

About Down Syndrome



Snif

Svenskt nätverk för information
kring fosterdiagnostik

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About Down syndrome

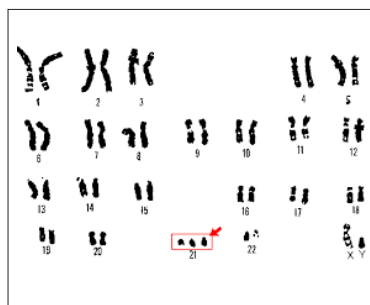
People with Down syndrome have featured in works of art, literature and scientific articles for centuries, and all around the world. Today in Sweden, 1 child in every 650 is born with Down syndrome. It is estimated that there are between 5,000 and 10,000 people with this diagnosis in Sweden. Down syndrome is not a disease or an illness, but is the name given to the distinct and specific characteristics of the syndrome.

These were first compiled and described in 1866, by the English doctor and social reformist, John Langdon Down.

It was not until 1959, however, that the French doctor, Jérôme Lejeune, discovered that the syndrome that Langdon Down had described was caused by an additional copy of chromosome 21. This most common form of Down syndrome (Trisomy 21) is found in around 94% of people with the diagnosis. In almost all cases, Trisomy 21 is caused by a random deviation during cell separation. More information about the various forms of Down syndrome can be found in the list of reference links on page 12.

It has been established that the extra copy of chromosome 21 can originate either from the mother (approx. 95%) or the father (approx. 5%). The probability of a child being born with Down syndrome increases with the age of the mother, although the reason for this remains unknown. It has not yet been possible to connect Down syndrome to any aspect of the mother or father's actions, either before or during pregnancy, and neither has it been possible to connect it to any environmental factors.

On pages 7 and 8, you can read more about the health and cognitive development of people diagnosed with Down syndrome.



The initial period

Every newborn child with Down syndrome is, first and foremost, an individual with a unique personality and with the same basic needs as every other infant – love, care, food and sleep. The child will most closely resemble their parents or siblings, although they are also likely to exhibit some of the features that are associated with Down syndrome.

For many families, the initial period after birth will be filled with the questions and emotions that can arise with confirmation of Down syndrome. How will this affect our family? Will we be able to continue working as much we'd expected? Will I be able to love my child? It can therefore feel reassuring to know that both knowledge and support are available from various sources, including specialists, interest organisations and other parents. As with all new-born children, it is important that the family quickly makes contact with a paediatric healthcare centre for the usual procedures, such as weight and measurement checks, vaccinations and contact with other parents. It is also relatively common for children with Down syndrome to require greater contact with the healthcare system – around half of all children with Down syndrome are born with some kind of heart defect, for example. Nowadays, heart defects are operated on at an early stage, with very good results. Other commonly occurring medical conditions, such as intestinal obstructions, are checked at birth and then regularly afterwards, in accordance with the medical care programme for children and young people with Down syndrome (see page 12).

When a child is born with Down syndrome, the family is referred to the habilitation service for children and young adults in their local area. Here they have access to a range of resources, such as physiotherapists, speech therapists, special needs educators, psychologists and counsellors. Parents can receive guidance and support that can help to make family life easier and encourage the child's development. Assistance from the habilitation services is always provided in collaboration with the parents, and it may take different forms, depending on the age of the child and the needs of the family at any particular time. The habilitation service also provides information about the statutory rights that apply for people with disabilities, and about the financial and practical support that is available to the family.



The family

Most parents of a child with Down syndrome have no prior experience of the diagnosis or of children with a disability. It is therefore not unusual to, for example, feel anxious about how this might affect the parents' relationship with each other, how any siblings might react to the new situation, or how other people will treat the family and its newest member.

Research at Uppsala University, however, shows that most parents of a child with Down syndrome live a normal family life. The study examined factors such as time spent caring for children, frequency of divorce or separation, parental stress, health, employment, absence due to ill health and temporary parental benefit. It was also noted that both mothers and fathers of children with Down syndrome spent more time away from work to care for a sick child than average. There are also families that face more challenging situations, which could be due to factors such as the child's support and care requirements, and/or the family's socio-economic circumstances.

Parents of a child with Down syndrome are entitled to apply for a childcare allowance on the grounds of the child's disability. They can also apply for temporary parental benefit for the care of a child when the child is aged between 2 and 18 years (in certain cases, this is available until the age of 23).

Temporary parental benefit can also be transferred to another person who can stay at home from work in order to care for a child who is sick. Parents are also entitled to 10 contact days per child, per year. These can, for example, be used for visits to preschool and school, until the child turns 16.

