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## Research Article

# Challenges to accessing crucial services in the management of children having Autism Spectrum Disorders: Caregivers' perspective in Kenya

## Abstract

**Background and introduction:** Autism Spectrum Disorder is a global public health concern which has attracted little attention from African countries such as Kenya. As a result, children with ASD and their caregivers are facing significant barriers to accessing crucial services compared with the general population.

**Methodology:** A qualitative, descriptive phenomenological study utilizing Focus Group Discussions (FGDs) was conducted.

**Analysis:** The data was transcribed verbatim before QSR N'Vivo 10 was used to organize and analyze the data from transcripts of field notes and interviews. Content analysis was used to identify important ideas and concepts.

**Findings:** One theme, namely, "the burden of caring for children with ASD" was identified.

**Implications and recommendations:** Occupational therapists and other relevant stakeholders should provide accessible services that will promote the quality of life for children with ASD and their caregivers in Kenya.

## Abbreviations

ASD: Autism Spectrum Disorder; CRPD: Convention on the Right of Persons with Disabilities; EARC: Educational Assessment and Resource Centre; FGD: Focus Group Discussions; KNCHR: Kenyan National Commission of Human Rights; KOTA: Kenyan Occupational Therapy Association; NHIF: National Hospital Insurance Fund; PWD: People with Disabilities; UN: United Nations

## Introduction

Autism spectrum disorder is a diagnosis that is given to individuals with autism, Asperger's disorder or pervasive developmental disorder not otherwise specified [1,2]. As a neurodevelopment disorder with onset in childhood, it is characterized by symptoms that include impaired social communication and interaction, as well as restricted, stereotyped behaviour, activities and interests [1,2]. The disorder tends to persist into adolescence and adulthood [2]. Individuals with autism spectrum disorder can also exhibit

nonspecific symptoms like phobia, tantrums, sleeping problems, eating disorders and self-injury [1,2]. Children with ASD and their families therefore require a range of professional interventions due to the child's unique behaviours and other accompanied challenges.

There are a few studies available focusing on the challenges faced by caregivers of children with autism spectrum disorder in accessing earlier and detection plus other supportive services in Kenya. In Kenya, like the rest of the developing world, developmental disorders such as ASD have attracted little attention from the government and other stakeholders regarding establishing support services for affected individuals [3,4]. These discrepancies have hampered the efforts to address ASD-related needs and service provision [5].

The World Health Organization [2] and data from those countries which are able to capture data of ASD, indicate that one in every one hundred and sixty-two children has ASD and subsequent disability. On the contrary, the Kenyan government and other stakeholders have taken little initiative to establish

the prevalence and the impact of ASD and to allocate resources for research and training of professionals to support children with ASD and their families. Children living with disability in Kenya comprise approximately 1% of Kenya's population of over 40 million people comprises of children living with disability [6-10].

In 2008, the member states of UN were informed of the need to take ASD seriously as a public health concern and to take necessary measures to address among others, provision of all crucial services to children diagnosed with ASD and their caregivers [9]. The financial impact of taking care of children with ASD is substantial. Lavelle et al., [11]. Reported that care givers with children with ASD were utilizing health services more than those parents who did not have children with ASD. In the same study, it was reported that a greater proportion of these children required special education. Overall, all these services were associated with higher costs for caregivers [11]. In Kenya, like the rest of the developing world resource planning and implementation, research and training in the establishment of managed care for developmental disorders such as ASD takes place in a haphazard manner or does not exist at all [12]. The challenges of taking care of children with ASD in terms of accessing crucial services is enormous. Statistics from countries that have improved diagnosis and reporting systems, reflect the rising number of children diagnosed with ASD globally [13]. Therefore, mechanisms need to be in place to ensure that affected children and their families can access crucial services.

According to the Kenya government's health policy commitments, all Kenyans ought to access healthcare facilities for comprehensive services for health needs. Hospitals should be easily accessible, i.e., the distance to the hospital should not be beyond 15 kilometres. Also, these healthcare facilities should be accessible regardless of whether individuals are able to pay or not [12]. There are lot barriers to realizing the government of Kenya Ministry of Education's framework and Kenya Health Policy 2014-2030. These documents emphasize the fact that a child has the right to education, healthcare, social services and participation regardless of her/his disability. Children with ASD and their caregivers are a vulnerable group who often experience health inequalities and significant barriers to accessing crucial services compared with the general population. For example, the number of health professionals in Kenya is below the international standard of 23 skilled health professionals per population of about 10,000 people [14,15].

