

Assessing the implications of social work services to children with autism in Tanzania

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ABSTRACT

The desk review method guided by ecosystem theory was employed to review and present findings on the roles of social workers in the lives of autistic children in Tanzania. Dar es Salaam was used as a case study where social workers engage and address the special needs of autistic children. Findings show that there are specialised autistic services in Dar es Salaam more than any other region and that social workers play a significant role backed up by the Tanzania Child Act of 2009. Some health professionals and caregivers are not aware of the role of social workers in the care of autism. Social workers however address the needs of autistic children by promoting full and meaningful inclusion of autistic children in social functioning and accessing public goods and services. Social workers also empower autistic children and their families through home and school visits, policy advocacy and using different forms of empowerment with other professions to meet their needs. Despite these roles, their contributions are not well recognised. The paper concluded that social work training does not inform practice towards intervening with autistic children. Therefore, the paper recommended that there should be more advocacy by social workers to increase public awareness of their roles in autistic services and integration of autistic services in training and social welfare services. Social work training institutions should integrate competence to address the needs of autistic children.

Keywords: ASD, autism, autistic children, developmental delays, social work, Tanzania.

Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopment disorder that presents within a range of complex developmental disorders that are characterized by difficulties in social interaction, verbal and nonverbal communication, and repetitive behaviours (Rezendes & Scarpa, 2014). With ASD on the rise, it is essential to understand how the disorder affects families and what the family needs about specialized services from social workers

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(Comegys et al., 2014). Children affected with autism have variable presentations; therefore, the disorder is now termed Autism Spectrum Disorder (ASD) (Manji et al., 2013). ASDs, also called pervasive developmental disorders, constitute a group of neurodevelopment disorders that coalesce around a common theme of impairments in social functioning, communication abilities, and repetitive or rigid behaviours (Manji et al., 2013).

Global reports have shown that a child with ASD may appear to develop normally, withdraw, and become indifferent to social engagement. Children with ASD may fail to respond to their names and often avoid eye contact with other people (Lembuka, 2024). They have difficulty interpreting what others are thinking or feeling because they can't understand social clues, such as tone of voice or facial expressions, and don't watch other people's faces for clues about appropriate behaviour; they lack empathy and have poor social interactions (Manji et al., 2013). Globally, social workers have moved to the forefront in case management, community interaction, and social skills training among the professionals working with children with ASD (Comegys & Guggemos, 2014). Social workers provide professional support to children with ASD and their families. Social workers encounter children with ASD in various areas, including schools, day care, child welfare settings, social service organizations, hospitals, clinics, and mental health treatment facilities (Dababnah et al., 2015).

The involvement of social workers in children with autism is not accidental, as throughout history, social workers have been involved in various community activities and social problems worldwide (Lembuka, 2022). The increasing prevalence of autism spectrum disorders is a global public health and social concern that has captured social workers' attention to realize the specialized services to vulnerable populations affected by ASD, including children with autism (Dababnah et al., 2011 & CDC, 2009). The social work profession has positioned itself to enhance the well-being of individuals and help them to meet their basic needs, especially the vulnerable, and work towards empowering them, i.e., the vulnerable, oppressed, those living in poverty, and people with disabilities such as ASD (Karns, 2017).

Reports have shown that even in developed countries, autistic children are often subject to stigma and discrimination, including unjust deprivation of health care, education, and opportunities to engage and participate in their communities (Ganz, 2017). Moreover, social workers' position in helping deal with the problem is not yet highly identifiable (Australian Association of Social Workers, 2021). In the spirit of critical social work, they are conceptualizing autistic children as neuro-diverse challenges existing paradigms to change the status quo and liberate persons marginalised by oppressive methods and

systems. Social workers are well-suited to provide special needs and promote a social justice agenda for children with autism (AASW, 2021).

In the USA, the prevalence of ASD is currently estimated to be 1 in 59 children in the United States (Baio et al., 2018). This figure represents a 151% increase since the Centres for Disease Control and Prevention (CDC) first began to monitor the prevalence of ASD in 2000 (Christensen et al., 2016). American social workers are often part of the goal-planning process and are often responsible for creating and supporting individualised services for children with autism (Christensen et al., 2016).

