

Challenges of Raising and Caring for Someone with High Functioning Autism

(From one parent to another!)

Everyone knows that having a severely autistic child is extremely challenging and stressful. However many people take for granted what it is like to raise a child with high functioning autism. They often assume that because these children can talk and many do so quite well that it is just like raising any other child and that these children have no REAL impairment except for the fact they are a bit "Socially awkward." Some may even assume the kids will "Grow out of it," or even worse that the kid is really just a spoiled brat!

WRONG!!!!!!!!!!!!!!!!!!!!

There are MANY challenges faced by high functioning autistics and their families. Some autistic individuals may learn better coping skills and social skills but they will NEVER grow out of it, nor will a "better parenting system," change it unless the current parents are completely neglecting their kids. I know several families with high function autistic children as well some high functioning adults. This is for them to bring awareness to some of the challenges they face every day!

Self-Care deficits

Even though individuals with high functioning autism are physically able to take care of themselves, they often have some self-care deficits. These deficits are NOT ALWAYS because they don't know how, though in some cases they don't know how, or from being lazy, but rather these deficits are often due to the fact that they don't THINK to do them. This is often believed to be because it doesn't register with them the way it does with you or me. We naturally feel the need to shower, brush our hair and our teeth on a regular basis. But for someone with high functioning autism, unless it is part of their own routine, it will not occur to them to do these tasks on a regular basis. This may also be due to discomfort from these things due to sensory issues or not liking the feeling of these self-care rituals. It is also common for them to get so involved in their special interest they forget everything else. One common self-care deficit, I have noticed, is those individuals will wear the exact same outfit every day. This is very common and I believe it has to do with the need for sameness. Another common deficit is they won't dress appropriately for the weather or special occasions. This may be due to both sensory issues as well as wanting to wear a certain outfit or not seeing the point of changing the way they are dressed. Remember some individuals are hyper or hyposensitive to hot or cold.

Another reason for self-care deficits in people with high functioning autism is sensory issues. Many people on the spectrum have mild to severe sensory issues. These can easily get in the way of self-care. Some people on the spectrum hate the feel of water on their skin or the feel or sound of a toothbrush scraping against their teeth. The flavour and texture of toothpaste may also cause some individuals discomfort. Some people on the spectrum hate having their hair brushed or cut because of sensory issue as well as an aversion to change. Some individuals will not do thing like shower because the can't stand the feeling or water or may love the feel of water but hate the sticky feel of the water on their bodies when they get out.

Safety

Concerns about the safety of a loved one with high functioning autism keep many parents and families awake at night often haunting their dreams. This may seem odd to you, "These kids can talk and are often very intelligent, thus their parents and families should have no more worry than any other parent right? WRONG! Even though these individuals are considered high functioning personal safety if VERY OFTEN mildly to severely impaired. One reason for this is that these individual often have no REAL sense of danger. This varies from individual to individual. When I say no REAL sense of danger, I am not saying they are not afraid of thing or they don't see anything as dangerous, I mean they often don't recognize or more likely process a dangerous situation. One example of this is an individual who is terrified to go on an escalator at the mall, yet the same individual may bolt right out into the street an hour later. In cases like this, it is that their brains don't make a connection or register the immediate and very really present danger.

Past the age of ten or so parents often, don't really worry about the dangers of other people outside of their child falling in with the "wrong group." This is NOT the case for parents of children with high functioning autism. This is because these individuals can't read body language, are often very trusting and don't really register or understand what are and are not appropriate boundaries in relationships with other people. These individuals are far more likely to become victims of a crime. They are also prime targets for sexual predators.

Their inability to read people makes it a lot easier for people to deceive them. Often times these individuals can be convinced to do something they might not want to do or comply with out really understand they can say no or why they should say no. This may also be because they are taught to comply from a young age. Some individuals may end up being hurt or used by a "friend," but they continue to spend time with them and communicate with them regularly often baffling parents' family and friends. This is often for several reasons, not understanding appropriate boundaries, not understanding why what they are being asked to do is wrong or thinking it is what you are supposed to do. They still care about the friend and they don't think it will happen again. They may also feel that if they don't communicate with this friend and do as they are asked they are being a bad friend. A great deal of individuals on the spectrum love and forgive unconditionally. This will also cause them to be used or abused repeatedly.

