Focusing on the Invisible



Special Olympics Global Report on the Health of People with IDD

Factsheet

— WHAT IS THE GLOBAL REPORT? —

- People with intellectual and developmental disabilities (IDD) die 16-20 years sooner than the general
 population due to preventable health conditions—diseases or illnesses that could be avoided or managed
 through effective prevention and early treatment. During the course of their lives, people with IDD
 disproportionately experience a variety of health challenges, such as obesity, diabetes, heart and respiratory
 diseases, and mental health conditions. These poorer health outcomes are not inherent to people with IDD;
 rather, much of the cause lies in health systems.
- Part of the Rosemary Collaboratory initiative, Special Olympics global health report, Focusing on the Invisible,
 points to major gaps in health systems when it comes to people with IDD. These gaps include poor data, lack
 of awareness, inadequate policies, and insufficient engagement of people with IDD in policymaking and
 health decision-making.
- The global health report draws on existing literature, as well as case studies of people's lived experiences and promising practices, many of which were identified through System-Level Assessments (SLAs) in 11 sites (described below). The global report also includes qualitative analysis of interviews and focus group discussions with 77 clinicians in seven sites, as well as quantitative analysis of survey responses of around 300 health workers from over 40 countries. Close to 700 individuals with IDD from almost 50 countries responded to a universally designed survey that was co-developed alongside three individuals with IDD from the United States, the United Kingdom, and Zimbabwe who work as consultants for Special Olympics International.
- The global report encourages health systems globally to take action and develop health policies and practices that address the unique needs of people with IDD.

KEY TAKEAWAY

People with IDD are often invisible, unseen, or overlooked when it comes to their health needs. This population is rarely captured or represented accurately in public health data gathering or in policymaking. As a result, public policies and services often do not take their needs into account and are not designed to promote health equity. There is a need to adopt a social and rights model of disability. Rather than focus on individual-level "impairments," this approach emphasizes the role of society-wide barriers and affirms neurodiversity, which includes different cognitive abilities, communication styles, and ways of interacting socially and engaging in personal care. The findings from the SLAs and other data gathering were grouped into four sections:

- 1. Governance, Leadership, and Engagement
- 2. Person-Centered Care
- 3. Health and Care Workforce
- 4. Data for Monitoring and Research

Each section includes recommendations that, if implemented, would build on the targeted actions from the <u>2022</u> World Health Organization *Global report on health equity for persons with disabilities*, in terms of ensuring health systems strengthening activities also benefit people with IDD.

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Check out Special Olympics global report, Focusing on the Invisible, website! #InclusiveHealth

ABOUT ROSEMARY COLLABORATORY

- Rosemary Collaboratory is a health systems strengthening initiative that represents an expanded effort by Special Olympics to tackle the health system issues that drive the health disparities people with IDD often experience. This initiative builds on lessons learned from nearly 30 years of implementing health programming and partnerships with decision-makers, creating a strong baseline understanding and intuition of what governments and health systems need to do to achieve health equity for people with IDD.
- Named in honor of Rosemary Kennedy, sister of Special Olympics' founder Eunice Kennedy Shriver, the Collaboratory works to ensure that people with intellectual disabilities are fully included in health systems worldwide.
- The 11 sites included in the initiative are: Chinese Taipei, India, Ireland, Morocco, Nigeria, Pakistan, Paraguay, South Africa, and, in the United States, Pennsylvania, Washington, and Wisconsin.

- Special Olympics collaborated with the Missing Billion Initiative (MBI) to develop a new, IDD-specific module to MBI's existing System-Level Assessments (SLAs) on disability inclusion in health systems, to evaluate the extent of inclusion of people with IDD in health systems.
 The SLA contains almost 60 indicators to assess gaps, highlight access issues, and identify progress for people with IDD.
- Rosemary Collaboratory encompasses three components: data collection, including the SLAs (completed in 2024); the global report (launching in 2025); and policy, systems, and environmental change work in Rosemary Collaboratory sites, tailored to their identified priorities (launched in 2025 and ongoing).
- The aim of this initiative is to use the collected data to drive health systems improvements related to inclusion of those with IDD, while targeting barriers that have been identified and prioritized with the leadership of those with IDD. These barriers include limited accessibility, provider biases, a lack of training among health and care professionals, social barriers, discrimination, poor data collection, and lack of targeted policies.

