

# A Parent's Guide to Advocacy





## What is Advocacy?



### Advocacy

The act of pleading or arguing in favor of something, such as a cause, policy, or interests, or active support of an idea or

Part of being a parent is wanting the best for your child, and ensuring that they have every opportunity to grow up to be their happiest self. Every parent advocates for their child.

That said, parents of people with intellectual or developmental disabilities will find themselves having to advocate more frequently for the services and supports their child needs.

### **Advocacy is strategic communication that is used to:**

1. Ensure that a need is met;
2. Shape the policies of service providers, and;
3. Remove barriers for all persons with disabilities.

Advocacy can take different forms. It can be a self-advocate voicing their needs, or a loved one speaking up to give a voice to someone who may be unable or struggle to communicate their needs. Ultimately, advocacy is about **relationships**: your relationship with your child, and their relationship with the world.

# First Steps

Before you start advocating for your child, it is important to remind yourself of what you want to work towards. Advocating for your child will not always be easy, so these reminders can help you re-centre on why you are advocating.

## As easy as A,B,C!

A. VISION



B. PATHWAY



C. NEED



# A. VISION

One of the best ways to remind yourself of why you are advocating is to picture what you want your child's life to look like. Every parent wants the best for their child, and having a clear picture to focus on can give you direction for your advocacy.

**Write down** what you envision for your child. Put it into concrete terms, and share your vision with someone who you know will support you.

Try to be as **specific** as possible. You could break it into categories. What do you want for their education? Where would you like to see them living? What do you imagine for relationships for your child? What do you want them to have the chance to experience?

This vision will continue to expand and grow as your child does. As they grow, include them in this process. Ask them what they see for their future, and what they want for themselves.



## B. PATHWAY

The heart of advocacy for all parents of persons with intellectual disabilities is **inclusion**: for persons with disabilities to have access to the same opportunities as their peers, and to be contributing and valued members of their communities.

Inclusion is not achieved by “special” classrooms or workplaces separate from their peers, but by supporting persons with disabilities to follow as “typical” a pathway as possible.

This is why we advocate — to allow our children to follow the path to fulfilling lives that are rich with strong relationships.

Your advocacy should centre around helping your child to follow this “typical” pathway. There will be times when the path may stray toward segregation and marginalization. This is what we want to avoid.

## C. NEEDS

To follow the normative pathway, persons with disabilities may need some extra supports or services. To gain these extra supports, parents advocate to organizations, services providers and agencies to access the services they offer and to meet the needs of their children.

For each moment of advocacy, we recommend putting a name to your need. Again, put it into concrete terms, and be as specific as possible.

What is the need?

Why is this a need for your child?

Who can help you meet this need?

Who will support you in advocating?

How will you achieve this?



## Gathering Information

Before you go into a meeting, make an important phone call, or write an email to a service provider, it is always best to prepare yourself, and go in with as much information as possible so you are not surprised. There may not always be time to prepare in advance, but these steps can help you stay ready to advocate. Here are some tips to help you with this.

- **Document** your research and be organized. Keep all the information you find in a binder or a notebook.
- **Who** are you going to contact for this need? What agency or organization? Who within this organization do you contact? Does this need the Supervisor's approval, or can a case worker help you?
- **What** are the criteria for this service?
  1. Eligibility? Exclusions?
  2. How do you apply?
  3. What is actually provided?
  4. Does anything affect what is provided, like income or priority of needs?
  5. Is there a waitlist?
- **Scan** through the program's policy for this information, or ask someone who has applied for this service before.
- **Know** your rights and responsibilities. It is important to know what you are entitled to by law, and what you are responsible for.

# Communication Tools



Advocacy is about communicating your needs strategically. It is important that you are firmly stating your need, and that you are contributing to creative and positive solutions. We recommend these methods for advocating effectively.

- Be confident when communicating your needs, but not aggressive. State your need respectfully while remaining firm on your position and your values.
- Listen actively to what is being said, and pay attention to the other person's body language. Try to understand the other side's position, their rationale and their values. This shows you are working toward a positive solution.
- Be confident, but know your vulnerabilities. If you know that you are likely to get upset or angry, you can prepare for this.



