Down Syndrome International

About Down syndrome

Produced by

Down Syndrome International

Welcome!

This pack has been produced by Down Syndrome International to provide information about the key topics relevant to people with Down syndrome.

If you want more information, or if you need support, we encourage you to contact our network member organisation in your country.

Find contact details for our network members on our website at www.ds-int.org/contact-us

The Down Syndrome International team.

Down Syndrome International is dedicated to improving the quality of life and advocating for the rights of people with Down syndrome globally.

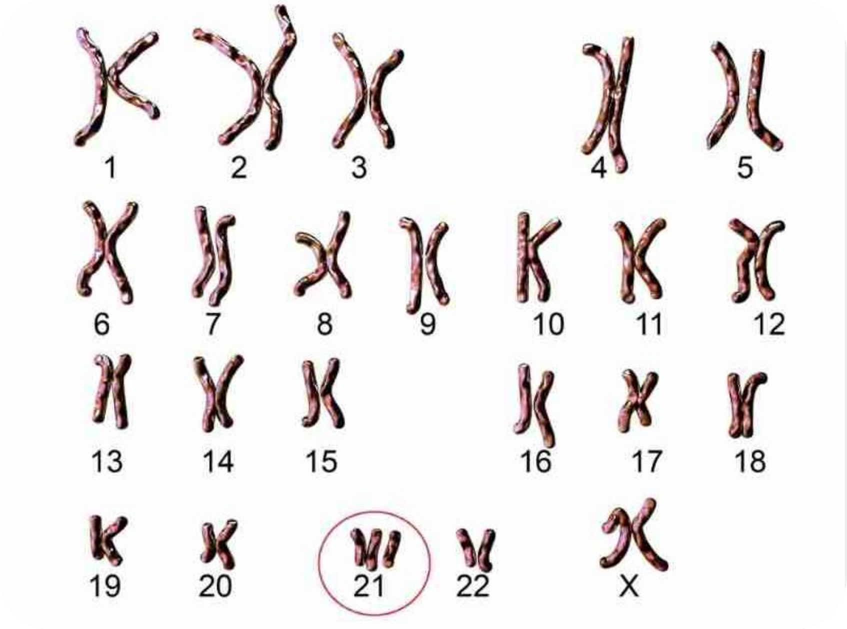
Your support enables us to create lasting change.

Donate today:

In this pack:

Click on this icon anywhere in the document to return to this page.

What is Down syndrome?



Down syndrome (also known as Trisomy 21) is a condition in which a person has an extra **chromosome** (see below).

Down syndrome occurs naturally – there is no known cause.

Around 1 in every 800 babies will be born with Down syndrome.

Chromosomes.

All living things have chromosomes.

Chromosomes act like an instruction manual that defines how our bodies look and how they work. For example, they say what colour our eyes will be or how tall we will grow.

Most people have 23 pairs of chromosomes – 46 in total.

People with Down syndrome have an extra chromosome added onto the 21st pair – 47 in total.

What is Down syndrome?

What this means for people with Down syndrome.

People who have Down syndrome usually have an intellectual disability. This is different in each person.

Some health conditions are more common in people with Down syndrome. You can find information about these on our child health and adult health pages.

Resources:

The best people to answer many questions about Down syndrome are people with Down syndrome.

Visit our website to watch videos made by people with Down syndrome - www.ds-int.org/what-is-down-syndrome

Diagnosis.

Prenatal testing.

In many countries, pregnant women are offered tests to see if their unborn baby has a genetic condition, like Down syndrome. This is called prenatal testing.

The pregnant woman can choose whether or not to take the tests.

In many countries, health professionals have been trained to help women make the choice that feels right for them.

Ultrasound scans can show signs that a baby might have Down syndrome.

Blood tests can also show if a baby is more likely to have Down syndrome.

Ultrasound scans and blood tests cannot say for certain that a baby has Down syndrome. These tests can only give information about the likelihood of the baby having Down syndrome.

To confirm that a baby has Down syndrome, professionals can test a sample of tissue or fluid from the baby.

They will look at the chromosomes in the cells to say for certain if the baby has Down syndrome.

