



Down syndrome explained

Produced by



Introduction.

This guide provides bitesize introductions to some of the key topics relevant to people with Down syndrome.

If you would like to read more on any of these topics, please visit the 'Down Syndrome Explained' pages on our website (www.ds-int.org).



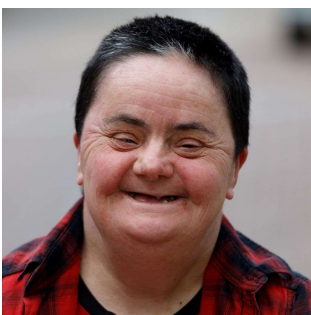
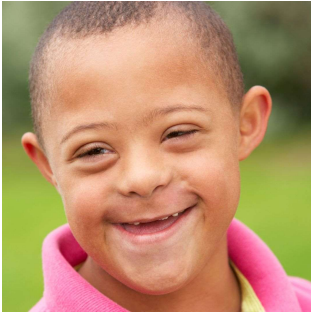
If you have any questions or need support, please contact us:

Email: contact@ds-int.org Phone: +44 (0)1395 493108

Or contact our organisation contact in your country.

You can find contact details on our Global Contacts page -

www.ds-int.org/Pages/Category/global-contacts



In this guide:

[What is Down syndrome?](#) Page 4.

[New parents.](#) Page 5.

[Health.](#) Page 11.

[Child health.](#) Page 12.

[Adult health.](#) Page 16.

[Education.](#) Page 21.

[Employment.](#) Page 29.

[Advocacy and human rights.](#) Page 33.

[Inclusive participation.](#) Page 38.

[Research.](#) Page 40.

[World Down Syndrome Day.](#) Page 41.

[About DSi.](#) Page 42.

What is Down syndrome?

Down syndrome (or Trisomy 21) is a condition in which a person has an extra chromosome.

Chromosomes are "packages" of genes in the body. They determine how a baby's body forms and functions as it grows.

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

Down syndrome occurs naturally – there is no known cause.

Down syndrome usually causes varying degrees of intellectual and physical disability and associated medical issues.



New parents.

Prenatal testing.

In many countries, screening for Down syndrome is offered to pregnant women of all ages.

Ultrasound scans can show signs that a baby has an increased chance of having Down syndrome.

Certain blood tests can also detect if a baby is more likely to have Down syndrome.

Neither ultrasound nor blood tests can confirm a diagnosis. These tests can only provide you with information about the likelihood of having a baby with Down syndrome.



To confirm a diagnosis, tests that take samples of foetal tissue or fluid from the baby need to be carried out.

It is your choice whether or not to take the tests.

In many countries health professionals have received training to help women to make informed decisions that feel right for them.



Explaining the diagnosis.

In some countries health professionals have received training on how to deliver and explain a Down syndrome diagnosis.

Receiving news about a diagnosis can be overwhelming and families often cope with a range of emotions during that time.

New baby.

Congratulations on the birth of your baby!

If your baby is healthy, his/her needs will be just like other babies. You don't need to do anything different or special at this stage.

Your baby's health.

Some health conditions are more common in children with Down syndrome. It is important that you are aware of this and if possible that your baby is screened for these. Some countries have systems in place to ensure this takes place.



Local support.

Meeting other parents locally can give you some much needed moral support and advice from like-minded people.

Feeding your baby.

Many babies with Down syndrome are able to breastfeed successfully from birth.

A few babies have medical problems which affect feeding.

Weaning your baby is likely to be much like weaning any other child, but sometimes they can be slower to learn how to suck, chew and swallow.

Some babies with Down syndrome are particularly sensitive to different textures and prefer smoother foods and familiar flavours. As with any child, the priority is to provide a healthy and balanced diet.

Ask a qualified professional, for example a health visitor or speech and language therapist with expertise in feeding, if you are worried or need advice on feeding and weaning.



Development.

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

They are helped by being socially included in their families, schools and communities.

They are helped to learn new skills by being shown how to do them and by having enjoyable ways to practice.