Despite this, they access healthcare services less often and have poor experiences when using these services. In addition, the lack of diagnostic services hinders early intervention [6,14,16-26]. Consequently, caregivers of children diagnosed with autism spectrum disorder receive little support in the form of information concerning the causes and management of ASD. A lack of professional help from the government further hampers service development and support [13,20]. Studies in Canada, Oman and Saudi Arabia confirm a lack of resources and training of professions, hindering inclusion of children with ASD in relevant institutions because of inefficient policies [3,5,21].

Measures taken by other countries include improved diagnostic and reporting systems and availing resources, which are needed to support these children and their families [22,23]. According to Baio et al., [13] the continuous rise in the number of ASD cases may be the result of advances in diagnostic tools and more available information concerning ASD. On the other hand, the high prevalence rates have direct impact on service provision and other mechanisms needed to address impairments related to ASD [24,25]. It is also significant to consider the prevalence of this condition for research purposes and other measures needed to address the challenges accompanying ASD [13,25].

With the increasing number of cases of ASD in Arab countries there was a need to develop a tool for diagnosis and guidance in the interventional process. Therefore, the adoption of the Checklist for Autism in Toddler M-CHAT [26], was useful for the early detection of ASD in children who were at risk. The tool was used for children who were below 18 months old and were suspected to be at risk. Since the questionnaires used in this tool were meant for western countries, it was translated into Arabic and modified to suit all Arab countries including Egypt and Tunisia, which shared religious faith but different social cultural, ethnic and political background. The tool was tested for six months involving all Arab countries and was reliable and valid for use. One of the advantages of its use was that it was easy to use it without necessarily requiring trained persons in regions where there was scarcity of trained professionals managing children with ASD [26]. In Kenya, like other sub-Saharan countries, children with disabilities are faced with difficulties in accessing specialized rehabilitation and other necessary support due to financial constraints and stigma from the community [26].

On the other hand, relevant measures have proven to be beneficial in the process of addressing issues concerning children with ASD and their families. Noting that initiatives may get resistance such as cultural prejudice towards children with disability, inaccessible schools and health facilities and poverty [6,14,16-19], studies conducted to establish the general population's beliefs about ASD reported that a lack of information about and treatment of ASD [4,5]. The solution they noted was creating awareness through media houses and facilitating training of healthcare professionals. The studies which were conducted in England and northern Carolina informed the researcher of the strong views on why there should be more reliable guidelines to enable early diagnostics for ASD in children. This will ensure that healthcare professionals are well trained, and parents have accurate information concerning ASD to limit confusing information from other sources [27-29]. Creating awareness is, however, not only the responsibility of government, but must be a collaborative effort by all service providers and stakeholders [24]. A good example of an educational program was implemented in Iran. This program proved to be vital in supporting affected families [27]. The surveillance approach provided by a network of investigators ascertained the potential ASD cases for the purposes of intervention planning purposes [30].

Failure to implement the available policies to support children with ASD hinders children from accessing healthcare and educational services. Their freedom to fully participate in the community is hampered by the lack of an empowerment strategy for enabling them to live with the condition [14,15,24]. The government of Kenya enacted the Persons with Disabilities Act (2003), which outlines how persons with disabilities' issues should be addressed. This includes: access to education, training, healthcare and barrier free environments. The Children's Act (2001) also combines all available laws and policies on children to ensure improvement of well-being of all children without any discrimination [9,10].

The enactment of the Persons with disabilities Act No. 14 of 2003, led to the establishment of a national council for persons with disabilities whose main role was to advocate for the rights of persons with disabilities [9]. Despite the Rights of Persons with Disabilities Article 8 of the Convention on the Rights of Persons with Disabilities (CRPD), which was adopted by the Kenyan government to ensure information about disabilities is disseminated, there are still widespread prejudice towards people with disabilities (PWDs), including children with ASD and their families. According to Kenya National Commission on Human Rights (KNCHR) it is also the responsibility of the governments of the day to utilize the available tools to disseminate the information about disability to the public [9]. However, due to challenges in the implementation of policies [11,12,18], access to healthcare services in Kenya remain inadequate in the areas of inclusive education, shortages of trained personnel and support from the government agencies [14,15,24].