Diagnosis.

Newborn testing.

When a baby is born, professionals will look for physical features that are common in people with Down syndrome. They may make an initial diagnosis of Down syndrome.

But these features can also be found in babies without Down syndrome. So, a test is needed to confirm the diagnosis.

To confirm that a baby has Down syndrome, professionals can test a sample of blood from the baby.

They will look at the chromosomes in the baby's blood cells to say for certain if the baby has Down syndrome.

If there is an extra chromosome 21 in all or some cells, the baby will be diagnosed with Down syndrome.

Diagnosis.

Explaining the diagnosis.

In some countries health professionals have been trained to deliver and explain a Down syndrome diagnosis. It is important to give factual and unbiased information.

Receiving a diagnosis can be overwhelming and families often feel a range of emotions during that time.

If you are delivering or receiving a diagnosis of Down syndrome, please contact our network member in your country.

Our members promise to always give honest and unbiased information. They can share information about life for people with Down syndrome in your country, and direct the family to support and services.

If the family would like to connect with other families who have a child with Down syndrome, our members can facilitate this.

Find contact details for our network members on our website at www.ds-int.org/contact-us

Your new baby.

Congratulations on the arrival of your baby.

If your baby is healthy, their needs will be the same as any other baby. You don't need to do anything differently.

A safe and loving environment is the most important thing you can give your baby.

Your baby's health.

Some health conditions are more common in children with Down syndrome.

In some countries, children with Down syndrome will be tested for these conditions as part of their usual healthcare.

Find information about the health conditions that are more common in children with Down syndrome on our child health pages.

Your new baby.

Feeding your baby.

Breast milk contains antibodies that help protect babies from infections.

Many babies with Down syndrome can breastfeed. Some mothers and babies need help to get started.

Breastmilk can be expressed and given to the baby using a bottle or cup.

A few babies have health problems which make feeding more difficult.

If you want help with feeding, always ask a qualified professional, for example, a health visitor or speech and language therapist with expertise in feeding.

Moving onto solid food.

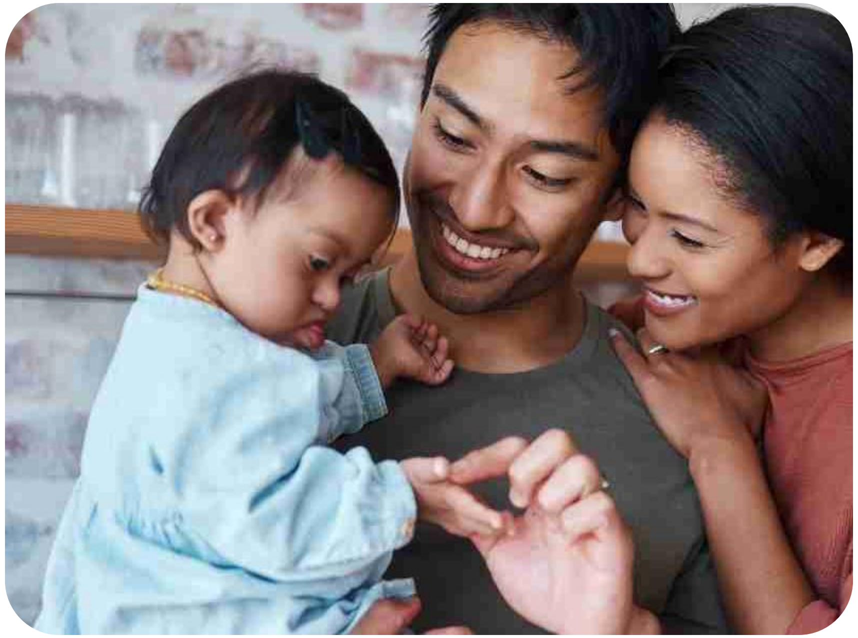
Some children with Down syndrome take longer to learn how to suck, chew and swallow.

Some babies with Down syndrome are sensitive to different textures and prefer smoother foods and familiar flavours.

As with any child, it is important to provide a healthy and balanced diet.

If you want help with feeding, always ask a qualified professional.

