaction with a person with autism is going to be of a very different quality to that obtained as a passive listener via the radio. The value of schools as a site of interaction with people with autism and therefore as a site of learning and understanding about ASD, should be recognized, and in fact, as shall be shown later, we find that on several important survey questions, there was an even better understanding among teachers than among healthcare professionals on the knowledge and beliefs about autism. Day-to-day, ongoing, continuous interaction with people with ASD is common in school environments for the entire school community, whereas this is not the case for the healthcare professionals who may see a patient only once for a very limited time, in an environment unfamiliar to the patient, a factor which is known to stress people with ASD. This places teachers, school communities, and the school environment in general, as valuable sites of collective understanding about autism in Eswatini.

Knowledge of symptoms and etiology, and beliefs

The average level of agreement when 17 common ASD symptoms were put to the caregiver and general population group showed that two thirds (66%) correctly agreed that each was indeed an autism symptom. This indicates that there is a fairly high level of understanding of the symptoms that can constitute autism. However, the survey portion of the study did not ask about symptoms that were not characteristic of autism. Future studies should add this as a component, or alternatively, ask respondents if they are able to identify symptoms of autism without being prompted.

Any programme to educate the public and improve knowledge of autism symptoms should focus on highlighting the social difficulties that people with autism experience. For example, the key symptoms with the least recognition by the general population were failure to respond to their name, being unable to talk, and disinterest in playing with other children and also playing in the usual way, and information campaigns should highlight that these are common symptoms.

Unlike knowledge of symptoms, knowledge of the etiology of autism was poor. However, there was a fair amount of uncertainty, with respondents frequently answering that they did not know the answers to questions, especially questions about whether autism was curable or preventable. Current medical understandings of ASD indicate that autism is not curable, and while it may be preventable if sufficient causative environmental factors were to be identified, it is currently not known to be preventable. On this matter, in our study, a large proportion of the general population respondents (44%) did not believe that autism was inherited or that it occurs naturally. (Likewise, 23 percent of caregivers ascribed the causes of autism to something that they did not know, or causes other than genetics). This is an important finding of the study, namely the generalized belief in the general population that autism does not have a genetic basis. Supporting this was the fact that the number of people in the general population who believe that autism was preventable was quite high, at 30 to 35% (the same question was asked twice in two places). Also, one in five of the general population said that ASD could be cured, whereas current medical approaches do not believe it is curable.

Large number of respondents - nearly one in five (18%) in the general population survey--provided answers that indicated the idea that autism was the result of problems that occur in pregnancy, and to a lesser degree, in labour or as a result of a traumatic early childhood. Notably, those who cited pregnancy issues usually did not directly blame the mother for personal negligence, but rather cited social ills such as abuse and various life stresses. This is notable because it speaks to an underlying assumption that autism is preventable and it places the burden of preventing a child having autism on the mother. In the general population, even though about 50% said they believed autism was not preventable, a third (35%) said they thought autism was in fact preventable. If autism is believed to be preventable, and if autism is still occurring, then someone or something must be responsible or to blame. This set of beliefs about the etiology of autism is thus potentially an unrecognized source of stigma. While it is known that children with autism themselves suffer stigmatization, the family, and especially the mothers may also be suffering a high degree of stigmatization. That there is a degree of this level of stigmatization on the mother and family is nevertheless supported to some extent in the comments and answers received across the entire study, for example, the high proportion of people who agreed with the statement “autism is a frowned-on condition” (the baseline average response across all surveys was that 76% of people agreed with this statement). The level of stigmatization on the rest of the family and in particular the mother was not deeply probed by this study, and should be investigated in future Knowledge, Attitudes and Practices studies on autism in the country.

Comparing knowledge levels was revealing. Beliefs and knowledge about autism among healthcare professionals and educators was noticeably different. When comparing beliefs and knowledge about autism between healthcare professionals and educators on the one side, and the general population and caregivers on the others side, the healthcare professionals and educators displayed higher levels of knowledge for the most part. This is evident when the baseline on the questions about “beliefs about autism” is examined. However, on certain key questions, there was an extreme variance, with healthcare workers and to a lesser extent, educators not nearly as knowledgeable as the general population and caregivers. The table below compares some of the survey answers. The "Baseline" column represents the average percentage of people agreeing with the statement across all surveys. Outlying statistics have been highlighted in order to draw attention.

Table 18: Comparative knowledge levels and beliefs

	Baseline	**Agree**	**Health care workers**	**Education workers**	**Care givers**
		General population			
ASD happens in poor families	10%	13%	0%	7%	18%
Children with ASD need special education	82%	79%	76%	91%	80%
Children with ASD have intellectual disability	63%	71%	47%	67%	68%
Autism is a frowned-upon condition	76%	72%	76%	82%	73%
Autism is epilepsy	19%	29%	12%	7%	27%
Autism is preventable	23%	30%	29%	15%	17%
Autism is caused by parents' negligence	29%	50%	18%	20%	26%
People with ASD need to be isolated	10%	21%	6%	2%	11%
Autism exists only in childhood	12%	12%	18%	7%	11%
Autism is curable if diagnosed early*	39%	21%	59%	69%	8%

*The statement put in the General Population and Caregivers' surveys was "Autism is curable".