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



Early intervention.

'Early intervention' (including speech and physiotherapy) can help the development of children with Down syndrome.

Ask your doctor, local health professional or local support network what is available in your area. The intervention that your child receives will depend on their needs and local availability.

How can I help my baby develop?

Spending time in face to face interaction with your baby is one of the best ways to help your baby learn. 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.

Play together. Follow your child's lead and support their learning in sensitive and responsive ways. Get into your child's world, copying his/her play with your own toy that is the same as his/hers, repeating things your child enjoys, taking turns, showing your child you are having fun, being animated and playful are just some of the ways you can help your child learn.



As you play together you can show your child the next step and encourage your child to copy you. We know that children with Down syndrome learn especially well by being shown things.

The most important experiences for a child with Down syndrome come from being a member of a happy, loving and active family – and from doing all the things that families normally do.

Health.

Everyone should have the right to enjoy the highest attainable standard of health, without discrimination.

[Article 25](#) (Health) of the UN Convention on the Rights of Persons with Disabilities (CRPD).

For people with Down syndrome, this can be realised if:

- any health diagnosis is based on what is presented, without any bias or discrimination;
- the right health surveillance or treatments take place when they are required and
- people are supported to understand their healthcare needs and make their own choices.

This is what we would expect for any person.



Child health.

Heart problems.

Roughly half of babies born with Down syndrome will have a heart defect but less than one in five have a serious problem.

It is important to identify any serious problems in the first two months of life because early treatment may be needed. The UK Down's Syndrome Medical Interest Group (DSMIG) recommend that by 6 weeks of age a formal heart assessment including echocardiogram has been carried out which should identify nearly all serious problems.



Eyesight.

The eye problems which may affect children with Down syndrome are commonly those which occur in any group of children – they just tend to occur more frequently and sometimes to a more marked degree. Therefore it is especially important to have their eyes checked.

Ears and hearing.

Ears and hearing should be examined at a yearly health check.

Most children with Down syndrome will have otitis media with effusion (glue ear) in childhood. This is sometimes treated with ventilation tubes (grommets). Glue ear usually resolves in adolescence but may persist in some people.

Hyperacusis is more prevalent in individuals with Down syndrome. Hyperacusis is an increased sensitivity to sounds. Individuals may feel pain or discomfort when they hear sounds that most people are able to tolerate. If suspected, a referral to an audiologist is recommended.



Thyroid disorder.

Thyroid problems are more common in people with Down syndrome than in the general population.

Babies born with Down syndrome should have a routine blood spot test in the first six weeks of life followed by a screening blood test when they reach their first birthday. Children with Down syndrome should have a screening blood test at least every two years.

Sleep problems.

Sleep problems are common in children with Down syndrome. These can be behavioural or physical in nature (related to sleep disordered breathing) or a combination.

Sleep disordered breathing is characterised by repeated pauses in breathing during sleep (sometimes referred to as sleep apnoea).

Sleep problems should be investigated by a specialist to exclude underlying causes.



Coeliac disease.

Coeliac disease is a type of malabsorption where the bowels are unable to absorb particular nutrients from food. Coeliac disease is more common in people with Down syndrome.

Treatment of coeliac disease is by special diet excluding gluten. This should be supervised by a dietitian.

Epilepsy.

Epileptic spasms are uncommon epileptic seizures. Epileptic spasms occur in around 5% of children with Down syndrome.

Epileptic spasms usually occur in children aged between 3 and 6 months old and not older than 12 months.

Families may notice that their child's head will suddenly nod forwards. Sometimes the arms or legs will also quickly move and their child may become upset. The movements are very brief (lasting less than a second), but may occur in "clusters" where several of these movements occur close together. These clusters may happen after the child wakes from sleep.



Neck instability.

The joints at the top of the spine and at the base of the skull allow us to shake and nod our heads. In people with Down syndrome, the ligaments (tissue that connects one bone to another bone thus holding a joint together) are stretchier. So joints may be looser and more flexible which can lead to slippage of the vertebrae (the bones that surround and protect the spinal cord).

