

3.21
Canada's
Down Syndrome
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Summer 2021
ISSUE #7

Q&A:
*Puberty,
Relationships
and Sexuality*

TEEN TALK:
*Advice for
Today's
Teens*

**Building
Entrepreneurial
Skills into
Everyday Life**

**TEENS IN
FANTASYLAND:**
*When Imaginations
Get Carried Away*

The **Teen Issue**

Plus: *GROWING UP: An Interview with Aaron Waddingham*



"I remember when I was a teen, I did make some mistakes. Some things I had to learn the hard way, but they were good life lessons I had to learn by myself." - Alana, Edmonton

As Alana so astutely points out, teenagehood is a time of learning and growth. We score some wins, make some mistakes, experience independence, discover ourselves, and explore our world. And that's exactly what we'll do here in the Summer 2021 issue of **3.21: Canada's Down Syndrome Magazine** – explore the world of teenagers with Down syndrome. Welcome to our first ever **Teen Issue!**

In these pages we'll meet a remarkable young entrepreneur and a budding actor. We'll hear from teens and adults as they share the lessons they learned growing up. We'll learn how to help teens separate fantasy from reality and answer your burning questions on the topics of relationships, puberty, and sexuality.

Though the teen years may seem daunting, adolescence can be one of the most exciting and rewarding times of life. As editors we discovered so much information about the teen years when putting this issue together – we hope you make some new discoveries too.

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

Kristen Halpen
Marketing & Communications Manager
Canadian Down Syndrome Society

Glen Hoos
Director of Communications
Down Syndrome Resource Foundation



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Cover Photo: Aryta Persaud
Design & Layout: Curve Communications Group



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LIKE IT'S YOUR BUSINESS:

BUILDING ENTREPRENEURIAL SKILLS
INTO EVERYDAY LIFE

by Adelle Purdham

I'M BOSS LADY.

Anasuya Sarma, a fifteen-year-old with Down syndrome who goes by Anu, has much to celebrate. This past year, she was hired for a Rogers commercial set to air shortly, and her artwork, a beautiful waterfall painting, was commissioned by a Ryerson University gallery.

Now, Anu is riding high from the recent launch of her latest project, an entrepreneurial enterprise called Lovebirds by Anu. Anu has been called a 'lovebird' as a term of endearment since she was born. She created the business with the help of her mom, Aryta Persaud, a former corporate businesswoman who changed career paths to pursue teaching following her daughter's birth.

Lovebirds began as a single-product business. The Indian-inspired lip balms, reflective of Anu's South Asian roots, come in a pouch with three tropical flavours: guava, cardamom and mango.

"It's soft. Put it on your lips, like a shiny sun. Smells like summer and spring," says Anu.

Customers receive the lip balm trio in a pouch assembled by Anu for only \$10. When

asked how many pouches she thinks she'll sell, Anu's reply is confident. "Like, 400."

On launch day, Lovebirds sold out of stock within a few hours, and has a long waiting list of orders. "We're completely overwhelmed by the support," says Aryta. Customers are impressed by Anu and vocal about wanting to support a young female entrepreneur.

Anu has plans to experiment with new flavours, perhaps chai, candy cane or lychee. She would also like to one day bake something as a business, "like cakes" she says, "or ice cream. But not hard ice cream—gelato."

With her outgoing personality, winning charm, and drive, Anu is likely to sell many more than 400 pouches—but that isn't the point of the business, according to Anu's mom. In her more than fourteen years of teaching business classes, Aryta has seen students from all walks of life—students who may not traditionally be considered high academic achievers—thrive and feel a sense of pride when given the opportunity to run something on their own.

Executing a business boosts self-confidence, but it also helps students develop tangible skills. Aryta's high school business students work on communication skills, collaboration skills, teamwork skills, negotiating, and perseverance. They must write, type, create, and present, as well as master the art of small talk, and the elevator pitch.

"These are all the same things that Anu needs to learn, just at a different level," says Aryta. Creating Lovebirds with Anu gave Aryta an authentic reason to be working on these skills at home with her daughter.

Aryta runs a special program in her school with her grade 12 business students that culminates in a TED Talks-style conference with invited speakers, and focuses on kindness, social justice, and social entrepreneurship. Students are required to create business plans and run events tied to the curriculum leading up to and during what she calls 'Kindness Week,' with an underlying theme of mental health. What makes the program unique is that many of the events involve a partnership between Aryta's business students and the students in the Developmental Disabilities (DD) program.

Some of Aryta's former students, now in their thirties, have come back to her and said that interacting with someone with a disability through her classes was one of the best experiences

they've ever had. "It takes that scary feeling or that stigma away," explains Aryta. "Also, because they're grade 12, the 'big man on campus,' the younger students in the school see that it's okay."

While her students learn how to run an event, they're also learning how to be inclusive. The spirit of collaboration and teamwork is in the details, from matching t-shirts to choreographed dances. High schoolers from both classrooms run events together, carrying out tasks such as collecting money at a photo booth during a Halloween dance, or even organizing puppy therapy.

As an educator, Aryta explains, "It's a question of being creative. How can I make inclusion a priority? It takes a bit of time to think it through, but there is always a way."

A zest for entrepreneurship runs in the family. Aryta and her husband Raj both have experience in the corporate world. Anu's older brother, Satya Sarma, created an app, 'My New Friend,' designed to help kids with disabilities find friends and set up playdates in their neighbourhood. Satya saw that his sister was sometimes lonely and wanted to make a difference. His app landed him in a commercial, and when he pitched the idea, Anu was there—as was a representative from Microsoft who asked her if she'd use her brother's app. She said, "Of course!"

But Aryta points out, "I think the entrepreneurial spirit is there in all our kids. They can always find something that they're able to monetize somehow."

Parents seeking business ideas for their child should ask themselves: What is my child naturally good at? What are they drawn to? What do they like to do?

"Anything these days can be turned into a business," Aryta points out. Anu has keen business acumen. Her family helped her set up a classic lemonade stand on their driveway. "I've never seen a kid get \$10 for a glass of lemonade before," says Aryta with a smile.

Anu is also an expressive drama queen. Her parents knew she had it in her to perform and be the centre of attention. She likes to play teacher and show everyone what to do.

