DSAO DOWN SYNDROME ASSOCIATION OF ONTARIO

School Transitions:
A GUIDE FOR FAMILIES OF STUDENTS WITH DOWN SYNDROME

Introduction

This booklet aims to support parents and others as they plan educational transitions for and with students with Down syndrome. The information, tips and approaches recommended here will be relevant to these transitions:

- from home or childcare into Full Day Kindergarten (FDK)
- from FDK to Grade 1 (elementary school), and through the elementary grades
- from Grade 8 to Grade 9 (secondary school), and through the secondary years
- from secondary school to postsecondary study and/or activities
- when a student moves to a different school or returns to school following a prolonged absence for medical reasons or after receiving care, treatment, or rehabilitation at another institution.

Table of Contents

Why a booklet about transitions?

Transitions are defined as changes from one situation to another, and transitions bring both difficulties and opportunities to the lives of students with Down syndrome.

Families and caregivers are often anxious about how their young person with Down syndrome will manage through a transition, and they live with constant concern about the capacity of the educational system to respond to their child's strengths and needs.

Students with Down syndrome may be excited to progress to the next level, but they can find change difficult, and they benefit from preparation for their transition to a new environment.

Principals and teachers benefit from the transition process, where they gather information about the particular learning style of the student with Down syndrome and hear first-hand about the techniques that have helped the student succeed in previous settings and grades.

When transition planning is done in an atmosphere of trust and positive expectations, it allays worries and rededicates everyone to the ongoing effort to help the student with Down syndrome achieve to their highest capacity.

TRANSITION PLANNING FOR STUDENTS WITH DOWN SYNDROME IS EFFECTIVE WHEN:

1) everyone involved is familiar with the purpose of each step of the transition planning process and agrees on the rights of the parents and the student with Down syndrome to contribute their expertise and express their preferences

2) there is respect for the culture, language and prior learning of each family

3) all parties participate and communicate in good faith, using plain language, and with a willingness to sympathetically overcome gaps in understanding

4) the student's individual needs, strengths and wishes are at the centre of the process

5) there is agreement that the learning profile of students with Down syndrome is unique and typical solutions may not be particularly effective

6) all parties are committed to the clarification of goals and roles, and mutual learning about how the student with Down syndrome learns best.

If properly done, transition planning

- helps the key players become aware of one another and prepare to work together
- clarifies expectations and reduces stress
- ensures continuity of service and the sharing of successful practices among school board personnel, agencies and partners
- supports the student with Down syndrome through positive and fulfilling school experiences.

How to use this booklet

This booklet is divided into four sections, which cover transitions into Kindergarten, Elementary, Secondary, and Post-Secondary.

Parents are welcome to read the sections that fit their needs, and to return to the booklet as their child progresses through the school system.

The sections on the Identification, Placement and Review Committee **(IPRC)** process and the Individual Education Plan **(IEP)**, however, are relevant to transition planning from Kindergarten to Secondary, and parents may wish to consult those two sections more frequently.

Remember that individual school boards work within Ministry of Education guidelines on IPRCs and IEPs, but they may interpret them differently according to their past practices and board philosophy. In the end, though, boards are expected to meet the standards which the Ministry of Education has set.

The Identification, Placement and Review Committee Process (IPRC)

The families of exceptional students should be invited to attend several IPRC meetings in their child's school career:

- when the child starts kindergarten
- when the child transitions into elementary school (Grade 1)
- when the child transitions into the Junior division (Grade 4) and the Intermediate division (Grade 7)
- and another when they start high school.

Some Boards invite parents to yearly IPRCs and/or send the parents a form to indicate that they are prepared to "waive" (i.e., "do without") an IPRC for that year. If your child's school has not contacted you about an IPRC at the beginning of the school year, and you believe it is necessary to hold one, the family can request an IPRC. This request must be made to the principal, in writing.

The purpose of the Identification, Placement and Review Committee (IPRC) process is to

1) Discuss and **identify** the nature of the student's exceptionality
2) Decide on the best **placement** for the student
3) To **review** and possibly change either of the above decisions.

There are four basic steps in the IPRC process:

A Information Gathering

Parents can prepare for the IPRC by gathering information about their child from many sources: medical professionals, therapists, and community organizations.

School personnel will prepare for the IPRC by requesting and obtaining relevant educational assessments and amassing documentation that sheds light on the student's strengths, needs and learning patterns.

B The meeting

Parents/guardians will be invited to the IPRC meeting and should make every effort to attend. They may request a meeting time that accommodates their schedule. Parents may also invite someone to accompany them.

In addition to the school principal there will be several school board and school personnel in attendance. It is the responsibility of the school team to demystify the process and avoid acronyms and jargon. Clarity and plain language will make the process easier for everyone.

Newcomers to Canada, and parents/guardians who speak a language other than English may be supported by a settlement worker (SWIS) and an interpreter so that the process can be clearly explained and the parents' point of view is understood and included.

C The decisions

After discussion, the participants in the IPRC will arrive at agreements about

a) The nature of the student's exceptionality (many students with Down syndrome are designated as having an Intellectual Disability)

b) The educational placement which best suits the student. School boards in Ontario have been instructed to consider a placement in an age-appropriate class in the child's neighbourhood school as the first, best option for any student receiving Special Education supports.

D The implementation

Thirty school days after the IPRC has been accepted, the student's IEP should be ready for review and implementation.

If new evidence comes available, or if the student's educational profile changes, the IPRC can be adjusted.

Important Details / Updates:

What is described above is the IPRC process as it is outlined in **Ontario Regulation 181/98**. Because of differences among school boards across the province, there are variations in practice, such as in the frequency and level of formality of the IPRC meetings.

It is also very important to acknowledge that the provincial IPRC guidelines indicate that there are five possible placements for exceptional students:

- **A regular class with indirect support** where the student is placed in a regular class for **the whole day**, and the teacher receives specialized consultative services.
- **A regular class with resource assistance** where the student is placed in a regular class for **the whole day or most of the day** and receives specialized instruction, individually or in a small group, within the regular classroom from a qualified special education teacher or Educational Assistant.
- **A regular class with withdrawal assistance** where the student is placed in a regular class while receiving instruction outside the classroom, for **less than 50 per cent of the day**, from a qualified special education teacher.
- **A special education class with partial integration** where the student is placed in a special education class for **at least 50 per cent of the school day** and is integrated with a regular class for **at least one instructional period daily**.
- **A full-time special education class** where the student spends the **whole day** in a smaller class for children with similar needs and with a special education teacher and educational assistants.

This range of placements is not available in many boards, particularly those that follow a philosophy and policy of full inclusion. This is an important detail for parents to be aware of: many school boards do not offer the choice of placement options that is mentioned in the provincial guidelines, and indeed, some school boards, particularly at the elementary level, frequently offer a regular class placement.

ADVICE FROM ONE PARENT TO ANOTHER:

> *I was told that children with Down syndrome were not eligible for an IPRC. I felt powerless and I didn't know how to find out if that was true, but I knew I wanted my daughter to have an IPRC! I wish I had known that I didn't have to accept what the school was saying, and that I could have searched the Ministry's own policies online.*

To know what the Ministry of Education says about the IPRC process:
http://www.edu.gov.on.ca/eng/general/elemsec/speced/identifi.html

To read the legal regulations that govern IPRC and IEP processes:
https://www.ontario.ca/laws/regulation/980181

Individual Education Plan (IEP)

By contrast with the IPRC process, which is narrow in its scope, and which usually occurs no more than once a year, the Individual Education Plan document is frequently written and rewritten. The IEP is often referred to as a “living document”, and the presence of additions, small edits and refinements are indications that the IEP is being consulted and evolving.

Some key facts about the IEP purpose and process:

Why have an IEP?

Students with Down syndrome may require additional supports in the form of accommodations or modifications to benefit from the Ontario curriculum, as it is usually delivered. Alternative programming, or programming that is in a different from the Ontario curriculum may also be needed. An IEP is, as the name suggests, a plan that the family and teaching team (and the student!) agree on, as to how the learning needs of the exceptional student will be addressed.

Who writes the IEP?

Typically, the classroom teacher collaborates with the members of the Special Education Resource team to write the IEP. Family members who wish to have input into the IEP should signal this early on to the teacher, as many school boards only consult the family to get their approval and signature after the IEP is complete.

Who consults the IEP?

Parents should read every IEP to see if they are satisfied that it presents a challenging but sympathetic approach to the education of their child. Ideally, all teachers and support staff who have contact with the student will contribute to, and then consult the IEP.

Because teachers have so many students' needs to consider, it is optimal if they intermittently refresh their memories about the goals and strategies that are expected to contribute to each student's success.

If teachers forget to consult the IEP, the student doesn't get the teaching they need, and the IEP won't evolve, and an evolving IEP is the best type to have. If parents never read the IEP, their understanding of their child can't be included in it.

When is the IEP produced?

The teaching team works on IEPs in the early days of each term, and the family must receive a copy of the IEP within the first thirty school days of each reporting period.

See Special Education in Ontario, K–12

What does an IEP contain?

