Our Say in Our Health:

What People with Intellectual Disabilities and their Supporters Say About Health Access Around the World

July 2025

WHAT IS IN THIS REPORT?

Acknowledgements

Down Syndrome International (DSi) and Humanity & Inclusion (HI) would like to thank everyone who contributed to this global consultation and report to make it possible.

The global consultation was led by Nathan Rowe (DSi) and Brooke Winterburn (HI), with support from Andrew Boys, Robin Gibson, Anna Sands, Emma Bishop (DSi) and Dr Alessandra Aresu (HI).

The report was written, edited and designed by Nathan Rowe (DSi), Brooke Winterburn (HI), Esperanza Hughes-Salinas (London School of Economics (LSE)), and Kendall Scherer (LSE), with support from Andrew Boys (DSi) and Anna Sands (DSi).

Focus Group Discussion in Rwanda for the Global Consultation run by Rwanda Down Syndrome Organisation (RDSO) in June 2024. © Down Syndrome International

We thank everyone who gave feedback on the survey methodology and supported the global consultation:

- Darryl Barrett, Kaloyan Kamenov and Mélanie Gréaux from WHO
- Anjela Jenkins, Hamza Alzahran from Special Olympics International, and consultants with lived experience - Kiera Byland, Renee Manfredi, Nyasha Derera
- Francine van den Driessen Mareeuw from Tilburg University
- DSi member organisations, with special mention to Natalie Graham from Down Syndrome Australia and Laura LaChance from Canadian Down Syndrome Society
- The DSi Ambassadors Committee - Fahim Sultana, Andrew Domahidy, Morgan Maze, Sheri Brynard, Muthoni Hirst, Halis Güney, Carlos Ramirez, Eileen Dunne, Chaica Al Qassimi, Charlotte Woodward, Pearl Lüthy, Stuart Campbell, Janet Charchuk, Andrew Oswin, and Ijale Moyosore.
- International Disability Alliance

Data was analysed by Esperanza Hughes-Salinas (LSE), Xiaoyi (Ada) Liu (LSE), and Kendall Scherer (LSE). Dr Aliaa Shanab and Ahmed Salem supported with early data analysis.

Most importantly, we sincerely thank the more than 750 individual respondents who took the time to participate, especially the 139 people with Down syndrome and other intellectual disabilities, along with their families and support persons, who openly shared their experiences. Thank you also to the DSi member organisations who organised focus group discussions (in Japan, New Zealand, Nigeria, Rwanda, Saudi Arabia, and Taiwan) and the people who participated. Your voices are vital to making healthcare fairer for everyone. Your honesty, insight, and courage in sharing both positive and difficult moments have deepened our understanding and were essential in shaping this report.

We are also grateful to the 118 organisations who contributed (across DSi's global member network and beyond) **including nearly 50 organisations of persons with disabilities.** Thank you for sharing your expertise, and for your ongoing work to promote the rights and inclusion of persons with disabilities.

Foreword

It is with pride that Down Syndrome International (DSi) shares this Global Report with you. It marks a significant milestone in making healthcare fairer for people with Down syndrome and other individuals with intellectual disabilities.

As the global network of individuals with Down syndrome and their families, we believe it is a fundamental right that people with disabilities and their families have a say in the decisions that affect their lives.

This report reflects the hard work and dedication of many individuals and organisations within our international network. Thank you to all who contributed; you have shown the strength and unity of our community.

Our powerful partnership with Humanity & Inclusion has shown what can be achieved when organisations of persons with disabilities, like DSi, are genuinely valued and respected.

The next steps are crucial. We all need to keep speaking out together to bring about change, both globally and in our own nations.

Bridget Snedden, President, Down Syndrome International

Janet Charchuk, Board Member, Down Syndrome International


At Humanity & Inclusion, we are convinced that hearing directly from persons with intellectual disabilities is essential to advancing health equity and addressing the barriers that prevent equal access to health information and services. However, silence has prevailed for far too long – alongside discrimination, poor quality services, and inaccessible health information.

With this unprecedented report, we move from silence to action. This has been made possible thanks to the leadership of Down Syndrome International. Building on the important work on health equity for persons with disabilities led by WHO and its partners, and in collaboration with Humanity & Inclusion, DSi has taken a decisive step to break the silence.

As we share this report, the findings from this first consultation already highlight the need to do more. They highlight the importance of taking an intersectional approach in future efforts – by prioritising women's health, improving the transition from child and adolescent healthcare to adult care, and addressing major gaps in healthcare for adults and older people with intellectual disabilities.

It has been an honour to collaborate with Down Syndrome International. This has been an invaluable learning experience, which has confirmed that complementarity, meaningful participation, mutual trust, and the leadership of organisations of persons with disabilities are essential to promoting health equity for persons with disabilities. I am deeply grateful to the organisations and individuals who contributed to this initiative, and for the opportunity to work alongside DSi. We look forward to continuing this journey and taking joint action to ensure that the right to health of persons with intellectual disabilities is acknowledged, respected, and fulfilled.

Dr Alessandra Aresu

Director,
Health and Protection Division,
Humanity & Inclusion

Executive Summary

People with intellectual disabilities face some of the starkest health inequities in the world today. These inequities are systemic and widespread, resulting in poorer health, reduced life expectancy, and frequent denial of the right to health. To better understand and address these challenges, Down Syndrome International (DSi) and Humanity & Inclusion (HI) conducted a global consultation in 2024 involving over 750 individuals (including 136 people with Down syndrome and intellectual disabilities, their families and support persons) and 118 organisations (including nearly 50 organisations of persons with disabilities) from more than 100 countries.

Our consultation aimed to fill key gaps in the global evidence base, particularly around the real-life experiences of people with Down syndrome and other intellectual disabilities when accessing healthcare. The report uses an adapted health systems AAAQ framework (Availability, Access for All, Acceptability, and Quality of Care) to analyse barriers and propose a roadmap for more inclusive health systems.

Key Findings

- **Availability**: Both general and disability-specific health services are frequently unavailable, especially beyond childhood and in low- and middle-income countries. Services often drop off sharply after age 18, with older people facing significant care gaps.
- **Access for All**: Access to healthcare remains deeply unequal. Many face financial, physical, and communication barriers, with accessible information still rare. Costs, particularly for specialist services like speech therapy or transport, often prevent people from seeking care.
- **Acceptability**: Discrimination and disrespect in healthcare settings are common. Many respondents reported being ignored, mistreated, or excluded from decisions. Informed consent and autonomy are often not respected, particularly for younger and older adults.
- **Quality of Care**: Only a quarter of respondents were satisfied with the care received. Misdiagnosis, long waiting times, and lack of reasonable accommodations were recurring issues. Many health professionals lack training in inclusive, rights-based care.

These inequities are not inevitable. They result from health systems that exclude people with intellectual disabilities from design, delivery, and decision-making. Core causes include the absence of organisations of persons with disabilities (OPDs) in health governance, the lack of inclusive tools and training, and insufficient data to make gaps in health access and outcomes visible.

A Vision for Inclusive Healthcare

Our report sets out a vision of inclusive healthcare systems where services are accessible, person-centred, and co-designed with people with intellectual disabilities and their representative organisations. This includes:

- Rights-based laws and policies aligned with the UNCRPD
- Meaningful participation of OPDs in health system governance
- Inclusive training for health workers, delivered in part by self-advocates
- Accessible health information and better use of disability data
- Affordable care, assistive technologies, and digital health tools

Recommendations

To realise this vision, we have identified three priority areas for investment:

1. **Invest in OPD Leadership for Systemic Change**
   Organisations of Persons with Disabilities (OPDs), including self-advocates and family networks, must be resourced and supported to engage meaningfully in all aspects of health system governance. This includes long-term investment in their technical and organisational capacity to influence policy, budgeting, service design, and accountability processes.

2. **Equip Health Systems with Inclusive Tools and Guidance**
   Health systems require co-developed tools, standards, and training that reflect the needs of people with intellectual disabilities and support inclusive, rights-based care. This includes accessible information, adapted consent processes, inclusive communication, and guidance for institutions to assess and improve practices, ensuring OPDs are supported to monitor progress.

3. **Share and Scale Inclusive Practices Globally**
   Promising inclusive health practices remain fragmented and underused. Global efforts must prioritise documenting what works, strengthening the evidence base, and creating platforms for OPDs to lead knowledge exchange and influence policy. Improved data collection and commitment to scaling rights-based, context-appropriate solutions are essential to closing equity gaps.

Janet Charchuk sharing the results of this report at the Global Disability Summit, 2025. © Down Syndrome International

Introduction

> **It's like I am a syndrome, not a person.**
> *- Woman aged 25-34 with Down syndrome from Canada (ID 13)*

Worldwide, there are an estimated 1.3 billion people with disabilities. They face inequitable health outcomes, including poorer health access and outcomes, often leading to lower life expectancy (World Health Organization [WHO], 2022).

This violates their human right to health under the UN Convention on the Rights of Persons with Disabilities and presents a significant barrier to the achievement of Sustainable Development Goal 3, a global commitment to ensure healthy lives and promote well-being for all at all ages by 2030 (United Nations, 2015).

People with Down syndrome and other people with intellectual disabilities are among the most impacted by these inequities. For example, worldwide, people with Down syndrome die on average 20 years earlier than the general population (WHO, 2022, p.16). In the United Kingdom, children with intellectual disabilities are eight times more likely to die before the age of 17 (WHO, 2022).

People with intellectual disabilities also have higher rates of chronic conditions such as diabetes, cardiac disease, mental health conditions, and thyroid dysfunction (WHO, 2022). They are also more likely to live in environments and have lifestyle factors that put their health at risk. For example, by adolescence, people with intellectual disabilities are already 1.5 to 1.8 times more likely to be overweight or obese WHO, 2022).

This situation is largely preventable; a 2014 report found that 37% of premature deaths of people with intellectual disabilities in the UK could have been avoided with good quality health care (Heslop et al. 2014).

Following the publication of WHO’s Global Report on Health Equity for Persons with Disabilities in 2022, Down Syndrome International and Humanity & Inclusion agreed to work together to understand more about these severe health inequities faced by people with intellectual disabilities.

A key first step was to address gaps in the available evidence on health equity for persons with intellectual disabilities, including:

- A lack of data on the specific barriers faced by people with intellectual disabilities when accessing health services.
- Missing perspectives and experiences from people with intellectual disabilities and their families.
- Inadequate global data, with much of the research coming from the UK or other high-income countries.

In 2024, Down Syndrome International and Humanity & Inclusion worked together to develop and run a global consultation on health equity for persons with intellectual disabilities. The aim was to understand the experiences of people with Down syndrome and people with intellectual disabilities in accessing quality health information and services, the common barriers faced, and how these differ by demographic factors.

The consultation included surveys and focus groups discussions for people with Down syndrome and intellectual disabilities, family members, support persons, and organisations. A total of 754 individuals and 118 organisations from over 100 different countries responded to the surveys.

The report also presents a way forward for what need needs to change to address health inequity for people with intellectual disabilities, including looking at the root causes of the unfair health outcomes, suggesting what an inclusive healthcare system could look like, and making recommendations for actions to be taken by key stakeholders.

About Down Syndrome International and Humanity & Inclusion

Down Syndrome International is the global network of people with Down syndrome and their families and member of the International Disability Alliance. Together, the Down Syndrome International network speaks up for the human rights of all people with Down syndrome around the world.

Humanity & Inclusion, also known as Handicap International, is an international NGO that promotes the right to health for persons with disabilities worldwide, working in partnership with organizations of persons with disabilities, health providers, and in collaboration with World Health Organization.

DSi Advocacy Officer Emma Bishop shares preliminary findings of this report at a side meeting at the Global Disability Summit in Berlin. ©2025 GRÉAUX. WHO

Methodology

Where the data came from

This report analyses data from two surveys as part of the Global Consultation on Health Equity for People with Down Syndrome and Intellectual Disabilities, which was conducted with shared responsibility by DSi and HI. Both surveys recorded responses using Microsoft Forms. The individuals survey collected data from respondents with Down syndrome, respondents with intellectual disabilities other than Down syndrome, their families and support persons. The individuals survey was offered in English, Spanish, French, and Chinese. The organisations survey collected data from respondents who are affiliated with organisations that conduct work relating to people with Down syndrome or intellectual disabilities. The organisations survey was only conducted in English. All survey questions are available in Appendix B.

The Global Consultation also conducted focus group discussions (FGDs) with DSi members to gather direct insights from people with Down syndrome or intellectual disabilities, their family and support persons. This was done to address the limitations of online surveys and provide additional accessible options for participation in the Global Consultation. However, the FGDs are beyond the scope of this report.

The Global Consultation was constructed by consultations with DSi member organisations to design the surveys and FGDs. In the construction of the Global Consultation, DSi met with 37 national member organisations representing people with Down syndrome and intellectual disabilities and their families to understand their experiences and aid with the design of the survey. Feedback was also received on the design of the Global Consultation from two DSi member organisations, the WHO, and Special Olympics International. Feedback on the individuals survey was received from four self-advocates and the DSi Ambassadors Committee, an international group of people with Down syndrome that advises DSi on its work.

Clarification of Respondent Identification

Respondents to the 'individuals survey' were asked to identify themselves from six categories:

1. A person with Down syndrome
2. A person with an intellectual disability (other than Down syndrome)
3. A family member of a person with Down syndrome
4. A family member of a person with an intellectual disability (other than Down syndrome)
5. A support person of a person with Down syndrome
6. A support person of a person with an intellectual disability (other than Down syndrome)

When referring to a person with intellectual disabilities other than Down syndrome, this report uses the term 'person with an intellectual disability'. When referring to a support person who is not a family member of the person they support, this report uses the term 'support

How we collected the data

The surveys were disseminated via email to all DSi member organisations (approximately 150) via the DSi mailing list (19,000+ recipients) and via DSi social media channels including Facebook, X, Instagram, and LinkedIn. DSi also asked member organisations to share the survey links with people in their own countries. The survey was open on Microsoft Forms from 22 March 2024 to 5 September 2024.

How we analysed the data

The dataset was anonymised and securely stored on Microsoft OneDrive, accessible only through institutional accounts. Both the original and the cleaned/reshaped datasets were saved in a restricted-access OneDrive folder to ensure data protection and confidentiality. Each respondent was assigned a unique numerical identifier, e.g. ID209. Data cleaning involved removing two duplicate responses.

Spanish, French and Chinese responses were translated by Google Translate and double-checked by the analysis team who spoke all three languages. Some responses to the English survey were in other languages such as Arabic and Hindi; these were also translated using Google Translate.

Thematic analysis

The qualitative free-response sections of the surveys were analysed using an inductive thematic analysis, conducted manually. All free-response sections of the individuals survey were analysed thematically. Responses to open-ended questions were carefully reviewed. Keywords and phrases were noted for each response. When common words emerged across multiple responses, they were grouped into themes, and the Find function was used to quantify their frequency.

For questions where common keywords were insufficient for direct theming, responses were manually categorised into preliminary themes identified during the initial review. This process was also done for themes within questions for a deeper analysis.

Parents Group Discussion in Rwanda for the Global Consultation run by Rwanda Down Syndrome Organisation (RDSO) in 2024. © Down Syndrome International

Quantitative analysis

STATA, a statistical software, was used for both the data cleaning and quantitative analysis. Due to an imbalance in the number of responses from certain groups, analytical methods[1] were used to ensure representative results and make comparisons across key demographic variables such as gender, age, rural/urban, disability type, and the income level of the country of residence.

Descriptive analysis

All descriptive graphs were made using Excel pivot tables, with values expressed to one decimal place. The data was not manipulated. Chi Squared Tests for significance were done using the Excel *CHISQ.TEST* function.

Country income level categorisation

Countries were categorised into income level according to the 2022 World Bank classification: high income countries (HICs), upper middle-income countries (UMICs), lower middle-income countries (LMICs) and low-income countries (LICs). Countries were also classified into level of healthcare expenditure as a percentage of the country's GDP according World Bank data.

---

[1] See Appendix I for a more detailed explanation of the quantitative methodology.

