Down Syndrome International

humanity & inclusion

Our Say in Our Health:

What People with Intellectual Disabilities and their Supporters say about Health Access Around the World

This is a summary of our report.

Thank you

Down Syndrome International (DSi) and Humanity & Inclusion (HI) would like to thank everyone who helped with this consultation and report.

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).

Thanks to everyone who gave feedback on the surveys and focus group materials, including:

- Darryl Barrett, Kaloyan Kamenov, and Mélanie Gréaux (World Health Organization)
- Anjela Jenkins and Hamza Alzahran (Special Olympics International), and consultants with lived experience - Kiera Byland, Renee Manfredi, Nyasha Derera
- Francine van den Driessen Mareeuw (Tilburg University)
- DSi member organisations, especially Natalie Graham (Down Syndrome Australia) and Laura LaChance (Canadian Down Syndrome Society)
- The DSi Ambassadors Committee
- 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 individual respondents who took the time to participate. 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 organisations that contributed. Thank you for sharing your expertise and for your ongoing work to promote the rights and inclusion of persons with disabilities.

Message from DSi

Bridget Snedden, President
and
Janet Charchuk, Board Member, Down Syndrome International

We are a global network of people with Down syndrome and their families.

We are happy to share this Global Report with you.

This report is a big step forward in making healthcare fair for people with Down syndrome and other people with intellectual disabilities.

We believe it is very important that people with disabilities and their families can help make decisions about their lives.

This report was made with the hard work of many people and organisations in our network.

Thank you to everyone who helped. You have shown that our right to good health is important for our community.

Our work with Humanity & Inclusion is a good example of what we can do when people with disabilities are included as equals.

Now we must take the next steps. We must keep speaking up together to make real change – around the world and in our own countries.

Message from HI

Alessandra Aresu, Director, Health and Protection Division, Humanity & Inclusion

At Humanity & Inclusion, we believe it is very important to listen to people with intellectual disabilities about their health.

For too long, people have been ignored. They have faced discrimination, poor services, and health information that is hard to understand.

This report helps change that.

Thanks to the leadership of Down Syndrome International, and work with the World Health Organization and Humanity & Inclusion, we are starting to take real action.

The results show that we must do more—especially to support women, young people, adults, and older people with intellectual disabilities.

It has been a great honour to work with Down Syndrome International on this report. We have learned a lot.

We are very thankful to all the people and organisations who took part and shared their experiences.

We look forward to continuing this important work together, to make sure the right to health is respected for all.

Introduction

Over 1 billion people in the world have disabilities.

Many have worse health and die younger.
This is not fair and goes against their human rights.

People with Down syndrome and intellectual disabilities are some of the most affected.

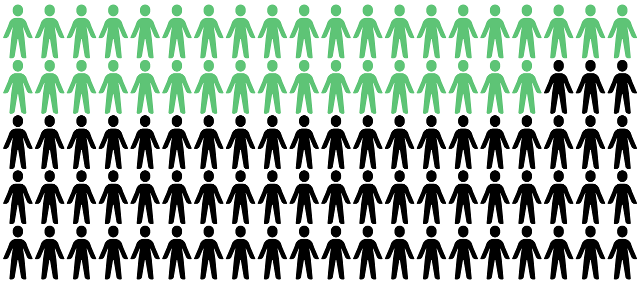
In the United Kingdom (UK)

Children with intellectual disabilities are:

- 8 times more likely to die before age 17.
- Have more health problems like diabetes, heart disease, and mental illness.
- Many are overweight by their teens.

But this can change.

In the UK, 37% of early deaths could have been stopped with better health care.



There was not enough research about:

- Barriers that stop people with intellectual disabilities from getting healthcare.
- What people with intellectual disabilities and their families think.
- What is happening globally, including in lower income countries.

Down Syndrome International and Humanity & Inclusion want to help.

In 2024, we asked people around the world about their health.

We spoke to people with intellectual disabilities, families, and support workers.

Over 750 people and 120 organisations from nearly 100 countries took part.

Our report shares what needs to change:

Why healthcare is not fair.

What an inclusive health system looks like.

And actions that need to happen.

What we did

Because some information was missing, Down Syndrome International and Humanity & Inclusion wanted to hear from people with intellectual disabilities.

We collected information through surveys and discussions in groups.

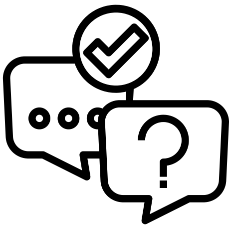
Our survey was available in 4 languages - English, French, Spanish, Chinese
We shared the surveys by email to our supporters and on social media.
The surveys were also shared by DSi member organisations.

DSi member organisations ran focus groups in their countries:

Discussion with self-advocates run by Rwanda Down Syndrome Organization in June 2024

- Japan
- New Zealand
- Nigeria
- Rwanda
- Saudi Arabia
- Taiwan

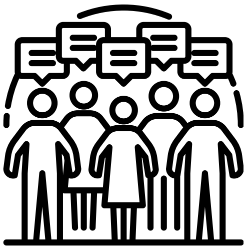
Who we heard from - People



754 people told us about their experiences.

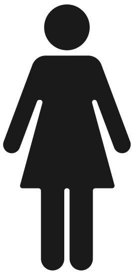
This included:

- People with Down syndrome and intellectual disabilities
- Family members
- Support persons



136 people with Down syndrome and other intellectual disabilities

79% of the family members and support persons were women.



50% of the people with Down syndrome and intellectual disabilities were women or girls.

We heard from people in

95 countries

Most people were from Europe and North America.

81%

of people lived in towns and cities.

