

Brief facts on Autism

in children and young people

Regional assessment clinic



Contents

This information is intended for guardians of a child or teenager who has undergone a neuropsychiatric assessment at the Regional assessment clinic and has received a diagnosis of autism.

This brochure describes in brief:

- What is autism
- Autism diagnosis
- Causes of autism

What is autism

All children are different. This is true of children with and without autism. They also develop and mature at different paces. The ability to control your behaviour is important for independence and for being able to function with others.

Even if we understand that children have differences, as a parent you might become worried or concerned if your child differs too much from other children their age. You might also wonder why their behaviour is so difficult to influence the usual way, for example through prompts and reprimands.

Your child needs to have self-control, for example to concentrate on a task they did not choose, to follow instructions and rules, or to let others speak without interrupting.

Expectations that the child can manage such things will go up as they get older, and part of parenting is equipping your child for greater independence. Because all children are different, different things are also required of different parents to do this.

Autism may be an explanation for a child struggling to control themselves. Autism is a condition that involves significant problems creating, participating in and understanding/being understood in social contexts. In

addition, autism involves a need for patterns and routines and a limited ability to handle new impressions in the moment. People with autism therefore tend to prefer predictability and clear structures.

Autism involves changes in the brain that produce symptoms in several important areas that are linked to cognitive abilities, that is, how the brain receives, processes, stores and produces information. Our cognitive abilities help us to plan and organise our work in the short and long term, evaluate results, solve problems and make decisions.

As previously mentioned, all children have unique personalities that impact how their disability is expressed and what consequences it has. How much of an impact the diagnosis has on a child's daily life also depends on their environment, which means their challenges may look different and vary as they grow up.

Autism can be an asset in some situations, especially when the child gets to choose their activity. But it can also often mean the child struggles to handle many demands of daily life, especially at school.

Autism is not a disease and has nothing to do with intelligence. Rather, it is about a person functioning differently than might sometimes be expected in daily

life. Autism does not only bring challenges, but can also be described in terms of strengths. For example, people with autism are often honest, logical and good at thinking outside the box.

Most people with autism learn to compensate for their challenges by intentionally thinking of and using learned strategies in social situations. For people who do not have autism, this almost always happens automatically, through social intuition.

Intentionally thinking about this in every context requires a great deal of mental energy and can create anxiety, which means that people with autism often need more rest than others might after spending time with people or doing new things.

Many highly functioning adults with well-developed language skills learn to hide their restrictive and repetitive behaviours, but intense special interests can also be a source of joy and success. They can provide positive opportunities in education and careers later on for some individuals. Often, people who showed clear challenges in these areas as children no longer do as adults.

Autism diagnosis

Autism is a diagnosis of symptoms. That means the diagnosis is based on the symptoms you have, not due to having something “wrong” inside your body.

Stringent diagnosis criteria must be met in order for a child to be diagnosed with autism. This is because children can function in many different ways, without it necessarily meaning the child has a diagnosis.

For a child to be diagnosed with autism, they must have significant difficulties relative to their age. They must have difficulties in the previously mentioned main clusters: social interaction and restrictive, repetitive behaviours. How these symptoms are expressed in reality is described on the next page.

The challenges need to have been present for a long time and produce such significant daily problems that they constitute a disability. The challenges should also be evident in multiple environments, for example at home and at preschool or school.

Social interaction

Social interaction and social communication difficulties with autism should be apparent in the following three areas.

Social reciprocity

Social reciprocity refers to the ability to interact with others and to share thoughts and feelings. Already in young children with autism, this presents as little to no initiative taken to interact, not sharing feelings with others, and less frequent or no mimicking of others' behaviours.

Children who speak often use language in a more one-sided and less reciprocal way. For example, they name and ask for things, instead of talking about and sharing feelings and experiences with others. Adults and teens with developed language may find it hard to know how and when to start a conversation. It can be hard to know what is and is not appropriate to say at different times.

Non-verbal communication

Non-verbal communication is communication conveyed without words. This could be body language, gestures or facial mimicry. In young children, lack of non-verbal communication presents through not pointing to, showing, or going to get something to

share their interest. In very young children, this often shows up as using others as tools to achieve something – for example, taking someone’s hand and placing it on a jar to have it opened, or pulling someone with them in order to have something taken down from a shelf.

Create, maintain and understand relationships to others

Social interest may be limited, but also unusual or lacking. This can be especially clear in young children. For example, it might present through the child not engaging in flexible pretend play with others, or doing so less than expected. Many preschool-age children play all by themselves or play their own game, but side-by-side with other children. Slightly older children may play with others. In that case, the other children often need to follow very specific rules for how to play the game.

Young people and adults often struggle to understand how to behave with others in different situations. Maybe they prefer to do activities on their own or to spend time with much younger or much older individuals. Many want friends, but don’t really know what friendship involves or how to make and keep friends. Of course, there are also many young people with autism who have friends, but even for people with functioning relationships, socialising often

demands a huge amount of mental energy and can be exhausting.

