Practical guide for care givers

Adults with Autism Spectrum Disorders

By

Anna Sjölund & Susanne Bejerot

This book is dedicated to Professor Christopher Gillberg in gratitude for his outstanding contributions to increasing the understanding and acceptance of unusual people.

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Practical guide for caregivers – Adults with Autism Spectrum Disorders by Anna Sjölund & Susanne Bejerot. Illustrations: Ossian Humble. Translation into English: Amanda Hicks. Layout: Erkki Kärkkäinen. Authors: Anna Sjölund & Susanne Bejerot, Stockholm, Sweden, 2012.

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Foreword

This book came about because it fills a need. A combination of group therapy and education for six adults with Autism Spectrum Disorders (ASD) and four home caregivers for three hours per week for thirty-seven weeks was made possible by a grant from The National Board of Health and Welfare and a generous grant from the L.J. Boëthius' Foundation. In this way, individuals with ASD could be offered the possibility, in a small group, to learn about their functional disorders and to find means to deal with them. At the same time, we wanted to educate the caregivers who work with individuals with ASD. The caregivers would have the advantage of truly understanding how functional disorders are experienced through intimate discussions with the participants with ASD and, at the same time, they would receive theoretical knowledge and practical tools to help them in their work. This was our vision, which we, for the most part, have succeeded in realising.

From our filmed group sessions and written material, Anna Sjölund, previous ombudsman for the National Society for Autism and Asperger's syndrome in Sweden, has compiled a text which, with her solid knowledge of ASD and her own experience of having worked as a caregiver, has been indispensable for the actualisation of this book.

It is not always easy to understand the importance of the role caregivers play when the profession as such does not require formal education and is not well paid. After many years' work with adults with psychiatric functional disorders, it is clear to me that there are certain factors which are crucial in determining whether the individual will live a dignified life: something meaningful to do (preferably work or study), well-functioning living accommodations and someone kind and considerate to turn to for help in managing daily tasks.

Having help to manage daily life is a condition for being able to work or live independently. Parents, who are best at practical help as long as the person in question is a child, are seldom the best suited when the person is an adult. That is where caregivers enter the picture. Unlike parents, who have spent decades acquiring knowledge on their child's special way of being, the caregiver meets a person they do not know at all. If that were not enough, caregivers have seldom been educated in the area of ASD.

The individual with ASD has a different way of relating to himself and to the world around him—a way which can seem incomprehensible to an outsider. To the world, it may seem like the person with ASD lacks common sense, but it is not that simple, and merely guessing at how to relate to a person with ASD is not a good method. Without a thorough knowledge of ASD, it is difficult to know why something is challenging for a person with ASD or to understand how important it is to relate to the individual properly; i.e., straightforwardly, clearly, receptively, humbly, patiently and in a friendly manner.

As most people with ASD do not excel in small talk and have difficulties in expressing gratitude both in speech and in body language, tending instead to say exactly how they see the situation—and in a straightforward manner—there is the risk that caregivers can feel attacked or wounded and in turn risk acting defensively. This is never good. On the other hand, if the caregivers are too protective they can be seen as meddlesome and the person with ASD will feel that his integrity has been violated.

The caregiver's role is further complicated by the difficulties with which a person with

ASD can have in formulating or even understanding his own needs or in following sound advice. This can depend on various things, such as difficulties in seeing consequences or an inability to make use of advice that requires a change in the situation; for people with ASD, change is often difficult to handle.

A caregiver must have a great amount of patience and put a lot of time into motivational work. ASD involve unequal aptitudes, which can lead to an individual being very good at one thing while not being able to accomplish a simple practical task independently.

Although this book is a guidebook for the caregiver, personal instruction is also needed. Caregivers need personal instruction in order to work effectively, while the person with ASD needs someone with whom to discuss things, should their relationship with their caregiver in anyway fail.

This book was written to help people with ASD in their daily lives. Also individuals with other cognitive functional disorders can find the information to be of value. This book is not intended to teach people with ASD to be “normal”. This book is about helping another person to live with dignity, on their own conditions and, where possible, to deal with obstacles as effortlessly as possible.

This book is dedicated to you, the caregiver, to help your job become meaningful to you and your clients. It can be beneficial for the target group, their close friends and relations or others who wish to learn the practical aspects of helping in daily routines. This book is free to copy. Hopefully it will be downloaded, printed and read by many.

Susanne Bejerot, MD,
Project Manager

Introduction

> ***To help someone, I must really understand more than what he does; first and foremost, I must understand what he understands. If I cannot do this, it does not help that I can do more or that I know more.***
>
> Sören Kierkegaard (1813-1855)

Autism spectrum disorders (ASD) include the diagnoses autism, atypical autism and Asperger's syndrome. ASD can even occur as symptoms in certain congenital syndromes. The diagnoses overlap so that separating them is redundant and confusing. Recently, the use of the umbrella term "ASD" has been on the rise. ASD are characterized by:

1. Persistent deficits in social communication and social interaction across contexts.
2. Restricted, repetitive patterns of behavior, interests, or activities that may include hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment.

The limitations can vary from total incapacitation, which is rare, to a more subtle, but just as functionally disabling, deviation. How severe the limitation is can vary in the same individual at different ages, but the severity always lies in functioning reciprocally: A person with ASD can perhaps communicate well when it is a matter of their own ideas or interests yet have grave difficulties in picking up on and interpreting signals from others. The functional impairments are influenced by the individual's aptitudes. A minority of individuals with ASD possess an extremely high intellectual gift, while others can be mentally retarded or completely lack language.

Functional impairments are influenced by the individual's propensity for change and their flexibility. It is not about their unwillingness but rather their inability, analogous to colour-blindness, which no one is expected to "practice until perfect.

The diagnosis ASD is defined by behaviour, meaning that it starts with the individual's behaviour, not its causes. ASD is based on deviations in various brain functions, which can be genetic and independent of upbringing. Deviations in brain function in turn affect how information is handled; i.e., how the individual interprets and experiences sensory input from the world around him, how he understands the context and how he solves problems. This leads to the individual having difficulties in planning and organizing everyday life. The functional impairment can express itself differently in different people and during different stages of life.

Many have uneven aptitude profiles, which means that the individual can be very knowledgeable and competent in certain areas while having great difficulties in other areas. The difficulties noticed by those around the individual with ASD represent the unusual way the person processes information and the ways by which he attempts to compensate for his difficulties. For outsiders, it is incomprehensible that a person who has undergone an advanced university education cannot manage to keep himself clean, fold a shirt or fry an egg, but these paradoxes are a part of the ASD nature. Interpreting behaviour from a pop-psychology or psychodynamic understanding does not only lead one in the wrong direction, it can be damaging and insulting to the person with ASD.

Guidance

This book provides guidance in understanding ASD and target the high-functioning group (e.g. Asperger's disorder). It demonstrates how to develop a template for assessing functioning in everyday life and for analysing the need for care and documenting it in a care profile. Each section ends with an illustration of a hypothetical client we have named Christina, including space for the caregiver's assessment. The caregiver must periodically evaluate, update and develop the care profile. When the individual's circumstances change, the contents of the analysis must also be changed. It is important to understand that all difficulties worsen in situations where the individual with ASD has less energy, such as when he is tired or under stress. A person with ASD can feel exhausted after hoovering a room or having had an hour-long conversation. Stress can occur in a number of situations which others cannot even imagine as stressful, such as when shopping, having visitors or answering the telephone.

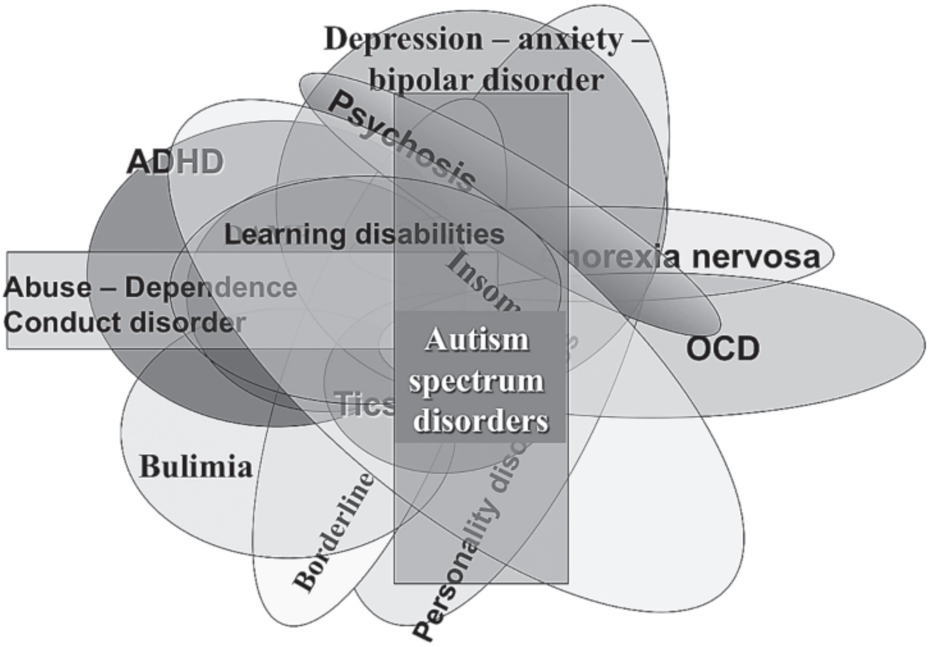
We are aware that certain parts of this book can be viewed as too elementary for working with certain individuals, yet too advanced for others and that it can feel humiliating to be related to on the wrong level. In our experience, the most common scenario is where expectations and demands are too high.

To the caregiver we would like to say that you are often the most important person in your client's life. This is both a privilege and a challenge. We hope this book will be of help to you, but it does not replace competent personal instruction – something that is indispensable in the work of a caregiver.

Part 1

Mental Symptoms and Psychiatric Conditions

Other psychiatric symptoms and psychiatric conditions



People with ASD sometimes have mental symptoms or psychiatric diagnoses that can be seen as a part of ASD. Many first diagnosed with ASD as adults have previously been diagnosed with depression, OCD, a personality disorder such as borderline, avoidant or schizotypal personality disorder, anorexia nervosa, ADHD, social phobia or psychosis. In this section we shall try to explain these terms. Other conditions, such as epilepsy, allergies or intestinal troubles often accompany ASD, but these conditions are beyond the scope of this book.

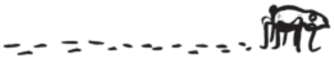
About one person in three of the so-called normal population will have a mental illness of some sort at some point in their life. People always try to understand why they are hit with an illness or calamity, and try to make sense of it by turning to their own knowledge base and using cultural explanations. At times, there can be a clash of cultures when people with ASD have their own explanations for why they are not well mentally. The truth is that mental illness is not dependent upon one reason, any more than is diabetes or eczema. But it is well known that people with ASD have an increased tendency to develop certain types of mental problems more so than others and that these psychiatric conditions can differ from how they are expressed in people without ASD.

Caregivers play an important role in helping the individual to accept help and treatment for his or her psychiatric problems. Many are afraid to seek care and those around them can make it even worse. Ideas such as one's mental illness is “all Mother's fault” and mental illness is cured by meditation, running, magnetic bracelets or relaxing talks are all opinions; they are not scientific facts. It is important that professionals keep their private theories to themselves.

Most of the psychiatric disorders mentioned here can, unless otherwise specified, be helped by cognitive behaviour therapy, on the condition that the therapist is knowledgeable about ASD, otherwise she can do more harm than good. Treatment with medication such as antidepressants, especially the serotonin reuptake inhibitors (SRIs), have an effect on fear, depression and OCD in most cases, whether ASD is involved or not.

Phobias, posttraumatic stress disorder and other fears

Almost everyone is afraid of something and some fears are more common than others. Many of the most common phobias, such as fear of spiders or snakes, do not usually affect the person with ASD. On the other hand, things that do not generally cause fear in others can elicit extreme fear in people with ASD. They can have unusual phobias, such as for metal jewellery. Fear of heights – acrophobia – is also common, possibly due to the unusual sensory perception which makes the person feel more unsafe in high places.



Many people with ASD experience an intense fear in situations they previously found only uncomfortable, such as during medical examinations. They can feel terror when they bump into an old schoolmate who bullied them. It can lead to the individual refusing to go to the doctor or to where they imagine their old schoolmate might show up. For some, anything that reminds them of the unpleasant situation can lead to anxiety. It resembles post traumatic stress disorder (PTSD) that in neurotypical people arises first after they have been exposed to severe assault or threat.

You can help the person with ASD by going through what is going to happen during a visit to the doctor, enabling him to prepare himself for it. Many find help by having someone else, such as a caregiver, follow along and do the talking for them, thereby avoiding misunderstandings. Cognitive behaviour therapy can help in cases of phobia, where avoidance behaviour is prominent.

Panic attacks and generalised anxiety

Panic attacks are characterised by a sudden terror that comes out of nowhere, possibly accompanied by chest pains, trouble breathing, and/or dizziness. The terror reaches its maximum within minutes. Panic attacks make the individual afraid to be alone and many find that it feels like they are having a heart attack or are being smothered. This type of anxiety is unusual in ASD. People with ASD are more likely to have protracted anxiety. Of course they can feel sudden fear but they usually do not have the typical physical symptoms of a panic attack.

Stomach problems, muscle tension, nervousness, sleeping problems and anxiety over everything imaginable are not unusual in ASD, so that the diagnosis GAD (Generalised Anxiety Disorder) fits, the risk being then that the problem is "psychologised" and not taken seriously. There are reasons to believe that physical symptoms in individuals with ASD in most cases have a biological base.

Social anxiety

Most people feel uncomfortable if they unexpectedly find themselves the centre of attention. Embarrassment leads to possible blushing, a pounding heart and a voice that sounds uncertain and that does not really carry. Some even find that their hands shake or they perspire. People with social phobia find that these physical signs are triggered far too easily and they endure constant exaggerated fear for many situations in which they might be scrutinised and judged by others. This leads to their retreating from social contact, dwelling on how they might have been perceived and feeling that they have made fools of themselves..

Many people with ASD describe social anxiety but it differs from usual social anxiety in that it really does rest on a lack of skill in reading others' social signals and in interacting naturally in conversation. People with ASD often experience social interaction as so difficult that they feel they constantly make fools of themselves. In real social phobia, as opposed to that of the person with ASD, the individual has adequate social skills but does not think they do. In ASD, the individual does not usually blush, shake, or perspire in social situations, which is typical for social phobia.

Individuals with ASD can be helped by serotonin reuptake inhibitors as these usually lessen anxiety and depression. Cognitive behaviour therapy, however, is not an especially effective treatment for social anxiety in people with ASD.

Compulsions

Compulsive behaviours are usual with ASD, yet not all compulsive behaviours are OCD (Obsessive Compulsive Disorder). The need for routine that characterises ASD can be difficult to differentiate from OCD, but the need for routine – to do things the same way each time that is found in ASD – is in itself an energy-saving strategy. It explains why the individual purchases the same products every time they shop and why they are unwilling to move furniture around – it allows them to use their energy for other things. Real OCD is caused by obsessions that lead to the person feeling an intense discomfort if he does not perform the action in a certain way. If the "just right feeling" can't be reached, the individual will repeat the action time and again to achieve that feeling of rightness. Another type of common compulsion is exaggerated hand washing due to a fear of contagion or repeated checking for fear of having forgotten to lock the door or turn off the stove.

Hoarding

Hoarding, which really should not be classed as a compulsion at all, involves an individual who finds it so difficult to throw things away that their home becomes cluttered from floor to ceiling. Compulsive hoarding is common in ASD for several reasons: An individual with ASD can have difficulty experiencing that things still exist if the things are no longer in his line of sight. Every decision to toss out an item is complicated, even if it is just an old newspaper. First, it must be read thoroughly, which there is seldom time for, and so it never gets tossed out. Newspapers must also be read in order. And on it goes. The hoarding can also be due to things being "good to have on hand" or because there is a love of the things, even if they have no value in the eyes of others. Those with ASD who have trouble seeing consequences or have difficulties in categorising things can find it hard to know what should be tossed out and what should be kept.

All types of OCD can occur in ASD. As a home caregiver, you can help the individual by not simply taking and tossing out things for him. It is better to come to an agreement that for every item that will be taken into the home, another must be taken out (preferably several items) and help him to find ways to get things sorted. It can also be helpful to demonstrate normal behaviour and allow the individual with ASD to try to mimic it. Calming reassurances such as "it's OK", "I'll check for you and see if it's locked", etc. do not help OCD, they only calm things for the moment.

Both medication and cognitive behaviour therapy can help ease OCD.

Eating disorders

In anorexia nervosa, the individual has a faulty body image perception and perceives herself as overweight when in reality she is not. She will diet in secret, pretend to eat or purge and take laxatives to lose weight. Extremes in exercise are part of the picture.

In ASD, anorexia nervosa is more common than expected. Many people with ASD feel disgust toward eating certain things and many are vegetarians for various reasons. Some can develop extreme eating habits or think that starvation is somehow purifying or that a very limited food intake is healthy. Anorexia nervosa is more common among women than men, but relatively many men with ASD demonstrate self-starvation behaviour. People with ASD can, however, starve themselves for other reasons than slimming down. Some, for example, find eating unpleasant; chewing can be taxing or the consistencies of certain foods, not least of all meat, can feel disgusting. Others like only one certain food, which can be compared to their dislike of variation. Some get stomach aches as soon as they eat and many are overly sensitive to gluten or lactose. Loss of appetite is common in depression. If the person is very thin or loses weight, they should seek professional help. Binge eating can occur in ASD, but is not common.

Personality disorders

A person with a personality that deviates so greatly from the norm that it cannot be seen as a normal variation is said to have a personality disorder. Roughly 12 % of the population has a personality disorder.

Many people with ASD have been diagnosed with personality disorders before being diagnosed with ASD. There are about a dozen different personality disorder diagnoses. Borderline personality disorder is the one that is seen as especially difficult to treat and is diagnosed mainly in women. A certain percentage of those diagnosed with borderline personality disorder or the more modern term, emotionally unstable personality disorder, really have ASD.

Typical of borderline is hypersensitivity to separation and an exaggerated experience of rejection, which results in anger and the feeling of being offended. Even self-harming behaviour such as cutting and suicide are found in borderline.

A small group of those with ASD cut themselves or harm themselves seriously to ease anxiety. Unlike true borderline personality disorder, people with ASD are not impulsive, are seldom substance abusers and are not manipulative or dramatic. Furthermore, their feelings of being rejected are often well grounded in reality. The best treatment for a person with ASD and self-harming behaviour is not always obvious, but it is important that the therapist understands people with ASD and is knowledgeable about autism.

Tourette's disorder & tics

Tourette's disorder is characterized by recurrent vocal and motor tics that are bothersome to the individual. Most who have minor tics are not bothered by them.

Tics are often seen in eye blinking, neck or jaw movements or grimaces. Tics can be sounds, such as throat clearing, sniffing, individual words and swear words. They might be an irresistible desire to mimic others' movements or words, or to lick, smell or spit. The feeling that the sound or twitching must be made builds up slowly, rather like the feeling prior to a sneeze, but it is much stronger. Tics can also be expressed as self-harming behaviour such as punching oneself. The tics are most often more disturbing for others than for the individual and the person with tics can go through spontaneous periods of improvement or worsening, without anyone understanding why.

Some ease the pressure to tic by using the strategy of ticking when in the lavatory or some other private place before going to meetings, etc. Unfortunately, there is no really helpful treatment for tics. Medication has side-effects and psychological treatments (such as habit reversal) are not usually effective enough. This does not mean that treatment is unhelpful and not worth trying. Tics are more common in people with ASD than in the general population.

ADHD and ADD

ADHD (attention deficit/hyperactivity disorder) is similar to ADD (attention deficit disorder) but includes impulsive behaviour. About a third of those who are diagnosed with ASD as adults are also diagnosed with ADHD or, more likely, with ADD. ADD entails difficulty with attention but it lacks the hyperactivity and impulsive behaviour of ADHD. ADD can be viewed as a symptom of ASD, even though far from all people with ASD have problems with attention and concentration. In many ways, ADHD and ASD are opposites. People with ASD tend to be detail oriented, socially reticent and firm in their principles and they tend to choose their words carefully, while people with ADHD are often the opposite – associative, dramatic, contact seeking, impulsive and spontaneous. The risk of substance abuse and smoking increases in ADHD, while it is much lower with ASD. Difficulties in planning, organising and carrying out tasks unite ASD and ADHD and both groups can need a great deal of help functioning in their daily lives.

People with ADHD usually improve with stimulant medications and people with ASD can also find help with such treatment. Cognitive behaviour therapy and cognitive aids can probably make daily life easier for both groups, even if they do not cure either one.

Depression

Everyone can feel down or sad sometimes but if it continues longer than a couple of weeks and reaches a certain depth, it is depression. Depression is considered a widespread disease as it affects so many. Depression is said to have a distinct quality, quite different from sorrow or despondency. The individual who is suffering from depression usually feels both hopelessness and emptiness and has trouble believing that things will ever get better. Some feel an intense anxiety with panic attacks and a gripping uneasiness in their stomachs. Sleep is affected; it is common for the individual to wake up early and feel anxious, and to have nightmares. People suffering from depression usually feel they have no energy and just showering and getting dressed can feel insurmountable. Some are easily irritated, snapping at those around them, lose interest in things they previously enjoyed, isolate themselves and lose all desire to live.

People with ASD can feel depressed and develop depression. Sometimes it can be difficult for those around them to understand that the person is depressed because he does not talk about it and he is difficult for others to read emotionally. Because people with ASD are seldom able to appeal to others' compassion or to ask for care and are more likely to be dismissive, they risk being left without help.

