

Fall 2024

ISSUE #20

3 Canada's Down Syndrome Magazine 21

Breaking the Stereotype:

*People with
Down Syndrome
Can Thrive in
Higher
Education*

TRICKY TRANSITIONS

What's Your Child's Path?

*Planning for Employment
After Graduation*

Clear Boundaries for Healthy Relationships in the School Setting

The Back to School Issue

Plus: Self-Advocate Q&A with Current and Former Students

Life as a student is full of tricky transitions.

It starts off small. At first, you're changing grades, classmates, and teachers. But soon, you're preparing to grapple with more complex transitions like changing schools, going through puberty, and maybe choosing post-secondary programs or picking a career.

In this issue, we explore the challenges and learning opportunities within these school transitions and provide practical advice for teachers, caregivers, and students on how to navigate them.

Learn how to discuss boundaries for healthy relationships at school. Discover the tools needed to prepare for the right career path. Learn practical ways of managing tricky day-to-day transitions like going from bus to classroom, lunch time, and switching classes. Finally, explore the variety of post-secondary

education options that are available to students with Down syndrome and hear from people who thrived in their programs.

We hope this issue helps to smooth the student journey and pave the way for a successful future after graduation, no matter the path.

Have a great school year!

Courtney Cassel
Marketing and Communications Manager
Canadian Down Syndrome Society

Glen Hoos
Director of Communications + Sustainability
Down Syndrome Resource Foundation

Drop us a line and share your article ideas at
321DSMagazine@gmail.com.



4 14 24

4 Breaking the Stereotype:
*People with Down Syndrome Can
Thrive in Higher Education*

8 What's Your Child's Path?
*Planning for Employment After
Graduation*

12 Tricky Transitions

18 Clear Boundaries for
Healthy Relationships in the
School Setting

25 Q&A with Current and Former
Students

28 DSRF Corner

30 CDSS Spotlight

For a free digital
subscription to 3.21, visit

CDSS.ca
or **DSRF.org**

Cover Photo Models: Dadyar Yasin

Cover Photo Credit: Hilary Gauld, One for the Wall Photography

Design & Layout: Curve Communications Group



Breaking the Stereotype: People with Down Syndrome Can Thrive in Higher Education

By Laura LaChance

For years, far from true is the stereotype that people with Down syndrome (DS) stop learning after high school. More and more people than ever before are showcasing not only the possibility but the tremendous success that individuals with DS can achieve in lifelong learning and pursuing ambitions. With creativity, the key to success lies in personalized support systems, inclusive teaching methods, and a strong belief in potential. Many individuals are exploring various pathways to further their knowledge and skills. As with all youth, it will take hours of discovery, sifting through websites, questioning, application and interviews.

For people with Down syndrome, the journey of learning and growth doesn't end with high school graduation. More children are in regular classes resulting in a new cohort of young adults who have been around mainstream education their whole lives. Some want to

attend postsecondary courses because they are focused on a job sector and want to be more employable. Others go because they really love learning or they think it sounds like fun and they want to have a good time. Or in their family, everyone else is going and they want to go too.

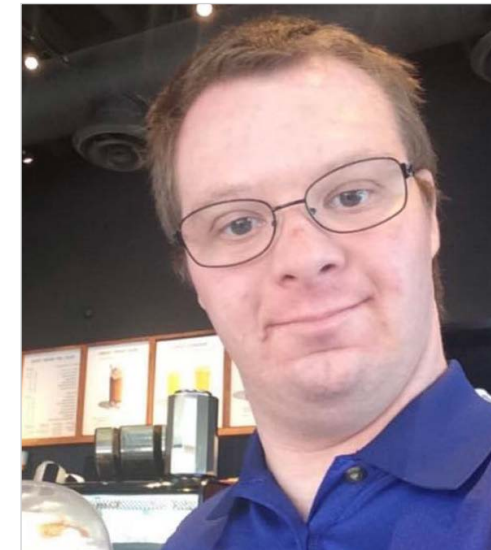
A variety of pathways are available that cater to individual needs and aspirations, allowing one to continue their education, enjoy developing new skills, and pursue interesting jobs.

It's time to look at the way people with Ds are supported and what could be expected. Today's youth are smashing stereotypes and historical beliefs. Although a mentor may be required and it may take longer, people with Ds can reach learning goals. Creative planning beginning early during the high school years can lead individuals to meaningful experiences in their local communities.

Some inclusive postsecondary education pathways are specifically designed to support individuals with intellectual and developmental disabilities, including those with Ds. These programs often include:

- **Tailored Academic Courses:** Students can take regular or modified versions of traditional college courses that align with their interests and career goals.
- **Training for Independence:** These programs often include instruction in daily living skills such as cooking, budgeting, and transportation, which are crucial for independent living.
- **Employment Training:** Students receive hands-on training in specific job fields, like office administration or retail, preparing them for employment.

An example: Ontario College CICE Program options: <https://www.ontariocolleges.ca/en/programs/education-community-and-social-services/inclusive-education>



Jason Helmond is a graduate of the Georgian College CICE program.

Jason: I did an extra year of high school. I didn't get accepted the first time as there was a big waitlist. When I was accepted I really enjoyed my food and beverage courses. We used Blackboard Learning App as an accommodation tool. Learning facilitators helped me understand and use it. Having the credentials helped me to find part-time work that I love. I love to get out and keep busy and be active. I have a lot of volunteer hours too!

Community Colleges and local School Boards may also offer a flexible selection of courses for further education.

- **Non-Degree Courses:** Individuals with Ds can enroll in classes that interest them without the pressure of pursuing a degree. General interest courses in the arts, photography, music, computer skills, and more are commonly available.
- **Vocational and Certificate Programs:** These often shorter programs focus on practical skills for specific jobs. For instance, a certificate in office skills can help students gain employment in administrative roles.

For some, apprenticeships provide on-the-job training and are a fantastic way for individuals with Ds to learn new skills while earning a pay cheque. These programs typically offer:

- **Practical Experience:** Apprentices work alongside experienced professionals in fields like culinary arts, carpentry, or healthcare.
- **Mentorship:** Apprentices receive guidance and support from mentors who help them navigate their new roles and responsibilities.
- **Certifications:** Many apprenticeships lead to recognized certifications, which can enhance employment prospects.

Online Learning Platforms

The rise of online education has made learning more accessible than ever before. With dedicated supports, online platforms offer:

- **Accessibility Tools:** Many online courses offer assistive technologies, such as screen readers and speech-to-text software, to support diverse learning needs
- **Flexible Learning:** Students can learn at their own pace and on their own schedule, making it easier to balance learning with other commitments.
- **Wide Range of Courses**

Supportive Community Programs

Various community-based programs offer continued learning and development opportunities for individuals with Ds. These include:

- **Workshops and Classes:** Local community centers often provide workshops on topics such as arts and crafts, technology, and fitness.
- **Support Groups:** Groups where individuals with Dscan connect with peers, share experiences, and learn from each other.
- **Volunteering:** Many people with Ds choose to volunteer in their communities, gaining valuable skills and contributing to society.

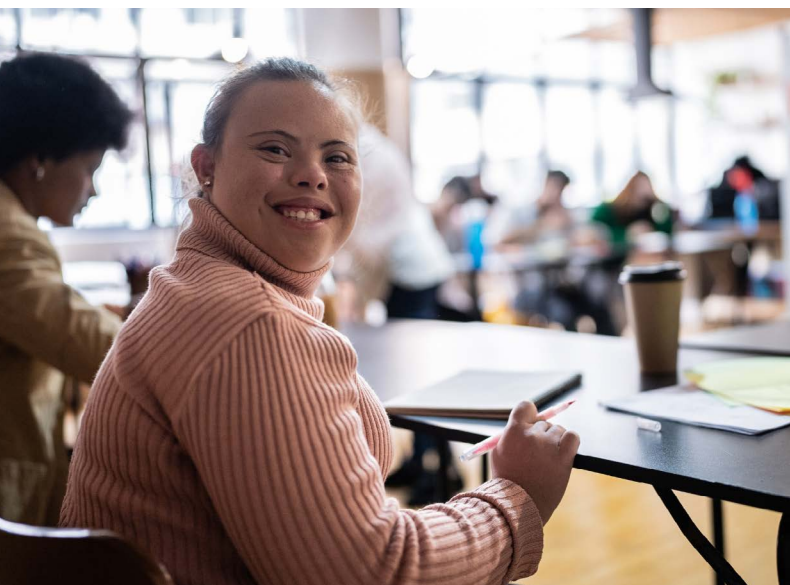


How to Support Continued Learning

For families and caregivers looking to support a person with Ds in their pursuit of lifelong learning, consider these tips:

- 1 Explore Interests:** Encourage pursuing areas they are passionate about, whether it's cooking, art, or technology.
- 2 Research Local Programs:** Look into various educational programs and resources available in your community or online.
- 3 Provide Encouragement:** Support and encourage their learning journey, celebrating their achievements along the way.
- 4 Utilize Resources:** Take advantage of educational resources, assistive technologies, and community support networks.
- 5 Explore cost and be creative**
- 6 Explore support personnel as needed**

With a variety of educational pathways and support systems in place, there are numerous opportunities to continue developing skills, gaining new knowledge, and achieving personal goals. While all pathways are not available in all regions, remember that postsecondary education is not a guarantee to successful employment in today's competitive job market. By fostering an inclusive and supportive environment, we can help people to thrive in all aspects of their lives long past high school graduation.



our community



I'm Remembering Both

Keep the love going for what matters.
Support individuals with Down syndrome and the ones you love in your Will.

willpower.ca/charities/canadian-down-syndrome-society



What's Your Child's Path? Planning for Employment After Graduation

By Courtney Cassel

1

Does your child know what they want to do after high school? Will they be applying for jobs, attending a postsecondary program, or pursuing a personal passion? Whether your child chooses the path of employment or not, it's important that they are given the support and information to make that decision for themselves.

High school students are often prepared for employment from an early age, with exercises in self-discovery, resume building, workplace exposure, and skill building. But what about students with Down syndrome?

"Research has shown that even before students with disabilities reach higher education, they have encountered challenges that have impacted their ability to focus on career development. These include the direct impact of their disability on their learning, the amount of time required to compensate for a disability, and the low expectations of others. These factors often combine to create a lack of vocational awareness."¹

Setting the expectation that a student with Down syndrome is not going to work after graduation does not give them the chance to develop the skills and confidence necessary to make that a possibility. If that attitude is built into the way we approach career planning for students with disabilities, it is going to make securing paid employment and achieving later-in-life milestones more difficult, like living independently.

2

"We know that young people with developmental disabilities are not given the same access to COOP and to paid summer jobs. Those things that you probably had as a young person and it helps you get a job as an adult. Young people with disabilities need the same."

- Dr. Jennifer Crowson, Ph.D., Diversity and Inclusion Specialist

You may already have a transition plan that addresses employment for post-graduation as part of your child's Individualized Education Program, and that is an excellent start. You can also help your child build a solid foundation of employable skills, self-confidence, and workplace knowledge by working through these career planning steps. These four steps and resources address some of the most noted challenges that students with disabilities face with career development:

- Being comfortable with their disability
- Building self-esteem and confidence
- Learning about their disability and its impact on learning or the work environment
- Acquiring the self-disclosure skills and the ability to request accommodations
- Gaining traditional employment experiences²

3

Step 1: Build a Foundation

Everyday opportunities and experiences can help young people with Down syndrome reflect and build on their skills. Through those experiences, they can learn about themselves, have social interactions, learn about their values, what they are good at, and what they don't like, all of which can be important and helpful elements for career exploration.

Setting the expectation that your child will help with household responsibilities is a simple way to help them build these foundational skills, such as:

- Helping plant and maintain a vegetable garden
- Watching younger siblings for short periods of time
- Mowing the lawn
- Doing the laundry
- Setting the table and washing dishes after meals
- Helping with food preparation such as simple washing and cutting tasks
- Assisting grandparents with chores, like weeding a flower bed
- Helping to plan, prepare, and decorate for family events like birthdays, weddings, holidays, and anniversaries

Step 2: Create a Career Action Plan

A career action plan will let your child dive deeper into their workplace values, what motivates them, what they are good at, what they don't like to do, and what they are looking for in a job. Learning more about themselves and the different types of jobs available to them can help your child build motivation to work.

You can download your own Career Action Plan workbook from CDSS.ca/Resources/Employment and to get started, have an open conversation with your child about their goals for themselves. Try asking things like what makes you happy, who do you look up to and why, what is one



4

thing you would love to do when you're older, and what is one thing you do not like doing?

Step 3: Develop Employable Skills

In this step, you should focus on helping your child discover which skills and strengths they already have, which they would like to improve on, and which ones they have no experience with and would like to learn more about. Employability skills can include teamwork, reliability, having a positive attitude, paying attention to safety, and many others. They are also known as 'transferable skills' that make an individual employable.

You can use this [Employability Skills Tracker](#) as a visual aid for tracking your child's progress as they identify and work on improving specific skills over time (we recommend at least 12 weeks). Eventually, your child will be able to include their best employability skills on their resume.

Step 4: Explore Career Options

Once your child has an idea of what is important to them, what they are good at, and what they want from their job, they can start to explore job options that might be the right fit for their skillset.

Sit down with your child and come up with a list of potential jobs that interest them. Try to help them imagine what a typical day at that workplace would be like and what tasks might be involved. Once you have a breakdown of the tasks involved in a job, you can start comparing the tasks with their experience, skills and interests. After you have narrowed down the list to a few potential job options, help your child explore them further by:

- Reading job descriptions online, watching career videos, and looking through descriptions on university websites.
- Speaking to people in your network who might be willing to talk to your child about their job or even allow

them to shadow them for a partial day to experience the day-to-day environment.

- Setting up a job shadow or information tour. This is a great way to gain exposure to the environment they might be working in, which can be a critical factor depending on their comfort level with crowds, loud noises, high-energy situations, darkened lighting, etc. MentorAbility is a national program you can connect with that helps set up job shadow and information tour opportunities.
- Ruling out jobs that are not the right fit for your child is just as important as honing in on the right opportunity that will help them flourish.

1. Hitchings et al., *The career development needs of college students with learning disabilities: In their own words*. *Learning Disabilities Research & Practice*. 2001.

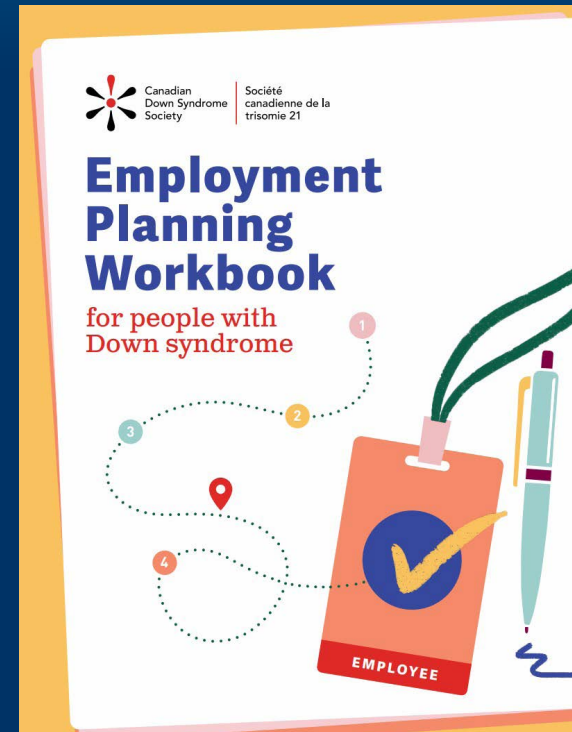
2. Briel, L., & Wehman, P. (2005). *Career planning and placement*. In E. Getzel & P. Wehman (Eds.), *Going to college: Expanding* (pp. 291–305). Baltimore, MD: Brookes Publishing.



Plan Your Career Path with the Employment Planning Workbook

Figuring out which job is right for you is hard. This planning workbook can help you to make your decision by exploring what you like, what you don't like, what you're best at doing, and what kind of jobs might be related to those skills. Download your own workbook for free and visit [CDSS.ca/Resources/Employment](https://cdss.ca/Resources/Employment) for more guidance:

https://cdss.ca/wp-content/uploads/2021/04/Employment_Planning_Workbook.pdf



Looking for Work in Your Area?

Join Inployable and connect to inclusive employers hiring near you! You'll also receive career building advice and invites to skill building opportunities. It's free to join at [CDSS.ca/inployable/](https://cdss.ca/inployable/).

<https://cdss.ca/inployable/>



Season 10

Now Playing

explaining DS to your child
speech development
mental wellness for parents
100th episode celebration
and much more!

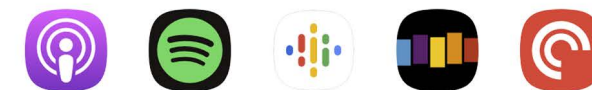
DSRF.org/podcast



Hosted by Marla Folden, SLP
+ Hina Mahmood, OT

The LowDOWN

A Down Syndrome Podcast



Tricky Transitions

By Dr. Susan Fawcett, with Glen Hoos

Nothing says “back to school” like a good old-fashioned pop quiz! So let’s do this.



Q: Name an activity that surprisingly takes up 25% of a student’s school day?

A: Transitions!

Bet you didn’t get that one! But it’s true: efficient transitions eat up a quarter of the average student’s time spent in school. Now just imagine what percentage they end up taking up if they are inefficient!

A transition involves moving from one activity to the next. A typical school day includes dozens of transitions: from bed to the morning routine, from home to school, from class to class and activity to activity, from school to the bus or car, etc.

Many children with Down syndrome struggle with transitions and require extra time to successfully move from one activity to another (thereby increasing that 25% number). Too much time spent in transition means the student is missing out on learning opportunities, and even preferred activities. It is frustrating for all involved: the student, the educator, and the parents. The cumulative effect of stress further harms learning outcomes.

Although transitions take up a sizeable portion of the day, educators tend not to plan for transition time when devising schedules. Successfully navigating transitions requires forethought, creative strategies, and the development of routines – which are really a way of organizing transitions.

Q: What constitutes a successful transition?

A: Trick question! It looks different for every student!

Every student has different support needs, so a successful transition will look different for each one. The table below outlines general characteristics of successful and unsuccessful transitions. Think of it as a spectrum. The goal is to help the student move from the left side of the chart towards the right.



Unsuccessful Transition: Characteristics

- Takes an unreasonable amount of time
- Student does not comply with educator’s request to make transition
- Student is engaged in off-task behaviours throughout transition
- Educator and student feel stress
- Transition may not be completed at all
- Student’s escape behaviours are reinforced (strengthened over time)
- Student misses out on learning and social opportunities

Successful Transition: Characteristics

- Takes a reasonable amount of time
- Student complies with educator’s request to begin transition
- Student demonstrates on-task behaviours throughout transition
- Educator and student feel proud of the student’s ability to complete the task
- Transition is completed
- Student’s adaptive behaviours are reinforced (strengthened over time)
- Student participates in learning and social activities

Q: Why are transitions difficult for children with Down syndrome?

A: Transitions may be difficult for cognitive reasons, behavioural reasons, or because of poor transition routines.

Children with Down syndrome may have cognitive difficulties that contribute to poor transitions. These may include:



- impaired memory
- a need for “sameness” and predictability
- reduced ability to process verbal instructions/auditory information
- inability to adequately verbalize their needs and wants
- inherently low level of intrinsic motivation

In behavioural terms, here’s the scenario that plays out. The above cognitive difficulties set the student up for unsuccessful transitions as soon as an educator makes a demand of some sort, e.g. “Time to go inside and do some math worksheets!” These kinds of instructions then result in challenging behaviour on the part of the student, which has the consequence of delaying or avoiding the transition to the next activity, i.e., an escape function of behaviour. If the student delays or avoids a non-preferred activity (the transition or the thing they don’t want to do next), then they are more likely to engage in these challenging behaviours in the future given similar circumstances. Finally, there could be trouble with the transition routine itself. Transition routines need to be developed in accordance with the child’s unique skills and needs in mind. The objective is to find something that works for them, which may look quite different from other children.

The table below identifies common mistakes that adults make during times of transitions with children with Down syndrome, along with possible solutions. How many of these do you recognize from your own experience?



Q: Are there any proven strategies for creating positive transition routines?

A: There sure are – and you’ve come to the right place!

Transitions don’t have to be scary. By implementing principles of positive behaviour support (PBS), we can create transition routines that play to a child’s strengths and help them succeed.

There are two general types of strategies: preventative and consequence-based. Preventative strategies are always preferred; it is more effective to solve a problem before it happens than to deal with a situation that’s gone off the rails.

Preventative Strategies

1. Set up clear behavioural expectations ahead of time

Set the stage by telling the student in advance what to expect, and what the order of events will be. A visual

schedule and/or social story can help with this. Or, even better, film the student completing a successful transition, and then have them watch it!

2. Make effective requests

Presenting effective requests means making your request in a way that increases the likelihood of compliance and/or cooperation. Here are some guidelines:

- make eye contact and get on your student’s level
- use a firm, confident, positive, upbeat tone of voice in an appropriate volume
- use statements & simple language
- be specific
- make realistic requests (appropriate for student’s age and ability)
- make one request at a time, and be patient: wait 20-30 seconds for your student to respond before you repeat or give another request
- follow through with the request (even if this means helping your student)
- give praise for following directions

Common Error	Possible Solution
Not giving enough warning about the impending transition	Give a countdown; use a visual timer
Not telling the student what is happening next	Visual schedule
Inadvertently communicating your own stress to your student during the transition (eg. through volume or tone of voice, body language, or facial expressions)	Use a neutral face and a firm, confident tone of voice
Telling the student it’s time to go and not following through with this	Keep your promise!
Going from a highly preferred activity to a non-preferred or aversive activity (e.g., going from recess directly to academic work)	Need an intervening activity that lessens the blow of the upcoming non-preferred task (rather than trying to transition from playing on an iPad to working on math homework, insert another fun activity in between; eg. walk like a penguin over to the table and choose a pencil)

Below are some examples of ineffective requests. Can you spot the errors?

“We need to get going because they’re waiting for us!”
(non-specific, too much language)

“First get your coat, put it on, grab your mittens and don’t forget to say goodbye.” (multiple requests, too much language)

By contrast, here are some examples of effective requests:

“Time to go!”

“Coat on.”

“Put toys away.”

3. Offer choices

A better way than effective requests to initiate a transition involves offering a choice to the student. Offering choices involves presenting a student with two or more options of tasks or activities. Once the student chooses, the parent or educator honours the choice. Research has shown that children with developmental disabilities are more cooperative when offered choices during a task or activity, and this is true even when the choices are non-preferred activities.

Children need to experience self-determination in their lives from an early age: the ability to act as a causal agent in one’s own life. Offering age-appropriate choices is one way to give them this experience. Here are some guidelines for providing choice:

- within a particular situation, identify the type of choice to which your student is likely to be responsive
- limit the choice to 2-3 options
- after your student chooses 1 option, immediately honour the choice
- praise the student for making a choice, or for engaging in the task or activity

Here are some examples of effectively offering choice as part of a transition routine:

“Do you want 1 more minute or 2 more minutes?”

“When we get outside, do you want to go on the slide or the swing?”

“Hold my hand or Ermengarde’s hand?”

“Should we skip or walk?”

4. Provide visual supports

Visual supports include any visual material that is given or shown to a student for the purpose of aiding understanding or memory, or creating predictability. Visual supports are used alongside daily schedules, task sequences, and behavioural expectations.

Children with Down syndrome attend, learn, and remember more effectively through the visual modality. Auditory processing (listening to information) and working memory tend to be weaker, so whenever possible, auditory messages should have visual material alongside them.

The regular use of visuals requires you to plan and be prepared for situations, which is crucial for successful transitions. Visual supports enhance predictability for your student. Enhanced predictability is important because it decreases the anxiety that often comes with not knowing what is happening next.

5. Incorporate preferences

Students with Down syndrome have lowered levels of intrinsic motivation. They may not do something just because it’s expected of them. By embedding your student’s preferred items, activities, or interactions into routines or tasks that are difficult or non-preferred (such as transitions), you give them a reason to want to cooperate.

Making hard activities more appealing will make it more likely that your student will attend to and complete difficult tasks and routines. Embedding preferences lightens the mood during an otherwise tough routine or task, and having fun together contributes to a better teacher-student relationship.



Here are some guidelines for incorporating preferences into transition routines:

- identify any currently preferred elements during the transition routine
- identify any preferred items or activities that can be added in to the routine (if necessary, observe your student for a few days to aid with this, or consult their parents, therapists, classmates, friends, or siblings)
- incorporate the preferred items/activities into the transition

Never underestimate the value of using “silly-ology” to make your interactions more fun! Make strange faces or noises, break into song and dance, put random objects on your head, pretend to be a vehicle or an animal while walking, exaggerate your actions... anything that makes your student laugh is fair game and useful for putting them in a cooperative frame of mind.

Consequence-Based Strategies

A consequence is something that happens in response to an action. While you might associate consequences with

bad choices or behaviour, we are talking about positive behaviour support. The student needs to know what behaviours they should be doing, not just what they should not be doing. This means rewarding desired behaviours in a way that motivates further cooperation, otherwise known as positive reinforcement.

Verbal praise (a behaviour-specific, positive comment) and/or non-verbal praise (a positive action or gesture such as smiling, clapping, high-fiving, fist bumping, or cheering) should be given immediately after the child engages in good behaviour. Consistent praise feels good, and over time it will contribute to an increase in appropriate, adaptive behaviour during transitions.

More praise leads to more positive educator-student interactions, resulting in a healthier relationship and less problem behaviour.

Here are some guidelines for dispensing praise:

- use specific language: the child needs to know exactly what it was they did right so they can do it again in the future
- be sincere; use an enthusiastic/upbeat tone of voice (or whatever tone your student prefers)
- smile: augment verbal with physical praise



- use varied wording to avoid satiation/boredom
- aim for a 5:1 ratio of praise to correction or criticism

Consider the following examples of praise done well:

“Good listening to Ms. Chattypants!”

“Great work going inside!”

“Shoes off – perfect”

“Wow! We got to gym so fast today!”

“You did an amazing job standing up when that timer went off.”

Q: You are outside at recess with 5-year-old Ian, who has Down syndrome. It is time to go back inside, which is always tricky. How might you approach this situation?

A: By implementing all the strategies you’ve learned from this article!

The likelihood of achieving a successful transition increases as you combine several of the strategies we’ve discussed.

There’s no perfect recipe that works every time with every child, but you might try something like this:

1. Get Ian’s attention; show him a timer.
2. Say, “We’re leaving in 5 minutes.”
3. Four minutes later, get Ian’s attention; show him the timer and say, “We’re leaving in one minute.”
4. One minute later, get Ian’s attention.
5. Say, “Ian, look here.” (Ian looks at you)
6. Say, “Go inside. Your iPad is in the classroom.” (show visual schedule)
7. Ian accompanies you inside.
8. Praise Ian: “Great job getting in the door!”
9. Give Ian an elbow bump.

As you work with the child over time and consistently use these techniques, you may just find that transitions go from tricky to triumphant more often than not!

Ostrosky, M. M., Jung, E. Y., & Hemmeter, M. L. (2002). Helping children Make Transitions between Activities. What Works Briefs

Meet Your Mindsets Mentors

Try rock climbing with Wyatt, figure skating with Meg, weight lifting with Kyle, or running with Abigail. Discover a new sport or activity that you love in the new Mindsets Wellness Program!



Kyle Landi
Weight Lifting



Meg Ohsada
Figure Skating



Aaron Waddingham
Taekwondo



Wyatt Smuszko
Rock Climbing
and Basketball



Jessica Parsons
Yoga



Abigail Adams
Triathlon

**MINDSETS WELLNESS PROGRAM
COMING OCTOBER 2024**



**Preregister and Meet More Mindsets Mentors at
www.CDSS.ca/Mindsets**

Clear Boundaries for Healthy Relationships in the School Setting

By Andrea Lee, with Glen Hoos

School is a communal activity. Throughout their school career, most students interact and build relationships with hundreds of people: classmates, teachers, EA's, librarians, school administrators, bus drivers, and more.

For a student with Down syndrome, navigating this vast social network is complex. It is also a fertile learning opportunity through which they will develop core relational skills that they'll practice for the rest of their lives. By helping students understand foundational concepts like touch, consent, and boundaries, we equip them for a lifetime of rewarding relationships.



TOUCH

As mammals, the sensation of touch is good for all of us. Touch builds social connections and conveys acceptance. When done right, touch feels good and makes people happy. It can lower stress, help your immune system, calm your heart rate, and lower blood pressure.

Consider a hug: It involves deep pressure over large parts of the body, including the shoulders, back, and arms. This can help calm the nervous system and organize the sensory system. And best of all, hugs are easy to ask for without much expressive language. All you've got to do is put your arms out, lean in, and make people happy!

On the flipside, when you are not getting enough touch, it can have significant negative consequences. It can cause stress, anxiety, depression, and sleep issues. During COVID-19 lockdowns, many of us become familiar with touch starvation. Many of my colleagues, friends, and family shared with me that when they couldn't see anybody, they were surprised by how much they missed the physical sensation of touching and being touched. They couldn't remember the last time they touched somebody, even just a friendly high five, and it really impacted their mental health. So, we want to make sure that our students with Down syndrome are getting the touch they need (keeping in mind that everyone requires different amounts and types of touch).

Typically, adolescents as a group are at risk of touch starvation. Smaller children generally get lots of physical contact as they play, wrestle, cuddle, and hug family and friends. But often as people go through puberty, suddenly nobody is touching them – at the very age when they most need positive affirmation.

Now, let's think about why people with Down syndrome might be extra susceptible to touch starvation. They may have fewer friends and social opportunities. Communication may be more difficult, so they may have trouble asking for what they need. They may be more likely to be single due to a lack of opportunity or relationship education.

I teach my students about different types of touch, and we talk about them in detail, with visual aids. There are many ways to touch somebody, and most of them are not romantic or sexual in nature. I include smiles and waves

even though they're not technically forms of touch; they are part of a natural sequence where you may smile at someone or wave at them, and as you get to know them better you might progress to high fives, fist bumps, handshakes, or hugs.

This leads us to an extremely crucial concept: consent.



CONSENT

Consent is a foundational principle that needs to be taught and practiced early and often. It is not reserved for sexual acts; bodily autonomy is absolute and applicable to all forms of touch. I have the right to my body and I make the choices about my body.

Sometimes I ask my students, "Have you ever had an itchy nose?" When they say yes, I follow up with, "Who do you have to ask before you scratch it?"

They may answer, "My mom," or "My doctor." But it's a trick question. The answer is: nobody! You do not have to ask anybody for permission to scratch your nose. You are the boss of your body, and if you are itchy, you can scratch it.

And then we make an important connection: other people have control over their own bodies, too. This is the concept of individual agency. Yes, you're the boss of your body, but you are not the boss of anybody else's body. They get to make their own choices. Just like you, they get to choose who they touch and who they do not touch. It might be you, and it might not be you.

These lessons can begin at the earliest ages. I saw a YouTube video of a teacher welcoming her kindergarten students



There are also rules for asking for consent:

- Both people have to say yes
- If somebody says no, I can ask for something different one time: no pestering or harassing
- Consent can be given verbally or non-verbally (eg. through eye contact, smiling, nodding, etc.)
- Consent must be informed and enthusiastic

With my group classes for students with Down syndrome, we start every class by practicing consent. We use class consent menus which include things that are situationally appropriate for our classroom, for being in public, for classmates and friends, and for dating relationships. We take turns asking each other questions, and it is a really fun relationship building activity. They might say to me, “Andrea, I want to dance.” And I’m like, “Oh, with who?” “With the whole class. I just want a dance party.” And then I have to consent to that as the teacher running the class. Sometimes I’ll say yes, and sometimes I’ll say no. It’s very empowering to give people the chance to ask for what

they want. If they can’t have what they want, it’s a good learning experience. It is disappointing, but maybe they’ll get something next time.

BOUNDARIES

I mentioned that I have different consent menus for different relationships and environments. This is tied into the notion of boundaries. Boundaries are partially defined by the type of relationship that two people have with one another.

For example, I ask my students, what kinds of things do they see boyfriends and girlfriends doing, and what do they see people doing with their paid helpers (eg. teachers, EA’s, and caregivers)? Some types of touch may be appropriate for romantic partners, while other types of touch may be appropriate with a paid helper. And, confusingly, some types of touch may be appropriate for both types of relationships, but they convey different meanings depending on the context.

each morning. She posted a greeting menu outside the classroom, and the kids get to pick what kind of greeting they want, whether that’s a fist bump, a hug, a silly dance, or nothing at all.

Teaching self-advocacy is so important for folks with Down syndrome. I can say no, and I can tell someone when I don’t like something. I find so many of my students with Down syndrome are people pleasers. There’s a lot of built-in compliance because of all the specialists they’ve seen through the years, where they are often rewarded for being compliant and following directions. That’s an important skill in some situations, but they also need the confidence and ability to say no when something is hurting them, making them uncomfortable, or they just don’t want to do it. It’s a matter of safety.

We need to give kids multiple ways to say no. It can be verbal or spoken through an AAC device. It can also be conveyed non-verbally, by holding up their hands in a ‘stop’ gesture, looking away, or even walking away. These are all valid ways of saying no.

When I teach consent, I say that consent is an agreement. Consent means saying yes. We do not want force compliance. We want bodily autonomy for everyone. So, we want people to be saying yes, and we want them to feel okay about saying no.

What does this look like in practice? With my students, it looks like this: you will ask, you will wait, and then you can get your hug. It can be hard with younger children, where they’re just so cute and they want to hug everybody. But I’ll still make them pause to show them that I had to agree to this hug, and the choice to agree or not agree is up to me. And then they get the hug.

Here are some useful rules for giving consent:

- I am the boss of my body: what I say goes
- I can change my mind at any time: I can stop whenever I want
- I can say no one time and yes the next time, I can say yes one time and no the next time
- I can say no to one person and yes to another person





misunderstand a kind comment from a stranger or celebrity on Instagram as a sign of friendship.

From there, you can discuss the boundaries that are appropriate for those in each circle. You might have the Hug Circle and the High Five/Handshake Circle, for example. This may be different depending on your culture, and your level of comfort with the people in your life. Personally, I hug my friends and give them high fives, but I know some people who give kisses on the cheek or hold hands with their friends. Different people have different boundaries, and that's okay.

For paid helpers, there are additional considerations. Does your school or workplace have a child code of conduct? If so, what boundaries do they mandate? How often are you supposed to be letting students sit in your lap, and until what age? When is it okay to hold hands? How many hugs should you be giving? Should you have the same boundaries with students who have Down syndrome as you do for other students, or is there room for some flexibility?

Finally, what happens if someone crosses boundaries? I like using the language "expected and unexpected" versus "good and bad" or "appropriate and inappropriate." It leaves out the judgment. I explain that in this type of relationship, in this scenario, or in this place, that was unexpected. There's a program called Cool and Not Cool used for teaching students with autism spectrum disorder which follows similar principles.

For somebody who crosses boundaries a lot, contracts work well. You can come up with the expectations together, and the consequences for breaking those expectations, such as taking a break. This type of collaboration generates more buy-in, which often results in greater success.

Relationship skills are complicated. Each of us spends a lifetime developing them. With the right support, students with Down syndrome can build meaningful, mutually respectful relationships with others in every circle of their life. And isn't that what we all want?

With paid helpers, there are various kinds of activities, some of which involve touch, such as hand-holding. But holding hands would be for practical purposes, such as aiding someone's balance or safely crossing the street. It is not romantic, like it is when a couple holds hands. You want to make it very clear that as a paid helper, it is your job to help your students. You are not their friend (at least, not in the same sense as those who have social relationships with them), and you are certainly not a romantic partner or prospect. Students with Down syndrome may need help understanding these distinctions and respecting the boundaries.

I use Terri Couwenhoven's People in My Life model, similar to the Circles of Intimacy program, from her book Teaching Children with Down Syndrome About Their Bodies, Boundaries and Sexuality. You begin with the student in the centre, and the circles around them are the relationships they have, starting with their closest family members, then going out to their friends, their acquaintances, and so on. This tool helps the individual define different relationships they can have including family, romantic partners, friends, acquaintances, paid helpers, community helpers, and strangers.

Terri also has a friendship checklist that you can adapt and use to help the student determine who in their life falls into each category. This can be particularly tricky in this age of social media, where it's easy for some students to

Q & A

with Current and Former Students



1. What school and program did you graduate from?

I graduated in 2021 from the Humber College North Campus Community Integration through Co-operative Education (CICE) program.

2. What skills did you learn during your program?

I learned skills that helped me become more prepared and more independent. The CICE program helped me to communicate better, be more self-aware, be a better leader, and learn how to advocate for myself.

3. What have you been doing since graduating?

Since I graduated from Humber College, I have proven to myself and many others that Down syndrome hasn't stopped me from "rocking life" as a self-advocate, public speaker, and multi-talented artist. You can look at my Linktree to see everything that I have accomplished so far. @jessica.rotolo20

Jessica
Toronto, ON

1. What school and program did you graduate from?

I attended the University of British Columbia, Kelowna campus. This is the same school my sister studied at, so I knew I wanted to go there! I graduated from the faculty of Creative and Critical Studies, majoring in Cultural Studies with a minor in Women's Studies. I was able to go to university through the Steps Forward Program which offered me supportive services to help me learn.

2. What skills did you learn during your program?

I learned so many new skills at University that it's hard to narrow it down! I developed a lot of independence and related to that, time management skills. I was responsible for getting myself to class on time, for completing assignments, and studying for quizzes and tests. It was also up to me to ask my professors questions when I didn't understand something I was learning.

I gained confidence to speak up and contribute in class. It can be intimidating to speak in front of many, sometimes hundreds, of other students. But my professors encouraged me and reminded me that my voice was important.

I practised many social skills. I attended classes with my peers and, often, studied and worked with them on projects. I made life-long friendships at University, which is really special. I also interacted with my professors. They were all so nice and supportive.

Most of my classes were in cultural studies. I really enjoyed learning about other minority groups and what they have gone through to be included. It's helped me to understand more about being an advocate.

6. What do you want to do now that you have graduated?

I'm not sure what my future holds, at this point. Right now, I'm enjoying being able to say I'm a university graduate. I know all of the skills I've learned and the confidence I've gained will be an asset for anything I do. I am a Health Messenger for Special Olympics BC and currently I'm using my voice to help my disabled peers to stay healthy, mentally and physically.



Kassidy
Kelowna, BC



Sarah Shishido
Burnaby, BC

1. What do you enjoy about school?

I love seeing my best friends and enjoy learning new things.

2. What's your favourite school subject?

My favorite subject is science. I love learning about my genetics, especially more about Down syndrome or my family genetics.

3. What do you find challenging at school?

I love school but I don't like getting bullied. It does happen sometimes.

4. What are you hoping to learn this year?

I am excited to learn more about biology. I would also like to learn about my Mom's family history as I studied my Dad's side of the family in grade 10.

5. What do you want to do in the future when you're all finished with school?

I am not sure what I want to do after high school. I need more time to think about it and experience life.



Sarah Schouten
Burnaby, BC

1. What's your favourite school subject?

Art and Science.

2. What do you find challenging at school?

Some kids.

3. What are you hoping to learn this year?

Science and English.

Eleanor Stewart Introduced as DSRF's New CEO

The Down Syndrome Resource Foundation is thrilled to announce the appointment of Eleanor Stewart as our new Chief Executive Officer, effective August 26, 2024.



Eleanor has worked at DSRF since 2008. She is a BC certified teacher with a Masters in Educational Psychology specializing in reading and exceptionality from Simon Fraser University, and an education degree from McGill University. Eleanor pioneered many of DSRF's adult educational classes, including those aimed at improving reading skills and developing social communication and community navigation skills. She has also served as an instructor in DSRF's one-to-one literacy program for children, youth, and adults with Down syndrome.

In her most recent role as DSRF's Director of Education Programs and Services, Eleanor managed DSRF's group education and recreation programs; mentored new teachers; supported the development of new programs; facilitated various workshops, webinars, and community presentations; and responded to community requests for information about teaching children with Down syndrome.

"I am honored to step into this new role and lead an organization that has significantly influenced my development over the years," says Eleanor. "I am thrilled to lead our exceptional and dedicated team, all committed to DSRF's mission and its vital services. Leveraging my background in education and programs and leading with kindness, curiosity, and humour, I aim to ensure DSRF continues to support our families with the services they need and deserve."

DSRF is excited to move into the future under Eleanor's

direction as we seek to bring our world-class Down syndrome services to even more families across British Columbia. She embodies our organizational values of integrity, dedication, client-centredness, community, inclusion, expertise, and empowerment, and is the right person to lead our team.

We would also like to thank our Director of Development Jason Campbell, who served as Interim CEO for five months while continuing to lead our fund development efforts. We appreciate your service, Jason!

The LowDOWN: A Down Syndrome Podcast Celebrates its 10th Season

When The LowDOWN team gathered to record its first podcast episode in March 2020, it was difficult to foresee that four years later we would be celebrating our tenth season.

Just as we were about to hit 'record' for the first time, we were informed that the DSRF office was closing at the end of the day due to the coronavirus. It would be six months before we would see each other again face to face.

Nevertheless, we proceeded with an abbreviated first season, produced entirely remotely. Eight more seasons followed,

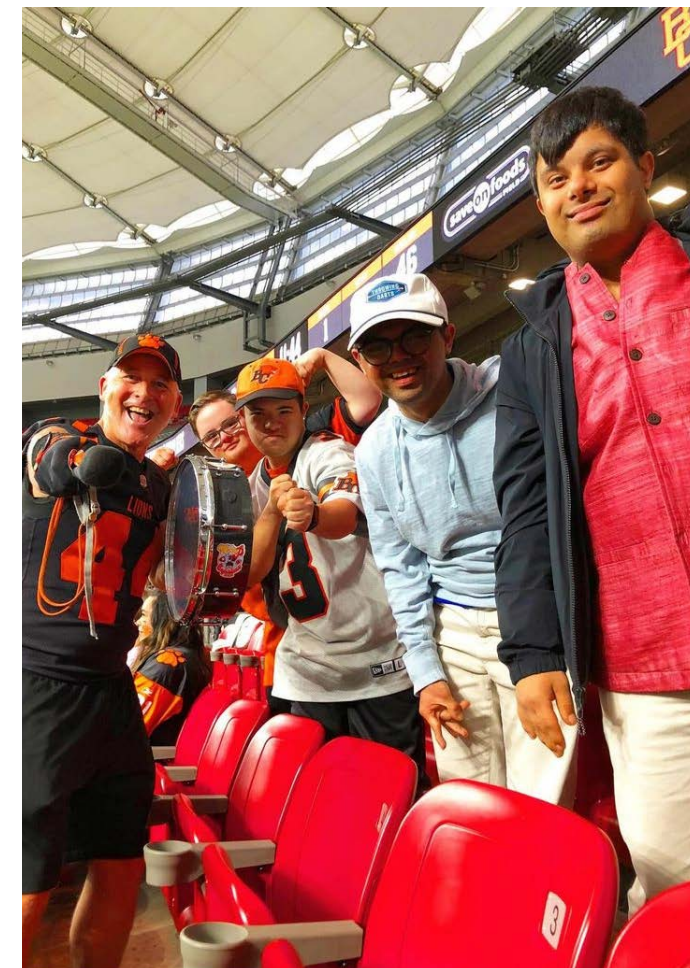


covering every Down syndrome-adjacent topic imaginable, with a superstar lineup of guests including dozens of self-advocates and some of North America's leading Down syndrome experts.

This fall we will present our 10th season, with topics including explaining Down syndrome to your child, speech development, phonics, ableism, mental wellness for parents, and the impact of climate change on people with Down syndrome. We will also celebrate our landmark 100th episode by taking questions from the listening audience for hosts Hina Mahmood and Marla Folden.

Thank you all who have listened and help lift The LowDOWN into the top 10 of all podcasts in downloads per episode. If you aren't yet a listener, find The LowDOWN on your favourite podcast app or at [DSRF.org/podcast](https://www.dsrf.org/podcast).

Cameras Roll on New Short Film



This summer, production began on the latest instalment in DSRF's short film series. The new film, *Kindred Spirits: Chronicles of Down Syndrome Friendship*, will celebrate the special friendships that people with Down syndrome form with one another. Three groups of adults will give us a glimpse inside their unique relationships, while DSRF experts provide insights for helping loved ones with Down syndrome cultivate meaningful friendships with one another. The film will be released in Fall 2024.

FRIENDS OF DSRF

We are grateful to announce that Macquarie Group has generously matched the \$34,000 raised by Run Up for Down Syndrome's top fundraiser, Geoff Gates! With this, we have officially hit our \$250,000 fundraising goal for the event. Thank you to Geoff, Macquarie, and each and every runner and donor who contributed to this awesome achievement.

The Ames Family Foundation has generously donated \$26,000 in support of DSRF's Employment Support Service, our upcoming short film on friendship for people with Down syndrome, and season 10 of *The LowDOWN: A Down Syndrome Podcast*. We are so thankful for the foundation's exceptional support of each of these projects.

Kiwanis Club of Vancouver has provided \$2,212.50 in support of DSRF's summer camps program. Thank you Kiwanis for contributing to a great summer of learning and fun!

The Starbucks Foundation Charitable Fund, held at Vancouver Foundation, donated for \$1,350 towards Run Up for Down Syndrome. We are grateful for Starbucks' longtime support of this event.

UPCOMING AT DSRF

Up the Down Market Vancouver: *Sept 19, 2024*

Up the Down Market Calgary: *Oct 10, 2024*

Up the Down Market Toronto: *Oct 30, 2024*

DSRF presents... *A Magical Morning: Dec 13, 2024*

FIND US / TAG US

@DSRFCanada on all our platforms



[DSRF.org](https://www.dsrf.org)

Down Syndrome
Resource Foundation



CDSS SPOTLIGHT

Mindsets Wellness Program Launching October 2024 Your Health Journey Starts Here

We are very excited to announce that the much-anticipated Mindsets Wellness Program will be launching in October! There are over 200 people across Canada who have already signed up and are ready to get active, eat healthier, and feel better.

The Mindsets approach to building healthy habits includes peer-led videos to introduce new sports and activities, introductory level recipes curated by nutrition experts, and self care exercises to help manage everyday mental health challenges like anger, confusion, depression, and anxiety.

Using the Mindsets App, participants will be able to complete their weekly goals in fitness, nutrition, and self-care while tracking their progress. The app will encourage and guide participants towards achieving research-based program milestones for improving mental and physical health, such as exercising for 30 minutes three times a week. New Mindsets Mentors videos, recipes, and exciting new features will be added to the app each month, so there will always be more to discover!

Visit our website to see a preview of the Mindsets Wellness Program App and to preregister for the program: <https://cdss.ca/mindsets/>



Assume That I Can... Be Employed! Share Your Employment Story for DEAM

Let's show the world the many contributions that people with Down syndrome make to the workforce! We are looking for employment stories and advice to share across the country during Disability Employment Awareness Month this October. Help us to confront employment stereotypes about people with Down syndrome and inspire others to try different career paths! Share your employment story or advice with us at info@cdss.ca and please include your name, location, employer, position, and a photo (if possible.)

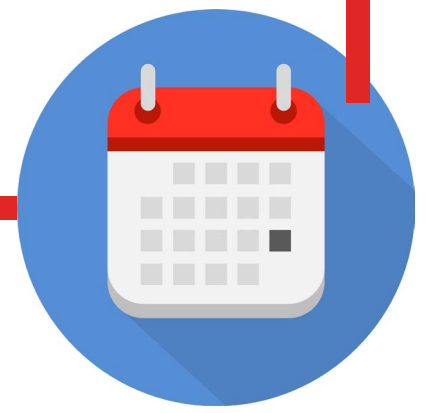
Important Dates

**Community Learning Webinar:
Managing Your Mental Health**
September 19th

**Community Learning Webinar:
How to Find Paid Employment**
October 17th

Light It Up for NDEAM
October 17th 2024

Canadian Down Syndrome Week
October 20th - 26th



Breaking Down Stereotypes, One Photo at a Time Celebrating 10 Years of Down Syndrome Advocacy

CDSS is proud to support DECADE, a new photo series by Hilary Gauld of One for the Wall celebrating over 10 years of authentic representation for the Down syndrome community. Alongside our team and Waterloo Wellington Down Syndrome Society, Hilary has worked for a decade to capture everyday moments and under-represented members of our community in campaigns like Here I Am, Love Means, and Just Ask Me. These projects not only served to improve representation for people with Down syndrome of all ages, but also acted as a powerful visual message as we confronted stereotypes together.

The full DECADE photo series and film by Digital Sabbath will be released online and at a live screening event during Canadian

Down Syndrome Week this October, but we would like to share this sneak peek of a few of our favourite photos:

Learn more about the DECADE photo series and live event and what else is happening this Canadian Down Syndrome Week on our website: <https://cdss.ca/canadian-down-syndrome-week/>



BACK TO SCHOOL RESOURCES FOR PARENTS AND TEACHERS:

LEARNING TOGETHER IN THE SCHOOL COMMUNITY



Welcoming students with all abilities together in regular classrooms takes effort from everyone in the school community to make it successful. Inside this resource, Learning Together in the School Community, you'll find important information for practical guidance for teachers, education assistants, school support staff, substitute teachers, classmates and peers, parents, and school administrators.

Download "Learning Together in the School Community" and inclusive education resources at [CDSS.ca/Resources/Education](https://cdss.ca/Resources/Education)

JOIN OUR COMMUNITY


FIND US / TAG US

@CdnDownSyndrome on all our platforms



CDSS.ca



THE ANSWER COMPANY 
presents

UP THE DOWN MARKET



Vancouver | Sept 19, 2024
Calgary | Oct 10, 2024
Toronto | Oct 30, 2024

DSRF.org/UDMD

Maili Wong, CFA, CFP®, FEA
Senior Portfolio Manager
The Wong Group at
Wellington-Altus
Private Wealth
UDMD National Chair

**Down
Syndrome** 
Resource Foundation



Jodi Klukas
Ambassador
Down Syndrome
Resource Foundation