## Taking Action

When scheduling a meeting, or planning a phone call, try to ensure that the person who has the decision-making power will be part of the conversation. This way, you can make sure the right people are hearing your case.

You are entitled to have a second person with you for moral support, to take notes on what is said, and to interject when you need a break. Always try to have someone with you to support you, whether it's a family member, a friend, or professional advocate.

When you go into a meeting, or make a phone call, make sure you have a list of the points you want to cover, your questions for the professional, and your concerns.

Most importantly, **always document every interaction!** Keep a log of all the phone calls, emails and meetings you have, who attended, and the outcome. We recommend using the following template to help you stay organized.



<b>Date and time:</b>	_____
<b>Type of contact</b>	<i>email</i> ____ <i>in person</i> ____ <i>phone</i> ____
<b>Person you spoke with</b>	_____
<b>Position &amp; Organization</b>	_____
<b>Their contact information</b>	<i>email</i> _____ <i>phone</i> _____
<b>Summary of your conversation</b>	_____ _____ _____ _____ _____
<b>Next Steps By when?</b>	_____ _____ _____ _____ _____

Follow up email sent? Yes \_\_\_\_ No \_\_\_\_ When? \_\_\_\_\_



## Compromises

Most of the time, you will come to a compromise. In those instances, make sure that you know your ideal alternative, and stick to it. Our tendency to compromise comes from the pressure we feel to cooperate with those who have higher power.

However, when a compromise is needed, it should **always** serve the interests of the most vulnerable party first — that of your child. Do not settle for a compromise on the basis that is the “least worse” option. This devalues your child and undermines your advocacy efforts. Know your rights and the rights of your child.

# The Appeal

Hopefully your initial request will be approved, but in the event that it is not, most government or government-funded organizations will have an appeal process you can follow.

Review the requirements of the appeal carefully. Make sure to take note of any deadlines for completing the appeal. The appeal will most likely require some supporting documents.

Take the time between filing the appeal and your next meeting to revise your position, how to present your case, and incorporate any new information you have learned.

Present your case to the appeal committee. If your appeal is accepted, be sure to share your experiences with others who are also looking for this service.

If you are denied again, ask them for a written response with the rationale for the denial. Often the parties will let you know if there are follow-up items you can complete to alter the decision. If no follow-up is requested, we recommend speaking to your MLA or the appropriate Ombudsmen, and see if they can offer their assistance in moving your case forward.

# Supports

While the process of advocating for your child may be overwhelming at times, you are not the first to have worked through the barriers and systems persons with disabilities face. There are many families and support groups to guide you through your advocacy journey.

If you ever feel stuck, or unsure of what to do next, reach out to self-advocates, families and advocacy agencies who have successfully navigated the different services to meet their own children's needs. They can give you tips about what has or has not worked, and how to ensure that you can access the services that you need for your child. Things may seem less daunting if you have people in your corner to support you.



## Tips from other Parents

### 1. Find a friend within the system.

Advocating for your child can be challenging to navigate by yourself. Having someone as a contact who works with these services can be a life-saver. This can be a social worker at the hospital or a specialist with the Early Behaviour Intervention Centre.

### 2. Make and maintain connections with the people involved with your child's care.

All children have many professionals cycling in and out of their life, like teachers, doctors, nurse practitioners, and early childhood educators. For children with disabilities, these professionals and the relationships we form with them, can make or break your child's inclusion and quality of care. It is important to form positive, friendly and collaborative relationships with these professionals.



### **3. Connect with parents who also have children with disabilities.**

Parents have reported that having a child with a disability can be a lonely experience. They see the “neurotypical” children develop their independence and the parents of those children begin to see the next phase of their children’s lives — leaving the nest. It can be disheartening when you can’t relate to those parents, and they can’t relate to you.

Having someone who understands exactly what you’re going through, and who can support you, can be a powerful and comforting thing.

