

Advocacy

A toolkit about advocacy, where you may need it, and some tips along the way.



For those on the autism spectrum, advocating for yourself can be challenging. Perhaps you're an Autistic adult, struggling to make your views, needs, and wishes truly heard. Maybe you are a parent, determined to advocate for your child. Or you have a friend or relative who, for a variety of reasons, can't effectively communicate for themselves. Although some individuals may be naturally comfortable with advocating, remember that advocacy skills can be learned and practiced. If needed, ask a close friend, family member, or an advocacy organization for support.

There are a wide variety of circumstances and locations where you might consider advocating, such as:

- Within your own family, whether immediate or extended relatives
- Throughout your local community and in groups you participate in
- Acquiring program funding for yourself or a family member
- At your child's school or at a post-secondary institution you attend
- Where you work, with your employers and co-workers
- Participating in the bigger picture, encouraging changes in the system or government



At Home

When you first tell family members (about your diagnosis or your child's), their reactions and emotions can run the gamut. Some may embrace it, be supportive, or want to learn more. Others may not believe it, be judgmental, or not really comprehend what autism is. Once you're ready to share the news, good advocacy includes sharing accurate information. This can encourage understanding and acceptance, and correct misconceptions. You may also choose to voice your expectations regarding positive language and acceptance of autistic traits. If there are family members who cannot accept the diagnosis or your guidelines, you may have to set strong boundaries to those relationships, for your well-being or that of your Autistic loved one.

In Your Community

You may choose to advocate in groups or at locations where it makes sense to do so in your life. This may include clubs, sports/activity organizations, churches, stores you frequent, doctors offices, etc. The benefit may be that you feel more comfortable participating in those groups, or more relaxed when visiting various places. With some good information and context from you, they may gladly accommodate your neurodiverse needs. Keep in mind that people around you might take their cue from your behaviour and language. In public, be aware of how you speak to your Autistic child and how you respond to your child's actions. Are you giving them choices? Are you modelling acceptance? If you are an Autistic adult, be aware of how you talk about yourself: give yourself some grace.

At School (Pre-K to Grade 12)

Here are some great tips on how to be a strong advocate for your child's needs in the school system in Alberta

- Know your rights and responsibilities in Alberta. Here are important links that you can explore.
 - Alberta Education Act <https://www.alberta.ca/education-guide-education-act>
 - Inclusive Education https://bit.ly/AB_InclusiveEducation
- Be informed about options and programs available at your school and within your school division. You can sometimes find this on a school's website. You should also check your school division's website, and look for departments such as 'Diverse Learning Needs' or 'Inclusive Education'. If not, you may need to phone and ask. This information is especially important if you consider school programming an important factor when you're planning a move.
- Request everything in writing. If you had a verbal meeting, summarize the conversation as you understood it, and email it to everyone involved. Keep **written/typed** records of *everything*. This can include:



- Any Individual Program Plan (IPP), Instructional Support Plan (ISP), Individual Educational Plan (IEP), etc.
- All emails between you and employees of the school or school division.
- Notes you took at any meetings you attended regarding your child's education.
- The communication book that travels between school and home each day, if you use one.
- Reports, observations, or instructions from any specialist visiting the school.
- When preparing for a meeting, be sure to write down the points you want to talk about and bring them with you. Don't forget to add at least one positive thing the school is doing that you are happy about.
- Don't go to meetings alone. Whenever possible, have a support person with you. This could be your spouse, a relative, a close friend, or even a paid coach. There are various reasons why having someone with you can be helpful.
 - They can take notes for you so that you can focus on the conversation.
 - Often, there are several educators at meetings regarding support for students with disabilities (teacher, principal, aide, etc.). Having someone with you can make things feel more comfortable and balanced.
 - If your family has been struggling to fulfill the needs of your child, you may understandably be frustrated and/or exhausted, and become emotionally upset. A support person can help to ground you, or even help you to express your concerns when you are overwhelmed or feeling defensive.
 - Different minds decipher conversation in diverse ways. Your support person may pick up on details you missed, or interpretations you didn't consider.

Advocacy in Post-Secondary Education

In Alberta, many post-secondary institutions have intentional programs, policies, or services that aim to include and support neurodiverse students. As you begin to advocate for the accommodations you need, you may find that there are some things they provide more readily, and other supports they haven't considered yet.

Unlike grade school (where your parents may have done most of the advocacy), at the post-secondary level, you are expected to initiate the request for accommodations, and to participate in the process as much as possible. However, if needed, you can get guidance from your parents, a person you trust, or from an organization (see our list of *Disability Advocacy Organizations* below).

