

Holland Bloorview

Kids Rehabilitation Hospital

Advocacy Tool Kit

for parents of children and youth with
autism spectrum disorder (ASD) and other
neurodevelopmental disorders (NDDs)



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Autism Intervention Research
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This tool kit was created only as a guide for families to develop advocacy and negotiation skills and does not constitute medical or other professional advice.

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Contributors

This tool kit is based upon the original [Autism Speaks Advocacy Tool Kit](#) and we would like to acknowledge the original authors and contributors. The tool kit has been adapted to meet the needs of a Canadian audience.

We are indebted to a great team of people who contributed to the development of this Canadian version of the tool kit, including the co-chairs of the Autism Speaks Autism Treatment Network (ATN) Toronto Family Advisory Board (FAB), **Philippa Howell** and **Oksana Romanov** (Family Leaders), Holland Bloorview Kids Rehabilitation Hospital, the ATN Toronto site coordinator **Salina Eldon** (Holland Bloorview), the ATN registered nurse (RN) **Cathy Petta** (Holland Bloorview), **Lori Beesley** (Parent), **Jennie Ormson** (MSW), **Liam Cosgrove** (Self-Advocate), and **John Howell** (Parent, Holland Bloorview Family Advisory Committee Member).






June 15, 2018









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About this tool kit

The goal of this tool kit is to provide basic knowledge of advocacy and negotiation skills along with useful, practical tools. **Although this tool kit is primarily focused on autism spectrum disorder (ASD), the information contained is useful for families who have children with all types of neurodevelopmental disorders.** This tool kit will show how to apply advocacy skills to different situations throughout early childhood and adolescence. The content of this tool kit is adapted from the original Autism Speaks (US) Advocacy Tool Kit. Information in this tool kit has been provided by members (families and staff) of the [Autism Speaks Autism Treatment Network \(ATN\)](#)¹ [Autism Intervention Research on Physical Health \(AIRP\)](#) Toronto Site at Holland Bloorview Kids Rehabilitation Hospital. This project was funded by [Autism Speaks Canada](#).



How to use this tool kit

Download and save the interactive pdf to access all media links



The light blue text in this document indicates a link that you can click on for additional information. You will also find an extensive list of resources at the end of this document.

- Navigate through the pages by clicking on arrows at the top right of the page.
- Navigate through sections by clicking on tool bar located on the left side of the page.
- Use the map icon to access the map of Canada. You can then select your province or territory in order to access local resources.





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Part 1: What is advocacy?

Introduction

Advocacy refers to the process of supporting and enabling others to express their views, experiences, and concerns. When your child was given a diagnosis of ASD, you were probably introduced to a world you never imagined, full of unfamiliar terms and acronyms (e.g. ABA, IEP, SLP, BIP, etc.) – which can be different depending on where you live and what services your child may require.

See [TDSB Acronyms](#) as an example.

As a parent, you now have to navigate multiple systems (e.g. health care, education, insurance, and government). You need to be sure that your child is receiving the services to which they are eligible and that you pursue the services they require now and in the future. It's important for you to be able to speak up for your child's needs without alienating those who work with them and with you.

It's important that your perspective is heard, respected, and taken into account. Without being aware of your concerns, individuals cannot help address them or support you and your child. With your lived experiences and goals top of mind, be confident and reach out to people to ensure that your child's needs are met and gaining the best possible outcomes.

The importance of advocacy

Advocacy is important for many reasons. First, while we may think our concerns are or should be obvious, that is not always the case. It is important to communicate your views and concerns, alongside your desired solutions.

For example, your child's school may not recognize that you are unhappy with his or her progress or that there are ongoing behavioural issues at home that may benefit from support by the school team.

Advocacy comes in different forms: Systemic, individual, and self.

1. **Systemic advocacy** is when an agency or association speaks on behalf of their community (e.g. [Autism Speaks Canada](#), [Canadian Autism Spectrum Disorders Alliance](#).)

We speak on behalf of those who are unable to speak for themselves

2. **Individual advocacy** is when a person voices the needs on behalf of another individual (e.g. a parent speaks on behalf of a child, or a therapist makes recommendations)

I can speak up on behalf of another

3. **Self-advocacy** is when individuals with ASD advocate for themselves

I can speak up for myself

As a parent, you may be the person primarily responsible for supporting your child's future. As a result, it is necessary for you to be proactive in ensuring that their needs are met within the family, in school and ultimately, in the community. At some point, you may find yourself needing to advocate on their behalf for services, support, acceptance and inclusion.

It is also important that your child learns to advocate for him/herself, by developing self-advocacy skills. Depending on his or her age and ability, this can mean anything from communicating their preferences at home (e.g. *letting you*

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*know they'd rather have an apple than an orange for a snack), to communicating coping strategies at school (e.g. *learning how to let the teacher know that they need a body break*). An adult with ASD may have to learn how to let an employer know that they need a reasonable workplace accommodation (e.g. *a change in workspace lighting*).*

Self-advocacy is also crucial to remembering the importance of advocating for yourself (as caregiver), and providing opportunities for self-care.

The seven principles of advocacy²

The principles listed below may seem overwhelming at first. You as a parent or a caregiver will develop the skills necessary for each of these over time—and at your own pace. At times, family members (spouse, siblings, parents and even close friends) can help to reduce some of the load by sharing roles/tasks based on their strengths.



1. **Take responsibility – Be a leader:** Your child's future is in your hands. This is your chance to set goals and develop a plan of action. Decide what is best for your child.



2. **Learn – Be an expert:** Make a reading list. Include educational policies and protocols, and read them. Build a network of experts, who you might want to refer to or rely on for advice. Attend conferences, workshops and webinars. Educate yourself on translating [Internet science resources](#).



3. **Think critically:** Read and evaluate all the information you have before responding. Keep in mind your goal/goals, make a list of pros and cons, and be prepared to discuss and reach a compromise.



4. **Speak with authority – Be proactive:** Take the first step. You know your child best. Some strategies include: asking for a meeting with those you are advocating to, and providing helpful resources and documentation. Bring the cookies, be confident in meetings, and take notes.



5. **Document – Be prepared:** Keep your notes close at hand, and do your best to document everything. Documentation can also help you feel prepared and in control, and this information can then be shared with others as needed to support your child. Choosing a filing system is also critical, be it digital or paper, whichever suits you best.



6. **Collaborate – Be a team builder:** The aim is to achieve your goal/goals with everyone to whom you advocate. Contribute to their environment; volunteer where possible, and allow them to ask for your help or advice.



7. **Educate – Be a voice for your child:** Share your experiences, resources and sensitize others to the needs of your child and the community supporting him or her. Your lived experiences are important for other people to understand. This will in turn encourage or strengthen you in your role as an advocate.

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Steps to effective advocacy

Think of the advocacy process as a series of steps that can be taught and learned. Most of these steps relate to preparation.

1. **Identify the goal of your advocacy.** You may have one or several goals.

- What are you hoping to accomplish? Of course, your goal as a parent is to attain the best possible outcomes for your child. But what are you specifically hoping to achieve?
- What are some acceptable outcomes? Perhaps you have researched a program where you feel there is more benefit for your child and placement in that program would be your ideal outcome. Or is there a service that you need access to for your child?

2. **Develop a plan or strategy.**

- What facts and arguments support your position? What evidence can you gather to support your view – i.e. to demonstrate that there is a new opportunity or that something isn't working the way you'd like it to?
- If relevant, what rights do you have, what laws apply, what resources exist or what benefits or services are you entitled to? What is your child entitled to? How will you demonstrate that the program or service is not appropriate or could be improved?

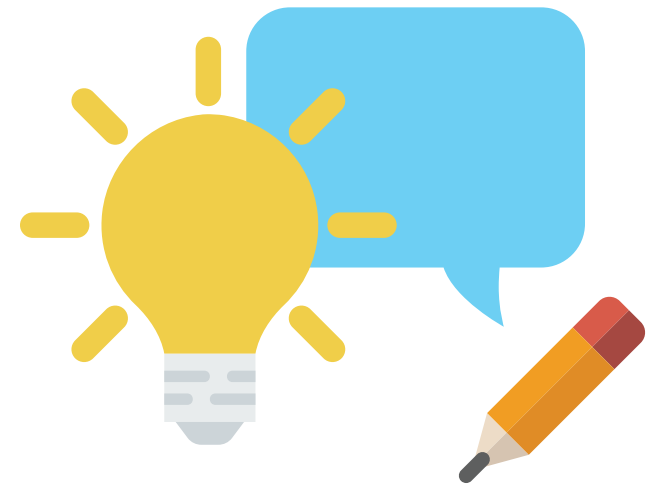
3. **Consider the perspective of the party to whom you are advocating.** The perspective of the other party, or the possible reaction to your advocacy, will not necessarily shape your goals. However, it should shape your strategy. Be mindful of both the concerns and the feelings of the other party and plan your approach accordingly.

You want to preserve a good working relationship with them, especially if they will continue to play a role in your child's education/community program. A variety of factors may shape the response you encounter.

- Anticipate and understand the situation, the individual's position and what information they are providing to you.
- How might you address issues or differences of opinion?

4. **Be aware of emotions – on all sides.**

- Your advocacy should be rational. It's important to avoid being governed by emotion and to avoid making your advocacy personal.
- The other party may be governed by emotion. It's important that they understand that your advocacy is based on rational considerations and is not personal to them.



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5. **Understand to whom you are advocating and to whom you ultimately need to advocate.**

- a. Does the person you are addressing have the authority to grant your request or resolve your situation? Are they empowered to grant your request?
- b. If you are advocating to someone who lacks sufficient authority, no matter how hard you press— and regardless of whether they are sympathetic to your position— they will be unable to grant your request. The goal of your advocacy with the team might then be to get them to support you in bringing your request to the appropriate level — to make them allies and not opponents.