Limitations of the data and the report

Down Syndrome International and Humanity & Inclusion conducted this consultation and produced this report without any dedicated funding and with very limited human resources. Most of the work was done by a small number of staff in addition to their existing responsibilities, with generous support from DSi member organisations and students from the London School of Economics' Department of International Development.

While we are pleased with the response to the consultation, several limitations were identified:

- **Underrepresentation from Asia and Latin America:** Although responses were received from all regions, Asia and Latin America were notably underrepresented.
- **Language imbalance:** Despite the survey being translated into Chinese, French, and Spanish, the majority of responses were submitted in English.
- **Ambiguity in some survey questions:** Certain multiple-choice options, such as "ok," were open to interpretation and could be seen as either positive or negative. Additionally, terms like "accessible healthcare information" were not clearly defined in open-ended questions, leading to varied interpretations.
- **Gaps in demographic data:** While the survey collected information on gender, age, country, and rural/urban location, it did not explore other potentially relevant characteristics which could influence healthcare access. For example, differences for LGBT+ people, people in ethnic minorities, indigenous people or for people with different incomes.
- **Limited analysis of organisational and focus group data:** Due to time constraints the individuals survey had the most in-depth analysis.
- **Insufficient depth in some topic areas:** Certain areas would have benefited from additional questions. For example, questions to better understand health financing methods (e.g. private or public insurance), locations within countries, social protection schemes to cover additional disability-related healthcare costs, and more detail about health outcomes.

We would encourage future research exploring health equity for people with intellectual disabilities to take these into account in research design.

Who we heard from

Individuals

754 people answered the individuals survey, including 675 responses in English, 31 in French, 14 in Spanish, and 34 in Chinese. Most respondents were family members of someone with Down syndrome, with the next group being people with Down syndrome (Fig. 1a).

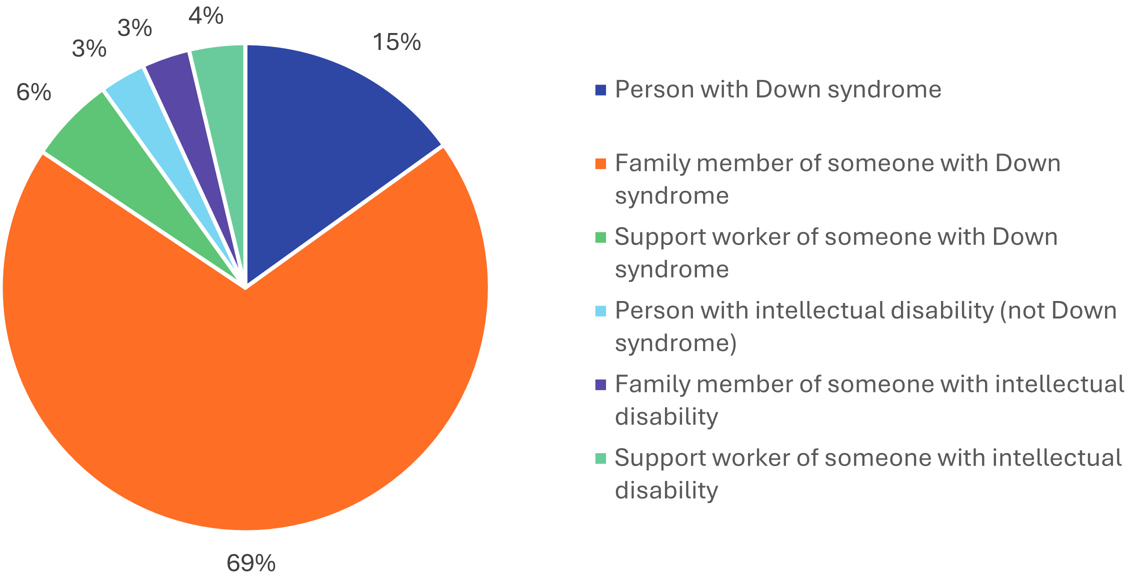


Figure 1a: Distribution of respondent identity (individuals survey)

95 countries were represented by survey respondents. There was an over representation of respondents from Europe and North America (Fig. 1b). The most common country respondents lived in was the United States (19.8%) followed by the United Kingdom (13.4%), Canada (6.5%), Ireland (5.3%) and China (4.6%). 81% of all respondents lived in an urban area, which is in line with the international average.

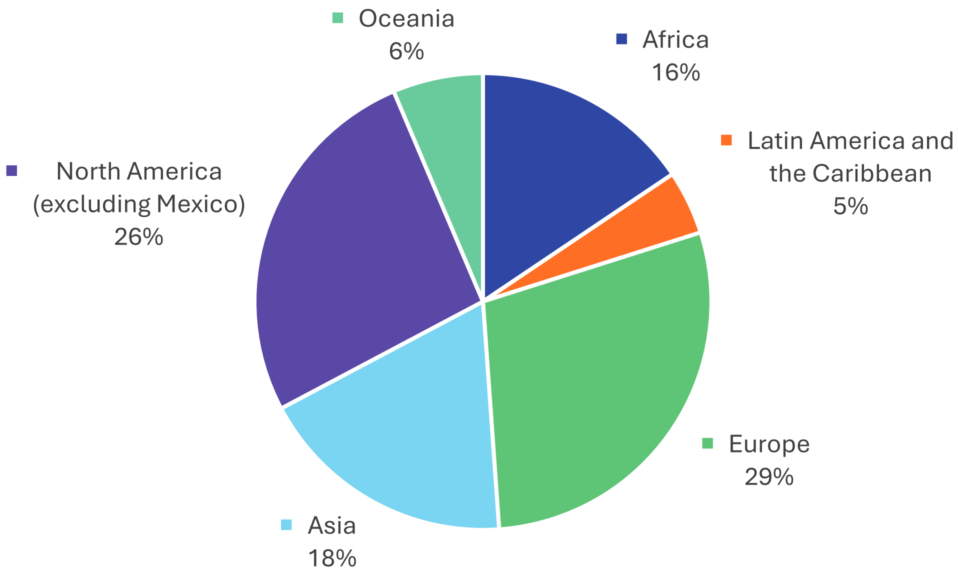


Figure 1b: Respondents of the individuals survey by continent. Mexico is included in 'Latin America and the Caribbean'

Using country income data from the World Bank, countries were categorised into four groups: high income (e.g. Spain), upper-middle income (e.g. China), lower-middle income (e.g. India), and low income (e.g. Togo). Most respondents to the individuals survey were from high-income countries (63.3%) (Fig. 1c).

The gender distribution of people with Down syndrome and intellectual disabilities was representative of the global distribution (see Fig. 6a). One person was non-binary and 11 preferred not to say. However, the gender distribution of family members and support persons answering the survey was not even, with 79% of them being women (see Fig. 6b).

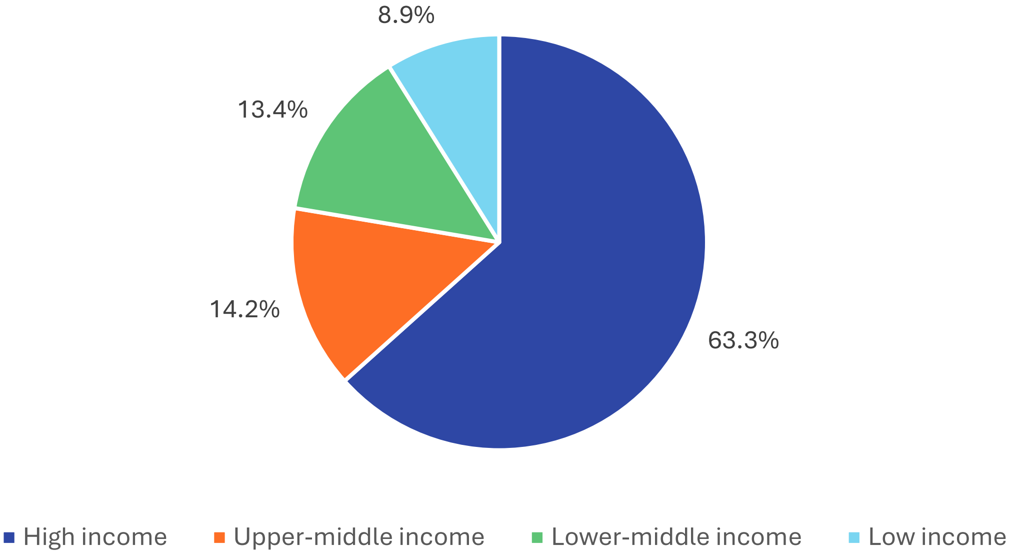


Figure 1c: Percentage of respondents by country income level (individuals survey)

Organisations

118 people answered the organisations survey from 56 countries, with the largest continent group being Africa (Fig 1d). Approximately 44% of the organisations work on a local level in a particular area of their country, while 48% operate nationally. 5% work globally and 2.5% regionally.

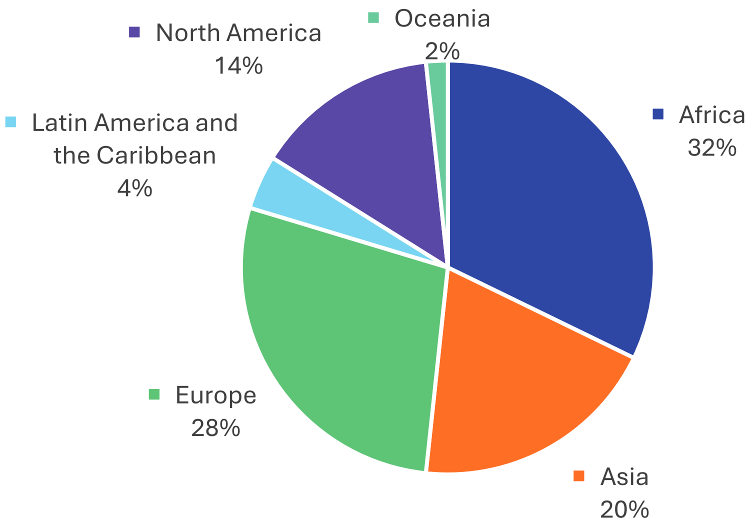


Figure 1d: Respondents of the organisations survey by continent

The largest group of organisations were organisations of persons with disabilities (OPDs) with 47 (40%), but national or local NGOs, service providers, and international NGOs also responded. There was one respondent each from a UN Agency, a private business, and a consortium of research centres (Fig 1e).

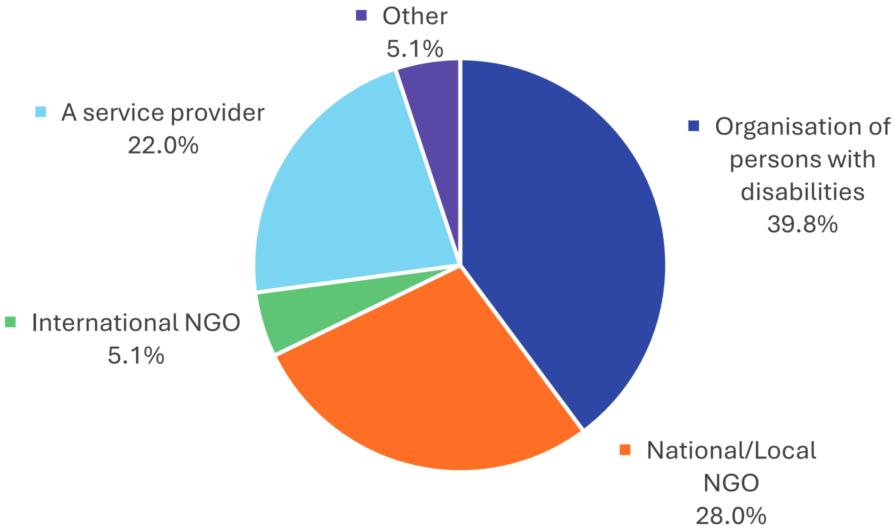


Figure 1e: Respondents by type of organisation (organisations survey)

Results

This section presents key findings from the consultation on healthcare for people with Down syndrome and intellectual disabilities, including comparisons by demographics, and examples of health advocacy by respondents.

The main results are organised using an adapted version of the Danish Institute for Human Rights' AAAQ Toolbox (2013), incorporating a disability rights perspective. Definitions were updated and 'Accessibility' was changed to 'Access for All' to avoid confusion caused by differing uses of the term 'accessibility'. See below for the updated version.

Updated AAAQ Framework

Availability - Health services are available in sufficient quantity, including mainstream services and specialist services that people with disabilities need to access, such as early identification and intervention.

Access for all - healthcare services are non-discriminatory, affordable, and all physical environments, information and communication are accessible to everyone.

Acceptability - healthcare services respect medical ethics and cultural appropriateness while upholding the dignity, autonomy, and informed consent of persons with disabilities through inclusive and non-stigmatizing practices.

Quality of care - healthcare is safe, effective, timely, equitable, and responsive to individual needs, with reasonable accommodations, assistive technologies, and trained personnel to ensure quality healthcare for persons

The findings reveal disparities in healthcare access and quality, often shaped by the respondent's country income level, urban or rural location, and reliance on public vs. private systems. In many low- and middle-income countries, respondents face multiple overlapping barriers: services may be distant, unaffordable, or simply unavailable. Even in high-income countries, families often describe care as fragmented or insufficiently inclusive. These results underscore systemic gaps in meeting the healthcare needs of people with Down syndrome and intellectual disabilities.

> **From the moment [people with Down syndrome] are born, they experience discrimination, even from medical doctors and nurses.**
>
> *- Female support person for a boy aged 13-17 with Down syndrome from Mongolia (ID 68)*

Availability

‘Availability’ means that health services are available in sufficient quantity, including mainstream services and specialist services that people with disabilities need to access, such as early identification and intervention.

Availability of different health services

Respondents were asked about the availability of different health services, including mainstream health services that everyone needs and specific services needed by people with disabilities.

The most commonly unavailable mainstream health services were:

- Sexual and reproductive healthcare
- Early childhood development
- Mental health services
- Specialist services (such as heart operations)
- Geriatric care (care for older persons)

In the free-response section, dental and oral health were also mentioned repeatedly in relation to lack of availability of services to meet the needs of people with intellectual disabilities. The specialised service of speech therapy was mentioned as being particularly unavailable across multiple countries.

> **My baby [has a] heart defect... and none of the hospitals in Ethiopia have the capability to do the necessary surgery to correct it.**
>
> *– Male family member of a girl aged under 12 with Down syndrome from Ethiopia*

> **Dentistry with sleep apnoea is extremely difficult [...] I [have to] travel 800 miles to get basic cavities taken care of after [...] getting every specialist to sign off, while waiting for referrals for months.**
>
> *– Female family member of a man aged 18-24 with Down syndrome from the United States (ID 266)*

> **Services for speech therapy [are] almost not existent.**
>
> *– Female family member of a boy aged 13-17 with Down syndrome from Rwanda (ID 95)*

Reported availability of services may be affected by a lack of information about how to access health services and support. The survey asked families and support persons of people with Down syndrome and intellectual disabilities how easy it was to find information about accessing health and support services. Across low- and middle-income countries, over half said this was hard, with the challenge growing as country-income level dropped (Fig 2a).