As mentioned earlier, families who have a child with Down syndrome are referred to their local habilitation service for children and young people. This is a major source of knowledge and experience for families who have a child with the diagnosis. Together with the specialist staff at the habilitation service, the family can discuss the various types of support that may be appropriate, in accordance with the family's needs and wishes.

In addition to this, there is a broad range of literature concerning families' experiences, sibling relationships in families with a child with a disability, and how to create a supportive home environment that benefits the whole family.



The first years

For all small children, the family is still the centre of their world. This world gradually expands with time, not least when the child begins to attend preschool. This is no less true for children with Down syndrome, and they are offered a place at preschool in the same way as other children. If there is any need for additional support at preschool, all children are entitled to receive this, regardless of any diagnosis.

As children with Down syndrome can have a greater need for continuity and support in their educational development, there may also be reason for them to have a place at preschool even if their mother or father is on parental leave with a younger sibling. Because children with Down syndrome can often have an impaired immune system, many families choose to begin with a few hours at preschool every day, before gradually increasing the rate of attendance over a period of time.

A child with Down syndrome has the same need to communicate with their surroundings as any other child, although their language development may be delayed. Collaboration between the family and the preschool concerning communication is important, and there are many different ways to encourage and develop the child's ability to communicate. Research has shown that the use of sign language (for example) can help the language development of children with Down syndrome. This means that people speak to the child but reinforce the words by simultaneously using signs from Swedish sign language. In this way, the signs become a visual aid to support the spoken language. The use of pictorial support – either alone or in combination with signing – is another way of conveying and clarifying linguistic messages.

The habilitation team provides support throughout the child's early years. It is the needs of the child and the family that determine which of the occupational resources in the team will work with them. These needs will be different for different families. In the child's earliest years, it is common to receive assistance from speech therapists, physiotherapists and special needs educators. The team also includes a counsellor and psychologist. Acceptance of habilitation support is voluntary.

The so-called LSS Act (Act concerning Support and Service for Persons with Certain Functional Impairments) gives families the right to apply for support, which is available in various forms. For small children, this could include help to relieve the pressure at home, temporary accommodation, or access to a respite family with whom the child can stay sometimes. Many families do not have any need for LSS measures at this time, although others need them from them a very early age.



Development milestones 0–4 years

Almost all people with Down syndrome have an intellectual disability. This may mean that it takes them longer to learn and to understand, but this impairment does not affect their feelings or emotional needs. Through training, access to stimulating experiences and individual adaptations, the development of a child with Down syndrome can be affected positively. This, in turn, can contribute to better-developed abilities and capacities, and greater interaction with their surroundings.

Below is a list that shows the development of various abilities during the first four years of life – both for children with and without Down syndrome.

| | Typical development | Development with Down syndrome |
|-----------------------------|----------------------------|---------------------------------------|
| Smiling | 0.5–3 months | 1.5–3 months |
| Rolling over | 2–10 months | 2–12 months |
| Sitting up | 5–9 months | 6–18 months |
| Crawling on stomach | 6–11 months | 7–21 months |
| Crawling on knees | 7–13 months | 8–25 months |
| Standing | 8–16 months | 10–32 months |
| Walking | 8–18 months | 12–45 months |
| Speaking (individual words) | 6–14 months | 9–30 months |
| Speaking (sentences) | 14–32 months | 18–46 months |



Health/Care programme

The general health of people with Down syndrome has improved dramatically in the space of just a few generations. The average life expectancy in 1974 was 34 years, but today it is just over 60 years. There are several crucial factors behind this change. In recent decades, children with Down syndrome have been able to remain in their home environment, and have grown up together with parents and siblings. This development occurred in conjunction with growing demands for a good care system in Sweden, and a medical care programme was developed during the 1980s. Since the development of the care programme, great advances have been made in the treatment of even the most common medical problems linked to Down syndrome. The combination of all these factors has resulted in a very positive effect on the general health of children and adults with Down syndrome.

The care programme

Most children with Down syndrome have mild or moderate developmental impairment, but this can be severe in others. Down syndrome entails a risk of certain medical problems, although almost all of these are treatable. Those that occur most commonly include sensitivity to infection, visual and/or hearing impairment, and sleep apnoea. It is also more common for children with Down syndrome to be born with heart defects or intestinal obstructions. These are often treated within a few months after birth. It has also been shown that people with Down syndrome are at lower risk of heart attacks, strokes and certain forms of cancer.

Recent research suggests that they are more likely to have an autism spectrum disorder (ASD) or ADHD than was previously thought. From the age of around 3 years, indications of ASD can be identified using questionnaires for parents and preschool staff. An equivalent approach can be used for ADHD from the age of around 5 years. If any indications are identified, investigations can be initiated. For a child with ASD or ADHD, there is much to be gained from education and the right educational approach. Here the habilitation team plays a key role.