Last year, Aryta ran a fashion show at her high school to promote inclusion and body positivity, and Anu was one of the models. After that experience, Anu adopted the attitude of 'Look at me, I'm famous!' and that is when Aryta and Raj began submitting her photos for acting.

When it came time for casting calls, Anu was at ease. "Anu sees this as normal," says Aryta. "This is just what we do." Including Anu in all aspects of family life and exposing her to a variety of experiences has helped prepare her for opportunities in business and employment.

Anu herself has no interest in submitting to casting agencies. "I'm basically her secretary," says Aryta. It wasn't that Anu explicitly said she wanted to be in a commercial, but her parents were seeing her personality and thought that might be something for her. After her experience working with Rogers, Anu regularly asks when she can do another one.

The exposure to different experiences led to employment and Anu's first paycheck. Traditionally in her culture, the first paycheck goes to a parent or grandparent. When Anu decided to bring it to her grandfather and ask him to open it, Aryta was in tears. Anu just shook her head in typical teenager fashion. "Mom! So random."

Anu's interest in art developed in a similarly organic way. Following Saturday morning art lessons where she learned to draw with crayons, pencil crayons, and use watercolours, Anu received an easel and paints for her birthday. She began experimenting by following step-by-step YouTube instructional videos.

Aryta posted one of Anu's paintings, a waterfall, to social media, and reminiscent of **The Hiring Chain** phenomenon, where one person sees the abilities of an individual with Down syndrome and the message spreads from there, a former business student of



Aryta's organized Bodies in the Balance, an online art gallery dedicated to providing a platform for chronically ill, disabled, immunosuppressed and immunocompromised individuals. After seeing Aryta's photo of Anu's painting on social media, Anu received an official invitation from Aryta's former student (who had partnered with disabled students in Aryta's classroom) to the online gallery that included a stipend for her work, as well as the title of Ryerson University artist.

Starting a Business

When it comes to organizing a business, Aryta suggests starting small. What is manageable for you and your VIP? From there, break down tasks into steps and prepare beforehand. Give yourself extra time.

Aryta incorporated entrepreneurial skills into Anu's every day life. She turned Anu's interest in planning her outfits and lunches for the week into a lesson in how to use a spreadsheet. Now Anu knows how to input her orders for Lovebirds into Excel, "and when she's adding the numbers of how much money she made, it's more meaningful to her."

To create opportunities for a child to succeed, use their language. For example, in Anu's Lovebirds spreadsheet, "sales revenue," which is a big fancy term, becomes "how much money?" "Quantity" is labelled, "how many?" That is Anu's language. It's a question of making the terms specific to the individual. These are the same concepts grade 11 entrepreneurship students are learning, just explained differently.

Anu and Aryta also practised how to write in a Word document and prepare a PowerPoint presentation. Currently as a grade eight student, Anu gives oral presentations about her weekend every Monday.

To run a business successfully, an individual needs to know how to talk to people and make small talk, as well as how to follow directions. Aryta created conversation starters for Anu to rehearse at home. She breaks down larger chunks of information into manageable bits. Additional skills such as how to write things down, keep a list, prioritize, keep a schedule, and plan are important not just for running a business, but for living a full life. With Lovebirds, reading a script is part of Anu's sales pitch to neighbours and friends, and in learning to memorize and practice her lines, she's improving her memory and developing perseverance.

Whether or not your family wants to start your own company with your loved one with Down syndrome, developing the skills necessary to run a business overlap with the qualities of becoming a good employee. According to Ingrid Muschta

from the Ontario Disability Employment network (ODEN), "Employers are looking for the same things they are looking for in other employees: dependability, reliability, and motivation. It's not the hard skills, but rather the soft skills—any employer will train an employee on the technical parts of the job, but no employer is capable of teaching an employee to be motivated. Motivation comes from within and with years of developing that skill, and starts way, way early—before leaving elementary school."

Traditional education and rote learning is out of fashion these days. Kids want to know, what can I get from this? How is this going to help me later in life? "That is where Lovebirds came from," Aryta explains. "This will help her in life." Maybe Anu will never sell lip balm again, but she knows how to input data into Excel. She knows how to make a presentation. She has acquired transferable skills. The idea of Lovebirds was to give Anu something of her own in which she could feel a sense of pride, confidence, and ownership; to tap into areas that are not necessarily academic and give her many more topics of conversation to bring into the world.

One thing that will never go out of style is kindness, and promoting inclusion in the classroom and beyond, out into the community. "It's quite popular," Aryta acknowledges of her classes, which are usually full.

When asked if she thinks that other people with Down syndrome should start their own businesses, Anu's answer is firm and resolute.

"Oh yeah," she says. "Definitely."



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TEENS IN *Fantasyland*

***WHEN IMAGINATIONS
GET CARRIED AWAY***

By Susan Fawcett, PhD, RSLP



Selena Gomez is my girlfriend.” “Shawn Mendes is my brother.” “I did a triple backflip on my skateboard yesterday.” “I’m moving to Miami to party and live in an apartment by myself.”

The teachers and therapists at the Down Syndrome Resource Foundation are regaled with tall tales on the regular. Since we all have dreams, aspirations, and goals – many of which never come to fruition – parents may struggle with striking a healthy balance between encouragement of dreams and what is realistically attainable for their teenagers with Down syndrome. Along a similar vein, parents often have concerns about teenagers who become too absorbed in the fantasy world associated with their favourite movies and TV shows.

WHAT IS “FANTASYLAND” AND WHY DOES THIS HAPPEN IN PEOPLE WITH DOWN SYNDROME?

Teenagers and young adults (and even sometimes older adults) with Down syndrome have a strong tendency to become enmeshed in fantasy worlds. For example, they may repeatedly watch certain scenes from favourite movies and

then act them out, report that they know or are friends with certain celebrities, or participate in role play and/or self-talk alone in their rooms.

Experts in the field of mental health in people with Down syndrome have proposed that this development of a rich fantasy life may stem from their relative strength in visual memory (McGuire & Chicoine, 2006). In addition, the crossover between reality and fantasy may be developmentally appropriate for teens and adults with Down syndrome (for example, something akin to younger children’s belief in the tooth fairy). The authors point out this blurring of lines between reality and fantasy is not likely to indicate psychosis, which is a serious mental health diagnosis involving a person’s compromised relationship with reality. Psychosis, symptoms of which include hallucinations and delusions, is rare in individuals with Down syndrome.

