



DISABILITY-INCLUSIVE HEALTH SYSTEMS

At least 15% of the world's population—one billion people—live with one or more disabilities and suffer poor health outcomes due to inadequate access and availability of health services. The mortality rate of women in sub-Saharan Africa with disabilities is three times higher than that of women without disabilities. A recent study in Kenya shows that the child mortality rate is four times higher among children with disabilities.

Especially disturbing are the rates of sexual and gender-based violence experienced by people with disabilities, which is eight to ten times higher than for non-disabled persons. People with disabilities are three times more likely to be denied health services than those without disabilities and 50% more likely to experience catastrophic health expenditure.¹

Addressing access to HIV testing and care for people with disabilities would help move us towards reaching PEPFAR's 95-95-95 goals, while the COVID-19 pandemic has underscored the increased vulnerability of people with disabilities—as well as their lack of access to services.²

HEALTH CARE BARRIERS FOR PEOPLE WITH DISABILITIES

Adopted in 2006 and ratified by 182 countries, the United Nations Convention on the Rights of People with

Disabilities defines people with disabilities as “those who have long-term physical, mental, intellectual or sensory impairments which may hinder their full and effective participation in society on an equal basis with others.”³

To achieve Sustainable Development Goal 3 in health and universal health coverage, it is critically important to reach this large, diverse group. Reasons for lack of access to health services include the following:

- Low visibility of disability and low priority at the policy level;
- Fragmented advocacy efforts around specific impairments, especially at the country level;
- Poor provider attitudes, knowledge and skills, and lack of training modules on disability in pre-service and in-service curricula;
- Physical and communication barriers at health care facilities;
- Lack of health insurance coverage or explicit denial of coverage to people with disabilities;
- Widespread stigma and discrimination, coupled with lack of awareness at the community level of the needs and rights of persons with disabilities; and
- Persons with disabilities not included in design, implementation, and monitoring of programs

1 Heydt, P and Kuper, H. The Missing Billion: Access to Health Services for 1 billion people with disabilities (2019). https://static1.squarespace.com/static/5d79d3afbc2a705c96c5d2e5/t/5f284cb69af8a9396df3f81c/1596476607957/v3_TheMissingBillion_revised_0620.pdf

2 R. Armitage, L. Nellums. “The COVID-19 response must be disability-inclusive” The Lancet 2020. Available at <https://www.thelancet.com/action/showPdf?pii=S2468-2667%2820%2930076-1>

3 <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

URC EXPERIENCE WITH DISABILITY INCLUSION

With expertise in client-centered quality care and programmatic experience in providing services to people with disabilities, URC is well positioned to play a leadership role in “leaving no one behind” in access to quality health services. Since 1965, URC has helped countries build and sustain resilient health systems by supporting local partners in implementing science-driven, scalable solutions. URC is committed to disability-inclusive programming to address the needs of people with disabilities by integrating disability awareness into project activities to improve access and quality of health care services for all. Examples of our work are many.

- With funding from the CDC, under its Lubombo Region Project, together with the national TB Control Program, URC produced and disseminated health promotion materials for the deaf populations in eSwatini on TB and HIV prevention, diagnosis, and treatment.
- Under USAID’s Health Evaluation and Applied Research Development (HEARD) Project, URC in collaboration with WHO, supports key international professional organizations such as the International Society for Wheelchair Professionals and International Society for Prosthetics and Orthotics on developing, launching, and distributing WHO Standards for Wheelchair Service Provision.
- Under USAID’s global ASSIST Project, URC worked across Latin America and the Caribbean to support health workers establish physical spaces for children offering early stimulation, rehabilitation, and physical therapy. With URC support, integrated care of children affected by Zika provided a concrete example of health system services for children with developmental disorders operated within the broader system. The Zika emergency provided an opportunity for health systems to make more visible their response to children with disabilities, largely invisible before this work. The processes established to identify, locate, register, link to care, and follow up Zika-affected cases could be used for other congenital disorders, both at the community and facility levels.
- Under USAID’ Systems for Health Project, URC built 26 Community-Based Health Planning and Services (CHPS) compounds and accompanying residences in underserved areas of Ghana. As part of the construction

planning process, URC engaged communities to guide CHPS compound redesign. As a result, all facilities and washrooms were made accessible for people with disabilities, including doors for wheelchairs and facility entrances with ramps and railings. Under the auspices of the Grants Program led by URC, the University of Ghana’s School of Public Health developed solutions to address challenges faced by women with disabilities in family planning and maternal and child health services. After the project trained health care providers and “Safer Birth Buddy” volunteers, only 6% stated that women with disabilities do not need family planning services versus 67% prior to the training. Newly trained providers and volunteers successfully reached 1,165 women with disabilities, of which 90% received information on family planning for the first time. After one year of implementation, 32% visited a health facility for family planning services, more than doubling contraception use among this group.

