

Tanzania | June 2025

System-level analysis of early detection and referral systems for children with, or at risk of, disability in mainland Tanzania

Report

Stevens Bechange, Zara Durrani, Humaira Hansrod, Ignatus Jacob, Edwin Maleko, Daniel Munday, Oliver Njogopa and Priscilla Wahome



thrive

This report contributes to knowledge and understanding of community and primary healthcare systems for early detection and referral of children with, or at risk of, disabilities in resource-limited settings in sub-Saharan Africa, and looks at the factors that enable or constrain these systems.

Authors

Stevens Bechange, Sightsavers

Zara Durrani, Oxford Policy Management

Humaira Hansrod, Oxford Policy Management

Ignatus Jacob, independent consultant

Edwin Maleko, Sightsavers

Daniel Munday, Oxford Policy Management

Oliver Njogopa, Government of the United Republic of Tanzania, Prime Minister's Office – Labour, Youth, Employment, and Persons with Disability

Priscilla Wahome, Oxford Policy Management

Recommended citation

Bechange, S., Durrani, Z, Hansrod, H., Jacob, I., Maleko, E., Munday, D., Njogopa, O. and Wahome, P. (2025). *System-level analysis of early detection and referral systems for children with, or at risk of, disability in mainland Tanzania*. Thrive, Oxford Policy Management. https://thrivechildevidence.org/wp-content/uploads/2025/10/Thrive-Report_System_analysis_early-detection_referral-systems_children-with-disabilities.pdf

Disclaimer

The Thrive programme is funded by UK International Development from the UK government and by New Zealand's Ministry of Foreign Affairs and Trade (MFAT). It is managed by Oxford Policy Management in collaboration with the Institute for Fiscal Studies.

The findings, interpretations, and conclusions expressed in Thrive publications are entirely those of the author(s) and do not necessarily represent those of the Thrive programme or Oxford Policy Management, our funders, or the authors' respective organisations. Copyright for Thrive publications remains with the author(s).

Acknowledgements

This study report is the product of intensive work by several players who made different contributions, and in many forms. We would like to thank the study participants who generously contributed their time and expertise through interviews and focus group discussions as part of this research, including parents and caregivers, community health workers, government staff, NGOs and international organisations working in the disability sector in Tanzania. We also extend our gratitude and acknowledge the unwavering support and leadership of the stakeholders listed below, whose coordination and technical inputs were very helpful throughout the planning, implementation and report writing phases of the study:

- Permanent Secretary, Prime Minister's Office – Labour, Youth, Employment, and Persons with Disability
- Director, Persons with Disability Unit, Prime Minister's Office – Labour, Youth, Employment, and Persons with Disability
- officials from the President's Office – Regional Administration and Local Government
- officials from the Ministry of Health
- officials from the Ministry of Education, Science and Technology
- officials from the Ministry of Community Development, Gender, Women and Special Groups
- local and district-level government officials from Tanga, Lindi and Shinyanga
- National Institute for Medical Research.

We also extend special thanks to Catherine Fidelis Amri for her inputs on design, Beatrice Mkani for her support with training and pilot, Huma Irfan for her work on coding, and the entire data collection team – Julieth Manyara, Beatrice Bilikwija, Shimwe Ngeze, Afisa Ramadhani and Sharon Sije – for conducting the interviews and discussions as well as for the transcriptions. We also wish to recognise colleagues from the Oxford Policy Management and Sightsavers Tanzania country offices for logistical support: Deogardius Medardi, Kaley Milao, Zera Ombeni and Feliciano Kinabo.

Finally, we are grateful to Esther Elisaria, Elena Schmidt, Kate Gooding and the Thrive quality assurance team for their guidance and review of this study report.



Oxford Policy Management
Ground Floor, 40–41 Park End Street, Oxford, OX1 1JD T: +44 (0)1865 207 300
Registered in England 3122495
thrivechildevidence.org | @Thriveevidence

Contents

Executive summary	i
Introduction.....	1
Methodology	6
Findings.....	12
Discussion.....	42
Conclusion	49
Recommendations	50
References	51
Appendix A – Rationale informing sample selection	58
Appendix B – Topic guides.....	59

Acronyms and abbreviations

CHW	community health worker
DHIS	district health information system
DHS	demographic and health survey
FGD	focus group discussion
HMIS	health management information system
IDI	in-depth interview
MoCDGWSG	Ministry of Community Development, Gender, Women and Special Groups
MoEST	Ministry of Education, Science and Technology
MoH	Ministry of Health
NGO	non-government organisation
OPD	organisation of persons with disability
PD-MIS	persons with disability management information system
PHC	primary health care
PMO-LYED	Prime Minister's Office – Labour, Youth, Employment, and Persons with Disability
PO-RALG	President's Office – Regional Administration and Local Government
RCH	reproductive and child health
UN	United Nations
UNCRPD	UN Convention on the Rights of Persons with Disabilities
UNPRPD	United Nations Partnership on the Rights of Persons with Disabilities
UNICEF	United Nations Children's Fund
WHO	World Health Organization

Glossary

Assistive devices: As stated in the National Assistive Technology Strategy,¹ assistive devices are devices whose primary purpose is to maintain or improve an individual's functioning and independence to facilitate participation and to enhance overall wellbeing. They include items such as wheelchairs, glasses, prosthetic limbs, white canes, hearing aids and digital solutions such as captioning, speech recognition and time management software.

Assistive technology: An umbrella term covering the systems and services related to the delivery of assistive products and services. This includes innovative means and mechanisms designed to assist people with a disability to live independently at home or in residential facilities and improve quality of life.

Children at risk of disability: Those who, due to biological, environmental, or social factors, have an increased likelihood of developing physical, cognitive, sensory, communication, or behavioural impairments that may affect their ability to fully participate in daily activities and reach developmental milestones.

Children with a disability: For the purpose of this study, children with a disability includes those under the age of 5 who have physical, mental, intellectual, sensory, or developmental impairments that may hinder their full and effective participation in society on an equal basis with others.

Diagnostic equipment: Specialised devices and technologies used by healthcare and developmental professionals to assess, detect and monitor physical, cognitive, sensory, or developmental impairments in children.

Disability: Physical, mental, intellectual, or sensory impairment that, in interaction with various barriers, may hinder a person's full and effective participation in society on an equal basis with others.

Inclusive education: The approach in which learners with disabilities and special needs, regardless of age and disability, are provided with appropriate education within regular schools.

Screening tools: Structured instruments, checklists, or procedures used to quickly assess whether a child may be at risk of developmental delays or disabilities. They are designed to identify early signs of impairment across physical, cognitive, sensory, emotional, or social domains – often before symptoms become more pronounced.

¹ Government of the United Republic of Tanzania. (2024). *National assistive technology strategy 2024–2027*. <https://www.kazi.go.tz/uploads/documents/en-1734703693-NATIONAL%20ASSISTIVE%20TECHNOLOGY%20STRATEGY-2024-2027%20SIGNED%2021-11-2024.pdf>.

Executive summary

Introduction

The problem

Early detection of disabilities in children is key to effective and inclusive early childhood development. Early detection enables the design and implementation of effective follow-up and rehabilitation services so that further delays in the child's development are prevented. Existing evidence suggests there is an urgent need to strengthen disability identification systems across countries and especially in resource-limited contexts, such as Tanzania, where the number of children who survive but who are not thriving is ever increasing.

Moving towards a solution

Strengthening programmes to identify and support children with disabilities requires more evidence on the strengths and challenges of existing early identification systems. We need evidence about both 'what works' and 'why it works' in relation to early detection and empowerment of parents, including evidence on the role of health and education providers at community level. This report presents findings from an exploratory qualitative study examining the functionality, interconnections, and adaptability of community health workers (CHW) and primary healthcare (PHC) systems in regard to facilitating early detection and referral of children with, or at risk of, disabilities in in purposively selected regions of mainland Tanzania.

Research objectives

Five main research questions guided our study:

- What are the main policies and guidelines for the early detection and referral of children with, or at risk of, disability in mainland Tanzania at the primary and community health levels?
- How are the current primary and community health systems for early detection of disability in pre-school children structured, and how are they connected with other systems involved in referrals and follow-up?
- What factors contribute to the strengths and weaknesses of these systems, including for different types of disability?
- How effective are the existing primary and community systems for detection and referral from the perspective of service providers and other stakeholders?

- What lessons does the Tanzania case study provide on strengthening integrated service delivery systems for early detection and referral of children with, or at risk of, disability, nationally, regionally and globally?

Methods

This descriptive study draws on qualitative data collected between November 2024 and February 2025. The study included an initial document review and stakeholder mapping, followed by primary data collection to gather the perspectives from purposively selected stakeholders: parents and caregivers of children with disabilities, community leaders, service delivery staff, policymakers and policy implementers. Data was collected through in-depth interviews (IDI), group interviews, and focus group discussions (FGDs) with a non-probabilistic, purposive sample of 40 stakeholders from Tanga, Lindi and Shinyanga regions.

We used a modified version of the World Health Organization's (WHO's) six building blocks of health systems as the primary organising framework to guide study design, data analysis, and reporting (WHO 2007). Data was analysed thematically.

Ethical approval was obtained from the Ifakara Health Institute Institutional Review Board (IHI-IRB) and the National Institute for Medical Research (NIMR). Overall permission to conduct the research was obtained from the Tanzania Commission for Science and Technology (COSTECH).

Key findings

- Despite the strengthening of policy oversight for disability service delivery through the Prime Minister's Office – Labour, Youth, Employment, and Persons with Disability (PMO-LYED), the involvement of multiple government ministries, departments, agencies, and non-government organisations (NGOs) makes coordination difficult. Gaps in policy dissemination and varied levels of understanding persist across government. Although NGOs supply vital resources, integrating their work into government frameworks remains challenging.
- While formal definitions of disability in the country align with international standards, practical understanding differs across government sectors, healthcare workers and communities. Insufficient clarity creates confusion in service eligibility and healthcare interventions for children with disabilities.
- At the community level, stigma, misinformation and traditional beliefs often lead to neglect, social isolation and barriers to early detection and seeking care for children with disabilities. Efforts to raise awareness are increasing but challenges remain in shifting perceptions and improving access to services.
- A range of constraints hinder good practice in early detection and referral for children with disabilities. The persons with disability management information system (PD-MIS) has been used to track disability information in pilot regions but is not yet accessible or used in all regions. In the research districts and

communities, formal disability documentation systems were not yet established, and as a result families rarely received written proof of their child's condition, making access to services harder.

- A shortage of healthcare workers means that disabilities in children often go undetected in PHC settings. While CHWs play a crucial role, they are often not provided with adequate training on disability identification, making detection inconsistent. Efforts are underway to scale up the number of CHWs and to improve their training but financial challenges hinder progress.
- Funding for childhood disability services in the country remains limited, with external donors continuing to play a significant role alongside government efforts. This contributes to gaps in early detection and referral for children at risk.
- While it is government policy for children under 5 (including those with disabilities) to be treated at no cost at public sector health facilities, many families still face out-of-pocket costs, including consultation fees, medical expenses and transportation.
- Basic screening tools are often scarce, especially in rural areas, forcing health workers to rely on observation. Budget priorities frequently overlook essential disability-related supplies, limiting care and interventions for affected children.
- Health facilities and CHWs record disability inconsistently, relying on general health forms that do not differentiate between impairments and verified disabilities. Some NGOs and government agencies run separate disability tracking initiatives but insufficient coordination leads to duplication and missed opportunities.

Conclusions

This study has highlighted strengths and challenges of early detection and referral for children with disabilities in a resource-limited setting. The findings are not generalisable to the whole of Tanzania but may provide insights that are useful for other regions of the country.

While CHWs play an important role in connecting families to health care, they do not consistently receive the training and resources they need to properly identify disabilities. Stigma around childhood disabilities discourages parents from seeking help and financial struggles make early care difficult to access. At the same time, informal support networks among parents have proven useful in guiding families towards services and providing encouragement but they cannot replace a more organised system.

Stronger coordination between government agencies and NGOs is needed to improve detection and referral for children with disabilities and to make services more integrated in Tanzania. Increased resource allocation can help train and motivate CHWs and PHC workers to better identify and refer children in the early years. Families should be empowered to recognise early signs of disability and feel confident seeking assistance. Addressing financial barriers, reducing stigma and improving data tracking for referrals will also help ensure children with disabilities receive timely care and support.

Introduction

Background and rationale

In 2021 there were over 50 million children with disabilities under the age of 5 in low- and middle-income countries (Kamiya 2021). There are two major United Nations conventions relevant to children with disabilities: the UN Convention on the Rights of the Child (UN 1989) and the UN Convention on the Rights of Persons with Disabilities (UNCPRD) (UN 2006). Both conventions affirm that children with disabilities have the right to develop to their full potential and that governments should guarantee that children with disabilities receive high-quality education on an equal basis with others (Le Fanu et al. 2022; Smythe et al. 2021). This commitment is also reinforced in the Sustainable Development Goals, specifically targets 4.5 and 4A, which aim to promote inclusive and equitable education for all (UN n.d.).

Early detection of disabilities in children is key to achieving these educational and developmental goals. If disabilities in children are not detected in time they may worsen, making interventions more challenging (Scherzer et al. 2012). Early detection can also help families, healthcare professionals and specialists to provide appropriate specialised services to support the inclusion and participation of children with disabilities in schools and the wider community. However, scaling up early childhood development programmes without recognising children's individual needs may lead to lifelong inequities. Children with disabilities often struggle to access these programmes, which deepens existing health and education disparities (Lynch et al. 2023).

In resource-poor settings there are often gaps in the identification of children with disabilities in the early years. Children with disabilities also continue to face stigmatisation, prejudice and various forms of exclusion (Sood et al. 2022; Smythe et al. 2020). In sub-Saharan Africa, negative attitudes towards disability remain one of the most pervasive barriers to inclusion (Adujna et al. 2020; Adujna et al. 2024; Mkabile et al. 2021). Stigma and discrimination influence parents' decision-making, sometimes leading to them hiding children or not sending them to school. In Tanzania, cultural beliefs and limited awareness contribute to misconceptions about the causes of disabilities in many communities (Swai et al. 2024; Tungaraza 2012). Families of children with disabilities continue to experience difficulties in accessing facility-based child health services, resulting in limited interactions between children with disabilities and healthcare providers (Buhori 2024; Nyanza et al. 2023; Mesiäislehto 2024). There is some evidence to suggest that community and public healthcare (PHC) workers, who are most accessible to the local populations, are not equipped to screen and diagnose impairments (Mafwiri et al. 2016; Kakoko et al. 2023).

A 2024 global review of early detection and rehabilitation interventions for child functioning outcomes related to disabilities in children under 5 highlighted the importance of locally grounded research from outside high-income settings (Smythe et al. 2024). To strengthen health services in countries that experience the highest prevalence rates of disabilities, more understanding is needed of the existing policies and guidelines for early detection of different types of impairments, and of how these policies and guidelines are implemented in practice, including barriers and areas for improvement. This understanding may enable targeted allocation of limited health and early childhood development resources.

This study set out to address these gaps by conducting a detailed analysis of early detection and referral of children with disabilities in mainland Tanzania. The analysis extends beyond policies and processes to examine the functionality and practices within the primary and community healthcare systems, which form the backbone of a whole-of-society approach to health (World Health Organization (WHO) 2018). PHC provides comprehensive care for people's health needs throughout their lifespan as close as feasible to communities and people's day-to-day lives. It ranges from promotion and prevention to treatment, rehabilitation and palliative care. An integrated approach to early detection of disabilities in children through PHC settings is an effective and efficient way to deliver essential services to all (Smythe et al. 2024; Bohaligah et al. 2015).

Overview of the healthcare system in Tanzania

The healthcare system in Tanzania broadly falls into three functional levels: primary, secondary and tertiary. PHC services are provided through a network of dispensaries, healthcare centres and district hospitals, with varying catchment sizes and capacities. As of 2023, there were 11,805 health facilities, including 436 hospitals, 1,126 health centres and 7,804 dispensaries (Ministry of Health 2023). The key distinction between dispensaries and health centres is that dispensaries provide outpatient care only, while health centres are expected to provide around-the-clock care; therefore, patients that require inpatient care are referred from dispensaries to the nearest health centre. In reality, many dispensaries have undergone an informal expansion of services and now provide child and maternal health services, which may require inpatient stay: for example, around births. Primary health facilities and district hospitals fall under the direct responsibility of the District Medical Officer, who is appointed by the President's Office – Regional Administration and Local Government (PO-RALG) but who formally reports to the local council. In order to assure the coordinated delivery of health services at the local level, the District Medical Officer and Council Health Management Team are required to prepare a Comprehensive Council Health Plan that guides the delivery and development of health services. There is also a system of committees (at the district and facility level) to support public participation, oversight and accountability (Maluka and Bukagile 2016).

Secondary and tertiary healthcare are provided by public regional and national hospitals, as well as several specialised private hospitals, located primarily in the big cities. Patients are referred to higher levels of the healthcare system when required for more urgent medical needs. While the infrastructure of Tanzania's healthcare system is more equitably distributed across the country than other kinds of infrastructure (Kitole et al. 2023; Binyaruka et al. 2024), many rural communities do not have a health facility that is easily accessible. In addition, the country faces several significant challenges related to the provision of healthcare services at the community and PHC level, including limited funding and expenditure on health care (Nabyonga-Orem and Asamani 2023). Very few healthcare centres and dispensaries have the relevant equipment and commodities needed to run effective PHC services (Isangula et al. 2023; Mselle et al. 2021). The training of healthcare workers, their efficient deployment across rural and urban health facilities, and their motivation are also acknowledged to be major challenges (Sirili and Simba 2021; Msacky 2024).

Box 1: Note on terminology

Throughout this report, we use the internationally accepted term 'children/people with disabilities'.

Disability is the broad term used to describe the barriers that individuals face as a result of impairment or of limitations to their activities, or an inability to participate fully in society. This study therefore adopts an understanding of disability, aligned with the UNCRPD, that describes people with disabilities as those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others (UN 2006).

This definition is also broadly consistent with Tanzania's 2004 Policy on Disability, which defines disability as 'the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, mental or social factors' (Aldersey and Turnbull 2011).

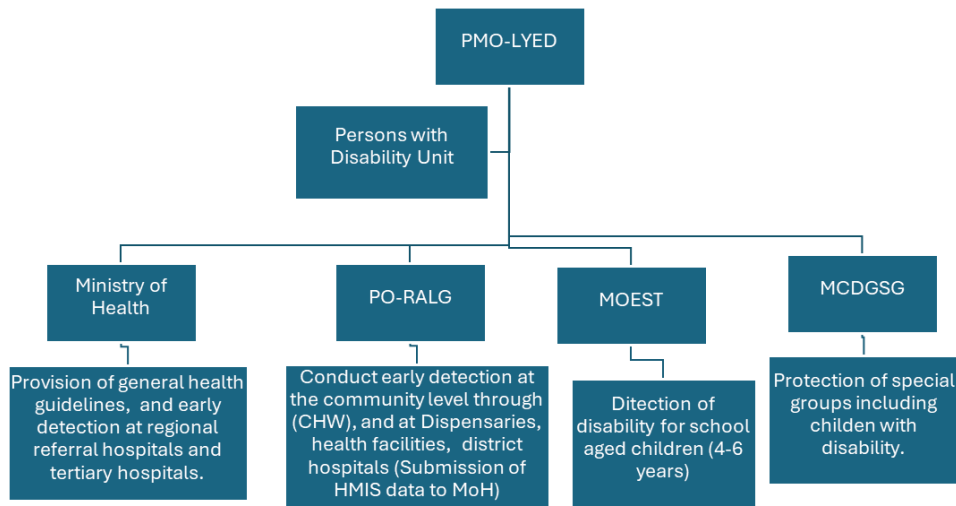
Existing policy and governance structures

Tanzania has a range of policies guiding disability issues (Aldersey and Turnbull 2011; Nyimbi and Kajiru 2024) and there are multiple ministries and government agencies designated to monitor policy implementation at different levels. The Prime Minister's Office – Labour, Youth, Employment, and Persons with Disability (PMO-LYED) is the designated focal point responsible for realising the rights of persons with disabilities, in accordance with the Persons with Disability Act 2010.

The Persons with Disabilities Act 2010 has also resulted in a National Advisory Council that is tasked with monitoring and evaluating the implementation of the Act and the UNCRPD. The Council includes representatives from the village, ward, district, regional and national levels, including: local government authorities; the Attorney General's office; relevant ministries; the Association of Tanzania Employers; the Commission for Human Rights and Good Governance; civil society

organisations; and organisations of people with disabilities (OPDs) (UNPRPD 2022).

Figure 1: Government ministries responsible for early detection of children with disability



Prevalence of disabilities and healthcare

Based on data from the 2022 Demographic and Health Survey (Ministry of Health et al. 2022), which included the Washington Group short set of questions (Hanass-Hancock et al. 2023), in that year approximately 8% of the population aged 5 or older had some level of difficulty in at least one functioning domain, and 3% had a lot of difficulty or could not function at all in at least one domain. For children and young people aged 5–24, a 2021 situational analysis that also used the Washington Group short set of questions, estimated that around 600,000 individuals, or 2.3% of the population, were living with disabilities (UNICEF 2021). The most common difficulties reported among children included problems with sight, walking and self-care. Each of these challenges affected approximately 1.2% of children.

As is the case in several other countries in sub-Saharan Africa (Adugna et al. 2020; Mwangi et al. 2022), children with disabilities in Tanzania face significant barriers to accessing healthcare services. Key challenges include:

- limited availability of specialised health services, especially in rural areas
- limited early identification and intervention for children with disabilities
- financial barriers, with many families unable to afford healthcare costs
- physical inaccessibility of health facilities
- stigma and discrimination from healthcare providers, especially for girls with disabilities who are seeking services
- limited provision of assistive devices and difficulty maintaining them (Swai et al. 2023; Ndibalema 2025).

Study objectives and research questions

The study's main objectives are to:

- conduct a systematic analysis to map and assess existing models of early detection and referral pathways for children with, or at risk of, disabilities in mainland Tanzania – focusing on the primary and community health system (the key entry point for early years)
- understand the strengths and weaknesses of the existing systems
- generate evidence on how these systems could be strengthened in Tanzania and similar settings.

The study was further guided by five key research questions.