Some individuals don't register that strangers may not always have good intentions and may wish to deceive them. This goes back to being unable to read people and often being unconditionally trusting. So if a stranger offered to show them something of their special interest they would likely go with them. YES I am saying some individual might fall for "I have my puppy in my car if you would like to come see her, she is really friendly," or "Can you help me get home I don't feel so well/need help with my bags."

Other safety concerns might be that if lost scared or injured many individuals may hide or runaway, they might not recognize the police or emergency responder's uniforms. Some individuals may become unable to speak when under a lot of stress or afraid. Another safety issue is that some individuals might be forgetful. This becomes a safety issue when they light a candle or put the stove on to cook something. Then they start doing something else, like reading about their special interest, going online, or watching TV; and forgetting what they were doing a few minutes ago, they may decide to go out because they forgot about the lit candle or the food cooking. Some people may have adverse reactions to fire alarms or again when concentrating on one thing they might block them out altogether. Some individuals might ignore pains or injuries that need attention and go on with the day as they normally would.

Wandering

97% of individuals with autism wander. Wandering can be very dangerous. Many people with autism are drawn to water sources, have a love for water, and will go right into a lake or river. They don't have the sense of danger to tell them that this can be dangerous. Not so shocking, the number one cause of death among individuals who do wander is drowning. Being drawn to things like train tracks or small places is also common and can be deadly as well. When you have an autistic child that wanders, you need to be vigilant 100 percent of the time. Many families live in "the house of locks," locking both inside and outside the house in a desperate attempt to keep their loved one inside and safe. When your child is a wanderer, looking away for even a moment is dangerous. It only takes a moment for a child to slip away and when they do, you don't know if you will find them and if you do, if they will be alive, when you find them. These are only a few common safety concerns.

Changes in routine

Individuals on all ends of the spectrum have their own little routines and ways they expect things to be. When plans change and their routines are interrupted, they are at best unpleasant to be around. "Oh come on, everyone gets upset when it comes to unexpected change that's no big deal," WRONG AGAIN! For individuals on the spectrum unexpected changes or unwanted ones can throw them off completely. Best-case scenario, they are upset and angry for a few hours or worst-case scenario, they may stop functioning all together. Often when a routine is disturbed, the person will shut down completely and not be able to continue with their day normally. Unexpected change will also commonly trigger a meltdown in varying degrees.

Sensory issues

Many individuals on the autism spectrum also have sensory issues no matter where they are on the spectrum. They maybe hypersensitive to touch, colours, tastes, smells, sounds, lights and textured. Many individuals are sensitive to many things within varying degrees. This will cause them to avoid certain foods, materials and places. Often these individuals become overwhelmed in public and experience sensory overload causing a meltdown. With many individuals, sensory information comes in unfiltered. This means they get hit with all the smells, sights, sounds and sensation at once. That combines with heightened senses can make a busy area overwhelming. As I said before certain toothpastes, tags and textures can really bother them and may even be painful to these individuals

Meltdowns

Meltdowns are NOT the same thing as a temper tantrum. There are distinct differences. A meltdown is when individuals lose all control of themselves. They may throw things or fall to the ground kicking and screaming, or they may hit their head repeatedly. Often time they may appear to have lost their temper and are yelling. Meltdowns might take the form of inconsolable crying. Some individuals may engage in self-injurious behaviours during such as head banging, biting themselves, or punching themselves repeatedly. Meltdowns are often caused by an accumulation of factors such as frustration, verbal over load (being given too many verbal instructions at once), sensory over load, unexpected change routine, and/or trouble understanding or communicating something. It is important to remember these behaviours are **not** in the individual's control.

Meltdowns often come in varying degrees from very mild where they may seem moody to extreme where they shut down completely or scream yell and cry. Individuals may say things they don't really mean during meltdowns as well. The degree of the meltdown often varies on the events of the day. Lack of sleep has been shown to increase the likelihood of meltdowns. No one enjoys going through a meltdown especially those going through it. Many people stare and criticize. This doesn't help.

