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

ACKNOWLEDGEMENTS

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INTRODUCTION LETTER FROM DAVID DUNCAN

Dear Reader,

It means a lot that you're taking the time to learn about the health of people with intellectual and developmental disabilities (IDD), like me. Many of us aren't living our best lives because we aren't as healthy as we could be. This is because we are overlooked, invisible, excluded, and so are our needs.

That's why this report is so important.

I myself have had both good and bad experiences with health care. I've been to doctors who didn't listen to me, who made me feel like I didn't matter. I've also had care from people who took the time to understand me, including my autism, and who made me feel like I was part of the process. That made all the difference.

In April 2024, I joined the Editorial Review Group for this report as it was being set up. In May, my fellow Special Olympics athletes with IDD around the world gave me their trust to serve as the Chair of the Global Athlete Leadership Council (GALC). The GALC gets feedback from athletes across our regions and shares the feedback with Special Olympics International, to help decide the direction of the global Special Olympics movement. I've helped shape this report from the beginning, when it was just a concept. It's been a long

journey, and I'm proud of what we've created and how it captures the voices, needs, and wishes of my fellow athletes and me. All along this journey, I have thought about why Special Olympics would publish this report. It's because Special Olympics has done, at a smaller scale, much of what we are calling on you to do.

Special Olympics Healthy Athletes screenings are just one example. The experience isn't frightening, like when you go to a general hospital. The volunteer doctors have been trained to work with us: they are kind, they use visuals and simpler language, and it's just such a supportive environment. I have friends who have had bad experiences with health care in the past who make the effort to go to Healthy Athletes screenings because the experience is better.

So, I know it's not impossible to do and I even know what it looks like!

Give people with IDD a seat at the table. Listen to our unique perspectives. We want to be included in what's going on; we have our own views and challenges that might be a little different. Give us a say and the supports we need to use our voices, claim our health, and live our best lives. Give us a line in the curriculum, the budget, the policy document, the survey ... and don't forget to let us be a part of writing those lines.

We are not asking for special treatment. We are asking for a level playing field. We want to be seen, heard, and respected. We want the chance to live healthy lives.

Here's hoping this report helps make that a reality.

Yours truly,
David Duncan
Chair, Global Athlete Leadership Council
Special Olympics

EXECUTIVE SUMMARY

People with intellectual and developmental disabilities (IDD) face severe health disparities worldwide. Over the course of their lives, people with IDD disproportionately experience a variety of health challenges, such as obesity, diabetes, heart and respiratory diseases, and mental health conditions. The result is that people with IDD die 16-20 years sooner than the general population due to preventable 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 and care workers. The needs of people with IDD and efforts to address their needs are under-reported and under-researched, leaving their health challenges unaddressed.

Through the newly launched Rosemary Collaboratory initiative, Special Olympics International (SOI) is accelerating efforts to address inequities that individuals with IDD face in health systems worldwide—issues that Special Olympics Founder Eunice Kennedy Shriver's sister, Rosemary Kennedy, experienced 60 years ago and still persist today. The Collaboratory highlights challenges, best practices, and gaps that people with IDD face within health systems. In early 2024, Special Olympics engaged teams in 11 Rosemary Collaboratory sites across nine countries, including Chinese Taipei, India, Ireland, Morocco, Nigeria, Pakistan, Paraguay, South Africa, and the United States, to assess the level of inclusion of people with IDD in each location's health system. These data are complemented in this report by desk reviews of relevant research, case studies of people's lived experience, and surveys completed by over 1,000 people with IDD and members of the health and care workforce in over 50 countries.

The 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 the targeted actions for governments highlighted in the recent World Health Organization *Global report on health equity for persons with disabilities*, this global report provides recommendations specific to the needs of people with IDD. 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 unveiled some startling findings:

- Almost no Rosemary Collaboratory sites had specific indicators or policies outlined for people with IDD;
- In a survey of over 700 people with IDD from nearly 50 countries, 2 in 3 people do not make their own health decisions or ONLY do so occasionally;
- Only 52% of people with IDD surveyed said they always understand their health care provider;
- 66% of health worker survey respondents thought improving data collection on the health of people with IDD would be a very important measure to improve health services for this population.

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

Governance, Leadership, and Engagement

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

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;
3. Back policies pertaining to the health of people with IDD with adequate funding and resources and ensure that national regulations address their specific needs; and
4. Empower people with IDD to actively participate in human rights monitoring, including reporting on rights violations, and ensure that systems are in place to support their involvement.

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:

1. Strengthen supported decision-making by revising legislation to align with the United Nations Convention on the Rights of Persons with Disabilities and ensuring 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 and Care Workforce

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

1. Require comprehensive, evidence-based training for 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:

1. Improve data disaggregation by disability types to ensure people with IDD are accurately captured in health data systems;
2. Make health data publicly accessible through dashboards or reports in accessible formats to 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 David Duncan, Chair of the Special Olympics Global Athlete Leadership Council and member of the Editorial Review Group for this report, eloquently sums up:

> Give people with IDD a seat at the table. Listen to our unique perspectives... Give us a say and the supports we need to use our voices, claim our health, and live our best lives. Give us a line in the curriculum, the budget, the policy document, the survey… and don't forget to let us be a part of writing those lines.

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INTRODUCTION

The 2022 World Health Organization (WHO) *Global report on health equity for persons with disabilities* indicates that people with intellectual disabilities are dying at a rate six times higher than the general population from conditions that could have been prevented or treated effectively with quality health care.[1] This reality persists despite relevant actions and progress in global health generally. In 2015, the 193 United Nations member states agreed to the 2030 Agenda for Sustainable Development, which includes the Sustainable Development Goals (SDGs) and was intended to be a "blueprint to achieve a better and more sustainable future for all" by 2030. One of the 17 SDGs (SDG3) focuses on ensuring healthy lives, promoting well-being for all, and ensuring more people benefit from universal health coverage (UHC). Health is also linked to the achievement of other SDGs, such as those related to poverty (SDG1) and inequality (SDG10), to name just a few.

People with intellectual and developmental disabilities (IDD) die 16-20 years sooner than the general population due to preventable health conditions.[2] Moreover, during the course of their lives, people with IDD disproportionately experience a variety of health challenges, such as obesity, diabetes, heart and respiratory diseases, and mental health conditions.[3] As progress against the SDGs is measured, it has become evident that in order to reach the stated goals, 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 over 50 years.

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

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. She never wavered in her belief that every person deserves to be treated with respect and have the opportunity to be included. With an annual reach to over 3.8 million people with IDD in over 200 countries and jurisdictions, as well as having trained over 114,000 health workers between 2019 and 2024, Special Olympics is part of a global movement for health equity for persons with disabilities, with a focus on those with IDD, whose needs are often most invisible.

Leveraging this global footprint, the Rosemary Collaboratory initiative, which includes this report, as well as global and country-level advocacy, 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 these movements in order to make health for all a reality.

WHO ARE PEOPLE WITH IDD?

The World Health Organization (WHO) defines intellectual and developmental disabilities as "a group of developmental conditions characterized by a significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behavior, and skills."[4] Such conditions include, but are not limited to, Down syndrome, Fragile X syndrome, Fetal Alcohol Syndrome Disorder, and autism spectrum disorder.

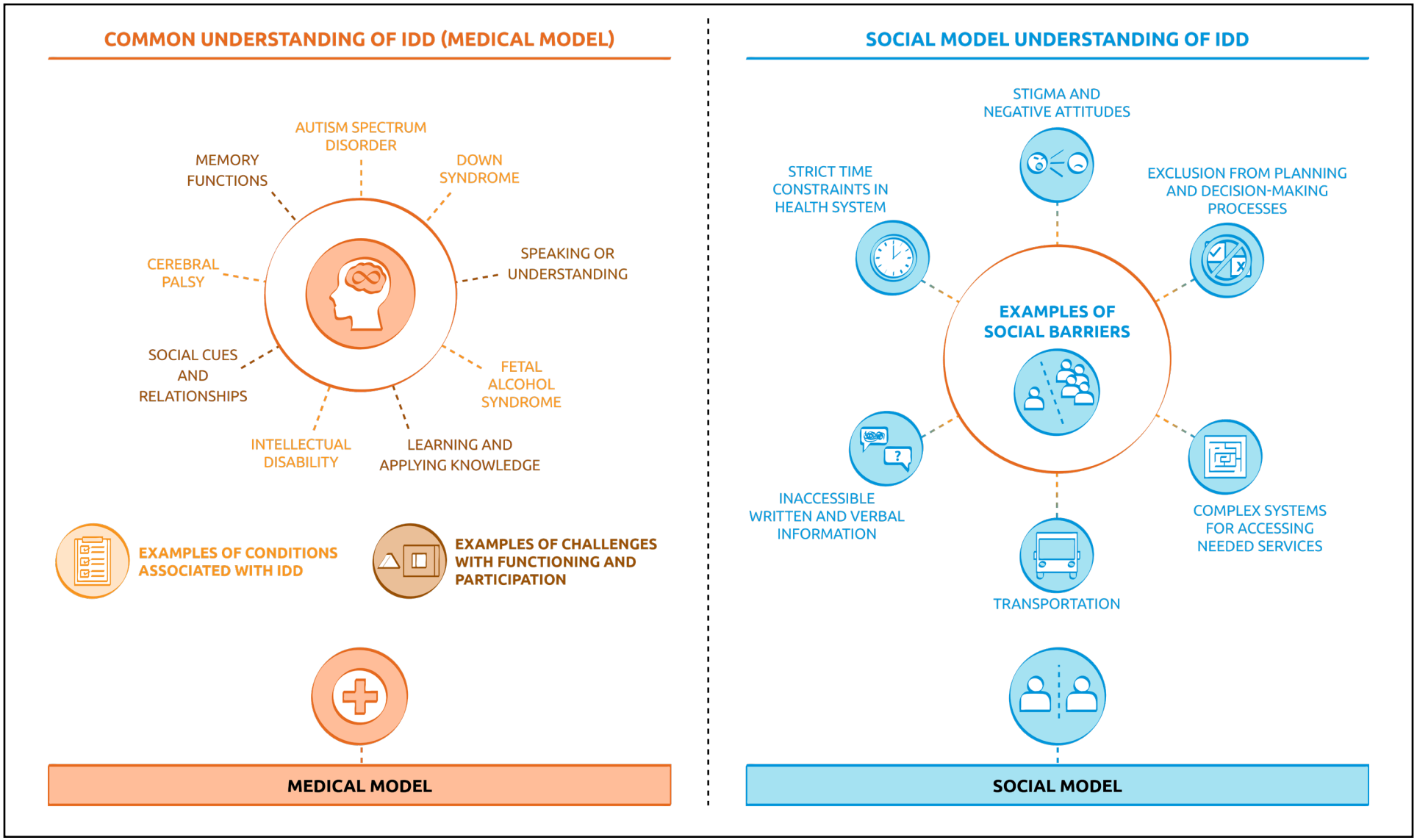
People with IDD are a diverse group due to diagnosis, type(s) of functional challenges, and support and collaboration needs and preferences.[1] Challenges related to vision, hearing, and mobility may have visible manifestations, making them more tangible and familiar to those in the health ecosystem, 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.

The medical model of disability frames disability as requiring treatment or management through medical intervention. As illustrated in the case study of Nicole*[2] 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. 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.

[1] 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 in the World Health Organization's 2025 Guidance on mental health policy and strategic action plans. Some images in this document use the infinity symbol (∞) to refer to people with IDD.