Attention is also drawn in particular to the following: "Autism is epilepsy" – 12 percent of healthcare workers incorrectly agreed with this;

"Autism is preventable" – 29 percent of healthcare workers incorrectly agreed; "Autism exists only in childhood – 18 percent of healthcare workers incorrectly agreed, showing less knowledge than even the general population. These however were the only questions where healthcare workers fell short. For the rest, they displayed on average better knowledge.

Attention is further drawn to a few other interesting numbers. The baseline shows that almost a quarter of all respondents (23%) believe that autism is preventable. Half the general population said that autism was caused by parents' negligence, with a third of all respondents also agreeing.

Additionally, a significant proportion of respondents from all surveys said they thought people with autism should be isolated. In fact, the average response to the statement "People with autism should be isolated" was that one in ten agreed, with the highest agreement levels coming from the general population. This is an important finding and one that deserves to be addressed, since the extreme belief that people with autism are so different that they need to be isolated is connected with ongoing stigma about autism. This is a minor finding and future awareness programmes need to address education about this attitude and the fact that no person does better when isolated, that social isolation is often considered a form of torture, and that all people have basic human rights including the right not to be isolated. Such education should be directed towards people at all levels of society, including teachers and healthcare professionals, who were not immune from expressing this attitude.

A large proportion of respondents across all surveys thought that Children with ASD should not be mainstreamed. This is against government policy and inclusive education. While not the same, the comparison shows that educations workers have by far the strongest belief that "Children with ASD need special education". This does not necessarily mean that educators are against mainstreaming (in fact the attitudes survey conclusively found that educators were not opposed to mainstreaming per se), but it does show that educators were in favour of mainstreaming *so long as they had additional support*, in the form of assistance in classes, or training, or additional materials in order to cater to the "special education" needs of children with ASD.

The baseline shows an average one in five (19%) people fail to distinguish between autism and epilepsy. While autism and epilepsy are two distinct conditions, they nevertheless do frequently occur together. Almost a fifth of respondents across the surveys indicated that they thought that autism WAS epilepsy. Education about the difference is thus a point to be raised in future education and awareness programmes.

The majority of respondents in the general population survey said they would be comfortable being in close proximity to a person with autism, such as being on a bus or in the same room with someone with ASD, but few said they would be comfortable hugging a person with autism. This is an apt attitude given that people with autism are often hypersensitive to sensations and have difficulty with interpreting regular social relations. However, it is important to note that the attitudes people express explicitly when asked, are often very different to attitudes they implicitly and privately hold. Hence, while the survey may find a generally fairly high level of social acceptance of autism, in reality, because these are self-reported attitudes where people are incentivized to appear more tolerant than they really are, the reality about non-acceptance and stigma towards people with autism may be hidden. In fact, this was the finding of one recent study conducted in the United States of America (See Dickter, Burk, Zurman et. al., 2020), which showed that reported attitudes on acceptance of autism behaviours was very different and far more positive than the implicit biases people held (Dickter, Burk, Zurman et. al., 2020).

The value of this study's assessment of the knowledge of symptoms, etiology, attitudes and beliefs about autism is that information campaigns can target those areas of knowledge known to be insufficient. Furthermore, training of professionals can be tailored to emphasize increasing the understanding of autism in areas where our survey has demonstrated that there is incomplete knowledge.

Experience of caregivers

The data from the caregivers survey, which also functioned as the household level survey, provided some key insights into the lived experience of those who carry the weight of the complications to normal life that come along with autism. It is significant but not surprising that 91% of the primary caregivers are women with an average age of 49. Most caregivers are one generation older, but a sizeable proportion are two (ie the caregivers are grandparents). These are important baseline confirmation.

A 2008 study published in Pediatrics comparing over 2000 families with an ASD child against other families with special need children found that families with a child with autism were “significantly more likely to have problems regarding access to care and unmet needs, and their families have greater financial, employment, and time burdens compared with other children with special health care needs” (Kogan, Strickland, Blumberg et. al., 2008). While our study was not comparative, the responses from the caregivers nevertheless indicate that these same stresses are widespread in Eswatini.

The study provides strong evidence that caregivers are, in general, under heavy and continuous stress. The major sources of stress are financial, dietary, demands on time and the demand for constant care and high levels of attention, and worries about the person with ASD’s future. The study established that the most immediate needs in terms of material supports are primarily finances, food, transport, and sanitary wear in the form of diapers and where needed, menstrual pads. Access to schools and health services is discussed under the Institutional Environment section.

Poor hygiene behaviour and a lack of toilet training are two of the specific behaviours that caregivers say give them high levels of stress. This is in addition to dietary behaviours: in fact, dietary behaviours such as being picky eaters or eating a lot were the most often cited stress from behavioural attributes that cause stress for caregivers.

A study from the USA comparing the situations of 2088 children with autism against 26751 other children with other special needs found that children with autism spectrum disorder were “more likely to live in families that report financial problems, need additional income for the child's medical care”, and have parents who “reduce or stop work because of the child's condition” (Kogan, Strickland, Blumberg et. al., 2008). Even though our study did not compare needs of ASD families against the needs of other families with a special needs individual, our study nevertheless confirmed that all of these factors are also factors in their own right in the Eswatini context, although we were unable to ascertain how they compare against other special needs conditions.