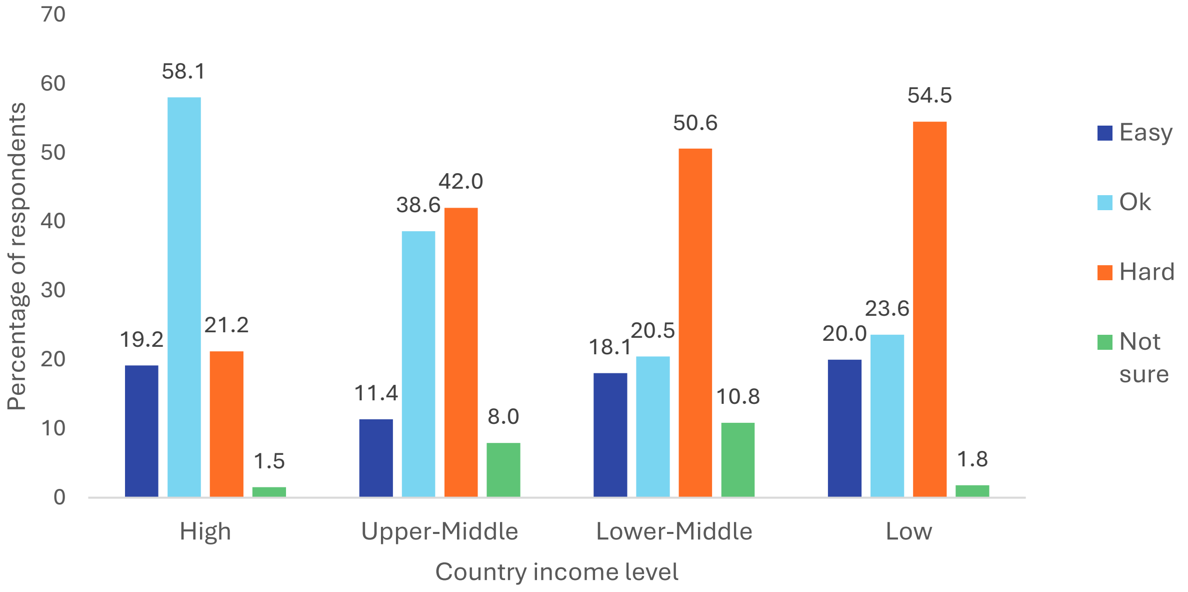


Figure 2a. Ease of finding accessible and good quality health information about Down syndrome and other intellectual disabilities

Availability differences by age group

Respondents reported that availability of health services worsens for many people with Down syndrome and intellectual disabilities once they become an adult, with a ‘cliff-edge’ of available services after the age of 18 in some countries.

> **We found as soon as she turned 18 there are no services available. It's disgraceful.**
>
> *– Woman from Ireland with a female family member with Down syndrome aged 18-24 (ID 267)*

There is also a lack of continuity between paediatric and adult care, with little support and guidance for families during this transition. Only 9% of respondents to the organisations survey said the transition was easy or very easy (Fig 2b).

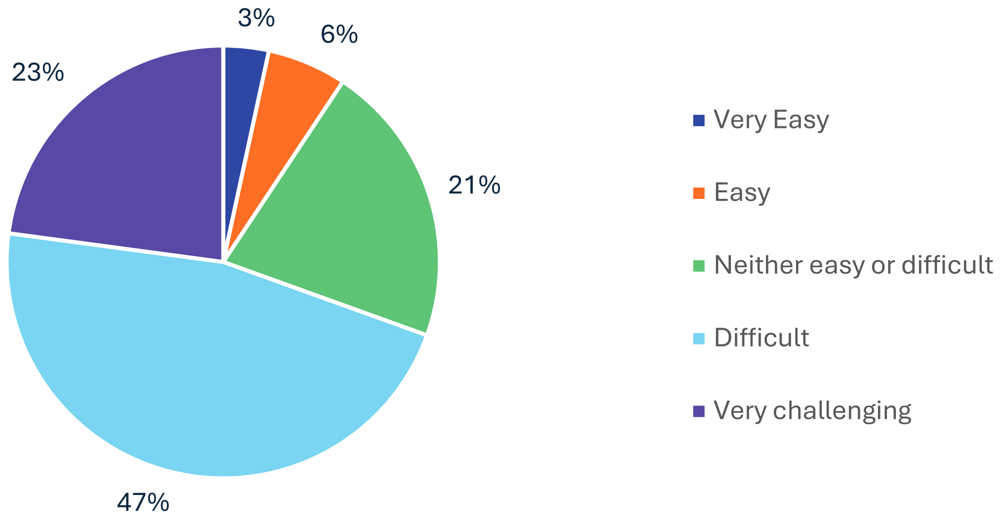


Figure 2b: Ease of transition from child to adult health services for people with Down syndrome and intellectual disabilities. Data from organisations survey.

Respondents also highlighted availability issues for older people with Down syndrome and intellectual disabilities. This situation is worse in lower income countries, with availability decreasing as country income decreases.

> **There is a great lack of information and appropriate healthcare services available for adults with Down syndrome and their families. Specifically, in the areas of healthy aging, menopause [...]**
>
> *– Female family member of a woman aged 45-54 with Down syndrome from Canada (ID 153)*

Location of services

Location of health services is a common barrier to availability. In some countries respondents from rural areas reported more issues with availability of health services than those in urban areas. However, not all countries in the survey had such a clear urban/rural divide in availability. Country income and/or health system maturity could potentially play a role in this, but this would require further research.

Impact of poor availability

Availability is interlinked with the other parts of the AAAQ framework, with poor availability of state services negatively impacting access for all and quality of care.

Many respondents with Down syndrome and intellectual disabilities have to access private healthcare because public healthcare is inadequate, insufficient, and uncomprehensive. Respondents report using private healthcare for services including physical therapy, occupational therapy, and speech and language therapy, and to access assistive devices such as orthotics, glasses and hearing aids.

Private health services are often difficult to afford, resulting in challenges with access for all. Many respondents mentioned wait times as an issue, as described in more detail in the ‘Quality of Care’ section. Poor availability is a significant cause of long wait times.

> **National Health Insurance [...] is woefully inadequate for the many healthcare challenges for persons with Down Syndrome.**
>
> *– Female family member of a girl aged 13-17 with Down syndrome from Ghana (ID 76)*

> **All healthcare services have been private and paid by me. State services are scarce and deficient; one must pay for everything and unless one has unlimited resources, there's no way to provide all supports needed.**
>
> *– Female family member of a man aged 18-24 with Down syndrome from Panama (ID 65)*

> “Most of the services needed to boost her development (occupational therapy, speech, [physiotherapy], etc.) are not available in public healthcare. Besides, there’s specialized services like nutrition on Down syndrome or dentist healthcare on Down syndrome that simply doesn’t exist on the country.”
>
> *– Female family member of a girl under 12 with Down syndrome from Portugal (ID519)*

> “Doctors and medical personnel are leaving Puerto Rico for better salaries in the United States, therefore, the number of professionals available in Puerto Rico is diminishing. It can take four to six months to find an appointment. This applies to everyone residing in Puerto Rico.”
>
> *– Female family member of a woman aged 18-24 with Down syndrome from Puerto Rico (ID 2)*

> “Special services for adults probably not available and whatever available I would research extensively before receiving or applying any such guideline.”
>
> *– Male family member of a woman aged 18-24 with Down syndrome from Thailand (ID 12)*

Access for All

‘Access for All’ means that healthcare services are non-discriminatory, affordable, and all physical environments, information and communication are accessible to everyone.

Unequal access for people with disabilities

Access to healthcare is not equal for everyone. Fewer than 50% of organisations said that health services for people with intellectual disabilities are the same as those for people without disabilities.[2] The gap is wider for adults: 59% of organisations said children with Down syndrome and intellectual disabilities get similar healthcare to other children, but only 36% said the same for adults.[3]

Non-discrimination

Two respondents (of 82) with Down syndrome reported being denied care by healthcare providers. While further details would be needed to confirm whether this was directly due to disability, these reports raise concerns about potential discrimination on the basis of intellectual disability.

> “ **I had fever repeatedly but no hospital would take me. We went to several hospitals but no one would take us.** ”
>
> *– Woman aged 35-44 with Down syndrome from China (ID B13)*

> “ **The hospital didn't take me, I have to sign disclaimers.** ”
>
> *– Woman aged 35-44 with Down syndrome from China (ID B13)*

---

[2] Questions QG14, QG18, and QG26. Questions were pooled across group the organisation represents or works with (e.g. ‘people with Down syndrome only’) and averaged across age group (‘children’, ‘young people’ and ‘adults’). ‘Similar’ refers to respondents who answered ‘agree’ and ‘strongly agree’.

[3] Chi Squared Test. P= 0.0014

Affordability of healthcare

Affordability means that healthcare must be financially accessible, so that cost doesn't stop people from getting the care they need. This includes things like public health insurance or subsidies to help cover extra costs related to disability. In this report, 'state or public services' refer to government-funded healthcare systems (e.g. the National Health Service in the United Kingdom) and financial support programmes for healthcare (e.g. Medicaid in the United States).[4]

The results show that affordability is a major issue for people with Down syndrome, other intellectual disabilities, and their families. Fewer than half the respondents believe healthcare is affordable (Fig. 3a). Families and support persons perceive healthcare to be much less affordable than people with Down syndrome and intellectual disability (Fig 3b). This may be related to who makes the decisions regarding healthcare or who manages healthcare expenses, as discussed in the Acceptability section.

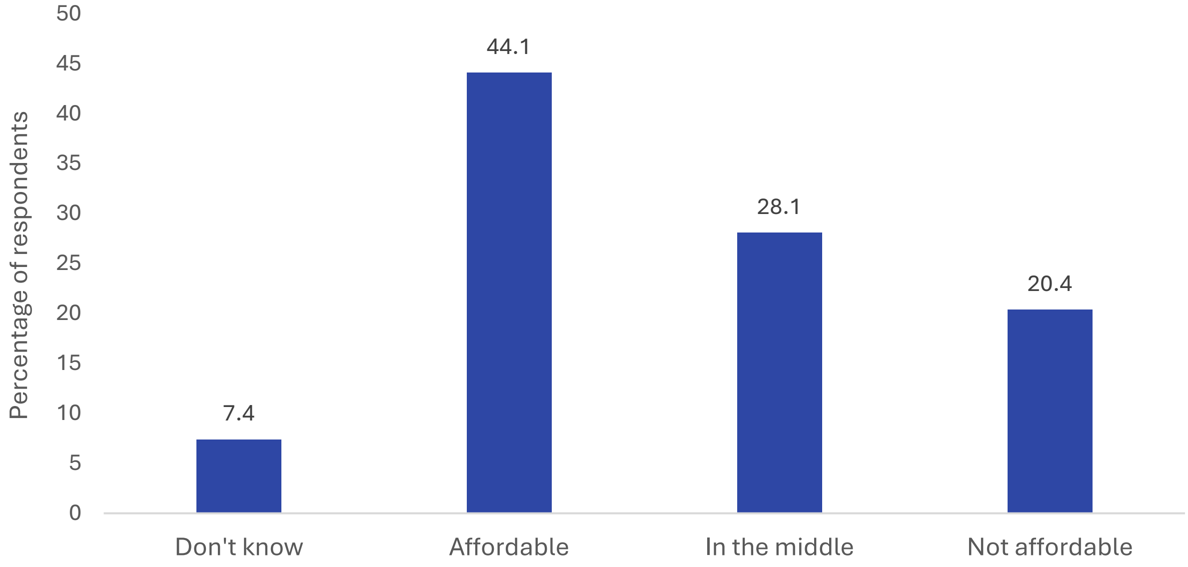


Figure 3a. Affordability of healthcare according to all respondents

---

[4] For an in-depth analysis of the health systems of these two countries, see Appendix C.

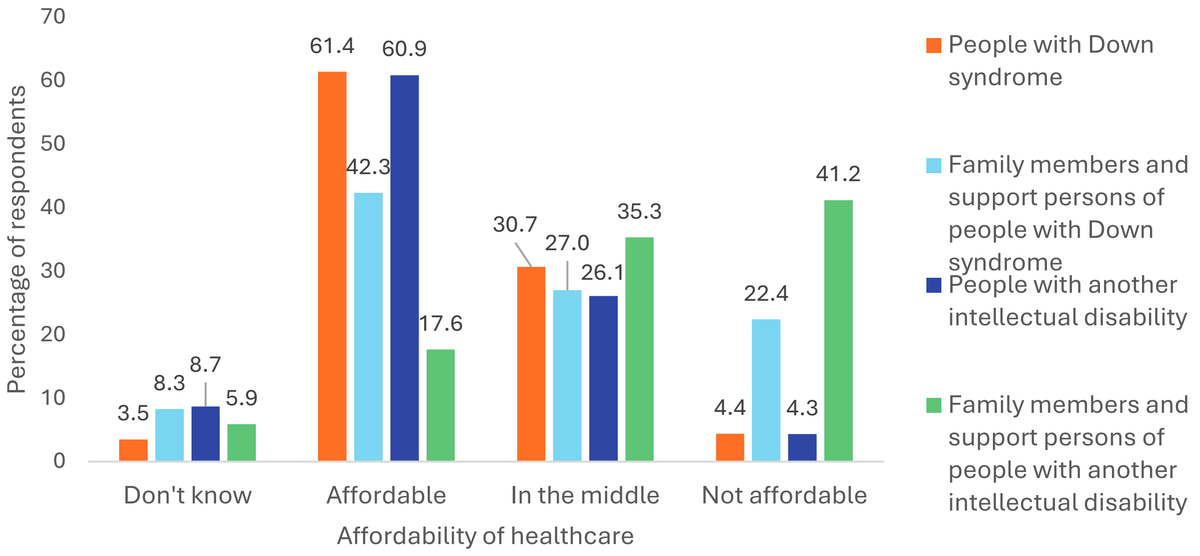


Figure 3b. Perception of healthcare affordability for people with Down syndrome or another intellectual disability

Affordability is especially poor in low- and middle-income countries (Fig 3c), but some respondents in high-income countries also find it difficult. Nearly a quarter of respondents in high-income countries don't know of any financial support for health services (Fig 3d).

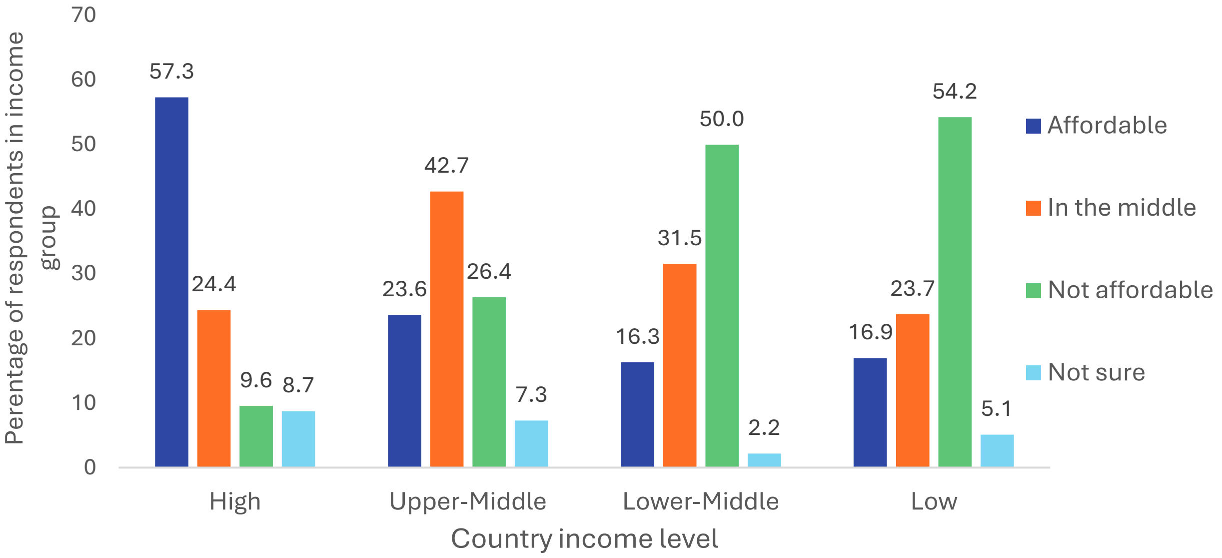


Figure 3c: Affordability of healthcare by country income level

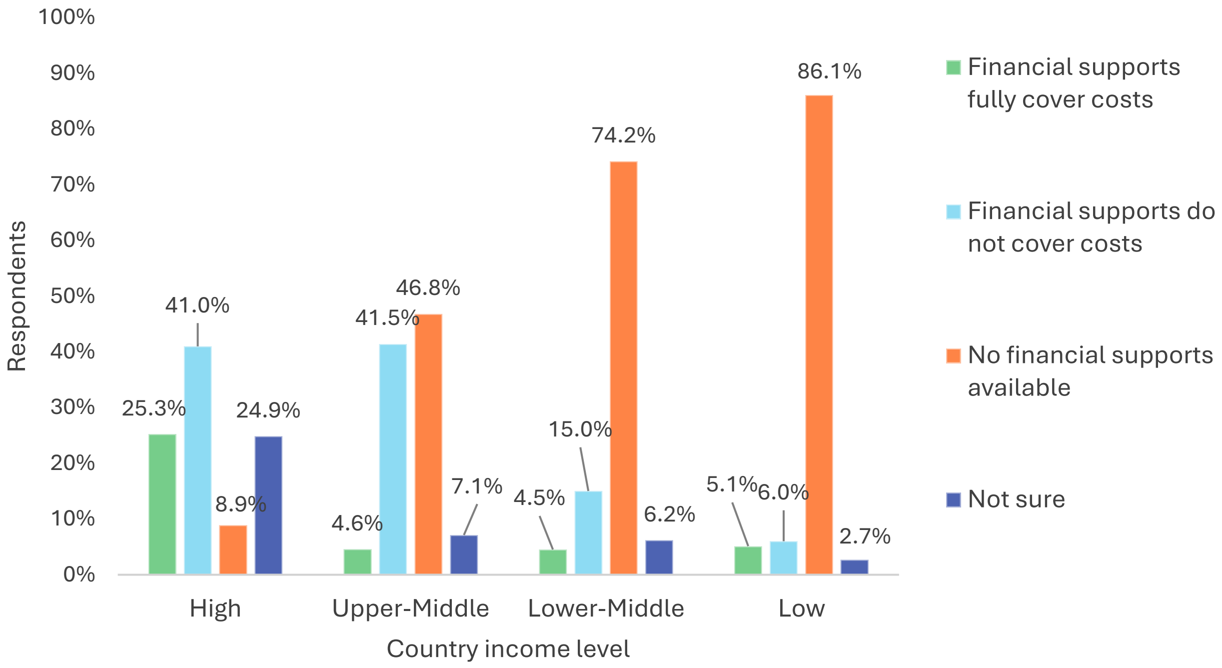


Figure 3d: Regression: Availability of financial support for health services by country income level