Your new baby.



Local support.

Some families find it helpful to meet other families who have a child with Down syndrome.

Our member organisation in your country can help you to connect with other families.

Find contact details for our network members on our website at www.ds-int.org/contact-us

Early development.

Children with Down syndrome develop at different rates and in different ways. They have individual strengths, interests, talents, and needs.

Children with Down syndrome are helped by being socially included in their families, schools, and communities.

They learn new skills the best by being shown how to do them and by having fun ways to practice.

Like all children, they benefit from high expectations and support at home and school.

All children with Down syndrome will have an intellectual disability.

An intellectual disability affects a child’s ability to learn compared with other children of their age. It does not mean they cannot learn.

Children with Down syndrome usually take longer to reach developmental milestones and they will need some additional support.

The level of disability varies from person to person. Some people will need more support than others.

Early development.

Early intervention.

Children with Down syndrome benefit from ‘early intervention’. This includes therapies to help with development of speech and motor skills (movement).

The intervention that your child receives will depend on their needs and what is available where you are. Your healthcare team or local support group will be able to direct you to these services.

How can I help my baby develop?

One of the best ways to help your baby learn is face-to-face interaction.

Copy your baby’s noises and expressions and wait for your baby to respond to you. Be patient.

You can show your baby new expressions, noises, things to touch and feel and see what your baby thinks of these.

When you play together, let your child take the lead. Copy their play and try taking turns. Encourage your child to copy you and show them the next step.

Children with Down syndrome learn well by being shown things and with lots of repetition.

They also learn the best when they are having fun!

Down Syndrome International

Health.

We are working hard to make health better.

In some places, people with Down syndrome can access the healthcare they need.

In other places, they do not get any healthcare at all.

This is not fair!

Access to healthcare is a human right.

We are working on advocacy, training and resources to help improve healthcare systems for people with Down syndrome.

Support our work: www.ds-int.org/support-us

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Health.

Some medical issues are more common in people with Down syndrome.

In some countries, people with Down syndrome will be tested for these issues as part of their usual healthcare.

This helps professionals to find and treat any problems they may have as early as possible.

In this space we include recommendations for testing.

Health.

Heart.

Around half of babies born with Down syndrome will have a heart problem. Less than one in five children has a serious heart problem.

Children with Down syndrome should have a formal heart assessment including an echocardiogram in the first 6 weeks of life to look for any serious problems. This is recommended by the UK Down’s Syndrome Medical Interest Group.

Heart problems are common in people with Down syndrome.

People with Down syndrome should have regular heart checks so that any problems can be found and treated as early as possible.

Our cardiac consensus document will help health professionals to give good care to people with Down syndrome who have heart problems. You can learn more on the next page.

Cardiac consensus statement.

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Journal of
Congenital Cardiology

REVIEW **Open Access**

Cardiac disease in Down Syndrome: literature review and international expert consensus in collaboration with Down Syndrome International (DSi)

Andrew Constantine[1,2], Robin Condliffe[3], Paul Clift[4], Robert Tulloh[5], Katrijn Jansen[6], Konstantinos Dimopoulos[1,2*] and on behalf of the CHAMPION Steering Committee

Abstract

Background: Congenital heart disease is common in patients with Down syndrome, yet clinical recommendations relating to its diagnosis and management in this patient group are lacking.

Main body: We discuss the ongoing collaboration between an international panel of cardiovascular experts and expert stakeholders from Down Syndrome International, an international disabled people's organisation with membership of organisations and individuals from 136 countries worldwide. The aim of this collaboration is to describe best clinical practice, focusing on 10 key areas relating to Down syndrome and cardiac disease, from prenatal diagnosis to the care of patients in areas of differing resource availability.

Conclusions: The planned expert consensus statement on cardiac disease in people with Down syndrome aims to foster communication between experts, direct future research and inform future practice guidelines for the diagnosis and management of cardiovascular disease in people with Down syndrome.