Caregivers’ overwhelming said that that their primary worry was when they die there will be no one to look after the person with ASD to the same degree. This underscores how alone caregivers feel, and how they are in need of all kinds of support. Beyond the material supports already indicated, counselling support and knowing that they are not alone, and any support that provides relief for the caregiver (i.e. allows the caregiver to have a few hours of time off) would be appropriate ways to reduce the stress they carry and allow them time to tend to other areas of their lives.

The unrelenting demands for emotional energy and attention from caregivers indicates just how important it is for children with autism to be in school. Aside from the education function, schools expose the ASD child to the wider world, provide them with opportunities to interact with others beyond their caregivers and household members, and provide the caregiver with a few hours where they do not have to be “on duty” looking after the ASD child. Having children with autism in schools is also an important means of fostering tolerance and understanding of the condition. It is not only children with autism who learn from school, but others in the school community who have the opportunity to learn about autism and people with disabilities because they are not kept in segregated schools.

While schools are incredibly important locations in the lives of people with autism and their families, however, simply shifting the burden of care wholesale to educators to deal with without providing them with the additional support they need results in unintended negative consequences. Schools need to be supported with additional staff and be equipped with knowledge, skills and some resources to deal with Children with ASD, otherwise, as this study makes clear, educators are forced to either ignore the ASD child, or devote excessive attention to them that takes away from the rest of the learner body, a problem where classes are already often overcrowded.

In general, caregivers were found to be under a lot of stress, with little support and not much awareness of their needs from other sectors of society. Few educational or health professionals, for example, mentioned the food issue or the financial strain issue, yet these were the chief sources of stress for caregivers. The lack of widespread understanding of the specific needs of ASD caregivers was also found in a study conducted in Goa, India, which concluded that “professionals from the health, education, and religious sectors have a low awareness of the unique needs of families living with ASD which leads to a considerable economic and emotional burden on families” (Divan et. al, 2012).

PHYSICAL AND INSTITUTIONAL ENVIRONMENT

Educational environment

The demographics of the sample show that only 46% of the children of school and ECCD-going age were in school (based on the 231 individuals in the caregiver survey). This is unacceptably low and there should be efforts to increase enrollment. Reasons provided for a child not being in school included schools being too far, especially special needs schools, exclusion because the child cannot talk, exclusion due to not having birth certificates, a lack of toilet training and exclusion because the type of education desired was expensive. Caregivers were mostly keen to send the children to school, but social and institutional barriers and lack of support for dealing with Children with ASD were a hindrance.

Eight percent of the children with ASD were in special needs schools. This number is lower than what was found in the Becerra (2017) study, where 22 percent of children with ASD attended a special needs school (however, this study represented a wealthy cohort).

In the schools and ECCD centres, it is striking to note the vast experience that exists inside these institutions. Teachers were well-educated and also had a lot of experience in their profession, of 8 years on average, and a quarter had over 15 years' experience. A key finding of this study is that most teachers (76%) say they have worked with special needs children. More than one in four say they have more than 5 years' experience working with special needs children. Teachers showed high levels of awareness of autism. All of these numbers representing *experience* and *contact* with special needs people were much higher than the averages we found in the health care professionals we interviewed.

Teachers are in their jobs for the long haul, and given the sticking power of the job, investing in their skills and supporting their development and ability to cope would be a worthwhile use of resources since they tend to stay in the job and therefore returns on such investments will continue through their careers.

Despite the experience in the classroom, it was clear that the general understanding of autism symptoms and etiology was not as good as it could be. For example, a large majority of teachers thought that autism is something that can be outgrown with treatments, and two thirds thought it was curable if diagnosed and intervened on early. It is possible that teachers fail to distinguish autism from other types of special needs, or that they view autism purely in a functional way: namely, if the social and otherwise deficits can be overcome or drastically reduced, then this is as good as a "cure".

The experience of working with special needs children and children with autism was frequently not felt to be adequate, and a number of teachers expressed that they had not been trained at all on working with such children. Like the caregivers, many teachers felt overwhelmed by the special needs children in their classrooms. The chief problems identified were that the Children with ASD require extra attention and time, and that they are slow learners. This was a key finding of the survey, and efforts to assist teachers should address this number one complaint, namely the extra time and attention required for children with ASD. Balancing the extra attention required with the needs of the rest of the class was a main challenge, and it is somewhat surprising that behavioural issues with children with ASD formed a much smaller part of the teachers' challenges compared with the time and attention issue. In fact, large numbers of people in the general population reported that children with ASD were disruptive in class., yet in open questions in our teachers' surveys, this was not a complaint teachers had.

More than four out of five teachers agreed that children with ASD require a special education. But an analysis of their agreements to various questions indicates that teachers strongly believe that Children with ASD should be mainstreamed, that they should not be excluded, but also that the existing mainstream schools and classrooms strongly need more support from government in the form of 1) Skills for the teachers, 2) Additional staff, particularly staff highly trained to deal with ASD and therapists, and 3) More resources (such as learning materials) for children with ASD. In other words, teachers are in favour of mainstreaming, but appear to be desperate for additional support to accommodate children with ASD. Such supports requested were both for additional staff/highly trained staff. For example, the provision of occupational therapists, speech and language therapists, psychologists as well assistant teachers would vastly help the teachers in mainstreaming children with ASD. These interventions have been found to be helpful in other contexts since “specialized therapies such as OT and ST target core symptoms in self-regulation, cognition, and social-communication skills. Similarly, social skills training, a common treatment method for adolescents, can be effective for those with high-functioning autism in natural, everyday educational settings (Becerra et. al. 2017).