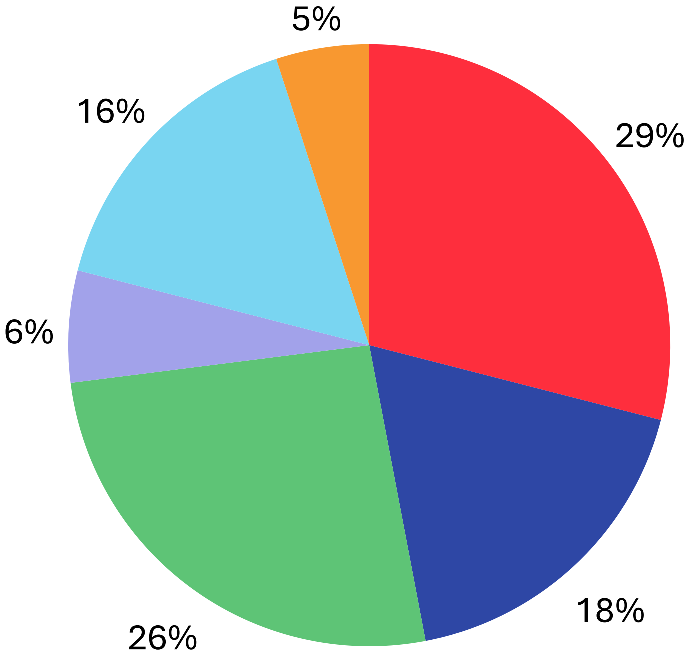
This chart shows how many people were from each continent. Mexico is included in ‘Latin America and the Caribbean’.

● Europe ● Asia

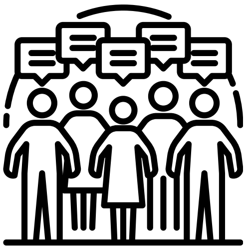
● North America (excluding Mexico)

● Oceania ● Africa

● Latin America and the Caribbean



Who we heard from - Organisations.



118 organisations gave their views.

These included:

- Organisations of people with disabilities
- Global, national or local NGOs
- Organisations that provide support to people with Down syndrome
- A few others, including one from the United Nations

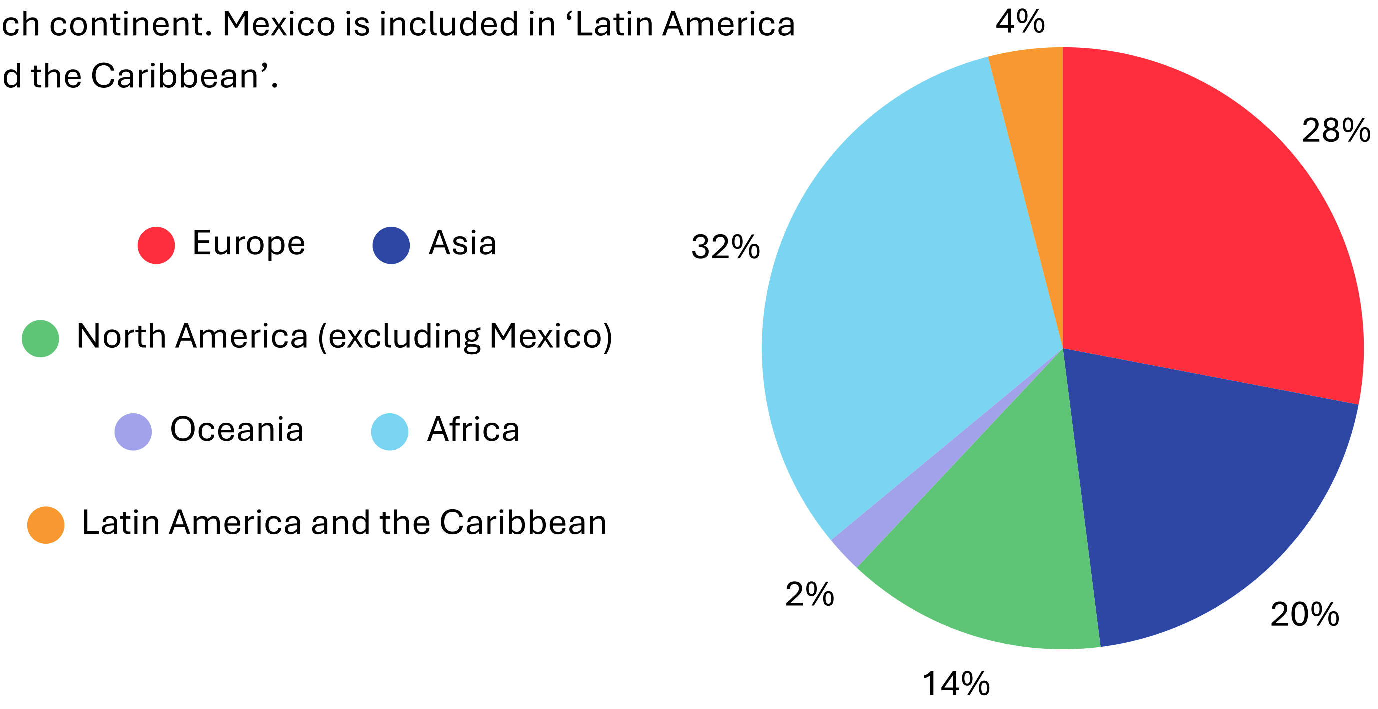
49 organisations of people with disabilities

We heard from organisations in

56 countries

Most were from Africa and Europe.

This chart shows how many organisations were from each continent. Mexico is included in 'Latin America and the Caribbean'.



What we found

We looked at four different areas to check if health care is fair and good for people with disabilities:

Availability

This means there are enough health services, including the services that everyone needs and services for people with disabilities, like speech or occupational therapy.

Access for Everyone

This means that everyone can get the healthcare they need: without discrimination, at a cost they can afford, and with accessible buildings, information, and communication.

