

# Lesson 1: Autism

You can read the content of the lesson 1 videos here.

## Autism diagnosis

Research is underway to determine the causes of autism, but we don't have all the answers. What we do know is that the brain functions somewhat differently, which impacts development in general.

We also know that autism is often hereditary, but there are certain environmental factors that may play a role. In that case, it is usually a vulnerability at the foetal stage that is impacted by these environmental factors. But this is unrelated to improper child-rearing or any lifestyle factors connected to pregnancy and delivery; rather, the factors for understanding the causes of autism are much more complex.

While the autistic brain does work differently, autism is not considered a disease, but rather a different way of functioning. There is no medication and we do not talk in terms of 'curing' autism. However, an individual can develop, and symptoms can improve enough that they no longer have as much of an impact on daily life.

The diagnosis is not permanent, but rather a description of how things look here and now. When it comes to the prognosis: some people with autism will need support for the rest of their lives, while others won't need as much support and can manage most situations on their own.

A factor for success is finding a setting in which the individual's different way of operating is actually an asset.

You can read more about this at [autism.se](http://autism.se) or 1177.

## Developmental differences

People go through a relatively similar development process throughout childhood and young adulthood. But children with autism develop differently from what we would call typical development of children in general.

This entails a different frame of reference, different ways of understanding the world, and different ways of communicating, behaving and interpreting sensory input. Using the word 'different' makes space for autism to not have to be something negative or something to correct.

But it is something we will always have to consider, whether you are the parent or the child.

## Concurrent diagnoses

It is common for people with autism to have other concurrent diagnoses and symptoms.

The combination of autism and other diagnoses affects how an individual's autism is expressed as well as the degree of disability.

ADHD entails a fundamental difficulty to regulate attention, activity level and impulse control. Just like autism, this diagnosis is a developmental disability and it is not uncommon to have both at once.

A language disorder means having particular difficulties with language itself, for example with vocabulary, grammar, pronunciation, understanding sounds, or language comprehension and expression. A language disorder diagnosis is made if these difficulties are greater than what could be explained by autism, where deficiencies with verbal and non-verbal communication are part of the symptom criteria under social communication.

Learning difficulties are common with autism, such as low intelligence or intellectual disability, what was previously known as mental retardation. Abilities may be imbalanced, or an individual could have specific learning difficulties, for example with reading and writing, or dyscalculia.

A cognitive assessment is conducted to determine the level of cognitive strengths and weaknesses, so that the school can provide the proper support and stimulation.

Psychiatric conditions such as depression, anxiety, OCD, or eating disorders can affect people with autism, just like anyone else. Such conditions could be due to a variety of causes, such as excessive demands, life events and genetics.

Autism is overrepresented with certain kinds of medical conditions, for example with some chromosome abnormalities or genetic conditions. But usually, these kinds of clear links are not found in a chromosome analysis.

## Causes and prognosis

In the past, several different diagnoses were used in the area of autism:

- Autistic syndrome.
- Asperger's syndrome.
- Autism-like conditions or atypical autism.

These are all included in what we now call autism.

Autism is a developmental disability, which simply means that a different early development process is behind the symptoms seen with autism.

When we investigate and make an autism diagnosis, we usually use the international diagnostic manuals, called the DSM-5 and ICD 10.

For autism, developmental differences and symptoms are described in the two areas of social communication and interaction, as well as restricted or repetitive behaviours and interests, and also perception differences.

It is also important to remember that this is a developmental difference and not a disease.

Even the diagnosis is the same, there are massive variations between different individuals with autism. The diagnosis is made when the symptoms result in a disability in daily life.

## **Iceberg metaphor**

The iceberg metaphor reminds us that what we see with autism can be explained by the things we don't see. Many behaviours are clearly visible, such as speech or linguistic differences.

There might also be different movement patterns. There might be outbursts or shutting down in various ways. Food may be an issue. These are all things that you might think you would want to change.

But to truly make change for the child, it's important to recognise what is beneath the surface. We will address cognition and perception differences in lesson 2.

Only then can we help a child with autism to develop in the best possible way.

## **Feelings about the diagnosis**

The diagnosis of a child/teen may stir up a lot of emotions and reactions, both for the parents and for the child/teen.

When actually receiving the diagnosis, it can be easy to feel overwhelmed by all the information and emotions may be on a rollercoaster. You might feel everything from anger, sadness, worry and fear to shame and guilt. It might also feel like a relief, and could serve to validate something you had already suspected.

There are no right or wrong reactions or feelings and it is important to respect one another, regardless of your reactions.

In addition to you as parents, many people around your child will be affected. So it's good to gradually come to an agreement on how much information you want to share and with whom.

## **Autism Sverige (Autism Sweden)**

If you have a child with autism, you can join a local district association through which you can meet others in a similar situation and find help.

Many people find it nice to have a place to go where you don't have to explain anything. It's also nice to have a forum, such as a parenting group, where you can be yourself, and once we have met, where the kids can be themselves as well.

Find more information about the association and local district associations at [www.autism.se](http://www.autism.se). You will also find loads of tips and advice there about school, the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), and other organisations with which you may come into contact.

You are welcome to contact any district association. It does not have to be the one nearest to where you live.

## **Individually tailored initiatives**

We generally divide tailored initiatives for kids and teens with autism into three parts. Together, the parts aim to improve quality of life and reduce the degree of disability in the child or teen.

The first part involves improving your own and others' understanding. Once we have a better understanding, we can also start to adapt the environment by changing and clarifying it for the child or teen.

It is also important to keep in mind that the child/teen might need help developing their abilities and finding strategies for better functioning in daily life.

As we said, there is no cure or medication for autism, but there are medications for other associated challenges, such as issues with sleep or anxiety. Such medication can alleviate symptoms and improve functioning.

## **Social support**

Various forms of social support are available to you and your family when you have a child with a disability.

The Swedish Social Insurance Agency offers different forms of financial aid, such as child carer's allowance and an additional cost allowance.

The child carer's allowance is based on the care and supervision your child needs beyond what is typical for a child of the same age without a disability.

Additional costs are costs due to the child's disability that are in addition to what is common for a child of the same age without a disability. You are eligible for this allowance as long as you are responsible for the child's care.

You can also apply to the Swedish Social Insurance Agency for so-called contact days or VAB, for example to take a parenting class like this one.

Read more on the Swedish Social Insurance Agency's website under "If the child has a disability" to learn what applies for you and your child.

You can apply for practical support and various initiatives from the municipality in accordance with the Social Services Act, and in accordance with the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS).

You apply for initiatives in the municipality or neighbourhood where you live and there is in fact no limit to what you can apply for. This might involve support for you as parents, but also initiatives for the child, for example to help improve independence.

When you apply for initiatives from social services, they are obligated to investigate quickly. They always conduct an individual assessment and after that you will receive a written decision.

Social services can also offer support and initiatives that support you as a parent. Read more about what applies where you live on your municipality or neighbourhood's website.

BUP can offer guidance and support for parents, as well as treatment for your child. For example, a parenting class like this one, contact with an occupational therapist, or medical or psychological treatment for your child.

Parents and children can also receive help and support from various associations and organisations.