Antidepressants are usually effective, while the effect of psychotherapy for people with ASD has not been well investigated. As a caregiver, you can help the individual to be active and make a clear connection between their actions and how they feel. Above all, it is important to listen and take any problems seriously, should the individual complain of feeling down, whether you the caregiver see it or not. There are many self-help books for depression but none written especially for people with ASD.

Psychosis

The term psychosis designates a disturbed perception of reality. Schizophrenia is a form of psychosis but even people with bipolar disorder are often psychotic during phases of their illness.

In schizophrenia, the illness process develops relatively slowly and the personality is changed by the illness. The person can hear voices making insulting remarks or voices talking to each other or to him. Others present will not hear these voices. Visual and tactile hallucinations can also occur.

People who are held in extreme isolation or who are deprived of sleep sooner or later develop psychotic symptoms, imagining things or hearing voices or sounds that do not exist. This is called reactive psychosis. People with ASD very likely have a lower threshold for being affected by this type of psychosis if they are exposed to stress. Stressors such as being forced to move or change their occupation can be enough to trigger a psychosis in a susceptible person with ASD. The reactive psychosis states that can affect a person with ASD are usually acute and run their course, but they might need medication during a period of transition.

There are people with ASD who have been misdiagnosed and others who have been wrongly diagnosed with ASD when it is a matter of schizophrenia. It is possible to confuse the diagnoses because in both cases the individual tends to misinterpret the world around them and others' motives; in both cases the individual can have trouble carrying out daily tasks or keeping up with their hygiene; and in both cases the individual appears very suspicious and has ideas and conceptions that the world around them finds strange. With schizophrenia, the individual has not always been this way, whereas in ASD, the person has always been perceived as "special" or strange by those around him. In schizophrenia, the person is perceived as incoherent in their thinking and feels that thoughts are transmitted to or drawn out of them. This is not so in ASD.

With knowledge of how the individual has behaved earlier in life, it is usually not difficult to distinguish between the diagnoses. One curiosity is that people with schizophrenia are often smokers, while the opposite is usually true in ASD. If a person has a psychosis, whether or not he has ASD as well, he should be treated by a psychiatrist.

Part 2

Home Care

The role of home care

In order for caregivers to give the individual help in creating a meaningful and well-functioning daily life, both an understanding of how ASD can manifest and some pedagogic know-how are necessary. It is not enough to be nice and to smooth things over. If a well-meaning caregiver says “My home is messy, too”, “I also think it’s tough to do the shopping”, or “I also think it’s hard to talk on the telephone”, it can seem like the individual's difficulties are not taken seriously – that they are being trivialised or diminished. This helps no one.

The caregiver needs to know the vulnerabilities of those with ASD. She needs to be able to respond to that which seems strange or difficult for the individual with autism and, at the same time, be straightforward and clear without lacking respect for the individual. This is difficult. One must keep in mind each person’s condition, needs and will to create change. The caregiver must find stratagems, develop aids, convey different strategies for different situations, and do all this in a respectful manner and at the appropriate level of the person in need of help. The difficulties that people with ASD have affect them in every important area of life. As a rule, they need a caregiver’s help both practically, as a sort of life coach, and as a social interpreter.

In order to respond well to an individual with ASD, one must be capable of seeing to the individual’s needs and desires, and be able to distinguish them from one’s own needs and values. That which intuitively feels right for the caregiver is seldom the same as that which is right for a person with ASD. It is the duty of the caregiver to help the individual with those difficulties he encounters on a daily basis, not to try to make him “normal”.

The work requires empathy and the abilities to change perspective, to be prepared to think differently and to reflect over how situations are experienced from within by the person with ASD. One must continually put oneself in the individual’s shoes, seeing how he experiences the world. It is important to respect what the individual considers to be important content in his daily life, even should it not correspond with that of the outside world.

Approach and continuity in home care efforts

As a person with a functional disorder, of course you want to be treated like an adult.

In my experience, before you receive home care, you have to be able to say what it is you need help with. That's very difficult for me. I can't imagine what situations I might end up in. Theoretically, I can reason out what might be a good way to work things out, but I become completely handicapped when I land in these situations. I believe you should have a long period of time in which to get help with figuring out just what help you need and why it you need it.

I think it's important that help should vary from person to person…. We have quite different needs. Another thing that varies is how you learn to do ordinary things in a more effective way in your own home. But I think it's easier to remember when you figure out for yourself how to do it, even if this seems on the surface to take more time. What is important is that the method sticks in your mind and in your routines, so that the change becomes permanent. If you've discovered a new way that works, it sticks permanently. If someone comes to your home with new methods that should be implemented at home, it can easily feel oppressive; there won't be any lasting changes in how you manage things. The caregiver has to be tactful and keep a low profile in their contact; then a lot will happen. Otherwise I, at least, would have run off really fast if my caregiver hadn't shown me unwavering respect.

The most important thing is that the caregiver has been educated in autism and understands that we are all different. They must be able to make our daily lives easier so that we can utilise our strengths better, and so that our difficulties don't tire us out too much. I think it's of great importance that we get help with such things as economy; hygiene; eating habits and times; routines, schedules and check lists; time aids; rest and relaxation.

I think it's better that few caregivers come to my apartment than that many do. It's also important that they really listen to what I have to say and that they don't make a lot of decisions.

I've had problems with my caregiver and don't know what I should do. It always worked well earlier, but since I got a new person, it doesn't work out. She was in my home once and things went totally wrong. Now I'm thinking of terminating home care.

It seems like I have to educate the personnel myself about my difficulties. With all the changes of personnel, I'll soon have educated 50 people… Is it really supposed to work this way?

I have two caregivers who are really good. They come twice a week, each on their own day. One day we go shopping for food and do the laundry, and the other day we clean and do whatever else needs to be done. They've also helped me to send applications and buy clothes. With their help, life works pretty well now. But when someone new comes, it will be so hard.

If care efforts are carried out in different ways by different caregivers, it is often both stressful and confusing for people with ASD. An individual's functioning and care profile can be made by charting out which underlying factors might cause difficulties for the individual, preparing compensatory strategies for dealing with them, and then summarising the results.

That caregivers quit, get sick or go on maternity leave cannot be avoided. However, the quality of a client's care can be maintained by documenting the client's care needs and how they wish them to be met. In this way, situations that might be stressful for the client can be minimized.

Example of a ”How to relate” document

When you relate to me, it is important that you:

- accept that I don’t look you in the eye when I talk, as eye contact makes it difficult for me to concentrate on what you are saying.
- do not expose me to sudden changes; spontaneous outings and changes are stressful.
- do not expose me to difficult choices; choosing between more than two things is stressful for me.
- do not expose me to loud or sudden sounds, as they are difficult for me to deal with.
- notify me in advance as to who my caregiver will be; I need to be prepared for whomever comes to my home; otherwise, I get anxious.

When I get anxious:

- don’t talk so much; I can’t sort through what you’re saying when I’m not feeling well.
- don’t touch me—don’t even come close to me—as that makes me feel threatened.
- don’t ask how I’m feeling; I have trouble figuring that out for myself and the question is stressful.

What specifically should be taken into consideration when relating to the individual?

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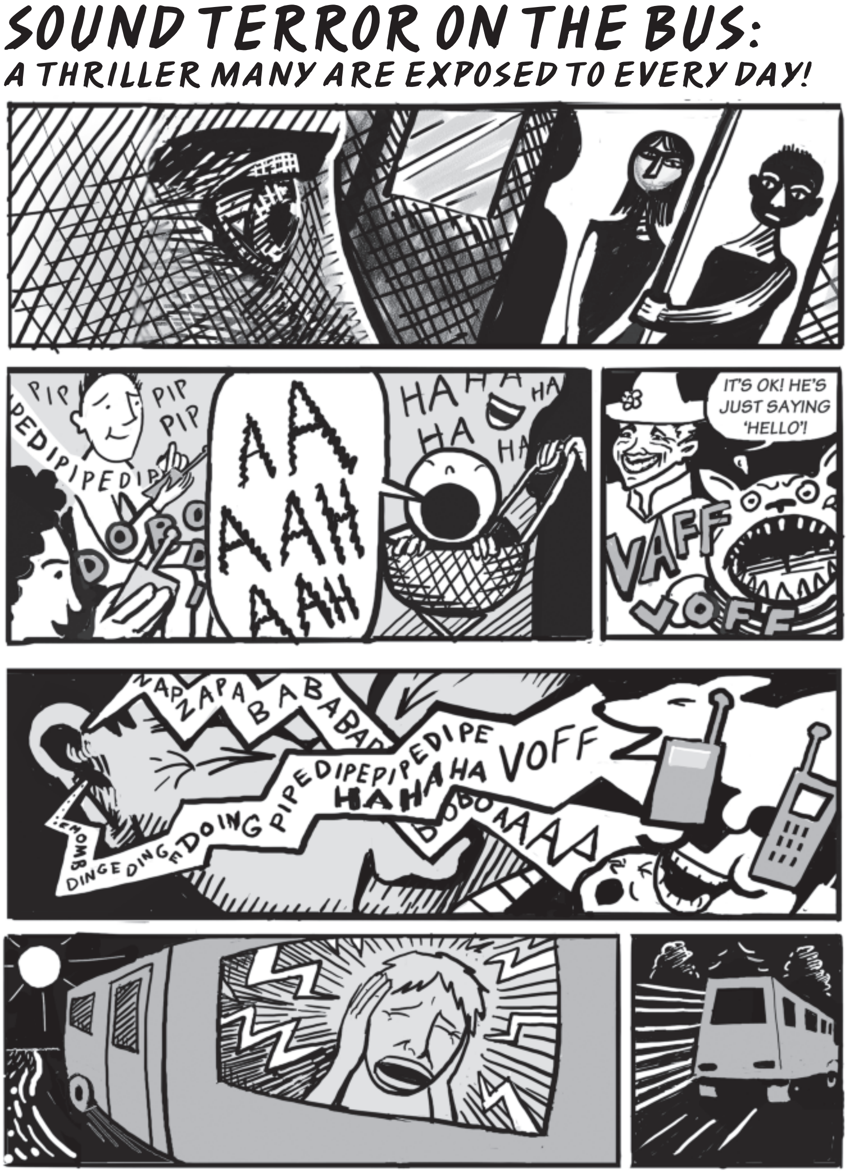
Part 3

About Autism spectrum disorders

What are autism spectrum disorders?

Those behaviours one sees in individuals with ASD depend on causes hidden beneath the surface ...

To understand people with ASD and to help them in their daily lives, one should possess knowledge of ASD and understand the different ways people with ASD think and feel that can lead to their unusual behaviour. Today there is a great deal of research on cognitive functioning in ASD. Three partially overlapping theories have been developed that describe difficulties with reading other people's mental states (mentalising), creating a comprehensive picture and being able to generalise rather than getting bogged down in details (central coherence) and planning and assessing one's performance (executive functions). The theories can make it easier to understand problems in people with ASD.



Unusual perception

> *I am in great need of a filter that can be mounted somewhere between all sensory perception pathways and my brain. Could someone please invent one? I''ll pay you well! And I can assure you that, when it comes to needing one or two filters, I'm not alone in ASD's outer space.*
>
> *What I want to say is that I suffer a great deal from not being able to sort through my sensory perceptions, whether they come rushing through my eyes, ears, nose, or skin. I need help to sift through them. I can't concentrate. My brain runs at high speed 24 hours a day and I have no peace of mind!*
>
> *I can't sit and read anywhere I might risk hearing or seeing something. It's enough just to see a bird fly past on the periphery or to hear a dog bark to make me have to reread the same sentence or paragraph again and again.*
>
> *I can't watch TV if Dad has turned on his reading lamp in the same room or if Mum is clattering around in the kitchen. I can't hold a coherent conversation if there is too much sound and/or movement in the room.*
>
> *Popping sounds, shadows, car headlights – not even a thick blanket at the window helps. My sleeping problems and my very high functioning brain are going to shatter me. Soon! So…. Anyone have a filter?*

Perception means the brain's ability to receive, identify, differentiate, understand and react to impressions from the different senses.

For a total experience of what is happening, we need to be able to coordinate perceptions we receive through our senses. People with ASD have a different way of perceiving, interpreting, coordinating and giving meaning to the perceptions they receive. They can have difficulty in switching between different sensory experiences and in using several senses simultaneously. Many have difficulty in automatically sorting out irrelevant perceptions. These difficulties in coordinating the senses influence the ability to shift attention. In situations where the person is feeling stress or is tired, their perceptual difficulties usually increase.

For people with ASD, the brain's way of receiving and processing sensory perceptions can lead to:

- the brain registering sensory perceptions much too intensively. The person is overwhelmed by sensory perceptions and notices all stimuli, has difficulties in identifying important information and, in addition, becomes exhausted and/or stressed.
- the registering of perceptions is much too weak. The person doesn't understand the information, something like a person with a hearing impairment

- the reaction of senses other than the one stimulated. The individual can, for example, experience pain from a certain sound or a particular colour.

Following is a list of various perceptual disorders which can occur in ASD::

Auditory perception: hearing

Unusual auditory perception can involve:

- not perceiving auditory perceptions at all, or not being able to create an intelligible context of verbal information (pictures can be more effective).
- experiencing certain sounds as very unpleasant or painful.
- having extremely good hearing and even hearing things that others don't hear, leading others to believe that the individual is hallucinating.
- experiencing sound in a different way than most; that is, a distortion of sound.
- having trouble localising the direction from which a sound emanates.
- having difficulty understanding what is said over background sounds, such as in a restaurant.

Tactile perception: touch

The skin is equipped with a number of receptors for receiving sensations of touch, pressure, cold, heat and pain. If one experiences touch as unpleasant or painful, it can lead to one withdrawing from physical contact. Unusual tactile perception can involve:

- preferring hard-handedness to a soft touch (this is common in ASD.
- having a special fondness for or disliking of certain fabric or articles of clothing. Many prefer clothes like sweatpants that are loose, while newly washed clothing can feel stiff and unpleasant to wear.
- experiencing temperature and pain in an unusual way; for example, thinking it pleasant to have one's teeth drilled, while experiencing the wind against one's skin as unbearable.
- difficulty in determining pressure or weight; for example, hugging too hard or using excessive force to lift a full glass, causing its contents to spill.

Visual perception: sight

Unusual visual perception can involve:

- experiencing bright light as unpleasant and therefore refraining from going outdoors on a sunny day.
- experiencing certain colours and patterns as unpleasant and so wanting to dress solely in one colour or in black.
- experiencing a situation rich in visual stimuli as stressful and therefore feeling strong displeasure in department stores or at amusement parks, such as Disneyland.

- difficulty in determining distance, which leads to approaching or standing too closely to others when speaking.
- difficulty in recognizing places, which makes it hard to find one’s way around, even if one has visited these places many times, which leads to one reluctantly going out alone.
- difficulty in recognizing others' faces, which makes one reluctant to participate in social contexts and causes embarrassment.

Smell and taste

An unusual perception of taste and smell can involve:

- experiencing certain tastes as bitter, which can make one unwilling to eat vegetables.
- not being able to stand certain tastes in combination with a certain consistency or temperature, such as a strong-smelling cheese and cold ice cream.
- having trouble standing certain smells that, for example, make one feel nauseous, such as aftershave, petrol fumes or perfume.

Having unusual perception can also be experienced as very pleasurable by people with ASD. For example, feeling certain surfaces, experiencing certain smells or tastes, looking at glittering items that spin and the fascination of certain sounds or other sensory experiences can be relaxing and positive.

The reason behind the behaviour ...

Many people with ASD are hypersensitive to a lot of sensory stimulation but that does not mean they can explain it to those around them or even put it into words for themselves. They experience displeasure in certain situations but do not understand why. Therefore, those around them must make suggestions in words or pictures of what the problem might be and then try using compensatory strategies. Many, however, have difficulty in changing their behaviour or in accepting good advice and so changes must be introduced in a way that does not make things worse; that is, changes must be implemented gradually, in cooperation with the individual with ASD and with advance planning and clarity. Surprises must be avoided. Time for adjustment before making a change is something everyone needs, but people with ASD need much more time than others.

He is threatening and aggressive

For Nils, trips with public transportation often ended in catastrophe. Riding the bus at rush hour made him panic. When he got help from his caregiver detailing why he experienced bus travel as so difficult, they were able to find strategies to compensate for his difficulties. While mapping out his problems, it became evident that, in situations with a lot of visual and auditory perception, everything just "flowed together", leaving Nils feeling jostled and inundated. The strategy used was the wearing of sweatshirts with hoods. Nils could pull up the hood over his head and screen off some of the difficult peripheral sensory perceptions. He also made sure to always have his mp3 player and something to read with him. In this way, Nils could shut out the bothersome visual and auditory perceptions, which otherwise caused him great stress on bus rides.

She bites and scratches at shower time

At shower time, Stina would often become aggressive and act out. When her caregiver helped Stina to identify why the shower situation was so difficult for her, it became evident that Stina's unusual perception caused her to feel pain from certain types of touch on her skin. For Stina, showering was painful. The tiny jets of water felt like a cascade of needles against her skin. As her apartment had no bathtub and no room to install one, her caregiver removed the shower head. The soft stream of water running evenly over her skin made it possible for Stina to shower without experiencing discomfort.

He holds his hand over his eyes when he goes out for a walk

When Charlie walked in the sunshine, he always held one hand over his eyes. It looked very strange. When his caregiver helped him to identify why he needed to walk with his hand over his eyes, it became clear that he was extremely sensitive to light. The caregiver explained that it looked weird to walk around with a hand over his eyes, which Charlie had not previously understood. Together, they went out and purchased a suitable pair of sunglasses, which made it possible for Charlie to cover his eyes to block out the sun.

Her nails are long and dirty but she does not want to clip them

When Kathy's caregiver tried to clip her nails, Kathy grew terrified and tried to get away by scratching and biting. When the caregiver helped her to identify why the situation was so difficult to handle, it became evident that Kathy experienced pain when clipping her nails. When the caregiver helped her to schedule nail clipping so that they only clipped one nail per day, directly before breakfast, Kathy was prepared for what would happen, and she could handle the situation without panicking.

Identification of unusual perception

Together with a simulated client, Christina, we have identified what she experiences as difficult in her daily life due to her unusual perception. In order to understand how difficult certain sensory perceptions can be experienced, they can be rated from 0-10 (0 = no problem and 10 = extremely difficult). If the person has difficulties with numbers, happy faces can be used to illustrate the degree of difficulty.

Tactile perception Scale

- Difficulty: Wearing clothing of certain fabrics; the washing instruction labels are scratchy. (7)
  Strategy: Purchase only comfortable clothes, cut out all clothing labels.
- Difficulty: Tolerating light touch such as friendly pats on the arm. (6)
  Strategy: Avoid exposing Christina to this. Write it up in the "How to Relate" Document.
- Difficulty: Chewing food of certain consistencies, such as tough meat. (5)
  Strategy: Avoid buying food with these consistencies.

Visual perception

- Difficulty: Judging distance, walking into things. (4)
  Strategy: Be considerate. Do not nag or scold when such accidents occur
- Difficulty: Tolerating light from strong lamps, such as fluorescent lights. (6)
  Strategy: Make certain to purchase the right sort of lamps and light bulbs for the home.
- Difficulty: Feels nauseous from the colour orange. (9)
  Strategy: Personnel avoid orange clothing and buying orange products.

Auditory perception

- Difficulty: Hearing what someone says when in an environment with disturbing background noises. (8)
  Strategy: Take difficulty into consideration when choosing a place for a conversation.
- Difficulty: Tolerating the noise of Hoovers, fans and screaming children. (9)
  Strategi: Buy a quiet Hoover or mop and dry the floor instead of hoovering. Leave the area when children scream or fans whir.

Vestibular perception

- Difficulty: Keeping her balance on uneven or slippery terrain. (4)
  Strategy: Use walking poles on walks over uneven terrain and buy traction cleats for winter shoes.

Kinaesthetic perception

- Difficulty: Assessing strength, such as when opening a milk carton or a bag of crisps (4)
  Strategy: Avoid buying difficult packaging. Buy a good pair of scissors to hang in the kitchen. Write "cut here" on packaging that is difficult to open.

Coordination

- Difficulty: Using multiple senses at the same time, such as speaking with someone while looking them in the eye. (9)
  Strategy: Avoid trying to make eye contact while speaking to her.

Pleasurable

- Walking barefoot on wooden floors, smelling the scent of wood, feeling logs. (10)
- Feeling smooth stones. (8)
- Watching flowing/rushing water. (8)

Identification of unusual perception

Does he/she have an unusual experience of or difficulty in handling certain sounds?
…in handling certain visual perceptions?
…of or difficulty in handling certain perceptions of touch?
…of or difficulty in handling certain smells and tastes?
…in using multiple senses simultaneously?

Other

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What structure, aid, strategy or type of care can compensate for the difficulties?

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Examples of positive experiences of the unusual sensory perception

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In what types of situations can the individual enjoy his or her unusual sensory perception?

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Person in charge: …………………………………… Date of evaluation: ……………………………………

Motor difficulties

> *I remember all those hours in physical education in school as one long series of humiliations. It wasn't enough that you had to undress and run around in those silly clothes, but you had to participate in team sports (I was always the last one chosen – and always with a sigh) and you had to jump over the horse, go ice skating and learn complicated dance steps. All of it was impossible for me. Ball sports were the most loathsome. Suddenly a ball would come sailing along and I would be surprised and scared. Everyone on the team would be irritated with me. Finally, I just refused to join and ditched every lesson. My fine motor skills are no better. I still can't tie my shoes, so I use Velcro on my gym shoes or tie them with double knots so loose I can put on my shoes without tying them up. I was released from wood shop; the teacher thought it would be safest that way.*

Many people with ASD are clumsy and have obvious problems with motor skills. Also common is difficulty with assessing distance and keeping their balance. This can make it tough to walk on uneven terrain or to use stairs, as the individual can be afraid of falling. Others can have problems getting their left and right hands to cooperate and so prefer to use just one hand at a time.