The IEP can be a lengthy document. Here are some key features to look for:

1. A list of the student's personal strengths and needs
2. A selection of learning expectations from the different curriculum topics being taught in that school year
3. Indications as to whether, in each curricular area, the expectations of your child's learning are
   - **Accommodated** from the standard curriculum (your child is expected to learn what the other students are studying, while being more, or differently, supported)
   - **Modified** (your child is working to achieve expectations that are part of the Ontario curriculum, but at a different level from what the other students are learning)
   - **Alternative** (your child's learning expectations are outside the Ontario curriculum, but meaningful and important to your child)
4. A list of accommodations (ways the teaching team helps your child attend and learn, i.e "preferential seating") and teaching strategies (techniques that are effective with your child, i.e. "one-on-one instruction and review")

Is there any particular feature I should check?

An IEP succeeds or fails on the level and choice of learning expectations and the teaching strategies that are selected to achieve those expectations.

If your child is a capable athlete or artist, for example, it may be sufficient for them to be accommodated to succeed in Physical Education or Art classes, and the IEP should reflect this.

In some instances, your child with Down syndrome may be studying in the same curricular area as their classmates, just on modified expectations. To choose an overly simple example, in Grade 5 Math, when the rest of the class is studying division with regrouping, your child may be making groups with manipulatives, which is an FDK learning objective.

In other areas, your student with Down syndrome may be working on non-curricular, alternative expectations. As an example, your child may be enrolled in a Grade 10 Information Technology class. While the other students are working on issues of "access to online services" and analyzing examples of "identity theft", your child may be learning by leveraging the use of those same online platforms (like Google) to make greeting cards. Supervision and/or safe controlled access to these platforms should be identified.

The IEP should convincingly communicate a feasible and instructionally sound plan for teaching a particular unit of study/ expectation to the student.

How do I know if I can have confidence in the IEP?

- Do you agree that the instructional goals are appropriate for your child?
- Does the document “sound like” your child?
- Do the goals change and develop from semester to semester? (If so, this may indicate that the teaching team has a good eye on your child’s progress.)
- Is your child happy at school? (If so, this may be evidence that the instruction is appropriate and well-suited.)

Parents get so many copies of these IEPs. Why should we continue to stay alert to them?

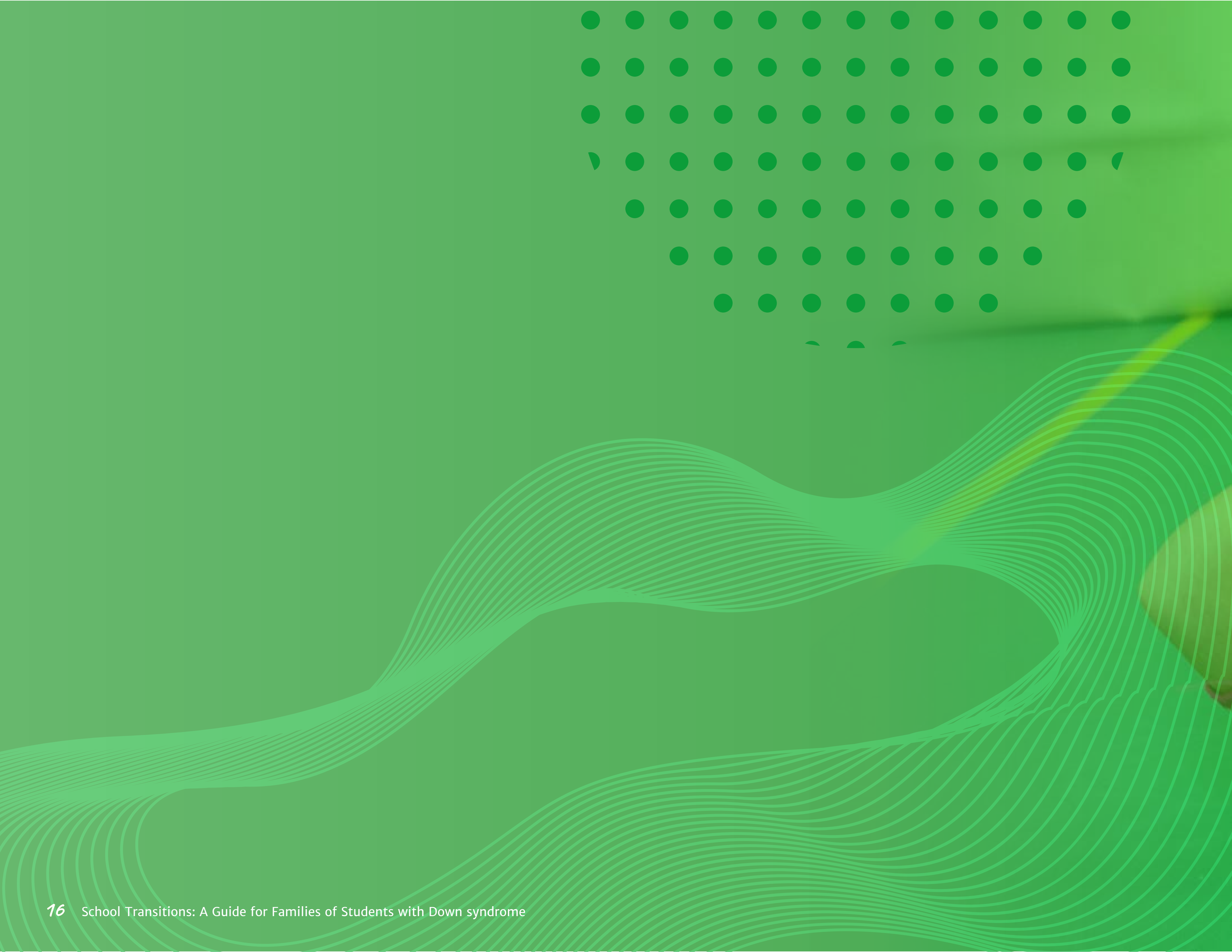
Parents can’t be at school every minute, but monitoring the IEP gives you a picture of what your child’s day might be like. In this sense, you are accompanying your child along their learning journey at school.

Your child’s report card tells of their progress towards mastering the expectations that are outlined in the IEP. You will read the report card in a more informed manner if you are keeping up with the changing IEP.

The IEP is an “accountability tool”. Everyone from the principal to members of the teaching team to the student and the family has agreed on the plan that is outlined in the IEP, and when family members stay alert to the changes in the IEP, they are honouring and monitoring the implementation of the plan.

To read more about the IEP process, follow this website:

https://www.ontario.ca/page/individual-education-plans



Transition into Kindergarten

Transition into Kindergarten

Checklist for Parents: The Process

Before Year 1

WINTER/SPRING	SUMMER	EARLY FALL
Go online to Board's website to learn about dates, procedures for Kindergarten enrolment	Complete needed assessments (hearing, vision, etc.)	If you haven't already, notify school if interpreter will be needed, if you will be accompanied when attending the IPRC
Register child for Kindergarten online	Assemble material for IPRC documentation	Attend IPRC, review IPRC decision
Inform school that you will be registering a child with Down syndrome	With child, read stories about school, discuss transition to school	Assemble ideas you may have for IEP
Attend Board pre-Kindergarten information sessions with your child	Get clarity on bussing, take part in program to practice bus skills, if available	Find mutually convenient time to discuss IEP with FDK teaching team
If the school can accommodate it, visit the Kindergarten classroom with your child so the child knows what to expect	With child, brush up on other "school" skills (i.e., using the toilet, eating independently, etc.)	Troubleshoot and address small difficulties early
With child, read stories about school, discuss transition to school		

Through Years One and Two

Maintain communication with teaching team (teacher and ECE)	Read every report card (issued in January and June)
Keep notes on new learning by child, “what’s working” at home	Consult periodically on adjustments to the IEP

Focus on the Family

Young children with Down syndrome are highly valued members of their families, which have already accompanied them through a wide range of experiences, even before they enter the Ontario education system. There is no one way to be a good parent of a child with Down syndrome, however, so awareness of the diversity of family experiences is important.

Young children with Down syndrome transition into Kindergarten from a variety of educational contexts:

- Home
- Daycare
- Nursery school
- Community programmes (i.e., story hour at the library, swimming lessons)

Young children with Down syndrome may have had a range of experiences before entering kindergarten:

- Medical intervention including surgery/surgeries
- Assessment by experts (i.e., hearing, vision)
- Exposure to therapies (i.e., physical therapy/PT, speech language/SLT, occupational therapy/OT)

Their families will have diverse backgrounds:

- They may be new to Ontario
- They may speak a language other than English at home
- They may come from urban or rural locations
- They may belong to racial, ethnic, religious, or other communities or groups that have been marginalized, and may feel less included in the school
- They may already be linked to a local Down Syndrome association or support group

Each family's way of understanding Down syndrome will affect how they interact with the educational system. Family members can cycle through various thoughts about having a person in their family with Down syndrome, which they may view as:

- a blessing
- a curse
- God's gift to special parents
- something their child might grow out of
- a condition that will barely affect their child
- a normal aspect of human diversity.

