



## Developmental Disabilities and Mental Health

Developmental disability is an umbrella term that covers a wide range of skills and abilities. Some developmental disabilities have a genetic origin (such as Down syndrome), some may be caused by illness or injury prenatally (such as Fetal Alcohol Spectrum Disorder - FASD) or during childhood (acquired brain injury), and sometimes there is no known cause. In general, individuals with developmental disabilities will have more difficulty than same-aged peers with problem-solving (thinking and reasoning/cognitive skills), and will require varying levels of support with daily living skills. The level of support required will depend on a range of factors, including: cognitive level, developmental stage, level of mobility (physical limitations), and language/communication skills.

In Ontario, in keeping with Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008), **developmental disability** refers to significant limitations in both:

- ***cognitive functioning***-intellectual capacity to reason, organize, plan, make judgements and identify consequences; and
- ***adaptive functioning***-capacity to gain personal independence, based on the person's ability to learn and apply social skills (learning and following social norms), practical self-care skills (activities of daily living), and conceptual skills (like reading, writing, and money sense) to everyday life.

Limitations are likely lifelong, and affect major life activities such as personal care, language skills, and learning abilities. Approximately 1 to 3% of people in Canada are estimated to have a developmental disability (Centre for Addiction and Mental Health – CAMH).

Individuals with developmental disabilities experience social and learning challenges on a regular basis, and are at increased risk of developing mental health problems throughout their lives. In the context of the information presented here, **mental health problem** refers to symptoms of mental health challenges (i.e., anxious feelings or low mood) in general that may range from mild concerns to more significant challenges, and may or may not meet criteria for an official diagnosis (e.g., Generalized Anxiety Disorder).

In Ontario, and in most parts of Canada, the term **dual diagnosis** refers to a combination of a developmental disability and mental health problem. (Outside Canada, dual diagnosis can refer to other combinations of diagnoses.)

For a number of reasons, it is difficult to get an accurate picture of how many people with developmental disabilities struggle with mental health. However, estimates tell us that people with developmental disabilities are **three to six times more likely** to struggle with mental health than the general population (CAMH). The most common struggles are with anxiety, depression, and disruptive behaviour.

In general, although mental health difficulties among individuals with developmental disabilities are common, they are often **underdiagnosed**. This is in part due to a process called *diagnostic overshadowing*, which means that symptoms of mental health concerns are incorrectly assumed to be related to a child or teen's developmental disability, rather than a co-occurring mental health issue. Difficulties making a clear and accurate mental health diagnosis is further complicated by communication difficulties, and potentially unexpected behaviours or reactions (for example, may present as aggressive when feeling sad or lonely).

The relationship between mental health and developmental disabilities is complex, and can change over time. How mental health problems present in children and teens with developmental disabilities will be unique to each individual. Similarly, how each individual communicates their experiences will vary depending on communication skills and level of understanding about their experiences and symptoms, which can make it tricky for psychologists and medical doctors to make a mental health diagnosis. A multi-disciplinary team approach that uses a 'multiple needs' and 'whole person' approach is essential to ensure an accurate diagnosis and treatment plan.



**Key elements for helping to identify if an individual with a developmental disability may also be experiencing mental health challenges:**

*Could there be an undiagnosed medical problem?*

In part due to limited communication skills, many individuals with developmental disabilities have physical health concerns that may go unnoticed and untreated. This may be due to an individual not reporting pain or discomfort (or having a higher pain tolerance than same-aged peers). However, pain and discomfort may be expressed through agitation, aggression, and/or withdrawal, which are also common symptoms of

mental health problems. It is important to include a full physical exam, as well as hearing and vision tests and dental checkups, when assessing for potential mental health concerns. 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 to determine if there are changes in mental health and well being.

### *Are expectations and supports appropriate for the level of need for the individual and family?*

It is important to consider if the supports that an individual and/or their family is receiving are enough to provide sufficient structure and assistance, and not leading to an individual or their family feeling overwhelmed. In some cases, providing additional supports can help reduce overall stress, and reduce or alleviate concerning symptoms and behaviours, leading to an improved state of mental health. Often a treatment plan for a child or teen with a dual diagnosis will include recommendations for additional supports for parents and caregivers, and/or therapeutic support for the whole family *to help ensure that the needs of the individual's support system are also met.*

## Symptoms of mental health concerns – what you may see:

As communication skills may be limited for children and teens with developmental disabilities, it can be very challenging for parents and educators to know what is causing the child or teen to feel discomfort or distress. Observing behaviours and noticing things happening in the environment, will be helpful in identifying patterns and sources of distress. Behaviours that present as defiant or aggressive (to self or others) may be an indication that the child or teen is feeling stressed in some way (e.g., sad, confused, scared, tired, hungry, anxious, and/or unprepared). It is important to question if the child or teen is experiencing distress because their needs are not being met, and the challenging (problematic) behaviours we see are actually their attempt to cope.

