

AUTISM



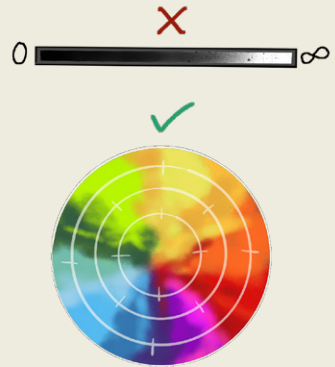
www.einhverfa.is

Autism

Autism is a lifelong neurodevelopmental condition that impacts our perception, both internal and external, as well as communication with other people and the world around us.

Autism is usually congenital, and presents differently for each individual depending on our age, maturity and capabilities. Because of this diversity, autism is often described as a spectrum.

The Autism spectrum is not a linear scale of “0 to 100% autistic”. It’s much more nuanced and better described as a color wheel consisting of all the different traits involved. Each person’s impression on this wheel is different, much like a fingerprint.



The risk of functioning labels

“Functioning labels” or categorization of autistic individuals as either “high functioning” or “low functioning” is unhelpful, as these labels mainly focus on external presentation instead of the inner reality. First of all, Autism is a lifelong and fluctuating condition. How we appear to other people often has more to do with the present situation and how we are feeling at that moment.

Those labelled “low functioning” will miss out on many opportunities in life because their capabilities will be undermined and strengths overlooked.

Those labelled “high functioning” are denied necessary support and assistance because their struggles are ignored.

Autism is Autism. We all deserve the chance to find our strengths and the necessary support to use them.

Sensory issues

We often find it difficult to process sensory information and frequently spend a lot of energy to learn unwritten social rules and understand what is expected of us in a given situation.

"At the end of the day, there is nothing better than to lie down in complete silence until the buzzing in my ears and brain goes away".

Human beings receive information through the five senses: sight, hearing, touch, taste and smell. We also have internal senses, such as the vestibular organs of the inner ear and proprioceptive sensors in muscles and joints, as well as many other internal monitoring systems.

All of these different senses must work together in order for us to function and stay regulated in daily life. This happens automatically for most people, but that is not always the case for autistic people.

For us, sensory processing consumes more energy and some sensory input can be highly disturbing, even painful.

Examples of sensory issues:

- A clothing tag or seam causing irritation
- Problems with texture and taste of certain foods which can seem like pickiness or even an eating disorder
- Harsh or flickering lights
- Loud sounds, commotion or electronic ambience
- Unexpected physical touch

Our senses can be highly sensitive or weak and can fluctuate sporadically from one extreme to the other. Some of us experience Synesthesia, a phenomenon that occurs when stimulation of one sense can trigger a response in another, like being able to "hear colours".

Sensory struggles are often very draining and can be a source of anxiety, pain and fear as well as disruption in daily life and social interactions.

This can be so overwhelming that we become unable to process sensory input, much like a computer that freezes. This is why a sensory-friendly environment is so important.



Shutdown, Meltdown and Burnout

Overwhelming sensory stimulation can trigger what is called “shutdown” and “meltdown”.

Shutdown refers to a situation where we become like a frozen computer. We clam up, retreat into ourselves and lose the capacity to express ourselves as we normally would.

Meltdown looks more dramatic on the outside. It is a highly distressing experience involving movements and sounds we make because we cannot handle the situation we are in.

Both of these reactions are extremely draining. They are never on purpose. In fact, they are best compared to having an allergic reaction, where your body responds in an uncontrollable way.

It is best, if possible, to prevent shutdowns and meltdowns from happening. When they do happen the best way to resolve them is to be able to exit the unbearable situation and recover in private, often with the suitable resources for the autistic individual.

Good communication is key to being able to avoid shutdown and meltdown, as is an environment which is sensory-friendly and relaxing.

Continuous strain on our already fragile energy supply can eventually lead to burnout. Autistic burnout, although not much researched, is quite well known in the autistic community.