Here are some other resources:

- You can read up on post-secondary resources, rights, responsibilities, and more on the Government of Alberta page. <https://www.alberta.ca/resources-students-disabilities>



- There is a guide by the Alberta Human Rights Commission, called 'Duty to accommodate students with disabilities in post-secondary educational institutions.'
<https://albertahumanrights.ab.ca/media/cumfoet/duty-to-accommodate-students-with-disabilities.pdf>
- Check out advocacy tips from the Learning Disabilities & ADHD Network - Calgary Region.
<https://ldadhdnetwork.ca/advocating-for-yourself-in-post-secondary/>
- Disability Related Employment Supports (DRES) provides supports to help people with disabilities succeed in school and find rewarding careers. Go to the link and scroll down to 'Educational Supports'. <https://www.alberta.ca/disability-related-employment-supports>
- If an Autistic individual has an intellectual disability as well: Inclusion Alberta has been partnering with post-secondary institutions across the province for more than 30 years to include students with intellectual disabilities to participate in regular programs of study and campus life.
<https://inclusionalberta.org/what-we-do/inclusive-post-secondary/>

Advocating for Funding, Services and Programs

Advocacy can be a valuable tool in this area. Pursuing funding, services, or programs can present a learning curve, but may prove well worth the effort if successful, as they can make a positive difference in the lives of Autistic individuals and families. Whether you need assistance from Alberta Health Services, access to an organization's programming, or funding from FSCD (Family Support for Children with Disabilities) or PDD (Persons with Developmental Disabilities), there is much information to be absorbed, and processes to learn.

FSCD: <https://www.alberta.ca/fscd>

PDD: <https://www.alberta.ca/persons-with-developmental-disabilities-pdd>

Learn the system. Read up on eligibility criteria, what's provided, the application process and how long it takes, appeal processes (if any), and the applicable regulations. Websites can often supply much of the information you need to get started. To get more details, phone or email the organization, department, or program office directly. Knowing the terminology, process, and guidelines will put you in a stronger position to advocate for yourself or your loved one.

Ask the right person. When you phone or email to ask questions, ask a person who likely has the knowledge or information needed. The admin person may be friendly, but could give you erroneous advice. Regardless of who you speak to, if you feel they gave a vague or incorrect answer, move up to the next person (like a supervisor or manager), or ask where you could learn more about the subject or process.



Advocacy at Your Place of Employment

If you are working, you might find that there are challenges in the workplace related to being neurodiverse; barriers that are preventing you from being the best employee you can be. Sometimes it just takes communication with your employer, and a simple change or two, to empower your best performance.

It is important to clearly describe what accommodations you need to be most effective at your job. Offering solutions while clarifying the challenges you face will illustrate your commitment to performing well. Be sure to highlight your strengths during the conversation, to help them focus on what you are capable of.

Request everything in writing. If you had a verbal meeting, summarize the conversation as you understood it, and email it to everyone involved. Keep written/typed records of everything.

On this page by *Self-Advocacy@Work*, you will find practical steps for Self-Advocating at Work (<https://selfadvocacy.au/self-advocacy/self-advocacy-skills/self-advocating-work>). You can also check out this article from Reframing Autism for ideas on self-advocacy: Establishing Workplace Adjustments: How I Learned to Advocate for My Autistic Needs (<https://reframingautism.org.au/establishing-workplace-adjustments-how-i-learned-to-advocate-for-my-autistic-needs/>).

Resources:

- The Alberta Human Rights Commission: Duty to Accommodate at Work. Read this document to learn more about your rights and responsibilities. *“Employers have a duty to accommodate employees or job candidates because of a protected ground to the point of undue hardship.”* <https://albertahumanrights.ab.ca/issues-at-work/duty-to-accommodate-at-work/>
- Disability Related Employment Supports (DRES) provides supports to help people with disabilities succeed in school and find rewarding careers. Go to the link and scroll down to ‘Workplace Supports’. <https://www.alberta.ca/disability-related-employment-supports>
- This is an excellent self-paced online course that is FREE to take through The University of British Columbia, entitled Autism and Neurodiversity in the Workplace. Autistic adults took part in creating this course. You might like to check it out for ideas on what support at work could look like for you. You may even, in the friendliest of ways, tell your employer about the course if you think they may be interested in learning more about the benefits of encouraging neurodiversity in their business or organization. <https://circa.educ.ubc.ca/autism-in-the-workplace/>
- A Guide to Balancing Work and Caregiving Obligations. This guide provides tips for developing accommodation solutions that are in harmony with human rights law, and outlines the rights and responsibilities of the employee, the employer, unions and/or employee representatives. https://www.chrc-ccdp.gc.ca/sites/default/files/2020-07/a_guide_to_balancing_work.pdf



