

Focusing on the Invisible

Special Olympics Global Report on the Health of People with IDD

Four-Pager

ABOUT ROSEMARY COLLABORATORY

Rosemary Collaboratory is a newly launched initiative led by Special Olympics that aims to accelerate efforts to address inequities that individuals with intellectual and developmental disabilities (IDD) face in health systems worldwide. During the first half of 2024, Rosemary Collaboratory engaged teams at 11 sites around the world to assess the state of inclusion of people with IDD in their health system as one of three components of Rosemary Collaboratory. Based on those findings and other data sources, Special Olympics has generated four key recommendations centered around: **Governance, Leadership, and Engagement; Person-Centered Care; Health and Care Workforce; and Data for Monitoring and Research.**

REPORT SUMMARY

People with 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. Rosemary Collaboratory builds upon lessons learned and relationships forged by Special Olympics through nearly 30 years of community-level health programming. Special Olympics global health report, *Focusing on the Invisible*, part of the Rosemary Collaboratory initiative, provides recommendations for policy change and feasible steps for governments to take urgent action.

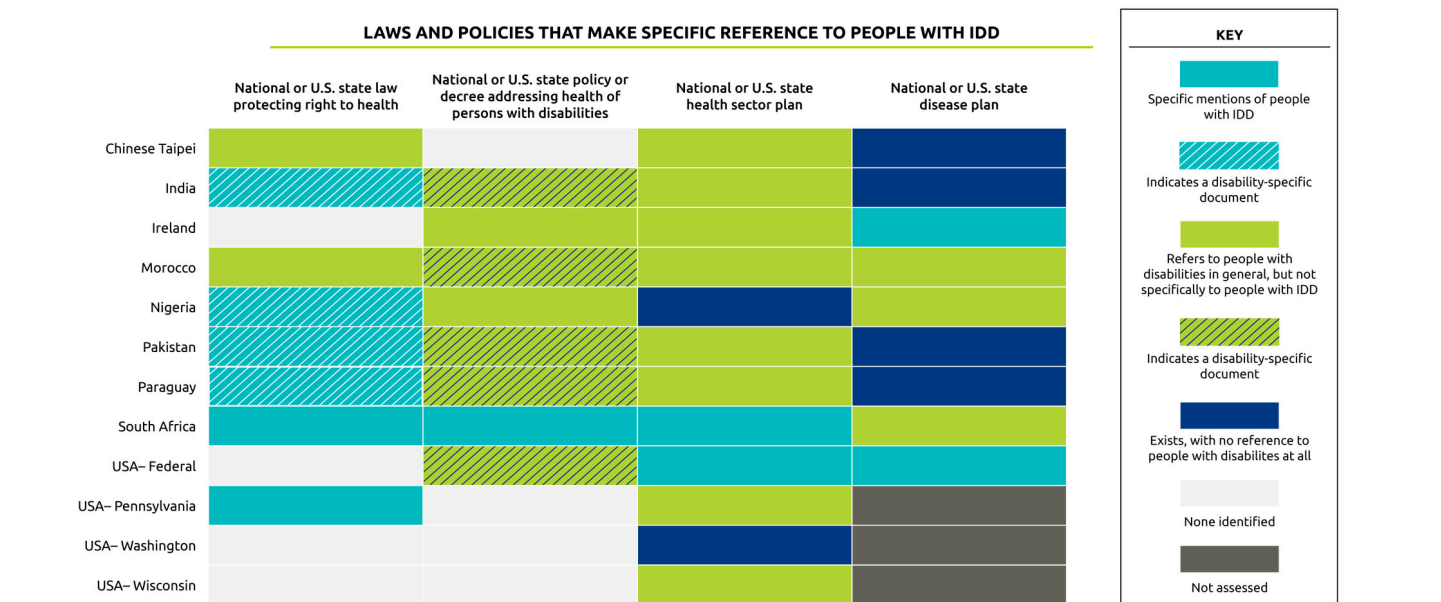
GOVERNANCE, LEADERSHIP, AND ENGAGEMENT



To build inclusive health systems, people with IDD must actively be involved in shaping the policies that affect their lives. Their voices matter, and their health needs must be clearly visible in every policymaking space that impacts their well-being.