Acceptability

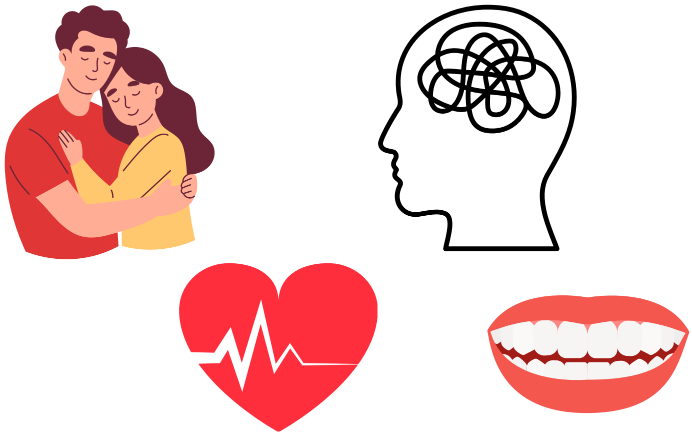
This means healthcare treats people with disabilities with respect, supports their choices and makes sure they give informed consent for all treatment.

Quality of care

This means healthcare is safe, works well, and meets each persons' needs, with reasonable accommodations and trained staff to give the best quality care.

What we found - Availability

Availability is a big problem. Some healthcare services are not available at all.



The most unavailable general services were health services related to sex and having children, mental health, cardiac (heart), and dental services.

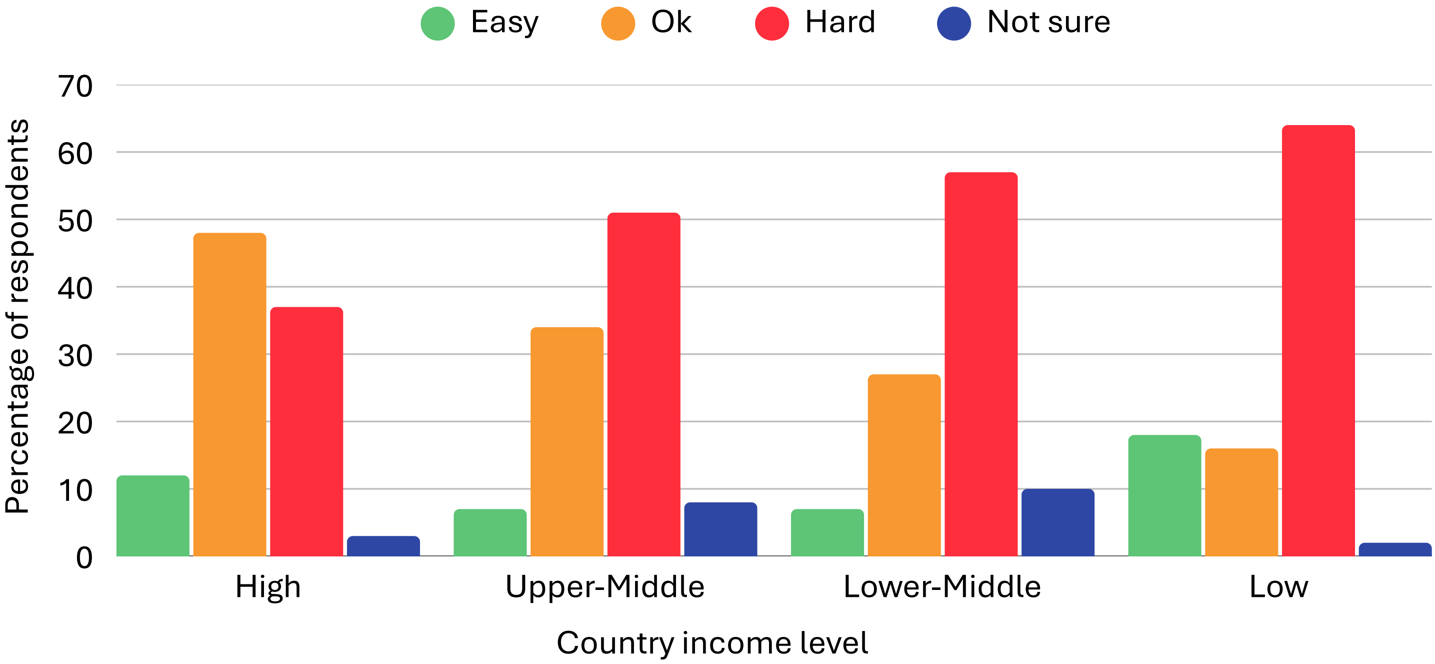
The most frequently unavailable specialist service was speech therapy.

> ***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

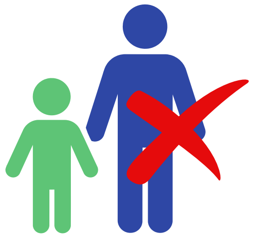
> ***Finding a mental health specialist who also understood developmental disabilities was impossible.***
>
> - Female family member of a man aged 25-34 with Down syndrome from the United States

> ***Services for speech therapy [are] almost non-existent.***
>
> - Female family member of a boy aged 13-17 with Down syndrome from Rwanda

This chart shows how easy it is to find information about access to health and support services by country income:



> ***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



Healthcare was less available for over-18s and for older people. This was worse in lower income countries.

People in outside cities and towns had more problems with availability.

