One in a Hundred is on the Autism Spectrum

– Information about ageing with autism spectrum disorders for the social and health care field

Autismi- ja Aspergerliitto ry
One in a Hundred is on the Autism Spectrum

Why is the term autism spectrum used?

The autism spectrum disorders (ASD) are neurobiological developmental disorders in the central nervous system. The spectrum includes a number of different diagnoses. At the moment, this cluster is considered to include autism, Asperger syndrome, Rett syndrome, disintegrative disorder, and pervasive developmental disorder (so-called atypical autism). Diagnosing the autism spectrum is going through a change: after 2018, the overarching umbrella diagnosis used will be “autism spectrum disorder”.

According to different studies, approximately one percent of the population* is on the autism spectrum and the number of diagnoses is growing. Based on this, it can be estimated that there are 54,000 people on the autism spectrum in Finland. The ageing proportion of the population is growing and, at the moment, there are more than one million people aged 65 years or over. Statistically, one in a hundred of them is also on the autism spectrum.

Many people have heard the words “autism” and “Asperger” and may have thought that these diagnoses are more related to childhood or youth. This, however, is not the case. Autism spectrum disorder is a life-long syndrome that causes individual and varying disabilities.

Many adults and ageing persons on the autism spectrum have not been diagnosed correctly. Their special characteristics may not have been recognized and thus they have not had the opportunity to receive the necessary support and rehabilitation.

This guide provides information about the special characteristics related to the autism spectrum, the prevalence of the autism spectrum, and how to proceed if you come across an ageing person on the autism spectrum in your work. This guide uses the terms “autism spectrum person” and “autism spectrum people” to describe the whole autism spectrum.

Characteristics of the Autism Spectrum

The autism spectrum disorder manifests itself uniquely on each person on the spectrum. There are, however, some visible and recognizable characteristics in the behavior of all autism spectrum people. Autism spectrum people typically have difficulties in three areas, but for all of them, the characteristics manifest uniquely.

Some autism spectrum people live independent lives, either without support or with very limited support, whereas others require specific support throughout their lives. The specific characteristics can be thought as forming the visible top of an iceberg. Behind these visible difficulties, there are varying neurocognitive debilitative factors which account for the visible behaviors.

Specific difficulties both manifest themselves uniquely in autism spectrum people as well as affect their ability to function. The Asperger syndrome is one of the diagnoses of the autism spectrum. The Asperger people are often near or above the average intelligence of the population. They have less difficulty in producing speech, but may find it hard to interpret the speech, expressions or gestures of other people. Rehabilitation can have a positive effect on these difficulties and lessen their effect on the person’s life.
All autism spectrum people have difficulties of varying degrees in the following areas:

Social Interaction
Autism spectrum people find it more difficult to understand other people’s emotions and to express their own. This may, for example, mean difficulties in establishing friendships or relationships required in working life. An autism spectrum person may have difficulties in establishing eye contact or they may react unusually with expressions and gestures. In working and student life, using free time outside actual tasks for social interaction may be challenging.

Social Communication
Autism spectrum people have varying degrees of difficulty understanding and producing both verbal and non-verbal communication. An autism spectrum person may interpret spoken and written language very literally and may not recognize sarcasm, for example. The person’s expressions or gestures may be unusual when talking to other people and they may have difficulty both processing and remembering the discussed matter.

Social Imagination
An autism spectrum person has difficulties in perceiving different situations outside their own range of experience. This complicates adjusting to new situations and interpreting the behavior and actions of other people. An autism spectrum person may find it difficult to place themselves into another person’s situation and to perceive other person’s feelings.

In addition to these, autism spectrum people may express sensory hypersensitivity or hyposensitivity related to, for example, sounds, smells, tastes, lights, colors, and touch. These sensory characteristics are estimated to affect up to 90% of autism spectrum people. The most easily identifiable are the sensitivities related to sight and sound. Hypersensitivity and hyposensitivity may even manifest within the same sensory area and they may vary substantially throughout the person’s life, even daily.
Sensory characteristics (hypersensitivity and hyposensitivity):