Many have problems with body awareness and in coordinating their muscles – in using moderate force. Moving a heavy piece of furniture then becomes even more difficult because, added to the weight is the demand to regulate muscle strength while the individual manoeuvres himself without colliding with anything. In order to carry out tasks with the body, the individual must concentrate on how every segment should be done and in which order, step by step, and that is very taxing.

Learning to ride a bicycle or drive a car can be impossible, as the ability is never automatised. Everyday tasks can take a great deal of time and be considerable trouble to learn. Then, just when everyone believes that the task has been learned, all the learned stages can be forgotten. It is frustrating and saps energy.

These problems in motor functioning lead many people with ASD to avoid or refuse to do practical tasks, causing others to accuse them of being lazy – an unfair accusation.

How to make things easier

People with ASD do not always come up with solutions to problems, though the solutions are seen as obvious by others. Everyday routines with several stages can be made easier by using how-to lists that describe each step point by point. The lists can be laminated and hung where they will be used. For those who have an easier time understanding pictures, the text can be exchanged for a sequence of pictures of each stage, photographed in the individual's own home.

How to fry eggs

1. Take out the frying pan and put it on the hob.
2. Take out eggs and cooking oil or butter.
3. Turn on the hob.
4. Wait until the frying pan is warm.
5. Pour in the oil or put a pat of butter in the frying pan.
6. Crack the egg against the edge of the frying pan.
7. Fry the egg.
8. Turn the egg if you want it fried on both sides.
9. Take the egg out of the frying pan.
10. Turn off the hob.

After you have eaten

1. Toss out the food scraps that you don't want to save to eat another day.
2. Place the leftovers you want to save in a plastic box and put it in the refrigerator.
3. Rinse the plate and utensils.
4. Fill the sink with warm water and a few drops of washing-up liquid.
5. Do the washing-up using a washing-up brush.
6. Rinse in a tub of clear running water.
7. Place the clean dishes on the drying rack.
8. Let the dishes dry (about two hours).
9. Put the dry dishes in the cupboard.
10. Put away every item in the place indicated by the labels on the shelves.

The reason behind the behaviour ...

She's dumped milk on the kitchen floor

Opening a milk carton always upset Christina. The tab said, tear here – something she always tried, but never succeeded in doing. It often ended with her throwing the milk carton on the floor. When her caregiver helped her to identify why the situation was so difficult for her, they were able to work out a strategy. While figuring out the problem, it became clear that Christina's poor fine motor skills and literal interpretation of the instructions were what caused her outbursts. The caregiver helped her to buy a pair of scissors, which they then hung by a string in a place they were easily seen in the kitchen. When Christina bought milk, the caregiver always wrote cut here on the tab. In this way they took care of one stressful part of Christina's everyday life.

He always causes accidents

For Charlie, it was difficult to move around in places where things were placed close together. Due to his poor ability to assess distance, he often bumped into things and other people. In places like supermarkets with narrow aisles, his problems almost always led to things falling down. He often heard himself called an "oaf". To save money, Charlie shopped at a discount shop, but the goods were stacked close together and the place was always full of shoppers. This was very stressful for Charlie and exhausting for him to be on the constant look-out to avoid bumping into people and items. After identifying the problem, the strategy his caregiver came up with was simple: shop in a smaller store.

Identification of motor difficulties

Together with Christina, we have identified things that, due to her motor difficulties, she experiences as difficult in her everyday life. In order to understand just how difficult certain motor skills-related actions are for her, we have helped her to describe the difficulties on a scale of 0-10.

NOTE: In those situations where Christina has less energy than usual (as when stressed), her difficulties increase.

Fine motor skills

Scale

- Difficulty: Tying shoes, buttoning small buttons. (5)
  Strategy: Buy shoes without laces or with elastic laces,
  avoid buying clothes with small buttons.
- Difficulty: Sending text messages. (6)
  Buy a mobile phone with larger buttons.

Automatising

- Difficulty: Automatising many elements of everyday life. (8)
  Strategy: Use compensatory aids (for example, an electric toothbrush)
  and write how-to lists.

Balance

- Difficulty: Holding her balance on uneven ground and when it's slippery. (4)
  Strategy: Use walking poles when out in uneven terrain and buy traction
  cleats for the winter.

Body awareness

- Difficulty: Judging strength, as when opening a milk carton (4)
  or a packet of crisps, etc.
  Strategy: Avoid buying bothersome packaging. Buy a pair of scissors.
  Ask for help.
- Difficulty: Noticing if she's buttoned her blouse properly (4)
  or if her clothes are on inside-out.
  Strategy: Hang up a full-length mirror in the hall so that she can check
  her clothing before she goes out.

Your identification of motor difficulties

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What structure, aid, strategy or type of care can compensate for the difficulties?

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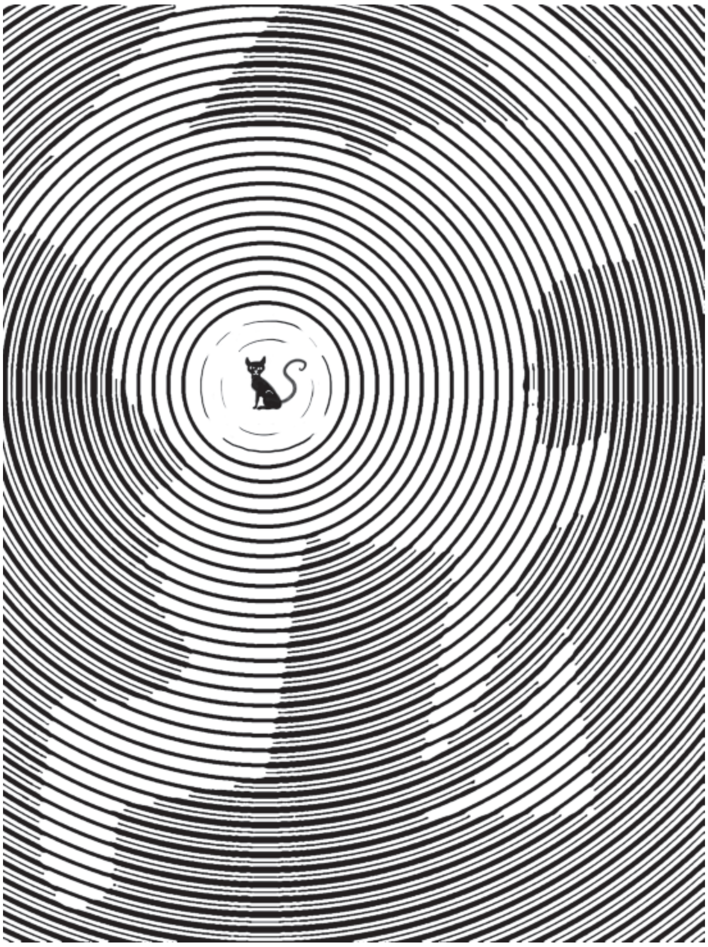
Person in charge:.. Date of evaluation: ....

Detail-focused thinking

For the person who experiences the world through details, details have great meaning in everyday life.



To have continuity and meaning in daily life, it is necessary to understand the overall context and meaning, to be able to categorise according to function and to ignore that which is unimportant. Most people have a brain that automatically makes the world around them comprehensible and predictable – it creates a total picture of a situation through taking a sort of bird's eye view of things. If we listen to a lecturer, for example, we do an immediate assessment, noting her gender and approximate age, and create an understanding of her personality, style and what she has to say to us. Only then do we perhaps take notice of her jewellery, what it looks like and where she probably bought it, what colour hair she has, that she lisps a little, and so on. People with ASD, however, begin from the opposite direction, perceiving and building up their picture starting with the details. They might first take notice of the jewellery, then the dress and so on. It takes much longer to take in the whole scenario. It is like they are laying out puzzle pieces one at a time – they cannot put their attention on everything around them all at once. This is especially difficult for those individuals with ASD and mental retardation, as they can get stuck on details, making them unable to create a complete picture (although some of these individuals are rather good at speaking).

The same sort of difficulties impact the understanding of speech. Most words we use are given meaning from the context in which they are spoken or written, and when we speak, our use of pitch, intonation and pauses adds meaning and content beyond the words. For a person with ASD, it can be difficult to catch the intended meaning of what is said, as they listen more to the words than to what is being said.

Individuals with ASD often get upset or confused when details are changed; in their eyes, everything is changed when a part is changed. Understanding hyper-selective thinking and perception makes it is easier to understand why people with ASD can be so unhappy about changes and why they need to be carefully prepared for everything new. It also makes it easy to understand why they enjoy repetition, routine, and keeping things the way they are – a world where everything can change when a detail is changed is both unpredictable and unreliable and demands a lot of energy of the individual.

Being so focused on details is not only a detriment; it also has its benefits, as it does in tasks where precision and attention to detail are more important than speed: some research tasks, taking a position in certain legal questions, quality control and proofreading are some examples.

Many people with ASD possess impressively independent thinking that is not shaped along the paths of others – it is certainly not always politically correct, but it is refreshing and thought provoking.

The reason behind the behaviour ...

He refuses to take his medicine

Nils had a very difficult time handling a situation where certain details he was accustomed to were changed. He had used one medicine for quite some time when a caregiver picked up his prescription from the pharmacy. The packaging was different. The pharmacist had given the caregiver an equivalent yet less expensive product from a different pharmaceutical company. Because the bottle looked different, Nils thought the caregiver had given him the wrong medicine. When the caregiver realised why Nils did not want to take his medicine, she contacted the doctor, who wrote out a new prescription with instructions as to which pharmaceutical company's tablets should be given so that Nils would recognise the packaging.

He won't loan it out though he's not using it himself

Charlie's difficulties in handling changes were expressed in the following way: When Charlie's friend wanted to borrow his typewriter, they almost had a falling out over it. Despite not having used it in ages, he would not consider loaning it out as he could not imagine how his room would look without it. To help Charlie remain on good terms with his friend, the caregiver helped Charlie to write an e-mail, explaining to his friend why he could not loan out his typewriter.

He didn't recognise me today

Pete's caregiver became quite worried one day when Pete did not recognise her. She thought he was about to have a psychotic episode. Pete had a hard time learning to recognise people but tried to remember with the help of certain details of their appearance. When these details were changed, he had a hard time understanding that it was the same person. In this case, the caregiver had switched glasses - the detail Pete had used to "recognise" her - which is why he asked her who she was when she showed up. When the caregiver understood the reason Pete did not recognise her, she calmed down, knowing he was not psychotic.

She got angry at me while we were cleaning

A newly hired caregiver at Katherine's group home helped her to clean her apartment. When the caregiver poured Ajax instead of another product in the cleaning water, Katherine grew very upset and wanted the caregiver to leave. For Katherine, who associated a specific product with cleaning the floor, it was impossible to mop the floor if the details she associated with the situation differed. After this incident, the caregiver documented all the cleaning details that were important for Katherine so that everyone could help Katherine in a way that worked for her.

Identification of difficulties with detail-focused thinking and changes

Together with Christina, we have identified what she experiences as difficult in daily life owing to her focus on details. In order to understand how difficult certain things are for her, for example when details are changed, we have helped her to describe the difficulties on a scale from 0-10.

NOTE: In those situations where Christina has less energy than usual (as when stressed), her difficulties increase.

Scale

- Difficulty: Handling changes in bus routines (for example, should the bus change its number or route). (7)
  Strategy: Prepare her in good time for reorganisation or changes in local traffic.

- Difficulty: Handling changes in the home. (6)
  Strategy: Respecting Christina's wish to not want to move around the furniture, put up Christmas decorations, etc.

Your identification of difficulties with detail-focused thinking and changes

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What structure, aid, strategy or type of care can compensate for the difficulties?

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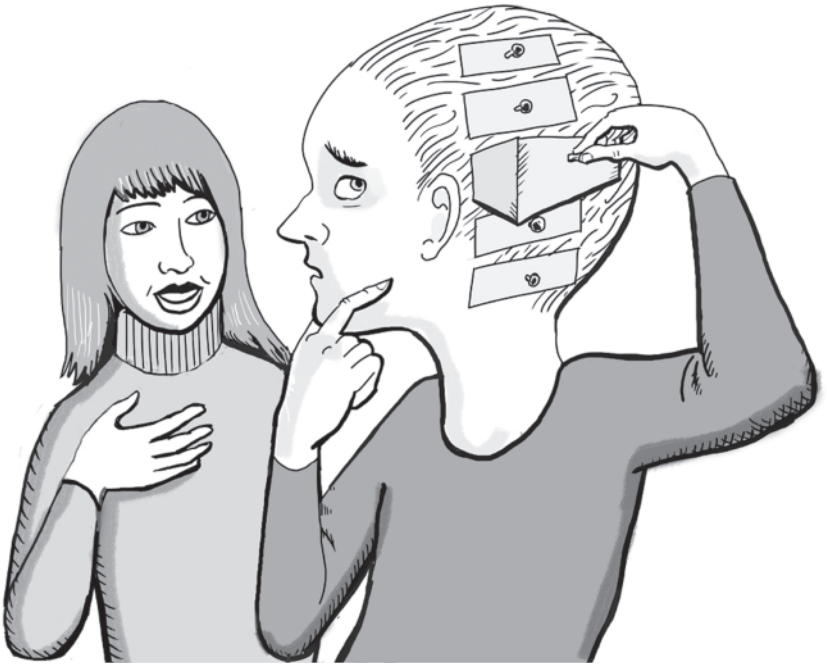
Person in charge: .... Date of evaluation: ....

Executive Functions

> ***If all knowledge were stuffed down in different bureau drawers, normal culture would open drawers where the information would spill over from one drawer to another. In the autistic culture, the various drawers don't have contact with each other.***
>
> Gunilla Gerland

> *I have a short in my start button and in my finish button. Someone has to push them so that I get started but they even have to hold them in so that I can finish.*

> *I was given the task of putting up fliers about a concert in town - it should have been an easy task. I had tape with me and a stapler as sometimes you need them. I walked around town until it got dark, but didn't find any good places to put up the fliers. Either the tape wouldn't stick or there wasn't enough room for my flyer or it was forbidden to put them up. I felt like a total failure.*



The ability to follow a strategy to reach a goal, to shift attention, plan, organise, inhibit irrelevant impulses, to assess and correct one's own behaviour, flexibility and working memory are usually summed up with the term executive functions, which are connected to the functioning of the frontal lobes. Should one have lowered executive functioning, one's sense of time is usually also poor.

Problems with executive functions can, in combination with detail-focused thinking, make it difficult for the person to see the connection between different events in time and to learn from their mistakes. If one does not understand that that which happened before caused that which happened after to go wrong, the environment becomes incomprehensible. For example, one does not see the connection between rent book—missed payment and eviction notice—eviction. One does not add one experience to another experience and one does not learn from mistakes. It can be just as difficult to imagine time in the future.

In ASD, deficient simultaneous capacity is more the rule than the exception – the individual cannot juggle several things at the same time. The need to orient oneself in the room while at the same time remembering to finish a task can cause the person to get off track. In order to finish a task, the instructions need to be broken down into steps. How-to lists that give step-by-step instructions on how to carry out a task usually make this easier.

The reason behind the behaviour ...

She has threatened the children in the yard

Malin's difficulties in understanding that events often have a connection gave her big problems. On day she rang her caregiver and screamed that someone was trying to kill her. She was convinced of it, as earlier someone had persistently tried the doorknob and rung the doorbell. Malin now sat in her apartment, terrified and with the blinds drawn. The caregiver asked her to describe what had happened prior to this. It turned out that Malin, who is extremely sensitive to sound, grew very stressed over the noise from the children playing in the yard. To handle her frustration, she had run out and screamed at the children, "If you don't shut up, I'll kill you!" The children told their parents, who then angrily rang at Malin's door. When the caregiver explained to Malin how the chain of events was strung together, she could understand the connection. When Malin later got her apartment sound proofed, her frustration over the noise outside stopped.

She is irresponsible when it comes to money

When it came to finances, Karen often clashed with her caregivers. One day Karen saw a leather coat she wanted. The coat, which had cost over 700 pounds, was on sale at half off. She bought the coat, feeling like she had made 350 pounds. She did not see that the consequence of her purchase was that she could not pay her bills. Karen's caregiver helped her with a visual picture of her finances. She photocopied £10 notes in the sum of Karen's monthly income then stacked them in piles according to Karen's various monthly bills and expenses. She then asked Karen how she wanted to spend those £10 notes that were left after all fixed expenses, such as food and rent, were paid. She demonstrated how to divide it up and take out a certain amount each week, how to open a savings account and put in a small sum every month, etc. When Karen could see this concrete presentation of her finances and could decide herself how to allocate her money, all conflicts concerning her finances ceased.

To help the person see the connection between cause and effect and to understand what is needed to reach a certain goal, it is good to help him to make the consequences of his choices clear. For example, sketch steps and write the individual's goal on the top step. On the rest of the steps, together with the individual, write in each step of what needs to be done to reach the goal. It can also be helpful to make a list of what the individual should do each day so that he can see it all and limit himself.

Identifying difficulties in executive functioning

Together with Christina, we have mapped out what she experiences as difficult in her everyday life due to her executive difficulties. To understand how difficult certain things are for her, we have helped her to describe her difficulties on a scale of 0-10.

NOTE: In those situations where Christina has less energy than usual (as when stressed), her difficulties increase.

	Scale
• Difficulty: Keeping track of and managing her finances. *Strategy: Visual demonstration of income and expenses. Internet bank. Help her to find an executor.*	(9)
• Difficulty: Keeping track of and managing her time. *Strategy: Help her with planning for the year, the month, the day. Whiteboard, calendar, pocket diary. Break down various activities so that it is easy to take in and handle.*	(6)
• Difficulty: Tossing out old newspapers and junk mail ads. *Strategy: Put up a sign on her mail slot, "No junk mail please". Have an agreement whereby she does not pick up free newspapers in town. Point out the financial benefit of reading the daily paper online instead of buying it. Those papers she has a hard time tossing out are placed in a box under the bed. Help her to mark it with the date and have an agreement with her that, should she not read a paper, the caregivers will toss out it after two months. Remind her that a lot of information is available on the Internet and is easily found by using Google, should she need the information at a later date.*	(9)

Your identification of difficulties with executive functions

Does he or she have difficulty planning and organising her or his time?
Does he or she have difficulty setting up a strategy and following it?
Does he or she have difficulty seeing the connection between different events and learning from his or her mistakes?
Does he or she have a hard time throwing out old newspapers and junk mail?
Anything else?

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What structure, aid, strategy or type of care can compensate for the difficulties?

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Person in charge: .... Date of evaluation: ....

Generalising

> ***Another consequence of my way of seeing the world was that it wasn't obvious to me that one thing could be located behind or under another thing. If I saw it, I understood it, but I connected it to only that which I saw. The moment I saw a ball that rolled in under a bureau, I knew that balls could be found under bureaus. I also understood that the ball was there even when I didn't see it and I could generalise so far that I understood that other balls could be hidden by large pieces of furniture.***
> ***I could add these experiences to my knowledge of the world and use it later, but it didn't tell me that there might be other things than balls under bureaus, or that anything might land under and behind other things so that they were hidden. My parents laughed at me and blamed me for my hopeless laziness; in their world, I didn't have the energy to lift one thing in order to search for another. God had never created a lazier child!***
> Gunilla Gerland, A Real Person: Life on the Outside,1996

People with ASD often have difficulty in starting with an overall picture and seeing similarities with another situation; that is, in generalising. An example of generalising is intuitively understanding what an apple, a pear and an orange have in common. Most people would say "fruit" but a person with ASD might see the rounded shape as a common factor. These difficulties also have to do with how the person uses learned skills. The individual therefore needs to practice the skill in an environment or situation where the skill will be used. If a person with ASD has learned to cook by taking a cooking class, it does not mean that he will automatically be able to cook at home in his own kitchen, where everything looks different from what was used in the cooking class. If the person has learned that it's a good principle to share a restaurant tab equally, even if the other has eaten something a little more expensive, it does not mean that the individual will generalise this insight to equally sharing the cost of a taxi home. The "rule" for sharing a restaurant check is seen as completely different from the "rule" of sharing the cost of the taxi.

The reason behind the behaviour ...

Now she can't go to the bank by herself

Lena had always been able to go to the bank by herself and make deposits and withdrawals, but when she changed banks, she could no longer do this. The new bank's deposit and withdrawal slips looked different. She had learned how to fill in the ones used by her previous bank, but she could not generalise the knowledge. When the caregiver brought home slips from the new bank and filled in a template, Lena could take the template to the bank and take care of her banking errands herself.

There's no order in his kitchen drawers

At first glance in Matt's kitchen drawers, it looked like he mixed his cutlery every which way. The knives were placed together with the pens, chopsticks, a pair of tweezers and a screwdriver and the drawer was filled to overflowing. When the caregiver understood that Matt sorted things by form and not by function, he could explain the benefit of sorting by function – it would be easier to find things in drawers when they were not overflowing.

She cannot take care of her hygiene any more

In her parents' home, Sophia always took care of her hygiene, but when she moved away from home, she was suddenly unable to shower or change clothes. At home, Sophia had learned routines for taking care of her hygiene, but in the new apartment, everything looked different. Sophia's caregiver had to help her to learn routines in the new apartment.

Your identification of difficulties with generalising

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What structure, aid, strategy or type of care can compensate for the difficulties?

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Person in charge: .... Date of evaluation: ....

Mentalising: understanding the perspectives of others

Mentalising is the ability to intuitively understand how other people think and feel. The ability is innate but develops successively from early childhood. This ability is reduced in ASD. Mentalising is a condition for creating a conception of what lies behind others' actions and reactions and it facilitates the understanding of white lies, metaphors and irony.

Difficulty in mentalising makes the behaviour of others incomprehensible. How can it be that a person behaves differently in a certain situation despite my treating her the same way? Social rules are completely unnecessary. Why should I wait for other people? Why should I adjust myself to the group? Conversations with others are uninteresting and difficult to understand. Activities are more interesting than friends. Provocation – one's own or that of others – cannot be understood. It is difficult to change perspective and follow reasoning that is based on feelings and opinion.