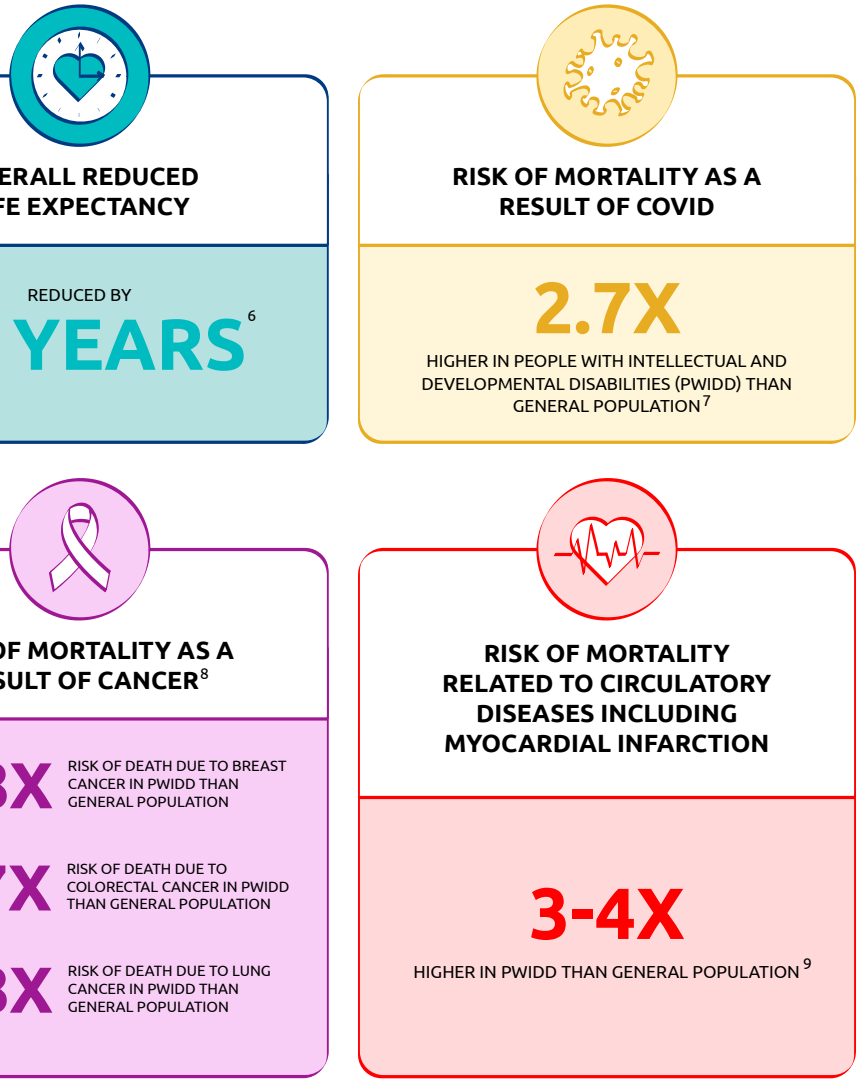
[2] The names of some individuals in the case studies in this report have been changed. Changed names are marked with an asterisk*. Real names and images are used with permission.



The social model of disability, by contrast, emphasizes 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.[5]

WHY THIS REPORT?

As has been mentioned, people with IDD disproportionately experience many health conditions that do not stem from diagnoses associated with IDD.



Echoing the social barriers that people with IDD face more broadly, people with IDD face a number of barriers when navigating and accessing primary health care. 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 someone to travel with the person with IDD. Furthermore, safety concerns may be heightened by stigma, discrimination, and violence.[10] Notably, among people with disabilities in general, transportation barriers have been linked to poorer health outcomes.[11]

PREMATURE MORTALITY

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 UHC target within the SDGs and for protecting health security.

This report highlights challenges, promising practices, and gaps that exist for people with IDD within the health system, including poor data, lack of awareness, inadequate policies, and insufficient engagement of people with IDD. In short, the health needs of people with IDD are often invisible, not because they are nonexistent, but because they are largely unseen or overlooked. As a result, their health disparities remain unacknowledged and unaddressed.

Overall, the need for further action to support people with IDD within health systems is clear. This report constitutes a call to action for governments and other stakeholders to focus on the invisible in order to meet the health needs of people with IDD and move towards health for all.

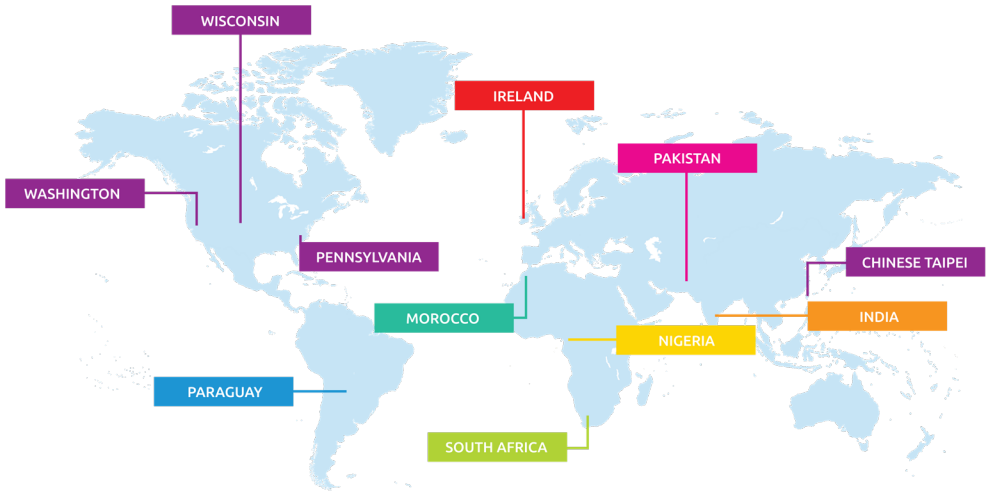
Support People and Caregivers:

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.

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 over 20 years implementing health programs in these locations, 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.

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 the health system, the two organizations developed a specific module to evaluate the extent of *IDD inclusion* in health systems. The SLA framework (depicted in Annex 1) includes four high-level components—system, service delivery, outputs, and outcomes—and 11 key leverage points. 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 workers, and public officials.

In addition to the findings from the SLAs in the 11 sites, this report also draws on other existing literature, as well as case studies of people's lived experiences and promising practices, many of which were identified through the SLAs. It also includes qualitative analysis of interviews and focus group discussions with 77 clinicians in seven sites, as well as quantitative analysis of survey responses of around 300 health workers from over 40 countries.

Individuals with IDD have been part of the entire process of the creation of this report and advocacy activities that surround it. For example:

- 30 individuals with IDD in South Africa from five provinces participated in focus group discussions for the completion of the SLA;
- Adults with IDD and family members in Ireland were part of the project advisory group and participated in two patient and public involvement meetings to review the SLA indicators, suggest additions, and identify relevant stakeholders; and
- Five individuals with IDD in the U.S. state of Pennsylvania responded to a survey that aimed to prioritize gaps that were identified through the SLA.

In addition, over 700 people with IDD from almost 50 countries responded to a universally designed survey that was co-developed alongside three individuals with IDD (from the US, the UK, and Zimbabwe) who work as consultants for SOI.[12] The consultants also shaped the report from early days, as well as reviewed and provided extensive feedback on several drafts of the report. Early versions of recommendations were also subject to the generous review of SOI's Global Athlete Leadership Council (GALC).[13]

SOI further convened an Editorial Review Group comprised of representatives from the community working on disability and health issues, including the chairman of the GALC.

CONTRIBUTIONS TO THE GLOBAL HEALTH EQUITY MOVEMENT

Special Olympics started the preliminary work for Rosemary Collaboratory, including this global report, over a year before the WHO *Health equity for persons with disabilities: guide for action* became publicly available in November 2024, followed by the WHO *Guidance on mental health policy and strategic action plans* in March 2025. However, the 2022 *Global report on health equity for persons with disabilities* and 2023 *Global report on children with developmental disabilities* were available and provided valuable grounding.

Rosemary Collaboratory moved forward with three considerations in mind:

- The role that WHO plays in normative leadership,
- The significant alignment between the indicators in the SLA and the targeted actions featured in the WHO's Framework to advance health equity for persons with disabilities through PHC [primary health care] (included in the 2022 *Global report on health equity for persons with disabilities*) (see Annex 2), and
- The IDD-and-health specific focus of this Special Olympics initiative, as a complement to related reports and frameworks.

Initial findings from the SLAs aligned extensively with the targeted actions and brought certain ones to the forefront that relate to the most critical health challenges that people with IDD face.

The relevant indicators (from the SLA) or targeted actions (from the WHO framework) were clustered to develop this report's four sections:

Governance, Leadership, and Engagement

Person-Centered Care

Health and Care 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 targeted actions to which this report's recommendations most relate are shown in a box with a purple outline.

The recommendations in this report are focused on health systems at large and do not cover diagnosis-specific responses. The aim is to both endorse and provide nuance to the WHO's targeted actions, giving needed visibility to the specific needs and demands of people with IDD.

GOVERNANCE, LEADERSHIP, AND ENGAGEMENT

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.

Most countries have ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which enshrines the rights to participation and to health, among many others.[14] However, there has been far less progress in implementing these obligations or creating an enabling policy environment across relevant sectors for promoting the health of people with disabilities, including people with IDD.

This section will explore the extent to which the needs of persons with IDD are reflected in national policies of the countries where the System Level Assessments (SLAs) 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 organizations of persons with disabilities (OPDs), 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.”[15]

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

Of the countries where Special Olympics completed the SLAs, India, Ireland, Morocco, Nigeria, Pakistan, Paraguay, and South Africa have signed and ratified the UNCRPD.[16] Following this, many introduced or amended laws or policies to align with the treaty. In Morocco, for example, the Ministry of Solidarity, Social Integration, and Family led the Integrated Public Policy for the Promotion of the Rights of Persons with Disabilities 2017-2021. The policy aimed to facilitate the full integration and active participation of persons with disabilities in all areas of life and enhance their access to essential services such as health care and education. Additionally, the policy aimed to reinforce legal protections, foster social inclusion, and ensure that individuals with disabilities could actively participate in decision-making processes. Similarly, Pakistan's National Plan of Action for Persons with Disabilities (2006) aimed to improve access to primary and specialized health services for people with disabilities. Following the devolution of power to the provinces in 2010, various provinces also developed disability legislation that protects the right to health.[17]

However, in practice, countries often fall short of addressing the specific needs of people with IDD in their implementation strategies. For instance, the SLAs uncovered almost no population health-related policies with specific indicators, targets, or metrics for people with IDD. The 2023 *Global report on children with developmental disabilities* provides examples of indicators that may be useful, such as vaccination coverage among children with developmental disabilities and mortality rate among children and young people with developmental disabilities, while the National Core Indicators in the United States represent another promising practice.[18]

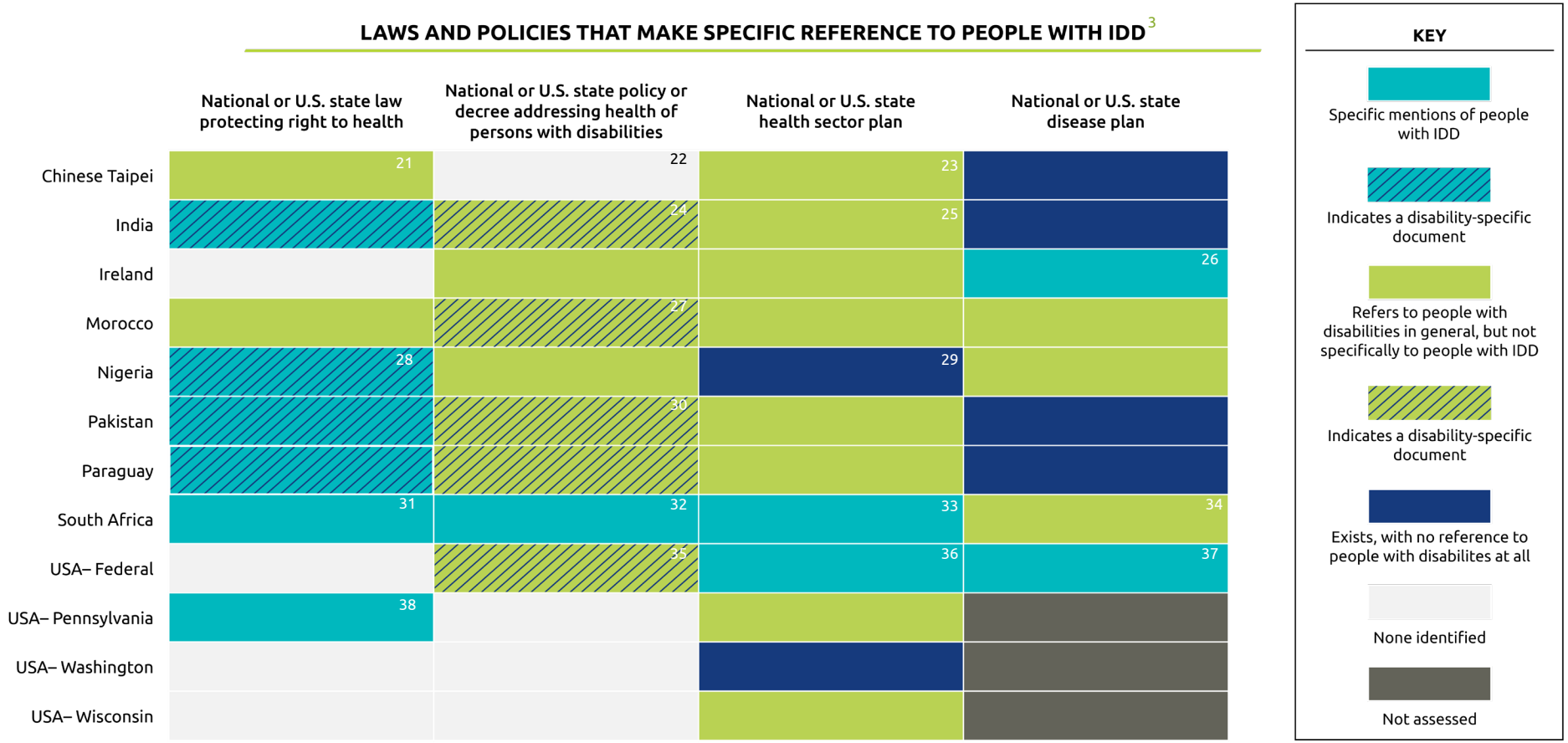
Some of the health-related initiatives focused on those with IDD that were identified through the SLAs include:

- Policies in Chinese Taipei that promote early childhood assessment and intervention for children suspected of or identified as having developmental delays or disability;
- Paraguay's National Comprehensive Care Program for Autism Spectrum Disorders (*Programa Nacional de Atención Integral a los Trastornos del Espectro Autista*); and
- India's *Rashtriya Bal Swasthya Karyakram* (RBSK), which aims to provide free early identification, intervention, and maintenance of health records with referral mechanisms for children with developmental delays and disabilities.

