A guide on autism spectrum disorders for families

This booklet is intended for families with a child recently diagnosed with an autism spectrum disorder.
What does autism spectrum mean?

In the WHO’s International Classification of Diseases (ICD), autism spectrum diagnoses are included under pervasive developmental disorders. The autism spectrum includes:

- autism
- Asperger’s syndrome
- childhood disintegrative disorder
- pervasive developmental disorder
- Rett’s syndrome

Autism spectrum disorders (ASD) are neurobiological developmental disorders of the central nervous system. According to current information, the diagnosis will be redefined in Finland in 2018. Following the change, all autism spectrum syndromes will be covered by the joint term **Autism spectrum disorder**. The term autism spectrum is, therefore, used in this guide.

Attention is often drawn to the characteristic features of the autism spectrum when a child begins to learn to speak or to practise social interaction skills.

The characteristic features of the autism spectrum include both functional impairments and strengths. These features vary from one person to another and in different contexts. The individual need for support also varies a great deal: some people may not need any support at all, some may need it occasionally and some throughout their lives.
THE CHARACTERISTIC FEATURES OF THE AUTISM SPECTRUM INCLUDE:

- unusual sensory responses, over- and under-sensitivity
- unusual or deficient social interaction and communication skills
- deviant way of understanding and perceiving the meaning of things and one’s surroundings
- difficulties with executive functioning
- special interests
- restricted or stereotypical behaviour.

Autism spectrum disorders are lifelong conditions, but their characteristics often vary at different times of life. Autism spectrum disorders are found worldwide, according to different studies in about 1% of the population. However, every day, the condition touches a much larger part of the population, including family members, relatives and professionals in various fields.

Autism spectrum diagnoses are more common in boys than girls. There may be several reasons for this, one of them being that the characteristics manifest themselves differently in girls and have not been identified before. The causes of the disorders may be varied and often remain unknown. A bad upbringing is not a cause of the disorders. The autism spectrum may be hereditary and thus several members of the same family may have an autism spectrum diagnosis or features of the disorder.

An autism spectrum disorder is usually diagnosed by a specialist together with other professionals. The examinations focus on evaluating the child’s behaviour. Confirming the diagnosis may be a long process and methods vary in different regions of Finland.
Rehabilitation

The aim of rehabilitation is to promote and enhance the child’s independence. This means practising skills and activities in the everyday environment. Each child has individual rehabilitation needs. The aim is to increase participation and to achieve a functioning everyday life, so that a child with an autism spectrum disorder can live as full and independent a life as possible in future. Rehabilitation, however, does not remove the ASD features, but rather supports the child’s overall development.

Early rehabilitation means autism rehabilitation which is started as early as possible. Early rehabilitation consists of individualised measures planned with regard to the child’s age and development levels with the intention of supporting the child’s development and coping abilities in everyday life. Early rehabilitation usually aims at teaching skills typical of the child’s age group and necessary for functioning in different environments. Early rehabilitation is based on information provided by the parents and obtained from the examination of the child. Rehabilitation is carried out by various professionals in cooperation with the parents, school or day-care centre.
Children with an ASD often have special traits relating to the senses. A sense may either be excessively sensitive or function extremely poorly. Sensory sensitivity may, therefore, be either over- or under-sensitivity and may vary even in the same person in different situations. A child may be under- or over-sensitive to sound, light, touch, pain, cold, hot, odours, flavours and other sensory stimuli. Monitoring the child’s functioning and behaviour can help in understanding how the child’s sensory system works. It is important to learn to identify the sensitivities and to take them into account in daily life. The sensitivities usually increase when the child is tired or stressed.
Communication and social interaction

Children with an autism spectrum disorder may have varying degrees of difficulty in producing or understanding speech. All are not necessarily able to communicate with speech and some may find it difficult to express their opinions. Difficulties may also arise in social communication where, for example, the literal interpretation of words and expressions can cause misunderstandings.

Some children with an ASD need so-called augmentative and alternative communication methods to supplement or replace speech. It is important to find a suitable communication method individually for each ASD child, by means of which they can express themselves and be understood in different environments. Communication can be supplemented with pictures, signs, plain language, writing, computer programs and various technical devices, such as communicators. Learning and enhancing a personalised communication method forms a part of the rehabilitation of children with an ASD.

An ASD may also make it difficult to interpret and understand other people’s body language and facial expressions or what other people think or how they feel. Children with an ASD can, however, learn these skills, for example, through social stories and practice.

Structuring

Children with an ASD often need support to be able to manage their environment and their own actions. For children with an ASD, learning is supported through the clear structuring of time, place and activities. A structured environment and guidance form a part of the rehabilitation of children with an ASD.
STRUCTURING MEANS CLARIFYING AN ENVIRONMENT BY USING PICTURES, TEXT, COLOUR CODES, RESTRICTED AREAS OR OTHER SIGNS. THEY INDICATE, FOR EXAMPLE, THE FOLLOWING:

- what will be done
- where it will be done
- who will be doing it
- for how long it will be done
- what will be done after the activity

Structuring may also mean breaking down an activity into smaller parts. The most common example of structure is a daily schedule with pictures. The schedule helps children with an ASD to organise their activities and to feel secure. Structuring enhances the learning of everyday skills and coping independently.