Where people live also affects affordability of healthcare. Those in rural areas are more likely to find healthcare unaffordable and have less access to financial support than those in cities. These affordability challenges are worse for people living in rural areas in low- or middle- income countries.

Increased government healthcare spending is linked to greater affordability of healthcare, but not necessarily to more direct financial support for healthcare costs.

> **[...] we have to pay out of pocket for all the services, we cannot afford the cost of speech therapy etc.**
>
> *– Female family member of a boy under 12 with Down syndrome from Antigua and Barbuda (ID 50)*

Private healthcare is often used when public services are unavailable, unacceptable or of poor quality, but it's costly. Many respondents described private care as expensive, with some saying they can't afford it even when it's needed. One person noted that families often have to decide which types of care to prioritise based on what they can afford.[5]

> **The total estimate[d] cost of [cardiac treatment] with […] travel [to India] is about 15000 USD. For us to get this amount of money is unthinkable.**
>
> *– Male family member of a girl under 12 with Down syndrome from Ethiopia (ID 499)*

Confusion often arises among parents and support persons regarding the coverage of parental private insurance or the availability of subsidies for people with intellectual disabilities over the age of 18.

Speech and language therapy was the was the most frequently cited unaffordable service in the free-response section, although the situation varied by country. For example, in Namibia it was reported there is only one state speech therapist for the entire country of three million people, but private care is too costly. In Japan, public speech therapy is said to be fully booked, and private therapy is expensive. In the United States, a respondent said that speech therapy costs are 'more than someone can genuinely afford without going into serious debt'.

Affordability of transport to access healthcare

Access for all includes being able to afford travel to healthcare. But transport is often less supported than healthcare itself. Significantly more respondents report that financial supports are available for healthcare than there are for transport. Those in lower-income countries are more likely to say transport is expensive and that there no financial support is available to help with transport costs (Fig. 3e and 3f).[6] However, almost half of the respondents in high-income countries don't know whether financial support for travel exists.

---

[5] In answer to QF11.

[6] Results are adjusted for skewed distribution of respondents (more in high income countries).

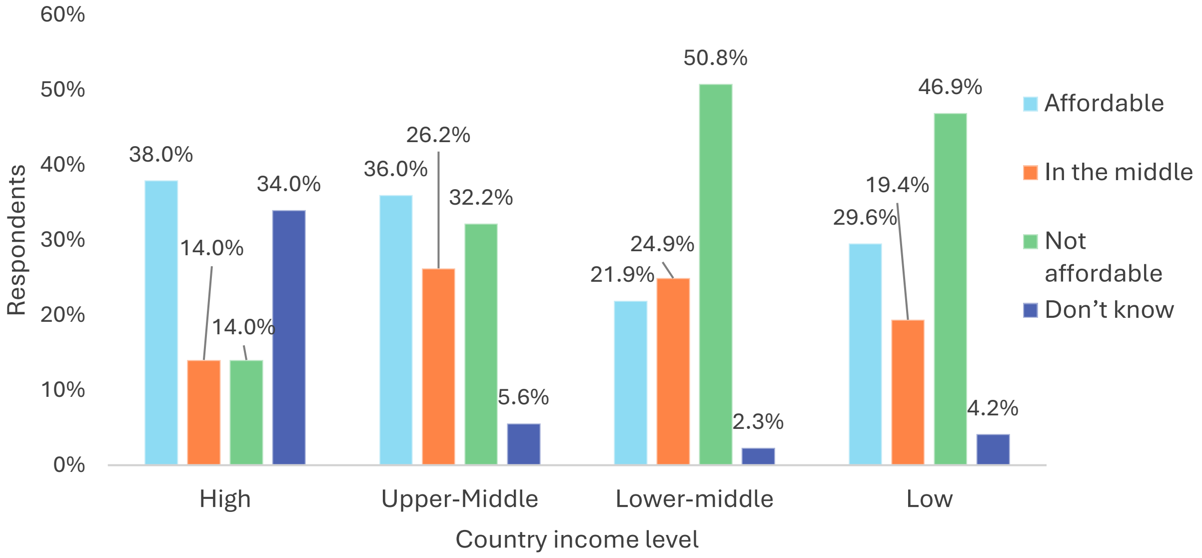


Figure 3e. Regression: Affordability of transport by country income level

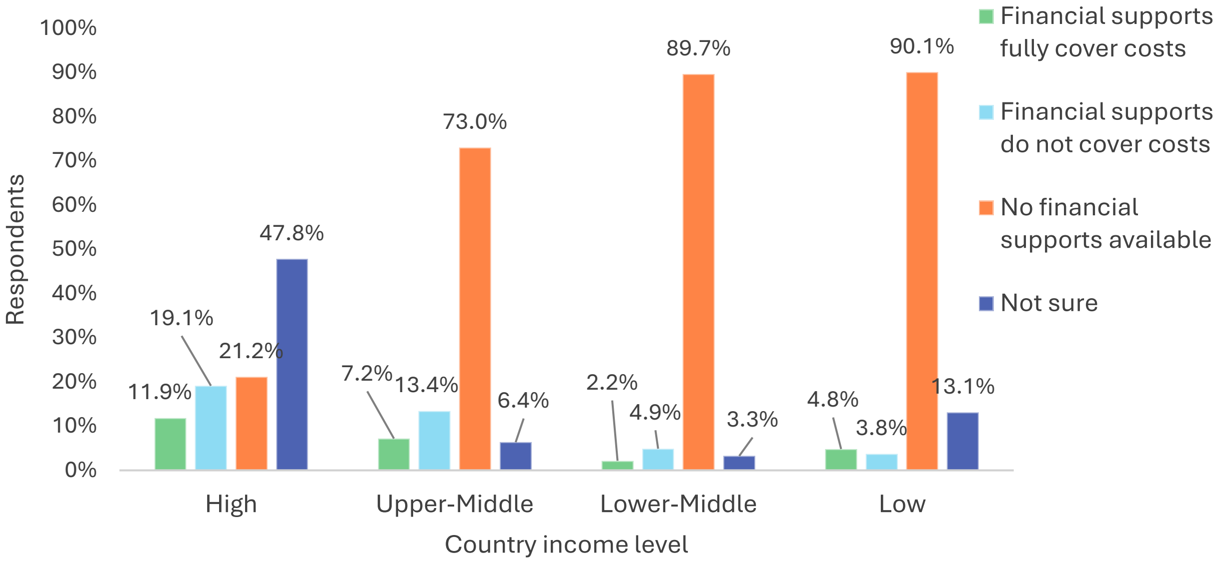


Figure 3f. Regression: Availability of financial support for travel by country income level

Increased government healthcare spending is positively associated with greater affordability of transport to access healthcare, and improved access to financial support for transport. Respondents living in rural areas are also less likely to have access to financial support for transport.

> **Social services reimburses travel expenses but it is a joke if the transport involves car/gas. The reimbursement is so minimal, it borders on ridiculous! But I still send in my requests.**
>
> *– Female family member of a man aged 25-34 with Down syndrome from Canada (ID 8)*

Physical Accessibility

Access for all means healthcare environments must be physically accessible. Physically accessible facilities are vital for access to healthcare. Results show that physical accessibility of health facilities significantly improves with country income level (Fig 3g). However, higher health spending as a share of GDP does not lead to better physical access - suggesting that how funds are used matters more than how much is spent. Respondents living in cities and towns are significantly more likely to find health facilities physically accessible than respondents living in rural areas.

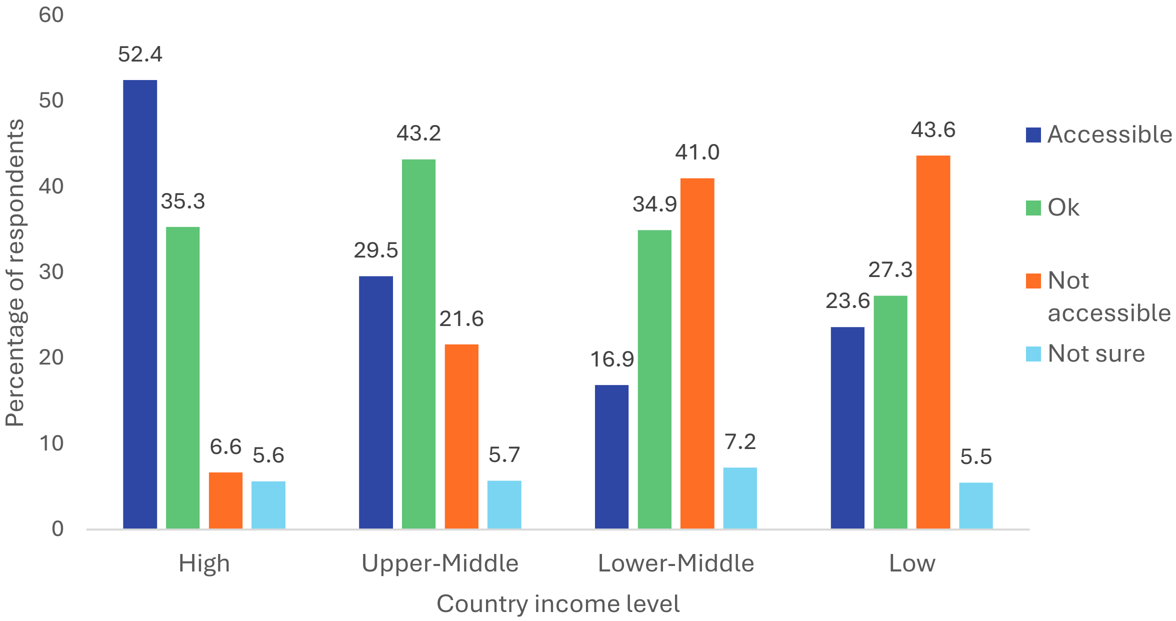


Figure 3g: Physical accessibility of health facilities for people with Down syndrome and other intellectual disabilities

Health information in accessible formats

Access for all means receiving health information in formats people can understand. But only 47% of people with Down syndrome or other intellectual disabilities say they can understand the information they receive (Fig. 3h). Over 50% of family members and support persons say that finding good quality health information in accessible formats is difficult (Fig. 3i). People in low-income countries also find this significantly harder than people in high-income countries, and tend to access fewer sources of health information overall.

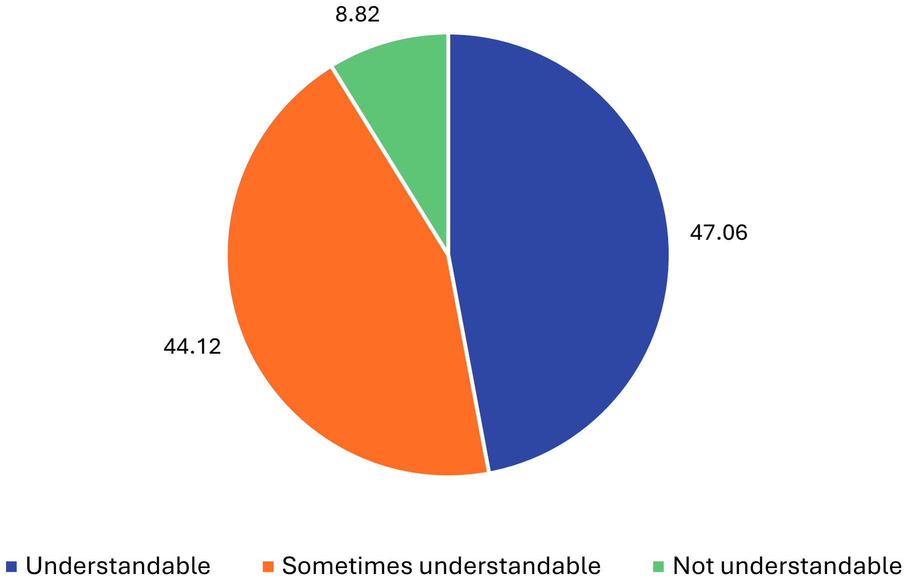


Fig 3h. Ease of understanding health information according to people with Down syndrome or intellectual disabilities (percentage)

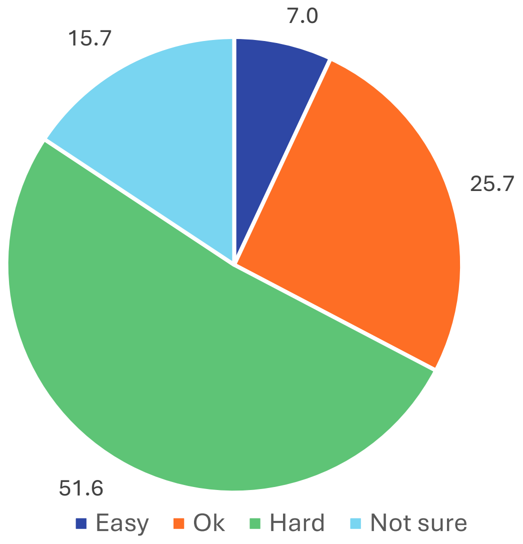


Fig 3i. Ease of finding good quality health information in accessible formats according to family members and support persons (percentage)

For those looking specifically for information on Down syndrome and other intellectual disabilities, finding it is hard - especially in lower-income countries (Fig. 3j). Only around 20% of people across all income levels say it is ‘easy’ to find accessible health information.

Some respondents say the information they receive is often out of date, showing the need for not just accessible formats but also current and relevant content.