### **4. Transition Plan early.**

Most parents have the desire to see their children eventually leaving the nest and discovering their independence in their own home. This transition from home to community living can be challenging for both parents and the person with the disability. Making a plan for this move early in the process can help ease the transition when the time comes. Finding a social worker to partner with you in making this plan can be helpful.



## 5. **Foster and promote a great circle of friends for your child.**

Often, parents of children with disabilities find themselves in the role of friend-maker for their children. Several parents have expressed that they wished they had cultivated a group of friends for their children, made those connections so that their children would not feel lonely or unliked. (Early Behaviour Intervention Centre)

## 6. **Know your rights.**

Before you start to advocate, it is important to know what rights you and your child have. There are areas in the school system, in doctors' offices and other services that have to accommodate your needs, and the needs of your child. Knowing your rights can give clear direction for your advocacy.

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## 7. **Be Mom and Dad first.**

As a parent of a child with a disability, you will have many roles to play: an advocate, a care provider, a therapist, a teacher. But the most important role you will play will be Mom or Dad. Other people are able to help with the other roles. Only you can be Mom or Dad. If you find these other roles are interfering with being a parent first and foremost pause what you're doing and find some help from your supports.

(Pitonyak, 2007)



## 8. **Most importantly: Self-care!**

No one will be able to go at one hundred percent all the time, even when advocating for their child.

You are at your best and most able to support your child if you take care of yourself. To take care of yourself, we recommend picking what causes are the most important to you, your family, and your child.

# Advocating for Adult Children



## Advocating for NEW Adults

Nova Scotia has a new law called the **Adult Capacity and Decision-making Act**.

On December 28, 2017, the Adult Capacity and Decision-making Act became law. It replaces the *Incompetent Persons Act*. This new law is for adults who cannot make critical decisions for themselves. For example, they may not make decisions because of a learning disability, mental health problems, brain injury, or other reasons. This law allows another person to make some crucial decisions for them.

# Advocating for Adults

## What happens when your child turns 19?

When a person turns 19 (the age of majority in Nova Scotia), they are **legally considered adults**. They are expected to make decisions about their own medical treatment, finances, and life in general. For these decisions to be binding in the legal sense, the person is deemed competent and able to understand the consequences of their choices.

It is now time for your young adult to advocate for themselves. This might be scary for you as a parent. It is difficult for most parents. But trust that having supported your child over their lifetime has taught them how to assert their rights.

Your young adult does not have to do this alone. They are allowed to have someone with them if they need to speak up, and they have resources in the community that will offer support and information.

Everything that you learned about advocacy earlier in this booklet still applies. The difference is that now you are the support person, and your young adult is the decision-maker.

### 3 Things to Remember

- Listen carefully to your young adult.
- Support them in making their own decisions, don't make decisions for them.
- You have guided your child well. Trust them to follow their own path.

### My young adult is not deemed competent

If you feel that your adult son or daughter can't make important decisions on their own, you can apply to be their representative under the **Adult Capacity and Decision Making Act (ACDMA)**.

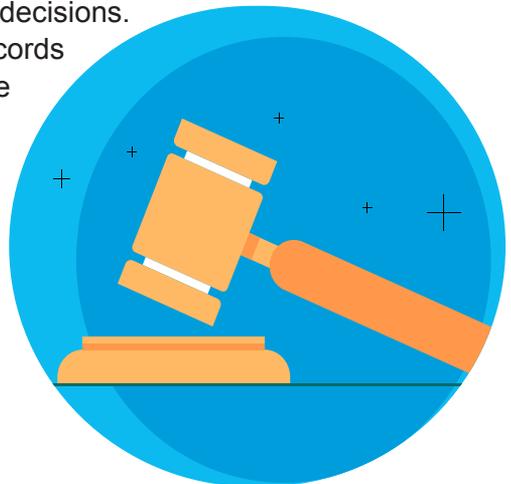


## Who can represent an adult?

Any person can represent an adult who cannot make their own decisions. Usually, it is a family member, but not always. The representative must be at least 19 years old, know the adult well, and respect the adult's rights, freedom, and liberty.