Adult health.

Heart problems.

Heart problems are very common in people with Down syndrome.

Regular medical reviews should be carried out throughout life. This will allow prompt diagnosis and management of previously undiagnosed cardiac disorders or new problems having developed.



Eyesight.

The eye conditions that occur in adults with Down syndrome are not unique to the syndrome – all occur in the general population. However, some conditions are more common in Down syndrome, or occur at a younger age in Down syndrome.

Ears and hearing.

Early onset age-related hearing loss (early onset presbycusis) is common in individuals with Down syndrome. The hearing loss may start in early adulthood. A yearly hearing assessment will detect the onset of the hearing loss.



Thyroid disorder.

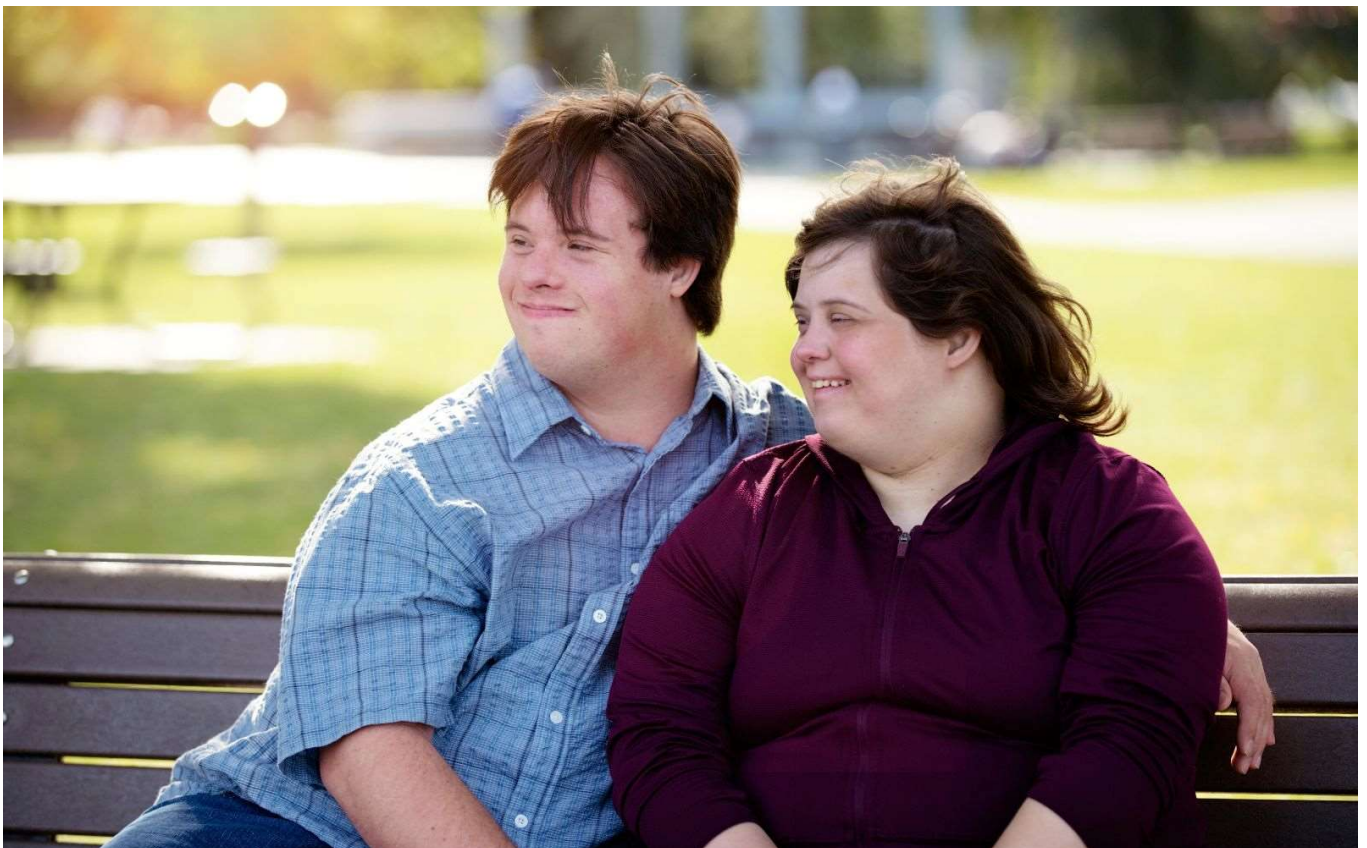
Thyroid problems are more common in people with Down syndrome than in the general population.