General Advocacy Tips for Families or Individuals

- Keep a journal. This can include appointments with doctors, specialists, educators, employment coaches, funding programs, or service providers. Specify times, dates, what was discussed and/or decided, and next steps.
- Showing emotion is okay. Sometimes we get overwhelmed however, getting angry or making meeting attendees feel verbally attacked is counterproductive to your goals. Stay focused on what you are trying to achieve, and clearly communicate your needs. Speak assertively, not aggressively.
- If you've exhausted your knowledge and strategies, consider finding help from someone with more experience or expertise, who has an outside perspective. This could be someone informal, like a fellow parent or an Autistic individual you know who has had success advocating with the organization you are dealing with. Or it could be more professional, such as a paid coach or navigator who was referred to you. It could be an advocacy organization (see our list of *Disability Advocacy Organizations* at the end).

Big-Picture Advocacy

Are you interested in affecting change in systems and policies regarding autism, or disabilities in general? It may not be as hard to participate as you think. Government bodies and other organizations are often looking for input on what's needed, and feedback regarding current policies or programs. You can write a letter to your local MLA, or to the Alberta Minister of Seniors, Community and Social Services (<https://www.alberta.ca/minister-of-seniors-community-and-social-services>).

You may see or hear the following types of opportunities being advertised in the news or on social media:

- Apply to serve on a public board or agency that interests you
- Take part in rallies
- Attend town hall meetings (in-person and virtual)
- Join letter-writing campaigns

The Government of Alberta has some tips on how to get involved (public engagement). <https://www.alberta.ca/public-engagement>



Online Advocacy Resources

- Effective Self-Advocacy - Video - <https://autismalberta.ca/videos/effective-self-advocacy/>
- Advocating for Yourself: First-Hand Perspective https://bit.ly/AO_advocating

Disability Advocacy Organizations

Advocate for Persons with Disabilities

The Office of the Advocate for Persons with Disabilities builds partnerships alongside Albertans with disabilities and includes community groups, advocacy organizations, caregivers and loved ones to help understand disability-related issues in Alberta. <https://www.alberta.ca/advocate-persons-disabilities>

Voice of Albertans with Disabilities (VAD)

Voice of Albertans with Disabilities (VAD) is dedicated to supporting individuals, organizations, government representatives, schools, business personnel, and employers to reduce the barriers and find solutions that prevent full participation. <https://vadsociety.ca/>

Inclusion Alberta

Inclusion Alberta is a family-based, non-profit federation that advocates on behalf of children and adults with intellectual disabilities and their families.

<https://inclusionalberta.org/what-we-do/individual-family-advocacy/>

Albertans Advocating for Change Together (AACT)

AACT is an Alberta self-advocacy network of people with developmental disabilities and their allies. The idea for the group came from the 2009 Self-Advocacy Summit. They are a united Alberta network that learns about issues and advocates passionately for positive change in society.

<http://www.albertaact.com/p/about-aact.html>

Alberta Council of Disability Services

ACDS advocates strongly for issues that affect the Community Disability Services (CDS) sector. They are viewed by the Government of Alberta and the CDS sector as a credible and trusted voice. They influence public policy by supporting members to have a collective voice, conducting sector-specific research, and offering regular updates on policy and legislative changes impacting the sector. <https://acds.ca/advocacy/>



Disability Rights

Alberta Human Rights Act – Disability, illness, and injury

“The Alberta Human Rights Act prohibits discrimination at work based on one or more protected grounds, including physical and mental disability. An employer cannot terminate, refuse to hire, or otherwise negatively impact an employee because of their disability, injury, or illness.”

<https://albertahumanrights.ab.ca/issues-at-work/disability-illness-and-injury/>

Government of Canada – Rights of people with disabilities

Canada seeks to reduce barriers and increase opportunities for people with disabilities, to ensure their full participation in our society. Our nation has a strong legislative framework that guarantees the equal rights of people with disabilities. In addition, a range of federal programs support the lives of Canadians with disabilities. <https://www.canada.ca/en/canadian-heritage/services/rights-people-disabilities.html#a1a>

The United Nations Convention on the Rights of Persons with Disabilities

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

<https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>