



Advocacy Kit

for Ontario Families, Caregivers and
Individuals with Disabilities

April 2019

(Adapted from the Ontario Autism Coalition MPP Lobbying Kit February 2019, with permission from our friends and partners at the Ontario Autism Coalition.)

The Ontario government recently announced its intention to launch a series of discussions, roundtables, meetings with families and experts, and online surveys in the month of May, specifically to discuss the status of disability services in Ontario.

The purpose of this Advocacy Kit is to provide guidance to Ontario families, caregivers and individuals with disabilities on how to effectively lobby the Government of Ontario to provide equitable and meaningful services to persons with disabilities. The Ontario Disability Coalition wants to help you effectively advocate for your needs, as persons with disabilities in Ontario.

This Advocacy Kit contains:

1. An MPP Letter/Email template, which can be used to contact your MPP to set up a meeting or to connect with your MPP.
2. The key talking points that you may want to focus on in your meeting. These notes will help guide your discussion. It provides the facts that you need as you ask for what is needed.

WHAT IS LOBBYING?

Lobbying is a process, which involves writing letters and meeting with politicians about concerns that we have. We lobby because we want the system to improve. We lobby because we live in a democratic society, and it is our right to lobby.

The Ontario Disability Coalition is presently lobbying the government to make the government aware that its current practice and policy of focusing and providing a comprehensive policy and program for only one diagnosis (i.e. Autism) is systemically discriminating against all other individuals with other disabilities across the province.

WHO DO WE LOBBY?

MPP's (Members of the Provincial Parliament) are our representatives before the Ontario Government. Our current government is a majority Progressive Conservative government. The MPPs in each riding belong to one of the four parties (PCs, NDPs, Liberals and Green Party). We are presently lobbying the Progressive Conservative MPPs as we have a majority government in which the PCs are in power. We are also lobbying opposition MPPs as they also can influence the party in power by applying pressure.

HOW TO LOBBY

Advocating effectively involves three important components:

- (1) A strong key message;
- (2) 1-2 key "asks" or solutions (things that you want to see happen or change); and
- (3) Your personal story.

WHERE TO START

(1) Find out who your MPP is and get their contact information:

Find out your electoral district by visiting the following website: <https://voterinformationservice.elections.on.ca/en/election/search?mode=electoralDistrict>

Once you know what electoral district you live in, find your MPP by visiting the following website: http://www.ontla.on.ca/web/members/members_current.do?locale=en

(2) Send an email or letter asking to set up a meeting (refer to the template in this kit)

(3) Set up an appointment to meet with your MPP

WRITING A LETTER/EMAIL TO YOUR MPP

Writing to your MPP about the issue that you have first-hand experience with can have a positive effect on your MPP.

Discuss in your letter your experience with Government of Ontario programs for persons with disabilities (please refer to the talking points provided in this kit to narrow down your focus).

Tell them what you think a viable solution is.

Keep your letter/email brief. Do not go beyond two pages, otherwise they are less likely to read your letter.

Please note that the sample letters provided are just a suggestion. You can modify it as you see fit. They are included at the end of the package.

These letters can be mailed, faxed or sent via email.

WHAT DO I DO IF THEY DO NOT REPLY?

If you have not heard back from your MPP constituency office within 3 days after sending your email or letter, call your MPP's constituency office to set up a meeting.

MPPs are usually in their offices on Friday. This is their day to meet with their constituents. If the Legislature isn't in session at Queen's Park, they are available most days.

Speak with the MPP's assistant or their coordinator. Be polite to whomever you are speaking with. They are what is standing in the way between you and your MPP. Being rude results in lost credibility and they will be less likely to want to assist you. Introduce yourself and formally request a meeting.

You may need to call the office more than once. You may need to leave more than one message. Be persistent.

ONCE YOU HAVE A MEETING SET

(1) Decide who will be coming with you to the meeting

You may want to bring other people to the meeting, but do not invite more than 2-3 people. Additionally, it is better that those who you invite to the meeting live in the electoral district (often MPPs only wish to assist and meet with their own constituents). It is considered respectful to advise the office who will be attending the meeting with you.