Getting lost in fantasyland may be more likely when a teen is bored, or not given the right level of challenge at school. During the current pandemic, there may be an even higher risk due to teens’ lighter schedules, or a feeling of anxiety or

sadness. How often do we all turn to the comfort and escape provided by TV when we feel this way?

Another possibility is that fantasy life may simply be the more enjoyable alternative for teens with Down syndrome much of the time. By the time they are teenagers, there is a large gap in the abilities of people with Down syndrome and their typically-developing peers. By this time, they may no longer have common interests with these peers, and may not be able to keep up in conversations. Meaningful social relationships may dwindle as a result. At this point, imagination, fuelled by movie characters, pop stars, and social media celebrities can take over.

This foray into fantasyland is likely also at play when we hear teenagers with Down syndrome express goals and dreams that are unrealistic. Having high expectations for people with Down syndrome is a good thing, and we all have dreams and goals that help us stay engaged and motivated. However, teens with Down syndrome often cling to aspirations that are not realistic or attainable. For example, they may express that they would like to marry Harry Styles or Mickey Mouse, or that they'd like to have jobs that may not be realistic for a person with an intellectual disability, such as being a teacher or an astronaut.

Because we are caring people who are genuinely interested in what teens with Down syndrome have to say, parents, teachers, and therapists tend to smile, laugh, or express surprise when these fanciful ideas are communicated. At first, we may think these are cute or creative, and we inadvertently reinforce these wishful expressions. We often ask questions about these unrealistic dreams, because they are interesting, and because the teen seems passionate about them. All of this teaches the teen that expressing these wishes gets plenty of attention from adults. Too late, we start telling them, "That's not going to happen!" By this time, the teens often have their hearts set, and we know how difficult it can be for people with Down syndrome to break free from ingrained interests and patterns of behaviour.

WHAT BEHAVIOURAL CHANGES SHOULD I WATCH OUT FOR?

There may be several symptoms or warning signs that your teen may be pulled too far into fantasyland. These include:

- Spending increasing amounts of time alone (e.g., in room at home), especially if engaged in self talk, repetitive role play, or spending time on screens
- Getting "stuck" on particular movies, or specific movie scenes
- The fantasy world interferes with the teen's participation in the regular routines of life; i.e., it's hard to redirect your teen back to usual activities
- Appearing to have full back and forth conversations with imaginary others; especially if these take the place of real interactions
- Expressing that they know or interact with celebrities; e.g., that a particular celebrity is their boyfriend or girlfriend

This is now an even more pronounced issue given the popularity of social media. Teens may have the perception that they really do know celebrities, given how often some of them post updates and videos, and the minute details of their daily lives that are shared. TikTok and YouTube videos are typically done in a conversational manner, including greetings (we have heard students at DSRF respond verbally to these greetings – "Hey! I'm good!"). In addition, teens may comment on posts, further encouraging the feeling of having genuine interactions. Most of us recognize that this is not a meaningful relationship, but this may be a very difficult distinction for teens with Down syndrome to make. The take-home message: closely monitor your teen's social media use!

WHAT STRATEGIES CAN I USE TO HELP MY TEENAGER WITH DOWN SYNDROME STAY CLEAR OF FANTASYLAND?

- Try to encourage your teen to engage in a variety of activities on a day-to-day basis. While routine is preferred and adaptive to a degree in people with Down syndrome, we also want to build in experiential diversity and flexibility. Help your teen choose a few items to do each day from a list of fun, educational, or physical activities, especially ones that involve interacting with others. You can compile this list of activity choices together!
- Limit time spent alone in their room, especially if screens are involved. Screen time is particularly problematic if the teenager is watching shows that include violence. And watch out for soap operas – they can be particularly troublesome (see sidebar).
- Keep in mind that while untrue statements like, "I went on a date with Justin Bieber" might sound like lies, the person with Down syndrome may fully believe these are true or real scenarios. Telling the person not to lie may carry little meaning, and disciplinary consequences for "lying" will likely be ineffective. If you contradict your teen, the most probable resulting scenario is that the two of you will be pulled into a disagreement or argument, which rarely has the outcome you were looking for. Don't draw undue attention to these statements: in most cases, the best course of action is to ignore the comment and change the topic.
- Teach your teen about real vs pretend, fiction/story vs non-fiction. This may not occur to parents as something that needs to be explicitly taught, as they may not have had to do this with typically-developing siblings. Try these activities to demonstrate the concept:
 - Outline all the differences between a real house and a dollhouse, as many teens will have played with a dollhouse when they were younger and this is a highly familiar concept overall
 - Show photos of an actor beside the character she or he plays in a movie, and discuss their differences. This may enhance their understanding that the person is playing a role, and that the character/show is not the same as real life
 - Ask a therapist or teacher for a "real vs pretend checklist"
- Ensure your teen with Down syndrome has regular, meaningful interactions with at least one friend who is at or near their developmental level. This will usually mean a teen who also has a developmental disability. Think about

how you would feel about only hanging out with people who you could not keep pace with intellectually. Your self-esteem would suffer, and you might also be tempted to look for escape from the situation, and/or alternative ways to spend your time.

WHAT STRATEGIES CAN I USE TO HELP MYTEENAGER WITH DOWN SYNDROME HAVE MORE REALISTIC DREAMS AND LIFE GOALS?

