

Focusing on the Invisible:

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



People with intellectual and developmental disabilities (IDD) experience significant health disparities, including higher rates of diabetes, anxiety, and depression. As a result, they die 16-20 years sooner than the general population.

Focusing on the Invisible: The Overlooked Needs of People with Intellectual and Developmental Disabilities and Actions to Strengthen Health Systems in the United States for Inclusion is a new report from Special Olympics that examines the factors driving these inequities and identifies opportunities to create more inclusive and accessible health systems.

This resource highlights key messages from the report and actions that decision-makers in health systems at every level, in every state, across the country can take to help people with IDD receive the care, attention, and respect they deserve.

KEY REPORT MESSAGES //////////////////////////////////////

- 1

The needs of people with IDD are too often overlooked in mainstream U.S. health systems, contributing to preventable health inequities.
- 2

Existing support systems don't reach everyone with IDD, leading to significant gaps in accessible and affordable care.
- 3

Gaps in clinical research and provider training leave the health system ill-equipped to meet the needs of people with IDD.

1. THE NEEDS OF PEOPLE WITH IDD ARE TOO OFTEN OVERLOOKED IN MAINSTREAM U.S. HEALTH SYSTEMS

The health disparities that people with IDD face are significant and without health-specific policies and practices in place that consider and address their challenges and needs, these health inequities persist.

- People with IDD in the United States experience health concerns at higher rates than those without functional limitations, impacting their quality of life and leading to a life-expectancy of 16-20 years less than the general population. For example, **people with IDD are 2.5 times more likely to have asthma, and nearly 9 times more likely to have anxiety or depression than those without functional limitations.**
- Many of the health disparities are preventable or treatable when the health needs of people with IDD are adequately accounted for within public health and health care policy and practice.
- Although the U.S. has strong disability rights policies and governance structures (e.g. the Americans with Disabilities Act), the needs of people with IDD are often recognized primarily through disability services rather than as a population whose health outcomes should shape and be represented in mainstream health policy.
- Their perspectives are also rarely embedded in permanent health sector decision-making processes, limiting their influence on quality standards, reimbursement policies, and accountability mechanisms.



2. EXISTING SUPPORT SYSTEMS DON'T REACH EVERYONE WITH IDD, LEADING TO SIGNIFICANT GAPS IN ACCESSIBLE AND AFFORDABLE CARE

Even when support exists, too many people with IDD face barriers to accessing affordable, person-centered health care that meets their needs.

- Existing support pathways like **Home and Community-Based Services (HCBS)** play an essential role in helping people with IDD access care, yet a substantial share of people with IDD are not connected to these benefits. Estimates suggest that **hundreds of thousands of eligible individuals remain without HCBS access**. Policies must enable the broader health system to deliver person-centered care by making accommodations and adaptations easier to access.
- Many of the health disparities are preventable or treatable when the health needs of people with IDD are adequately accounted for within public health and health care policy and practice.
- While many people with IDD are covered by Medicaid, Medicaid coverage is often not enough to cover treatment costs, leading to high out of pocket costs that can deter medical care or lead to financial hardships.
- Nearly **15% of people with IDD said they did not seek medical care within the past year due to cost**, compared to just over 4% of people without functional limitations.

3. GAPS IN CLINICAL RESEARCH AND PROVIDER TRAINING LEAVE THE HEALTH SYSTEM ILL-EQUIPPED TO MEET THE NEEDS OF PEOPLE WITH IDD

When health research excludes people with IDD, evidence gaps lead to their needs being overlooked. When health care providers are not trained to work with people with IDD, stigma persists, and quality, safety, and patient experience are adversely affected.

- **75% of federally funded research studies have deliberately excluded people with IDD** from participating even when they could be eligible. *Source: Disability Health Journal*
- Many health professionals feel ill-equipped to care for people with IDD, and health education programs generally provide limited training on caring for this population. **Only 40% of health professionals report feeling "very confident" in their ability to provide the same quality of care to patients with disabilities** as they do to those without disabilities.
- Communication barriers remain common: a survey by Special Olympics found that nearly **92% of respondents with IDD reported that someone, at least sometimes, explains things after their health care provider talks or gives instructions**, demonstrating that there may be significant margin for improvement of provider skills.
- Integrating IDD competencies into licensure, accreditation, and continuing education requirements could help build a more inclusive health workforce.
- Together, gaps in research and provider training reinforce one another, leaving the health system inadequately prepared to address the health needs of people with IDD.

To read and download the full report, visit:

<https://www.specialolympics.org/what-we-do/inclusive-health/rosemary-collaboratory/focusing-on-the-invisible-us>