Although the government of Kenya has gone a step further to ensure children with disabilities access education, some challenges remain, such as inadequate statistics on the number of children with disability, inefficient early diagnostic systems and a lack of comprehensive policy and guidelines addressing the needs of children with disability. Despite the cost-sharing system medical services remain costly and inaccessible to the majority of the population [31]. Furthermore, insufficient access to accessing healthcare services [10] and shortages of trained personnel managing children with disabilities [16,31] compounded the issue of poor service delivery. Due to these challenges many of the children with disabilities, among them those with ASD, do not benefit from the educational services offered. For instance, between the years of 1999 and 2008, fewer children with disabilities were enrolled in schools, compared to children without disabilities who attended school. Kenya may therefore benefit from the implementation of a comprehensive strategy for the inclusion of children with ASD [16].

In 1986 the Kenyan government introduced the Kenya Institute of Special Education to build capacity for children with disabilities like training teachers and research. Another focus was to connect these children within local resources [6,14,16-19]. The Educational Assessment and Resource Centre (EARC) was introduced in Kenya with the aim of identifying children with disabilities and referring patients for management [18,19]. In Kenya, teachers and healthcare workers agree that

early detection of ASD is difficult due to lack of resources and trained professionals.

The government also encouraged the non-governmental organizations and church-affiliated institutions to collaborate in assisting the children with disabilities. In addition, the government supported the organizations with human resources, finance and a good working environment [10,16,18,32]. Currently CBR is implemented in over ninety states and has been successful through involvement of the community and persons with disabilities and their families. However, on evaluation of CBR's effectiveness it was noted that more emphasis was directed at those persons with physical disabilities disadvantaging those with mental disabilities [31].

Difficulty with including persons with mental illness in the CBR programmes also prevent the children with ASD from accessing the crucial services in the community. Therefore, measures need to be taken to ensure access to crucial services as well as the implementable policies which will lessen the burden of taking care of the children with ASD.

### Purpose of this study

The purpose of this study was to describe challenges faced by caregivers of children with autism spectrum disorder to access the crucial services in Kenya. Exploring caregivers' challenges in accessing the crucial services will inform the relevant stakeholders on the need to address the barriers to accessing these services.

### Materials and Methods

A qualitative, descriptive, phenomenological study was conducted to obtain a better understanding of the lived experience of caring for children with ASD. Four focus group discussions (FGDs) were conducted with the caregivers [33,34]. The phenomenological approach entails finding the meaning of human experiences as told by the participants in the situation [33,34]. The process enabled the researcher to understand perspectives of participants as recounted by the study participants. A phenomenological approach was also suitable for understanding subjective experiences and what motivates people to behave in a certain manner [33-35]. FGD was also utilized to extract rich information from the participants and promote an element of sharing in a free and conducive environment.

### Study setting

The study was conducted at the occupational therapy clinic of Kenyatta National Hospital. The institution is a national referral facility that is situated in Nairobi, Kenya. It operates as the training and research institution for the University of Nairobi College of Health Sciences and other medical training institutions in Kenya and the surrounding areas. According to the Kenya Health Policy (1994-2010), Kenyatta National Hospital is mandated as the regional facility and therefore the hospital should set the working standards for all hospitals in the country. As a result of the specialized nature of the

hospital's services delivery, Kenyatta National Hospital faces operational constraints because of the high number of patients referred from across the country and from other East African regions [35]. Kenyatta National Hospital has a total of 22 outpatient clinics. The occupational therapy department runs one of these clinics. The department is divided into three units including the sensory integration unit, the general pediatrics unit and the physical dysfunction unit. Children with autism spectrum disorders receive follow-up appointments at the sensory integration unit. On average, 300 children with ASD are attended to at the sensory integration unit on a monthly basis. Approximately 300 children between the ages of three to seven years' access rehabilitation services every month at the Occupational Therapy department at Kenyatta National Hospital. Therefore, only 4000 children with ASD in an approximated population of 400,000 children with disability are attended to per year. This is a large percentage considering the challenges accompanying their care and the unpreparedness of the concerned institutions in addressing their plight [15]. The cost of care of these children is beyond the reach of many Kenyan families [19]; those seeking occupational therapy services at Kenyatta hospital pay approximately \$100 per month.