Things that don't help with meltdowns

- Yelling
- Criticism
- Staring
- Whispering
- Your judging

When a meltdown happens, you need to let it run it's course till the individual regains control. If there is SIB (self-injurious behaviour), try to stop it and move things to keep them safe during a meltdown. They don't consider others or their own safety! Don't judge and move on with life. Remember meltdowns happen; it is not the end of the world! YES, adults have them too. Many people don't know how to react

to them when adults have them, because it is "normal" for kids to have meltdowns but autistic adults have them too and it is just as normal!

Obsessions

Individuals on the spectrum usually become obsessed with a particular object or subject. This is what is referred to as their special interest. So how is this a challenge? Simple, you come home to your kids and they talk about 30 different things. They tell you about their day, their friends and about social dramas. When your child has high functioning autism, it is not this way. You come home and hear about 1 thing, their special interest. This will dominate 99 percent of your conversations. Within a week, you will know everything they know about the subject. They will peruse this interest to the exclusion of everything else. If their interest is a show or a movie, you will see it over and over again until the name of it makes you want to rip out your hair! However despite the desire, you must smile and sit through it or listen to them talk about their subject again and again. This isn't a bad thing they are very intelligent and this is how they try to express themselves to you. To keep communication open you must listen and maybe do some research on your own and try to share it with them. This can help form a bond. It is also important to note that if they correct the info they give you they are not trying to be mean or lecture you but instead they are trying to participate in the conversation and simply think you're wrong and want to make sure you have accurate info. Don't be offended. They have a great deal of trouble talking outside their interests.

Communication

Just because they are high functioning, it doesn't mean they are without communication deficits! People with high functioning autism can't read body language and often don't produce it or produce very little of it. This varies from person to person as to how much they can read and produce. However, for what they can read and produce they are very limited. They may have a flat or blunted affect (showing little to no emotions on their face)

Often times the body language they do produce does not match how they are actually feeling. Laughing when confused or frustrated is one example. Often time they may not have control of their voice; it may be too high or too low. They also don't have much if any control over the tone and the tone won't always reflect their actual mood or feelings. They may seem rude while not trying to be and may even be in a great mood. Another issue is they interrupt and emotions and display them differently - this causes many to think they are emotionless but that is the furthest thing from the truth.

Adults and children with Autism often have trouble understand figures of speech, because they tend to be very literal thinkers; but may learn to use them as they get older. This also means you need to be clear in your directions, instead of saying "shut the car door," you need to say "get in or out of the car and shut the door." They may be too honest and not filter their responses. Being unable to read nonverbal cues and body language means they don't realize when they are boring or have offended someone. This also means they can't tell when someone is lying to them or wants to deceive them. This causes safety issues. Often when it comes to communicating one on one, high functioning adult can do very well but in a group they may shut down. Meltdowns may also cause communication issues as some individuals will become nonverbal during a severe meltdown and when under distress. This again creates another safety issue.

Age appropriate interests or lack there of

Many high functioning autistics don't relate to their own age group. They may prefer the company of adults as kids, and/or have immature interests as adults. Many high functioning autistics still have and like buying toys especially if they relate to their special interest. They may like watching shows they are "too old for" and often may be mentally younger or older than their chronological age. Often it varies and in some ways they can be younger and in others they are mentally older than their age. They might not be interested in things kids their age are. A 20 plus year old might be happier receiving toys, books, and items of their obsession, than things others their age would want.

Sleep

Many autistic individuals at all ends of the spectrum have sleep issues. They may be up late into the night and wake up within a few hours. Another common issue is they will wake up several times in the middle of the night. The lack of adequate sleep increases likelihood of meltdowns and they become frustrated easier. This also means the parents get less sleep. Waking in the night can be a safety hazard if they decide to try to cook something and fall back to sleep while it is cooking.

Diet

Many individuals on the spectrum have very limited diet and may have specific routines surrounding their diets. They may only eat certain foods with a certain side on a certain day. Only want to eat one or two foods all the time for every meal. Still, others may need a bland diet, not being able to handle the sensation or spice of foods. (Due to concurring digestive issues with a large portion (but not all) of the individuals on the spectrum) individuals may be on and need to stick to a special diet like the GFCF diet. Many times, it is a struggle to get someone on the spectrum to try any new foods at all. Others on the spectrum may not want to eat at all or are hungry on rare occasions.

