



Autism Spectrum Disorder

hilft,
vermittelt und
verbindet

autismus

deutsche schweiz

Verein für Angehörige, Betroffene und Fachleute

Autism Spectrum Disorder

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“Autism is a blessing AND a curse. I notice beautiful things, like the crawling beetle in the grass, but not that the meadow on which the grass grows is a football field.”

Andreas, adolescent with autism



Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) and its typical symptoms

The term “autism” originates in the Greek language and means “to be self-centered”. Leo Kanner and Hans Asperger used it for the first time in 1943 and 1944, respectively, for children with profound developmental problems. The challenges autistic children, adolescents and adults face can vary widely in everyday life. Similarities can be seen, but also major individual differences. That is why one speaks of the autistic spectrum.



Is autism a disease, a disorder, a disability or a variant of human perception, feeling and thinking?

There are characteristics or symptoms for which specialists recognize a need for treatment or support and for which a great deal can be achieved with specific therapies and social training. Autistic people defend themselves against a negative image of autism. The impact of the symptoms on the everyday life of an autistic person plays a major role in the diagnosis. In this brochure, we assume that most of the children and adolescents with autism are delayed in their development and / or have great difficulties in everyday life. We use the term autism spectrum disorder (ASD), which is common today, and speak of symptoms, signs and challenges. At the same time, we know and value the strengths of autistic

*Most of the statements in the brochure apply to children, adolescents and adults. To keep the text simple, not all groups are always mentioned explicitly. The statements always apply to all genders.

people and are convinced that they make important contributions in all areas of society.

How do autistic people differ from unaffected, “neurotypical” people?

The signs of autism can be divided into two main groups:

- **Social symptoms** – e.g. limited social motivation and difficulties with social rules and concepts, limited verbal and nonverbal communication, problems empathizing with others or to read facial expressions.
- **Non-social symptoms** – e.g. restricted interests, repetitive behaviour, attention to detail, sensory hypersensitivity.

For diagnosing autism, clear signs must be present in both areas. The severity of the symptoms varies from person to person and may change over time.

The child psychiatrist Leo Kanner has described children in whom autistic symptoms were already evident in infancy or early childhood. These children often show

little interest in their counterparts. They do not seek eye contact, do not smile back, hardly respond to parental voice and do not “cuddle” like other children. They do not try to attract their parents’ attention or to guide them to the objects of their interest. Their language skills might be limited. They are often occupied with the same objects, for example turning the wheels of a toy car over and over again or lining up things. When excited, they may display noticeable or idiosyncratic hand and / or body movements. They are often hypersensitive to certain sounds. Their general development is often delayed. Children showing these signs of autism are diagnosed with “early childhood autism”.

The paediatrician Hans Asperger in Vienna noticed a different kind of children. They were older, had good language skills and intelligence, but had problems taking on other people’s perspectives and playing or studying with children in a group. They often had distinct interests, e.g. for data or timetables, and a great deal of knowledge

in their specialist areas. The diagnosis “Asperger’s Syndrome” was chosen for this form.

Very important:

The challenges described here can be seen in different ways and their impact on an autistic person’s everyday life can vary immensely. Moreover, no person with ASD has all the characteristics mentioned here. When difficulties are very pronounced, they usually show up early in life. These children may then be diagnosed with autism at the age of 2 to 3 years. If the characteristics are less apparent, they are often only noticed later by those around them or by the adolescent or adult themselves. The diagnosis is then sought in adolescence or adulthood, often later for girls and women than for boys and men.

Children with ASD who did not fit into either of these groups were diagnosed with “atypical autism”.

Until around 1980, the diagnosis of autistic disorder was only made in children who corresponded to the image of “early childhood autism”. Children with Asperger’s Syndrome and Atypical Autism are also included under the new concept of autism spectrum disorder (ASD). Therefore, an autism diagnosis which used to be rare has become much more common since then. Recent studies show that around 1% of all people are affected by ASD. Some studies from the USA provide significantly higher numbers.

Let’s have a look at some of the symptoms of autism

There are different models that can be used to explain the social and non-social aspects of ASD.

The social domain:
Neurotypical babies are highly responsive to their parents and significant others

in their life. They respond to looks, voice, smiles and touch. Autistic babies show much less of this social motivation. Interpersonal contact seems to give them little pleasure. Sometimes they even seem to avoid it. As a result, they have fewer social experiences and lag behind in their development early on.

Even very young children can perceive the emotions of others and adapt their behaviour. For example, they sense when their parents are afraid or angry in a situation.