These initiatives are to be lauded and sustained; however, they do not respond to the full range of health needs of people with IDD. Early intervention and diagnosis-specific programs tend to focus on a developmental delay or difference, such as communication or cognition, with the mandate for other health issues, such as treatment for congenital heart issues and routine vaccines, falling to someone else. In the sample of countries where SLAs were conducted, that "someone else" often needs additional support to meet the needs of people with IDD across the lifespan. This highlights the WHO's emphasis that what people with disabilities need that is most absent is access to all health services, not just those focused on their differences in functioning.[19]

Some countries have taken approaches that seem to acknowledge or address a wider range of health needs of those with IDD. For instance, the United States passed the Developmental Disabilities Assistance and Bill of Rights Act of 2000. It promotes access to services and supports, including funding specific programs for this population, such as "Empowering Youth with Intellectual and Developmental Disabilities to Manage Their Healthcare Transitions."[20] Ireland's Action Plan for Disability Services (2024–2026) outlines specific targets and actions for improving the overall health and well-being of people with IDD. South Africa's National Mental Health Policy and Strategic Plan (2023-2030) and Policy Framework and Strategy on Palliative Care provide the few examples identified through the SLAs where people with IDD were specifically considered in policies for the general population.

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.



[3] SOI recognizes that some countries may address IDD using other terminology, such as mental disabilities and psychosocial disabilities, as well as other, outdated terminology that is considered offensive. IDD, for the purposes of the application of the key in this table, takes into account specifically the terms "intellectual" and "developmental" in reference to a "disability(ies)," "disorder," or "impairment." 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 of government (e.g., provincial, national), as well as the distinct treatment that different domestic legal orders may give to international law. While recognizing that ratification of the UNCRPD and other international treaties can have direct legal effect in some legal systems, this column reflects strictly domestic laws, including UNCRPD implementing legislation. Therefore, this heatmap represents a sketch, rather than a complete picture.

FORMAL PROCESSES FOR ENGAGING PEOPLE WITH IDD AND THEIR REPRESENTATIVE ORGANIZATIONS IN HEALTH POLICYMAKING

Creating equitable health policies requires intentional inclusion of people with IDD in both the development of health policy and the monitoring of its implementation. 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.[39] 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 an OPD—through formal institutional arrangements, programmatic partnerships, advisory roles, or advocacy, to name a few options. As far as formal representation of people (or individuals) with disabilities in the national health sector, the SLAs uncovered several good examples. In Nigeria, Paraguay, and South Africa, there is formal representation of persons with disabilities in the health sector in place or planned; however, there is no specific requirement for, nor historical representation of, those with IDD. In Chinese Taipei, there has been formal representation of organizations of persons with IDD or their caregivers, through a group on the rights of persons with disabilities convened by the Ministry of Health and Welfare.[40] Finally, in Ireland, the National Disability Authority—an independent state body tasked with monitoring and supporting the development of disability policy and practice across the country—has a board that includes people with disabilities, as well as experts on the rights of persons with disabilities. As stakeholders of the board, people with IDD provide input on policies and practices at national health sector levels. This is in addition to IDD-focused OPDs and other civil society organizations.

Promising Practice – Nothing About Us Without Us Act

In 2024, the legislature of the U.S. state 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.[41] The IDD advocacy community in Washington was quite active in the development and passage of this unique legislation.[42]

As mentioned previously, participation of people with IDD in OPDs, who in turn participate in decision-making processes, is also an option. OPDs are organizations "that are led, directed and governed by persons with disabilities [with a] clear majority of their membership ... recruited among persons with disabilities themselves...."[43] Reporting on the results of a survey of its membership, which is comprised of OPDs, the International Disability Alliance (IDA) concluded that "[p]articipation of persons with disabilities is not equal across the diverse constituencies of the disability rights movement," with persons with intellectual disabilities among the groups "still largely left out of consultation and decision-making processes."[44]

People with IDD may have demands that diverge from those of other groups with stronger representation in OPDs. They may also have unique needs to be able to participate and provide input in the first place. Nevertheless, from IDA's survey, it appears that the willingness to include is there: OPDs expressed "[a] demand for diversity and inclusion of all groups, or specific groups of persons with disabilities considered underrepresented," and included those with intellectual disabilities as one such group.[45] This is a positive step because it is, indeed, essential to have representation of people with IDD in OPDs. In most sites, the SLAs identified engagement of OPDs with the health sector but were unable to pinpoint participation or representation of individuals with IDD within the OPDs, nor participation by IDD-related OPDs.[46]

Whether participation is by an individual or an OPD, representation is not sufficient. To enable meaningful participation of people with any kind of disability, IDD included, in health policy creation and implementation, laws must mandate accommodations. For those with IDD, some of the most crucial accommodations tend to be accessible information and documentation, individual support people who are equipped to support those with IDD, and trained group facilitators who are equipped to work with neurodiverse groups.

This report's recommendations emphasize and add nuance to the following targeted actions identified in the 2022 *Global report on health equity for persons with disabilities*:

1. Prioritize health equity for persons with disabilities
14. Engage persons with disabilities and their representative organizations in health sector process

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 and sub-national health policy processes. Ensure accessible documentation and spaces and provide trained facilitators and support people to foster meaningful engagement of people with IDD.

Back Up Policy Initiatives with Budget Commitments for People with IDD

Ensure that national regulations address the needs of people with IDD—for example, Germany's dental health reform made more frequent checks available for those with IDD than the general population, and policies, such as those referenced later, subsidize travel for support people of those with IDD.[47] Governments must establish clear implementation mechanisms and adequate budget allocations to ensure that policies translate into inclusive and accessible services.

Empower People with IDD in Human Rights Monitoring

Strengthen the participation of people with IDD and their organizations in national and international human rights monitoring mechanisms, including shadow reporting on the UNCRPD, effective documentation of rights violations, and sharing of lived experiences. This will require, if not a redesign of systems, an implementation of accommodations to foster an enabling environment where people with IDD are key stakeholders in monitoring and upholding their rights.

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 of the 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.[48] For example, people with IDD who live in congregate settings—which is common, especially where deinstitutionalization is still a work in progress—may have little control over their nutrition or living spaces. 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.[49]

In 2006, the UNCRPD promoted a rights-based approach to health, focusing on dignity, autonomy, non-discrimination, full inclusion, and accessibility. From the mid-2000s onwards, the WHO has adopted resolutions and frameworks to promote a similar vision—of people-centered and integrated health services.[50] This section focuses on actions that have been highlighted in various calls for a person-centered approach, that the System Level Assessments surfaced as particularly relevant and lacking for those with IDD. Such actions include:

- Ensuring the education, support, and legal capacity people with IDD need to make decisions and participate in their own care.
- Encouraging health promotion and ill-health prevention strategies to help shift care to outpatient approaches.
- Coordinating care across disciplines to improve accessibility for those with multiple and complex conditions.
- Addressing not just the medical, but also the social and emotional needs of people with IDD, including through cross-sectoral coordination.
- Ensuring that services are understandable, physically accessible, and culturally sensitive.
- Involving and coordinating among an individual's entire circle of support, including—where appropriate—caregivers, families, support workers, and health care providers.

Alejandro

I live in Asunción, Paraguay and I have Williams syndrome. Even though I'm the son of a doctor, my family and I faced many barriers in getting my diagnosis. This is due to the lack of specialized medical knowledge in my country.

From what I'm told, my family didn't receive support or information when I was little. Throughout my life, I've encountered obstacles when trying to access healthcare services, education, and professional training. I've even experienced discrimination and bullying.

I just finished university studying social work and am getting ready to defend my thesis. I'm working toward an independent life and becoming autonomous in all aspects of adulthood—including navigating the healthcare system. One major barrier for me is the lack of accessible, easy-to-read information. This makes it difficult to understand how to access health care services and make informed decisions.

My mother has always supported me and advocated tirelessly. The support of my caregivers—especially my parents and sister—has been essential. But now we're in a time of change. They continue to care for me, but they're also afraid something might happen to me. Sometimes they struggle to accept that I'm an adult. They don't always know how to support me in this new stage of life. I believe they need more tools to help me transition to a more autonomous adult life.

ACCESSIBLE AND AVAILABLE HEALTH SERVICES

Despite international and national commitments to health for persons with disabilities, inequitable access to health facilities and poorer quality of care persist. As discussed earlier, people with IDD experience particularly low levels of access to and uptake of preventive services (e.g., vaccinations, dental check-ups), screenings (e.g., diabetes, cancer), and curative care. These various disparities contribute to shorter lifespans and higher rates of disease among people with IDD compared to the general population.[51]

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. People with IDD point to fear and embarrassment—including fear of physical examination, fear of needles, or concerns over discrimination by care providers—as factors that prevent them from seeking care or following through with recommended health services.[52] Furthermore, while 95% of the people with IDD surveyed know where to go when they are sick and have a place to go for care, 70% said they need support to get to a health care provider.

The System Level Assessments identified persistent gaps across five key elements of accessibility and availability:

National Guidance on Reasonable Accommodations

Nine of the 11 Rosemary Collaboratory sites have issued some form of guidance addressing reasonable accommodations for persons with disabilities, including in health settings. However, it is rare that this guidance explicitly mentions IDD or provides specific directions on accommodations responsive to the needs of neurodiverse populations. India's Harmonised Guidelines & Standards for Universal Accessibility in India, 2021 are one positive exception. Its recommendations include the use of pictograms, quiet waiting areas, and different light intensities.

Accessible Health Information

The availability of health information in accessible formats for persons with IDD on national websites varies significantly. No information in such formats was identified in Morocco, Nigeria, Pakistan, and Paraguay. In contrast, Chinese Taipei, Ireland, and South Africa have made some materials available in plain language or specifically targeted to people with IDD. India, South Africa, and the United States' sites (especially the state of Washington) have promoted accessibility of health information through policies or guidelines, though implementation quality may vary.

Transport Subsidies

Transport subsidies for people with disabilities are in place at some level in nine of the 11 sites. These subsidies typically apply broadly to people with disabilities, rather than targeting the needs of people with IDD, such as travel with a support person. In the United States, all people with Medicaid insurance can use a non-emergency medical transport benefit. In recent analyses, approximately one-third to one-half of people with IDD were insured through Medicaid.[53]

Common challenges across sites include poor compliance by transport companies, limited physical and sensory accessibility of transportation, and the complexity of transport navigation that often necessitates the support of others.

Promising practices exist in India and Ireland, where free fares for those who accompany persons with disabilities further help address cost barriers.

Care Coordination

Seven of the 11 sites reported the existence of care coordination or support staff.

For instance, India relies on Anganwadi workers, frontline workers who are part of the Integrated Child Development Services Scheme (ICDS), for early identification and referrals, thereby reaching young children. Morocco employs socio-medical assistants. The United States has community health workers and managed care organizations with a care coordination function. In each location, these roles differ in scope and effectiveness; for instance, they may support identification of a developmental delay, but not provide coordination of needed services or ongoing support. Nevertheless, such roles provide a foundation on which countries can build.

Reimbursement Adjustments for Providers

Short appointment times are a key barrier to quality health care for people with IDD, particularly where reimbursement structures often disincentivize longer consultations, as in the United States. SLA findings indicate that many countries did not see reimbursement adjustments as relevant. This is supported by financial incentives for health workers being the fourth (of six) options labeled by health worker survey respondents as a key challenge. However, health care worker survey responses show that both U.S. (69%, n=48) and non-U.S. (54%, n=125) health workers view consultation time as a critical enabler of quality care. That is, globally, 57% (n=158) of all health worker survey respondents strongly agreed that expanding consultation time would improve the self-efficacy of health workers to provide care for people with IDD, with a further 34% (n=94) agreeing.

