



Special Olympics  
**Health**

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# 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

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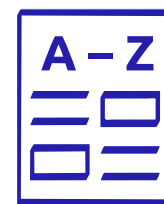
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# INTRODUCTION LETTER FROM JOEY MIER

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*Dear Reader,*

Thank you for taking the time to read this report. It means a great deal to me and to my fellow athletes to know that you are willing to listen to stories and experiences that are too often overlooked. At its heart, health equity begins with something simple but powerful: seeing the person, not simply the patient.

My name is Joey Mier, and I am a proud Special Olympics Wisconsin athlete. I have been a part of Special Olympics for more than 24 years. Special Olympics is my family and my passion, and my experiences have shown me what it truly means to be seen, heard, supported, and included.

Health equity is not an abstract concept. It is personal. It is about whether people with intellectual and developmental disabilities (IDD) are listened to, understood, respected, and included in decisions about our own health and well-being.

My own experiences have shown me that the health care system can be difficult to navigate for anyone, and even more challenging for people with IDD. My disability is invisible, and there have been times when I have felt misunderstood, rushed, or treated as a number rather than a person. At times, these

experiences have made me reluctant to seek care because I do not feel confident that providers understand me or my needs. Imagine needing to ask for help but not knowing how to ask for it or wondering whether you will be understood when you do.

During my annual eye exam, I picked out a pair of frames that I thought Medicaid would cover. No one explained to me in a way I could understand that the frames cost more than what Medicaid covered or that I would have to pay the difference. Later, I received a large bill that I could not afford. The experience was frustrating and caused me anxiety. It showed me how confusing health care costs and insurance coverage can be, and how important it is for people with IDD to have information explained clearly and accessibly.

The following year, I went to Special Olympics Opening Eyes, the vision screening discipline of Healthy Athletes. There, I received a full vision screening and a free pair of eyeglasses. The experience was completely different. I felt comfortable, supported, and included. What had once been frustrating and anxiety-inducing became a positive experience, showing me the difference that clear communication, understanding, and genuine support can make in health care.

Special Olympics has shown me what is possible when health providers have education, understanding, empathy, compassion, and most importantly, a willingness to listen to people with IDD about our own experiences. I hope this report reminds you that we can't live happily if we're not healthy. Health is about more than just getting medication or receiving treatment. 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. And that starts with you.

Live with kindness,

A handwritten signature in black ink that reads "Joey Mier III".

*Joey Mier*

*Special Olympics Wisconsin*

*Athlete Leadership Council Member & Health Messenger*



# EXECUTIVE SUMMARY

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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.

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 Care and Public Health Workforce



### Person-Centered Care



### Data for Monitoring and Research

#### 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.

”

# INTRODUCTION

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People with intellectual and developmental disabilities (IDD) die 16-20 years sooner than the general population due to preventable and treatable health conditions.<sup>1</sup> In particular, people with IDD disproportionately experience health conditions such as diabetes, respiratory diseases, and anxiety and depression.<sup>2</sup> Initiatives to improve population health will require public health approaches that keep people healthy, rather than simply treating the ill, as well as “creating a health care system that works well,” in the place of the current system that has been characterized as “less than the sum of its parts.”<sup>3</sup> People with IDD are among those that have been on the margins of these efforts. This exclusion is likely to leave them out of any gains and will ultimately stall progress towards key metrics such as improved population health and reduced health care expenditure. To advance U.S. health priorities and achieve objectives such as those contained in Healthy People 2030, more focused efforts are needed to address gaps, particularly in access to and quality of health services for people with IDD. The Special Olympics movement has been making such focused efforts for nearly 30 years.

## A MOVEMENT FOR INCLUSION AND HEALTH EQUITY FOR PEOPLE WITH IDD

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Special Olympics exists because the joy Rosemary Kennedy experienced and brought to others, as well as the challenges she faced, inspired her sister, Eunice Kennedy Shriver, to bring about a more inclusive world. With an annual reach of over 670,000 people with IDD across 50 U.S. states, the District of Columbia, and Puerto Rico, and 80,000 health care workers who have been trained by Special Olympics between 2021 and 2025, Special Olympics is part of a movement for health equity for persons with disabilities, with a focus on those with IDD, whose needs are often most invisible.

Leveraging this foundation, the Rosemary Collaboratory initiative, which includes a global report and this U.S.-focused report, as well as state-level policy, systems, and environmental change efforts, brings to bear the voices of people with IDD, alongside lessons learned and relationships forged through nearly 30 years of community-level health programming. This report urges others to join the movement to make health equity for all a reality.

# WHO ARE PEOPLE WITH IDD?

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The United States Centers for Disease Control and Prevention (CDC) says of developmental disabilities that they are “a group of conditions due to an impairment in physical, learning, language, or behavior areas [...that] begin during the child’s developmental period, may impact day-to-day functioning, and usually last throughout a person’s lifetime.”<sup>4</sup> A subcategory of developmental disabilities, intellectual disability is, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD), “a condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 22.”<sup>5</sup> Conditions associated with IDD include, but are not limited to, Down syndrome, Fragile X syndrome, Fetal Alcohol Syndrome Disorder, and autism spectrum disorder.

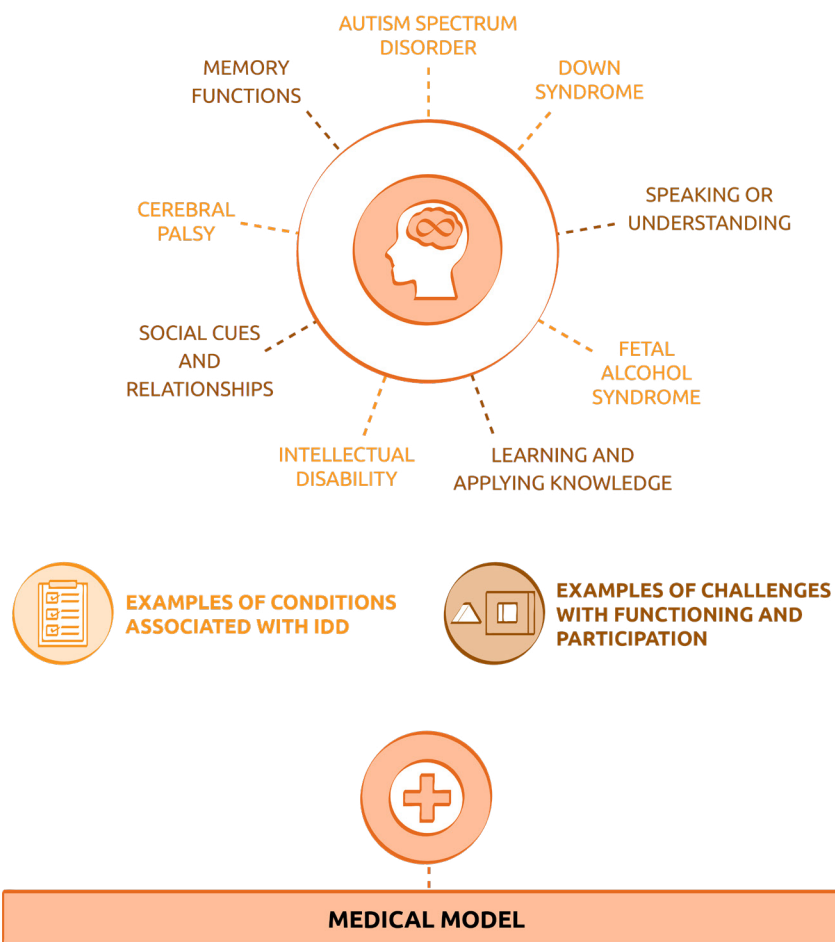
People with IDD are a diverse group due to diagnoses, type(s) of functional challenges, and support and collaboration needs and preferences.<sup>a</sup> Challenges related to vision, hearing, and mobility may have visible manifestations, making them more tangible and familiar to those in the health ecosystem, as well as the general public. Meanwhile, many people with IDD identify with the notion of having an invisible disability, which renders their needs invisible, too.

A key takeaway from this report is the need to adopt a social and rights model of disability. Rather than focus on individual-level “impairments,” this approach emphasizes the role of society-wide barriers and affirms neurodiversity, which includes different cognitive abilities, communication styles, and ways of interacting socially and engaging in personal care.

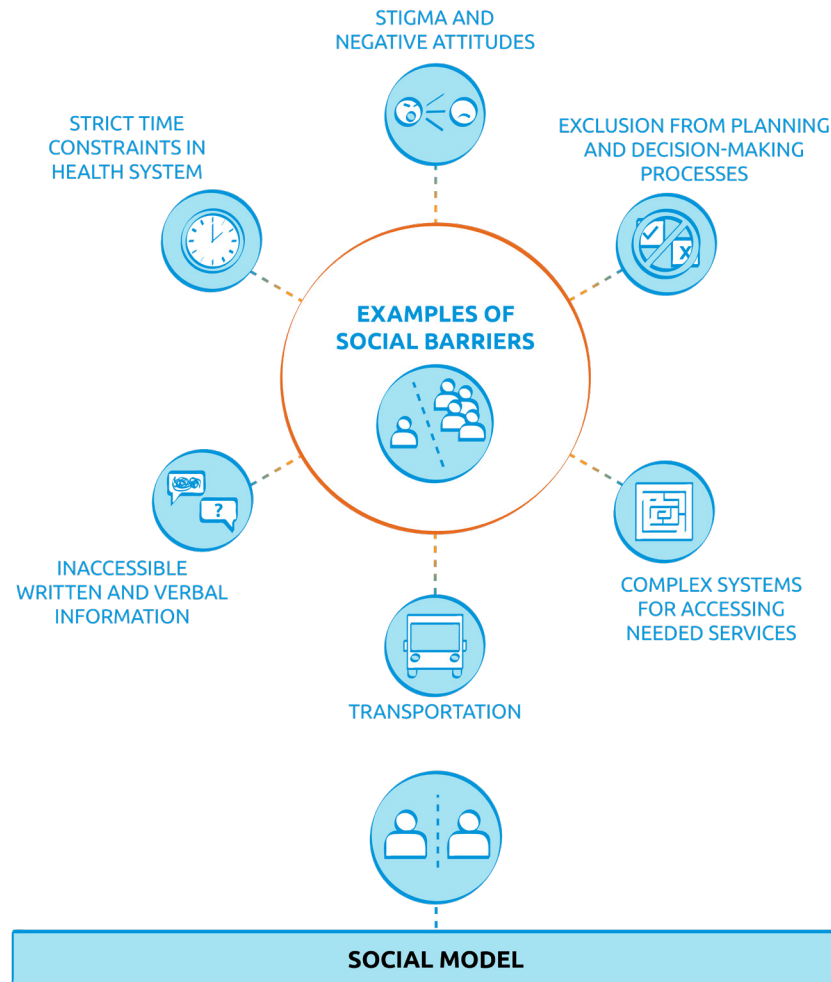
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<sup>a</sup>This document uses terminology that focuses on “differences” or “challenges,” rather than “impairments,” to move beyond the narrow, medical model that focuses on biological characteristics. This approach is similar to that [adopted and recommended](#) by the AAIDD. Some images in this document use the infinity symbol (∞) to refer to people with IDD.

## COMMON UNDERSTANDING OF IDD (MEDICAL MODEL)



## SOCIAL MODEL UNDERSTANDING OF IDD



The medical model of disability frames disability as requiring treatment or management through medical intervention. As illustrated in the case study of Marisa<sup>b</sup>, later in this report, a person who receives care related to their difference or disability, such as access to rehabilitation or assistive technology, still needs the same health services that are recommended for others, such as cancer screenings. For example, a wheelchair can affect mobility and a hearing aid can change access to communication, thereby removing important barriers that can affect health and participation. However, having access to these devices does not itself mean that a

<sup>b</sup>Real names and images of people with IDD are used with permission throughout this report.