In general:
The causes of autism spectrum disorders have not yet been fully understood. Several factors certainly play a role in the development. Genetic and environmental influences before, during or after the birth can affect the development of the brain and trigger the «autism spectrum disorder». It has been proven that this does not arise from poor upbringing or family conflicts.

With increasing age, children can also empathize with other people, put themselves in their place and adopt their perspective. These skills are of great importance for any form of communication and interaction. Autistic people struggle with this. They often misinterpret other people’s behaviour, which can lead to misunderstandings.

The non-social domain:
Almost all people with ASD are hypersensitive to certain stimuli. These may be specific sounds such as church bells, vacuum cleaners, children’s screams, loud bangs, a babble of voices or noise in general. Some have difficulty with bright light or a specific smell (such as food or perfume), while others are very sensitive to touch. Some cannot touch slippery or sticky things, cannot tolerate certain consistencies of food or are irritated by clothing labels or tight pants. Despite this, many people with ASD seek sensory stimuli to relax and calm themselves, to distract themselves or to stimu-

late themselves in boring moments. Children in particular may look at objects that spin or glitter. Others touch surfaces or tap on them.

Leo Kanner had mentioned in his article that autistic children are afraid of new



things and prefer to keep everything the same all the time. However, this fear of the unexpected or of program changes is also present in autistic adults. They stick to familiar procedures and aim to always do everything the same way. This is how they

try to protect themselves from surprises and new demands and reduce stress in everyday life. Usually, neurotypical people can analyse and understand a new situation rather quickly. This enables them to adjust to the new demands immediately. People with ASD first register various details but do not recognize the context and then do not know how to act. However, this perception for details can also be an advantage. Autistic people may recognize details that others overlook and can therefore perform certain tasks with particular care. They often also have an extremely good memory for details. People on the autism spectrum often orientate themselves strongly towards rules or structures. Their thinking is often “black and white”. Something either is right or wrong. They find it difficult to compromise. These non-social signs are also known as autistic perception or autistic thinking.

The Term “Autism Spectrum Disorder”

Many studies have shown that specialists generally agree when an autism diagnosis should be made, but opinions often differ with regard to the sub-diagnosis (e.g. early childhood, atypical, Asperger's). The American autism specialists have therefore decided to only use the diagnosis “autism spectrum disorder” (ASD) in their DSM-5 diagnostic system. In order to describe the individual with autism more precisely, it is recorded whether an ASD is present with or without a speech / language disorder, mental impairment or, for example, epilepsy. The severity of the autistic disorder is described in terms of the person's need for support (low, medium or high). The ICD-10 diagnosis system used by the World Health Organization and in Switzerland will probably be replaced by the ICD-11 in 2022 and is likely to closely align with the latest edition of the American Diagnostic and Statistical Manual (DSM).



The other side of autism

So far, most of the information has been about the difficulties and challenges that autistic people face in everyday life. However, they also have **many strengths**.

People on the autism spectrum are usually honest, open and direct in their communication. Ulterior motives and lies are foreign to them. If they are interested in a topic or activity, they can delve into it with great enthusiasm and perseverance and acquire a lot of knowledge and great skills. They carry out related activities conscientiously and with concentration. Work that requires precision and a sense of detail is particularly suited for many people with autism.

If they also succeed in integrating a special interest into a training program and a profession, the chances of successful professional development are very high.



Recognizing Autism Spectrum Disorder

The Diagnosis

Usually it is the parents who are concerned about the development of their child or adolescent and who have the impression that “something is wrong”. However, it can also be the case that professionals who see the child in a group are the first to express a suspicion. Adolescents and adults sometimes suspect themselves that they might be autistic, e.g. if they have found relevant information or questionnaires on the Internet. When a child is diagnosed, parents sometimes discover similar traits in themselves.

There is no specific test that can be used to diagnose an autism spectrum disorder. The diagnosis is based on detailed information about a person’s development and current condition and behaviour. In the case of

children, this is primarily done by speaking to the parents or specialists who know the child from day care, school or therapy. In the case of adults, the parents should also be asked about the development, if possible. The autistic person must provide detailed information about his or her past and current life. If available, close friends or life partners can be included in the process.

In the case of children, structured observations of play complement the investigation. It is often helpful to experience the child in a group situation. In the case of adolescents and adults, in addition to content-related statements, aspects of non-verbal communication, reciprocity in conversation and social understanding are analyzed. In order to be able to make a reliable diagnosis, specialists must have undergone



◀ *Even in the case of a suspected diagnosis, no time should be wasted unnecessarily and targeted support measures should begin as early as possible.*

specific further training and carry out such examinations regularly. For children with early childhood autism, the diagnosis can usually be made between the ages of 2 and 2½ years. In children with Asperger’s syndrome, the problems usually do not become apparent until kindergarten or school age. In adults, autistic symptoms are sometimes masked by depression, anxiety or compulsions, making the diagnosis more difficult.