Nicole*

I live with two of my friends in a community home not far from where I grew up and where my family lives near one of Pennsylvania's big cities. I work part-time at a local grocery store—I have been there for 25 years! I spend my free time playing golf with Special Olympics and volunteering at my neighborhood food pantry, bringing groceries to people who need them.

The staff at my community home give me day-to-day support, like reminders to stay on track with healthy eating, exercise, and taking my vitamins. I lift weights, swim and walk for exercise. But 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. Ever year, I see my gynecologist, primary doctor, and cardiologist. I also see my orthopedist, foot doctor, eye doctor and hearing aid doctor. Every year, I get my flu shot and COVID shots and mammogram.

My doctors 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 too stressed out.

I like when my doctors are patient, when I need them to repeat things and I wish my doctors would talk more to each other because that would be easier for me.

There are, therefore, many obstacles to person-centered care: inaccessible information, complex and uncoordinated systems of care, and physically and sensorially inaccessible health settings all make it difficult for people with IDD to take charge of their own health. Two ideas to help move toward a person-centered approach are health care or hospital passports and patient navigators. 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.[54] 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.[55] 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. Patient navigators have a similar "bridging" function between a person with IDD, the system or, more likely, multiple systems, programs, and providers with whom they need to interface.[56]

AGENCY, SUPPORT, AND DECISION-MAKING

The exclusion of people with IDD from decision-making regarding their own health is yet another example of their invisibility. The 2018 UN Disability and Development Report does not single out people with IDD, but it underscores that the exclusion of people with disabilities from health decision-making contributes to health disparities and hinders progress toward global goals.[57] Among the people with IDD surveyed for this report who responded to this question, 32% (n=203) reported that they make their own decisions about their health, 34% (n=217) said they do sometimes, and 34% (n=216) said they do not make their own decisions. To a separate question, the vast majority of people with IDD who responded (86%, n=543) reported having someone who helps them with health care decisions, while 14% (n=90) 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 often 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. As examples of this approach, the SLAs revealed that the Family Code in Morocco, using a variety of terminology inconsistent with the UNCRPD, considers people with mental disabilities (a term understood locally to include those with IDD) incapable of representing themselves legally and places them under parental authority. A similar situation persisted in Paraguay until a landmark reform in July 2025. Prior to this point, Paraguay's Civil Code, for example, stated that people who "due to mental illness, are not capable of caring for themselves or managing their property" shall be declared incapable and be subject to guardianships, despite this approach being in direct conflict with the UNCRPD and domesticating legislation (Law 3540/08).[58]

Next are situations in which legislation may not categorially 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.[59] 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.[60]

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.[61] Two of the three U.S. states where SLAs

were completed—Washington and Wisconsin—explicitly enable or promote supported decision-making.[62] India's Rights of Persons with Disabilities Act 2016 is similar—affirming the legal capacity of persons with disabilities while also contemplating limited guardianships and explicitly discussing support to persons with disabilities to make decisions. It is also true that some individuals with IDD may actively seek a guardianship, power of attorney, or similar arrangement to avoid feelings of isolation and to try to ensure that they have access to chosen support systems.

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

Sana

Sana was born in Pakistan with heart problems and epilepsy. Since birth, Sana had frequent health issues requiring continuous care and attention. Her mother, Naseem, works as a psychologist at a mental health institute in Lahore, Pakistan. Despite her professional background, Naseem found navigating the health care system overwhelming as her daughter faced frequent illnesses and delays in meeting developmental milestones.

As Sana grew older, she would run off, sometimes even leaving the house. "Even as she grew older, I kept her in my lap to manage her restlessness," Naseem shared.

When Sana had her first period at the age of 12, her family made a difficult decision: hysterectomy, a surgical procedure to remove the uterus. Her mother explained, "There was a question of managing her periods. She may have learned with guidance, but why burden her?"

The decision was influenced by the family's concerns about menstrual hygiene and fears of potential abuse. They observed that marriage is rarely possible for girls like Sana, and their considerations were made projecting lifelong dependency for Sana.

Naseem continues to believe this was the right decision for Sana and that parental consent should suffice for these decisions. She also maintains that the lack of clear guidelines or laws surrounding invasive procedures for individuals with intellectual disabilities places an immense burden on parents.[62]

Sana's story illustrates that even when laws are in place that respect the rights of persons with IDD, the attitudes of support people, family members, and society at large can still stand between individuals and their rights.[63] Clear guidelines and standardized protocols on decision-making can help bridge the law-to-practice gap and make it possible for individuals with IDD, support people, and health workers to pursue appropriate courses of action, both big and small.

Health decision-making is further complicated by the question of individuals' capabilities at different stages of life or moments in time. Being a child, a person with IDD, and a girl, Sana was almost certain to have her agency overlooked or denied. The 2023 *Global report on children with developmental disabilities* urges consideration of the evolving capacity of people with developmental disabilities as children and young people.[64] 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.

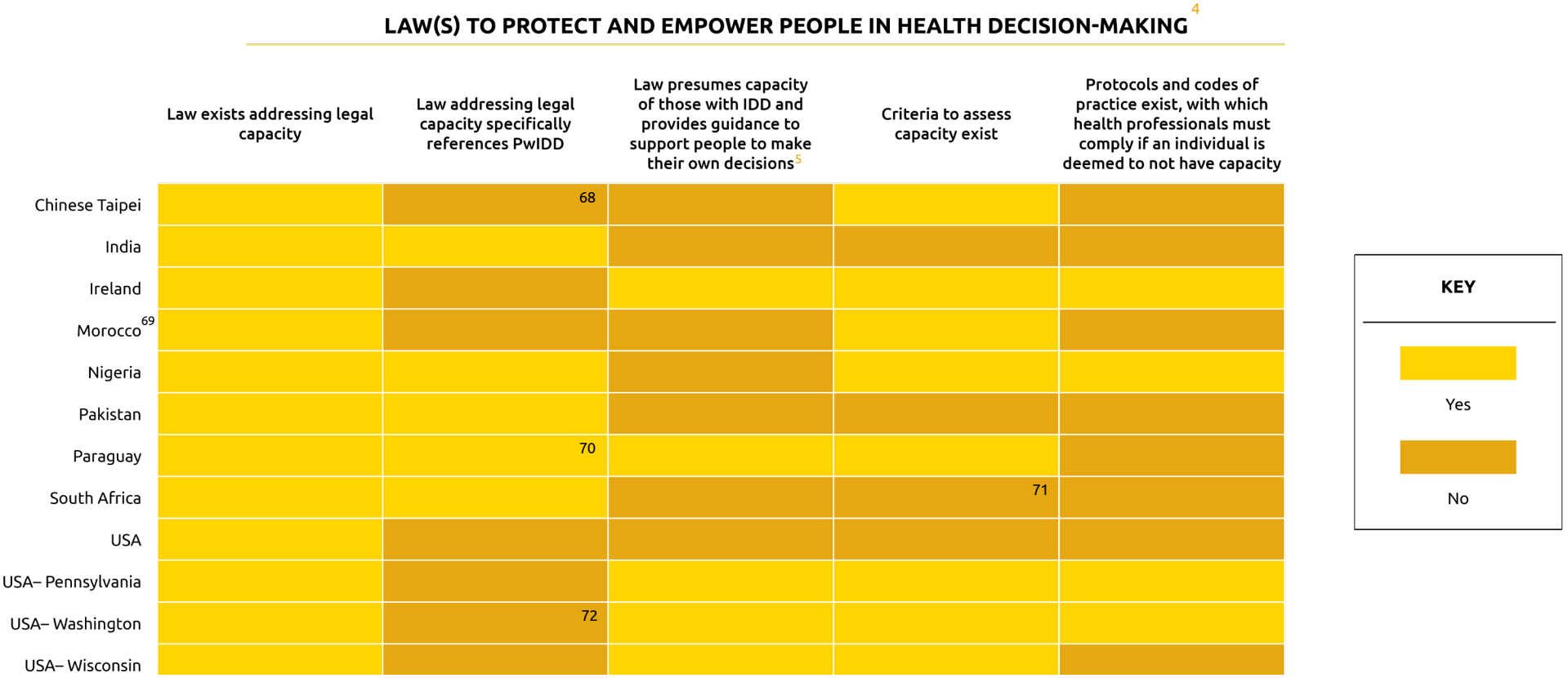
Legislation in effect in Ireland addresses these concerns about lack of guidelines and standardized protocols, as well as evolving capacity.

Promising Practice: Assisted Decision-Making (Capacity) Act 2015

Ireland's Assisted Decision-Making (Capacity) Act 2015 represents a global promising practice on this topic.[65] 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 is that the test 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.[66] 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.[67]

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



[4] SOI recognizes that some countries may address IDD using other terminology, such as mental disabilities and psychosocial disabilities, as well as other, outdated terminology that is considered offensive. IDD, for the purposes of the application of the key in this table, takes into account specifically the terms "intellectual" and "developmental," in reference to a "disability(ies)," "disorder," or "impairment." Attempt has been made to mention where other terminology, that may be locally referring to people with IDD, is used.In most instances, the specific references to IDD in the law addressing legal capacity are in the definition of disability.

[5] As indicated in this heatmap and discussed earlier in the report, few Rosemary Collaboratory sites have legislation that categorically denies persons with IDD of legal capacity. Nevertheless, because it is also rare that legislation provides guidance to support people to make their own decisions, many sites whose laws presume capacity appear as “no” because this column takes both features into account.

This report's recommendations emphasize and add nuance to the following targeted actions identified in the 2022 *Global report on health equity for persons with disabilities:*

22. Consider the full spectrum of health services along a continuum of care for persons with disabilities.
32. Provide appropriate reasonable accommodations for persons with disabilities

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:

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 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 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 (queue jumping). Governments and health institutions must ensure widespread implementation and training on the use of these accommodations to ensure their acceptance and uptake.

Strengthen and Implement Supported Decision-Making

Revise legislation to eliminate provisions that restrict the legal capacity of people with IDD and are not harmonized with the UNCRPD. 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,[73] (c) guidance and training for health 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.[74]

Make Information Accessible and 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[75] formats and materials developed using universal design principles, along with 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.

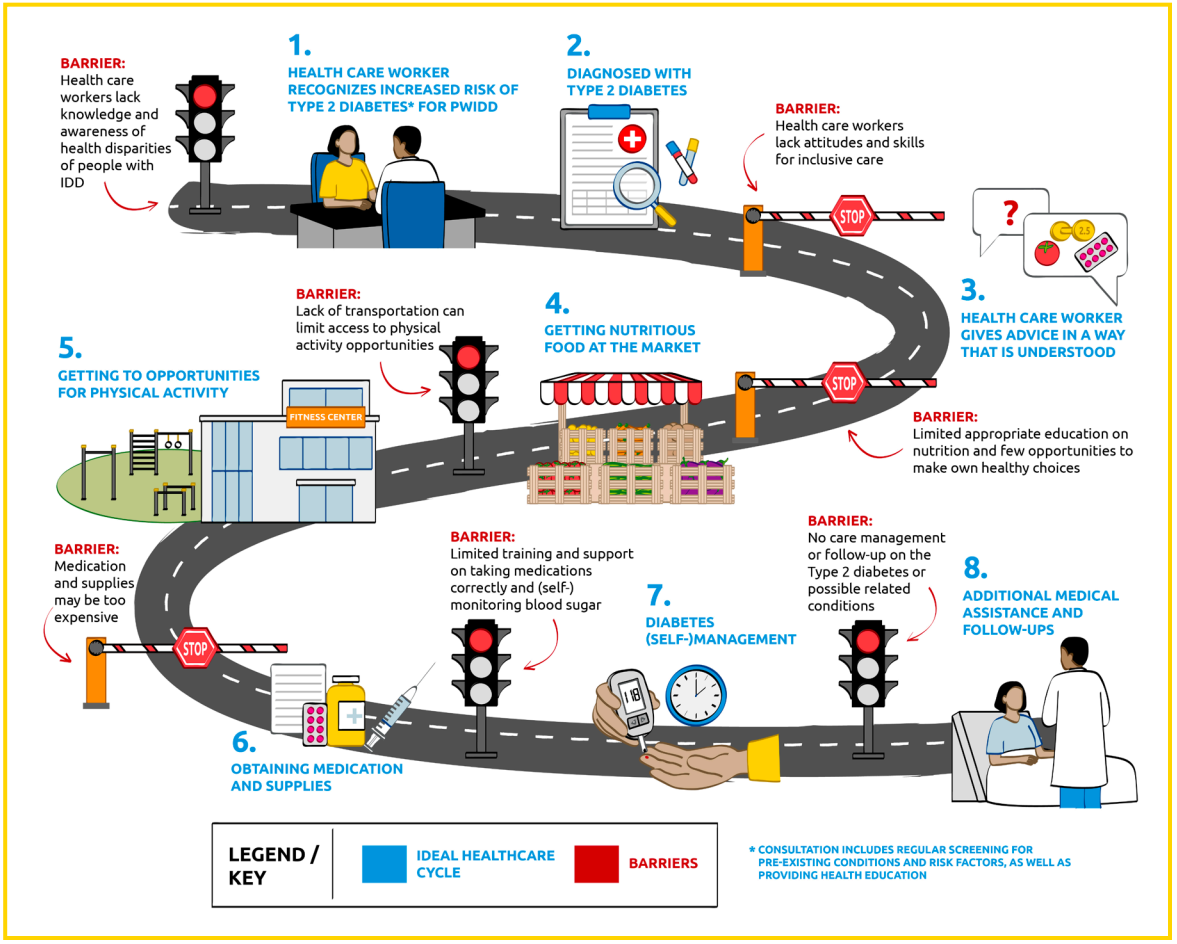
I caught a few of the recommendations—he said I needed to exercise more, eat small meals every three hours, and follow a low-sugar diet. He also suggested a diabetic drink, but my first thought was, "How am I going to afford that? I don't even

Michele

know if my insurance will cover it." *(continued)*

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 AND CARE WORKFORCE

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

Many health and care 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 and 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.