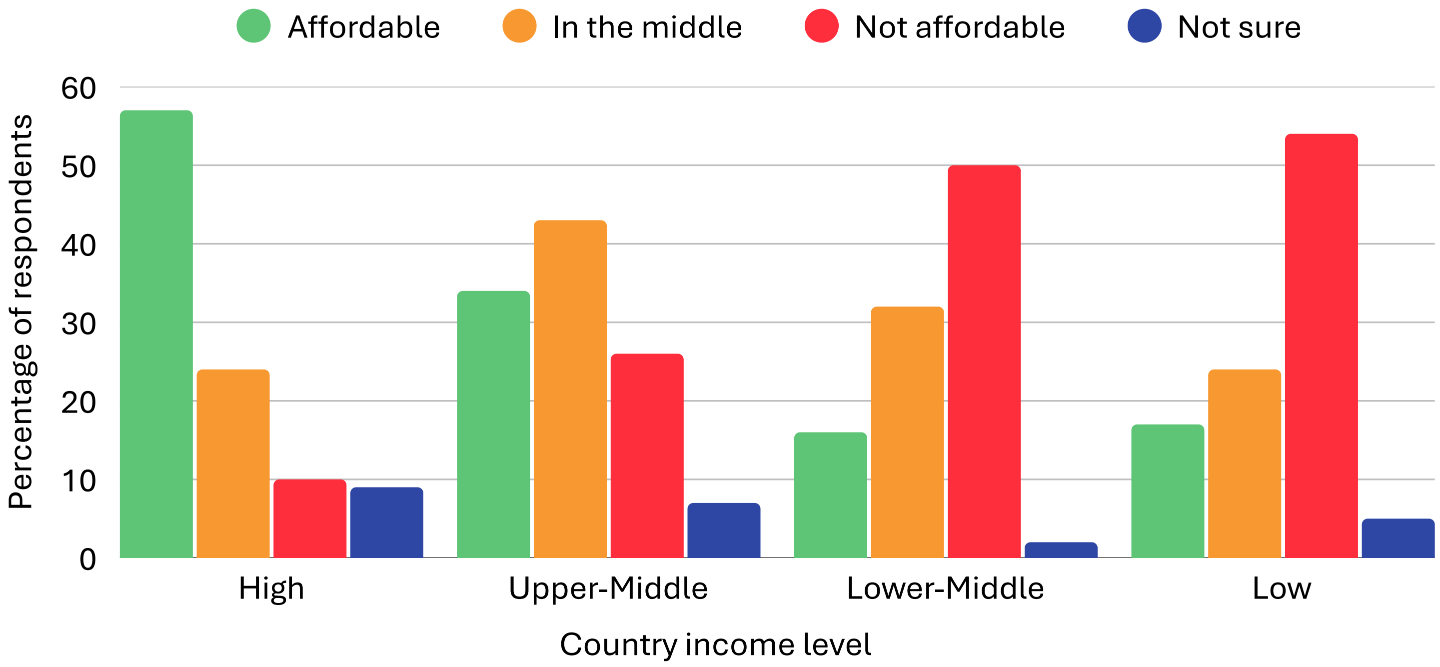
> ***We found as soon as she turned 18 there are no services available, it's disgraceful!***
>
> - Woman from Ireland with a female family member with Down syndrome aged 18-24

What we found - Access for everyone

People with Down syndrome and intellectual disabilities have worse access to healthcare than others.
Some people were denied healthcare completely.

Less than half of people said healthcare is affordable.
This is worse in rural areas and lower income countries.

This chart shows affordability of healthcare by country income:



> ***The 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

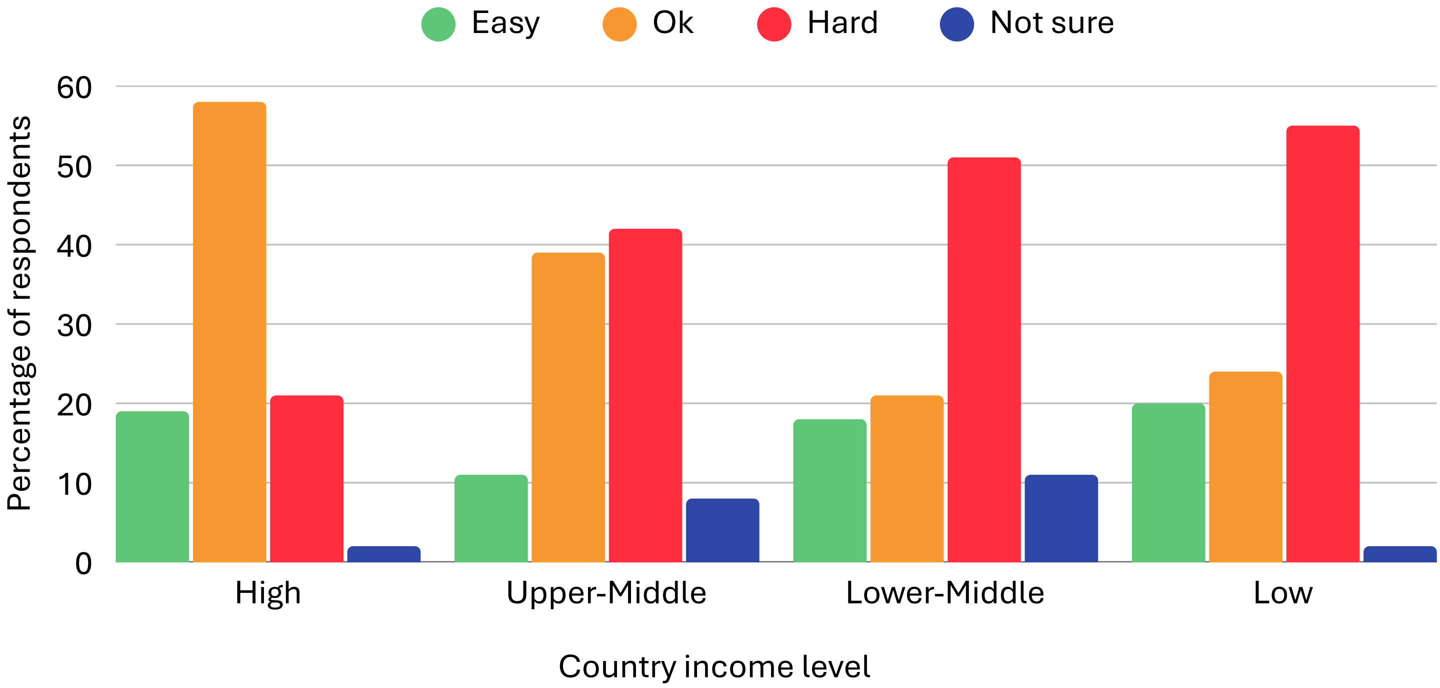
> ***A lot of vital services ... parents have to self-pay for ... having to make difficult decisions on what to finance or not in terms of care.***
>
> - A respondent from the United States

