EXECUTIVE SUMMARY

People with intellectual and developmental disabilities (IDD) face severe health disparities. In particular, people with IDD disproportionately experience a variety of health conditions, such as diabetes, respiratory diseases, and anxiety and depression. Furthermore, health systems are not designed to meet their needs. The result is that people with IDD die 16-20 years sooner than the general population due to preventable and treatable 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 care workers. The needs of people with IDD and efforts to address their needs are often under-reported and under-researched, leaving their health challenges unaddressed.

Through the Rosemary Collaboratory initiative, Special Olympics International (SOI) is accelerating efforts to address inequities that individuals with IDD face in health systems worldwide. These issues are not new. Many of them were faced by Special Olympics Founder Eunice Kennedy Shriver's sister, Rosemary Kennedy, 60 years ago and still persist today.

The Collaboratory highlights challenges, best practices, and gaps that people with IDD face within health systems. During the first half of 2024, Rosemary Collaboratory engaged teams in 11 sites across nine countries, including Chinese Taipei, India, Ireland, Morocco, Nigeria, Pakistan, Paraguay, South Africa, and the United States (U.S.)—including the national level and three different states, Pennsylvania, Washington, and Wisconsin—to assess the level of inclusion of people with IDD in each location's health system. These data are complemented by desk reviews of relevant research, case studies of people with IDD's lived experience, and surveys completed by over 1,000 people with IDD and members of the health care workforce in over 50 countries, including 236 people with IDD and 70 health care workers from 26 U.S. states.

This 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 a global report launched by SOI in 2025, this report provides recommendations specific to the needs of people with IDD in the United States. 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 unveils some significant findings:

- Health systems do not consistently identify or respond to the specific needs of people with IDD.
- People with IDD face barriers to person-centered care. even when services exist.
- The health care workforce is not trained to provide inclusive care for people with IDD.
- Gaps in data and research prevent health systems from fully understanding and addressing inequities experienced by people with IDD.

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



GOVERNANCE, LEADERSHIP, AND ENGAGEMENT

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

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; and
3. Ensure that federal and state health and related policies for the general population also account for the needs of people with IDD, so that access to appropriate care does not depend on whether a person receives Home- and Community-Based Services or not.



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, we must:

1. Promote supported decision-making as the default approach and ensure 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 CARE AND PUBLIC HEALTH WORKFORCE

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

1. Require comprehensive, evidence-based training for health care and public 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, we must:

1. Maintain and improve data disaggregation to ensure people with IDD are accurately identified in health data;
2. Make data on the health of people with IDD publicly accessible through dashboards or reports in accessible formats, to help 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 Joey Mier, Special Olympics Wisconsin athlete, sums up

> People with IDD deserve the opportunity to live healthy, fulfilling lives. We deserve to have our questions answered, our choices respected, and our experiences taken seriously. Health equity begins when we see the whole person and listen to what that person has to say.