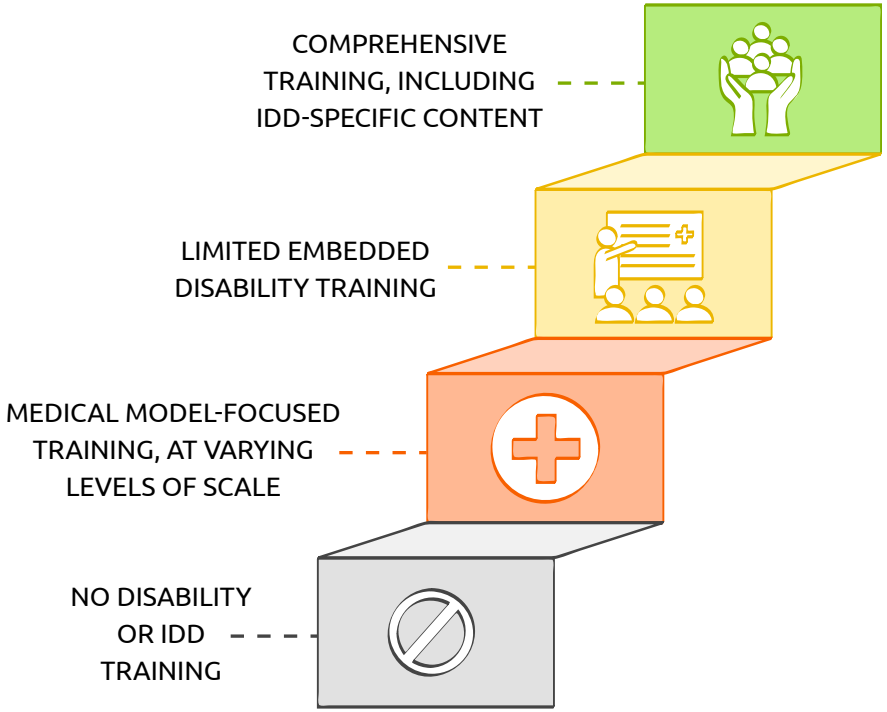
TRAINING IN ADDRESSING THE WIDE-RANGING NEEDS OF PEOPLE WITH IDD

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 workers, leaving many unprepared to provide quality care for these individuals, which is an ongoing challenge. Globally, there is wide variation in the extent and quality of such training—ranging from complete absence to comprehensive, competency-based programs. Understanding different approaches to training helps highlight both the gaps and the opportunities for reform.

Many health workers receive limited education on caring for people with IDD. For example, a survey of newly graduated medical practitioners in Malaysia found that only 28% had received more than five hours of instruction on IDD.[77] Even in countries where disability is included in medical curricula, IDD is often overlooked or only covered in terms of clinical and technical aspects, which serves to reinforce a medical model view of disability.

Effective care for people with IDD requires more than clinical knowledge. In Nigeria, the Medical and Dental Council medical curriculum includes dedicated modules on intellectual disability and related content in social medicine, indicating an effort to normalize disability training institutionally. In Pakistan, general competencies on disability care are included, but do not focus specifically on IDD. India, prior to recent curriculum reforms, had adopted this approach.

STEPS TOWARDS TRAINING AN INCLUSIVE HEALTH WORKFORCE



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. For example, diagnostic overshadowing occurs when health workers erroneously attribute an individual's health complaints or behaviors to their IDD.[78] Clinical knowledge alone is not sufficient for addressing this problem.

Adam

Salam, I'm Adam. I'm 16 years old and I live with intellectual disability and have epilepsy. I go to a care center that makes me really happy. I love playing football and riding horses there. Right now, I'm working with a team on a big project—we're building a statue of Africa using recycled plastic!

Because of my health, I have to take medicine every day and go to the doctor often. I see different health providers like neurologists and therapists. One time, I stopped taking my medicine because I wanted to feel more grown-up and independent. Back then, I didn't understand how important the medicine was. My family and the health providers at the center helped me get back on track and take my medicines daily. They talked to me kindly and explained everything to me. This helped me feel safe again.

Now, I really like it when health providers explain things clearly to me so I can make choices about my health.

One of the main challenges in caring for individuals with IDD is overcoming communication barriers. Health workers may speak very quickly or in complex jargon, and they may underutilize—for instance, due to lack of familiarity—assessment and diagnostic tools that exist for people, including those with IDD, who communicate non-verbally. Among the people with IDD who responded to the survey, 52% (n=344) indicated that they always understand their provider, yet 69% (n=457) of all respondents with IDD also said that someone helps explain things after their health care provider talks or gives instructions, demonstrating that there is significant margin for improvement of provider skills. In response to a question "what would help you get better healthcare?" one of the top three most frequently chosen responses (n=239) was "clearer, easy to understand instructions from healthcare providers." For their part, 61% (n=169) of the health worker survey respondents strongly agreed that IDD training would be an effective strategy for improving their self-efficacy, with an additional 31% (n=86) agreeing, and 74% (n=201) 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 22% (n=61) considering it moderately important.

Indeed, the 2022 *Global report on health equity for persons with disabilities* calls for training that covers both condition-specific needs (e.g., pressure sore prevention) and disability-inclusive approaches to health needs that are well represented among the general population (e.g., maternity care).[79]

Talha

Talha is the third of his parents' children with IDD. Experience with Talha's older siblings made his parents attuned to child development and forged their advocacy skills. Nevertheless, Talha encountered numerous barriers and had negative experiences with the health system in his native Karachi, Pakistan.

As Talha grew older, his parents noticed he watched TV at an unusually close distance. Talha's parents took him to visit four or five ophthalmologists, but none could determine his prescription. Talha couldn't read the letters they asked him to identify. They tried using dilating drops, but even then, they couldn't assign a proper number for vision correction.

With the support of Special Olympics Pakistan, Talha's parents took him to an institution that partners with Special Olympics on eye screenings, following a protocol that uses the symbol-based LEA acuity chart rather than the traditional letter chart. "There we were able to get the number in four or five minutes. And it was a perfect number," says Talha's father, Nauman, referring to the ability of professionals with the right training to get his son's accurate eyeglass prescription. People working at that institution know how to work with those with disabilities who, as Nauman observes, "may be verbal, but have difficulty in understanding what the doctor is saying."

To address these persistent gaps, the WHO has launched a process 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.

Currently, most countries lack licensing requirements that ensure health workers receive training in providing quality care to people with IDD after graduation and once they begin practicing. Health 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.

Promising Practice: IDD Training Across Professional Lifespan

In Oman, faculty from the University of Technology and Applied Sciences have been trained on the specific health needs of people with IDD. While the original focus was on physiotherapy, faculty from other health disciplines and academic departments have also been trained as part of the mission of interprofessional training. This is leading to faculty who collaborate to train students in the classroom, conduct joint research projects focused on sports and social integration of people with IDD, and provide opportunities for trained healthcare providers and students to work with people with IDD. In addition to reaching the future health workforce, steps are being taken to reach the current health workforce: the Oman Physical Therapy Association is committed to training physiotherapist members of the association and continued efforts towards professional education to improve health services delivered to people with IDD.

National governments and international health organizations should push for standardized licensure and renewal requirements and incentivize inclusive practices. Education and credentialing regarding quality care for people with IDD should be integrated at every stage of a health 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 workers, linked to appropriate accreditation or continuing education requirements.

This report's recommendations emphasize and add nuance to the following targeted actions identified in the 2022 *Global report on health equity for persons with disabilities:*

26. Provide training in disability inclusion for all health service providers

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 and care workforce require for inclusion:

Require Comprehensive and Evidence-Based Training

Make training for inter-professional health and care 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 and respectful.
ii. The training approaches are tailored to meet the needs of health 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 country's health systems 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 and 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 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 countries to track 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)

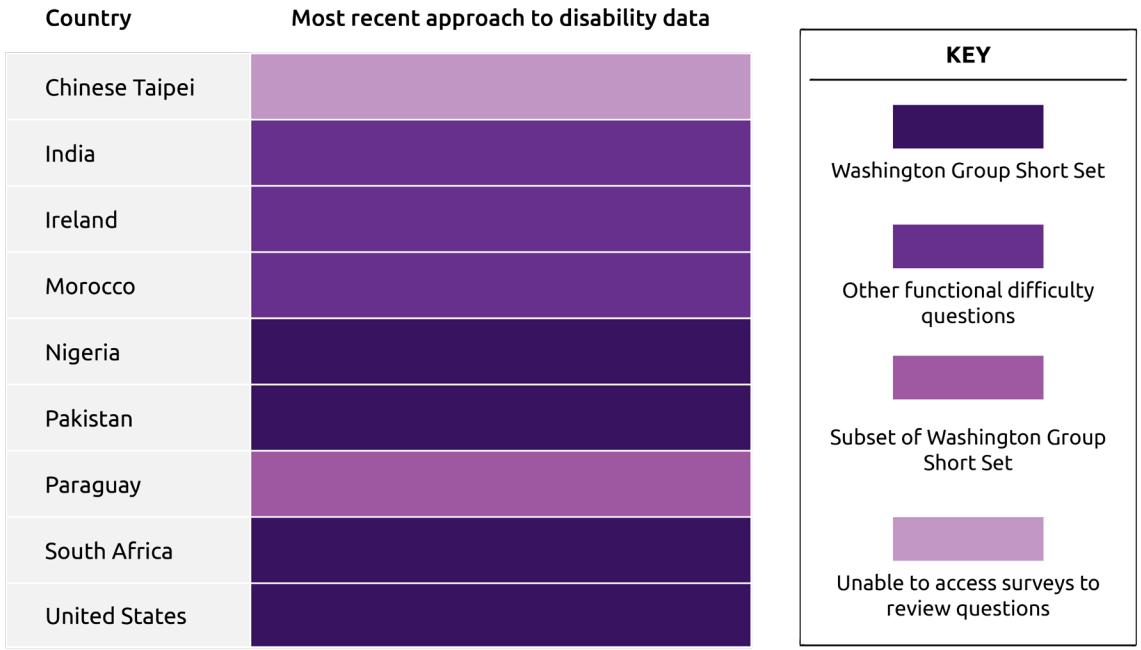
The Independent Monitoring for Quality (IM4Q) program operates across the U.S. state of Pennsylvania to ensure that the voices of people with IDD are heard. IM4Q's goal is to improve the quality of life and services for individuals with IDD by gathering their direct input and using it to propose policy 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 Rosemary Collaboratory 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) in their national censuses and public health surveillance. The WG-SS 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 sensitivity to identify people with IDD.[80]



Referring to desk research, including the Disability Data Initiative's review of population and housing censuses and household surveys[81], revealed that:

- Four out of the nine countries where SLAs were completed relied on the WG-SS,
- Four countries relied on other functional difficulty questions, one of which used a subset of the WG-SS, and
- One did not have any functional difficulty questions identifiable in publicly available documents.

Each location's most recent approach is detailed in Annex 3.