Availability of accessible, good quality health information is poor, especially in lower income countries.

Less than half of people with Down syndrome and intellectual disabilities say they receive health information in accessible formats.

Families also struggle to access good quality, accessible information.

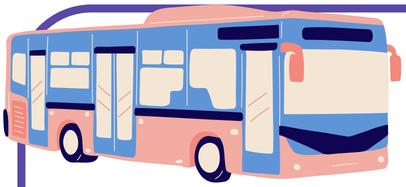
This chart shows how easy it is to find accessible and good quality health information about Down syndrome and other intellectual disabilities by country income:



> ***I was confused [...] 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

> ***[We can’t access] information about cancer or sex education. Even the Easy Read is too hard.***
>
> - Woman from the UK with a family member with Down syndrome aged 25-34

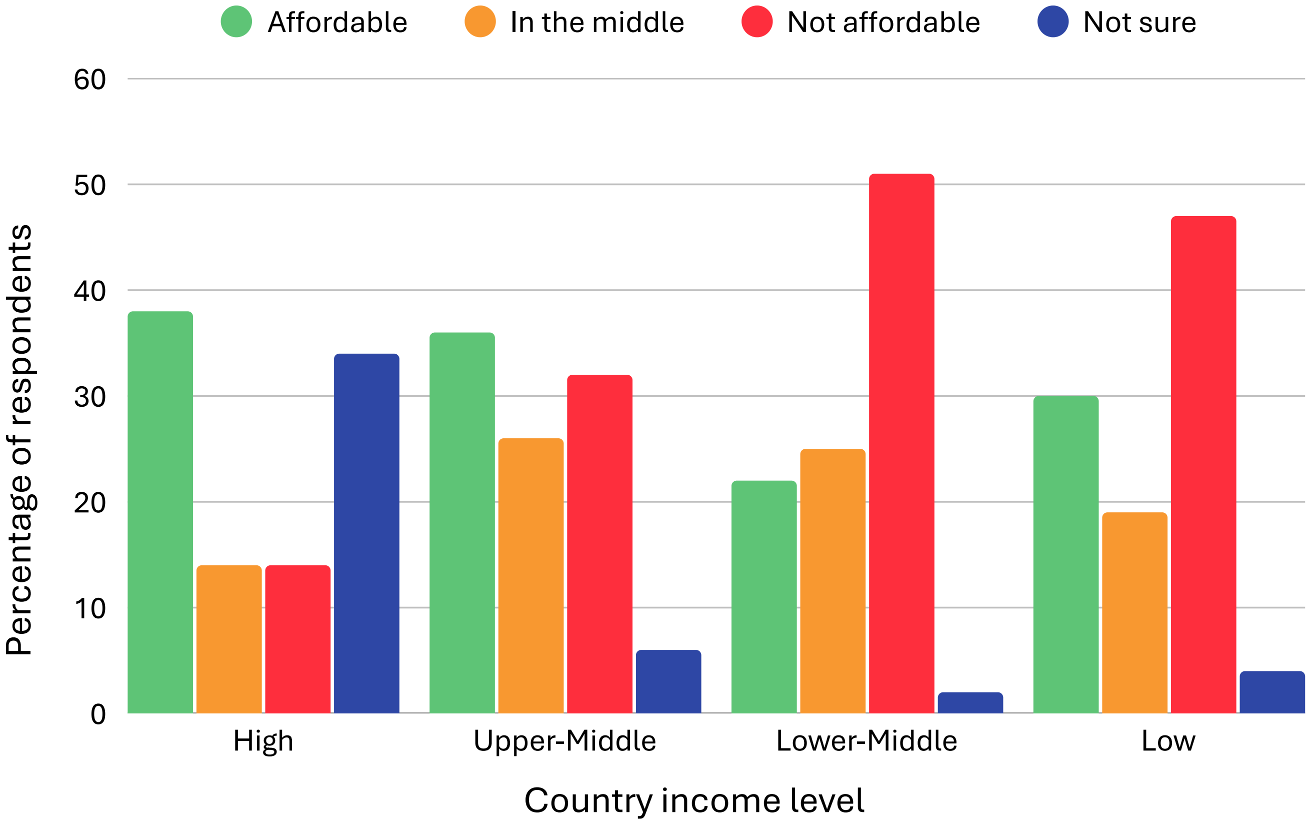
Physical accessibility: People in high-income countries are more likely to say health buildings are easy to get into. People in towns and cities also find them easier to access than people in villages.



Transport for healthcare is also a big problem.
The cost to travel to health services is stopping people from getting the healthcare they need.

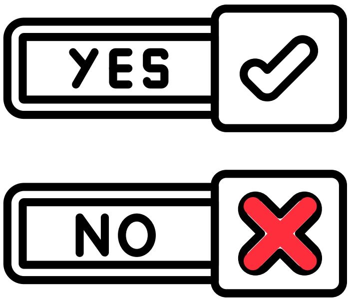
- Almost half of people in low- and middle-income countries said transport is too expensive and there is no support.
- People who live outside cities and towns find it even harder to travel to health services.

