HWDSB

We Help.

# Autism and Mental Health

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder that affects the way a person communicates and relates to people and the world around them. It is a wide range or spectrum of conditions characterized by challenges with speech and nonverbal communication, social skills, and repetitive behaviors, and can cause significant communication, social, and behavioural challenges. The learning, thinking, and problem-solving abilities of people with autism can range from very high (significantly above average) to very low (significantly below the average range). Autism exists in all cultures, ethnicities, races, and gender identities (Autism Ontario, n.d.). Approximately 1 - 2% of the Canadian population is on the autism spectrum which means there are approximately 135,000 people with autism in Ontario (Evdokia Anagnostou MD, 2014).

People with autism are at an increased risk of associated mental health issues, including, but not limited to: Anxiety, Attention-Deficit Hyperactivity Disorder (ADHD), Depression, and Obsessive-Compulsive Disorder (OCD). Recognizing and diagnosing these co-occurring conditions (happening at the same time) can be very challenging for parents and professionals alike because many symptoms of these conditions look similar to characteristics of autism, leading to "*diagnostic overshadowing*," or the mistake of attributing all symptoms to the individual's autism behaviours rather than looking for other or additional explanations. As difficult as it can be, identifying and treating the mental health issues is extremely important as these symptoms can cause *more* impairment to functioning than the underlying symptoms or behaviour patterns of autism as it can interfere with treatment, schooling, home life, and overall quality of life (Bailey, Looking Beyond Autism, 2016).

*The diagnosis of autism may mask or delay the diagnosis of a mental health concern.*

# Prevalence rates of mental health issues


Anxiety disorders affect up to 80% of people with autism (Joshua Nadeau, 2011). By contrast, they affect an estimated 3% of children and 15% of adults in the general population (Speaks, Autism and Health: A Special Report by Autism Speaks - Advances in Understanding and Treating the Health, 2017).

Attention-Deficit Hyperactivity Disorder (ADHD) affects an estimated 30 to 61% of people with autism versus 6-7% of the general population (Medical Conditions Associated with Autism, n.d.).



Obsessive Compulsive Disorder (OCD) affects 17-30% of individuals with autism and is 1.5-2% in the general population (David Worling, Looking Beyond Autism, 2016).

Depression affects an estimated 7% of children and 26% of adults with autism. By contrast, it affects around 2% of children and 7% of adults in the general population (Medical Conditions Associated with Autism, n.d.)


# Why are mental health issues often missed?

Earlier we discussed the concept of "*diagnostic overshadowing*" - the mistake that many parents and professionals make in assuming that all behavioural challenges or changes in mood a child with autism faces can be attributed to their autism. In addition to this concept, there are other reasons that can lead to under-diagnosis and under-recognition of mental health issues in people with autism (Bailey, 2016):

- Children with autism often use fewer *facial expressions* than their neurotypical peers, making it more challenging for adults to notice when they are feeling sad, frustrated, or even happy.
- When neurotypical people are feeling upset or worried, changes in their *prosody* (rhythm or tone of voice) may be noticed, for example, speaking quicker than normal, or using a softer (or agitated) tone. For a child with autism, these changes may not be as evident, or even possible if they are non-verbal.
- When feeling upset, children with autism may increase the use of *repetitive behaviours* (such as pacing or rocking) as a means to cope, which can make it very difficult to distinguish between a behaviour that brings pleasure and what behaviour may be a compulsion (not driven by pleasure).
- The child may not have the ability to *recognize in themselves* the change in their emotional state, rather, they just know that they do not feel happy and are unsure why. They may also struggle to find the words to describe a change in their feelings, or they may be non-verbal.
- Children with autism may not *express distress immediately*, but instead wait until, for example, they are home, to express vocally or through their behaviour, that they are unhappy. It is then challenging for parents and educators to identify the cause of the distress, and may mistakenly attribute it to the wrong source.

- It is essential to include a full physical exam, as well as hearing and vision tests and dental checkups, when assessing for potential mental health concerns. In part due to potentially limited communication skills and/or not reporting pain or discomfort, many individuals with autism have physical health concerns that may go unnoticed and untreated. Pain and discomfort may be expressed through agitation, aggression, and/or withdrawal, which are also common symptoms of mental health problems. This is an important step to identify potential physical health problems that could be affecting or adding to changes in mood, thinking patterns, or behaviour. It is important to treat any potential physical health concerns first, and monitor changes in mental health and well being.

# Autism and Anxiety

Studies suggest that up to 80 percent of people with autism experience significant anxiety (Joshua Nadeau, 2011). Social anxiety, or the extreme fear of new people, crowds and social situations, is the most common form (Speaks, Autism and Health: A Special Report by Autism Speaks - Advances in Understanding and Treating the Health, 2017), and yet can be very difficult to identify as deficits in social communication are part of the autism diagnosis. This leaves parents/caregivers and educators questioning the underlying cause of the child's avoidance of social situations – is it skill based (i.e., unsure how to approach peers), a lack of interest, or anxiety?