<table>
<thead>
<tr>
<th>SENSORY CHARACTERISTICS</th>
<th>HYPERSENSITIVITY (examples)</th>
<th>HYPOSENSITIVITY</th>
</tr>
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<tbody>
<tr>
<td>Sight</td>
<td>Avoids bright, flashing lights; Abundance of color or items causes anxiousness; Items or other things moving toward the person may cause anxiety</td>
<td>Seeks strong visual sensations</td>
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<tr>
<td>Sound</td>
<td>Certain audio frequencies are unpleasant: drills, sound of machinery and lighting, people’s voices (buzzing, humming, rustling); Sudden and loud noises (dogs barking, children crying, clapping); Multiple simultaneous sounds</td>
<td></td>
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<tr>
<td>Taste</td>
<td>Avoids sour tastes, strong spices, and unfamiliar tastes. Note: Texture, color, and smell are also important in food</td>
<td>Seeking strong sensations (chili, spicy foods)</td>
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<tr>
<td>Smell</td>
<td>Avoids strong smells and scents in the environment (people, foods, animals, nature)</td>
<td>Favoring strong smells (incl. so-called unpleasant smells)</td>
</tr>
<tr>
<td>Touch (surface and internal sense)</td>
<td>Touch, seams on clothing, materials, zippers, wash tags, socks, hair care, and showering are unpleasant. Sensitivity to pain</td>
<td>Especially pursuing sensations related to internal sense; Difficulty in recognizing pain</td>
</tr>
<tr>
<td>Proprioception and sense of balance</td>
<td>Motor clumsiness; Avoids high places, uneven ground; Escalators and elevators cause anxiety</td>
<td>Seeks movement, for example, rocking constantly</td>
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What Causes Autism Spectrum Disorder?

Autism spectrum disorders have both genetic and physiological contributing factors. Autism spectrum disorder shows multifactorial inheritance, but it is also affected by events that occur during fetal development. Autism spectrum disorder is not caused by dysfunctional parenting, bad upbringing or other such factors. Autism spectrum disorder is a permanent characteristic, but rehabilitation and an environment that supports the ability to function can have a significant effect on the wellbeing and coping of an autism spectrum person.

Autism Spectrum Diagnoses

Autism spectrum disorders are usually diagnosed by a multi-professional group using various symptom lists related to screening and evaluating, structured interviews, and observation metrics. The most important areas related to diagnoses are communication, social interaction, and areas of interest. The person’s complete developmental history is considered during the diagnosing process.

How to Identify Ageing Autism Spectrum People?

Diagnosing the autism spectrum has become more prevalent within the last few decades. Previously, autism spectrum people most likely made up the same percentage of the population as today, but based on symptoms, they were diagnosed with psychiatry or learning disability related diagnoses. Misdiagnoses may have led to incorrect treatment paths and ineffectual rehabilitation. In some cases, autism spectrum people may have been considered somewhat eccentric but actual need for diagnosis has not been perceived. Diagnoses of the autism spectrum have developed a lot during the 21st century, particularly among children and youths. Many adults and especially ageing people on the autism spectrum are still living without correct diagnoses and everyday support.
Autism spectrum people grow old just the same as everyone else. Therefore, it is likely that they are now or will in the future come under the sphere of care and services for the ageing. The autism spectrum covers a varying and diverse group of people; whose autism-related characteristics manifest uniquely with each individual. A typical ageing autism spectrum person is difficult to define. The characteristics related to the autism spectrum are permanent. The same characteristics that manifest themselves in childhood are also present in adulthood, though some adaptation and learning may have occurred.

Ageing autism spectrum people may

- Be reluctant to deviate from usual patterns and oppose change more than is thought normal with age.

- Use unusual eye contact in interactive situations. This may mean avoiding the other person’s gaze or even eye contact which lasts too long and seems uncomfortable.

- Have uneven motor skills. They may either be motorically average or seem very skillful in some respects and quite clumsy in others.

- Use very exact literary language while speaking or have an unusual “tone”.

- Avoid or dislike various social situations, especially when they lack structure. In particular, parties where people mingle and chat seem distressing. This is not related to shyness or timidity.

- Interpret things very literally. This can especially occur with different idiomatic phrases, which can be confusing to autism spectrum people. On the other hand, meanings of phrases may have become known with age, so confusion is often not as apparent as with younger autism spectrum people.
• Express a tendency to get along with or enjoy the company of other than their own specific peer group, such as contemporaries and colleagues.

• Express a larger than usual need or desire to be alone, outside of normal shyness or social withdrawal.