People with Down syndrome need regular screening blood tests throughout their lives.

Sexual health.

People with a learning disability have a right to express emotions and sexuality and develop relationships as an important part of a full and equal life based on a right to independence, control and life choices.

It is important that vulnerable children, young people and adults are protected but this should not be at the cost of respecting their human need to love and to be loved, to have friends and to express their sexuality (in ways that suit them and which are acceptable).



Mental health.

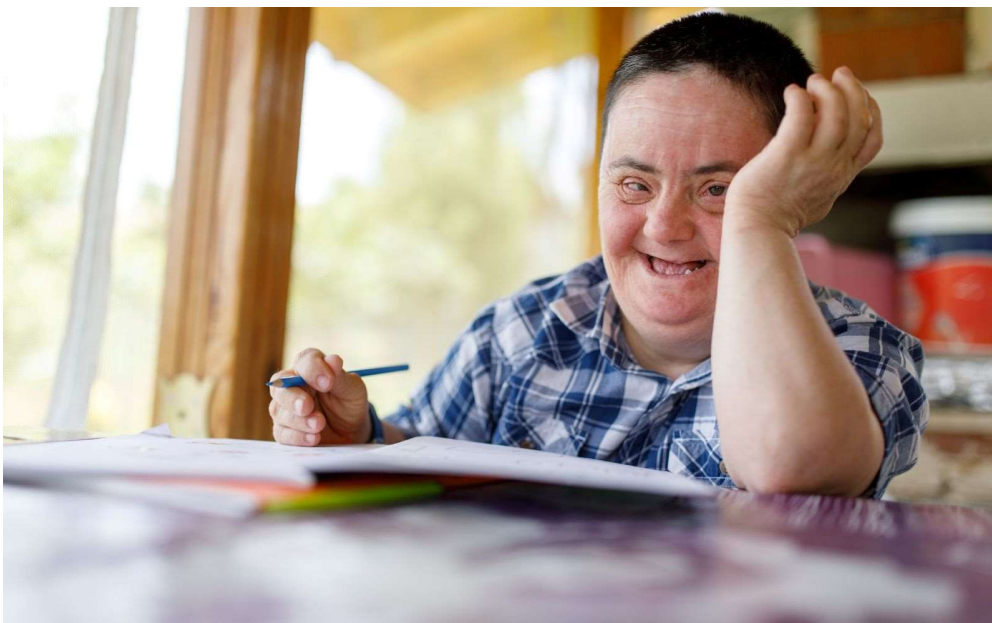
Many people with Down syndrome experience positive mental wellbeing and do not exhibit signs of poor mental health.

However, there are certain factors that may make people with Down syndrome more susceptible to poorer mental health. Certain biological differences, as well as everyday stresses that people with Down syndrome may find harder to deal with, may make people with the condition more susceptible to mood, emotional and other mental health problems.

Depression.

Depression is at least as common in people with Down syndrome as it is in the general population and the effects are the same.

As for all people who experience depression, it is important to ask for help. It is not normal for someone to feel depressed just because they have Down syndrome. Remember to be patient and that depression is an illness, and that most people get better with treatment and support.



Epilepsy.

Over 80% of people with Down syndrome and dementia develop seizures and this may be the presenting symptom of the dementia.

Alzheimer's disease.

Alzheimer's disease causes dementia. Its symptoms include impaired thought, impaired speech, and confusion.