When individuals with autism experience anxiety, it can increase the severity of behaviours associated with autism, which is most commonly evident through externalizing behaviours (i.e., acting out, tantrums, yelling), social avoidance, difficulties making and keeping friends, sleep problems and disruptions in family functioning (Joshua Nadeau, 2011). An increase in these types of behaviours, in turn, adds to the difficulty they often experience in relating to peers.

> Because the incidence of anxiety is so high in individuals with autism, it is more prudent to assume the child *does* have anxiety and to implement the appropriate strategies, than to assume they do not (Bailey, 2016).

People with autism often have difficulty controlling their anxiety once it has been triggered. For many of these individuals, their anxiety is *wrapped around autism symptoms* such as difficulty navigating social situations and extreme sensory sensitivities to loud noises, lights, tastes and smells. This can produce "anticipatory anxiety" when simply anticipating or otherwise thinking about an anxiety trigger produces extreme anxiety.

Yet another broad source of anxiety in those with autism involves the need for routine or sameness. This can produce anxiety in the face of changes in schedule or familiar people – for example, a new teacher, aide or even store clerk (Speaks, Autism and Health: A Special Report by Autism Speaks - Advances in Understanding and Treating the Health, 2017).

# Autism and ADHD

Attention-Deficit Hyperactivity Disorder (ADHD) is one of the most common mental health diagnoses that co-occurs with autism; however, this has not always been the case. Prior to 2013, the main diagnostic tool utilized by professionals identifying mental health issues, the Diagnostic and Statistical Manual of Mental Disorders (DSM), indicated that an individual could have *either* autism *or* ADHD, but not both. Since 2013, this has changed and professionals recognize that those with autism may also have significant difficulty sustaining their attention, resisting impulses, and regulating their behaviour. However, even with this

change in recognition, it continues to be commonplace that the diagnosis of one condition delays the diagnosis of the other, and thus treatment is also delayed. Add to this the fact that it can be very challenging to confidently diagnose ADHD in an individual with autism because both involve impaired social development and challenges in attention, learning and communication (Speaks, Autism and Health: A Special Report by Autism Speaks - Advances in Understanding and Treating the Health, 2017).

Strategies that have been proven helpful for children and adults with ADHD, such as medication and knowledge about the diagnosis, are also helpful for individuals with autism and ADHD. "Research shows the success rate for stimulant use is near 80 percent. These medications can bring substantial improvement to the 'core' symptoms of ADHD that undermine social, behavioral, or academic progress in a child with autism, such as poor focus, inability to complete a task, and impulsivity (Mark Bertin, 2021)." Dr. Bertin goes on to explain that for a child or adult struggling with both autism and ADHD, removing the added challenges of inattention and impulsivity, can positively impact the individual's life at home, work and when relating to peers. Academics can also be positively impacted because the child is better able to focus their attention.

A core component of both autism and ADHD is weak executive functioning. Executive functioning is the ability to control (regulate) one's behaviour (i.e., resisting impulses), emotions (i.e., responding developmentally appropriately when upset or excited, tolerating change), and cognition (i.e., organization, planning, sustaining focus, initiating tasks). The same strategies that are used to help a person with ADHD are helpful for those with ADHD and autism. These include:

- breaking tasks down into smaller steps,
- providing visual organization tools (e.g., story maps, graph paper), samples of completed tasks,
- check-ins to ensure understanding of the task, and
- help with time management (e.g., today we will write the introduction, then tomorrow the first body paragraph, etc.)

Dr. Russell Barkley, a renowned expert in the field of ADHD, has a series of keys for parenting a child with ADHD. These strategies should prove helpful for children with autism and ADHD. See the HWDSB infolet ADHD for an explanation of these strategies as well as additional suggestions that can be used at home and school to support your child.

# Autism and Obsessive-Compulsive Disorder (OCD)

Obsessive-Compulsive Disorder (OCD) is an Anxiety Disorder characterized by a) persistent and distressing thoughts and b) behaviors used to "cope with" those thoughts. A person with OCD often feels "compelled" to perform compulsive behaviours and believes that performing these behaviours will "keep bad things from happening." (Rastall, 2013).

Given the repetitive behaviours and restricted interests that are a hallmark of autism, it can be very difficult to distinguish between a child's individual patterns of behaviours, and obsessions or compulsions that are symptoms of OCD. A key to distinguishing between the two is looking at the role the obsessions and compulsions play. For example, a restricted interest is one that provides comfort and pleasure for the person with autism. It is a topic that is of interest to them and they may appear to think and talk about it consistently. An obsession, on the other hand, is an intrusive thought and does not provide pleasure. It is a thought that the person does not want invading their mind and seeks to stop (through repetitive behaviours or compulsions). Similarly, an individual with autism may engage in repetitive behaviours because those behaviours provide them with pleasure, whereas, a compulsion is used to reduce stress and not because they *feel* or *sound* good (David Worling, Looking Beyond Autism, 2016).