Having the correct diagnosis is a requirement for autism-specific support and assistance. The diagnosis can help young people and adults to better understand their problems in everyday life and to find solutions that work for them. Parents, friends and life partners, but also teachers or employers can obtain information about ASD and improve their support for the person on the spectrum.

Every autistic person is different

People with ASD have certain things in common. Nevertheless, every person (whether child, adolescent or adult) is different, and the typical symptoms can also express themselves differently, as shown in the following examples.

Communicating and speaking

Timo cannot speak at all. Clara talks about her favourite topic without interruption and does not notice that she is boring her fellows. Tina repeats words that she has just heard like an echo. Eric likes to talk about the topics he knows a lot about - he seems precocious and others often find him lecturing. Simone always takes a long time to answer a question.

Social interactions

Mike always wants to play the same game and is not willing to listen to what the other children want. Celine cannot tell from

her mother's voice and facial expressions whether she is angry or exhausted. Sandro does not understand the rules of group games and cannot actively participate. Marie doesn't know how to know how to approach someone or start a conversation. Making contact with others
Mia finds it difficult to look someone in the eyes - she prefers to observe out of the corner of her eye. Jonas has no restraints, asks indiscreet questions, even approaches strangers and doesn't realize that you can't just touch them. Sonja does not know how to approach someone, small talk is not possible for her.



“A conversation can sometimes sound like several TV programs are running at the same time.”

Temple Grandin

Hypersensitivity

Sarah is very sensitive to noise - the sound of a vacuum cleaner makes her panic. Certain smells are very unpleasant for Leon. Peter finds shopping exhausting. There are too many people in the supermarket and the lights are too bright. Unexpected touching is uncomfortable for Martin and stresses him out.

Challenges dealing with change

It is very important to Joel that he can always sit in the same seat in the classroom. It is very difficult for Anna when school lessons are spontaneously rearranged. Luis would prefer to eat the same thing every day. Peter always takes the exact same route to reach his destination - e.g. construction sites or detours cause him great stress and insecurity.

Distinctive interests

Felix has little imagination when playing and prefers to turn the wheels of his toy car. Sandra has a preference for complicated puzzles and patience games. Luca's special interest is trains. He spends hours learning everything about them. If a school subject is related to his special interest, Dominique can perform very well. Tim likes to sit in front of the computer for hours, playing games or finding informa-

tion about his special interest. Paul knows all about antique clocks. Lara is fascinated by rotating objects and can watch the washing machine turn for hours. Robert taps on all surfaces and listens carefully to the sounds they make.



Dealing with Autism Spectrum Disorders

Possible help and treatment approaches

“What is the best way to support a person on the autism spectrum?” is the most important and at the same time the most difficult question for parents and autistic people.

The choice of the right support measures always depends on the age and developmental stage of the child and the severity of the autistic symptoms. For young children with early childhood autism intensive behavioural therapy programs have been studied the most extensively. Other intensive early intervention programs are more oriented towards play therapy. All programs have a clear structure, working with the child 1:1 for several hours each day. This is intended to support the child’s development as broadly as possible.

Since the financing of such programs is not yet secured in Switzerland, unfortunately only some families who need support

actually receive it. For many children the focus is therefore put on “heilpädagogische Früherziehung” (early intervention). In addition, depending on the needs of the child, it may be helpful for them to attend speech therapy, occupational therapy and/or psychomotor activity. Older children, adolescents and adults primarily want to improve their social skills. The aim is for them to improve understanding the thoughts and feelings of their fellow human beings and to get along better in groups. They can also learn to develop strategies for coping with difficult everyday situations. Many of these goals are best learned in group settings. In these settings they also experience that they are not alone with their challenges.

However, it cannot just be a matter of making young people or adults with au-

tism “fit for their environment”. The people around them need to acquire autism knowledge in order to make their school, home and work environment more autism friendly. Through small changes to the environment, autistic people are able to use their

strengths and they are less affected by their weaknesses.

In school and training autistic children, adolescents and adults are entitled to adjustments in the form of compensation for disadvantages. In vocational training or at the workplace, the IV offers vocational integration and support measures, for example with coaches who support the autistic individual and advise employers.

For children, adolescents and adults with autism, autism-specific support and/or remedial measures tailored to their individual needs must be implemented. Not only autistic children benefit from targeted programs, but adolescents and adults alike. Social training or occupational therapy can be very useful for them.