The risk that a person with Down syndrome will develop Alzheimer's disease increases with age at a similar rate as it does in the general population, but 30 to 40 years sooner than is the case for people without Down syndrome.



Education.

Every child should have access to inclusive and equitable quality education.

[Article 24](#) (Education) of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, United Nations, 2006).

For children with Down syndrome, this can be realised if:

- full access is provided to education settings, without segregation or exclusion;
- each child is supported to learn and is given the same learning opportunities as others and
- all children have opportunities to develop interests, make friends and gain confidence and independence.

This is also what we expect for any other child.



International Guidelines for the Education of Learners with Down Syndrome.

DSi has developed and published International Guidelines for the Education of Learners with Down Syndrome.

The guidelines have been created to improve the availability and quality of education for people with Down syndrome around the world and to contribute to the realisation of their right to an inclusive education and lifelong learning.

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



Inclusive education.

It is gradually becoming more commonplace for children with Down syndrome around the world to attend community playgroups and nurseries, local mainstream schools and to join in social activities with typically developing siblings and friends. In addition, more young adults with Down syndrome are gaining qualifications and experiences and thereby succeeding in a wide variety of ordinary jobs.



The vast majority of children with Down syndrome will benefit from placement in a local mainstream school, receiving their education alongside typically developing peers of their own age. Research indicates that children with Down syndrome placed in the mainstream do at least as well if not better than children of similar ability in special schools. Regular opportunities to learn, interact and play alongside typically developing peers gives children with Down syndrome the role models they will need to encourage them to develop age-appropriate behaviour and sustain relationships. Placement in a school within their local community will also provide the opportunity to make friends with children they will see outside school.

While support may be required to facilitate learning, successful inclusion promotes independence. Although the demands of the curriculum may increase as the child gets older, they should progressively be more able to function as ordinary members of the school community, with help or support as and when needed.

Inclusive education benefits not only the child with Down syndrome, but also leads to greater understanding and less prejudice in the local community and ultimately in society at large. Children in inclusive schools learn to become more tolerant and patient and to support each other. They also learn to value diversity and to appreciate that everyone has something to bring to the life of the school.



Learning profile of a person with Down syndrome.

Generally speaking, children with Down syndrome develop more slowly than their peers, arriving at each stage of development at a later age and staying there for longer. Consequently, the gap between children with Down syndrome and their peers will widen with age. The degree of delay varies across developmental areas – motor, social, communication, cognition and self help. This is described as a specific learning profile associated with the condition – or a pattern of strengths and weaknesses. However children with Down syndrome will also vary as widely in their development and progress as typically developing children and each will have their own individual talents and aptitudes.



It is important that this specific learning profile is recognised in order that the most appropriate strategies are used so that children with Down syndrome are able to develop their knowledge, learn new skills and be included into school as effectively as possible. This profile incorporates the following strengths and weaknesses:-

Areas of strength:

- Strong visual awareness and visual learning skills.
- Ability to learn and use sign, gesture and visual support.
- Ability to learn and use the written word.
- Ability to learn from pictorial, concrete & practical materials.
- Keen to communicate and socialise with others.
- Tendency to model behaviour and attitudes from peers and adults.
- Structure & routine



Factors that inhibit learning:

- Auditory and visual impairment.
- Delayed motor skills – fine and gross.
- Speech and language impairment.
- Short term and working memory weaknesses.
- Shorter concentration span.
- Difficulties with consolidation and retention.
- Difficulties with generalisation, thinking and reasoning.
- Sequencing difficulties.
- Avoidance strategies.



Extra support in school.

The vast majority of children with Down syndrome will need more help than is normally available from the school's existing resources.

In some countries, an assessment of the educational needs of every child with learning difficulties is coordinated by local authorities leading to the creation of a document which outlines their specific needs and requirements.

In many countries, schools have a duty to adapt the curriculum as necessary for children with special needs. This can mean having more help in the classroom, using more hands on visual teaching or providing simpler work within the same topic.