Regardless of their backgrounds, most families of a young child with Down syndrome would admit that they have already had to confront profound questions, such as "What will happen to my child after I am gone?". And research indicates that parents of children with Down syndrome, in addition to their private joys and worries, have often experienced additional quandaries:

- They may already have encountered medical or other professionals who are pessimistic about their child's potential.
- They may have encountered reactions of pity, or the use of unhelpful language, such as the expression that their child "suffers from" Down syndrome.
- They may have had to defend their decision to pursue or ignore experimental or controversial therapies which promise to lessen the effects of Down syndrome.

Families arrive at the transition into Kindergarten, then, with individual histories and high hopes for their young child with Down syndrome. Respect for their different paths is essential.

There are ways in which families can prepare young children with Down syndrome for their transition to the challenges and routines of Full-Day Kindergarten:

- Be as diligent as possible about toilet training before school starts.
- Send food which your child can eat as independently as possible, in containers that are easily accessible by your child.
- Practice taking outdoor clothes off and on and zipping a backpack.
- Familiarize your child with routines for sitting and listening to a story, walking with a group, and stopping one activity and moving to another.

ADVICE FROM ONE PARENT TO ANOTHER:

Some Boards and individuals school administration teams are telling parents of Kindergarten-aged children with Down syndrome that their child can only attend school for partial days. If this happens to you, try to stay calm and investigate the reason. Often the best way to deal with situations like this is to understand what is motivating such a drastic move.

Focus on Communication and the Young Child with Down syndrome

All children who enrol in Kindergarten are still developing their language skills. Over their two years in Kindergarten, all students will improve their abilities to describe their feelings, use appropriate vocabulary for academic topics, and state their point of view. **Students with Down syndrome, though, have unique receptive and expressive communication challenges and a consistent need for support with communication**. The good news is that, in a stimulating therapeutic environment, three-, four- and five-year old students with Down syndrome can experience a notable growth spurt in their language skills.

The following techniques, used both at home and at school, can contribute to a smooth transition to the communication demands of Full-Day Kindergarten for a young child with Down syndrome:

- **Incorporate sign language** (ASL or invented) and pair it with spoken words [i.e., "Mmm ... what a nice snack you have! This is my favourite... apple slices!" (adult makes the sign for "apple")]

- **Supplement speech with gestures** [i.e., "Which paint brush do you want to use, the long (gesture or sign) one or the short (gesture or sign) one?"]

- **Read stories one-on-one with the child and review important words** [i.e., adult reads: "Good night moon and the red balloon. Aamar, can you touch the moon (gesture or sign)... yes – it's in the sky, isn't it? Now touch the balloon (gesture or sign)... good – what colour is that?"]

- **Direct the child's attention to interesting things and narrate with a focus on key terminology** [i.e., "Look at Gurpreet. He's building a tower! It's getting really tall (gesture or sign)! Let's count ... one ... two ... three ... four blocks! I wonder if he will add another block? ... What do you want to do now: build (gesture or sign) or knock down (gesture or sign)? .... Knock down (gesture or sign)? Good ... I'll build (gesture or sign), you count and then you can knock them down (gesture or sign)!"]

- **Leave communication gaps that require student input** [i.e., rather than just handing the student a ball at play time, ECE asks, "What do you want to play with?" and waits until the student responds, with gesture or words]

- **Employ extended wait times to allow the child time to formulate a verbal response without additional talk** [i.e., teacher asks student, "What should we all do before we eat snack, Esme?" ..... pause of 7 seconds ...... "What do we do before eating?" ...... pause of 8 seconds ...... Esme: "Wash hands."]

- **Respect home languages.** There are many examples of bilingual children who have Down syndrome. Communication in two languages offers cognitive advantages to all students.

Transition plans and IEPs for children with Down syndrome who are entering kindergarten must acknowledge the greatest challenge these children face: their communication skills lag behind those of their peers and require focussed development and support.

For more information, consult Fidler, D. J. (2005). The Emerging Down syndrome Behavioral Phenotype in Early Childhood: Implications for Practice. Infants and Young Children, 18(2), 86–103.

Focus on the Kindergarten Program

At present, the Kindergarten Program for Ontario is organized into four strands.

A student with Down syndrome will have an easier transition if their parents and the teaching team are aware of the ways in which these strands interact with the student's strengths and what the research says about supporting the learning of students with Down syndrome.

Strand	Support Implications
Belonging and Contributing	Many students with Down syndrome, because of their developmental levels, will tend to play and work in individual or parallel configurations. They will benefit from support to join and contribute to small groups. **AT HOME:** Encourage children to collaborate with you by guiding them to participate in well-defined, do-able tasks. (i.e., "Let's put these cans on the shelf. You hand that one to me and I'll put it away. Ooooh – heavy, isn't it?") **AT SCHOOL:** The suggestion to work with one other student (i.e., "Can you two fill this bin with blocks?") may be at an appropriately demanding level for the student with Down syndrome.
Self-Regulation and Well-Being	Research has established that young students with Down syndrome have significant difficulties with self-regulation. They can also be overwhelmed by the flurry of language that is addressed at them when they experience difficulties, (i.e., when a child doesn't want to return to class after outdoor play: "Let's go, Rene. Play time is over. Time to go back in. We're going to do some exciting stuff. See? Abby is going in. See? Emily is going in. Don't you want to sit beside Ji-Hoon? Come on – let's go. I'll ask Ji-Hoon if you can sit beside him. Come on – make a good choice.") **AT HOME:** Recognize the child's feelings but be firm about expectations. Parent: "I know you want me to carry you, but it's time to walk." **AT SCHOOL:** When the child has trouble with self-regulation, restate the expectation in simple language and then expect cooperation. Offer an effusive positive reaction when they gather themselves and comply.

Strand	Support Implications
Demonstrating Literacy and Mathematics Behaviours	Students with Down syndrome tend to over-achieve in Literacy and under-achieve in Mathematics. They benefit from multiple opportunities to be exposed to Literacy and Numeracy in everyday life and instructional situations. **AT HOME** (Literacy): Multiple, relaxed opportunities for reading and discussing familiar texts will provide important foundational Literacy experiences. (Numeracy): Natural Mathematics learning opportunities are often lost in everyday life, when they would teach valuable concepts. As an example, unloading the dishwasher is an opportunity to sort, classify and count cutlery. This is valuable Math learning. **AT SCHOOL** (Literacy): Young students with Down syndrome may have difficulty attending to, seeing, or hearing stories in group situations. Literacy lessons in small groups or one-on-one situations will have a greater impact. (Numeracy): Foundational concepts such as size ("Which one is bigger? Which one is longer?"), measurement ("How many cars can we line up in this box?") and location ("Put this behind the easel. This one goes in front of the easel.") are often ignored in the rush to teach number facts.
Problem-Solving and Innovating	Children with Down syndrome have been known to surprise their parents and teachers with their capacity to think "outside the box". Nevertheless, the research does point to their passive persistence in exploring alternatives, and their low motivation to start and accomplish tasks. **AT HOME:** Celebrate and reward repeated efforts. (Parent: "High five because you tried three times to get your boot on!") **AT SCHOOL:** Reward students for starting tasks that they dread. (EA: "Just do the first two and we'll sing for one minute!")

Young students with Down syndrome have distinctive learning styles and communication challenges. The transition to Kindergarten can be smoother if parents and school personnel understand how their unique learning profile interacts with the curriculum.

Just asking ...

Have you applied for Special Services at Home funding?

What is it?

Special Services at Home (SSAH) funding is a program of Ontario's Ministry of Children, Community and Social Services. It offers financial support to the families of children under the age of 18 who have physical and/or developmental disabilities.

Why should we apply?

This funding has two purposes:

1) It allows you to hire a person or people who can offer parental relief and supports

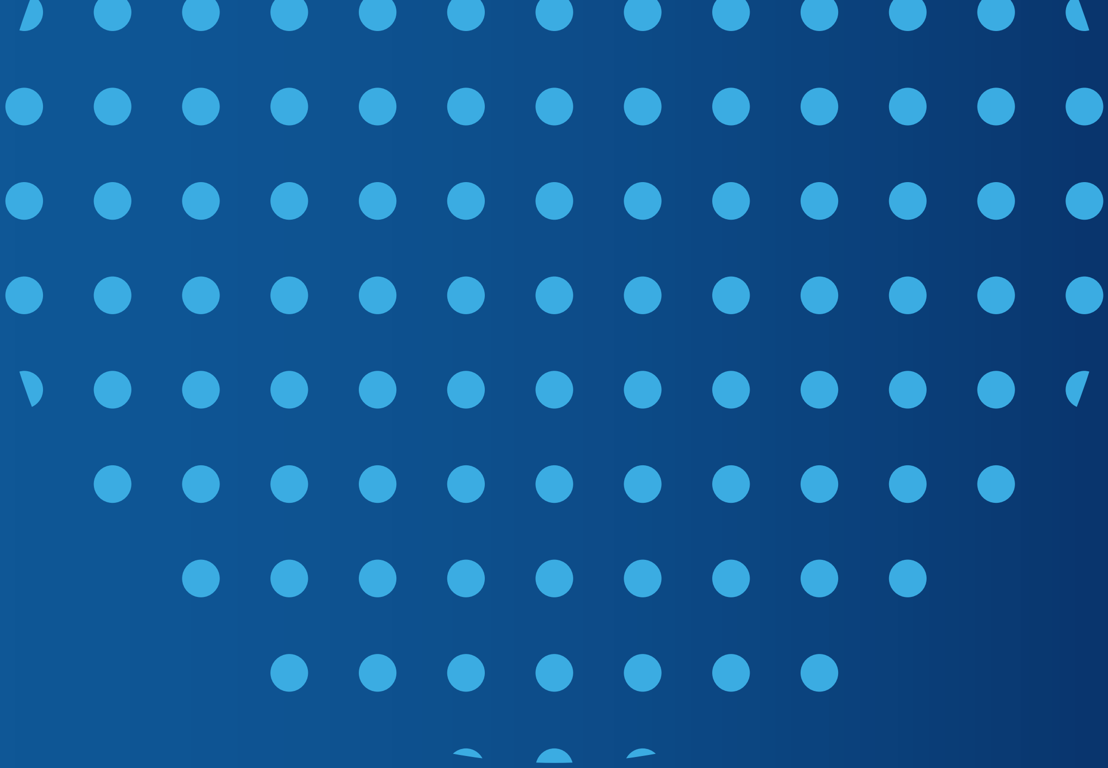
2) It helps your family pay for activities that will lead to your child's personal growth and development