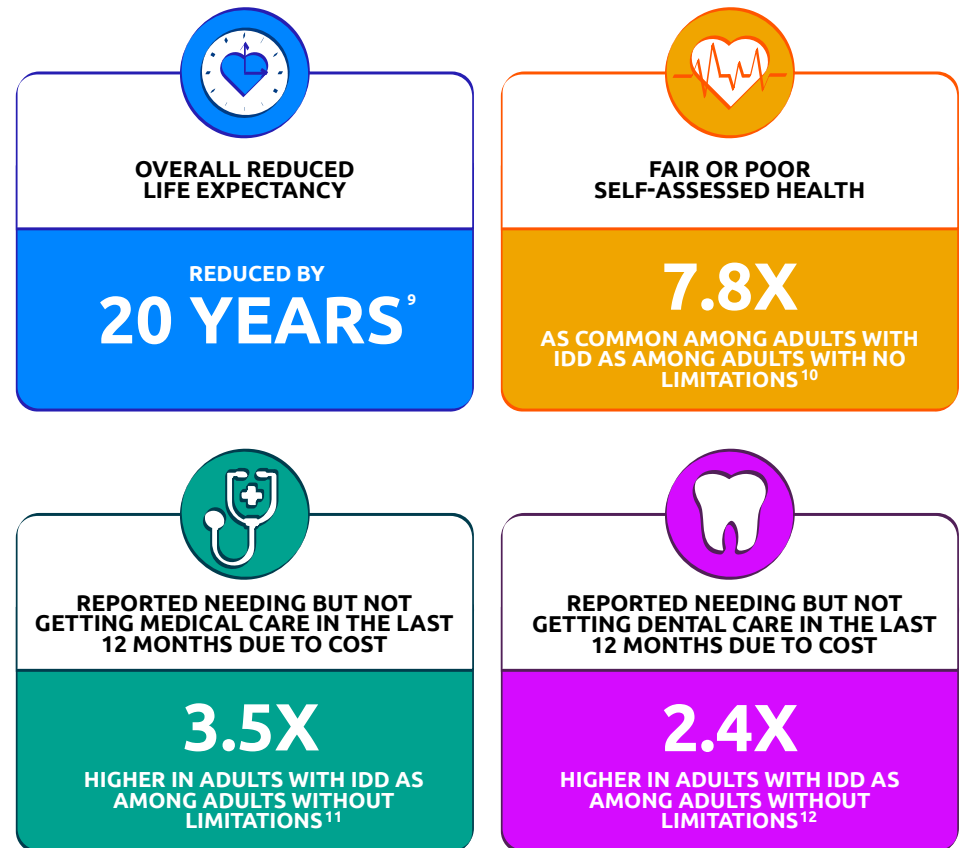
person is healthy or healthier than without them. By flattening people with disabilities, who are as multidimensional as those without disabilities, into an “impairment” or diagnosis, the medical model of disability does a disservice to all people with disabilities. This may be particularly the case for those with IDD, for whom medical interventions are often particularly ill-suited to responding to differences in ways that promote health. For many people with IDD, there are no equivalent medical or assistive interventions that directly address the underlying functional differences associated with IDD, making accessible services, effective communication, and individualized supports especially important determinants of health outcomes.

The social model of disability does exactly this. By emphasizing that disability arises not just from an individual’s differences, but from the interaction of those differences with barriers such as societal attitudes, inaccessible environments, and systemic inequities, this model shifts the focus from the individual’s diagnosis to the need for society to respond to and accommodate diverse needs.<sup>6</sup>

## WHY THIS REPORT

As has been mentioned, people with IDD disproportionately experience many health conditions that do not stem from diagnoses associated with IDD. They also experience some conditions indicative of poor health, like obesity and hypertension, at similarly high proportions as the general population, but a disparity is still present.<sup>7</sup> This is because poor access to health promotion programs and screenings result in people with IDD developing these conditions earlier in life and experiencing higher risk of more severe degeneration.<sup>8</sup>

### PREMATURE MORTALITY



Echoing the social barriers that people with IDD face more broadly, people with IDD face many of the same barriers when navigating and accessing primary care as those without IDD. Yet, those with IDD experience some barriers uniquely or more acutely, when compared with the general population, which can result in the full consequence of those barriers remaining relatively unseen.

For example, transportation is often cited by people with IDD as a barrier to inclusion, in general, and to accessing health services, in particular. All individuals are affected by transportation barriers such as limited public transportation, cost of public transportation that may be available or the cost of private alternatives, and the safety of different modes of transportation. Not only are people with IDD more likely to be indigent than the general population, *navigating* public transportation is an additional consideration that often gives rise to additional costs (and opportunity costs) for a support person or caregiver to travel with the person with IDD. In a 2017 study assessing the number of people in the U.S. who delay medical care each year due to transportation issues, 1.8% of the general population experienced this, compared with 7% of people living below the poverty level and 5.6% of Medicaid recipients.<sup>13</sup> The study found “strong association between functional limitation status,” which is a common proxy for disability, “and transport-delayed care above and beyond any sociodemographic or other health characteristics.” A 2022 study found that 17% of adults with disabilities “did not get needed health care in the [preceding] 12 months because of difficulty finding transportation.”<sup>14</sup> Furthermore, safety concerns may be heightened by stigma, discrimination, and interpersonal violence.<sup>15</sup> Notably, among people with disabilities in general, transportation barriers have been linked to poorer health outcomes.<sup>16</sup>

Ensuring people with IDD have access to quality health services, as well as a voice in how those services are designed and delivered, is important not only for their individual health, but for reaching the objectives in Healthy People 2030 and other public health strategies, plans, and programs.

This U.S. report builds on a similar report of global scope published in 2025 and highlights challenges, promising practices, and gaps that exist for people with IDD within health systems, including poor data, lack of awareness, inadequate policies, and insufficient engagement of people with IDD. The health needs of people with IDD are often invisible, not because they are non-existent, but because they are largely unseen or overlooked. As a result, their health disparities remain unacknowledged and unaddressed.

**This report demonstrates that the need for further action within health systems to support the health of people with IDD is clear. This report constitutes a call to action for government workers, from those involved in appropriations and other lawmaking to those making and implementing public health and human services policies; hospital and health system executives, who may shape institutional operations, staff training, and policies across many domains; and payers, who design and manage the financial incentives that influence how care is delivered. Focus on the invisible in order to meet the health needs of people with IDD and move towards health equity.**

## **Support People and Caregivers:**

Many individuals with IDD get help from support people to navigate daily life. Just as for people with and without other differences in functioning, the type and amount of support that individuals with IDD receive can vary across their lifespan.

Supporters themselves vary widely. They may be paid or unpaid, and their ranks include family members as well as employees or professionals with different levels of training. Across those categories, some supporters are positive, empowering, and collaborative. Others may be neutral or face their own challenges. Some may even, intentionally or not, keep the person with IDD from realizing their rights.

**Support people can play a key role in helping individuals with IDD overcome barriers to participation in society. While parts of this report are highly relevant to supporters, Special Olympics recognizes that stereotypes often cause people to underestimate what those with IDD are capable of. Too often, the distinction between supporting a person's rights and making decisions on their behalf is blurred. As such, this report centers on people with IDD themselves, while acknowledging the important but complex role of their supporters.**

## WHO IS THIS REPORT FOR?

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This report is intended for policymakers, public health professionals, health care providers, health system leaders, researchers, disability organizations, self-advocates, family members, caregivers, funders, and others working to improve the health and well-being of people with IDD and indeed the entire population in the United States. The report may be of particular interest to individuals and organizations involved in health policy, health care delivery, workforce development, disability rights, advocacy, and systems change efforts that affect the health of people with IDD and population health.

## HOW TO USE THIS REPORT

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This report is intended to support efforts to strengthen health systems and improve health outcomes for people with IDD in the United States. Readers may use the findings to better understand the barriers and inequities experienced by people with IDD, identify opportunities for action within their own spheres of influence, and inform policies, programs, practices, and investments that advance health equity. The report can also be used to support advocacy, guide strategic planning, promote collaboration across sectors, and inform future research and data collection efforts. Recommendations throughout the report identify priority areas for action and provide a starting point for stakeholders seeking to create more inclusive, accessible, and person-centered health systems.

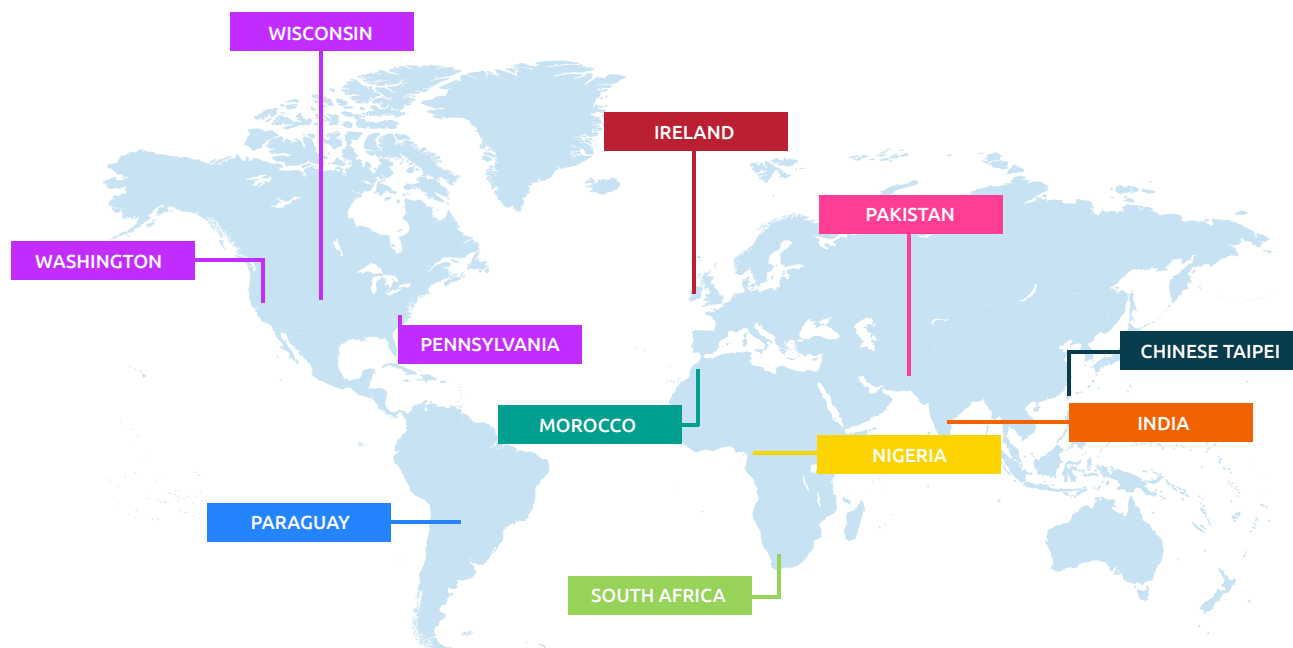
# DEVELOPMENT OF THE REPORT



In 2024, Special Olympics International (SOI) launched the Rosemary Collaboratory health systems strengthening initiative in 11 sites around the globe. This initiative builds on 30 years of Special Olympics Health programming, which created a strong baseline understanding and intuition of what governments and health systems need to do to achieve health equity for people with IDD.

Three of the 11 sites are states in the United States—Pennsylvania, Washington, and Wisconsin. These states represent a convenience sample and may not be representative of the entire United States.

SOI assembled teams in each site to gather health systems-level data using tools developed collaboratively by SOI and the Missing Billion Initiative (MBI). Based on MBI's existing System Level Assessment (SLA), which is designed to assess disability inclusion in a health system, the two organizations developed a specific module to evaluate the extent of inclusion of people



with IDD in health systems. This assessment and module were further adapted to application in the U.S. context with the help of experts from various disciplinary backgrounds with knowledge on the population with IDD, the U.S. health system, and disability rights. The SLA framework (depicted in Annex 1) has significant overlap with the World Health Organization-

defined building blocks of a health system and includes four high-level components—system, service delivery, outputs, and outcomes—and 11 key leverage points. The boundaries of the U.S. health system are defined differently across public health, health policy, and health services literature. The adaptation of the SLA for the U.S. took a broad, functional view that encompasses public health and health care, including the governance, financing, regulation, and delivery of services by public, private, and non-profit actors. Within each component is a set of indicators to assess gaps, highlight access issues, and identify progress for people with IDD.

## DATA COLLECTION AND ANALYSIS

To implement these assessments, country and global teams reviewed primary sources, such as policy documents and national datasets; conducted desk reviews of relevant secondary research; and convened stakeholders, including people with IDD, caregivers, health care workers, and public officials. Because in the U.S. health-related responsibilities are distributed across federal, state, and local governments and numerous payers, providers, and other organizations, relevant information was fragmented across multiple sources. Publicly available information was particularly limited or difficult to synthesize for privately financed or administered arrangements.

In addition to the findings from the System Level Assessments in the 11 sites, with a focus on those in the United States, this report also draws on other existing literature, as well as case studies of people with IDD's lived experiences, and promising practices, many of which were identified through the SLAs. It

also includes the survey responses of 70 health care workers from 26 U.S. states.

In addition, over 230 people with IDD from the United States responded to a universally designed survey that was co-developed alongside three individuals with IDD (from the U.S., the United Kingdom, and Zimbabwe) who worked as consultants for SOI.<sup>17</sup>

This report has been adapted from a global report, *Focusing on the Invisible*, which was developed with input from a global group of Special Olympics athletes as well as an Editorial Review Group comprised of representatives from the community working on disability and health issues globally.<sup>18</sup>

# STRUCTURE OF THIS REPORT

The relevant indicators (from the SLA) were clustered to develop this report's four sections:



**Governance,  
Leadership, and  
Engagement**



**Person-Centered  
Care**



**Health Care and  
Public Health  
Workforce**



**Data for Monitoring  
and Research**

Each section contains recommendations that, if implemented, would take the targeted actions further in terms of ensuring health systems strengthening activities also benefit people with IDD. The recommendations in this report are focused on health systems at large and do not cover diagnosis-specific responses.

# GOVERNANCE, LEADERSHIP, AND ENGAGEMENT

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**People without IDD may take for granted the relative ease with which they interact with processes and access services that meet their needs. As illustrated by the infographic in the introduction, this is not true for those with IDD. Laws, policies, and processes that are conceived of and enacted within the context of an exclusive framework are bound to perpetuate exclusion.**

The United States is one of the few countries worldwide that has not ratified the United Nations Convention on the Rights of Persons with Disabilities, which enshrines the rights to participation and to health, among many others.<sup>19</sup> Federal legislation including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Patient Protection and Affordable Care Act (ACA) contain provisions that promote similar principles of non-discrimination and access to health services. Despite these robust legal protections, gaps in the implementation of these protections and realization of the rights continue to exist for people with disabilities, including people with IDD, in the health sector.