In Europe, the problem of autism seems to be relatively low, where France has the lowest autism rate of 69.3 per 10,000 people or 1 in 144 people, whereas Portugal followed with 70.5 per 10,000 or 1 in 142 in 2017 (Hoang et al., 2019). At the same time, these findings indicate that there continue to be many children living with ASD who need services and support. More often than not, social workers engage to provide exceptional services to children with autism required throughout the growth process (Hoang et al., 2019).

In Asia, India is leading in cases of children with autism, and according to Action for Autism, over 18 million Indians are on the autistic spectrum (Swamy, 2022). The Action of Autism is one of the most well-known Indian NGOs helping children with autism and their caregivers by raising awareness about the condition and providing counselling services, specialised education, and training for parents and professionals (Swamy, 2022).

In Africa, autism is a condition highly misunderstood. The difference between the problem in Africa and other parts of the world is in who gets diagnosed and when. Children with autism in Africa tend to be diagnosed around age 8, about four years later, on average, than their American counterparts (Zeliadt, 2017). More than half of African children with autism are also diagnosed with intellectual disability, compared with about one-third of American children on the spectrum (Zeliadt, 2017). To date, almost all clinical interventions, service developments, research, and policy work for children and adolescents in Sub-Saharan Africa have focused on infectious diseases, such as Human Immunodeficiency Virus (HIV), Tuberculosis (TB), and Malaria, and on reducing infant mortality (Franz et al., 2017) with almost no focus on neurodevelopment disorders such as Autism. This indicates that the problem is not yet given attention; as a result, it seems to be non-existent (Franza et al., 2017).

Since its independence in 1961, the government of Tanzania, through the Ujamaa policy, prioritised the universal health care and holistic social welfare approach that facilitated accessible and equal health and social welfare services

including autistic children (Lembuka, 2024). The realization of the Ujamaa policy in Tanzania was contributed by stakeholders and social workers who have been putting efforts to ensure that all children, including children with ASD, can attain their fundamental human rights and access other social welfare services such as the introduction of specialised schools, special clinics and other public services workshops and seminars which bring together families, teachers, government officials, and social service providers to create awareness about the unique needs of children with autism (Department of Social Welfare, 2013).

It has been reported that still there is the existence of negative beliefs in some local communities toward autistic children and sometimes are often considered cursed, leading to social exclusion and physical violence. Still, several pioneering treatment centres in a few regions, such as Arusha, Tanga, Mwanza, and Dar es Salaam, address those concerns. However, autism is still poorly diagnosed and managed (Manji, 2018). This severe developmental disorder has social, societal, educational, psychological, and economic impact on the family (CGT, 2019). There is scarce data in Tanzania, like many other African countries, and most of these are from South Africa or Nigeria, with a few scattered elsewhere. Additionally, there is a deficit in the research on how well social workers provide specialised services to children with autism in Tanzania (Newsome, 2010).

Like other developing countries, autism is poorly recognised and managed, particularly in Sub-Saharan Africa. Data from Sub-Saharan Africa show that autism recognition and prevalence are increasing (Manji et al., 2018). It is still poorly diagnosed and managed, and there is very little information on risk factors, knowledge, and interventions. There are no translated and validated tools and inadequate expertise (Karns, 2017). The typical situation is a late diagnosis, and most of the time, cases of children with autism come with labelling children as stubborn, magical, and misbehaved (In Kiswahili language it is common to hear such terms as *amerogwa*, *anamapepo*, *mkorofi au msumbufu*) (Manji, 2018).

Tanzanian social workers support the World Health Organization (WHO) in recognizing that autism is a global public health issue. Social workers play vital roles for children with autism, 1) as legal obligations on child protection based on the Tanzania Child Act of 2009, and 2) as human rights practitioners or professionals, their contributions are not well recognized since the structure of autism care is purely positioned in clinical intervention (United Republic of Tanzania, 2009). On the other hand, the country's healthcare practice does not fully consider a non-clinician cadre to attend to patients with biological or physical challenges like children with autism (Ganz, 2017). To some extent,

this has continued to jeopardise the quality of care for children with autism who need holistic and multi-professional interventions (Ganz, 2017).