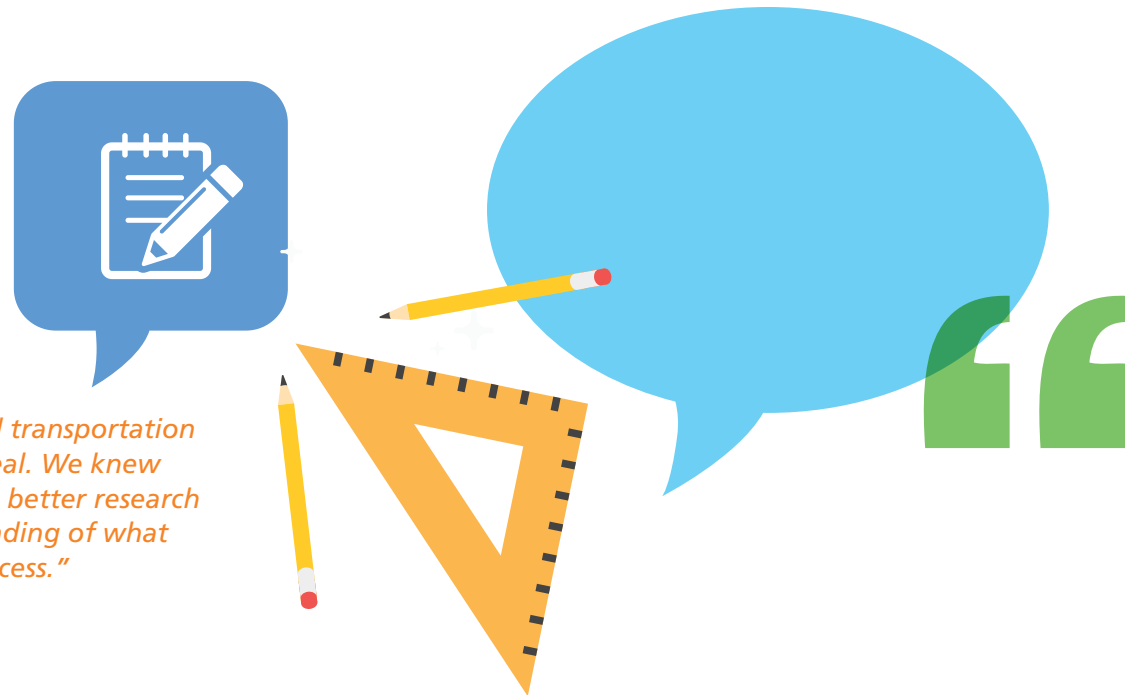
6. **Present your 'case'.** After thinking about your strategy, attend the meeting with those you are advocating to — let them know your concerns and point of view.

7. **Consider possible resolutions that might be acceptable to all parties.** Your child may be entitled to certain services as a matter of rights. In your advocacy, be open to and anticipate other resolutions that may be acceptable to all parties.

- 8. **Take notes or ask a companion to do this.** Write down the names and contact details of those present in the meeting. At the end of the meeting, list the outcomes of the meeting and make sure they are clear before you sign any documents. Ensure that you understand and agree to what you are signing. Define the next steps and schedule your next meeting before you leave the room.

“ After applying for specialized transportation and failing, we chose to appeal. We knew this meant that we had to do better research in order to gain an understanding of what the requirements were for access.”

Parent





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Part 2: Advocacy within your family unit

Introduction

When a family member is diagnosed with a developmental disability such as ASD, every person in that family is affected. Emotions may run high. In the beginning, family members may experience complex emotions such as grief, denial, relief, reassurance, sadness, anger and disappointment. Parents, siblings, grandparents and extended family may each have their own personal reactions.

Your loved one with ASD will have lifelong relationships with other family members, so you will need to develop strong foundations from the start. It helps to remember that raising all children, not only those with ASD, is a marathon, not a sprint. A diagnosis of ASD may be a new way of life. You may need to advocate for your child in many areas of his or her life, but first and foremost you will need to do so in the family arena.

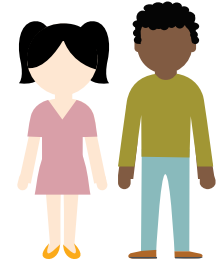
Roles within the family

Whether it is allowing additional time for your child with ASD to make transitions or having to cut short some family outings, over time your family will learn to adapt and adjust. Your first order of business is to provide a safe, loving environment for your child and your family. That means respecting everyone's needs.

Sibling needs

- For a sibling, it can be an adjustment to begin to understand that a brother or sister has ASD and what that means. What you can do: Talk to your children in clear and age-appropriate terms about what it means for their sibling to have ASD.

- Let them know what to expect. Be honest about the challenges, but be certain to talk about your child's many strengths. Let your children see how much you love their sibling with ASD for who they are.
- Let your children express the full range of their feelings in their own words.
- Let them ask questions and be prepared to listen to their feelings and thoughts with an open mind.
- Provide them with the resources to [learn more](#).
- Offer reassurance. Let them know that these feelings are normal and that the lines of communication are always open.
- Encourage your children to find ways to relate to their sibling with ASD. Help them find activities they can share and enjoy together.



“Being a sibling with two brothers with ASD can sometimes be hard because they are both very loud. It can also be fun because I like to watch them learn. When my brothers get more attention I think of it like this: there is a brother and a sister and one has all the diamonds in the world, and the other has all the gold in the world. Think of how that would make the person with all of the gold feel. Not that diamonds are more precious but they get a little bit more attention. Sometimes when my older brother has a meltdown I feel really bad for him because I know he can't help it.”

Sibling





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- Try not to cancel vacations or family celebrations. There are many activities you can enjoy as a family, with some accommodations, such as planning outings during quieter times of the day. Planning ahead can help alleviate stressful situations.

“We learned after several attempts that although our daughter loves to be outside, she doesn’t like to ‘live’ outside. As a family that camps often that was hard to comprehend. Now, she goes to respite and has a great time and we do something we love with her siblings.”

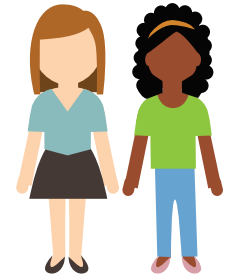
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- Give each child one-on-one time with each parent. A child with special needs may sometimes get the most attention in a family and other children may feel left out. Creating time to do something with your other children that they especially enjoy helps foster special moments together.
- Consider therapeutic ways to support family members (e.g. a guidance counsellor, a therapist, a sibling support group).
- Your children will sometimes encounter stares, comments or questions about their sibling. They may be embarrassed by their sibling’s behaviour and hesitate to have friends over. Teach them to answer questions directly by modeling appropriate responses. Every time you explain your child’s behaviour to an outsider, you can be sure your other children are listening. Teach them the language they will need to help advocate for their sibling.
- Teach them to advocate for their own needs by speaking up and take their complaints seriously.
- As they grow, keep them engaged in ongoing dialogue about their sibling’s future needs. Your children have a right to their own lives and to decide on the level of involvement they may someday have.

Parent needs

- Advocate for your own needs, too.
- Consider joining a parent advocacy group in your community. While everyone’s experience is different, it can be enormously empowering to see how other or more experienced parents advocate for their children.
- Above all, pace yourself. If you burn out, you’re not going to be able to help anyone.
- Ask for support when you need it. We’re all familiar with the saying that it takes a village to raise any child. Over time you will find or build your village.



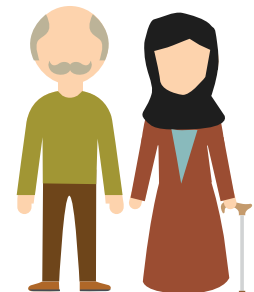
“After our first vacation together alone in 15 years, I asked my husband if he could always greet me first when he comes home from work before he hugs, kisses or listens to our children. I find it blows away all of my pent up anxiety and makes me feel like I’m part of a team.”

Parent



Extended Family Needs

- How or should you reveal your child’s diagnosis to extended family members? If your child is older and understands their diagnosis, take his or her feelings into consideration first and get his or her permission to share his or her diagnosis or any of the details related to it.





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Some things to consider:

- How often do you see that family member? Does he or she have daily or frequent contact with you and your family, or is this someone you rarely see? What is the relationship like with you/your child?
- If you do share, how much should you tell? How much do you want to get them involved?
- What reaction do you anticipate? Acceptance? Ignorance? Discomfort? Disbelief? How will you handle those reactions? It is possible that you may receive unwanted advice and responses, or questions from the person as they absorb information from you.
- When you disclose your child's diagnosis, be calm, clear and concise. You could say, *"Carter doesn't act the way he does because he's spoiled or defiant. He isn't misbehaving. He acts that way because he has autism spectrum disorder. His brain is wired differently. For Carter, his ASD makes it challenging for him to speak and understand other people; therefore he sometimes needs to do things in a different way than other children his age."*
- Keep it positive. Point out, *"People come in all shapes and sizes, and Carter has strengths and challenges just like anyone else. He learns differently, but he's smart and good at lots of things."*



For example, you might say:

"Carter doesn't talk much, but he has a good sense of humour."



"Conversations can be challenging for him, but he is really good with computers."

"It's difficult for him to play board games, but he's great at drawing pictures."

"Parties can be hard, because he gets overwhelmed when people sing the Happy Birthday song, but he really enjoys sitting at the table to share the birthday cake."

The more you educate your extended family about your child, the better they will understand your and your child's needs. You can:

- Provide articles, books and videos.
- Speak up about your child's strengths and accomplishments.
- Offer suggestions on what your child likes and how to best communicate with him or her.
- Above all, project sensitivity, respect and unconditional love for your child. Family members will take their cues from you.