The belief that everyone has the ability to intuitively read others is so deeply rooted that

we have a hard time understanding how people with ASD feel and think and what they mean. We have problems really believing what they say if we do not see that it agrees their gesticulations and or how they adjust their facial expressions or vocal pitch. This lack of agreement confuses us and, unfortunately, can also cause us to keep our distance. This can result in our excluding or bullying the person with ASD. Many people with ASD have experienced bullying, first in school and later on the job. Being bullied can lead to a lack of trust in others. Insults and injustice, which might lie decades back in time, can still feel like they occurred recently and many people have a hard time overcoming them. Because of difficulties in understanding others' perspectives, sometimes the individual with ASD can misunderstand an incident or not understand that it was only a joke and not meant seriously.

Identification of difficulties understanding another's perspective

Together with Christina we have identified what she experiences as difficult in her daily life due to her difficulty in reading others' intentions and feelings. In order to understand how hard certain situations are for her, we have helped her to describe the difficulties on a scale of 0-10.

NOTE: In those situations where Christina has less energy than usual (as when stressed), her difficulties increase.

Scale

- Difficulty: Understanding metaphors and things that are said "between the lines". (8)
  Strategy: Avoid metaphors and say what is meant. Be direct and clear. Check that both have understood correctly.

- Difficulty: Understanding social rules. (7)
  Strategy: Explain different social rules through social stories.

- Difficulty: Getting over insults, bullying and injustices. (9)
  Strategy: Write a letter to the person who bullied her and ask the person to explain himself or apologise.
  Strategy: Write down the chain of events and symbolically bury it.

Your identification of difficulties in understanding another's perspective

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What structure, aid, strategy or type of care can compensate for the difficulties?

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Person in charge: .... **Date of evaluation:** ....

Feelings

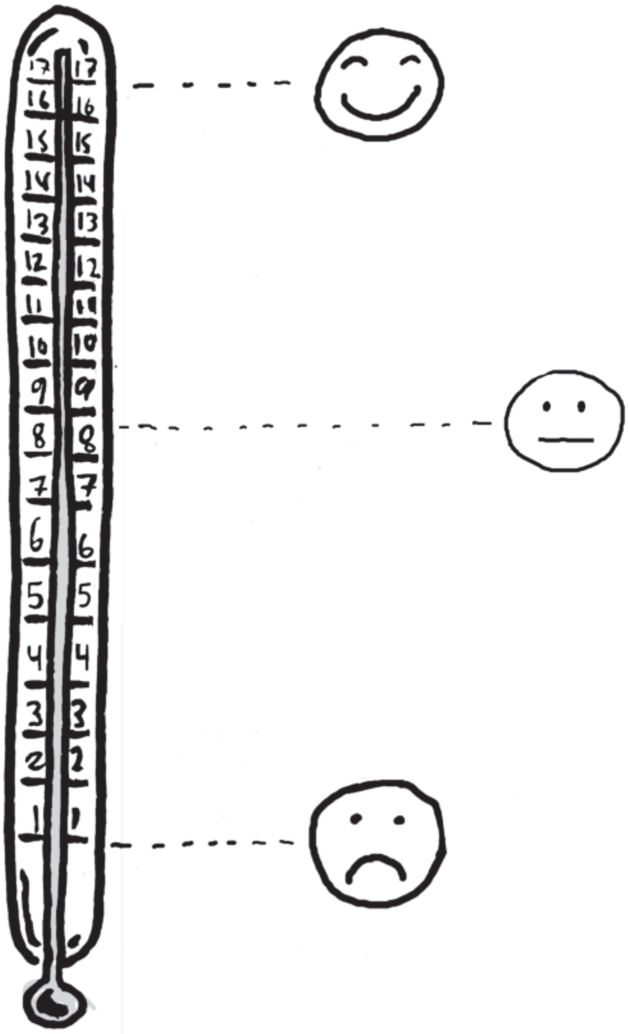
A common misconception is that people with ASD lack sympathy. This is a misunderstanding and likely occurs due to the common confusion of sympathy with empathy. When it comes to ASD, what is meant by the term empathy disorder is the difficulty in mentalising (theory of mind). People with ASD do not lack the ability to feel sympathy or compassion; it is the ability to empathise—to read another's body language, facial expressions and anything else that is said "between the lines". In order to recognize feelings in others, one must be able to notice and discover the right signals. Those signals we send apart from words are difficult for people with ASD to understand and register.

People with ASD have just as many feelings as others, but they can be expressed differently. They can also be sad, worried or happy or feel insulted by things that those around them might not expect. As they do not show through their facial expressions or body language that they are sad, under stress or worried, it is more difficult for others to read their emotional states and react to them properly. People with ASD often have difficulty in describing what they are experiencing emotionally and how they really feel. Many do not feel physical sensations from happiness, sorrow or anger, but that does not mean they do not have these feelings. The question, "How are you feeling?" can be experienced as very stressful and impossible to answer.

It is not unusual that people with ASD feel strongly for certain phenomena, things or places. For example, if they come to a place they like and discover that something has been painted or refurnished, they can have very strong emotional reactions. Water damage in a library where ancient manuscripts were kept and destroyed made one person with ASD severely depressed.

Small, unexpected changes of details in every day life can many times be more difficult to handle than greater changes for which the person has been prepared. One can clearly experience things in different ways and nothing is "better or worse" or "wrong".

The **CAT-kit** is an educational tool that can ease mutual communication between the person with ASD and those around him. It is visual working materials collected in a binder which can be used as a template when, for example, one wants to explain social interaction, relationships and feelings. It also makes it easy for others to understand how the person with ASD thinks. Among other things in the materials is a thermometer which can be an aid in explaining how difficult something can be.



Material Tips:

Callesen, K, Møller Nielsen A & Attwood T: The CAT-kit.
www.cat-kit.com 2003

The reason behind the behaviour ...

She cannot say how she feels…

Eva had problems in expressing and explaining how she felt; she never showed it through facial expressions or body language. For those around her, it was very difficult to read her. The caregiver did not notice that Eva was not feeling well, which led to overly high demands on her. Eva had no energy left over to take care of other things that those around her, not understanding how she felt, demanded of her. When the caregiver introduced a visual feelings thermometer, Eva was able to use its scale of 1-10 to express how happy, sad, angry, etc. she was in various situations. It did not only help Eva to express how she felt physically and emotionally, it also helped those around her to understand Eva better and to be able to take her emotional and physical condition into account.

Why was she sad?

When Stina was out on a walk with her caregiver, she suddenly became very sad. The caregiver did not understand the reason and Stina could not verbalise why she was suddenly so sad. It was not until several days later that she could explain: On the walk, they had passed a garden where all the beautiful bushes that Stina usually stood and looked at had been cut back. As she was not prepared for this, she was saddened that the bushes were gone.

She threw a tantrum at the pizza parlour

When Malin and her caregiver were served the food they had ordered at a newly opened pizza parlour, Malin was upset. It turned out that the type of pizza she always ordered had different ingredients than what she was used to. For Malin, who did not check the menu but simply said the name of the pizza, this situation was difficult to handle. When her caregiver understood why the situation was so difficult for her to handle, she helped Malin to always check the menu before ordering.

Why does he act that way?

When Nils got help to spring clean his apartment, he was suddenly so shaken that they were forced to stop cleaning, though the caregiver had no idea why. It was weeks later that Nils was able to describe how hard it was to be separated from old and broken things. He had a relationship to his possessions and felt a tremendous sorrow over being separated from them. When his caregivers understood how hard it was for him to throw out things, they prepared him for it for quite a long time and even found cellar space for him where he could stash some of the items.

Difficulties in social interactions

> *I was born socially blind and I live socially shipwrecked. In social contexts, it feels like I'm drowning. Can someone give me a social nautical chart, compasses and lifebuoys so I can navigate life's oceans?*
>
> *People are the hardest thing to understand; they move when you least expect it, they make different sounds and they make a lot of demands that are completely impossible to understand.*
>
> *Everyone is expected to know the rules, but how can you, when no one even tries to teach you the game? When I was a child, I tried to figure out how the rules of football might be conceptualized. This is how I thought they were:*
>
> *Football is played by 11 people, 10 + a goalie. The ball is kicked toward the goal, in order, by the players, the order dependent upon the numbers on their jerseys. The one who succeeds in kicking the ball through the goal gets 1 point. If a player tries to take the ball when it is not his turn, he gets a penalty. This means that he has to skip the next time it is his turn. When the match is over, the player with the most points wins.*
>
> *When the kids in the neighbourhood played football, I tried to play according to these rules. As we didn't have numbers on our shirts, I thought that you had to keep track of your number yourself. I was the newest one in the gang, so I thought: I'll wait until all the others have had the ball, then it must be my turn. But it was never my turn. The others played with such contempt for the rules that they tried to take the ball from each other and completely disregarded whose turn it was! (Now, of course, I know that there are two teams and that you have to fight for the ball.) When I told this to my psychologist 40 years later, he did not believe me! He said that anyone as intelligent as I could not have missed the whole point of football. But it's not about intelligence; it's about the ability to read the social rules..*

As it is difficult for people with ASD to see the whole and the context, it is also difficult to understand and judge social situations. Not knowing what is appropriate to say, do or comment on creates problems in being with others. Many people with ASD constantly try to understand and find the logic in social rules in different contexts. People with ASD who do not display the "right" behaviour in social contexts are sometimes treated like children or as though they are stupid, which they naturally experience as insulting.

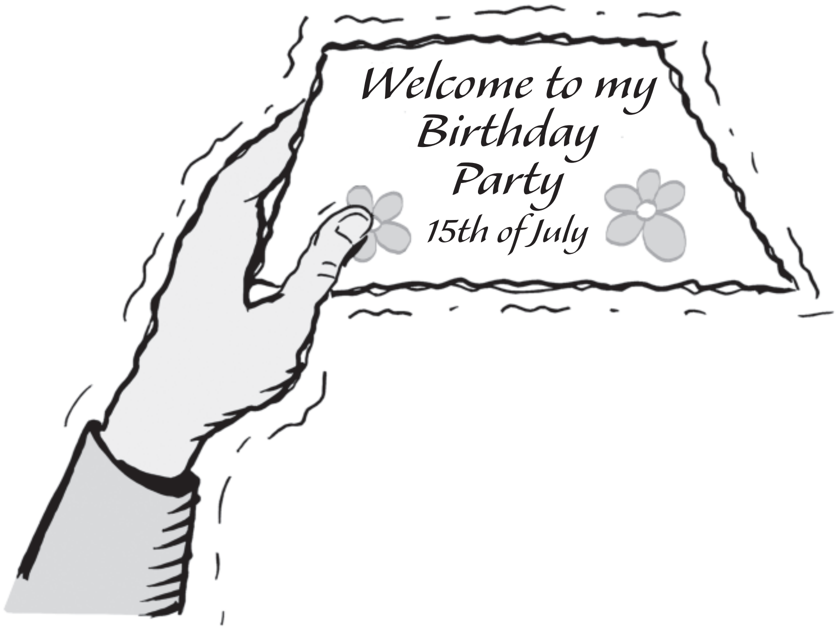
Socially acceptable behaviour requires good social understanding. Social understanding requires the ability to read people and understand what they feel, think and mean. Without it, it is difficult to interpret what others intend with their words and to understand their behaviour. Without social understanding, why people do things a certain way is incomprehensible and predicting what they most likely will do next is impossible. It can be very tiring for the person with ASD to get in the swing of things – that is, to try to grasp and then behave the "right" way.

Social understanding cannot simply be practised until perfect if the individual lacks the necessary foundation, any more than one might practice to gain perfect pitch. Every social situation is unique for the one who can generalise, and the polish that is needed to smoothly handle every single situation can hardly be taught. On the other hand, certain general social rules can be learned, leading to the person with ASD no longer feeling completely unsure in social contexts.

A small percentage of people with ASD seem to have the prerequisites for developing the ability to understand social interaction. These people seem to have a delayed maturation. They watch how others behave and imitate them in such a way that it looks natural. With time, this social behaviour can be automatised and then they no longer fulfil the criteria for ASD. For others, their behaviour can certainly seem normal, but it is not automatised; it is laborious and demands the individual's full and continual concentration. After a long conversation, the person might need to rest the entire day.

Social stories

Charlie had long wanted to study. His caregiver helped him to find a course and he was accepted. It did not take long before the instructor of the course contacted Charlie's caregiver. The instructor said that it was not working out with Charlie, as he disturbed the other students and interrupted the teacher. The caregiver, who knew Charlie well, offered to participate one day and to video film the lessons in order to identify the reasons for Charlie's difficulties. It became clear that what caused Charlie's problems was his belief that the teacher was speaking directly to him and wanted him to answer all the questions. When the caregiver wrote a social story explaining the situation to Charlie, he understood that the teacher was not speaking only to him, but to the whole group. When he understood this, he changed his behaviour in the classroom.



Social stories are short stories that describe a social situation and the subsequent social reactions. They are formulated to describe a certain problem area and can be used in a variety of contexts. The information should be clearly described and based on the individual's own experiences, skills and difficulties.

Social stories consist of three foundational sentence types: descriptive, directive and perspective sentences. The three sentence types are put together to form a social story. One condition for writing a goal-oriented and individually tailored story is that the writer understands the function of each sentence type and uses them consciously.

Descriptive sentences describe what is happening, what people do in a certain situation and why they do it. They are the backdrop of the story and highlight what is relevant in the situation while the irrelevant is left out. They help the individual to focus on important concepts and events, relate foundational information about a situation and describe this step by step. In descriptive sentences, those people who are involved are also presented. As a rule, social stories open with a descriptive sentence. The most common mistake is not using enough descriptive sentences in a social story.

Directive sentences are individualised statements that relate what is expected in a certain situation and how one should respond in order to negotiate the situation. Directive sentences often begin with, "I want/can/will…"

Perspective sentences illustrate others' reactions to a situation. They relate others' thoughts and feelings and explain why others react the way they do. Perspective sentences should not be too general, such as, "everyone thinks such-and-such"; "Some people think such-and-such" is better.

Following are examples of how one might write a social story to instruct the individual regarding suitable behaviour at a family member's 60th birthday party:

It is common that people invite family and friends to a party when they have a birthday. The one in charge of the birthday party usually offers the guests something to eat and drink. The guests at the party visit with each other. There is usually a lot of questions, talking and laughter.	***Descriptive sentences***
Most people enjoy birthday parties and think it is fun to meet and visit with each other.	***Perspective sentence***
I don't like all the sensory impressions of lots of people meeting. I think it's difficult to know which questions I can ask and what I can talk about with others. I get stressed out easily and I don't know how to act or what is expected of me.	***Descriptive sentences***
When my dad turns 60, he's going to have a party. He has invited a lot of relatives and friends	***Descriptive sentences***
Dad really wants me to be at his party.	***Perspective sentence***
I want to try to be at Dad's 60th birthday party.	***Descriptive sentence***
I can prepare myself for the questions and topics of conversation and I can write it all down on a piece of paper that I can carry in my pocket. That way, I can look at it from time to time and perhaps come up with something to say.	***Directive sentences***
My sister will be at the party. She will help me. She can whisper to me now and then and tell me what is happening and what I should do. That's OK.	***Descriptive sentences***
I can sit next to my sister at meal time.	***Directive sentence***
If I get stressed out, I can go to my room and listen to music. That's OK.	***Directive sentence***
My sister can remind me that I can go to my room if she sees that I am getting stressed out. It's assuring to know this.	***Descriptive sentences***

How do you introduce a social story?

Social stories are often about situations which can be difficult to understand and to accept. The most important thing with social stories is to give the person the possibility of acting appropriately in a certain situation. Naturally, it is important to listen to the individual and to take their feelings and thoughts seriously. Social stories are often a good springboard for continued discussions concerning important issues.

Just as there are guidelines for how one writes a social story, there are also guidelines for how to introduce and present a social story. Different people need to be introduced to the stories in different ways. Many are open to accepting this form of care, while others feel imposed upon and experience social stories as silly or beneath them.

Social stories should be used with great sensitivity toward, respect for and knowledge of the one to be helped by the stories, but it is important that the caregiver not take a negative initial reaction personally and, above all, one should not immediately see it as a sign that the story is useless. The reaction might be an expression of the individual's embarrassment over his lack of understanding of a certain situation that seems so clear when he reads the story.

The social story should be presented somewhere the individual feels safe and secure, such as at the kitchen table or while riding in the car.

If you presents a social story that does not work, you should look both at the content of the story and the form:

- Have I understood what the problem is?
- Have I described it correctly?
- Were the strategies I suggested correct?
- How did I present the story?
- Could the individual use the story under current conditions?

How a social story can be used as a job description for the caregiver

In order for the staff to know how a person prefers to be approached, you can write a type of reverse social story (see next page). It can be written more simply than is shown in the example, but the principle of keeping the person's perspective in mind is central. No matter which home caregiver comes along, they should know the background of why certain things are difficult for the individual to deal with, show respect for the individual and carry out home care in a way that is important to the individual.

Examples of how you can help the person to write a reverse social story

There are many situations in my daily life that are difficult to deal with. To organise my mail and to have an overview of what I need to buy takes a lot of energy. I have unusual auditory perception, making certain sounds difficult for me to tolerate. For example, I can't deal with the noise of the Hoover, as it feels like knives cutting through my head.	***Descriptive***
When you come to my home on Tuesdays, I'd like to start by putting in a load of washing. Then I'd like to sit in the kitchen and together with you organise my papers and newspapers. Don't ask how I feel and avoid small talk, as it's hard for me to handle. When we are done, I'd like you to help me write up a list of things to buy. Next, I'll go to the shops and buy what I need while you water my flowers, dust and hoover. When I get back, I'd like us to hang up the laundry and then have a cup of coffee. After that, I'd like you to help me transfer things from my monthly planning to my daily diary. When you leave, I'd like you to take out the trash and the old newspapers.	***Descriptive***
It's important for me to do all this in the same way and in the same order every Tuesday. I like routine and doing things in the same order. I don't like surprises and have difficulty handling unforeseen changes. Therefore, it's also important for me to know in advance who is coming to my home on Tuesday. For me, it takes a lot of energy meeting new people, and so I have trouble having home care comprised of new substitutes.	***Perspective***
In order for me to know who will be coming to my home on Tuesdays, I would like you to send me a text message with the information on Monday evening. Should the worker who planned to come suddenly become ill, and a substitute is called in, I might decide not to have help that day. Please respect my decision.	***Directive***
We have documented this together in order for you to be able to give me the care I need in the way I would like to have it. For me, this is a quality assurance by my caregiver, and for you it's a clear job description. Please bring this document with you on Tuesdays. When you return to the personnel premises, please put it back in my binder. Should you forget the document, there is a copy of it on the inside of my hall closet door.	***Directive***

Comic strip conversations

Comic strip conversations involve drawing while you talk in order to explain what you mean and to work through problematical situations and find solutions. By drawing stick figures and using colours, you can describe feelings (for example, red = angry, green = calm, yellow = neutral). Comic strip conversations follow the conversation, the drawing emerging as you talk and describe what people say and do and what opinions they hold and how they think and feel. They give a glimpse into the individual's perspective on a given situation and can form the framework of a social story.

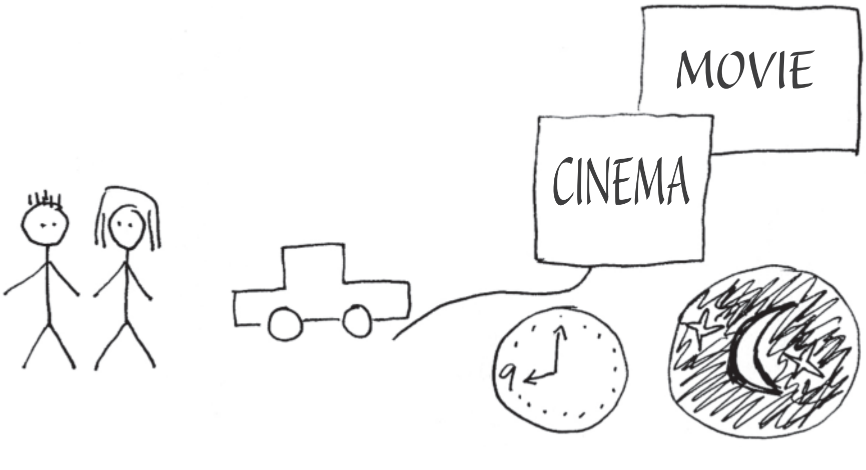
The Comic strip conversations builds on a common focus and interaction here and now. The exchange of information and change in perspective go more slowly than normally and the pictures help to increase understanding and help the person to visualise what is happening.

Comic strip conversations can feel embarrassing to carry out, especially at first, but they are a very good aid as verbal skills in people with ASD often hide a poor ability to understand the whole context.

How do you introduce a Comic strip conversation?

When working with a Comic strip conversation, the participants should sit next to each other. Paper and pens or a whiteboard should be at hand. Both parties should be able to reach the materials and see the drawing from the same direction. The environment should be well known and quiet; the kitchen table is a good choice.

There is a risk that the comic strip conversation will become a jumble of pictures. For this reason, it can be a good idea to divide up the paper into numbered squares like you see in comic strips. In the comic strips conversation's summary, it should be possible to visualise the entire chain of events. Alternative solutions can then be drawn as suggestions for what the individual can do or think the next time he finds himself in the situation.