Children with Down syndrome will generally benefit from speech and language therapy to help with their specific language difficulties.

All children have individual and different needs and there is no unique 'support package' that is right for all children with Down syndrome.



Employment.

We believe everyone should have access to employment in inclusive workplaces.

[Article 27](#) (Work and Employment) of the UN Convention on the Rights of Persons with Disabilities.

For people with Down syndrome this can be achieved if:

- work opportunities are provided by employers, in open settings, without segregation or exclusion;
- people have the support needed to apply for jobs, start in work and develop careers and
- people have opportunities to show the contribution they can make, develop good work relationships and gain confidence and independence.

This is also true of every person who currently faces barriers to employment.



Human rights.

'States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.'

[Article 27](#) (Work and Employment) of the UN Convention on the Rights of Persons with Disabilities.

Barriers to employment.

Stereotypes, mistaken assumptions and negative attitudes often combine to preclude people with Down syndrome and intellectual disability from employment.

Linked to these mind sets, factors such as lack of education and training can present further disadvantages in seeking jobs.



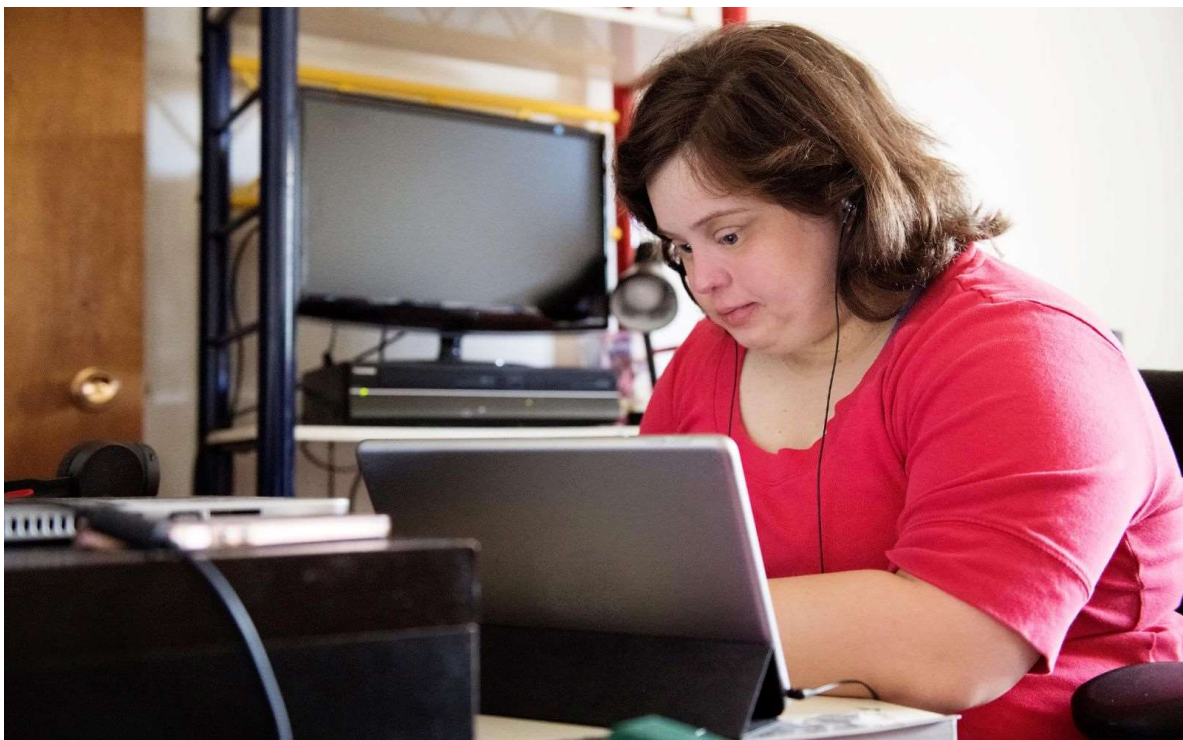
Benefits of employment for people with Down syndrome.