How do we apply?

Search Special Services at Home:
https://www.ontario.ca/page/special-services-home

You probably already have much of the documentation you will need for this application, and you can get help with your application from community agencies if you find the process challenging.

Your application, once approved, may be placed on a waitlist.



Elementary School Transitions

Elementary School Transitions

Checklist for Parents: The Process

Before Grade 1

SPRING	SUMMER	EARLY FALL
If the school can accommodate it, visit the Grade 1 classroom with your child so the child knows what to expect	Complete outstanding assessments (hearing, vision, etc.)	Assemble ideas you may have for IEP
With child, discuss transition to Grade 1 and the new learning model	With child, read stories about school, discuss transition to Grade 1	Find mutually convenient time to discuss IEP with teacher
Check to see if bussing, school entry routines have changed and practice new routines, if possible	With child, practice to maintain "school" skills (i.e., holding pencil, moving from one activity to the next)	
	Start using a visual schedule at home, to get your child used to knowing what is happening in a day, and ending up one activity to proceed to the next	

Transitions within the Primary Division (Grades 1 – 3)

- **All students in the primary division are developing the foundational language, Math and social skills that they will build on for the rest of their lives.**

- **Students with Down syndrome are no different: while their classmates are learning to express themselves accurately, read and do Math, the student with Down syndrome also needs to engage in those areas, possibly at a different level.**

- **From Grades 1 – 3 the student with Down syndrome should be able to learn from practical Science and Social Studies activities, participate in Music, Art, Drama and Physical and Health Education, and follow the class routines.**

- **They will not be indistinguishable from their peers, but all students in Grades 1 – 3 are on the same learning journey, and they all benefit from strong teaching techniques such as the use of visual images, hands-on experiences and scaffolded tasks.**

Moving from the Primary Division to Junior Division (Grade 3 to Grade 4)

Some of the differences between primary and junior instruction and learning may affect the transition of students with Down syndrome from Grade 3 to Grade 4 and through the Junior Division:

Primary Division Focus	Junior Division Focus	Implications for Students with Down syndrome
Learning to read	After they have developed reading proficiency, students in Grades 4 – 6 are expected to “read to learn” about more complex subjects	Most students with Down syndrome will continue to need work on decoding print and understanding what they read
Mastering the basics of six strands of Math	Six strands of Math investigated in greater detail	Many students with Down syndrome will benefit from focus on topics in the Number and Financial Literacy strands
Connecting content area subjects (Science, Social Studies) to students’ lived experience	Content area topics get more abstract	Many students with Down syndrome will need practical, hands-on ways to investigate topics like “biodiversity” and “matter and energy”
Physical layout of classroom encourages group work, communal learning	Physical layout of classroom may lend itself to more individual work	Students with Down syndrome will have individual reactions to this change; some will benefit

Moving from the Junior Division to Intermediate Division (Grade 6 to Grade 7)

Some of the differences between junior and intermediate instruction and learning may affect the transition of students with Down syndrome from Grade 6 to Grade 7 and through the Intermediate Division:

Junior Division Focus	Intermediate Division Focus	Implications for Students with Down syndrome
Teacher assigns and supports independent work	Students work on multi-part tasks and projects with a growing degree of independence	Some students with Down syndrome will have a capacity for independent tasks and projects if the topic is of interest (see Gabby Seewald's outstanding "Sharks" research project, cited in a new teacher training text: https://sites.google.com/view/gabby-q-seewald/my-passion-project), while others will need significant adaptation of these expectations
Teacher uses multiple methods to transmit information	Teachers tend to use talk/informal lecture as a central teaching methodology	Many students with Down syndrome have difficulty comprehending extended talk about abstract topics
Topics studied range from ancient times to present, in local and international contexts, and require imagination to deeply understand	Topics may also require critical thinking and the examination of assumptions (i.e., to detect "bias")	Thinking about thinking can be difficult for students with Down syndrome, but their opinions and experiences can be solicited and incorporated into class discussions
Friendships and co-working relationships are very important to students	Friendships, social relationships among students are nuanced and shifting	Students with Down syndrome may play similar video games, listen to similar music, and cheer for the same teams as their peers – social connections can still be strong

Through Grades 1 – 8, Transition Tips for Parents

- ✓ Maintain communication with teacher and other professionals
- ✓ Keep notes on new learning by your child, “what’s working” at home
- ✓ Read every report card (issued three times per year)
- ✓ Attend parent/teacher conferences, school events where possible
- ✓ Consult periodically on adjustments to the IEP (the IEP is a “living document” which should be reimagined when new learning, or other issues present themselves)
- ✓ Keep teaching team up to date on child’s involvement in clubs, sports, camps, travel, religious and cultural traditions and other learning opportunities
- ✓ Support child with homework and project completion, skills practice

And Then There Are Daily Transitions ...

While it is important for families and the school team to think carefully about yearly transitions, the daily and hourly transitions that are an inevitable part of elementary school can also be a significant source of stress for everyone involved. Anyone who has seen a child with Down syndrome out on the playground long after their peers have returned to class must have wondered why that transition couldn’t have gone more smoothly.

According to Dr. Susan Fawcett of the Down syndrome Research Foundation, the average teacher makes 300 – 400 demands of their students every day.[1] These demands often relate to changes in plan and transitions, and immediate compliance is expected. Children with Down syndrome have traits that mean that school demands can strike them in a unique way. Dr. Fawcett offers tips and guidelines for creating better daily transitions, which are equally applicable at home and school.

---

[1] Fawcett, Susan. Presentation, Canadian Down Syndrome Society Educator Conference, May 10, 2019

Understanding Transition Challenges for Students with Down syndrome[2]

Down syndrome Characteristic	Why this complicates transitions	Possible Remedy
Low levels of intrinsic motivation	Students with Down syndrome may have little desire to do the next activity They sometimes hesitate to abandon an activity they are currently enjoying merely because the timetable requires it	Inject a bit of fun (i.e., "Let's sing while we put these blocks away.") Bridge with enjoyable options (i.e., "Okay, Luis. Assembly is over. You can walk back to class with Renee.")
Difficulty processing verbal instructions	Students with Down syndrome may shut down because they don't understand	Avoid lengthy explanations which may be bewildering (i.e., "It's Science time, Fatima. Remember when we planted those beans last class? And you added water and we wrote your name on the jar? Well today you are going to make observations of your bean plants. Won't that be fun? Come on – hang up your coat – let's go. Everyone else is sitting down already." should be shortened to "Coat on the hook, Fatima. Remember your bean plant?")
Impaired memory and inability to predict	Students with Down syndrome often cannot picture what comes after the transition	Use words economically to create mental images (i.e., "We are going inside now and ... calculator time!")
Good social awareness	Students with Down syndrome are often adept at distracting and wasting time to delay difficult activities	Use social interactions as rewards for compliance (i.e., "When you finish your story you can read it to Mrs. Singh!")
Enjoy emotional exchanges of any type	Students with Down syndrome may be non-compliant just for the fun of creating a stir	Use a calm, neutral tone of voice when correcting a student with Down syndrome who is misbehaving during a transition, insist that they comply, and then praise them enthusiastically when they do. Reserving your own high energy and emotion for successful transitions is a way of ensuring there will be more.

---

2. Fawcett, Susan. See above.

Successful transitions are crucial at school and at home. Teachers and parents of children with Down syndrome must understand why the child reacts the way they do, and structure daily transitions so that they appeal to the child's strengths and interests, rather than directly intersecting with their vulnerabilities. Teachers and parents must also believe in their right to expect that a child with Down syndrome will transition appropriately and be consistent and firm in their approach.

