Autism Spectrum Disorder (ASD) in Children and Youth, Part 1: Could My Child be ‘On the Spectrum’?

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Summary: Autism spectrum disorder (ASD) is a brain difference that can bring incredible strengths, yet also make life challenging for children, youth and adults. Features include troubles interacting with other people; troubles with changes / transitions; troubles with external demands and expectations; troubles with sensory sensitivities. As a result of these stresses, people with ASD often struggle with problems with mood, stress and anxiety. Worse, usual treatments and services for "neurotypical" people may not work with those with ASD. Knowing that a person has ASD can make an immense difference. It helps them understand their "neurodivergent" strengths and their "gift of ASD", and makes it possible to have more appropriate supports and services.

Three Stories

Mohamed is a 4-yo who parents always sensed was different. He seemed more interested in objects than people. They tried putting him into a home daycare, but he was aggressive with the other kids and was thus unable to return. The daycare he attends reports that he is sometimes aggressive toward other children, and his parents are concerned because he only uses 3-4 words to communicate.

Thomas is a 10-yo boy who has always been into science and everything mechanical. He’ll take apart anything mechanical and is like an encyclopaedia when it comes to all things technical. On the other hand, he has trouble connecting with other kids his age and is bullied by others.

Jasmin is a 14-yo female who has always been introverted. She has always had an active imagination. She’d play for hours with her dolls and would create an elaborate fantasy world for each one of them. Now that she is older, she has more trouble with the expectations at school and home. Whenever parents try to ask her to stop doing her preferred activities, she has terrible meltdowns.

What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD) is a neurological condition that affects a person's ability to communicate, understand, play and relate to others.

Classic symptoms include:

- Problems with social communication and interaction:
  - Those with lower functioning ASD may have trouble with language, making it hard to communicate with others.
  - Those with higher functioning ASD may have typically developing language but may have:
    - Challenges with social communication. For example, they might have difficulty making eye contact, understanding gestures, body language and social cues.
    - Challenges seeing other's perspectives. They may see things from their perspective and act in inappropriate ways without realizing how their behaviours affect others or make others feel.
- Restricted or repetitive behaviours, interests or activities, which may include::
  - Unusual play with toys and objects. A child on the autism spectrum may play with toys but often will play with them differently than other children do. For example, a child playing with cars may line them up over and over again or be obsessed with parts of a toy or repeatedly take apart and put a toy back together.
- Rigid routines and preoccupation with routines or rituals.
  - People with ASD may have an extreme need for consistency and routines and may become distressed if there are changes in routines or if others make external demands, e.g. asking the child to come for dinner, get ready for school, etc.
- Difficulty following others' instructions, demands or expectations:
  - Their need for autonomy (e.g. preferred activities and routines) is so strong, that they may become distressed when others infringe on their autonomy (e.g. when others make a demand or request that takes them away from their preferred activity). Their actual fight/flight system can be triggered, with anger ("fight"), anxiety ("flight"), and tantrums / meltdowns.
- Sensory processing problems such as:
  - Hypersensitivity to sensory input, becoming distressed with sound, being touched or movement.
  - Under sensitivity to sensory input, seek out sensory input such as making more sound, touching everything, moving all the time. E.g. screaming, looking for squeezes on their head, heads or legs; spinning.
  - Because sensory processing problems make it hard to self-regulate, they have trouble being calm enough to learn and function.
- Coordination problems with such as troubles with balance and coordination.

Associated symptoms and conditions in people with ASD may include:

- Trouble paying attention. People with ASD are often distractible and inattentive, and this can be due to many reasons such as:
  - Sensory overload (e.g. too much sound such as the hum of the fluorescent lights)
  - Attention deficit hyperactivity disorder (ADHD)
- Problems with stress, anxiety and mood. Having ASD can make relationships, home and school extremely challenging, and as a result, they may be at a higher risk of having stress, anxiety or depression.

What is the 'Spectrum' of Autism Spectrum Disorder?

ASD is a "spectrum" as these conditions occur along a continuum, with three "levels" of severity that range from mild to moderate to severe.