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.[82]

In addition to the challenge of identifying people with IDD at a population level, these individuals are also largely underrepresented in peer-reviewed studies, clinical trials, national health surveys, and research investigating the social determinants of health.[83] One explanation for this underrepresentation is recruitment and participation barriers.[84] 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.

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.[85] 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.

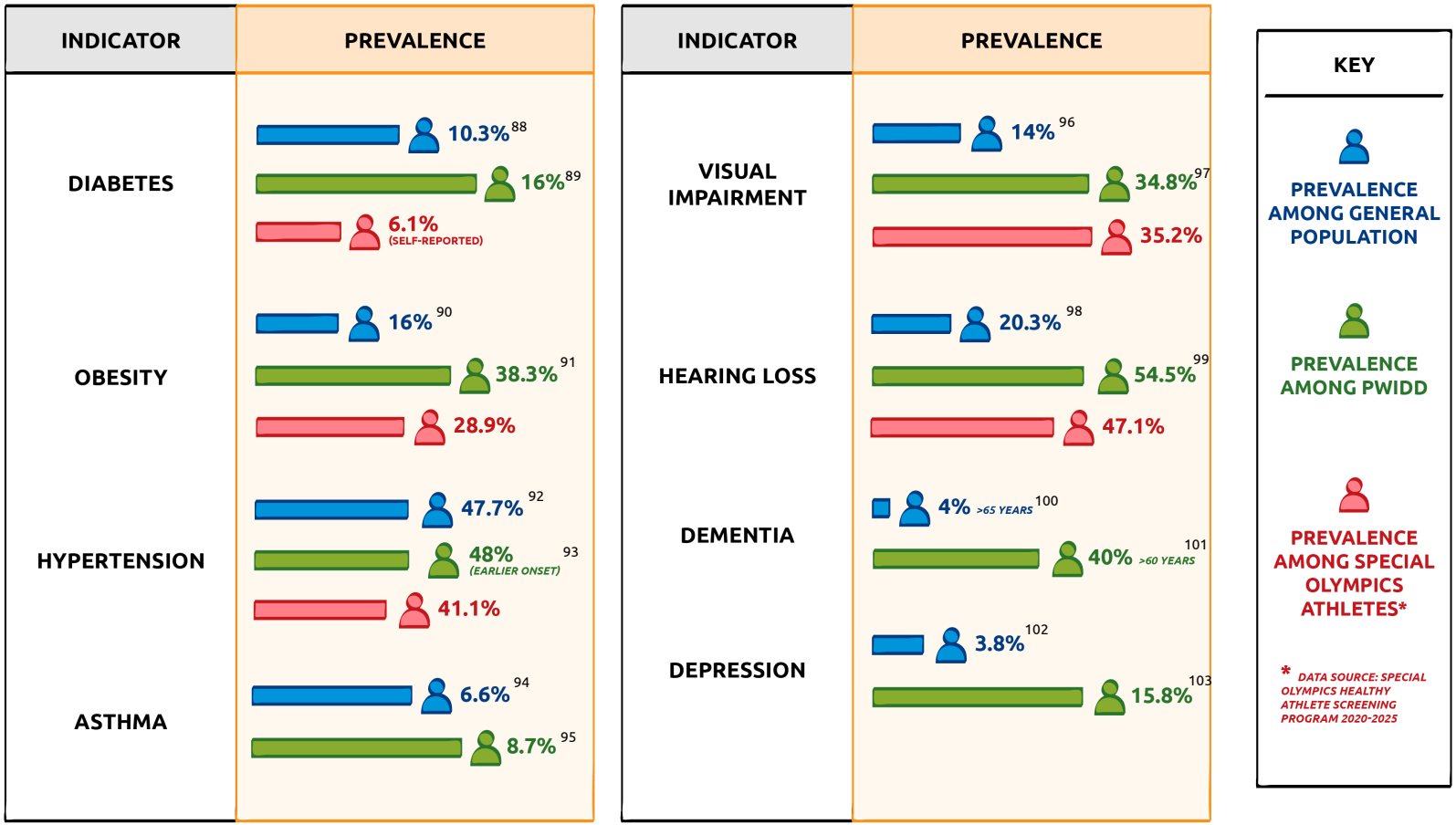
Although ethical concerns regarding data collection from people with IDD are important, these concerns should not prevent their inclusion in research. Instead, research practices should respect and accommodate their varying degree of ability to participate. Additional safeguards in recruiting and consent procedures for participants have been successful methods for gaining the approval of IRBs.[86]

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.[87] Additionally, trial recruitment efforts may be hindered by limited access to communication channels, such as telephones or community newsletters, disproportionately affecting individuals with IDD.

This population's absence or exclusion 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 FOR INCLUSION OF DATA RELATED TO PEOPLE WITH IDD INTO HEALTH DATA SYSTEMS

The research and data on health outcomes for people with IDD that do exist are often not representative or generalizable to the broader population of people with IDD and, therefore, not considered within country-level planning and resourcing of responses. Without accurate national data of both the health needs and gaps in delivery, governments and health and 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 government ministries to work together. This leads to confusion regarding the actual numbers and needs of individuals and impedes planning across sectors.[104] It also leads to insufficient financing and planning, which are key barriers to the implementation of even the best policies and approaches. Furthermore, it jeopardizes health security; disaggregated data is vital for disease surveillance and distribution, especially in an emergency-response situation like COVID-19.[105]

Finally, data also need to be systematically collected as part of a broader health system and larger information gathering efforts. Disaggregated data, as emphasized in SDG Target 17.18,[106] are crucial to revealing inequalities and ensuring no one is left behind.[107] These 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

DATA AS A DRIVER FOR ACTION AND ACCOUNTABILITY

Data are key to providing a baseline from which stakeholders, including the government, 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.

Promising Practice: Down Syndrome International-Humanity & Inclusion Global Consultation on Health Equity

"People look at the referral and see Down syndrome and they shut their mind to anything else. It's like I am a syndrome, not a person."

In 2024, Down Syndrome International (DSi) with Humanity & Inclusion (HI), ran 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. Some of the findings included these:

- Satisfaction with general healthcare is low among people with intellectual disabilities. Only 26% rated it as "OK" and just 15% were "satisfied."
- Healthcare is unaffordable for many people, especially in lower-income countries, where less than 20% said it is affordable. People are forced to choose between essential health services. *(continued)*

- Many people cannot access the services needed, including speech therapy and mental health services.
- Health providers often lack training in inclusive communication and person-centered care. As a result, people with intellectual disabilities face inaccessible health information, inadequate communication, and routine exclusion from decisions about their own healthcare.
- Transitions from child to adult healthcare are poorly supported, and there is more focus on the health of babies and children with intellectual disabilities than adults.
- There were reports of discrimination and denial of health care on the basis of disability.
- People with intellectual disabilities, particularly women and girls, face forced sterilization and limited access to sexual and reproductive health services.

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.

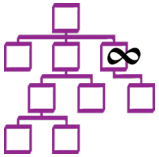
Last, data are valuable for organizations and communities advocating for the needs of people with IDD. These entities are often partners in collecting and validating data at the household and community levels. They also play an important role in investigating and elaborating on gaps in both data and 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.

This report's recommendations emphasize and add nuance to the following targeted actions identified in the 2022 *Global report on health equity for persons with disabilities*:

17. Engage persons with disabilities in research and include them in the health research workforce
39. Integrate indicators for disability inclusion into the monitoring and evaluation frameworks of country health systems

RECOMMENDATIONS

Effective data collection and analysis are fundamental to addressing the health disparities faced by people with IDD. These processes illuminate gaps in health 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 globally:



Improve Data Disaggregation by Impairment or Disability Types

Enhance existing data collection systems to ensure those with IDD are appropriately captured, using standardized measures and/or more tailored tools that more accurately capture their health status and needs.

Make Data Publicly Available

Provide open access to data on health outcomes and service coverage of people with IDD. Develop public dashboards or reports, in an accessible format, to enable organizations and individuals to monitor progress and identify systemic gaps.

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 intellectual and developmental disabilities (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 around the world. 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 fifteen 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. Greater investments in inclusion are necessary, and ensuring people with IDD have a say in those investments will make them as effective as possible.

Person-centered Care

Protect and promote provision of health information in Easy Read formats as a key accommodation. Requiring universal design in health system paperwork and processes can help improve quality and continuity of care, as well as the autonomy of people with IDD.

Health and Care Workforce

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

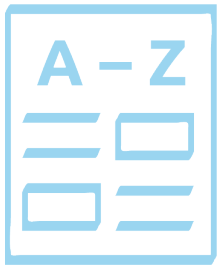
Data for Monitoring and Research

Improve data disaggregation by disability types to ensure people with IDD are accurately represented in health data systems, 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 seen, as well as empowered, supported, and included in every aspect of society, starting with their health.

GLOSSARY AND ANNEXES



CHW	Community Health Worker
GALC	Global Athlete Leadership Council
IM4Q	Independent Monitoring for Quality
IRB	Institutional Review Board
IDD	Intellectual and Developmental Disabilities
MBI	Missing Billion Initiative
MCO	Managed Care Organization
OPD	Organization of Persons with Disabilities
PALS	Patient Advisory Liaison Services
PHC	Primary Health Care
PWIDD	People (or persons) with Intellectual and Developmental Disabilities
RALC	Regional Athlete Leadership Council
SDGs	Sustainable Development Goals
SLA	System Level Assessment
SOI	Special Olympics International
UHC	Universal Health Coverage
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WG-SS	Washington Group Short Set on Functioning
WHO	World Health Organization

Annex 1:

Missing Billion System Level Assessment

Annex 2:

WHO Framework to advance health equity for people with disabilities through PHC

Annex 3: Disability-Related Data Gathering

Rosemary Collaboratory Site	Disability-related Data Gathering
Chinese Taipei	Various surveys featuring disability data are used including the Directorate of Budget, Accounting and Statistics' "Social Indicators Yearbook" , the Population and Housing Census and the Ministry of Health and Welfare's Disabled People's Living Condition and Demand Survey. These surveys do not appear to be publicly available, but the data charts indicate that questions are unlikely to be WG-SS (social indicators, census).
India	India's National Statistical Office implemented the National Sample Survey (NSS) 76th round in 2018 as the Survey of Persons with Disabilities. It does not include the WG-SS (see pages 4-6).
Ireland	The annual Healthy Ireland Survey as well as 2006 Census, and the 2006 National Disability Survey included disability disaggregation that delineates intellectual disability. In addition, the Irish Health Survey includes questions more similar to the WG-SS.
Morocco	Morocco implemented a national census and National Disability Survey in 2014, both of which included the WG-SS as well as a complementary set of questions touching on topics including family environment, accessibility, access to health care, and education for those indicating any degree of difficulty within the WG-SS.
Nigeria	Nigeria conducted the Demographic and Health Survey (DHS) most recently in 2023-2024 which features the WG-SS questions.
Pakistan	Pakistan conducted the Demographic and Health Survey (DHS) in 2017-2018 which features the WG-SS questions. Census 2023 included the WG-SS.

Rosemary Collaboratory Site	Disability-related Data Gathering
Paraguay	Paraguay conducted its most recent census in 2022 and used versions of the WG-SS with modifications. In 2012, one of the changes was to add an explanatory parenthetical to the question about the cognition domain, mentioning (among others) Down syndrome and autism. In 2022, the census included questions for only four domains: vision, hearing, mobility, and self-care.
South Africa	South Africa's most recent census was in 2022 and featured the WG-SS. The most recent General Household Survey was in 2024 and also includes the WG-SS. South Africa last conducted the Demographic and Health Survey (DHS) in 2016 which included the WG-SS questions.
USA	The National Health Interview Survey (NHIS) is conducted yearly and includes questions similar to the WG-SS. Additional questions probe some of the domains further, such as cognition and social functioning. The NHIS further asks if the difficulty began before age 22. The Behavioral Risk Factor Surveillance System (BRFSS) is a continuous survey that is conducted yearly. Beginning in 2016, BRFSS has used the questions that ask six functional limitation questions similar to the WG-SS, but answer choices are yes/no.

END NOTES

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[4] Carulla, L. S., Reed, G. M., Vaez-azizi, L. M., Cooper, S., Leal, R. M., Bertelli, M., Adnams, C., Cooray, S., Deb, S., Dirani, L. A., Girimaji, S. C., Katz, G., Kwok, H., Luckasson, R., Simeonsson, R., Walsh, C., Munir, K., & Saxena, S. (2011). Intellectual developmental disorders: towards a new name, definition and framework for "mental retardation/intellectual disability" in ICD-11. *World Psychiatry*, 10(3), 175–180. https://doi.org/10.1002/j.2051-5545.2011.tb00045.x.