(2) Preparing for the meeting

1-2 days before the meeting, call the MPP's office to re-confirm the meeting. If the meeting needs to be rescheduled, be polite and ask for another date.

Enquire about how long your appointment will be. Make sure you can get your message across in 15 minutes as these meetings are generally short.

Review the list of "*Key Talking Points*" provided in this kit, along with a review of the news regarding the most current issues in disability rights in Ontario.

Bring notes with you that you can refer to during the meeting.

Arrive to the meeting a few minutes early.

(3) During the meeting

You have a time limit so manage your time so that you get to the "ask."

Politicians love to talk—it is big part of what they're paid to do—so if they eat up too much of your time, interject with something like "I know your time is valuable and I want to be sure you're able to hear my/our message."

Tell your story (refer to "*How to Tell Your Personal Story*" in this kit), but keep it on point. They hear a lot of these stories and we love to talk about our kids.

Tell your MPP how the Government of Ontario is failing your child.

Refer to the talking points provided in this kit.

Be assertive, but polite. Be friendly. Do not be rude.

Speak to solutions, rather than problems. Do not get into any arguments.

Have a plan of who will speak and when they will speak. Make sure all points are covered.

Point out what information you have about the MPP's views on the situation that you can support. You want to convey a sense of collaboration.

Leave time at the end of the meeting to provide the MPP an opportunity to ask questions.

Ensure that your MPP understands what it is you are asking, and advise them that you will be following up with them.

(4) What to ask the MPP to do.

If your MPP is a government Cabinet Minister, ask them to bring up the problems/demands in the Cabinet meetings.

If your MPP is a member of the government party, ask them to bring up the problems/ demands during their caucus meetings, specifically with the Minister in charge of that specific ministry.

If your MPP is a member of the opposition party, ask them to bring up the problems/issues during Question period in the legislature. Ask your MPP to write a letter to the Ministry of Child, Community, and Social Services and the Ministry of Health to support you and to request a response.

AFTER THE MEETING

Send a thank-you letter to your MPP thanking them for taking the time to meet with you (refer to the template in this document).

Ensure that in your letter you highlight what you spoke about and what the MPP agreed to do for you.

Call the MPP at a later date to see if the MPP followed through on any of the promises he/she made.

HOW TO TELL YOUR PERSONAL STORY

Your personal story should reflect a concrete real life example of the issue that you are speaking to. Politicians are constantly being bombarded with information that deals with policies, funding, etc.

We need the politicians to hear real life examples and how these problems are affecting your family directly. You need to keep the following things in mind (the examples provided are in relation to a child with severe physical disabilities):

(1) Tell them who you are, where you live.

- My name is [Name], and I live in [City], in your riding.

(2) Tell them the challenges you are facing.

- I/My child is [years old] and have/has [diagnosis].

(3) Tell them how the challenges have affected your life.

- My child is living with severe disabilities. They affect her speech, gross motor skills, fine motor skills, feeding [etc.]. Her disabilities affect every aspect of our life.

(4) Keep your story simple. We understand that your child's situation may be complex. Try and keep your life story in a simplified version.

- My child requires frequent physiotherapy to acquire and maintain basic skills walking, to avoid surgery for as long as possible, occupational therapy to maintain her ability to feed herself, use her fingers to write with a pencil, zip up zippers, and speech therapy to learn and be able to maintain basic communication skills with her peers.
- Our local Children's Treatment Centre is unable to provide more than one/five/ten sessions a year for [insert]. My child requires far more therapy. We started private [therapy] and noticed an immediate improvement/maintenance, but we cannot afford more than [frequency].

(5) Provide very specific examples of how the problems are affecting your life.

- My child requires intensive physiotherapy, occupational therapy and speech therapy. Her needs are not being met by both the Children treatment Centre and the education system. Annual or crisis consultative therapy is not the answer. We cannot afford to continue to provide private therapy. We have already refinanced our house and have liquidated all of our assets including our RRSPs. My child deserves equitable help from the government, despite not having a diagnosis of ASD.