- **Policy and guidelines:** What are the main policies and guidelines for the early detection and referral of children with, or at risk of, disability in mainland Tanzania at the primary and community health levels?
- **Structure:** How are the current primary and community health systems for early detection of disability in pre-school children structured, and how are they connected with other systems involved in referrals and follow-up?
- **Determinants:** What factors contribute to the strengths and weaknesses of these systems (i.e. that enable or constrain them), including for different types of disability?
- **Effectiveness:** How effective are the existing primary and community health systems for detection and referral from the perspective of service providers and other stakeholders in terms of (a) safety (no harm); (b) coverage within communities; (c) accuracy of detection (e.g. determined via feedback/case reports); (d) equity; and (e) acceptability?
- **Learning:** What lessons does the Tanzania case study provide on strengthening integrated service delivery systems for early detection and referral of children with, or at risk of, disability, nationally, regionally and globally?

Methodology

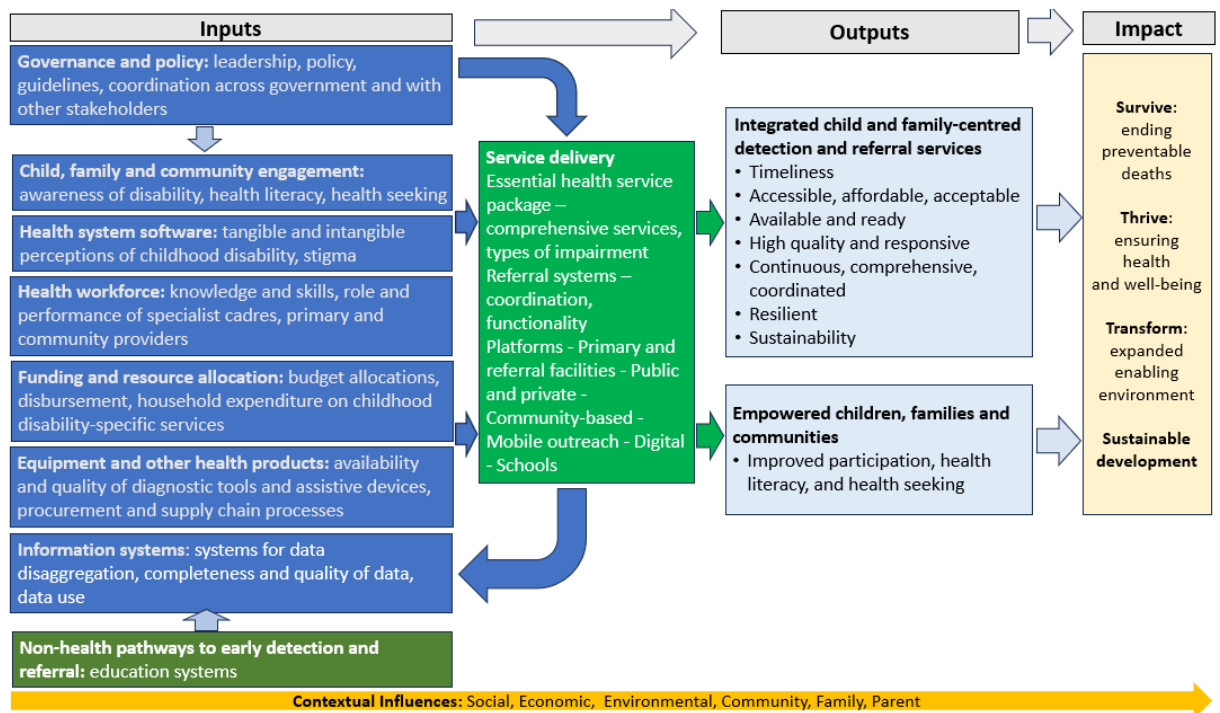
Study design

This is a qualitative descriptive study that draws on a set of qualitative data collected over a four-month period. It included an initial document review and stakeholder mapping, followed by primary data collection through the use of in-depth interviews (IDIs), group interviews and focus group discussions (FGDs). These discussions enabled us to gain a detailed understanding of how primary and community health systems provide early detection services to children with, or at risk of, disabilities, and to explore the interactions with other levels of the system through referral pathways and follow-up.

A modified version of the WHO health systems building block framework (WHO 2007) was adopted to provide an organising structure for the development of the research, and its conduct, and for the data analyses (see Figure 2). The original WHO framework describes a health system as having six interconnected blocks: leadership and governance; health financing; human resources; service delivery; essential medicines and procurement systems; and a health management information system (HMIS) (Doshmangir et al. 2025). The modifications that we made included setting out specific components, in line with our research questions and findings, under each of the functional input areas, as well as outlining the broad outputs and the impact. We also incorporated into the framework relevant health system 'software' inputs such as attitudes, stigma, understanding and perceptions of disability, and the linkages to non-health pathways to early detection and referral. Service delivery for disability detection and referral is seen as the culmination of the various functional inputs.

Strengthening the system for early detection and referral of children with disabilities requires giving attention to the constraints and opportunities within each of these interconnected pillars, as well as the socio-material aspects of the health system, which affect the organisation and delivery of services. The health systems processes and mechanisms examined in this study are analysed with an in-depth focus on context, health and non-health systems actors, and the 'software' aspects of socially constructed norms, values, and beliefs, and how these shape the organisation and delivery of early detection and referral services for children with disabilities (Burger and Gilson 2025; Mbau et al. 2023). The complex interactions across these systems' components, and what lessons these might offer for systems improvement, are analysed at community, PHC and policymaker levels (Schneider et al. 2021; Hanson et al. 2022).

Figure 2: Modified WHO Health Systems Building Blocks framework



Sampling strategy

Sampling for document review and stakeholder mapping

Relevant published and unpublished documents, and stakeholders, were identified through comprehensive online searches and preliminary key stakeholder meetings at the national and district levels. Documents were also identified through the publication databases of government and NGO websites.

Sampling for primary data collection

For the primary data collection component, the study employed a purposive and snowball sampling strategy to recruit a wide range of stakeholders with direct experience in service delivery, policy implementation and lived realities of disability across community, facility, district and national levels (see

Table 1). This covered the following:

- **Community level:** Parents and caregivers of children with disabilities, community health workers (CHWs), and community leaders (such as village leaders or chairpersons of disability committees) were recruited to explore shared practices, challenges, and perceptions related to early detection.
- **PHC facility and district level:** Public sector health facility managers, social welfare officers, rehabilitation professionals and district medical officers were recruited to better understand service delivery planning, resource allocation and coordination challenges.
- **National level:** Technical experts and policymakers from the Ministry of Health (MoH), PMO-LYED, PO-RALG, Ministry of Education, Science and Technology (MoEST) and Ministry of Community Development, Gender, Women and Special Groups (MoCDGWSG) were recruited, along with representatives from professional associations, NGOs/international NGOs and organisations of people with disabilities (OPDs).

Three regions in Tanzania – namely Tanga, Lindi and Shinyanga – were purposively selected for the community- and district-level fieldwork. These regions were chosen in collaboration with the government as part of an inception meeting in November 2024 to ensure geographic diversity and to reflect areas with a high prevalence of childhood disability and varying levels of health system capacity. Appendix A – Rationale informing sample selection, presents some of relevant indicators for the three study locations.

- Tanga combines rural and semi-urban contexts and has one of the highest disability prevalence rates amongst those aged 15 and over. It is also one of the pilot locations for rollout of the new CHW training module.
- Lindi had high prevalence of disability amongst those aged 7 or more in the 2022 census. It has relatively limited access to health services, and one of the lowest proportion of children on track in terms of the Early Childhood Development Index 2030 (see Appendix A). It is also a pilot location for the new CHW training.
- Shinyanga has somewhat lower prevalence of disability but a high infant mortality rate and offers an alternative case to explore reporting of disabilities in rural contexts.

Study participants were identified with the support of national, regional and district authorities. Snowball sampling was then used to reach additional study participants, particularly parents and community-level stakeholders, ensuring diversity across disability types.

Table 1: Sample size

Respondent category	Level	Type	No. interviews/FGDs per community	Total (targeted)	Total (achieved)
Household – parents/caregivers of children with disabilities	Community	IDI	4	12	12
Community key informants	Community	IDI	2	6	6
Service delivery staff – CHWs	Community	FGD	1	3	3
Service delivery staff – ward health facilities / district hospital-based health workers	Community/ district	IDI	2	6	6
District officers/healthcare managers – PO-RALG	Community/ district	Group interview	1	3	3
Government policymakers	Central	IDI	NA	6	6
Child-specific NGOs and programmes	Central/ community	IDI	NA	4	4
Total					40

Notes:

Community key informants – e.g. representatives from disability committees, community leaders, primary school representatives.

Government policymakers – health (MoH), education (MoEST), disability (PMO-LYED), community development and gender (MoCDGWSG), policy implementation (PO-RALG).

Primary data collection

Primary data was collected between November 2024 and February 2025 using separate IDI, group interview and FGD topic guides for parents, community leaders, CHWs, PHC workers, representatives of NGOs/OPDs, healthcare managers at the district level, and policymakers at the national level (see Appendix B). Both English and Swahili translations of the topic guides were prepared. These underwent multiple rounds of review by internal quality assurers, and as part of ethical approval processes (see below). Some adjustments were also made to the topic guides as part of practical administration during training and piloting activities (e.g. clarification of terminology and changes to probes).

Interviews were conducted by four experienced Tanzanian social science researchers at Oxford Policy Management Tanzania. Interviews were conducted in the preferred language of the participant, in the majority of cases Swahili, with each interview lasting an average of 75 minutes. Notes from the interviews and FGDs were taken and written up afterwards in English.

All IDIs, group interviews and FGDs were also audio recorded. Those in English were transcribed verbatim while those in Swahili were simultaneously translated and transcribed into English by trained research assistants.

Data analysis

Data was organised using QSR NVivo 14 Software (Lumivero 2023). To ensure analytical rigour, three members of the research team independently coded and discussed the data, and resolved discrepancies in their coding. A more detailed thematic analysis was then undertaken (Finlay 2021), using a mix of inductive and deductive approaches. Themes and sub-themes were identified based on the narrative content itself, examining each transcript line and paragraph in detail, but also based on the research questions and the pillars of the WHO health systems building blocks framework (WHO 2007). In this way, the analysis was an iterative process that involved developing themes and concepts from the data and then linking these to the analytical framework (Gupta 2025). The themes and sub-themes developed for different pillars of the framework were then discussed in more detail by the research team members and agreed in a series of workshop-style meetings.

Triangulation of preliminary interpretations was based on the consistency of findings across different sources and types of data (i.e. document review, stakeholder mapping, IDIs, group interviews and FGDs).

Quality assurance systems

Quality was ensured through the following mechanisms.

- The study leadership team – comprising the two principal investigators and two quality assurers (thematic specialists in disability inclusion and health systems) – provided ongoing peer review and engagement on key planning tasks, activities and technical outputs from the research design to the reporting and dissemination stage.
- The research protocol and design were initially quality reviewed by the Thrive Tanzania team, Thrive research directorate and UK Foreign, Commonwealth & Development Office to ensure the design and outputs were sufficiently rigorous and able to address the research objectives.
- During the research preparation phase, the study protocols and draft tools were externally reviewed by the Ifakara Health Institute (Institutional Review Board) and the National Institute for Medical Research Board, as part of their

clearance processes. The protocols and tools were revised to address feedback prior to data collection.

- Robust training, pre-testing, and data collection processes were put in place to ensure quality control during primary data collection.
- During the analysis and reporting stage, a series of meetings were conducted with the core research team and quality assurers to discuss initial findings, compare and extract trends, and develop conclusions. The draft study report was internally reviewed by the principal investigators and then with the two quality assurers for technical review. The resulting report was then passed through Thrive's independent quality assurance system at programme level.
- Two in-person validation workshops were conducted with government officials to share and collect feedback on the study findings, and to agree areas for recommended action in June/July 2025. This feedback has been incorporated into the final report and other external outputs.

Ethical considerations and approvals

Ethical approval for the study was obtained from the Ifakara Health Institute Institutional Review Board (IHI-IRB) on 4 October 2024, and the National Institute for Medical Research (NIMR) on 28 November 2024. Overall permission to conduct the research was obtained from the Tanzania Commission for Science and Technology (COSTECH). Written informed consent was obtained from all participants in the research. The data was anonymised using participant codes and broad respondent categories are used to maintain confidentiality.

To ensure ethical conduct, all study investigators and research assistants completed mandatory training in research ethics, safeguarding and data protection. They also signed the Oxford Policy Management and Sightsavers codes of conduct prior to data collection. The training equipped the team with the skills and awareness needed to handle sensitive topics, engage respectfully with vulnerable people and uphold the highest standards of professional integrity.

Findings

This section presents the key findings from the document review, stakeholder mapping and primary data collection. It is structured around the modified version of the WHO health systems building block framework. The chapter:

- first sets the context through discussion of the health systems block on governance and policy
- contextualises disability for families and community
- details the essential health service delivery package around childhood disability currently provided by CHWs and PHC workers
- deep dives into the various factors affecting service delivery through a discussion of the remaining health blocks – workforce, funding and resource allocation, equipment and other health products, and information systems.

Governance and policy

The key findings under this theme have been organised under two broad sub-themes: (i) governance structures and stakeholder coordination at national and subnational levels; and (ii) regulatory policies and guidelines.

Box 2: Summary of findings on governance and policy

- Policy development and oversight of disability issues in Tanzania has been strengthened by the recent creation of the Persons with Disabilities Unit within PMO-LYED.
 - The range of actors involved in disability detection encompasses not only several national ministries but also private organisations and NGOs. While there are emerging areas of collaboration, the diverse range of actors involved in service delivery, coupled with insufficient central oversight, contributes to limited system coordination.
 - Policy dissemination and understanding is weak in some contexts due to limited roll-out at lower administrative levels, inadequate training, and insufficient coherence between different policies.
 - External actors, such as NGOs, bring much-needed resources for implementation, but insufficient coordination risks limiting their effectiveness and undermining government systems.
-

Governance structures and coordination at the national and subnational levels

Overall oversight of disability policy sits within the PMO-LYED, while implementation is cascaded to the lower administrative levels and sector-specific ministries. Study participants explained that the PMO-LYED was established to oversee, facilitate, and promote all activities related to early identification of disabilities, which has significantly improved stakeholder coordination and oversight.

We [ministry name] establish, coordinate, and promote all programmes concerning early identification. But you should understand that this is a multisectoral issue so we will have components from the nutrition sector, representatives from the health sector, education, safety, and security. ... We do coordination and all these ministries will take the programme that we have developed and translate it into sector-specific programmes. (IDI with central government official).

There is limited integration across ministry or department when it comes to early detection and referral of childhood disability. Different ministries and government departments have responsibilities specific to their sector and level of governance. For example, within MoH, the Maternal and Child Health Department is critical for identifying and referring children with disabilities at the time of, or soon after, birth (see the later 'Service delivery' section for further details). MoCDGCSG also plays a critical role in establishing daycare centres and training caregivers who work with pre-school children. Likewise, MoEST is responsible for the identification and referral of children with disabilities when they enrol in school. District social welfare officers also play a key role in making referrals to health facilities and providing information about enrolling children with disabilities in education. It was further explained that the Social Welfare Office maintains a register of people with disabilities, and has guidelines on how to handle individual cases, according to their specific characteristics. CHWs are a key point of intersection between the health and community systems, as they report to both the village chair and the medical officer in charge of the nearest health facility. The role of these actors in the early detection of disabilities is discussed further in the 'Health workforce' section.

Although there have been various attempts to facilitate communication and cooperation across different ministries involved in disability issues, coordination is not very effective. This is partly due to the 2015 restructuring (devolution), which has led to duplication of work by various government structures (UNPRPD 2021). Many government officials have minimal expertise on disability issues, which makes it hard for them to effectively engage with other stakeholders on issues relating to disability inclusion (UNPRPD 2021). Furthermore, while there are OPDs and OPD federations in place, they are not always consulted, particularly at the regional and district levels, where their participation in decision making is very limited.

National and international NGOs and development agencies are also important players in the delivery of early identification and disability management policies. These stakeholders provide financial resources and supplies, including diagnostic equipment and assistive devices. Support from these external actors is generally well received and appreciated

From my experience, most of the referral costs are normally done by these NGOs. ... The government normally supports on small issues but a lot is done by these organisations ... For example, transport, meals, if there is a nurse accompanying the child, they do pay their per diems. (IDI with community leader, Lindi)

However, there are instances where coordination between NGOs and government structures is insufficient, which undermines the effectiveness and impact of their inputs. Many policymakers at central and district level, as well as community leaders, were unclear on the remit of the services provided by NGOs, although they highlighted the support provided by the United Nations Children's Fund (UNICEF) and by private organisations. NGOs were said to contribute to the fragmentation of care by focusing on specific health impairments, having limited scale or provision, and not planning for the sustainability of interventions after external funding comes to an end.

Sometimes these NGOs provide hearing aids, only for the children to [throw] them out. ... we request that the equipment they provide be helpful to the children. ... Some [NGOs] are not even registered, but they are in the schools doing their activities. (IDI with central government official)

Many people don't want to venture into that because they understand there is no established system to support these children. This is when you find religious organisations opening up centres. Otherwise, the system is not clear. (IDI with central government official)

Regulatory policies and guidelines, and their implementation

In 2021, the PMO-LYED issued the National Guidelines for Early Identification and Intervention for Children with Disabilities (Government of the United Republic of Tanzania 2021). The guidelines do not clearly indicate how services will be funded but are regarded by policymakers as the primary document regulating the delivery of early identification services. Different ministries also have their own sector-specific policies and guidelines regulating disability-related activities, specifically the guidelines of MoH, MoCDGCSG, and MoEST. However, policymakers from these ministries highlighted the need for simplified standard operating procedures and better coordination across the many actors involved in disability detection at local level. This was also linked to government priorities and funding, which affect implementation (see later section).

There has also been limited dissemination of these guidelines to the lower administrative levels and service providers, resulting in limited knowledge of the existing policies and uncertainties about the roles and responsibilities of different stakeholders. It was reported that in some cases documents are shared via WhatsApp, with no or limited accompanying orientation or training on their implementation. Some service providers were aware of the guidelines but had not started implementing them. Others said that they had never heard of or seen the guidelines. Many community leaders, parents and CHWs also displayed little knowledge of the available guidelines.

When it comes to policies and guidelines, for sure we don't have them, and I have never seen them. What we use most is experience. (IDI with health facility staff, Shinyanga)

All systems, not only MoH systems, need to link to each other. That's the big challenge. Just as we have said that we are in process of integrating these systems ... dissemination is a challenge as well because we have limited resources. You cannot disseminate only at the regional level. You need to go up to the grass root level ... That is why if you go to the facility, you will find the guideline but the implementation or usage of that guideline will be found in the cupboard. (Group interview with central government officials)

Contextualising childhood disability for families and communities

Family experiences of dealing with health impairments are shaped by various contextual influences and health system issues. This section first discusses (i) stakeholder understanding of disability, covering aspects of the 'Health systems software' and 'Child, family and community engagement' blocks. It then looks at (ii) the impact of social attitudes on family health-seeking behaviours.

Box 3: Summary of findings on contextualising childhood disability for families and communities

- While formal definitions of disability align with international standards, practical understanding differs across government sectors, healthcare workers and communities.
 - There is a strong tendency to equate disability with visible, physical impairments.
 - At the community level, stigma, misinformation and traditional beliefs often lead to neglect, social isolation, and barriers to early detection and seeking care for children with disabilities.
 - Informal support networks among parents, and in communities, have proven useful in guiding families towards services and providing encouragement.
 - Efforts to raise awareness are growing but challenges remain in shifting perceptions and improving access to services.
-

Understandings and awareness of disability

Formal definitions of childhood disability in Tanzania often align with international standards, however practical understanding and use of these concepts at local level is heavily influenced by observable factors and cultural interpretations. Understanding of disability on the part of officials, healthcare workers, and communities affects the lived experiences of children with disability and their families, as well as the ability of the health system to respond.

There is no clarity on the operational definition and understanding of disability across government stakeholders. Study participants from the different ministries, and even different departments within the same ministry, often had their own interpretation of disability. Some defined it through reference to health conditions that are either temporary or permanent, while others referred to functioning and the ability to perform certain tasks. It was also suggested that there is no consistency or coherence in the use of the term 'disability' within different policies. Such definitional divergences can create confusion and inconsistencies in eligibility criteria for services and support.

Yes there is a difference, since the MoH at times views disability as something that doesn't have to be permanent, but our office defines disability as a lack of functionality that must be permanent. (IDI with central government official)

Likewise, at the community level, knowledge and information sources about disability are not consistent, which leads to varying levels of awareness.

Hospitals, clinics and CHWs are the main sources of information but many parents said they received limited or unclear information about their child's diagnosis, and they did not always feel confident asking for clarification. Parents who were more educated, or who had support from friends or family, were able to deal with this situation better, through their own research and contacts. However, most parents reported continued gaps in knowledge about specific conditions, treatments, assistive devices and the rights of children with disabilities. Disability was said to be a complex topic and parents said they struggled to understand even when they tried to do so. Cultural practices and beliefs linked to shame and stigma also mean that parents are not always accepting of their child's disability, and this affects health-seeking behaviour.

One challenge you find is the parents do not have that knowledge and those who have, have denial. This delays the children from receiving the services. (IDI with NGO partners)

Beliefs about the causes of disability present a mix of emerging medical understanding and older cultural views. Disability was linked by respondents to early marriage, misfortune and witchcraft, and at times to perceived maternal actions during pregnancy, such as hiding pregnancies or not attending antenatal clinics, which was said to lead to malnutrition issues. Participants suggested these ideas could also lead to blaming mothers, potentially further contributing to stigma. Health workers also reported difficulties in explaining the medical reasons for disability when community beliefs are deeply entrenched. Although there are awareness campaigns by government and NGOs, their impact was

described as limited in contexts where traditional customs are strong or education levels are perceived to be lower.

There is also a strong tendency to equate disability with visible, physical impairments across various participant groups, especially at the community level (though this was also suggested by some government officials). This often leads to the under-recognition of non-physical or less apparent disabilities. Participants noted that physical disabilities (like clubfoot, missing or extra limbs, or albinism) are 'very easy' to identify, while less obvious conditions, like deafness, blindness, or intellectual disabilities, 'are often missed'. CHWs in Lindi for instance reported that their community often believes there is only disability when a body part is missing. This was different to the CHWs' own understanding of disability, which also gives consideration to limited functionality. This focus on what is visible means that conditions like albinism, which are '**most visible though not necessarily most common**' (IDI with community leader, Shinyanga), can receive more attention than less obvious disabilities like developmental delays or learning difficulties.

Influence of social attitudes and stigma on health-seeking behaviour

Social attitudes, often connected to traditional beliefs, misinformation and fear, result in stigma and influence family interactions with the healthcare system in relation to children with disabilities. Different groups of study participants in all regions linked disability to supernatural causes, bad luck, curses, or witchcraft, or suggested they saw them as a punishment for parents' actions.