Likewise, there were many requests for additional classroom materials and supplementary syllabus work for children with ASD. Such an approach is common in schools in Canada and the United States, where teaching assistants are used in classrooms, the children with ASD have an additional dedicated professional in the classroom specifically to assist them, classrooms may have technological features for use by the children with ASD, or teachers are given the freedom and resources to adapt their teaching and testing requirements to levels and expectations tailored to children with ASD (see, for example, Soltau, 2015).

Our study confirmed an extremely strong desire for professional development in the capacity of dealing with special needs children, and to upskill in understanding specifically, as well as skills, in the classroom. A key finding is thus an overall impression being one of “working with what you have”: namely, not designating more special needs schools that segregate special needs children from others, but rather equipping existing schools to better cope with special needs children in a mainstreamed environment, especially in terms of educating and upskilling teachers, and providing some additional, highly trained staff in schools.

Most were not aware of the National Inclusive Education Standards. Nevertheless, most teachers reported that their schools were indeed inclusive and that there were special needs children in their schools. Of those who reported that their schools were not inclusive, the major reasons given were lack of appropriate infrastructure, and lack of teacher training. This underscores the need for teachers to be trained on autism and special needs children in general, as well as the need to make schools accessible in terms of infrastructure.

Healthcare services

The most striking aspects of the healthcare environment that emerge from the study are that healthcare workers are inadequately trained and informed about autism, and that there are few services specifically offered and that are accessible for people with ASD.

The single biggest problem underlying this is the lack of a common diagnostic framework, and the lack of observational and interview tools adapted to the Eswatini context that would allow for a common understanding and common way to diagnose autism spectrum disorders in the country. This is discussed further later on.

Looking at healthcare respondent’s survey answers, and about one in ten caregivers said that issues around access to medicine, medical services and treatments were their biggest challenges in caring for a person with ASD. Nearly 50% said they require therapeutic services, and another 40% required mental health services, and 23% and a quarter required behavioural services. However, given the general lack of training on autism among healthcare workers, their assessment of such needs may not be accurate. Nevertheless, these were the identified needs from both healthcare workers and caregivers, and they were said in general to be largely going unmet, because fewer than a third (29%) of caregiver respondents said they were able to access the services they need at their local healthcare facility. About a third of caregiver respondents said they needed medication, but with only 15% indicating that the person with ASD was on a regular medicine it appears that access to medications is insufficient. However, it could be that a general lack of understanding about autism, and the fact that there are no medications to treat autism specifically (although there are medications to treat common comorbid disorders) the complaint about lack of access to medications should be probed in future assessments, in order to determine if the lack of medications referred to is for comorbid conditions. Our survey did not make this determination. Attention is drawn to the fact that there could be a life-threatening problem where comorbid conditions such as extreme allergies, asthma or epilepsy are involved, and because the autism compounds the difficulties of travelling, affordability, and waiting in queues in an intersectional manner, the lack of medications complaint should be specifically investigated. It should be noted that, in a survey covering 1155 children with ASD and who had private medical aid insurance in the USA found that “prescription medication use was high” with 48 percent having been on prescription medication at one point (Becerra, Massolo, and Croen, 2017).

There were a few comments that it is hard to access any services because it is difficult or impossible to take the person with ASD on public transport. Special attention needs to be paid to these extreme cases, and perhaps a home visit unit could be created to fulfill the service requirements of those people with this extreme need. The most common reason given for not accessing medical and treatment services was because they were unavailable (40%), followed by being unaffordable (20%), or hard to get to (17%).

Healthcare facilities were rated to be friendly by the vast majority in the household survey (more than 90% agreed)., but, as mentioned in the results section, this is to be interpreted as meaning that caregivers thought the attitudes of the service providers were friendly, not that the infrastructure or facilities or services on offer were friendly to people with ASD or other special needs. In fact, there were a number of comments from healthcare workers themselves that their facilities were not geared towards catering for all people with special needs, and specifically not for children with ASD.

It is interesting to compare our findings with a middle-income country, namely Poland. In a study of 311 parents of a person with ASD, the authors found that 93.5% had unmet needs in terms of access to services, and for people or whom services were theoretically available, 83% had barriers to accessing them. Also, most services were being provided by NGOs, schools and private clinics.

They also found that adults with ASD used services far less often than adolescents (61% vs 80%, respectively). “Mental health services were among the most used and the most needed services, followed by educational services, while needs for sensory/motor services remained largely unmet. Young people with a coexisting intellectual disability used more services than those without” (Płatos and Pisula, 2019).