Social scripts

> *I had a messy relationship with my relatives and had broken off all contact with them. When one of my parents died after a period of illness, a funeral service was planned. I panicked at the thought of confronting my relatives, considering how bad our relationship was. I didn't feel I could deal with the situation. I got advice from my psychologist, who also helped me with a so-called social manuscript. She told me that when my relatives contacted me in the church, which I was certain they would do, I should say, "This is a very serious and important moment for me and I don't wish to be disturbed". She told me that no one would then disturb me, as the one who did so would be giving the message that the moment was neither serious nor important, and such a message was hardly one would give at a funeral service.*
>
> *It worked out well. I said exactly what she said I should and those relatives who contacted me drew back without showing any sign of distress over what I had said. I sat alone in the pew at church, behind all the others, and left at the end of the service. I didn't take part in the get together after the funeral, but was satisfied I was able to be there for the ceremony. Had I not been able to be there, it would have been an eternal sorrow for me. With the help of this strategy, which I would never have been able to come up with myself, I could go to my parent's funeral.*

Social scripts are a form of detailed directive which can be given to a person with ASD in advance of a specific situation that the individual experiences as difficult. General advice is insufficient; it is the details of how the individual should act that inspire confidence. The details can even be the necessary prerequisite for the individual to even dare to enter into the situation.

A young man was uncertain how to engage his classmates at university in conversation. He asked his psychologist, who suggested he talk about such things that people who do not know each other well usually talk about. The psychologist made a list over subjects people usually talk about. It covered books people read and liked, television programmes and series, the latest news, current films, travel plans, children's problems at school and various things on the job. This list did not make things easier for the person with ASD, who wondered what he was supposed to do with the list. He needed a social manuscript in order to initiate a relationship with his classmates. Instead of the list, the following was written down:

> *At break time, smile a little at xx, whom you think might want to talk to you. If xx smiles back or at least does not turn away, at the next break, approach her. You can then ask xx what she thinks of the class and ask if she thinks it's interesting. Then you can say, "I'm thinking about going to see yy film. Have you seen it?" If xx has not seen it, you can say, "I was thinking of going to see it sometime this week. Would you like to join me?"?*

A social menu can also be used. For this, write down bullet points to make it easier for the person to remember how to behave in certain situations.

Social menu for mealtimes

- It is not OK to eat up the food that someone else has left on his plate, or drink the wine someone else has left in his glass.
- If a buffet is served, it is considered impolite to load your plate to overflowing. If you can't decide what to eat, you can return for more food once more, but not more than that.
- You are expected to arrive at the time you were invited. It is impolite both to come too early and to come much too late. Arriving 15 minutes late to a dinner party is OK, but it is not OK to let someone wait outside a restaurant when you have set a time to meet.
- You are expected to arrive in clothes that suit the occasion* and that are without holes and clean and to be clean yourself (to have showered and washed your hair the previous day, if not more recently). If you are a man, you should also have shaved, unless you sport a beard.
- You should bring a small gift to the host/hostess. Suitable gifts are a small bouquet of flowers or a box of chocolates
- Small talk is often a part of dinner parties; that is, people speak rather loosely or randomly on suitable topics, without going in all too deeply. People take turns speaking. Just talking on and on about whatever you are interested in, without giving those around you a chance to join the conversation, is considered quite rude.
- Certain topics of conversation are appropriate for small talk, while others are very inappropriate and can be seen as offensive to bring up at the dinner table.
- Those subjects that are appropriate to talk about can be found under the subheading “Plus topics”.
- Those subjects that are inappropriate and that should be strictly avoided are under the subheading “Minus topics”.

Plus topics that most often are appropriate to bring up during small talk:

- Good books you have read or good films you have seen, home decorating, the weather and sports.
- What you work with or are studying, your vacation plans or what you have done on your vacation.

Minus topics that should be strictly avoided as small talk:

- Your own and others’ sex lives.
- Asking how much the others at the table earn.
- Stories that have details about faeces, vomit, blood or snot.
- Details about murder, death or serious illnesses.

* What passes as suitable clothing differs, depending on the context. Most often, for men trousers, shirt and jacket are fine, while for women a dress, long skirt or nice trousers and a nice sweater or blouse would be considered suitable.

The reason behind the behaviour ...

He insults people

Nils often interpreted words and expressions literally and was therefore very upset at a meeting with his officer at the National Insurance office. His officer thought that he should be given an early retirement or sick benefits. Nils did not know what either of those entailed but, because he thought his officer looked much older than he, he replied that if anyone should retire it was certainly she!

Coffee breaks are a problem

Art and Malin were on a work-training programme at the local department store. They were given clear instructions on their job duties, which they appreciated and carried out well. At the coffee breaks, however, they both had problems, though for different reasons. Malin usually took her coffee break and sat in the corner, quietly drinking her coffee. She discovered – and was surprised to find out – that she was not only expected to fulfil her duties in the work area, but even to carry out such irrelevant things as being social with her colleagues at break time and remembering everyone's name and interests. Art had trouble understanding what coffee breaks were good for and why others expected him to take them – after all, he drank neither coffee nor tea.

Identifying difficulties in social interaction

Identification can be done with the help of an assessment sheet from the book "Assessing and Developing Communication and Thinking Skills in People with Autism and Communication Difficulties: A Toolkit for Parents and Professionals" by Kate Silver, Jessica Kingsley Publishers, 2005.

Difficulty

☐ Taking turns during an activity.

☐ Recognising his or her own feelings (anger, happiness, fear, etc.).

☐ Interpreting others' facial expressions, gestures and body language.

☐ Understanding social rules regarding physical contact.

☐ Keeping an appropriate distance from others while in conversation with them.

☐ Maintaining eye contact during conversations.

☐ Initiating a conversation.

☐ Taking turns talking during a conversation.

☐ Observing the listener's response and noticing if he or she is bored or confused.

☐ Clarifying what you mean, when necessary.

☐ Listening actively – giving feedback signals.

☐ Maintaining and developing a conversation in a small group.

☐ Ending a conversation in an appropriate manner.

☐ Interpreting others' signals that the communication has ended.

☐ Waiting an appropriate amount of time before answering in a conversation.

☐ Adjusting information, depending on what the listener knows.

☐ Understanding what should be private – the things about which one does not speak.

☐ Adjusting his or her manner of speaking, depending on to whom he or she is speaking.

Your identification of the individual's difficulties in social interactions

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What structure, aids, strategies
or care can compensate for the difficulties?

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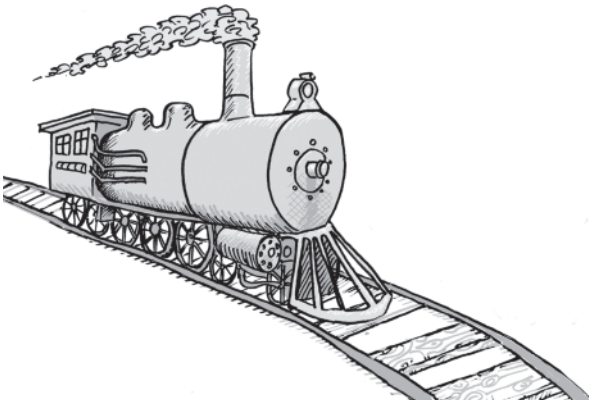
Person in charge:.. Date of evaluation: ....

Unusual imagination and interests



Part of the uniformity of people with Asperger syndrome is that many of us have very strong special interests. Other people also have that. But people with Asperger syndrome usually have very unusual interests, especially things with many details, and we are usually very strongly interested in them. It can be anything; we are not limited by any social comme-il-faut on what we should be interested in. Some of us are catalogue enthusiasts, some love to learn timetables by heart, while others want to know absolutely everything about different models of buses. It can happen that other people think these things seem like very boring hobbies and they try to make the party in question do things that others think are fun in the hopes that when he finally gets a taste of normal fun, he will enjoy it. And, of course, leave those weird interests behind ...

We are exceedingly attached to the interests we choose ourselves. We do not see certain subjects as nerdy; we remain tolerant and neutral to what others do and would appreciate it if others did the same for us. The thing is, just as for other people with their normal (= allowed?) interests, we find the hobbies we choose to be satisfying, fun and relaxing.

If you have had a challenging day, it is nice to relax with mathematics or to study the technical data of Hoover models or do chemical experiments or become absorbed in a thick tome on small, brown, inedible mushrooms. We have a blessed ability to become completely absorbed by that which we think is fun. In the right context, the ability is a gift from God. Others often think that the interests we choose are a little odd or that we are a little too persistent when carrying on with our interests, but who decides it's okay to like sports but not spiders?

Gunnel Norrö

Most people with ASD have imaginations and interests that lack social content and that others might find go overboard. Women's special interests are usually found in usual areas such as sports, environmental issues, literature, art, languages, politics, idols, horses or other animals, while men more often are interested in computers, all means of transportation, historical events and such things that can show up as phobias in others, such as snakes. Mentally retarded individuals can be fascinated by how the wash spins around during the centrifuge cycle.

Sometimes the interest is very limited, such as collecting firearms without ever even thinking about firing one, or buying necklaces without ever intending to wear them. The special interest is usually seen as excessive, unnecessary or a waste of time by those around the person, who might even try to limit it, no matter that the person with ASD enjoys his interest. It can even be the starting point of his future career. Sometimes the individual can suddenly tire and never want to take up his special interest again. This can also seem incomprehensible to others. Not all with ASD have special interests and this holds true especially for girls and women.

It can be of value to list the pros and cons of the special interest. If it takes up too much time so that it is a detriment to the individual (not the caregivers), limitations can be placed on it. To help visualisation of pros and cons, use plus and minus signs to help the individual make his own decisions about a whether a certain special interest should take up more or less time.

Pros: the benefits of the special interest

• Fills the time	(+)
• Gives a mental kick	(+++)
• Is relaxing	(++)
• Is original, makes the person feel special	(++)
• Increases self-confidence to be so knowledgeable	(+++)
• Fun to share one's knowledge with others	(+++)
• Often leads to contact with others who share the same interest	(+++)
• Can lead to employment where the special knowledge is sought after	(+)

Cons: the detriments of the special interest

• Takes up so much time the person doesn’t have time for anything else	(- - -)
• Interferes with sleep, health or safety	(- - -)
• Is seen as strange	(- - -)
• Is tedious for others	(-)
• Hinders contact with others	(- -)
• Useless knowledge	(-)

The reason behind the behaviour ...

She's reading the telephone book again

The caregivers discovered that Lena was reading the telephone book every evening. The caregivers wanted Lena to have a hobby that had substance to it and so wanted to offer her other, more meaningful hobbies. When they helped Lena to identify why she read the telephone book, which they considered boring, it turned out that Lena's special interest – reading the telephone book – helped her to wind down. It was unchanging and gave her a feeling of security and calm. When the caregivers understood why it was important for her, they let her continue her relaxing activity.

We've tried everything; he doesn't want to get in the shower

Nils had a lot of problems getting in the shower. He was not motivated to shower through social stories or other strategies that the caregivers tried. When they tried using his interest in computer games, he showered. The caregivers helped him to schedule time for computers every evening, after he had showered. Motivated by an activity to look forward to, it was easier to get him to shower.

He sits in front of the washing machine in the evenings

Charlie's caregivers worried about his sitting in front of the washing machine every evening. They tried everything to get him to try more meaningful activities. When they later spoke with Charlie's mother about it, they found out that Charlie had a special interest in washing machines and often sat in front of the washing machine when he felt stressed out or anxious. For Charlie, watching the clothes spin around was relaxing.

He talks about trains constantly

Bob's caregivers found it taxing to give Bob help. He talked incessantly about his special interest: trains. They were weary of all the information about trains that he dumped on them as soon as they stepped through his door. When they were given help to map out the situation, they understood that Bob needed clearer instructions on when it was okay to talk about his special interest. When they scheduled half an hour of the caregivers' time for coffee and "train talk", Bob knew in advance that he would have the possibility of talking about trains later. The caregivers could then also remind him if he forgot their agreement: "at seven o'clock, we have coffee and talk about trains". It motivated him so much that cleaning before coffee time went much better.

Identification of "feel good things"

Together with Christina, we identified her special interest and which factors and activities are important for her – so-called "feel good things". What is quality of life for her? In order to understand how meaningful, relaxing and fun certain activities are for her, we have helped her to describe these on a scale of 0-10.

NOTE: In those situations where Christina has less energy than usual (as when stressed), it is important to help her to schedule and to see that she can and gets to do "feel good things"

	Scale
• Relaxing: listening to Edith Piaf. *Strategy: Use as relaxing activity in some contexts.*	(8)
• Relaxing: reading books about France. *Strategy: Use as a relaxing activity before bed.*	(9)
• Relaxing: Sitting at the computer. *Strategy: Use as a relaxing activity when she gets home from work.*	(10)
• Relaxing: Doing yoga. *Strategy: Use as a meaningful and relaxing weekend activity.*	(6)
• Relaxing: Puttering; cutting and pasting collages. *Strategy: Use as a meaningful and relaxing weekend activity.*	(8)
• Relaxing: Taking a bubble bath. *trategy: Use as a meaningful and relaxing weekend activity.*	(10)
• Relaxing: Painting. *Use as a meaningful and relaxing weekend activity (drawing class?)*	(10)
• Relaxing: Lying on the sofa, watching videos *Strategy: Use as relaxing evening activity.*	(8)

Your identification of the person’s special interests and “feel good things”

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When can the special interest be used as a way to handle or prevent stressful situations?

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How can the special interest be used to motivate or as a reward?

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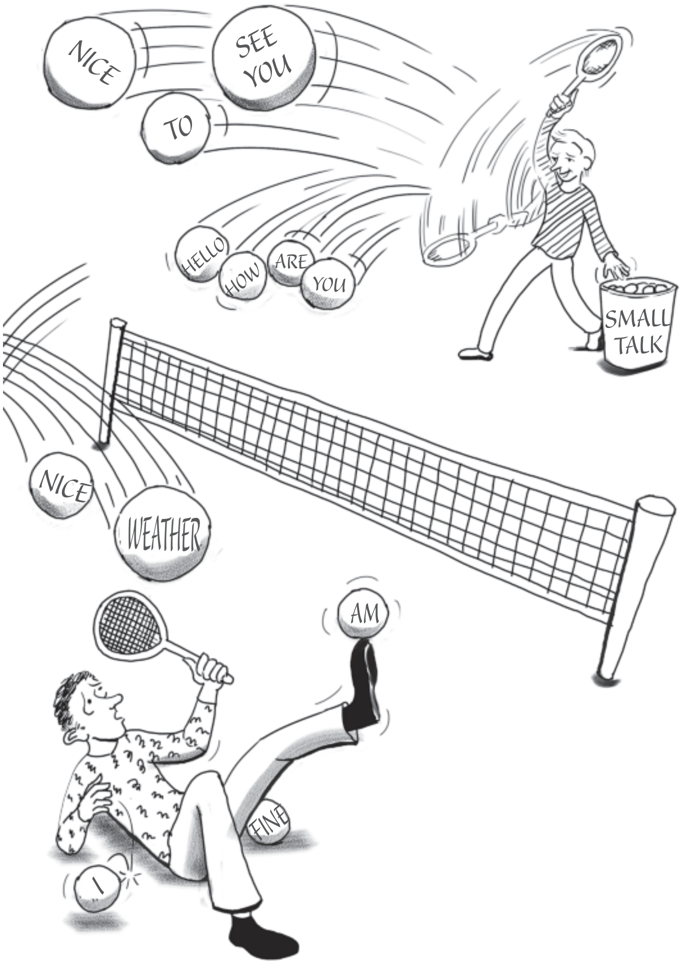
Person in charge:.. Date of evaluation: ....

Difficulties in reciprocal communication

> *One of the most frustrating things about having autism is that it is really hard to explain what you feel.*
>
> *I have problems with reciprocal communication, as it demands that both parties participate, and I can't keep up ...*



The leading difficulty for people with ASD is communication with others. Many interpret language literally and have problems understanding irony and idioms, such as "reading between the lines". Another difficulty is in finding a natural gap in the conversation to begin speaking. When the individual then gets the chance to jump in, the conversation can become all too detailed, transforming into a monologue that others find boring. The person with ASD can also have problems processing the information given by the others in the conversation. Sometimes the person with ASD can be so engaged with figuring out what he wants to say that he misses important information. When the individual has finished thinking, what he wanted to say is no longer appropriate and does not lead the conversation forward; instead, it seems to bring the flow of the conversation to a stand still.

Most people with ASD have great difficulties in answering open questions, such as “What do you need help with?” The way the question is formed is crucial. A question such as “Can you drive a car?” is often interpreted precisely as it is expressed. It is possible that the person has tried to drive a car on a deserted forest road and therefore considers himself able to drive a car. In reality, he might not even have a driver’s license and might never have driven a car at any other time.

It is easy to overestimate the individual’s ability for reciprocal communication, as people expect that everyone has the capacity for it. Many people with ASD have a large vocabulary and find it easy to express themselves, which is confusing for those around them. The level of the conversation easily falls on a level that is too high, which can result in misunderstanding or in the conversation becoming incomprehensible for the person with ASD.

Conversation techniques

It took years before I understood that people who spoke with me wanted my attention.

In meeting people with ASD, it is important to adjust communication methods and to stay a step ahead. The caregiver must know and use concrete communication techniques to help the person with ASD to identify and express the types of care he needs.

Listen without interrupting, be clear and structured in conversation, check to be sure you both mean the same thing, and give the conversation the time it needs. Give the person room to express and formulate himself. Do not use your own norms and values to interpret what the individual; rather, ask him to clarify what he means; for example, ask, "What do you mean by…?" or "Do I understand you correctly when I think you mean…?" As a professional, you ought to be able to remain neutral even though you might think the person with ASD has strange values.

The way you begin a sentence is important for how the person with ASD perceives what you say. It is a good idea to begin a sentence with something like, "I might be wrong, but I think…" or "Many other people with ASD have problems with… (general level). Do you?" (personal level).

Summarise; bullet points work well. It could be that you have unintentionally hurt the feelings of a person with ASD; if so, apologise or clarify the reason by writing a note.

Examples of various conversation techniques

There are many different techniques of conversation that you might use. Consider how different techniques might suit different people.

Conversation can be divided into three phrases. Begin a conversation with something that the individual is interested in. In this first phase, you should mostly listen, then begin commenting on what the person says. Start with giving clues around a theme. In the second phase, discuss the theme. End by summarising the opening phase and the theme phase.

Examples of conversation

1. Opening phase: Converse on something that the person finds interesting.
2. Theme phase: Discuss the theme.
3. Closing phase: Summarise first the opening phase, then the theme phase

Nåkkve Balldin, 2006.

Scales and statement forms

For a person with ASD, formulating and expressing how he experiences a certain situation or event can be difficult. Scales and statement forms can be good tools for demonstrating how he experiences things. A person with ASD will tend to hyper-analyse different events after the fact in an attempt to understand what others meant or to understand if he has behaved foolishly. By using a scale, you can help the person to assign significance points to the meaning of the behaviour. For example, “Forgetting to say happy birthday to Nils today is only a 1 and nothing you need to worry about”, or “Flirting with your friend’s boyfriend is a 10 and can mean that your best friend breaks all contact with you”.

If the individual has a problem understanding numbers, you can use happy faces with different expressions instead (see below).

Example of how scales can be used

- How difficult for you was the meeting with Social Services?

0 1 2 3 4 5 6 7 8 9 10

- How much do you like your new job?

0 1 2 3 4 5 6 7 8 9 10

How much do you like your new job?


=Very happy


= Calm, glad


= A little tense and nervous


= Very tense and nervous


= I want to run away screaming

How to use statement forms

If a person with ASD does not understand the context, a statement form with several options can be used. The aim is to present points of view and causes that can help the individual to understand the cause and effect of what has occurred.

Examples of how statement forms can be used

You are in this situation because those around
you don't understand your problems.

True	Partly true	False

It's hard for you to get across to others what they can do to help you.

True	Partly true	False

Nåkkve Balldin. 2006.

Pictures and text: The CAT-kit

The CAT (Cognitive Affective Training)-kit can be used as a basis for a discussion and to make events understandable. The CAT-kit contains pictures of different facial expressions which can be combined with various emotion words. A woman with ASD had problems keeping clean and she smelled bad. Using the CAT-kit, her caregiver asked her to choose a face that represented others' opinions of her. The caregiver then asked, "What do others think about you when you smell bad?" and asked her to choose an emotion word to describe this. The woman chose the word "astonishment". Using this information, the contact person could correct the woman's understanding through suggesting an emotion word with a more adequate description: "discomfort".

The CAT-kit is also a good tool for eliciting information which can, in turn, become the starting point for a social story.

Socrautic communication technique

This cognitive treatment model, developed by Vermeulen in 1999, involves using questions that move forward and lead to new insights. Questioning is used as a catalyst to help the individual to find answers. This method requires that the person with ASD is patient and has good language skills and adequate general intelligence. Preparation is essential and supervision necessary.

The questions should:

- be inviting; interesting for the individual.
- be formulated step-by-step.
- be logical.
- be goal oriented.
- not set value judgements

Conversation structure

- Define a concrete goal for the conversation.
- Prepare a line of thought, analyse in which directions the conversation might proceed.
- Figure out a good opening question.
- Ask questions – get answers – ask clarifying questions.
- Summarise often – in writing, if possible.
- Allow the individual to form his own conclusions.

1. Exploring questions – to clarify and understand what is said

Ask for concrete examples.
Ask for assumptions and ideas ("What do you think?", "How do you...?", "What do you mean?" etc.)

2. Leading questions

Questions that prove the assumptions or ideas.
Ask about the consequences of an assumption.
Give examples of hypothetical situations (If it is as you believe, what would happen if…?).

When to use Socrautic communication techniques

- to reflect over something that has happened and benefit from the experience
- during assessments
- when faced with difficult decisions
- during insight and self-knowledge work

When not to use Socrautic communication techniques

- when you don't have much time
- in panic situations
- if the person is confused
- when there is no real choice

Peter Vermeulen, "I am special-2. A Workbook to Help Children, Teens and Adults with Autism Spectrum Disorders to Understand Their Diagnosis, Gain Confidence and Thrive" (2005; 2012). Jessica Kingsley Publishers.