In Tanzania, the Gabriella Centre in Moshi, the Al-Muntazir Special Educational Needs Unit, and several other NGOs have organized public awareness programs to bring the issue of Autism or Usonji in Kiswahili to the fore and solicit support for these children (Manji et al., 2017). Despite social workers' engagement in providing specialised services to children with autism in Tanzania, the focus on Autism is farfetched. Lack of special training to address the needs of children with autism, shortage of adequate human resources for mental health, and teachers for special needs catering for Autism have continued to hamper the services to children with autism in Tanzania (Tanzania Association of Social Workers, 2017).

Since social workers are the guardians of human rights and vulnerable or marginalised populations, their interventions for children with autism are inevitable. The impact of autism spectrum disorders does not only affect children, but it goes beyond their families, neighbourhood, schools, and society at large. Once a child is diagnosed with ASD, the lifetime costs of caring for an individual with autism are estimated to be more than \$1.6 million (Schwartz et al., 2015), and societal costs are estimated at \$3.2 million (Ganz, 2017).

Experience from Tanzanian social workers has proven to be more holistic in addressing the special needs of children with autism and their families in their natural setting (Lembuka, 2024). The fact that social workers strive to use a holistic approach to engage various key child welfare stakeholders in the country, i.e., government, multi-stakeholders, and local communities at all levels, systems, and structures (Newsom, 2010). Despite having a shortage of social workers in the country yet they remained to be change agents in the lives of the children with autism, their families, and the communities they serve. Hence, one area in which social workers can and should function prominently is in the care of autism because the perception of people about autism is one central area that needs collective change (Karns, 2017).

The ecosystem theory can help us understand the roles of social workers in serving children with autism in Tanzania as the theory embraces ecology and a holistic perspective. According to the theory, the behavior of children with autism can be understood within the context of many levels of environmental influence. Context here refers to the wide range of systems that influence children with autism, including the caregivers and family, school, and local community, as well as broader cultural, economic, and political practices. Some of these variables have a direct impact, while some have an indirect impact on autistic children. Therefore, autism in children is a developmental process that can only be understood through the interplay of the individual and their

environment and not a static condition that exists within the child. The theory was considered relevant as its applicability in the social work profession is compatible with studying human behaviour and functioning in a social environment (Lembuka, 2021). Ecosystem theory is one of the core theories in social work that guide the practice, and early practitioners emphasized this in the profession concerning Mary Richmond, who integrated clients on the care plan with their surroundings for resource observation and psychosocial support (Bronfenbrenner, 2005).

Therefore, the paper provides a better understanding and oversight of the social worker's role in children with autism in the context of social work practice in Tanzania. The fact that social workers have relevant competence to understand the diversity of social groups and vulnerable populations, including children with autism. This review intends to determine the roles of social workers in serving autistic children in Tanzania taking Dar es Salaam as a case study.

Methodology

This qualitative research design is guided by a desk review research method to analyse the existing literature. According to Bhandari (2020), qualitative research involves collecting and analysing non-numerical data (e.g., text, video, or audio) to understand concepts, opinions, or experiences. The study used purposive sampling techniques to obtain specific information about the roles of social workers in children with autism. The simple random technique was employed to select the Dar es Salaam region among the 31 regions in Tanzania as an area of study. The purposive selection of social workers within the Dar es Salaam region who serve children with autism was thought to meet the study's objectives. Dar es Salaam region was randomly selected among all regions in Tanzania mainland. According to the Tanzania Association of Social Workers (TASWO) membership database of 2022, about 404 social workers are working in various social welfare and health service points in Dar es Salaam than all other regions of Tanzania (TASWO, 2022). Dar es Salaam was thought to be relevant to the review as many available social workers within the region provide specialised services to children with autism both in private and public settings (TASWO, 2017).