Children and teens with developmental disabilities often have long periods of heightened stress because it may be challenging for them to keep up with the fast pace around them, and prepare for unexpected events. This chronic state of being in high alert can lead to a change in brain chemistry and the nervous system, making it harder to tolerate frustration and remain calm.

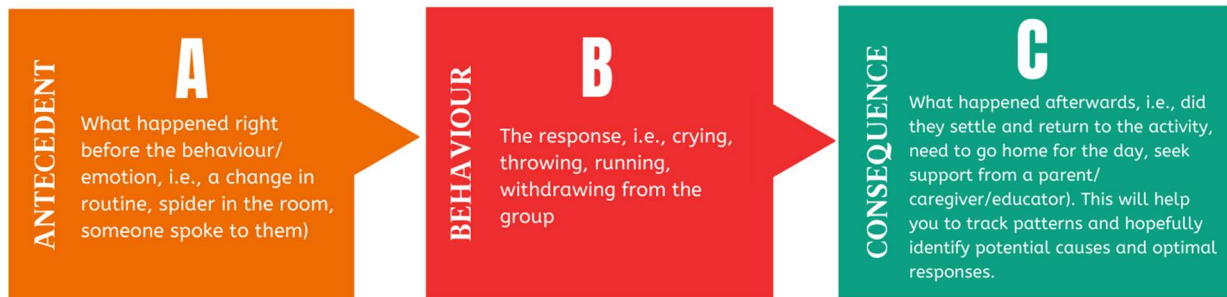


Children or teens with a developmental disability may express that they are feeling mentally unwell in the same manner as others, but it is important to remember that because of factors such as limited communication skills, they may express their distress in other ways too. For example:

- Difficulty getting to sleep, and/or difficulty staying asleep
- Changes in appetite
- Not enjoying things that they used to enjoy
- Self-injury
- Increased difficulty concentrating
- Sense of hopeless or helplessness
- Challenging or defiant behaviour
- Avoiding school and/or social outings

Parents and educators are encouraged to document challenging behaviours and/or periods of intense emotion to help identify potential patterns. Include time of day, ideas about potential triggers and what helped to bring back a sense of calm. It is important to try and document subtle changes. This will help to identify effective strategies and changes over time.

Consider using an **A-B-C** Chart to identify what may be causing the child/teen distress:



It is important to consider seeking additional assessment and support if concerns regarding mood, level of agitation, or sense of distress have increased and/or are prolonged (beyond 2 weeks), and are disrupting the child or teen's usual functioning. **If this occurs, it may be time for professional intervention. See below for additional supports at HWDSB and in the community.**

## Calming and De-escalating Strategies

Supporting basic human needs for feeling safe and secure, socially connected, and having a sense of purpose helps to enhance *everyone's* well-being. For children and teens with developmental disabilities, the connection with parents/caregivers, and supportive adults such as educators is particularly critical, as they are more dependent on others than their peers may be.

Children and teens look to the adults around them for guidance when faced with difficult situations, and especially so for children and teens with developmental disabilities. Parents and caregivers must be aware

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**Frequently feeling that things are beyond your control, and feeling like the world around you is moving much faster than you can make sense of it, becomes overwhelming.**  
**Experiencing this everyday, all day long, is exhausting.**

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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.**

Strategies presented below are aimed at reducing symptoms of anxiety and improving mood (the most common threats to well-being), and reduce potential behaviour/regulation problems that can arise when a child or teen's needs are not met. The strategies presented below are general, and may need to be adapted or modified to meet individual needs, recognizing that there is a considerable range in cognitive skills, memory functioning, and general mobility among children and teens with developmental disabilities.

These types of 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).

To help make strategies easier to remember and more comfortable to use:

- **Lots and lots of repetition and practice** – the more practice, the more automatic calming and coping strategies will be to use, and the easier it will be for children to use on their own
- Attention span may be short so **keep instructions short** – one step at a time
- **Slow down** the pace of instructions – give lots of thinking time
- It is likely that the child or teen will take things literally (at a very concrete level), so use familiar, **simple** vocabulary, and use **concrete examples** and demonstrations.
- Present new strategies in fun, game-like ways; make it personally **meaningful**- make connections with favourite characters, objects, toys, etc.

