

3.21
Canada's
Down Syndrome
Magazine

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ISSUE #9

Mental
Health for
Parents &
Caregivers

*THE GROOVE:
An Interview
with Dr. Brian
Chicoine and
Dr. Katie Frank*

*Community
Q&A: All
the Feels*

The
Mental Health
Issue

*Plus: MENTAL HEALTH AND DOWN SYNDROME:
A Q&A with Dr. Susan Fawcett*



is a joint publication of

If there's one thing we learned early on in the pandemic, it's the importance of having extra toilet paper on hand. But if there's *another* thing we've been reminded of throughout the past couple of years, it's the foundational role that mental health plays in each of our lives.

This is true for everyone, but it's extra important for people with Down syndrome and their caregivers, both of whom have a heightened risk of mental health issues including anxiety, depression, elevated stress levels, and more.

The past 21 months have been extraordinarily difficult for many in the Canadian Down syndrome community, and that's why we thought this was the right time to bring you the first issue of 3.21 Magazine devoted entirely to the topic of mental health and Down syndrome. Inside, you'll hear from professionals, parents, and self-advocates – all with excellent advice on caring for the emotional wellbeing of you and your loved ones. Nothing could be more important.

We would love to hear from you! Drop us a line at 321Magazine@gmail.com with your thoughts, story ideas and opinions.

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Mental Health & Down Syndrome:

A Q&A with Dr. Susan Fawcett



DISCLAIMER: Some of the questions we received were very specific to a particular person. Given that Susan has not had the opportunity assess these individuals, she will provide only general information and guidance in this article. Please consult your local mental health professional for more individualized assistance.

What is the most common mental health issue among children and adults with Down syndrome?

The most common issues differ depending on the age of the person. In children, dual diagnoses of attention deficit or other behavioural disorders are most common. In adolescents and adults, depression is more frequent. Obsessive compulsive disorder (OCD) and anxiety occur across the lifespan, but the type of anxiety tends to differ. For example, specific phobias (such as being fearful of dogs or needles) are common at all ages, but social phobias and generalized anxiety disorder are not typically diagnosed until teen or adult years.

Do symptoms of mental illness present differently in people with Down syndrome individuals versus individuals without Down syndrome?

Symptoms do indeed present differently! One contributing factor to this is that people with Down syndrome have difficulty with expressive language, so symptoms such as obsessive thoughts or feelings of worthlessness tend to be difficult to notice or assess. Another contributing factor is the inherent overlap between symptoms of Down syndrome and those associated with mental health issues. For example, people with Down syndrome have a strong preference for sameness and routine. This makes it more difficult to tell when a person has crossed the line into the pronounced rigidity that is associated with OCD.

What are the symptoms of depression, anxiety, OCD, and ADHD?

Before outlining symptoms, it is important to encourage caregivers to first thoroughly investigate potential medical causes of any changes in behaviour. In light of the previous question, I have included mainly symptoms here that tend to appear most often in people with Down syndrome.

Depression: decreased or lost interest in previously enjoyed activities (this may result in the person refusing to leave the house more often); irritability; changes in sleep or eating patterns, extra slow movement and reduced ability to transition from one activity to another; increased crying or appearing to be down or sad

Anxiety: avoidance of certain tasks or activities; increase in problem behaviour, especially if associated with non-preferred activities; irritability; restlessness; decrease in sleep; expressing worry about upcoming events (may manifest as repeating the same question frequently)

Obsessive-Compulsive Disorder (OCD): insistence on sameness; engagement in lengthy routines that follow the same order each time, coupled with becoming agitated if the routine is interrupted; hoarding, checking, or counting behaviours

Note: While typically-developing people with OCD tend to be very bothered by their obsessions and compulsions, this may not be the case for all people with Down syndrome (but often their families are bothered by the symptoms).



Attention Deficit Disorder (ADD) and Attention Deficit/Hyperactivity Disorder (ADHD): inability to sit still or seeming to move constantly; great difficulty concentrating (even on very short activities); high degree of distractibility; lack of impulse control, which may result in problem behaviours that seem to come out of nowhere, such as throwing objects or running away

Note: The overlap between ADD/ADHD and Down syndrome is pronounced! Think about whether your child is exhibiting these symptoms more frequently or intensely than other children with Down syndrome you have seen.

Are there any ways to prevent mental health issues from arising?

Yes – I’m so glad you asked! Prevention or early intervention is always the way to go, if possible. Having said this, a family history or a traumatic event are frequent contributors to the development of mental health issues, and these are tough, if not impossible, to prevent.

There are plenty of things that parents can do to support behavioural and mental health! From an early age, parents can promote the following domains: **activity, agency, flexibility, variability, reality, sociability, and self-esteem.**

- **ACTIVITY:** The role of regular exercise in supporting good mental health is well-documented. Build it in whenever possible!
- **AGENCY:** We want people with Down syndrome to be empowered to act as causal agents in their lives. You can help develop this by offering choices within daily routines, and teaching independence in daily living skills.



If adults help children too much, a phenomenon called learned helplessness may develop, essentially meaning that a person learns they don’t have control over their own lives. Not surprisingly, this can lead to depression.

- **FLEXIBILITY:** Routines can be really helpful and comforting for people with Down syndrome, but parents need to watch out for excessive adherence to routines or general rigidity. Try to introduce some new elements on a regular basis to allow them to learn how to be flexible and adaptable. Whenever your child with Down syndrome “goes with the flow,” reward them with plenty of social praise.
- **VARIABILITY:** Encourage your child to have a variety of interests, e.g., foods, sports, TV shows, favourite characters.
- **REALITY:** Keep your child with Down syndrome grounded in it. Emphasize real social interactions. Try to limit too much time on screens, especially watching the same thing repetitively, or watching highly dramatic/violent shows. Make sure your child doesn’t spend too much time interacting with imaginary friends and characters or reciting movie scripts; redirect them to real-life activities often. This is particularly important during the current pandemic, as people with Down syndrome may be feeling bored due to a combination of too much time at home and not enough extracurricular activities.
- **SOCIABILITY:** Encourage social interactions as much as possible. Be sure to include other peers with developmental disabilities in the child’s social circle. Remember that, eventually, this will likely be their peer group, more so than peers who are typically-developing.
- **SELF-ESTEEM:** Give your child a tonne of praise and encouragement – more than you think they need! Celebrate all successes with them, even the small ones. Ensure they participate regularly in activities during which they have a chance to experience mastery, i.e., activities they are good at.

