



# 5. Special healthcare needs of children with disabilities in Tanzania: Challenges and recommendations

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**Abstract** Children with disabilities have specialized health care needs. In Tanzania, political efforts have focused on improving these children's access to specialized health care. This chapter explores some of the key challenges still facing children who live with disabilities, despite these efforts. We discuss possible ways forward, including the development of effective assessments and intervention plans for this vulnerable population.

**Keywords** healthcare needs | healthcare access | challenges | children with disabilities | Tanzania

## INTRODUCTION

The United Nations Children's Fund provides a global estimate of 230 million children, ages 0–17 years, living with a disability, with 28.9 million children found in Eastern and Southern Africa (UNICEF, 2021a, 2021b). In Tanzania, in particular, more than half a million (611,398) children and youth ages 5–24 years, live with disabilities (Ministry of Finance and Planning, 2019). Of these children, the main types of disabilities include difficulty seeing (1.5 percent), hearing (1.3 percent), walking (1.2 percent), remembering (1.7 percent), communicating (1.2 percent), self-care (1.2 percent) and persons with albinism (0.6 percent). Such children have special health needs (Perrin, 2002), and they require timely and appropriate health care services.

Studies have found that being able to access health care services enables children with special needs to grow physically and emotionally. It helps them to develop the social skills and self-esteem required to reach their full potential as adults with a contribution to make to society (UNICEF, 2013; El-Daw & Hammoud, 2015). The family also benefits, as access to health care services helps families gain social

support (Schilling et al., 1984), assists them to develop more positive attitudes about their child (Gupta & Singhal, 2004) and improves their understanding and acceptance of their child's disability (Hong et al., 2014).

However, access to services for these children living with disabilities and children with special health care needs (CSHCN) is a global challenge (Vergunst et al., 2017). These children and their families do not have equal access to health care services compared to children who are able bodied. This is especially the case in low-income countries (WHO, 2015). In Tanzania, the infrastructure in most healthcare facilities is reported to present significant challenges for people with physical disabilities who need to access these services (Ndyamukama et al., 2022; Rohwerder, 2020). In this chapter we unpick some of these challenges, since these may be experienced by children living with disabilities and with healthcare needs. We then propose possible ways forward, including the development of effective assessments and intervention plans for this vulnerable population.

## **CHALLENGES TO ACCESS**

The challenges for children with special health care needs accessing specialized health care in Tanzania are varied.

### **Lack of resources**

A lack of state funding for disability services places an unsustainable financial burden on the family of the child living with a disability. Lack of health insurance, underinsurance, and insurance not paying for specific and critical components of care create serious challenges for the child and their family. Families are therefore largely compelled to make hard choices as to whether they are able use their family's limited resources to support their child's needs, and often they make substantial sacrifices to obtain adequate care (Mbwilo et al., 2010). They are often unable to do so, which leads to avoidable problems in the child's health, development and capacity to function. In other words, socio-economic impediments affect children with special health care needs and their caregivers' access to the healthcare services required (Nota et al., 2015) and substantially lower these children's quality of life (Adugna et al., 2020).

### **Poor communication between health services and caregivers**

The health status of children with special health care needs requires close frequent monitoring and communication between health care providers and between

health care providers and the families. Despite this, there is a paucity of information regarding how communication between health care providers and families can be best organized (Aruda et al., 2010).

### Lack of specialized centres

Evidence shows that care for CSHCNs is best delivered by specialized centres, as these can improve clinical outcomes, as measured by reduced hospitalizations and emergency department admissions. Comprehensive, specialized team-based care, even with limited resources, can improve the delivery of health care for children with complex medical needs and mental health disorders (Moeenuddin et al., 2019). Despite this, in Tanzania there are varied but on the whole inadequate human resources to deliver specialized services. The few facilities available are located in Dar es Salaam (Muhimbili University of Health and Allied Sciences, Elizabeth Glazer Pediatric Aid Foundation, Autism Centre, and the Comprehensive Community-Based Rehabilitation Centre Tanzania (CCBRT)). These facilities tend to focus on selected health aspects including mental disabilities, learning disabilities as well as hearing and visual impairments. Specialty centres are almost unavailable beyond the capital in rural communities, meaning that the distance from the family home and the availability and cost of transportation are major barriers to accessing health care for these children.

### Cultural discrimination

There is cultural discrimination against those with disabilities in Tanzania, and the levels of unhelpful myths surrounding disability are unacceptably high. Traditionally, special needs children were mostly kept hidden at home, and they were seen by some as a “shame” and “God’s punishment” on the family (Tanzania Mainland Legal and Human Rights Centre and Zanzibar Legal Services Centre, 2019). Within the family, mothers are particularly blamed for these children (African Initiatives, 2018). Because of these cultural beliefs, children living with disabilities can weaken family relationships and eventually lead to family breakdown (African Initiatives, 2018).

### Lack of knowledge on how to deal with the child in the family

Children with disabilities may be overprotected by their parents (African Initiatives, 2018), and some families have overly low expectations of the child’s

abilities and possible contributions to society (African Initiatives, 2018). This is linked to families lacking training on how to manage and work with their CSHCN and to clear information being largely unavailable or costly. There is also a lack of information regarding parental concerns and how these can be addressed (Aruda et al., 2010).