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Speaking up for your needs and desires within the family

Families of individuals with ASD need support and understanding, but it can be hard to ask for those things. You may feel as if your requests are inconvenient or annoying to others, but in reality, voicing your needs will make things go more smoothly for everyone.

For example, people with ASD often have sensory processing issues that may make it difficult to attend family gatherings. Holiday gatherings may be tough. People with ASD may find it hard to sit still at the table or keep quiet during a religious ceremony. They may dislike being surrounded by unfamiliar people, or be picky about new foods, or not easily tolerate changes in schedule.



Disagreeing with your parents and loved ones

You are trying to find a happy medium between getting your child's needs met and respecting the rights and feelings of other family members. Always take into account the feelings of the other person and try to see their point of view, but remember that you are the expert on the needs of your child.

Your child may not be able to ask for what they need yet, but you can. Be clear about your child's needs, calm and cordially. Think of your extended family as a team working towards a common goal: ensuring your child's emotional well-being.

If you need to disagree and hope to be effective, think about your approach. What is your goal or desired outcome? Do you have a plan to achieve it? What are your steps? Coming together with a solution can lead to the best outcomes.

If family members object to a particular behaviour of your child, ask yourself: is that behaviour in some way harmful to your child or others? Does the behaviour prevent your child from learning and moving forward, or is it simply quirky or different? For example, if your child's rocking, hair twirling or talking to him or herself distresses a family member, you could explain that it is simply a self-soothing behaviour. Your role as your child's advocate is to do whatever you need to make situations easier and more comfortable for them.



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Including the individual with ASD in decisions

Some individuals with ASD can verbally communicate their goals and desires while others may have difficulty with communication skills. As your family member with ASD ages, they will need to learn how to assess problems, speak up, ask for what they need and how to negotiate, and know their rights.

Part of this may involve learning if, or when, to disclose their diagnosis. If they have the ability to understand, talk to them about ASD. The more comfortable and open you are with the diagnosis, the more comfortable your child will be. Focus on their strengths and assure your child that the entire family is behind them to offer love and support. The skills you use to advocate for your child now can be the same ones you teach to your child as they grow, so they can become their own advocate as much as they are able to. They will need to communicate their needs and desires. This communication can range from expressing basic needs, such as telling others what they want to eat or that they are in pain, to handling a range of real life situations. It helps to role play different situations so that they can practice these skills.

Teach them to identify options and desired outcomes. You could ask *“What could you do if your friend’s radio is too loud?”* Help them formulate such appropriate responses as *“I’m sensitive to loud noise and your music is hurting my ears, could you please turn down the radio?”*



Your goal is to give them the skills that will someday enable them to advocate for their own needs to the best of their ability, in a work, community, or residential environment.





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Useful tip: How to prepare for family get-togethers

There are many things you can advocate for that will help make your child, you and your extended family more comfortable:

- Before an event, politely and firmly explain to family members that your child may not do well with changes in the schedule or may have difficulties tolerating certain things such as noise, different foods, party clothing, crowds, and unfamiliar people. Be clear about what your child can and can't tolerate. For example, let them know if your child doesn't like to be hugged or kissed, but that they welcome a high-five or handshake.
 - Whether it is a food allergy, sensitivity or sensory issue, share information about your child's dietary needs/restrictions. Offer to bring something you know your child will eat. If you think your hosts may be offended, you can always reassure them that it is not a reflection on their cooking.
 - Many on the spectrum may also have other health issues such as seizures. If there are specific things that trigger seizures for your child, for example flashing lights or a loud television, be proactive. Alert your hosts before you arrive and provide information on basic procedures for handling a seizure.
 - If you know other children will be present at an event, offer to give their parents age appropriate tools, so that they can explain ASD to their own kids before your family arrives.
- Ask for a quiet room or space that your child can retreat to during family events if they feel they need to get away from all the activity.
 - Be clear with your child about what to expect at family gatherings. Choose language appropriate to their level of understanding. Explain the schedule of events or create a visual schedule, including when you will leave. Give enough warning before changes, e.g. "in five minutes you will need to wash your hands for dinner" or "when this video ends it will be time to leave." Let your child control as much as they can.
 - Arrive early so your child can adjust to the environment before the room fills up.
 - Be sure to bring items that your child needs to feel comfortable, e.g. videos, books, photos, favourite toys, noise-cancelling headphones, electronic games, tablets, communication devices, etc.
 - If you and/or your partner think you may need to leave early with your child, consider taking two cars or making other appropriate travel arrangements ahead of time.



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Part 3: Teaching your child self-advocacy skills

“ While discussing my fears for my child’s future with my primary care physician she looked me straight in the eye and said “you know all your children are supposed to leave home”. This allowed me to recognize that she [my child] would, like her siblings, be able to be independent of us.”
Parent



Introduction

Teaching your child self-advocacy is as important as advocating on their behalf. It is never too early for them to start learning these skills. Model self-advocacy and trust that as you find your voice, you will be able to help your child find his or her voice as well. You may find it helpful to reach out to adults with ASD to learn about self-advocacy. Reading blogs written by people with ASD, or subscribing to social media channels for important and unique insights may be helpful in understanding and teaching your child to self-advocate.

Self-advocacy should be taught throughout a person’s lifetime. Like anyone else, individuals with ASD need to be able to speak up for themselves in order to obtain the help and support of others. Your child will do best when everyone involved understands the importance of him or her becoming a self-advocate and works to support him or her in the development of these skills. The skills you teach your child, whether it is related to independence, self-advocacy and/or negotiation, will empower your child for the rest of his or her life.

Becoming a self-advocate

Developing skills to self-advocate can start by teaching children choice making. Help them to identify what they like and don’t like, what they are good at and what they find tricky. As children develop it will be important for them to express their needs at school and in the community. Later on in life, advocating for themselves may mean making choices regarding adult day programming, applying for a job, or requesting a particular change or accommodation in the workplace.





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Three basic steps to self-advocacy³

Step 1 – Help your child to learn about him/herself:

Begin by teaching choice-making skills; focus on likes/dislikes and wants/needs: For example, your child can choose which videos he or she wants to watch, which clothes he or she prefers to wear, or that he or she doesn't want to wear a hat. Children can express these wants or needs through pictures, words, and gestures.

Help your child to understand him/herself as a learner (self-awareness/insight): Creating an "All about me" page or book can be very helpful in this area for young or older children, depending on their ability (See [Page 17](#)). You may also make lists or picture collages of: Interests ("I really like ..."), Strengths ("I am good at ..."), and Challenges ("Things that I find hard/tricky are ...").

Step 2 – Help your child learn what supports they need to be successful:

What helps your child to focus? e.g. *"It's hard to focus when there is a lot of activity going on around me. I need a quiet space."*

What helps your child learn? What helps your child to understand? e.g. *"It helps when you use pictures" or "It helps when you write the instructions down."*

What helps your child to remember: e.g. *"My schedule helps me to remember things."*

Help your child to identify/recognize when they need help. e.g. *"When there are too many people around I feel anxious. I need help to find a quiet space and to calm down."*



Help your child recognize what things make them anxious, upset, and uncomfortable, e.g. *"When there is too much noise, I begin to shut down. I cannot process what you are saying."*

Help them begin to recognize when feelings start so they do not lead to being completely overwhelmed, e.g. *"I know when I have to cover my ears that it is time to move to a quieter space."*

Teach them strategies that they can use to cope, e.g. *"when I am feeling anxious and want to run, I can use the swing to calm down."*



"In the past my daughter would often forget what she was asked to do between school and home. She now knows to ask for a short note from the teacher with written or visual instructions to help her remember by the time she gets home."

Parent



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Step 3 – Help your child learn to effectively communicate needs:

- Sometimes, communicating needs may pose a significant challenge for a person with ASD. First, your child has to recognize that the other person may not know or understand what he or she needs and therefore clear communication is necessary.
- Your child must also have an effective means of communicating and asking for what he or she needs (e.g. single words or phrases, picture symbols or gestures). Having the experience of asking for what is needed and getting it is crucial to the development of self-advocacy. It increases a child's self-confidence when they are successful, and they are more likely to continue to develop these skills.
- Teach your child specifically what to communicate when they are experiencing uncomfortable feelings, e.g. *"You can say to the teacher 'I am anxious', when you feel worried about something and your tummy is upset."*
- Teach your child to "ask" for what they need during these times, e.g. You can tell your child: *"When you are anxious you can say to the teacher 'I need some time to do deep breathing' or 'time to play with my fidget toy'" or "When you are angry, you can say to the teacher 'I need to take some space.'"*
- Use [Social Stories™](#) to teach kids about feelings and strategies.

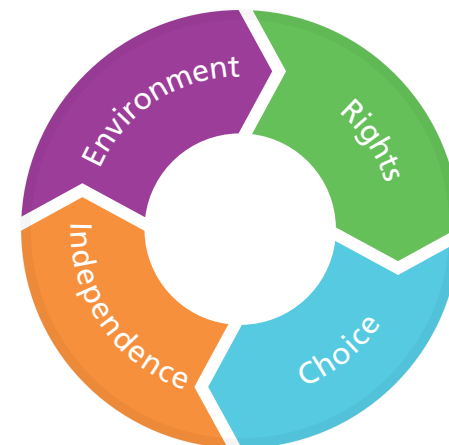


Self-advocacy skills at school and in the community

It can be difficult for any child to speak up in school. Given the social communication difficulties, this may be even more challenging for someone with ASD. It's important to work with your child to identify strategies that they can use at school (and in the community) when they are confused or upset. Help them identify which adult they feel safe communicating with (educational assistant, teacher, etc.), and practice or role-play situations and ways of communicating (verbal, written, symbols, or pictures).