What does treatment look like if you’re diagnosed with a mental health issue?

There are two major categories of treatment: pharmaceutical and psychological therapy or counselling. People with Down syndrome can benefit from either of these, or even better – both together! Medications work well for people with Down syndrome in the treatment of mental health issues, though a psychiatrist may take a very cautious approach, e.g., starting with a very low dose when trialling a new medication.

Traditional “talk therapy” may not seem like a good fit for people who have trouble expressing themselves via talking. But if a psychologist or counsellor uses a more structured approach, such as Cognitive Behaviour Therapy (CBT), this can work well for people with Down syndrome. This therapy includes modifying or learning new behaviours, learning what diagnostic categories such as “anxiety” and “OCD” are, learning to identify and express emotions, and changing unhelpful patterns of thought. It will be important to find a therapist who has experience modifying a CBT approach with people who have intellectual disabilities.

My daughter was in a bus crash a few years ago. She has been dealing with trauma, PTSD, nightmares, and OCD ever since. She has tools and strategies but she has changed. She is no longer independent, her problem solving skills have dramatically decreased, and she is fearful of the world – she no longer feels safe. How do I help my daughter feel safe again?

This sounds really stressful for your daughter, not to mention the rest of the family. It is possible that post-traumatic stress disorder, or PTSD, may take longer to resolve in individuals with Down syndrome. In people with Down syndrome, it is more common for a traumatic experience to cause OCD, anxiety, or PTSD. Further, it has been suggested that individuals with Down syndrome may experience all sorts of memories, perhaps particularly traumatic ones, as if they are happening in the present moment. This is due to relatively strong visual memory skills.

A traumatic event like a serious accident can have very long-lasting consequences on a person’s mental health. In addition, the regression in skills that may come following the traumatic event can be very hard on parents, who are used to a certain level of independence. Meeting your daughter where she is currently at and helping her slowly rebuild her skills from there, rather than focusing on what she can no longer do, may be helpful here for all of you. It can also be overwhelming to think about the many problems that may have developed since the traumatic event. With this in mind, try choosing one skill that would improve the quality of life for her and the family if she were to get it back. Enlist the help of an occupational therapist to help you break down the task into small chunks in order to help her rebuild her independence, one skill area at a time.

Note: If this issue is long-standing and affects your child’s daily life, I strongly recommend individualized help from a mental health professional.

Just Released:
Feeling Down, Looking Up

In November, the Down Syndrome Resource Foundation released a new short film, *Feeling Down, Looking Up: Mental Health and Down Syndrome*. *Feeling Down* features four families (including two self-advocates) sharing their mental health journeys. The film is hosted by Dr. Susan Fawcett, who lends her unique expertise as a mental health professional specializing in Down syndrome. *Feeling Down, Looking Up* is now available for viewing at DSRF.org/FeelingDown.



Our daughter is afraid of falling asleep and having nightmares, so she is sleep deprived. We have tried everything from mindfulness, music, aromatherapy, etc. but they don't stop the nightmares. How can we help her get a good night's sleep?

I am sorry to hear that sleep is so hard for your daughter! Nightmares or night terrors are a sleep disorder, and many sleep disorders are more common in Down syndrome.

It sounds like you have tried relaxation strategies and ways to make bedtime more pleasant, which are great ideas, but you may need an extra layer. She may need more understanding around what nightmares are, for example. A social story about nightmares that you can read together may be helpful, so that she understands that they are not real (even though they feel that way). You can include a discussion here about the difference between reality and pretend/not real.

Was there something that originally caused the nightmares? Is she able to talk about it with you, even in a limited way or with visual support? If so, this may help her work through the underlying issue. Note, though, that many night terrors are not caused by anything specific, but rather represent non-specific stress. You have the relaxation strategies already, now make sure you also have time built in before bed for emotional strategies such as comfort, cuddles, and reassurance.

Lastly, sleep deprivation will cause her anxiety to worsen. Is there a way to build in a short nap or rest period over the course of the day? While not a long-term solution for inadequate sleep during the night, a short period of daytime sleep may accomplish two things: much-needed rest, and the potential for her to “practice” sleeping in a safe environment with people who are comfortable and familiar right there with her. She will then experience sleep without nightmares, which may lessen her anxiety over time (nightmares typically happen in the early morning, long after someone first goes to sleep).

How do we help our children who have developed major medical trauma because of the things they have had to endure medically, whether it's being held down for a procedure/blood test, violating their sense of privacy by making them expose parts of their bodies to doctors, or having to stay in a hospital for an extended time (which involves a lot of unpleasant pokes and prods at the least)? Our daughter doesn't even like the word doctor and shudders just driving past the hospital. She has to be sedated now just to take blood.

How do we help her heal from the trauma, and support her for future procedures?

Because children with Down syndrome often have medical complexities, they are often no stranger to medical settings such as hospitals. It sounds like your daughter has endured a lot! She has developed a strong fear response to places, people, or words even loosely associated with the frightening experiences. This means that no matter which treatment you opt for, you will have to move slowly and carefully.

Thankfully, a set of approaches called exposure therapy can be very helpful with medical fears (or specific phobias of any kind). This therapy involves very gradually exposing a person to the fearful object or situation. Clinically, I have used this to help teens with Down syndrome overcome a fear of needles, for example. We begin by building a fear ladder, with less scary needle experiences on the bottom and the most scary ones on the top. We may start by looking at photos of needles, then watching videos of someone having a blood test, then look at and touch a real needle, then visit the lab where the teen will get the needle, working up to the final experience on the ladder – actually getting the blood test (or these days, the vaccine!). The Anxiety Canada website has great resources for exposure therapy. The Child Life program at BC Children's Hospital also has structured systematic desensitization (a type of exposure therapy) programs for children with developmental disabilities who have anxiety around medical and dental procedures. ●

Down Syndrome Mental Health Resources

The LowDown Podcast:

- Episode 3-2: Feeling Down: Mental Health and Down Syndrome (Guest: Dr. Robin Friedlander)
- Episode 3-11: Fresh Perspective: Cognitive Behavioural Therapy for People with Down Syndrome (Guest: Dr. Susan Fawcett)

Anxiety Canada

Adult Down Syndrome Center

CDSS Webinars:

Medical experts present on mental health topics such as living a 'best life,' Covid-19 and mental health, The Groove, OCD, and general mental wellness strategies.