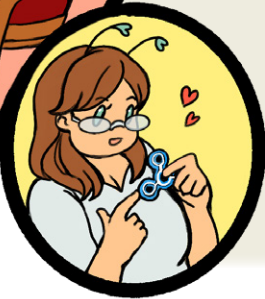
The symptoms, both physical and mental, are similar to that of workplace burnout. The difference lies in the cause, which does not have to be work-related, but rather life-related. Recovery from burnout can take a very long time.

Stimming

Most of us seek happiness and a feeling of security in familiar stimulation that protects against uncomfortable and unexpected sensory input and balances our nervous system. This is called “stimming” and is important to us our whole lives.



Stimming can be anything from a small tic to going on walks. It's any action that is repeated and has a calming or comforting effect. Some stimming is clear and visible, such as squirming in your seat, rocking back and forth, murmuring and mumbling, making sounds, hand movements, swaying and clapping. Other stimming can seem less obvious, for example knitting, biting fingernails or playing with hair.



Food

We all try our best to control the stressors of daily life, also in childhood. Things like light, sounds, movement, temperatures, sleep schedules, crowds and car rides are all something children have little control over. One thing that they can control is what they put in their mouth and sometimes what they wear. Autistic children seek comfort in knowing what the food they eat is going to be like.

We call this “samefood” and many of us hold on to this habit to some degree throughout our lives. Parents often worry about their autistic children’s monotonous and simple diet, but focusing on the food and trying to get the child to taste new things is rarely helpful. On the contrary, it can further add to the stress that the child is experiencing. A more useful approach would be to help out with other sensory stimulation. Try reducing strain on sight, sound, touch, etc. Try to identify when and where the child experiences discomfort and adjust the environment to help them regulate their nervous system. Find out how they stim and encourage that activity to help bring balance and wellbeing. Making the environment more calm and supporting will eventually open up the possibility to explore more types of food.

Familiar or predictable food is also preferable, such as pasta or biscuits that always taste the same. Fruits, berries and other foods that can change flavours even if they usually look the same are more challenging and can make us hesitant to try out new foods.

This is why we recommend that worried parents consider other sensory input, as the food itself is most likely just the tip of the iceberg. You can encourage your child's trust by increasing the predictability of the food's flavor, temperature and so on. Maybe there is noise around the table that could be calmed, you could use noise-cancelling ear covers, adjust the lighting, turn off the radio or other loud appliances and let the child wear comfortable clothing.

Interests



Having a special or intense interest is very common among autistic people. Sometimes those interests can seem peculiar or even at odds with our environment or age. What makes our interests “special” is mainly the passion and eagerness we have for them. Some of us have strong lifelong interests, as well as others that are diverse and variable over time.

Communication

Autistics and non-autistics have different communication styles. This applies to both how we express ourselves, what we say and how we communicate. Autistic people will often rather discuss facts or interests than participate in small-talk. The key to good communication is mutual interest in understanding each other and the willingness to experiment with different ways of communicating. Written language can help. Some autistic people find it easier to express themselves through writing than speaking. Autistic people are generally very literal, both in expression and communication. We tend to tell the truth and expect others

to do so as well. This can cause misunderstandings or even conflict, because of society's expectation that people should adjust their expression to appease the person they are speaking to. People don't always want to hear the truth.

Non-verbal communication can also be confusing for us. Things like facial expressions, body language and tone is something we can easily miss. Autistic people tend to use facial expressions and tone of voice differently and that can sometimes make it difficult for non-autistic people to understand us. Our vocabulary is often considered to be mature and some of us speak by "scripting" which means using pre-existing sentences from others, for example from books or movies. Not all of us use speech to express ourselves, some of us never speak and for others the use of speech can vary, depending on the situation.

Sensory issues can also influence our conversations. For example, delayed sound processing can make it difficult to talk on the phone. Maintaining eye contact during a conversation can also be problematic because it can take attention away from listening and thereby hinder communication. We are not being disrespectful by looking away, quite the contrary, we are trying to concentrate on listening to what is being said in the conversation.

Neurodiversity

Neurodiversity is a rather new term, used to describe the diverse nature of the human brain in regard to communication, education, attention, expression, etc. without resorting to pathologizing or medicalizing. The term includes all humanity, also those typically considered to be "normal".

