

EXECUTIVE SUMMARY

EASY READ

This is a summary of the global report by Special Olympics International called *Focusing on the Invisible: The Overlooked Needs of People with Intellectual and Developmental Disabilities and Actions to Strengthen Health Systems for Inclusion*.



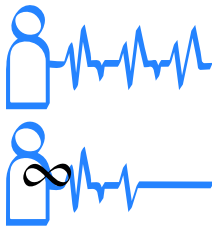
In this document, the infinity symbol (∞) is used to mean people with intellectual and developmental disabilities (IDD).



People with intellectual and developmental disabilities (IDD) have worse health than people without IDD.



People with IDD are more likely to get serious illnesses.



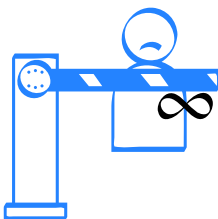
They live 16–20 years less than people without IDD because of health problems.



Many of these health problems can be stopped. Most of these health problems can even be prevented, or stopped before they happen.



People with IDD have specific needs when they get health services. For example, they are more likely to need help from someone else, extra time, and communication support.



There are many barriers that make it hard for people with IDD to get the care and services they need.

For example,



Doctors, other health workers, and people working in public health are not trained about people with IDD and how to care for them.



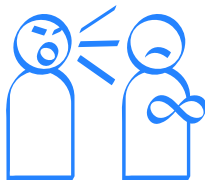
People with IDD and doctors and other health care workers don't always understand each other.



There is not a lot of data, or information, about the health of people with IDD.



Transportation to health services can be complicated, expensive, and unreliable.



Many people have stereotypes about people with IDD. Stereotypes are negative and untrue ideas. For example, many people don't know that people with IDD can live long, healthy lives.



Many health systems do not see or understand the needs of people with IDD because there is no awareness and training.



Special Olympics is trying to help make health systems work better for people with IDD. Special Olympics started a new initiative called Rosemary Collaboratory to do this. Rosemary Collaboratory was named for our founder's sister, Rosemary Kennedy.



Rosemary Collaboratory builds on lessons from almost 30 years of health work in communities. It finds real-life problems and good examples in health systems. Rosemary Collaboratory tries to get governments to help people with IDD live longer, healthier lives.



Teams in 11 sites across 9 countries are part of Rosemary Collaboratory. The United States is one of these countries. Three states are part of Rosemary Collaboratory. Those states are Pennsylvania, Washington, and Wisconsin.



They checked how health systems include people with IDD. The teams looked at research and real-life stories of people with IDD.



Over 1,000 people in more than 50 countries answered surveys. This included over 230 people with IDD and 70 health care workers from 26 U.S. states.



Special Olympics used all of that information to create this report that you are reading about.



This report explains why it is important for everyone to understand something called the **social and rights-based model of disability**. This model is different from the **medical model of disability**. (You can read an explanation of both models just below!)



Every person has different abilities and needs.



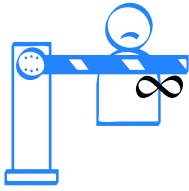
The **medical model** considers that different abilities of a person are a problem. So, it focuses on trying to change or “fix” things about a person.



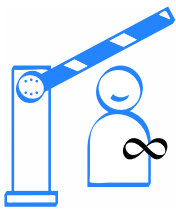
The **social and rights model** sees it differently. In this model, different abilities and needs are **not** a problem. It is normal for there to be differences between people.



Instead, the problem is that society, including people and systems, do not know how to support and work with all the differences between people.



That means that some people with different abilities and needs come across barriers. Barriers are problems that make it hard to do something.



The social and rights model of disability focuses on getting rid of the barriers. This can make it possible for everyone to enjoy their rights, like being healthy.



This report by Special Olympics looks at health for people with IDD, specifically.



This is because people with IDD and the needs of people with IDD are often only a small part of discussions about disability as a whole.



This report includes what people with IDD have said about their experiences, their needs, and their suggestions for health systems to work better.



This report tells governments to take steps or action in **four areas**:

- 1. Governance, Leadership, and Engagement**
- 2. Person-Centered Care**
- 3. Health Care and Public Health Workforce**
- 4. Data for Monitoring and Research**

The next pages give more detail about each of these four areas.



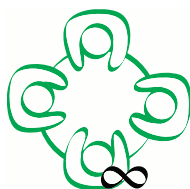
Governance, Leadership, and Engagement



Involve people with IDD in making policies. Rules and laws are examples of policies. Decisions about how governments spend money are also policies.



Teach everyone about the rights, needs, and talents of people with IDD.



Make sure people with IDD can join meetings and share ideas.



All people with IDD need good health services - not just those who have a waiver, or Home- and Community-Based Services. Give money and support so all people with IDD can have access to good health services.



Help people with IDD speak up if their rights are not respected.



Person-Centered Care



People with IDD need health services that meet their needs.



Health services should help people with IDD feel strong, safe, and understood.



Support people with IDD to make their own health choices.



Give people with IDD someone to help guide them through the health system.



Promote tools to make communication between people with IDD and health care workers, like doctors, easier.



Make it possible for things to go more slowly. Make appointment times longer, so everything doesn't go too fast.



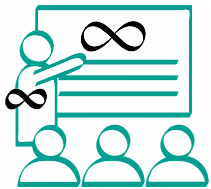
Share health information in ways that are easy to understand. That means simple written and/or spoken words along with pictures.



Health Care and Public Health Workforce



Health care and public health workers need the right skills and knowledge to include everyone.



Train health care and public health workers so that they learn about and meet people with IDD.

Include people with IDD in developing and giving the training and pay them for doing so.



Make people with IDD more visible in the health systems.

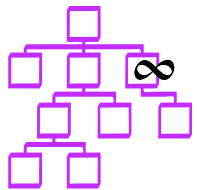


Data for Monitoring and Research



Data are numbers, facts, and other proof. Data show that people with IDD are in worse health than other people. Data can show what health needs people with IDD have.

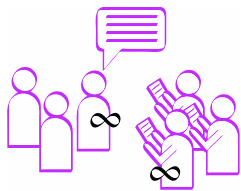
Data give proof of problems that exist. This can be used to help change policies.



Make it possible to identify, or find, people with IDD in health data.



Share data about the health of people with IDD in easy formats, like reports and website dashboards that show the main points.



Include people with IDD in research. They have important lived experience. They should be researchers and participants, just like other people.



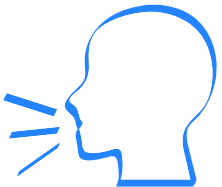
Use the results to make health services and policies better.



This is Joey Mier.



He is a Special Olympics Wisconsin Health Messenger and member of the Athlete Leadership Council.



Joey says:



My disability is invisible, and there have been times when I have felt misunderstood, rushed, or treated as a number rather than a person.



These experiences have made me reluctant to seek care because I do not feel confident that providers understand me or my needs.



Health is about more than just getting medication or receiving treatment.



People with IDD deserve the opportunity to live healthy, fulfilling lives.



Health equity begins when we see the whole person and listen to what that person has to say.



And that starts with you.

Special Olympics Health activities are supported by many sources, including in the United States, by Grant Number NU27DD000021 from the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS), with \$18.1M (64%) financed with U.S. federal funds and \$10.2M (36%) supported by non-federal sources. The contents of this resource is solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.



Special Olympics
Health

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