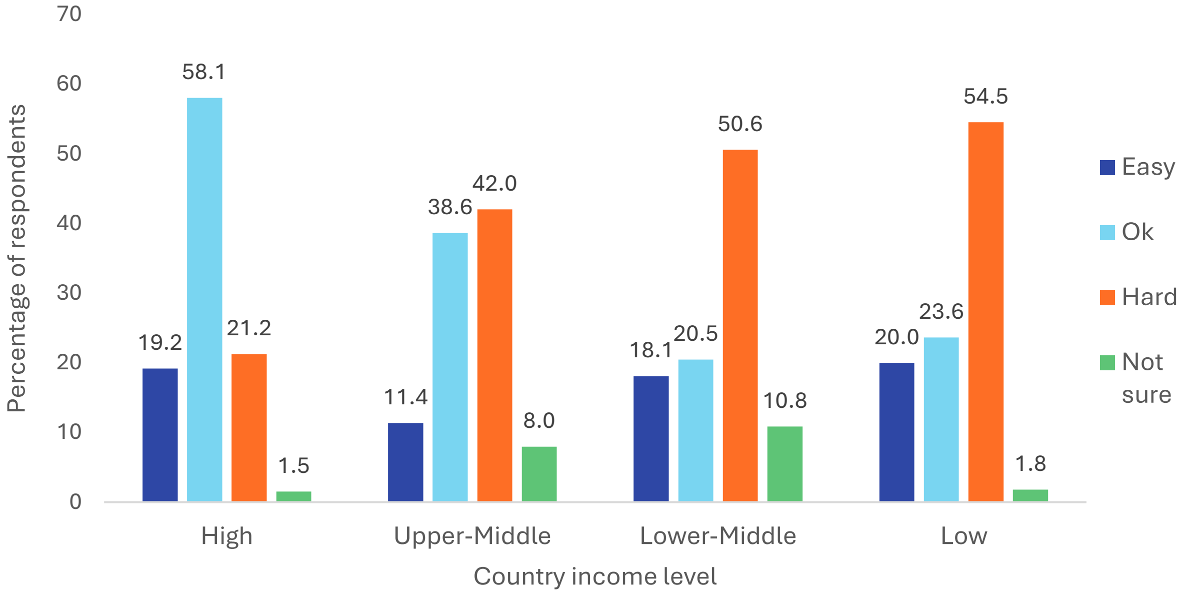


Fig 3j. Ease of finding accessible and good quality health information about Down syndrome and other intellectual disabilities

> **“I've honestly received the most healthcare information about my child’s diagnosis and how to help her, from her speech therapist... And with her advice, we got my daughter referred for a sleep study where we found she has Mild Obstructive Sleep Apnea and will now require [...] surgery.”**
>
> *– Female family member of a girl under 12 with Down syndrome from Australia (ID 313)*

Acceptability

'Acceptability' means that healthcare services respect medical ethics and cultural appropriateness while upholding the dignity, autonomy, and informed consent of persons with disabilities through inclusive and non-stigmatizing practices.

Unfair treatment

Over 45% of respondents report that people with Down syndrome and intellectual disabilities always or sometimes experience unfair treatment by healthcare workers. These experiences are more common in low- and middle-income countries, where respondents are over three times more likely to report always experiencing unfair treatment (Fig. 4a). There was a gender difference too, with more men report always being treated unfairly, while more women report never experiencing it. This may be influenced by differences in reporting by gender and warrants further investigation.

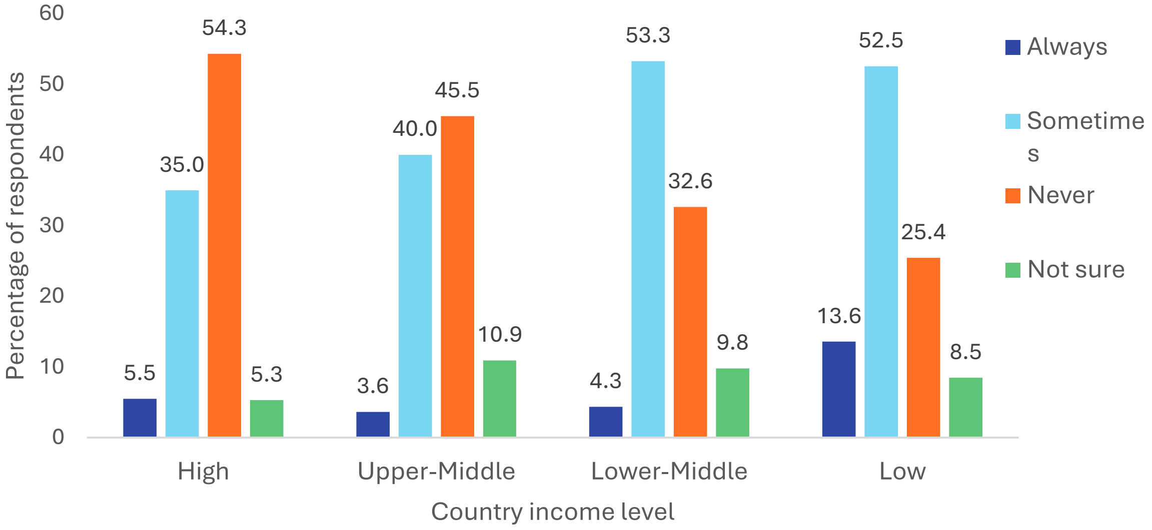


Figure 4a: Experiences of unfair treatments by doctors or other health workers towards people with Down syndrome and intellectual disabilities according to all respondents by country income level

When asked about bad healthcare experiences, people with Down syndrome and other intellectual disabilities shared examples including being treated disrespectfully, left out of decisions, treated without consent, and even facing violence.

Dignity in interactions with healthcare workers

When asked about positive and negative experiences, many responses from people with Down syndrome and intellectual disabilities were about how healthcare workers interact with them. A common issue was when healthcare providers spoke only to their support person. Others said they were ignored or not understood. On the positive side, some shared that being spoken to directly and having things explained clearly made a big difference.

> **“When I go to my doctor, it goes well, because she knows me well. I know how to explain why I came and where I have pain. The doctor speaks to me with simple words so I can understand.”**
>
> *– Man aged 25-34 with Down syndrome from France (ID C4)*

> **“I rarely go to the doctor but when I go the staff treat me well by talking nicely, cracking jokes and the take time to explain my situation.”**
>
> *– Man aged 45-54 with an intellectual disability from Seychelles (ID 474)*

Family members shared concerns too. Many said healthcare workers spoke only to them, ignoring the person with Down syndrome or an intellectual disability and treating them as if they can’t speak for themselves. A smaller group described mixed experiences, while others gave positive examples of direct communication.

> **“They generally talk about her, not TO her. If they talk to her, the tone is condescending. They usually operate on an assumption of incompetence until she speaks to them.”**
>
> *– Female family member of a girl under 12 with Down syndrome from the United States (ID 248)*

> **I was once scolded for answering for my [daughter]! I thought that was pretty cool.**
>
> *– Female family member of a woman aged 25-34 with Down syndrome from Germany (ID 188)*

> **They tell what they are about to do...they take time, ask questions at her and if she doesn't know it, they will ask us.**
>
> *– Female family member of a girl under 12 with Down syndrome from the Netherlands (ID 120)*

Autonomy and decision-making

Many people with Down syndrome or intellectual disabilities do not make their own healthcare decisions: 57% according to families and support persons and 46% according to people with disabilities themselves. Decision-making is lowest at older ages (Fig 4b). The responsibility for such decisions often lies with someone else (either family member, support person or health worker). One respondent said a doctor refused to let them sign a consent form for an operation, despite being over 21.

This may be due to assumptions that people lack the ability to make decisions, or because they aren’t given the support they need to do so. But in many countries people with Down syndrome and intellectual disabilities are also denied legal capacity, meaning they are not recognised by law as having the right to make their own decisions.

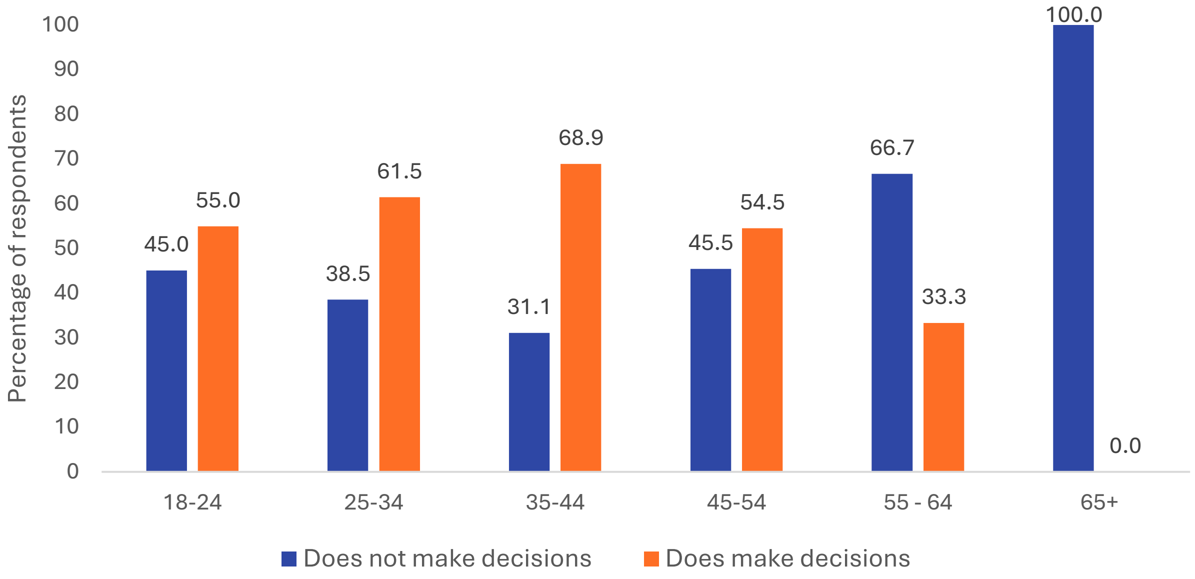


Fig 4b. Healthcare decision-making by adults with Down syndrome and intellectual disabilities according to family members and support people

> **The consultant was not really interested in what I said and listened to my parent only. He wasn't interested in how psoriasis affected me.**
>
> *– Man aged 18-24 with Down syndrome from Ireland (ID 487)*

> **My GP surgery are excellent - all the doctors talk to me and not just my mum. They explain things in a way I can understand and always give me the time I need to tell them things. They are very supportive.**
>
> *– Man aged 18-24 with Down syndrome from the United Kingdom (ID 193)*

Informed consent

Another aspect of Acceptability is that people must be informed and able to consent to their care. But only 29% of people with Down syndrome or other intellectual disabilities report that doctors and other health professionals always talk to them in ways they can understand (Fig. 4c). Without accessible communication, informed consent isn't possible.

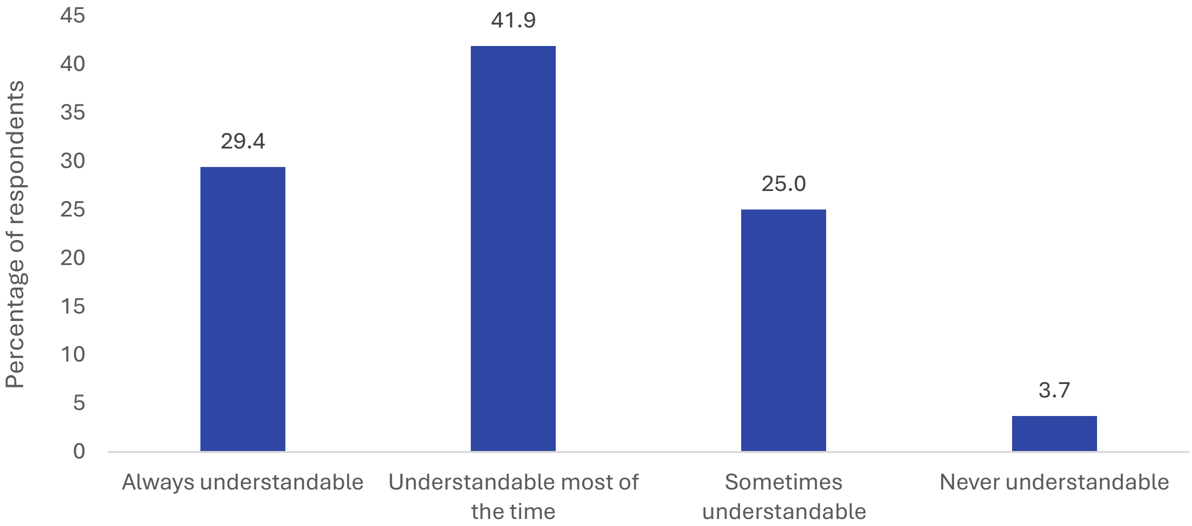


Figure 4c: Ease of understanding conversations with health workers according to people with Down syndrome and intellectual disabilities

> **I have had many bad experiences. The worst is when doctors don't listen to me or my support person, they just go ahead and try to do things, or they make assumptions that I will not cooperate and then they try to restrain me, or they don't give me pain medication or anaesthetic because they say people who have Down syndrome don't feel pain. It took eight years to get my health to improve mostly because people didn't listen or believe me.**
>
> *– Woman aged 25-34 with Down syndrome from Canada (ID 13)*

> **When I went to get a blood test, I said that I was scared to do it. The lady called in three other people to hold me down. My mother said no way and they left. When they are nice and talk with me, then I'm not scared.**
>
> *– Woman aged 55-64 with Down syndrome from the United States (ID 85)*

There were some reports of people with Down syndrome or other intellectual disabilities being treated without consent or against their will, including for serious and traumatic procedures. One respondent reported being injected with insulin without consent and one organisation reported instances of forced sterilisation and forced abortion.

> **There is forced sterilization and forced abortion targeting women and young females with Intellectual disabilities. Other disabilities receive special trainings on sexual reproductive health and rights but people with Intellectual Disabilities including Down Syndrome do not receive such education by service providers.**
>
> *– Executive Director of a local OPD in Zambia*

> **I went to the emergency room; I was injected with insulin without being informed or asked about whether I wanted it.**
>
> *– Woman aged 18-24 with Down syndrome from Switzerland*

> **I had gout and the emergency doctor explained everything very quickly and I didn't understand anything.**
>
> *– Man aged 35-44 with Down syndrome from Belgium (ID C25)*

Family of a child with a disability speaking with a doctor. © Jordimorastock.

Experiences of diagnosis of Down syndrome

Parents were asked about their experiences of receiving their child's diagnosis of Down syndrome or an intellectual disability. Since there were few responses about intellectual disability, this section focuses on Down syndrome.

Most parents received the diagnosis during pregnancy (18%), at birth (58%), or within the first 6 months (16%), though for some it took four years or more, likely due to poor training among healthcare professionals.

Many described negative experiences. Over a quarter (27%) said they received little or no advice or information, and some reported stigmatising or harmful responses from health professionals. Some who received prenatal diagnosis said they felt pressured to terminate the pregnancy.

> **No [advice or information was given upon diagnosis], except that he would know nothing when he grows up.**
>
> *– Female family member of a boy aged 13-17 with Down syndrome from China (ID B3)*

There were also positive experiences. Some parents were referred to specialists, Down syndrome associations, or support groups - highlighting the value of informed, compassionate care.

> **[We were told that our] only job is to love [our] baby and worry about therapy stuff as it comes.**
>
> *– Female family member of a boy under 12 with Down syndrome from Canada (ID 290)*

Quality of Care

'Quality of Care' means that healthcare is safe, effective, timely, equitable, and responsive to individual needs, with reasonable accommodations, assistive technologies, and trained personnel to ensure quality healthcare for persons with disabilities.

Satisfaction with health services

Across all health services surveyed, only 24.2% of respondents are satisfied with the quality of care received. Satisfaction is lowest for mental health services (49.1% not satisfied), geriatric care (43.7%), and sexual and reproductive health services (35.4%). Respondents living in lower income countries are less satisfied with health services overall than people living in higher income countries.