The association autismus deutsche schweiz helps, advises and mediates in all questions about autism.



“Life with autism is a miserable preparation for life in a world without autism. Politeness has set up many nooks and crannies that you can step into. Autistic people are masters at not leaving out any of them.”

Axel Brauns

What can relatives and caregivers do?

- Obtain advice and support from specialists
 - Seek contact with other families with an autistic child or adult
 - Recognize, appreciate and promote the strengths of the autistic individual
 - Look for therapies, social trainings and support measures that are tailored to the needs of the autistic individual
 - Create quiet “zones” where the individual can retreat to
 - Be patient, because autistic individuals need more time to express themselves
 - Try to understand the idiosyncratic thought processes and reactions and deal with them sensitively
 - Motivate the autistic individuals to participate in activities and come along, even if they might prefer to stay at home
 - Carefully plan changes and transitions, explain them precisely and implement them step by step
 - Find a school and later an apprenticeship where the person on the spectrum receives targeted support
- Ensure that caregivers, teachers, professionals, authorities and other stakeholders are as well informed as possible and work together
 - Find career counsellors who know enough about autism
 - Help to find a job adapted to their special interests and talents
 - Find a reference person or mentor at the workplace who knows the characteristics of the person with ASD and supports them in case of difficulties
 - Find a form of housing that allows independence and offers assistance
 - Help to find leisure activities that suit the person and bring them together with other people
- **Pay attention to the needs of the autistic individual and provide an autism-friendly environment**



As an autistic person I need ...

10 Things People on the spectrum would want you to know

First and foremost see me as a human being and not as an autistic person

Autism is part of who I am, but it is not all of who I am. If I feel that I am not trusted to do something, I can't try.

Distinguish between "I don't want to" and "I can't"

It's not that I don't want to listen to instructions – I often can't understand them. Approach me directly and communicate clearly. This is the only way I can understand you.

Avoid ambiguous statements

I take everything literally. I do not understand proverbs, puns, allusions or irony.

Listen to me, I am trying to communicate

It's hard for me to say what I need when I can't describe my feelings. I'm hungry, sad or scared and I can't find the right words for it. Observe my body language - the signs of what is going on with me are often visible, try to recognize and understand them.



Use drawings, show me examples - I am a visual person.

Show me how to do something instead of describing it. Visual support helps me.

Focus on what I can do – not on what I can't do

If I constantly feel that I am not good enough, I will avoid learning anything new.

Look for my strengths and remember: there is more than one way to accomplish something.

Help me with social interactions

Explain to me how to play with other children or how to start a conversation. Encourage me to reach out to others.

Have patience

Walk with me through my life and discover with me how far I can go.

Find out what causes my stress or my meltdowns.

When I get too stressed and everything is too much for me, I have a breakdown or may react violently. Help me find out what causes my stress and how to avoid such situations. I often don't fully understand

something and get scared. I might react violently because I can't express myself well. But pain, certain sounds, smells or even touch can also cause an outburst...

Accept and like me as I am

Remember that I did not choose to be on the autism spectrum. It happened to me and not to you. Without your support, my chances of living a successful life are smaller. With your help, my chances of living an independent, successful life are much greater than you may have ever thought...

(inspired by Ellen Notbohm, 10 things a child with autism wishes you knew, 2012)



Autism in Switzerland



There are about 80 000 autistic people currently living in Switzerland. The awareness of this topic has changed a lot in the last 20 years. The Federal Council summarized the most important challenges for autistic individuals and their families in a report. The suggestions for improvement were defined - but they still need to be implemented.

“Today, parents are still forced to find their own way. There are too many gaps and areas where support for autistic people is still missing.”

autismus deutsche schweiz connects parents, autistic individuals and professionals in order for everyone around them to be more aware of their needs. Become a member, too!

Verein autismus deutsche schweiz

A handwritten signature in blue ink, appearing to read 'R. Odermatt'.

Reto Odermatt, President



Autistic people need support and commitment.

Founded as a parents' association, today autismus deutsche schweiz is the official autism organization recognized by the Federal Social Insurance Office. The association is a network for parents, relatives, autistic individuals, and autism specialists. It offers fast and non-bureaucratic support and advice and raises awareness. The association organizes conferences and workshops and autism-friendly events. In addition, autismus deutsche schweiz is involved in politics and society so that people on the autism spectrum can be understood and supported as best as possible.

Becoming a member or making a donation enables autistic people to live a more stress-free and self-determined life.

Donation account PC 80-52832-2

www.facebook.com/autismus.ch, www.autismus.ch

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