In addition to providing an income for better life circumstances, employment enhances quality of life by providing a major sense of identity, independence, a sense of contribution and belonging and establishing additional relationships and interests.

Benefits for businesses and organisations.

Research has shown that people with Down syndrome are loyal employees, they increase morale in the workplace and are more likely to stay in their jobs than other employees.

When employed and supported in their work they not only contribute to the flourishing of business but also have a positive impact on colleagues and the overall professional climate.



Support and training.

In addition to advocating for the right to employment, some Down syndrome and intellectual disability organisations work to facilitate employment opportunities.

Some have established programmes to assist access to suitable jobs and to provide support and training.

Some of these programmes provide training to the employing organisation and their staff in addition to training for the employee with Down syndrome. This process has been found to allay fears about the employment and negative attitudes towards the disability and has enabled the entire organisation to become more inclusive.

Reach out to our organisation contact in your country.

You can find contact details on our Global Contacts page -

www.ds-int.org/Pages/Category/global-contacts



Advocacy and human rights.

What are human rights?

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

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.

They 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.

The Convention on the Rights of Persons with Disabilities (CRPD) is an international legal agreement. It exists to protect and promote the human rights of people with disabilities.



Convention on the Rights of Persons with Disabilities.

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) exists to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities, and to promote respect for their inherent dignity.

The Convention was adopted as a response to the fact that although pre-existing human rights conventions offer considerable potential to promote and protect the rights of people with disabilities, this potential was not being tapped. People with disabilities continued being denied their human rights and were kept on the margins of society in all parts of the world.

The Convention sets out the legal obligations on Member States to promote and protect the rights of people with disabilities.



Self-advocacy.

Self-advocacy is the ability to speak-up for yourself and the things that are important to you.

Self-advocacy means you are able to ask for what you need and want and tell people about your thoughts and feelings.

Self-advocacy means you know your rights and responsibilities, you speak-up for your rights, and you are able to make choices and decisions that affect your life.

The goal of self-advocacy is for you to decide what you want then develop and carry out a plan to help you get it. It does not mean you can't get help if you need or want it, it just means that you are making the choices and you have to be responsible for the choices you make.



When you have good self-advocacy skills you can have more control and make the life decisions that are best for you. Self-advocacy helps to empower you, to speak-up for yourself and make decisions about your life.

People with Down syndrome may need the support of advocates to become effective self-advocates.

DSi works with self-advocates with Down syndrome from around the world to learn about their lives and determine the best way to offer them support.



Advocacy.

Advocacy is acting with or on behalf of people with Down syndrome to resolve an issue, obtain needed support or promote a change in practices or policies.

Advocacy is essential for promoting and protecting the civil and human rights of people with Down syndrome and for establishing, maintaining or improving their quality of life.

Individuals and organisations can be advocates for people with Down syndrome.

DSi works with advocates in countries around the world to share knowledge and to offer information, advice and support, with the ultimate aim of improving quality of life for people with Down syndrome worldwide and promoting their inherent right to be accepted and included as valued and equal members of their communities.



Inclusive participation.

Everyone has the right to be involved in decision-making that affects them.

[Article 4.3](#) (General Obligations) of the UN Convention on the Rights of Persons with Disabilities.

People with intellectual disabilities have the right to take part and be included.

We call this "inclusive participation".

It means...

- getting information in a way we can understand;
- being able to share ideas, experiences and knowledge like everyone else;
- having the time and adjustments needed to take part.

Put simply, inclusive participation is about removing barriers.



Inclusive organisations.

Organisations must make sure that people with disabilities are involved in everything they do.

Many people face barriers that prevent them from playing key roles in organisations.

Such roles may include (but are not limited to):

- leadership and governance;
- development of activities or projects;
- publishing or broadcasting information that can be understood by everyone.

Every organisation should aspire to include everyone in its decision-making.

This can be achieved in any organisation, with the right processes in place and with a genuine desire to succeed.

Listen Include Respect.