Restricted and repetitive behaviours

To receive an autism diagnosis, a propensity to do things in a restrictive or repetitive way must be apparent (or have been apparent) in at least two of the following areas:

Repetitive or stereotyped behaviours of different kinds

For example, this might be flapping hands or wiggling fingers, or using objects in a repetitive manner (spinning, lining up), or using language in a repetitive and unusual way (stereotyped use of words, phrases, or tones, pronoun confusion, echolalia, i.e. immediately repeating what someone else last said).

Many people with autism may prefer to express strong emotions through movement rather than sounds and words – for example, by waving their hands instead of laughing or cheering.

Strongly bound to routines and resistant to change

Some may be disturbed by minor changes to routines and daily schedules, or to how certain things should be done, for example. This might involve a strong sense of routine and adhering strictly to rules. It could also be speaking and thinking in a nearly ritualised way, with little room for variation, for example, asking the same questions over and over, despite knowing the answer, or having a long bedtime story with many details that must be told each night.

Fixation on restricted interests that are unusual in intensity or focus

The intensity is the primary factor that is uncommon, but the interest itself may be unusual as well. A child could become fixated on toilet seats, vacuum cleaners, or special toys, for example. A teenager or adult might have a strong interest in a specific subject. Sometimes these interests are unusual for their age, but sometimes it might be a very common interest with an unusual expression – for example, a child interested in hockey might learn not only the team rankings throughout the years, but the players' individual stats as well.

Unusual reactions or interests associated with smell, touch, sight and sound

This could be excessively smelling or touching objects or surfaces, fascination with things that spin or sparkle, etc.

Some people may be hypersensitive or hyposensitive to different sensory impressions. For example, they may react to certain common sounds with severe discomfort, or be noticeably sensitive or insensitive to heat, cold, or pain.

It is not unusual for the same person to be both hypersensitive and hyposensitive at once – for example, to not feel when they have hurt themselves, but to also experience pain from water droplets in the shower, or to be disturbed by what others might perceive as an essentially undetectable noise, but to want to have the TV turned up to an extremely high volume.

Very strong reactions and routines like this are also often associated with restrictive and atypical food habits – if you are unusually good at noticing smells, tastes and consistency, then it may be hard to find something to eat that smells and tastes good, and also feels good in your mouth.

Other common concurrent challenges

It is common for the child to have other simultaneous struggles. Some examples of common challenges include dyslexia, learning difficulties, oppositional defiant disorder, trouble sleeping and ADHD.

Functioning differently from other children their age can negatively affect confidence. Some children and young people with autism feel like they are different and may experience anxiety and depression.

It is important that the child is treated with respect and understanding of the challenges they face. The child's challenges do not mean they are not trying, nor are these problems related to upbringing. A disability does not make a person "disabled" – rather, inadequacies in the environment create obstacles to functioning. It is therefore incredibly important for the people around your child to understand them well and to seek out information in order to bypass these inadequacies and to support the child in daily life.

Not being treated properly, insufficient adaptations, or too little time for recovery can often lead to issues with mental health, such as anxiety or depression.

There is no individual cause of autism. There are likely several causes, where both genetics and the environment are probably significant.

Causes of autism

How common is autism?

The behaviours and functioning that we associate with autism have probably always existed, but in recent years, more people than before have received this diagnosis. The increase is likely due mainly to the fact that knowledge about autism has increased among parents, schools and the medical system. Because the diagnosis only exists in relation to the environment, the evolution of society also plays a significant role in the fact that more people are diagnosed with autism today. Demands for independence and flexibility differ today from what they were only 25-30 years ago, both at school and at work.

Just over 1 percent of school-age children are estimated to have autism. Many still have symptoms as adults, but learn to handle the challenges or are able to choose settings in which their difficulties become opportunities.

Girls and boys with autism have similar basic problems and equally impactful disabilities.

Mostly boys receive a diagnosis of autism in childhood, but the difference between the genders shifts with rising age, as more women receive the diagnosis as young adults and adults. The fact that girls are diagnosed later than boys may be because knowledge of how autism expresses in girls at the group level is too limited among school staff and medical professionals. Either the challenges go unnoticed or they are misinterpreted. Girls are also sometimes very skilled at hiding their challenges. Parents often see girls' problems more clearly.

In conclusion – as you begin

Your child has now undergone a neuropsychiatric assessment and has received an autism diagnosis. The purpose of the assessment is to understand your child's unique strengths and what will be difficult in daily life, in order to best understand, help and engage with them.

Receiving a diagnosis can be overwhelming, completely obvious, and everything in between. Most children and young people learn over the years what helps them and find good strategies, but probably need support both from you and from the school on their way there.

For tips and advice on how you can continue to work on this, please see the leaflet "Self-care, support and treatment".