### Lack of knowledge in primary care professionals

Information on the basic primary care needs of CSHCN and their families is also unavailable for health. General or sub-specialty services, such as primary care physicians, are reported to have inadequate knowledge of and training with this population group (Adugna et al., 2020). They have little information or knowledge on how best to assist and empower parents and families (African Initiatives, 2018). They also have limited capacity to coordinate the care delivered by multiple services in order to support these children.

### Lack of data and research

Even though the United Nations Convention on the Rights of Persons with Disabilities of 2006 (United Nations, 2006) provides specific articles that call for the international collection (Article 31) and reporting (Article 36) of statistical data on disability, it is a major challenge to produce disability data that is valid and reliable and comparable with international statistics (Loeb, 2013). This lack of data stems from a limited understanding and definition of what disability is in children. It also arises due to stigma or poor detection systems that prevent the collection of reliable data (McNally & Mannan, 2013). The varying nature and severity of disability further complicate its measurement (Lindley & Mark, 2010). There are concerns therefore that the number of children with disabilities remains underreported in Tanzania and Africa as a whole (African Initiatives, 2018). Where, in higher-income countries, data on special needs children is more readily available from a large array of sources, including censuses, administrative records, national disability surveys, and national household surveys (UN Department of Economic and Social Affairs, 2010), data is less available in lower-income countries such as Tanzania. There are almost no recent studies that address CSHCN in Tanzania, and the few studies available have focused on problems mainly associated with mental illnesses (Lwoga & Mosha, 2013). Further, many children with disabilities and special health care needs are unidentified by the health care system and/or not declared by the family (Mbwilo et al., 2010).

## Lack of political will

There is a lack of political will and overall a lack of a practical pro-disability ethos in health care planning in Tanzania. Children living with disabilities and with special health care needs are largely invisible in Tanzanian governmental policies. Mentions of children with special health care needs are largely absent from Tanzanian National Health Policy historically. Specific guidelines for healthcare for persons with disabilities were only included in the National Health Policy in 2007; these sought to address barriers for people with disabilities to accessing health care services in the country (TEPDGHO, 2018). The 2010 Persons with Disabilities Act made provisions for health care, social support, accessibility, rehabilitation, education and vocational training, communication, employment or work protection, and promotion of basic rights for persons with disabilities. However, the act still fails to meet the standards of the Convention on the Rights of Persons with Disabilities, which is an international human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities (Rohwerder, 2020). The first National Policy on Disability (2004) set out the considerable challenges faced by people with disabilities in Tanzania and the intended measures to be taken to mitigate them, including a Disabled Persons' Development Fund (African Initiatives, 2018). The government also had the National Disability Mainstreaming Strategy (NDMS) of 2010–2015. Despite the variety of legislation to protect the rights of people with disabilities in Tanzania, implementation is weak and few detailed approaches exist. Moreover, awareness of national disability laws and policies is low, and most national and local plans and budgets do not cover disability issues, which makes implementation challenging. In addition, there are no established guidelines and rules to localize the implementation of the laws at grassroots levels.

## RECOMMENDATIONS

Based on these challenges that children with special health care needs face when accessing health services, we now propose four main ways forward in the Tanzanian context.

### Better identification of children with special health care needs

To provide, treat, support, and care for special needs children, it is important first to accurately identify these individuals (Stone-MacDonald, 2012). This is the starting point for increasing screening, improving diagnosis, and enhancing the

management of chronic conditions which together help children to live longer (Smythe et al., 2021). This process begins with a clear definition of what is meant by special needs, how we define children with *special needs* and specifically how we identify their *special health care* needs. With the latter in mind, we spell out each of these definitions, below.

The term “special needs” is used to describe a person with a difficulty or difference that requires more assistance or specialized services when compared to other persons. This includes difficulties such as physical, emotional, behavioural or learning disability or impairment that causes an individual to require additional or specialized services or accommodations. For instance, missing limbs may be classified as special needs when one needs assistance to walk to perform daily chores. Further, the types of special needs vary in severity: some may have little effects, others mild, while there are those with huge effects.

The general conceptualization of special needs also applies to children. A special needs child is someone who needs special attention measures that other children do not (Wilson, 2002). For instance, a child with a general learning disability finds it more difficult to learn, understand, and do things compared to other children of the same age. However, like all children and young people, children with learning disabilities continue to progress and learn throughout their childhood but more slowly (Wilson, 2002). A special needs child may have difficulties with their physical mobility or challenges communicating. They therefore need different or additional skills than other children to manage in the classroom and real-world settings.

For children, special needs are linked to a range of conditions including autism, cerebral palsy, Down syndrome, dyslexia, dyspraxia, blindness, deafness, ADHD, cystic fibrosis, cleft palate, and missing limbs. Speech or language delays, cognitive delays, social and emotional disorders, and learning disabilities are also included. Some children are born with these conditions, whilst others acquire them through disease, trauma, or environmental causes (Marrus & Hall, 2017). In both instances, these conditions impose limitations on these children when they perform daily activities. These challenges place substantial limitations also on their longer-term life aspirations (Solarsh & Hofman, 2006).