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[12] Additionally, a distinct survey of people with IDD covering similar topics was carried out slightly earlier in Paraguay, garnering 50 responses. While the surveys varied slightly in timing and items, efforts have been made to merge their data, where methodologically sound (questions in common).

[13] The Global Athlete Leadership Council (GALC) is one of the ways in which persons with IDD participate in setting the strategies and providing substantive governance to the Special Olympics movement. The GALC is made up entirely of athletes (persons with IDD), with at least one representing each of the seven Special Olympics regions. These individuals were nominated and voted by a group of their peers at the regional level (Regional Athlete Leadership Council, RALC). The membership of each RALC is comprised of athletes from the Special Olympics chapters within that region; Special Olympics chapters also have athlete leadership councils who advise on more localized issues, and athletes who go on to serve in the RALC and GALC typically start with local leadership opportunities. The GALC provides feedback, guidance, and ideas to the Special Olympics International Board of Directors and Leadership Team. The GALC meets online on a monthly basis, and each GALC member takes information/consultations shared at that meeting to their region's RALC, which takes the consultation to the chapter level. The information flow then reverses such that responses reach the GALC, which is able to convey the questions and recommendations of a global sample of those with IDD. Members in the GALC serve four-year terms, with RALC and local equivalents also rotating regularly (two- to four-year terms).

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[15] Committee on the Rights of Persons with Disabilities. (2018). *General comment no. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the convention* (CRPD/C/GC/7). United Nations. https ://docs.un.org/en/CRPD/C/GC/7.

[16] The United States has signed but not ratified the UNCRPD. Chinese Taipei demonstrated its commitment to the contents of the UNCRPD by passing the Act to Implement the Convention on the Rights of Persons with Disabilities (*Protecting the rights of children and the disabled*. (2022, September 29). Executive Yuan, R.O.C. (Taiwan). Retrieved July 24, 2025, from https://english.ey.gov.tw/News3/9E5540D592A5FECD/db39792e-781c-4604-90ca-a93a06c68b84#:~:text=Human%20rights%20are%20universal%20values,rights%20of%20these%20two%20groups).

[17] Shah, A., World Bank, & South Asia Poverty Reduction and Economic Management Unit. (2012). Making federalism work – the 18th Constitutional Amendment. In *World Bank Policy Paper Series on Pakistan*. https://documents1.worldbank.org/curated/en/687281468057882110/pdf/871020NWP0Box30ing0Federalism0Work.pdf; see, e.g., the Balochistan Persons with Disability Act 2017, the Sindh Empowerment of Persons with Disability Act 2018, and the Punjab Empowerment of Persons with Disabilities Act 2022.

[18] World Health Organization & United Nations Children's Fund. (2023). *Global report on children with developmental disabilities: from the margins to the mainstream*. https://www.unicef.org/media/145016/file/Global-report-on-children-with-developmental-disabilities-2023.pdf; Bonardi A., Krahn G., Morris A., & the National Workgroup on State and Local Health Data (2019). Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities. In *Administration on Intellectual and Developmental Disabilities*. https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/Final_State_Data_Paper_09.25.2019%20word%20master%20508%20compliant.pdf; Havercamp, S. M., & Scott, H. M. (2014). National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disability and Health Journal*, 8(2), 165–172. https://doi.org/10.1016/j.dhjo.2014.11.002; Krahn, G. L. (2019). A call for better data on prevalence and health surveillance of people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 57(5), 357–375. https://doi.org/10.1352/1934-9556-57.5.357.

[19] World Health Organization. (2011). *World Report on Disability*. https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability; World Health Organization., 2022, p. 97.

[20] *The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) funding allocations*. (n.d.). ACL Administration for Community Living. http://acl.gov/about-acl/developmental-disabilities-assistance-and-bill-rights-act-2000-dd-act-funding-allocations; *Center for Transition to Adult Health Care for Youth with Disabilities - Family Voices*. (2025, June 5). Family Voices. https://familyvoices.org/healthcaretransition/.

[21] The Act to Implement the Convention on the Rights of Persons with Disabilities intends to incorporate the UNCRPD into the domestic legal order. The People with Disabilities Rights Protection Act protects the right to health and refers to disability as including those with "mental impairments" who "can be regarded as suffering one of the following malfunction categories," where one such category is "mental functions and structures of the nervous system."

[22] There are, however, policies in existence since the early 1990s promoting early childhood intervention.

[23] The Handbook of Taiwan's National Health Insurance and the Project to Improve the Quality of Psychiatric Medical Services for People with Mental Disabilities both refer to those with mental disabilities, understood locally to include intellectual and developmental disabilities.

[24] The National Policy on Disabilities 2006 mentions the provision of special education, speech therapy, occupational therapy, and assistive devices for those with mental disabilities (understood locally to include intellectual disabilities). The National Health Policy 2017 "recommends an expansion of scope of interventions to include early detection and response to early childhood development delays and disability, adolescent and sexual health education, behavior change with respect to tobacco and alcohol use, screening, counseling for primary prevention and secondary prevention from common chronic illness—both communicable and non-communicable diseases." While important policies, neither promote access to a full range of health services for persons with disabilities.

[25] In India, Public Health is a state subject according to List II of the Seventh Schedule of the Constitution of India, therefore, the primary responsibility for health lies with the State and Union Territory Governments. However, the Ministry of Health and Family Welfare supports States and Union Territories to strengthen health care systems to provide universal access to quality health services. One major initiative is RBSK, discussed earlier, which offers free health screening and early intervention services for children aged 0-18 years to detect and manage what the program refers to as the 4 Ds "birth defects, diseases, deficiencies, and developmental delays."

[26] People with IDD, and the need for consideration of them in program delivery plans, were specifically mentioned in the National Sexual Health Strategy 2015-2020 and in Smile *agus Sláinte*: National Oral Health Policy.

[27] The 2016 Framework Act adopts a definition of persons with disabilities that differs slightly from that of the UNCRPD, which explicitly references intellectual disabilities. While the Act does not directly mention "intellectual disabilities," it uses the terms "mental [or] psychic" (in French – *mentales, psychiques*; in Arabic in Arabic – عقلية أو نفسية). These terms are generally understood to encompass disabilities related to intellectual and cognitive functioning. Legislative history suggests that the drafters intended to include individuals with IDD, and subsequent government actions further support this interpretation.

[28] In addition to including "intellectual…impairment" in the definition of disability, the Discrimination Against Persons with Disabilities Prohibition Act of 2018 states that "[a] person with mental disability shall be entitled to free medical and health service in all public institutions."

[29] The National Strategic Health Development Plan Framework (2018-2022) mentioned the prevention of disabilities caused by non-communicable diseases and neglected tropical diseases.

[30] The National Policy for Persons with Disabilities, from 2002, uses terminology now considered derogatory to refer to those with IDD.

[31] The legislation in question is the Mental Health Care Act, which affirms the right to mental health care specifically for "persons with severe or profound intellectual disability."

[32] The National Mental Health Policy Framework and Strategic Plan 2023-2030 indicates that "mental health conditions and behaviours" addressed by the policy include "neurodevelopmental disorders such as autism spectrum disorders [and] severe and profound intellectual disability accompanied by comorbid mental disorders." (p. 13) However, the focus is on mental health service provision, rather than a full range of health services.

[33] The National Policy Framework and Strategy on Palliative Care, 2017-2022 mentioned the unique needs of those with IDD.

[34] The National Strategic Plan for HIV, TB and STIs 2017-2022 included data on people with disabilities and their sexual and reproductive health and rights needs and risks. The new National Strategic Plan for HIV, TB and STIs, 2023-2028 identifies persons with disabilities as a priority group across its key actions, as well as outlining a minimum package of services inclusive of people with physical and mental disabilities.

[35] 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.

[36] 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.

[37] 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.

[38] 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.

[39] The United Nations Department of Economic and Social Affairs (2024) revealed the severity of under-representation of people with disabilities among public service personnel, highlighting that people with disabilities have "representation lower than half their share in the national population in several countries." (United Nations Department of Economic and Social Affairs. (2024). *Disability and Development Report 2024: Accelerating the realization of the sustainable development goals by, for and with persons with disabilities*. p. 46. https://social.desa.un.org/sites/default/files/inline-files/Goal3.pdf.

[40] This list was accessed and a copy saved locally in July 2024; however, the link appears to have broken since that time.

[41] Washington State Legislature, HB 1541, 2024 https://app.leg.wa.gov/billsummary?BillNumber=1541&Year=2023&Initiative=false; House Bill Report 2E2SHB 1541 https://lawfilesext.leg.wa.gov/biennium/2023-24/Pdf/Bill%20Reports/House/1541-S2.E2%20HBR%20FBR%2024.pdf?q=20250528095740.

[42] McCue, T. (2024, March 20). "Nothing About Us Without Us!" *DD Ombuds - Office of Developmental Disabilities Ombuds*. https://ddombuds.org/2024/03/20/nothing-about-us-without-us/.

[43] Committee on the Rights of Persons with Disabilities, 2018, II A. The International Disability Alliance (IDA), whose membership is comprised of OPDs, includes different criteria for different types of membership. For global and regional organizations, for instance, "The majority of its member organizations shall be organizations composed and governed by persons with disabilities or, in the case of persons with intellectual disabilities, composed and governed by persons with intellectual disabilities and family members…It shall have a majority of persons with disabilities in the governing bodies of the organization, or in the case of persons with an intellectual disabilities, persons with intellectual disabilities and family members are in the majority of the governing bodies of the organization." (International Disability Alliance. (2022). *Guidelines on seeking a Membership*. https://www.internationaldisabilityalliance.org/sites/default/files/membership_guidelines_final_20_01_23.pdf)

[44] The report is of survey findings on participation of OPDs in development programs and policies. While distinct subject matter from domestic governance, we were not able to think of reasons that similar dynamics would not apply. IDA does, however, state that the survey was the first of its kind and disclaimed the findings' representativeness of OPDs globally. (International Disability Alliance. (2020). *Increasingly Consulted, but not yet Participating: IDA Global Survey on Participation of Organisations of Persons with Disabilities in development Programmes and Policies*. p. 8).

[45] International Disability Alliance, 2020, p. 52

[46] The U.S. states are exceptions, likely in part because the Developmental Disabilities Assistance and Bill of Rights Act of 2000 requires all states and territories to create self-advocacy groups called state councils on developmental disabilities (*ACL Administration for Community Living*. https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities) and provides them with funding.

[47] Bundeszahnärztekammer, KZBV, Deutsche Gesellschaft für Alterszahnmedizin, & Berufsverband Deutscher Oralchirurgen. (n.d.). *Mundgesund trotz Handicap und hohem Alter: Konzept zur vertragszahnärztlichen Versorgung von Pflegebedürftigen und Menschen mit Behinderungen*. https://www.bzaek.de/fileadmin/PDFs/presse/AuB_Konzept.pdf;

Dental health reimbursement for people with disabilities in Germany. (2010). In *Missing Billion*. https://static1.squarespace.com/static/5d79d3afbc2a705c96c5d2e5/t/6442baa2d9b8d30777a235dd/1682094754815/MB+best+practice+Germany_vf.pdf.

[48] Recent estimates indicate that social determinants of health account for "between 30% and 55% of people's health outcomes." (Bhavnani, S. K., Zhang, W., Bao, D., Raji, M., Ajewole, V., Hunter, R., Kuo, Y., Schmidt, S., Pappadis, M. R., Smith, E., Bokov, A., Reistetter, T., Visweswaran, S., & Downer, B. (2025). Subtyping Social Determinants of Health in the "All of Us" Program: Network Analysis and Visualization study. *Journal of Medical Internet Research*, 27, e48775. https://doi.org/10.2196/48775). Of the general population, the WHO has stated "[s]ocial determinants of health equity outweigh genetic influences or health-care access in influencing health outcomes." (World Health Organization. (2025, May 6). *Social determinants of health.* https://www.who.int/news-room/fact-sheets/detail/social-determinants-of-health). Limited data specific to people with IDD are available. A cohort study in England, for example, found that people with intellectual disabilities are much more likely than the general population to die of causes that could be addressed by quality health care. (Hosking et al., 2016). An analysis of survey data of people with learning disabilities in England found that "[o]nce we allowed for differences in socio-economic factors and opportunities for social participation in the local environment, the increased odds of most health problems and risk factors amongst people with learning disabilities dropped dramatically." (Hatton, C. (2016, October 4). Health inequalities and the 'hidden majority' of adults with learning disabilities. *UK Health Security Agency.* https://ukhsa.blog.gov.uk/2016/10/04/health-inequalities-and-the-hidden-majority-of-adults-with-learning-disabilities/#:~:text=We%20found%20that%20people%20with,in%20itself%20a%20health%20condition).