The reason behind the behaviour ...

She looks confused

Lisa had a lot of trouble understanding various expressions but was embarrassed to ask. For a long time she had wondered what her father meant when he said, “A catnap on a full belly sure sits well.” Rather than ask him to explain, she tried to understand what he might mean: Catnap? What is “cat” and what is “nap”? And how does it sit well on a full belly? What does it look like? Why? You’re not supposed to sit on full bellies! And why was Daddy so satisfied when he left the room? Not until one day after a large meal when her mum said to her dad, “Go take a short nap” did she understand what her father meant by his expression.

She always answers with a complete essay if you ask her about something

Malin thought it was difficult to communicate with others. She was always uncertain of what she was expected to reply to others’ questions. She usually used others’ words and phrases or things she had heard on TV. When she was asked a question that fit with her “manuscript”, she had trouble deciding which phrase was the best to use, and so used several, making her answer long and difficult to understand.

Is he joking or really serious?

Nils worked as a janitor and interpreted others’ expressions literally, which often led to communication problems with his colleagues. On one occasion, he was to make sure that some desks, which stood in a corridor, were picked up as soon as possible. The person who was supposed to pick them up forgot. Nils then emailed him about it, writing: “Having desks standing in the corridor is becoming a problem for the working environment.” The man who had forgotten to pick them up replied: “Sorry. It wasn’t my intention that the desks create a working environment issue.” Nils then wrote back: No, no. You’ve misunderstood. It’s not the DESKS that are the working environment issue; it’s the PLACEMENT of them that’s the problem!”

Identification of language comprehension

To identify language comprehension, the assessment found in the book *Assessing and developing communication and thinking skills in people with autism and communication difficulties. A toolkit for parents and professionals* (Silver. K., Jessica Kingsley Publishers 2005) can be helpful.

Difficulty

☐ Understanding the general idea of a conversation.

☐ Understanding ambiguity and being aware of what is meant with a literal interpretation.

☐ Understanding implied meanings.

☐ Drawing conclusions.

☐ Understanding sayings and word play.

☐ Understanding what is most important in the information given.

☐ Awareness of one's own language difficulties and being able to use compensatory strategies, such as asking others to repeat or clarify what is not understood.

☐ Understanding metaphors.

Your identification of difficulties in mutual communication

To identify problems in mutual communication, the assessment found in the book *Assessing and developing communication and thinking skills in people with autism and communication difficulties. A toolkit for parents and professionals*, (Silver. K., Jessica Kingsley Publishers, 2005) can be helpful.

Difficulty

☐ Saying "no", "I don't want to", "I don't like" etc.
☐ Repeating what has recently happened.
☐ Explaining why and how.
☐ Greeting people.
☐ Asking questions in order to gain information and solve problems.
☐ Describing how he or she feels.
☐ Sticking to the topic in a conversation.
☐ Changing topics in an intelligible manner.
☐ Giving relevant information when discussing something.
☐ Describing something thoroughly.
☐ Interrupting in a polite manner.
☐ Apologising.
☐ Using language to reason and negotiate.
☐ Giving his or her opinions.
☐ Solving a conflict with the help of language.
☐ Compromising.

What structures, aids, strategies or care measures can compensate for the difficulties?

☐ ……………………………………………………………………………………………
☐ ……………………………………………………………………………………………
☐ ……………………………………………………………………………………………

How should the compensating structures, aids, strategies or care measures be presented and introduced?

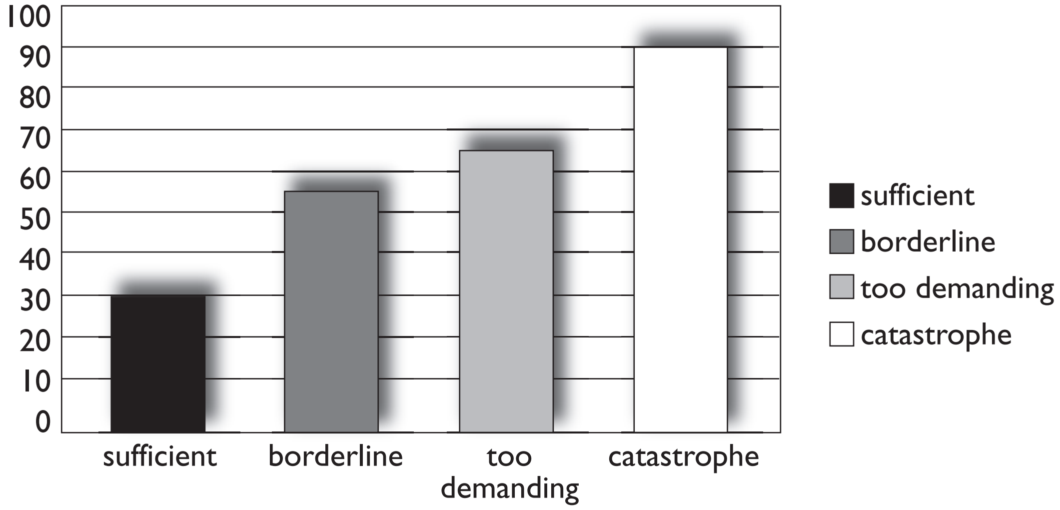
☐ ……………………………………………………………………………………………
☐ ……………………………………………………………………………………………
☐ ……………………………………………………………………………………………

Person in charge:……………………………… Date of evaluation: ……………………………

Part 4

Consequences of Autism Spectrum Disorders in Daily Life

Balance between demands and ability



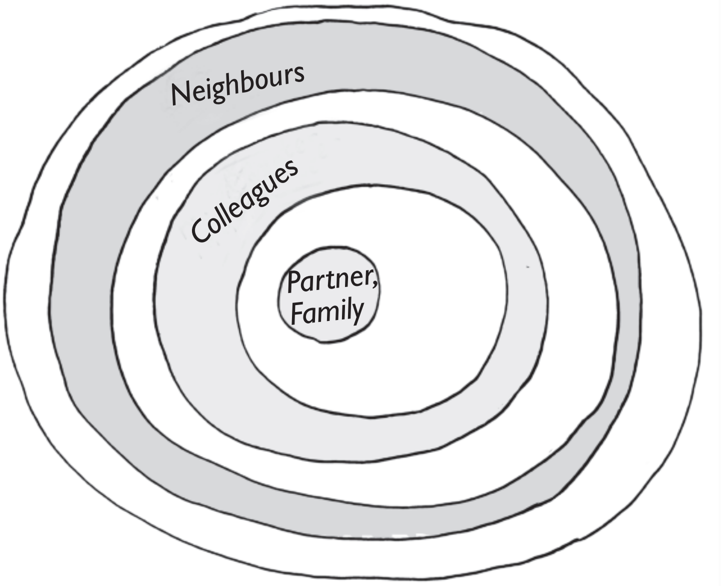
If people around me press me to reach 90% or more, the difference between 65% and 90% is too demanding; I don't have the energy. The risk for mistakes increases, I feel really stressed, can do less and it leads to the problem growing worse.

Consider this

What demands do everyday situations place on the individual in the areas in which he is functionally impaired (that is, those areas identified in the previous section)?

Relationships

> *The most difficult relationship for me is the relationship to myself. In order to live in a relationship, you have to be able to live with yourself.*
>
> *Society encourages people to be with others as though it's the best in all contexts. They say it's better to be with others than to sit alone at home and spend time doing what interests you. A happy variation is usually finding friends with the same interest so that you can spend time on your interest together. Friendship is made easier if you have something in common to talk about, and your interests are often the thing you have the easiest time talking about.*



People can sometimes think that the individual with ASD is indifferent to relationships simply because they cannot always express their feelings with their body language. In reality, what the person with ASD feels is not always the same as what he is expressing with his body language.

Many people with ASD say that they think relationships and social interaction are easier to deal with in contexts where they have a clear role. For example, it is easier to be with others while sharing a common interest. Clubs are often structured, with clear roles for how people interact, such as the meeting's agenda and a clear division of roles where one person is the chairman, another is the secretary and so on. For many with ASD, club life can be very important and meaningful. Many take part in political parties, chess clubs and the like. Others create contacts and networks in autism societies.

For those looking for a spouse or friend, there are websites for people with functional impairments where you can openly declare your diagnosis and describe the problems you have.

Friendship and family relationships

> *As a teenager, I understood that having friends meant people liked you. So, people didn't like me?*
>
> *As a proud owner of the diagnosis Asperger syndrome, I apparently have problems functioning socially. I have a question: Is it a problem? I'd like to answer that:* No, *not for me. I enjoy being by myself. I've never seen it as a problem, but others have. I withdraw sometimes when I think the crowd is too great or too noisy. Having my own space is sometimes a joy of unbelievable measure. I can be social when I please, which is probably one of the biggest reasons that I got the diagnosis so late. Sometimes, it's just nice to be alone.*
>
> *No, I don't want a girlfriend; you have to be with them even in your free time.*

Why does one have friends? For what purpose do you have them? How do you make friends? How often should one be in touch to stay in contact with someone? What exactly is moderate? For people with ASD, there are many questions concerning relationships. Some can have difficulties determining the relationship they have to another person and what the difference is between acquaintance and friend. Circles that illustrate how close different relationships are can be of help. In the innermost circle is the family and spouse, while those who are more or less strangers are in the periphery.

Family often plays an important role. Many have lived at home a long time before moving out and say their parents and siblings understand them best. But for some, it is exactly the opposite; some people with ASD have broken all or some contact with their families. One woman who thought her family had never understood or accepted her way of thinking and being expressed it this way: "My parents and I don't speak the same language. They speak Swedish; I speak Aspergerian."

Not spending much time with others can be solitude by choice. Many relate that during their childhood and teenage years, they tried to have friends solely because others had friends and they wanted to be like them. Many find loneliness becomes less painful when they are adults.

The reason behind the behaviour ...

He bought beer for the neighbourhood children

Charlie had trouble determining who his friends were and how he should behave to make friends. He started buying beer for the neighbourhood teens and invited them to a party at his place. Charlie thought he was being nice to them, and he thought the teens were his friends. When he was reported to the police, he felt insulted and deeply betrayed. When he got help understanding the context, he was confused over what he had done. He had just tried to be nice, after all. After this episode, his caregivers helped him to develop other areas of interest that he could share with people of like mind.

She's obsessed with facts

Malin did not know how to make friends. She had heard that if you showed an interest in someone, that person would feel flattered and maybe show an interest in getting together. She thought about what it might mean to show an interest in someone. One logical conclusion for her was to learn all their personal information by heart. When someone said their name, she could rattle off their address, telephone number, etc., but those she sought contact with still showed no interest in getting together with her. Using comic strip conversations, her caregiver showed her what others probably felt in the situation, thereby helping Malin to find better strategies for making friends.

She's a copycat

In a very obvious manner, Anna studied and tried to copy the other girls in class: their style of dress, expressions, ways of laughing and movements. It was her strategy for fitting in and being accepted. The strategy did not work as she had hoped; the other girls showed her very clearly that they did not want anything to do with her. She talked to her caregiver about it and they suggested she get involved with the student union instead. There she was given a clear role and could contribute her knowledge. She found friends who shared her involvement in studies and student politics.

Identifying difficulties in friendship and family relationships

Together with Christina, we have identified what she finds difficult with friendships and family relationships. In order to understand how difficult some things are for her, we have helped her to describe the difficulties on a 0–10 scale.

NOTE: In those situations where Christina has less energy than usual (as when stressed), her difficulties increase.

	Scale
• Difficulty: Remembering her family's special occasions. *Strategy: Help her to fill in these dates in her calendar and remind her to buy a gift.*	(7)
• Difficulty: Determining who is a friend and who is an acquaintance. *Strategy: Help her to see this by using "my circles" in the Cat-kit.*	(9)
• Difficulty: Participating in large family dinners and larger social mealtimes. *Strategy: Help her put together a "social menu."*	(10)
• Difficulty: Arriving on time at meetings with family and friends. *Strategy: Help her to schedule in "margin time" and to program the reminder function in her hand-held computer.*	(9)
• Difficulty: To stay in touch with or dare to contact friends and family. *Strategy: Help her by suggesting what she can suggest doing together when she contacts a friend. Remind or help her to schedule times to ring the person.*	(8)
• Difficulty: Finding scheduled meeting places when meeting with friends. *Strategy: Help her to choose meeting places she can find or give her clear directions.*	(7)

Your identification of difficulties with friendship, family and romantic relationships

Does he or she have difficulty remembering special occasions of family and friends?
Does he or she have difficulty determining who is a friend and who is an acquaintance?
Does he or she have difficulty determining how often and at what point
he or she should contact others?

☐ ....

☐ ....

☐ ....

☐ ....

☐ ....

What structure, aid, strategy or care effort can compensate for the difficulties?

☐ ....

☐ ....

☐ ....

☐ ....

☐ ....

☐ ....

How shall the compensated structure, aid, strategy or care effort be presented and introduced?

☐ ....

☐ ....

☐ ....

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☐ ....

☐ ....

Person in charge:.. Date of evaluation: ....

The reason behind the behaviour ...

She can't deal with her boyfriend

Lena was very infatuated with a man and he moved in with her. It was much harder to live with someone than she had imagined. Just the fact that her boyfriend took out the rubbish on a different day than she was used to was stressful for her. Lena thought her boyfriend did not understand when she felt overwhelmed by sensory impressions and needed to be alone. The boyfriend thought she was avoiding him and felt hurt. Lena felt she needed more time for herself. She explained her dilemma to a caregiver who helped Lena to formulate a letter to her boyfriend in which she explained her need to rest and to be alone. When her boyfriend understood that her avoidance of him did not mean that she did not love him but was due to her functional disorder, they made a deal whereby Lena would be undisturbed between five and seven every evening.

They never seem to talk to each other

Both Karen and the man she lived with had ASD. Both found being unprepared when the other started a quarrel to be unpleasant. They agreed to quarrel only on Thursdays at seven in the evening. They communicated mostly via email, even when both were at home. Both found emailing one another to be an ideal way of communicating.

How can he joke at a time like this?

Bill had a tough time understanding how his behaviour could affect other people's feelings. He had been in a relationship for a year when he broke it off. The girl was very upset and started to cry. “You don't have to be sad,” Bill said. “I'll soon find someone new.” She began crying uncontrollably and hit him with her purse. A very upset Bill recounted the incident for his caregiver, who used a social story to help Bill understand the effects of his comments and to explain what might have been more appropriate to say under the circumstances.

He didn't understand that tickets to the cinema could sell out

Nils planned to go to the cinema with his girlfriend but the tickets were sold out. It was very stressful for both of them as it was something neither of them was prepared for. Nils's caregiver suggested he purchase the tickets in advance next time. It had never occurred to Nils to do so. The next time he invited his girlfriend to the cinema, Nils bought the tickets in advance, which surprised his girlfriend and made her very happy. Nils thought the caregiver who had suggested it was a genius.

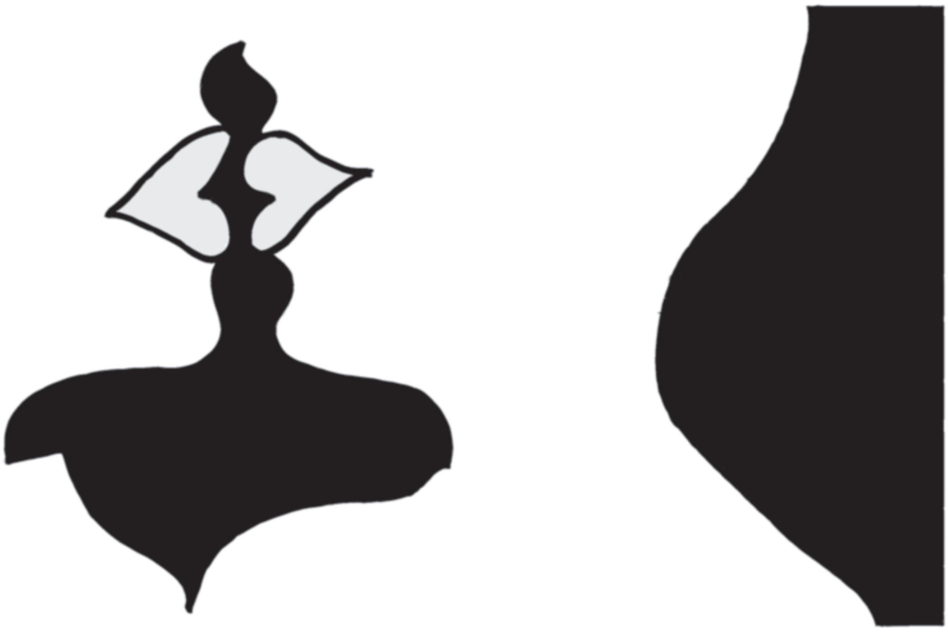
He really wants a girlfriend

James tried for quite a long time to find a girlfriend. He chatted on various dating sites and many women were interested in him as he expressed himself well in writing and he was good-looking. When they met in person, however, things did not go so well. He did not act the way the women had expected and they dropped him pretty quickly. His caregiver gave James a link to a site for people with functional disorders. He wrote about himself and explained his strengths and communication problems and soon got a reply from a young woman who also had ASD. They were quite happy together.

Romantic relationships and sexuality

There is a myth that states that people with ASD are not interested in relationships or sexuality and that they cannot live as spouses or partners or be parents. Most people with ASD are indeed single but many long for a love relationship.

People with ASD sometimes have a different outlook on relationships and sexuality than neurotypicals. Sexuality can fulfil various needs – needs of intimacy, mutual acceptance (giving and taking tenderness) and physical pleasure. Some people find that sexual pleasure is unimportant but the need to feel accepted is. It is easy for others to think of unusual sexual expression as a problem without it being a problem for the individual. One should think twice before trying to make someone change their sexual behaviour and ask oneself if the behaviour really is a problem and, if so, for whom. All sexual expression should be accepted as long as it does not hurt the individual or others.



When speaking of sex, it is easy to focus on the dangers, problems and importance of protection, but it is just as important to get across the message that sex is something positive. It is important to make it clear that one always has the right to say no; it is one's own body and sex should be on both partners' terms. Also of importance is information on social interaction and its unwritten rules. People with ASD can need help in interpreting various signals, such as noticing when someone is interested and when it is OK to take the initiative for sex or where it is OK to look for a partner.

An important point is learning the difference between what is private and what is public. For example, it is all right to satisfy oneself sexually while in the bathroom or bedroom, but not in public places. Unfortunately, it is not always that simple; there are always exceptions. Masturbating in your own room is not OK when others are visiting and neither is doing so in the bathroom when others are waiting to use it. One solution is to place a symbol, such as a green square, in the bathroom or bedroom when it is OK. Another would be to say that it is always OK in one's own room after nine o'clock at night, if one is alone. It is important to be able to give the individual concrete tips. Rather than say "You can't do that" to a person with ASD, you must say "Do this instead."

The reason behind the behaviour ...

He gropes the personnel

Nils groped several female personnel at his group home. When they discussed the problem with their supervisor, it became evident that Nils was trying to straighten their bra straps, as he was disturbed by small details that were not as they were "supposed" to be. He was also interested in zips and so he often asked the personnel if they had a zip on the back or front of their trousers. For Nils, it was not a sexual invitation but a genuine special interest in zips.

Inappropriate pick-up lines

Charlie had problems knowing how to show women he was interested in them. He had heard it was a good idea to invest his time in those with whom he had something in common. He thought about what he might have in common with the opposite sex, went to the nearest bus stop, and asked various women, "Hi. Can you speak Italian?" If the answer was in the affirmative, he said, "Me, too. We have something in common. Want to have sex?" He was surprised over the lack of response and complained about it to a male caregiver he trusted. When his caregiver, in a respectful manner, suggested more appropriate things to say and places to meet women, Charlie stopped trying to pick up women at the bus stop.

He thought he had to remain celibate

Peter could not stand making eye contact with others. When he had sex with women, he had to interrupt the act. He could not look someone in the eye and do anything else at the same time. When he finally dared to mention this to a caregiver, she first only listened to his problem. The following day she loaned Peter a book on the Kama Sutra – a book with pictures illustrating many positions where eye contact was not necessary. Peter, who had come to believe he would remain celibate the rest of his life, now saw many possibilities for sexual relations with a woman. He also learned it was a good idea to tell the woman that he could not make eye contact and that it was not because he did not enjoy looking at her.

Identification of difficulties with romantic relationships and sexuality

Together with Christina, we have identified what she finds difficult with romantic relationships and sexuality. In order to understand how difficult certain things are for her, we have helped her to describe the difficulties on a scale of 0-10.

NOTE: In those situations where Christina has less energy than usual (as when stressed), her difficulties increase.

	Scale
• Difficulty: Being touched lightly. *Strategy: Tell her boyfriend before they have been intimate and remind him about it before they have sex.*	(4)
• Difficulty: Kissing. *Strategy: Draw and explain what to do when kissing someone and how it can be done in different ways. Remind her to brush her teeth daily to avoid bad breath.*	(8)
• Difficulty: Gratifying herself. *Strategy: Tell her about aids for men and women or refer her to a clinic.*	(7)

Your identification of the individual's difficulties with romantic relationships and sexuality

Does he or she have problems being touched that makes it hard to deal with physical closeness?
Does he or she have difficulty knowing what is appropriate to say or do when meeting someone?
Does he or she have difficulty knowing how or where it is appropriate to masturbate?
Is he or she uncertain of what is expected of them when they have sex?

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What structure, aid, strategy or care effort can compensate for the difficulties?

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How shall the compensated structure, aid, strategy or care effort be presented and introduced?