Remember, self-advocacy can be as simple as choice making or requesting a break. It can also be more complex, for example, asking the teacher to write down the homework assignment so that it can be better understood and remembered. It's important to discuss these strategies with the staff at the school, to ensure success as your child begins to develop these skills. We want them to feel empowered as they find their voice.

Your child has the right to make choices. As he or she learns to advocate, he or she will gain the confidence to live a more independent life, and feel empowered to pursue their interests and goals.





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Useful tip:
All about me



A good way to begin to teach your child self-advocacy skills is to create an 'All about me'⁴ document and share this information with your child. Also share this with people who spend time with your child, so that they can better understand your child and further help your child to learn about him/herself and practice the strategies.

This document could contain basic information such as name, family members, school, where you live (house, apartment etc.), birthday, age and friends. It may also contain information such as 'How I communicate', 'Things I am good at' and 'My favourite things'.

Note: This should be a working document that will change over time as your child develops.

Additional information on how to make an "All about me" document/book can be found at the links below:

<http://autismontario.novosolutions.net/default.asp?id=175>

<http://connectability.ca/2011/04/15/all-about-me/>

<https://com-psychiatry-card.sites.medinfo.ufl.edu/files/2015/08/All-About-Me-Overview.pdf>

Things about me

How I
communicate

Things I am good at

Things that
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My favourite
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Tricky things

Health stuff

Sensory stuff



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Part 4: School advocacy

There is no federal department of education and no national system of education. In Canada, educational systems are similar but variations exist across provinces and territories.

In Canada, parents have the primary responsibility for ensuring that their children receive an education. However the Federal Government plays a crucial role in some aspects of education; the Constitution places the regulation, management and facilitation of education within the 10 distinct provincial and three territorial education systems.

In this section you will find basic information that will assist you in understanding the education system. You can use the advocacy principles and steps, to help you successfully advocate for your child's education. You will need to refer to the regional information on our [resource page](#) for specifics related to your geographical area. Eligibility criteria for special education services may vary from province to province and territory to territory.

The rights of a child are set out clearly in the [Canadian Charter of Rights and Freedoms](#) and the [United Nations Convention on the Rights of the Child](#).

Starting the process

Special education exists to address the unique needs of a child that may result from a disability and to assure that students with disabilities receive all needed aids and services. Special education laws and regulations are meant to protect a student with disabilities and ensure that they get the services and assistance to make effective progress. This system of laws and protections can be complex. This section will help you understand the key concepts of the education laws and how to be an effective participant in the special education process.

The evaluation process

Before your child can begin receiving special education services they must be deemed eligible for support. The first step in determining eligibility is a thorough evaluation in all areas of known or suspected need. Evaluations, also called assessments, provide valuable information regarding the nature and extent of your child's disability, as well as the impact the condition may have on his or her education.

Evaluations are generally conducted by the teacher involved with your child and a combination of special education staff and your school board's professional support services (e.g. psychology, social work, speech and language pathology, occupational therapy, physiotherapy...). Results from standardized testing, documented observation, parent and teacher questionnaires and past reports, are used if available. Please refer to regional information on the [resource page](#) at the end of this document for more detailed guidance. The findings of the evaluator should be presented in a formal report which is made available for use in individualized program planning. The strengths and needs identified through this process form the basis for your child's present levels of performance or your child's baseline of functioning in each area of evaluation.





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Why are assessments so important?

Assessments are like building blocks. They are the foundation of a solid plan that will allow your child to progress in his or her educational setting. Quality evaluations that indicate accurate and current skill levels ensure that goals are measurable year to year.

Assessments identify the nature and extent of your child's disability. They will help identify your child's areas of strength and challenges. If they are found eligible for special education with a qualifying condition under your provincial or territorial Ministry of Education's education regulations, goals must then be written to assist your child in overcoming the identified challenges.

The assessments provide a starting place from which the progress towards the annual goals is measured.

The determination of whether the program is offering your child an appropriate education depends on your child's progress throughout the year. As a result, it is important that you review these assessments to ensure that the baseline upon which your child's progress will be measured, is an accurate reflection of your child's ability. If the baseline or starting data is too low and not representative of your child's ability, the school will likely be able to show that your child made some progress and therefore meet its requirements under the law.

If you believe that your child requires special education or an assessment for specialized educational services, you should first review your regional information on the [resource page](#).

The role of independent assessments

Some parents may decide to pay for an independent psychoeducational assessment of their child. In most education systems this can be submitted to your school and/or school board to include in their assessment.

What if you do not agree with the results of the assessment?

Your education system usually provides a mechanism for parents to appeal if they disagree with the school's or school board's evaluation and program placement. When requesting an appeal, put your requests in writing and deliver it in a manner that will produce a proof of receipt for example, by registered mail. There are specific procedures on how to handle disagreements in most school board jurisdictions.





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School meetings: What can you expect?

On the day of your meeting to confirm special education services for your child, you will meet either at your child's school or at another board of education school or office. Each member of the team will introduce themselves. Remember to ask for a copy of the sign-in sheet with the attendee's contact information to be provided to you at the end of the meeting.

Your goal for school meetings is to identify how to ensure your child's needs are met while also understanding the structures available.

Depending on where you are in the process there are different levels of meetings for special education services for your child. Please check your regional information on the resource page for more details.

For example, in Ontario:

- You start with a consultation process meeting within the school itself. This can include the classroom teacher, other special education staff, the principal and parents.
- After this initial meeting a referral to a school-based team is initiated. This enables the strengths and needs of a student to be discussed by a broader team of representatives which can include special education and professional support services (e.g. psychology, social work, academic counselling, speech language pathology, occupational therapy and physiotherapy).
- The next step could be a meeting to discuss a referral for services, identification of needs and placement and review of assessments.

School meetings: What you should do

- Bring your list of goals.
- Listen to and think about different ideas or suggestions.
- Share reports and information where relevant.
- Take notes. You may wish to bring a companion to help you.
- Read any and all documents carefully before you sign them. If possible ask to take the documents home for a closer review.
- If a challenge arises, follow the correct chain of command, e.g. teacher then principal, then school board.
- Request an interpreter if required.
- **Never agree to anything that you do not wish to, or anything that you do not understand.**





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Part 5: ASD advocacy in the community

“As the mother of two boys with autism, I have discovered that most people are inherently kind and tolerant when it comes to autism. They will adapt their behaviour to my children once they understand their challenges. This is why I have always been open with disclosing their diagnosis in public. Autism is an invisible disability. Unless someone has experience to draw on, they may not recognize my boys’ unusual behaviours as autistic. It’s easy to mistake their challenges for mischief. I have taught my older son to speak up for himself and his brother. He will say ‘I have autism and that is why I need space and quiet.’ People almost always respond by changing their behaviour to accommodate the boys’ needs. My son is learning to advocate for himself and helping others learn about autism.”
Parent

Interactions in the community can vary – from acceptance and kindness, to looks of disapproval and unwanted input on parenting skills. Negative experiences in the community can cause families to feel isolated from, rather than engaged in, common community activities.

There is an important role to play in advocacy here, to help lead to positive changes within your community. Public transportation, stores and service providers of all types, places of worship, entertainment venues, lodging establishments and parks and recreation spots, to name a few, are all spaces ‘in the community’ that may pose challenges for people with ASD. Challenges can include unpredictable social interactions, possible sensory overloads and even ‘meltdowns’ that are difficult to manage.

The key to positive inclusion in all of these community spaces is detailed planning and advocacy to ensure a smooth process and avoiding (or managing) challenges should they appear.

Ontario is one of the first jurisdictions in the world to mandate accessibility standards in the public and private sectors. Research and review what resources and supports are available for people with disabilities, including ASD, in your local community. Additional information can be found at Accessibility for [Ontarians with Disabilities Act \(AODA\), 2005](#) and the [Ontario Human Rights Commission](#).

Connect with the ASD community in your region through websites and social media channels

- [Autism Speaks Canada](#)
- Local societies such as [Community Living](#).
- Provincial ASD organizations such as [Autism Ontario](#),
- Other local ASD organizations and associations
- Your School Board’s special education advisory committee
- Disability law advocates such as [ARCH Disabilities Law Centre Toronto](#)
- Major health care centres.

To disclose or not to disclose?

For caregivers of children with ASD and other more ‘invisible’ disabilities, the decision to disclose their diagnosis can be complicated. Many caregivers fear they and their child will be judged because of certain behaviours. (e.g. repetitive behaviour in a sandbox, inability to wait for their turn on the swing, chewing the handle of a shopping cart) and how you, the caregiver, may respond.

Ultimately, the decision of whether to disclose the diagnosis is entirely up to you and your child. In general, a good time to disclose a disability might be when you need to ask for reasonable accommodations (e.g. turn-taking on the swing).



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Planning community integration/outings

Be flexible.

We all want terrific results, but before we get into the details of your plan, it's important to remember that bad days do happen. If, in spite of all of your effort, your goal is just not going to be achieved that day – a smart move can be a short term retreat (options for which should also be in your plan). This will help preserve the possibility of a positive community activity in the future.

What could be the potential issues in an outing?

Now, think through the community activity. Is the goal of the trip to visit someone? To run a typical errand? To go to a show, visit the zoo, or just walk in the park? Think through each step and consider any potential stressors/triggers that may impact or interfere with your movements or activities (e.g. fare collection, security checks, lines, transfers, etc.) Consider all potential issues that could develop, such as delays, noise, crowds, and weather.

Are any adjustments needed for this activity?

What adjustments might help you continue the activity on a positive path if something were to negatively impact the plan and your goal? Might priority access, a quiet space, slower pace or extra time help? Could extra on-site assistance help you smooth out any potential bumps? You could also carry an 'emergency activity kit' when you venture out in the community.