Institutional capacities in our study were found to be inadequate. There was strong agreement that there needs to be more finances invested in training especially skilled staff, in general training of all staff to recognise ASD, and in investing in support services that can be offered to people with ASD and their families. On the human resources side, three quarters (76%) said they had never knowingly worked with a person with ASD, and those who had had only a year or two’s experience. Most said they had never been educated or trained on autism. The lack of experience and training was reflected in the knowledge and beliefs about autism. Two thirds (65%) of the healthcare professionals agreed with the statement that children with ASD grow up to be schizophrenic, nearly one in five thought ASD was caused by parental negligence, and 59% agreed that autism could be cured with early intervention and the right treatments. The healthcare professionals were keen to received training and education on autism, particularly to be equipped to recognise and diagnose autism, but also to be skilled to offer services and referrals, which they felt they were not currently equipped to do so. The lack of coordination and referrals has been noted as a significant complaint by other studies, for example, an American study covering 1049 caregivers that found only 14 percent of parents looking after a child with ASD agreed that care coordination between various service providers was adequate (Sobotka, Francis, Vander Ploeg Booth, 2015).

The lack of human capacity in healthcare professional skilled on recognising autism was reflected in the demographics of the ASD rate of diagnosis, where only 50 percent of those with or suspected to have ASD were actually diagnosed by a healthcare professional.

The average age of diagnosis by professional in Eswatini was 3 years old. This is younger than what a US study found, where the average age of diagnosis was at 4 years old (see Zuckerman, Lindly and Chavez, 2016). The age of diagnosis is important, as it is widely acknowledged that when it comes to autism, early interventions lead to improved outcomes. The Zuckerman et. al. study further found that later diagnosis was associated with high levels of psychotropic drug use. They also found that children with an older age of diagnosis, or a longer delay between first being suspected of having autism and having a professional diagnosis of ASD, used different types of health services to those who were diagnosed earlier (see Zuckerman, Lindly and Chavez, 2016). The consequences of this for Eswatini are unknown, but this finding should nevertheless be born in mind.

Internationally, autism spectrum disorders are receiving more attention, more funding and more awareness, but much of this is predicated on the ability to recognise and diagnose autism. If Eswatini is to assist those with ASD and their families, the ability to professionally recognise and diagnose autism is essentially “ground zero” when it comes to raising funds and awareness about ASD. Therefore, it is recommended that the Ministry of Health be allocated a specific budget to training healthcare professionals to develop a common diagnostic framework for identifying autism in the country, which will assist in enabling healthcare workers to recognising and diagnose ASD, and to recognise what kinds of services a person with ASD may require (mental health services, behavioural therapies, speech therapy, art therapy, e.t.c.)

Violence and perceived safety

Schools were rated by caregivers as the safest place outside of the home. However, the average safety rating was 6 out of 10, which means there is room for improvement. Bullying in schools not very well explored in the country, and this study did not probe this feature deeply, and furthermore this study did turn up some evidence that bullying from both teachers and other students is indeed an issue. Most of this evidence is from the comments made by teachers to open-ended questions, and answers from caregivers to the question “Has your child been physically abused by other children?” (29% said “Yes”). Many of the comments indicate that the bullying is not exclusively the result of stigma, but also the result of a general lack of understanding by teachers, other students, and the population at large about what autism is, how it presents, and the special way in which people with autism see the world and the empathy they deserve. Therefore, bullying at school is an aspect that needs to be investigated and possibly addressed.

Most children travel to school on foot, and usually with other children. This travelling in groups generally affords the caregivers confidence that the other children will look after the child with autism. Some of the main fears about travelling to school are that the child will stray or that their road awareness is not good and they will be hit by a car. Future programmes to assist children with autism should look at this aspect and promote a culture where children take protective roles towards their peers and look after any Children with ASD in their group and neighborhood when in the streets for whatever reason.

The safety rating in communities was widely distributed, although the mean, median and mode were all around 5.5 out of 10. This is a poor rating. In addition to this, thirty-eight percent of caregivers said that the person with ASD in their care had been verbally abused at home or in the community. This establishes a baseline level of verbal abuse of people with autism, indicating that it is very common. One way to address this is to use education programmes to increase awareness about what autism is, and how people with ASD are vulnerable to exploitation and thus may need extra eyes on them and protective people to watch out for their interests.

In terms of sexual abuse, 7 percent of caregivers said they were aware of the person with ASD in their care having been sexually violated. There were 13 cases across the 201 households surveyed. In 9 of the 13 cases, the perpetrator was known to the victim. Only in 3 cases was the perpetrator a total stranger. Since 11 of the 13 cases were reported to the police, this shows a high degree of confidence in the justice system and that the justice system will serve justice to the people with ASD. Of those cases reported to the police, 45percent of the time (5 of 11 cases) the perpetrator was punished. However, it is unclear whether the punishment was always through the institutional criminal justice system. Nevertheless, these are still much higher rates of reporting to police and punishment of the perpetrator than usual.

Lack of a common diagnostic framework

While there was in general a good knowledge of the symptoms of autism in each survey, it also appears that understandings of what autism is are fuzzy and not well-defined. In other words, despite a good understanding of what many of the symptoms of autism are, there was also a poor understanding of what is not autism. It appears that other special needs and other conditions are confused with autism, or even that the word 'Autism' is being understood as a generic term for special needs of certain natures.