This chart shows how affordable transport to health services is reported to be, by country income level:



What we found - Acceptability

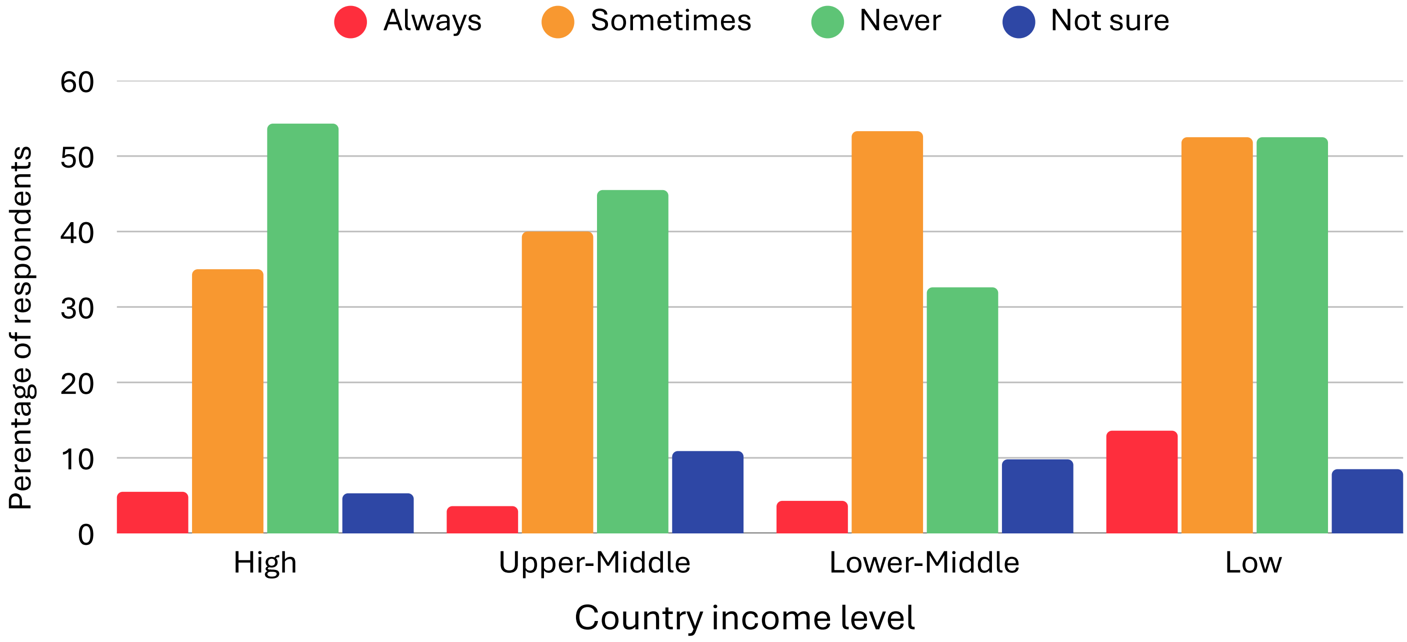
Over 45% of people with Down syndrome and intellectual disabilities always or sometimes face unfair treatment by healthcare workers.



Some people were treated without their consent or experienced violence.

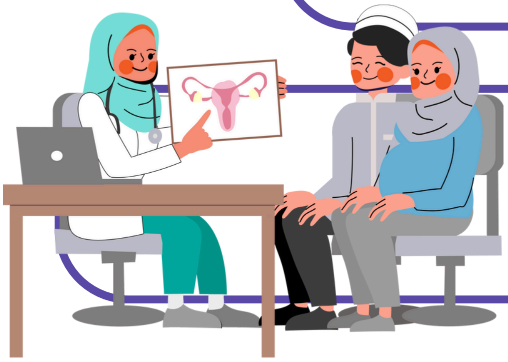
> ***From the moment [people with Down syndrome] are born, they experience discrimination, even from medical [practitioners].***
>
> - Female support person for a boy aged 13-17 with Down syndrome from Mongolia

This chart shows experiences of unfair treatment by doctors or other health workers towards people with Down syndrome and intellectual disabilities:



Healthcare workers often ignore people or speak to their family member or support person.

Less than half of people with Down syndrome and intellectual disabilities said they make their own healthcare decisions.



Only 29% of people with Down syndrome and intellectual disabilities said healthcare workers always speak in ways they can understand.

> ***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

> ***When 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

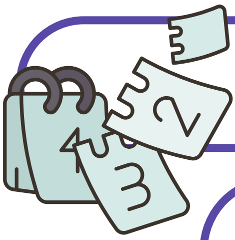
Some people told us what good experiences with doctors and health workers can look like.

> ***My general practice 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

What we found - Quality of care

Less than a quarter of people said they are satisfied with the quality of their healthcare. This was worse in lower income countries.

People were least satisfied with mental health, older persons, and reproductive and sexual health services.



Long wait times are a problem, with some people waiting years for services.

Many healthcare providers don’t have a good understanding of Down syndrome and intellectual disabilities or don’t use a rights-based approach.