Laws and Policies in Place to Ensure the Right to Health for People with IDD

The data presented here point out laws and policies identified through System Level Assessments (SLAs) completed at each Rosemary Collaboratory site, showing how health-related laws and policies vary in their inclusion of people with IDD. All 11 of the sites have areas of improvement and strength, and across the board there have been improvements in policy implementation.



GOVERNANCE, LEADERSHIP, AND ENGAGEMENT (CONTINUED)

The table above shows that laws and policies don’t often mention people with IDD (turquoise in the table). When they do, it’s usually in laws about people with disabilities (striped boxes). Most of the time, people with IDD are only mentioned as part of the general definition of disability. Health policies more often talk about people with disabilities as one group (green in the table). That’s helpful, but people with IDD sometimes have special needs that others may not understand. So, general policies might not always help them fully. This table doesn’t say that only naming people with IDD makes a policy good, or that policies without that (green or dark blue in the table) are bad. It just shows different ways countries handle this and gives us a chance to learn from them.

Formal Processes for Engaging People with IDD and Their Representative Organizations in Health Policymaking

Creating equitable health policies also requires the inclusion of people with IDD in both policy development and monitoring of its implementation. The SLAs uncovered several good examples, including in Nigeria, Paraguay, and South Africa, where there is formal representation of people with disabilities in the national health sector, either individually or through organizations of persons with disabilities (OPDs)—organizations led, directed, or governed by persons with disabilities. However, in most sites, the SLAs identified engagement of OPDs in the health sector, but people with IDD were not necessarily captured in OPD representation or participation.

PERSON-CENTERED CARE



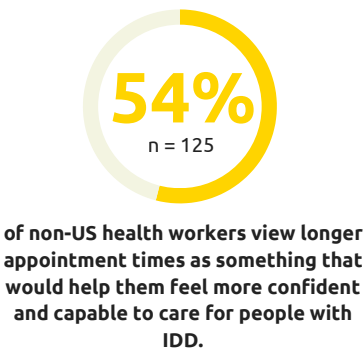
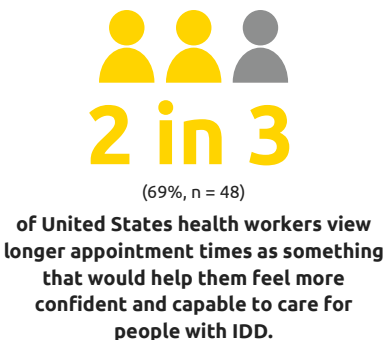
Meeting the health needs of people with IDD requires a person-centered approach—one that empowers individuals to take charge of their health journey. People with IDD often face barriers to making decisions about their health, navigating care, and being understood by providers.

Accessible and Available Health Services

The data presented here calls attention to the obstacles to person-centered care, including inaccessible information, complex and uncoordinated systems of care, and physically and inaccessible health settings. The SLAs in 11 sites identified persistent gaps across five key elements of accessibility and availability.

THESE ACTIONS INCLUDE:

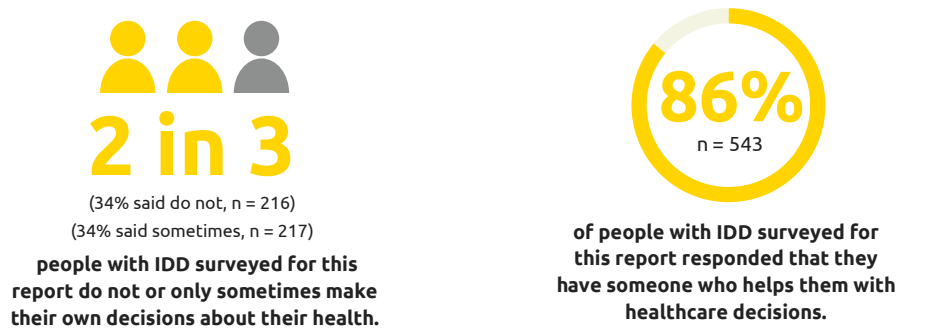
- **National Guidance on Reasonable Accommodations:** 9 of the 11 sites have issued some form of guidance addressing reasonable accommodations—or changes or adjustments to ensure people can get the care they need—for persons with disabilities, including in health settings. However, it is rare that this guidance explicitly mentions IDD or provides specific directions on accommodations responsive to the needs of neurodiverse populations.
- **Accessible Health Information:** 3 of the 11 sites have made some materials available in plain language or specifically targeted to people with IDD.
- **Transport Subsidies:** 9 of the 11 sites have transport subsidies in place at some level that typically apply broadly to people with disabilities rather than specifically targeting people with IDD.
- **Care Coordination:** 7 of the 11 sites reported the existence of care coordination or support staff, though their reach and effectiveness for people with IDD varies.
- **Reimbursement Adjustments for Providers:** SLA findings indicate that many countries did not see reimbursement adjustments as relevant. However, health worker survey responses show:



PERSON-CENTERED CARE (CONTINUED)

Agency, Support, and Decision-Making

The data presented here draw attention to the exclusion of people with IDD from decision-making regarding their own health. Most SLA sites have legislation that addresses legal capacity in some way—legal capacity includes whether an individual is allowed to make their own health decisions or not. In some instances, laws specifically mention people with IDD (or a similar category) to limit their legal capacity in a targeted way. Fortunately, this is no longer the main approach. Legislation that is not only neutral but actually promotes supported decision-making has taken hold in 5 of the 11 SLA sites (only 2 outside of the U.S.). Most, but not all, of those sites have also developed specific guidance, protocols, and protections, which are crucial safeguards.



LAW(S) TO PROTECT AND EMPOWER PEOPLE IN HEALTH DECISION-MAKING

	Law exists addressing legal capacity	Law addressing legal capacity specifically references PwIDD	Law presumes capacity of those with IDD and provides guidance to support people to make their own decisions	Criteria to assess capacity exist	Protocols and codes of practice exist, with which health professionals must comply if an individual is deemed to not have capacity
Chinese Taipei					
India					
Ireland					
Morocco					
Nigeria					
Pakistan					
Paraguay					
South Africa					
USA					
USA- Pennsylvania					
USA- Washington					
USA- Wisconsin					

KEY

Yes

No

HEALTH AND CARE WORKFORCE

People with IDD face stigma and unique communication barriers when accessing the health system and interacting with health workers. Comprehensive, evidence-based training can help bridge the gap between patients and providers.

Training in Addressing the Wide-Ranging Needs of People with IDD

Many health and care workers enter the workforce with little to no preparation to address the unique needs of people with IDD. SLA findings share that most Rosemary Collaboratory sites lack licensing requirements that promote IDD training for health professionals once they have graduated and started to practice. The data presented on the next page draw attention to the main challenges people with IDD face when seeking care—challenges like communication barriers.



of people with IDD surveyed for this report indicated they always understand their provider.



of people with IDD surveyed for this report said that they have another person explain things after the provider talks or gives instructions.



of people with IDD who took the survey, one of the top three most frequently chosen responses to the question 'What would help you get better healthcare?' was 'Clearer, easy to understand instructions from healthcare providers.'

As for healthcare worker respondents:



agreed or strongly agreed that IDD training would be an effective strategy for improving their self-efficacy.



considered continuous professional development on disability healthcare to be a very important or moderately important measure to improve health services for people with IDD.



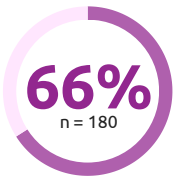
considered inadequate health worker training was a key challenge for the health of people with IDD in the arena of service delivery.

DATA FOR MONITORING AND RESEARCH



Effective data collection and analysis is essential in addressing the health disparities faced by people with IDD. Robust data help identify where health systems fall short and hold decision-makers accountable.

Data can be used to drive government accountability, empower communities, and initiate targeted interventions. The data presented here underline how disaggregated data—or data broken down by category or group—and strong data-driven monitoring are crucial to revealing inequities.



of health worker survey respondents considered improving data collection on the health of people with IDD to be a very important measure (the highest possible response) to improve health services for people with IDD.