In all situations, medical checks are important to ensure early detection and prompt treatment. The care programme for Down syndrome was created in order to ensure the conditions for fair and equal care, and to provide support for families, carers and healthcare personnel. The programme for people with Down syndrome aged 0–18 years was completely reviewed in 2013, and is updated regularly. There are at least 20 experts from all around the country who contribute with their expertise to ensure that the care programme is as comprehensive and relevant as possible. A link to the care programme is included in the reference links on page 12.



School

At the time of writing (2023), it has been more than 55 years since all children and young people with an intellectual disability became subject to the obligation to attend school, and this has been followed by additional legislation. Today, parents and guardians are largely free to choose which form of school their child will attend – regular compulsory school or compulsory school for pupils with learning disabilities.

The curriculum of the latter form is adapted for pupils with intellectual disabilities. Both school forms provide the opportunity to study in accordance with the curriculum for compulsory schools for pupils with learning disabilities.

There is also the opportunity to switch between school forms during their schooling.

As Down syndrome almost always involves some degree of learning difficulty, these pupils are entitled to special support measures, regardless of the form of school they attend.

Gymnasium school for pupils with learning disabilities is a non-compulsory, four-year school form. Today, it encompasses both national and individual programmes. The nine national gymnasium school programmes focus on courses that prepare pupils for occupations, and include workplace-based learning. This means that the student gains practical experience at a workplace for at least 22 weeks.

If a person has attended a school for pupils with learning disabilities and wishes to continue studying after gymnasium school, they can do so at Lär vux (adult education for people with learning difficulties) or at certain folk high schools (adult education centres). There are also public study circles that are specifically aimed at people with an intellectual disability.



Adolescence

For all people, adolescence is a period that is characterised by major changes, both physical and emotional. This is no less true for young people with Down syndrome.

Their family continues to be important, but friends, or a desire to have friends of their own age, become even more important for youngsters with Down syndrome. As with other young people who are approaching adult life, many begin to think about their own identity and their sexuality. Many also feel a strong desire for greater independence.

Some young people with Down syndrome can also struggle with the increased awareness of their disability, and can have many questions about how it will affect their life. This is something that other young people do not have to even think about.

As youngsters with Down syndrome do not form one homogeneous group, there are major variations in the amount of support they will need in order to become more independent. The Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) provides various support measures to help them to be able to live their lives in the same way as other people of the same age. This could, for example, involve a companion service, short periods of supervision or a contact person.

The importance of repeated practice and training is particularly significant for people with an intellectual disability. It can therefore be especially important for young people to develop and maintain good habits (e.g. concerning diet and exercise), so that these are well-established when the time comes to move away from the family home.

The range of adapted or inclusive leisure-time activities and conversational groups is much greater than was available for previous generations. Many municipalities also have special initiatives regarding the provision of summer jobs for young people with intellectual disabilities.

The gymnasium school curriculum for pupils with learning disabilities features workplace-based learning (APL), which serves to provide an introduction to working life. The final year of gymnasium school also provides an opportunity to initiate discussions concerning any LSS measures that may be needed by the young adult.



Adult life

The longest phase of life – adulthood – has been characterised by dramatic changes for people with Down syndrome. Within the space of a single generation, the average life expectancy has almost doubled, and a child who is born with Down syndrome today (2017) has a good chance of celebrating their 65th birthday.

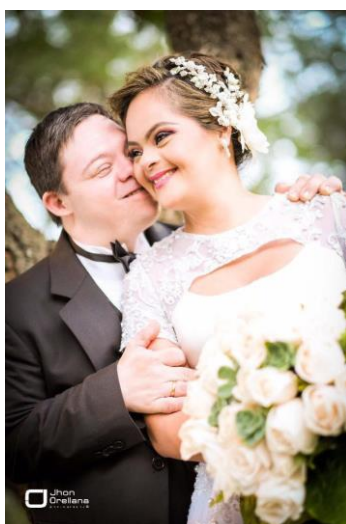
This positive development reflects the many societal developments that have benefited people with intellectual disabilities. LSS (the Act concerning Support and Service for Persons with Certain Functional Impairments), which we have already mentioned elsewhere in this brochure, was introduced more than twenty years ago. Some of the most important LSS measures for adults with Down syndrome include the rights to residential arrangements with support, daily activities and a companion service. Various forms of financial support for adults are also available. In recent years, several alternatives to the organised daily activities have been developed, including working with subsidised wages or supported gainful employment. People with Down syndrome have also become more visible in several new contexts, including in advertising, art, theatre and fashion, to name but a few.