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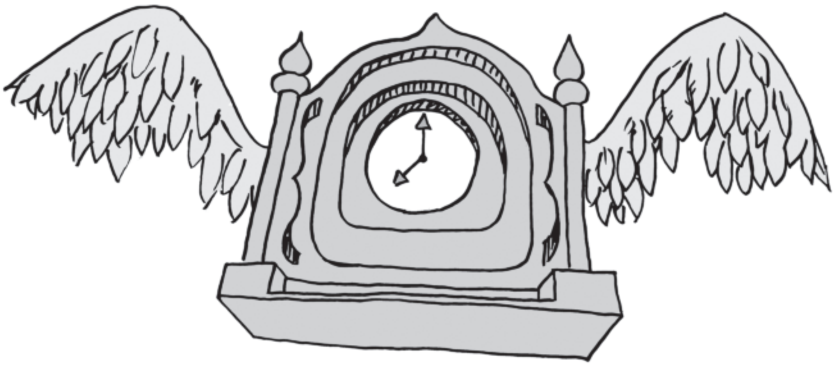
Person in charge:.. Date of evaluation: ....

Leisure time and free time

> *The worst thing I can imagine is not doing anything. I panic when I don't know what I'm going to do. As long as I have something to keep me busy, I'm fine both weekdays and weekends, though it takes a lot of effort.*



Keeping busy in unstructured situations takes the ability to plan, organise and take the initiative. In other words, it makes great demands on abilities that are deficient in people with ASD.

To organise free time, you have to be able to understand and keep an eye on time. When can you take part in the activity? How long does it take to complete it? When do you need to stop so that you can go on to the next activity? Most of us use calendars, day planners or clocks to make time visible and have an overview of life. Time for most people with ASD, however, is too abstract; they cannot place themselves in and "see" time. As a consequence, most people with ASD feel lost in this sea of time and have great difficulties in having "enough" time.

There are aids that can make time easier to grasp. A lot of people find a Time Timer to be helpful. The Time Timer visually demonstrates the passage of time using a red disk that disappears as time passes. There are hand-held computers with special functions visually demonstrating the passage of time that also have a reminder alarm and note-writing capabilities. Large day planners with different colours for different days creates a visual system based on colour that is helpful for many. Using different colours for different things helps to demarcate them; it can be used to visually mark off time and various events during the day, the week, the month or the year. Many people find that simply programming their cell phones is a great help.

File folders with registers can be helpful. For planning a year in advance, a year-long register (January to December) can be used, with planning done month by month. Each month's planning can then be moved to a monthly planner with a register of 1-31. This way, all important papers can be collected and organised.

Identification of difficulties with leisure time and free time

Together with Christina, we have identified what she experiences as difficult with leisure time and free time. To understand how difficult some things are for her, we have helped her to describe the difficulties on a scale of 0-10.

NOTE: In those situations where Christina has less energy than usual (as when stressed), her difficulties increase.

	Scale
• Difficulty: Handling unstructured time between work and dinner. *Strategy: Help her to fill in a weekly planner with her activities between 4 p.m. and 6 p.m.*	(9)
• Difficulty: Leaving on time for various activities. *Strategy: Help her to find time aids with reminder functions. Before especially important meetings, her caregiver should call and remind her.*	(9)
• Difficulty: Getting things done on her weeks off. *Strategy: Fill in her weekly planner with no more than three things to do each day.*	(5)

At most 3 activities per day			
	Morning	Afternoon	Evening
Monday	laundry	washing up	
Tuesday	class	class	
Wednesday		pay bills	cinema with Sarah
Thursday	clean house	gym	
Friday	class	class	
Saturday	museum	dinner at P’s	
Sunday			

Your identification of the individual's difficulties ' in organising leisure time and free time

What meaningful activities does he or she have?
How many activities can he or she have each day?
How long can he or she carry on with an activity?
What does he or she like to do with others?
What does he or she like to do alone?
What factors make it difficult for him or her to have a meaningful pastime?

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What structure, aid, strategy or care effort can compensate for the difficulties?

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How shall the compensated structure, aid, strategy or care effort be presented and introduced?

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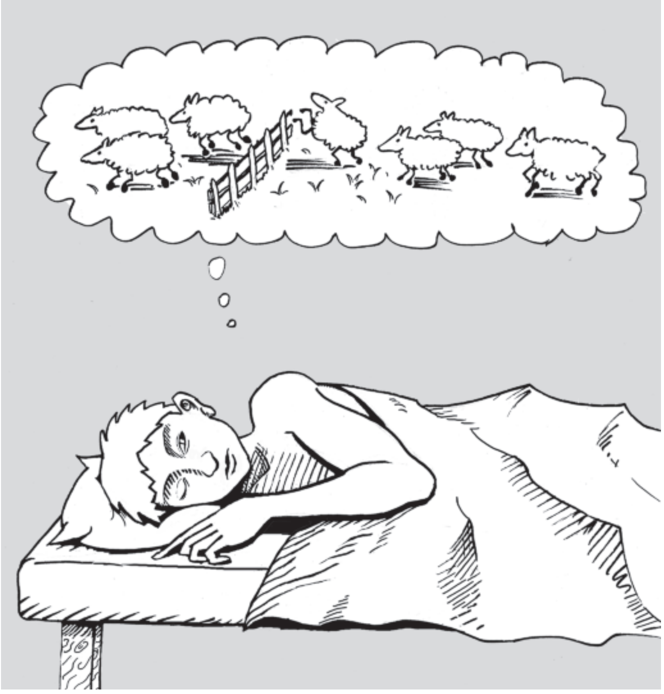
Person in charge:.. Date of evaluation: ....

Sleep

I don't associate my bed with sleep. For me, it's a place of brooding and writhing in sweaty sheets.

I see everything, hear everything and smell everything – and I mean everything! It's not so strange that my energy consumption is great. Still, I can't sleep. Despite my dose of sleeping pills, I lie there in bed, totally tense.



Many people with ASD have problems sleeping, both falling asleep and sleeping through the night. The difficulties can have various reasons – everything from a physical expression of anxiety that makes it hard to relax and fall asleep to disturbances in the environment. Many are disturbed by sounds from neighbours, from running radiators, humming refrigerators or droning ventilation. Some are happiest when they can be awake at night, when it is calm and quiet, while others have so little need of sleep that they are awake much of the time.

Sleeping problems can also depend upon difficulties in stopping what they are doing. Many get stuck at the computer and suddenly it is three o'clock in the morning. There is software that installs a clock on the computer screen. You set it to count down the time. There is also an adaptor that shuts down the computer at the set time.

Waking up on time is another common problem. Many are not awakened by common alarm clocks. For these people, a "shake-and-awake" clock—a clock with both sound and vibration—can be of great help. Electronics shops have alarm clocks that do more than just ring; for example, some clocks roll out over the floor.

If the individual lies awake and hyper-analyses the day's events or if their brain seems to go into overdrive, writing can help. If you're afraid of forgetting something and it's keeping you awake, it can help to write it down. For some, keeping a notebook and pencil next to the bed is the answer, while others prefer to use voice recorders.

One woman with ASD used to write in her a diary every night. She wrote down all the good events and experiences in a special notebook, but she wrote all the negative things on scratch paper which she then tore up. On the days she felt depressed, she would read from her notebook filled with positive things; it reminded her that her life was actually pretty good.

The reason behind the behaviour ...

He drinks a lot of wine

For many years, Carl drank a bottle of wine every night. When his caregiver asked him why he drank so much wine, she found out he was very sensitive to sound and therefore had a hard time falling asleep. When his apartment was sound-proofed, his problem falling asleep disappeared and he no longer needed wine.

She doesn't want to sleep

Mary had a very difficult time falling asleep. When her caregiver helped her to identify why she had such a hard time, they realised that the cause was Mary's sensitivity to light. She was disturbed by light that came in through the slits in the Venetian blinds. When she installed black roller blinds, her sleeping problems ceased.

She gets stuck at the computer

Lena got stuck in front of the computer each evening and because of it had a tough time getting to bed. Her caregivers solved the problem by helping her to purchase an adapter for the computer that switched the current off at 11 pm.

Why does she sleep so poorly?

Anne had problems with her sense of balance and feeling where her body began and ended. When she went to bed, she felt as though she were falling backwards, which made her feel dizzy and unsafe. Then she was given a "ball blanket" – a blanket filled with plastic balls that form the blanket snugly about the body. She could then feel the contours of her body and was able to sleep better.

Identification of possible causes of sleeping problems

Together with Christina we have identified possible causes of her sleeping problems. To understand how difficult certain things are for her, we have helped her to describe her difficulties on a scale of 0-10.

	Scale
• Difficulty: Sleeping when the neighbour is noisy. *Strategy: Use ear plugs.* *Also, check into sound-proofing the bedroom wall.*	(7)
• Difficulty: Feeling where her body begins and ends. Christina says it feels like she is falling backwards when she lies in bed. *Strategy: If possible, borrow a "ball blanket" a couple of nights. If it helps, apply for funds to purchase one.*	(9)
• Difficulty: Sleeping when she feels she has too many thoughts. *Strategy: Keep a notebook and pen beside the bed to write down some of those thoughts. Borrow a self-help book from the library on how to sleep better.*	(8)
• Difficulty: Sleeping despite good advice, self-help book and ball blanket. *Strategy: Make an appointment with the doctor for a prescription for sleeping pills or melatonin to help regulate her circadian rhythm.*	(5)

Your identification of possible causes for sleeping problems

Does he or she have difficulty ending activities before bed?
Does he or she have difficulty sleeping if disturbed by various sounds?
Does he or she difficulty sleeping if the room is too light or too dark?
Is he or she able to get up on time in the morning?
Anything else?

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What structure, aid, strategy or care effort can compensate for the difficulties?

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care effort be presented and introduced?

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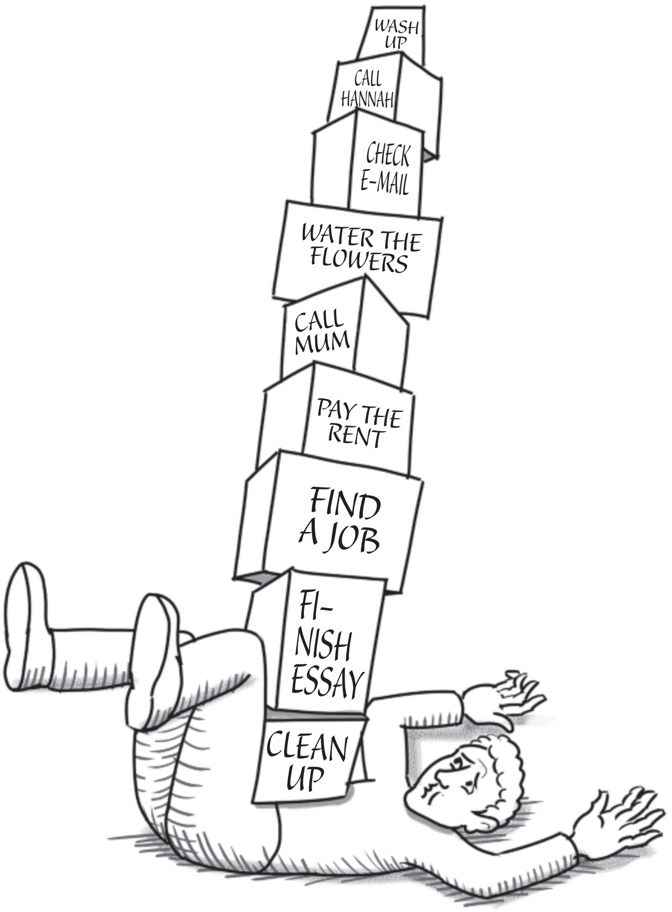
Person in charge:.. Date of evaluation: ....

Stress: When demands exceed ability

It's stressful to feel flooded by impressions, lack an oversight of and the ability to plan your time, and to always be interrupted.

For me, it's stressful to feel like I don't have command of a situation or I don't have control over what is happening near me. Routines, rituals and stereotypes are ways to ease the inner chaos. For me, the greater the chaos on the inside, the greater is my need for control and structure on the outside.

I get stressed out by common things just as other people do, but I can't handle it. When I tried to open a pot of paint, I couldn't figure out how. I tried everything I could, but nothing worked. I finally just lay down on the floor and cried.



The ability to handle stress, flexibility, social competence and the ability to carry on several things at the same time are all difficult for the person with ASD. There are an endless number of situations where others' demands exceed the individual's abilities. Living in an environment where there are demands that are too high for the individual to meet robs him of a great deal of energy and leads to reactions caused by stress. Presumably, stress is a far greater problem for people with ASD than for others, though they do not show it.

Usual causes of stress for people with ASD include being inundated with information and impressions, having to make difficult choices, not understanding context, not understanding other people, not understanding the significance of what is being said, time pressures, unpredictability, changes, not understanding the meaning of what is happening around them, not being able to influence a situation, feeling infringed upon, having nothing to do and having no one to turn to for advice. Another stress factor can be the poor sense of direction, which is common for those with ASD. An individual can have difficulties recognising his surroundings and finding his way around, even in his own neighbourhood; for many, it seems like they were born without an inner compass. Many even have trouble recognising other people (prosopagnosia), which is another stressor for them.

There are both short-term and long-term stressors. A short-term stressor might be entering a department store full of shoppers. A long-term stressor might be living on a noisy street, being harassed at work, constantly being corrected or feeling that a caregiver does not understand one's needs.

Stress and the inability to handle a situation can lead to great psychological reactions, such as insomnia, depression and anxiety. Stress probably even contributes to a worsening of compulsive behaviours, such as when a person gets "stuck" and seems to be paralysed. Even psychotic episodes can arise as a result of stress. Behavioural problems such as aggression, acting out or self-harming behaviours are often reactions to stress caused by unusual perception, being unprepared for changes or by communication difficulties. Should the caregiver identify the circumstances under which the reactions to stress arise and try to understand and pinpoint the cause of the reaction, she can stay one step ahead and be more likely to prevent the reaction from arising again.

What causes increased anxiety? Which situations are stressful? It is a good practice to document common causes of stress and write down what happens when the individual feels under stress and anxious. It is also important to ask questions such as, "What can one do to help the person avoid stress?" and "What strategies can be used in those situations the individual finds difficult to cope with?"

There are coping strategies that help the person handle the stressors that inevitably exist. These can be of great help for certain individuals. There are two types of coping: problem-focused coping and emotion-focused coping. Problem-focused coping entails doing something about the stressor, such as using ear plugs if sensitivity to sound is a stressor. Emotion-focused coping entails the individual adjusting to the situation by learning to handle his emotional reactions to discomfort. For this, a qualified supervisor is needed; otherwise there is a risk of assault. Avoidance of stress-inducing situations can be a good strategy, but it must be weighed against the possibility of negative consequences, such as isolation.

Steps and strategies

> *Everyone criticises you for doing things the wrong way, which leads to more stress. What you need not someone who says, "You can't do it like that"; rather, you need someone who explains and shows you, "Do it this way instead".*

One way to help the person with ASD to gain control over his daily life is to create routines and strategies for handling difficult situations. Other ways include making certain the individual can rest and spend time by himself and aiding him to recognise the behaviour and emotional signs that indicate that he is under stress and to help him learn to say no, stop or I can't stand it any more! Many find help from "traffic signals"; that is, choosing between a red, yellow or green card to use when words are not enough. A yellow or red card signals "I can't take much more of this; get me out of here".

Teaching the person to hold up a hand to show that he needs a time out can be of help. By identifying which situation cause stress reactions, caregivers can offer the individual strategies that can prevent many such reactions. For those who are sensitive to sound, it can be a good idea to always have earplugs on hand; for those with light sensitivity, sunglasses should always be available; and so on. A small kit – a sort of first aid kit for stress – can be kept readily available.

- Help the individual to find breathing room in his daily life. Identify how long he can stand to be with others and help him to set time limits.

- Help him to find balance. Even situations that the individual experiences as positive can demand a lot of energy. If this is the case, help the person to do something relaxing before and after the activity.

- Help the individual to find relaxing activities and strategies in order to sleep well and sleep enough.

- Help the person to get a handle on and have some control over his environment. Find a structure that works for him. Visual aids can lend a good general view of things and help with structure. Use notebooks, a whiteboard, schedules, calendars or hand-held computers.

- Help the individual to find coping strategies if he tends toward self-harm or acts out in stressful situations. He might look at a relaxing picture that he keeps in his wallet or feel a piece of soft flannel he keeps in his pocket, or listen to music or a relaxation audio on his mp3 player. He might go into another room or smell a piece of perfumed fabric, perhaps make a phone call or take a relaxing shower or even drink a glass of milk or water.

Identifying stressors

Together with Christina, we have identified what she experiences as stressful in her daily life. To understand how difficult some things are for her, we have helped her to describe what she finds stressful on a scale from 0-10.

NOTE: In those situations where Christina is under stress, she tends toward self-harm. She scratches or cuts herself to deal with her anxiety. She needs help to recognise her early stress signals and to direct her to more appropriate behaviour in these situations.

Scale

- Stressor: Unstructured time, not knowing what she should do. (8)
  Strategy: Christina needs a visual overview of time. She needs to know what she should do, how long she should do it, with whom she should do it and what she should do next. Helping her with her annual, monthly, weekly and daily planning helps her to visualise time. An overview of daily and weekly planning can be drawn on the whiteboard in the hall. Annual and monthly planning can be collected in a binder or folder with a clearly labelled register. Find out what is important to her quality of life, then schedule "feel good things" into her daily planning. So that she feels secure when she gets help in her home, work with her on "backwards social stories" so that everyone, including short-term personnel, understand why it is important that Christina's care is carried out in specific ways.

- Stressor: Sudden changes. (10)
  Strategy: Minimise the risk for sudden changes by letting all personnel know how stressful sudden changes are for her and by all personnel sharing the same views and working in the same way. To have access to a strategy during changes that cannot be predicted, make a red "emergency card" for her and glue it to the stress kit that she keeps in her purse and near the telephone in the bedroom. The card says that she should call the personnel to help her find new strategies.

- Stressor: Loud sounds. (7)
  Strategy: Loud sounds can happen anywhere. Christina should always have access to ear plugs and an mp3 player to shut out other sounds. There should always be ear plugs in her stress kit that she keeps in her purse and bedroom.

- Stressor: Difficult choices. (6)
  (Many situations which demand difficult choices create stress.).
  Strategy: By being conscious that this can create great stress for her, she should not be exposed to situations where she has more than two alternatives from which to choose. For example, when going to a restaurant, choose a restaurant that offers a menu that can be studied in advance, such as online.

- Stressor: Social situations. (5–10) depending on the situation
  Strategy: In social situations, Christina finds it very stressful to not know what is appropriate to wear and talk about. She needs help finding an escape, in case the social situation becomes too difficult for her. A social menu, which should be introduced through a social story, can be a good aid for her. Acceptable excuses to leave social situations can be written down. This way, she will know that she has an escape route.

Christina's recognition of early signs of stress
When I'm feeling stressed out and anxious:

- I get restless, wound up and hyper..
- I wander around, back and forth.
- I usually feel my heart pounding faster.
- I usually break out in a cold sweat.
- I often start playing with my hair.

When I notice these signs, I ring the personnel to get help with strategies to handle my stress. If it's busy, or if I don't feel like talking, I'll take out my stress kit.

- If the stress is due to sounds that bother me, I'll put on my mp3 player and play music to shut out the sounds.
- If I don't feel like listening to music, I'll put in my ear plugs
- If the stress is due to visual impressions, I'll put on my sun glasses.
- I'll take out my stress balls and squeeze them.
- If I am at work, I can go sit in a nearby room and be alone for fifteen minutes.

Your identification of things that are stressful for the individual

What causes increased anxiety? Which situations are stressful?
What does he or she do when he or she is anxious? How does he or she feel when anxious?
What can be done to help the individual avoid stress? Which strategies can be used in situations that they find difficult to handle?

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What structure, aid, strategy or care effort can compensate for the difficulties?

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How shall the compensated structure, aid, strategy or care effort be presented and introduced?

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Person in charge:... Date of evaluation: ....

Food and mealtime situations

> *I can't deal with the stress of eating around others. I can't stand being disturbed while I'm eating, either; it gives me a stomach ache.*

It is common that people with ASD have difficulties with food and mealtime situations, which can depend on many different things. Literally interpreting language can be one reason. During the time when the government recommended eating six to eight slices of bread daily, Nils did so. The consequence was that he ate almost nothing other than bread. When Peter read that people should eat every four hours, he set his clock to remember to eat every four hours…even during the night.

Unusual perceptions, which are common in people with ASD, can make it difficult to eat in environments with a lot of visual and auditory impressions, to eat food of certain consistencies or to be able to stand certain smells. During times of stress, the unusual perception of touch can increase and makes it difficult to chew. The feeling of holding a metal utensil can be unbearable and make the individual choose to eat with their hands. Oversensitivity for taste can lead to the person tasting the tiniest grain of salt or not being able to taste anything and dumping spices on their food. Many don't feel hunger or satiation.

Problems with organisation can lead to food being forgotten, the consequence being that there is no food in the home or that the person comes home from the shops empty handed because the shops were out of everything on the list. For others, it can be difficult to cook the right amount of food.

For the person with ASD, changes in detail can be hard to tolerate. It can make it difficult to eat a product one used to like before the packaging was changed, making the same product feel somehow like a different product. Drinking morning coffee can be hard if the mug one associated with morning coffee happens to break.

Most social mealtime situations place demands on social and communicative skills. For most people with ASD, company at the dinner table is a torment. It is very stressful to have to put up with everything. All the sensory impressions that go with the situation can be intolerable. Having to think about proper table manners like not eating with your mouth open and not talking while eating, keeping up with the conversation and contributing to it, having to think about when you can help yourself to the food, expecting and then noticing the signals for when to begin eating and not knowing in advance what will be served are all very stressful for the person with ASD.

The reason behind the behaviour ...

She always dumps a lot of spices on the food I prepare

Lena always spiced her food to the extreme. When the caregivers helped her to identify why she always put a lot of spices on her food, they understood it was because of Lena's unusual sensory perception. Without spices, Lena could not taste the food. When the caregivers realised this, they stopped all their comments on her spicing habits.