• Possess poor social skills. This may manifest, for example, as reluctance to answer greetings, which can easily be considered rudeness. Similarly, in structured situations, such as meetings and interviews, the person may appear to have much better communication skills.

• In general, be interested and enthusiastic about things that most other people do not consider interesting. These may include repetitive tasks and well-structured meetings. They may in turn try to avoid more informal social situations, such as parties and other events.

• Have a particular interest they wish to focus on. At times, these interests may seem quite unusual to outsiders.

• Have very exact memories of dates and events from their past, including what people said, historical details, etc.
Towards More Autism-friendly Service

Establishing autism-friendly services requires recognizing the autism spectrum people’s special requirements relating to social interaction, the effect of environmental factors, and communication. Successfully targeted small changes can have a positive influence and increase the autism spectrum person’s ability to function. Accessible services are autism-friendly services.

What is meant by autism spectrum and accessibility?

It means, for example:

- Recognizing individuality and accepting diversity. Each person is different.
- Taking into account differing sensory functionality. Many autism spectrum people have unusual sensory responses. These may include hypersensitivity to sounds or smells, for example.
- Using communication methods which support or replace speech. Some autism spectrum people require pictures for communication.
- Structuring. Visual or written daily schedules clarify everyday living.

Accessibility means that everyone is provided the opportunity to function and participate equally with others, regardless of their characteristics. Individuality means that the definition of accessibility also varies between autism spectrum people.
Tips for building autism-friendly environments in communal living

Most of us enjoy peaceful and clear living environments. For autism spectrum people, peaceful living is not just a question of comfort, it is often an absolute requirement. Loud environments are especially challenging to autism spectrum people. The sensory-friendliness of living space is a key factor in increasing the wellbeing of an autism spectrum person.

Group living (group homes, retirement homes, etc.)

The minimization of sensory overload is the most important thing in building and remodeling autism-friendly living environments. People usually favor peaceful and clear living spaces, but for autism spectrum people, clear and disturbance-free living environments are even more important. Noisy environments may be especially distressing to autism spectrum people. Modifying the environment to make it as peaceful and clear as possible is the best way to support an autism spectrum person.

Autism-friendliness in a community

Autism spectrum people may be distressed by changes related to their living environment. For example, springtime and holiday housecleaning with changing the lines may increase the anxiety and lift the stress level of an autism spectrum person. If changes are to be made in the environment, they should be done in a predictable fashion and in a mutual understanding with the autism spectrum person. Autism spectrum people require more privacy; at times, they may be ready to participate in group activities, while sometimes they want to be left alone. They may be satisfied to observe the activity through an open door, for example. Autism spectrum people benefit from being able to withdraw to their own room as necessary or in general be able to leave a space which they consider noisy, for example.
There are neutral, calming, disturbing, and stimulating colors. Colors can be used, for example, to indicate common and private spaces. The resident’s preferences should be followed as much as possible when choosing colors for personal living spaces.

Surface material selection is a significant factor in ensuring the autism-friendliness of a living environment. All sorts of echoes, sharp noises, and rattles may disturb an autism spectrum person to a much larger extent as has conventionally been thought. Even small unnecessary noises (creaky doors etc.) should be fixed without delay.

Shiny and reflective items, such as bright lights, mirrors, glass, etc. may disturb autism spectrum people. Changes and alternatives to these are possible with regard to safety aspects.

Some autism spectrum people may have a tendency to handle objects and surroundings somewhat heavy-handedly. Sturdy and resilient items and materials should be favored.

Tips for ensuring the accessibility and autism-friendliness of a living environment can be found in the accessibility guide compiled by the Satakunta University of Applied Sciences (SAMK):

Routines related to living arrangements

For autism spectrum people, the predictability of things and events is especially important. An autism spectrum person may feel anxiety if daily routines, for example, mealtimes are changed with regards to schedule and location. If these types of changes are to be made for some reason, the autism spectrum person should be given time to prepare for the change and discuss related actions in advance.

Sitting in a certain chair or in a certain place and potentially using the same or similar clothes may be more important to an autism spectrum person than usual. Recognizing and respecting the special need is preferable within reason, without endangering health and safety. Anticipating and discussing the matter in advance will facilitate adapting to changes with regard to this special need as well.