Anxiety

A surprisingly large number of individuals on the spectrum also have a high rate of anxiety that may manifest as odd or unusual phobias. Some individuals will suffer from severe separation anxiety. Stranger anxiety is also common among individuals the spectrum. No matter what form the anxiety takes it can be very challenging to deal with.

Isolation

Parents of individuals on all ends of the spectrum may feel isolated and alone. They often don't know where to turn for help and may become increasingly frustrated. They feel as though they have to deal with this alone. Individuals on the spectrum are often socially isolated and have few if any friends. Some may not even want friends. While others want friends but struggle to make and keep them. Often time parent have said their kids friends out grew them. Some kids with autism want friends really bad but due to their lack of social

understanding, and communication deficits they are unable to make or keep friends. Leaving those living with autism wondering what's wrong and why no one wants to play or spend time with them. I remember my cousin Alyssa used to cry herself to sleep some nights because all she wanted was a friend but instead she was bullied.

Bullies

Bullies are often major issues for adults and children with high functioning autism. Often kids will gang up on them and tease or mock them. Many individuals are very sensitive about criticism and even mild bullying can be extremely damaging and traumatizing. Bullies are relentless too and the scariest part? The adult or child might not share that they are being bullied because they are afraid or don't understand they don't have to put up with it.

Stimming

Stimming is short for self-stimulatory behaviours. These are a series of repetitive behaviours such as rocking, pacing, head banding, hand flapping, chewing, object watching, objects spinning or spinning one self. These are only a few examples. This is done to help regulate oneself during times of extreme emotions or over stimulation.

"They SEEM so Normal!" Finding acceptance and compaction

Acceptance is often a MAJOR struggle for high functioning individuals. Parents, family members, advocates, close friends and the individuals themselves have to fight everyday for acceptance and understanding. There are many reasons for this. One reason is that people assume that high functioning autism means that these children and adults are without any REAL challenges. They assume that the kid's only REAL challenge is they are just a bit socially awkward or shy.

Another common issue is that people won't believe the child/ individual is autistic at all! People can't see that your child has autism because they are verbal and in many cases very verbal. People will see your child acting "oddly," or having a meltdown and they will judge you and your child.

They make assumptions, stare and whisper nasty remarks. There are also people who will make rude comments to your face. Some people have actually accused these parents of making excuses for their "poor parenting and badly behaving children," They have no idea the daily struggles these families face.

What is most baffling is how people will often say "you/he/she doesn't LOOK autistic." This is because autism doesn't have any obvious physical abnormalities. You can't tell if someone is autistic JUST by looking at them, especially if they are on a higher end of the spectrum.

Learning: Adults and children with autism also learn differently. Most but not all are visual learners and need to be shown how to and then guided in doing something. They don't learn like other kids. Great tools for learning are pictures and repetition. A reward system helps a lot too. Many individuals need to try and figure it out in order to learn as well. They may also need extra time and a lot of patience.

Regression

Regression is often said to be rare in individual with high functioning autism after age 3, but I have not found this to be the case. Regression is actually somewhat common. Many things may cause an individual to regress or appear to regress, changes in health-- if you see regression, get a check-up; there could be a health issue that has gone undetected-- major change such as transitioning schools, or moving; or several major changes within a year can all contribute to regression. Trauma can also cause regression. Regression is not defined as seeming more autistic but rather the loss of previously acquired skills. Some may seem more autistic but be gaining new skills

REMEMBER

It is important to remember that autism affects everyone differently. No two people are exactly the same in their deficits, and the severity will also differ from individual to individual. It is also important to remember that as the child grows older their special interest, routine, sensory issues and sensory needs will often change. A child who stimmed mildly but was very sensitive to tags and such, may become used to them but still need to stim a lot more. Individuals present the characteristic of their autism differently! When you have met one person with autism, you have only met ONE person with autism and have only seen one form it can take!

Even though they are high functioning, their functioning level can shift from day to day. Some days they may seem to be functioning higher than others!

By Samantha Driscole