In our community, many people believe that having a child with a disability brings misfortune. In societies where tribal customs are deeply ingrained ... People might perceive the parent as someone who continuously gives birth to children with such conditions, resulting in discrimination and isolation. (IDI with community leader, Shinyanga)

Families often face direct social pressure in terms of mockery, social exclusion and insulting comments. One parent in Shinyanga recounted being told at a funeral gathering, 'You should cover your child with a cloth or hide them. Aren't you ashamed?'. Likewise, parents of children with albinism described the fear induced by myths that '**limbs from a person with albinism can bring them good fortune**', and comments like '**oh your son has albinism, that means you are going to get rich**' (IDI with parent, Tanga). Parents also reported hearing others use derogatory nicknames for children with disabilities. In extreme cases, stigma can contribute to neglect and violence, as was reported by one representative of an NGO who discussed the case of a girl with an intellectual impairment who was repeatedly sexually abused while the community remained silent.

One of the most common parental reactions to the stigma surrounding disability is to 'hide' their children. Parents reportedly do this due to shame or fear of community judgement, or to protect their children from ridicule. In some cases, parents of children with disability were reported to relocate to new villages when the community became aware that they had a child with disability. Most study participants argued that this isolation can limit children's social interaction,

educational opportunities, and access to essential services. A community leader stated:

You find that when a parent discovers that his or her child has such a challenge, he or she doesn't want to expose them to the community. They will enclose them inside. (IDI with community leader, Shinyanga)

Healthcare beliefs and stigma also influence families' health-seeking behaviour.

It was reported that some parents deprioritise the needs of children with disabilities, while others consult traditional healers instead of seeking medical care. Participants suggested this could delay diagnosis, lead to missed opportunities for early intervention, and sometimes result in harmful practices. A community leader in Shinyanga, for instance, recounted an incident where a child with a dislocated hand died after traditional treatment worsened the condition. However, most study participants did acknowledge increasing levels of awareness and communication on this issue in communities. The role of CHWs as embedded support within the community was reported to facilitate this. Not only do CHWs share information, and issue referrals, but in some cases, they also accompany and/or finance children's visits to hospitals for follow-up.

For our people in this community, even if someone is sick ... he or she will not be taken to hospital. They will go to the witch doctor. The distance [to the health facility] contributes to this but also people still hold beliefs that when one gets sick, some sicknesses are not for hospital attention but rather to be reported to the witch doctor. (IDI with community leader, Shinyanga)

Nonetheless, there has been some progress in attaining positive shifts in community attitudes towards disability. Community respondents said this has been mostly achieved through community forums organised by CHWs and stakeholders, opening up the space for community dialogue and trust-building. This has contributed to greater cooperation from some families and a reduction in denial or concealment of children with disabilities. Additionally, successful cases of treatment and rehabilitation upon community referrals were also said to have helped increase openness and normalise disability to an extent.

In the past, if you received information that a certain household had a child with a disability and tried to make follow-up, the family would not cooperate. But, nowadays, those who still do not cooperate are few. Now, when you try to follow up, most families provide full cooperation, unlike before when they would deny having a child with a disability. (FGD with CHWs, Shinyanga)

Box 4: Experiences of caring for children with disabilities

Families caring for children with disabilities face many daily challenges. These problems include gaps in information about, and understanding of, disability, negative social attitudes, limited access to services, weak information systems, and financial constraints.

Caregivers, mostly mothers, say it requires great personal strength to look after children in these circumstances. One parent described it as a ‘a challenge that requires a strong heart, first and foremost’. Daily care involves constant supervision, help with everyday activities like feeding and self-care, and managing specific health needs. For some parents, like those with children with albinism, there are also strong fears for their children's safety because of harmful myths and threats of violence in surrounding communities.

There are so many shocking news I hear from people about children with albinism being kidnapped ... my son's condition has been registered by the local government leaders in this ward. This made me worry even more because you never know who has access to those registers and may be the ones who want to harm our children ... I don't think he is safe to a large extent. (IDI with parent, Tanga)

There is also a significant financial burden on parents of children with health impairments. Costs associated with the identification and referral of disability include doctor's visits, special treatments (like physiotherapy), assistive devices, medicines, and sometimes special food. Parents often reported having to forgo treatment and prioritise food and survival when faced with such pressures. The financial burden is amplified when caregivers have to work less or stop working to provide care. Many families feel they are left to manage alone, although a small number of parents reported receiving support through insurance or from the local Social Welfare Department.

Despite these challenges, parents show strength and resilience in coping with their children's disability, often with help from friends and family. Support from spouses, relatives, and community members was reported to be very important. Sharing experiences with other mothers was reported to provide emotional comfort and access to practical advice on caring for children with disabilities. One parent shared how hearing other mothers' stories helped her feel ‘comforted’. This informal support is often used to fill in for parents' inconsistent access to organised support, for example from CHWs or NGOs. While some parents reported receiving help from these sources, others said they had never found such services or met CHWs in their area.

Service delivery systems for disability detection and referral

This section covers issues around the accessibility of healthcare services, and it describes the essential health service package available to children with disabilities, from the detection of impairments to verification and documentation, as well as referral support. It also reflects on the inclusivity and safety of these services for children with disabilities and their families.

Box 5: Summary of findings on service delivery systems for disability detection and referral findings

- There are three main channels for identifying disability: home and community-based identification (via parents, CHWs and other social networks); medical examinations at health facilities; and identifying disability via the education system through schools and early childhood development centres (once the child reaches school-going age).
- Community-based disability identification via parents and CHWs generally focuses on observing children growth and developmental milestones, rather than use standardised screening tools in health. Screening in health facilities mainly relies on clinical records and growth charts.
- Verification of disability usually takes place in specialised hospitals by practitioners for the different types of disability but not all parents go through this process.
- There is limited formal recognition of disabilities within the existing system, and as a result families rarely receive written proof of their children's condition, making access to services harder.
- Formal referral and follow-up processes for support exist but are inconsistently followed in practice. Challenges such as late or incorrect referrals, and issues with parents gaining referral letters, limit health-seeking.
- Tanzania's service delivery systems for disability are generally seen as safe, inclusive and fair, and as promoting equal treatment for all.

Accessibility of health services

The vast majority of parents of children with disabilities rely on the public healthcare system at the local level. Demand-side influences on health-seeking behaviour were discussed in the previous section. In terms of supply, most parents in the study reported being within less than an hour's commutable distance from the nearest healthcare centre, often a dispensary or health centre, with larger regional hospitals being further away. More remote, rural communities were reported to be more cut-off from essential services and therefore tend to use traditional health treatments. Private providers were also mentioned but cost considerations usually mean that these are accessed by those with more resources or some insurance cover.

We start here at the health centre. If treatment is not successful here, you are referred to Jakaya [Referral facility in Kishapu]. If Jakaya does not work, you proceed to Mwanza Regional Hospital, and if it also fails, you are referred to Bugando. (IDI with parent, Shinyanga)

There are notable variations in the distribution and activities of CHWs, resulting in different coverage across communities. Participants explained that although the current system prescribes ‘two CHWs to work in every sub-village to act as a link between the villagers and the health system’, in practice this is not always possible. A number of parents in Lindi and Tanga reported limited availability of CHWs in their area.

Not all villages have CHWs, so in some areas there won't be anyone going door to door to follow up with. So there are people who do not have access ... this is simply due to the lack of sufficient human resources to reach all areas – especially in the rural areas. In such cases we rely on the parents to report or to make the journey to the hospital. ... At other times we make an effort to reach them via outreach programmes. (IDI with health facility staff, Lindi)

Disability detection systems

Early disability detection within the community and PHC system in the country focuses on screening. Children who are suspected to be at risk of disability are referred to specialists in larger health facilities for diagnosis of disability, which requires specialised knowledge and equipment. However, as previously discussed, the ability of the system to detect all children with disabilities on time is influenced by social awareness around disability, as well as the accessibility and nature of service delivery. At the community level the onus is often on the parents to follow through and to fund the detection process up the health facility hierarchy. One health facility representative at the central level also observed that ‘the child with disability is never seen as an emergency’, which may delay detection and prioritisation.

Although policy guidance is available, we found from both the document review and interviews with stakeholders that Tanzania does not currently have a clear and standardised system for identifying disability in children in practice.

Policymakers referred to PMO-LYED's 2021 National Guidelines for Early Identification as a training manual on disability detection and intervention for children. Although the guidelines mention various local actors, such as parents, health workers, CHWs, teachers, and village leaders, who would benefit from its processes, stakeholders and health service delivery staff at community level did not usually refer to the guidelines. Study participants across the sample communities described three main channels for disability identification: community-based identification (via parents, CHWs, and other social networks); medical examinations at health facilities; and disability identification via the education system (once the child reaches school-going age).

Parents, and primarily mothers, are seen as critical for the early detection of disability in children. Several healthcare providers, policymakers, community leaders, and even parents themselves, referred to mothers as the ‘first identifiers’ of disability, especially in the case of home births. This was often attributed by respondents to their proximity and their constant observation and contact with

their child. Some study participants, however, acknowledged that this is not sufficient, as many health conditions or impairments cannot be easily detected. They argued that more work could be done with mothers at the antenatal stage, particularly in raising their awareness about disabilities and the importance of seeking care early.

If the mother explains that the child does not pass stool despite sucking enough milk then that is an indicator that the child may have a health problem. ... parents have a big role to play in detecting disability in their children, that is why we do our best to teach these women who give birth at our facility. (IDI with health facility staff, Lindi)

Once a disabling condition or impairment is suspected, parents follow various routes, including informing their CHWs, informing their village leaders, self-referral to medical facilities, seeking advice from informal social networks, or other pathways based on their own research. Some parents reportedly do nothing. If parents share information with their CHW or another village official, it is passed to the village executive officer (community leader), who informs health facility staff, who then follow up with the family. However, a key challenge with this is that many parents do not follow up on the referrals made. Participants often put this down to insufficient financial resources or to parental beliefs and stigma. Alternatively, they said that some parents feel that their child is functioning well and so do not see value in further follow-up.

Some parents rely on their social networks to detect disability and seek support. Several parents spoke of informal routes for detection of disability, via family members or other social contacts with medical backgrounds (e.g. interaction with a local nurse in the market). In a small number of cases, more educated mothers, for instance those with college degrees, spoke of doing their own research to understand their child's condition and treatment, and to find relevant support facilities.

I was just going to buy some things. A local nurse saw me, and that's when she told me that this child might have issues and that I should take her to Jakaya to see the doctors who deal with bones. So, I went. When I got there, they told me to register. I registered, and when they examined my child, they said the spinal cord had not yet strengthened. (IDI with parent, Shinyanga)

CHWs may identify children with disability during their door-to-door community visits. Study participants noted that CHWs are expected to conduct home visits every two weeks, although there are seasonal variations due to parents' availability in farming areas. During these visits, CHWs rely on information from parents on their children's disability and do not conduct any specific examinations. CHWs, health facility staff and district managers were clear that the focus of these household visits is not on disability detection per se but mainly on nutrition and general maternal and child health issues. Although the process is still seen as helpful in identifying suspected health conditions or impairments, CHWs do not have specific training on, or knowledge of, disability identification (see 'Referral and follow-up systems'). The CHW role is more as a liaison for examination and referral, rather than detection or diagnosis.

Each sub-village has two CHWs working there and they are the ones responsible for collecting health information in that area for the [overall community] population. ... the census form requires you to fill out information on the number of disabled persons in your sub-village, people who are able to work, children under 5 years, elders. ... these forms are used by CHWs when we go for door to door visitation. This form has to be photocopied since the form will be distributed to the sub-village chairman and the village chairman, before bringing them here to the medical officer in charge. ... the medical officer in charge then takes the reported cases to the social welfare for action. That is why the social welfare is able to link children with speech impairments to the schools and other children with special needs to the appropriate facility. ... at our level once the report is written in the HMIS, the other steps are above our level. (FGD with CHWs, Lindi)

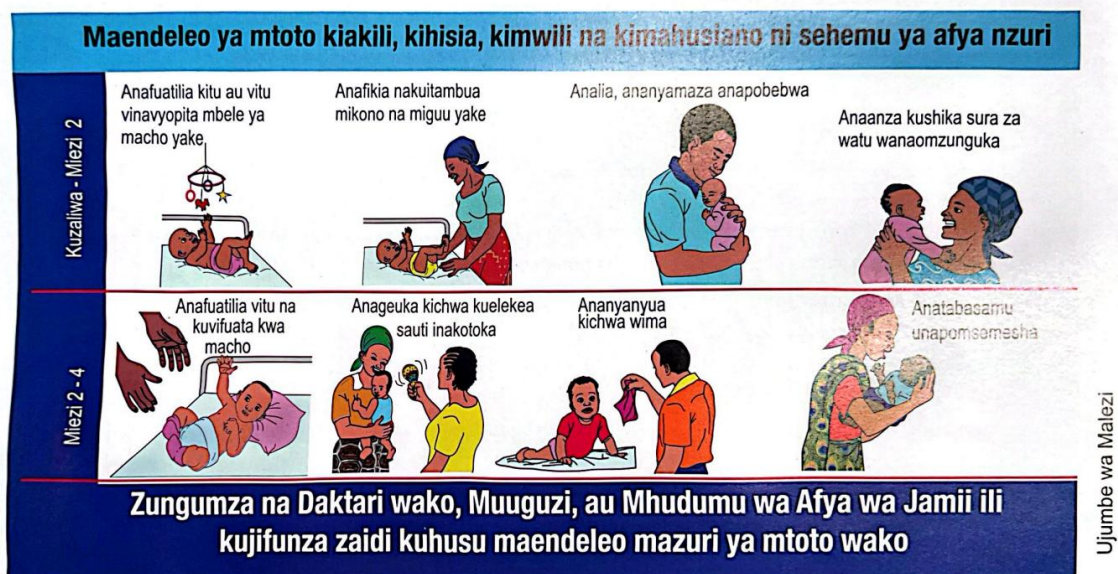
Childhood disabilities are also identified as part of medical examinations at health facilities. Health facility staff reported that some disabilities are detected before birth as part of prenatal ultrasounds. In such cases, the mother is given special attention and at times referred to a larger district hospital. More commonly, however, and especially in the case of visible and/or physical disabilities, these are identified at birth. Midwives and doctors in health facilities conduct a 'head-to-toe' assessment of the child immediately after birth, during which they detect any impairments. Several parents and health facility staff also referred to delayed crying upon birth being a symptom of the baby being unwell. MoH study participants described a schedule for postnatal hospital visits for new mothers and babies but this was only confirmed by a few parents.

There are postnatal check-ups that the mother needs to adhere to. Before being discharged we do a full assessment or examination of the child to see if there are any congenital abnormalities. In case there are some conditions which were not picked up during the examination, they can be picked up in later dates when parents come back for the postnatal check-ups. (IDI with health facility staff, Tanga)

Disabilities can also be detected during routine clinic visits in the first five years of life. These are offered to all children as standard practice in Tanzania and can be helpful for detecting impairments. The routine clinic visits involve parents taking their child to lower-level health facilities, where the health facility staff monitor the child's development using reproductive and child health (RCH) cards, and conduct basic tests such as speaking to the child at different volumes to assess hearing, and asking the child to identify objects or colours to assess sight.

Figure 3: Reproductive and child health book cover

Kuzaliwa hadi miezi minne (0 – 4)



The mother/parent of the child is also asked if the child faces any particular challenges. These routine checks serve as a screening function to identify potential cases, which are then referred to higher-level facilities with specialist equipment/tests for confirmation.

While generally seen as helpful, there is some evidence of impairments being missed or not appropriately managed during these routine checks, especially when the child is younger. For example, one mother in Shinyanga reported that she was told her child had delayed speech and walking but no action was advised; the child was later diagnosed with cerebral palsy.

After giving birth I was going to the hospital for check-ups, the doctors observed that my child was not reaching the same milestones as his friends. So the doctors told me that his development will be delayed. They also told me that when I gave birth to him he did not cry, and there is a 50/50 chance that he will grow up with a disability or things may change as he grows. (IDI with parent, Lindi)

Disabilities can also be identified once children enrol in schools. This route of detection was reported to be useful for non-visible disabilities and learning impairments. Two different routes were mentioned. Community-level participants in Lindi and Tanga mentioned that door-to-door school enrolment takes place at the ward level every October to register children for schools. This is a combined effort by community leaders, local education officers, doctors/nurses from local health centres/dispensaries and teachers trained to identify disabilities in children. Radio announcements and other local communication channels are often used to inform parents of such visits. However, interviews with NGO partners suggested that this is not always effective, as some children with disabilities are identified but not necessarily enrolled in schools and their needs

are not adequately addressed. The second route mentioned for identification was once the child is already in school. Teachers were reported to have a key role in identifying children facing challenges in learning or peer interactions based on their classroom observations. Health facility staff in Tanga reported that some development programmes also work directly with schools to identify children with disabilities and refer them to health facilities.

Box 6: Appropriate age for detecting childhood disabilities

Study participants communicated a general understanding that there is no one specific age for detecting disability in children. This was particularly the case among policymakers and health facility staff. They recognised that detection takes place on a continuum and depends on the type of disability.

Some disabilities, like hydrocephalus or missing limbs, can be detected prenatally via ultrasound. Visible physical disabilities like albinism, cleft lips and club foot, are usually identified at birth. Vision, hearing, speech and mobility impairments usually take slightly longer to detect and are usually associated with the child's ability to meet developmental milestones up to 2 years of age. In some cases, doctors also advise parents/carers to wait for the child to get a bit older as some impairments can self-correct. The diagnosis of Down syndrome is one example of this: although it can be noticed at birth, medical staff may advise waiting before concluding there is a disability. Finally, learning impairments are usually the last to be detected and often become apparent once the child is of school-going age (5–6 years old).

Tools used for surveillance and assessment of children at risk

Community-based disability identification via parents and CHWs does not use any specific tools and is generally focused on children's growth and development milestones. Participants pointed out that this type of assessment relies primarily on observations of visible conditions and impairments like albinism and physical deformities. CHWs did report using mid-upper arm circumference (MUAC) tapes and weight measuring scales to conduct general assessments of the child's health and nutrition status. These are recorded on the child's clinical or RCH card. Service delivery staff and more knowledgeable mothers reported using these cards to track children's progress against milestones they are expected to meet. CHWs sometimes use basic screening tests to check for visual and hearing impairments during their door-to-door visits. In the absence of clear guidance, there was reported to be wide variation and improvisation in the options proposed for screening intellectual disabilities. For example, some CHWs reported asking a child to count money, or to draw a car on a piece of paper and to observe their behaviour afterwards. Study participants from MoH also noted that limited guidance is shared with local-level implementers in this regard.

On the issue of tools, the way we describe disability is broad. ... Honestly, there are limited tools down there [in the community]. There are a few [tools], we can't say there are none. They are not sufficient, that is the word. ... The CHWs will not know what tools they are required to have. The CHWs have just started. (IDI with central government officials)

Disability screening in health facilities, while slightly more formal, also mainly relies on clinical records and growth charts. A large number of health facility staff referred to 'head-to-toe' assessments conducted by midwives and doctors at birth. One nurse in Tanga also referred to Apgar scores. As the child grows older, generic growth monitoring tools like RCH cards, clinical cards and growth charts are used, and if a child is unable to meet a milestone or there is some variance, then it is seen as indicative of an issue. Answers from parents or guardians are also used to supplement clinicians' observations. In specific cases where a child has been referred to the facility for an examination, facility staff reported using basic sounds and objects to check hearing and vision, and referring more complicated cases. MoH staff and parents criticised RCH cards for not having enough space to write down developmental concerns.

We use the same growth monitoring tools as for all children. If a child has a disability, it becomes evident as they reach developmental milestones at ages two, three, four, or five. ... We track growth using clinic cards. Every time a child comes in, we update the records. (IDI with health facility staff, Shinyanga)

Participants from professional associations were aware of more specific developmental monitoring tools but these are often used only in small-scale pilots. For example, representatives from the Paediatric Association of Tanzania mentioned a pilot with the Malawi Developmental Assessment Tool, which needs further research and adaptation. Likewise, study participants from the Tanzania Early Childhood Development Network (TECDEN) reported a pilot conducted on the WHO's Global Scales for Early Development (GSED), which has a component on disability. However, they complained about the length and the workload associated with the use of this tool. Research on the Global Scales tool was reported to be under way at some national hospitals.

Verification and documentation systems

Verification of suspected disability is usually done in specialist hospitals, often based on referrals from lower-level facilities at district and ward levels. Participants explained that CHWs can only refer cases to ward or district health facilities, and this is usually done via referral forms or letters. When parents/guardians visit specialist hospitals with their child, they are first required to register, then go through a triage process, and are assigned to the respective specialists for observation and testing.

Some parents or guardians face challenges completing the verification process for their child's suspected disability. At least three parents and one health facility representative said that some parents perceive that further confirmation may not significantly change their child's care pathway, often due to limited information or financial constraints, or in some cases because they believe their child is eating and functioning well. For example, a mother of a child with cerebral palsy in Shinyanga said that she had suspected her child was not well and after this was reaffirmed by the child's teacher in school, she did not make further effort to confirm the diagnosis because the child's condition '**did not cause him visible distress**' and seeking medical help was expensive. In many cases, financial

constraints and insufficient information on the process and costs of taking up services limits parents' ability to follow through with the referral.

I have not registered my child anywhere because I am not aware if there is any registration of children with disabilities, I don't even know where to start with the registration. (IDI with parent, Lindi)

After a disability is confirmed, there are opportunities to seek financial assistance to manage the costs of care. These are discussed further in 'Funding and resource allocation', and include fee exemptions provided by the Social Welfare Office or financial support from insurance providers or NGOs. However, these do not appear to be very established systems and were not widely corroborated by parents.

Even when disability is verified, there is currently no formal disability documentation system in place for children with disability at community or district level. Nearly all parents reported that they did not receive any documentation that confirmed their child's disability. Even when a child's impairment was recorded, parents were not given any written proof of this, which meant that they had to often repeatedly describe their child's condition when seeking support or advice. MoH participants confirmed that hospitals and health facilities do not provide any type of documentation.

I have never been given any kind of documentation. They just take the information such as the child's name and my name and leave. We have not been given any IDs or serial numbers where if they enter it in a system it would provide you with all the information on the child. (IDI with parent, Tanga)

I did not go through any confirmation process, first of all when the nurse told me that my son's hair was blond she did not explain further. My brother-in-law came to visit us once, he is a medical doctor [and confirmed my child has a skin condition]. So we were not given any official comment from the doctor, nor was it documented in his RCH clinic booklet. So even when I left the hospital I wasn't given any document stating that my child has a disability. (IDI with parent, Tanga)

Some parents mentioned 'clinic cards' but these are the generic cards issued for all children and are not specific to children with disability. Observation of RCH cards suggests there is a field to record 'birth defects' and a section for making notes towards the end, but there is no dedicated section for disabilities. Health facility staff reported that sometimes a letter is written to the district heads or the child's school to confirm their disability. This helps exempt the child from certain activities, and/or helps them to access support services. However, this letter is provided only on special request from parents and is not issued by health facilities as a standard practice. It also appears that this is a general medical fitness letter, and not something specific to children with disabilities.