- Remind yourself that almost everyone has dreams that do not become full reality (otherwise, I would have enjoyed a stint as a professional ballerina!). It is a healthy developmental process.
- If you hear your teen persistently express an unrealistic goal, it is important not to inadvertently encourage this by laughing or asking the teen questions that lead them further down the path of fantasy, entertaining though answers to these may be (e.g., "Who will be your bridesmaids when you marry Mickey Mouse?"). Instead, try the following sequence:
 - First, model back any part of the teen's dream that may be attainable. "It sounds like you really want to get married / live on your own / make some good money!"
 - Then, gently point out what aspect is not realistic: "You can have a boyfriend or get married, but not to Mickey Mouse."
 - Share an unrealistic dream you once had, including feeling great about your current life even though you did not attain the dream: "I used to want to marry Joey Tribbiani from Friends! I had a huge crush on him! Isn't that funny? But I couldn't. We didn't live in the same city. We didn't know each other. I only saw him on TV, never in person. I never talked to him or gave him a hug. But then I met your Dad, and I got married to him instead! That's been pretty great!" Gather more real-life examples of this from peers and other adults in your teen's life. You could even have your teen do a survey.
 - Clearly outline the reasons why this particular dream cannot happen: "You can't marry Mickey Mouse because he is not a real person, cartoons can't marry people, he lives in Disneyland and you live in Canada, etc."
 - Finish with a positive action by making a plan together for how your teen can achieve her or his goal of getting married one day. Try to find a role model with Down

THE DAYS OF OUR LIVES

In my years at DSRF, I have seen many detrimental effects in teens and adults with Down syndrome who spend too much time watching soap operas. Soap operas, or other similarly dramatic shows (possibly including many reality TV shows; e.g., consider “The Real Housewives of...” series), may be particularly appealing to people with Down syndrome due to the overly dramatic, almost cartoon-like, facial expressions, body language, and gestures performed by the characters. Many people with Down syndrome are highly empathetic and socially motivated with an ingrained flair for the dramatic. The problem is that “Days of Our Lives” is not a cartoon – the characters are clearly real people, enacting scenes in familiar places, with storylines that continue over months or years. All of this makes it harder for the teen to distinguish reality from fantasy.

The results of watching too much? At DSRF, we’ve seen re-enactments of scenes they’ve watched (slamming doors, yelling at coworkers or peers), and ordinarily calm teens and adults who have episodes of violence (kicking walls or punching peers). I would highly recommend limiting your teen’s viewing of soap operas, reality shows or any other show that depicts violence. At the very least, try to watch these with your teen, and debrief afterwards about the unreality of what they have just viewed.

syndrome who has accomplished this. Outline the steps your teen will need to take and then help them get started. In the marriage example, you will want to address building life skills so they can live independently as part of a couple, as well as the rules for dating and learning relationship skills. (Andrea Lee, our Comprehensive Sexual Health Educator at DSRF, is a great resource for this information; see her article in this issue of 3.21 or contact her at andrea@dsrf.org.)

I have always encouraged parents to have high expectations of their children with Down syndrome. But we all need to take care to ensure we bolster only those goals and dreams that are at an appropriate level. Actually achieving goals, or the small steps on the way to bigger goals, do wonders for self-esteem. And couldn’t all teens with Down syndrome use a self-esteem boost?

REFERENCES

McGuire, D. & Chicoine, B. (2006). Mental wellness in adults with Down syndrome: A guide to emotional and behavioral strengths and challenges. Woodbine: Bethesda, MD.

*A new edition of this book has been published, and will soon be available for loan from DSRF’s resource library.

Please email Susan Fawcett if you have questions or concerns about your teen: susan@dsrf.org



INVEST IN INDIVIDUALS WITH DOWN SYNDROME

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Success in the market is all about navigating uncertainty - and nothing has created more uncertainty this year than COVID-19.

After successfully pioneering the virtual edition of Up the Down Market in 2020, DSRF is currently planning for in-person events in the fall of 2021. If this proves impossible due to the current COVID-19 landscape and provincial health guidelines, we are ready to shift back to a virtual event, which would be hosted through Zoom and an online game portal that brings the UDMD experience to your home or office.


Whether it takes place in person or virtually, at Up the Down Market, you and your team will go head-to-head with the heavyweights of finance and industry, buying and selling shares in fictitious companies to see who’s the savviest and shrewdest. News broadcasts fuel the trading frenzy as competing teams brave the ups and downs of the market and vie for the coveted Up the Down Market trophy - and bragging rights for the next year.

As you play, you’ll be investing in something more significant than just stocks and bonds. Through Up the Down Market, a deposit is made toward a brighter future for individuals with Down syndrome - a compounding investment that pays lifetime dividends to so many families.

**Vancouver: Oct. 7, 2021 | Toronto: Oct. 28, 2021
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Event Website: [DSRF.org/UDMD](https://dsrf.org/UDMD) Event Sponsorship Contact: Maria Marano (maria@dsrf.org or 604-444-3773)





PUBERTY, RELATIONSHIPS AND SEXUALITY FOR TEENAGERS WITH DOWN SYNDROME

A Q&A with Andrea Lee

Andrea Lee is a BC Certified Teacher who teaches group educational programs for young adults at the Down Syndrome Resource Foundation. Inspired by her students and seeing a need for the entire Down syndrome community, Andrea has recently graduated from Option's Sexual Health Educator Certification program, the only one of its kind in Canada. She is currently completing her practicum at DSRF, developing group and one-on-one programs for all ages. She is excited to offer comprehensive sexual health education and guidance for people with Down syndrome, helping them establishing fun, healthy, and safe relationships with themselves, their bodies, and others.

We asked students and parents to submit questions for Andrea, and the response revealed the depth of interest in this topic, with over 50 questions received. Below is a selection of the questions and Andrea's responses.

QUESTIONS FROM PARENTS

What is a good approach for explaining sex and where babies come from? (I have a 14-year-old son with Down syndrome and a 9-year-old daughter without Down syndrome) and it's a current topic in our household as my 9 year-old has been asking questions.

I know it can feel like big pressure to have "the sex talk" with your children, but I would approach it as many small talks while looking for teachable moments when they come up. Keep it simple, straightforward, and, if needed, don't be afraid to say, "That's a great question. I'm not sure what to tell you at the moment. I will get back to you as soon as I'm ready and I have the right information." I would recommend finding some good books or videos to help the conversation. You are laying out a foundation and letting them know that you are a trustworthy and safe resource for both of them. If they have more questions eventually, they will know they can ask you.