Focus on Communication and the Student with Down syndrome

In the elementary years, the communication issues of students with Down syndrome will continue, so the need for communication support remains unchanged. Ideally, students with Down syndrome will receive support with their communication skills from several sources:

1. The Speech Language Pathologists and other communication professionals employed by the school board and/or the Local Health Integration Network (LHIN)
2. The instructional team at the school, which will work with the student to support their receptive language skills and help them express themselves in both academic and social contexts
3. The family, which will employ supportive strategies at home, and look for opportunities to expose the student to stimulating language experiences when the child is not in school

The research on the unique communicative abilities of children with Down syndrome has not reached fixed conclusions, but there is a consensus on some points. Everyone agrees that **children with Down syndrome have large deficits in expressive speech and language**. This means that they speak less frequently than their classmates, and their utterances are less developed, and use more fractured grammar, than the utterances of typically developing children who are years younger. Children with Down syndrome fare slightly better in terms of receptive vocabulary: they sometimes understand words they cannot yet use themselves. Surprisingly, there seems to be little correlation between the communicative ability and the intelligence of students with Down syndrome, which means that they can be quite capable while being communicatively compromised.

Research findings have also concluded that **students with Down syndrome demonstrate great difficulties with intelligibility**. In fact, most elementary-aged students with Down syndrome have significant difficulty being understood by anyone outside their closest circle.

There are several repercussions of these findings:

1. **The expertise of Speech Language Pathologists and other communication professionals is essential to the school success of students with Down syndrome.** SLTs may have to consider giving diagnoses to students with Down syndrome that have not commonly been allocated to them in the past. Dyspraxia is rarely acknowledged in children with Down syndrome, but many of these students have the characteristics to justify such a diagnosis and giving it to them might be a significant move in getting them the support they need.

2. When students with Down syndrome are seen by speech language pathologists, these professionals may instinctively use the same techniques that they use for typically developing students. **Given the unique speech and language profile for young people with Down syndrome, however, SLPs may have to tailor their methods and their techniques**. As an example, Dr. Shelley Velleman has argued for "phonotactic" rather than "phonetic" therapy, with a focus on "word or syllable shape" as a possible way of addressing the special challenges faced by students with Down syndrome. (Velleman, S. L. (2002). Phonotactic Therapy. Seminars in Speech and Language, 23(1), 043–056.)

3. The current division of responsibility for the same child being shared between should be monitored to efficiently leverage the length of service (school board SLPs deal with their language issues, while Local Children's Treatment Center's SLPs deals with their articulation and phonetic issues). ("He/she has received service for four years – there's nothing more we can do.") must be re-examined. The communicative profile of students with Down syndrome is more complex, and requires more intervention, than previously understood. **IEPs should reflect the ongoing and genuine requirement for students with Down syndrome to receive expert language support for longer than has been offered until now.**

4. **The teaching team at the school will benefit from professional development** on how to ensure that the slightly higher receptive capabilities of the student with Down syndrome are met, while their weaker expressive capacities are supported. There are many resources around to address this need. (See Communication Resources section below.)

5. **Families must continue to read to their children, even as they progress through elementary school, and take all other opportunities to support their children to communicate clearly and accurately about the topics that interest them.**

NB: *No IEP for a student with Down syndrome, at any grade level, is complete without a plan for the development of the student's verbal communication skills. There are opportunities to support and extend the communicative ability of students with Down syndrome in every academic subject.*

The Speech Language Pathologists and other communication professionals employed by the school board and/or the Local Children's Treatment Center's. Speech and Language services can be accessed through **https://www.ontario.ca/page/childrens-rehabilitation-services**

The following techniques, used both at home and at school, are appropriate to students with Down syndrome as they move through the elementary years:

- **Supplement speech with gestures** [i.e., "Liam, do you predict that the magnet will attract (gesture or sign) the button or the paperclip? Okay – let's see you try! Let's see if it attracts (gesture or sign) the paperclip. Good! What happened? (Student responds.)"]

- **Read stories and academic material one-on-one with the student and review important words and phrases** [i.e., adult reads an illustrated Indigenous legend: "The Creator placed the swimming creatures in the water. He placed the crawling things and the four-legged animals on the land. He gave life to all the plants and insects of the world." Okay ... so show me a "swimming creature". What do you call that? (Student responds.) Yes – a fish. Now show me a "crawling creature" .... etc."]

- **Direct the student's attention to interesting things and narrate with a focus on key terminology** [i.e., "Watch Shakina. She's going to serve. Look what she does – she hits the volleyball with her fist. Can you show me your fist? Okay! I'll hold the volleyball up high, you hit it with your fist. ... Nice! One more time!"]

- **Leave communication gaps that require student input** [i.e., before the student logs on to their iPad, EA asks, "Are you going to choose a Math game or a spelling game?" and requires the student to respond, with gesture or words, before they can start]

- **Employ extended wait times to allow the child time to formulate a verbal response without additional talk** [i.e., teacher asks student, "Take a look at the colour wheel, Pierre. Which colour complements green? ..... pause of 7 seconds ...... "Which colour is opposite green?" ...... pause of 8 seconds ...... Pierre: "Red."]

- **Respect home languages.** There are many examples of bilingual children who have Down syndrome. Communication in two languages offers cognitive advantages to all students.

Focus on the Curriculum

Elementary students in Ontario transition through eight grades, three divisions and multiple subjects. A student with Down syndrome in Grades 1-3 (the Primary Division) will find many of the subjects are closer to their learning level than some of the subjects in Grades 7 and 8 (the Intermediate Division). In this circumstance, the IEP takes on great importance, as it represents an evolving plan for making school relevant and accessible for the student with Down syndrome over their eight-year elementary school experience.

Following are some important tips for Parents and Teachers when collaborating to improve Elementary IEPs for students with Down syndrome:

1 CONSULT EARLY AND OFTEN WITH THE FAMILY

The family of the student with Down syndrome has been observing their young person's growth and developing interests, and they are aware of their skill level. Before the IEP is finalized, teachers should consult with the family to see if they have any contributions, ideas or concerns.

2 ALWAYS ASSESS

Receiving teachers should base their IEP discussions on assessments of the academic skills of their new student with Down syndrome. It is not enough to read last year's report card or ask the Educational Assistant, "So ... how is her reading?". Rather, the teacher should take the time to sit with the student with Down syndrome while they do Literacy and numeracy tasks, in order to develop a personal sense of the student's skill profile.

3 PRIORITIZE SKILL DEVELOPMENT OVER THE MEMORIZATION OF CONTENT

In their future lives, students with Down syndrome will benefit more from having strong Literacy and numeracy skills and the ability to communicate and be understood, than if they have specific information that they may not find relevant, i.e., "Three types of landforms." The best IEPs for students with Down syndrome prioritize their Literacy and numeracy, communication and Learning Skills, while promoting their natural interests and their strengths.

4 SET AMBITIOUS EXPECTATIONS

Families and teachers who expect that young people with Down syndrome can learn and do well in school will usually be rewarded, because ambitious expectations have an effect. Most students with Down syndrome will learn to read, some very well, and many will learn to write to express their thoughts. Most students with Down syndrome will develop content area subject preferences (some are eager to work on science topics, while others will prefer Geography or History). Many students with Down syndrome eventually develop skills (some can sing, others can act, others are exceptional athletes) that that are genuinely remarkable. Setting and maintaining high expectations, then, is appropriate because students with Down syndrome are capable of meeting ambitious goals.

5 CONSULT THE EXPERTS ON TEACHING STUDENTS WITH DOWN SYNDROME

Down syndrome is a complex condition, and it is not yet fully understood by scientists or researchers. One thing is clear: common sense ideas of how to educate student with Down syndrome are insufficient for teaching students who have this diagnosis. Rather, it is important to refer to the resources that have been created by people with deep experience in the field.

There are three outstanding sources of resources on teaching speech, reading and Mathematics to children with Down syndrome.

- Down Syndrome Education International offers resources, how-to materials and research reports which originated in the outstanding 30-year career of Professor Sue Buckley. https://www.down-syndrome.org/en-gb/resources

- The Down Syndrome Research Foundation (DSRF) was established in British Columbia by Jo Mills, a physiotherapist who developed an interest in the needs of children with Down syndrome. It is now Canada's preeminent source of research and practical resources for classroom teachers and parents of young people with Down syndrome. https://www.dsrf.org/

- The Canadian Down Syndrome Society has also developed and posted excellent resources for families and professionals at all levels of the education system. https://cdss.ca/

A Note on Behaviour:

There are several stereotypes about students with Down syndrome, such as the notion that they are routinely sweet and good-natured. Some teachers are surprised, then, when students with Down syndrome exhibit negative behaviour. Teachers and Educational Assistants have reported that students with Down syndrome can be stubborn, contrary and rude, and they are often deliberately disobedient. Students with Down syndrome also run away more than other students.

Why might this be?

There are several contributing factors:

- Some children with Down syndrome **prefer attention and emotion, even if it is negative**, over an absence of attention and emotion, so they engage in negative behaviour just for the pleasure of the ensuing exchanges.

- Other children with Down syndrome **need time to process** what is being asked of them or something that has just happened; when they aren't given sufficient processing time, they can be angry or rude.