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TOUGH TERRAIN, GOOD TERRAIN:

Reflections on Mental Health for Parents of Children with Down Syndrome

By Eli Norman, MA-CPSY, RCC

Earlier this fall, our family went on a beautiful forest hike along the ocean in West Vancouver. My wife and I have three kids, including our youngest daughter who has Down syndrome. She is 12 years old, and lately she has been insisting that we always call her “Big Girl” (sometimes even instead of her name) because she is adamant that she is absolutely not a “Little Girl” anymore. Our family goes on forest hikes regularly, and Big Girl is a strong hiker who is capable of tackling some difficult trails. Quite often, when we encounter other people on the trail, Big Girl will greet them with a very friendly wave and say, “Hi there!” And then, after she thinks that they are out of earshot (which they never are), she loudly declares, “Look Dad... Those are our friends!” Our family loves this, of course, and I’m sure that it puts a smile on the faces of most of “our friends” as well.

However, on this particular hike, Big Girl was stuck in an awful mood for some reason. Instead of a warm greeting and a declaration of newfound friendship, the other hikers encountered a very grumpy Big Girl declaring, “This is MY trail! Get off!” And then, when she thought they were out of earshot (which they never were), she would make spitting noises. Apparently Big Girl did not get the memo that spitting is usually frowned upon during a pandemic.

My wife and I made every effort to figure out what was wrong and help Big Girl get to a better place. We tried several approaches, but nothing worked and we felt powerless. We felt badly for the other hikers, for our other two kids, and for our daughter. It was a difficult day.

In some ways, life with Big Girl is like a long hike. There is lots of good, beautiful terrain marked by good times (such as a warm greeting and newfound friends), but there is also lots of tough terrain marked by challenging times (such as getting stuck in a bad mood and demanding the trail all to herself).

I work in the field of mental health as a Registered Clinical Counsellor, and both my professional and personal experiences have taught me that all the tough terrain that comes with having a child who has a disability can pose significant challenges to the psychological and emotional well-being of parents. But I’m also aware that we sometimes find ourselves in good terrain that brings some unexpected benefits to our well-being. So let’s explore a bit of the tough terrain and a bit of the good terrain of mental health for parents of children with Down syndrome.

TOUGH TERRAIN: “WHAT IF...?” THOUGHTS

Many parents are all too familiar with negative thoughts that begin with “What if...?” This type of thinking is often connected to feelings of worry and anxiety. I’ve been having “What if...?” thoughts about Big Girl since the day she was born: “What if we’re not up to the challenge of parenting a child with Down syndrome?” “What if something goes wrong with her heart surgery? Or ear surgery? Or eye surgery?” “What if our other kids grow to resent Big Girl, or us, for all the difficulties that they’ve had to endure?” Just like falling dominoes, a first “What if...?” thought is usually followed by a second thought that tends to be worse, and then a third, and so on. It is very common to make the mistake of foreseeing negative outcomes as far more likely than they actually are. Some people find it helpful to try and practice “balanced thinking.” When you find yourself thinking, “What if things turn out badly (insert negative outcome here)?”, try and follow it up with the positive thought, “What if things turn out well (insert positive outcome here)?”

GOOD TERRAIN: LIVING IN THE MOMENT

Mindfulness has been a helpful focus in mental health in recent years. Mindfulness helps us to live in the moment and not spend so much time ruminating on what has happened in the past or worrying about what will happen in the future. Big Girl is usually fully engaged in experiencing whatever is going on in the present, and rarely seems to be caught up in worries about the past or the future. And she’s helped me get better at this, too, as I attempt to resist living in my future or past worries, and instead try and join Big Girl in living in the moment whenever I can.

TOUGH TERRAIN: EXTRA BUSY SCHEDULE

Most parents in our society have busy and stressful lives as they juggle the schedules of themselves and their children. It seems like an ironic twist of fate that children with Down syndrome, who are required to be on time for so many extra appointments, are also the children who can be the most difficult to hurry up! This challenge is often caused by the evil twin of “Living in the Moment,” known as “Stuck in the Moment.” The extra appointments (often combined with the difficulty of transition times for many children with Down syndrome) result in extra stress for parents. It’s important to learn to manage our stress levels by engaging in healthy stress-relieving activities on a regular basis, as well as limiting the number of stressors in our lives when possible. In the midst of the busy-ness, we need to be sure to make time for ourselves. I know that this isn’t easy, but if we neglect ourselves, then we may start to feel overwhelmed and burnt out, and this will make the tough terrain even tougher.

GOOD TERRAIN: OL’ FASHIONED LAUGHTER

Some say that laughter is the best medicine, and I believe that there is some truth to this. Big Girl has a great sense of humour and loves to be ridiculously silly, and she especially loves it when other family members join her in the silliness. I think that being silly and laughing is very beneficial for our mental health, and Big Girl has provided our family with countless moments of medicinal laughter.



TOUGH TERRAIN: "SHOULD-ING"

The word "should" is quite a problematic word for many people, and I think it can be extra difficult for parents of children with a disability. I often find myself discouraged by thoughts such as, "We should be working harder to connect Big Girl with more of her peers," or "We should be working harder to let Big Girl do more things for herself more often, instead of taking the easier road of doing things for her." "Shoulds" are often good aspirations, but parents can only do so much, and the list of "shoulds" can sometimes feel endless for parents of children with Down syndrome. Too much "should-ing on yourself" is connected to feelings of guilt, and even depression. Try and resist setting unrealistic expectations for yourself, and give yourself compassion and forgiveness as you do your best in this very difficult job.

GOOD TERRAIN: CELEBRATION & GRATITUDE

Gratitude has been connected to positive psychological well-being. Big Girl loves to celebrate the things that she is feeling grateful for. If there is something that has made her happy, then she wants everyone to know it. Big Girl gets very excited about birthdays, holidays, family movie night, and any other occasion when we have fun together as a family. For instance, in the beginning of October, Big Girl decided that my birthday is fast approaching, and she now wishes me an excited "Happy Birthday, Dad!" a few times a week. We'll see if she keeps this

up until my actual birthday... which isn't until February. Big Girl's enthusiasm about good times is contagious, and I know that she makes these family moments much more special for all of us. She reminds me that we have much to celebrate as a family, and this helps me practice more gratitude in my life.