This section will explore the extent to which the needs of people with IDD are reflected in policies of the states where the System Level Assessments were completed, recognizing that gaps between policy and practice are common and significant. Also contained in this section is a discussion of ways in which people with IDD are engaged, as individuals or through disability-led and self-advocacy groups, in leading or shaping the health sector in these jurisdictions. “The motto ‘nothing about us without us’ resonates with the philosophy and history of the disability rights movement, which relies on the principle of meaningful participation.”<sup>20</sup>

# LAWS AND POLICIES IN PLACE TO ENSURE THE RIGHT TO HEALTH FOR PEOPLE WITH IDD

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Some of the countries where the SLAs were completed have positive rights traditions, meaning that the government may be required to take action to make rights a reality.<sup>21</sup> This is in contrast to the United States, whose legal tradition mostly focuses on prohibiting active wrongs by the government and other parties, rather than compelling these actors to act a certain way.<sup>22</sup> Often characterized as a “freedom from” approach to rights, typically the U.S. government is not required to provide services of different kinds—for instance, health services—but, if it decides to provide them, it must do so without discrimination.<sup>23</sup> However, the ADA defines discrimination to include failures to make reasonable modifications or take steps necessary to ensure that individuals with disability are not “excluded, denied services, segregated or otherwise treated differently.” This recognition of a positive obligation to provide reasonable accommodations is a departure from the dominant approach in U.S. legal tradition and is well-documented in the ADA-related technical guidance.<sup>24</sup> In summary, as shown below, there is no widespread right to health in the US, but the ADA does require that ADA-covered entities take steps to eliminate barriers to access to services.

The following table highlights laws and policies identified through the SLAs, pointing out those that include reference either to IDD specifically or to disability more broadly. The graphic shows how health laws and policies vary in their inclusion of people with IDD. Lack of specific references, especially in national disease plans, can lead to their invisibility in health responses, as seen during the COVID-19 pandemic.

## LAWS AND POLICIES THAT MAKE SPECIFIC REFERENCE TO PEOPLE WITH IDD<sup>c</sup>

|                     | National or U.S. state law protecting right to health                                                                                                                                                                           | National or U.S. state policy or decree addressing health of persons with disabilities                                                                                                                            | National or U.S. state health sector plan                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | National or U.S. state disease plan                                                                                                                                                                                                                                                    | KEY                                                                                                                                      |
|---------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------|
| USA<br>Federal      |                                                                                                                                                                                                                                 | The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act both address the health of persons with disabilities. They are complemented by administrative guidance (policy) and case law. | The United States does not necessarily have a health sector plan as may exist in other countries. Within Healthy People 2030, a ten-year goal-setting initiative within the Office of Disease Prevention and Health Promotion within the Federal Department of Health and Human Services, some of the 507 objectives are specific to people with IDD and others to people with disabilities generally; however, the specific mentions of people with IDD are narrow to the context of (de)institutionalization.                                                                                                                                                                                                                                                | Most disease-specific plans in the United States include indicators related to disparities, including for people with disabilities. The National Plan to Address Alzheimer's Disease includes various actions related to those with IDD, in general, and Down syndrome, in particular. | Specific mentions of people with IDD (stripes indicate a disability-specific document)                                                   |
| USA<br>Pennsylvania | The Mental Health & Intellectual Disabilities Act of 1966 requires the State assure the availability and equitable provision of adequate mental health and intellectual disability services for all who need them. <sup>d</sup> |                                                                                                                                                                                                                   | <p>The State Health Improvement Plan, Pennsylvania Department of Health, 2023-2028 makes mention of people with disabilities as among those at increased risk and whose needs for each goal will be addressed through individual strategies.</p> <p>The Pennsylvania Developmental Disabilities Council 2022-2026 State Plan included quality health care as an objective within Goal 2: Social and System Change.</p>                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                        | Refers to people with disabilities in general, but not specifically to people with IDD (stripes indicate a disability-specific document) |
| USA<br>Washington   |                                                                                                                                                                                                                                 |                                                                                                                                                                                                                   | <p>Washington State is currently developing its 2025-2030 State Health Improvement Plan. The previous iteration did not mention people with disabilities.</p> <p>The Washington State Developmental Disabilities Council 2022-2026 State Plan contains two health-related objectives: on supporting people with co-occurring IDD and mental health challenges and on enhancing the public health workforce.</p>                                                                                                                                                                                                                                                                                                                                                | Recognizing that state health improvement plans tend to integrate characteristics of a health sector plan (a separate indicator) and state disease plans, the existence of disease plans was not assessed at the state level.                                                          | Exists, with no reference to people with disabilities at all                                                                             |
| USA<br>Wisconsin    |                                                                                                                                                                                                                                 |                                                                                                                                                                                                                   | <p>The Wisconsin State Health Improvement Plan, 2023-2027 (Implementation Guide) refers to people with disabilities in multiple places, including increasing access to the Birth to Three program for children with disabilities. People with IDD are mentioned only as part of a partnership landscape related to supporting the delivery of mental health and substance use prevention and treatment services that meet the unique needs of all Wisconsinites.</p> <p>Health was not an explicit part of the Wisconsin Board for People with Developmental Disabilities State Plan, 2022-2026. However, the plan's priorities include improving access to supports and to public services and public programs, of which health would be a prime example.</p> |                                                                                                                                                                                                                                                                                        | None identified                                                                                                                          |
|                     |                                                                                                                                                                                                                                 |                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                        | Not assessed                                                                                                                             |

<sup>c</sup>SOI recognizes that some laws and policies may address IDD using other terminology, such as mental disabilities and psychosocial disabilities, as well as other, outdated terminology that is considered offensive. The colors in this table take into account specifically the terms “intellectual disabilities” or “intellectual and developmental disabilities.” Attempt has been made to mention where other terminology that may be or have been relevant to referring to people with IDD is used.

<sup>d</sup> Before the late 20th century, the scientific and health care communities often conflated people with intellectual disabilities and psychiatric conditions into a single category, leading to both being addressed under the same framework and with the same treatments, which included institutionalization, restraint, punishment, and overmedication ([Lunsky et al., 2021](#)). When intellectual disability later came to be recognized as distinct from psychiatric conditions, another misconception persisted: that people with intellectual disability could not also experience mental health conditions. As a result, emotional distress, behavioral changes, and psychiatric symptoms were often attributed to the intellectual disability itself rather than recognized as signs of a co-occurring mental health condition, a phenomenon now known as diagnostic overshadowing. Recognition of what is now termed a "dual diagnosis" did not begin to emerge until the 1970s and later ([Bongiorno, 1996](#); [Bradley et al., 2019](#)).

In contrast to many other countries, the United States has legislation, policies, institutions, and funding—namely those flowing from the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)—specifically focused on people with IDD. As part of the move towards deinstitutionalization, health system governance in the U.S. developed Medicaid waivers that allow the provision of home- and community-based services (HCBS).<sup>25</sup>

As is discussed further in the next section, HCBS is an integral way through which people with IDD can access a range of services they need to be as healthy as possible. A downside of this approach, which may be experienced by the 40%+ of people with IDD who do not receive HCBS, is that the health system recognizes people with IDD primarily through eligibility for disability programs rather than as a population whose health outcomes should influence mainstream health policy that affects all people with IDD. The result curtails the access to needed services for people with IDD who do not receive HCBS—a population that numbered between 283,000 and 711,000 in 2024.<sup>26</sup>

U.S. preventive health policy routinely differentiates screening recommendations and corresponding coverage on the basis of factors such as age, sex, and elevated disease risk.<sup>27</sup> Recent breast cancer policies, for example, require coverage not only of screening mammography but also additional imaging, pathology services, genetic counseling, and patient navigation for certain populations.<sup>28</sup> Despite well-documented differences in health risks and health care needs among people with IDD, governance mechanisms within the broader health sector have been slower to incorporate these differences into the standards, quality measures, financing arrangements, and accountability structures that shape health care delivery.

### **Promising Practice – Streamlined Processes for People with IDD to Access Expanded Coverage**

Pennsylvania has implemented a good practice to streamline the process by which individuals could obtain dental care beyond the basic benefit limits. As a result of this change, individuals with intellectual disabilities, or four other qualifying conditions, no longer need to present additional documentation to support a Benefits Limit Exception.<sup>29</sup>

Furthermore, the needs of people with IDD have not historically been well-represented in aspects of health system governance related to quality measurement and accreditation. The National Committee for Quality Assurance (NCQA) and Joint Commission accreditation standards provide intermediate governance. Through their role defining standards, measures, and accreditation requirements against which organizations are assessed, they shape health system behavior. NCQA and the Joint Commission both incorporate disability within broader umbrellas, such as equity, and NCQA recently went a step further to incorporate an expanded set of considerations related to reasonable accommodation and accessibility into their Health Outcomes Accreditation.<sup>30</sup> New in 2026, the reach and impact of the standards within this accreditation are yet to be seen.

The United States has strong governance, including policies and institutional mechanisms, for the inclusion of people with disabilities. This exists largely separate from the health system, which may limit its effectiveness. Furthermore, these advances have not always been accompanied by or translated into incorporation of people with IDD within the institutions and processes that shape health system priorities, quality standards, reimbursement policies, and accountability.

## FORMAL PROCESSES FOR ENGAGING PEOPLE WITH IDD AND THEIR REPRESENTATIVE ORGANIZATIONS IN HEALTH POLICY MAKING

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Creating equitable health policies requires intentional inclusion of people with IDD in policy development processes. Their participation in monitoring policy implementation is also crucial to continuing to steer towards equitable objectives. People with IDD are severely underrepresented in public office and other positions of influence, reflecting a long history of institutionalization, social exclusion, and persistent stigma.<sup>31</sup> The exclusion of people with IDD from policymaking serves to perpetuate the invisibility of this community and its needs.

People with IDD may, like other people with disabilities, participate in policy processes in their individual capacity or through a disability-led or self-advocacy group—through formal institutional arrangements, programmatic partnerships, advisory roles, public comment periods, or advocacy, to name a few options. At the federal level, the United States Department of Health and Human Services (HHS) includes the Administration for Community Living (ACL) which, “is structured to provide general policy coordination” alongside specific programs for its various focus populations.<sup>32</sup> At the time the assessment was completed, ACL convened or supported various groups that included lived experience experts, including the President’s Committee for People with Intellectual Disabilities.<sup>33</sup> In addition to being housed within HHS, ACL’s objectives specifically include

and extend beyond health: “...to enhance access to quality health care and long-term services and supports for older adults and people with disabilities; to promote consistency in community living policy across other areas of the federal government; and to complement the community infrastructure, as supported by both Medicaid and other federal programs, in order to better respond to the full spectrum of needs of seniors and persons with disabilities.”<sup>34</sup>

State-level executive mechanisms also exist, such as the Governor's Committee for People with Disabilities in Wisconsin, the recently reconstituted Governor's Advisory Commission on People with Disabilities in Pennsylvania, and the Governor's Committee on Disability Issues and Employment in Washington, which has sought to formalize its active involvement in the Governor's Interagency Council on Health Disparities via mandated participation.<sup>35</sup>

At the state level, in every state, Developmental Disabilities Councils provide a formal outlet for people with IDD to participate in advocacy related to policy making. The DD Act mandated the creation of these Councils and requires that people with DD, and certain family members and guardians of people with DD comprise at least 60% of the Council membership.<sup>36</sup> The balance of the membership is supposed to be comprised of representatives of state agencies and partner organizations; in the states examined, at least one state-level health-related agency was represented.<sup>37</sup> This type of arrangement may promote aligned policy development across agencies; however, the SLAs uncovered limited indication that permanent mechanisms for engaging organizations of or individuals with disabilities exist *within* the health sector. This may perpetuate an idea that the needs of people with

disabilities can only be addressed by specialized means, rather than by focusing on improving the inclusivity of the systems that serve the general population. Furthermore, the influence of people with disabilities through these formal mechanisms on core health policy decisions is limited or, at a minimum, diffuse and difficult to track.

## Promising Practice – Nothing About Us Without Us Act

In 2024, the legislature of Washington passed the Nothing About Us Without Us Act (Washington State Legislature, HB 1541, 2024). It requires that all state task forces, work groups, and advisory committees working on issues affecting underrepresented populations include at least three individuals with direct lived experience with the issue.<sup>38</sup> The IDD advocacy community in Washington was quite active in the development and passage of this unique legislation.<sup>39</sup>

Whether people take part as individuals or through disability-led and self-advocacy organizations, representation alone is not enough. Meaningful participation in the creation and implementation of health policy requires adequate resourcing to provide the reasonable accommodations already protected by law. For people with IDD, the most crucial of these are typically accessible information and documentation, individual support people with adequate training, and group facilitators skilled at working with neurodiverse groups.