### Study population

The study population consisted of the caregivers of 300 children with autism spectrum disorder who were attending the occupational therapy clinic at Kenyatta National Hospital during the period of study in the months of June and July 2015.

### Sampling

A purposeful sampling technique was used to select participants. Each FGD session comprised of six caregivers divided into four groups while taking into consideration their socio-economic backgrounds, different cultures and age groups [33-34]. The selected participants were identified based on the caregivers' information rich accounts of their experience of caring for a child with ASD. The severity of the children's condition was not considered as Kenyatta National Hospital does not have capacity to measure the severity of this condition.

### Sampling criteria

To be eligible to take part in the FGDs, participants had to have met the following criteria. The selected participants had to:

- Have been bringing their children with ASD for therapy at Kenyatta National Hospital for at least the last three months;
- Have been a caregiver of a child with autism spectrum disorder for at least one year prior to the study;
- Have been aged 18 years and above;
- Be willing to give informed consent;
- Be able to share their story to give the researcher insight into their experiences;

- Have proficiency in Kiswahili which is an official language spoken by over 90% of the population in Kenya.

### Data collection

Four focus groups of ninety minutes each were conducted in a neutral place [33,34,36], especially structured to ensure confidentiality within the department. All FGDs were conducted in Kiswahili. Data collection sessions were held twice a month. Each focus group comprised of six participants (Tables 1-4), a group large enough to generate rich discussion [33,34,36]. Predetermined questions were asked with the belief that the participants' comments could influence and stimulate the thinking and sharing among the participants. The four groups were designed to be homogenous to reduce inhibition as well as produce rich discussions. The questions were designed to be short, to the point, open ended and non-threatening [33,34,36]. Questions were also worded in a way that all participants could understand. All questions asked by the researcher were introductory to the topic and were meant to make participants comfortable; they were explorative and checked if there were any important issues missed during the discussions [33,34,36]. The focus group questions were also structured to probe the emotional, social and economic burden involved in raising children with ASD [33,34,36]. Other questions were also intended to determine the accessibility of supportive services to these children and their families [33,34,36].

Participants who were related, like mother and son-in-law, were allocated to different groups. Handwritten notes were retyped immediately after every FDG, taking approximately eight hours, in clearly written wording including all observed nonverbal expression from the participants. Individual member checking sessions of twenty minutes each were conducted with all twenty-four participants to ensure the captured information reflected the true views of the participants. The total number of data collection hours was twenty-two hours. The decision to stop the FGDs was made after data saturation (recurrence of similar information in data sets) was reached.

The first FGD constituted two fathers and two mothers of children with ASD who were not couples, and two caregivers, as indicated in Table 1. Similarly, the second FGD had two fathers and two mothers and two caregivers, as indicated in Table 2. The third FGD had two fathers, three mothers, and a grandmother of a child with ASD (Table 3) and the fourth FGD had a couple (mother and father of a child with ASD) and four caregivers with ASD, as indicated in Table 4. All the caregivers had one child with ASD.

**Table 1:** Participants of FGD ONE.

Participants	Number
Father	2
Mother	2
Caregiver	2
Total	6

**Table 2:** Participants of FGD TWO.

Participants	Number
Father	2
Mother	2
Caregiver	2
Total	6

**Table 3:** Participants of FGD THREE.

Participants	Number
Father	2
Mother	3
Grandmother	1
Total	6

**Table 4:** Participants of FGD FOUR.

Participants	Number
Father	1
Mother	1
Caregiver	4
Total	6

During the FGD sessions, handwritten notes of the discussion were taken. In order to enhance the credibility of the content shared by participants during the discussion, each session was recorded on video.

Strategies used to obtain the approval of the participants to record the session included establishing rapport with the participants and assurance of complete confidentiality [17,21,32,34]. The participants were informed in advance that the session was to be recorded on video and informed consent was sought. The participants were informed that taking handwritten notes was to make sure all participants' contributions were accurately recorded. The research focus group guide [17,21,32,34] (Appendix 3) outlines the questions asked during the FGDs.