"Neurodivergent" refers to people who have a nervous system that falls outside of the societal norm. In Iceland, the term "skynsegin", composed of the words "skynjun"(sensory) and "hinsegin" (different, other), is sometimes used to describe neurodivergence. Autism, ADHD, OCD, Tourettes and dyslexia all fall under the "neurodivergent" umbrella.

There is a significant overlap between neurodivergent qualities. Around half of autistic people also have ADHD. It's also common for us to have dyslexia or dyscalculia, and compulsive behaviors or tics. This is important to keep in mind when considering seeking a diagnosis for children and adults, because one diagnosis does not necessarily rule out another

Camouflaging and masking

Many of us who are on the spectrum go to great lengths to hide our autistic traits by “masking” or “camouflaging” and will vent our frustrations in private. This can make us appear different at school to how we are at home and cause our struggles to go unnoticed.

It is important to acknowledge our condition even if it is not visible or obvious at school or in the workplace and accommodate our needs. Communication support is vital to help us interact with our peers. Consideration for our sensory needs greatly influences our health and wellbeing. This applies to all genders, although it is more common for women and girls to camouflage their autism at school or work and they often require much more support than people might think.



Autism is rarely visible from the outside. We often put on a mask to fit in better, intentionally or not. We observe people around us and shape our behavior accordingly. This mask can be useful, but it is also incredibly energy consuming. It takes a toll to “keep up appearances.”

Non-binary

Certain links exist between the autism spectrum and non-binary identities. Identifying outside the gender binary (male-female) is much more common within the spectrum than outside of it.

Executive function

We all have a wide variety of skills. We can show exceptional skills in some areas and a lack in others. Sometimes this has to do with interest, as we can immerse ourselves in our interests and resist participating in things that don't appeal to us. More often, this imbalance is related to issues with executive function.

Executive function refers to the ability to turn thoughts into actions, such as:

- Starting a task (beginning),
- Switching between tasks (changing)
- Finishing a task (stopping)

Getting support and understanding for impaired executive function is important throughout our lives. Household chores and cooking are examples of tasks that rely on these skills and the ability to organize. Executive function struggles are not limited to studies and school.

Support at crossroads in our lives is also crucial to help us transition into new and different roles. Milestones such as graduating from one school level to another or moving out for the first time both call for new aptitude since the circumstances have changed.

Mental health

Many of us experience mental health issues at some point in our lives and might receive a diagnosis for an anxiety disorder, depression or a personality disorder before an autism diagnosis is even considered. Spotting the difference between an eating disorder and just having difficulty eating due to sensory processing issues can be hard.

Numbers show that mental illness is more common for “less visibly” autistic people. Self-harm and suicidal thoughts are also prevalent for said autistic individuals, which goes to show that “less visible” autism is not evidence of better mental health, quite the opposite. It is incredibly important to raise awareness of all the different nuances so we can all receive appropriate support.

Finding the source of mental distress and paying attention to when it happens is vital. It's better to handle the root of the issue and to adjust the environment to our needs rather than to focus on consequences or outward behavior, such as avoiding school.

Feelings of anxiety can be caused by lack of predictability, difficulty with expression, and being insecure in one's ability to read and interpret social cues and social situations. Many of us are constantly thinking about how to be “normal” and to avoid doing anything that could be considered inappropriate. Bullying is a large source of anxiety and depression, as people on the spectrum are much more likely to become victims of bullying than non-autistics.

Mental distress can cause problems with digestion, sleep and eating, which can make us more withdrawn and less able to deal with daily stressors. All this combined can often lead to self-harming behaviours.

Experience has shown that therapy or intervention for psychological symptoms based on the needs of non-autistic people does not meet our needs properly. Ineffective therapy can also worsen the problem because we blame ourselves for poor progress with evidence based methods and support from specialists that we know to be effective for other people.

From all the above mentioned points, one can easily see that autism awareness is a key factor in treating our mental health.