The problem is fundamental, because at the heart is a lack of experience, training, and tools to allow health care professionals to diagnose autism within the framework of a consistent understanding. Very few of the healthcare professionals we surveyed said they had treated a person with ASD, and even then, the number of years of experience was extremely low. Even though half of the individuals with ASD recognized in the caregiver survey were said to have been diagnosed by a healthcare professional, this level of aptitude and ability to diagnose was not actually reflected in the healthcare institutional investigations. The healthcare professionals doing the diagnoses do not seem to be working from a common diagnostic framework.

A common diagnostic framework is essential. Autism is a spectrum disorder, with a variety of presentations, and different clusters of presentation. It is characterised by social difficulties, but so are many other disorders such as Post Traumatic Stress Disorder. It is thus absolutely critical to note that the differential diagnoses for autism have a wide range, and spans genetic conditions, mental health conditions, alcohol fetal syndrome, symptoms of neglect and abuse, unrelated intellectual disabilities, other developmental delays, and even hearing impairments and delayed speech disorders, all of which can lead to an expression that may be mistaken for autism. The ability of healthcare professionals to accurately distinguish between autism, and similar presenting disorders is crucial, in terms of treatment, but also in terms of the ability to establish an accurate prevalence rate.

Further, existing tools for diagnosing autism were mostly created in western cultural contexts. They consist of observational checklists and interviews on the part of the healthcare practitioner, and they mostly exist in English and have not been translated. It is known that these tests have extreme western cultural biases built in. In very recent years there have been moves to develop autism diagnostic tools for African contexts, and this include work being done in South Africa, and in the nearby province of KwaZulu-Natal.

Without a common diagnostic framework, establishing prevalence accurately is difficult and can only be done on a "best available information" basis. The apparent overlap with other special needs conditions will remain so long as there is not a common understanding of what Autism is in the Eswatini context, and a common tool and framework that is adapted to the Eswatini context is in use to diagnose it. The lack of a common understanding and common diagnostic framework for autism is identified by this study as a major knowledge gap, and a primary area for the channeling of funds to address this situation.

Economic Environment

The household/caregiver survey revealed that generalized poverty was a prime factor making life for those with ASD and their caregivers and families more difficult. Almost a quarter of respondents cited financial inadequacies or poverty directly as their main challenge in being an ASD caregiver. This was by far the biggest category of hardship cited. Many went on to say that the person with ASD has particular requirements and needs, such as certain diets, medication and medical services, that are expensive.

The demographics of the household sample show an average monthly income of E874, and an average household occupancy of 7 people. This translates to a monthly per capita income of E124.92, well below all standards that describe and set poverty levels. The major consequence of poverty appears to manifest in a lack of food and ongoing food stress, although there were additional comments about not being able to afford clothing, transport and medical care and medications.

The food issue takes on a particular dynamic in ASD. Regular food on a schedule is usually required for those taking medications, both to help the body absorb the medication, and to assist the body to keep the medication down. Not having food or reliable food interferes with the ability to take required medications. But there is a further and more important factor at the intersection of food stress and autism. One of the common symptoms of autism is sensory sensitivities. In addition to sensitivity to light and sound, many individuals with ASD have a sensory sensitivity to foods and food textures, in addition to preferred routines around food. Often people with ASD will only eat certain foods, and this results in an extremely limited range of food they will eat, sometimes only one or two foods. It is not uncommon to find individuals with ASD refusing to eat and preferring to go hungry rather than eat foods they do not want to. Many caregivers cited the lack of food or need for a special diet as the prime major stress in their caring. Some said that the person with ASD's diet was prioritized over other needs in the household. Many felt poorly about themselves for not being able to provide the preferred foods.

Some caregivers said that their own economic potential and ability to earn an income was severely hampered by the fact that they are the major caregivers of a person with ASD, because the latter takes up so much time and energy. Caregivers also overwhelming expressed the common single fear that the person with ASD will never be independent enough to look after themselves, particularly in terms of the ability to earn a living. High levels of worries about the person with ASD's future were also found in the Becerra study in the USA (Becerra, Massolo, Croen, 2017). This is underscored by the fact that half of children with ASD are out of school, and of those who have been to school, progressing to a high form and finishing school was found by our study to be an uncommon Scenario in the country.

Conclusions

This study establishes a baseline for the experiences, unmet needs, and level of access to services for those with autism spectrum disorder and those around them. It also establishes a baseline of the prevalence of autism spectrum disorders based on best available information. The data collected has enabled a description of the social, institutional and economic conditions that prevail. The main challenges faced by those with autism and their caregivers and families are described. The gaps in health and education services and the challenges faced by those who must deliver these services are also made evident.

The primary challenges faced by people with autism and their caregivers are financial in nature, although stressful living brought on by the constant care needs were also found to be a significant factor. Average household income is low enough to threaten the ability of people to survive and thrive. The addition of a person with ASD to the household places extra financial strain on resources, as they often have particular ongoing medical and dietary requirements. This is in addition to the emotional stress caused by the person with ASD lacking independence, needing plenty of supervision and attention, and their having difficulty with normal social relationships. Food is an additional particular source of stress, since many households report not being food secure, and also, that the person with ASD in their care will only eat certain foods.