With the increasing life expectancy, there is also a greater need for good medical care throughout adult life. There is a care programme for adults with Down syndrome, which is a particularly important resource for family, carers and healthcare personnel. The effects of ageing often appear earlier than for others, and there is an increased risk for certain conditions, such as Alzheimer's disease. As for everybody, preventive measures, such as a good diet and an active lifestyle, are very important, and this is an area in which people with Down syndrome may require additional support. The LSS act came into force in 1994, with the stated aim of promoting equality in life conditions and full participation in community life, so that the individual can have the same opportunities to live as others.

Together with other societal developments, this legislation has been extremely important for people with Down syndrome, especially for those who have entered adulthood since it was introduced. For this group, having their own apartment, friends to spend their free time with or romantic relationships are no longer unobtainable dreams, but have become part of everyday life for a great many more people than was previously possible.



Photo: Malin Stenström/Gotland's Allehanda



Links to reference sources

FUB – For children, young people and adults with intellectual disabilities

<http://www.fub.se/>

The Swedish National Down Syndrome Association

<http://www.svenskadowndforeningen.se/>

Snif – Swedish network for information concerning prenatal diagnostics

<http://www.snif.one/>

About Down syndrome

<http://www.svenskadowndforeningen.se/downs-syndrom/>

About Down syndrome for new parents

<https://www.svenskadowndforeningen.se/ny-foralder/valkommen-alskade-barn/>

Welcome to our world – a film about young children with Down syndrome

<https://vimeo.com/29138284>

Welcome to our world – a film about school and Down syndrome

<https://vimeo.com/28867032>

Welcome to our world – a film about adulthood and Down syndrome

<https://vimeo.com/32360534>

Down syndrome – medical care programme 0–18 years

<https://snpf.barnlakarforeningen.se/wp-content/uploads/sites/4/2023/01/230129DS-wardprogram-2017-rev-2022-2.pdf>

Habilitation service for children and young adults

<https://www.1177.se/barn--gravid/vard-och-stod-for-barn/funktionsnedsattning-hos-barn/>

IAKM Sverige – Interest group for language training and development

<https://www.iakm.se/>

The Swedish National Agency for Education – about compulsory school for pupils with learning disabilities

<https://www.skolverket.se/undervisning/anpassade-grundskolan>

Upper secondary school for pupils with learning disabilities

<https://www.anpassadgymnasieskola.se/>

SPSM – National Agency for Special Needs Education and Schools

<https://www.spsm.se/>

Sweden's folk high schools – studying with a disability

<https://www.folkhogskola.nu/lattlast/att-studera-med-funktionsnedsattning/>

Swedish National Agency for Education – special education for adults

<https://www.skolverket.se/undervisning/vuxenutbildningen/komvux-som-anpassad-utbildning-pa-grundlaggande-niva>

Swedish Public Employment Service – support for those with a disability

<https://arbetsformedlingen.se/for-arbetsokande/extra-stod/stod-a-o/kategorier/stod-a-o-for-dig-med-funktionsnedsattning>

LSS – Act concerning Support and Service for Persons with Certain Functional Impairments

https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa_sfs-1993-387

National Board of Health and Welfare – Does your child need help from society?

<https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/kunskapsstod/2017-10-4.pdf>

Swedish Social Insurance Agency – if your child has a disability

<https://www.forsakringskassan.se/privatpers/funktionsnedsattning/om-ditt-barn-har-en-funktionsnedsattning>

About Snif

Snif (the Swedish network for information concerning prenatal diagnostics) was formed in 2015 in order to facilitate cooperation between a number of relevant professions and special interest organisations. Snif includes representatives from the Swedish National Down Syndrome Association, the National Association for People with Intellectual Disability (FUB), The Heart Childrens' Fund, the National Association for Rare diseases Sweden, the National Board of Health and Welfare and from maternal healthcare, as well as gynaecologists, geneticists, genetic adviser, prenatal specialists, pediatric neurologists, professor of medical ethics and a representative from the Centre for Rare Diagnoses. A representative of Smer (the Swedish national council on medical ethics) has reviewed the text of this informative brochure.

Snif's objective is to work to ensure fair and equal access to neutral, high-quality information, knowledge and communication with regard to prenatal diagnostics. We also aim to contribute to maintaining the health and topicality of the ethical debate in society concerning these issues. Our work also includes the creation of relevant and up-to-date written information relating to prenatal diagnostics that can be used independently, regardless of geographical location within the country.

The target group for this brochure includes prospective parents, professionals and other interested parties.

The brochure provides a concise, fact-based, general overview of what Down syndrome is and of the potential implications. The information is not to be used for medical evaluation. All decisions concerning a patient's care must be discussed with the care provider.