### Data analysis

Inductive content analysis was used to analyze raw data [33,34,36]. Source of raw data included field notes and video tapes. The data was transcribed verbatim before analysis was done. To ensure that the transcription reflected the totality of the discussions and facilitated analysis, transcription conventions such as symbols and word emphasis were used. To ensure that the transcribed data were accurate, the taped discussions were watched and listened to while cross-checking with the transcripts. During this cross-checking, any nonverbal behavior that was captured in the recording was inserted in the field notes.

The transcribed data were then read through to enable the researcher to gain familiarity with the text. The focus group guide (Appendix 3) was instrumental in enabling the researcher to organize and summarize the data [34-36]. The next step of data analysis involved identifying ideas and concepts. The

N'Vivo software package was used to organize and analyze the field notes and video files that were derived from the FGD sessions [34-36]. Meaningful units were coded. Codes were clustered into subcategories and these subcategories were then grouped into categories. The categories were labeled with descriptive phrases (Appendix 5). Important themes and ideas which recurred were noted. To ensure rigor of the process, a qualitative researcher who was not involved in the research was consulted to do an audit trail [34-36]. Finally, the researcher made connections between themes. Paradoxes and conflicting themes were also explored. Those themes which expressed similar opinions were merged (Appendix 5) [34-36].

### Ethical considerations

The study was conducted after approval by the Hospital Health Research Ethics Committee (Appendix 6). All the principles of ethics in research were observed during the study including provision of information concerning the study and obtaining consent in a language well understood by caregivers before and during FGDs with caregivers (Appendix 1-3) [34-36].

The researcher ensured the study obtained accurate information by employing rigor and trustworthiness of the study through inclusion of credibility, transferability, dependability, confirmability, triangulation of data, peer debriefing, as well as member checking [34-36].

### Results

The findings revealed a main theme, "The burden of caring for children with ASD". The two categories forming part of this theme include, "The caregivers' emotional dilemmas" and "Difficulty accessing crucial services in the management of children having ASD" (Table 5). This article will report on the findings of category 2. Findings from category 1 have been reported elsewhere. Description of the participant's experiences and detailed caregiver's profiles are provided in Appendix 4.

**Table 5:** Theme, Categories and Subcategories.

<b>Main theme:</b> The burden of caring for children with ASD.
<b>Category 2:</b> Difficulty accessing crucial services in the management of children having ASD.
<b>Subcategories:</b>
2.1 It is difficult to get support from family and community members.
2.2 Caregivers' frustrations regarding support from service providers.

### Theme: The burden of caring for children with ASD

This theme describes the challenges caregivers undergo in the process of seeking crucial services for their children with ASD. The caregivers highlighted their tribulations in striving for healthcare, education and other supportive services from the government. For instance, one participant (David) painfully explained how the condition of his child had drained him financially:

*"...little support from the government, this will drain you out."*  
(David)

Participants found it extremely difficult to access services needed by their children. They reported difficulty having to live with the child with ASD and experienced little support from service providers.

## Category 2: Difficulty accessing support and crucial services in the management of children having ASD

Participants discussed in detail the social and financial challenges, the burden of getting professional services as well as how their children's condition was affecting caregivers' commitment to work. Their perceptions are described under the following two subcategories: 'It is difficult living with a child having ASD' and 'Caregivers' frustrations to get support services'.

*Subcategory 2.1: It is difficult to get support from family and community members*

There are three areas, as narrated by the caregivers, which make it difficult for them to live with their children. The children's challenging behaviours and their inability to express themselves burdens the caregivers in social aspects and financially while seeking professional services for their children with ASD.

For instance, these children are regarded to be troublesome, which confines the caregivers to desperate situations of ensuring that they keep them away from the community for their children's (with ASD) own good. In fact, the desperation to keep these children out of trouble leads to the caregivers hiding them, as noted by *Hespon*:

*"these parents hide their children to protect them."*

Most of the caregivers restrict themselves to participate in activities involving social gatherings due to their children's volatile behaviours so that they do not get seen as those who "can't discipline" their children. They are mostly uncomfortable particularly when such behaviours occur in public and more so when it happens in front of a group of people who do not understand why children with ASD behave uniquely. It is worse when those who are supposed to be close to them are unreceptive, particularly the siblings who saw them as a "burden".