To represent an adult, a person applies to the court. The court decides if the person is a suitable representative. The person must prove that the adult cannot make some decisions. The adult has a right to participate in the court process and to receive legal advice and support if they want. <https://novascotia.ca/just/pto/FAQ-adult-capacity-decision.asp>

1. Apply to the courts to represent your young adult.
2. The court will decide if you are a suitable representative.
3. You will have to prove that your young adult cannot make some decisions.
4. When approved, keep records of the decisions you make for your young adult.



Continue to advocate as you have been to ensure your young adult's rights under the **UN Convention on Human Rights**, which translates to:

- People are free to make their own choices.
- No one will be discriminated against.
- Disabled people have the same rights to be included in society.
- Disabled people are to be respected for who they are.
- Everyone should have equal opportunities.
- Everyone should have equal access.
- Men and women should have equal opportunities.
- Disabled children should be respected for who they are as they grow up.

Listen to your young adult and encourage them to make the decisions they can.

Make sure that they understand your decisions and are aware of decisions being made as much as possible.

Consider doing a **PATH** with your young adult to draw a picture of what they want their future to look like. **Inclusion Nova Scotia** has staff trained to do PATH.



## Thanks to ...

**Inclusion Alberta's Pocket Guide to Advocacy.**

<http://inclusionalberta.org/clientuploads/documents/2010%20PocketGuide%20to%20Advocacy.pdf>

**Nova Scotia Association for Community Living Advocacy Guide**

**Notes for Parents** Pitoniyak, D. (2007)

Retrieved from:

<http://www.dimagine.com/wp-content/uploads/2018/03/Parents.pdf>

**The Ripple Effect: Family Advocacy and Leadership**

Development presentation

**Parents who shared their experiences with us.**



# Resources for Advocates

Inclusion Nova Scotia	<a href="http://www.InclusionNS.ca">www.InclusionNS.ca</a>
Human Rights Commission of NS	<a href="https://humanrights.novascotia.ca">https://humanrights.novascotia.ca</a>
Information Access and Privacy	<a href="http://www.novascotia.ca/just/IAP">www.novascotia.ca/just/IAP</a>
Government of Nova Scotia	<a href="http://www.novascotia.ca">www.novascotia.ca</a>
Disability Support Program	<a href="https://novascotia.ca/coms/disabilities/index.html">https://novascotia.ca/coms/disabilities/index.html</a>
School Boards and Public Schools	<a href="http://www.ednet.ns.ca">www.ednet.ns.ca</a>
Early Intervention in Nova Scotia	<a href="http://www.nsecdis.ca">www.nsecdis.ca</a>
Nova Scotia Residential Agency Association	<a href="http://www.nsraa.ca">www.nsraa.ca</a>
People First of Nova Scotia	<a href="http://www.peoplefirstns.ca">www.peoplefirstns.ca</a>
Inclusion Canada	<a href="http://www.inclusioncanada.ca">www.inclusioncanada.ca</a>
National Community Inclusion Initiative	<a href="http://www.communityinclusion.ca">www.communityinclusion.ca</a>
Inclusive Education Canada	<a href="http://www.inclusiveeducation.ca">www.inclusiveeducation.ca</a>
People First of Canada	<a href="http://www.peoplefirstofcanada.ca">www.peoplefirstofcanada.ca</a>
Disability Tax Credits	<a href="https://www.canada.ca/en/services/benefits/disability.html">https://www.canada.ca/en/services/benefits/disability.html</a>
Registered Disability Savings Plan	<a href="http://www.rdsp.com">www.rdsp.com</a>
Access 2 Entertainment	<a href="http://www.access2card.ca">www.access2card.ca</a>
Disability Travel Card	<a href="https://www.easterseals.ns.ca/disability-travel-card">https://www.easterseals.ns.ca/disability-travel-card</a>
Inclusion International	<a href="http://www.inclusion-international.org">www.inclusion-international.org</a>
UN Convention on the Rights of Persons with Disabilities.	<a href="https://www.un.org/development/desa/disabilities">https://www.un.org/development/desa/disabilities</a>









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