Level 1, Mild Autism, Requiring Minimal Support	• Only require minimal support to help them function. • Able to communicate verbally, but may have trouble with social situations • May have problems with non-verbal skills, e.g. reading social cues, reading other's facial expressions, etc. • May have trouble understanding social cues and how to have a two-way conversation or keep a friendship or relationship. • May have restrictive or repetitive behaviours. • Intellectually, they may have average or above-average intelligence when it comes to school subjects. • Such people might have been diagnosed with **"high functioning ASD," Asperger Syndrome, or PDD NOS in the past.**
Level 2: Moderate Autism, Requiring Substantial Support	• More severe challenges than those with Level 1 but less than those with Level 3. • Troubles with social skills. • May be unable to communicate verbally with others. • May have significant troubles with following school or other routines; may react with emotional or behavioural outbursts.
Level 3: Severe Autism, Requiring Very Substantial Support	• Significant problems with communication skills; may not be able to communicate at all verbally or non-verbally. • They prefer doing their activities and may experience significant stress if 1) there are changes in routines or 2) asked to follow routines (such as school routines). • May require 1:1 support (i.e. an adult being with them) for various daily routines. • Often have learning disabilities and may have intellectual disabilities (i.e. formerly known as mental retardation). • In the past, they might have been diagnosed with **Autistic Disorder.**

High Functioning ASD (aka ASD, Level 1) can be Hard to Identify

When people have strong symptoms of ASD, it is easier to identify and diagnose.

However, some people have very high functioning ASD, which makes their symptoms very subtle and harder to diagnose.

Many of the diagnostic criteria for ASD are based on classic symptoms in males. However, now we know there is a wider range of people on the spectrum than we realised. Many people with ASD are very good at trying to fit in, copying others and "playing the neurotypical game" (Holliday, 2012), which can include females, but males too.

	"Classic" symptoms	Higher functioning ASD
Communication	People with classic ASD can range from being non-verbal (thus requiring picture exchange communication systems / sign language) to being verbal.	People with higher functioning ASD will have normal and even superior verbal language skills. However, they may struggle with understanding non-verbals such as other's tone of voice, facial expressions. They may lack awareness or be hyperaware.
Social Skills	People with classic ASD may have very limited motivation to engage socially, to being very motivated but having difficulty navigating social situations. May have difficulty taking the perspective of others, or understanding body language. Awareness of these challenges varies greatly.	Higher functioning people with ASD may appear to have good social skills superficially, for example, having learned social rules about how to greet others, be polite, etc. They may be able to make friendships, but they may struggle with keeping long-term relationships.
Empathy, theory of mind	Tends to be "clueless, oblivious, unaware" about how others are feeling; usually doesn't worry or seem to care about what others think and feel; may come across as self-centred and selfish.	Higher functioning people with ASD may struggle to understand others' thoughts and feelings, yet they are still worried about offending others or making a social mistake. They may be sensitive to others' emotions, especially negative ones but struggle with understanding why others feel this way.

Attachment needs	People with classic ASD may seem perfectly happy to be attached to their preferred activities and interest, and not interested in connecting with people.	People with higher functioning ASD may deeply crave relationships (or at least acceptance) with other people. However, repeated rejection from others can lead to social anxiety and giving up trying to connect to others. They often do best with fellow people with ASD with similar preferred activities and interests.
Behavioural Characteristics	Classic ASD interests are technological or scientific areas such as science, technology, engineering, nature (e.g. dinosaurs.) Intense, focused interests, the topic, and the intensity of the interest may vary. Some individuals may engage in self 'stim' behaviours. May need additional support with daily tasks and routines	Non-classic ASD interests may include creative interests: • Fiction such as reading or writing fiction (e.g. fantasy, science fiction) • Creating a fantasy world, • Creating a new persona, • Talking to imaginary friends, • Nature such as animals. Writers with ASD have said that "animals and imaginary friends are safe and cannot betray you."

Strengths of ASD

There are many examples of famous people with ASD who will tell you that the reason they have been to excel and succeed, is precisely because of their ASD.

Famous examples include:

- Greta Thunberg, climate and environmental advocate.
- Elon Musk, entrepreneur and business magnate with SpaceX, Tesla and others.
- Bill Gates, founder of Microsoft
- Daryl Hannah, actor
- Courtney Love, singer
- The characters from Big Bang Theory, who range from more mild, to more severe.

Classic strengths include:

- Being good at following rules and laws, as well as trying to understand things according to rules and laws (Baron-Cohen, 2003).
- Show the great depth of knowledge in areas of interest, which can help them become experts in their fields of interest.
    - Classic examples include science, engineering and computers.
    - Other examples include creative fields such as arts, music, drama, and social sciences (e.g. people with ASD make excellent anthropologists, as they can be extremely objective when observing any system.)
- Being able to focus their attention for long periods of time, even on tasks which others may find boring or mundane (such as programming).
- Being able to stay objective, and not be as affected by 'peer pressure' or others' opinions (e.g. people on the spectrum report being less influenced by peers when it comes to clothing trends or pressure to try drugs).
- Visual strengths. Many may have exceptional (even "photographic") visual memory (i.e. memory for things that they have seen). These strong visualization skills (the ability to think in pictures) may help in many fields including engineering and design.
- Auditory and verbal strengths. Many people with ASD are strong at remembering what they have heard, or have strong verbal skills, which helps in many professions, e.g. writer, editor, etc.
- Strong analytical and logical reasoning skills, helpful for many fields such as accounting, engineering, and computers.
- Having a super work ethic, as they tend to be punctual, reliable, dependable and very accurate.