Other participants also lamented that these children have impaired communication skills making it difficult to be understood. As a result, Jane resorted to over protectiveness:

*"It's not that he can tell you, mum, I was hurt and so you don't allow him to go out to play with other children."*

Taking care of children with ASD demands attention, for instance, the participants noted that they were always cautious of their children's behaviours and that it was difficult for such families to be committed to other activities without keeping in mind the welfare of the affected children. On the other hand, according to some participants the financial impact of seeking professional services is enormous. Some participants noted

that frequent visits to consult with professionals as well as taking the child for therapy regularly has also drained them financially. It was also surprising that even those participants who considered themselves fortunate to access professional aid, expressed their frustration at the long procedures before they were attended to, as expressed by Liz:

*"I wish this department understands what we (care givers) undergo when we come from far, we have to make payment at cash point, these children become restless and agitated, sometimes you are told there's a network problem at the cash point, it's bad! Imagine I come all the way with this child, one hour another hour! I am told cash points are not working, can you arrange we make payments at occupational therapy department?"*

In summary, the participants shared openly their frustrations concerning the lack of support from family and community members as well as the high costs and poor quality of professional services available for children with ASD and their caregivers.

## Caregivers' frustrations regarding support from service providers

The participants raised a lot of issues pertaining to the government agencies and the lack of policies aimed at taking care of ASD children's welfare. For instance, Calleb and Boaz felt that the government agencies should formulate mechanisms which will ensure the community is well informed on the available services for issues of autism spectrum disorders. In this way, the participants felt that the managing of these children would be easier for those responsible for their care, as well as alleviating the community's negative perception towards these children and their families.

The participants indicated that the government should prioritize rehabilitation services when addressing the issue of skilled professionals qualified to handle their children's conditions by lamenting that most of them are concentrated in Nairobi's Kenyatta National Hospital.

They also expressed their concern at the lack of skilled professionals who are able to manage children with ASD, particularly in occupational therapy and places of education for children with ASD. Unavailability of services discourage most of the caregivers from working outside Nairobi. For instance, Zipporah said that she declined to take a job offer outside Nairobi because she thought of her child's care and distance from (KNH) Kenyatta National Hospital after finding out that there were neither occupational therapists nor schools that provided for the special needs of her child.

The participants also shared their frustration at the government giving low priority to the needs of children with ASD; they noted that the government should ensure that good policies are formulated to address the concern related to trained professionals in schools and hospitals on how to manage children with ASD. The participants further recommended that their government commit to the budgetary allocations for treatment and research in ASD because for them this was a national disaster, as was noted by Tom who wondered!

*“I want to know what the cause is, is it’s like nobody really knows, our government can’t initiate research project, KEMRI is doing research on AIDS and Ebola... This condition of my child is it not national disaster? Where’s budget for research and treatment!!”*

According to this study, it was not surprising for the caregivers to advise on how they thought things could be done differently if their children with ASD and many others with similar conditions could benefit. For instance, the participants emphasized the need to have free outpatient medical services for all children who attend KNH’s Occupational Therapy outpatient clinic under the cover of medical aids such as National Hospital Insurance Fund, which currently caters for inpatients services only.

Another major disappointment is when the caregivers felt that the government has not been able to ensure that there are qualified teachers in schools to manage these children. More importantly the caregivers felt there should be occupational therapists posted to schools whose responsibility will be to identify these children early enough and intervene, unlike currently where the caregivers have to seek out OT services in the hospital as suggested by Kezie:

*“The available schools should have occupational therapists and skilled teachers, yes schools are there but all those I have gone to (schools) I am told they have no experience on handling such children, those who accept to take him, every time I get calls your child is troublesome come and take him home, it makes me continue changing school (sad face) I feel very bad”*

Two participants lamented that the Department of Occupational Therapy at the hospital is not well organized to make it easier to manage the children with ASD. Their concerns were noted with the shortage of sensory integration therapists. While other participants like James wondered why the non-governmental organizations and religious organizations could not work with the government to alleviate the difficulties experienced by the children with ASD and their families.

According to the participants, the government and other stakeholders have failed to ensure there are working systems which can enable those with ASD and their families get assistance.

In conclusion, the findings highlighted emotional, social and economic challenges for caregivers of children with ASD. Therefore, the following chapter will discuss this study’s findings while highlighting links between different categories and subcategories.