Referral and follow-up systems

Referral and follow-up processes are understood in principle. Study participants at national and community levels were confident in describing the formal process. CHWs are meant to make referrals to regional hospitals through dispensaries, health centres and district hospitals, and to provide parents with letters outlining the treatment needed for their child. CHWs are also meant to provide follow-up checks to confirm that the process has gone smoothly and to remind parents to take their child for follow-up treatment. A different approach is taken when a mother gives birth to a child with a visible disability at a hospital. In one such case, a parent received an immediate referral from the doctors to a specialist hospital due to the severity of the child's condition.

In practice, however, formal referral procedures are not effectively followed and there is a disconnect with the actual roles and responsibilities of CHWs. Parents often highlighted limited engagement with CHWs in the community following diagnosis of their child's disability (for example through home visits). This was linked to funding challenges and insufficient knowledge of CHW roles. CHWs highlighted that they do not have funding support to enable them to move within communities and undertake home visits. Many can only undertake home visits once every few months, reducing their perceived visibility in the community. Some CHWs also reported being unsure about the process of undertaking home visits, the referral process and follow-up checks.

When referrals are made by CHWs, further challenges emerge, such as late or incorrect referrals, and challenges in parents gaining referral letters. In Shinyanga, parents noted that CHW referrals are often late or require several visits to district health facilities to ensure that the referral letter is produced. Parents in Lindi and Shinyanga highlighted that CHWs often refer incorrectly, either referring children who are too young to receive treatment (resulting in them being turned away at the hospital) or referring them to health facilities a long distance from their home, despite suitable facilities being closer.

The process takes a long time, and the government has yet to establish smooth systems for the referral process. It requires money to travel and survive once families arrive at referral hospitals. In some cases, when they reach the health facility, they're told things like, 'The hospital hasn't budgeted for this treatment,' or, 'The specialist isn't available today; come back in three days.' These kinds of setbacks cause many villagers to lose hope. (FGD with CHWs, Lindi)

As a result, many parents go directly to regional hospitals to register their child for treatment. One parent in Shinyanga noted that a doctor had told her to bypass the community referral process due to the time it took to receive an official referral.

Despite the challenges with the referral systems, most study participants at the community level who managed to access treatment and follow-up support said it was broadly effective. For many parents across all regions, the simple fact that treatment was being given to their children was enough to make them feel that the system is effective. This was especially the case when their child's treatment began and concluded quickly.

For me, the process is going well. Since we were given a referral, we went to Shinyanga. ... I see that the process is just fine. (IDI with parent, Shinyanga)

They are doing their best because there are people I used to see there [hospital] whose legs are bent. But with the help of God and their [doctors'] skills, they get better. Even when I took my child there [hospital], I had hope that he would get better. To date I am grateful, even if he is not fully recovered, but he is able to walk and run. (IDI with parent, Lindi).

In some cases, there also appears to be a framework of community support to ensure that children regularly attend follow-up appointments. Parents across all regions highlighted that some doctors and nurses, as well as CHWs, community leaders, and family members play a role in ensuring that disabled children receive follow-up treatment. Often this goes beyond their formal role and extends to support in more practical ways, such as transporting families to regional hospitals where needed, or paying for certain treatment costs.

Inclusivity and safety of disability detection and referral systems

Service delivery systems for disability are generally seen as inclusive and fair, promoting equal treatment for all. Parents, healthcare providers and government representatives were aligned in suggesting there is little discrimination (positive or negative) from service delivery staff in their dealings with children with disability.² Treatment was usually reported to be provided on a first-come-first serve basis, or based on the severity of illness. A community leader in Tanga also commented that hospital infrastructure is increasingly accommodating of people with disabilities compared to other public spaces. This also aligns with Tanzania's health policies, which recognise the right to health service delivery for all.

There is limited evidence of discrimination based on gender or ethnicity in medical treatment. Some study participants attributed this to high levels of community awareness on gender. Ethnic divides were also not reported to be very stark or important in the Tanzanian context. Healthcare providers usually associate fair treatment of all their patients with a sense of duty and responsibility in servicing their communities. However, one parent flagged that CHWs aligned to an opposing party reportedly skipped their household during community visits.

Health services for disability detection and referral are also generally considered to be safe, although some parents expressed concerns about the physical safety and documentation of disabilities in children. Health facility managers reported that they maintain a friendly environment, and use safe testing and tools, and that some facilities (e.g. the hospital in Shinyanga) even have dedicated spaces for social welfare services, to ensure the privacy and comfort of parents and children with disabilities. This was confirmed by parents who reported that the equipment used in health facilities is not harmful to their children and is usually used in their presence. Parents also appreciated the doctor-patient interaction and said their

² It is possible for discrimination to be underreported or difficult to detect in some cases.

children are treated well and are comforted, and there is time for consultation. However, some parents reported feeling a degree of insecurity around their children's treatment in facilities, which was often linked to community perceptions (see 'Contextualising childhood disability'). For example, a mother reported that she did not feel comfortable asking questions from a nurse because she feared the nurse would inject her child with something harmful. As discussed in **Box 4**, some parents also expressed concern about data privacy in health facilities, especially when it comes to children with albinism.

Health workforce

This section covers key aspects relating to (i) the availability and performance of the workforce, and (ii) the knowledge and skills of specialist cadres of primary and community providers when it comes to service delivery relating to childhood disability.

Box 7: Summary of findings on the health workforce

- A shortage of healthcare workers limits the detection of disabilities in children in PHC settings. CHWs play a crucial role but barely have any training on disability identification, leading to inconsistent detection.
- MoH has recently launched a revised standardised training package for CHWs, but roll-out has not yet been scaled, and the revised curriculum does not directly focus on early detection of disabilities.
- NGOs and international NGOs sometimes provide training and resources to CHWs on disability detection.

Availability and role of service providers

A review of the policy documents revealed a significant shortage of medical professionals in Tanzania, with the average ratio being 0.1 doctors per 1,000 people, which is well below the WHO recommended level of 1 per 1,000 (Kwesigabo et al. 2021; Government of the United Republic of Tanzania 2023a). The availability of doctors varies across the country. To address the urgent need for more service providers, the country has introduced a clinical officer training programme with a shorter three-year duration, compared to the standard five-year medicine programme (Mkony 2021; Jensen 1967).

Primary data indicates that the current staffing structure in PHC systems leaves some room for disabilities to go undetected and/or untreated in a timely manner. Service delivery staff, such as midwives and health facility managers, said they focus on maternal and child health, growth monitoring and general treatment of illness. While these activities can closely link to disability monitoring and early detection, it is not the primary focus. Specialised doctors were also reported to be available only in tertiary and regional hospitals and study participants reported a shortage of medical specialists, particularly ophthalmologists, neurologists, and behavioural and speech therapists. This is consistent with our document review,

which also revealed a significant shortage of specialists – for example, less than 20% of the required neonatologists are available, less than a third of the required psychiatrists are available and approximately 40% of the required ophthalmologists are available (Government of the United Republic of Tanzania 2023a). It was reported that this shortage of specialist cadres leads to long queues and overcrowding in referral hospitals – in Lindi, for example, a government official reported that the number of neurologists remains very limited nationally, indicating a need for continued investment in specialist training.

Some health facility staff also reported that there is limited coordination between midwives, maternity doctors and paediatric ophthalmologists, resulting in missed opportunities for diagnosis, treatment and referral of children after birth.

Tanzania also implements a CHW programme to try to cover the shortage of mid-level professionals. Documentary evidence shows that this programme dates back to the late 1960s when the first village-based volunteer CHWs were trained. In 2014, the country approved the National Community-Based Health Programme policy guidelines (Government of the United Republic of Tanzania 2014), leading to the establishment of a national public sector cadre of paid CHWs. The pilot class graduated in November 2016, and as of 2023 there were 20,487 CHWs active in the country (Government of the United Republic of Tanzania 2023b). CHW responsibilities include a mix of health promotion and basic curative services provided within the community, including tasks such as implementing community health interventions; collecting and analysing community-based data; conducting household visits and community education; identifying patients needing referral; and collaborating with other community-based cadres (e.g. volunteers), as well as with local governance structures and community groups. There are no formal user fees for services provided by CHWs at the household level. CHWs are administratively supervised at village level by executive officers and technically supervised at a health facility level. The goal of the government is to scale up this cadre to 137,294 CHWs in the next five years (Government of the United Republic of Tanzania 2024). However, there are a number of financial and logistical challenges that prevent the rapid scale-up of this service (Owoputi et al. 2024).

As discussed earlier in the ‘Service delivery’ section, evidence from the primary data indicates that CHWs can play a key liaison role in early identification and referrals. Where CHWs are present, policymakers suggested that their close interaction with the community during household visits contributes to an overall trusting relationship. They were described as having a dual role: both as community educators, and as a liaison point between households and PHC providers at facility level when it comes to disability services. However, community respondents suggested that, in practice, the role of CHWs is more unstructured and focuses primarily on general community health and nutrition issues. For example, they encourage expectant mothers to attend antenatal/postnatal clinics, help mothers to develop birth plans, provide vaccination reminders, and monitor maternal and child nutrition, with the ultimate goal of reducing maternal and infant mortality.

To us, CHWs are very important in the work we do, and to be honest they are also key players in early identification of disabilities among children. The

CHWs play both the social role and the health role. (IDI with central government officials)

After detecting a case [of childhood disability] we have to report it first to the chairman of the area ... then the chairman will take the information to the VEO [village executive officer]. But if it is a serious case then we have to report it immediately to the medical officer in charge at the dispensary, so that the case can be referred for further management as early as possible. (FGD with CHWs, Lindi)

Knowledge and skills of service providers

There was a general perception among stakeholders that healthcare workers do not have sufficient training and capacity to identify children with disabilities at an early age. As discussed in the 'Governance and policy' section, parents, health facility staff and CHWs indicated that due to insufficient clear operational guidance and training, service providers often deal with disability based on their personal experience and intuition. This, coupled with limitations around diagnostic tools, contributes to a focus on more visible physical impairments, at the expense of other types of childhood disabilities.

My friend, leave alone the child, but the government systems are not comprehensive even for the elderly person. CHWs don't understand anything concerning disability issues. We propose that, let CHWs be trained on inclusion and accessibility and be provided with correct guidelines for identifying disability cases and reporting them to the proper authorities. (IDI with disability NGO)

MoH has recently launched a revised standardised training package for CHWs. This is currently being piloted in certain districts. Study participants noted that the new training manual does not include a module on early disability identification processes and procedures for children. This was also confirmed by the document review.

There is the training package for CHWs that was launched not too long ago. This training package does not have the component for early identification. Now if the training manual doesn't have this component, then that shows a gap already. I have also observed that at the community level there is no tool for identification of children with disability. (IDI with central government official)

Some CHWs also receive training on disability detection from NGOs and international NGOs. Study participants in Shinyanga, for instance, described a month-long training of CHWs in Kishapu on the early identification of disabilities, conducted with support from the Tanzania Red Cross Society. The training covered areas such as identifying households with children with special needs and providing support to these households in the form of health insurance and essential supplies.

Funding and resource allocation

This section presents an analysis of health financing systems for disability detection and referral in terms of the (i) government's budget allocation and (ii) financial costs to families.

Box 8: Summary of findings on funding and resource allocation

- Funding for childhood disability services in Tanzania remains limited, with external donors continuing to complement government efforts. Strengthening budgetary support could help address existing gaps in early detection and referral for children at risk.
- There is limited clarity among different government ministries as to the responsibility for the budget allocation for disability.
- Despite the fact that government policy states that children under 5 should be treated at public sector health facilities for no cost, many families still face out-of-pocket costs, including consultation fees, medical expenses and travel.
- Parents of children with disabilities can apply to the Social Welfare Office for approval of fee exemptions, or can cover healthcare services through insurance, but these financial support systems are not always available, known, or accessible.

Budget allocation

There are insufficient financial resources in the public healthcare system to effectively implement childhood disability identification and intervention policies. While not discussed in detail, interview narratives suggested that activity financing is frequently supported by development partners, supplementing government resources. District and hospital-level managers pointed out that there are some funds allocated by the government to support children's health but these funds are not specifically for meeting the needs of children with disabilities.

The process of budget allocation is undertaken in consultation between national ministries and stakeholders at the regional and district levels. In principle, district officials are meant to escalate information on the number of people with disabilities in their district to regional and national budget-setters. Government officials at the central level indicated that guidelines are in place on what proportion of the health budget should be allocated to disability services, although this guidance often does not translate into guaranteed disability funding allocations for individual health facilities. Community leaders also noted that budget allocation often also does not reflect the reality of disability prevalence at the community level. This was put down to weaknesses in the information being sent to budget-setters in regard to accurately assessing how much money is needed for disability detection and follow-up. This is discussed further in the later section on information systems.

There also appears to be some degree of confusion among different government ministries as to the responsibility for the budget allocation for disability. Study participants from line ministries involved in establishing policy direction on disability detection, referral and follow-up denied that they had responsibility for budget allocation. On the other hand, representatives from PMO-LYED highlighted that the budgets for disability are decided upon in consultation with these

ministries. This reflects broader challenges for coordination of the financial responsibility and supply side of disability detection.

Financial costs for participants

The differential ability of parents to cover the costs associated with the detection and follow-up of disability also influences their children's access to treatment. As per policy guidance in the Health Sector Strategic Plan 2021–2026 (Ministry of Health 2021), treatment in public health facilities is meant to be free for all children under 5 and for people with disabilities. However, in practice, several study participants indicated that clear implementation plans do not exist for the policy commitment to fee exemptions. Most parents of children with disabilities were also unaware of this policy and reported they are often asked to pay consultation fees and cover associated costs, like the costs of blood tests and medicines. Some parents reported that initial treatment was free for their child, but then later they were asked to pay money to continue treatment. Transportation costs to reach facilities are also prohibitive for some families.

There is another policy which states that these children with disabilities, when they go to be treated in hospital, they need to receive treatment freely. I have also read this policy. Although it is never followed all that much, but there are such writings. (IDI with community leader, Lindi)

To be honest, I have not seen any government programmes that directly support families with disabled children. If you have money, you might access services, but if you are struggling financially, survival takes priority. (IDI with parent, Shinyanga)

Some participants suggested that parents of children with disabilities can apply to the Social Welfare Office for approval of fee exemptions and/or to cover healthcare services through insurance. For example, district managers in Tanga and MoH representatives reported that parents can approach the Social Welfare Office via their community leaders, for support with financial assistance. It was also reported that the hospital where disability is detected at times facilitates this process by writing referral letters. However, healthcare providers noted that the process of application for fee exemptions is lengthy and bureaucratic as it involves multiple stakeholders and different levels of approvals, and it is not clear whether the time lags cause any delays in providing care. Likewise, one household in Tanga reported having a private organisation's 'membership card', while another was recommended to obtain an 'insurance card' by a private doctor to help cover some costs of care for their disabled child.

You know it's expensive for children with disabilities, so having health insurance helps cover some of the expenses. The doctor is the one who advised us to get insurance for him. (IDI with parent, Tanga)

Equipment and other health products

This section presents an analysis of essential supplies relevant to early detection and follow-up care for children with, or at risk of, disabilities. The findings are

organised around two interlinked sub-themes: (i) access to diagnostic equipment and assistive devices; and (ii) procurement and supply chain processes.

Box 9: Summary of findings on equipment and other health products

- Basic diagnostic equipment such as vision screening devices for visual impairments are often scarce, especially in rural areas, forcing health workers to rely on observation. Many CHWs conflate diagnostic equipment with developmental screening tools.
- The provision of assistive devices is reportedly not included in referral pathways. Where possible, families either improvise, purchase the assistive devices privately, or rely on donations.
- The budget does not always include key items needed to help children with disabilities.
- Procurement roles across ministries and at district level are not clear. This results in limited planning and accountability for the supply chain for disability services.

Access to diagnostic equipment and assistive devices

The document review found there is a shortage of equipment and resources for the early identification and follow-up support of disabilities. This is confirmed by the primary data. The Health Sector Strategic Plan 2021–2026 (Ministry of Health 2021) details that while the provision of medicines has improved, adequate diagnostic equipment and treatment remains unavailable for some conditions. Likewise, although the National Disability Policy (2004) promotes inclusive service delivery, families and frontline workers consistently reported that public health facilities rarely provide these items. Health facility staff and CHWs across all study locations reported a shortage of basic screening equipment, such as audiometers, standardised vision charts, and ultrasound machines. This was said to impede the ability of service delivery staff to conduct standardised assessments to screen for disabilities.

Many CHWs conflate diagnostic equipment (e.g. Tumbling E and Snellen eye charts) with developmental screening tools (e.g. milestone checklists and structured behavioural observations – discussed earlier in ‘Service delivery systems’). One CHW in Lindi noted that they ‘*use a sheet of paper with letters ... if the child fails to read it from two metres, we suspect visual impairment*’. As discussed earlier, overreliance on visual observation impacts the detection of more hidden or complex disabilities. CHWs reported that without equipment to support structured assessment, children with intellectual, sensory, or communication impairments are often overlooked. This affects the trust communities place in health workers.

Sometimes parents ask us, ‘How will you know what is wrong just by looking?’ They expect machines or tests, but we only have our training and a form. (FGD with CHWs, Shinyanga).

Geographical disparities in the distribution of screening equipment are also a concern. It was reported that urban health facilities are more likely to have some

screening equipment, while rural areas rely primarily on CHWs, who have a shortage of any formal tools. For example, a CHW from Lindi stated that, 'In the village we don't have those machines, we just look at the child and ask the mother some questions.' Interviews with health facility managers also confirmed that few centres, especially in more remote areas, have equipment such as audiometers, EEG machines or even standardised vision charts.

We have no specialised equipment, not even an audiometer; we refer everything to the regional hospital. (IDI with health facility staff, Shinyanga)

The provision of assistive devices is reportedly not included in referral pathways. Across study sites, families reported paying for anticonvulsants, sunscreen, physiotherapy aids and orthopaedic shoes. This is usually the case when public health facilities either have inadequate stock or do not list the needed items within their standard packages. Assistive devices, such as corrective shoes for clubfoot, paediatric wheelchairs, therapy seating, and standing or walking frames, were the items most often cited as missing by study participants. Some parents also said there was limited follow-up from frontline workers to confirm whether their child received the recommended support after referral.

Those things [like therapy chairs, adapted shoes, and medication] are not included in the regular treatment ... they have to be bought separately. (Group interview with district officials, Lindi)

Where possible, families either improvise, purchase the assistive devices privately or rely on donations. Parents reported using sticks, water bottles or modified chairs to substitute for mobility aids and therapy equipment. Most families who received assistive devices did so through informal or personal channels, such as NGOs or members of parliament, rather than as part of structured post-detection care. These pathways are unevenly available and largely depend on location, social ties or chance. As such, while some families reported benefiting from these informal arrangements, others remained unaware of how to do so.

We just use what is around, like a bottle for exercise or a stick for balance. (IDI with parent, Shinyanga)

Honestly speaking, in Tanga when we are in need of wheelchairs, we usually ask our member of parliament and he brings them for us. ... yes, there is also an NGO in Moshi who we can request for assistance. (IDI with Community Leader, Tanga)

Procurement and supply chain processes

Procurement roles across ministries are not clear, resulting in limited planning and accountability for the supply chain for disability services. This was reported by participants across all levels, from community providers to national decision makers. At the national level, despite PMO-LYED being designated as the national disability focal point, as discussed earlier in this chapter, it does not have

budgetary control or implementation authority across other ministries. Likewise, while MoH was reported to oversee general medical procurement through the Medical Stores Department, other ministries and agencies, such as PMO-LYED, PO-RALG, and MoEST, were also said to hold partial mandates related to procurement of disability-inclusive health services but without clear lines of accountability.

We only play a small part in mobilising resources... the [entity name] is responsible for actual procurement. (IDI with central government official)

The stakeholder mapping exercise found that ministries develop their own plans with limited communication, resulting in duplication of effort and unclear prioritisation. There is limited evidence of shared forecasting or joint procurement planning, even with multiple actors involved in supporting children with disabilities. This was confirmed in the primary data, with participants across sectors emphasising that procurement planning for disability-related supplies rarely occurs in a coordinated or strategic way. This limited coordination was said to contribute to delays, making it difficult to track what has been procured and by whom.

Sometimes we don't know if it's PO-RALG, the MoH, or the PMO that will act. So, it ends up being no one. (IDI with central government official)

At the district level, it is also not clear what drives local procurement priorities. District managers explained that although some national guidance exists, it does not provide specific line items for disability-related equipment. As a result, local decision makers can exercise discretion and local budgets often tend to prioritise operational elements like fuel or allowances over screening tools or assistive devices. Likewise, some study participants from NGOs and the government explained that, because disability-related commodities are not included in the Medical Stores Department's standard lists, health facilities often rely on what donors can provide, or on equipment and/or assistive devices that can be sourced locally. This creates disparities in what is available across districts and facilities.

Each centre sets its own budget ... usually for fuel or food, not for screening tools. (Group interview with district managers, Lindi)

We rely on donors or what we can get on the market; it's not structured. (IDI with NGO partner)

There is also some evidence that procurement processes do not tend to prioritise the assistive devices needed by children as part of follow-up support. A number of participants expressed concern over more visible items, such as ICT infrastructure, often being prioritised in budget allocations, while essential assistive devices, like walkers, splints or therapy kits, remain scarce at the community level. While stakeholders acknowledged that ICT systems might support the collection and reporting of routine health data, they questioned whether such investments could address the immediate needs of children with disabilities.

For example, 120 computers were procured ... but children with disabilities still have no walking aids. (Group interview with district officials, Tanga)

... We know the computers are important, but people expect children to get therapy or walking devices. Those are never there. (IDI with health facility staff, Shinyanga)

Disability information systems

Strengthening disability reporting is particularly important for the early detection of disabilities in children, as timely and accurate data enables early interventions, better health outcomes and more inclusive policy planning. Tanzania's HMIS currently collects data on childhood disability through a mix of national tools, digital platforms, and local practices. This sub-section (i) outlines the various disability reporting systems operating at different levels in Tanzania, (ii) presents evidence on the quality and completeness of the data collected and (iii) discusses the availability, storage and use of disability data.