> **“ I was confused at the gyne [gynecologist]. I did not understand what was going on. I wanted to know about birth control. The staff was nice, but I did not get the birth control and still don't understand what I need. ”**
>
> *– Woman aged 18-24 with Down syndrome from the United States (ID 514)*

> **“ Finding a mental health specialist who also understood developmental disabilities was impossible. After 3 years, I gave up. ”**
>
> *– Female family member of a man aged 25–34 with Down syndrome from the United States (ID 216)*

> **There are insufficient professionals who specialise in Down syndrome and other neurodivergent disabilities. I have been looking for the past four years for a psychiatrist who has experience in Down Syndrome as well as mental health issues.**
>
> *– Female family member of a woman aged 25–34 with Down syndrome from the United Kingdom (ID 399)*

> **Most doctors do not seem to have experience treating older adults with Down Syndrome. It has been a struggle when she has to be hospitalized or needs a specialist who has no experience with individuals with Down Syndrome. Most have been accommodating, however.**
>
> *– Female family member of a woman aged 45-54 with Down syndrome from the United States (ID 249*

Waiting times

Timely care is a key part of the quality of care, but long waiting times are frequently mentioned by respondents, with some waiting years. Long wait times are likely to be related to low levels of availability of healthcare services.

> **The wait times for therapy [...] are extremely long, at times over a year.**
>
> *– Male family member of a girl under 12 with Down syndrome from the United States (ID 129)*

Health provider understanding of disability

Quality care must be responsive and informed, but many healthcare providers lack knowledge of Down syndrome and intellectual disabilities, or do not approach disability from a rights-based perspective. Respondents from many regions of the world mentioning this as a problem.

> **[The] doctor who told us the result didn't know very well about people with disabilities and Down syndrome.**
>
> *– Female family member of a woman aged 35-44 with Down syndrome from Japan (ID 139)*

This lack of understanding of disability places responsibility on family members and support persons to manage care. Some respondents said they wouldn’t receive adequate care unless they initiated it. This is likely to increase inequalities in access to healthcare for people who don’t have good support networks, or lack of continuity of care or referral pathways.

> **I find it’s me that has to initiate check-ups, vaccines etc.**
>
> *– Female family member of a woman aged 18-24 with Down syndrome from New Zealand (ID 491)*

> **You have to find the right doctors and therapists all by yourself. You have to know which health issues could be relevant and how to treat them. The [...] health of your child [...] is your responsibility.**
>
> *– Female family member of a girl under 12 with Down syndrome from Germany (ID 614)*

Understanding of disability also affects communication. Many respondents said poor provider knowledge made it hard to communicate with the person with a disability.[7]

> **Health care providers are not well informed or educated about this condition, so very few are able to communicate well with persons with down syndrome a lot of stereotypes [are] often shown during communication.**
>
> *– Female support person for a woman aged 25-34 with Down syndrome from Zimbabwe (ID 455)*

Stigma and misconceptions about people with disabilities are likely a key factor in the mistreatment that people with Down syndrome and intellectual disabilities report, as mentioned in the Acceptability section.

> **[Doctors and nurses have made] assumptions that I will not cooperate and then they try to restrain me, or they don't give me pain medication or anaesthetic because they say people who have Down syndrome don't feel pain.**
>
> – Woman aged 25-34 with Down syndrome from Canada (ID 13)

These gaps in understanding can have serious consequences. Some respondents reported being misdiagnosed or their symptoms being attributed to having Down syndrome or an intellectual disability. This is often called 'diagnostic overshadowing'.

---

[7] This theme arose across multiple different questions.

> **Health care providers continue to give us information on how the disability can be cured.**
>
> *– Female family member of a girl aged under 12 with an intellectual disability from Ghana*

> **We heard way too often symptoms 'blamed' on Down syndrome. That's the easy answer when the doctor hasn't got a clue.**
>
> *– Female family member of a woman aged 18-24 with Down syndrome from Ireland (ID 287)*

> **An optician mixed up the prescriptions for both eyes. To this day I'm still suffering the effects of this mistake.**
>
> *– Man aged 18-24 with Down syndrome from Morocco (ID C31)*

Provision of reasonable accommodations

Healthcare providers have a responsibility to provide reasonable accommodations, the changes or adjustments that a person needs so they can access health services. Examples include sending Easy Read letters, giving more time for appointments, or allowing a support person to accompany the person.

38% of respondents say that there are no reasonable accommodations in healthcare settings for people with Down syndrome and intellectual disabilities. As country income level decreases, more respondents report that reasonable accommodations are not provided (Fig. 5a).[8] However, even in high income

---

[8] Responses to the French language survey for this question have been excluded due to an error in the options presented to respondents.

countries, only 19.3% of respondents say reasonable adjustments are provided systematically.

> **They did not allow my personal assistant to stay with me in emergency room, while I was feeling bad and frightened, and I cannot speak or make gestures, I cannot communicate without my personal assistant.**
>
> *- Man aged 25-34 with an intellectual disability from Argentina*

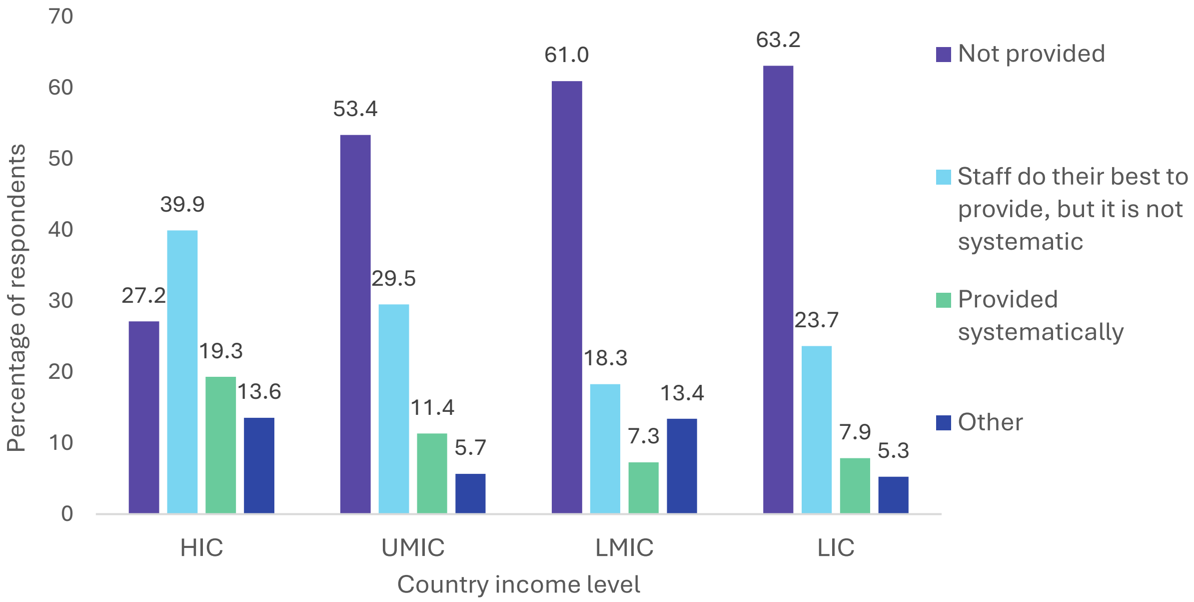
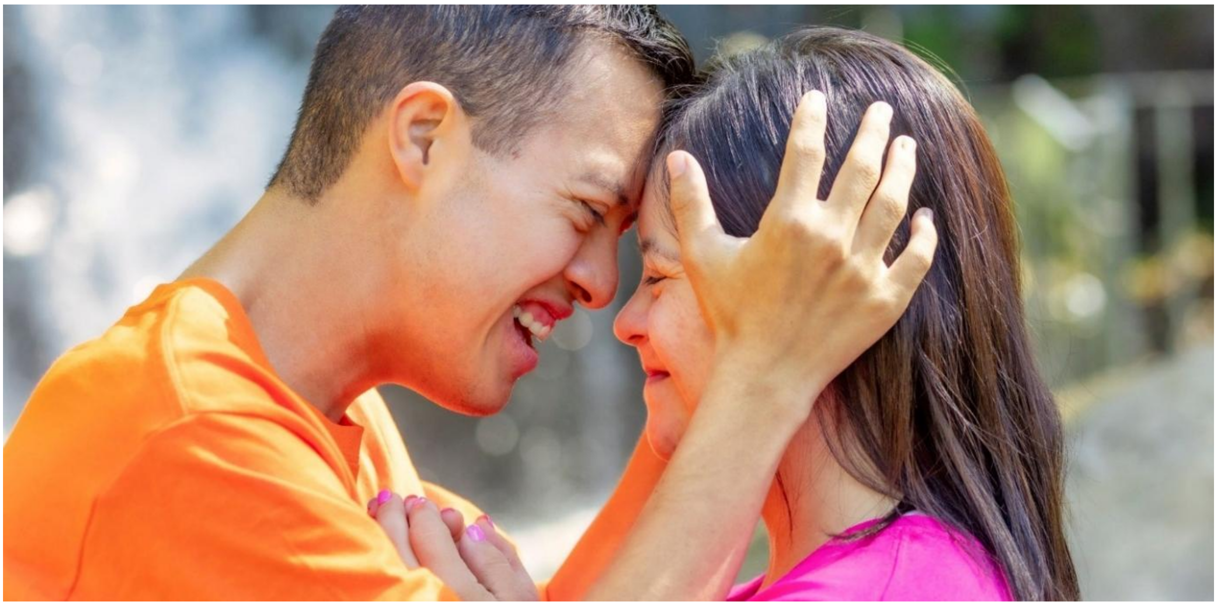


Figure 5a: Provision of reasonable accommodations by healthcare providers to people with Down syndrome and intellectual disabilities by country income level

How Gender, Age and Where You Live Change How People with Intellectual Disabilities Experience Healthcare

We asked people about their gender, age, which country they were from and whether they lived in a city or a rural area. We also used country-level data to compare things like healthcare spending and income. This helps us understand if some groups of people with intellectual disabilities have different experiences with healthcare, and if they face more barriers than others. Some comparisons based on these factors are included in other parts of the report. This section gives a short summary of each main factor.

As explained in the ‘Limitations’ section, the survey did not ask enough questions to fully understand the experiences of people of different ethnic minorities, Indigenous people, people with different sexual orientations or people with different income levels.



Man and woman with Down syndrome. © Arturo Pena Romano Medina from Getty Images Signature.

Gender

The gender of people with Down syndrome and intellectual disabilities who answered the survey was almost evenly split between women/girls and men/boys (Fig. 6a). There was one person who identified as non-binary, and 11 that chose not to say.

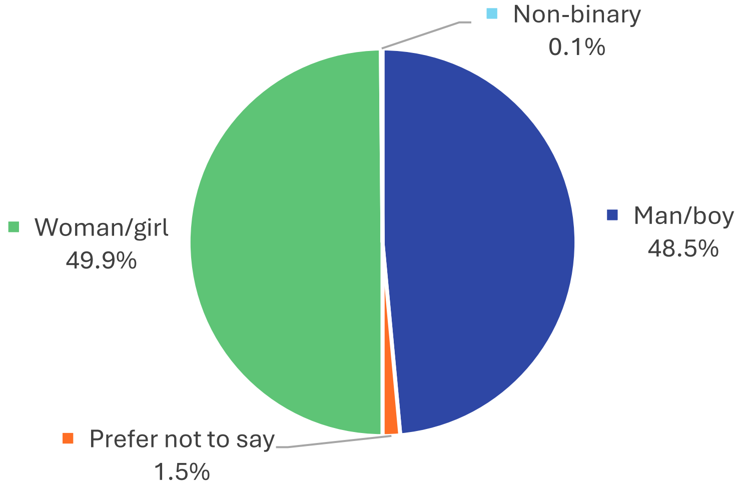


Fig 6a. Gender of people with Down syndrome or another intellectual disability

Most of the family members and support persons who responded were women (79%), revealing ongoing gender inequality in care and support work globally (Fig. 6b).

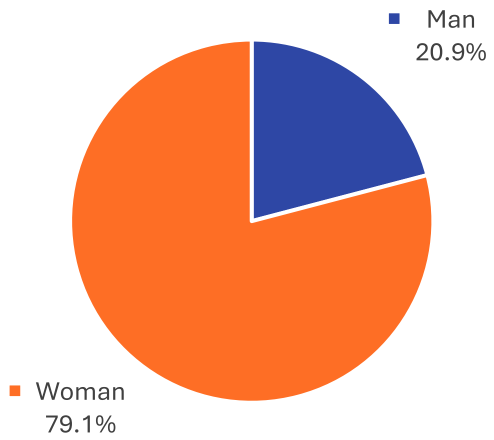


Figure 6b: Gender of family members and support workers responding to survey

There is strong global evidence that women and girls with disabilities face greater barriers to healthcare, including higher levels of discrimination, limited access to services, and poorer health outcomes. Consistent with wider evidence, the survey also found evidence of serious gender-based violations and barriers that affect women and girls with intellectual disabilities:

- Reports of violations of sexual and reproductive rights, including reports of abortions being advised as the preferred option in pre-natal counselling, and one report of forced sterilisations and forced abortions (in Zambia).
- Poor quality or a complete lack of sexual and reproductive health services.

At the same time, in some areas, women and girls with intellectual disabilities reported fewer barriers than men and boys, or the data was mixed. For example:

- Availability of health services: More men and boys reported that services were unavailable. However, family members and support persons of women and girls were less likely to report trying to access services such as child development or reproductive healthcare—possibly reflecting social or cultural expectations that restrict access for women and girls in the first place.

- Experiences of unfair treatment: More men said they *always* experienced unfair treatment from health providers, while more women said they *never* did. This may point to differences in expectations, perceptions, or reporting, or reflect the influence of family members or support persons in mediating healthcare experiences.

- Decision-making in healthcare: While family members and support persons saw no gender difference in who made healthcare decisions, more women with Down syndrome and intellectual disabilities than men reported making their own healthcare decisions—this is encouraging for women, though further exploration into this gender gap is required.

These findings may reflect differences in how people report or access healthcare, or how the survey captured gender-related issues. There is need for more research to better understand how gender affects healthcare access, experiences, and outcomes for people with intellectual disabilities.

Age

Most people who answered the individuals survey were young. The great majority of people (87.8%) with Down syndrome or an intellectual disability were between the ages of 18 and 44, and the most common age bracket was 25-34. Most support persons and family members supported someone who was under the age of 18. There were very few people over the age of 55 who answered the survey, so more research needs to be done to collect information from older people.

The survey showed that age impacts healthcare access and experience, particularly for adults and older people with Down syndrome and intellectual disabilities in several important ways:

- Fairness of access to healthcare: 59% of organisations said children with Down syndrome and intellectual disabilities get similar care to others, but only 36% said the same for adults.

- Lack of availability services for adults with intellectual disabilities: Many respondents said services drop off sharply after age 18, with little support during the transition from child to adult care. Only 9% of organisations said this transition was easy. Older people with Down syndrome and intellectual disabilities also face more gaps, especially in poorer countries.

- Satisfaction with care: Nearly half of families (45.3%) said they were not satisfied with the services available for older people with intellectual disabilities. This high level of dissatisfaction suggests that, even where services exist, they may not meet the needs of older adults. Although only 6.2% said these services were completely unavailable, the data points to a gap between availability and adequacy, with issues such as poor quality, lack of accessibility, or services that are not adapted to the realities of ageing with an intellectual disability could be contributing factors.

- Decision-making in healthcare: fewer young adults and older people were reported to make their own healthcare decisions compared to those in middle age (see Fig. 4b, ‘Autonomy and decision-making’).

A woman with Down syndrome © Portishead1 from Getty Images Signature.

Country income

Respondents from lower-income countries reported more issues with healthcare than those in higher-income countries across many areas, although sometimes the differences were complex. This included:

- Finding health information: people in lower-income countries reported more difficulty finding accessible and high-quality health information and information about Down syndrome and intellectual disabilities (see Fig 3h and 3i). They also reported using fewer sources of information.

- Physical accessibility: reported physical accessibility to health facilities decreased as country income level decreased (see Fig 3g).

- Affordability of healthcare: healthcare was reported as less affordable in low- and middle-income countries, although respondents in some high-income countries also find it difficult (see Fig 3c).

- Affordability of transport: people in lower-income countries found transport to healthcare more expensive and said that financial support for transport is less available than for people in higher-income countries (see Fig 3d and 3f). However, almost half of respondents from high-income countries did not know if there were financial supports.

