

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, including Ireland, 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.**

SITE-LEVEL SUMMARY

Ireland is one of the only European Union member states without a fully realized universal health system, making it an outlier in Europe. While its healthcare system currently consists of a mix of public and private healthcare services, Ireland aims to move towards a universal health system, known as Sláintecare, by 2030. The purpose of this two-pager is to highlight the state of inclusion of people with IDD in Ireland's health system, including data, promising practices, and areas of strength and growth.

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.

Several Irish policies either specifically mention people with IDD or the need to consider them within program delivery plans. These policies include: **National Sexual Health Strategy 2015-2020, Smile agus Sláinte: National Oral Health Policy, and Sharing the Vision: A Mental Health Policy for Everyone.**

Area of Growth: Formalizing Inclusion of people with IDD in Health Governance

In 2023, responsibility for specialist disability services was moved out of the Department of Health and into the Department of Children, Disability, and Equality. The ministers of these departments consult with each other, as well as with organizations of persons with disabilities (OPDs), regularly. However, there does not appear to be a designated team or person within the Department or Minister of Health offices responsible for ensuring health access for people with disabilities or people with IDD, nor a specific advisory group or role for people with disabilities or OPDs within that Department.

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.

In the absence of a universal health coverage system, mechanisms are in place to subsidize healthcare services for people with IDD; according to the 2019 Census, 81% of people recorded to have an intellectual disability benefitted from one of these programs.

PERSON-CENTERED CARE (CONTINUED)

✓ Transport Subsidies

Ireland has a free travel scheme designed to support older people and persons with disabilities to travel freely on all public transport for daily needs, including seeking healthcare. In addition to traveling free of charge, individuals may also have a companion travel with them at no additional cost. Additional travel supports include a reservable door-to-door transport services for rural residents.

✓ Addresses Legal Capacity/Decision-Making

Ireland's Assisted Decision-Making (Capacity) Act of 2015 is universally designed legislation that recognizes that every individual's capacity evolves during their lifetime. It created a Decision Support Service. Its mandate includes registering and regulating decision-making assistance agreements for people who need decision-making support and decision supporters, maintaining a searchable register of such agreements, connecting individuals in need of decision-making support with supporters, supervising decision supporters, and investigating complaints.

✓ Care Coordination

Several different care coordination services, including the **Patient Advocacy Service** and hospital-specific **Patient Advisory Liaison Services (PALS)**, support different populations of patients. The **National Advocacy Service for People with Disabilities** provides free and independent support for people with disabilities, including healthcare support.

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 people with IDD and providers.

Certain Irish universities have developed courses on caring for patients with IDD. However, these courses have been developed on a university-by-university basis, meaning that contents vary across institutions. All nursing training programs in Ireland include some contents related to IDD. In faculties of medicine, only one of five approved universities in Ireland were identified to offer a core competency module on disability in healthcare.

DATA FOR MONITORING AND RESEARCH



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

According to analyses of 2016 Census data by Ireland's Central Statistics Office, the standardized mortality rate—a measure that compares death rates between different groups—for people without disabilities in Ireland from 2016-2017 was **302 per 100,000 people**. In comparison, the standardized mortality rate for people with disabilities was **1,232 per 100,000 people**—nearly four times higher.

Effective data collection and analysis are essential to addressing health disparities faced by people with IDD. These processes highlight gaps in health care delivery and can serve as powerful tools for driving policy change and accountability.