Call ahead to customer services

Most organizations and service providers in the community, especially larger businesses, have some type of customer service component (often specialists on

their staff) available to assist you and others with special needs or requirements. It's critical, to call them to plan ahead. Sharing your concerns and information ahead of time is essential, even if it's something like, *"I'm accompanying a child with ASD, a developmental disability. We're planning to do _____. I don't expect I'll need help but if I do, are there any suggestions, resources, or staff you may have available to help me?"*



Most 'people-focused' organizations, from your local airport security to the cinema at the mall, have policies in place designed to assist people with disabilities or those with special requests. If you reach out to them ahead of time or even as you arrive, you are successfully advocating.

Advocating for additional services

Keep in mind that accommodations, from the perspective of service providers, aren't always available on demand (especially at peak usage times) or individually tailored. Judge whether the organization seems responsive to your requests. Inquire about specific policies on admittance of service animals, use and provision of assistive devices, whether they charge a fee for someone accompanying a person with a disability, etc.

If their current policies don't make sense to you, as an advocate you can consider asking to address the matter and sit down with their management.



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“After researching the right camp experience for my daughter we had a very successful pre-visit in the spring. She met her counsellor, saw her room and where she would participate in all the camp activities! On the first day of camp her room was decorated to welcome the campers and she broke down. Nothing was the same. Her counsellor, when we explained our daughter's response, immediately took the decorations down and started again with her, rebuilding her confidence bit by bit accommodating her needs. She returned proclaiming that she had an amazing time and is looking forward to going to camp again. We're looking forward to making the same preparations next year with a few additional suggestions.”
Parent



Creating a community around your child

It is important that all children feel a part of the community in which they live. Building connections that will last beyond school will be important to your child's overall quality of life. A good way to begin this process is to use the “Circles Program” as a way of organizing and recognizing the important people in your child's life and determining when disclosure of a diagnosis is helpful.



Useful tip: Circles program

You may complete this with your child if they are able.

While you may have communicated your child's diagnosis to your family members you also need to consider those who have daily or frequent contact with your child in the community. The question is “What is your child's community?” Does it include a local recreation centre, a hair salon, a library, a neighbour? All these sections of the community can be easily categorized by how often they interact with your child and how much they need to know. You can create a visual aid for yourself and your child similar to the James Stanfield Company's [Circles Program](#) (please see pages 24 and 25).

Note: This should be a working document that will change over time as your child develops.

The second purpose of this type of visual aid or diagram is to help you and your child understand where support is available to you already as well as how to build it into your lives.

How you advocate for your child will often be seen by your child. You can use this tool as an opportunity to be the role model for your child's future self-advocacy. They see how well you are teaching others to respect them.

Take this visual and build your support network outwards from home.



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Community categories: Think of people in your child's life for each category below; Use this information to complete the Template on page 25.

Home

Your child, his or her caregivers and siblings (and others who may live in the home).

Family

Immediate and extended family, grandparents, closest and best friends, neighbours, support workers and residential settings, e.g. respite and group homes 'the people you can't imagine living without'.

Friends

These are different from your closest family friends. These are people you don't see often, who might be neighbours or friends and family, who are far away.

You may not be ready to share your child's diagnosis just yet (or ever) with certain individuals, but you might want to choose to tell some friends, who have an occasional interaction with you and your child.

Advising a neighbour of your situation can make a big difference further down the line if your child takes to wandering, or riding their bike on the sidewalk, or not acknowledging them when they say 'hi' in the morning. Discussing the situation with a few close neighbours can build a strong circle of support for you and your family on your street or in your apartment building.

Community

These are your bus drivers, local childcare drop in centres, hair salon, dentist, community centre and police station.

Although the earlier 'circles' are people you know, there are people you don't know personally, who will be able to back you up as you advocate for your child.

School

This will become the largest part of your support network but doesn't always crossover into other areas and isn't always available outside school hours.

As you advocate within your school you will gain some great tools and be able to share them with your support network, which will help them in caring for your child. Consistency in care is key and your collaboration with the school will give the rest of your support network the confidence to carry through what is happening at school.

Case Worker / Service Navigator

Often you will be asked if you have someone who coordinates your care or your resources. You might consider that to be you, but it's healthy to have an outside source to support you in this role. You should list agencies that can support you with recreation, funding, respite, and resources for therapy and care. In Ontario, for example, these would include Community Care Access Centre (CCAC), Community Living, Extend-A-Family, Autism Ontario, your local City Councilor and MP/MPP, etc.

Strangers

People who your child may come into contact with during their daily lives, but have no direct relationship with.

There will always be people who will feel awkward around your child and who may not appreciate all of his or her wonderful, unique qualities. When people observe you interacting with your child, they will witness and learn from how you support him or her. This may lead to greater comfort and more positive interactions, increasing the probability that others may advocate for your child when necessary.



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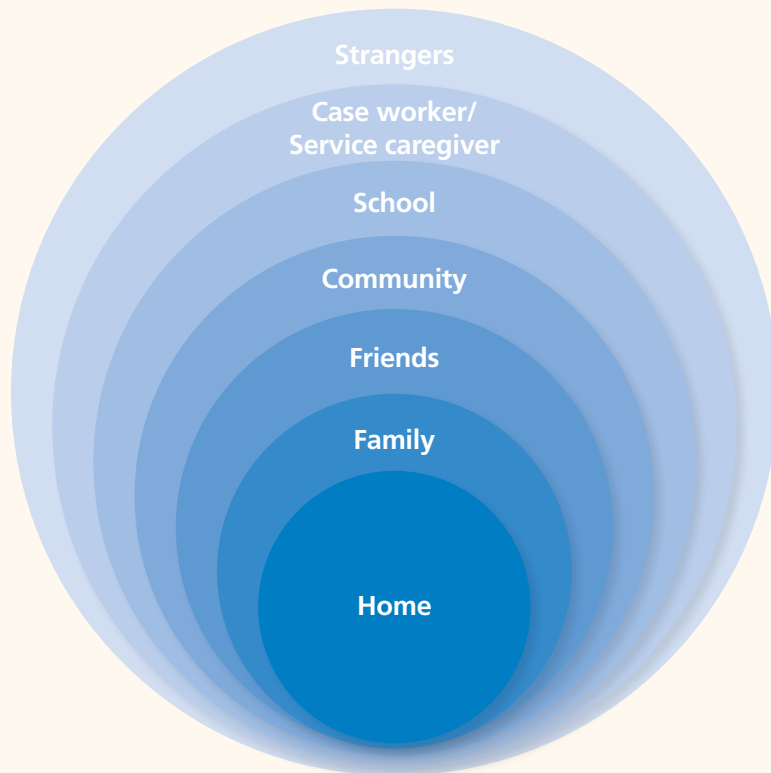
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List the people you feel belong in each category,
in order to create your child's community.



Home

Family

Friends

Community

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Caseworker/Service caregiver

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Part 6: ASD advocacy in health care

Preparing for a visit to your Primary Care Provider (PCP)⁵

Children with ASD have the same primary health care needs as those without ASD. They need regular audiology, vision, dental check-ups, etc. We also know that gastrointestinal (GI) issues, sleep disturbance and seizures seem to occur more frequently in children with ASD. These children also display behavioural changes which can be related to health issues, e.g. sleep disturbance, constipation, pain (GI, dental cavities and abscesses), seizure onset and mental health issues such as anxiety. Sometimes, it's hard to figure out what is going on, as your child may have difficulty with communication and identifying the location and level of pain or discomfort.

Remember:

- Know your child and their signs and symptoms of distress.
- Write down all concerns to take to your Primary Care Physician (PCP) appointments and make sure everything is addressed before you leave.
- Track issues such as sleep/wake times, frequency and type of bowel movement and urination, behaviours such as sticking hands in mouth or touching neck or chest with fist, arching neck and the relationship of these behaviours to lack of sleep, constipation, reflux, and/or pain. Take the data to your child's PCP. Concrete data is better than subjective descriptions.
- Prepare your child for visit/investigation, e.g. visual schedules, social stories, rewards, etc.

- Call ahead of visit if you can. Inform the office of potential difficulties to problem solve.
- Be firm: insist on same care/investigations/referrals to specialists that other children would receive.
- Remember, you know your child best so you can help others understand them too.

An Important note about mental health

Children and youth with ASD may also experience mental health issues such as anxiety and depression. It's important to pay attention to signs of mental distress (e.g. increased withdrawal, agitation or aggression, changes in sleep patterns) and communicate these to your child's PCP. Medication and/or cognitive behaviour therapy can be useful in addressing some of these issues. Your child's PCP may need to initiate a referral to a developmental pediatrician, pediatric neurologist or child psychiatrist.





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Educating your Primary Care Physician

Share information on resources with your primary care physician and encourage them to share these with their colleagues. These resources may include the [ATN tool kits](#), which cover topics such as sleep, constipation, feeding, PICA, dental, blood draw, medication and visual schedules, etc. Other resources include the ATN [AIR-P Pediatric Supplements \(2012 and 2016\)](#), the [Health Watch Table](#) and [Health Care Access Research and Developmental Disabilities \(H-CARDD\)](#). Information contained in these documents and website may assist PCP's in improving the primary care of their patients with ASD.

Preparing for an emergency room visit

Before you are in a situation where you need to visit the emergency room, prepare a document or a file about your child which includes the following:

- Diagnosis and co-morbidities
- A copy of their immunization card
- How your child communicates best
- Triggers (e.g. sounds, words, actions etc.)
- Sensory issues
- Strategies to help your child to cooperate, and reduce anxiety
- A description of how your child typically behaves
- Medication: current, previous and if anything was discontinued
- Previous investigations and results
- Allergies

Consider asking your PCP to call ahead to the emergency room.