- Unfair treatment: people in lower-income countries reported much more unfair treatment in healthcare, with those in low-income countries more than three times more likely to always face unfair treatment (see Fig. 4a).

- Dedicated support persons in health facilities: people reported that there are significantly fewer dedicated support persons in lower income countries.

- Communication with health providers: families and support persons reported better communication between health providers and patients in higher-income countries (see Fig. 4c). However, people with Down syndrome and intellectual disabilities in high-income countries found it worse. This could be due to increased knowledge of rights and higher expectations.

- Reasonable accommodations: more people in lower-income countries reported that reasonable accommodations were not provided, although even in high-income countries, only 19.3% said adjustments are provided consistently (see Fig. 5a).

- Satisfaction and availability: people in lower-income countries were less satisfied with health services overall and reported less availability of older persons' healthcare.

- Transition to adult care: there was no significant difference in ease of transition from child to adult care between countries of different income levels – it is difficult everywhere.

Government health spending

Country data from the World Bank was used to assess whether increased government healthcare spending[9] was linked to improved access, quality, or other key areas covered in the survey. Results were mixed for different areas:

- Physical accessibility: Countries that spent more on healthcare did not have better reported physical accessibility of health facilities, suggesting how health budgets are allocated matters more than how much.
- Affordability of healthcare: Increased government healthcare spending was linked to better reported affordability of healthcare, but not to increased reported levels of access to direct financial support for healthcare costs.

---

[9] as a proportion of GDP.

- Affordability of transport: Higher national healthcare spending was linked to increased reported affordability of transport to healthcare, as well as to better access to financial support for travel.

Comparisons between people with Down syndrome and other people with intellectual disabilities

People with Down syndrome reported fewer barriers than other people with intellectual disabilities across several areas of healthcare access in this survey. For example, respondents with other intellectual disabilities were more likely to say that most health services were unavailable, communication with providers was poor, health information was not accessible, unfair treatment was more frequent, reasonable accommodations were lacking, and satisfaction with services was lower—except in specialised care.

However, this does not mean that people with Down syndrome do not face serious challenges in healthcare. Instead, it may reflect differences in support networks, service pathways, or how people with different disabilities experience and report healthcare. Additionally, people with intellectual disabilities and their family members and support persons only made up approximately 10% of the total individual respondents, so more research is needed to understand further specific experiences they face in accessing healthcare.

Differences based on rural compared to urban location

81% of all respondents to the individuals survey live in an urban area, which is in line with the international average. Respondents from urban areas reported less issues than those in rural areas in some questions, for example:

- Service availability - some family members and support persons said healthcare availability was worse in rural areas, but others said they could access services in rural areas - suggesting this varies by country or region.
- Physical accessibility - people in urban areas were significantly more likely to find health facilities physically accessible than those in rural areas.
- Healthcare costs and financial support – people in rural areas were more likely to find healthcare unaffordable and reported less access to financial support for both healthcare and transport - especially in low- and middle-income countries.

> **Now that we live in a rural area of France, rather than a suburb in the UK, access to support groups has been difficult. We find that the attitude towards disability is very different to that in the UK.**
>
> *- Female family member of a boy aged 13-17 with Down syndrome from France (ID C3)*

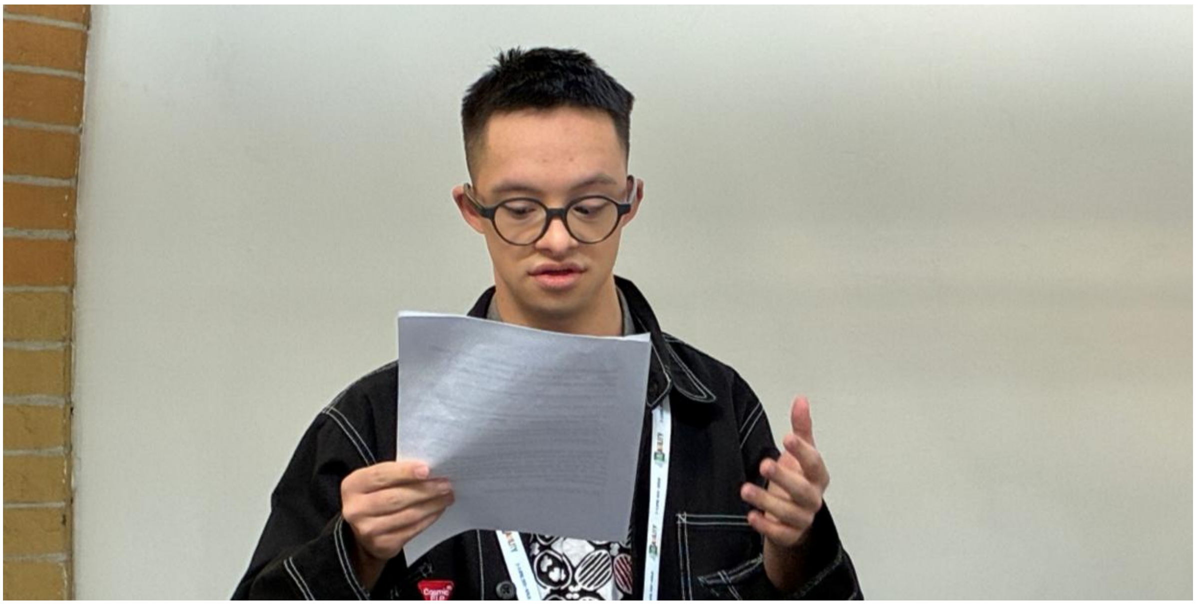
> **He lives in a city, therefore healthcare services [are] accessible.**
>
> *- Male family member of a boy under 18 with Down syndrome from Nigeria (ID 376)*

Advocacy: Speaking up for our right to health

People with Down syndrome and intellectual disabilities must be able to speak up for better healthcare - both for themselves and for fairer, more inclusive healthcare systems. Organisations of persons with disabilities play a vital role in this advocacy, as a representative voice of individuals and families.

Governments are required by the UN Convention on the Rights of Persons with Disabilities to involve people with disabilities, through their representative organisations, in shaping all laws and policies that affect them.

This section will share real-life experiences of individuals and organisations involved in health advocacy, that were shared in the consultation.



Morgan Maze, DSi Ambassador and self-advocate from Indonesia, presenting preliminary results of this report at the Global Disability Summit, in Berlin, April 2025. © Down Syndrome International

Advocacy by individuals about their own health

37% of people with Down syndrome and other intellectual disabilities said they had spoken up about their health (Fig 7a). Examples include someone advocating for a specialist referral at an appointment and another submitting a complaint to challenge a misdiagnosis.

Since many said they hadn't spoken up about their health or weren't sure, more training and support are needed to help people feel confident advocating for their health during appointments and interactions with the health system.

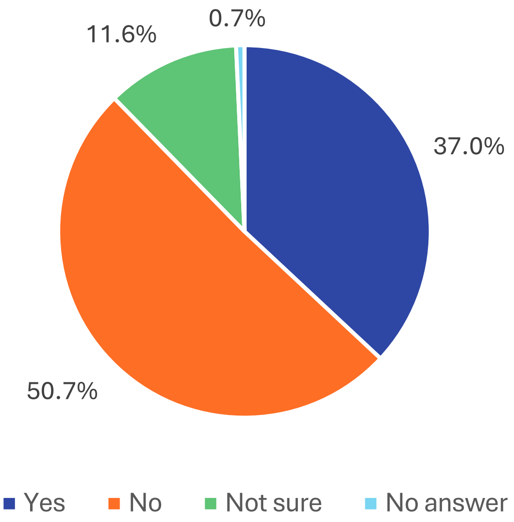


Figure 7a: Percentage of people with Down syndrome or intellectual disabilities who have participated in health advocacy or have spoken up about their health

> **We must continue to raise awareness about the importance of equity and accessibility in health for most people with intellectual disabilities. In particular, we must educate health professionals to improve medical care and the government must create better ways to make this human right, which is access to health, accessible.**
>
> *- Woman aged 18-24 with Down syndrome from Puerto Rico (ID A12)*

> **I co-wrote a letter.. [to challenge] 'clinical negligence' and .. that I had been misdiagnosed with borderline personality disorder.**
>
> *- Non-binary person aged 18-24 with an intellectual disability from the United Kingdom*

Advocacy by individuals to improve healthcare systems

Nearly one-third (29%) of people with Down syndrome and other intellectual disabilities said that they had spoken up to improve how healthcare is provided in their country (Fig 7b). Some of the examples of advocacy provided were from events organised by Down Syndrome International as part of the report development, including an event at the United Nations in New York.

> **I'm a Health Ambassador for Down Syndrome Australia and I have spoken to more than 500 health professionals.**
>
> *- Woman aged 25-34 with Down syndrome from Australia*

Examples of this advocacy included:

- Teaching healthcare professionals how to treat people with disabilities fairly
- Campaigning for annual health checks for people with intellectual disabilities
- Speaking at the United Nations about health equity
- Presenting at the World Health Assembly with the World Health Organization

However, the majority, 62.3%, said they had not been involved in advocacy to improve health systems, and 8% were unsure (Fig 7b). This reveals another gap, and an important opportunity, to invest in the capacity and supports needed for people with intellectual disabilities to advocate to strengthen health systems to make sure they provide quality health care that meets their needs. It also highlights the importance of ensuring the diversity of representation of voices and experiences within disability rights movements. And supporting health and disability rights organisations to ensure meaningful participation of people with intellectual disabilities in their advocacy towards health equity and systems change.

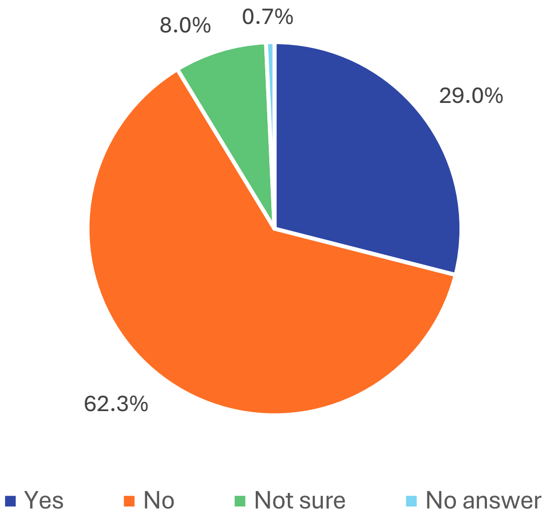


Figure 7b: Percentage of people with Down syndrome or intellectual disabilities who have participated in advocacy or have spoken up about making healthcare better in their country

Advocacy by organisations

This section focuses on advocacy by 47 organisations of persons with disabilities, which made up 40% of survey respondents. This included a range of different organisations:

- Geographic focus - one was global, one regional, 25 national (53%), and 20 local (43%).
- Country income level – almost half of OPDs were from high-income countries, but there was better representation than in the individuals survey (Fig 7c).

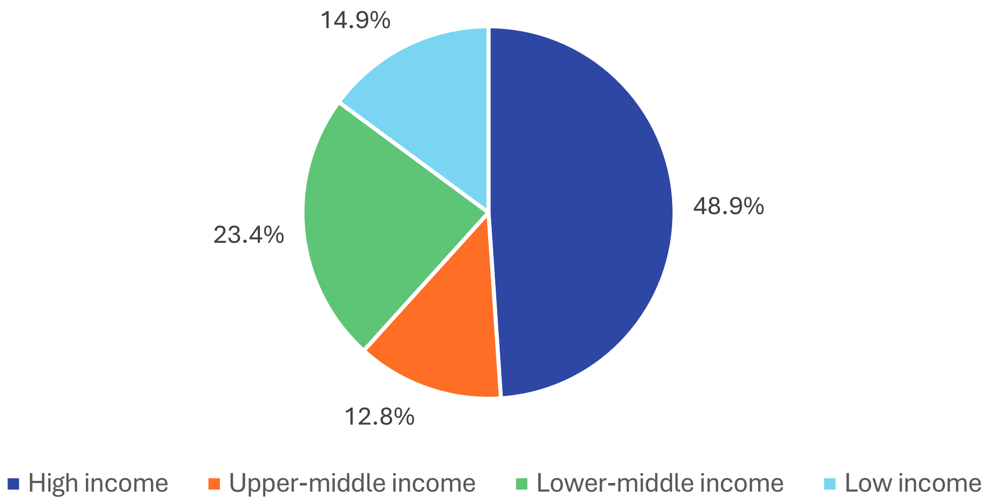


Figure 7c: Percentage of organisations of persons with disabilities by country income

The majority (55%) of organisations of persons with disabilities had experience running healthcare advocacy campaigns. However, examples shared showed that some were actually providing services, due to issues with the healthcare services in their countries.

Examples of advocacy for systemic changes, such as changing laws and policies, included:

- Pushing for laws to stop discrimination against people with intellectual disabilities when it comes to organ transplants.
- Helping create a national plan to improve healthcare for people with intellectual disabilities.
- Advocating for people with intellectual disabilities to get higher priority on waiting lists for national health services.

Some organisations focused on helping health professionals better understand how to provide quality care for people with disabilities. For example:

- Training for healthcare workers
- Presentations about Down syndrome at medical conferences
- Training videos about disability and healthcare

Others worked to raise awareness about health in their communities and networks. For example:

- Running media campaigns about inclusive healthcare

- Creating Easy Read materials on key health topics
- Organising outreach programmes to share important health information

Just over one quarter (28%) of organisations had done research into the health challenges faced by people with Down syndrome or intellectual disabilities. However, 53% said they were interested in learning how to do this kind of research.

Overall, the survey findings showed there is interest and existing good practice examples from organisations of persons with disabilities working to strengthen the health system and promote equity for people with intellectual disabilities. This presents an opportunity for governments, health service providers and research institutions to work in partnership with organisations of persons with disabilities, to scale and embed these examples and improve equity across health systems.

Janet Charchuk sharing results from this report at the Global Disability Summit, 2025.
© Down Syndrome International

Summary of findings

The Global Consultation revealed widespread and systemic barriers to healthcare for people with Down syndrome and other intellectual disabilities. These barriers were evident across all four dimensions of the adapted AAAQ framework described on page 4: Availability, Access for All, Acceptability, and Quality of Care.

Availability

Availability of healthcare services is a significant concern. Respondents reported that both mainstream services including sexual and reproductive healthcare, mental health care, cardiac care, and dental services, and disability-specific services like speech therapy are often unavailable. Many people in low- and middle-income countries reported struggling to find information about how to access health services.

Availability also varies by age. Many respondents said services drop off sharply after age 18, with little support during the transition from child to adult care. Only 9% said this transition was easy. Older people with Down syndrome and intellectual disabilities also face more gaps, especially in poorer countries.

Location matters too. People in rural areas reported more problems, though this varied by country. Poor availability affects access and can compromise quality, pushing many to use private healthcare, which is often very expensive. Long wait times are also a common result.

Access for All

‘Access for All’ means that healthcare services are non-discriminatory, affordable, and all physical environments, information and communication are accessible to everyone.

Access is not equal for people with disabilities. Fewer than half of organisations say people with Down syndrome and intellectual disabilities have the same healthcare access as others, with access worse for adults. Two people with Down syndrome reported being denied care.

Affordability is a major issue, especially in low- and middle-income countries. Fewer than half of respondents believe healthcare is affordable, and rural areas face greater challenges. Private care is often used when public services fall short, but it's expensive. Speech therapy was the most frequently cited unaffordable service, with examples from Namibia, Japan, and the U.S.

Transport costs also limit access. Financial support for travel is less common than for healthcare, especially in low-income and rural areas. Even in high-income countries, many don't know if support exists.

Physical accessibility improves with country income, but people living in rural areas still face more barriers. How health budgets are allocated matters more than how much is spent.

Only 47% of people with Down syndrome or other intellectual disabilities say they receive health information in accessible formats. Families also struggle to find good quality, accessible information, especially in low-income countries. Many said the information was outdated, showing the need for clearer, more current content.