- Sometimes **students with Down syndrome shut down if they are subjected to a barrage of language**, i.e., "Time for Math, Zion. Get your Math book out. No – not that one – your Math book. Come on – you love Math; Math is your favourite, isn't it? Let's go – Math book in three. Three, two... come on – Math is going to be fun today. I need you to have your Math book on your desk. Make a good choice!"

- Students with Down syndrome consistently demonstrate **an impulse to avoid extending themselves to do difficult things.** In order to avoid tasks that strike them as difficult, **they overuse their considerable social skills**. Sometimes they accomplish this by being distractingly cute (there are examples in the literature of babies with Down syndrome, only months old, blowing bubbles and successfully distracting scientific researchers from the experimental tasks they were conducting!). On other occasions, a student with Down syndrome will use their social skills in a negative way and say or do something rude or difficult that succeeds in getting them away from the task they hoped to avoid. Running away to avoid a challenging task or to have the fun and distraction of being chased is a common strategy.

What can be done to minimize negative behaviour?

A

Give attention and emotion to the student with Down syndrome when they are doing what you ask. Keep your reaction and feedback to a minimum when they are knowingly causing difficulties. Flood them with positivity when they get back on track and join the target activity.

B

Allow processing time. When the student is processing the demands of a task, avoid overwhelming them with language. Where possible, be silent until the student has had time to think through their feelings about a particular situation. **It may feel awkward to wait ten seconds or more** for a response but wait time can be a key factor in lessening difficult behaviour.

C

In rare circumstances, in response to a student's negative behaviour, the teacher may have to acknowledge that the b**ehaviour is a form of communication**: perhaps a classroom task is actually beyond the student's abilities. In that circumstance, it is appropriate for the teacher to adjust their demands. Alternately, the student may be communicating boredom and may require more varied activities than they currently are being offered.

D

Otherwise, the best way to reduce negative behaviours is to **set firm expectations and insist that the student with Down syndrome stay on track.** This requires the teacher to be aware when the student is trying to avoid a daunting task, to calmly restate the expectation and to redirect the student as necessary.

Communication Resources

At its 2019 Educators Conference, the Down Syndrome Research Foundation recommended the following resources on communication:

Kumin, L. (2001). Classroom language skills for children with Down syndrome: a guide for parents and teachers (1st ed.). Bethesda, MD: Woodbine House.

Kumin, L. (2012). Early communication skills for children with Down syndrome: a guide for parents and professionals (3rd ed.). Bethesda, MD: Woodbine House.

Kumin, L. (2008). Helping children with Down syndrome communicate better: speech and language skills for ages 6-14 (1st ed.). Bethesda, MD: Woodbine House.

Pepper, J., Weitzman, E., & Manolson, H. A. (2004). It takes two to talk: a practical guide for parents of children with language delays (Fourth edition.) Toronto, Ontario: Hanen Centre.

https://teachmetotalk.com/ (Website of Laura Mize, SLT)

Secondary School Transitions

Secondary School Transitions

Checklist for Parents: The Process

Before Grade 9

GRADE 8 YEAR	SUMMER	EARLY FALL of GRADE 9
Research secondary school programs/options in your area	With student, practice different "school" skills (i.e., new transportation routines, changing for Phys Ed, using a locker and lock)	Assemble ideas you may have for IEP
If the schools can accommodate it, visit preferred programs with your young person, discuss and compare	Do regular "drive-bys" of the secondary school to discuss the transition and allay any concerns	Find mutually convenient time to discuss IEP with Spec Ed team/teacher and/or subject area teachers
Apply to attend the program/school you have chosen		With school team, discuss potential issues early on in school year, to head off larger difficulties
Prepare for and participate in IPRC		
With your young person, discuss transition to Grade 9 and the new learning model		

Through the Secondary School Years

- As practicable, maintain communication with teachers and other professionals
- Keep notes on new learning by student, "what's working" at home
- Read every report card
- Attend parent/teacher evenings, school events where possible
- Consult periodically on adjustments to the IEP (IEP is a "living document" which should be reimagined and updated as new learning / difficulties present themselves)
- Keep the teaching team up to date on student's involvement in clubs, sports, camps, travel, religious and cultural traditions and other learning opportunities
- Support child with homework and project completion, skills practice

Issues Unique to Secondary School

The transition of students with Down syndrome from Grade 8 to Grade 9 is not just a change from elementary into secondary school: it is also a transition to a different set of practices and a different educational culture. It is important for families and students to be aware of how secondary schools are organized and how they operate, and the unique opportunities they offer.

1

Multiple models, Varying degrees of inclusion, Academic focus?

There is a wide range of programme models for young people with Down syndrome who are enrolled in high school, and it is important to conduct thorough research about the various programmes and the different models they use. Different school boards, for a variety of reasons, offer different instructional options, or placements, to students.

These are the most common models:

Full inclusion: students with Down syndrome take all their classes with typically developing peers

Partial inclusion: there is a separate program for students with developmental disabilities, which they leave for part of the day to take courses with their typically developing peers

Specialized program: a separate program for students with developmental and other disabilities, where they spend the full instructional day

Some school boards maintain these models until the student with Down syndrome is 18, and then the student is invited to convert to a different program, with a focus on transitioning to life in the work force or at college or university.

The family and the student with Down syndrome should visit and compare the available program options. **One of the key questions to investigate is: what is the degree of academic focus of the program?**

- Some students with Down syndrome want to continue to improve their Math and Literacy skills and follow up on areas of academic interest such as Science or Information Technology or Drama. These students might prefer a program where they can continue to be involved in the mainstream academic activities of a school.
- Other students with Down syndrome may wish to focus on developing practical skills for life after secondary school. They may wish to attend a specialized program where they can practice life skills such as cooking and doing laundry.
- Many students with Down syndrome and their families have a strong interest in the work they will do after secondary school. They may wish to attend a specialized program where they can discover and build their vocational interests, skills and plans.

2

Increased Independence

For all students, secondary school is a time of increased independence, and for students with Down syndrome, increased independence may be exactly what they are wishing for. Their family members should keep informed about the degree of independence the student with Down syndrome has at school, and how they are managing it.

Some scenarios to be alert to:

Is the student with Down syndrome monitored by school personnel to an appropriate degree? (Every Ontario school has the safety of all students as the top priority, but your child may be capable of more, or less, independence than the school is offering.)

With whom does the student with Down syndrome have friendly relationships? Parents may be delighted to learn that the cafeteria staff or the Math teacher or a fellow student know and appreciate their child, and that their child has independently formed bonds with people at school.

Does the student have roles in the school that accord them respect and social value? If your child is managing the props for the school play, they will probably earn the respect of their peers. If they are assigned the job of spraying the tables in the cafeteria, they may not experience what the experts call "social role valorization".

3 Secondary School Organization

Secondary school is organized quite differently from elementary school.

In secondary school, the year typically is divided into two semesters, and in each semester, students study 4 subjects in four 70-minute periods per day. This means that a student has four different teachers in one semester, and it is possible that they will have another four different teachers in the second semester. It can be challenging for teachers to get to know the strengths and needs of students with Down syndrome in the hectic days at the beginning of the semester, but nevertheless, the teachers are expected to describe on the IEP how they plan to accommodate the exceptional students in their classes.

Another significant difference is that the amount of communication with home is generally reduced, for at least two reasons: 1) student independence is valued, and 2) every teacher who teaches an academic class may be teaching up to 90 students a day. In those circumstances, communication with individual families can be challenging. This makes IEP meetings and parent-teacher nights particularly important, as they represent key opportunities for family and caregivers to interact with the school team.

4

Unique Opportunities in High School

Would your young person enjoy being involved in **student government?**

Would they like to play on or manage a **sports team?**

Do they aspire to appear in the **drama, dance, art or music show**, or **sing in the choir?**

Would they like to be involved with **fundraising, volunteering, or mentoring?**

Would they like to belong to a **club or group**: photography, Gay-Straight Alliance (GSA), or the pastoral team?

You and your young person with Down syndrome may wish to keep a record of their passing interests and hopes, as school personnel would certainly be open to discussing the extra-curricular interest of your young person with Down syndrome.

About the Curriculum

Some students with Down syndrome arrive in secondary school at age 14, and don't plan on leaving until age 21. That makes for a long secondary school career, and it is important that the curriculum continues to evolve to meet the needs of these students.

It is clear, when a student with Down syndrome moves from elementary to secondary school, and particularly when they attend an IPRC with their family members to discuss their first daily schedule, that this is an exciting transition.

After that, however, the moves from secondary grade to secondary grade are more subtle (i.e., when they move from Grade 9 to Grade 10, the student doesn't necessarily change rooms or teachers as they do in elementary school), and indeed the impetus to keep updating the curriculum in some secondary school programs can lessen, and the transition can lose energy and purpose.

Parents and guardians of a student with Down syndrome in secondary school may have to be particularly vigilant. If they sense that their child's learning has slowed or stalled at some point in their secondary school journey, they may want to:

1) Keep secondary teachers and others energized about the continued learning potential of their student with Down syndrome, and

2) Suggest that the teaching team consult Down syndrome-specific teaching resources when drafting the student's IEPs.