Institutions are constrained by a lack of resources. However, the institutional constraints are primarily human resource in nature. There are few autism-specific services offered by healthcare facilities. Healthcare professionals, whilst they are aware of autism, they are typically not trained to recognise and diagnose autism, nor to identify similarly presenting yet very different disorders. The lack of a common diagnostic framework, and low level of training of healthcare professionals specifically on ASD, has knock-on effects. One is that the ability to very accurately ascertain prevalence of autism in the country is affected. With a low capacity to diagnose and a hampered ability to accurately establish prevalence of ASD, advocating for additional funding and attention for autism support both nationally and internationally will remain challenged.

Educators are faced with similar problems of a lack of skills and training to deal with children with special needs. However, it is encouraging that despite the tough conditions, educators are typically keen to enhance their skills in this regard. We found the same positive attitude and high level of willingness to be trained to deliver better services among health care professionals. Teachers overwhelmingly call for specific staff trained in special needs to be taken on in mainstream schools. Notably, only about half of the school-aged children in our study were attending school, and this is a significant problem that could be mitigated by having schools that have greater capability to take on multiple children with ASD.

Caregivers report a high level of verbal abuse and bullying, and stigmatization. This was confirmed by the teachers. It was also confirmed by the general attitude question where a baseline of 3 out of 4 respondents across all surveys agreed that autism was “a frowned upon condition”. More seriously, our survey confirmed that there is a level of sexual abuse of individuals with ASD, although access to justice in these known cases was typically higher than usual, with a high proportion of cases reported to police.

The prime recommendation of this report is to develop a common diagnostic framework based on tools that have been locally-adapted to the Eswatini context, and then train healthcare professionals in these. Advancing the knowledge and skills of teachers and investigating assigning specially-trained educational professionals to schools to assist the schools regarding the children with Children with ASD. Furthermore, supporting caregivers in their efforts, particularly with food and access to education and healthcare-based therapeutic services for children with ASD, and upskilling teachers and healthcare professionals to provide these services, are additional prime interventions recommended.

Recommendations

- **Develop (or adapt from existing tools) a culturally-appropriate and context-specific diagnostic tool for Eswatini (observation and/or interview based):**
    - **Government:** Ministry of Health and/or DPMO to commission development and approve a tool. Ministry of Education is important to involve for consultation.
    - **Partner/donors:** Assist with funding, and human resources support for development/adaptation of such a tool.
    - **Organizations:** Schools and health care facilities and appropriately placed NGOs and FBOs, such as Autism Eswatini to assist with input into symptoms and context-relevant diagnostic tools that will work.
    - **Community/households:** Parents/caregivers should be heavily consulted for input into diagnostic tool development.
- **Put in place systems, interventions to facilitate early identification of children and people with ASD including Training of healthcare professionals, and some educators, on administering the Eswatini-specific autism diagnostic tool to enable them to accurately diagnose ASD earlier:**
    - **Government:** prioritize this as an agenda item, budget for it. The key ministry is MoH, also DPMO. Ministry of Education is important to involve for consultation.
    - **Partners/donors:** Assist with funding for systems and equipment and human resource capacity, particularly in training on-the-ground and possibly also by providing spaces for such training. Major partners, such as pediatric universities and similar international medical research units operating in the country should be brought in as participants. Some partners may be able to provide knowledge capacities.
    - **Organizational level:** Professionals at Health facilities, and some educators participating in being trained on a diagnostic tool. NGOs are also crucial in this regard and those that have experience in working with individuals with ASD, such as Autism Eswatini should be brought on-board to play a leading role.
    - **Community/household level:** Consult Tinkhundla, parents and caregivers of people with ASD for their input and consent, and make room to involve lay persons from the community who may wish to be more heavily involved (perhaps by being trained).
- **Develop a culturally-appropriate and context-specific language lexicon / dictionary for autism in Eswatini:**
    - **Government:** Ministry of Health and/or DPMO to commission development and approve a tool.
    - **Partner/donors:** Assist with funding, and human resources support for development/adaptation of such a tool

  - **Organizations:** Schools and health care facilities, and appropriately placed NGOs and FBOs, such as Autism Eswatini to assist with input.
  - **Community/households:** Parents/caregivers should be heavily consulted for input.
- **Carry out an assessment of therapeutic service needs in the country to facilitate increased access to therapeutic services for people with ASD. Assess the need for counselling services for both ASD individuals and caregivers, and behavioural interventions, and occupational therapy, and speech therapy:**
  - **Government:** Ministry of Health, or DPMO, or appropriately-designated high-level government body to commission investigation. Ministry of Education to be consulted as a partner.
  - **Partners/donors:** Assist with funding, and human resource capacity, knowledge capacity.
  - **Organizations:** Schools and health care facilities participate in providing insight into services needed. NGOs such as Autism Eswatini can play a key role in both assessing and providing these services to sections of the population, if they are properly funded and supported to do so.
  - **Household:** Caregivers participate in providing insight into services needed.
- **Establish a framework to strengthen referral networks between service providers, schools, Tinkhundla, and NGOs. Schools particularly are ideally placed to refer children to local healthcare facilities for services and diagnoses. Health facilities and schools should have local memorandums of understanding to share knowledge and skills. Schools are locations where health professionals may be able to see the range of special needs for children with autism in a safe and familiar-to-the-child environment, and learn from the teachers just as much as the teachers may learn from the HCP. International experience shows that the earlier the intervention, the more benefit it has, hence referral networks should particularly target identifying and referring individuals of a very young age:**
  - **Government:** Ministry of Health and Ministry of Education, Ministry of Tinkhundla.
  - **Organizations:** Health care facilities and schools establish links and develop their own MoUs. Organizations with a history of experience with ASD, such as Autism Eswatini are also key nodal points, but need to be funded properly in order to function as a link and referring network expert.
  - **Community:** Tinkhundla to be informed and consulted about the process.