A girl with Down syndrome attends a clinic in Sri Lanka. © Ph. Merchez / HI

Acceptability

‘Acceptability’ means that healthcare services respect medical ethics and cultural appropriateness while upholding the dignity, autonomy, and informed consent of persons with disabilities through inclusive and non-stigmatizing practices.

Over 45% of respondents said people with Down syndrome and intellectual disabilities always or sometimes face unfair treatment by healthcare workers. This is more common in low- and middle-income countries. Some people shared experiences of being disrespected, excluded from decisions, treated without consent, or even harmed.

Many people with Down syndrome and intellectual disabilities said how healthcare workers interacted with them made a big difference. Being ignored or spoken about, instead of being spoken to, was common. while being addressed directly and clearly was seen as positive. Families also said healthcare workers often spoke only to them, not the person receiving care.

Autonomy in healthcare decision-making for people with intellectual disabilities is limited. Only 46% of people with disabilities and 57% of families said the person made their own decisions. This is lowest at younger and older ages. Some are denied legal capacity or not given the support needed to decide for themselves.

Informed consent is also a concern. Only 29% of people said doctors always spoke in ways they could understand. Without clear communication, informed consent isn’t possible. Some reported being treated without consent, including for serious procedures like forced sterilisation or injections.

Quality of Care

‘Quality of Care’ means that healthcare is safe, effective, timely, equitable, and responsive to individual needs, with reasonable accommodations, assistive technologies, and trained personnel to ensure quality healthcare for persons with disabilities.

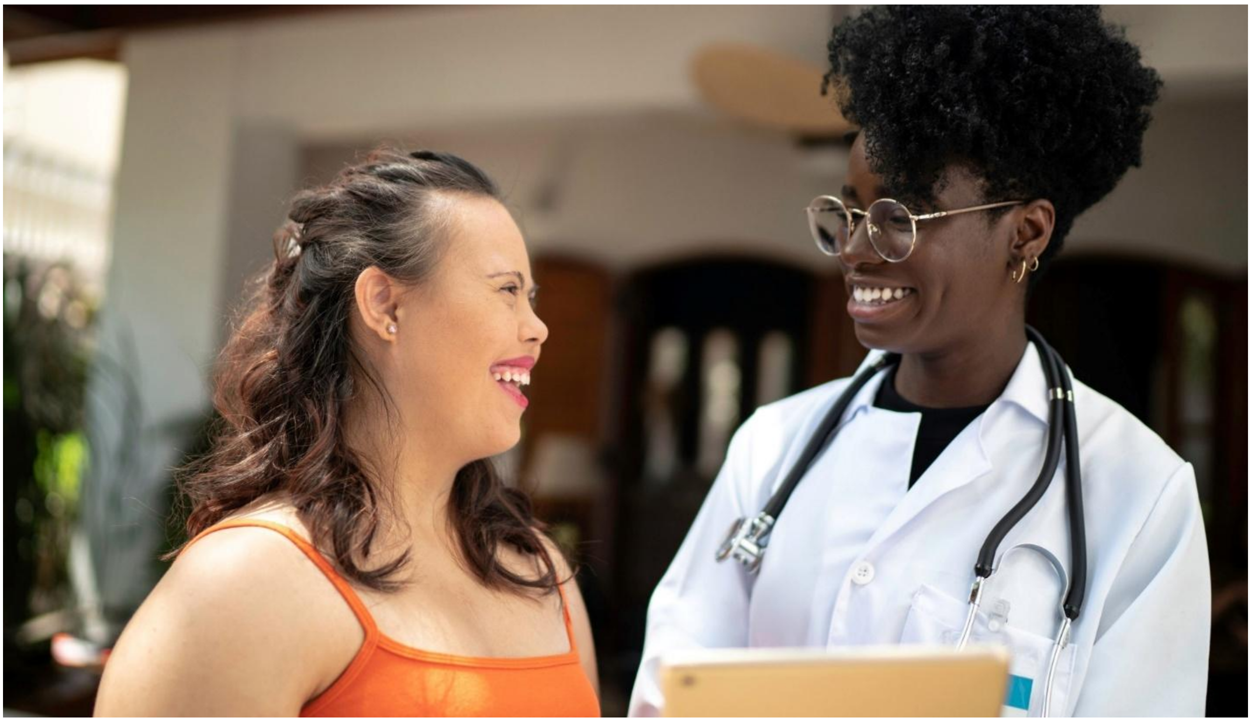
Only 24.2% of respondents are satisfied with the quality of care. Mental health, geriatric, and sexual and reproductive health services had the lowest satisfaction. People in lower-income countries reported lower satisfaction overall.

Long waiting times were a common issue, with some people waiting years. This is likely linked to poor availability of services.

Many healthcare providers lack knowledge about Down syndrome and intellectual disabilities or don't use a rights-based approach. This puts pressure on families to manage care and can lead to unequal access, especially for those without strong support networks.

Poor understanding also affects communication. Some people are misdiagnosed or have their symptoms wrongly blamed on their disability—known as 'diagnostic overshadowing'.

Nearly half of respondents said no reasonable accommodations were provided in healthcare settings. These include things like Easy Read letters or longer appointments. Even in high-income countries, only 19.3% said such adjustments are provided consistently.



Woman with Down syndrome talking to a doctor. © FG Trade from Getty Images Signature.

What needs to change?

What causes these unfair health outcomes?

People with intellectual disabilities experience worse health outcomes than the general population. These inequities are not the result of individual impairments, but of health systems that consistently fail to include and respond to the needs and rights of people with intellectual disabilities. These failures are both systemic and structural—and they are preventable.

Health systems are too often designed, funded, and delivered without the participation of people with intellectual disabilities or their representative organisations (OPDs). This exclusion means that the barriers they face—such as inaccessible health information, discriminatory attitudes, and lack of reasonable accommodation—are rarely identified or addressed in health policies, service delivery, or workforce training. As a result, people with intellectual disabilities are often unable to access services on an equal basis with others.

A key driver of these inequities is the lack of meaningful engagement of OPDs in health governance. OPDs are not routinely included in health planning or monitoring processes. Even when opportunities exist, OPDs frequently lack the resources, technical capacity, or tools needed to advocate effectively or participate in complex health system strengthening efforts. Tools such as a CRPD-Compliant Health Budgeting Toolkit, health equity advocacy guides, or training on how to analyse gaps in health equity are still not widely available or used.

On the side of duty bearers, governments and other health stakeholders often do not understand the specific barriers that people with intellectual disabilities face, nor how to design inclusive systems that address them. There is a widespread lack of training, tools, and good practices tailored to ensuring accessibility, consent, communication support, or data collection. Health workers may lack the knowledge and confidence to provide quality care to people with intellectual disabilities, and national health information systems often fail to collect adequate data about this population, making these inequities invisible.

In short, people with intellectual disabilities face systemic exclusion both from health services and from the processes that shape those services. Without urgent investment in inclusive system design, the capacity of OPDs, and the tools needed to support both communities and governments, these inequities will persist. Addressing these root causes is not only a matter of health systems reform, it is a matter of rights and justice.

What would an inclusive healthcare system look like?

An inclusive healthcare system is one where people with intellectual disabilities can access the same standard of care as everyone else – without discrimination, without additional barriers, and with the right supports in place. It is built on a foundation of rights, equity, accessibility, and accountability. In such a system, health services are not only available, but they are also designed with, by, and for people with intellectual disabilities.

Policies and Laws That Promote Inclusion and Rights

In an inclusive system, national health laws and policies uphold the rights of people with intellectual disabilities to the highest attainable standard of health. These policies are not developed in isolation: governments actively partner with organisations of persons with disabilities (OPDs) to ensure laws are fair, inclusive, and responsive to real-world needs. This means embedding the principles of the CRPD in all levels of health governance, from national strategies to local implementation guidelines.

Meaningful Participation in Health Policy and Governance

Inclusive health systems are shaped by the people they serve. OPDs representing people with intellectual disabilities, including self-advocates and family networks, are formally included in the design, monitoring, and review of health services. Their participation is not tokenistic – they are resourced, trained, and empowered to influence decisions. Health equity monitoring includes feedback from OPDs, ensuring that services are held accountable for delivering quality care to all.

Inclusive and Accessible Health Care Services

Health services must be accessible in every sense: in physical, information, communication, financial, and attitudinal ways. An inclusive health system ensures that people with intellectual disabilities receive respectful, person-centred care that meets their needs. Services are designed to accommodate diverse communication needs, allow for supported decision-making, and provide continuity of care. OPDs are involved in reviewing the accessibility and quality of services, using tools and indicators that reflect lived experiences.

Trained and Supportive Health Workers

Health workers are at the frontlines of inclusion. In inclusive systems, all health professionals are trained in disability rights, communication support, and inclusive practice. Importantly, this training is delivered in part by people with intellectual disabilities themselves, sharing their expertise and shaping respectful care. Health facilities also actively recruit, hire, and support health workers with disabilities, promoting representation and breaking down stigma from within.

Accessible Health Information and Inclusive Data

Health information is accessible to everyone, using clear language, visual formats, and communication supports. People with intellectual disabilities have the information they need to make decisions about their health. At the system level, data is disaggregated to reflect diversity in experience of disabilities and collected in partnership with OPDs to understand gaps in access, treatment, and outcomes. This evidence is used to drive improvements, shape health policies and priorities and allocate resources to address equity gaps.

Equitable Access to Medicines, Assistive Technologies, and Digital Health

Medicines, assistive technologies, and health-related products are available, affordable, and adapted to meet the needs of people with intellectual disabilities. Digital health tools and online services are accessible by design, not as an afterthought. OPDs help test and validate the accessibility of new technologies, ensuring no one is left behind in the shift to digital healthcare.

Affordable and Equitable Health Coverage

An inclusive healthcare system ensures financial protection. Governments allocate adequate budgets for disability-inclusive healthcare and make it easier for people with intellectual disabilities and their families to understand and access support for healthcare costs. OPDs monitor spending to ensure funds are used effectively to close equity gaps. Health insurance schemes are inclusive, and no one is denied coverage on the basis of disability.

Recommendations

Creating inclusive, equitable health systems for people with intellectual disabilities requires transformation across every level of health governance and service delivery. The following recommendations outline key systemic gaps and the actions needed to address them, grouped under three priority areas for change: investing in OPD leadership, equipping health systems with the right tools and guidance, and sharing and scaling inclusive solutions globally.

1. Invest in OPD Leadership for Equitable Health Systems

Organisations of Persons with Disabilities (OPDs), including self-advocates and family networks, are powerful agents of change. Yet, they are rarely resourced or supported to engage meaningfully in health system strengthening efforts.

To change this, governments, donors, and international actors must invest in long-term support for OPDs to engage in health policy development, service design, budgeting, and accountability processes. This includes building technical and organisational capacity to engage in health systems work, strengthening governance structures, and ensuring access to practical tools and training to support evidence-based advocacy.

2. Develop Tools to Improve Health Systems and Services

Health systems often lack the tools and guidance needed to ensure accessibility, inclusion, and quality of care for people with intellectual disabilities. This gap is especially evident in-service delivery standards, accessible information, and health worker training.

There is a clear need to co-develop tools, standards, and training materials with OPDs and health professionals that can be adapted to different national contexts. These resources must support inclusive communication, consent processes, and equity-focused service design. They should also guide health workers in delivering rights-based care and help institutions assess and improve their own practices.

Governments and service providers require clear operational guidance to deliver inclusive care, and OPDs must be supported to monitor and hold systems accountable to these standards.

3. Share and Scale Global Good Practices and Solutions

There is also a need to create safe, supported spaces for OPDs to collaborate, exchange learning, and contribute to global health policy dialogues. Ensuring that people with intellectual disabilities are leading this work (from local health initiatives to global platforms) is essential to designing systems that reflect their rights and realities.

While promising practices for inclusive healthcare exist, they remain fragmented, under-documented, and underutilised. Stakeholders lack access to consolidated resources or platforms to share evidence, tools, and strategies that work for people with intellectual disabilities.

To accelerate progress, a stronger global evidence base is needed. This includes mapping good practices across health system areas, documenting what works (and why), and ensuring OPDs are leading these efforts. Improving how data is collected and used (including the inclusion of people with intellectual disabilities in national health statistics) is also critical to identifying and closing equity gaps.

Global health actors must commit to sharing successful approaches and scaling solutions that are contextually relevant, cost-effective, and rights-affirming.

Conclusion

This Global Consultation marks a significant step forward in recognising and addressing the systemic exclusion of people with Down syndrome and other intellectual disabilities from healthcare systems worldwide. Through the voices of over 750 individuals and 118 organisations (including nearly 50 organisations of persons with disabilities (OPDs)) this consultation has shed light on persistent and avoidable inequities in access, quality, dignity, and participation in healthcare.

Findings across the adapted AAAQ framework – Availability, Access for All, Acceptability, and Quality of Care – reveal that people with intellectual disabilities continue to face widespread and entrenched barriers in healthcare. These include discriminatory attitudes, inaccessible services and information, lack of autonomy in decision-making, and poor quality of care. Such inequities are rooted in health systems that have systematically failed to include, consult, or respond to the specific needs and rights of people with intellectual disabilities.

In many contexts, services drop off after childhood, with limited or no support during the transition to adult care. Essential supports like speech and language therapy are often excluded from public health systems, leaving families to shoulder high out-of-pocket costs or go without. Decision-making is often controlled by others, rather than supported, and accessible information is lacking. Healthcare workers frequently lack training in inclusive practices and disability-sensitive communication, which further undermines the quality of care. The widespread absence of disability-inclusive content in healthcare education and professional training means providers are often ill-equipped to deliver equitable, respectful, and person-centred care to people with intellectual disabilities.

These challenges are made worse by intersecting discrimination on the basis of gender, age, and geographic location, which leaves women and girls, older people, and those in rural areas particularly underserved.

The consultation also highlights a critical gap: people with intellectual disabilities, their families, and OPDs are too often excluded from shaping the health systems that are meant to serve them. Their insights, expertise, and lived experiences remain underused in health governance, policymaking, and service design. Yet their participation is not only essential for realising the right to health, but it is also key to building more responsive, resilient, and equitable systems for all.

This report is both a call to action and a roadmap for change. It underscores the need for governments, donors, and global health actors to work in genuine partnership with a diverse representation of OPDs; to co-create the tools, training, and standards needed for inclusive care; and to document, share, and scale what works. Achieving health equity for people with intellectual disabilities is not just a long-term aspiration, it is a concrete and attainable goal. It requires listening to those most affected, allocating resources where they are needed, and ensuring people with intellectual disabilities and their representative organisations have a central role in shaping solutions. By doing so we can fulfil the commitment of Sustainable Development Goal 3: ensuring healthy lives and promote well-being for all by 2030, and truly leave no one behind in our efforts towards achieving universal health coverage.

Progress will depend on meaningful action, equitable partnerships, and rebalancing who holds power in decision-making. With increasing leadership from self-advocates, families, and disability organisations globally, now is the time to act. Together, we can build health systems that uphold dignity, enable autonomy, and achieve the highest attainable standard of health for all.

References

Heslop, Pauline, Peter S. Blair, Peter Fleming, Matthew Hoghton, Anna Marriott, and Lesley Russ. 2014. "The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study." *The Lancet* 383 (9920):889-895. doi: 10.1016/S0140-6736(13)62026-7.

United Nations. 2015. "Sustainable Development Goals 3: Ensure healthy lives and promote well-being for all at all ages." United Nations, accessed 4 April. https://sdgs.un.org/goals/goal3.

World Health Organization. 2022. Global report on health equity for persons with disabilities. edited by Rehabilitation and Disability (NCD) Team Noncommunicable Diseases and Disability and Rehabilitation (SDR) Team Sensory Functions: World Health Organization.

World Health Organization. 2022. *Highest attainable standard of health for persons with disabilities WHA76.19*. EB152/23 World Health Assembly, accessed 26 June 2025. https://apps.who.int/gb/ebwha/pdf_files/EB152/B152_23-en.pdf.