Health care is the maintenance or improvement of health via the prevention, diagnosis, treatment, recovery, or cure of disease, illness, injury, and other physical and mental impairments in people. Health care is delivered by health professionals in fields including but not limited to medicine, dentistry, pharmacy, midwifery, nursing, optometry, audiology, psychology, occupational therapy, physical therapy, and athletic training. Children living with a disability or disabilities will have special health care needs related to the challenges they face. There are four major

domains of these challenges (Castellani et al., 2022). They include physical challenges such as muscular dystrophy, multiple sclerosis, chronic asthma, and epilepsy; developmental challenges such as Down syndrome, autism, dyslexia, and processing disorders; emotional challenges like bipolar, oppositional defiance disorder; and sensory impairment such as being blind, visually impaired, deaf, or with limited hearing. All these conditions require medical management, health care interventions, and/or the use of specialized services or programmes offering services of a type or amount beyond that required by children generally. Because of that, the federal Maternal and Child Health Bureau define children with these special health care needs as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998).

The clarity and breadth of defining a child living with a disability and their special health care needs have contributed to the acceptance and mainstreaming of disability. It should be included in all future Tanzanian health policy formation and health/social care professional training.

### Alleviating the financial burden of disability

More government funding directed at CSHCNs and tax incentives to encourage the use of specialized treatment and medications could alleviate the financial difficulties experienced by parents and caregivers. More comprehensive health insurance could also be introduced in Tanzania and be deemed essential for children and youth with special health care needs. With adequate financial support, these children would be better able to access critical care and services such as diagnostic testing, primary care, specialty care, hospital services, prescription drugs, therapies, mental health services, durable medical equipment and supplies, hearing aids, and other health-related services. Access to comprehensive care and services is critical for detecting health problems, preventing the deterioration of physical or mental health, and maximizing a child’s potential to learn, play, and develop along with his or her peers. Some of these services may benefit only a small handful of children, but for these children, they will make the difference between life and death.

### Improved communication and coordination of health information

Chronic disease experienced by many CSHCN requires multiple types of care from different providers in different kinds of medical settings. Better

coordination of care is required than is currently available (WHO, 2015). The latter, if done effectively, is also likely to help to reduce the cost of care (WHO, 2015). Improved communication between schools and their primary health care providers is particularly important, and there is a strong argument that there should be more investment in school health services (Aruda et al., 2010). Schools have a part to play in the diagnosis of children with special needs, and they may be suitable locations for conducting initial screening tests to identify the children who may have special needs. These screening tests are designed to identify academic or learning problems and sensory or physical problems in young children (Lipkin & Macias, 2020).

### Increasing specialized services and upskilling of primary care professionals and caregivers

There needs to be measures to redress the limited provision of specialized services for children with disabilities in Tanzania. This means a wider coverage of these services to access children, especially in rural communities.

Alternatively, there is a need to upskill primary care professionals and other caregivers. This would entail providing more health information to Tanzanian parents/caregivers and primary care professionals alike (for example, community doctors and nurses). Appropriate information would help them engage in “better-informed decision-making, better and more tailored treatment decisions, stronger patient-provider relationships, increased patient compliance and better medical outcomes” (Czaja et al., 2009, p. 126). Further, Tanzania’s health care systems need to ensure that children living with disabilities have their special health care needs addressed in both home and community-based settings in addition to specialist provision.

Providing information to families and primary care professionals may improve awareness of children’s needs at a district and local level that may filter up into improved awareness in secondary care as well as state policy-making, service monitoring and evaluation. Part of the district- and local-level awareness could include upskilling Tanzania’s cadre of village health workers, who serve to mobilize communities and link them to health centres, dispensaries, and hospitals (United Republic of Tanzania, 2019). Promoting awareness also involves promoting awareness of disability in the wider population, so that the isolation and shame that families, mainly mothers, experience (African Initiatives, 2018) can be alleviated. Community-based parent support groups could be another way of achieving this.



## Prioritizing research and national data sets

Research on paediatric health and childhood disability is needed to enhance the evidence-based practice and policy-making in sub-Saharan Africa in general and Tanzania specifically. A broader range of stakeholder perspectives is required in future studies including the voices of the children themselves, their parents and caregivers, and primary healthcare professionals. Data repositories including data on health financing of CSHCN are also required. Further research is required to identify further gaps and barriers to care and develop activities related to these identified areas.

## CONCLUSION

Attitudinal problems, poverty, inadequately trained healthcare professionals, and physical inaccessibility are perceived to be major barriers to healthcare access for CSHCN in Tanzania as in low- and middle-income sub-Saharan African counties. Likewise, efforts for policy development and improving physical accessibility, public disability awareness, and professional and parental support are key facilitators that need to be promoted. Thus, health care professionals working with CSHCN should be aware of these barriers and facilitators to develop effective assessments and intervention plans.

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