Students with Down syndrome can improve in many skill areas in their Secondary school years. Following are some key resources that have the potential to bring new ideas and teaching strategies to secondary educators:

Hodgdon, L. A. (1995). *Visual strategies for improving communication: practical supports for school and home*. Troy, MI: Quirk Roberts Pub.

Horstmeier, D. (2004). *Teaching Math to people with Down syndrome and other hands-on learners* (First edition.). Bethesda, MD: Woodbine House.

Oelwein, P. L. (1995). *Teaching reading to children with Down syndrome: a guide for parents and teachers*. Bethesda, MD: Woodbine House.

Have you applied to the Passport Program?

What is it?

The Passport Program is a program of Ontario's Ministry of Children, Community and Social Services. It offers financial support and guidance to families of people over the age of 18 who have developmental disabilities.

Why should we apply?

This funding has two purposes:

1) It allows the family to hire a person or people who can offer relief and supports
2) It helps the family pay for activities and projects that will lead to the further community involvement, independence, and flourishing of the person with Down syndrome.

How do we apply?

Search Passport funding online or follow this link:
https://www.ontario.ca/page/passport-program-adults-developmental-disability

You probably already have much of the documentation you will need for this application, and you can get help with your application from community agencies if you find the process challenging. There are several steps to this application, one of which involves meeting with a representative of Developmental Services Ontario (DSO) to gather information and discern potential opportunities for your young person with Down syndrome.

Your application, once approved, may be placed on a waitlist, which means your family may not immediately start to receive funds.

What have families used their Passport money for?

With Passport funds, families of young people with Down syndrome have been able to:

- Hire a personal trainer and purchase fitness equipment for the young person with Down syndrome
- Start a business for the young person with Down syndrome to manage
- Engage a support worker to travel to England with the person with Down syndrome
- Enrol the person in tai chi and pottery making classes

Transition to Post-Secondary Life

Transition to Post-Secondary Life

FOCUS ON THE PROCESS

As challenging as the other transitions can be, parents and caregivers usually dread the transition to post-secondary life the most. The school system offers young people with Down syndrome a safe, engaging environment for five days a week, ten months of the year, and after secondary school ends, it falls to the families to support their young person in constructing a new life. As frightening as this prospect may be, however, it can also be a source of new opportunities, new learning and significant personal growth.

There are several factors that must be acknowledged if this transition, which will unfold over months and years, is to bring a good life for this generation of young people with Down syndrome and successive generations:

1. Government, regardless of its political orientation, is a slow-moving engine of social change. Families cannot count on government programs to be the single source of solutions for their young people with Down syndrome.

2. Some government programs offer solutions that do not work for young people with Down syndrome, anyway. By promoting a philosophy of “independence” when many people with Down syndrome do better in an ethos of “interdependence”, families should continue to work with schools and decision makers to find individualized solutions that lead to optimal solutions to the question of how to make a good life for adults with Down syndrome.

3 Smaller, local associations, such as Down Syndrome Associations and Community Living groups, while they may not see themselves as powerful, might be in a good position to understand and helpfully address some of the needs of young people with Down syndrome in a particular local area.

4 Groups of parents can be very powerful in articulating a vision of the kinds of innovations that are needed to secure the future of their young people with Down syndrome, and they can support each other, share information and help create solutions.

The prospect of their transition to the post-secondary world for young people with Down syndrome sometimes inspires hopeless comments like, "There's nothing out there!", or "It's like falling off a cliff – with no safety net!"   It is understandable that families feel concerned, even panicky, but a systematic approach might yield up more options than expected.

A systematic approach to the post-secondary transition could look like this:

1 Construct a vision of what a good life for your young person might look like, in the immediate and slightly-longer-term future. The young person with Down syndrome should be consulted in the design of this vision.

2 Survey the local agencies that work with young people with Down syndrome and gather information on the available options and programs. Follow up on co-op placements and other transition experiences your child may have had, while in secondary school.

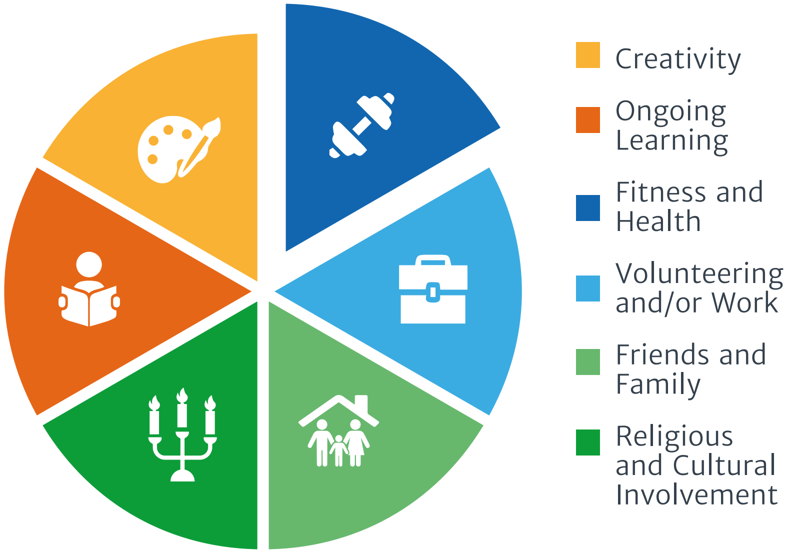
3 Network with other parents to share ideas, information and services.

PROCESS STEP 1
CONSTRUCTING A VISION OF YOUR CHILD’S LIFE

As the experts in this field often assert, people of all abilities who have a high quality of life usually fill their lives with a wide range of meaningful experiences. Below is a representation of the basic components of a good life that should be included in any “visioning” exercise.

Remember: if there is a disproportionate emphasis on one sector (“He/she has to get a job!”), it can lead to the neglect and disregard of other potentially enriching activities.

The components of a good life



It is very important to centre the opinion and past successes of the young person with Down syndrome in any process to arrive at a vision for their life. Many families have found that a consultative process where family members of all generations, past teachers and coaches, and other significant people are consulted, can lead to “outside the box” thinking and networking.

The following are examples of activities that have contributed greatly to the post-secondary lives of young adults with Down syndrome around the province:

Involvement in their religious / cultural community (attending religious and cultural events, learning sacred music or rituals, contributing to the community, volunteering at events, taking Tai Chi classes)

Creativity (visual arts, dance, drama, fashion design and sewing, making TikToks, DJing, joining an improv group or drum circle)

Fitness and health (Special Olympics, developing cooking skills, learning to do yoga, working out, walking/running, playing golf, belonging to a bowling league)

Volunteering and/or Work (volunteering at the food bank, in a seniors’ centre, canvassing for a political party, part- or full-time employment)

Engaging with Friends and Family (visiting, offering childcare, contributing eldercare, planning birthdays and holidays, following a local sports team)

Ongoing Learning Experiences (travelling, enrolling in classes, taking pottery classes, learning to work in watercolours, taking college or university courses)

Additional Comments:

A Once a vision is arrived at, families should not feel pressured to support the young person to do all their preferred activities at once. Some things can wait, and people's interests evolve! It is important to keep a record of the results of the visioning work, however, because real life can intrude and good ideas can slip away.

B There are other, weighty questions that may impinge upon visioning exercises for young people with Down syndrome, including the complex issues of housing, transportation and financial support. There are resources that offer guidance on these complex topics. One of the best is **Safe and Secure: Six Steps to Creating a Good Life for People with Disabilities**. This book was written by Al Etmanski, a founding member of the PLAN Institute for Caring Citizenship. Among other themes, it stresses the importance of families banding together to create the changes their young people require, and engaging in political action to alert government to the inclusive policies and services that are needed.

PROCESS STEP 2
SURVEY LOCAL AGENCIES AND PROGRAMMES

It is important to know which agencies in your area offer programmes that are appropriate for young adults with Down syndrome.

The obvious first choices are the local Community Living organization, the local chapter of Special Olympics and agencies that do employment support and job coaching, but there are often numerous other organizations and opportunities that parents might not know about, when they are embarking on the transition to post-secondary life.

After studying their websites, connect with the agencies and learn how they might be able to support your child. Because it is easy to forget about programs that might indeed be helpful and appropriate for your young person with Down syndrome, it is acceptable to request a recurring annual interview, on an ongoing basis, to learn if new programmes have been launched, and to keep your young person's needs and interests on their radar.

When your child was a secondary school student, they may have made connections with prospective employers through co-op and work placements. It is a good idea to return to those connections during the transition to post-secondary life, to learn if they may want to offer additional opportunities to your young person, or if they might have advice about further training that would benefit them.

PROCESS STEP 3
NETWORK WITH OTHER PARENTS

Some families find it exhausting to survey all the possible opportunities for their young person with Down syndrome, and they would be right – it is a lot.

The solution is to band together with other like-minded people who have family members who need similar supports, and to share information and insights. By assembling a database of options, they support one another and get to solutions more quickly.