Parents of children with Down syndrome face many joys and many challenges as they encounter the good terrain and the tough terrain that comes with having a child with a disability. If you are one of those parents, then I hope you are able to benefit from travelling through many moments of beautiful terrain with your child. And when you find yourself overwhelmed by the tough terrain, then I encourage you to reach out for the support that you need from loved ones, professionals, and organizations such as the Down Syndrome Resource Foundation and Canadian Down Syndrome Society. Best wishes on your journey. ●

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My name is Zamaan and I am the founder and CEO of the Grano-la Kid. I was born with Down Syndrome and very often people with DS are overlooked for jobs, school and many other opportunities. So instead of letting people decide my fate, I decided to take charge and give myself the opportunity to do something I love (cooking and baking) and make it my business. When you eat my granola, you are not only helping my business succeed, but you are eating nutritious food that is going to help YOU get started on achieving your goals - just like me. So, dig in and tag me on IG @thegranolakid and tell me how you are smashing your goals!

THE GROOVE

IN PEOPLE WITH DOWN SYNDROME

AN INTERVIEW WITH DR. BRIAN CHICOINE AND DR. KATIE FRANK

This interview is adapted from Dr. Brian Chicoine and Dr. Katie Frank's October 27, 2021 webinar presentation 'The Groove,' hosted by the Canadian Down Syndrome Society, and also available digitally at: <https://bit.ly/3lkoK6v>.



Dr. Chicoine is Medical Director at the Advocate Medical Group Adult Down Syndrome Center in the United States. Dr. Chicoine co-founded the Adult Down Syndrome Center in 1992, which has served and documented the health and psychosocial needs of over 6,000 adolescents and adults with Down syndrome since inception. Dr. Chicoine has provided medical care for adults with intellectual disabilities for over 30 years, and has presented and written extensively on caring for adults with Down syndrome.



Dr. Katie Frank is an Occupational Therapist, also at the Advocate Medical Group Adult Down Syndrome Center. Most of Dr. Frank's work has been focused on individuals with Down syndrome of all ages. Her experiences range from treatment and evaluation as well as facilitating groups for people with Down syndrome, conducting trainings for staff, families, and caregivers, and offering a variety of other educational opportunities.

This talented pair touched on a number of key topics about the groove, including:

- ✓ **DEFINING THE GROOVE**
- ✓ **ADVANTAGES AND DISADVANTAGES OF THE GROOVE**
- ✓ **PROBLEMATIC GROOVES, INCLUDING DIAGNOSIS AND TREATMENT OF OBSESSIVE-COMPULSIVE DISORDER (OCD)**
- ✓ **SHARING STRATEGIES TO ADDRESS PROBLEMATIC GROOVES, AND ESTABLISHING NEW GROOVES**

PART ONE: AN INTRODUCTION TO THE GROOVE

WHAT IS THE GROOVE?

Dr. Chicoine: The groove is defined as a set pattern or routine on one's actions or thoughts, as well as a preference for sameness, repetition, or routine. We call it 'the groove' because it is a well-worn path, created from a desire to complete a task from start to finish. Grooves can give order and structure to people's lives, can increase independence, can actually enhance performance and function, and can also help people manage stress. Grooves can become problematic when they start to interfere with one's life. We often say "grooves are a good thing, until they are not."

WHAT ARE SOME EXAMPLES OF GROOVES SEEN OFTEN IN PEOPLE WITH DOWN SYNDROME?

Dr. Chicoine: A groove can be any precise, unchanging routine performed in order to complete a task. It can be anything from meticulous care of someone's room and personal items, closing doors and blinds or turning lights off, the repetition of phrases or songs, asking the same or similar questions, listening to the same music, or watching a television show or movie on repeat.

WHAT ARE SOME POSSIBLE DISADVANTAGES WITH GROOVES?

Dr. Chicoine: As mentioned previously, a groove is a good thing, until it is not a good thing. Grooves can become problematic and excessive either when someone can't deviate from the groove itself, if an interruption to the groove mid-task means the person cannot move forward to completion, or when transitions or changes are not possible due to the groove, meaning the person gets 'stuck.'

Sometimes, the groove "works" for the individual but not for those interacting with him or her. If the other person does not appreciate or acknowledge the person with Down syndrome's tendency towards the groove,

then that person may end up "fighting" the groove. For example, if someone with Down syndrome needs to take a task to completion, appreciating

that need and developing ways to work around it are much more likely to be successful than just trying to stop the tendency and expect them to stop mid-task.

WHEN SHOULD THE GROOVE BE CHALLENGED?

Dr. Chicoine: You have to really look at the priorities when deciding whether or not to challenge a groove. Ask yourself, "Is the groove really a problem?" That said, the groove should be challenged when it impacts safety, when it impacts a person's function in daily life, or when it impacts the rest of the family.

It does not have to be challenged all the time either. In certain environments you may want to challenge it, such as when you are travelling, or visiting someone's house and it is going to cause an issue. But generally speaking, if it is not problematic, you can simply let it be.

You can also look at the groove as a continuum, ranging from most functional to OCD levels of impact. Looking at it based upon how it impacts the lives of the individual as well as the lives of others is a good approach to deciding just how problematic it is.

PART TWO: STRATEGIES TO ADDRESS PROBLEMATIC GROOVES AND/OR ESTABLISH NEW GROOVES

Dr. Frank:

ON EDUCATING OTHERS: It is important to educate others who interact with the person with Down syndrome about the groove. Learning about the groove helps us understand when it might make sense to challenge the individual and when it may make sense to challenge the environment. Sometimes, it is necessary to challenge the groove (the person with Down syndrome) because of safety, the need to teach flexibility, or other reasons. Sometimes others (the "environment") need to know about the groove and let it go if it is not problematic or develop ways to work around it.

ON ENCOURAGING FLEXIBILITY: Many people with Down syndrome do not like to be flexible. However, life will sometimes require it. There are ways to help encourage flexibility: Start by picking a behaviour that is possible to change. Then pick a good time to encourage flexibility. Try to select a time when there is no urgency to complete the task. For example, if you are working on getting dressed, don't practice a change in routine in the morning, when you need to be somewhere.

Like a needle in the groove of a favourite record played on repeat, the groove is not always a bad thing ...until it gets stuck.



Additional strategies include trying to provide alternative behaviours that are more appropriate. Breaking down the task into manageable steps can help identify where the task is getting stuck. This is often assisted by the use of visual supports.

It can be helpful to ensure that all participants are open to change and not stressed during new teachings. Try to build the word 'flexible' in to conversations, and recognize and point to situations where you see flexibility. Often this is recognizing when other people are being flexible, and simply acknowledging it.

ON SETTING EXPECTATIONS: You can address problematic grooves by giving choices and alternatives, and by setting guidelines. Sometimes it is simply about limiting the number of options. For example, if someone's groove is to pack multiple pieces into a backpack prior to leaving, set a limit of two or three of each object to decrease the time it will take.

You can also use visuals. Often visuals are thought of as childish, but if you think about visuals as a list, we all use visuals. It can also be a written list, of course, if the person can read. This is a helpful way to know what comes next. You can also set expectations by setting time limits.

ON PRACTICING SOCIAL SKILLS: These are important to learn in order to be successful in the community. You can do this through simple compromise, and by explaining to them that if they are told "no," it does not necessarily mean they are in trouble. Practice flexible thinking, and make asking for help a positive thing. Everyone asks for help; it is not a sign of dependence. Work on managing emotions by practicing not 'acting out,' and working on strategies to calm down when necessary.

ON IMPLEMENTATION: Preparing the body helps to set the stage in order to challenge the groove. Our bodies are like teeter-totters, and often we need to balance them by utilizing sensory strategies. Try pairing the problematic groove with another desired activity, for example, 'first we make the bed, then we eat breakfast.' Or try pairing changes together, which can help to interrupt grooves. One individual with Down syndrome we see at our clinic was sleeping in the living room. After attending summer camp for six weeks, he was told he needed to sleep in his bedroom. Two months later, he is still sleeping in his room thanks to the interruption.

PART THREE: COMMON GROOVE SCENARIOS

Dr. Frank:

LENGTHY ROUTINES: Morning and bedtime routines can be helped by giving choices, setting guidelines, setting time limits, using visual supports or lists. Preparing the night before for the morning and setting timers can help too. If something takes too long, simply consider moving it to another time of the day.

OVERALL SLOWNESS: This can be very challenging. Try joint compression and other sensory input methods, and use of visual supports.

DIFFICULTY GENERALIZING SKILLS ACROSS DIFFERENT ENVIRONMENTS: This is seen often when parents live in two houses, or the individual travels to other homes i.e., grandparents' house. This can actually be beneficial to the groove. Try to encourage flexibility, set guidelines, use visual supports and pair challenges together.

DIFFICULTY COMPLETING JOB TASKS: This can be challenging if tasks need to be completed in a certain order, or if interruptions cause issues. To help either of these scenarios, ensure others are educated about the groove, build in flexibility, and set guidelines.

SITTING IN THE SAME SPOT: This is very common; examples include insisting on sitting in the same seat in a car, on a bus or on a train during a commute. The key here is to work on building in flexibility, whether that is through taking turns, or giving options – you could increase from one specific seat to three on a bus or train for example.

WEARING THE SAME OUTFIT: Try limiting options in closets, or suggest 'home clothes' vs 'going out clothes.' You can also try to establish days of the week outfits. Keys are to focus on flexibility, offer choices (but not too many), and set guidelines.

GETTING 'UNSTUCK' (REPEATING SAME WORDS OR PHRASES):

Remember that we are trying to facilitate a change instead of getting frustrated. Set guidelines, give the person a time limit, or so many 'times' a day to ask the question or raise the topic.

HOW DO YOU ESTABLISH A NEW GROOVE?

Dr. Frank: First, get unstuck. Set guidelines and use visuals. I don't recommend going at a faster pace; this will likely cause the individual to shut down. Many have seen success in establishing a new groove following another change, be it the return from a holiday, a new environment, or even returning to activities following Covid.

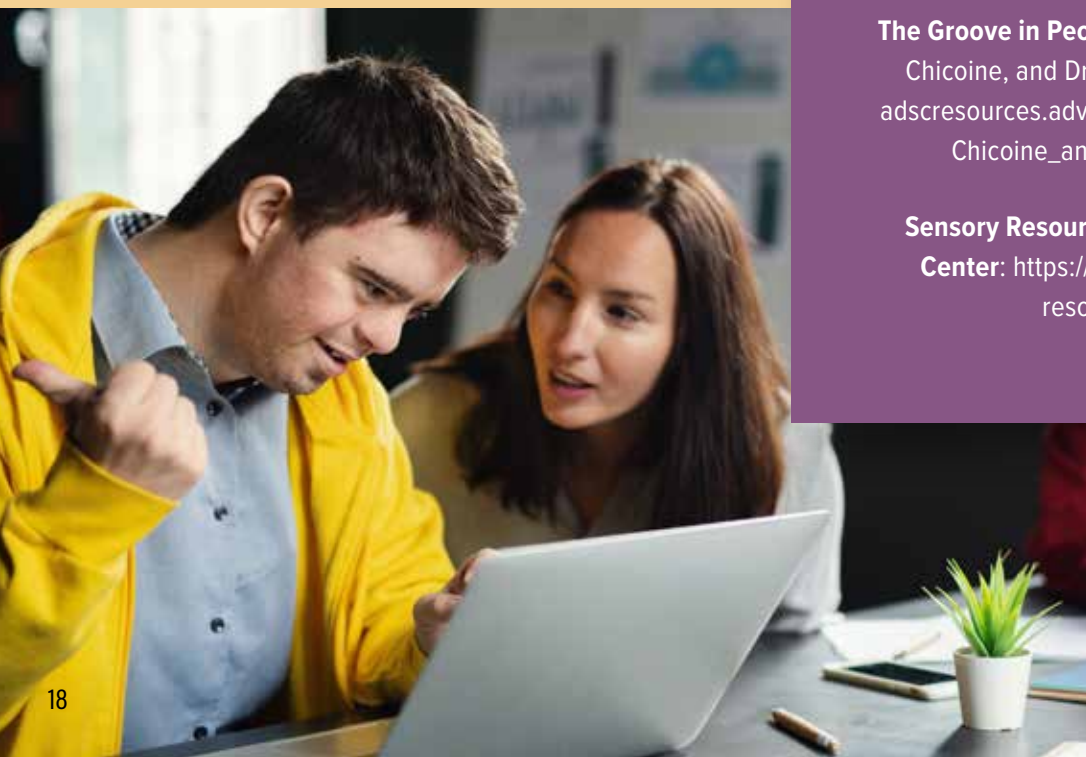


PART FOUR: WHEN GROOVES BECOME PROBLEMATIC: OBSESSIVE-COMPULSIVE DISORDER (OCD)

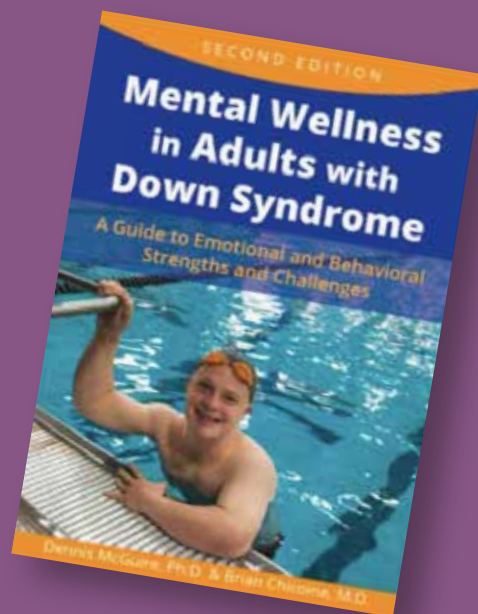
Dr. Chicoine: OCD is often associated with anxiety. A common stereotypical example of OCD is repeated handwashing, although that behaviour is not seen frequently in people with Down syndrome. For people without Down syndrome, this compulsion, like handwashing, is often upsetting to the person. They don't want to do it but "have to." On the other hand, a person with Down syndrome generally isn't upset about doing their OCD behaviour. They only get upset when someone 'blocks' their groove/OCD behaviour. A groove is considered OCD when it creates persistent thoughts, impairs function and limits opportunity. An imbalance of neurotransmitters in the brain is likely a contributing cause of OCD.

HOW IS OCD TREATED?

Dr. Chicoine: We focus first on non-medicinal strategies, all covered by Dr. Frank. But if the compulsion is so strong that those strategies do not work, we treat with medications. I should note that often the medications are used to 'soften' the behaviour, so that the non-medicinal strategies can be more effective. Then, once we see some success, we focus on the non-medicinal approaches. Medications can include antidepressants, benzodiazepines, and mood stabilizers. Our approach in using medications is always to 'start low and go slow,' because side effects can cause issues and even limit success. ●



RECOMMENDED RESOURCES



Mental Wellness in Adults with Down Syndrome,
by Dr. Dennis McGuire and Dr. Brian Chicoine

<https://www.woodbinehouse.com/product/mental-wellness-in-adults-with-down-syndrome-a-guide-to-emotional-and-behavioral-strengths-and-challenges/>

The Groove, by Dr. Dennis McGuire (online article): <https://adsresources.advocatehealth.com/resources/the-groove/>

The Groove in People with Down Syndrome - by Dr. Brian Chicoine, and Dr. Katie Frank (webinar slides): https://adsresources.advocatehealth.com/assets/1/13/8.25.2021_Chicoine_and_Frank_-_The_Groove.pdf?2005

Sensory Resources from The Adult Down Syndrome Center: <https://adsresources.advocatehealth.com/resources/?category=Sensory>



Share some Holiday Cheer with Official Kids Socks from:

 Canadian Down Syndrome Society

 Société canadienne de la trisomie 21



The perfect stocking stuffer! Kids socks come in four sizes.



100% of profits donated to CDSS!

\$16!

Kids socks are sold three to a pack!
No more lost socks!

Don't miss out!
Dec. 6 is the standard shipping deadline!

FridaySocks.com
Buy Canadian, Support Canadian.



Community

Q & A

All the Feels

Q What are some things that make you happy?

Kristina: I love summer, and the warm sun. My pet, friends, and teachers also make me happy.

Gabriella: I like meeting new people.

Paul: Family, friends, my support workers, and my girlfriend. I enjoy spending time with my dad watching hockey and football. I also like wood working and building stuff, swimming with the Dolphins Swim Club, and eating a good meal.

Chris: Family, friends, and going to dinner and a movie are the things that make me happy. I missed these things during the beginning of the pandemic.

Darryl: Beautiful days in my garden, in the sun.

Kate: Listening to music, watching The Voice, and my family.

Christopher: My friends, family, and faith make me happy.

Q What are some things that make you sad?

Jodi: It makes me sad when people make other people feel like they are not good enough and think less of themselves.

Paul: Missing my friends, sports, and social gatherings due to the COVID-19 pandemic. Previous support workers that I no longer stay in touch with. Name calling and bullying.

Aaron: My grandpa passed away, and so did my old dog.

Kate: It makes me sad when I don't see my friends. Also, sad music, rain, and being sick.

Kristina: When someone hurts my feelings.

Chris: Funerals... losing someone I love. Two of my Aunties passed away last year within a few months of each other. I really miss them!

Christopher: When my family goes away.



Aaron



Gabriella



Christopher

Q What are some things that make you mad?

Chris: I don't like being bossed around and told what to do. I like to make my own choices.

Kate: War and rude people make me mad.

Gabriella: It makes me mad when my brother comes into my bedroom.

Jodi: What makes me mad is people getting into fights and getting into trouble and telling people off.

Darryl: When people don't follow the rules, like no fighting and no hitting. Also, when people don't understand me.

Paul: When people treat me like a child, especially other adults. Also, when others don't respect my personal space.

Christopher: I get mad when people are rude and interrupt me.

Q What do you do when you're feeling upset?

Anastasia: Sometimes I cry alone, or I find my friends and talk about it.

Paul: I usually go to someone for help. I express how I am feeling and why I am feeling this way.

Chris: I enjoy spending time alone doing colouring when I am upset.

Jodi: I go somewhere quiet and I cry, or I just hang out with friends who are also looking for quiet.

Kathleen: I cry alone, or go to my mom and dad.

Kate: I go to my bedroom for some alone time.



Jodi



Kathleen

Aaron: My sister helps me by giving me hugs.

Jodi: My counselor; I find that very helpful. Also, my mom.

Anastasia: My parents, my brother and sister, co-workers, teachers, and DSRF staff.

Paul: I go to a parent, roommate, or friend. They help me to understand why I am feeling this way and help me feel better.

Chris: I talk to my parents, and they listen. Also, when I was having some trouble in the past, I talked to Susan at DSRF.

Q Who do you go to for help with your feelings?



Anastasia



Darryl



Kristina



Kate



Paul



Chris

Q What makes you feel better?

Paul: Talking with family and friends about what is bothering or upsetting me is helpful. I also like alone time, and watching a movie or show.

Chris: I do not like talking about my feelings. I would rather just go for a walk or a long drive and listen to my music with my earbuds on.

Aaron: Going to the spa!

Darryl: My family will make me a special dinner. Dancing and singing with my friends, going to the gym, walking, hugs, and handshakes all make me feel better.

Jodi: Hanging out with my friends and doing things such as going for walks and watching movies. I read books on my own and do drawing and artwork. I also exercise.

Kate: Listening to music and singing along.

Kristina: Watching funny movies.

Anastasia: Hugs! Listening to music and relaxing in the bathtub. Making someone laugh.

DSRF CORNER

**Photographer,
Entrepreneur,
Ambassador,
Newsman – and now,
Klukas Award Winner**

Andrew Bingham wears many hats—and now, he can add George Klukas Achievement Award winner to his growing collection of titles.

Andrew is a lifelong DSRF student who has engaged in virtually all our programs and services enroute to becoming the accomplished entrepreneur, advocate, and role model that he is today.

Over the past number of years, Andrew has continued to develop his reading and speech skills, particularly his articulation. He has become an exceptional public speaker, which has enabled him to become an effective spokesperson for DSRF and all people with Down syndrome.

Andrew works as an Ambassador for DSRF, and within that role he stars in a monthly newscast: DSRF News with Andrew Bingham. Through the first year of the show, Andrew has improved by leaps and bounds as a news host, and now confidently reads his scripts with a teleprompter. In producing his newscast, Andrew exhibits inspiring persistence and a determination to get every word right, refusing to give up until he nails each and every line.



Andrew also has a job at Nester's Market. And because he's clearly not busy enough, Andrew also operates his own small business called **Through Andrew's Eyes**, through which he sells greeting cards featuring his own stunning photography. Andrew donates 100% of all sales to DSRF.

Andrew has a fierce desire to advocate for people with Down syndrome. He regularly dreams up awareness campaigns that he wants to develop, to educate the world about the value and contributions of people with Down syndrome. Andrew will no doubt be representing DSRF for many years to come.

The Klukas Award is presented annually to an adult student or alumnus of the Down Syndrome Resource Foundation in recognition of their personal growth and accomplishments. Andrew is an extremely deserving winner of the 2021 Klukas Award. Congratulations, Andrew!

"DSRF is a Game Changer!"

Earlier this year, the Down Syndrome Resource Foundation surveyed our families to find out how we're doing with respect to empowering individuals with Down syndrome to reach their full potential. The results were encouraging.

88% of respondents say their child's confidence has increased through their involvement with DSRF. The same percentage indicate that DSRF has contributed to their child's ability to participate in community activities. **84%** say their connection to DSRF has made them feel significantly more hopeful about their child's future, and **100%** would recommend DSRF to other families.

If you haven't discovered all that DSRF has to offer, we invite you to visit us today at **DSRF.org**. We have resources for individuals and families of every age and life stage – and wherever you are, there is a place for you at the Down Syndrome Resource Foundation.

Holiday Shopping Made Easy - and Empowering

Make the holidays doubly wonderful by giving awesome gifts made by awesome entrepreneurs with Down syndrome!

For a tasty stocking stuffer, look no further than The Granola Kid. DSRF student Zamaan Jivraj launched his granola business this past fall, and it was an immediate smash hit. Try The Granola Kid's Naked, Go Nuts, or Coco-Yummy varieties – or better yet, enjoy all three! Place your order at **thegranolakid.com**.

As mentioned above, you can find Andrew's photographic cards, including a festive selection of holiday designs, at his



Etsy shop at **DSRF.org/Andrew**. You'll never see the world the same way again after seeing it Through Andrew's Eyes!

Finally, be sure to check out DSRF's Down Syndrome Swag Shop, where you'll find clothing, baby items, and plenty of other Down syndrome merchandise. Show the world that "Love Lives on the 21st Chromosome" with the eye-catching designs at **DSRF.org/shop**.

2022 DSRF Calendar

While it may seem like we've been stuck in an endless time loop since March 2020, ready or not – 2022 is upon us! Count the days with the 2022 DSRF wall calendar, featuring 12 exquisite photos of individuals with Down syndrome by our multi-talented occupational therapist Hina Mahmood. The calendar is also packed with key dates for DSRF programs and events throughout 2022, at least to the extent that we can predict what the year ahead will bring. Purchase your calendar by calling our office at 604-444-3773.



UPCOMING AT DSRF

DSRF's Winter Festival Express - December 10, 2021

World Down Syndrome Day - March 21, 2022

FRIENDS OF DSRF

Thank you to all the companies and participants who made our inaugural Up the Down Market Canada a huge success, raising over \$300,000 to benefit people with Down syndrome. Special thanks in particular to Diamond Sponsors The Air Canada Foundation and The Answer Company; Platinum Sponsors LiUNA and Sun Life Global Investments; Sapphire Sponsors CIBC Asset Management, Phillips, Hager and North Institutional, and Willis Towers Watson; Emerald Sponsors Cidel Asset Management, Foyston, Gordon and Payne, Gestion de Placements

TD, Jarislowsky Fraser Limited, Manulife Investment Management, and TD Asset Management; Gold Sponsors Beutel Goodman Investment Counsel, Lincluden, MFS Investment Management, Pacific Blue Cross, RP Investment Advisors, and Steadyhand; and Media Sponsor CTV. Together, you have made an investment in individuals with Down syndrome that will generate lifetime dividends.

DSRF is proud and grateful to be located in Burnaby, BC, where people with Down syndrome are valued members of the community. The City of Burnaby is very supportive of the work of DSRF, and recently granted \$10,000 towards our one to one services for children with Down syndrome. Thank you very much to our hometown!

The Lohn Foundation has provided a generous grant of \$3,000 in support of DSRF's educational programs and services for children and youth with Down syndrome. We are deeply grateful for the Foundation's long-term support.

FIND US / TAG US

@DSRFCanada on all our platforms



CDSS SPOTLIGHT

Canadian Down Syndrome Week

Oh Canada! Pride and joy were felt across our great country over Canadian Down Syndrome Week. #SeeTheAbility and #MoreAlikeThanDifferent awareness campaigns were wonderful representations of groups, teams, and communities celebrating individuals and educating others about Down syndrome.

At CDSS we shared our latest resources: Learning Together in the School Community. See below for more details about these valuable assets that have been added to our collection of free, life stage materials on our online resource hub. And speaking of our resource hub, we also launched our new website! The easy-to-navigate site is full of materials to quickly download and share, inspirational stories from Canadians, and ways to get involved with the Down syndrome community. Don't forget to check out our live social feeds on the site and follow along.



There were #LotsOfLights! Across Canada landmarks lit up the skies in blue and yellow, CDSS pumpkins lit up doorsteps on Halloween, and feet lit up in lively colour with our new CDSS socks.

The week was also about learning: CDSS hosted highly-regarded medical professionals during a series of free webinars, each topic focused upon mental health and

CANADIAN DOWN SYNDROME WEEK! Oct. 24-31

wellbeing. Lastly, we unveiled our next big initiative: Bridging the Digital Divide. Learn more about this project that supports inclusivity, communication and learning via technology: <https://cdss.ca/technology-initiative/>, and see our ad on page 9.

Hats off to the Canadian community for the incredible week, and for all you do throughout the year.



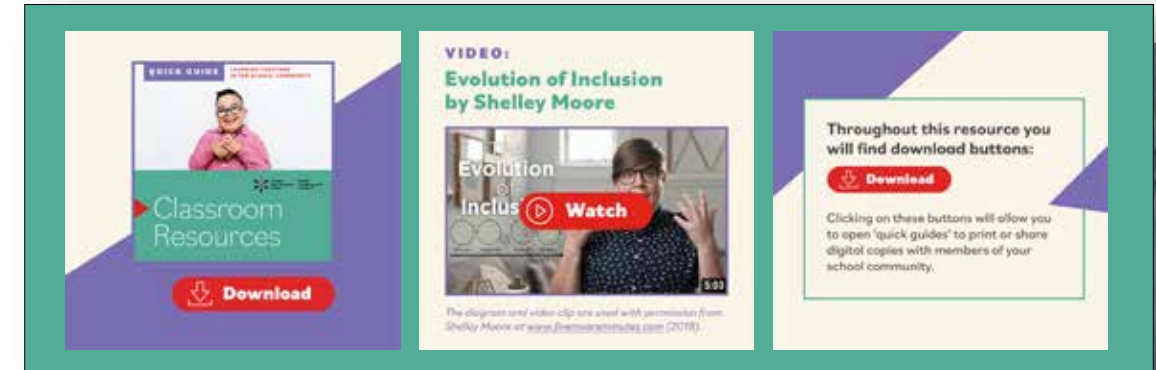
CDSS Resource News

Last year for Canadian Down Syndrome Week, CDSS focused upon improving our supportive employment series of resources. We launched an Employment Planning Workbook, and a new Employment Resource Hub, available to all Canadian employers and job seekers.

In 2021 CDSS prioritized education. With the rise of technologically-advanced tools for students and educators, the importance of students learning together, and the ability to more easily share resources through technology, our 2012 Educator Package had become dated.

These 2021 resources were created with a strong focus upon:

Firstly: Recognizing that we must educate the school 'community' as a whole about students with Down syndrome. That community includes teachers, education assistants, school administrators, support staff, substitute teachers, classroom visitors, classmates, and parents. Our resources now include 'quick guides' for each of these valuable community members.



Secondly, CDSS developed all of these documents to be easily shareable, downloadable, and printable. Interactive videos are placed throughout the main resource, with live links serving to engage and broaden the expertise shared. The digital age offers many benefits to the Down syndrome community, and this has been highlighted in these new resources.

This series of FREE resources is available in both French and English. Discover them for yourself, and most importantly, share amongst your entire school community today.

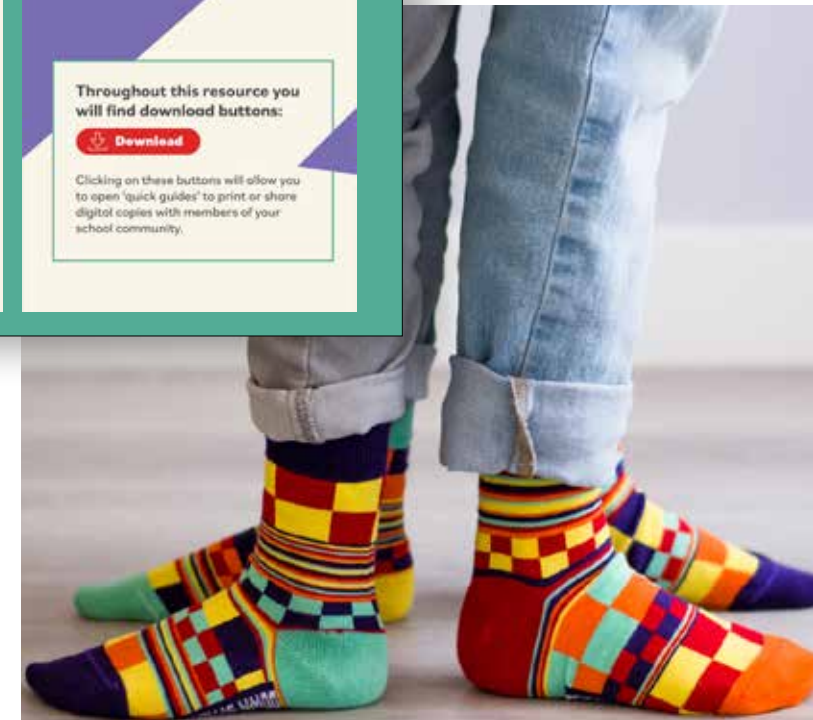


As you may have seen on our social media channels, **Project Understood** is now one step closer to reality as Google AI has announced Project Relate. Thanks goes to all Canadian Project Understood participants, who's dedication to recording phrases will eventually help the Down syndrome community, as well as many others with atypical speech to be better understood.



Google is looking for more people with Down syndrome to test their new Project Relate app. If you participated in Project Understood you can still fill out the form to possibly be involved in this phase of the project:

Click [here](#) for more information and the form. You should get a response from Google in the next few months.



SAVE THE DATES

- World Down Syndrome Day happens March 21 – mark your calendars Canada!
- December 6 is the LAST DAY to order your official Canadian Down Syndrome Kids Socks from Friday Sock Co. in time for Christmas. Don't delay – order today! See our ad page 19.

FIND US / TAG US

@CdnDownSyndrome on all our platforms



THE DOWN SYNDROME RESOURCE FOUNDATION PRESENTS



FEELING DOWN LOOKING UP

Mental Health and Down Syndrome

REBECCA
HOOS

KATIE
OLIVER

DAVID
SHUTTLEWORTH

AARON
WADDINGHAM

NOW PLAYING AT [DSRF.ORG/FEELINGDOWN](https://www.dsrf.org/feelingdown)