Keywords: Down syndrome, Trisomy 21, Congenital heart disease, Epidemiology, Prenatal diagnosis, Cardiac surgery, Long-term outcomes, Healthcare resources

Introduction

Cardiovascular disease is one of the most common health problems in people with Down syndrome. Congenital heart disease (CHD) of various types complicates up to 50%, and there is a predisposition to the development of pulmonary hypertension and other acquired cardiovascular conditions as a result of related co-morbidities such as obesity and sleep apnoea.[1, 2] Even though the impact of cardiovascular conditions on the long-term outcome of people with Down syndrome is well-described,[3, 4] current Down syndrome-specific recommendations focus mainly on non-cardiovascular health. When cardiac disease is considered in clinical guidelines, the focus is on acquired cardiovascular conditions, e.g. lipid management, coronary artery and cerebrovascular disease, rather than on CHD.[5, 6] Furthermore, guidance for specialists who provide CHD-specific care to people with Down syndrome is lacking. Over recent decades, for better or worse, CHD management in people with Down syndrome has differed significantly to that of the general population, and between different countries and healthcare systems, and is a topic often neglected by the wider medical community. The

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Full list of author information is available at the end of the article

We worked with heart experts from around the world to write an article about heart conditions in people with Down syndrome.

The article will help health professionals to give good care to people with Down syndrome who have heart problems.

It includes best practices in diagnosis, treatment, lifelong follow-up, and prevention of complications.

The article has been published in ‘Circulation’, a world-leading cardiovascular journal.

Visit
www.ahajournals.org/doi/epub/10.1161/CIRCULATIONAHA.122.059706

Health.

Eyes.

People with Down syndrome are more likely to have problems with their eyesight. These are the same problems that any person could have.

It is important to have regular eye checks to find and treat any problems they may have as early as possible. This will minimise the effects of the problem.

People with Down syndrome have poor visual acuity. This means that what they see is not as detailed or clear as it is for other people. This is the case even when they are wearing glasses.

People with Down syndrome benefit from having big and bold printed materials and pictures.

Health.

Ears.

Many children with Down syndrome get glue ear. Glue ear is where the middle part of the ear canal fills up with fluid. It often improves as children grow up but can stay in some people. Glue ear can be treated with small tubes called grommets inserted into the eardrum.

People with Down syndrome may also have hyperacusis. Hyperacusis means being very sensitive to sounds. Sounds that are okay for most people might hurt or bother them.

If someone has hyperacusis, they should see an audiologist. An audiologist is a doctor who helps with hearing problems.

It is common for people with Down syndrome to begin to lose their hearing at a younger age than other people.

Ears and hearing should be checked every year to make sure ears and hearing stay healthy.

Health.

Thyroid.

People with Down syndrome are more likely to have thyroid problems.

Regular blood tests help doctors to check for thyroid problems.

Babies with Down syndrome need a blood test in the first six weeks. They also need another blood test when they turn one year old.

People with Down syndrome should have a blood test every two years.

Coeliac disease.

Coeliac disease means your body can’t take in some parts of food. This condition is more common in people with Down syndrome.

To feel better, you need to eat food without gluten. A dietitian can help you with this.

Health.

Neck instability.

The joints at the top of the spine and the base of the skull help us move our heads.

People with Down syndrome have stretchier ligaments. This means their joints can be looser and more flexible.

Loose joints can cause the bones in the spine to slip. If a bone slips too much, it can press on the nerves.

This slipping can happen slowly or suddenly, like in a whiplash injury. It can cause problems if not treated.

If a doctor thinks there is neck instability, they will send the person to a specialist. This could be an orthopedic surgeon or a spinal neurosurgeon.

Health.

Emotional wellbeing.

Many people with Down syndrome feel happy and do not show signs of bad mental health.

But some things can make people with Down syndrome more likely to have mental health problems.

Their bodies can be different, and daily stresses can be harder for them.

These differences and stresses can lead to mood, emotional, and other mental health issues.

Child health.

Sleep.

Children with Down syndrome often have trouble sleeping.

These problems can be due to behaviour or physical issues.

One physical issue is called sleep-disordered breathing, where breathing stops and starts during sleep. This is also known as sleep apnoea.

A specialist should check sleep problems to find the cause.

Child health.

Epilepsy.