Families can cooperate to share more than research and information: they can share supports. Since transportation is a real challenge in the transition to post-secondary life, families who alternate driving responsibilities to deliver their young people to programs they both attend will find the mutual assistance very helpful. Families who provide social opportunities for a group of friends with or without Down syndrome (i.e., game nights, movie excursions, group dates at a club) make a generous gift to the whole community and may find that other families reciprocate. When each family approaches post-secondary transition on their own, it can be very tiring, but sharing the responsibility is a relief for everyone involved.

It may seem too much to ask, but it is important to remember that parents can innovate and organize, too. The Down Syndrome Research Institute (DSRI) was a summer camp/school that was founded in London by Andy Loebus, the parent of a young person with Down syndrome. Nothing like DSRI has existed in Ontario before or since Andy's initiative, which ran for 12 summers in London and also expanded to Peterborough, where it ran for 11 summers. Parent-initiated programmes are significant because they can address the real needs of families and young people with Down syndrome.

POST-SECONDARY EDUCATIONAL OPPORTUNITY: CICE

In community colleges across Ontario, the Community Integration through Cooperative Education Certificate Programme (CICE) offers opportunities for post-secondary students with intellectual disabilities to follow a two-year course of study. These are inclusive programmes, with competitive application procedures, but it is widely agreed that they send graduates out into the world with enhanced abilities and relevant job skills.

Ontario students with Down syndrome have attended CICE programs in various colleges around the province. They have had different living arrangements: some have bussed to campus from home, while others stayed in apartments near the campus, and a few have lived in residence. Some have taken out student loans to pay their tuition, while others have used their savings. All have agreed that community college was a wonderful experience which helped them develop their independence and problem-solving skills and provided them with clarity about their future career directions.

Here are links to some representative CICE program websites:

www.flemingcollege.ca/programs/community-integration-through-cooperative-education

www.lambtoncollege.ca/cice/

www.fanshawec.ca/programs/cit2-community-integration-through-co-operative-education/next

www.georgiancollege.ca/academics/programs/community-integration-co-operative-education/

www.saultcollege.ca/programs/community-integration-through-co-operative-education/community-integration-through

POST-SECONDARY EDUCATIONAL OPPORTUNITY: KING'S COLLEGE, LONDON

The Disability Studies Department at King's University College in London has created a program that uses a design that may be unique in the world. The program is called the Intellectual and Developmental Disability (IDD) Co-Learning Pathway, and it brings Community Participants (people with IDD) together with Disability Studies students to co-learn in specially designed courses. These courses centre the lived experience of the Community Participants and offer them many ways of communicating and learning with their King's College counterparts.

The IDD Co-Learning Pathway program is in the development stage, and it does not yet provide a full- or even part-time option for people with Down syndrome who are transitioning to post-Secondary life. It does, however, testify to the importance of expanding the range and type of post-secondary options that are available for young adults with Down syndrome.

RESOURCES

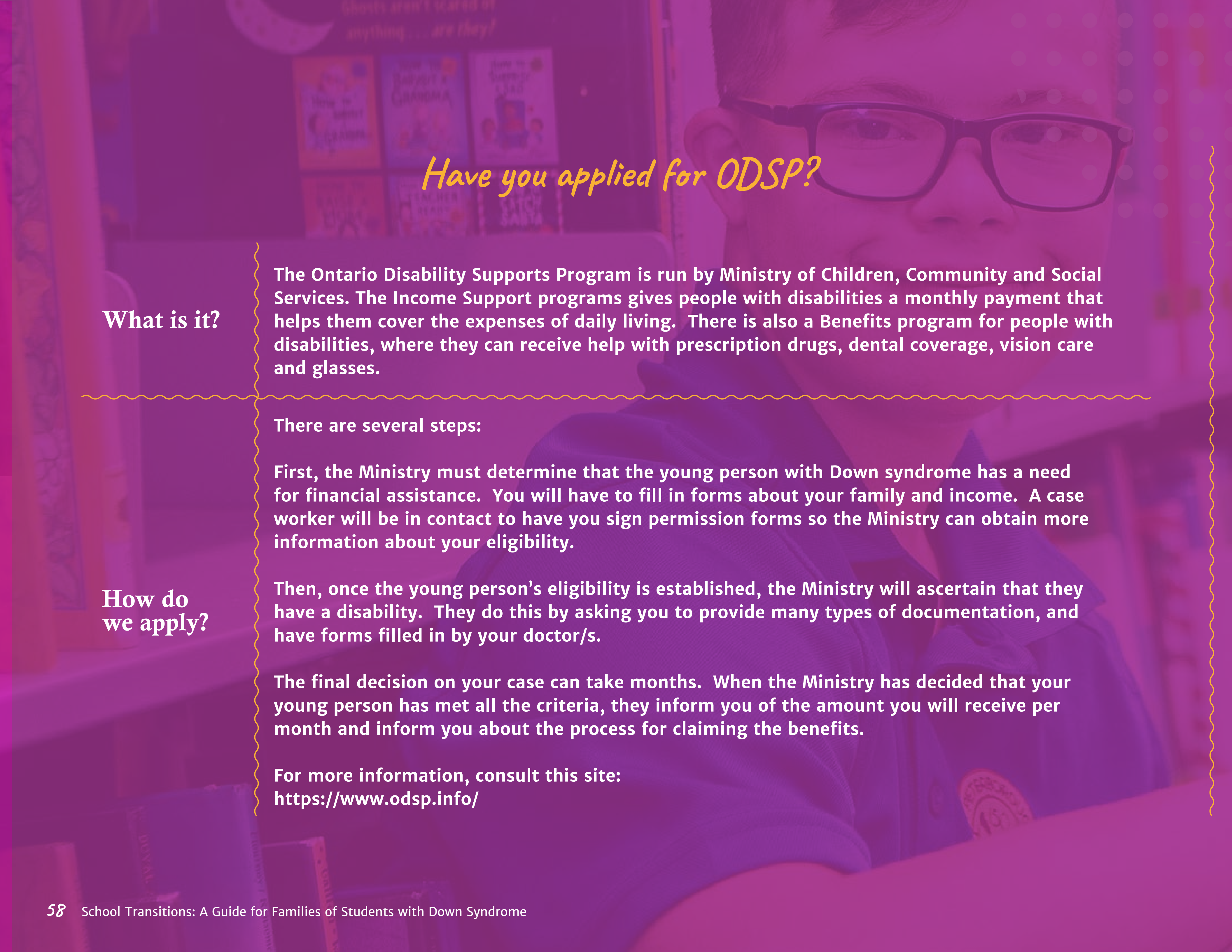
Adulthood lasts a long time, and people with Down syndrome and their families will encounter many joys and challenges as they journey together. It is important to stay up to date on the issues that may arise by reading ahead about issues and positive approaches. These are some key texts that can inform the transition to post-secondary:

Etmanski, A., Collins, J., Cammack, V., & Styan, J. (2009). Safe and secure: six steps to creating a good life for people with disabilities (RDSP ed.). Vancouver, B.C: PLAN.

Medlen, Joan E. Guthrie. (2006). The Down syndrome Nutrition Handbook: A Guide to Promoting Healthy Lifestyles. Portland, OR: Phronesis Publishing, LLC.

McGuire, D. E., & Chicoine, B. (2021). Mental wellness in adults with Down syndrome: a guide to emotional and behavioral strengths and challenges. Bethesda, MD: Woodbine House.

Simons, J. A. (2010). The Down syndrome Transition Handbook: Charting your child's course to adulthood. Bethesda, MD: Woodbine House.



Have you applied for ODSP?

What is it?

The Ontario Disability Supports Program is run by Ministry of Children, Community and Social Services. The Income Support programs gives people with disabilities a monthly payment that helps them cover the expenses of daily living. There is also a Benefits program for people with disabilities, where they can receive help with prescription drugs, dental coverage, vision care and glasses.

How do we apply?

There are several steps:

First, the Ministry must determine that the young person with Down syndrome has a need for financial assistance. You will have to fill in forms about your family and income. A case worker will be in contact to have you sign permission forms so the Ministry can obtain more information about your eligibility.

Then, once the young person's eligibility is established, the Ministry will ascertain that they have a disability. They do this by asking you to provide many types of documentation, and have forms filled in by your doctor/s.

The final decision on your case can take months. When the Ministry has decided that your young person has met all the criteria, they inform you of the amount you will receive per month and inform you about the process for claiming the benefits.

For more information, consult this site:
https://www.odsp.info/

Acknowledgements

Visit **www.schooltransitions.ca** for this digital guide and helpful forms

Jennifer Shields, BA, BEd, MA – *Writer and Editor*
Debra Reid, Down syndrome Advocate – *Project Director*

Brenda Stein Dzaldov, OCT, MEd, PhD – *Research and Writing*
Norma Christensen – *Research and Writing*

Rebekah Littlejohn – *Photography*

Domenic Gentilini, *DSAO Chair*

Creative Design
HUBNEST

Digital
union strategies

Digital
IMPRINT MG

Concept and Direction by:
DSAO DOWN SYNDROME ASSOCIATION OF ONTARIO

Funding provided by:
Ontario

The views expressed in this publication are the views of the DSAO and do not necessarily reflect those of the Province of Ontario

DSAO
DOWN
SYNDROME
ASSOCIATION
OF ONTARIO