Distributing sufficient information about the autism spectrum in the community is also important for the wellbeing of the autism spectrum person. It may not be enough that the employees and rehabilitation staff are aware and able to interact with the autism spectrum person if the rest of the community expects the person to engage in social interaction equally and does not understand the behavioral special characteristics, such as the sensory characteristics or the importance of routines. Providing information about these special needs must be done in mutual understanding with the autism spectrum person in their terms.

Many autism spectrum people enjoy performing various repetitive tasks. If there is a repeated everyday task, which the autism spectrum person can safely perform, this is definitely something that should be utilized. This may also increase the autism spectrum person’s inclusion as a member of the community.
In private homes

Many of the aforementioned things also apply to autism spectrum people living in private homes. However, private homes are usually already built and decorated according to people’s preferences. In this case, an autism spectrum person may find it hard to throw away a broken item or allow alterations which can increase safety in their residence. Sufficiently anticipating these types of changes and explaining the matter to the person’s satisfaction will enable adapting to these changes. At times, living at home may require accepting outside help (household workers, visiting nurses, cleaning) to support everyday living. This generally means encountering unfamiliar and potentially varying people. Practicing social skills and educating the aid personnel about the autism spectrum person’s special needs are a significant part of ensuring successful interactions.

Tips for contact work can be found, for example, in the guide on contact support for living, published by the Finnish Association for Autism and Asperger’s Syndrome (in Finnish):

ASUMISEN LÄHITUKI AUTISMIN KIRJON AIKUISILLE.

Information about autism spectrum for healthcare professionals (doctors, nurses, paramedics, dentists, etc.) has been compiled below. This information is intended to support encounters with autism spectrum people. Some of this information may also be useful for hospital staff.

At the doctor’s office

When making an appointment for an autism spectrum person, the first or last consulting hour are preferable. Spending time in the waiting room may be exceedingly difficult for autism spectrum people so keeping the waiting time as short as possible will facilitate the success of an examination or procedure.

Waiting in a hospital or health center hallway increases the stress level of an autism spectrum person. Reasons for this may include sensory overload, changes to the schedule, etc. If waiting cannot be avoided, it would be best to find a quiet space where the outside stress can be more easily controlled. If none of the above options are available, it can be suggested that the person and their potential escorts wait somewhere else (for example, in a car or outside) and ask them to return just before the estimated time for the consulting. Even before the actual consulting, it should be made sure that the upcoming situation has been processed with the autism spectrum person in a manner suitable to them, for example, using a social story.

At the doctor’s office, the autism spectrum person could have a communication passport (information about how the person communicates) and information on, for example, how they react to touch and pain (hypersensitivity/hyposensitivity), how they express pain, and information about factors that may increase anxiety.
How to inform an autism spectrum person about a procedure as a patient?

**Always explain who you are, what you are doing, and why.** Show pictures of what is going to happen during the procedure. You can also use other visual aids, such as a doll or another person (escorts are often willing to help with this).

**Use clear and simple language.** Speak in short sentences. Autism spectrum people may interpret verbal communication very literally, so it is best to avoid figurative speech and instead only use concrete language. For example: “this injection will only sting once, no more than that.”

**Make requests as directly and clearly as possible.** For example, instead of ”could you stand up” or ”could you sit down” say ”stand up” and ”sit down”. The autism spectrum person may speak perfectly clearly in your opinion, but they may have difficulty in understanding spoken language. Avoid body language, gestures, and expressions without concurrent verbal instructions as these may not be understood easily.

**Make sure that you receive all the information you require.** Autism spectrum people may not necessarily give you information about themselves if you do not ask for it clearly. Therefore, do not assume, ask!
Examinations and procedures

Examination and procedure situations may be especially distressing to autism spectrum people as patients. In these situations, they have to let unfamiliar people come very close and they may have to expose themselves to unpleasant sensations. Various procedures and, for example, hospital stays can be managed with far less stress if a close relative or friend is there to support the autism spectrum person.

Explain who you are, what you are doing, and why. If the autism spectrum person is accompanied by an escort, ask for their help, especially if the person uses communication methods that support or replace speech.

Do not expect or pursue eye contact, especially if the patient seems anxious. The lack of eye contact does not necessarily mean that the patient is not listening to you. Some autism spectrum people can concentrate better when they do not have to listen and look at the same time.

Provide enough time to process information. Even if the person does not communicate verbally, they may still understand speech.

Autism spectrum people may find it difficult to place themselves in other people’s situations. They may not understand what others are going to do, but might expect others to know what they are thinking.