Being visual learners, folks with Down syndrome will be drawn to the pictures in a book. As parents, it is nice to have a script to follow and answer questions as they come up. Children and teens will take in what they are ready for and ignore the rest. There are lots of great books, including some specifically for people with Down syndrome, such as:

- ***What Makes a Baby* by Cory Silverberg**
- ***Talk Sex Today* by Saleema Noon and Meg Hickling**
- ***Sex is a Funny Word* by Cory Silverberg and Fiona Smyth**
- ***The Girls' Guide to Growing Up* and *The Boys' Guide to Growing Up* by Terri Couwenhoven**
- ***Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality: A Guide for Parents and Professionals* by Terri Couwenhoven**

Some may prefer videos to books. Amaze (amaze.org) has a variety of videos made about bodies, relationships, and sex. Watch a video together and see if this brings up questions. The videos are a bit quick for some of my students and perfect for others.

How do you know your teen is ready for certain sexual health topics? I don't want to give them info that they aren't ready for and cause confusion.

Here's the good news – you can't introduce things too early! Discussing topics earlier than you think you should is often the best time. Do it before they are asking questions, because they can't ask questions about things they don't know about yet! Plus, you might not want the questions that come up from them learning about sexual health topics from TV, movies, social media, or their peers. Keep it straightforward, simple, and honest. Ignoring topics can teach them to feel guilty or shameful of certain feelings and thoughts and those are likely the feelings and thoughts we don't want them to be hiding from us. We want them to get the right information from a person they can trust. That's you!

However, you are correct – some things will go over their heads or maybe even gross them out. A child or teen, with Down syndrome or without, will pay attention to what they are ready for. It won't confuse them. You can give them a whole spiel on some topics and they'll pick out one word that piqued their curiosity, so go with that for now. Books and picture books are great so they can point out what they are interested in. I recommend many books throughout this article.

Now if they're grossed out? Encourage that! Finding something gross is a healthy, normal reaction to something you and your body is not ready to see or do. People touch *what!?* It goes *where!?* Depending on what the topic is, reassure them that it is your body and your choice. Slogans work well with folks with Down syndrome. Try, "My body, my choice!" or "I'm the boss of my body!" You never have to do something you are not ready for, something that sounds gross, something that sounds scary, or anything you don't want to do with your body or another person's body. One day, it might sound interesting or appealing, and you will be there to discuss it with them in more detail then.

My son is 14-years-old and still needs assistance in the bathroom and with showering. I have noticed on occasion some self-exploration and erections. I know it's natural, however I am not sure how to respond/react. Sometimes in other circumstances noticing a behaviour can result in him engaging in it more and I am concerned that this could have the same outcome.

You are right; it is natural. It can also be awkward!

Erections are natural and can happen for many reasons. If he asks, you can tell him that when his penis stiffens, it is called an erection and it is something that a normal, healthy penis



does. It could be because he is excited, it could be because he is touching it, it could be because he is thinking about something sexual, and it could be for no reason at all. This may be a good reminder for everyone, too – we often make things feel more awkward when they are sexual, but this might not be the case with erections.

Self-exploration could also be for many reasons. It could be sensory, it could be calming, it could be sexual. All of these reasons are valid. However, whatever the reason, it needs to be done in private.

Make sure your son has a time and place to be in private in your home. He needs to be able to identify the private places he has (his bedroom with the door closed, maybe even his bed when the room is empty if he shares a bedroom, the bathroom with the door closed, maybe only a particular bathroom depending on your living situation). Establish a knocking rule in the home before you are entering these private places. Assure him he will have privacy, but if there is a reason someone needs to check on him, they will announce they are coming in first and then he is no longer in private. If he does need help in the shower or with the bathroom, tell him when you will check on him in a set number of minutes and still give him privacy as much as possible. Then explicitly teach that self-touch and self-exploration of his body is healthy and normal, but it is done in private. This way, even if acknowledging the behaviour does lead to him doing it more often, at least he is doing it in the safety of his own bedroom or bathroom when no one else is around.

As for erections, they may happen in public or in private. That is difficult to control. It might be useful to teach ways to hide an erection if you are in public. Wearing a longer shirt that can be pulled over the erection, sitting down so the erection is less visible, and placing a bag or books in front of the erection are some easy ones.

My 16-year-old daughter flirts with every male in sight, including complete strangers. How can we teach her to interact with people appropriately and respect personal boundaries?

This one is pretty tricky if you want her to stop her flirtatious impulses. How can you stop a behaviour when you have no control over the reactions of strangers and others she is approaching? If one of them plays along, flirts back, or pretends to be her boyfriend, she will be positively reinforced and want to do it again. If one of them gets angry at her or rejects her, she may be negatively reinforced and possibly still enjoy the interaction with him. She has a desire to be included and connect with some cuties; who can blame her? However, I love that you asked not how to stop this, but how to teach her to do it appropriately.

Greeting skills can be taught and practiced with a speech language pathologist or through social skills instruction. The Program for Education and Enrichment of Relationship Skills (PEERS) was originally developed for people with autism spectrum disorder (ASD) and other socio-emotional problems. The Semel Institute for Neuroscience and Human Behavior has a great website with short role play videos from PEERS. Many of them show a good and bad example of many skills related to dating, like how to flirt with your eyes, how to handle rejection, how to ask someone if they have a boyfriend or girlfriend, and asking someone out on a date. There are also lots of videos of non-dating related social skills, like starting a conversation, entering a group conversation, and different ways to use humour. Teaching these social skills may give her the interactions, attention, and inclusion she likely desires without having to flirt.

The videos give discussion questions at the end of the video. If discussion is not enough, the questions would make a

good social story or contingency map. If I asked someone out in a good or expected way, what might the feelings and consequences be for the person I ask out? What about for me? If I ask someone out in a bad or unexpected way, what might the feelings and consequences be for the person I ask out? What about for me? If deciphering the nuances of social conflict is difficult, consulting an educator or therapist trained in the Social Thinking methodology (www.socialthinking.com) may be beneficial.

Depending on how she is flirting, you might want to think about what kind of modeling she is being exposed to – media, social media, school peers, family members, and so on. It might be worth it to get her school and community team on board with this. “I want my daughter to learn how to greet young men in an expected, appropriate way. We have taught her to say _____. Could you help her do this at school/during outings/in the community?” Sometimes things need to be made a priority. With a good team and a lot of consistency, it can improve. Good luck!