He only eats certain things

Charlie usually ate whatever was served, but had periods where he would refuse to eat most things. During these times, he would get by on soup and avocados. When his caregivers helped him to identify why he periodically ate only soup and avocados, they could see that it occurred in conjunction with periods of stress. At such times, Charlie's unusual perception increased, making it painful for him to chew. When the personnel understood this, they made certain Charlie always had soup available at home.

He eats with his fingers

Rather than eat with utensils, Nils ate with his fingers. When the caregivers helped him to identify why he had problems using utensils, they realised it could be due to his unusual perception. He could not stand the feel of stainless steel against his skin. When they gave him plastic utensils, he always ate with them.

She forgets to eat…

Malin often forgot to eat. She realised she could use the strategy of always making a meal for herself when she fed her cats. "If I forget to feed my cats, they always remind me!"

Your identification of the individual's difficulties with mealtime situations

Can he or she plan their daily mealtimes?
Can he or she cook the right amount of food?
Can he or she use food preparation and other kitchen appliances properly?
Is he or she able to eat with others?
Does he or she have problems with eating food of certain consistencies
or using certain utensils?
Anything else?

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What structure, aid, strategy or care effort can compensate for the difficulties?

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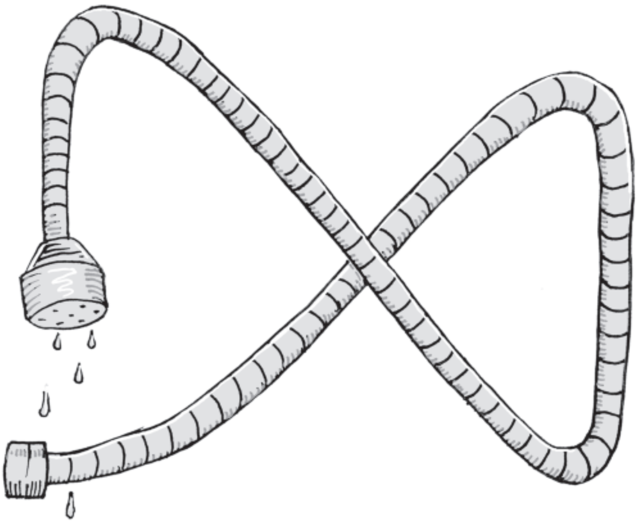
Person in charge: .... Date of evaluation: ....

Hygiene

When I was younger, my mum said that if I showered often and smelled good, I'd get some friends. Now I'm 42 and still don't have friends, so I've stopped showering.

What do I think others think when they notice I smell bad?
I think they're surprised.



Keeping up with good hygiene is often a problem for people with ASD, but the reasons for this are varied. It can depend on problems getting started, problems automatising the steps and knowing in which order they should be performed. Shower instructions, enclosed in plastic and hung in the bathroom, can help. Instead of text, a sequence of pictures illustrating how and the order in which to wash can be used. If the individual tends to lather up repeatedly in a compulsive manner, the shower instructions can include instructions on how many seconds each body part should be lathered: "When you wash your arms, count to ten, then rinse your arms and continue".

Body parts located at the extremities can easily be neglected. Feet can be forgotten, resulting in cracked heels and long toenails. Untended feet can also be due to the person having misplaced their nail clippers or because it hurts to clip their nails.

A social story can help the individual understand why it is important to keep up good hygiene and how often it should be done. It can also describe when it is necessary to bathe or shower. For example, it is not necessary to wash after reading a magazine; this is not obvious to everyone. It can be worthwhile to understand the impression dirty nails gives and that you can be treated badly for wearing dirty clothes or shoes that are falling apart.

The problem can be the opposite: the individual washes too much or too often. The cause can be an unusual perception that makes the person feel sticky despite having washed. Talcum powder can be used to make the skin feel drier. In more difficult cases, behaviour therapy or medication can be necessary.

Shower instructions

- Put clean clothes (socks, underwear/panties, shirt and jeans) on the chair in the bathroom.
- Take off the clothes you are now wearing and put them in the dirty clothes hamper.
- Get under the shower.
- Get wet all over, including your hair and all of your body.
- Take the bottle of shampoo and squeeze out a little into the palm of your hand.
- Massage the shampoo into all of your hair and around your ears and neck.
- Rinse the hair for a minute or two.
- Take the bottle of soap and squeeze out a little into the palm of your hand.
- Soap up your arms and upper body, including your navel.
- Squeeze out another small amount into the palm of your hand.
- Soap up your armpits.
- Squeeze out another small amount into the palm of your hand.
- Soap up your legs, feet and between your toes.
- Squeeze out another small amount into the palm of your hand.
- Soap up your private parts then your bottom. If you are a man, pull back your foreskin and soap up then rinse off your penis. Rinse the soap off.
- Stand under the shower so that your entire body gets wet and all the soap and shampoo rinse off.
- Turn off the shower.
- Get out of the shower.
- Dry your entire body with a bath towel. Start with your head, then your arms, then your feet and legs, then your stomach and back, then your private parts and your bottom.
- Use deodorant in both armpits.
- Put the deodorant back in the bathroom cabinet.
- Put on the clean underwear/panties. If you're a woman, put on a clean bra.
- Put on the clean socks.
- Put on the clean shirt.
- Put on the clean jeans.
- Leave the bathroom, turn off the light and shut the door.

The reason behind the behaviour ...

He doesn't brush his teeth

Peter couldn't brush his teeth. When his caregiver helped him to identify why he couldn't, it turned out that Peter had to think about how many times he brushed every tooth to be able to do it. He had problems automatising the movements. When his caregiver helped him to purchase an electric toothbrush, he could brush his teeth himself.

He refuses to go to the dentist

Charlie didn't want to go back to the dentist because the dentist had complained about how Charlie brushed his teeth. Charlie had damaged his gums because he brushed too long and too hard in one spot. When the caregiver explained the situation to the dentist, Charlie was given an appointment with the dental hygienist instead. The dental hygienist took the time to kindly show Charlie how long and how hard he should brush. She explained to Charlie that the dentist didn't mean to complain about how Charlie brushed his teeth, but wanted to help him to avoid damage, but that the stressful work situation made it so that the dentist did not have the time to explain this in detail to Charlie. Charlie understood why the dentist was so short with him and no longer felt insulted.

She no longer brushes her teeth

Lena suddenly refused to brush her teeth. When her caregiver helped her to identify why she refused, it turned out that a new employee had purchased a new toothbrush of the wrong colour and firmness and had also bought the wrong toothpaste. The hard bristles hurt Lena's mouth and Lena associated brushing her teeth with the colour, so her toothbrush had to be yellow. When the caregiver realised why Lena no longer wanted to brush her teeth, she made certain the reason was documented in a special notebook on Lena's needs and made a standardised shopping list with the right sort of toothbrush and toothpaste to buy.

She uses too much soap and shampoo

Stina had problems knowing how much soap and shampoo to use when she showered or washed her hair and so she used up nearly a full bottle almost immediately. When her caregivers noticed this, they helped Stina to buy several small plastic bottles and poured the right amount of soap and shampoo into the small bottles. In this way, Stina could shower and take care of her hygiene herself.

He stinks

Charlie didn't shower or brush his teeth. When his caregiver helped him to identify why he didn't, she realised that he didn't understand how to take care of his hygiene. He also had problems understanding how he should carry out the various steps. The caregiver wrote a social story that explained why it was important and that also introduced shower instructions.

Identification of problems with hygiene

Together with Christina we have identified what she experiences as a problem with hygiene. To understand how difficult certain steps are for her, we have helped her to describe the difficulties on a scale of 0-10.

NOTE: In those situations where Christina has less energy than usual (as when stressed), her difficulties increase.

	Scale
• Difficulty: Knowing when, how often and how long to wash her hands. *Strategy: Clear instructions on the inside of the bathroom cabinet and in her wallet.*	(8)
• Difficulty: Knowing how long to shower. *Strategy: A timer with a time interval of 10 minutes placed in the bathroom cabinet, easily seen from the shower.*	(9)
• Difficulty: Knowing in what order to do what when showering. *Strategy: Write or draw a shower routine and enclose in plastic.*	(8)
• Difficulty: Remembering when her period is about to start. *Strategy: Write the letter M in the calendar each month when her period is due and be sure there are tampons and sanitary pads at home.*	(7)

Your identification of the individual’s difficulties with hygiene

Does he or she have difficulty seeing the reason for taking care of his or her hygiene?
Does he or she have difficulty knowing in which order he or she should
carry out the various steps?
Does he or she have difficulty knowing how much soap or shampoo he or she should use?
Does he or she have difficulty knowing when to wash his or her hands?
Anything else?

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What structure, aid, strategy or care effort can compensate for the difficulties?

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How shall the compensated structure, aid, strategy or care effort
be presented and introduced?

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Person in charge: .... Date of evaluation: ....

Organisation of the home and daily life

The sad thing is that when your executive functioning is out of whack, you can live like a Bohemian even if you're a pedant. Your goal of neatness is much greater than your ability to reach it. What you have to learn is the art of lowering your level of ambition – to be moderately messy – so that you can reach your goal. It can occur through a logical analysis together with someone else.

Keeping things tidy at home takes a lot of my free time, especially since I can't help collecting newspapers and other things. I have stuff spread out all over the floor because there's no room anywhere else and that's why I don't vacuum very often. First I have to pick up everything on the floor, which can take hours. By then I'm usually too tired to clean any more.

I decided to wash my clothes. When I started toward the laundry room, I noticed the post lying on the hall table. "I should check the post before I do the laundry", I told myself. I put the laundry on the table, tossed the junk mail in the bin under the table and noticed that the bin was full. I put the bills back on the table and decided to empty the bin first. Since I have to go past the post box on the way to empty the bin, I figured I might as well pay the bills first. I saw my cheque book lying on the table, but there was only one cheque left. My extra cheques are on the desk, so I head for the bedroom, where I find a bottle of juice, and start to drink it. I'm going to start looking for my cheques, but first I have to just put the juice away so I don't spill it all over my desk. The juice is getting warm and should be put back in the fridge to keep it cold.

On the way to the kitchen to put the juice in the fridge, I spot a vase of flowers on the counter. They need water. I put the juice on the table and see my

> *glasses that I've been looking for all morning lying on the counter. Best I put them back on my desk, but first I'll just water the flowers.*
>
> *I put my glasses on the kitchen counter and fill a watering can with water, when I suddenly catch sight of the television remote control. Right; I'd put it on the kitchen table. Tonight, when I go to watch television, I'll be looking for the remote; yesterday I forgot I'd put it on the kitchen table. I'd better put it back, but first I'll just water the flowers.*
>
> *I add a little water to the vase but most of it lands on the floor. I put the remote back on the table and get some paper towels to dry the water. Next, I go back to the hall to try to remember exactly what it was I had planned to do.*
>
> *At the end of the day, the laundry is still not washed, the bills are not paid, there is a bottle of warm juice on the counter, the flowers are not watered, there's still only one cheque in my cheque book, I can't find the remote or my glasses and I have no idea what happened to the mail.*
>
> *I try to understand why nothing has been done today. It's confounding, as I know I've been busy all day and I'm exhausted!*

It's frustrating having the need for a pedantically clean and organised home when you don't have the ability to make or keep it that way. The high level of ambition and fixation on details make cleaning an insurmountable task for many with ASD, as they tend to get stuck on every little thing. Many have an all-or-nothing mentality; if the cleaning and sorting are not carried out according to an inner vision, the individual is not able to do it at all.

Organising the home and important papers is difficult for most people with ASD. Helping the individual to achieve a foundational order is important. Practical and inexpensive storage boxes can help. Drawers and shelves can be labelled so the individual always knows what is where. Transparent plastic boxes make it easy to see what is inside. Many people have too many kitchen utensils in their kitchen drawers, too many sweaters in their closets and holey socks that they don't use, and this makes it even harder to have a clear view of things and to keep things in order.

To create a little order so that you have a well-arranged home, toss out broken things and put what you no longer use in the cellar.

For those who need pictures for a visual overview, a digital camera can be a good aid. Photos that are plasticised can be used to show where things belong. Pictures can also be found on the Internet. A picture of a sweater, for example, can be printed out, laminated and used as a sign on a closet shelf. For those who think it's embarrassing to show off their poor working memory, the inside of closets and drawers can be marked instead.

To know in which order to carry out the steps of cleaning, a how-to list can be helpful. The various steps can be photographed and the photos made into a diagram depicting the order in which cleaning should be carried out. The important thing is that the level of ambition for cleaning is reasonable; the floor doesn't need to shine and, should the individual not feel the need to make his bed, he can skip it.

Simple colour schemes are a clear and easy way to find things. Bills and papers that need attention in the near future can be placed in a red folder; whatever can be sorted later can be placed in a green folder and so on. Office supply shops offer all sorts of folder systems that make it easy to sort papers.

For those with a poor perception of time, cleaning can feel like an eternal project. If you time each step in the cleaning routine and then divide up the various steps into zones (Mondays I clean zone 1 = the kitchen), cleaning can be easier to deal with.

For those with problems staying motivated, cleaning for 10 minutes then doing something else for 10 minutes, then cleaning for 10 minutes can help. Or why not compete against yourself or someone else to see who can put away the most in 10 minutes? Motivation can also be increased by promising yourself a reward after cleaning: perhaps a film or pastry or some other favourite food.

To help a person remember things like when to change the bath towels, divide up each month's weeks into four different colours. On the whiteboard or in a time planner, write "week 1 = yellow", which means it's time to change to yellow bath towels. If week 2 = blue, change to blue bath towels, and so on. To remind the person to change their bedding once a month, write down that they should do so on "yellow weeks". A diagram of a thermometer with colour markings can be used to show the clothing that is suitable to wear according to the temperature, which can make it easier to choose what to wear.

Your identification of the individual's difficulties with cleaning

Can he or she judge when it's time to clean?
Can he or she judge how much time the cleaning will take?
Can he or she toss out old newspapers, junk mail and such?
Can he or she dust and hoover?
Can he or she mop the floor?
Can he or she take out the rubbish when it's time?
Can he or she judge when it's time to change the bedding and towels in the bathroom?

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What structure, aid, strategy or care effort can compensate for the difficulties?

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How shall the compensated structure, aid, strategy or care effort be presented and introduced?

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Person in charge:.. Date of evaluation: ....

Your identification of the individual's difficulties with doing the washing up

Does he or she use the right amount of washing-up liquid and water?
Can he or she tell when the dishes are clean?
Can he or she put away the dry dishes?
Can he or she use various sorts of washing-up liquids and tools?

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What structure, aid, strategy or care effort can compensate for the difficulties?

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How shall the compensated structure, aid, strategy or care effort be presented and introduced?

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Person in charge: .... Date of evaluation: ....

Your identification of the individual's difficulties with laundry and clothing

Does he or she take the initiative to shower?
Can he or she book time in the laundry room in advance?
Can he or she sort the laundry?
Can he or she hang the laundry to dry?
Can he or she fold the dry laundry?
Can he or she hang the clean clothes in the closet?

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What structure, aid, strategy or care effort can compensate for the difficulties?

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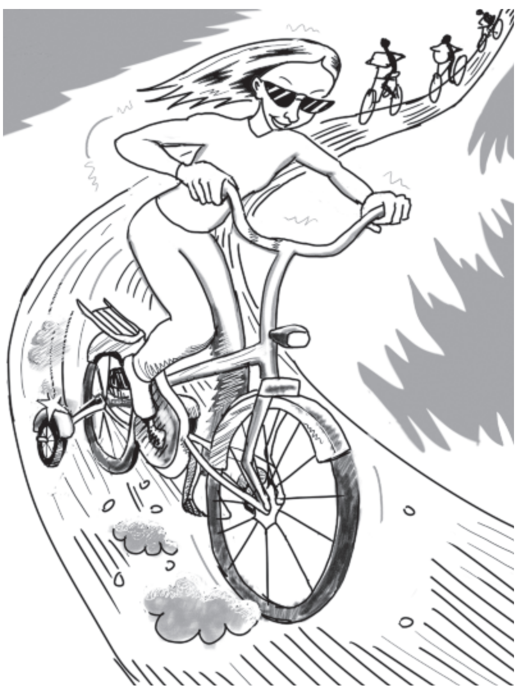
Person in charge: .... Date of evaluation: ....

Part 5

Various aids for and perspectives on the diagnosis

Aid: a comprehensive concept



An aid can be anything from good advice to a method, schedule or alarm. Before aid is offered, despite what sort of aid it is, you should consider how the individual will feel about accepting it and how it should be introduced. Will the person even use the aid when it's needed? Some things can be too complicated and therefore become stressors. Simple solutions tend to work best in the long run.

Some individuals require the help of another person to be able to use an aid. You have to demonstrate and explain it, then ask him to use it so that you might see that he really has understood and can use the aid, and then correct him if needed. Repetition can be necessary. Lists and sequences of pictures showing how the various steps should be carried out (preferably placed in a binder) can be of help for those with problems automatising.

Consider how long a person might need to practice in order to master a certain step. How long an individual must continue practising will depend on a few things: how important it is for him to be able to carry out the step himself, how long he's practised without making any headway and mainly how he feels about the task. Sometimes it's better to allow the person to skip a task and turn to the personnel for help instead, or to try other, hopefully better, aids to reach the goal. Subjecting someone to a task that he lacks the ability to carry out or that he considers extremely boring, stressful or difficult is, in the long run, a type of abuse.

Certain people have a solid network of friends, family, social workers or personnel from various agencies who can contribute resources that can make a great difference. Network meetings are invaluable for setting goals, agreeing on mutual aid contributions, doing follow ups and discussing future needs.

Your identification of the individual's difficulties using the telephone and/or text messaging

Can he or she ring various authorities?
Can he or she say no to offers from telephone marketers?
Does he or she have problems knowing how often to ring someone?
Does he or she have problems knowing what times are appropriate to ring others?
Does he or she have problems with text messaging? If so, why?
Does he or she get anxious about speaking on the telephone?
Anything else?

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Person in charge:.. Date of evaluation: ....

Your identification of the individual's difficulties with contact with authorities and agencies

Does he or she have difficulty knowing which forms to fill out?
Does he or she know what to bring up in meetings?
Does he or she have enough time to catch all the information given in meetings?
Does he or she feel anxious before meetings with people at agencies
or government authorities?
Anything else?

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Person in charge:.. Date of evaluation: ....

Your identification of the individual's difficulties with dentist and doctor appointments

Does he or she have difficulty waiting in the waiting room?
Does he or she have trouble checking in with the receptionist?
Does he or she have difficulty handling body contact (unusual tactile perception)?
Does he or she have an unusual way of experiencing pain?
Is he or she he or she afraid of the dentist?
Does he or she usually react unusually to medication?
Does he or she have problems verbally giving important information about him- or herself?
Anything else?

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Person in charge:... Date of evaluation: ....

Perspectives on the diagnosis

There's no stigma in getting a diagnosis that explains what causes your difficulties. However, the way the world looks at the diagnosis can be a stigma.

It was a relief to get the diagnosis. It explained why I've always felt different from others.

It's both fascinating and a comfort to meet people like me; now I know I'm not the only one.

Many adults with autism spectrum diagnosis describe the moment they got the diagnosis as a turning point, with mixed feelings of relief and sorrow. It's a relief to put a name on it and to get an explanation for why you are different and why you have certain difficulties. But there is also sorrow when you receive a slip of paper that names your shortcomings in black and white.

ASD is not a disease or a disorder that needs a cure. Some believe ASD is not a diagnosis but a description of a way of being and relating to the world that is different from most but not necessarily worse. The diagnosis can explain certain difficulties the individual has. People with ASD experience the details of things, which can be both good and bad, depending on the situation. Otherwise, two people with ASD can differ as greatly as two people who are neurotypical – that is, as two people without ASD. The diagnosis can be a prerequisite for others to understand the individual and to offer the right care and aids without being custodial or seeing the individual as an object in need of help. The person with ASD must feel respected, understood and accepted for his special condition and the diagnosis can help him to better understand himself. It is important that the individual get professional help to understand how his thinking and way of experiencing the world can differ from others' and to help him know how ASD can express itself in daily life, so that he can get adequate care and find aids and strategies to help him compensate.

Meeting others with with autism spectrum disorder

For many, the discovery that they are not the only ones in the world who are unusual is liberating. They find they can gain new and positive insights by exchanging experiences with others who go through and understand the world the same way they do. Societies for autism have special groups and mailing lists for people with ASD. Some have magazines made by and for adults with autism. There are many international websites dealing with autism and made especially for people with ASD.

links

http://www.lookingupautism.org/
http://www.autismspeaks.org/

Susanne Bejerot is a psychiatrist, psychotherapist and a researcher at the Karolinska Institutet in Stockholm. For a decade she worked with adults with autism spectrum disorders and ADHD. She has also worked with people with intellectual disabilities and behavioural problems. For many years her research was focused on obsessive compulsive disorders (OCD) and she wrote a text book on OCD. She is also the author and illustrator of a book about psychiatric disorders (on rhyme) and she is a renowned lecturer on psychiatry in Sweden.

Anna Sjölund is a CBT trained therapist and supervisor of staff working with people with autism spectrum disorders. She has worked with people with autism spectrum disorders for roughly two decades and began her career within housing support. She has also worked as an ombudsman at The National Society of Autism in Sweden. She is the author of the book "Support in everyday life". The Practical Guide for Caregivers – Adults with Autism Spectrum disorder is her second book.

From an anonymous reviewer of this book at Jessica Kingsley Publishers:
"Caregivers are generally undereducated for their jobs, and poorly paid, therefore showing high turnover, which is detrimental to the clients. This book would be very useful to such caregivers, making them better equipped to be successful in their jobs, and perhaps more likely to enjoy them. Also, it is written in such a way as to be immediately useful, and not primarily academic, because it explains its points functionally, with excellent examples, lots of charts, workbook type interventions, and other aids."