# RECOMMENDATIONS

Strengthening health systems to better meet the needs of people with IDD requires that they be meaningfully involved in policymaking and their needs be made visible in policies, as promoted by the following recommendations:



## **Support Public Awareness of and Advocacy by People with IDD**

Implement campaigns, developed with and by people with IDD, that promote positive images of people with IDD and make visible the health inequities that are often unseen, as well as their causes. Invest in building the capacity of people with IDD for meaningful participation, representation, and inclusion in public initiatives promoting awareness and realization of their right to health.



## **Mandate Formal Representation and Needed Accommodations for Participation of People with IDD in Health Policymaking**

Guarantee the formal representation of people with IDD and their organizations in national, state, and local health policy processes. Ensure accessible documentation and spaces and provide trained facilitators and support people to foster meaningful engagement of people with IDD.



## **Ensure that Federal and State Health and Related Policies Account for the Needs of People with IDD**

Governance structures should require disability inclusive policy design so that access to services and supports appropriate to the needs of people with IDD—including those that differ from the general population—does not depend on whether a person is enrolled in Medicaid HCBS.

# PERSON-CENTERED CARE



Effectively meeting the needs of people with IDD and moving towards health equity requires shifting from a purely medical approach to one that respects their individuality, dignity, and active participation in their own care. While some aspects that contribute to poorer health and comparatively higher premature mortality of people with IDD are the result of congenital or genetic risk factors, a non-negligible proportion of this population's vulnerability to disease is related to the social context in which they live.<sup>40</sup> For example, people with IDD who live in congregate settings—which include 8% who live in institutions (defined as housing 7 or more people) and 15% who live in group homes (defined as housing 6 or fewer people)—may have little control over their nutrition or living spaces.<sup>41</sup> Because they may not be able to decide what they eat or how close they are to others in such settings, people with IDD can face a greater risk of communicable and non-communicable diseases, as evidenced during the COVID-19 pandemic.<sup>42</sup>

The ADA, passed in 1990, promotes dignity, autonomy, non-discrimination, full inclusion, and accessibility.<sup>43</sup> The DD Act of 2000 further promotes “individualized supports” and “consumer- and family-centered, consumer- and family-directed” services.<sup>44</sup> The ACA endorses similar principles, and in 2014, the Centers for Medicare and Medicaid Services (CMS) published final rules explicitly requiring person-centered planning as part of HCBS.<sup>45</sup> While one estimate indicates that less than half of people with IDD receive paid supports through their state

IDD agency, another found that over 60% of adult Medicaid enrollees with claims for autism, intellectual disability, and Down syndrome used HCBS in 2022.<sup>46</sup> Regardless of the estimate used, a substantial proportion of people with IDD are not connected to HCBS. As a result, the realization of person-centered care for people with IDD cannot depend exclusively on HCBS and other disability-service systems, and it must also be reflected in the broader health system.

This section focuses on policy or implementation gaps related to person-centered approach, that the System Level Assessments surfaced as particularly relevant and lacking for those with IDD.

## John

I'm John. I live in Pennsylvania and have Asperger's syndrome. I have been a Special Olympics athlete for more than 10 years—I am a basketball player and a bowler. I also work part-time at a convenience store near my home. I live in a big city and have a lot of support, including my mom and a local non-profit organization that helps with my services. Still, I have had a hard time finding doctors and especially dentists who understand and can meet my needs when I get care.

When I visit my primary care doctor, short appointments make me feel rushed and anxious. I feel and do my best when a doctor takes time to explain things step-by-step and check if I understand. I want an environment that treats me as a whole person, offering extra time for explanations, a quieter waiting room, or simple reassurance before a procedure.

Going to the dentist is particularly hard for me. The bright lights, unfamiliar tools, and loud equipment are overwhelming. But I know it's important for me to go. My mom and I spend a long time working with insurance, calling around, and traveling so that I can get dental service with sedation like I need. I want decision-makers to not think of things like sedation dentistry as 'extras', because they are necessary for some people, like me.

## ACCESSIBLE AND AVAILABLE HEALTH SERVICES

Despite national frameworks regarding accessibility and efforts to improve access to health for people with disabilities, inequitable access to health services and poorer quality of care persist.

As stated in a December 2025 study by the U.S. Government Accountability Office: "People with disabilities may encounter barriers related to accessibility in the U.S. health care system; these barriers can affect the quality of their care."<sup>47</sup>

Many of the difficulties people with IDD face in accessing health services are consistent with those confronted by the broader community of people with disabilities and by people of lower socio-economic status more generally. People with IDD point to fear and embarrassment—including fear of physical examination, fear of needles, or concerns over discrimination by health care providers—as factors that prevent them from seeking care or following through with recommended health services.<sup>48</sup> Furthermore, while 92.8% of the 236 people with IDD in the U.S. who responded to the SOI survey know where to go when they are sick and have a place to go for care, 60.2% who responded to another question about support needs (N=206) said they need support to get to a health care provider.

## The System Level Assessments identified persistent policy gaps across two key elements of accessibility and availability:



### Guidance on Reasonable Accommodations

The Americans with Disabilities Act (ADA) applies to health care organizations that provide services to the public. The ADA mandates that health care organizations create reasonable modifications of policies, practices, and procedures to accommodate the needs of individuals with disabilities, use communication modalities that can be understood by individuals with disabilities, and ensure physical accessibility of facilities.

The ADA applies to individuals with all types of disabilities, including IDD. However, in practice, little attention from federal agencies and policymakers has focused on how the ADA provisions should be interpreted to apply to individuals with IDD specifically in the health care context. Neither the U.S. Department of Justice nor the Office for Civil Rights at the U.S. Department of Health and Human Services maintains written interpretive guidelines on this topic. For example, communication may be an area in which individuals with IDD would benefit from health care facilities' use of clear guidelines; however, ADA guidelines on communication, including guidance issued by the ADA National Network, primarily focus on ensuring accessibility for individuals with mobility or sensory impairment and on use of universal accessibility symbols in posted signage.

No additional state-level legislation or general policy guidance was identified in the states examined. However, state-level contracts reinforce the obligations of service providers to provide accessible services and reasonable accommodations.<sup>49</sup>



### Provider Incentives and Supports

Short appointment times are a key barrier to quality health care for people with IDD, as provider reimbursement structures often disincentivize longer consultations. U.S. health care workers identified insufficient incentives to care for people with IDD as a significant challenge. Nearly three-quarters of the 70 respondents (74.3%, n=52) rated provider incentives as a significant or key challenge, while 76.5% (N=68) supported enhanced provider assistance, including increased payments. Respondents also overwhelmingly supported longer consultation times (97.5%, N=67), suggesting that current financing and care delivery structures may not fully support the time required to provide quality care for people with IDD.

## Marisa

I live with my best friend in a community home in a town near Pittsburgh, Pennsylvania. The staff at my community home help me with reminders to stay on track with healthy eating, exercise, and taking my vitamins and medications. I lift weights and walk for exercise. Living near my mom is really important for my health since she helps out a lot. I have some health issues, like with my heart and my hearing and arthritis. That means I have to see a lot of different doctors. Every year, I see my gynecologist, primary doctor, and cardiologist. I also see my foot doctor, eye doctor and hearing aid doctor. Every year, I get my flu shot and Covid shot and mammogram.



In April 2026, I fainted and my staff called for the ambulance. My staff rode with me in the ambulance to the emergency room. Staff called my mom and dad and they came to the hospital. I stayed for two days, and my mom stayed with me the whole time. The doctors told me that I had pneumonia, and I have been on oxygen since then. I have a big oxygen concentrator at home and a portable one for when I leave the house. The portable one has two batteries so I can go to church, shopping, and out for dinner. I need the oxygen all the time.

Before the pneumonia and oxygen, I worked part-time at a local grocery store (I worked there more than 25 years), volunteered at a food pantry, and played golf with Special Olympics.

Now, all of my doctors (except one) work at the same hospital. They have a portal with all my information, and I can look at it too. This helps the doctors keep track of my medical care. They don't always talk to each other, but they ask me questions and listen to me. I also ask them questions sometimes. My mom helps keep some of the information they need so that I don't get confused. I like when my doctors are patient and listen to me. Sometimes, I need them to repeat things because I have hearing aids. I like all my doctors and hope I don't need to be on the oxygen forever. I want to play golf!

## Beyond the policy gaps, the assessments further identified important implementation gaps:



### Care Coordination

Care coordination is within the scope of a variety of roles throughout the U.S. health care delivery system. However, availability of care coordination differs across and within different states and contexts.

The federal Medicaid program encourages care coordination in various ways, in order to control costs and improve quality for beneficiaries. For example, the ACA created an optional state Medicaid plan benefit establishing "health homes" for people with certain chronic conditions. States can apply to CMS to amend their state Medicaid plan to receive a 90 percent enhanced federal match for the establishment of health home services. Health homes integrate physical and behavioral health services (both mental health and substance abuse) and long-term services and supports for high-need, high-cost Medicaid populations. States may target health home services to individuals with: (1) two chronic conditions; (2) one chronic condition and risk for a second; or (3) a serious mental illness. Health home services can include comprehensive care management, care coordination, transitional care, and referrals to community and social support services.

States may, but do not have to, offer health home services as part of their state plan, which sets out the services that traditional Medicaid enrollees in the state can receive.<sup>50</sup> States may also offer these services through waivers, which have different, typically more restrictive, eligibility requirements than Medicaid state plan services.

As of October 2025, 19 states (including Washington and Wisconsin) and the District of Columbia offered health home services. Only seven of these locations considered IDD to be a qualifying condition and specified that qualification for health home services required that a person with IDD have, or be at risk for, a second qualifying chronic condition.<sup>51</sup>



## Transport Subsidies

In recent analyses, approximately one-third to one-half of people with IDD were insured through Medicaid.<sup>52</sup> Medicaid's Non-Emergency Medical Transportation (NEMT) benefit is a mandatory benefit to ensure access to medically necessary care.<sup>53</sup> Unfortunately, many challenges persist with respect to wait times, trip denials, missed pickups, and communication barriers.<sup>54</sup>

At the state level, it is common for public transit providers to offer discounts to people with disabilities, as in Pennsylvania's Persons with Disabilities Half-Fare Program. Federal law requires agencies that receive certain federal funds to provide such discounts, though the definition is relatively narrow and could be interpreted to exclude those with IDD.<sup>55</sup> Some states also offer and/or fund additional transit programs, such as Pennsylvania's Persons with Disabilities Program, Washington's Dial-A-Ride, and Wisconsin's County Elderly and Disabled Transportation Assistance. Across the board, here, too, implementation is widely variable with the same issues of wait times, trip denials, missed pickups, and communication barriers that affect NEMT.<sup>56</sup> Furthermore, individuals who may provide support to people with IDD are not necessarily eligible for subsidized transportation, which can make transport subsidies less effective at addressing transportation barriers to health care for people with IDD.<sup>57</sup>

One area where policy has advanced is access to health information. As of 2024, federal regulations for Title II of the ADA require states to adhere to Technical Standard Web Content Accessibility Guidelines (WCAG) 2.1, Level AA standard, at a minimum. Users with cognitive or learning disabilities—a group that includes many people with IDD—were one of three groups for whom WCAG 2.1 sought to improve accessibility guidance, vis-à-vis WCAG 2.0. However, it is difficult to assess the real-world impact of these requirements because health information is dispersed across numerous websites and service platforms, making accessibility difficult to evaluate consistently at a systems level.

Taken together, many obstacles, including complex and uncoordinated systems of care, physically and sensorially inaccessible health settings, and (likely) inaccessible health information impede person-centered care and make it difficult for people with IDD to take charge of their own health. One idea to help move toward a person-centered approach is the use of patient navigators. Patient navigators provide a “bridge” between a person with IDD and the system—or, more likely, multiple systems, programs, and providers with whom they need to interface.<sup>58</sup>

Another strategy for promoting person-centered care is health care or hospital passports. Health care or hospital passports are patient-held documents that consolidate an individual's critical health information, including medical history, medications, sensory preferences, and communication strategies.<sup>59</sup> These documents are not in use everywhere, and they are not always used appropriately. For instance, providers do not always take the time to review them.<sup>60</sup> Nevertheless, by providing an alternative means for health care workers to understand and effectively address the needs of people with IDD, such documents help promote patient safety by addressing communication barriers that may limit access to appropriate health services for people with IDD.



### **Health Passports**

With the support of SOI, the Jefferson Center for Autism and Neurodiversity piloted the use of health passports for people with IDD in the form of a patient-controlled mobile (cell phone) app initially developed in Ireland. The app supported patients to communicate important health information, identify preferences and support needs, and request accommodations. The first phase of the pilot consisted of qualitative semi-structured interviews with eight people with IDD and nine support people, recruited from throughout the Philadelphia area, between April and September 2025. The second phase involved a national quantitative survey that was completed by eight people with IDD, 12 support people, and 19 providers from October to November 2025. Individuals with IDD, support people, and providers collectively felt that the app met their needs, felt user-friendly, seemed practical and feasible to integrate into health care visits. Participants believed it could enhance communication, increase autonomy and self-advocacy, improve care quality, and support more patient-centered care.