QUESTIONS FROM TEENS AND YOUNG ADULTS WITH DOWN SYNDROME

What’s a good age to date?
– T., age 17 and R., age 19

There are many good ages to start dating. Some people start dating in their teens (usually in high school) and some people start dating when they are an adult. Often adults, like your parents, might be worried about you dating too young because they want to make sure you know how to set boundaries for yourself. Are you able to say no to someone who wants to do something you do not want to do? Can you stand up to someone you like? Do you know what it means to treat someone with respect and care and to have someone do the same for you? A good age to date is when you can answer ‘yes’ to all of these questions.

Some other things to think about: Who will pay for my dates? Do I need to be old enough to save my money or have a job? How will I get to my dates? Am I old enough to be safe when out in the community or will I need a supporter to help me out? These won’t stop you from dating, but it should be something you think about.

Take the Dating Readiness quiz in *Boyfriends and Girlfriends* by Terri Couwenhoven.

Other than bowling, where are good places to go on dates? – C., age 23

When you are planning a date, think of your mutual interests. These are things that you both like so that everyone is having fun. Do you both like hockey? You can go to a hockey game (although this can be expensive!), go to a restaurant to watch the game, play hockey at a park, go ice skating, or go for a walk and talk about hockey. Almost everyone likes food! Some food-related dates can include going to your favourite restaurant, trying a new restaurant, picking a recipe to make together at one of your homes, going to a bakery, or having a picnic. Sometimes your friends, family, and even teachers or other paid helpers might have good date ideas in your community.

Some things to consider:

- **How much does it cost?**
- **How am I going to get there? Will I walk, get a ride from someone, or take the bus?**
- **Will we need a family member or friend to hang out with us, too? Maybe it would be good to think of something you would all enjoy.**
- **Should we go out during the day or the night?**

Can you only have sex at 2pm? – A., age 17

The time of the day doesn’t really matter for having sex. What matters is that both partners are consenting (they agree to this type of touch) and they are in a private place. You should also know how to have sex safely and respect any rules that your family, religion, culture, or community has about sex.



TEEN TALK

Advice for Today's Teens

Often the best advice comes from people who have been there. With that in mind, 3.21 Magazine asked young adults with Down syndrome from across Canada to offer helpful advice to today's teens.

Matt, Ontario

Work smart and ask for help when you need it to learn. Things you learn at home can help you at a job. Like managing money, keeping things clean, and following routines.

It is good to learn new skills, those help you with being independent. Before I left home I learned about cooking, banking and healthy food portions.

Keep motivating yourself to be healthy and feel good about it!

Ren, Ontario

Be yourself, you're perfect.
Some days are hard, try to smile.
Learn hard, Work hard.

Paul, Alberta

Stay in school and find your true interests while you're there.

Learn how to put together a resume, and apply for the job that you want. It is important to do your job well.

Find activities that you enjoy to stay in shape while having fun. Follow the Canadian Food Guide and maybe use an eating schedule to know what to eat and when to eat.

experiences

Andrew, BC

In high school I would suggest trying as many classes as you can that interest you. I did cooking, photography, and woodwork.

This is a great time to get involved in your community and become as independent as you can. I did work placements and took the bus everywhere. This was good training for when I started college.

I enjoyed dating for a time, but found it limited other things I wanted to do. I made friends through my sports and through a social club called Friday Friends.

I also started to learn about financial independence with my own bank cards and cheques (with oversight by my parents).

friends

Janet, PEI

Join clubs at school to make friends.

Be yourself and people will like you for who you are. Inclusion is really inclusion when you don't even see it happening.

Take courses on life skills so you can learn about independence, jobs and the world.

Alana, Alberta

It is good to be independent, it is absolutely okay to ask for help when needed too!

It is healthy to talk about different milestones with your family whenever you feel comfortable opening up about things that are changing with you.

Jason, Ontario

At school, get help from your EA. Use an agenda to keep track of assignments. Make sure you do your homework and hand in all assignments on time and also arrive on time to every class.

Give yourself time to do tasks on your own. Be patient with yourself. People your age can do many things, it just takes time. Learn simple tasks like tying shoelaces.

It's a good feeling to have independence. You get more freedom but if you need a hand, then always ask.

Being in a relationship is a good feeling. It's always good to ask for permission from the parents to date someone. Be patient. It takes time.

relationships

Jodi, BC

It is very important to do things that you like doing on your own to become more independent. You can also be independent when you meet people to hang out with, but doing things on your own is also good sometimes.

When you share your feelings with someone you might feel nervous at the beginning. Try to know if the person is right for you.

It is very important to be healthy and fit. Your brain should stay healthy, it helps you when you need it to.

independence

discoveries

dating

Chris, BC

Always stay positive and friendly to keep your social circle large.

Involve yourself into the community for future contacts for employment opportunities.

Special Olympics was a way to meet new people that became long term friendships.

GROWING UP

An Interview with
**AARON
WADDINGHAM**
conducted by
his parents



Photo: Ryan Walter Wagner

TELL US ABOUT YOURSELF.

I am Aaron Waddingham. I just turned 18. I am funny. I am excited sometimes. I am happy and a lover boy.

WHAT HAVE YOU FOUND CHALLENGING ABOUT GROWING UP?

I have found talking hard because people ask me a lot of questions. Growing up is hard but sometimes easy. That's it.

ONE OF THE HIGHLIGHTS OF YOUR TEEN YEARS WAS APPEARING IN A TELEVISION COMMERCIAL FOR NINTENDO. HOW DID THAT FEEL?

I was on TV! I am like a God! I got paid for it. I bought a new phone, new watch and new Airpods Pro.

DID YOU LIKE GETTING PAID FOR YOUR NINTENDO COMMERCIAL?

Paycheque is my middle name.

NOW THAT YOU ARE 18, WHAT KINDS OF THINGS ARE YOU LOOKING FORWARD TO BEING ABLE TO DO?

Drinking and voting. Voting is a huge thing! I want to find a job and be a businessman. And also, be an actor. Auditions take a while, so I will be a businessman. I want to act in a Dwayne Johnson movie.

YOU ARE GRADUATING FROM HIGH SCHOOL THIS MONTH. CONGRATULATIONS! DO YOU PLAN ON CONTINUING YOUR EDUCATION AFTER YOU GRADUATE FROM HIGH SCHOOL?

I am going to Grade 13 in September. I want to work after high school. College is way too hard. I might go to acting school.