- **People with ASD with extreme needs and comorbid conditions, such as epilepsy, ADHD, intellectual disabilities, cerebral palsy, chronic illnesses and other disorders or disabilities require focused and targeted support. This should possibly fall under the ambit of the local Inkhundla who should identify these families in need, and channel resources towards them (such as home visits by healthcare professionals, or sponsorship from NGOs for related health and medical commodities such drugs.)**
  - **Government:** Promote this agenda. DPMO, MoH, Ministry of Education, Ministry of Tinkhundla are key ministries.
  - **Partners/donors:** provide funding support for aid.
  - **Organizations:** NGOs, schools, healthcare facilities, and organizations such as Autism Eswatini should play a role in identifying those in need, providing services, disbursing

    aid/necessities, as according to what kind of organisation they are and how well placed they may be for any one of these functions.
  - **Community:** Identify those in need.
- **Train all social services providers, including teachers to better be able to deal with Children with ASD in service provision centers including classrooms:**
  - **Government:** Different government ministries to investigate interventions and develop training programmes
  - **Partners/donors:** provide funding support. Partners and donors could also develop and run programmes themselves from their own facilities, in consultation with MoH and MoET
  - **Organizations:** Frontline service providers for each sector participate in training. Smaller organizations, such as Autism Eswatini, could also be funded to run programmes to equip teachers with skills.
- **Employ teaching assistants in the classroom to assist the main teacher with attention on ASD and other special needs children:**
  - **Government:** Promote this agenda. DPMO, MoH, MoET
  - **Partners/donors:** provide funding support.
- **Allocate more resources to specially trained professionals to assist teachers with special needs children in mainstream schools, including professionals who can offer psychosocial/counselling support:**
  - **Government:** Promote this agenda. DPMO, MoH, MoET
  - **Partners/donors:** provide funding support.
- **Raise awareness among the donor community and healthcare corporations who sell products in the country about the extreme need for sanitary wear (diapers and menstrual materials) that exists among families with an person with ASD:**
  - **Government:** Promote this agenda. Solicit donations and raise awareness in the donor community of these specific needs. DPMO, MoH, Ministry of Education, Ministry of Tinkhundla are key ministries.
  - **Partners/donors:** provide funding support for aid.
  - **Organizations:** Identify those in need. Provide services, disburse aid/necessities.
  - **Community:** Identify those in need.

- **Prioritize providing food assistance to families with a family member with ASD. Raise awareness about the special food sensitivities and needs common in people with autism:**
  - **Government:** Promote this agenda. Solicit donations and raise awareness in the donor community of these specific needs. DPMO, MoH, Ministry of Tinkhundla are key ministries.
  - **Partners/donors:** provide funding support for aid.
  - **Organizations:** Identify those in need. Provide aid, disburse aid/necessities. There is a key role for NGOs and FBOs to play here, but they need to be informed of the specific challenges of ASD and why families with an individual with ASD may be particularly vulnerable.
  - **Community:** Identify those in need.

- **Highlight among the donor community that assistance with clothing needs, especially winter clothing is needed among families with a person with:**
  - **Government:** Promote this agenda. Solicit donations and raise awareness in the donor community of these specific needs. DPMO, MoH, Ministry of Tinkhundla are key ministries.
  - **Partners/donors:** provide funding support for aid.
  - **Organizations:** Identify those in need. Provide aid, disburse aid/necessities.
  - **Community:** Identify those in need.
- **Investigate ways to increase access to birth certificates for Children with ASD:**
  - **Government:** Ministry of Home Affairs and the MoET as a partner and the support of the DPMO are key.
- **Institute a country-wide policy that allows caregivers of a person with ASD in queues with a person with autism to jump to the front of government service queues, especially in healthcare and home affairs:**
  - **Government:** DPMO, and parliament, to set such a policy and disseminate it to all stakeholders. The DPMO will also be responsible for the implementation, monitoring and evaluation as well as review of the policy.
- **There is a need to increase awareness in the general public about what autism is and what the symptoms are, and how to treat people with autism with dignity and reduce the stigma. A radio communications campaign could help increase awareness at a low cost:**
  - **Government:** DPMO and MoH as well as MoET to design, implement, monitor and evaluate the campaign
  - **Organizations: Organizations with experience with ASD should be funded to help consult and develop information campaigns. Information drawn from the survey results of this study is also valuable.**
- **Advocacy for vocational training centres which cater for individuals with autism and other neurodevelopmental disorders so as to foster financial independence, lessening caregiver burden and improved quality of life for individuals with ASD:**
  - **Government:** through the appropriate ministry, it should set up training centres for people with neurodevelopmental disorders and other mental health disorders
  - **Partners/donors:** These are to assist with the funding and appropriate support to ensure the program is sustainable and that its intended audience does actually benefit from it.

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