## Discussion

The study focused on the challenges faced by caregivers of children with autism spectrum disorder. Kenya, like other developing countries ASD have attracted little attention from the government and other stakeholders to support these children and their families [2,9-12]. This is despite United Nations and the World Health Organization emphasize that countries should strive to addressing issues pertaining to ASD [2,9,24]. Children with ASD and their caregivers find it difficult

to access the crucial services. These vital services includes rehabilitation, schools, support from government and other stakeholders, including facilitation of research in ASD [12-15,17,19,24,26,27]. Resource planning and implementation, research and training in the establishment of managed care for developmental disorders such as ASD takes place in a haphazard manner or does not exist at all [12,17]. The Kenya government’s health policy commits that all Kenyans to access comprehensive healthcare facilities within the 15 kilometres which is not the case. This is addition to a lot of barriers observed in an endeavour to realize the government’s effort through the Kenya Ministry of Education’s for right to education for all children. Similarly, studies in Canada, Oman and Saudi Arabia confirm that a lack of resources and training of professionals hinders inclusion of children with ASD to relevant institution because of inefficient policies [5,7,23].

However, improving on measures which include investing on diagnostic and reporting systems and availing resources to support these children and their families facilitates services delivery [13,14]. For instance Baio et al. [18], reports that advancing on diagnostic tools facilitate the availability of information concerning ASD. It’s for this reason that the Arab countries were motivated to develop a tool for diagnosis and guidance in the interventional process. Consequently, they adopted the Checklist for Autism in Toddler M-CHAT [29], which useful for the early detection of ASD in children who were at risk despite the scarcity of resources [29].

Likewise, cultural prejudices as a result of lack of information hinder the treatment of children with ASD [2,4,5,8,12,13,16,19-21,26,28,29]. But studies conducted in developed countries have shown that availing enough information, training of healthcare professionals and ensuring a collaborative effort from other stakeholders alleviate such confusions [24,26-30].

In addition, failure to implement the available policies can be a hindrance for these children to access to crucial services. The government of Kenya has enacted several legislations including the Persons with Disabilities Act (2003), the Children’s Act (2001) and the enactment of the Persons with disabilities Act No. 14 of 2003 [6,9,10,12,16]. But due discrepancies in the implementation processes, access to crucial services remain elusive [6,9,10,12,16].

On the hand the cost incurred in taking care of children with ASD is enormous, this includes the cost of occupational therapy and other healthcare services. Similar high cost in health and special education services have been reported in other studies [3-5,11,20].

## Implications for OT practice

This study highlighted the challenges of caregivers of children with ASD face to access the crucial services meant to benefit their children. The care of these children is a collaborative effort which includes rehabilitation, schools, support from government and other stakeholders, including facilitation of research in ASD [2,6,8,10,15,16]. However, there are shortcomings in accessing skilled health professionals and

the meeting of norms and standards [14,15], which therefore demands fair distribution professionals to needy areas by incorporating the relevant authorities. Occupational therapy practitioners should partner with caregivers to identify ways of providing responsive and tailor-made services focusing on supportive and conducive environments in which children with ASD and their caregivers can participate. Measures should be taken to ensure policies which address issues concerned with the welfare of children with ASD are never implemented, in addition to developing guidelines meant to address issues pertaining to children with ASD and their caregivers.

## Conclusion and Recommendations

There is need for a legislation comprehensive strategy for early diagnosis, support and treatment of children with ASD and their caregivers should be implemented. Clear targets for education and health promotions are required and monitoring of progress at all levels of service delivery needed. Health professionals and service providers should commit to updated and regular training on the care and support of children with ASD and their caregivers, a requirement which should be enforced by OT's professional registration body. In addition, undergraduate health professional curricula should include content on the diagnosis, care and support of persons with ASD.

## Limitations and delimitations

The primary limitation in this research is the researcher's position as an occupational therapist at Kenyatta National Hospital at the time of the research. Transcripts were translated from Kiswahili to English. It is also important to note that the small number of participants means that one must be cautious in generalizing the findings. Strengths of the study include bracketing that was used to distinguish between practitioner and researcher roles. The fact that the FGDs were held in Kiswahili allowed participants to share freely in their home language.

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