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Useful tip: In case of emergency document

Create this tool for yourself and your child. This document should include everything listed on this template, as well as anything additional you think would be useful when caring for your child.

Name

Date of birth

Address

Health card number

Family	
In case of emergency contacts	
School	
Autism diagnosis	
Other diagnoses	
Medications I/my child is taking to help with autism	
Symptoms	
Other medications	
Special diet or supplements	
Medications stopped	
Drug allergies	
Diagnostic tests completed	
Blood group	
Immunizations	
Additional insurance	
Resources used in the community	
Exercise routine	
Health provider – main Primary Care Physician	
Health providers – other	
Dentist	
Pharmacy	
Who makes health care decisions	
Special needs/considerations	



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Part 7: Self-Care

“Don’t forget to advocate for your own needs as a parent/caregiver”

Jennie Ormson, Social Worker

Have you been advised by your doctor, your child’s pediatrician and maybe even your friends or family to “take care of yourself”? Self-care is a lovely concept and may be one of the first things to fall by the wayside when you’re faced with caring for a child with ASD. Time, money and resources – all of the necessary self-care ingredients – are in short supply. This brief guide to self-care addresses challenges and provides a real-world approach that can be tailored to fit your particular situation.

“I felt very guilty the first time we sent our child to respite care. I thought this showed I couldn’t meet my responsibilities as a parent.

Now I realize it gives us all a chance to breathe, and also to focus on our other children uninterrupted.”

Parent



The Challenge

Two opposing forces amplify stress for caregivers: the add-ons and the take-aways. Added stress can include preparing different foods, planning transitions from one part of the day to another, meetings with school, clinic appointments, endless application forms to complete and demanding physical labour such as dressing and bathing.

The take-aways, the things that fall by the wayside, are usually the very activities that regulate stress: exercise, nourishing meals, adequate sleep, time on our own and moderation of caregiving. We drop our good habits and increase our bad habits. As a result, we can feel overwhelmed. Our lack of self-care reduces our ability to function well.

We’ve all heard the oxygen mask analogy: before you put on anyone else’s oxygen mask, you need to put on your own or you won’t be able to take care of anyone. That approach works beautifully when you’re on a plane that hits rough turbulence or is losing pressure. But it’s tough to translate that into the real world with a child with ASD.

In real life, we can’t always take care of our own needs first – but the key is to remain a priority on our list of things to care for. Without self-care we start to feel burnt out, overwhelmed and resentful. That resentment should be an alarm in your brain that tells you that you have slipped off your list and you need to put yourself back on.

We are complex creatures with different preferences and needs. Our families also have different preferences and needs. What fills up and recharges one of us might absolutely drain and exhaust the next person. Our children have different strengths and challenges and we have varying levels of support. Discovering what works for you and what doesn’t work for you is vital. Keep in mind, what seems to be the perfect method of self-care this month — at this stage of your life — may change. Kids grow and change, obligations shift and unforeseen circumstances pop up, impacting even the best-laid plans. The key is to not slip off the list again, just to make some tweaks and adjustments that work with your new circumstance.



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Step One: Eliminate

The crucial initial step in building a solid foundation for self-care is eliminating all unnecessary elements. Living with a child who has ASD may bring unique challenges to both the physical and mental space. There are additional aids and devices that add clutter as well as a multitude of appointments and meetings vying for time in your calendar.

In order to assess what can be eliminated you may want to enlist the help of a friend who will help you separate what you actually need and use from what you used to (or think you may one day) need and use. Undertaking an audit of your home may take time and seem like one more thing to add to the “to do list.” However – by not looking over your space and schedule with a critical eye, you risk remaining trapped in the vicious cycle of feeling overwhelmed. This time is an investment in your day-to-day well-being.

Inevitably, feelings of guilt and inadequacy may arise during this part of the process. There is always more we can do for children facing challenges and it is difficult determining when enough is enough. We are told there are limitless therapies, treatments and interventions to help our children reach their potential. There is a steady stream of shared information, seminars, workshops, books and agencies encouraging us to do more, but we cannot do it all. Eliminating comparisons with other families and remaining disciplined about our choices is essential.

Safeguarding the balance of what can be undertaken with the time, energy and financial resources available is crucial. As a result, we need to make very careful choices about the people in our lives. One of the very enlightening outcomes of having a child with ASD is that you quickly discover whom you can and cannot rely on for support.

At times, this discovery leads to crushing disappointments or delightful surprises. Sometimes a shared history is not a good enough reason for maintaining a friendship. It’s okay to say no to someone in lieu of taking time for yourself. Add ‘no thank you’ to your repertoire so you can focus on the things that keep you feeling good. Say ‘yes’ to a select number of events and enjoy those with your full heart.

Developing a judgment-free network will help to keep you afloat and recharge your battery. Investing the time to develop clear communication with your partner will also eliminate hours of misunderstandings, hurt feelings and miscommunication. Eliminate what isn’t essential to make room for accomplishing what is necessary with grace and confidence.





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Step Two: Streamline

Once you've streamlined life to the essentials: possessions, commitments and relationships, move on to keeping things simple and streamlined by building in rituals and routines. The goal is to execute those essentials in the simplest way possible.

Building in structure and systems may sound remarkably boring or uninteresting, but it actually frees up time and energy by managing the chaos. Routines and rituals are a vital piece of the self-care puzzle. They can be daily, weekly, monthly or annually.

Scheduling for self

When planning your schedule for the month, just as you do with the activities for your child, add in self-care, social time and your regular caregiver responsibilities. Think small and simple rather than epic. Self-care doesn't have to be an afternoon at the spa. It could be as simple as giving yourself ten minutes to sit and drink your coffee after putting your child on the bus or sinking into a hot bath for fifteen minutes after the children are in bed.

Minimal, incremental changes over time lead to sustainable moments to recharge your batteries. Scale back or eliminate chores by sharing them with someone else. Make a comprehensive list of what chores you do in a week or put up a blank sheet of paper in your kitchen and add to it every time you find yourself doing something around the house. Then when your page is full (which it will be quickly), see which ones you can share with your partner or someone else and see if you can pare some of them down to doing twice a week— like laundry. For example choose two days that you know you can do laundry leaving space in the week for 'emergency loads' rather than drowning in piles of unwashed clothes.

Social events

Reexamine your contribution to social events: Do you really need to bake one of your spectacular pies this time? How about a smaller hostess gift? Or simply a touching handwritten card that addresses how much you appreciate them? Consider your motivation for giving. Are you giving because it's expected? Do you worry about what other people will think of you? All of us have too much on our plates and we don't need to increase it. Ditch the expectations of others. Let go of the emotional judgments.

Weekly rituals

Weekly rituals could include Friday night movie at home or a quick and easy Sunday dinner. A monthly ritual could include a phone call with a far off friend or stealing away for a thirty minute hike. Consider areas where you can build in routines and rituals to simplify your own life. It's not about working harder, it's about working smarter. The ease and pleasures built in with rituals and routines will ground you and keep you on track.

Balance

No discussion on self-care is complete without mentioning balance. We hear an awful lot about work-life balance. If you feel that you've struck a balance that works for you stick with it. For most of us this is not a realistic goal. Rather than aiming for balance, aim for being grounded and focused amidst the imbalances that life throws our way.

Jim Harrison, author of *Legends of the Fall* says "life is a fundamentally unreliable experience." Getting grounded in that unreliability and unpredictability is a vital element of self-care. Think about what helps you get grounded. Is there a ritual? A breathing exercise? A mantra? Write down three grounding experiences that you can return to when life doesn't go according to plan A.



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Step Three: Small Pleasures

One of the easiest ways to approach the add-ons of self-care is to build on the ideas of rituals and routines. Mindfully enjoying the tiny pleasures that dot our everyday life helps us shift from autopilot to a spirit of optimism and gratitude.

What is a daily pleasure that you can realistically add in to your life as a caregiver? Something you can cherish even if it's just five minutes. By necessity, the pleasures require that you fully attend to them and really be in the moment. Let's pretend you're a coffee lover. Rather than mindlessly brewing your cup or making your espresso, slow down and enjoy the sounds of it burbling and brewing. Notice the aroma. Take a few deep breaths while you're waiting and set an intention for the day.

Don't wait for someone else to bring the pleasure into your life. The rescue team is not coming – you can be your own rescue team. Learning to ask for what you need is a great strength. Many times people will be willing to help, but they aren't sure what or how to offer. Saying to a friend or neighbour, "I would love to enjoy a cup of tea on the porch with you, would you like to come over?" may lead to the highlight of your week.

To get started, follow these simple steps:

1. Think about a pleasure or indulgence that you'd like to make a part of your weekly routine.
2. Write it down and decide where it's going to fit in to your week.
3. Start including this in your day-to-day life. (Put your plan into action.)
4. Remember, life is all about plan B, what works this month may not work next month or next year. So just like great business plans, revisit your self-care plan every few months.

You can do this. You need to do this. You deserve to put yourself back on the list.





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Part 8: Words of Advice

Advice from a mom

Lori Beesley

The Art of Advocacy

“Advocacy does not have to be confrontational.”

I have spent countless hours advocating for my son over the years. During this time I have developed what I like to call the *iron fist in the velvet glove* approach to advocacy. It's not confrontational, negative or aggressive but it is firm and clear, collaborative and effective.

I like to think of determination as an iron fist.....

I always tell parents that the first thing that you need to do is determine what it is that you want. Is it extra help in the classroom? What does that look like? Is a full-time education assistant (EA) needed all day, every day or can your child manage some time without support? Be specific about what you are asking for and do your homework. Is it realistic? Has anyone else received what you are looking for and how did they do it? Once you have determined what it is you want this becomes your goal. This is what you will be advocating for.