WHAT KIND OF WORK DO YOU WANT TO DO AS AN ADULT?

Acting. But it takes a while to get auditions. Actors are creative and do imaginative things and improv. Improv means you always have to say yes. You have to be strong, confident and firm.

WHAT ARE YOUR INDEPENDENCE GOALS?

My independence goals mean I can stay home... I can cook by myself not with an adult. And I can order pizza. I want to be like my parents and copy them in the future.

WHO LIVES AT HOME WITH YOU NOW?

My annoying parents (ha, ha!). They force their son to do chores. I have to put the garbage away.

DO YOU WANT TO MOVE OUT?

I want to move out to Toronto, to a penthouse. It would have a pool, a hot tub, a spa service, a bar servant and hire a chef, butler and my personal favourite, a sauna.

WHEN YOU ARE AN ADULT, DO YOU HAVE TO DO CHORES?

Not all the time. My personal favourite, my butler, will do my chores.

WOULD YOU LIKE TO GET MARRIED?

My plan is to get married in the most beautiful place, like Miami, on a yacht.

WHAT IS THE MOST EXCITING THING ABOUT BEING AN ADULT?

I will be able to move out and spend time in life.

IS THERE ANYTHING ABOUT BECOMING AN ADULT THAT MAKES YOU NERVOUS?

I am not nervous about anything. I am excited instead.

IS THERE ANYTHING YOU FEEL YOU STILL NEED TO LEARN BEFORE YOU'RE READY FOR ADULT LIFE?

I have to keep learning how to treat people nicely. That is important for everybody.

WHAT ARE YOUR HOPES AND DREAMS?

First, I hope that this COVID nightmare is over. My dreams? Listen to my head which will say what I need. I will be a famous and exotic person and people will take photos of me. I want more cool activities, more socializing.

A FAMILY PHILOSOPHY ABOUT GROWING UP

-BY MIKE WADDINGHAM AND SUE ROBINS, AARON'S PARENTS

Our family is laser-focused on making sure that Aaron lives a rich and rewarding life. We have realized that it is our responsibility as his parents to make sure that happens.

Aaron talks – a lot! – about wanting to be a working actor. People say it is his dream but really it is his goal. Why can't he be an actor if he wants to be? It is something he's actively working towards and it gives him huge purpose in his life. Plus, as you can tell from his interview, Aaron has expensive tastes, so he will need a well-paying job.

Aaron is growing up, just like his brothers and sister did. We want for Aaron what we wanted for our other kids: to discover a career that lights him up, to find love, to move out and to gain confidence. Most of all, we want him to be fully and truly himself.





Feeling DOWN?

The COVID-19 pandemic has taken a toll on everyone, and the impact on the mental health of individuals with Down syndrome and their families has been particularly pronounced.

People with Down syndrome already have elevated risk of developing mental health conditions such as anxiety, depression, and obsessive compulsive disorder, and a year of isolation and absence of routine has only exacerbated such problems. Family members, meanwhile, have seen their already high levels of stress intensified even further by the pressures of caring for their loved one without the usual support systems, and fears around their loved one's health.

After introducing mental wellness services in 2019, DSRF is developing a number of resources to support the mental health of people with Down syndrome and their family members. Earlier this year, Dr. Susan Fawcett presented a 6-part parental wellness series, "There's Ups and There's Downs," introducing several approaches and strategies aimed at reducing parent stress. These sessions are now available as a video series, at [DSRF.org/parentstress](https://www.dsrf.org/parentstress).

This summer, we will be rolling cameras on our latest short documentary, this one focusing on mental health issues for adults with Down syndrome. You'll hear self-advocates and families sharing their own struggles with anxiety, depression, anger, fear, and more, with Dr. Fawcett providing a professional perspective on how to cope with and overcome these conditions. Watch for the release of this video before the end of the year.

Now Playing: The LowDOWN Podcast, Season Three

Dr. Fawcett also recently returned to The LowDOWN: A Down Syndrome Podcast to discuss cognitive behavioural therapy as an approach to managing mental health concerns in individuals with Down syndrome. This episode brought The LowDOWN's third season to a close – a season that also featured shows on developing reading skills, toilet training, nutrition, medical equipment adherence, the RDSP, and much more. Find all these episodes on your favourite podcast app, or at [DSRF.org/podcast](https://www.dsrf.org/podcast).

We'll head back into the recording studio this summer to record Season Four. Subscribe today so you don't miss an episode when they start dropping in September.



Chris Nikic: 1% Better

Another recent guest of The LowDOWN, Chris Nikic, connected with DSRF's adult students for a special presentation and Q&A over Zoom in early May. The world's first Ironman with Down syndrome inspired the students with his 1% Better philosophy, challenging them to push themselves to improve just a little bit every day. As Chris has demonstrated, this approach – applied consistently over time – can propel any person to achievements we never imagined possible. It was a perfect message for all of us as we begin to emerge from the pandemic and consider what's next.

Chris' session with the students was part of his work as the Special Guest Race Ambassador for DSRF's Run Apart for Down Syndrome presented by Eurorite. As of the release date of this issue of 3.21 Magazine, there's still time to join Chris and hundreds of others at this virtual event on June 6, and run or walk wherever you are to empower people with Down syndrome to overcome obstacles and reach their dreams. Learn more and register at [DSRF.org/RunApart](https://www.dsrf.org/RunApart).



UPCOMING AT DSRF

Run Apart for Down Syndrome – June 6, 2021
(virtual event)

Up the Down Market Vancouver – October 7, 2021

Up the Down Market Toronto – October 28, 2021

Action 21 Montreal – November 18, 2021

FRIENDS OF DSRF

A massive thank you to SVP Vancouver for generously donating \$45,000 in the third year of DSRF's engagement with Social Venture Partners. In that time, SVP has invested \$180,000 to build DSRF's fund development and communications capacity, which has been extraordinarily valuable in helping us navigate the COVID-19 pandemic. We are forever grateful to SVP!

More than \$120,000 was raised for DSRF's educational programs and therapy services through Lunch with Leon: a virtual event featuring Leon Tuey in conversation with Tracey McVicar. Thank you very much to everyone who attended and donated, and to Leon and Tracey for their enlightening and entertaining discussion.