Services and Supports Can Make Massive DIfference

People with ASD have many strengths; however they may face various stresses at home, school and other environments.

For example:

- Sensory sensitivities can make it difficult outside of home.
- Social interactions can be stressful, with problems making and keeping relationships, leading to loneliness. They are often bullied and taken advantage by others.
- Troubles with changes and transitions can make daily life a struggle.

Due to all these stresses, as people with ASD grow older, many of them may develop depression and anxiety. They may seek out help with supports and services geared towards 'neurotypical people', such as talk therapy and medications. Yet despite these interventions, they may end up still struggling, because the 'neurotypical' treatment has not addressed underlying issues with their ASD. 'neurodivergence'.

For this reason, it is important to identify people with high functioning ASD.

Appropriate intervention can make a significant difference in helping the person with autism spectrum disorder (ASD) and all those who interact with the person, including family, relatives, teachers, and classmates. The right intervention will depend on what the needs of the individual are.

When a proper diagnosis is made, people with ASD invariably experience relief.

"After I was diagnosed, it all made sense -- why daily life was overwhelming, why everything was too loud and too bright, why I struggled with people and social interactions. It was such a relief to know that I wasn't alone, and that there was a name for this. Though its better late than never, its too bad that I wasn't diagnosed as an adult -- I wish I had known when I was a child."

-- Adult with ASD

Wondering About ASD in Ontario?

Are you wondering about ASD in a loved one (or yourself)?

- Start by seeing a health care professional for an assessment for ASD such as your family physician, nurse practitioner or pediatrician.
- Are you in Ontario?
    - Publicly funded Autism Diagnostic Hub
        - Contact a diagnostic hub where psychologists and pediatricians can do an assessment and make a diagnosis. https://www.ontario.ca/page/au...
    - Psychologist in private practice
        - Publicly funded services such as AutismDiagnostic
        - Hubs can take quite a while to be seen, thus some families may prefer to see a psychologist in private practice.
        - Visit link below and click on CONDITIONS > select Autism Spectrum Disorder (ASD)
            - https://www.ementalhealth.ca/i...

After a diagnosis, the next step will be connecting to appropriate services and supports.

Three Stories, Part 2

Mohamed (4-yo), Thomas (10-yo) and Jasmin (14-yo), were all very different, but all had the following things in common:

- Troubles with communication;
- Troubles relating to other people;
- Over-connected to their preferred activities and troubles engaging in typical age-appropriate expectations at home and school.

Fortunately, their parents were able to connect them with professionals to assess for ASD.

After confirming a diagnosis of ASD, the professionals met with the family and helped connect them to appropriate services and supports such as:

- Publicly funded services for ASD.
- Support associations such as Autism Ontario;
- School supports: Letting the school know made it possible for the school to develop more appropriate support.

Websites (English)

Autism Ontario has a detailed list of educational resources
www.autismontario.com

Online Asperger Syndrome Information and Support,
http://www.aspergersyndrome.org/

"Understanding the Student with Asperger Syndrome: Guidelines for Teachers" by Karen Williams, 1995, FOCUS ON AUTISTIC BEHAVIOR, Vol. 10, No. 2.
http://www.udel.edu/bkirby/asperger/karen_williams_guidelines.html

Books (English)

General

Complete Guide to Asperger's Syndrome, by Tony Atwood, 2006.

More Than a Mom: Living a Full and Balanced Life When Your Child Has Special Needs, by Amy Baskin and Heather Fawcett, 2006.

A Mind Apart: Understanding Children with Autism and Asperger Syndrome, by Peter Szatmari, 2004

The OASIS Guide to Asperger Syndrome: Completely Revised and Updated, by Patricia Romanowski Bashe, 2005.

Look Me in the Eye: My Life with Asperger's, by John Robison, 2008. Written by an adult diagnosed with ASD (previously known as Asperger Syndrome) later in life, it gives an excellent first-hand account of what it is like having ASD.

For Females with ASD

Safety Skills for Asperger Women: How to Save a Perfectly Good Female Life, by Liane Halliday, Willey, 2011.

Pretending to be normal: Living with Asperger’s Syndrome, 2010, by Liane Halliday.

Life on the Autism Spectrum - A Guide for Girls and Women, by Karen McKibbin and Tony Attwood, 2015.

About this Document

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