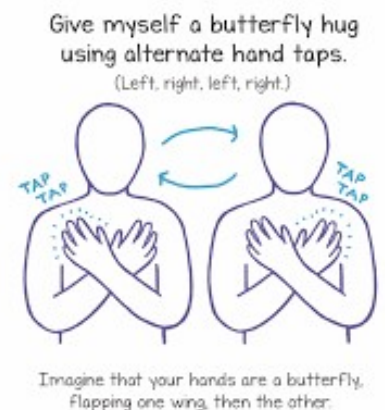




- Build on areas of **strength** and allow children and teens to do as much as they can on their own to help build confidence and independence.



- Our brains seek out patterns and is calmed by things that are familiar. **Maintain a regular and consistent routine** 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 make us feel happier.
- **Mindfulness Exercises (being present in the here-and-now)** helps to calm the brain. Taking deep, slow breaths (belly breathing) signals our body to release hormones that cue the brain and body to relax by slowing the heart rate and increasing focus. Deep breathing can be used anytime - it is portable and always with you! [More information](#).
- Teach your child to use **Progressive Muscle Relaxation (Tense and Release)** to relax when feeling agitated or stressed. This involves tensing or squeezing particular muscle groups in your body (easiest to start from your toes and work up towards the forehead) for 5 seconds each, and then release the tension and notice how your muscles feel when you relax. [More information](#).
- **Grounding exercises** encourage us to focus on the things around us, rather than on the thoughts and feelings that are distressing us. Ask the child or teen to concentrate on things around them – what do you see (name colour of object near by), what do you hear, what do you smell, what do you feel (e.g., floor under their feet or chair behind their back). Encourage the child or teen to breath deeply for added benefit. [More information](#).
- **Butterfly Hug:** The Butterfly Hug Method (originated and developed by Lucina Artigas, 1998) can calm and rebalance the nervous system using bilateral stimulation. Have the child or teen fold their arms across their chest so that their left-hand rests on their right shoulder, and the right-hand rests on



the left shoulder. Tap one hand and then the other, alternating like the flapping of a butterfly's wings. Alternate at a rate of one tap per second. Continue as long as it takes for the emotion to subside. [More information](#).

- **Validate (listen and acknowledge) feelings:** When your child or teen expresses (in words or behaviours) that they are feeling upset, sad, or angry, listen and let them know that you want to understand what they are feeling. This approach does not mean that you agree/accept what they are saying or doing, but rather that you recognize that this is true to them. Before responding, consider what you are going to say – is it helpful and kind? For example, there are helpful ways to recognize their emotions and acknowledge that something is important to them:
  - “I can see how upset you are”
  - “Please tell me more – what else?” and
  - “I can understand why you would feel that way “
  - “No wonder you are feeling sad because.....”

## 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 a developmental disability 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.

Here are a few key elements in optimizing a self-care plan to help reduce negative feelings:

- Maintain a structured routine each day that includes focusing on a positive way of thinking and doing things that you enjoy. Following a routine will bring comfort and stability, which help to enhance a sense of well-being.
- Sometimes you cannot change or “fix” the problem, but find different ways of coping
- Make time to connect with others. Developing meaningful relationships with others is an important component of well-being. Connecting with other families facing similar challenges can be extremely helpful.
- Seek opportunities to be creative (e.g., art, dance, music).
- Look for the humour – laughing is a powerful stress reliever.

## Sources of Information

[Dual Diagnosis: An Information Guide](#)

[Depression in People with Intellectual Disabilities](#)

Peter Marks - *Conscious Classrooms for Students with Autism and other Developmental Disabilities: Balancing Body, Brain, Behaviour and Being.* (2018)

## Additional resources and supports

[Contact Hamilton for Children's and Developmental Services](#) – central access service to mental health and/or developmental services in Hamilton

[Community Living Ontario](#)

[Anxiety Canada](#)

[NADD](#): National Association for the Dually Diagnosed - An association for persons with intellectual disabilities and mental health needs

Easy and Fun Mental Health Activities to try at home from [School Mental Health Ontario](#)

<b>CRISIS:</b> Call 911 / Visit your local hospital emergency room	
<b>URGENT:</b> <b>Kids Help Phone</b>  24/7 counselling and information for youth: • 1-800-668-6868 • kidshelpphone.ca	 Mental health crisis outreach and support for all ages. • 905-972-8338 • coasthamilton.ca
<b>NON-URGENT:</b> <b>HWDSB Helps.</b>	Get help or share anonymous tips using... • Text to 905-963-0066 (standard rates apply) • The HWDSB Helps app for iOS and Android. • Web chat - <a href="http://www.hwdsb.on.ca/wehelp">www.hwdsb.on.ca/wehelp</a>