Communication is the velvet glove.....

You need to be able to clearly state what it is that you need, more with facts than emotion (this is the hard part). For example, come prepared to a school meeting with proof that integration (if this is what you need) has been a successful way of learning for children with ASD. Print out copies of articles that support your point of view and put packages together for all attendees. If you know of schools where there is extra support in classrooms, identify the school, the principal, the student population and the number of support staff. Make a list and include it in the package.

Documentation might end up being very useful for staff at your child's school to advocate on your child's behalf; they might appreciate being armed with additional facts and information.

This approach can begin to establish you as a team player. By demonstrating that you have done your homework and are prepared with facts, you also gain respect and show that you are not someone who is easily set aside or overlooked. Bring samples of school work or come armed with ideas to help support your cause. For example, if the teacher is discussing the fact that your son is always showing aggression when it's time for recess, you could respond with: "I understand and it must be very difficult to have to deal with this every day. I think it may be because he is anxious about the upcoming unstructured time. Maybe it would be helpful to have an EA with him at that time to support him during the transition and it would make your classroom run more smoothly.

You could also try assigning him a rotating 'buddy' (classroom peer) every day 10 minutes before recess and allow them to take the attendance to the office at that time. This could create a distraction and help with that situation. I bet if we worked together, we could come up with additional ideas, and maybe even get the other children involved in some solutions."

In this way, you are reacting to a negative with facts, logic and solutions – not emotion. By staying focused on your goals, it can help to keep your emotions in check. One way to keep emotions in check during meetings is to bring people who support you. Never attend alone. If you start to get emotional, you could take a moment to collect yourself and let someone who is one step removed, deal with the situation. Take a breath, remember your goal, stay focused and then step back into the discussion.



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Diplomacy is a velvet glove....

To be a good diplomat it helps if you've already established a reputation for diplomacy as an involved parent at the school. I always made an effort to attend as many school council meetings as possible and tried as much as possible do some volunteering at high visibility—low effort events. It might take some experience to figure out what those are. I wanted to establish a good relationship with other parents (parents of your child's peers might end up advocating on your child's behalf if they know you from last month's bake sale), as well as show the staff that I was invested in the school.

Try not to be the parent that only shows up when there is a problem. If you show up to say "good job and thank you" then when you come to ask for something or advocate for your child, you have an established positive relationship to build on. You should be prepared and willing to meet halfway and compromise at times. By showing that it's not always your way or no way, you will establish yourself as a respected parent who people want to help. If they trust your judgment, you can walk the line between tactful diplomacy and revealing that iron fist when you really need to.

The ability and willingness to listen are key tools you should have when resolving a situation. By saying "I hear what you are saying" and repeating back what they have stated followed by "I understand how difficult this must be at times. I also know you became a teacher because you have the best interest of all children and students at heart. I know you want them all to be the best that they can be, including my child. What can I do to help? Statements like these establish the fact that you are not going anywhere and are standing firm and looking to partner with them to establish a team mentality and build towards a successful relationship.

If this doesn't work at the local school level, don't go dragging your story around the school yard. It will only result in a negative reputation. Instead, inform the people involved that you have decided to step up your advocacy to the people assigned to deal with the situation in order to make it successful for everyone.





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Advice from a self-advocate

Liam Cosgrove

Hi there, my name is Liam and I am 13 years old. I have autism, which means I don't understand some things such as what to do or not to do in different situations, or why other people behave the way they do. I have a younger sister and a little brother. My little brother is very hyper and he has autism too.

I am in grade 8, which means I am a big boy. I have lots of friends at school. Sometimes at school I teach my friends about autism and how it affects my brain. They say "ok" and always greet me when I am pacing around the schoolyard. It's important for my friends to know how to treat people who are autistic.

I am an ambassador at Holland Bloorview Kids Rehabilitation Hospital. This makes me feel very happy because I get to give tours of the hospital to lots of important people. I have toured my local Member of Parliament, the Premier of Ontario and the Chief of the Toronto Police. And now, the Chief and I are good buddies. I go to the police headquarters and meet lots of police officers and tell them about autism. It is a very cool place. I was also on the news once when I met my Member of Parliament. I think it's important for autistic people to be on the news, so that people can understand what autism is about.

I played an important role in creating the Dr. Stuart D. Sims Chair in Autism at Holland Bloorview. This special scientist position will help autistic people by learning and teaching more about autism. I did a lot of stuff to help fund the Sims Chair. I gave some speeches and my brother and I helped raise money. I feel happy about helping other autistic people.

My mom takes me to Holland Bloorview, Ripley's Aquarium, police headquarters and to special events. Sometimes it's crowded and noisy and full of strangers. It really bothers me when strangers talk to me and reach out. My mom encourages me. She says I should tell the people that I am autistic and that means they shouldn't touch my shoulder

because it makes me feel very uncomfortable. My mom stays close to me when we are out in public and helps me calm down when I get scared.

On my old school bus, the kids were loud and they threw things at me. My mom called the bus company and my school and got me a new driver. I feel comfortable on my new bus because I have my own assigned seat. My mom also goes for meetings at my school to help decide what is best for me. She always talks to me about what I want as well.

My mom takes me to the Autism Research Centre at Holland Bloorview to do lots of research. I am teaching scientists about autism and what effects autism has on me. This research will help doctors provide care for other autistic people.

Parents should know that autistic kids may find school difficult. The work is hard, it's very noisy and busy and we have to deal with a lot of people. Parents can come to the school for a meeting to talk about how their kids are doing and how to help them work. When parents take their kids to the doctor it's important to tell the truth, that way the doctor can know what they should do to help. Remember to tell your kids that it's going to be okay and that they can do it.

Autistic kids should stay close to their parents when out in the community so that they don't get scared. If the kids get scared their parents can tell them that it will be okay. Hold their hand in the line-up at the store, crossing the street and at a pet shop. If parents are at the store and the kid wants something they can't have, the best thing to do is just leave the store. Try and help them save their money to buy it next time.

Parents of autistic kids should think about the good times. It helps you get through the bad times like when your kid hits someone, or when they are bothered in crowds or has a big cry. Some of the good times are getting a new pet (like a cute pug), playing video games or seeing special people.

Thank you for reading.



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A father's perspective

John Howell

Advocacy can seem daunting at times. Over and over again, you find yourself faced with resistance, lack of knowledge and misunderstanding. And each time, you have to lift yourself up, again and again, to work with the people whose decisions will influence your child's future. It's hard not to become discouraged.

During these difficult and challenging times, it's crucial to remind yourself that when it comes to your child there is only one expert—you. Nobody knows their temperament, moods and mannerisms, like you do. You know their favourite foods, what songs to sing to calm them to sleep. And when they need to sleep! You can tell if that smile is a happy smile or the start of a meltdown. Or, when silence a good thing and when it's the sign of a meltdown? You know how to tell them apart!

So just before you walk into that room, supported by all the tips and guidance you just learned in this tool kit, understanding when to negotiate and when to stand your ground—remember to stand up straight, push back your shoulders, take a deep breath and say the following: The only expert in the room that truly knows my child is... ME!





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GENERAL LAWS & LEGISLATION

[Canadian Charter of Rights and Freedoms](#)

[United Nations Convention on the Rights of the Child](#)

[United Nations Convention on the Rights of Persons
with Disabilities](#)

EDUCATION

Alberta

[Alberta Education](#)

[Early Childhood Services \(ECS\) and Special Education Needs](#)

Early Childhood Services (ECS) is often a child's first exposure to a structured learning environment.

[Standards for the Provision of Early Childhood
Special Education](#)

[Standards for Special Education \(Amended June 2004\)](#)

[Role of School Boards](#)

Terms Used: Early Childhood Services (ECS) referral, identification and assessment; Coordinated Services (CS); ECS child/children; Individualized Program Planning and Evaluation (IPPE), Individualized Program Plan Implementation (IPPI), Family-oriented decision-making (FODM)

British Columbia

[Ministry of Education](#)

[Special Education Services: A Manual of Policies,
Procedures and Guidelines – April 2016](#)

The principal of the school is responsible for the implementation of educational programs (School Act Regulation 5(7)(a)).

[Distributed Learning – Active Policy](#)

Terms Used: Referral to school-based teams, Identification & Assessment, Individual Education Plan (IEP)

Manitoba

[Manitoba Education](#)

[Student Services, Planning and Programming for Students
with Special Learning Needs](#)

Legislation, Standards and Policies:

[Appropriate Educational Programming Regulation 155/2005](#)

[Standards for Student Services](#)

[A Handbook for Student Services](#)

Terms Used: Students with Special Learning Needs, Individual Education Plans (IEPs), School-based student support teams, SSU consultant

New Brunswick

[Department of Education and Early Childhood Development](#)

General Information: (506) 453-3678

Fax: (506) 457-4810

Email: edcommunication@gnb.ca

[Early Childhood Development \(Division\)](#)

[Family Services Act \(S.N.B. 1980, c. F-2.2\)](#)

[2005-19 Interventions for Autistic Children under FSA](#)

[Services for Preschool Children with Autism Spectrum Disorders](#)

[Education Act](#)

Policy 332A - Inclusive Education: www2.gnb.ca/content/dam/gnb/Departments/ed/pdf/K12/policies-politiques/e/322A.pdf

New Brunswick Human Rights Commission: [Guideline on
Accommodating Students with a Disability](#)

[The New Brunswick Human Rights Act Explained
Strengthening Inclusion, Strengthening Schools](#)

Terms Used: Inclusive Education; Personalized learning plan (PLP), School-based Education Support Services (school-based ESS) Team, Education Support Services (ESS) Team



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Newfoundland and Labrador

[The Department of Education and Early Childhood Development](#) is responsible for administering the following legislation:

- [Public Libraries Act](#)
- [Schools Act, 1997](#)
- [Teacher Training Act](#)
- [Teachers' Association Act](#)
- [Child Care Services Act](#)

[Department of Education and Early Childhood Development Exceptionalities](#)

[Neurodevelopmental and Related Disorders](#)

[Teaching Students with Autism Spectrum Disorders](#)

Terms Used: Children and Youth with Diverse Needs/ Exceptionalities, exceptionalism, special education service, Individual Support Services Plan (ISSP), child's ISSP; Individual Support Services Planning (ISSP), ISSP team, ISSP model, ISSP process; ASD

Northwest Territories

[Education, Culture and Employment](#)

[Inclusive Schooling and Student Support](#)

[Resources](#)

[Ministerial Directive on Inclusive Schooling 2016](#)

[Directive ministérielle sur l'intégration scolaire](#)

[Individual Education Plans](#)

[Student Support Plans](#)

[NWT Program Support Guide](#)

[Dealing With Child Abuse](#)

[Counselling](#)

[Français \(en cours de traduction\)](#)

Terms Used: Individual Education Plan (IEP), IEPs, Student Support Plan (SSP)

Nova Scotia

[Education and Early Childhood Development Student Services Division](#)

Autism in Education:

[Transition to School for Learners with ASD](#)

[Current Research Regarding Time-Out](#)

[Developing and Implementing Programming for Students with Autism Spectrum Disorder](#)

[Evidence-Based Practice](#)

[Sensory Differences and ASD](#)

[Service Dogs and Children with ASD](#)

Terms Used: Individual Program Plan (IPP); exceptional abilities, exceptional student, exceptional children; Autism Team, Implementation Management Program Team (IMPT), Early Intensive Behavioural Interventions (EIBI); SETT Framework (Student: Abilities, strengths, needs; Environments: Physical settings, available resources; Tasks: Activities and situations in which the student will be expected to communicate; Tools: Strategies and devices the student needs to communicate within environments and tasks)

Nunavut

[Department of Education](#)

[Student Support and Wellness](#)

[Legislation and Policies](#)

[Consolidation of Inclusive Education Regulations](#)

Terms Used: Inclusive Education, Foundations for Inclusion, IQ, Student Support Services (SSS); Individual Student Support Plan (ISSP); Individual Education Plan (IEP); school team



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Ontario

[Ontario Ministry of Education](#)

[Special Education/Parents](#)

[PPM 156 on “Transitions”](#)

[PPM 140 on “Using ABA strategies in the Classroom”](#)

[The Individual Education Plan: A Resource Guide \(2004\)](#)

[Individual Education Plans: Principals’ Roles and Responsibilities](#)

[Ontario School Roadmap for Children with Special Needs
\(09/11/2014\)](#)

[Shared Solutions \(MOE, 2007\)](#)

[Pro Bono Law Ontario](#) Tel: 416-977-4448 or
866-466-PBLO free

[ARCH Disabilities Law Centre](#)

Terms Used: Individual Education Plan (IEP), IPRC, SEPRC, PPMs

Prince Edward Island

[Department of Education, Early Learning and Culture
Legislation](#)

[Special Educational Needs](#)

For Families and Students:

[Autism Services](#)

[Individual Educational Planning \(IEP\) for Students](#)

[Services for Students who are Blind or Visually Impaired](#)

[Services for Students who are Deaf or Hard of Hearing](#)

[Transition Planning for elementary students](#)

[Transition Planning to Secondary School](#)

[Transition Booklet](#)

For Educators:

[Provincial Joint Committee on Class Composition](#)

[Special Needs Grant](#)

[Special Education Resources](#)

[Minister’s Directives and Policies](#)

Other Resources:

[Early Years Autism Services](#)

[Autism Funding Guidelines](#)

[Educating Children about Autism in an Inclusive Classroom](#)

[A Resource Guide for Parents of Children with Autism:
Supporting Inclusive Practice](#)

[Building Social Skills: A Resource for Educators](#)

Terms Used: Individual Educational Planning (IEP), Early Years Autism Team, autism services, Intensive Behavioural Intervention (IBI), autism consultants, board consultants

Quebec

[Ministry of Education for Higher Education and Research \(ENG\)](#)

[Ministère de l’Éducation, de l’Enseignement supérieur et
de la Recherche \(FR\)](#)





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SPECIAL EDUCATION

[Issues of Inclusion and Integration in the Classroom](#)
[Organization of Educational Services for...
Students with Handicaps.](#)

[Basic School Regulation, c. I-13.3, Education Act](#)

Each school board establishes the Special Needs Advisory Committee. Complementary Educational Services are provided at the board level. The school principal gathers a meeting to address the creation of an IEP and a Positive Performance Profile (PPP).

Terms Used: Individualized Education Plan (IEP), Positive Performance Profile (PPP), Special Needs Advisory Committee (SNAC)

Saskatchewan

[Ministry of Education](#)
[The Education Regulations, 2015](#)
[Supporting Students with Additional Needs](#)
[The Ministry of Education Regulations, 2007](#)
[The Education Act, 1995](#)

Terms Used: "Pupil with intensive need," special needs, referral, Inclusion and Intervention Plan (IIP), support team, transitions

Yukon

[Department of Education](#)
[Support for Students](#)
[Additional information about Student Support Services](#)

OTHER RESOURCES

[Making a Difference: Working with students
who have Fetal Alcohol Spectrum Disorders](#)
[Behaviour Support Plans](#)
[School Based Team](#)
[Student Learning Plans](#)
[Access 2 Entertainment](#)
[A Parent's Guide: Individual Education Plans](#)

Terms Used: Individualized Education Plan (IEP), School-Based Team (SBT), Student Learning Plan (SLP), Behaviour Support Plan (BSP); strengths and needs.





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Acknowledgements

We would like to acknowledge the people who took the time to review the contents of this tool kit and provide invaluable feedback; the Autism Treatment Network (ATN) Family Advisory Board members (**Aracely Cruz, Bonnie Wiltshire, Connie Putterman, Eleanor Makar, Estrella Gubatina, Giselle Romanino, Regan Daly, Rosalie Ferguson, Susan Cosgrove, Adrienne Zarem, Brenda Relf, Cindy Rose, Jennie De Medicis, Jessica Brian** (Psychologist & Clinician Scientist, Holland Bloorview Kids Rehabilitation Hospital), **The Health Literacy Team** at Holland Bloorview Kids Rehabilitation Hospital, **Alyssa Willoughby** (Teacher, TCDSB), **Pam Green** (NP, Holland Bloorview Kids Rehabilitation Hospital), **Susan Menary** (Retired Chief of Autism Services, TCDSB), **Lisa Kanigsberg** (RA, Holland Bloorview Kids Rehabilitation Hospital), and **Rachel Easterbrook** (RA, Holland Bloorview Kids Rehabilitation Hospital).

Very special thanks to those who made additional contributions; **Adrienne Zarem** (Parent, Advocate, Holland Bloorview Family Leader, ATN Family Advisory Board), **Brenda Relf**, (Parent, Advocate, ATN Family Advisory Board), **Cindy Rose** (RN, Parent, ATN Family Advisory Board), **Jennie De Medicis** (Parent, Advocate, ATN Family Advisory Board), **Susan Cosgrove** (Parent, Advocate, Holland Bloorview Family Leader, ATN Family Advisory Board), and **Kaya Cosgrove** (Sibling, Advocate).

Certain sections in this toolkit were individually produced and we would like to acknowledge **Jennie Ormson MSW**, for compiling the section on self-care. Jennie is a clinical social worker in private practice in Toronto and for over 20 years she's been helping people navigate life's emotional rollercoaster. We would also like to acknowledge **Lori Beesley** for compiling the Advice from Parents section. Lori is the mother of a 20 year old with ASD. A very special thanks to **Liam Cosgrove**,

Holland Bloorview Ambassador and self-advocate extraordinaire for his insight, wisdom and advice to parents. Final thanks to **John Howell** for his comprehensively written Conclusion: *A Father's Perspective*. John is a parent of three children, two of whom have ASD on different parts of the spectrum. He is an advocate and Family Advisory Committee Member at Holland Bloorview Kids Rehabilitation Hospital.

The authors would like to thank the **Autism Treatment Network (ATN)** for funding the graphic design of this publication.

Finally, the author(s) of this publication acknowledge and thank **Autism Speaks Canada Family Services Community Grants** as the funding agency for the project leading to this publication. The views expressed in this publication do not necessarily express or reflect the views of Autism Speaks Canada or any other funding agency.





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References

1. The Autism Treatment Network (ATN) is a collaboration of Autism Speaks® and some of the finest children's hospitals and academic institutions in North America, specializing in multi-disciplinary medical care for children with autism. Together, they work to develop evidence-based protocols and standards of care for many of the most challenging medical conditions surrounding autism today. ATN best practices are shared with physicians and medical facilities nationwide to improve outcomes for all children with autism. The Autism Intervention Research Network on Physical Health (AIR-P) is a collaborative among the Autism Speaks Autism Treatment Network (ATN), the Clinical Network Coordinating Center (CCC) at Massachusetts General Hospital for Children (MGHfC), and the Health Resources and Services Administration (HRSA).
2. For this discussion we referred to Areva Martin's book *The Everyday Advocate: Standing Up for Your Child with Autism or Other Special Needs* (2010)
3. Discussion based on document: *Take Ten Series*. CanLearn Society, Calgary 2013
4. Our example is adapted from the Autistic Society UK Passport
5. A primary care provider can be a nurse practitioner, a general practitioner or a family physician. Primary health care services in Canada can be provided by health professionals such as nurses, nurse practitioners, physicians, dietitians, physiotherapists and social workers.