Diagnostic Criteria

According to international standards, an autism diagnosis is based on an individual having:

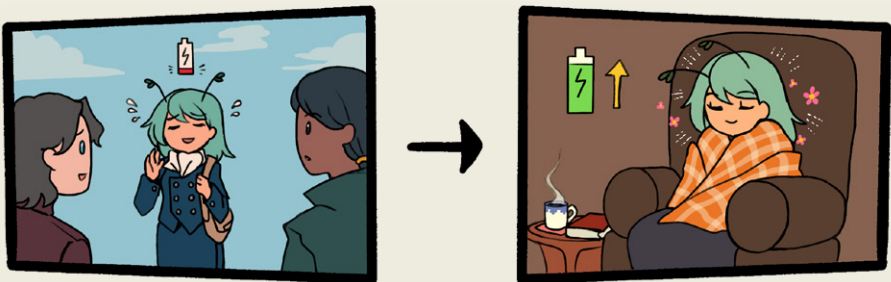
- Impaired social skills
- Impaired language and communication skills
- Repetitive and unusual behaviours

These standards are all based on how non-autistic people see us and interpret our behavior, not on how we experience the world.

Today it is generally accepted that our way of communicating is not defective, though it certainly differs from the “norm”. Non-autistics do in fact have a reduced capability when it comes to understanding autistic communication. But since we are the minority, our method is considered inferior. This communication challenge is called the “double empathy problem” and it refers to a mutual lack of understanding, much like people from different cultures and languages attempting to understand each other.

Helpful Advice

Visual cues (pictures and text) can be helpful, especially within the school system. Social stories are good examples and are well suited to prepare for changes or working with unwritten rules and subjective things like feelings



Energy accounting

A big part of creating an autism-friendly space is being aware that stimuli can become overwhelming. This could happen, for example, when many types of information are given all at once, demands are too high, social interactions become too intense or when sensory assault causes discomfort.

Schools and workplaces should offer **sensory friendly spaces** where one can escape the ruckus of the day when needed. These rooms should have comfortable lighting, be free from noise pollution and provide comfortable furniture for resting, as well as stimming options like spinning or swaying. Yoga balls and bean bags are good choices, and even ceiling-mounted chairs that hang in the air and allow you to spin around or swing.

A **sensory kit** is something that should be available in a sensory friendly space. They can be put together differently depending on the situation or the individual but they should always have some sort of stim toys and something that reduces sensory overload. Weighted blankets, noise-cancelling headsets, eye masks and other related items are very useful and good to have in a kit.

Many of us create our own sensory kits that we take with us wherever we go. Some of these are discreet, like sunglasses or hoodies, while others are more obvious like stim toys or small weighted blankets.

Having options and solutions like these can increase our confidence in daily life and reduce anxiety in demanding situations.

The importance of diagnosis

“Let’s give the child the benefit of the doubt” is sometimes heard when the possibility of seeking an autism diagnosis comes up. This view is based on the outdated idea that an autism diagnosis is something to be ashamed of or could be troublesome later in life.

It is most commonly those of us who are good at masking that meet this kind of attitude, the exact same people who most often experience anxiety and other mental disorders, possibly due to lack of support.

So whatever doubt the child is supposed to benefit from is rarely any good. Most of us who get diagnosed as adults have carried all kinds of labels in life even though the autism label did not find us until later. We have been called harsh, eccentric, hypersensitive, difficult to deal with, nerds and so on. The autism label is most often a welcome change, allowing us to finally understand that we’re not a failed neurotypical but a perfectly acceptable autistic person.

An autism diagnosis should be a cause for celebration, as it helps us to find our way towards better understanding ourselves. It is also a guide to help us find our community, the people who understand us without the need for any explanation, who speak the same language.

Knowing yourself is a human right



Einhverfusamtökin

This booklet is written by Guðlaug Svava Kristjánsdóttir, project manager of Einhverfusamtökin (The Icelandic Autistic Society)

in collaboration with Ásdís Bergþórsdóttir, Laufey Gunnarsdóttir, Laufey Eypórsdóttir and Þóra Leósdóttir.

Illustrations: Valrós Gígja
Booklet design: Sylvia Kristjánsdóttir

For more information:
Einhverfusamtökin,
Háaleitisbraut 13, 108 Reykjavík
www.einhverfa.is,
einhverfa@einhverfa.is,
Tel: 5621590



Stjórnarráð Íslands
Félagsmálaráðuneytið



Reykjavíkurborg