**Difficulties with executive functioning**

Children with an ASD may find it difficult to control their actions. It may be difficult for them to comprehend how long an activity lasts, in which order things are best done, and how much time has elapsed during the activity. Difficulties with executive functioning can often be affected by structuring and predicting. A child may need instructions for both repetitive daily routines and new situations. With the help of the structure, the child has the opportunity to learn to cope increasingly more independently in everyday life.
Challenging behaviour

Challenging behaviour is often defined as behaviour which the people around a person find disturbing, harmful or dangerous. Children with an ASD may have challenging behaviour – or behaviour interpreted as such. The reasons for challenging behaviour may include deficient communication skills, unusual sensory responses, difficulties with executive functioning, lack of structure, difficulties in social interaction, stress, insecurity, changes, transitions, etc. It is important to analyse the reasons for and the events preceding the challenging behaviour in order to be able to learn an alternative way of dealing with the situation together with the child. Influencing challenging behaviour often also requires making changes to the environment and procedures. The changes aim to influence the situation in such a way that the child will not have to resort to challenging behaviour and is given the opportunity to learn alternative ways of acting. Intervening in challenging behaviour often requires support from rehabilitation professionals.

Routines and rituals

Rituals, routines and restricted interests are common in children with an ASD. Routines give these children a feeling of security. Changes in daily activities are a cause of anxiety to many. Certain regularities and routines help the child to prepare for different procedures and events.

Ritualistic behaviour may also be a child’s way of coping with a situation and of experiencing pleasure. Such behaviour may be, for example, repetitive body movements, rocking, hand flapping or walking on tiptoes.
Sleep

Problems falling asleep and sleeping issues are fairly common in children with an ASD. They may have a lesser need for sleep or difficulties in identifying tiredness. A regular evening routine, a sleeping environment which stimulates the senses as little as possible or, for example, a heavy blanket may alleviate the child’s sleeping problems.

Eating

Eating problems may be due to unusual sensory responses. The sensations in the mouth or the smell, taste, colour or composition of food may be insurmountable obstacles to eating for a child with an ASD. The best results in alleviating problems related to eating are usually obtained by rewarding and not by forcing. It is quite common that a child with an ASD does not want different foods to be mixed together, but rather that all the different foodstuffs are placed separately on the plate. Sensory problems relating to eating may vary in different situations and change with age.

It is important to discuss the challenges, difficulties and successes faced in everyday life with the professionals responsible for rehabilitation. Finding the correct procedure may take time and the parents’ experience and knowledge of the child is valuable information to the professionals.

For further information:

THE FINNISH ASSOCIATION FOR AUTISM AND ASPERGER’S SYNDROME
www.autismiliitto.fi
Support and services
The forms of support are always determined individually. Support should be tailored according to the child’s needs and not on the basis of the diagnosis (needs-based support).

Public healthcare is responsible for drawing up a rehabilitation plan. Normally, the body that has examined the child draws up the rehabilitation plan together with the parents, therapists and, for example, the day-care centre or school.

Drawing up a service plan is the responsibility of the local authority, but the initiative is usually taken by the family, which is in contact with the local authority’s social services. The services needed by the family are entered in the service plan. The plan is binding on the local authority and no decisions deviating from the plan may be made without just cause.

For further information on rehabilitation and service plans: www.thl.fi

Disability allowance granted by the social insurance institution of Finland (Kela): The Disability Allowance for persons under 16 years of age is intended for children with a long-term illness or disability. A condition for being granted the allowance is that the child needs treatment, care and rehabilitation for a minimum period of six months to such an extent that it requires a greater commitment from and imposes a greater strain on the family than caring for a non-disabled child of the same age.

The diagnosis of an illness or disability does not alone determine a child’s entitlement to disability allowance. The entitlement to the allowance and the amount of the allowance are determined on the basis of the extent of care, attention and rehabilitation the child needs (Kela 2016). The child and the family are eligible for different therapies and rehabilitation, for example, in the form of a family support course. In addition to Kela, a commitment to pay for rehabilitation may also be granted by health centres and local authorities.

For further information contact your local social services department (service counsellor or social worker) or Kela at www.kela.fi

Free legal advice is offered by Jukka Kumpuvuori on Mondays to Sundays from 5 pm to 6 pm, at tel. 050 552 0024.
## Service Helpline

Offers guidance and information on rehabilitation, education and social security on Mondays to Thursdays from 12 AM—3 PM at tel. 050 467 3130 and by email at palveluneuvonta@autismiliitto.fi.

## Good Start Peer Support

Peers offer support to families in which a member has recently been diagnosed with an ASD. Good Start peers are the right persons to contact when you have not yet found a suitable peer support group and want someone with the same experience to listen and talk to. The Good Start peers are volunteers trained by The Finnish Association for Autism and Asperger’s Syndrome.

To contact a Good Start peer, please fill in our web form at www.autismiliitto.fi/vertaistuki

or contact us by email at arjessa.alkuun@autismiliitto.fi

## Member Associations

Offer members peer support, organise events, provide training and share expertise on the autism spectrum. The associations operate on a voluntary basis and there is regional variation in the activities organised. As member benefits, members receive the Autismi magazine and are eligible for reduced fees for training events organised by The Finnish Association for Autism and Asperger’s Syndrome.

For more information about the member associations see: www.autismiliitto.fi/jasenyhdistykset

## Peer Families

Peer families offer support when you want to talk through big or small problems or feelings or just share your thoughts. They are the right people to contact when you are wondering how to cope with everyday life or when you want to share good experiences. The peer families are volunteers trained by The Finnish Association for Autism and Asperger’s Syndrome.

For peer family contact information see: www.autismiliitto.fi/vertaistuki
The Finnish Association for Autism and Asperger’s Syndrome promotes autism awareness through its activities

THE MISSION OF THE FINNISH ASSOCIATION FOR AUTISM AND ASPERGER’S SYNDROME

The Finnish Association for Autism and Asperger’s Syndrome promotes and safeguards the interests and equality of people on the autism spectrum and their families in society.

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