Participants also felt it filled an important gap in health care, particularly for visits with new providers, transitions in care, and emergency situations. Key areas for improvement included integrating the health passports into electronic medical records, enabling information sharing across devices, adding sections for emergency contacts and communication needs, allowing users to upload health documents and insurance information, and incorporating a calendar for upcoming appointments.



### **Disability Status and Accommodation Needs in Electronic Health Record**

Pursuing similar goals as a health passport, the University of Colorado Department of Family Medicine piloted the use of a paper-based questionnaire intended to document disability status and accommodation needs for inclusion in electronic health records across the UCHealth system. The questionnaire, which asked six yes/no questions about functional limitations, was based on census questions and received feedback from individuals with IDD. The questionnaire also included a checklist of available resources offered by the clinic to meet accommodation needs, such as sound amplifiers, magnifiers, communication boards, signature guides, clear masks, gait belts, and wheelchairs. If a patient self-identified as having an IDD based on the questionnaire, clinic staff would place a sunflower symbol outside of the patient's room to discreetly alert staff that a patient had an IDD and might require accommodations.

With approximately 2,250 questionnaires administered in one clinic and a completion rate of over 95%, evaluation of this pilot demonstrated increased documentation of disabilities and accommodation requests in electronic health records. Within a four-month window of implementing this new workflow at the clinic, the proportion of patients documented as having any disability increased from 3.8% to 5.3% and accommodation requests increased from 2.7% to 3.0%; no significant changes were observed in clinics that had not yet implemented this workflow during the same period. Furthermore, patients with and without disabilities reported that they appreciated how providers proactively inquired about disabilities and accommodations rather than requiring patients to repeatedly advocate for themselves. The hope is that the pilot findings and patient feedback will help support UCHealth to build the questions into the electronic health record-driven check-in processes and send them to all patients at least annually.

Making disability status and accommodation needs visible to the health care workforce supports a more accessible, person-centered approach. It enables proactive accommodation planning, improves the identification of people with IDD, facilitates the timely accommodations, and helps ensure that people with IDD are represented in quality improvement efforts.

## AGENCY, SUPPORT, AND DECISION-MAKING

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The exclusion of people with IDD from decision-making regarding their own health is yet another example of their invisibility.

“Involvement in healthcare decisions is associated with better health outcomes for patients.”<sup>61</sup> Among the survey respondents with IDD in the U.S. who responded to the question (N=183), over one-third (38.4%) reported that they make their own decisions about their health, 36.8% said they do sometimes, and 24.9% said they do not make their own decisions. To a separate question, the vast majority of the 184 people with IDD who responded (85.3%) reported having someone who helps them with health care decisions, while 14.7% said they do not.

There are several related ways in which laws affirm or deny the ability of people with IDD to make decisions for themselves. First, laws can explicitly remove the legal capacity of people with IDD, meaning that they are not legally allowed to make decisions for themselves, including those related to their health. Laws that automatically or categorically have this effect are rooted in negative assumptions about the decision-making abilities of people with IDD. They typically transfer full authority to guardians, who may or may not involve the individual with IDD in decisions about their own life. While categorical deprivation of this kind used to exist in the U.S., this is no longer the case.<sup>62</sup>

Next are situations in which legislation may not categorically strip people with IDD of legal capacity but permits others to seek this same effect on a case-by-case basis. For example, each of the states in the United States—including the three where SLAs were conducted—have a guardianship law in place.<sup>63</sup> One study found that an average of 40% of people with IDD in a U.S. sample of over 25,000 people with IDD had a guardianship arrangement, while another study estimated that over 1 million Americans with IDD are under guardianship.<sup>64</sup>

Some jurisdictions are beginning to propose supported decision-making alongside laws that continue to permit other approaches. As of 2021, laws in nearly one-quarter of U.S. states specifically mentioned supported decision-making, despite the vast majority of states requiring courts to consider less restrictive options for shared or substitute decision-making.<sup>65</sup> Two of the three U.S. states where SLAs were completed—Washington and Wisconsin—explicitly enable or promote supported decision-making.<sup>66</sup> The law of the third—Pennsylvania—requires consideration of less restrictive alternatives to guardianship, without promoting supported decision-making.<sup>67</sup>

Nevertheless, laws that deprive people with IDD of legal capacity are not the only barriers to inclusion in health decision-making.

## Renee

My name is Renee Manfredi and I am 40 years old. My dad is a service member, so my family has moved a lot during my life. I have lived in six different states and overseas.

When I was younger, I did not feel comfortable at the doctor's office. Doctors would often ask a lot of questions very quickly, and I did not always know how to respond. Sometimes appointments felt rushed, and when I felt overwhelmed, I would shut down and stutter instead of speaking up. I remember one doctor being very abrupt and rude because he did not recognize that I had a disability. After he left the examination room, my mom pulled him aside and explained that I had an intellectual disability and needed more time to process information and answer questions. Once the doctor understood that I had autism, the interaction improved.

This is a challenge I often face when accessing health care because my disability is not visible. When I walk into a room, people often assume I do not need any support. But when I find myself at a loss for words, hesitate, or look to my mom for help, they can become confused or frustrated. My mom is able to explain my needs and provide important context that doctors and other health care providers might otherwise miss.

When I was 26, my parents and I jointly made the decision to pursue guardianship to help me feel safe and confident while navigating health care situations. At that time,

supported decision-making was not as widely recognized, understood, or available as it is today. With our frequent moves, we wanted to make sure I would have consistent support, like someone in the room with me so that providers could also give information to my parents. I wanted to have a voice in my health care no matter where we lived. At the time, guardianship seemed like the best option for our situation.

Over the years, a lot has changed. Supported decision-making has come a long way and gives people with intellectual and developmental disabilities more opportunities to direct their own lives while still receiving the support they need. I have changed too. Even though my parents are my guardians, they have always encouraged me to make my own health care decisions and speak for myself. I have grown into a strong self-advocate. I am much more confident speaking up about my health, asking questions, and sharing my concerns. Having my mom's support has been an important part of that journey.

I believe all people with IDD should have access to the support they need to make their own decisions, have their voices heard, and be empowered to advocate for themselves.



As Renee's story demonstrates, the absence of clear and widely adopted supported decision-making frameworks can leave individuals with IDD and their families navigating uncertainty about how best to secure both support and autonomy. Clear guidance, standardized protocols, and greater awareness of supported decision-making can help close this gap and reduce reliance on more restrictive alternatives.

Health decision-making is further complicated by the question of individuals' capabilities at different stages of life or moments in time. An approach that accounts for evolving capacity would best serve people with IDD, as an individual's ability to make decisions may change throughout his or her lifetime.

Legislation in effect in Ireland addresses these concerns about lack of guidelines and standardized protocols, as well as evolving capacity and may be a useful reference as states innovate toward validating and promoting supported decision-making.

## **Promising Practice – Assisted Decision-Making (Capacity) Act 2015**

Ireland's Assisted Decision-Making (Capacity) Act 2015 represents a global promising practice on this topic.<sup>68</sup> It includes a presumption of the capacity of everyone in Ireland. In order to enable people to make their own decisions, the Act has led to the creation of three types of decision-making agreements, which seek to provide support to those who may face difficulty in making decisions and outlines a functional test to assess capacity. An important feature of the test is that it acknowledges that capacity is not linear; the test may indicate that a person does not have capacity at one time but does have capacity at another stage. Finally, in order to implement the various elements of the Act, the Decision Support Service was created. This service made available a comprehensive list of protocols and codes of practice for various health professionals to comply with when individuals are deemed not to have the capacity to make their own decisions.

The effectiveness of all tools, resources, and systems related to supported decision-making must bear in mind the needs of the “end user” or intended decision-maker, lest the absence of reasonable accommodations and accessibility perpetuate exclusion.<sup>69</sup> Without such considerations, good practices for supported decision-making are not consistently implemented, and when information is provided, it is often filled with jargon, making it inaccessible, thereby perpetuating the exclusion of people with IDD from meaningful participation in their own care.<sup>70</sup>

The table below summarizes the System Level Assessment findings about how legal capacity is protected and that protection operationalized.

| LAW(S) TO PROTECT AND EMPOWER PEOPLE IN HEALTH DECISION-MAKING <sup>e</sup> |                                                                       |                                                                                                                    |                                   |                                                                                                                                    | KEY                          |
|-----------------------------------------------------------------------------|-----------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|-----------------------------------|------------------------------------------------------------------------------------------------------------------------------------|------------------------------|
| Law exists addressing legal capacity                                        | Law addressing legal capacity specifically references people with IDD | Law presumes capacity of those with IDD <i>and</i> 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 |                              |
| USA - Federal                                                               |                                                                       |                                                                                                                    |                                   |                                                                                                                                    | <div>Yes</div> <div>No</div> |
| USA - Pennsylvania                                                          |                                                                       |                                                                                                                    |                                   |                                                                                                                                    |                              |
| USA - Washington                                                            |                                                                       |                                                                                                                    |                                   |                                                                                                                                    |                              |
| USA - Wisconsin                                                             | <sup>71</sup>                                                         |                                                                                                                    |                                   |                                                                                                                                    |                              |

<sup>e</sup> SOI recognizes that some legislation may address IDD using other terminology, such as mental disabilities and psychosocial disabilities, as well as other, outdated terminology that is considered offensive. The colors in this table take into account specifically the terms “intellectual disabilities” or “intellectual and developmental disabilities.” Attempt has been made to mention where other terminology, that may be locally relevant to referring to people with IDD, is used. SOI further acknowledges the difficulty in capturing the complexity of health systems, who may divide responsibilities across different levels and actors. Therefore, this heatmap represents a sketch, rather than a complete picture.

# RECOMMENDATIONS

Person-centered care, by definition and for all people, encompasses a wide range of considerations. Recommendations that are more salient to people with IDD, and therefore often not considered, include:

## Strengthen and Implement Supported Decision-Making



Embed, through legal and policy frameworks, supported decision-making as the default model, to guarantee that people with IDD can actively participate in health decision-making. Enabling policies and resources for supported decision-making include: (a) guidance and training for people with IDD and support people to understand supported decision-making, (b) plain language materials, visual aids, lists of benefits and risks, and other tools for people with IDD and support people to use in supported decision-making,<sup>72</sup> (c) guidance and training for health care workers and judicial officers (also involved in determining capacity), and (d) institutional infrastructure to supervise those who are supporting the decision-making and connect people who require support to people who can provide it, as in the Decision Support Service in Ireland.<sup>73</sup>

## Establish Patient Navigators



Ensure policies and accommodations go beyond the traditional focus on physical accessibility. People with IDD often have complex health or other needs that require coordination through the health system and sometimes linking with other sectors. Health systems should establish a patient navigation function to bridge gaps between people with IDD and providers and ensure access to appropriate care and resources; this could be achieved through training of existing health care workers or creation of a new cadre.

## Improve Quality and Continuity of Care with Accommodations Focused on Communication



Adopt and standardize the use of health/hospital passports, extended appointment times, and other accommodations that help improve care by improving communication. Health care workers should be enabled, empowered, and appropriately incentivized to have longer appointments with people with IDD, as well as provide accommodations, such as prioritizing those with IDD to shorten wait times in unfamiliar environments. Governments and health institutions must ensure widespread implementation and training on the use of these accommodations to ensure their acceptance and uptake.



### Improve Health Literacy among People with IDD

Provide health education and information in accessible formats for people with IDD to enhance health literacy, promote autonomy, and improve health outcomes. This should include resources in Easy Read<sup>74</sup> and plain language audio formats, materials developed using universal design principles, and health education that addresses unique learning needs—all approaches that likely benefit populations well beyond those with IDD.

## Michele

I live in the state of Washington, in the United States. Recently, I was diagnosed with type 2 diabetes. At the appointment, the doctor didn't ask how I prefer to communicate. He talked a lot about how diabetes would affect my life, but it felt rushed. He didn't use any visual aids or stop to make sure I understood. I left feeling overwhelmed and worried about making mistakes.