An autism spectrum person may not understand the concept of personal space. They may intrude on other people’s space while demanding more space for themselves than usual. Autism spectrum people need guidance on this.

Do not hold on to the person, while taking a blood sample, for example. Even though the situation may be distressing, the autism spectrum people can learn to trust people when things are not done suddenly or forced. Provide enough time, do not rush the situation.

Some autism spectrum people are especially sensitive to light. In particular, unsteady neon lights may cause sensory overload. On some autism spectrum people, lights may also cause epileptic seizures.
Sensory overload

The senses of autism spectrum people can be overloaded easily. In a doctor’s office, sensory overload can be increased by various sounds, lights, smells, and crowds. In a sensory overload situation, an autism spectrum person will attempt to decrease the effect by shutting down some of their senses, withdrawing to a more peaceful place, or by soothing themselves through self-stimulating behavior (so-called stimming), such as jumping, hand flapping, fiddling, or rocking. All of the aforementioned behaviors are methods used by the autism spectrum person to decrease sensory overload and they should not be restricted, unless it is absolutely necessary.

Pain

Autism spectrum people may have a very high threshold for pain. An autism spectrum person may, for example, have a fracture or a severe infection without any visible signs. The person may also have an unusual way of reacting to pain (laughter, singing, removing clothing, etc.). Restlessness and personally atypical behavior may be the only visible signs of pain.

Injections (inoculations, blood tests, etc.)

The first thing to do is to explain as clearly as possible what is happening and why. Using pictures or objects to support communication may be helpful in these situations.

An autism spectrum person may be both hypersensitive and hyposensitive to pain. Some people may feel pain for very small things, while others do not seem to react to pain very much at all. It is therefore recommended that pain should be minimized in any case, by using a medicated plaster, for example. The person or their escort can provide the best information about the situation.
Dental care, optician, x-ray, etc.

At a dental clinic, sensory overload may be caused by bright lights shining into the person’s eyes, noises from the equipment, and the taste and sensations caused by the instruments used. The devices used by an optician to check the person’s eyesight may overload the senses. These same types of challenges may also be encountered during an x-ray examination. If it is possible for the autism spectrum person to familiarize themselves with the situation in advance on location and sufficient time is set aside, the visit should go without problems.

In summary

A visit to a doctor’s office may be highly stressful to an autism spectrum person and may cause sensory overload and challenging behavioral situations. These situations can be prevented by becoming familiarized with the autism spectrum person’s personal way of acting and perceiving the world. Always clarify the autism spectrum person’s individual special needs with regard to the situation, by asking them and their potential escort as possible. According to the law, everyone has the right to make decisions regarding their care, based on their ability for self-determination.
Text: Elina Havukainen

ADDITIONAL INFORMATION
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Autismi- ja Aspergerliitto ry.
Nuijamiestentie 3 B, 00400 Helsinki
www.autismiliitto.fi
facebook.com/Autismiliitto
twitter.com/Autismiliitto

1st edition (8/2016)
An autism spectrum person:
- May be hypersensitive or hyposensitive to light, sounds, pain, touch, smells.
- May have a very literal understanding of language.
- May have difficulty with open-ended questions.
- May require more time to answer questions.
- May have a unique reaction to medication.
- May be distressed if a scheduled meeting is moved.

All encounters are unique, but you can support an autism spectrum person by:
- Asking clear, precise, and so-called closed-ended questions (for example, did you understand this form).
- Providing the person sufficient time to answer a question before asking a new one (Count to ten silently. Do not rephrase the question unless asked to do so).
- Making sure that you have been understood.
- Processing one issue at a time. The fact that the person speaks clearly does not necessarily mean that they have understood what you have said.
- Relieving the person’s sensory overload by, for example, adjusting the lights or sound.
- Scheduling meetings so that the autism spectrum person does not have to wait for a long period of time.

In closing:
- Ask the person what they want and if they want to talk.
- Remember that everyone is unique.
- Speak calmly, precisely, and clearly. Do not, however, underestimate the person you are talking to.
- Use standard language. Avoid slang, sarcasm, metaphors, and irony.
- Do not force eye contact. Looking straight into the eyes may feel threatening or painful for some autism spectrum people.
- Avoid sudden changes.
- Avoid unnecessary touching. When you have to touch, say so before you do it.