PROMOTING INCLUSIVENESS IN GLOBAL HEALTH

To address access barriers and ensure provision of quality health care services for persons with disabilities, health systems can employ a range of quick wins and long-term solutions (see Table 1).

MEASURING DISABILITY INCLUSION

Measuring disability can be integrated into routine monitoring systems. Project evaluations should include reviewing inclusive components of programs. To measure and monitor social inclusion, it is important to collect and disaggregate data for all program outcome indicators at a minimum by gender, age, and disability status. Disability data can be disaggregated in several ways, such as:

- Disability versus no disability (data collected through optional self-reporting);
- Type of disability (physical, mental health, intellectual, sensory, etc.); and
- Status of disability (permanent versus temporary).

Analyze percentage of project beneficiaries with disabilities and to what extent they were able to access and participate in services on an equitable basis with others. Use disability baseline figures, in addition to project targets, to understand project performance in this regard.

Table 1: Quick wins and long-term solutions

Measure and learn	Partner with people with disabilities to address stigma and discrimination	Build on and adapt existing structures, tools, and resources
<ul style="list-style-type: none"> Clearly define and include standard indicators for persons with disabilities in monitoring, evaluation, and learning plans to routinely assess and monitor access to health care by people with disabilities; Include a comprehensive assessment of inequities in access and utilization of care by people with disabilities in Gender Equality and Social Inclusion analyses; Include disability accessibility in existing health facility readiness assessment tools as part of quality improvement interventions; and Apply an implementation science approach to disability inclusive interventions to support uptake of evidence-based interventions by documenting and disseminating implementation learning across different contexts to inform acceptability, adaptability, feasibility, efficiency, and scalability. 	<ul style="list-style-type: none"> Partner with local and international organizations of people with disabilities for ongoing contribution and feedback on the design of disability-inclusive interventions; Partner with organizations of people with disabilities to adapt and modify service delivery; Train providers in stigma reduction and effective communication with people with disabilities—to improve accessibility and utilization of health services; Advocate for the inclusion of people with disabilities into national and sub-national plans for COVID-19 prevention, treatment and vaccination, including social and behavior change (SBC) approaches for demand creation; and Build advocacy capacity by bringing together different civil society organizations, community-based organizations, and disability-specific organizations to identify common barriers, challenges, and opportunities. 	<ul style="list-style-type: none"> Utilize or adapt existing URC, WHO, and other tools and resources for country assessments and provider trainings (see list of resources below); Build cadre of communication and health promotion professionals to design SBC materials for people with disabilities; and Modify or adapt service delivery models to improve accessibility.

To promote an internationally agreed and standardized method of collecting data on disability, the Washington Group on Disability Statistics (the Washington Group) under the auspices of the United Nations Statistical Commission has developed a few brief [questions](#) to allow for the disaggregation of data by disability. Questions are centered on six functional domains: seeing, hearing, walking, cognition, self-care, and communication, based on a model generated by the WHO.

During project evaluation, ensure that persons with a range of disabilities participate in key informant interviews and focus group discussions, and ideally include persons with disabilities in needs assessment teams. To support representation of persons with disabilities, ensure that programs include male and female adults and children with physical, hearing, visual, sensory, intellectual, and cognitive challenges. This will help to better understand the extent to which persons with disabilities are reached and engaged in projects and will provide information on gaps and needs going forward.

SELECT RESOURCES AND TOOLS

- Support rollout of UN toolkit for inclusive health services through country-led assessments. Available at <https://www.un.org/esa/socdev/documents/disability/Toolkit/Inclusive-Health.pdf>
- Support development of peer support groups for people with disabilities. Available at <https://apps.who.int/iris/bitstream/handle/10665/329594/9789241516778-eng.pdf>
- Incorporate existing checklists/toolkits to ensure that WASH/IPC measures are disability inclusive. Available at <https://www.lshtm.ac.uk/research/centres-projects-groups/penda#resources>
- Adapt URC's tools for parents/caregivers of infants/children affected by Zika for broader range of disabilities. Available at <https://www.urc-chs.com/sites/default/files/urc-zika-1804-v5.pdf>

For more information, visit the URC website: <https://www.urc-chs.com>
 Contact: Laura McGough, *Senior Technical Advisor*, lmcgough@urc-chs.com

UNIVERSITY RESEARCH CO., LLC

5404 Wisconsin Avenue, Suite 800, Chevy Chase, MD 20815 | www.urc-chs.com