Epileptic spasms happen in about 5% of children with Down syndrome. They usually start when the child is 3 to 6 months old. They do not happen after 12 months.

Signs of spasms include the child's head nodding forward. The arms or legs might also move quickly, and the child could get upset.

The movements are very short, lasting less than a second. They can happen in groups, often after the child wakes up.

If you think your child is having spasms you should speak to a medical professional as soon as you can.

Adult health.

Sexual health.

People with intellectual disabilities need to love and be loved just like anyone else.

People should be able to express their sexuality in ways that are right for them. This means they can choose how to show their love and feelings.

It is important to keep children, young people, and adults safe. This should not stop them from having a full life. They need to have control and make their own choices.

Adult health.

Depression.

People with Down syndrome can get depression just like anyone else. The effects of depression are the same for everyone.

If you feel depressed, it is important to ask for help. Having Down syndrome does not mean you should feel sad.

Be patient with yourself or others who have depression.

Depression is an illness, and most people get better with treatment and support.

Remember, getting help and support can make a big difference. You are not alone, and things can get better.

Adult health.

Alzheimer's disease and dementia.

Alzheimer’s disease makes people forget things. It can also make it hard to think and talk clearly.

People with Down syndrome can get Alzheimer’s disease at a younger age than others. They might get it 30 to 40 years earlier.

It is common for people with Down syndrome and dementia to have seizures. Seizures can be the first sign of dementia.

If the person already has seizures, they might change. The number, type, or strength of seizures can be different.

It is important to watch for these changes. This helps doctors give the right care.

Education.

We are working hard to make education better.

Many children with Down syndrome do not get the help they need to learn.

Some children with Down syndrome are sent to special schools.

Some children with Down syndrome do not go to school at all.

This is not fair.

We want all children to get a good education, including children with Down syndrome.

We are working on advocacy, training and resources to help improve education systems for people with Down syndrome.

Support our work: www.ds-int.org/support-us

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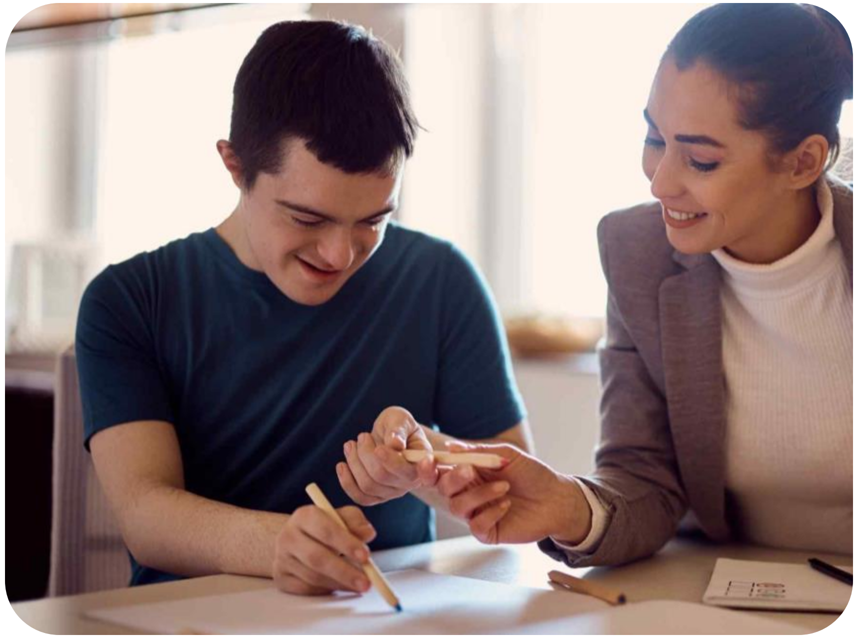
Education.



In the past, children with Down syndrome did not go to mainstream schools or join in social activities alongside other children.

This is still the case in many places.

Some children with Down syndrome are sent to special schools. Some children with Down syndrome do not go to school at all.

We now know that children with Down syndrome learn just as well, if not better, by being included in mainstream schools and activities.

All children should get the same chances to learn as other children. They should get extra help to learn if they need it.