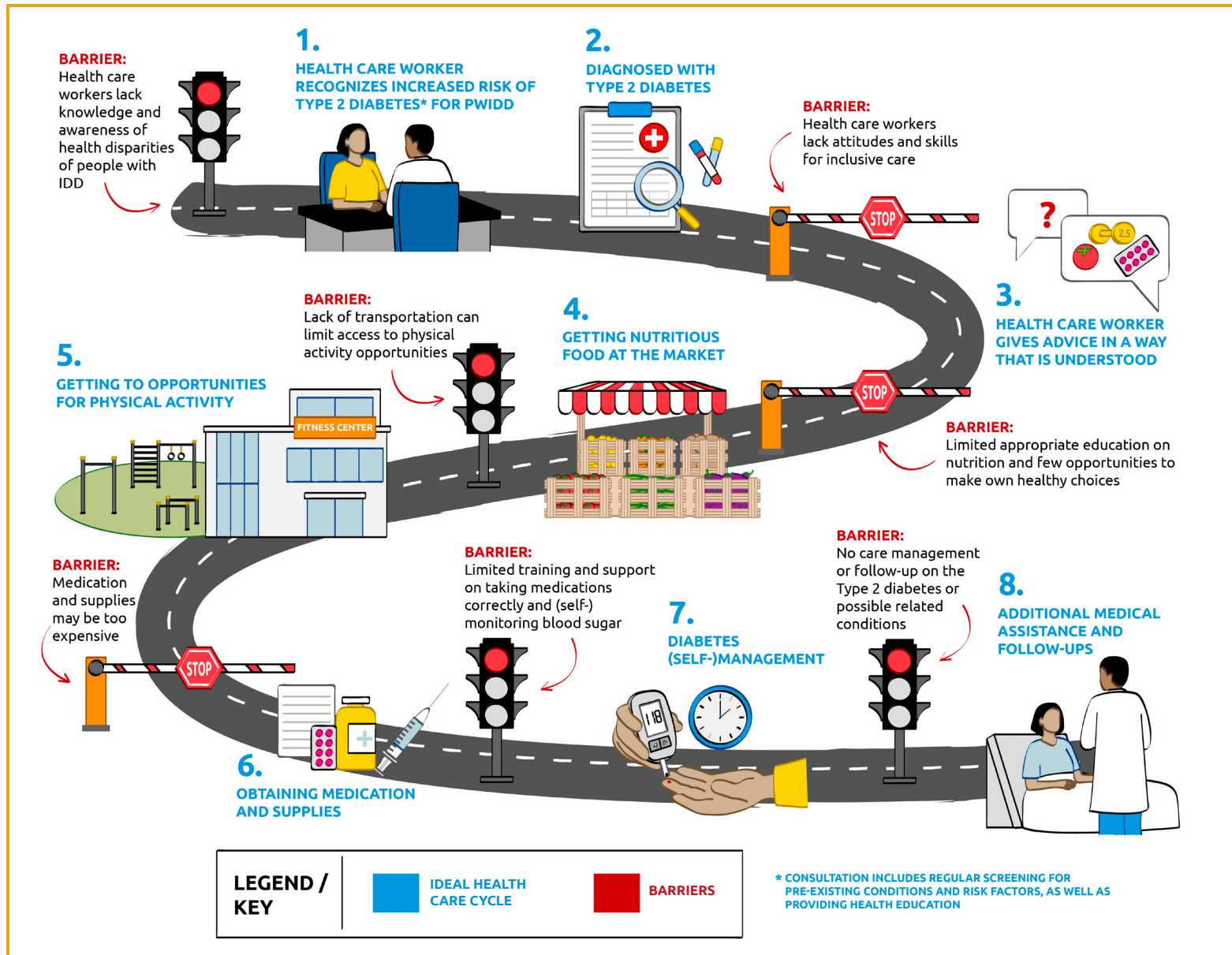
I caught a few of the recommendations—he said I needed to exercise more, eat small meals every three hours, and follow a low-sugar diet. He also suggested a diabetic drink, but my first thought was, “How am I going to afford that? I don't even know if my insurance will cover it.”

Also, there's no fitness facility nearby where I live. The closest one is over 20 minutes away, and since I don't drive and there's no public transportation here, getting there is impossible.

I want to follow the doctor's advice, but it's tough. No one checks in to see how I'm doing or if I need help, and it feels

like once I leave the office, I'm forgotten. I sometimes need extra guidance and reminders to stay on track, but there's no system in place to provide that support.





# HEALTH CARE AND PUBLIC HEALTH WORKFORCE



The lack of systematic training for the health care and public health workforce is central to the challenges that people with IDD face in the health sector.<sup>75</sup> This pertains not only to clinicians, such as doctors and nurses, but also to health care workers more broadly, including community health workers, non-medical staff working in the health sector, social workers, psychologists, and other direct care providers working in interprofessional collaboration.<sup>76</sup>

Many health care and public health workers enter the workforce with little or no preparation to address the needs of people with IDD. These unseen needs perpetuate a cycle of inequity, as providers lack the tools and resources needed to provide adequate health services for people with IDD.

This section will explore the critical need for training programs that equip health care workers to better serve individuals with IDD. It also highlights examples of progress, proposes recommendations for inclusive training curricula, and underscores the importance of building a workforce that is skilled, compassionate, and inclusive.

## TRAINING IN ADDRESSING THE WIDE-RANGING NEEDS OF PEOPLE WITH IDD

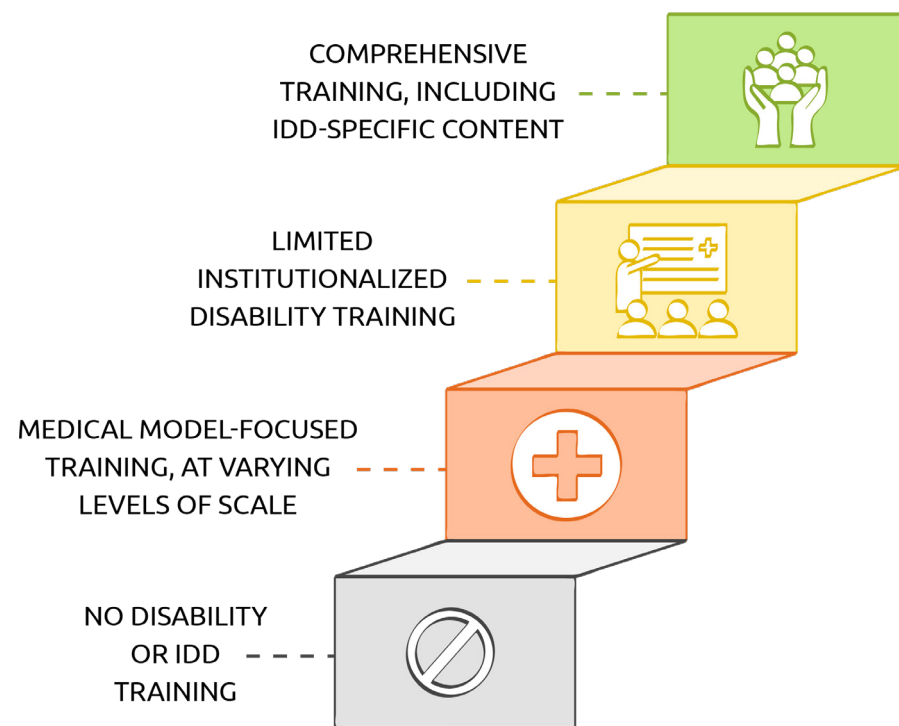
A workforce trained to address the unique needs of people with IDD is essential for achieving health equity. However, there are significant gaps in the training guidelines for health care workers, leaving many unprepared to provide quality care for these individuals, which is an ongoing challenge. Nationwide, health care students and professionals receive little to no education on caring for this population, but there are varied possible approaches for delivering such training.

Many health care workers receive limited education on caring for people with IDD. For example, a 2015 survey to deans of 167 American medical schools revealed that that only 52% of the 75 who responded reported that their curriculum included disability awareness.<sup>77</sup> It is not clear whether IDD was among the disabilities that were included in those curricula. Other studies have reached similar conclusions about the low reach of disability content to health care workers.

Where disability is addressed in the curriculum, it is often through "...isolated, one-time lectures that fail to provide trainees with sufficient tools to approach disabled patients with a balance of knowledge and humility."<sup>78</sup>

Effective care for people with IDD requires more than clinical knowledge. Beyond understanding specific conditions, providers must also know how to communicate effectively with individuals, understand their health priorities, ensure they feel safe, and provide support beyond just the biomedical aspects of care.

The delivery of quality care to people with IDD is often affected by providers' attitudes on and assumptions about caring for this population. One explanation provided by an expert on disability rights is that health care workers tend to rely on the medical model of disability, which " 'view[s] disability as connected to disease, and diseases are to be cured or avoided.' "<sup>79</sup> On a related note, analyses of a 2019 survey of 714 practicing U.S. physicians nationwide found that more than 80% of respondents considered people with significant disability to have a worse quality of life than those without disabilities.<sup>80</sup> Biases like this can lead to diagnostic overshadowing, which is when health care workers erroneously attribute an individual's health complaints or behaviors to their IDD.<sup>81</sup>



## Cindy

My name is Cindy Bentley, and I am an athlete with Special Olympics Wisconsin. I am lucky that today I have a doctor who listens to me and has helped improve my health over the past couple of years. But it was not always that way.

Before finding my current doctor, I had a physician who did not listen to me or treat me with respect. During visits, instead of looking me in the eyes, she would have her back turned to me while typing on her computer, even after I asked her to turn around. I did not feel like she was listening, and because of that I believe many of my health concerns were not properly addressed.



One time, I went to her because I had a severe cold and my asthma was acting up. She told me to go home and manage it, but my condition got worse and I eventually ended up in the emergency room with pneumonia. When I later changed doctors, I learned there were other things that had been missed too.

Important tests had not been completed, some of my medical information had not been kept up to date, and I was being prescribed more medication than I needed to be on.

Today, I have a doctor who listens to me and respects me. When he reviewed my medical records, he found that I was overdue for important tests and we spent much of the next year catching up on the care I had missed. He also looked at my medications, connected me with specialists, and helped me make a plan to improve my health.

One of the first things he talked to me about was my weight and how it was affecting my health. He encouraged me to join a gym and work with a trainer. Since then, I have lost about 35 pounds, and I feel healthier than I have in many years.

My doctor did not have much experience working with people with intellectual and developmental disabilities before meeting me, but he took the time to listen and learn. That made me feel respected.

If there is one thing I want doctors to understand, it is that people with intellectual and developmental disabilities have a voice. We may not know everything, but we do know our own bodies. My doctor did not know everything about disability when he met me, but he took the time to listen and learn. Every person with IDD has a voice, and doctors need to hear it.

Cindy's experience demonstrates that technical expertise alone is not sufficient for quality care. Even when providers lack formal training in disability health, respectful attitudes, active listening, and a willingness to learn from the person receiving care can lead to more positive health care experiences.

In addition to attitudinal barriers, skills and confidence gaps among providers are also very present. Only 40.7% of the providers who responded to the 2019 survey felt very confident that they could provide “the same quality of care to patients with disability” as those without.<sup>82</sup> Bridging communication differences is a frequently cited challenge to caring for individuals with IDD. Health care workers may speak very quickly or in complex jargon. They may underutilize assessment and diagnostic tools that exist for those who communicate non-verbally, including people with IDD. Among the 187 people with IDD in the U.S. who responded to this question on the survey implemented by SOI, only 5.9% (n=11) responded that they do not understand what their health care provider says to them, with a further 46.5% (n=87) responding that they understand “sometimes.” Yet 91.8% of all respondents with IDD (n=169) also said 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. For their part, 61.8% (n=42) of the 68 health care worker survey respondents strongly agreed that IDD training would be an effective strategy for improving their self-efficacy, with an additional 31% agreeing, and 64.2% of respondents (N=67) considered continuous professional development on disability health care to be a very important measure to improve health services for people with IDD, with an additional 32.8% considering it moderately important.

## Peris

My name is Peris Bennett. I participated in the Standardized Patient Program (SPP) pilot that Special Olympics worked on with the University of Maryland School of Nursing.

The SPP is an initiative that trains and pays people with intellectual and developmental disabilities (IDD) to pretend to be patients in clinical education settings. Through the SPP, health care students gain practical experience communicating with and caring for people with IDD. This is important because many health students are not taught how to care for people like me. The experience also taught me more about the health care field and helped me build confidence in skills such as public speaking and self-advocacy.

As a Standardized Patient, I pretended to be a patient experiencing a headache and students conducted an assessment. After students assessed me, their professor and I gave them feedback. We gave feedback on things like communication, professionalism, eye contact, and respect.

During the SPP, I was also able to help the students by answering their questions about how I like health care providers to treat me. They asked a lot of good questions, some questions I never heard before and some were hard to answer. It was intense, but I felt respected and comfortable to answer because the students were kind and they shook my hand.

To address these persistent gaps, the World Health Organization has launched a Technical Group to develop global standards for competency-based disability inclusion education and training. Its first consultation, held in February 2025, brought together experts, including people with disabilities, to guide this work with a goal to publish these standards by the end of 2026. Additionally, the National Council on Disability voted to approve a major policy brief on disability clinical care and competency in August 2026. The approved brief recommends clearer disability competency requirements and emphasizes a goal of training across the full career pathway. The full report is expected to be released by the end of 2026. Similar efforts are underway to embed disability competencies into mainstream health professions education. Since 2009, Special Olympics has advanced the integration of IDD content into medical and other health professions curricula. This work has included collaboration with the American Academy of Developmental Medicine and Dentistry through the National Inclusive Curriculum for Health Education initiative focused on embedding IDD content into medical school curricula. Current efforts focus on promoting the Inclusive Health Fundamentals, a turnkey, interprofessional curriculum developed in alignment with the Core Competencies on Disability for Health Care Education, the National Consensus on Disability Competencies for Health Care Education, and the Canadian Consensus Guidelines on Primary Care of Adults with Intellectual and Developmental Disabilities.<sup>83</sup>

## Promising Practice - Florida Gulf Coast University Marieb College of Health & Human Services

Six programs—nursing, physical therapy, exercise science, public health, occupational health, and physician assistant—incorporated the Special Olympics-developed, five-module, inter-professional curriculum called Inclusive Health Fundamentals. Individual faculty members decided into which course they would integrate the content and used a broad range of strategies such as assigning the modules one at a time, assigning them interspersed throughout the course, and allowing students to self-pace.