Box 10: Summary of disability information system findings

- Health facilities and CHWs record disability inconsistently, relying on general health forms that do not differentiate between impairments and certified disabilities. Health impairments are sometimes recorded also at the community level through the village executive office.
- Tanzania's national HMIS is designed to channel data from community and primary care levels to the national level. However, the use of multiple, different electronic health recording systems creates silos and data gaps. Some NGOs run separate disability tracking initiatives, but insufficient coordination leads to duplication and missed opportunities.
- There are also challenges with the current HMIS in terms of ensuring that data collected on disability is effectively used for planning and resource allocation.
- The government has recently made efforts to address these issues by initiating a national persons with disability management information system (PD-MIS) under the PMO-LYED. Recent improvements and revisions to the HMIS have also supported data integration in public systems.

Information systems at various levels

At the PHC level, health information is typically recorded in general ledgers or on clinical cards at health facilities. Healthcare workers, including CHWs, often did not differentiate between the recording of impairments or health conditions and the recording of disability (which is established once an impairment or condition is certified).

Tools used for documentation, such as ledgers and clinic cards ... capture the child's records, including immunisation and monthly check-ups. The ledger book records all the child's details, whether they have a disability or

not. There is no separate book specifically for children with disabilities.
(Group interview with facility managers, Shinyanga)

In addition to facility-based reporting, health impairments are also sometimes recorded at the community level through the village executive office. At times, this is done as part of the national census process. For example, a community leader in Tanga reported that disability information is collected as part of the census data in a process that starts with the street chairperson, with the help of CHWs. This information is then registered in the chairperson's office, using hard copies of the data. In other cases, for example, health facility managers in Shinyanga and Lindi reported that CHWs help fill out general health forms for children, which have a section for recording disabilities. These reports are then shared with the village sub-chairman and chairman for their records, before being passed to the medical officer in charge in the local health facility.

Tanzania's national HMIS is designed to channel data from community and primary care levels to the national level. The paper-based HMIS is typically used at dispensaries and health centres, with data intended for entry into the electronic District Health Information System 2 (DHIS2) by district staff. While MoH participants described this as standard procedure, they also acknowledged the long-standing challenge that many higher-level health facilities use numerous different electronic health record systems that do not interconnect. This 'lack of interoperability', as described by an MoH study participant, creates data silos, making it difficult to track patients, avoid double-counting, or gain a comprehensive national view of any health condition, including childhood disability.

There is also evidence of ad hoc or parallel data collection systems emerging in response to some of the challenges with the official system. Health providers in Lindi mentioned a social welfare officer using an 'Excel sheet ... to identify skin patients [which] they update each year'. Similarly, CHWs in Shinyanga reported using 'our own form No. 3 [provided by an NGO], in which we identify them [children with disability] and submit every month to the Social Welfare Office'. Furthermore, some NGOs have undertaken projects to support the government's disability information systems, but integration of these systems has been challenging. For example, it was reported that UNICEF's efforts to develop an HMIS to register cases of disabilities in children at birth did not integrate with existing government systems, resulting in a 'limited coordination' between the government and NGO partners. Likewise, in Shinyanga region, partners such as World Vision have supported short-term disability data collection efforts, though within a limited geographical scope, in two wards.

The government has recently made efforts to address these issues by initiating the national persons with disability management information system (PD-MIS) under the Prime Minister's Office. There was low awareness of this system among frontline implementers and district officials who participated in the primary research across the study regions. In discussions, central government officials suggested that initial PD-MIS training to date had been confined to a few pilot districts like Kishapu and Kahama, and many health providers in Tanga and Shinyanga reported never having heard of the system. However, the system is in its early stages and learnings from pilots conducted are yet to be applied in wider

implementation that sees the system functioning as an integrated national resource.

Quality and completeness of data

Across all three study regions, implementers at facility and district levels, as well as national-level stakeholders, highlight the inadequacy of current systems for tracking childhood disability. This results in limited visibility of children with disability in information systems. For example, health providers in Tanga and Shinyanga said they do not maintain dedicated registers for children with disabilities at health facilities. While health providers in Tanga mentioned using HMIS to record diagnoses, they also conceded that *'it's just a general form for reporting all conditions including disabilities'*, and that information from DHIS2 is not a reliable source of exact numbers, since some patients seek care elsewhere. Another health provider in Lindi stated that the HMIS form *'does not indicate anything on disabilities'* specifically. This means that even if a child with a disability is identified, their condition may not be recorded in a way that allows for meaningful analysis.

Likewise, as discussed earlier in the 'Service delivery systems' section, the widely-used RCH books are also not a comprehensive tool for systematic recording of childhood disabilities. MoH study participants noted that the RCH book, while helpful for tracking developmental milestones, has *'nowhere to record'* specific disability concerns, stating:

It [RCH] is not very clear and we would wish this book to be updated on that section because it would have been a good tool to be used for early detection. (FGD with central government officials)

Recent improvements and revisions to the HMIS Form number 3 represent a significant advancement in the integration of community-level data into the national health information systems. Study participants reported that CHWs were previously required to fill HMIS Form 3 and Form 10, which primarily captured facility-based data, limiting the scope of information available for community-level decision making. The revised HMIS interface makes provision for CHWs to document health-related data gathered from households, creating a more complete and accurate picture of the local health context. As a result, CHWs are said to be better equipped to monitor and identify health trends, including child development monitoring, such as vaccination follow-ups and the disability status of members of the households in their domain.

These changes have brought a sense of accountability of my roles and make me observant in the community so that I may have the correct information to fill in the HMIS, including information on the number of household members, their ages, occupation, their economic status, infrastructure in the household, disabilities, nutritional status and the like. (FGD with CHWs, Lindi)

Given the limited integration of formal reporting systems, data on disabilities is frequently informal and unstructured. The data is usually collected on the basis of narrative reports or community-led identification through social networks. Community leaders, for instance, reported having no readily available information

on childhood disability prevalence rates in their region and often rely on ad hoc information through sub-village chairpersons.

Availability, storage and use of disability information

Key stakeholders shared varying perspectives on the availability and storage of disability data. For example, discussions with government officials indicate that data about people with disabilities is available and stored centrally, albeit with delays in referrals for specialised treatment and care. However, this was often not supported at the community level.

Yes, even if you want information on the total number of children who were identified and provided with referral you can easily obtain the data. However, there are usually delays in referral so that is the challenge we face. (IDI with central government official)

There are no records at the community level providing information on people with a disability. When we need this information, it means that it's when we shall start asking from the sub-village chairmen to provide me with information if there are children with disabilities in his or her area. But personally I don't have this record. (IDI with community leader, Shinyanga)

The DHIS remains the main data platform used in health facilities. However, it remains unclear the degree to which it is used in collating data on disability, with usage appearing to be limited to certain referral centres, with no clear integration of data collected at community level. Moreover, the information available in the DHIS seems to be inclined more towards general health conditions and are not disaggregated by variables such as age, type of disability, region or severity.

The data we have is generalised and not specific say to age, region, etc. [Having information like] this ... helps us to prioritise patients based on the severity of the case. So, if the magnitude of the disease is not that severe, then we do not have to utilise a lot of resources. (Group interview with district officials, Tanga)

Another challenge for the current HMIS with regard to disability is ensuring that the collected data is effectively used for planning and resource allocation.

Gatekeepers such as district-level managers recognise that the generalised data is a shortcoming because it does not support targeted planning and lobbying for more resource allocation for inclusive service delivery. Furthermore, MoH study participants indicated they do not typically use the current systems for budgeting and instead consult relevant entities like PO-RALG to obtain any required data.

Discussion

Our study contributes to knowledge and understanding of the community and primary health systems for early detection and referral of children with disabilities in a resource-limited setting and looks at some of the factors that enable or constrain these systems. The research has revealed different dimensions of system functionality in Tanzania and shows that there is currently limited focus on identifying children early and empowering parents, health service providers and other actors at the community level to detect and refer these children.

We identified a wide range of practices and experiences from policymakers, implementers and the recipients of services, which offer plausible explanations for the limited focus on early identification and care of children with, or at risk of, disabilities. The majority of these findings indicate the importance of awareness and understanding of disabilities by parents and service providers, support structures for families of disabilities, and coordinated policy implementation and coordination between services. Four themes which, to differing degrees, cut across the pillars of the WHO health systems strengthening framework stand out.

First, perceptions of childhood disability were reported to be important for early identification and are worth emphasising. This is because parents or families of children with disabilities do not always prioritise early identification of disability through medical routes due to embarrassment, a sense of personal wrong-doing, or other personal, family issues. This finding from our study can be compared to a recent multi-country study from Malawi, Uganda and Pakistan (Lynch et al. 2023). In a qualitative study with parents of children with disabilities, healthcare workers and teachers, Lynch et al. found that stigma continues to negatively impact the identification of, and support for, children with disabilities. In our study, positive perceptions of childhood disability by healthcare workers were reported as being particularly important in helping parents to overcome self-stigma and make early decisions to seek care for their children. The complexity of community perceptions and self-stigma means that CHWs and PHC workers need to be provided with disability-focused training, tools and practices to enable them to work more sensitively with parents and to accommodate their fears and needs (Geniets et al. 2025; Torres and Ohajunwa 2025). Good relationships between parents and health workers, notably CHWs, nurses, and midwives, will build trust and receptiveness towards their messages.

Our study also demonstrates the importance of informal networks for parents of children with disabilities in facilitating early identification and referral. Peer support from other parents in the community or at the health facility, and a sense of belonging to a group of parents who share similar experiences and who one could go to for support, are important factors in influencing health-seeking behaviours. Information and positive encouragement from other parents with lived experience were reported to have enabled parents in our study to engage the healthcare system with optimism and played an important role in the acceptance

processes for their child's diagnosis. Therefore, in the drive to prioritise strengthening the formal community health system, more emphasis also needs to be placed on developing more informal networks of parents of children with disabilities. Government and partners involved with childhood disability need to strengthen these elements of early identification and intervention for children with disabilities at the community level. These aspects of the community health system have been found to be important for other childhood health interventions in other resource-limited settings as well (Ferraro et al. 2024; Grennan et al. 2022).

Second, parents, PHC workers and policymakers who participated in the study placed value on the role of CHWs in effective identification and referral for children with disabilities. They noted the close interactions and trusting relationships that CHWs usually have with community members, which often comes across as a form of social contract. However, insights gained in FGDs with CHWs revealed significant concerns regarding their motivation and the level of support they receive within the healthcare system. Many CHWs shared that they had gone for months without any meaningful compensation, which affected their morale and ability to undertake identification and referral of children with disabilities effectively. Additionally, training on the early detection of disabilities was reported as insufficient, leaving CHWs feeling ill-equipped to identify and refer children. This is consistent with findings from other studies, which indicate that while CHWs are recognised as valuable contributors to the healthcare system, their contributions are often acknowledged only superficially (Santosh and Kane 2025; Ndegwa et al. 2025). Government, NGOs and other stakeholders appreciate the role of CHWs but fail to translate this recognition into tangible support such as financial incentives, structured training programmes and career development opportunities (Miranda et al. 2025; Hodgins et al. 2025). CHWs interviewed in our study felt undervalued, underpaid and unsupported, despite being on the frontlines of healthcare delivery. These challenges raise a larger question around the need for meaningful investment in CHWs to ensure their effectiveness and sustainability in the healthcare system. A long-term vision for CHW funding and the scale-up of the salaried CHWs programme is uncertain and does not seem to have been widely embraced in the light of competing priorities in the country.

Third, the harsh economic circumstances faced by many people in this setting mean that most parents would not immediately seek care for their children, even if they had all the correct information. What was most revealing from interviews with parents, however, was the fact that in the face of these difficulties, most remained determined to mobilise resources that would enable them to take up a referral for their children. Government support was reported to be limited but other resources came to the fore in such circumstances, including support from family and relatives, the wider community and NGOs. The remarkable similarity of parents' narratives about the support (or gap in support) they may have received, and what this meant for them, to some extent reflects the views of other study participants. Participants from NGOs, for example, argued that for early identification of disability in children to be effective, the service should be provided free at the point of delivery, and delivery systems should be decentralised to 'close-to-parents/families' levels of the health system. Other

studies with parents and caregivers of children with disabilities have shown the importance of reducing the costs of seeking care (directly and indirectly), and the use of outreach mobile clinics or health facilities close to people's homes (Gizaw et al. 2022).

Fourth, and closely related to the above three themes, the critical role of assessment tools in effective identification and referral of children with disabilities was evident – but this interpretation requires caution. The tools that the community and primary health workers need to screen children were reported to not always be readily available because of limited resources at the district level, competing priorities and health system weaknesses, and bottlenecks in procurement and distribution systems. One might anticipate widespread use of basic assessment tools by CHWs to identify and refer children with disabilities, given the central role of CHWs in maintaining all health records at the community level. However, there was little evidence of good practice in the use of assessment tools in the identification and referral services at the community level. This was revealed by CHW narratives about improvised methods, and reliance on observation and judgement to identify children with disabilities in the community. A minority of the CHWs that we interviewed had been creative with the assessment tools provided to them by NGOs for other disease programmes or nutrition work in the community. For example, they did not hand over excess assessment tools when the NGO programmes came to an end but instead used those forms for screening of disability in children. Understandably, assessment of impairments is different to other disease programmes, and CHWs spoke about a deep sense of frustration around the inability of the system to provide them with the appropriate forms to screen children in the community for functional difficulties.

Limitations

While this study provides valuable insights, its findings and implications should be viewed with consideration of certain limitations.

First, although all the major stakeholder groups were represented in our purposive sample, responses from study participants may not have been representative of the larger population of policymakers, healthcare workers within the primary and community health systems, parents of children with disabilities, community leaders and NGOs. To compensate for this, we triangulated evidence obtained from different respondent groups and through the use of the different topic guides, and also complemented primary data collection with a scoping review that involved documentary analysis and stakeholder mapping (Marlina et al. 2025; Meydan and Akkaş 2024).

Second, study participants were identified and approached through formal government structures at the community, district and national levels. While this approach ensured an organised and systematic recruitment process, it may have inadvertently excluded certain key stakeholders with extensive knowledge of early identification and referral systems for children with disabilities. In addition, those who were selected may have been less open during interviews due to concerns

around this being perceived as criticism of existing systems. Consequently, valuable insights into the challenges and potential improvements in early intervention efforts for children with disabilities may not have been fully captured. To compensate for this, we adopted robust informed consent procedures, emphasising confidentiality and anonymity, and we triangulated evidence across different respondent groups,

Third, there were some inconsistencies identified across participant responses around certain themes. These included, for example, distinctions between the different stages of disability detection, verification, documentation and referral; and the use of assessment tools. This is likely to reflect varied experiences with and knowledge of existing systems. In addition, the varied understandings of disability as a technical concept may mean that respondents interpreted it in different ways. In addition, the research assistants, while experienced in qualitative research methods, were not all thematic specialists on disability, bringing a risk that they might not fully explore some nuances. To mitigate this problem, the two field teams were structured to balance researcher expertise, and training and pilot activities focused on consistency in the delivery of questions. Debriefs with the core research team were also used to collate findings across interviews.

Fourth, themes related to the strengths and weaknesses around how early identification and referral services for children with disabilities are funded, which would be of interest, did not emerge as explicit within our analysis, which might reflect a limitation of the topic guides we used. Detailed information on funding was not captured through the use of our topic guides. Study participants raised issues around the limitations of the current financial provision for disability, but understanding allocations would require detailed methods for budget and expenditure analysis.

Finally, having minimal demographic information about the parents (e.g. household size and family socio-economic status), and CHWs and PHC workers interviewed, may have limited the understanding of the potential for demographic variation in our analysis.

Implications for practice and policy

Our findings are based on a very rich body of qualitative data. Nevertheless, because the study was conducted in just three of the 26 regions in mainland Tanzania, questions regarding the transferability of findings beyond the study setting necessarily arise. However, while the specifics are likely to differ nationally, regionally and globally, there is evidence to suggest that the limited focus on early identification and care of children with disabilities that we found in our study may be a persistent feature across many countries in sub-Saharan Africa (Adugna et al. 2020; Genovesi et al. 2022). In South Africa, for example, a recent literature review highlighted the urgent need to empower caregivers, and health and non-health professionals to address early childhood intervention and early childhood development needs of children with disabilities (Karisa et al. 2022). Lynch et al. (2023) have drawn similar conclusions from their study with

parents and professionals in Malawi, Pakistan and Uganda, highlighting the scarce evidence of good practice in identification and referral services for children with disabilities. We therefore suggest that the weaknesses and strengths of the PHC and community health system that our study identified may be transferable – though not generalisable – across many other low- and middle-income settings.

In this study's setting in Tanzania, where data on childhood disability remain scarce and the availability of specialists trained in disability diagnosis is highly limited, the process of determining and certifying a child's disability does not follow a standardised or formally documented approach. Unlike the structured confirmation processes reported by Barron in the United States (2001), where formal assessments lead to an official documentation of disability, the absence of clear guidelines and well-established procedures in our study setting creates uncertainty among parents and caregivers. Additionally, insufficient integrated counselling and provision of disability-related information – similar to what Vanderpuye et al. (2025) have documented in Ghana – means that families are often left without essential guidance regarding their child's condition, available support services and intervention options.

Findings from interviews conducted with both parents and senior technical staff at MoH reveal that disability documentation does not occur in a formalised manner. Instead, disability identification is often informal, and highly dependent on individual healthcare workers' expertise and available resources, leading to inconsistencies in diagnosis, access to services, and eligibility for government support. Inadequate formal procedures for identifying and recognising disabilities may hinder timely support for children and create challenges in implementing policies and delivering services. With limited official documentation of disability, families struggle to secure financial assistance, educational accommodations and medical treatment, perpetuating inequalities in disability care. Our findings are consistent with those of international reports that point to the numerous benefits of formal disability documentation, such as the World Report on Disability (Frontera 2012) and the World Report on Vision (WHO 2019).

To address these challenges, policy measures should focus on developing standardised diagnostic and documentation frameworks, ensuring that all children at risk undergo consistent assessments and receive formal recognition of their disabilities. Our findings further suggest that strengthening coordination between healthcare providers, social services and educational institutions will be crucial in facilitating early detection, guiding families through intervention pathways and guaranteeing access to necessary support structures. Additionally, embedding disability counselling and awareness programmes within dispensary and health centre settings could empower parents with relevant knowledge, enabling them to make informed decisions and to advocate for their children's rights effectively.

Unanswered questions and further research

Key related areas for future research fall into two broad areas. First, there is a need to explore how varying local interpretations and perceptions of childhood disability affect policy implementation, service delivery and parental awareness. To gain a deeper understanding of the pathways for identifying children with disabilities in the early years in this setting, it is essential to investigate how cultural, functionality-based or medical condition-based perceptions of disability shape policies and their implementation, influence the organisation and delivery of services, and impact parental decision making. By analysing these variations in perceptions and their broader effects, we would be able to improve early identification strategies and develop targeted interventions to better support children with disabilities and their families.

Second, there is a need to gather further evidence across countries on the strengths and challenges of strategies and systems for early identification, to allow experience sharing and to identify effective approaches for strengthening these systems. This includes further multi-country evidence about the effectiveness of current strategies for early identification and for empowering health, social and education providers at the community level to identify and refer these children. Doing so in different country settings in the region would be vital for comparing models of early detection, referral systems and community-based intervention programmes to determine what works best across various settings. UNICEF (2024a) has long advocated for integrating disability screening into routine maternal and child health care, ensuring that parents, CHWs and PHC providers are equipped with the skills, knowledge and resources to facilitate early diagnosis and intervention. We are hopeful that ongoing (UNICEF 2024b) and future research in these areas in different contexts can inform such integrated services and better programmes to identify children with disabilities.

Conclusion

This study has highlighted the strengths and challenges around early identification and referral systems for children with disabilities in a resource-limited setting in sub-Saharan Africa (Tanzania). Qualitative interviews with a wide range of purposively selected stakeholders identified a series of nuanced and interconnected factors both within and beyond the wider health system that enable or challenge efforts to detect disabilities early and connect families with services in the healthcare system.

Key issues include stigma surrounding childhood disabilities, which can discourage parents from seeking help for their children. Our findings also highlight the important role of CHWs, who closely interact with families and help connect them to healthcare services. However, CHWs are often not provided with adequate training and resources for disability screening, limiting their ability to identify children in need of intervention. Informal parent support networks emerged as another crucial element, as parents who have lived experience with disabilities can offer encouragement and practical guidance to others facing similar challenges. Additionally, financial difficulties prevent many families from seeking care early enough for their children, especially in the absence of accessible and affordable services.

Our findings suggest several opportunities for improvement:

- strengthening coordination within government, and between government agencies and NGOs, could ensure services are more integrated and sustainable
- there is an urgent need for increased funding to support disability programmes and for improved training of CHWs and PHC workers to enhance their ability to screen and refer children effectively
- families and communities should be empowered to recognise early signs of disabilities and seek assistance without fear or hesitation
- efforts should be made to collect data that tracks referral patterns, identifies gaps and strengthens connections between healthcare, education and social welfare services.

Recommendations

The recommendations listed below were developed by officials from different government ministries, agencies and departments during a two-day workshop to validate the study findings held in Dodoma in July 2025. In no specific order of priority:

- Ensure frontline workers – including CHWs, social welfare officers and teachers – have an adequate understanding of national guidance in this area, and the skills to identify children with disabilities.
- Ensure frontline workers and facilities have assessment tools and basic equipment to identify children with disabilities, as well as the skills to use these tools, equipment and systems.
- Strengthen coordination structures for identification between government and other stakeholders.
- Strengthen the underlying health system – including provision of stipends for CHWs, supply chains and budget allocations – to contribute to more effective early detection systems.
- Use awareness, behaviour change communication and educational campaigns to address disability-related stigma and discrimination and increase understanding among decision makers, policymakers and communities about the benefits of identification and referral.
- Revise guidelines so that health facility governing committees and village health committees include a representative of people with disabilities.
- Strengthen formal support groups and develop informal peer support groups where parents can share experiences, provide encouragement and guide each other in accessing services and addressing disability-related stigma.
- Strengthen existing data tracking mechanisms to identify gaps in service delivery, measure effectiveness and improve coordination across health, education and social services.