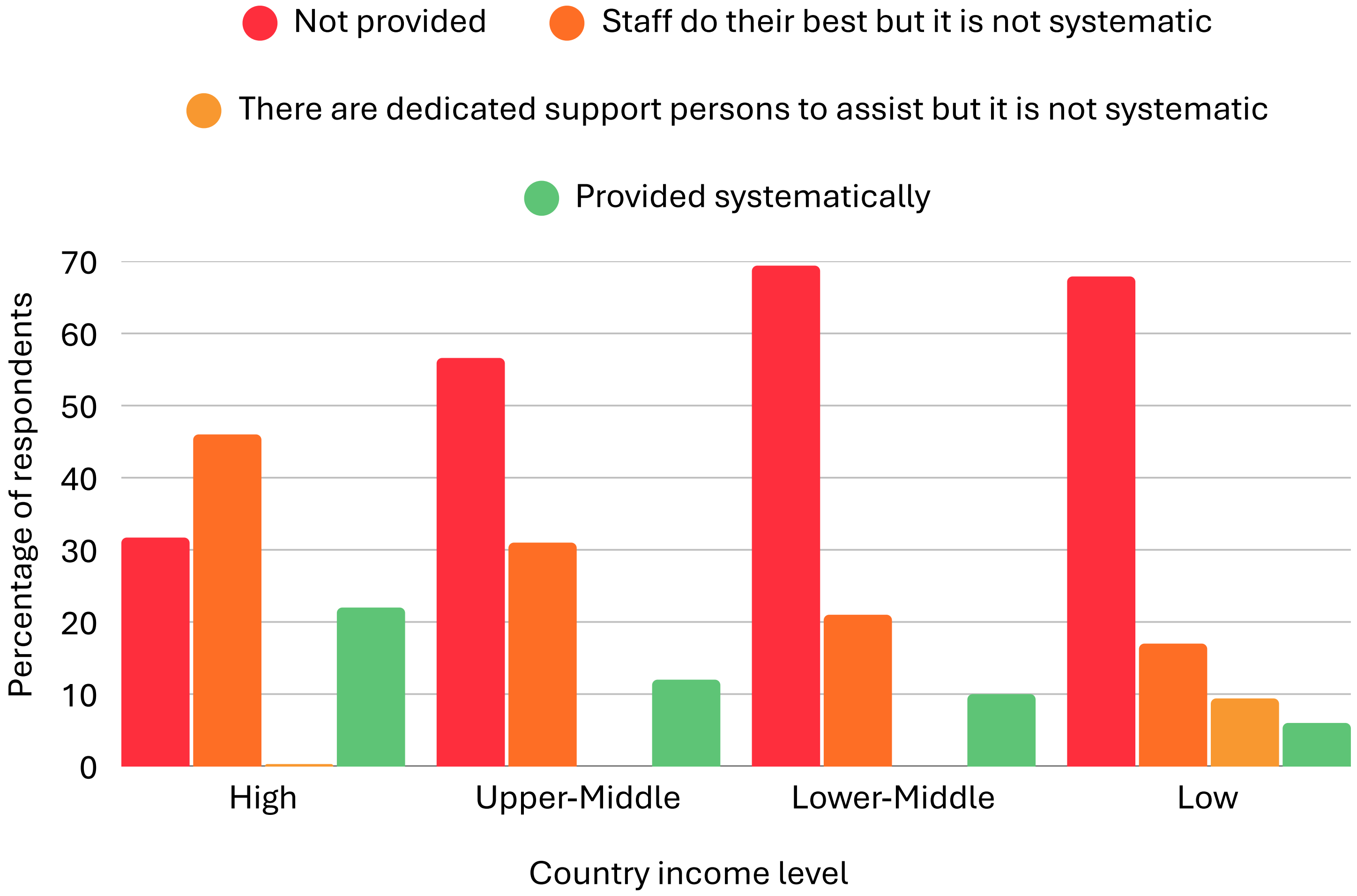
> ***Health care providers continue to give us information on how the disability can be cured.***
>
> – Female family member of a girl aged under 12 with an intellectual disability from Ghana

> ***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

> ***[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

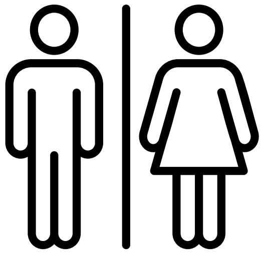
Nearly half the people said no reasonable accommodations are provided. This includes things like Easy Read letters, longer appointments, or letting a support person attend too.

This chart shows the provision of reasonable accommodations by healthcare providers to people with Down syndrome and intellectual disabilities by country income level:



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

How age, gender, where you live, and your country affect your healthcare

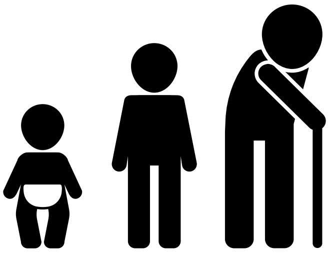


Gender:

Women and girls with intellectual disabilities often face more problems getting good healthcare. Some said they had been forced to have medical procedures, like sterilisations, and many could not get the sexual and reproductive health services they need.

But in some cases, women and girls reported fewer problems than men and boys. For example, more men and boys said that health services were not available when they needed them, and more said they were always treated unfairly by health workers.

More research is needed to understand these gender differences better.



Age:

The survey showed that adults and older people with intellectual disabilities often find it harder to get good healthcare than children.

Many services stop after age 18, and only 9% of people said the move from child to adult care was easy.

In lower income countries, older people with Down syndrome and intellectual disabilities face even more gaps in care. Families are often unhappy with the healthcare available for adults and older people, and older adults have fewer chances to make their own health decisions.

Where you live:

People living in rural areas often have a harder time getting healthcare than those in cities. They said services were harder to find, clinics were less accessible, and healthcare cost more, especially in lower income countries.

Governments spending more money on healthcare doesn’t always mean better access. People said healthcare was more affordable in countries that spent more, especially for travel costs, but this did not always mean clinics were easier to reach or that people got financial support.

Speaking up about healthcare

Speaking up about your own health

Over one-third of people with intellectual disabilities said they had spoken up about their health.