Children also need chances to make friends and explore things that interest them.

This is inclusive education.

Education.

Being in a mainstream school gives children with Down syndrome the chance to learn from their typically developing peers and develop age-appropriate social skills.

They can also make friends with children they will see outside of school in their local community.

For other children, learning alongside a child with Down syndrome teaches them about diversity and inclusion. They become more tolerant and patient. They learn that everyone has something to offer.

Education.

Learning profile of a person with Down syndrome.

Children with Down syndrome learn new skills more slowly than other children. For example, motor skills, social skills, communication skills, cognitive skills, and self-help skills.

Each child has their own mix of strong and weak points. The speed of learning different skills varies between children with Down syndrome, just like other children.

This mix is called a learning profile. It shows what they are good at and what they find hard.

By recognising each child's learning profile, we can use the best strategies to help them learn new skills and be included in school.

Education.

Things children with Down syndrome are often good at:

- Learning by looking and being aware of what is around them.
- Learning and using signs and gestures.
- Learning to read and write.
- Learning from pictures and practical activities.
- Communicating and being with other people.
- Learning behaviours and attitudes from other people.
- Following a familiar structure and routine.

Education.

Things children with Down syndrome often find harder:

- They are more likely to have problems with eyesight and hearing.
- Motor skills take longer to develop.
- Speech and language skills take longer to learn.
- Remembering and processing information or instructions.
- Focusing for long periods of time.
- Using something they have learnt to solve a different problem.
- They might try to avoid doing things they find hard.

Education.

Extra support in school.

Most children with Down syndrome need extra help at school. The usual school resources are often not enough for them.

In some places, local authorities check what each child with intellectual disabilities needs. They write a document about these needs and tell schools what they should do to meet each child's needs.

The school can use more visual teaching or give simpler work on the same topic. This helps children with intellectual disabilities understand better.

International Guidelines for the Education of Learners with Down Syndrome.

We worked with teachers and experts in education to write these guidelines.

By following these guidelines, everyone can learn better. Teachers can teach better, and managers can run schools better.

This helps learners with Down Syndrome have a good education.

Read the guidelines at www.ds-int.org/education-guidelines

Employment.

We are working hard to make employment better.

Inclusive employment means everyone gets a chance to work together at the same jobs.

They should be treated fairly with the same rights, rules and pay as others.

They should have support and training to grow their skills and be successful.

We are working on advocacy, training and resources to help improve employment systems for people with Down syndrome.

Support our work: www.ds-int.org/support-us

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Employment.

Having a job can make life better in many ways, not just by earning money.

Work can help people feel good about themselves, be more independent, and feel part of a group.

It also helps people make new friends and find new hobbies.

Local support.

Our members can direct you to support available in your country.

Find contact details for our network members on our website at www.ds-int.org/contact-us

Employment.

Benefits for businesses and organisations.

Studies have shown that people with Down syndrome are good workers. They often stay in their jobs longer than other workers.

They help make the workplace a happier place. They also make their work friends feel better.

This makes the whole work area nicer. Everyone feels good and works well together.

Because of this, people with Down syndrome are important to businesses.

Employment.

Barriers to employment.

People with Down syndrome often face wrong ideas about them. These ideas can stop them from getting jobs.

Some people think they can’t do the work, even if they can. This makes it hard to get hired.

Employers might not even think about hiring someone with Down syndrome. They might not believe they can do the job.

Not having enough education can also be a problem. Without the right training, it is hard to find work.

People with Down syndrome might not have the skills needed for some jobs. This makes it even harder to get hired.

We need to change these wrong ideas and help with training. This will make it easier for people with Down syndrome to find jobs.

Employment.

Support and training.

Some organisations have programs to help people with Down syndrome and learning disabilities get good jobs.

They also teach the employers and other workers. This helps them feel more confident about hiring people with Down syndrome.

This teaching also helps change wrong ideas about people with Down syndrome.

In the end, the whole company becomes more inclusive for everyone.

Local support.

Our members can direct you to support available in your country.

Find contact details for our network members on our website at www.ds-int.org/contact-us

Inclusive employment case study.