Course evaluation included the Adapted Disability Attitudes in Healthcare Scale, a survey tool used to measure health care providers' attitudes toward people with disabilities, particularly people with IDD. It is designed to assess whether training programs improve disability awareness, comfort, respect, and confidence in providing inclusive health care. Evaluation results demonstrated statistically significant improvement in students' attitudes towards people with IDD.

The approach garnered positive feedback from students and faculty and led to the modules being required in all programs at the college (the six programs listed above, as well as social work).

A community-led national agenda for improving health outcomes for people with IDD has proposed incorporating IDD competencies throughout the educational continuum and identified accrediting bodies, licensing organizations, and other entities responsible for educational standards and clinician credentialing as important drivers of future systems-level change.<sup>84</sup> There has already been significant progress in dentistry: since 2019, the Commission on Dental Accreditation has required U.S. dental schools to train their students in managing treatment of patients with “special needs”, which may include people with cognitive and/or developmental disabilities.<sup>85</sup>

Currently, states also lack licensing requirements that ensure health care workers receive training in providing quality care to people with IDD after graduation and once they begin practicing. Health care workers’ training should be continuous, build on prior knowledge, and address how to adapt service delivery to an individual with IDD’s life stage and evolving needs.

State governments and professional associations should push for standardized licensure and renewal requirements that include competencies for caring for people with IDD. Education and credentialing regarding quality care for people with IDD should be integrated at every stage of a health care worker’s career, ensuring that whenever a person with IDD seeks care, there is an increased likelihood of a trained, competent provider available. Training must be integrated into mainstream provider education—not as an optional add-on, but as a core competency for all health care workers, linked to appropriate accreditation or continuing education requirements.

# RECOMMENDATIONS

People with disabilities as a group face stigma, and people with IDD additionally face unique communication barriers and the invisibility of many of their needs. The following recommendations will promote the knowledge, skills, and attitudes that the health care and public health workforce require for inclusion:



## Require Comprehensive and Evidence-Based Training

Make training for inter-professional health care and public health teams mandatory in curricula, accreditation, and continuing professional development. Such training should combine various methods, including standardized capacity assessments, didactic sessions, case studies, simulation-based learning, and experiential learning that includes people with IDD ensuring that:

- i. People with IDD are active collaborators in the development, delivery, and review of training content, reflecting real-world experiences and serving as standardized patients where appropriate. Their participation must be voluntary, respectful, and paid.
- ii. The training approaches are tailored to meet the needs of health care workers across different disciplines, including non-medical staff, support workers and traditional healers, while addressing the varied needs within the IDD community.



## Monitor Progress with Standardized Measures

Evaluate the effectiveness of health workforce training using standardized yet adaptable measures that assess patient satisfaction with care received, accessibility, and desired health outcomes. Each state's health system should integrate key, measurable indicators into broader impact evaluations to ensure accountability and continuous improvement in training outcomes.



## Promote and Ensure Visibility of People with IDD within the Health System

Promote an understanding that health services are for all by ensuring people with IDD are depicted in health system materials. Include people with IDD in the health workforce, including as patient navigators. These approaches can enhance person-centered care and help challenge stereotypes.

# DATA FOR MONITORING AND RESEARCH



**The experiences of people with IDD in health systems are often unnoticed, leaving their needs invisible to health care providers, decision-makers, and society. The absence of disaggregated data masks the disparities faced by this population, impeding progress and blocking equitable care. Monitoring the unique needs of people with IDD and ensuring that health care workers are equipped to meet them is not possible without data.**

This section explores how monitoring through systematic collection, disaggregation, and use of data across all components of health information systems offers a pathway to actionable change. This includes data not only on access to services but also on health outcomes—for instance, rates of preventable illness among people with IDD, premature mortality, or exposure to risk factors. Monitoring also requires tracking of the implementation and impact of inclusive actions. For example, when disability content is added to medical training curricula, it is critical to monitor both the rollout and its real-world effects on provider attitudes and patient experience.

Strong data-driven monitoring and research systems can drive government accountability, empower communities, and catalyze targeted interventions. This section explores promising practices and recommendations for closing these data gaps, emphasizing the transformative potential of making the invisible more visible.

## Promising Practice - Independent Monitoring for Quality (IM4Q)

The Independent Monitoring for Quality (IM4Q) program operates across the U.S. state of Pennsylvania to ensure that the voices of people with IDD are heard. IM4Q's goal is to improve the quality of life and services for individuals with IDD by gathering their direct input and using it to propose policy changes. This ensures that services meet their unique needs and preferences. Rather than focusing only on what agencies think is important, IM4Q ensures that people with IDD have a voice in the conversation. Their input helps shape services to better align with personal goals, like finding a job, living independently, or accessing specialized health care.

The program conducts about 5,000 interviews each year, engaging directly with individuals receiving services, their families, and others who know them well. By including people from diverse living situations, like family homes, small group settings, and larger residential centers, IM4Q captures a broad range of experiences. These insights help identify strengths and areas needing improvement. For example, access to communication devices, voting opportunities, or more personalized employment support are topics that have been touched on during interviews. It also covers health-related topics such as sufficient levels of care, emergency preparedness, quality of medical/dental care, access to care, and ability to communicate health needs. Over time, IM4Q's findings have guided policy changes and system-wide enhancements, making Pennsylvania's IDD services more person-centered, responsive, and inclusive.

The information that IM4Q gathers is actively used to drive policy and funding decisions that shape real-world services. For instance, when multiple interviewees and their families highlighted a lack of appropriate communication devices, the Pennsylvania Office of Developmental Programs made it a priority to ensure those supports were more readily available. Similarly, when individuals interviewed indicated they wanted to vote and were not registered, efforts were made to improve civic participation for people with IDD to vote.

One of the gaps identified by the SLAs conducted through the Rosemary Collaboratory initiative is that there is limited population data related to people with IDD and their health outcomes. A major reason for this is that many countries and states rely on the Washington Group Short Set on Functioning (WG-SS) or similar tools in their national censuses and public health surveillance. The WG-SS, which is the global data standard for disability and is used in the National Health Interview Survey (NHIS), identifies functional impairments and represents significant progress in standardizing data collection related to those with disabilities. It has, however, been criticized for not distinguishing between developmental and adult-onset impairments, which is one of the reasons it lacks the sensitivity to identify people with IDD.<sup>86</sup>

Furthermore, even non-WG-SS questions have limitations in capturing those with IDD as distinct from others with impairments in domains of cognition and communication, resulting in a recognized undercounting of those with IDD.<sup>87</sup>

In addition to the challenge of identifying people with IDD at a population level, these individuals are also largely underrepresented in clinical research, creating gaps in the evidence needed to improve health services and outcomes.<sup>88</sup> One explanation for this underrepresentation is recruitment and participation barriers.<sup>89</sup> Studies often rely on methods and designs that are inaccessible, such as lengthy or complex surveys, travel requirements, or the need for high literacy levels in consent forms.<sup>90</sup>

Gaining informed consent also poses logistical challenges; while many individuals with IDD can provide consent, others may have substitute decision-making arrangements, adding layers of complexity and extending study timelines.<sup>91</sup> In many instances, Institutional Review Boards (IRBs) view people with IDD through the lens of a vulnerable population, rather than an underrepresented one, and may exclude this population out of a sense of protection. One study of 97 clinical trials across four therapeutic areas found that cognitive or intellectual grounds for exclusion were one of those frequently used (42% of studies).<sup>92</sup> Only 46% of the studies examined provided a justification for excluding people with cognitive disabilities, but this was high compared to justifications for other exclusion categories. A review of National Institutes of Health-funded clinical trials, eligibility criteria for nearly 75% of the trials examined directly or indirectly excluded adults with intellectual disability.<sup>93</sup>

Although ethical concerns regarding data collection from people with IDD are important, these concerns should not prevent their inclusion in research. Instead, research practices should respect and accommodate their varying degrees of ability to participate. Additional safeguards in recruiting and consent procedures for participants have been successful methods for gaining the approval of IRBs.<sup>94</sup> In a Canadian review of clinical trials, over 90% were found to be designed in ways that excluded people with IDD, even though simple adjustments—such as presenting consent forms orally—could have enabled participation.<sup>95</sup> Equitable access to research opportunities is crucial to achieving health equity.<sup>96</sup>

This absence or exclusion of people with IDD from mainstream research limits studies to specialized areas, dissemination of findings, and the integration of the findings into broader public health policies. Addressing these barriers is essential to ensuring that people with IDD are not only visible but prioritized in research that informs health and social policy.

## NEED TO BETTER BE ABLE TO IDENTIFY PEOPLE WITH IDD IN HEALTH DATA

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Challenges in identifying and tracking people with IDD at a population level, across health, administrative and other data systems, limit the ability to measure health outcomes and support effective policy and health system planning.<sup>97</sup> Without accurate data of both the health needs and gaps in delivery for people with IDD, governments and health care workers will struggle to allocate resources to any of the recommendations made. The lack of data makes it difficult to pinpoint both systemic access barriers, such as the absence of accessible communication, and more concrete service gaps, like inadequate transportation or limited availability of specialist care.

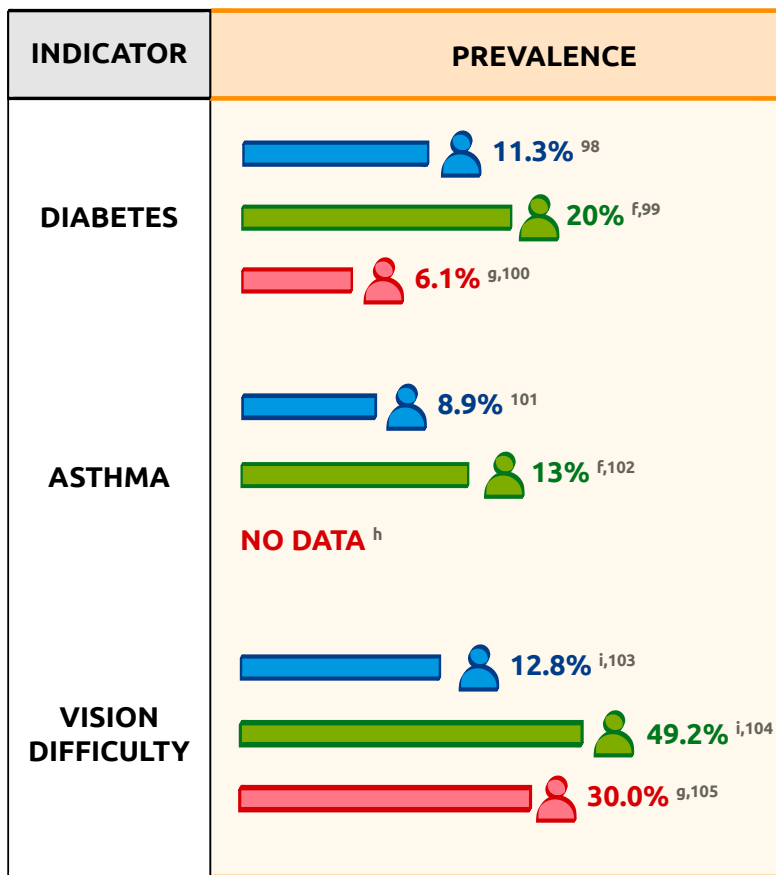
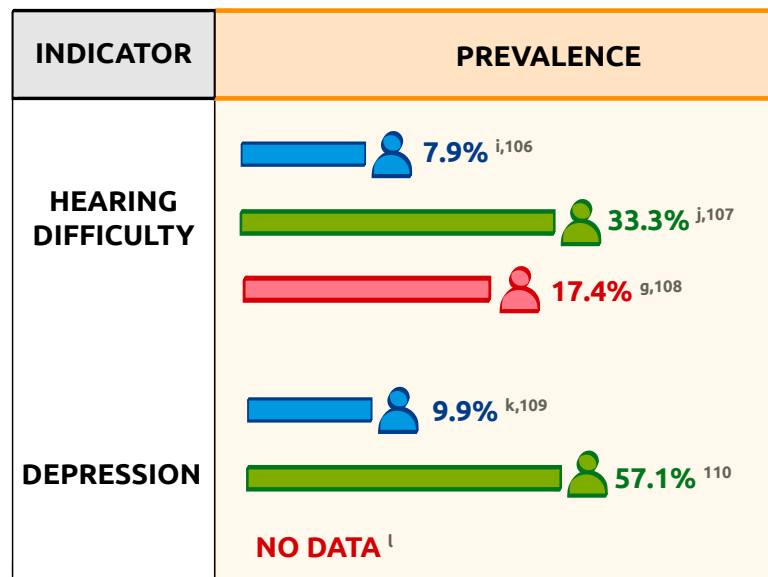
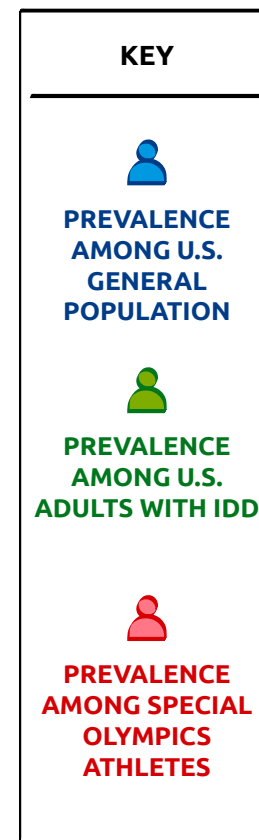
The absence of systemic data also undermines efforts for collaboration, including the ability of different departments and agencies to work together. This leads to confusion regarding the actual numbers and needs of individuals and impedes planning across sectors.<sup>111</sup> It also leads to insufficient financing and planning, which are key barriers to the implementation of even the best policies and approaches.