The documents were purposively selected from reliable sources both published and unpublished. A total of 15 studies and 15 reports from Tanzania concerning social work practice to children with autism were purposively selected, screened, and independently reviewed against predetermined criteria for eligibility under a systematic review. The following libraries were physically visited: The Tanzania Association of Social Workers (TASWO), and Association of Schools of Social Workers in Tanzania (ASSWOT) libraries. Also, online databases like AJOL, Google Books and Google Search were used. The final search was conducted on 30 August 2023. No date restrictions were

placed on the search. Reference lists and hand searching were undertaken to identify additional papers (Babineau, 2014). Papers were considered ineligible if they focused on autistic children, and social work or were review articles, opinion pieces/articles/letters, or editorials. Duplicates were removed and title and abstract and full-text screening were undertaken using the Cochrane systematic literature review program (Babineau, 2014).

Results

Table 1, provides an overview of specialized services to children with autism in both public and private settings in the Dar es Salaam region. The table stipulates how most available services to children with autism in Tanzania involve specialized services, special education, home visits, therapies, rehabilitation services, etc. Observation from the table shows that there are inadequate specialized services for children with autism in the country and these limitations have recently captured social workers' attention in serving children with autism (TASWO, 2018).

Table 1: List of available specialized services to children with autism in Dar es Salaam

SN	Name of Institution/Centre	Type of Service	Location
1	Strategic Alternative Learning Techniques (SALT)	Alternative Learning	Dar es Salaam
2	Hanna Bennie School	Special education needs	Kigamboni – Dar es salaam
3	Al-Muntazir Special Education Needs (AMSEN)	Special education needs	Upanga - Dar es Salaam
4	Royal Elite School	Special education	Mbezi Beach – Dar es salaam
5	Autism Therapy and Behavioural Learning Centre	Specialized service	Kunduchi – Dar es salaam
6	Mtoni Diakonia Centre	Specialized service	Mtoni Mtongani – Dar es salaam
7	Tusha Rehab Centre	Rehabilitation services	Mtoni Mtongani - Dar es salaam
8	Peninsula English Medium School	Special education	Msasani - Dar es salaam
9	Kaizora Therapy Centre	Therapy services	Dar Es Salaam
10	Sure Starts Children Centre	Special education	Ada Estate - Dar es Salaam
11	Jamadel Centre	Therapy services	Dar Es Salaam
12	Sarm's Occupational Therapy and Rehabilitation Centre	Occupational Therapy and Rehabilitation Centre	Nadharia Street, Kijitonyama
13	Godiana Pre & Primary School	Special education	Mabwepande - Dar es Salaam
14	Sunrise Nursery and Primary School	Special education	Chato Street – Mikocheni – DSM
15	Yombo Vocational Training Centre for Intellectual Impaired Youths	Vocational Training	Yombo – Dar es Salaam
16	Baba Oresta - Bunju Shule	Special education	Bunju – Dar es salaam
17	Bubble Guppies	Rehabilitation service	Goba - Njia Nne
18	Antonia Verna Rehabilitation Centre	Rehabilitation service	Dar es Salaam
19	3 Zones Autism Centre Tanzania	Rehabilitation service	Dar es Salaam
20	Kingdom School	Special education	Tegeta Salasala
21	Sinza Special School	Special education	Sinza Dar es Salaam
22	Msimbazi Mseto	Special education	Msimbazi – Dar es salaam

Source: Lukiza (2023)

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Social work intervention for children with autism is not quite different from other specialized services in the country; existing literature has shown that most interventions in Tanzania have been specialized in behaviour and communication therapies, where many programs address the range of social, language, and behavioural difficulties associated with autism spectrum disorder (Lembuka, 2024; Lukiza, 2023).

In public health settings, particular referrals, zones, and national hospitals present multi-professional teams, including social workers who have facilitated special services to children with autism, such as Muhimbili National Hospital in Ilala Municipal Council-Dar es Salaam. Despite the lack of adequate expertise in communication therapies, social workers either refer/link children with autism to attend this service and sometimes supervise such services for the interests of children. Some programmes focus on reducing problem behaviours and teaching new skills. Other programmes focus on teaching children how to act in social situations or communicate better with others. Applied behaviour analysis (ABA) can help children learn new skills and generalise these skills to multiple situations through a reward-based motivation system (Stoddart, 2017).