We published a case study on best practices in the inclusive employment of people with intellectual disabilities in Bangladesh.

The case study gives recommendations for the government of Bangladesh and employers to make inclusive work environments for persons with intellectual disabilities and all other employees.

The case study can be used by governments around the world to make work places more inclusive.

Read the case study at ds-int.org/inclusive-employment-case-study

Advocacy and human rights.

We support self-advocates to speak up for their rights.

People with Down syndrome often do not get to make choices about their own lives.

Others make decisions for them without asking what they want or think.

This means their rights are often not respected.

We believe everyone should have a say in decisions that affect them.

Support our work: www.ds-int.org/support-us

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Advocacy and human rights.

What are human rights?

Human rights are the basic rights and freedoms that belong to every person in the world, from birth until death. They apply regardless of where you are from, what you believe, or how you choose to live your life.

People with Down syndrome have the same human rights as everyone else.

Human rights can never be taken away, although they can sometimes be restricted – for example if a person breaks the law, or in the interests of national security.

These basic rights are based on shared values like dignity, fairness, equality, respect, and independence. These values are defined and protected by law.

Advocacy and human rights.

CRPD Convention on the Rights of Persons with Disabilities

Convention on the Rights of Persons with Disabilities.

The United Nations Convention on the Rights of Persons with Disabilities (sometimes called the “CRPD”) is an international agreement on the rights of people with disabilities.

The CRPD was made because people with disabilities were not getting their human rights. They were being treated unfairly.

The CRPD tells countries what they must do to help people with disabilities. Countries that sign it must follow these rules.

Follow this link to learn more about the CRPD: https://ds-int.org/the-convention-on-the-rights-of-persons-with-disabilities/

Advocacy and human rights.

Self-advocacy.

Self-advocacy means speaking up for yourself and what matters to you. It is about saying what you want and need and sharing your thoughts and feelings.

Self-advocacy also means knowing your rights and making decisions about your life. You can still ask for help, but you decide what happens.

Being a self-advocate means you are responsible for your choices. You learn to handle the results of your decisions.

This helps you live a more independent and happy life.

When you can speak up for yourself, you can make better choices for your life.

People with Down syndrome might need help to speak up for themselves.

Advocacy and human rights.

Advocacy.

Advocacy means speaking up for someone else. It can help fix problems, get support, or change rules that affect people with Down syndrome.

Advocacy is important to protect the rights of people with Down syndrome.

It helps them get the same chances as others and be treated with respect.

People and groups can be advocates for those with Down syndrome. They work to make sure their voices are heard and their needs are met.

Our network works with advocates from all over the world sharing knowledge, advice, and support.

Together we advocate for the rights of people with Down syndrome.

Inclusive participation.

We are working hard to help organisations work more inclusively.

Organisations should include people with disabilities in everything they do.

The problem is many people with intellectual disabilities are not included in a meaningful way.

They face barriers that stop them from having key roles.

We are working on advocacy, training and resources to help organisations to include people with Down syndrome and intellectual disabilities.

Support our work: www.ds-int.org/support-us

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Inclusive participation.

What is inclusive participation?

Inclusive participation means that everyone can take part.

It means that everyone is included in a meaningful way and everyone is valued.

In order for inclusive participation to happen, barriers must be taken away:

- Information must be given in a way that everyone can understand.
- Everyone must be able to share ideas, experiences, and knowledge like everyone else.
- Everyone must have the time and adjustments needed to take part.

The Listen Include Respect guidelines.

LISTEN
INCLUDE
RESPECT
International Guidelines
for Inclusive Participation

We are working with Inclusion International to develop international guidelines so organisations can make their work inclusive.

The guidelines help organisations understand what they need to do to make sure people with intellectual disabilities are included in their work.

Visit the Listen Include Respect website to learn more:
www.listenincluderespect.com

Down Syndrome International

Research.

Research into Down syndrome is ongoing in many fields.

Our network works with research groups worldwide to advance knowledge of Down syndrome.

Our role is to speak up on behalf of the global Down syndrome community and to share key updates with the community.

Support our work: www.ds-int.org/support-us

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