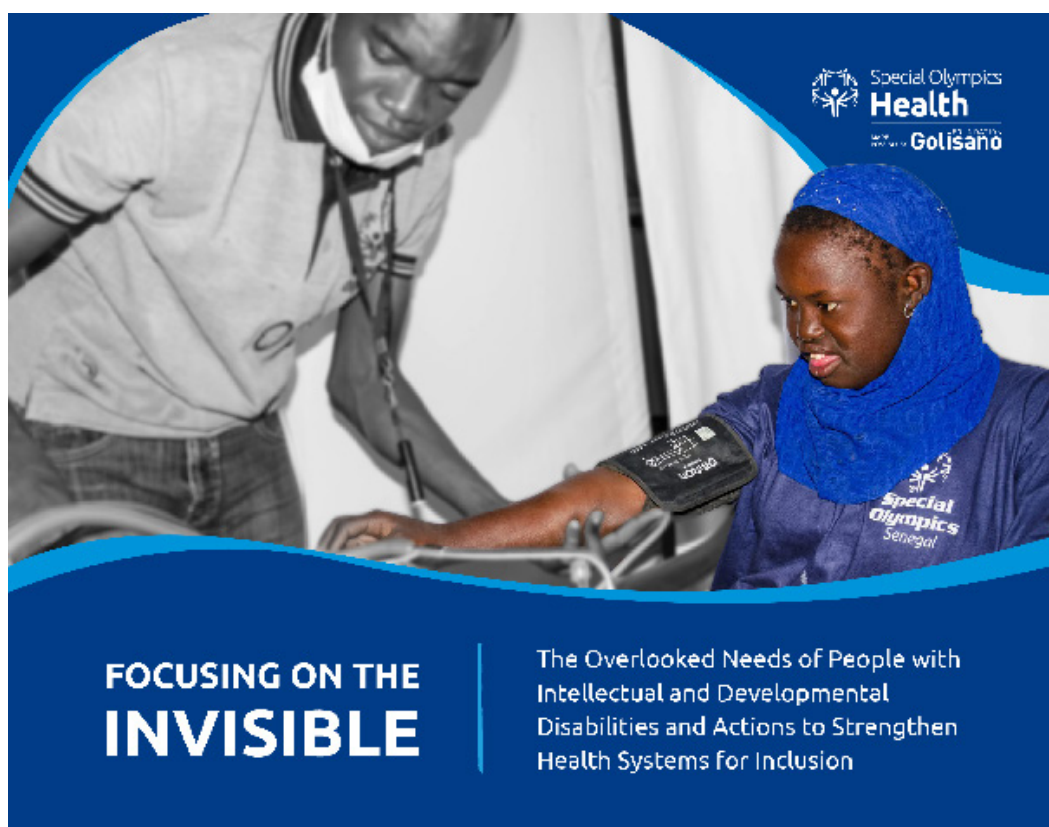


EXECUTIVE SUMMARY

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 and other health workers are not trained about people with IDD and how to care for them.



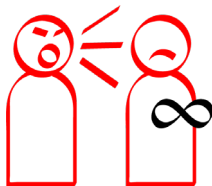
People with IDD and doctors and other health workers don't always understand each other.



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.



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.



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.



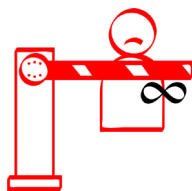
The **medical model** considers that different abilities of a person are a problem. So, it focuses on trying to change or “fix” things about a person.



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.



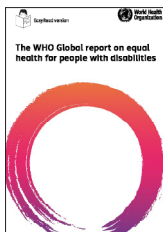
That means that some people with different abilities and needs come across barriers. Barriers are problems that make it hard to do something.



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 builds on a report that the World Health Organization (WHO) wrote.



The WHO report talks about health for people with all disabilities. It proposes 40 things governments can do to take to make the health of people with all disabilities better.



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 and Care 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.



Give money and support to health services for people with IDD.



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 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 and Care Workforce



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



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

Include people with IDD in developing and give the training.



Make people with IDD more visible in the health systems.

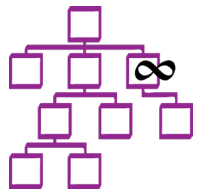


Data for Monitoring and Research



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 systems. Gather data collection by different disability types.



Share health data in easy formats, like reports and website dashboards that show the main points.



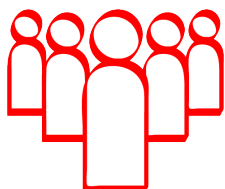
Include people with IDD in research. They have important lived experience. They should be researchers and participants, just like other people.



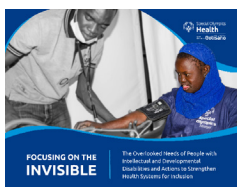
Use the results to make health services and policies better.



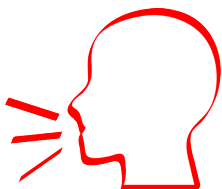
This is David Duncan.



He is the Chair of the Special Olympics Global Athlete Leadership Council.



He is also a member of the group that guided this report by Special Olympics.



David says:



Let people with IDD be part of the decisions.



Listen to what we have to say.



Give us the support we need to speak up.



Help us take care of our health and live our best life.



Include us in training plans, budget plans, policies, and surveys.



Let us help write those plans too.



Special Olympics
Health

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POSSIBLE BY **Golisano** FOUNDATION