Through multi-professional intervention, social workers have been engaging in educational therapies for children who attend general or special education services in Tanzania; experience has shown that children with autism spectrum disorder often respond well to highly structured educational programs (Manji, 2017). Advocacy activities from the Lukiza Autism Foundation in Dar es Salaam are one of the remarkable pioneers of change and public awareness in the country toward children with autism. Following the increase of public awareness and change that successfully influenced the establishment and improvement of specialised programmes for children with autism that typically include a team of specialists and various activities to improve social skills, communication, and behaviour (Lukiza, 2023). The country has continued to experience the mushrooming of more new preschools and primary schools specialized in serving children with autism for the past five years. With support from social workers and other professionals, preschool children receive intensive, individualised behavioural interventions, which, in most cases, show good progress from learning competence to social skills (Autismontario, 2014).

Social workers conduct family therapies to parents and other family members necessary for raising a child with Autism; this can be done through home visits or clinical attendance. Most family therapy focuses on capacitating parents and family members on how to play and interact with their children in ways that promote social interaction skills, manage problem behaviours, and teach daily living skills and communication (Lembuka, 2024). Sometimes, families decide to hire social workers to provide individualised therapies depending on autistic

children and their respective family needs, including psychosocial care and support, speech therapy to improve communication skills, occupational therapy to teach activities of daily living, and other relevant life skills (Stoddart, 2017). Sometimes, social workers monitor the clinical attendance of a child with Autism and make a follow-up on specific medications that help to control symptoms. For example, certain medications may be prescribed to a hyperactive child; antipsychotic drugs are sometimes used to treat severe behavioural problems, and antidepressants may be prescribed for anxiety (Stoddart, 2017).

Providing relevant information to parents/guardians, family, and extended family members is an essential intervention to secure the welfare of children with autism. Social workers play a broad role in supporting children and youth with ASD and their families by addressing stigma, judgments, and negative attitudes toward children with autism (TASWO, 2017). Parents and other family members benefit from talking to a social worker to address the various emotions and stress of having a child with ASD in the family and to ensure their needs are met (DSW, 2013). It was observed that the social workers are working with ASD children in a peer approach that entails friendship and relationships to address difficulties with social skills, mood, and anxiety and provide help in various life transitions and tasks from childhood adolescence into adulthood (Stoddart, 2017). Social workers in Tanzania mainly apply the case management approach to address the needs of ASD children; social workers work with other professionals and become an essential part of a team in supporting a child with ASD (URT, 2020).

The school setting is a second social institution that ASD children will come into contact with after the family setting, and the presence of school social workers in some primary and secondary schools has significantly contributed to the welfare of ASD children (Weiss et al., 2013). The government has deployed social welfare workers to the ward level, and they work closely with other structures at the community level, including education settings at the community level. Both social welfare workers and teachers may consult and advise the parents or guardians when a child is suspected to need special education services. Social workers are frequently involved in evaluating student behaviour and mental health concerns (Weiss et al., 2013). After the consent, further counselling services are provided to individual students, facilitate groups, assist families with community resources, and consult with teachers, parents, and other service providers in the student's life (Dababnah et al., 2011).

Discussions

The involvement of social workers in ASD children is challenged by the health behaviour practice in the society where the general understanding of the public towards ASD children is purely medical and disregards the psychological and psychosocial intervention of social workers. This is because they are not fully aware of the roles and functions of social workers in intervening in ASD client systems. The same applies to medical professionals who are not aware of social workers' roles and functions in medical services, including children with ASD (William, 2014). Advocacy is one of the core functions of social workers as it positions social workers as an unwavering support system that will ensure that service users are independent of service providers in the long run. They stand and speak for the marginalised and vulnerable groups until their voice is heard and acknowledged (Dalrymple et al., 2013).