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

Visit the Listen Include Respect website to learn more -

www.listenincluderespect.com/



Research.

Research relating to people with Down syndrome is ongoing in many fields.

DSi works with members and research groups across the world to advance knowledge of Down syndrome.

We are working with the following organisations and their members, with our role to advise on behalf of the global Down syndrome community and advise the community of key updates.

Trisomy 21 Research Society (T21RS)

T21RS is a scientific organisation of researchers studying Down syndrome, founded to promote basic and applied research, stimulate translational research and apply new scientific knowledge to develop improved treatments.

International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD)

This special interest research group on Down syndrome, which forms part of IASSIDD, works in partnership with DSi to encourage research and the application of research in the field of Down syndrome.

The Down Syndrome Consortium - National Institutes of Health

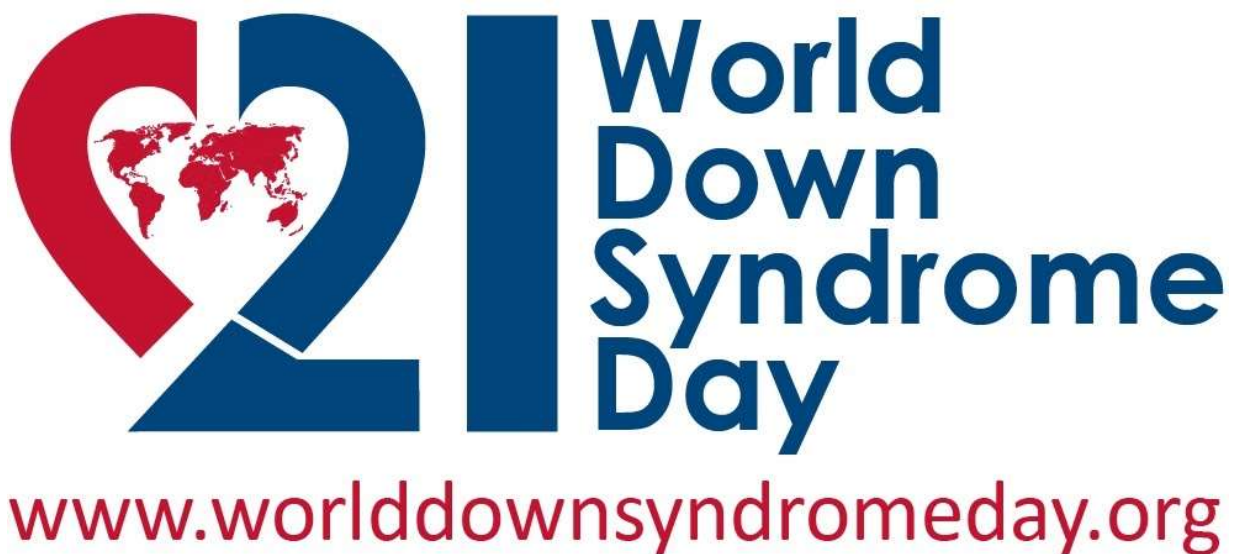
This U.S. based consortium of NIH and organisations interested in Down syndrome was formed to encourage the exchange of information about Down syndrome research, support and care. Work includes the DS-CONNECT registry.

World Down Syndrome Day.

World Down Syndrome Day (WDSD) is a global awareness day which has been officially observed by the United Nations since 2012.

On **21 March** each year, the Down syndrome community creates a single global voice advocating for the rights, inclusion and well being of people with Down syndrome.

Find out more on the WDSD website - www.worlddownsyndromeday.org/



About DSi.

Down Syndrome International (DSi) is a UK based international disabled people's organisation.

We work with a global network of self-advocates, organisations representing people with Down syndrome, and other international organisations of people with disabilities.

We are committed to improving quality of life for people with Down syndrome, promoting their right to be included on a full and equal basis with others.

Donate today.

Your donation will help improve the lives of people with Down syndrome worldwide. We cannot continue our vital work without your support and are incredibly grateful for every donation.

www.ds-int.org/donate-today