Additionally, if debating between obsessions and compulsions, and restricted interests/ repetitive behaviours, it can be helpful to look at the subject of the thought/action. For example, is it a 'typical' or common obsession (e.g., washing/cleaning, checking, counting, need for symmetry, mental rituals, ordering, or hoarding)? If not, it may be an area of interest or behaviour that provides pleasure. Careful observation, tracking with attention to context or the environment, and multiple sources of reporting will help distinguish what seems to be driving or motivating the behaviour.

# Autism and Depression

Although not as common as anxiety, ADHD or OCD, the rates of depression in people with autism is much higher than that seen in the general population. Similar to other mental health conditions, depression can be challenging to diagnose as symptoms and behaviour patterns of depression are similar to autism, especially related to social communication. For example, low tolerance for frustration and social isolation, as well as having a "flat" or unemotional facial expression are common symptoms of both autism and depression. As a result, it can be difficult seeing beyond behaviour patterns of autism to the underlying symptoms of depression. In addition, many people on the autism spectrum have difficulty identifying and expressing how they feel (Sterling, 2015).

Parents and caregivers are often the first to notice their child's low mood and/or depression as they are aware of their child's interests and thus often notice when their child no longer expresses interest, or gains pleasure from something they had previously enjoyed. This is even more important for children who are non-verbal as they are unable to express orally the change in their mood and thoughts. Things to watch for include: self-isolation, no longer enjoying the things they had previously enjoyed, irritable and/or aggressive behaviours, decreased psychomotor activity (not as active as they had been), increased stereotyped behaviours, diurnal variation (feeling low in the morning but feel better as the day goes on), and changes in sleep, appetite, and weight (Bailey, Looking Beyond Autism, 2016).

# Treating Mental Health Issues

Although research identifying the best treatment plan for individuals with autism and mental health concerns is limited, strategies informed by Cognitive Behavioural Therapy (CBT) appear to be the most effective in regulating emotions and increasing tolerance for uncertainty (Clinic, n.d.). However, given its reliance on the ability for an individual to reflect on their own thoughts, feelings, and behaviours, this can be a challenge for some people with autism. A modified approach that includes the core components of CBT (exposure, coping skills, problem-solving) that is tailored to the ability of the child and personalizing around the child's interests is highly recommended. For example, rather than focussing on having the child reflect on their own *cognition* (thinking skills), the focus is placed on their *behaviour*.

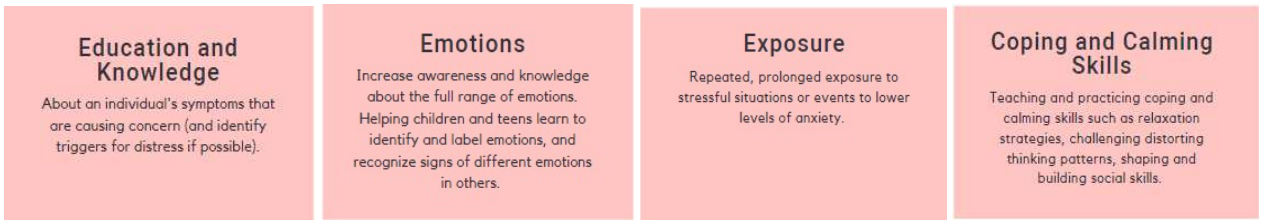
Treatment strategies to support mental health challenges will take longer for children and teens with autism to learn than their neurotypical peers, and will require a highly individualized approach, with a significant amount of repetition/practice.

Treatment approaches have more parent or caregiver involvement as these trusted adults can help to model and practice strategies, as well as monitor changes in behaviour and mood, and reinforce/reward desired behaviours. It is also important to remember that children and teens look to the adults around them for

guidance when faced with difficult situations. Parents and caregivers must be aware of how they handle themselves in these situations as their level of distress or agitation can *either fuel or reduce the child or teen's distress.* **Feelings of anxiety and distress are highly contagious. Adults help to create the most optimal environment through their own calm, and by being present and composed.**

Research has shown that the rates of depression and anxiety increase in people with autism who have higher cognitive functioning skills (i.e., I.Q.). Research also indicates that the possibility of successfully engaging in treatment approaches, such as CBT, also increases with a higher level of cognitive functioning (Speaks, 2017).