References

- A dugna, M., Ghahari, S., Merkley, S. and Rentz, K. (2024). Children with disabilities in Eastern Africa face significant barriers to access education: A scoping review. *International Journal of Inclusive Education*, 28(10), pp. 2281–2297. <https://doi.org/10.1080/13603116.2022.2092656>
- A dugna, M.B., Nabbouh, F., Shehata, S., Ghahari, S. (2020). Barriers and facilitators to healthcare access for children with disabilities in low and middle income sub-Saharan African countries: a scoping review. *BMC Health Services Research*, 20, 1–11. <https://doi.org/10.1186/s12913-019-4822-6>
- Aldersey, H.M. and Turnbull, H.R. (2011). The United Republic of Tanzania’s national policy on disability: A policy analysis. *Journal of Disability Policy Studies*, 22(3), 160–169. <https://doi.org/10.1177/1044207311397877>
- Barron, B.A. (2001). Disability certifications in adult workers: a practical approach. *American Family Physician* 64(9), pp. 1579–1586. <https://pubmed.ncbi.nlm.nih.gov/11730313/>
- Binyaruka, P., Martinez-Alvarez, M., Pitt, C. and Borghi, J. (2024). Assessing equity and efficiency of health financing towards universal health coverage between regions in Tanzania. *Social Science & Medicine*, 340. <https://doi.org/10.1016/j.socscimed.2023.116457>
- Bohaligah, K.M., Bohaligah, M.M. and Bohaligah, S.M. (2015). Preventive strategies for pediatric health in primary healthcare: A systematic review. *Cureus*, 17(2). <https://doi.org/10.7759/cureus.78719>
- Buhori, J.A. (2024). The blind eye on health care services of children with disabilities: a case of Mburahati Ward–Dar es Salaam–Tanzania. *Tanzania Journal of Community Development*, 3(2), 1–16.
- Burger, N. and Gilson, L. (2025). How has the concept of health system software been used in health policy and systems research? A scoping review. *Health Policy and Planning*. <https://doi.org/10.1093/heapol/czaf001>.
- Doshmangir, L., Sanadghol, A., Kakemam, E. and Majdzadeh, R. (2025). The involvement of non-governmental organisations in achieving health system goals based on the WHO six building blocks: A scoping review on global evidence. *PLoS ONE*, 20(1). <https://doi.org/10.1371/journal.pone.0315592>
- Ferraro, K., Leal, J., Sutton, A., Peters, S. and Pinter, C. (2024). The critical role of parents within a Learning Health Network. *Frontiers in Pediatrics*, 12. <https://doi.org/10.3389/fped.2024.1428758>
- Finlay, L. (2021). Thematic analysis: the ‘good’, the ‘bad’ and the ‘ugly’. *European Journal for Qualitative Research in Psychotherapy*, 11, 103–116. <https://doi.org/10.24377/EJQRP.article3062>
- Frontera, W.R. (2012). The world report on disability. *American Journal of Physical Medicine & Rehabilitation*, 91(7). <https://doi.org/10.1097/PHM.0b013e318255982e>

- Geniets, A., Omogi, J., Hakimi, L., Lakati, A. and Winters, N. (2025). Mitigating moral distress by enhancing healthcare workers' understanding of challenges faced by carers of children with disabilities in low-resource settings in Kenya. *Global Health Action*, 18(1). <https://doi.org/10.1080/16549716.2025.2452159>
- Genovesi, E., Jakobsson, C., Nugent, L., Hanlon, C. and Hoekstra, R. A. (2022). Stakeholder experiences, attitudes and perspectives on inclusive education for children with developmental disabilities in sub-Saharan Africa: A systematic review of qualitative studies. *Autism*, 26(7), pp. 1606–1625. <https://doi.org/10.1177/13623613221096208>
- Gizaw, Z., Astale, T. and Kassie, G.M. (2022). What improves access to primary healthcare services in rural communities? A systematic review. *BMC Primary Care*, 23(1), 313. <https://doi.org/10.1186/s12875-022-01919-0>
- Government of the United Republic of Tanzania. (2014). *National community-based health programme, 2014. Policy guidelines: Towards a sustainable cadre of CHVs/CHVs in Tanzania*. Dar-es-Salaam: United Republic of Tanzania.
- Government of the United Republic of Tanzania. (2021). *National guidelines for early identification and appropriate interventions for children with disabilities (Mwongozo wa Taifa wa Utambuzi wa Mapema na Afua Stahiki kwa Watoto Wenye Ulemavu)*.
- Government of the United Republic of Tanzania. (2023a). *Human resources for health. Strengthening health systems- improving services*. Tanzania mainland country profile. <https://www.moh.go.tz/storage/app/uploads/public/66d/aee/5d2/66daee5d219a1012587045.pdf>
- Government of the United Republic of Tanzania. (2023b). *Community health road map: United Republic of Tanzania*. <https://r4d.org/wp-content/uploads/Tanzania-and-Zanzibar-Community-Health-Roadmaps.pptx.pdf>.
- Government of the United Republic of Tanzania. (2024). *Integrated and coordinated community health workers (ICCHE) plan*. Dar-es-Salaam: United Republic of Tanzania.
- Grennan, L., Nicula, M., Pellegrini, D., Giuliani, K., Crews, E., Webb, C., Gouveia, M-R, Loewen, T. and Couturier, J. (2022). "I'm not alone": a qualitative report of experiences among parents of children with eating disorders attending virtual parent-led peer support groups. *Journal of Eating Disorders*, 10(1), 195. <https://doi.org/10.1186/s40337-022-00719-2>
- Gupta, R. (2025). Thematic analysis of qualitative data: a relational, recursive and reductive (3R) approach. *Qualitative Research Journal*. <https://doi.org/10.1108/QRJ-07-2024-0164>
- Hanass-Hancock, J., Kamalakannan, S., Murthy, G., Palmer, M., Pinilla-Roncancio, M., Velarde, M.R., Tetali, S. and Mitra, S. (2023). What cut-off (s) to use with the Washington Group short set of questions? *Disability and Health Journal*, 16(4), 101499. <https://doi.org/10.1016/j.dhjo.2023.101499>
- Hanson, K., Brikci, N., Erlangga, D., Alebachew, A., De Allegri, M., Balabanova, D., Blecher, M., Cashin, C., Esperato, A., Hipgrave, D., Kalisa, I., Kurowski, C., Meng, Q., Morgan, D., Mtei, G., Nolte, E., Onoka, C., Powell-Jackson, T., Roland, M., Sadanandan, R., Stenberg, K. et al. (2022). The Lancet Global Health Commission on financing primary health care: putting people at the centre. *The Lancet Global Health*, 10(5), e715-e772. [https://doi.org/10.1016/S2214-109X\(22\)00005-5](https://doi.org/10.1016/S2214-109X(22)00005-5)

- Hodgins, S., Lehmann, U., Perry, H., Leydon, N., Scott, K., Agarwal, S., Marcus, H., Ved, R., Olivas, E., Ballard, M., Mbewe, D., Odera, M., Petit Homme, S., Otieno, B., Wutete, P., Chikumba, A., Muyingo, P., Kyakuha, J., Harcourt, E., Chowdhury, M., Musoke, D. et al. (2025). Comparing apples with apples: A proposed taxonomy for “Community Health Workers” and other front-line health workers for international comparisons. *PLoS Global Public Health*, 5(2), e0004156. <https://doi.org/10.1371/journal.pgph.0004156>
- Isangula, K.G., Lyimo, M., Ndungile, Y. and Robert, E. (2023). Nurses' preparedness for disaster response in rural and urban primary healthcare settings in Tanzania. *Rural and Remote Health*, 23(2), 1–11. <https://doi.org/10.22605/rrh7547>
- Jensen, R.T. (1967). The primary medical care worker in developing countries. *Medical Care*, 5(6), 382–400. <https://www.jstor.org/stable/3762969>
- Kakoko, D., Kigadye, E. and Hean, S. (2023). Special healthcare needs of children with disabilities in Tanzania: Challenges and recommendations. In *Change Agents: An interprofessional book about children with disabilities in Tanzania and Norway* (pp. 94–105). <https://doi.org/10.18261/9788215057903-23-05>
- Kamiya, Y. (2021). Current situation of children with disabilities in low-and middle-income countries. *Pediatrics International*, 63(11), pp. 1277-1281. <https://doi.org/10.1111/ped.14904>
- Karisa, A., Samuels, C., Watermeyer, B., McKenzie, J. and Vergunst, R. (2022). Priorities for access to early childhood development services for children with disabilities in South Africa. *South African Journal of Childhood Education*, 12(1), 1119. <https://doi.org/10.4102/sajce.v12i1.1119>
- Kitole, F.A., Lihawa, R.M. and Mkuna, E. (2023). Equity in the public social healthcare protection in Tanzania: does it matter on household healthcare financing? *International Journal of Equity Health*, 22(1), 50. <https://doi.org/10.1186/s12939-023-01855-0>
- Kwesigabo, G., Mwangi, M.A., Kakoko, D.C., Warriner, I., Mkony, C.A., Killewo, J., Macfarlane, S.B., Kaaya, E.E. and Freeman, P. (2021). Tanzania's health system and workforce crisis. *Journal of Public Health Policy*, 33, S35–S44. <https://doi.org/10.1057/jphp.2012.55>
- Le Fanu, G., Schmidt, E. and Virendrakumar, B. (2022). Inclusive education for children with visual impairments in sub-Saharan Africa: Realising the promise of the Convention on the Rights of Persons with Disabilities. *International Journal of Educational Development*, 91. <https://doi.org/10.1016/j.ijedudev.2022.102574>
- Lumivero. (2023). *NVivo (Version 14)*. <https://lumivero.com/products/nvivo/>
- Lynch, P., Nabwera, H. M., Babikako, H. M., Rasheed, M., Donald, K. A., Mbale, E. W., Stockdale, E., Van den Heuvel, M., Mwesige, A.K., Gladstone, M. (2023). Experiences of identifying pre-school children with disabilities in resource limited settings – an account from Malawi, Pakistan and Uganda. *Disability & Society*, 1–21. <https://doi.org/10.1080/09687599.2023.2181769>
- Mafwiri, M.M., Jolley, E., Hunter, J., Gilbert, C.E. and Schmidt, E. (2016). Mixed methods evaluation of a primary eye care training programme for primary health workers in Morogoro Tanzania. *BMC Nursing*, 15, 1–10. <https://doi.org/10.1186/s12912-016-0163-5>

- Maluka, S.O. and Bukagile, G. (2016). Community participation in the decentralised district health systems in Tanzania: why do some health committees perform better than others? *The International Journal of Health Planning and Management*, 31(2), E86–E104. <https://doi.org/10.1002/hpm.2299>
- Marlina, E., Purwaningsih, M., Al Hakim, S. and Maryati, I. (2025). Ensuring trustworthiness in qualitative research: The role of triangulation techniques. In *Qualitative Research Methods for Dissertation Research*, pp. 347–376. <https://doi.org/10.4018/979-8-3693-3069-2.ch012>
- Mbau, R., Musiega, A., Nyawira, L., Tsofa, B., Mulwa, A., Molyneux, S., Maina, I., Jemutai, J., Normand, C., Hanson, K. and Barasa, E. (2023). Analysing the efficiency of health systems: a systematic review of the literature. *Applied Health Economics and Health Policy*, 21(2), 205–224. <https://doi.org/10.1007/s40258-022-00785-2>
- Mesiäislehto, V. (2024). Relational, ableist and gendered sites of violence: perspectives of Tanzanian girls with disabilities on access to sexual and reproductive health services. *Forum for Development Studies*, Volume 51, pp. 25–47. <https://doi.org/10.1080/08039410.2023.2264857>
- Meydan, C.H. and Akkaş, H. (2024). The role of triangulation in qualitative research: Converging perspectives. In *Principles of Conducting Qualitative Research in Multicultural Settings*, pp. 98–129. <https://doi.org/10.4018/979-8-3693-3306-8.ch006>
- Ministry of Health. (2021). *Health sector strategic plan July 2021 – June 2026 (HSSP V): Leaving no one behind*. https://extranet.who.int/countryplanningcycles/sites/default/files/public_file_rep/TZA_Tanzania_Health-Sector-Strategic-Plan-V_2021-2026.pdf
- Ministry of Health (MOH) [Tanzania Mainland], Ministry of Health (MoH) [Zanzibar], National Bureau of Statistics (NBS), Office of the Chief Government Statistician (OCGS), and ICF. (2023). *Tanzania demographic and health survey and malaria indicator survey 2022 key indicators report*. <https://dhsprogram.com/pubs/pdf/PR144/PPR144.pdf>
- Ministry of Health. (2023). *Tanzania health facility atlas 2023*. <https://www.moh.go.tz/storage/app/uploads/public/674/eb8/6d6/674eb86d688d4542845162.pdf>
- Miranda, A.V., Praha, R.D., Sirmareza, T., Aditya, R., Rachmad Nugraha, R., Rastuti, M., Asmara, R. Petersen, Z. and O'Donovan, J. (2025). Professionalisation of community health workers: Time for a formal contract. *The International Journal of Health Planning and Management*. <https://doi.org/10.1002/hpm.3897>
- Mkabile, S., Garrun, K.L., Shelton, M. and Swartz, L. (2021). African families' and caregivers' experiences of raising a child with intellectual disability: A narrative synthesis of qualitative studies. *African Journal of Disability (Online)*, 10, 1–10. <https://doi.org/10.4102/ajod.v10i0.827>
- Mkony, C.A. (2021). Emergence of a university of health sciences: health professions education in Tanzania. *Journal of Public Health Policy*, 33(Suppl 1), S45–S63. <https://doi.org/10.1057/jphp.2012.51>
- Msacky, R. (2024). Retention of Human Resources for Health in the Decentralised Health System in Tanzania: Does Training matter? *Journal of Policy and Development Studies* 16(1):74-91. <https://doi.org/10.4314/jpds.v16i1.5>

- Mselle, L., Sirili, N., Anaeli, A. and Massawe, S. (2021). Understanding barriers to implementing referral procedures in the rural and semi-urban district hospitals in Tanzania: Experiences of healthcare providers working in maternity units. *PLoS ONE*, 16(8), e0255475. <https://doi.org/10.1371/journal.pone.0255475>
- Mwangi, L.W., Abuga, J.A., Cottrell, E., Kariuki, S.M., Kinyanjui, S.M. and Newton, C.R. (2022). Barriers to access and utilization of healthcare by children with neurological impairments and disability in low-and middle-income countries: a systematic review. *Wellcome Open Research*, 6, 61. <https://doi.org/10.12688/wellcomeopenres.16593.2>
- Nabyonga-Orem, J. and Asamani, J.A. (2023). Evolution of health sector strategic planning in Tanzania: What have we learnt and how can we improve? *The International Journal of Health Planning and Management*, 38(3), 662–678. <https://doi.org/10.1002/hpm.3609>
- Ndegwa, N.M., Richard, M.R., Busumbigabo, A., Agbor, A.P. and Karanja, J.W. (2025). *Community health dynamics*. IPR Journals and Book Publishers.
- Ndibalema, P. (2025). Perspectives on barriers to learning opportunities among deaf children in Tanzania. *International Journal of Educational Research Open*, 9. <https://doi.org/10.1016/j.ijedro.2025.100468>
- Nyanza, E.C., Kapesa, A., Maduka, T. and Madullu, M.T. (2023). Disability inclusion in malaria services in western Tanzania: A rapid barrier analysis. *African Journal of Disability (Online)*, 12, 1–13. <https://doi.org/10.4102/ajod.v12i0.1270>
- Nyimbi, I. and Kajiru, I. (2024). Education for persons with disabilities in Tanzania: Assessment of policy and legal framework efficiency. *Inclusive Education Developments in Africa* (pp. 117–145). Springer.
- Owoputi, I., Hoddinott, J., Kayanda, R., Kerr, R.B. and Dickin, K. (2024). Community health workers' targeting of women for health and nutrition home visits in rural Tanzania: A mixed-methods study. *Current Developments in Nutrition*, 8(6). <https://doi.org/10.1016/j.cdnut.2024.103780>
- Santosh, S. and Kane, S. (2025). A critical review of literature and a conceptual framework for organizing and researching urban health and community health services in low-and middle-income countries. *Health Policy and Planning*, 40(2), 259–271. <https://doi.org/10.1093/heapol/czae104>
- Scherzer, A.L., Chhagan, M., Kauchali, S. and Susser, E. (2012). Global perspective on early diagnosis and intervention for children with developmental delays and disabilities. *Developmental Medicine & Child Neurology*, 54(12), 1079–1084. <https://doi.org/10.1111/j.1469-8749.2012.04348.x>
- Schneider, H., Olivier, J., Orgill, M., Brady, L., Whyle, E., Zulu, J., San Sebastian, M. and George, A. (2021). The multiple lenses on the community health system: implications for policy, practice and research. *International Journal of Health Policy and Management*, 11(1), 9. <https://doi.org/10.34172/ijhpm.2021.73>
- Sirili, N. and Simba, D. (2021). It is beyond remuneration: Bottom-up health workers' retention strategies at the primary health care system in Tanzania. *PLoS ONE*, 16(4). <https://doi.org/10.1371/journal.pone.0246262>
- Smythe, T., Adelson, J.D. and Polack, S. (2020). Systematic review of interventions for reducing stigma experienced by children with disabilities and their families in low-and middle-income countries: State of the evidence. *Tropical Medicine & International Health*, 25(5), 508–524. <https://doi.org/10.1111/tmi.13388>

- Smythe, T., Scherer, N., Nanyunja, C., Tann, C.J. and Olusanya, B.O. (2024). Strategies for addressing the needs of children with or at risk of developmental disabilities in early childhood by 2030: a systematic umbrella review. *BMC medicine*, 22(1), 51. <https://doi.org/10.1186/s12916-024-03265-7>
- Smythe, T., Zuurmond, M., Tann, C.J., Gladstone, M. and Kuper, H. (2021). Early intervention for children with developmental disabilities in low and middle-income countries—the case for action. *International Health*, 13(3), pp. 222–231. <https://doi.org/10.1093/inthealth/ihaa044>
- Sood, S., Kostizak, K., Stevens, S., Cronin, C., Ramaiya, A. and Paddidam, P. (2022). Measurement and conceptualisation of attitudes and social norms related to discrimination against children with disabilities: A systematic review. *International Journal of Disability, Development and Education*, 69(5), pp. 1489–1504. <https://psycnet.apa.org/doi/10.1080/1034912X.2020.1786022>
- Swai, E.A., Moshi, H.I., Msuya, S.E., Lindkvist, M., Sörlin, A. and Sahlen, K.G. (2024). Adaptive adjustment to the needs of families caring for children and adolescents with physical disabilities in north-eastern Tanzania: a grounded-theory study. *Global Health Action*, 17(1), 2354009. <https://doi.org/10.1080/16549716.2024.2354009>
- Swai, E.A., Msuya, S.E., Moshi, H., Lindkvist, M., Sörlin, A. and Sahlen, K.G. (2023). Children and adolescents with physical disabilities: describing characteristics and disability-related needs in the Kilimanjaro region, north-eastern Tanzania—a cross-sectional survey. *BMJ Open* 2023, 13(1). <https://doi.org/10.1136/bmjopen-2022-064849>
- Torres, M.A. and Ohajunwa, C.O. (2025). Care perspectives: Mothers of children with disabilities in a peri-urban setting in South Africa. *African Journal of Disability (Online)*, 14, 1–9. <https://doi.org/10.4102/ajod.v14i0.1463>
- Tungaraza, F.D. (2012). Who sinned? Parents' knowledge of the causes of disability in Tanzania. *International Journal of Special Education*, 27(2), 216–224. <https://eric.ed.gov/?id=EJ982875>
- UNICEF. (2021). *Situation analysis of children and young people with disabilities in mainland Tanzania and Zanzibar*. <https://www.unicef.org/tanzania/reports/children-and-young-people-disabilities-tanzania>
- UNICEF. (2024a). *Monitoring children's development in the primary care services: Moving from a focus on child deficits to family-centred participatory support: Report of a virtual technical meeting*. <https://knowledge.unicef.org/resource/monitoring-childrens-development-primary-care-services-moving-focus-child-deficits-family>
- UNICEF. (2024b). *Ongoing study – Systematic analysis on early identification, intervention and referral pathways for children with developmental delays/disabilities in Eastern and Southern Africa*.
- United Nations (UN). (1989). *Convention on the rights of the child*. General Assembly resolution 44/25. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>
- UN. (2006). *Optional protocol to the convention of the rights of persons with disabilities*. Sixty-first session of the United Nations General Assembly by resolution A/RES/61/106. <https://www.ohchr.org/en/instruments-mechanisms/instruments/optional-protocol-convention-rights-persons-disabilities>
- UN. (n.d.). *The 17 goals*. Department of Economic and Social Affairs. <https://sdgs.un.org/goals>

United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD). (2022). *Situational analysis of the rights of persons with disabilities in Tanzania*. https://unprpd.org/new/wp-content/uploads/2023/12/CR_Tanzania_2022-e95.pdf

Vanderpuye, I., Okai, M-P., Miezah, D., Opoku, M.P and Mensah, G.E. (2025). Formal and informal support services available to parents of in-school children with disabilities in Ghana. *Children and Youth Services Review*, 169. <https://doi.org/10.1016/j.chilyouth.2025.108127>

World Health Organization (WHO). (2007). *Strengthening health systems to improve health outcomes. WHO's framework for action*. https://iris.who.int/bitstream/handle/10665/43918/9789241596077_eng.pdf?sequence=1&isAllowed=y

World Health Organization. (2018). *A vision for primary health care in the 21st century: towards universal health coverage and the Sustainable Development Goals*. <https://www.who.int/docs/default-source/primary-health/vision.pdf>

World Health Organization. (2019). *World report on vision*. <https://www.who.int/publications/i/item/world-report-on-vision>

Appendix A — Rationale informing sample selection

Region	Disability incidence* (15+ years)	Disability incidence** (7+ years)	General HH poverty [†]	Educational attainment ^{††}	Facility delivery [‡]	Postnatal checks ^{‡‡}	Distance from health care [§]	Early Childhood Development Index 2030 ^{§§}	Under 5 mortality [¶]	Roll-out of new CHW training pilot ^{¶¶}
National average	16.1% (F); 13.7% (M)	11.4%	61.0%	28.7%	81.4%	41.4%	47.4%	47.0%	23	Select districts
Tanga	23.0% (F); 20.2% (M)	10.4%	72.5%	29.6%	65.6%	59.7%	31.8%	46.6%	36	Yes
Lindi	14.9% (F); 12.7% (M)	14.4%	81.0%	37.7%	96.2%	15.2%	57.3%	21.5%	14	Yes
Shinyanga	14.2% (F); 10.9% (M)	8.8%	72.5%	27.0%	81.1%	40.7%	42.3%	45.4%	44	No

Notes:

* Disability incidence (15+ years) – experience difficulty in at least one domain. Source: Tanzania, DHS 2022.

** Disability incidence (7+ years) – experience difficulty in at least one domain. Source: Tanzania Census 2022.

† General household poverty – % distribution of population in lower three wealth quintiles. Source: Tanzania, DHS 2022.