Finally, data need to be systematically collected as part of a broader health system and larger information gathering efforts. Disaggregated data are crucial to revealing inequalities and will support greater understanding of how health systems are reaching and serving people with IDD over the course of their lifecycles, not in just one or two moments in time. Supporting the evolving capacity of these individuals will require data-based interventions.

## DATA AS A DRIVER FOR ACTION AND ACCOUNTABILITY

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Data are key to providing a baseline from which stakeholders, including the governments, can confirm the impact of programs and course-correct if improvements in access to care and overall health and wellbeing of people with IDD are not being achieved. The responsibility for gathering data on population health, including the health of people with disabilities, rests with governments. However, many organizations outside of government are gathering data about people with IDD, their health, and the factors that influence their health.



<sup>f</sup> Figures for adults with IDD come from the National Core Indicators–IDD In-Person Survey, which covers adults receiving Medicaid-funded developmental disability services. They do not represent all U.S. adults with IDD.

<sup>g</sup> Athlete figures are self-reported at Healthy Athletes screening and may understate true prevalence.

<sup>h</sup> Asthma is not screened through Healthy Athletes.

<sup>i</sup> Uses a “broad” definition of difficulty on the Washington Group Short Set. “Broad” counts anyone reporting at least some difficulty.

<sup>j</sup> Estimate is from the National Survey on Health and Disability, a small sample and not a population-based estimate.

<sup>k</sup> These data are for U.S. adults with no functional limitations, not the general population.

<sup>l</sup> Special Olympics Healthy Athletes Strong Minds is beginning to collect data on self-reported depression and access to counseling.

## Promising Practice – Down Syndrome International – Humanity & Inclusion Global Consultation on Health Equity

**“I met a doctor who talked to me like a baby in a loud voice.” - Man aged 25–34 with Down syndrome, United States**

In 2025, Down Syndrome International (DSi) and Humanity & Inclusion (HI) published a global consultation on health equity to understand the challenges faced by people with Down syndrome and people with intellectual disabilities in accessing quality healthcare. 754 individuals and 118 organizations from 95 countries responded, including 139 people with Down syndrome or intellectual disabilities. The United States was the single largest country of response, with 149 respondents (19.8% of the total) and almost a third (29.9%) of all responses from high-income countries.

### **Some of the U.S. findings included:**

- Financial coverage falls short: of 27 U.S. respondents who mentioned Medicaid, only 7 said it covered all their medical costs.
- Families just above the income threshold are squeezed out - 8 respondents said they could not access Medicaid, and applying for waivers or Social Security Disability Insurance was described as difficult and frustrating, with one parent told their daughter was not “special needs enough” to qualify.
- Specialist and adult services are hard to find: families reported traveling long distances, and in one case 800 miles, for dentistry and dual-diagnosis psychiatry. One mother spent three years searching for a mental health specialist who understood developmental disabilities before giving up.
- Wait times within public coverage cause real harm – one family reported their daughter going nearly a year without hearing aids while navigating Medicaid appointments and coverage.
- Health care providers rarely communicate directly with the person with Down syndrome or intellectual disability. Family members repeatedly described doctors speaking about, not to, their relative – including adults in their twenties and thirties, and people who use assistive communication devices.
- Transitions from pediatric to adult healthcare are a cliff edge: services that were straightforward through children’s hospitals become significantly harder to access in adulthood, particularly adult dentistry and psychiatry.
- Diagnosis experiences are often negative: When informed that their children have Down syndrome, U.S. parents described being given little or inaccurate information, and being repeatedly encouraged to terminate the pregnancy.

**“I was confused at the gyne [gynecologist]. I did not understand what was going on. I wanted to know about birth control. The staff was nice, but I did not get the birth control and still don’t understand what I need.” – Woman aged 18-24 with Down syndrome from the United States**

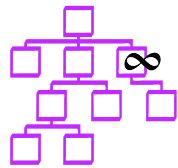
**“When I went to get a blood test, I said that I was scared to do it. The lady called in 3 other people to hold me down. My mother said no way and they left. When they are nice and talk with me, then I’m not scared.” – Woman aged 55-64 with Down syndrome from the United States**

Governments should be prepared to consider and act upon the results of such data, especially when their own efforts may not be capturing the same data or doing so adequately. For instance, Special Olympics Healthy Athletes® data provide a valuable snapshot of the health status of the subpopulation of people with IDD who participate with Special Olympics, just as the SLAs and surveys conducted by SOI provide a baseline to help inform governments of the gaps in health systems for people with IDD. However, these sources are not exhaustive. Collecting high-quality data, at a far greater scale, is essential.

Lastly, data are valuable for organizations and communities advocating for the needs of people with IDD. These entities are often partners in collecting and validating data at the household and community levels. They also play an important role in investigating and elaborating on gaps in both data and response outcomes, as well as sharing that information with governments. Their role as liaisons and advocates is crucial to ensuring that health systems develop with IDD inclusivity in mind and the needs of this population are *not* invisible.

# RECOMMENDATIONS

Effective data collection and analysis are fundamental to addressing the health disparities faced by people with IDD. These processes illuminate gaps in health service delivery and serve as powerful tools for driving policy change and accountability. To ensure that health services for this population are equitable and effective, the following recommendations should be considered nationally:



## **Maintain and Improve Data Disaggregation that Identifies People with IDD:**

Preserve and enhance existing data collection methods, such as an “age of onset” question in addition to standard functional limitation questions, to ensure those with IDD are appropriately captured, in order to more accurately document their health status and needs.



## **Strengthen Equitable, Public Access to and Reporting of Data on Health of People with IDD**

Expand access to data on health outcomes and service coverage of people with IDD. Improve the ability to identify and monitor people with IDD across health data systems and translate existing data into accessible reports and dashboards that support accountability, track progress, and highlight persistent health disparities.



## **Advance Inclusive, Data-Driven Research with and for People with IDD**

Utilize participatory data collection methods that directly involve people with IDD and their advocates to ensure inclusive and representative data for policy and service improvements. Invest in research that identifies promising practices for health service delivery to people with IDD, ensuring their active representation in both study design and execution. Integrate research findings into broader public health strategies to enhance services, policies, and health outcomes for people with IDD.

# CALL TO ACTION



Invisible, unknown, disrespected. These words characterize the experiences of people with IDD in health systems worldwide. As a result, they experience significant health disparities, including higher rates of obesity, diabetes, heart disease, and mental health issues than the general population.

## This is where you come in.

The work to close these gaps is ambitious and crucial, yet feasible, and there is a part for everyone to play.

Share this report to help make people with IDD, their needs, and their demands more visible to decision-makers in health systems at every level, in every state, across the country. This is crucial because the responsibility rests with those decision-makers to help people with IDD receive the care, attention, and respect they deserve and help them live longer, healthier lives. Among the thirteen recommendations in this report, meaningful progress on the following four recommendations over the next three to five years is possible and will help drive the necessary focus on people with IDD and achieving health for all.



### Governance, Leadership, and Engagement

Invest in the visibility and voices of people with IDD in health policies. Greater investments in meaningful inclusion in health are necessary and ensuring people with IDD have a say in those investments will make them as effective as possible.



### Person-Centered Care

Address reimbursement, administrative, and provider-level constraints that limit access to longer appointments for people with IDD. Longer appointments can support more effective two-way communication, improve the accuracy of information exchange, and provide time to address the often-interconnected health and social needs of people with IDD.



### Health Care and Public Health Workforce

Make training for inter-professional health care and public health teams mandatory in curricula, accreditation, and continuing professional development, incorporating people with IDD in the development and delivery of training.



### Data for Monitoring and Research

Improve data disaggregation to accurately identify people with IDD in health data and publish health data about those with IDD in accessible formats.

Despite the vastness of the health disparities that people with IDD experience, the solutions they need are often overlooked.

**By working together, we can ensure that people with IDD aren't just seen, they are empowered, supported, and included in every aspect of society, starting with their health.**

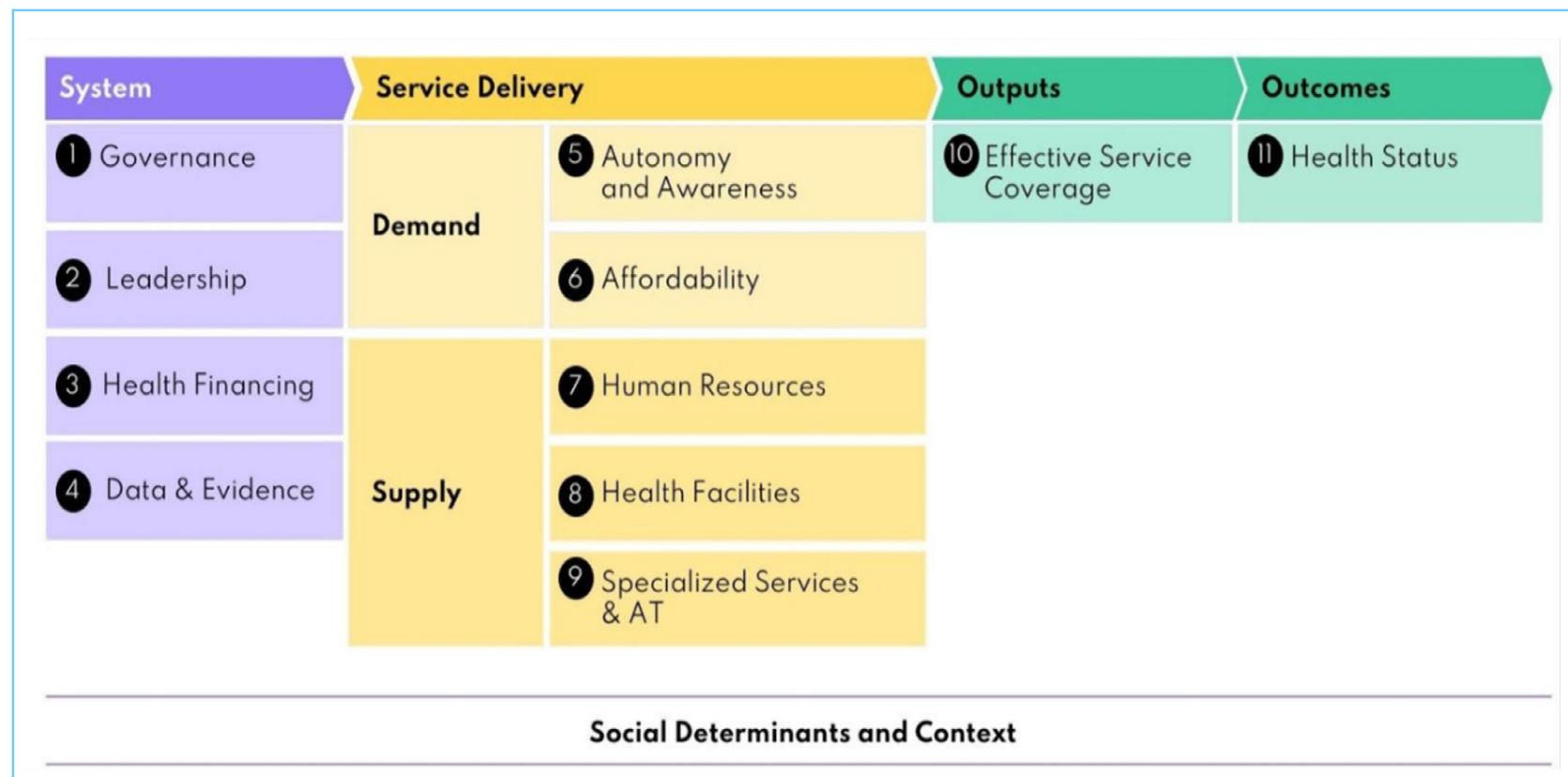
# GLOSSARY, ANNEX, AND ENDNOTES



|              |                                              |
|--------------|----------------------------------------------|
| <b>ACA</b>   | Patient Protection and Affordable Care Act   |
| <b>ACL</b>   | Administration for Community Living          |
| <b>HHS</b>   | U.S. Department of Health and Human Services |
| <b>IDD</b>   | Intellectual and Developmental Disabilities  |
| <b>IM4Q</b>  | Independent Monitoring for Quality           |
| <b>IRB</b>   | Institutional Review Board                   |
| <b>MBI</b>   | Missing Billion Initiative                   |
| <b>NEMT</b>  | Non-Emergency Medical Transportation         |
| <b>SLA</b>   | System Level Assessment                      |
| <b>SOI</b>   | Special Olympics International               |
| <b>SPP</b>   | Standardized Patient Program                 |
| <b>WG-SS</b> | Washington Group Short Set on Functioning    |

# ANNEX

## Missing Billion System Level Assessment



## ENDNOTES

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