Longtime DSRF supporter the Edith Lando Charitable Foundation has donated \$4,000 to our educational programs for children and youth with Down syndrome. The Foundation is dedicated to building the self-esteem of young people, and they are certainly growing the confidence of DSRF's students. Thank you!

DSRF has been awarded a Canada Summer Jobs Grant from Employment and Social Development Canada. This will be used to hire staff for our summer school program, which returns this summer.

Thank you to all the generous sponsors who have ensured that this year's Run Apart for Down Syndrome will be a great success: Eurorite, LiUNA, Ignite Management, Borden Ladner Gervais LLP, Prospera Credit Union, G&F Financial, CTV Vancouver, the Vancouver Canadians, Spirit Ridge Lake Resort, Pioneer Distributors, Kintec, and the Vancouver Art Gallery.

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Down Syndrome Resource Foundation

Together. Hand in Hand.

CDSS SPOTLIGHT



Fundraise My Way

This spring we launched our new fundraising platform: Fundraise My Way. Now individuals and groups can set up an event to support CDSS in just five easy steps. It's also mobile friendly! Turn your birthday, virtual event, yard sale, corporate or sporting event into a meaningful fundraiser. Discover more [here](#).

Getting Greener!

Throughout 2020 and 2021 we encouraged our community and donors to 'go green' by switching to digital communications and tax receipts from CDSS. This has been a big success for us - and for Mother Nature. We ask all supporters to join the movement today – email StayInTouch@CDSS.ca to update your information!



Mindsets Study

Are you an adult with Down syndrome? See our ad on page 34 and get involved in this incredible research study about exercise and cognition for people with Down syndrome.



Join CDSS June 23 for our next FREE webinar!

Eric Goll from Empowering Abilities works together with families to help their loved ones with developmental disabilities create their own awesome 'ordinary' life. Join us the evening of June 23 as he presents an overview of his program - all with a focus on *Planning for the Future*. Register by clicking on the poster!



Join The Walk With Ambassador Shelley Moore!

CDSS is thrilled to have author, researcher, teacher, consultant, speaker, PhD Candidate and inclusivity advocate Shelley Moore as our Walk Ambassador in 2021. Join Shelley and others supporting the Down syndrome community as we walk across Canada!



The CDSS Walk for Awareness Happens June 12 - 20! See our ad on page 9 and register or donate today!

This walk does more than drive awareness, it supports literacy. CDSS is launching our new National Literacy Initiative in September for families who have new readers. The program will include three online sessions led by Natalie Hale of Special Reads, as well as support materials and books - geared towards the child's reading level - delivered to homes in Canada. The online sessions and materials will be available in either English or French.

The Special Reads website (<https://specialreads.com>) has testimonials from parents of children with Down syndrome,

and make sure to visit their frequently asked questions; many are specific to Down syndrome and reading.

More details are available on social media @CdnDownSyndrome, and registration is FREE here: www.CDSS.ca

All funds raised in the Walk for Awareness will go DIRECTLY to bringing these reading materials to homes, and providing the online support sessions to families. Support the Walk, and help make literacy a national priority.



Our new CDSS.ca website launches this summer! We can't wait to share it!



FIND US / TAG US

@CdnDownSyndrome on all our platforms





Can we strengthen our minds by strengthening our bodies?

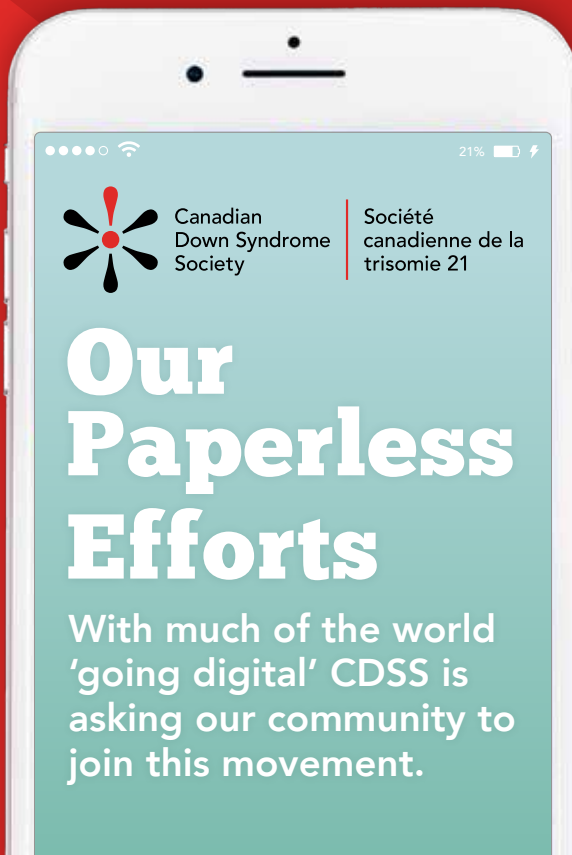
The Canadian Down Syndrome Society and BrainHQ are going to find out with a first-of-its-kind 8-week research study.

Initial pilot studies have shown that for people with Down syndrome, physical exercise does more than just strengthen the body—it makes the mind stronger, too. But we need more data to prove it.

That's why the Canadian Down Syndrome Society, with the support of Brain HQ, is launching a research study, examining just how much physical exercise affects mental fitness.

Our hope is that publishing our findings will help make physical exercise an integral part of cognitive therapy.

To learn more, visit mindsetsstudy.com



If you currently donate to CDSS and receive tax receipts, or any other mail from us by Canada Post, we encourage you to switch to email by contacting us with your current email address. Please include your previous email or mailing address to ensure accuracy of your records.

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Independent Housing Models for People with Down Syndrome

A SHORT FILM FROM THE DOWN SYNDROME RESOURCE FOUNDATION

DSRF.org/HomeSweetHome



Down Syndrome
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Together, Hand in Hand.

*"I just had to reach out to say thank you for existing! Wow. What an important resource. I am inspired by **The LowDOWN Podcast**, which has been saving my life over here in relative isolation. I love this podcast so much."*
- LowDOWN Listener

Season 3 out now!

SUBSCRIBE AT **DSRF.ORG/PODCAST**

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A Down Syndrome Podcast