†† Educational attainment – completed primary. Source: Tanzania, DHS 2022.

‡ Facility delivery – % of live births in 2 years preceding survey delivered in a health facility. Source: Tanzania, DHS 2022.

‡‡ Postnatal checks – % of newborn babies not receiving a postnatal check. Source: Tanzania, DHS 2022.

§ Distance from health care – travel time <30 mins (women). Source: Tanzania, DHS 2022.

§§ Early Childhood Development Index 2030 – % developmentally on-track. Source: Tanzania, DHS 2022.

¶ Under 5 mortality – deaths per 1,000 live births for the 10-year period before the survey. Source: 2022-TDHS-MIS.

Appendix B — Topic guides

This appendix presents the seven semi-structured guides used for data collection as part of this study.

Tool 1: In-depth interview with household — parents and caregivers of child(ren) with a disability

Region	
District	
Community	
Facilitator's name	
Note-taker's name	
Date	
Interview starting time	
Interview ending time	
Status of interview	Completed Incomplete Refused
Additional (contextual) notes for interview – if any:	

Consent [10 mins]

Written informed consent to be administered to the respondents prior to the discussion [use Informed Consent form – Tool 1].

Background and introduction [5 minutes]

1. We would like to ask you for some **general information** about you to begin.

Gender (<i>do not ask out loud</i>)	Male Female
What is your age?	
What is your marital status?	Married Widowed Living in a partnership Single
How many children do you have?	
What is your education level?	
How long (in minutes) does it take you to get to the nearest health centre or dispensary from your home?	

2. We understand that you have a **child(ren) with [or at risk of] a disability**. Can you please explain what kind of disability your child(ren) has?

Identifying a child has a disability [15 minutes]

The following questions ask how you first identified that your child had a disability and the process for the identification and confirmation of the disability.

3. Please describe to me about **how you found out** your child had a disability/risk of disability. [If required probe for:
 - a. How old was your child then?
 - b. How did you identify what the specific problem was for your child?
 - c. Was there a particular expert that told you about your child's disability? (Probe if a PHC worker, CHW, or other healthcare staff was involved.)
 - d. Did you have to follow any process to confirm or verify that the diagnosis made was correct? Please explain. [or: Was your child referred to anyone else (e.g. for further investigation, confirmation of diagnosis, treatments, etc.)?]
4. How was your **experience** with the process by which your child's disability was detected? Please describe
 - a. Probe: Were you able to understand and follow the information shared with you? Did you feel comfortable asking questions if you needed more information?
 - b. Was there anything that worried you?
 - c. Do you have any feedback or suggestions for improvement?
5. How, if at all, has the [mention specific **disability**] **affected your child's** ability to [see/hear/move/learn/communicate/other]? (*data collector to choose a specific function from this list as per child's disability*)
 - a. Is your child going to school? Why or why not?
6. Have you **registered/reported** your child's disability anywhere? If so, please explain where the child was registered, and describe how the process of registration happened.

- a. Probe: school, organisations of children with disabilities, district, village/street roster, etc.
 - b. Do children/families receive any type of document/certificate after a disability is confirmed and registered? Please describe.
7. **[If respondent answers Yes to 6b]** Does having **documentation** of a child's disability affect their **access to support services** in any way? How so?
- a. Why do you think it is (or is not) important?
 - b. Have you used this documentation to access support in the case of your child? Why or why not? To what extent was it helpful?

Caring for a child with disability [15 minutes]

Thank you very much for that. The next questions will ask you about your experience and knowledge of caring for your child.

8. Caring for a child with a disability is an important task on a parent/caregiver. How has your **experience of caring for your child** been so far?
 - a. What are some of the things that help you care for your child?
 - b. What are some of the challenges you face in caring for your child?
9. Is there any **specific knowledge** parents/caregivers must have to care for a child with a disability? Please explain.
 - a. Where do you get information on how to care for your child? (probe e.g. other parents, CHWs, health facilities, disability committees, internet sources, etc.)
 - b. Why do you use this source(s) specifically?
 - c. Has the information been helpful? How?
10. Does your child have regular **follow-ups** (or check-ups) with healthcare staff regarding his/her disability? If yes, please explain (frequency, who with, feedback on effectiveness)
11. Are there any **financial costs** involved for the family in getting the diagnosis or treatment for your child's disability? If so, what are the main costs?
 - a. How were these costs paid?
12. To what extent do you think you have the **relevant support you need** to care for your child?
 - a. Who provides this support? (probe e.g.: relatives, community, government, NGOs/private sector, religious bodies, school, etc.)
 - b. To what extent and how does it help?

Access to services [15 minutes]

We will now ask you about your experience of accessing different services for your child.

13. If your child needs medical support or care, are there any **health workers or services in your community** that you can access? (e.g. CHWs, volunteer services/NGOs, therapy, rehab centres, support groups)
- Please tell us about your experience with these services (share examples if possible).
14. Are there any **other health facilities or bigger hospitals** you can access if your child needs them? (e.g. ward health facility, dispensaries, district hospitals, private clinics, etc.)
- Please tell us about your experience with these services (share examples if possible).
 - If people here need to go to a bigger hospital, where do you think they will go to? Why?
15. If a child with a disability needs **essential medicines related to their disability**, how can this child's parents/caregivers access these medicines?
- Have you encountered any challenges in accessing these or other services? Please explain.
16. If a child with a disability needs **assistive devices related to their disability** (e.g. wheelchair, hearing aids, glasses, etc.), how can this child's parents/caregivers access these?
- Have you encountered any challenges in accessing these or other services? Please explain.

Experience with health services [10 minutes]

The following questions will ask you about your views and experiences about different health services targeted for children with disabilities.

17. To what extent do you feel **your child is safe and away from harm** in using the current systems available for disability detection and support?
- Why or why not?
18. What factors do you think might affect the **experience with referral and support services** for a child with disability in the community and in larger health facilities?
- If required probe for:
 - child's age (e.g. a small child vs a teenage child)
 - gender (e.g. boy child with disability vs girl child with disability)
 - Type of disability (e.g. a child who cannot see and a child who cannot walk)?
 - Why or why not? Please explain
19. Is there anything else that you have seen that is better or worse in the services you get for your **child with disabilities compared to your other children** (or compared to children of your wider family or other people in the community)?

- a. Please explain (e.g., if a disabled child and non-disabled child needed the same measles vaccinations, would they both be able to access these in the same way?)

Recommendations for Improvement [5 minutes]

We are almost at the end of the discussion and would now like to hear your opinion on government/other services and support.

20. Are there specific areas where you feel your government and/or community can provide **additional support to parents/children** with disability?
 - a. What recommendations would you suggest to improve health and care services for children with disabilities?

Thank you for your time and responses. This is the end of the discussion.

Do you have any questions for us?

Tool 2: In-depth Interview with community leaders /disability committee/primary school representatives

Region	
District	
Community	
Facilitator's name	
Note-taker's name	
Date	
Interview starting time	
Interview ending time	
Status of interview	Completed Incomplete Refused
Additional (contextual) notes for interview – if any:	

Consent [10 mins]

Written informed consent to be administered to the respondents prior to the discussion [use Informed Consent form – Tool 2].

Introduction [5 mins]

Thank you for taking the time to speak to us. We'd like to start by first understanding a bit more about your role and the structure of health services in your community when it comes to meeting the health needs of young children [< 6 years].

1. Can you tell us about who you are and what **your role in this community** is?
 - a. Probe: how long they are in this role, who else they interact with as part of this role.
2. What kinds of **healthcare services and/or health workers** do children in this community have **access** to?
 - a. Probe: CHWs, PHC workers, hospitals, etc.

Knowledge of disability identification processes and policies [20 minutes]

Next, we'd like to understand a bit more about how disability is understood and detected at the community level, in particular when it comes to disabilities in children.

3. What do you **understand** by the term disability?
 - a. Probe for understanding of different types of disabilities (visual, hearing, physical, intellectual, albinism etc)

- b. What are the main sources of disability related information at the community level? Please discuss their effectiveness.
 - c. Please share if you are aware of any local or national policies related to early detection and referral of children with disabilities?
4. Are there any children in this community who have some type of **disability**? If yes, can you please describe the **process**, if any, by which **different types of disabilities get identified and diagnosed** in children in your communities?
 - a. Probe: who are the actors/sectors involved (parents, health workers/facilities, schools, NGOs, others etc – note to data collectors, prompt for actors in bold if not mentioned)
 - b. At what age(s) and stage(s) are children screened?
 - c. Are there any differences in detection processes based on the type of disability?
5. Once disability is detected, is there any **process to confirm or verify** the diagnosis? Please explain what this process involves.
 - a. Where /Who is responsible for confirming disability? (e.g. for further investigation, confirmation of diagnosis, treatment, etc.)
 - b. Are there any systems for reporting/registering cases of disability in children following detection? (Probe at local and district level, including use of village and street disability committees and registers.)

Experience with health services and referral support [10 minutes]

Thank you for that. We'd now like to understand more about the existing systems and experiences with health services and referral support for children with disabilities.

6. What, if anything, is the process to refer children who have been identified to have a disability **to specialised treatments and services** (e.g. therapy, special education, routine medicines)? Please describe.
 - a. What type of support is provided to the child and/or family of the child with disability through the referral and follow-up activities?
 - b. Who is involved? Probe for examples of coordination between actors, including the role of CHWs and ward/district health facilities.
7. What **feedback** have you heard or seen from parents of children with disability/community members on these referral and treatment services?
 - a. Probe: positive feedback (provide examples)
 - b. Probe: challenges (provide examples)
8. With children you may have seen whose disability was detected, were there any **financial costs** involved for the family in getting this diagnosis or treatment? If so, what were the main costs?
 - a. Do you know how these costs were paid? Does it vary between families?

- b. Apart from the cost for the family, are there any other expenses involved (for e.g. for health service providers, CHWs, community members or schools)?

System effectiveness [10 mins]

We'd now like to get your views on how you think the current detection and referral systems are functioning, and understand some of the main factors that influence (i.e. that enable or constrain) them.

9. To what extent do you think the current systems for disability detection and referral are **accessible to all** children in the community? Why or why not?
 - a. Probe: coverage within communities (particularly in rural/more remote parts of districts)
 - b. Probe: equity considerations (e.g. by gender, poverty, remoteness, ethnicity, etc.)
10. What are some of the factors that **enable or challenge** the work of the government and its service providers in providing disability detection and referral support to children? Please describe why.
 - a. Enabling factors (e.g. personnel, resources, easy to use tools, coordination with other actors, governance structures, etc.)
 - b. Challenges (e.g. knowledge of parents, staff workloads, resource constraints, accessibility to children.)
11. **[if not discussed in Q5]** Are you aware of any other **private/non-state/other sector** actors who work on disability detection and referral for children in your community? Please describe
 - a. Probe for religious/voluntary/NGO/INGOs/schools services
 - b. How, if at all, do they interact with government services?

Attitudes and community support [10 minutes]

We would now like to understand a bit about the general attitudes of community members when it comes to engaging with children with disabilities.

12. How do members of this **community generally behave** with children with disabilities?
 - a. How informed do you think community members are about the challenges faced by children with disabilities, and/or their parents?
 - b. Have you observed any stigmatization or negative attitudes towards children with disabilities in your community? If yes, can you provide some examples?
13. To what extent are **community spaces and events** (e.g. places of worship, markets, festivals, or activities) accessible and inclusive for children with disabilities?
 - a. Do you think schools in your community are accessible and inclusive for children with disabilities? Why or why not? (Please share examples.)

14. What **steps can be taken to raise awareness and reduce stigma** to promote a more inclusive environment around disability in your community?
- a. Probe: Are there any awareness campaigns or educational programs in your community that specifically address disability-related issues? Please describe
 - b. Probe: Are there existing support networks or organizations in your community that focus on children with disabilities and their families? Explain.

Government support for communities [5 minutes]

We are almost at the end of the discussion and would now like to hear your lessons and suggestions.

15. Are there specific areas where you feel your government and/or community can provide additional support to **improve the way disabilities are detected and referral services** are provided to children/parents of children with disabilities? Please explain.
16. In your opinion, how can the government better **support communities** where there are children with disabilities?

Thank you for your time and responses. This is the end of the discussion.

Do you have any questions for us?

Tool 3: Community health worker (FGD)

Region	
District	
Community	
Facilitator's name	
Note-taker's name	
Date:	
Interview starting time:	
Interview ending time	
Status of interview	Completed Incomplete Refused
Additional (contextual) notes for interview – if any:	

Consent [10 mins]

Written informed consent to be administered to the respondents prior to the discussion [use Informed Consent form – Tool 3].

Profile of group participants [10 mins]

Participant name (only to be used to facilitate the discussion)	Education	Age (years)	Years of experience working as CHW/PHC	Indicator (for FGD)
1.	1. None 2. Primary 3. Middle 4. Secondary 5. Tertiary			P1
2.				P2
3.				P3
4.				P4
5.				P5
6.				P6

Introduction [5mins]

Thank you for taking the time to speak to us. We'd like to start by first understanding a bit more about your role when it comes to the health needs of young children [< 6 years]

1. What are your main **roles and responsibilities** as CHWs in your communities when it comes to:
 - a. antenatal care of mother and unborn baby during pregnancy

- b. during and after birth of baby
 - c. in early years of child's life
2. Who do CHWs report to? Please describe the **CHW system governance** structure.

Understanding and awareness of disability in children [10 mins]

Next, we'd like to understand a bit more about how disability is understood and determined at the community level, in particular when it comes to disabilities in children.

3. As a CHW, what do you **understand** by the term disability?
 - a. Probe for understanding of different types of impairment (visual, hearing, physical, intellectual, albinism, etc.).
 - b. Is there any difference between how you/the health sector defines disability and how people think about disability within local communities? Please explain.
4. When identifying disabilities, is there a **specific age** before which disabilities should be identified? If so, what is that age?
 - a. Why do you say so/what are the reasons?
 - b. In practice, at what age is disability usually detected/identified in the population? Why?
5. Are there **any children** with, or at risk of, disabilities in the communities in which you work?
 - a. If so, what are the most common types of disability in children that you have come across in your work as CHWs? Please explain.
6. What are the main sources of **disability related information** at the community level? Please discuss their effectiveness.

Disability detection and referral systems [25 mins]

Thank you for that. We'd now like to understand the processes for early detection and referral of disability in children more deeply, including the role of CHWs.

7. As **CHWs**, have you ever played a **role in identifying** a child with disability? If so, what was your role?
 - a. Do CHWs get any specific training or resources on identifying disabilities?
 - b. How do CHWs interact with other actors involved in disability detection, including organisations of children/persons with disabilities?
8. Can you please describe the **process**, if any, by which **different types of disabilities get identified and diagnosed** in children in your communities? Please be as specific as possible (i.e. at what age, how and by whom)
 - a. Describe the full pathways from detection to diagnosis and follow up for:
 - visual impairments
 - hearing impairments (including communication challenges)
 - physical functioning impairments

- intellectual impairments or learning disabilities
 - others (e.g. albinism).
- b. Probe: Any differences in detection processes based on the type of disability?
9. Are you aware of any specific **developmental monitoring tools** to detect disability in children? Please describe/
- a. Have you ever used any of these tools?
 - b. What sort of training did you receive on using these tools?
 - c. Have you faced any challenges in applying these tools in your communities?
10. **[If not already discussed in Q7/8]** Is there any **formal process for certification** of disability once it is detected/suspected in a child? What does that process involve? Who conducts the certification?
- a. What kind of documentation do children receive after a disability screening?
 - b. Do CHWs have any role in this? If so, what role?
11. As **CHWs**, have you ever played a **role in supporting** a child/ parents of a child with disability with **referral and follow-up processes**? If so, how? Please be as specific as possible and share examples.
- a. Who is involved? Please describe the actors involved, including your role.
 - b. What type of support, if any, is provided to the child and/or family of the child with disability through the referral and follow-up activities?
12. With children you have seen [if applicable] whose disability was detected, were there any **financial costs** involved for the family in getting this diagnosis or treatment? If so, what were the main costs?
- a. Do you know how these costs were paid? Does it vary between families?
 - b. Apart from the cost for the family, are there any other expenses involved (e.g. for CHWs or community members or schools/health service providers)?
13. Are there any systems for **reporting/registering cases** of disability in children following detection?
- a. Probe at local and district level, including use of village and street disability committees and registers
 - b. Do you, or other service providers in the community or district use this information in any way? How so?

System effectiveness [10 min break + 30 mins]

A — Participatory activity (20 mins)

Check with the participants if they would like to break for 10 minutes for snacks and refreshments at this point before continuing.

We'd now like to do a short activity with you using this chart paper and some coloured markers to understand how you think the current systems for the disability detection and referral for children are functioning, and the main factors

that you think influence (i.e. enable or challenge) CHWs when it comes to providing disability detection and referral support to young children (<6 years)?

Instructions: Please look at the chart below. It has four (4) headings:

- **strengths** refers to what you think are some of the advantages of the current system
- **weaknesses** refers to what you think are the shortcomings of the current system
- **enabling factors** are things that facilitate or support CHWs in delivering disability detection and referral support to children [for facilitators: e.g. training and support, coordination with other actors]
- **challenging factors** are things that limit CHWs ability to provide disability detection and referral services [for facilitators: e.g. knowledge of CHWs, knowledge of parents, workloads, resource constraints, accessibility to children].

Please list down what the group feels are some of the relevant aspects are under each heading. Please try to prioritise, so that things that you think are more important are listed towards the top of the boxes, and things that you think are less important are listed towards the bottom of the boxes.

We will spend 10 minutes on the chart and then have a follow-up discussion for 10 minutes.

Strengths	Weaknesses
Enabling factors	Challenging factors

Please describe what the group has listed in the chart. Please explain why you have listed these factors, and discuss your prioritisation.

B — FGD continuation (10 mins)

1. **[If not already discussed]** To what extent do you think the current systems for disability detection and referral are **accessible to all** children? Why or why not?
 - a. Probe: coverage within communities
 - b. Probe: equity considerations (e.g. by gender, poverty, remoteness, ethnicity etc)

2. **[If not already discussed]** How **effective** are the existing systems (discussed above), in terms of **accuracy and timeliness** of disability identification and referral services for young children (<6 years)? Why or why not?
 - a. Probe by type of disability
3. **[If not already discussed]** What sort of **feedback do you hear from parents/community** members on the disability detection and referral processes available to them?
 - a. Probe: Acceptability and feedback from parents/community
 - b. Probe: safety (no harm) of children
 - c. Areas of concern

Learning [5 mins]

We are almost at the end of the discussion and would now like to hear your lessons and suggestions.

4. Are you aware of any **recent changes** in policies and guidelines around the early detection and referral of children with disability in Tanzania? Please describe.
 - a. Have these policy/guidance changes affected you, in your role as CHWs, in any way when it comes to disability detection and referral?
5. What **additional support**, if any, do you need to help deliver your role as CHWs in relation to disability detection and referral in children (<6 years)?

Thank you for your time and responses. This is the end of the discussion.

Do you have any questions for us?

Tool 4: In-depth interview with [ward/district] health facility representative

Region	
District	
Community	
Facilitator's name	
Note-taker's name	
Date	
Interview starting time	
Interview ending time	
Status of interview	Completed Incomplete Refused

Additional (contextual) notes for interview – if any:

Introduction [5mins]

Thank you for taking the time to speak to us. We'd like to start by first understanding a bit more about the structure of health services, and your role when it comes to meeting the health needs of young children [< 6 years].

1. Please briefly describe how **health services are structured and governed** at the district and community level?
2. What are your main **roles and responsibilities** as [ward/district] health facility workers in your [ward/district] when it comes to:
 - a. antenatal care of mother and unborn baby during pregnancy
 - b. during and after birth of baby
 - c. in early years of child's life

Understanding and awareness of disability in children [10 mins]

Next, we'd like to understand a bit more about how disability is understood and determined at the local and community level, in particular when it comes to disabilities in children.

3. As a [ward/district] health facility staff, how do you **understand** or define the term disability?
 - a. Probe for understanding of different types of impairment (visual, hearing, physical, intellectual, albinism, etc.)
 - b. Is there a difference between how clinicians like yourself understand disability or impairments and how people think about disability within local communities? Please explain.

4. When identifying disabilities, is there a **specific age** before which disabilities should be identified? If so, what is that age?
 - a. Why do you say so / what are the reasons?
 - b. In practice, at what age is disability usually detected/identified in the population? Why?
5. Have you come across any **children with, or at risk of, disabilities** in your in your work as [ward/district] health facility staff?
 - a. If so, what are the most common types of disability in children that you have come across? Please explain.
6. What are the most common sources of **disability related information** at the community level? Please discuss their effectiveness.

Disability detection and referral systems [20 mins]

Thank you for that. We'd now like to understand the processes for early detection and referral of disability in children more deeply, including what your role is as part of this [ward/district] health facility.

7. Can you please explain **how**, if at all, different types of disabilities/impairments are currently **identified and diagnosed in young children** (< 6 years) in your [ward/district]? Please be as specific as possible (i.e. at what age, how and by whom) including explaining the role, if any, played by the [ward/district] health facility.
 - a. Describe the full pathways from detection to diagnosis and follow up for:
 - visual impairments
 - hearing impairments (including communication challenges)
 - physical functioning impairments
 - intellectual impairments or learning disabilities
 - others (e.g. albinism).
 - b. Probe: Are there any differences in detection processes based on the type of disability?
8. **[If not already discussed]** Does your **[ward/district] health facility** play a **role** in identifying child with disability? If so, what is your role?
 - a. Do staff at these facilities get any specific training on identifying disabilities?
 - b. What resources and medical supplies are available to facility staff for this purpose?
9. **[If not already discussed]** Please explain the role of **other sectors and actors** in identifying and diagnosing different types of impairments.
 - a. Probe: role of parents, **CHWs**, health facilities, **schools**, community actors, other actors/**NGOs** etc (*for facilitator: prompt for actors in bold if not discussed*)

- b. Is there anyone parents/caregivers are most likely to consult first if they observe/suspect a disability in their child? Who is this and why?
- c. How, if at all, does the [ward/district] health facility interact with other actors involved in disability detection? *(for facilitator: prompt for CHWs and organisations of children/persons with disabilities if not discussed)*
10. Is there a **difference** between how the process of disability identification is described in the relevant **policy guidance** and how it actually happens in **practice**? Why or why not?
11. Are you aware of any specific **developmental monitoring tools** to detect impairments in children? Please describe.
- a. Have you ever used any of these tools?
- b. How well are these tools adapted to the local context? Have you, or other actors you are aware of, faced any challenges in applying these tools?
- c. What sort of training did you receive on using these tools?
- d. What other tools/criteria do you think may be helpful to screen young children for disability?
12. Is there any formal process for **certification** of disability once it is detected/suspected in a child? What does that process involve? Who conducts the certification?
- a. What kind of documentation do children receive after a disability screening? Is it helpful for accessing support services?
- b. Do [ward/district] health facilities have any role in certification? If so, what role?
13. Is there any process to support a child/parents of a child with disability with **referral and follow-up processes**? If so, please describe. Please be as specific as possible and share examples.
- a. What type of support is provided to the child and/or family of the child with disability through the referral and follow-up activities?
- b. Who is involved? Please describe the actors involved. Probe for examples of coordination between actors, including the role of [ward/district] health facilities.
14. With children you may have seen whose disability was detected, were there any **financial costs** involved for the family in getting this diagnosis or treatment? If so, what were the main costs?
- a. Do you know how these costs were paid? Does it vary between families?
- b. Apart from the cost for the family, are there any other expenses involved (e.g. for health service providers, CHWs, community members or schools)?
15. Are there any systems for **reporting/registering cases** of disability in children following detection?
- a. Probe at local and district level, including use of village and street disability committees and registers
- b. Probe if respondent is aware of aggregation at national level, including Persons with Disability Management Information System (PD-MIS).