[49] Landes, S. D., Turk, M. A., Formica, M. K., McDonald, K. E., & Stevens, J. D. (2020). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability and Health Journal*, 13(4), 100969. https://doi.org/10.1016/j.dhjo.2020.100969.

[50] World Health Organization. (2015). *WHO Global Strategy on People-centred and Integrated Health Services: Interim Report.* https://iris.who.int/bitstream/handle/10665/155002/WHO_HIS_SDS_2015.6_eng.pdf?sequence=1; World Health Organization. (2016). *Framework on integrated, people-centred health services.* (A69/39). https://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1.

[51] World Health Organization (2022); O'Leary et al. (2018); Heslop et al. (2013); Lauer and McCallion (2015); Kuper and Smythe (2023); "Intellectual and Developmental Disabilities—an Under-recognised Driver of Cancer Mortality," 2024; Cho et al. (2024).

[52] Doherty, A. J., Atherton, H., Boland, P., Hastings, R., Hives, L., Hood, K., James-Jenkinson, L., Leavey, R., Randell, E., Reed, J., Taggart, L., Wilson, N., & Chauhan, U. (2020). Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review. *BJGP Open*, 4(3), bjgpopen20X101030. https://doi.org/10.3399/bjgpopen20x101030; Moskowitz, L. J., Braconnier, M., & Jeffay, M. (2019). Anxiety and Phobias in Individuals with Intellectual Disabilities. In *Autism and child psychopathology series* (pp. 813–842). https://doi.org/10.1007/978-3-030-20843-1_44.

[53] The SLAs in the United States involved more detailed analysis of two national data sets: the National Health Interview Survey (NHIS) and the National Core Indicator Survey on Intellectual and Developmental Disabilities (NCI-IDD). The NHIS uses Washington Group Short Set questions, whose limitations as relates to the population with IDD are described in the Data for Monitoring and Research section of this report. NCI-IDD is a smaller, more focused survey on adults with IDD who receive Medicaid services. For the purposes of NHIS analyses, SOI operationally defined adults with IDD as adults aged 22-85 who reported having severe limitations (i.e., a lot of difficulty or being unable to perform) in one or more of three core WG-SS limitations (i.e., cognition, self-care, and/or communication), and reported that this limitation occurred before the age of 22. This group still may underestimate the population with IDD who has less difficulty. Among the NHIS group, 62.3% reported having public health insurance; responding to a separate question, 49.2% reported Medicaid insurance and 13.7% reported dual coverage (Medicaid and Medicare). Among the NCI-IDD respondents, 33.4% had Medicaid only, while 37.5% had Medicaid and Medicare.

[54] Northway, R., Rees, S., Davies, M., & Williams, S. (2017). Hospital passports, patient safety and person-centred care: A review of documents currently used for people with intellectual disabilities in the UK. *Journal of Clinical Nursing*, 26(23–24), 5160–5168. https://doi.org/10.1111/jocn.14065.

[55] Northway et al. (2017).

[56] Budde, H., Williams, G. A., Scarpetti, G., Kroezen, M., & Maier, C. B. (2022). What are patient navigators and how can they improve integration of care? [Policy brief]. *Policy Brief*, 2. https://iris.who.int/bitstream/handle/10665/350972/Policy-brief-44-1997-8073-eng.pdf?sequence=1; Brunelli, V. N., Beggs, R. L., & Ehrlich, C. E. (2021). Case study discussion: The important partnership role of Disability Nurse Navigators in the context of abrupt system changes because of COVID-19 pandemic. *Collegian Journal of the Royal College of Nursing Australia*, 28(6), 628–634. https://doi.org/10.1016/j.colegn.2021.04.007.

[57] United Nations Department of Economic and Social Affairs, 2024. p. 91.

[58] Original text reads "Serán declarados incapaces y quedarán sujetos a curatela los mayores de edad y los menores emancipados que por causa de enfermedad mental no tengan aptitud para cuidar de su persona o administrar sus bienes, así como los sordomudos que no sepan darse a entender por escrito u otros medios, que se hallen en las mismas circunstancias." (Código Civil Del Paraguay (Ley N° 1183/85). Article 73. https://www.oas.org/dil/esp/codigo_civil_paraguay.pdf).

[59] Kelly, A. M., Hershey, L. B., & Marsack-Topolewski, C. N. (2020). A 50-state review of guardianship laws: Specific concerns for special needs planning. *Journal of Financial Service Professionals*, 75(1), 59–79. https://commons.emich.edu/fac_sch2021/260/;

Georgetown University Center for Child and Human Development. *Guardianship statutes in the states*. Complex Moral Issues: End-of-Life Decisions for Adults With Significant Intellectual Disabilities. https://gucchd.georgetown.edu/complex/guardianship-statues.html.

[60] Bradley, V., Hiersteiner, D., St. John, J., & Bourne, M. L. (April 2019). What do NCI data reveal about the guardianship status of people with IDD? In *National Core Indicators Data Brief*. https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf; National Council on Disability. (2018). *Beyond guardianship: toward alternatives that promote greater Self-Determination*. https://www.ncd.gov/assets/uploads/docs/ncd-guardianship-report-accessible.pdf.

[61] Jonathan Martinis and others, "State Guardianship Laws and Supported Decision-Making in the United States After Ross and Ross v. Hatch: Analysis and Implications for Research, Policy, Education, and Advocacy," Journal of Disability Policy Studies (2021), available at https://journals.sagepub.com/doi/abs/10.1177/10442073211028586.

[62] National Resource Center for Supported Decision-Making. (n.d.). *SDM around the USA: U.S. Supported Decision-Making Laws*. Support Without Courts for People With Disabilities. https://supportwithoutcourts.org/sdm-around-the-usa/; Washington State Legislature, Uniform Guardianship, Conservatorship, and other Protective Arrangements Act https://app.leg.wa.gov/RCW/default.aspx?cite=11.130; 2017 Wisconsin Act 345 https://docs.legis.wisconsin.gov/2017/related/acts/345.

[63] This dynamic exists beyond the context of forced sterilization. *See, e.g., Malachie: From Chains to 2019 World Games*. (2018, August 15). Special Olympics. https://www.specialolympics.org/stories/impact/malachie-from-chains-to-2019-world-games; Human Rights Watch. (2023). "*Better to make yourself invisible*." https://www.hrw.org/report/2020/06/04/better-make-yourself-invisible/family-violence-against-people-disabilities-mexico.

[64] World Health Organization & United Nations Children's Fund, 2023.

[65] *Decision-making and Consent: Assisted Decision-making*. (2020). Inclusion Ireland. https://inclusionireland.ie/wp-content/uploads/2020/12/Decision-making-and-Consent-Assisted-Decision-making-Capacity-Act-2015-1.pdf.

[66] Sullivan WF, Heng J. Supporting adults with intellectual and developmental disabilities to participate in health care decision making. Can Fam Physician. 2018 Apr;64(Suppl 2):S32-S36. PMID: 29650742; PMCID: PMC5906782.

[67] Bigby, C., Whiteside, M., & Douglas, J. (2017). Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. *Journal of Intellectual & Developmental Disability*, 44(4), 396–409. https://doi.org/10.3109/13668250.2017.1378873; Downs, J., Keeley, J., Skoss, R., Mills, J., Nevill, T., Schippers, A., Lindly, O., & Thompson, S. (2024). Perspectives on the essential skills of healthcare decision making in children and adolescents with intellectual disability. *International Journal for Equity in Health*, 23(1). https://doi.org/10.1186/s12939-024-02204-5.

[68] Article 14 of the Civil Code provides that the court may appoint a guardian for "any person who is not able to make declaration of intention, receive declaration of intention, or who lacks the ability to discern the outcome of the declaration of intention due to mental disability." As noted earlier, "mental disability" is understood locally to include IDD.

[69] As noted earlier, the Family Code in Morocco, using a variety of terminology inconsistent with the UNCRPD, considers people with mental disabilities (a term understood locally to include those with IDD) incapable of representing themselves legally and places them under parental authority. While it provides some criteria for assessing capacity, these appear to be less detailed and more subjective than criteria detailed in other sites' legislation.

[70] As noted earlier, until 2025, the Civil Code stated that people who "due to mental illness, are not capable of caring for themselves or managing their property" shall be declared incapable and be subject to guardianships, despite this approach being in direct conflict with the UNCRPD and domesticating legislation (Convention on the Rights of Persons with Disabilities Law 3540/08).

[71] The person petitioning for appointment of an administrator for the property needs to articulate why they feel the person with severe or profound intellectual disability is incapable of managing their property. (The Mental Health Act, No. 17 of 2002, Chapter VIII, section 60(2)).

[72] Washington law states that "a person who is of the age of consent to make a particular health care decision is presumed to have capacity, unless a health care provider reasonably determines the person lacks capacity to make the health care decision due to the person's demonstrated inability to understand and appreciate the nature and consequences of a health condition, the proposed treatment, including the anticipated results, benefits, risks, and alternatives to the proposed treatment, including nontreatment, and reach an informed decision as a result of cognitive impairment." (RCW 7.70.068 https://app.leg.wa.gov/rcw/default.aspx?cite=7.70.068).

[73] *Supported Decision-Making: Frequently asked questions.* American Civil Liberties Union. https://www.aclu.org/wp-content/uploads/legal-documents/faq_about_supported_decision_making.pdf; National Resource Center. (2024, April 4). *Supported Decision-Making Tools for supported Decision-Making.* https://supporteddecisionmaking.org/resource-library/.

[74] Sullivan WF et al. (2018); National Council on Disability. (2019). *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities.* https://www.ncd.gov/assets/uploads/reports/2019/ncd_turning-rights-into-reality_508_0.pdf.

[75] *Easy read.* Foundation for People With Learning Disabilities. https://www.learningdisabilities.org.uk/learning-disabilities/a-to-z/e/easy-read.

[76] See, e.g., World Health Organization (2022). p. 226; Mkabile, S., & Swartz, L. (2022). Traditional healers' explanatory models of intellectual disability in Cape Town. *Transcultural Psychiatry*, 59(3), 263–273. https://doi.org/10.1177/13634615211055967.

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[78] Diagnostic overshadowing among groups experiencing health disparities. (2022, June 22). *Sentinel Event Alert, A complimentary publication of The Joint Commission.* https://www.jointcommission.org/-/media/tjc/documents/resources/patient-safety-topics/sentinel-event/sea-65-diagnostic-overshadowing-6-16-22-final.pdf

[79] World Health Organization (2022). p. 215.

[80] *Advantages and Limitations of Washington Group-Short Set.* Arab Digital Inclusion Platform. https://e-inclusion.unescwa.org/node/1358#:~:text=Less%20effective%20for%20children%20aged,the%20nature%20of%20environmental%20barriers.

[81] *Disability Statistics Database (DS-QR).* Disability Data Initiative. https://ds-qr.disabilitydatainitiative.org/DS-QR/#.

[82] Gordon, C. (2023, December 19). *NCD Letter to Census on proposed change to disability questions in American Community Survey.* National Council on Disability. https://www.ncd.gov/letters/2023-12-19-ncd-letter-to-census-on-proposed-change-to-disability-questions-in-american-community-survey/; Havercamp, S.M., Krahn, G., Larson, S., Weeks, J.D. and the National Health Surveillance for IDD Workgroup (2019). Working Through the IDD Data Conundrum: Identifying People with Intellectual Disability and Developmental Disabilities in National Population Surveys. Washington, DC: Administration on Intellectual and Developmental Disabilities. https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/National_Data_Paper_AIDD-ACL_09.25.2019%20508%20compliant.pdf; Hall, J. P., Goddard, K. S., Ipsen, C., Myers, A., & Kurth, N. K. (2024). Counting everyone: evidence for inclusive measures of disability in federal surveys. *Health Affairs Scholar*, 2(9). https://doi.org/10.1093/haschl/qxae106.

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[85] Brooker, K., Van Dooren, K., Tseng, C., McPherson, L., Lennox, N., & Ware, R. (2014). Out of sight, out of mind? The inclusion and identification of people with intellectual disability in public health research. *Perspectives in Public Health*, 135(4), 204–211. https://doi.org/10.1177/1757913914552583.

[86] Grady, C. (2015). Institutional review boards. *CHEST Journal*, 148(5), 1148–1155. https://doi.org/10.1378/chest.15-0706; Havercamp, S.M. et al. (2019).

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[89] Balogh, R. S., Lake, J. K., Lin, E., Wilton, A., & Lunsky, Y. (2014). Disparities in diabetes prevalence and preventable hospitalizations in people with intellectual and developmental disability: a population-based study. *Diabetic Medicine*, 32(2), 235–242. https://doi.org/10.1111/dme.12573.

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