They spoke up about things like asking to see a specialist or challenging a wrong diagnosis. But many had not, or were not sure how, so more training and support is needed to help people feel confident to speak up during appointments or when something feels wrong.

Speaking up to make healthcare fairer

Nearly one-third of people with intellectual disabilities said they had spoken up to help improve healthcare in their country.

Some people gave talks or shared their ideas at important events at the United Nations and with the World Health Organization.

They spoke up about things like asking for yearly health checks for people with intellectual disabilities, teaching doctors to treat people with disabilities fairly, and making sure healthcare is fair for everyone.

But most people had not been involved in this kind of advocacy. This shows that more support and training is needed to help people with intellectual disabilities take part in making health systems better and fairer for everyone.

How disability organisations are helping to make healthcare better

More than half of organisations of persons with disabilities said they had done advocacy work about healthcare.

Many organisations of persons with disabilities are working to make healthcare better and fairer for people with intellectual disabilities.

They are doing things like trying to change unfair laws, training health workers, creating Easy Read health materials, and sharing health messages through media and outreach. Some also provide services themselves because healthcare systems in their countries are not working well.

28% of organisations of persons with disabilities said they had done research, and over half (53%) said they want to learn how to do research on health and disability.

This shows a big opportunity for governments and health services to work with these organisations to help make healthcare better for everyone.

What causes these unfair outcomes?

People with Down syndrome and other intellectual disabilities have worse health outcomes than others. This isn't because of their disability, but because health systems don't meet their needs.

Health systems are very often planned and run without asking people with intellectual disabilities or their organisations. So, problems like hard-to-understand information, unfair treatment, and lack of support are often missed. This means they don't get the same care as others.

One big reason is that organisations of persons with disabilities are not invited to take part in health planning. Even when they are, they often don't have enough money, training, or tools to take part. Helpful resources are missing or not used.

Governments and health workers often don't understand the needs of people with intellectual disabilities. They don't get enough training on how to talk, give support, or collect the right data. So, the problems stay hidden.

In short: people with intellectual disabilities are left out. This is unfair. We need to fix the system so everyone gets good care and respect.

What would a fair healthcare system look like?

Inclusive healthcare means people with intellectual disabilities get the same care as everyone else. There should be no discrimination or extra barriers. The system must be fair, accessible, and built with people with intellectual disabilities.

Here are some key parts of an inclusive healthcare system:

Laws and policies that support inclusion and rights.
Governments should work with organisations of persons with disabilities to make sure health laws are fair and follow disability rights rules like the Convention on the Rights of Persons with Disabilities (CRPD).

People with intellectual disabilities help shape health systems.
Organisations of persons with disabilities, including self-advocates and families, should be part of planning, checking, and improving services. They need training and support to take part fully.

Health services are inclusive and accessible.
This means making buildings, information, and attitudes more welcoming. Services should support different ways of communicating and supported decision-making. Organisations of persons with disabilities should help review how accessible and good the services are.

Health workers are trained and supportive.
All health workers should learn about disability rights and how to give respectful care. People with intellectual disabilities should help teach this. Health workers with disabilities should also be hired and supported.

Health information is accessible, and data is inclusive.
People with intellectual disabilities need information in accessible formats to make choices about their health. Data should be collected with organisations of persons with disabilities to show where care is lacking and how to improve it.

Medicines and health tools are available, affordable and accessible.
This includes assistive devices and digital health tools. Organisations of persons with disabilities should help test these tools to make sure they work for everyone.

Healthcare is affordable and fair.
Governments should fund inclusive healthcare and make it easy for people with intellectual disabilities to get financial help. Organisations of persons with disabilities should help track how money is spent to make sure it closes gaps in care. Health insurance must include everyone, not leave people with disabilities out.

What needs to change.

To build fair and inclusive health systems for people with intellectual disabilities, we need big changes at every level. These recommendations focus on three key areas:

- supporting organisations of persons with disabilities,
- creating the right tools to improve health systems,
- and sharing good ideas globally.

1. Invest in leadership by organisations of persons with disabilities

Organisations of persons with disabilities, including self-advocates and families, can lead change - but they often don't get the support they need.

Governments, donors, and global partners should give long-term support so these organisations can help shape health policies, services, budgets, and accountability.

This means building their skills around health advocacy, improving how they are run, and giving them tools and training to speak up with evidence.

2. Create tools to improve health systems and services

Many health systems don't have the tools to make care accessible and inclusive. This includes service standards, accessible information, and training for health workers.

We need to create these tools together - with organisations of persons with disabilities and health professionals - so they work in different countries. These tools should help with communication, consent, and fair service design. They should also help health workers give rights-based care and help services check and improve what they do.

Governments and providers need clear guidance to deliver inclusive care. Organisations of persons with disabilities should be supported to check that systems follow these standards.

We also need safe spaces where these organisations can learn from each other and take part in global health discussions. People with intellectual disabilities should lead this work - from local projects to global platforms.

3. Share and grow good ideas from around the world

There are already good examples of inclusive healthcare - but they are scattered and not well shared. Many people don't know where to find helpful tools or ideas.

We need better global evidence. This means collecting and sharing what works, why it works, and how to do it. Organisations of persons with disabilities should lead this work.

We also need better data - making sure people with intellectual disabilities are included in national health statistics.

Global health leaders must commit to sharing what works and expanding solutions that are fair, affordable, and based on rights.

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July 2025

Full report

Read our full report to learn more.

Visit ds-int.org/health-equity-global-report/ or scan the QR code below:

Our Say in Our Health:
What People with Intellectual Disabilities and their Supporters Say About Health Access Around the World
Social media toolkit

Social media toolkit

Use our social media toolkit to share our global report and speak up to make healthcare fairer for people with intellectual disabilities.

Visit ds-int.org/health-equity-global-report/ or scan the QR code below: