3.21
Canada's
Down Syndrome
Magazine

Summer 2025
ISSUE #23

Let's Eat Together:

Navigating Feeding Development for Your Child with Down Syndrome

The New Parents' To Do (and To Don't) List

What Do You Know About Down Syndrome? Test Yourself!

Growing at Their Own Rhythm:

A Guide to Early Development in Down Syndrome

The New Parents Issue

Plus: *If I Knew Then What I Know Now - Parent Q&A*

3.21 Canada's Down Syndrome Magazine is a joint publication of

Canadian Down Syndrome Society | Société canadienne de la trisomie 21

Down Syndrome Resource Foundation

Having a baby should be one of the happiest times in your life. Sometimes, though, it comes with an unexpected twist that throws you for a loop. For many, finding out that your baby has Down syndrome is scary, and can even overshadow the thrill of becoming a parent to a beautiful new life.

It doesn't have to be this way.

While there are many emotions to process when your child is diagnosed with Down syndrome, know this: there is so much joy in the journey.

It's a journey best navigated in community. While a magazine is no substitute for flesh-and-blood people, in these pages you will find the collective wisdom of parents who have walked these steps before you, supplemented by the knowledge of professionals who have served as reliable guides for many families.

Every child's path is beautifully unique, and we hope this special New Parents issue of 3.21 Magazine will help you and your child on your way. **Welcome to the family.**

Glen Hoos
Director of Communications + Sustainability
Down Syndrome Resource Foundation

Courtney Cassel
Marketing and Communications Manager
Canadian Down Syndrome Society

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

Cover Photo Model:
Heriberto Aviles (father), Brenda Garcia (mother), Nathan and Grayson (sons), Guelph, ON

Cover Photo Credit:
One for the Wall Photography

Design & Layout:
Curve Communications Group

For a free digital subscription to 3.21, visit

DSRF.org
or CDSS.ca

In this issue of 3.21 Canada's Down Syndrome Magazine

Let's Eat Together:

Navigating Feeding Development for Your Child with Down Syndrome

By Riley Rosebush, MSc. RSLP, with Glen Hoos

Eating together connects us to family and culture, and creates opportunities for learning. When a child meets their nutrition and hydration needs, they can thrive in their development with a strong foundation to grow and participate in daily life.

If you have a child with Down syndrome, you might be navigating some unique challenges when it comes to feeding. It's important to know that you are not alone. In fact, research indicates that around 80% of individuals with disabilities can experience feeding difficulties in infancy and childhood.(1)

While these challenges are common, remember that with the right support, your child and family can thrive, even with feeding differences. Let's take a closer look at why feeding can be a bit more complex for children with Down syndrome and what you can do to help. Pull up a seat at our table and let's feast (on information).

Understanding the Building Blocks of Eating

It's easy to take a seemingly simple skill like eating for granted, but it involves a remarkable number of coordinated steps. Let's visualize drinking from a cup, imagining every skill involved.

First, your child needs to be sitting with a stable and supported position, allowing for good control of their head and neck. This can be a starting point for difficulties due to lower muscle tone and postural instability, which are common in children with Down syndrome.

Next, they need to see and recognize the cup, which can be harder if they experience any visual impairments. Then, they need to recognize the internal feeling of thirst to be motivated to reach for it. Reaching out and lifting the cup involves coordinating their visual and motor skills to use their hands and arms to lift the cup without spilling, using just the right amount of force. Bringing the cup to their mouth and tilting it to get the right amount of liquid also requires precision. They need to be able to hold the liquid in their mouth with the right amount of tension in their cheeks, lips, and tongue and seal their lips to avoid any spills.

Finally comes swallowing. This intricate process involves lifting the tongue, gathering the liquid, scooping it back, and swallowing correctly. Believe it or not, around 30 pairs of muscles and nerves need to work together for a safe and effective swallow,(2) and this is largely an automatic process controlled by the nervous system. If there are any missteps along the way, it can be difficult for your child to drink enough and stay hydrated while avoiding having food and liquid enter their lungs.

References:

1 Manikam, R., & Perman, J. A. (2000). Pediatric feeding disorders. Journal of Clinical Gastroenterology, 30(1), 34–46. https://doi.org/10.1097/00004836-200001000-00008

2 Jean, A. (2001). Brain stem control of swallowing: Neuronal network and cellular mechanisms. Physiological Reviews, 81(2), 929–969. https://doi.org/10.1152/physrev.2001.81.2.929

Why Might Feeding Be More Challenging for Children with Down Syndrome?

As you can see, eating is a complex skill, and children with Down syndrome may face difficulties at various points in this process as they grow and are expected to eat and drink a wider range of foods independently. Here are some other contributing factors:

Health Status and History

Issues like reflux, constipation, food allergies, sensitivities, and other gastrointestinal complications are more common in children with Down syndrome and can affect their hunger and motivation to eat. Other health issues that impact alertness, attention, or cause pain can also make feeding challenging. A baby's early feeding experiences also matter. For example, a significant number of infants with Down syndrome (around 48%) require tube feeding after birth, which can mean missed opportunities for developing their oral feeding skills.

Physiology and Oral Development

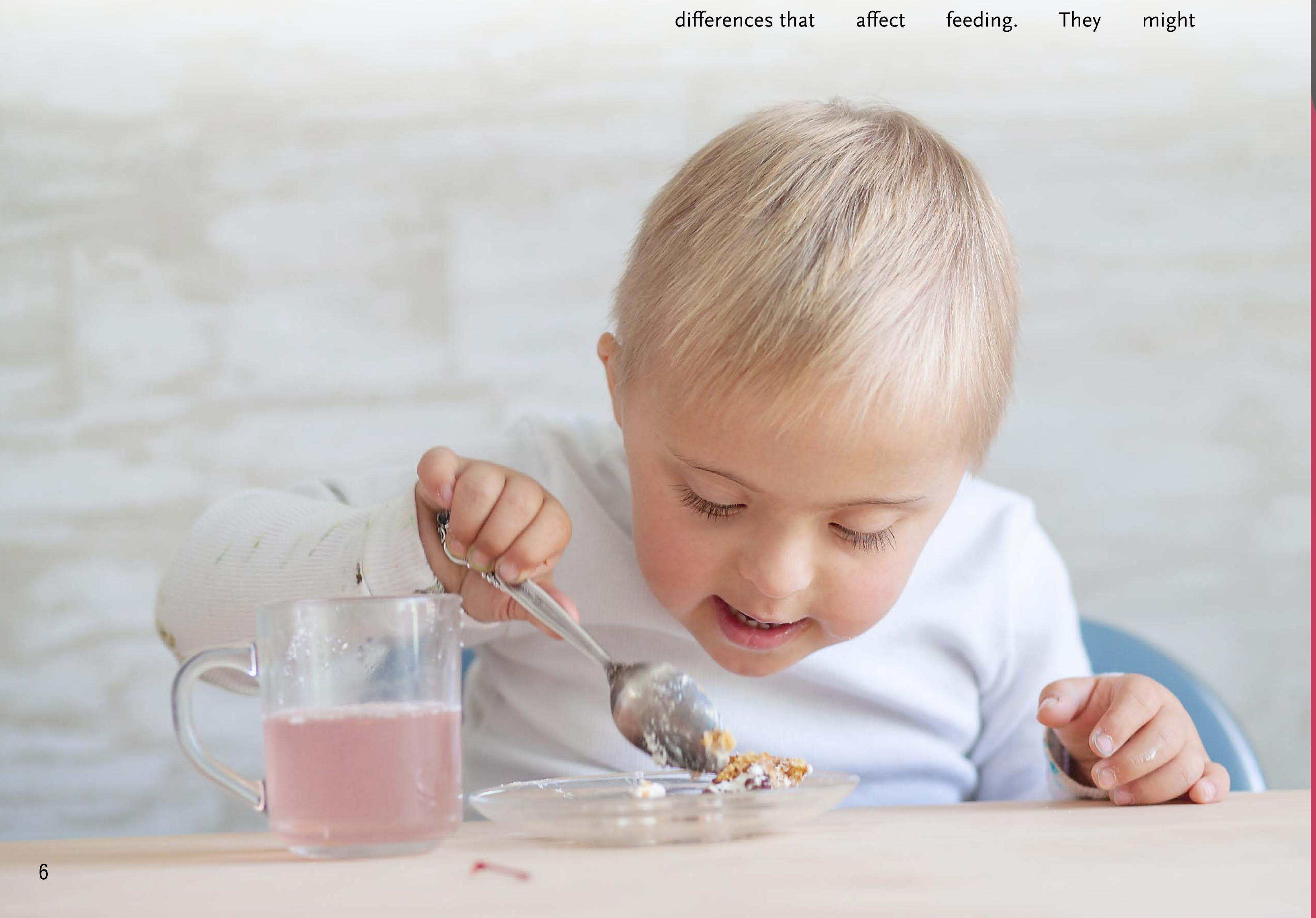
Skills like chewing, swallowing, and bringing food to the mouth can be more difficult. Children with Down syndrome may have differences in their mouth and body structures, such as a high and narrow palate and potential teeth alignment issues. There can also be challenges with tongue movement, muscle tone, range of motion, and coordination, which are all important for managing food in the mouth.

Fine and Gross Motor Development

Eating and drinking require precise movements of the mouth and body. Since Down syndrome is associated with lower muscle tone and potential difficulties with motor planning and coordination, every step, from sitting to picking up food and managing it in the mouth, can be more difficult.

Sensory Processing

Many children with Down syndrome have sensory differences that affect feeding. They might



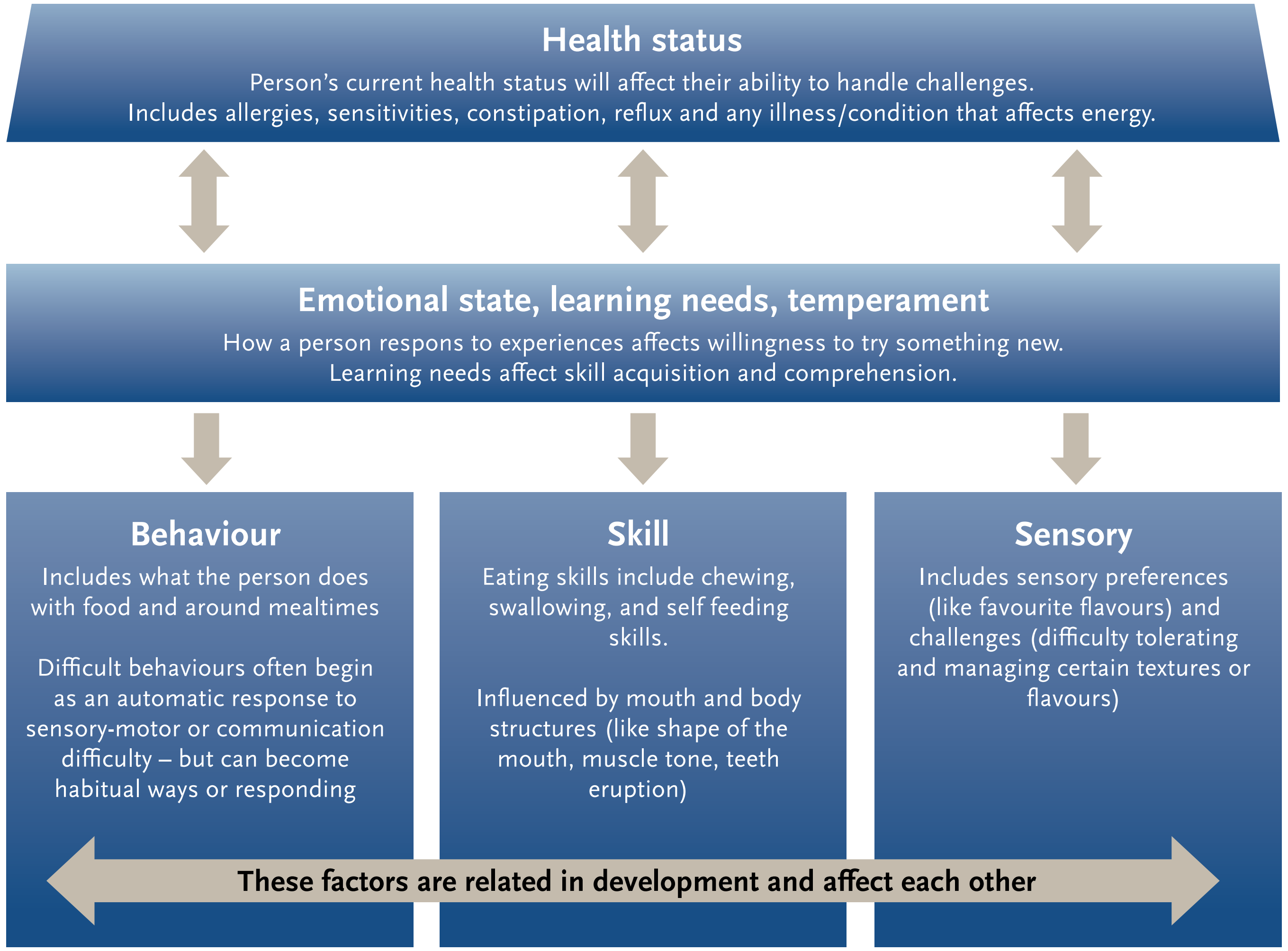
be hypersensitive (more sensitive) to certain tastes, smells, temperatures, or textures, which might make eating certain foods an unpleasant experience. On the other hand, if they are hyposensitive (under-responsive) in their mouth, they might have trouble locating food and responding appropriately. Think about the awkward feeling after dental freezing – a similar lack of sensation can affect how the mouth muscles are cued to move. It's also important to remember that the ability to sense internal feelings like hunger, fullness, and thirst (processes that are a part of our interoception) might be different in individuals with Down syndrome.

Emotional State, Learning Needs, and Temperament

Your child's mood and personality significantly influence their experience with mealtimes and their willingness to try new things. Understanding your child's unique learning style and temperament and then adapting how you introduce new skills can make a big difference in creating a positive feeding plan that doesn't cause more stress.

Behaviour

Mealtime can sometimes trigger challenging behaviours in children with Down syndrome. Often, these behaviours start as a response to sensory-motor or communication difficulties but can become habits over time. If eating isn't a pleasant experience due to the factors mentioned above, it can become something they want to avoid, leading to behaviours that interfere with eating and social participation at mealtimes. Understanding the underlying reason for these behaviours is the first step in creating a supportive feeding environment and setting achievable feeding goals.



Health status

Person's current health status will affect their ability to handle challenges.
Includes allergies, sensitivities, constipation, reflux and any illness/condition that affects energy.

Emotional state, learning needs, temperament

How a person respons to experiences affects willingness to try something new.
Learning needs affect skill acquisition and comprehension.

Behaviour

Includes what the person does with food and around mealtimes

Difficult behaviours often begin as an automatic response to sensory-motor or communication difficulty – but can become habitual ways or responding

Skill

Eating skills include chewing, swallowing, and self feeding skills.

Influenced by mouth and body structures (like shape of the mouth, muscle tone, teeth eruption)

Sensory

Includes sensory preferences (like favourite flavours) and challenges (difficulty tolerating and managing certain textures or flavours)

These factors are related in development and affect each other

When to Seek Support

Eating is not just about getting enough nutrients; it's also a social activity and a time for family bonding. As a speech-language pathologist, I become concerned if mealtimes are a consistently negative experience for the child and family. It's crucial for overall development that eating is enjoyable. If you have concerns about your child's growth, nutrition, or mealtime behaviours, a clinical evaluation to understand the root causes is important.

What Can You Do?

If you have concerns, a great first step is to use the free online screening tool for pediatric feeding disorder on the Feeding Matters website. Feeding Matters is an organization that is dedicated to supporting children and families experiencing feeding difficulties. Their questionnaire can provide immediate feedback on how your child is doing compared to age expectations and help you identify areas of concern. You can then share these results with your child's healthcare team.

Who Could Be on Your Feeding Team?

Your pediatrician or family doctor can help identify any underlying health issues and may refer you to a gastroenterologist for digestive concerns or for a swallowing assessment.

Your therapy team plays a vital role. A speech-language pathologist can assess and address oral development issues and provide feeding therapy. An occupational therapist can help with seating, utensil use, and drinking from a cup, among other things. A board-certified behaviour analyst can help implement positive strategies to address mealtime behaviours. It's beneficial to seek out therapists with specific training in feeding issues.

For infants still breast or bottle-feeding or transitioning from tube feeding to breast or bottle feeding, a board-certified lactation consultant can offer valuable support at this stage.

A dietitian can assess your child's nutritional intake and suggest ways to ensure they are getting the necessary nutrients within their dietary limitations.

Finally, don't forget to take care of yourself. If you are experiencing anxiety or stress around your child's eating, a psychologist can help you cope and process any potential trauma from early feeding experiences. Remember, you are not alone and you deserve a supportive team.

Navigating feeding development can have its ups and downs, but with understanding, support, and a collaborative team, you can help your child develop a positive relationship to feeding and truly thrive!

For more information and resources on feeding and swallowing for people with Down syndrome, visit DSRF.org.

The New Parents' To Do (and To Don't) List

By Glen Hoos

Welcoming a baby with Down syndrome into your world is an exhilarating, exhausting, joyous, chaotic, confusing, fun, and at times overwhelming experience. There is a lot to feel, a lot to learn, and a lot to process.

Deep breath.

As you navigate these early days, you'll want to take it one step at a time and focus on what's truly important. We hope this New Parent's To Do (and To Don't) List will help you discern where to put your attention and fully enjoy your first days, weeks, and months as a family.

✓ To Do: Celebrate Your Baby

First things first: congratulations on your beautiful baby! Adding a precious child into your family is always cause for celebration.

Count her fingers and toes. Scan his face, looking for features that resemble mom, dad, and siblings. Delight in the sound of her squeaky cry. Dress him in that adorable outfit you had picked out for coming home from the hospital. Send photos to your family and friends. Soak it all in and fully inhabit this special moment in your life.

✕ To Don't: Stifle Sad Feelings

There are many emotions to process when you learn that your child has Down syndrome, and not all of them are happy. Joy, love, gratitude, sadness, and fear can and do co-exist, tangled up with one another in a messy heap of feelings. It is okay to feel all of them.

It is common to experience a sense of loss when your baby is born with a disability – and on top of that, to feel guilty about having any negative feelings. This is perfectly normal, and it does not mean that you don't love your child with your whole heart; nor does it mean that you and your baby do not have a wonderful life ahead of you.

Your journey will hold much joy, but it also may not be exactly what you had expected when you started out. There is a sadness in that realization which must be acknowledged in order to fully embrace the path that lies ahead. Take time, be gentle with yourself, and engage in whatever kind of self-care you find most healing.

✓ To Do: Learn About Down Syndrome

Here's some great news: there has never been a better time to have a child with Down syndrome. There is more information and support available today than there has been at any point in history.

When you are ready to dip your toes into the Down syndrome waters, there is a wealth of accessible information to help you understand Trisomy 21 and how it may impact your child. At the Down Syndrome Resource Foundation, we offer resources to help you at every stage of life, including videos, podcasts, articles, and a comprehensive information library. For a guided, self-paced introduction, you might consider our free online course, Down Syndrome 101. And of course, DSRF is just one source of information. The Canadian Down Syndrome Society and many other wonderful organizations in Canada and around the world also provide tremendous educational resources.

✕ To Don't: Attempt to Learn it All Right Away

With all this information at your fingertips, it may be tempting to immerse yourself in an effort to become an overnight expert in all things Down syndrome. We would caution against this.

Take it slow and steady. You don't need to know everything today. Down syndrome is a lifetime journey, and you can and should learn as you go. Focus on what matters most in your current stage of life: gaining an understanding of the basics of Down syndrome, and the health and development of children with Down syndrome (more on this below). Other things will come in due time.

It is important to maintain balance. Down syndrome is now a part of your life – but it is not your entire life. Keep it in perspective, and don't let it become your sole frame of reference.

Caregiver Conversations

Join us for our new four-part video series sharing real-life experiences and advice from caregivers in the Down syndrome community.

Watch the full series at
www.CDSS.ca/Community-Learning/

Canadian
Down Syndrome
Society

✓ To Do: Childhood Medical Screenings

Thanks to medical research, a better understanding of Down syndrome, and shifting societal norms, people with Down syndrome can expect to live longer, healthier, and happier lives than ever before. However, when a child with Down syndrome is born, his or her family is quickly introduced to a world of medical specialists, tests, and appointments that they may have never previously encountered. Those early days can be undeniably overwhelming.

Down syndrome can be accompanied by a variety of medical conditions, so it is important that you work with your pediatrician to complete all the recommended medical screenings for young children with Down syndrome.

In 2022, the American Academy of Pediatrics updated their pediatric health care guidelines for children and teens with Down syndrome. Hopefully your pediatrician is already familiar with these guidelines, but if not, be sure to draw their attention to this essential resource.

✗ To Don't: Google Every Possible Medical Complication

The list of medical issues that your child will be screened for is long. Do yourself a favour and resist the urge to google every potential medical complication associated with Down syndrome. That is a recipe for unnecessary stress.

While it's important to have everything checked, no child will have every comorbidity, and in most cases, the majority of them will not apply to your individual child. Stay on top of the necessary tests and take another deep breath. If the doctor identifies any concerns, that would be the appropriate time to begin investigating them.

✓ To Do: Take Prudent Financial Steps

There are some important financial matters to take care of early in the life of a child with Down syndrome. Chief among them is to apply for Canada's Disability Tax Credit.

The Disability Tax Credit is a non-refundable tax credit created by the federal government to assist people with disabilities and their families with the costs of having a disability or substantial impairment. It accomplishes this by reducing the amount of income tax the disabled person and/or their caregivers pay.

The application must be completed by a medical professional. In most cases, children with Down syndrome qualify for the credit, which provides a significant financial benefit to your family.

Another topic to explore is the Registered Disability Savings Plan (RDSP). Once your child has qualified for the Disability Tax Credit, they are also eligible to open a Registered Disability Savings Plan (RDSP). The RDSP is a Canada-wide registered matched savings plan specifically for people with disabilities. It is intended as a long-term savings plan (minimum of ten years), and the earlier you begin making contributions, the sooner your child will be able to benefit.

The government of Canada makes generous matching and standalone contributions to an individual's RDSP, allowing money to accumulate quickly. However, there are restrictions around when and how that money can be withdrawn, which are important to understand in order to determine whether the RDSP is the right financial tool for your loved one with Down syndrome. We recommend speaking with your financial planner about this.

✗ To Don't: Try to Predict the Future

When thinking about finances (or any other issue pertaining to your child, for that matter), don't make assumptions about what their future holds. Every day, people with Down syndrome are breaking down barriers and achieving things that others never thought possible.

Will your child engage in post-secondary education? Maybe, maybe not. Will he or she live independently, and be able to fully or partially provide for himself or herself as an adult? Perhaps, perhaps not. To whatever extent is possible for your family, it is prudent to plan for a range of possibilities, but don't prematurely close any doors on your child.

✓ To Do: Connect with Other Down Syndrome Families

Parents consistently say that connecting with others in the Down syndrome community is an essential source of support. Whether you're getting to know a family that is a little further up the Down syndrome road, or others who are at the same stage as you, there is great value in making this journey as part of a community.

A great way to meet other families is by plugging in to your local Down syndrome service organization or support group. There are also online Down syndrome communities, such as the Canadian DS Support-Awareness-Pride Facebook group, and many similar provincial and local groups.

✗ To Don't: Compare Your Child to Others

When getting together with others, be careful not to fall into the comparison trap. Whether or not the other children have Down syndrome, comparing your child's development to others is not helpful.

Every child develops at their own pace. Milestones are achieved at different rates, even amongst children with Down syndrome. Development is not a race; focus on the forward progress you are making and not the speed with which you are making it.

✓ To Do: Hold Your Expectations Loosely

Down syndrome is a curveball you likely were not expecting. But then again, no one's trip through life goes exactly as planned; it's how we respond that matters.

Just as with any child, some of your expectations as a parent will be met; some will not; and some will be surpassed in ways you can't even imagine yet. Don't cling tightly to expectations that are outside of your control, such as mastery of a particular skill, or the long-term achievement of independence. Instead, focus on what you have power over: providing your child with the support they need to thrive and become the very best version of themselves.

✗ To Don't: Put Pressure on Your Child – or Yourself

Down syndrome affects each person differently. There is no way to predict in advance what your child's strengths and challenges will be, or what they will achieve throughout life.

Some people with Down syndrome run marathons and star in Hollywood films. Others live independently, work in grocery stores, and get married. Still others require more support and live a meaningful and satisfying life that does not include paid employment, but is enriched by recreation and the love of family and friends.

And you know what? It's all good.

Keep dreaming big dreams for your child, but don't tie your value as a parent (or their worth as a person) to what they achieve. That's not what life is about for any of us.

Welcome to life with Down syndrome. I promise you, it's a fun ride.

WHAT DO YOU KNOW ABOUT DOWN SYNDROME?

Test Yourself!

By Sarah Caraher

If your baby has just received a diagnosis of Down syndrome, you likely have a lot of questions. While you're researching Down syndrome, you'll probably encounter several misconceptions about the future capabilities of your child along the way. It's important to understand what Down syndrome is—and isn't— so you can focus on loving and supporting your child. We have included some of the most important facts for new parents in this true or false exercise. Test yourself and learn what Down syndrome is really about!

True or False: Down syndrome is a disease.

False

Down syndrome is not a disease, disorder, or defect. It is a naturally occurring chromosomal arrangement that has always been a part of the human condition. The occurrence of Down syndrome is universal across racial and gender lines.

Unlike an illness, Down syndrome does not require treatment, prevention, or a cure. It is inaccurate and offensive to refer to people as "suffering from Down syndrome." While people with Down syndrome may go to speech or motor therapy, these are not treatments but simply activities that support development, like they would for any child.

True or False: There are different 'levels' of Down syndrome.

False

There are not varying degrees of having Down syndrome, you either have it or you don't. There are three types of Down syndrome - Trisomy 21, Translocation, and Mosaicism - but an individual's level of functioning is not determined by which type they have. The effects of the extra genetic material will be unique for each individual. Like everyone else, a person with Down syndrome will have their own strengths, likes, dislikes, talents, personality, and temperament. The extra genetic material from Down syndrome results in a developmental disability, but it is impossible to suggest the exact impact this will have on any individual. Down syndrome is just one part of who your child is; they will have their own distinct abilities and potential.

True or False: Down syndrome has no known cause.

True

Down syndrome is a randomly occurring condition that is estimated to affect approximately one in every 781 births in Canada. It has no known cause and nothing a parent did or did not do during pregnancy increases the chances of Down syndrome. In most cases, it is not hereditary. Of the three types of Down syndrome—Trisomy 21, Translocation, and Mosaicism—only Translocation can be inherited. Translocation accounts for just 2–3% of people who have Down syndrome, and within that small group, only about one-third inherit it from a parent.

True or False: People with Down syndrome are always happy.

False

People with Down syndrome experience a full range of emotions just like the general population. Potential issues with social isolation can even increase the likelihood of someone with Down syndrome experiencing anxiety or depression.

True or False: All children with Down syndrome will not be able to speak.

False

The majority of children with Down syndrome will be able to speak, however, it is important to note that some people with Down syndrome are non-verbal, some prefer to use visual aids like communication boards, and others may use an Augmentative and Alternative Communication (AAC) device. Speech pathology is also a common support for children with Down syndrome while they are developing their verbal communication skills. Speech therapy is one of several early intervention supports available to help your child reach their milestones at the pace that's right for them.

True or False: Adults with Down syndrome cannot live on their own.

False

Many adults with Down syndrome live on their own or with a roommate. Some adults with Down syndrome do need additional support for tasks such as meal planning and managing finances, but there are a variety of living arrangements available offering different levels of independence. Often adults with Down syndrome choose to continue living with their parents; however, this occurs for a variety of reasons: their parents are their primary caregivers, housing costs are too high, there are no appropriate housing options in their area, etc.

It is becoming increasingly common for young individuals with Down syndrome to focus on developing independent life skills like cooking, money management, and navigating transit, which will enable them to live on their own in the future. For example, CDSS Awareness Leader Paul Sawka built these skills before moving in with a supportive roommate in Calgary.

True or False: People with Down syndrome can participate in sports and fitness activities.

True

People with Down syndrome can absolutely play sports and engage in fitness activities like weight lifting, crossfit, and swimming. Misconceptions about people with Down syndrome not being able to swim or build muscle tone are incorrect. Participating in sports is often encouraged from a young age to help build muscle tone, which can be naturally lower in people with Down syndrome, and has even been proven to improve cognitive abilities like short term memory and decision-making. There are many accomplished athletes with Down syndrome including marathon runners, bodybuilders, and triathletes who continue to challenge outdated assumptions and redefine what's possible.

As with all physical activities, any person needs to consider pre-existing health conditions and fitness levels so as not to push themselves beyond what is safe.

True or False: People with Down syndrome can get married.

True

People with Down syndrome have desires and romantic aspirations like anyone else, and they can and do get married when they meet the right person. Across Canada and around the world, there are people with Down syndrome marrying neurotypical partners, partners who also have Down syndrome, and same-sex partners. You can learn more about romantic relationships in the Down syndrome community from the CDSS photo essay Love Means.

True or False: People with Down syndrome cannot have children.

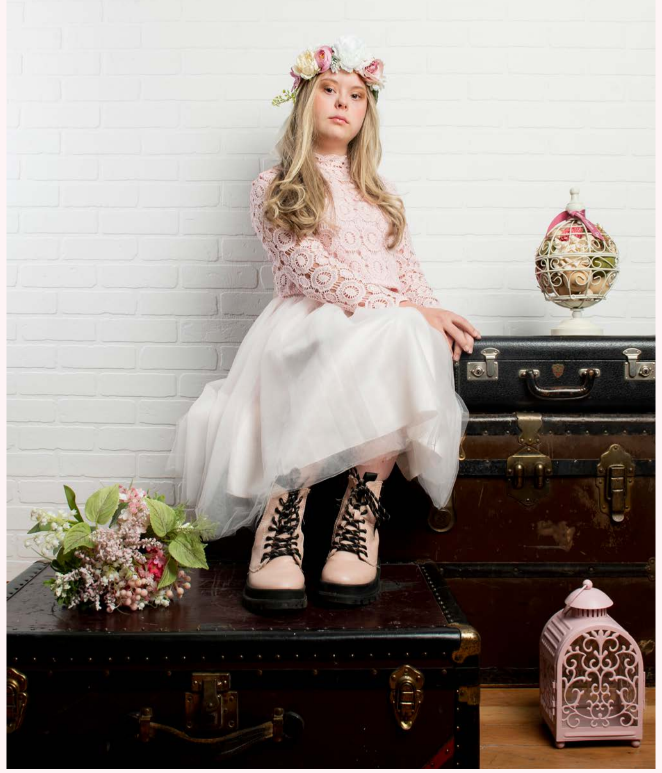
False

People with Down syndrome can have children, although fertility varies between individuals and can often present challenges. Approximately 50% of women with Down syndrome are able to have children with a 35–50% chance of passing the genetic condition on to their baby. Many men with Down syndrome have very low fertility rates, but can pursue fertility treatments and other options with their partner.

True or False: All people with Down syndrome have the same physical characteristics.

False

There are some physical features that many people associate with Down syndrome - such as having almond-shaped eyes, a short stature, or a small nose - however not all people with Down syndrome have these characteristics. Each person with Down syndrome is uniquely affected, including their physical characteristics.



True or False: Adults with Down syndrome can have a successful career.

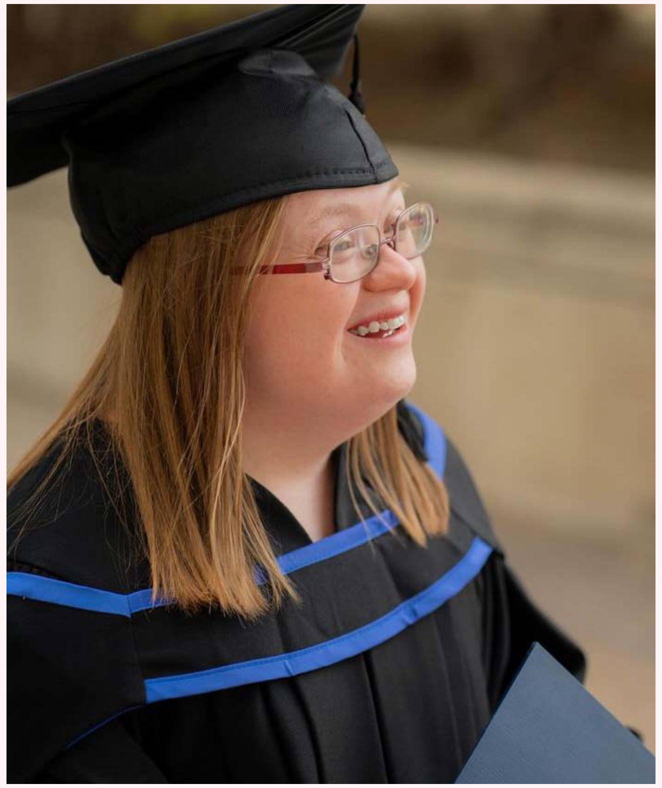
True

Adults with Down syndrome can have full-time jobs and build successful careers. Several Canadians with Down syndrome have reached international acclaim in fields such as human rights advocacy, fashion design, acting, and bodybuilding. One of the main reasons the unemployment rate for jobseekers in Canada with Down syndrome remains over 50% is because it is difficult to find paid, full-time opportunities. Organizations like CDSS and many others are actively working with Canadian employers to increase the number of job opportunities for Canadians with Down syndrome across the country.

True or False: People with Down syndrome can go to college and university.

True

An increasing number of universities and colleges offer inclusive post-secondary education programs which allow people with Down syndrome to work towards a diploma or degree. There are many examples of people with Down syndrome graduating and going on to work in their field of study, with these numbers trending upwards in recent years.



True or False: People with Down syndrome have an increased risk of certain health concerns.

True

Some conditions such as congenital heart defects and Alzheimer's disease are more common in people with Down syndrome than in the general population. Given the appropriate medical care and treatment, most individuals with Down syndrome can lead healthy lives. It's important to remember that not everyone with Down syndrome will experience these health concerns. Access to healthcare providers who understand the specific needs of people with Down syndrome is critical, but can be challenging in rural or remote areas of Canada.

True or False: If a person has Down syndrome, they cannot have another intellectual disability.

False

It is possible for people with Down syndrome to have another intellectual disability. In fact, 16% - 18% of individuals with Down syndrome have a dual diagnosis of Autism known as Down Syndrome Autism Spectrum Disorder, or DS-ASD. This is one example of the extensive overlap in the disability community which is why many advocacy efforts focus on shared goals, such as inclusive healthcare and support systems. If you suspect that your child may have both Down syndrome and Autism, it's important to consult with your local healthcare provider about an evaluation so that you can seek the proper support and early intervention programs.

> The most important truth: your child is not defined by their diagnosis. Like all children, they will have their own interests, strengths, and personality. Down syndrome is just one part of who they are!

GROWING AT THEIR OWN RHYTHM:

A Guide to Early Development in Down Syndrome

Understanding milestones, individuality, and the environments that shape children with Down syndrome — a warm and empowering guide for new families.

By Dr. Rudaina Banihani, MD, MMEd, Associate Professor, Department of Pediatrics, University of Toronto, Staff Neonatologist and Developmental Pediatrician, Director of Neonatal Follow-up Clinic, Department of Newborn & Developmental Pediatrics, DAN Women & Babies Program, Sunnybrook Health Sciences Centre

Welcoming Your Baby: The Start of a Beautiful Journey

Welcoming a baby with Down syndrome is the start of a rich and rewarding journey — one full of learning, connection, and discovery, not just for your child, but for you and your family too. In these early days, it's natural to wonder how your child will grow and what they might need. This guide shares what we know about early development and how everyday experiences can help your baby — and your family — thrive together.

What Are Developmental Milestones?

Developmental milestones are skills children reach around certain ages as they grow — like smiling, sitting, crawling, walking, and saying their first words.

Understanding how development unfolds in the early years can offer clarity and reassurance. More importantly, it helps shift the focus away from specific timelines and toward how a child is growing in areas like movement, communication, and social interaction.

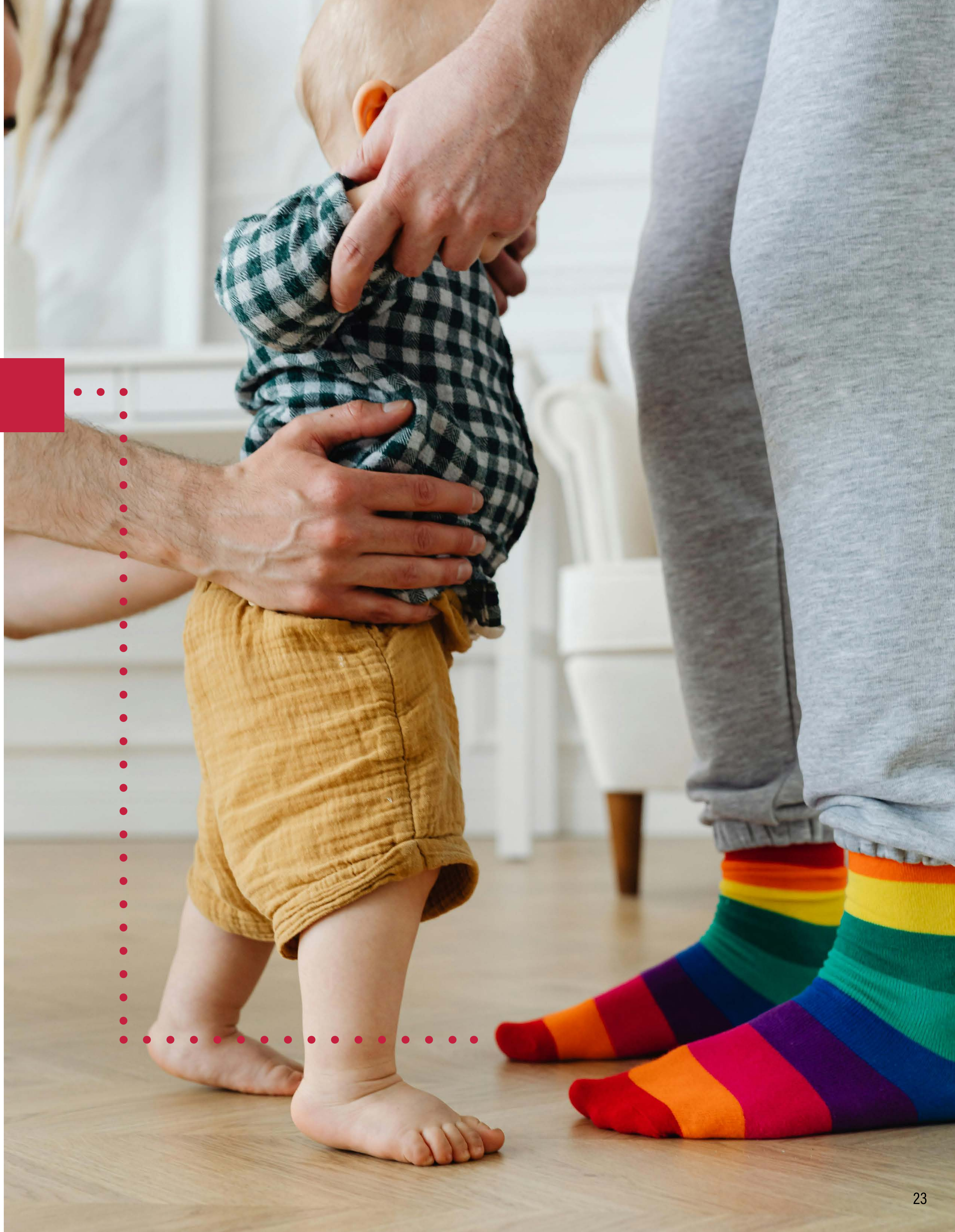
Every child's journey is unique. While many children reach milestones around similar ages, others move at their own pace. This is especially true for children with Down syndrome.

Children with Down syndrome go through the same stages of development as other children, but often on a timeline that's uniquely their own. Some milestones may take longer to appear, and that's expected. With the right support, your child will continue to develop and build new skills in their own time.

What to Expect: Similarities and Differences

Children with Down syndrome experience the same stages of development as other children, though the timing may differ. For example:

- Sitting independently may occur between 8 and 11 months (1).
- Walking often begins between 18 and 36 months (1).
- First words usually appear between 18 and 24 months (2).



Social and emotional development is often an early strength and tends to follow a similar timeline to other children. Many babies with Down syndrome enjoy interaction, respond to familiar voices, and form strong bonds with their family — sometimes even earlier than expected.

As with all children, development doesn't follow a straight path. It's shaped by a combination of factors, including health, environment, and individual differences.

Learning by Watching: How Your Child Engages with the World

Children with Down syndrome often learn best by observing first. They like to watch, take things in, and understand what's expected before they jump in. Sometimes this can be mistaken as hesitation or a lack of interest — but it's actually how many of them process and learn.

Children with Down syndrome

They notice patterns in routines, copy what others do, and respond well to gestures, pictures, and demonstrations. A child may seem quiet during a new activity, but over time, after watching others, they begin to join in — often with growing confidence.

Understanding this learning style helps you create opportunities that feel natural and supportive. Repeating songs, routines, or simple activities builds familiarity. Encouraging your child through play, reading, or outings — even just to the park or the grocery store — can spark engagement and language in ways that are both fun and meaningful.

Development is Dynamic: Understanding Variability and the Down Syndrome Phenotype

Children with Down syndrome often show a developmental profile that includes shared patterns across areas like movement, memory, language, and learning. For example, many have strengths in visual learning and social awareness, and differences in motor coordination, expressive speech, or short-term memory. Knowing about these patterns can help parents and professionals anticipate areas where support may be helpful.

But no two children grow in exactly the same way. Development is shaped not just by biology, but by a child's interests, temperament, health, and the environment around them. Even when children share similar needs, how they respond to experiences, routines, and learning opportunities can be very different.

This is why environment matters so much. A supportive and responsive setting — whether at home, in playgroups, or at school — helps children build skills over time. Consistent routines, visual supports, peer play, and plenty of interaction all play a role. These experiences help children feel included, understood, and ready to take part.

As *Down Syndrome Victoria* wisely notes: "What happens after birth will be far more important in shaping the outlook for any individual with Down syndrome than the presence of an extra chromosome."

The Role of Early Intervention

Early intervention refers to the support provided in the first years of life to help children develop skills in areas like movement, communication, and everyday activities. This is a key time for brain development, when small, consistent support can make a lasting difference.

For children with Down syndrome, early intervention often includes:

- Physiotherapy, to support motor development and coordination
- Occupational therapy, to encourage independence in daily tasks
- Speech and language therapy, to build early communication skills

The goal isn't to rush development, but to build skills and confidence in ways that support each child's unique strengths.

Communication: A Key Area to Support Early

Communication doesn't start with words — and it isn't limited to speech. We all communicate in different ways: through sounds, eye contact, gestures, and the way we respond to others. This is just as true for children with Down syndrome.

While spoken language may take time, communication starts much earlier. Your baby is already expressing themselves through eye contact, smiling, babbling, and gestures. Recognizing and responding to these early forms of communication sets the foundation for language to grow.

Parents play a key role in supporting early communication by reading together, talking through everyday routines, responding to their sounds, and using tools like baby sign language. What matters most is engagement — a shared rhythm of attention, response, and connection.

Celebrating Your Child's Journey

Development is not a race. Every milestone is a personal victory built through patience, repetition, and joy. Celebrate progress — not in comparison to others, but in recognition of how far your child has come.

Rethinking Milestones

Milestone charts can be helpful, but they don't define your child's potential. They're one reference point — not a finish line. When caregivers and professionals understand both the general patterns and the individual variability in development, they're better equipped to recognize strengths, notice emerging skills, and offer the right kind of support.

Above all, children with Down syndrome — like all children — thrive when they are seen, supported, and believed in.

Focusing on Strengths: The F-words for Child Development

The F-words — Function, Family, Fitness, Fun, Friends, and Future — offer a practical way to think about a child's development beyond milestones or checklists.

These six areas focus on everyday life: what a child can do, who they spend time with, how they move, what they enjoy, and how we can support their growth over time. It's a reminder that development is about more than skills — it's also about relationships, routines, and opportunities to take part.

References:

1. Canadian Down Syndrome Society. Milestone Timelines for Children with Down Syndrome. https://cdss.ca
2. Fidler DJ, Most DE, Philofsky A. The Down syndrome behavioural phenotype. Down Syndrome Res Pract. 2009;12(3):37–44.
3. National Down Syndrome Society. Early Intervention and Education. https://www.ndss.org
4. National Down Syndrome Society. Autism Spectrum Disorder and Down Syndrome. https://www.ndss.org/resources/autism-spectrum-disorder-and-down-syndrome/
5. Rosenbaum P, Gorter JW. The 'F-words' in childhood disability. Disabil Rehabil. 2012;34(17):1554-1560.
6. Baumer N, et al. Developmental Milestones for Children With Down Syndrome. Pediatrics. 2024;154(4):e2023065402.
7. Bull MJ. Developmental milestones for children with Down syndrome. Pediatrics. 2024;154(4):e2024067475.
8. Rosenbaum PL, Imms C, Miller L, et al. Perspectives in childhood-onset disabilities. Disabil Rehabil. 2024. doi:10.1080/09638288.2024.2394647.
9. Down Syndrome Victoria. What do you know about Down syndrome? 2008.

If I Knew Then What I Know Now: Parent Q&A

Joyce

(Mom to Holly, age 10), Comox, BC

What do you wish you knew about Down syndrome when you were first starting out?
That there are wonderful communities made up of families who love someone with Down syndrome in so many cities across the country who would welcome us without question, where we could connect with others with families like ours. And that raising a child with Down syndrome opens so many opportunities we wouldn't have been a part of otherwise.

What really helped you in your first year as a parent to a child with Down syndrome?
Treating her like any other baby. Presuming competency, and modifying our parenting approach to meet our baby's needs, as required.

What was the best piece of advice you received as a new parent?
When you're giving a medical history, which you'll do often, remember to tell them she has Down syndrome - it's surprising how often you'll forget that tidbit. (And I learned just how true that was.)

Raelyn

(Mom to Brooklyn, age 2), Wyoming, ON

What do you wish you knew about Down syndrome when you were first starting out?
I wish I knew how lucky we were to have a baby with Down syndrome. I wish I knew Down syndrome is not the worst thing your child can have and that there are millions of diagnoses out there and millions of disorders out there and millions of other things that any potential child could have and to not worry about the small things. I wish I knew the family support from our "lucky few " family would be the strongest support group ever. I wish I knew that I would become the voice for my little girl and I wish I knew how much strength she would give me to be her biggest advocate. I wish I knew how much love I would have as soon as I saw her because if I knew all of that, I would not have worried so much.

What really helped you in your first year as a parent to a child with Down syndrome?
What helped me the most is connecting with people that I had reached out to on social media groups. I made a couple really good friends and it was nice to share feelings and thoughts and fears and victories and tears and laughs and smiles. I wish I knew that we would make it to a year and look back and think "What was I so worried about?" I wish I knew just how much joy and love my little girl brings to everybody she meets. She is the light in our lives. And I enjoy helping others, seeing the light and the positivity that she brings. And what helps me the most is trying to educate others to see our kiddos as just that - who they are, not what they're diagnosed with. I never want her to be defined by her diagnosis because yes, it's part of who she is, but it is not who she is at the same time

I wish I knew how much stronger I would become as a mom in this first year and I wish I knew how lucky we really are to have her.

What was the best piece of advice you received as a new parent?
The best piece of advice that I received as a new parent to a baby with Down syndrome was to stop overthinking it and just enjoy your baby for what they are - a newborn baby. Stop labelling everything as Down syndrome or related to Down syndrome. Yes, she has Down syndrome, but she's not defined by it, so just enjoy every single moment. Try not to be too consumed by the rest because everything works out and those little newborn moments go by so fast.

Vito

(Dad to Gianpaul, age 14), Etobicoke, ON

What was the best piece of advice you received as a new parent?
To take it one day at a time, enjoy and learn from each day. No matter how challenging that day can be, it is only one day.

What do you wish you knew about Down syndrome when you were first starting out?

At first I thought having a child with Down syndrome meant giving more than I could give. Not true!

I learned to look at life in a whole new perspective. No matter how busy, stressed, or tired I may be, seeing the smile, getting the affection and love from my son changes everything instantly. A child with Down syndrome has the gift to change the world as we see it to a more simple, loving, gracious one.

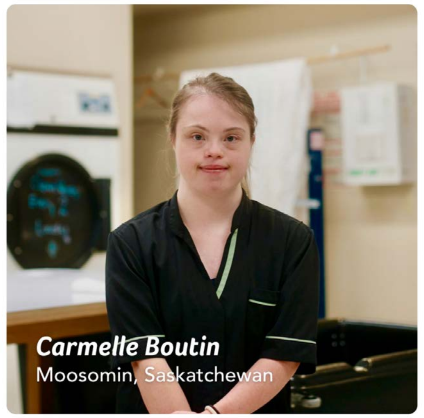
What really helped you in your first year as a parent to a child with Down syndrome?
My wife really embraced the gift we were given and took the lead in learning and understanding about Down syndrome and the Down syndrome community. In doing so, we met and talked to many parents and families who had a child with Down syndrome. The more we communicated and got involved, the more we felt at ease.

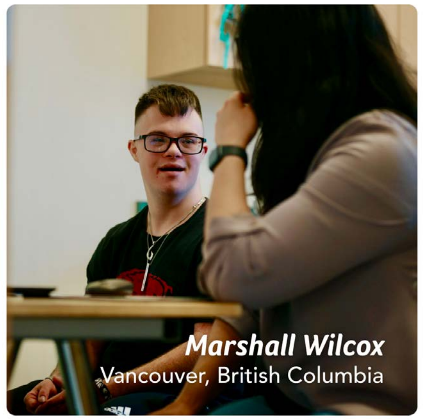
CDSS SPOTLIGHT

Introducing Unified Voices: Part 1, A Canadian Documentary from Director Moses Latigo Odida & CDSS

We are very proud to present Unified Voices: Part 1, a Canadian documentary that explores the lives of Canadians with Down syndrome and their experiences living in vastly different communities across the country. This federally funded short film is in celebration of National AccessAbility Week and highlights the diverse tapestry that is the Down syndrome community.

In Unified Voices: Part 1, Director Moses Latigo Odida introduces us to three Canadians, their communities, and their unique challenges and triumphs with education, employment, and social inclusion.


Carmelle Boutin
Moosomin, Saskatchewan


Marshall Wilcox
Vancouver, British Columbia


Élisabeth Faucher
Sherbrooke, Québec

Carmelle Boutin
At 25 years old, Carmelle finds strength in her resourceful nature and the supportive atmosphere of her rural Saskatchewan town. Working at a local hotel and a resource center for people with different abilities, she benefits from a community that truly cares about her well-being.

Marshall Wilcox
Marshall, soon turning 20, resides in the bustling city of Vancouver and loves basketball. He cherishes his interactions at the Down Syndrome Resource Foundation, which offers enriching programs like human sexuality training. Despite familial love, Marshall yearns for a deep friendship.

Elisabeth
Élisabeth is in her 30s and living in a group home in her small town of Sherbrooke, Québec. She balances work at a university with her passion for chocolate-making and knitting. The Down Syndrome Association in Sherbrooke further enriches her life with essential life skills navigating life's challenges.

"During production for this project, one major theme I identified is that we are best positioned to overcome the challenges we face through community. This is as true in big cities like Vancouver B.C. as it is in small towns like Moosomin, Saskatchewan, or in French-speaking Sherbrooke Quebec. Our joys and challenges are either magnified or diminished depending on our proximity to community."
- Moses Latigo Odida, Director and parent of a child with Down syndrome.

We invite you to watch part one at UnifiedVoices.ca today!

Down Syndrome WALK

Thank you to everyone who has supported the Down Syndrome Walk so far! Hundreds of donations from across the country have come in and we hope to reach our biggest goal yet of $35,000 before the walk ends on June 14th. Now more than ever, people with Down syndrome need to be heard and given equal access to basic rights like education, employment, and healthcare.

You can visit DownSyndromeWalk.ca to see our Team Leaderboard and total donations for this year's walk! We appreciate your continued support as we work towards an inclusive future for Canadians.

Canadian Down Syndrome Society | Société canadienne de la trisomie 21


Caregiver Conversations

Join us for our new four-part video series sharing real-life experiences and advice from caregivers in the Down syndrome community.

Watch the full series at
www.CDSS.ca/Community-Learning/

CAREGIVER CONVERSATIONS NOW AVAILABLE!

Take a look into the lives of four caregivers in the Down syndrome community and learn from their experiences looking after a loved one. What is one thing you wish you had started earlier, how did you learn to navigate the advocacy system, and how do you fight caregiver burnout are just a few of the topics we explore together.

Watch all four episodes of the series at https://cdss.ca/community-learning/

JOIN OUR COMMUNITY

FIND US / TAG US

@CdnDownSyndrome on all our platforms

CDSS.ca

DSRF CORNER

DSRF Students Call on Federal Government to Strengthen the Canada Disability Benefit

This year's World Down Syndrome Day theme was, "Improve our Supports." In this spirit, DSRF's Speaking Out class produced a video urging the Canadian government to strengthen the Canada Disability Benefit to lift people with Down syndrome and other disabilities out of poverty.

As Jason says in the video, "We have lots of hopes and dreams for our futures. We think the Canadian government and Prime Minister could help us better by giving us more money. We deserve more than $200 per month!"

Click here to watch the video, and please join us in calling on the government to #BetterTheBenefit.

Kindred Spirits: Chronicles of Down Syndrome Friendship

Each year, the Down Syndrome Resource Foundation releases a short film on a topic related to Down syndrome. In these films, we share the lived experiences of people with Down syndrome and their families, along with expertise from DSRF's team of professional Down syndrome specialists.

Our latest film was released in March. *Kindred Spirits: Chronicles of Down Syndrome Friendship* celebrates the special friendships that people with Down syndrome form with one another. Four groups of adults and teens 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 features motion graphics created by Joseph Woloshyn, a young artist with Down syndrome, with compositing by Jennifer Danvers. This is the fourth DSRF film to which Joseph has lent his talents. We are so grateful for his awesome contributions. Special thanks to his dad Bruce, as well!

Kindred Spirits was recently featured at the 3rd Annual Down Syndrome Film Festival in Vancouver, and can be viewed for free on DSRF's website and YouTube channel.

Hope Restored

Heading into her teen years, Rebecca was thriving. She was curious and socially engaged, displaying a spunky dimension to her personality that endeared her to everyone around her.

In her early teens, Rebecca was losing hair due to alopecia, and one morning she screamed at her reflection in the mirror. She rapidly became withdrawn and disengaged, losing previously mastered skills. She retreated into a private fantasy world, which morphed into full-blown psychosis. She lost her spirit, and her personal and intellectual development stalled.

Over the next few years, Rebecca and her mom Jane received support from DSRF's mental wellness team. DSRF staff sent Rebecca's psychiatric team information about Down Syndrome Regression Disorder, and thanks to this intervention, the psychiatric team was able to give Rebecca the correct diagnosis and prescribe the right course of psychiatric meds.

DSRF staff helped Rebecca re-engage and rediscover many of the skills she had lost, while also helping her parents cope with the changes their daughter had experienced. Today, the light is back in Rebecca's eyes and her saucy side is re-emerging. Her family's hope for Rebecca's bright future has been restored.

Learn more about DSRF's mental wellness services for people with Down syndrome and their families at DSRF.org/MentalWellness.

DSRF's 30th Anniversary Triple-21 30-for-30 Challenge

Celebrate 30 years of DSRF by securing a brighter future for people with Down syndrome!

Join us in our 30th year by becoming one of 30 new Triple-21 partners. Your monthly gift of $21, $32, $121, $210, or an amount of your choice will help individuals with Down syndrome flourish for years to come. Plus, 21% of your support will provide financial aid to families in need, ensuring that no one is left behind. Be part of this milestone—make your impact today!

Partner Benefits:

- 21% off tickets to DSRF's annual December holiday breakfast
- FREE 3.21 Magazine subscription (e-version)
- FREE Down Syndrome Academy subscription ($100 annual value)

Email shelley@dsrf.org for more details.

Down Syndrome
Resource Foundation

FRIENDS OF DSRF

We are so thrilled at the overwhelming success of our World Down Syndrome Day 3-2-1 Challenge, which raised over $12,000 for mental wellness support for people with Down syndrome - a new record for this campaign. This includes a $3,210 matching gift from the BC Maritime Employers Association. Thank you to BCMEA and everyone else who generously supported this campaign.

Run Up for Down Syndrome took place on June 1 at Burnaby's Swangard Stadium. Thank you to all the participants and supporters who made BC's biggest annual Down syndrome event a huge success once again! Special thanks to presenting sponsor Upper Canada Forest Products, t-shirt sponsor LiUNA Local 1611, media sponsor CTV, and event sponsors the BC Maritime Employers Association, Beedie, Mott Electric, RBC, and Starbucks.

The Ames Family Foundation has granted DSRF $25,000 in support of various initiatives including Baskets of Love, summer camp programs for children, youth and adults, and production of our next short film. We are so grateful for the Foundation's ongoing support.

Social Venture Partners has granted DSRF $850 for professional development. SVP is a valued long-term partner and we appreciate their investment.

UPCOMING AT DSRF

The LowDOWN: A Down Syndrome Podcast (Season 11 premiere): ***Sept 3, 2025***

Up the Down Market Vancouver: ***Sept 18, 2025***

Up the Down Market Calgary: ***Oct 16, 2025***

Up the Down Market Toronto: ***Nov 5, 2025***

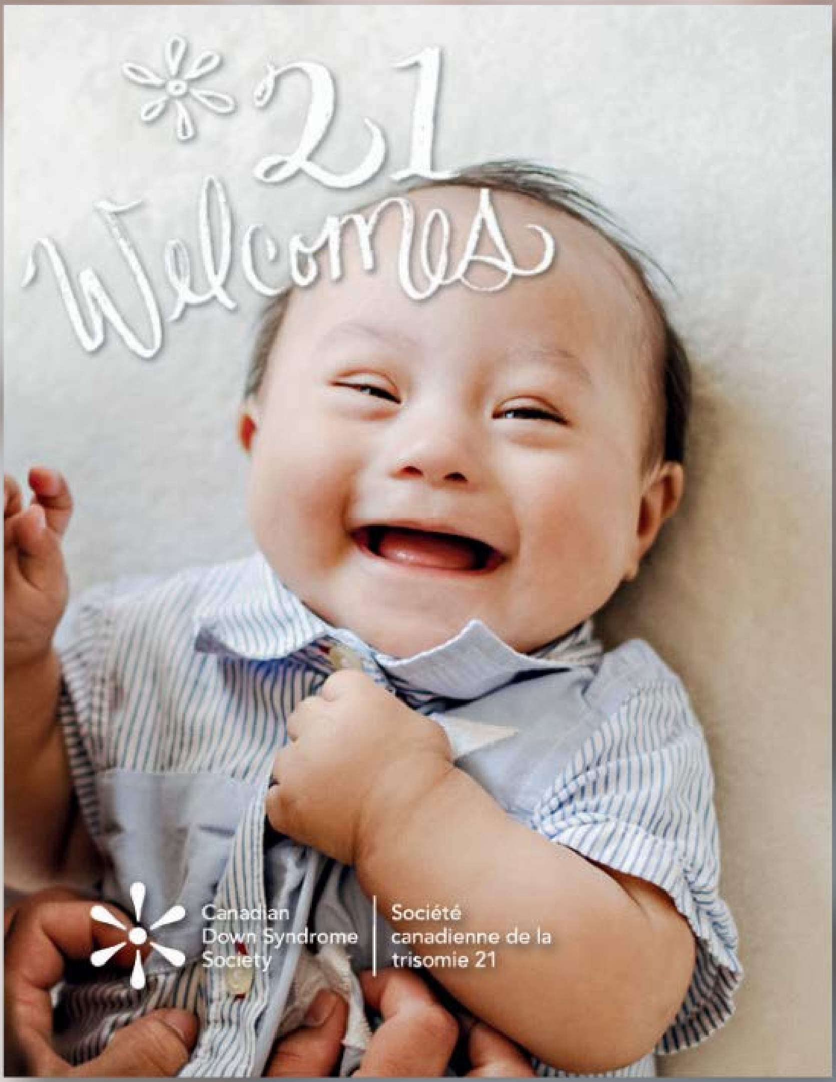
FIND US / TAG US

@DSRFCanada on all our platforms

DSRF.org

Canada's Guide for New Parents in the Down Syndrome Community

Feel supported right from the start of your journey with advice from parents, messages from self-advocates, and essential information about feeding, early interventions, and more.



Available for free in English and French at
www.CDSS.ca/Resources/New-Parents/