

# FOCUSING ON THE INVISIBLE

The Overlooked Needs of People with Intellectual and Developmental Disabilities and Actions to Strengthen Health Systems for Inclusion

## EXECUTIVE SUMMARY

People with intellectual and developmental disabilities (IDD) face severe health disparities worldwide. Over 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. The result is that people with IDD die 16-20 years sooner than the general population due to preventable health conditions.

One of the biggest reasons for this is that the health needs of people with IDD remain largely invisible in health systems. This leads to major gaps in services and many barriers to care. These barriers include limited accessibility, provider biases, and a lack of training among health and care workers. The needs of people with IDD and efforts to address their needs are under-reported and under-researched, leaving their health challenges unaddressed.

Through the newly launched Rosemary Collaboratory initiative, Special Olympics International (SOI) is accelerating efforts to address inequities that individuals with IDD face in health systems worldwide—issues that Special Olympics Founder Eunice Kennedy Shriver's sister, Rosemary Kennedy, experienced 60 years ago and still persist today. The Collaboratory highlights challenges, best practices, and gaps that people with IDD face within health systems. In early 2024, Special Olympics engaged teams in 11 Rosemary Collaboratory sites across nine countries, including Chinese Taipei, India, Ireland, Morocco, Nigeria, Pakistan, Paraguay, South Africa, and the United States, to assess the level of inclusion of people with IDD in each location's health system. These data are complemented in this report by desk reviews of relevant research, case studies of people's lived experience, and surveys completed by over 1,000 people with IDD and members of the health and care workforce in over 50 countries.

The report highlights the importance of adopting a social and rights-based model of disability to improve health system experiences and outcomes. This approach shifts the focus from individual differences to societal barriers and recognizes neurodiversity, which includes different cognitive abilities, communication styles, and ways of interacting with others.

Building on the targeted actions for governments highlighted in the recent World Health Organization *Global report on health equity for persons with disabilities*, this global report provides recommendations specific to the needs of people with IDD. With this report, SOI aims to bring to bear the voices of people with IDD, alongside lessons learned and relationships forged through nearly 30 years of community-level health programming.



## EXECUTIVE SUMMARY CONTINUED

The report unveiled some startling findings:

- Almost no Rosemary Collaboratory sites had specific indicators or policies outlined for people with IDD;
- In a survey of over 700 people with IDD from nearly 50 countries, 2 in 3 people do not make their own health decisions or ONLY do so occasionally;
- Only 52% of people with IDD surveyed said they always understand their health care provider;
- 66% of health worker survey respondents thought improving data collection on the health of people with IDD would be a very important measure to improve health services for this population.

The report urges governments and other stakeholders to address health equity for persons with IDD through actions in four key areas.

### Governance, Leadership, and Engagement

Governments must require that people with IDD be meaningfully involved in policymaking, so that their needs are considered and made visible in policies. To ensure equitable representation and purposeful participation:



1. Raise public awareness of the rights, needs, and contributions to society of people with IDD, guaranteeing their inclusion in developing and implementing campaigns which reflect their needs and lived experiences;
2. Mandate formal representation and accommodations to allow meaningful participation of people with IDD in health policy processes;
3. Back policies pertaining to the health of people with IDD with adequate funding and resources and ensure that national regulations address their specific needs; and
4. Empower people with IDD to actively participate in human rights monitoring, including reporting on rights violations, and ensure that systems are in place to support their involvement.

### Person-Centered Care

Person-centered care for people with IDD involves recognizing and accommodating their unique health needs in a way that is both empowering and affirming. To achieve this:



1. Strengthen supported decision-making by revising legislation to align with the United Nations Convention on the Rights of Persons with Disabilities and ensuring policies and resources, including training, tools, and systems, are in place to enable supported decision-making;
2. Establish patient navigators to help people with IDD navigate health systems and to coordinate care across specialties and services across sectors;
3. Improve quality and continuity of care by promoting and enabling the adoption of communication-focused accommodations, such as health passports and extended appointment times; and
4. Make health information accessible and improve health literacy by requiring and ensuring the provision of materials in Easy Read formats and developed using universal design principles.



### Health and Care Workforce

People with IDD face stigma and unique communication barriers when accessing the health system and interacting with the health and care workforce. To improve the knowledge, skills, and attitudes that the health and care workforce require for inclusion:

1. Require comprehensive, evidence-based training for health workers, incorporating various learning methods and ensuring active collaboration with people with IDD in the development and delivery of training;
2. Monitor progress using standardized measures to assess the effectiveness of training, patient satisfaction, and health outcomes, with accountability for continuous improvement; and
3. Ensure visibility of people with IDD within the health system by depicting them in materials and including them in the workforce, in roles such as patient navigators, to challenge stereotypes and enhance person-centered care.



### Data for Monitoring and Research

Effective data collection and analysis are essential to addressing health disparities faced by people with IDD, as they help identify gaps in care and drive policy change. To drive evidence-backed and equity-based policymaking:

1. Improve data disaggregation by disability types to ensure people with IDD are accurately captured in health data systems;
2. Make health data publicly accessible through dashboards or reports in accessible formats to track progress and highlight systemic gaps; and
3. Advance inclusive, data-driven research by involving people with IDD and their advocates in participatory data collection, ensuring their active representation in research design, and using findings to improve health services and policies.

**As David Duncan, Chair of the Special Olympics Global Athlete Leadership Council and member of the Editorial Review Group for this report, eloquently sums up:**



Give people with IDD a seat at the table. Listen to our unique perspectives... Give us a say and the supports we need to use our voices, claim our health, and live our best lives. Give us a line in the curriculum, the budget, the policy document, the survey... and don't forget to let us be a part of writing those lines.