- c. What types of disabilities are currently officially being recorded in health sector records in Tanzania? Which are not? Why?
- d. Do you, or other service providers in the district or community use this information in any way? How so?

System effectiveness [15 mins]

We'd now like to get your views on how you think the current detection and referral systems are functioning, and understand some of the main factors that influence (i.e. that enable or constrain) them.

16. To what extent do you think the current systems for disability detection and referral are **accessible to all** children? Why or why not?
 - a. Probe: coverage within communities (particularly in rural/more remote parts of districts). Is it mandatory for all children?
 - b. Probe: equity considerations (e.g. by gender, poverty, remoteness, ethnicity, etc.)
17. How **effective** are the existing systems (discussed above), in terms of **accuracy and timeliness** of disability identification and referral services for young children (<6 years)? Why or why not?
 - a. Probe by type of disability
 - b. Probe for safety (no harm) of children
18. What are some of the **factors that enable or challenge** the work of the [ward/district] health facility staff in providing disability detection and referral support to young children (<6 years)? Please describe.
 - a. Enabling factors (e.g. training and support, supplies and resources, availability of easy to use tools, coordination with other actors, governance structures)
 - b. Challenges (e.g. knowledge of parents, workloads, resource constraints, accessibility to children)

Learning [5 mins]

We are almost at the end of the discussion and would now like to hear your lessons and suggestions.

19. Are you aware of any **recent changes** in policies and guidelines around the early detection and referral of children with disability in Tanzania? Please describe.
 - a. Have these policy/guidance changes affected you or other local actors in any way when it comes to disability detection and referral?
20. What **recommendations or lessons** would you share for improving government systems and enhancing support for children with disabilities in your district? Please elaborate.

Thank you for your time and responses. This is the end of the discussion.

Do you have any questions for us?

Tool 5: Group interview with district officers (Social Welfare Officer, Head of Health, Social Welfare and Nutrition Services Division, Health Promotion Coordinator)

Region	
District	
Community	
Facilitator's name	
Note-taker's name	
Date:	
Interview starting time	
Interview ending time	
Status of interview	Completed Incomplete Refused
Additional (contextual) notes for interview – if any:	

Consent [10 mins]

Written informed consent to be administered separately to the respondent prior to interview [use Informed Consent Form - Tool 5]

Profile of group participants [5 mins]

Participant name (only to be used to facilitate the discussion)	Title/Role	Years of experience working as district officer	Indicator (for group interview)
1.			P1
2.			P2
3.			P3

Introduction [5 min]

Thank you for taking the time to speak to us. We'd like to start by first understanding a bit more about your roles (SWO, HoH, HPC), and the structures available at district level when it comes to the young children's health and welfare.

1. What are the role and responsibilities of various government institutions/ ministries when it comes to service delivery around disability at district level?
 - a. Probe: What is your role in this arrangement?
 - b. How do the different actors interact with each other? Why or why not?

System-level analysis of early detection and referral systems for children with, or at risk of, disability in mainland Tanzania

Disability policy and guidelines [15 mins]

Next, we'd like to understand a bit more about how disability is embedded and determined in Tanzania's policies and guidelines.

2. As a SWO/HOH/HPC, what do you **understand** by the term disability?
 - a. Probe for understanding of different types of impairment (visual, hearing, physical, intellectual, albinism, etc.).
 - b. Are there any differences between how you (PoRAGL) / health /social welfare sector defines disability? How do people within local communities think about disability. Please explain.
3. Tanzania has established guidelines and policies to promote children's development and welfare of people with disabilities including children. What are the **main policies and guidelines** on disability and access to services/referral?
 - a. Do any of these deal with disabilities in children? If not mentioned, probe for: National Guidelines for Early Identification and Intervention for Children with Disability of the Prime Minister's Office – Labour, Youth, Employment and People with Disability.
4. How, if at all, have these policies and guidelines been **disseminated at the district level**?
 - a. Did you receive any training? How long was the training/orientation, who delivered it?
 - b. Do you have any general comments on the mode of dissemination?
 - c. To what extent have these policies/guidelines been implemented in your district? Why or why not?
5. When identifying disabilities, is there a **specific age** by which disabilities should be identified? If so, what is that age?
 - a. Why do you say so/What are the reasons?
 - b. In practice, at what age is disability usually detected/identified in the population? Why?
6. Does the district government and administration **allocate any specific resources/budget** for provision of disability related services?
 - a. Please describe what these are (financial, human resources, other), and how are they used?
 - b. Are there any specific guidelines around planning for disability-specific services in your district? Please explain.
 - Probe if not mentioned: Are there mechanisms within the Comprehensive Council Health Planning Guide to ensure inclusive planning that considers detection, support services, and early intervention for children with disabilities?

Disability detection and referral systems [30 mins]

Thank you for that. We'd now like to understand the processes for early detection and referral of disability in children more deeply, including what the role played by PHCs and CHWs.

7. Can you please describe **how** and by **whom** different types of disabilities are currently identified and diagnosed in young children (<6 years) at the district level.
 - a. Who are the main actors (probe for different actors, e.g. parents /CHWs/ PHCs/schools/community members/NGOs, etc.)? Who plays the most important role?
 - b. At what age(s) and stage(s) are the children screened/identified?
 - c. What protocols are in place (e.g. who is the first line of detection; frequency of screening, etc.)?
 - d. Are there any differences in detection processes based on the type of disability?
8. Are there any specific **developmental monitoring tools** that are used to detect disability in children? Please describe.
 - a. To what extent are the tools adapted to the local context?
 - b. What sort of training do service providers (e.g. CHW, PHC workers, teachers) receive on using these tools?
 - c. Have you received any feedback from those applying these tools in your communities?
9. Is there any formal **process for certification of disability** once it is detected/suspected in a child? What does that process involve? Who conducts the certification?
 - a. What kind of documentation do children receive after a disability screening? Is it helpful for accessing support services? Why or why not?
10. After disability is detected, is there any **process for referral and follow-up** for the child? Please describe and share examples.
 - a. Who is involved? Please describe the actors involved and examples of coordination between actors.
 - b. Is any type of support provided to children and/or families of children with disability in your district? Please explain (what support? by whom? is it helpful?)
11. Are you aware of any **systems for reporting/registering cases** of disability in children?
 - a. How is the flow of information recorded from the community/the health facility to the district level? (Probe for use of village and street disability committees and registers, and Persons with Disability Management Information System (PD-MIS)).

- b. Does the district have the population of the children with disability in proportion to all children in the district?
 - c. What types of disabilities are currently officially being recorded in health sector records in Tanzania? Which are not? Why?
12. How, if at all, is data on disability in children **used by the district in decision making** and resource allocation for services?
- a. Probe: if information is used to plan for provision of service delivery in the district (e.g. assistive devices/capacity building of first responders?).
 - b. Probe: if information is used to engage and support children/families of children with disability.
13. Please share your views on the **resources available** (equipment, personnel, workloads) to district service delivery staff to conduct thorough disability screenings of children and ensure timely follow-up?
- a. What training and resources are available for PHC workers to effectively detect and manage potential disabilities in children?
 - b. What training and resources are available for CHWs to effectively detect and manage potential disabilities in children?
 - c. What training and resources are available for other actors (e.g. school teachers or disability committees)
 - d. Are there different training or resources for different types of disabilities? Please explain.
14. Are you aware of any other **private/non-state sector actors** who work on disability detection and referral for children in your district? Please describe.
- a. Probe for religious/voluntary/private (NGO/INGOs) services
 - b. How, if at all, do they interact with government service delivery systems in the district?

Effectiveness of health and community systems [20 mins]

We'd now like to get your views on how you think the current detection and referral systems are functioning and understand some of the main factors that influence (i.e. that enable or constrain) them.

15. To what extent do you think the current systems for disability detection and referral are **accessible** to all children? Why or why not?
- a. Probe: coverage within communities (particularly in rural/more remote parts of districts). Is it mandatory for all children?
 - b. Probe: equity considerations (e.g. by gender, poverty, remoteness, ethnicity, etc.)
16. How **effective** are the existing systems (discussed above), in terms of **accuracy and timeliness** of disability identification and referral services for young children (<6 years)? Why or why not?
- a. Probe by type of disability

- b. Probe for safety (no harm) of children
17. What sort of **feedback** do you hear from parents/community members on the disability detection and referral processes available to them?
- a. How well do you think current practices address the needs and concerns of families and caregivers?
18. What are some of the factors that **enable or challenge** the work of the district service staff in providing disability detection and referral support to young children (<6 years)? Please describe.
- a. Enabling factors (e.g. training and support, supplies and resources, availability of easy to use tools, coordination with other actors, governance structures.)
 - b. Challenges (e.g. knowledge of parents, workloads, resource constraints, accessibility to children.)

Learning [5 mins]

We are almost at the end of the discussion and would now like to hear your lessons and suggestions.

19. Are you aware of any **recent changes** in policies and guidelines around the early detection and referral of children with disability in Tanzania? Please describe.
- a. Have these policy/guidance changes affected you, or other district service delivery staff, in any way when it comes to disability detection and referral?
20. What **recommendations or lessons** would you share for improving government systems and enhancing support for children with disabilities in your district? Please elaborate.

Thank you for your time and responses. This is the end of the discussion.

Do you have any questions for us?

Tool 6: In-depth Interview with Central Government (MoH, MoEST, PMO-LYED, MoCDGWSG, PoRALG)

Respondent's name	
Respondent's organisation	
Respondent's designation	
Facilitator's name	
Note-taker's name	
Date	
Interview starting time	
Interview ending time	
Status of interview	Completed Incomplete Refused
Additional (contextual) notes for interview – if any:	

Consent [10 mins]

Written informed consent to be administered separately to the respondent prior to interview [use Informed Consent Form - Tool 6]

Introduction [5 mins]

Thank you for taking the time to speak to us. We'd like to start by first understanding a bit about your role and governance arrangements for service delivery around disability in Tanzania.

1. What are the role and responsibilities of various government institutions/ ministries when it comes to governance and service delivery around disability in Tanzania?
 - a. Probe: What is your (institution's) role in this arrangement?
 - b. How do the different actors interact with each other? Why or why not?

Disability policies and guidelines [10 mins]

Next, we'd like to understand a bit more about how disability is embedded and determined in Tanzania's policies and guidelines.

2. How is disability **defined** in the Tanzanian context?
 - a. Is there any difference between the formal health sector definition of disability and how people within local communities think about disability? Please explain.
3. What are the main **policies and guidelines** around disability in mainland Tanzania?
 - a. Do any of these deal with disabilities in children? If not mentioned, probe for: National Guidelines for Early Identification and Intervention for

Children with Disability of the Prime Minister's Office – Labour, Youth, Employment and People with Disability..

- b. To what extent have these policies/guidelines been implemented in practice? Why or why not?
4. When identifying disabilities, is there a **specific age** by which disabilities should be identified? If so, what is that age?
 - a. Why do you say so/What are the reasons?
 - b. In practice, at what age is disability usually detected/identified in the population? Why?
5. Does the government **allocate any specific resources/budget** for provision of disability related services?
 - a. Please describe what these are (financial, human resources, other), and how are they used?
 - b. Are there any specific guidelines around planning for disability-specific services?

Disability detection and referral systems [20 mins]

Thank you for that. We'd now like to understand the systems for early detection and referral of disability in children (<6 years) including the role played by PHC workers and CHWs.

6. Can you please describe **how** and by **whom** different types of disabilities are currently identified and diagnosed in young children (<6 years) in Tanzania?
 - a. Please elaborate and explain current systems in place in communities and in health facilities. (Please describe it for any type of impairments: visual, hearing, communication, physical, intellectual, etc.)
 - Who are the main actors? Who plays the most important role?
 - At what age(s) and stage(s) are the children screened/identified?
 - What protocols are in place (e.g. who is the first line of detection; frequency of screening, etc.)?
 - Are there any differences in detection processes based on the type of disability?
7. Are there any specific **developmental monitoring tools** that are used to detect disability in children in Tanzania? Please describe.
 - a. To what extent are the tools adapted to the local context?
 - b. What sort of training do service providers (e.g. CHW, PHC workers) receive on using these tools?
 - c. Have you received any feedback from those applying these tools?
8. After disability is detected, is there any **process for referral and follow-up** for the child? Please describe and share examples.
 - a. Who is involved? Please describe the actors involved, including the role, if any, of CHWs and PHC workers.

- b. Do children/families receive any kind of documentation after a disability screening (e.g. certificate/card)? Is this helpful for accessing support services? Why or why not?
9. Are there any **systems for reporting/registering cases** of disability in children in Tanzania?
 - a. How is the flow of information recorded at various levels (community/health facility, district, national level)? Probe for use of village and street disability committees and registers, and Persons with Disability Management Information System (PD-MIS).
 - b. What types of disabilities are currently officially being recorded in health sector records in Tanzania? Which are not? Why?
10. How, if at all, is **data on disability in children used** by the government in decision making and resource allocation for services?
 - a. Probe: if information is used to plan for provision of service delivery (e.g. assistive devices/capacity building of first responders?)
 - b. Probe: if information is used to engage and support children/families of children with disability.
11. [if not discussed above] Is any type of **support provided** to children and/or families of children with disability? Please explain.
 - a. What type of support is provided and by whom?
 - b. What are the benefits/disadvantages of this support to the child/family?
12. Are you aware of any other **private/non-state sector actors** who work on disability detection and referral for children in Tanzania? Please describe.
 - a. Probe for religious/voluntary/private (NGO/INGOs) services.
 - b. How, if at all, do they interact with government services?

System effectiveness [15 mins]

We'd now like to get your views on how you think the current detection and referral systems are functioning and understand some of the main factors that influence (i.e. that enable or constrain) them.

13. To what extent do you think the current systems for disability detection and referral are **accessible** to all children? Why or why not?
 - a. Probe: coverage within communities (particularly in rural/more remote parts of districts)
 - b. Probe: equity considerations (e.g. by gender, poverty, remoteness, ethnicity, etc.)
14. How **effective** are the existing systems (discussed above), in terms of **accuracy and timeliness** of disability identification and referral services for young children (<6 years)? Why or why not?
 - a. Probe: How acceptable are the existing early detection and follow-up procedures to families and caregivers?

- b. Probe: safety (no harm) of children
15. What are some of the **factors that enable or challenge** the government and its service providers in providing disability detection and referral support to children? Please describe why.
- a. Enabling factors (e.g. personnel, resources, easy to use tools, coordination with other actors, governance structures, etc.)
 - b. Challenges (e.g. knowledge of parents, staff workloads, resource constraints, accessibility to children)

Learning (5 mins)

We are almost at the end of the discussion and would now like to hear your lessons and suggestions.

16. Are you aware of any **recent changes in policies and guidelines** around the early detection and referral of children with disability in Tanzania? Please describe.
- a. How do these changes affect existing structures and actors?
 - b. To what extent have the new changes been implemented? Why or why not?
17. What **recommendations or lessons** would you share for improving government systems and enhancing support for children with disabilities? Please elaborate.

Thank you for your time and responses. This is the end of the discussion.

Do you have any questions for us?

Tool 7: In-depth interview with representatives from children's disability NGOs/programmes

Respondent's name	
Respondent's organisation	
Respondent's designation	
Facilitator's name	
Note-taker's name	
Date	
Interview starting time	
Interview ending time	
Status of interview	Completed Incomplete Refused
Additional (contextual) notes for interview – if any:	

Consent [10 mins]

Written informed consent to be administered to the respondents prior to the discussion [use Informed Consent form – Tool 7].

Introduction [5 minutes]

Thank you for taking the time to speak to us. We'd like to start by first understanding a bit about your role and the arrangements for service delivery around disability in Tanzania.

1. Please tell us about the **work of this NGO/programmes** when it comes to working with children with disabilities.
 - a. Target communities/locations
 - b. How does this NGO/programme engage with children with disabilities and their families?
2. Who, in your opinion, are the main stakeholders when it comes to **governance and service delivery around disability** in Tanzania?
 - a. What are their roles and responsibilities?
 - b. How, if at all, do you collaborate with these other actors (e.g. probe: interactions with government actors, CHWs, rehab centres, schools, etc)?

NGO systems around disability [20 minutes]

Next, we'd like to hear a bit more about your understanding of disability and the processes for detection and referral of disability in children within your NGO/programme.

3. How is disability understood and **defined** as part of your NGO's programmes?
 - a. Is there any difference between your NGO's definition and the formal health sector definition of disability? Please explain.
 - b. How do people within local communities think about disability? Please explain.
4. When identifying disabilities, is there a **specific age** by which disabilities should be identified? If so, what is that age?
 - a. Why do you say so/What are the reasons?
 - b. In practice, at what age is disability usually detected/identified in the population? Why?
5. Can you please describe how your NGO/programme **identifies** children with disabilities and their families?
 - a. What protocols are in place (e.g. frequency of screening, age at which children are screened, etc.)?
 - b. What types of impairments do you screen for? Why? (Probe: visual, hearing, communication, physical, intellectual impairments, etc.)
6. Are there any **specific developmental monitoring tools** your organisation uses to detect disability in children? Please describe.
 - a. To what extent are the tools adapted to the local context?
 - b. What sort of training do those administering them receive?
 - c. Are there any challenges in applying these tools?
7. What type of support, if any, does your NGO/programme provide to the child and/or family of the child in terms of **referral and follow-up activities**?
 - a. For how long do you provide the child/family with support? Are there any sustainability mechanisms in place?
8. Does your NGO/programme have any **systems for reporting/registering cases** of disability in children? Please describe.
 - a. How is the case data recorded? Is this linked to government data systems in any way? Why or why not?
 - b. How, if at all, is data on disability in children used by your NGO/programme in decision making and resource allocation for services?
9. Do you face any **challenges** in your work on disability detection and referral support for children in Tanzania?
 - a. How do you deal with these challenges?
 - b. What lessons have you learnt?

Knowledge and reflections on government systems [25 minutes]

Thank you that was very helpful. We'd now like to know more generally about how you feel disability is determined within government systems in Tanzania, and your views on the effectiveness of these structures.

A. Policies and guidelines

10. What, if any, are the main **policies and guidelines** around disability in mainland Tanzania?
- Do any of these deal with disabilities in children? If not mentioned, probe for: National Guidelines for Early Identification and Intervention for Children with Disability of the Prime Minister's Office – Labour, Youth, Employment and People with Disability.
 - To what extent do these policies/guidelines affect your work?
 - Are you aware of any recent changes in policies and guidelines around the early detection and referral of children with disability in Tanzania? Please describe.

B. Structure of current government/formal systems

11. How are the current **primary healthcare** and **community healthcare systems** structured for **early detection** of disability in young children (< 6 years)? Please elaborate and explain in communities and in health facilities.
- Who are the main actors? Who plays the most important role?
 - At what age(s) and stage(s) are the children screened/identified?
 - What protocols are in place (e.g., who is the first line of detection; frequency of screening etc.)?
12. After disability is detected, is there any formal/government **process for referral and follow-up** for the child? Please describe and share examples.
- Who is involved? Please describe the actors involved, including the role, if any, of CHWs and PHC workers
 - What support is provided to the child and/or family of the child with disability?
13. Are there any **differences in detection processes/ referral systems** based on the type of disability observed in children? Probe for:
- visual impairments
 - hearing impairments (including communication challenges)
 - physical functioning impairments
 - intellectual impairments or learning disabilities
 - others (e.g. albinism).

C. Effectiveness of existing systems

14. To what extent do you think the current systems for disability detection and referral in Tanzania are **accessible** to all children? Why or why not?
- Probe: coverage within communities (particularly in rural/more remote parts of districts)
 - Probe: equity considerations (e.g. by gender, poverty, remoteness, ethnicity etc)

15. How **effective** are the existing systems (discussed above), in terms of **accuracy and timeliness** of disability identification and referral services for young children (<6 years)? Why or why not?
 - a. Probe by type of disability
 - b. Probe for safety (no harm) of children
16. What do you think are some of the **factors that enable or challenge** the government and its service providers in providing disability detection and referral support to children? Please describe why.
 - a. Enabling factors (e.g. personnel, resources, easy to use tools, coordination with other actors, governance structures, etc.)
 - b. Challenges (e.g. knowledge of parents, staff workloads, resource constraints, accessibility to children)

Recommendations [5 minutes]

We are almost at the end of the discussion and would now like to hear your lessons and suggestions.

17. Are there any **innovative practices or successful models** that your NGO has implemented? Please describe.
18. What **recommendations or lessons** would you share for improving government systems and enhancing support for children with disabilities? Please elaborate.

Thrive

Thrive is a multi-country research programme that aims to support countries to turn what we know about positive early childhood development into practical, scalable, low-cost programmes, able to transform societies over multiple generations. Working closely with policymakers and other stakeholders, Thrive aims to build understanding of early childhood development service delivery models and how they can be provided cost effectively and at scale, and how these systems can innovate, improve, and better serve children and communities in low- and middle-income countries.

Our five focus countries are Bangladesh, Ghana, Kiribati, Sierra Leone and Tanzania.

The Thrive programme is funded by the UK's Foreign, Commonwealth & Development Office and by New Zealand's Ministry of Foreign Affairs and Trade. It is managed by Oxford Policy Management in collaboration with the Institute for Fiscal Studies.

Oxford Policy Management
Ground Floor, 40–41 Park End Street, Oxford, OX1 1JD T: +44 (0)1865 207 300
Registered in England 3122495
thrivechildevidence.org | [@Thriveevidence](https://www.instagram.com/Thriveevidence)