The involvement of social workers in ASD children in the Dar es Salaam region represents a national picture of their intervention, and the review highlighted the vivid gaps of segment and scattered services that need more holistic and multi-professional care to be offered to autistic children. Also, reviews have shown an urgent need to feature social workers more prominently in the care of autistic children, primarily from early detection, referral points, and psychosocial care and support services (Olaitani et al., 2022). The community of health providers also needs to be sensitised and made aware of the critical role of social workers in any multi-disciplinary team to provide care to children with autism (Olaitani et al., 2022).

In the autism continuum of care, social workers should be on the frontline in identifying effective treatments and creating early intervention plans that will continue to assist ASD children in improving, maintaining, adapting, and functioning within their learning environment and social development (Kebede et al., 2021; Olaitani et al., 2022). The need for social work to be more integrated in health settings in Tanzania and beyond is inevitable through the applicability of the medical and social models of disability, noting that the social model of disability perspective is consistent with the social work profession's person-in-environment approach that is relevant in addressing the unique needs of ASD children (Jolynn, 2016).

The presented findings are from the selected ASD service points in Dar es Salaam, where secondary data was sourced using a purposive sampling method that could have been biased. Also, the study excluded literature that was concerned with stakeholders on ASD care such as teachers, parents, and clinicians. It can be said that their knowledge and experience of ASD children is still not known. This is a limitation as it is hard to develop an inclusive intervention without considering all stakeholders. Therefore, the area of ASD still demands comprehensive research to establish the challenges and gaps in

the continuum of care for children in Tanzania, where it can be conducted in various locations while prioritizing rural areas.

The study provides recommendations based on the reviewed literature and the author's observations. With increasing challenges, various efforts that have been taken by the government and stakeholders toward the continuum of care have little impact compared to the unique needs of children with ASD in Tanzania. Most of these efforts have side-lined social workers and, on the other hand, have not placed children with ASD at the centre. The study therefore recommends the following;

- Working in a professional team while serving children with ASD exposes social workers to new experiences and also improves the quality of life of children with ASD. Therefore, social workers are called upon to work in various teams to gain more satisfaction from working together in multi-professional teams.
- Since parents, guardians, and family members are the first observers and identifiers of ASD in a child; it is, therefore, important to focus particular educational campaigns on the general public especially parents, guardians, and family members about early signs of ASD.
- There is a need to develop a national policy guideline on ASD in Tanzania that will consider social workers and all critical stakeholders in comprehensive intervention on the ASD continuum of care.
- Current social work training institutions should endeavour to provide special training in ASD intervention necessary to identify, screen, and provide quality care to these children with special needs.
- Social workers should create psycho-educational support groups for parents, guardians, and close family members of children with ASD. This will go a long way in helping them to acquire unique life skills for dealing with children with ASD and to accommodate their social needs learning needs, and communication skills.

Conclusion

Tanzanian social workers do not work on an isolated island but instead with the client system and other professions that need more emphasis on a multi-professional and holistic approach to realize the rights and unique needs of children with ASD. They have multiple and complex needs that demand multi-professional intervention for effective services. Effective functioning of multi-professional teams is essential in improving care outcomes, reducing the risk of harm, and enhancing both the client system and social workers' satisfaction. Working with a multi-disciplinary team will provide more opportunities for social workers to acquire new experience and competence necessary to improve the quality of service. On the other hand, it's an opportunity to provide comprehensive ASD care. With each professional team member focused on a

different aspect of the child's need, providers are more likely to identify areas of need and subsequently effectively manage those needs.

Social workers should ensure they maintain the value of collaboration in the continuum of care for ASD children. It can be enhanced by increasing social worker knowledge and skills relevant to autism care, eventually resulting in improved quality of ASD children, patient and family-centred care, and higher satisfaction with healthcare services for children with autism and their families (Morris et al., 2018). The roles of Tanzanian social workers in serving and promoting specialised services to children with autism are limited, and their roles and functions are limited to direct social work practices. Apart from the lack of a specific policy guideline on ASD in the country, many challenges and opportunities for ASD and children with autism have not been prioritised by the national agenda or relevant stakeholders on child welfare.

Conflict of Interests

The authors have declared no conflict of interest with respect to this research work.

Declaration

The authors declare that this paper has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere.

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