



Tanzania | September 2025

# Early detection and referral for children with or at risk of disability in mainland Tanzania

**BRIEFING**

## About this briefing

This briefing highlights the key findings from an exploratory qualitative study examining services for early detection of disability through the community and primary health system in mainland Tanzania.

## Acknowledgements

We would like to thank the study participants and stakeholders who generously contributed their time and expertise through participating in interviews and focus group discussions carried out as part of this research. We also acknowledge the support and leadership of the Government of Tanzania, and specifically the following stakeholders who supported the study and provided technical inputs throughout the planning, implementation and reporting:

- Permanent Secretary, Prime Minister's Office – Labour, Youth, Employment and Persons with Disability (PMO-LYED)
- Director, Persons with Disability Unit (PMO-LYED)
- Other officials, PMO-LYED
- Officials from Lindi, Tanga and Shinyanga districts
- Officials from the President's Office – Regional Administration and Local Government (PO-RALG)
- 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

## Recommended citation

Thrive. (2025). *Early detection and referral for children with or at risk of disability in mainland Tanzania*. Thrive briefing, Oxford Policy Management. <https://thrivechildevidence.org/resource-centre/early-detection-and-referral-for-children-with-or-at-risk-of-disability-in-mainland-tanzania/>

## Related publication

Bechange, S. et al. (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/resource-centre/system-level-analysis-of-early-detection-and-referral-systems-for-children-with-or-at-risk-of-disability-in-mainland-tanzania/>

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# Introduction

This briefing presents findings from an exploratory qualitative study examining early detection and referral systems for children with and at risk of disability through the community and primary health system in mainland Tanzania.

This study was conducted in collaboration with government and key stakeholders between November 2024 and August 2025. It involved document review and primary data collection with national policymakers and with parents of children with disabilities, community leaders, service delivery staff and local governments in Tanga, Lindi and Shinyanga. The study adopted a modified version of the World Health Organization building blocks framework to guide the research (WHO 2007).

## Why focus on early detection for children with disabilities?

### Early detection of disabilities in children is key to improving health, education, equity and development outcomes

In 2021 there were over 50 million children with disabilities under the age of five in low- and middle-income countries (Kamiya 2021).

Two major United Nations conventions address children with disabilities: the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. 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. This commitment is reinforced in the Sustainable Development Goals, including targets 4.5 and 4a, which promote inclusive and equitable education for all.

### If disabilities are not detected in time, they may worsen, making interventions more challenging (Scherzer et al. 2012)

Early detection can help families, healthcare professionals and specialists provide appropriate services that support children's inclusion and full participation in schools and the wider community.

### In resource-limited settings, early detection services are often insufficient

Children with disabilities and their parents often struggle to access early detection and follow-up support, deepening the challenges they experience (Lynch et al. 2023). Health system weaknesses, stigma, discrimination and economic issues lead to gaps in the identification of children with or at risk of disabilities in the early years. (Sood et al. 2022; Smythe et al. 2020). Strengthening identification systems is essential to support health, equity, and inclusive national development. Action is especially urgent in resource-limited contexts such as Tanzania, where an increasing number of children survive but lack the support to thrive.

## Research on early detection is limited

A 2024 global review of early detection and rehabilitation services for children under 5 highlighted the importance of locally grounded research to inform service improvements (Smythe et al. 2024). More understanding of existing policies and guidelines, and their implementation, including barriers and areas for improvement, could inform targeted allocation of health and early childhood development resources.

## What is the context for children with disabilities in Tanzania?

The Government of Tanzania has committed to the inclusion of people with disabilities and developed guidelines for early detection and related activities. However, children with disabilities and their families continue to experience inequalities, stigma and difficulties accessing appropriate education and health services (Buhori 2024; Nyanza et al. 2023; Mesiäislehto 2024).

## How many children are potentially affected by this issue in Tanzania?

The 2022 Demographic and Health Survey estimated the prevalence of disability among children aged 5–19 as between 2.7% and 4.1%, with a higher prevalence among older age groups (Ministry of Health, National Bureau of Statistics, Office of Chief Government Statistician and ICF 2023). The recent census indicated a prevalence of 8.8% for children aged 7–11, 9.1% for those aged 12–16 and 7.8% for those aged 17–21 (National Bureau of Statistics and Office of the Chief Government Statistician 2025). The prevalence of disability in children under 5 is currently unknown.



# Key findings

## Governance, policy and guidance

- While there are policies and guidelines on inclusion of people with disabilities, early detection and related activities, their dissemination has been inconsistent, and understanding varies across government stakeholders.
- While formal definitions of disability in the country align with international standards, practical understanding differs across government sectors, healthcare workers and communities. This lack of clarity creates confusion in regard to service eligibility and healthcare interventions for children with disabilities.

## Community and social contexts

- At 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.

## Resourcing

- Funding for childhood disability services remains limited and partly reliant on external donors. Funding shortages contribute to gaps in early detection and referral.
- 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.
- With too few healthcare workers, disabilities often go undetected in primary healthcare settings. Community health workers play a crucial role but often lack adequate training on disability identification, making detection inconsistent. Efforts are under way to scale up the number of community health workers and to improve their training – but financial challenges hinder progress.
- Basic screening tools are often unavailable in local health facilities, especially in rural areas, forcing health workers to rely on observation or improvised tools. Budget priorities frequently overlook essential disability-related supplies.

## Information systems

- Health facilities and community health workers 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 gaps in coordination lead to duplication and missed opportunities.
- There is no formal system for documenting disability, so families in our study rarely received written proof of their child's condition, making access to services harder.

# Recommendations

Based on the findings of this study, the following recommendations were co-developed together with officials from different government ministries, agencies and departments during a two-day workshop in July 2025.

- Ensure frontline workers – including community health workers, social welfare officers and teachers – have an adequate understanding of national guidelines 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 associated systems.
- Strengthen coordination between community health workers, primary care facilities, secondary and tertiary hospitals, and other implementing partners such as community-based organisations and NGOs, to ensure joined-up identification and referral services.
- Strengthen the underlying health system – including provision of stipends for community health workers, 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 to ensure that people with disabilities are represented on health facility governing committees and village health committees.
- 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.

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# 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 that are 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 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.

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