At the core, CBT-informed treatment approaches have 4 parts:




Additional strategies include:

- The range in symptoms or behaviour patterns related to autism, as well as the vast range in cognitive skills and communication skills, highlights the need to build on each person's strengths and individualized modifications related to cognitive and verbal abilities. Personalized modifications will also need to take an individual's ability to reflect on their own thinking into consideration (David Worling, Looking Beyond Autism, 2016). In particular, many individuals with autism have difficulty "picturing a situation and picturing how it could have a different outcome" which can make cognitive aspects of a CBT approach challenging (Yuhas, 2019). Modifications that include additional work to challenge and change fixed or rigid thinking patterns will be required for many individuals.
- Children or teens with autism may show intense and sudden bursts of anger and frustration, and often take longer to regain a sense of calm as compared to their neurotypical peers. Difficulties with behaviour regulation can make developing and practicing coping strategies such as mindfulness particularly challenging. As a first step, it is helpful to begin with a treatment approach that focuses on the behaviour itself, such as directly teaching anger management or desensitization techniques, and reinforcing replacement behaviours with a reward system (Speaks, Autism and Challenging Behaviors: Strategies and Support, 2016).
- As anxiety can also arise from misunderstanding social cues, increased focus on emotional awareness and developing/practicing social skills are essential components to include in skill building aspects of treatment. Include ways to help individuals understand that some of their behaviours are atypical and caused by neurological differences.
- Modifications to help support communication and social challenges may also include using pictures, concrete language, lists, videos, and social stories. It is also helpful to modify materials around a child or teens interest (i.e., incorporate restricted interests to maximize their engagement in practicing strategies).
- Coping and calming strategies are most effective when they are integrated into daily activities, and used/practiced regularly so they can become automatic and routine – and children and teens are then more likely to then be able to independently use these strategies when needed. Also, using calming

strategies on a regular basis can help reduce the production of hormones associated with stress (cortisol), and can help change future reactions to stress (increase tolerance for frustration, and make it easier to reach a state of calm).

- Due to a lack of insight common among individuals with autism, gains and progress tend to be narrow and specific, limiting their ability to generalize their skill or transfer what they have learned to new or different situations. An individual treatment plan for *each* trigger or source of stress may be required. Directly teaching problem solving skills and prevention strategies to help individuals generalize their skills is an important element to build into a treatment plan.
- Our brains seek out patterns and is calmed by things that are familiar. Maintain a regular and consistent routines as much as possible, and have a schedule and list of routines visible for easy reference. Provide warnings about upcoming transitions. This will help to create consistency for children and teens, but also for family members or a classroom as a whole, and reduce feeling anxious about unexpected events for everyone.
- To avoid overstimulation, monitor excess noise, clutter, and high level of activity to make environments as calming and predictable as possible.
- Incorporate opportunities for physical movement multiple times throughout the day. Exercise increases the functioning of neurotransmitters like dopamine, and makes us feel happier (positively affects mood).
- Treating symptoms of ADHD, anxiety, and/or depression with the addition of medication may also be an option. Before making any decisions about medication, begin by talking to your child's doctor. You need to ensure that you are getting information from a credible source. As with anything, be wary of information on the internet, especially when the source is unknown, or it is an individual's personal opinion -- and not grounded in fact and research.

# Impact on Family

When any child or teen experiences a mental health challenge, there is a negative impact on the whole family that can be overwhelming. It is particularly challenging for a family of a child or teen with autism as the family may already be drained and struggling to cope depending on the level of need required to support their child or teen's daily living needs. Reach out to others for support. This will help you and your child to feel less isolated as well as give your child opportunity to practice social skills and self-regulation skills in different environments.

The physical, emotional, and social impact on parents and primary care givers is particularly intense (often referred to as compassion fatigue). Self-care for parents and primary caregivers is essential. When family members are feeling their best, they are better able to support each other. Get to know what kinds of activities and thoughts make you feel better or worse. Some strategies may be relatively quick and easy ways to boost your energy, while others may be more complex and require more time and planning.

## Additional Resources

* Autism Mental Health Literacy Project (AM-HeLP) Mental Health Literacy Guide for Autism -
* *Autism: What Does It Mean to Me? A Workbook Explaining Self Awareness and Life Lessons to the Child or Youth with High Functioning Autism or Asperger.* Catherine Fahaerety, 2014, published by Future Horizons Inc.
* *The ASD Feel Better Book: A Visual Guide to Help for Brain and Body When You Feel Bad for Children on the Autism Spectrum.* Joel Shaul, 2017. Jessica Kingsley Publishers.
* *Autism and the Stress Effect: A 4-step lifestyle approach to transform your child's health, happiness and vitality.* Theresa Hamlin. 2015. Jessica Kingsley Publishers.
* Contact Hamilton for Children's and Developmental Services – central access service to mental health and/or developmental services in Hamilton
* Anxiety Canada
* Easy and Fun Mental Health Activities to try at home from School Mental Health Ontario

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