SAMPLE LETTER TO YOUR MPP (Regarding Funding for Therapy)

Date

NAME OF MPP/PARTY LEADER

Address of Office

Re: Meeting request from (your name)

Dear MPP (First Name Last Name),

As a constituent in your riding, I am writing today to express my concerns with the government's recent announcement on April 2, 2019, that the needs of anywhere **from 25,000 to 50,000 children, youth and adults with disabilities in Ontario will not be addressed** until the government finalizes its Ontario Autism Program.

The stark reality is that all individuals with disabilities, irrespective of labels, require and are deserving of appropriate therapeutic interventions. No individual should be forced to wait their turn for life-altering therapies while the government limits its focus to only one diagnosis.

The government needs to ensure that the advantages being afforded to children with a diagnosis of autism through the OAP, such as access to Direct Funding Options for physiotherapy, occupational therapy, and speech therapy, are equally available to children, youth and adults with any other disability in Ontario.

To do otherwise is systemic discrimination.

[INSERT YOUR PERSONAL STORY HERE]

The government's policies and practices towards individuals with any disability other than autism are devastating and discriminatory. Children, youth and adults with any disability need access to the appropriate intervention at the right time and with the appropriate intensity.

I look forward to meeting with you to discuss these issues and ways in which we can work collaboratively to ensure that all individuals with disabilities receive the appropriate, customized, and intensive intervention they require.

Sincerely,

Your Name

Your Address

Your Contact Number

cc. The Real Waitlist – Ontario Disability Coalition Proposal

SAMPLE LETTER TO YOUR MPP [Regarding Passport and the Noah and Gregory Law]

DATE

YOUR NAME

YOUR ADDRESS

NAME OF MPP/PARTY LEADER

ADDRESS

Re: Meeting request from YOUR NAME

Dear MPP FIRST NAME LAST NAME,

As a constituent in your riding, I am writing today to bring to your attention that there are approximately 40,000 people living with developmental disabilities in Ontario and there are over 14,000 adults with disabilities in Ontario waiting for funding through the Passport program.

On the 18th birthday of an individual with a disability they are cut off from their childhood supports, too then be put on 2-5 years-long waitlists for adult supports. This stark reality leaves us, them, and their families, suffering with overwhelming physical, financial and emotional distress. We are ALL in crisis situations.

[INSERT YOUR PERSONAL STORY HERE]

We are asking you to actively support the amendment to the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act of 2008. It is known as Noah and Gregory's Law (Transition to Adult Developmental Services and Supports) 2018. Noah and Gregory's Law passed Second Reading with all-party, unanimous support on February 21, 2019, and was referred to your committee.

I am asking that you please call up Noah and Gregory's Law for study as soon as possible, so that can then move on to Third Reading expeditiously. Please be a champion alongside the thousands of families affected. This bill will bring relief to families. If Noah and Gregory's Law passes, as our children turn 18 years of age, they will celebrate a new reality in which they will no longer be cut off of their supports. They will continue to be involved in their communities and live as independently as possible. Their families will no longer be abandoned to fend for themselves, thereby continuing to contribute to their young adult's quality of life.

Noah and Gregory's Law will help us take care of Ontario's most vulnerable citizens, and end family despair. Please do everything you can to ensure that this bill is studied and referred back for Third Reading as soon as possible.

I look forward to your prompt reply.

Sincerely,

YOUR NAME

Your Contact Information

KEY TALKING POINTS

(1) Providing funding for only children with one disability is systemic discrimination, and wrong.

In creating the Ontario Autism Plan (OAP), the Government of Ontario has inadvertently set-up a provincial disability strategy that preferences the needs of children with one form of disability (Autism Spectrum Disorder (ASD)) over all other children with disabilities in Ontario.

The current practice and policy of the Ontario Government has created an adverse and negative effect on children with any other disability, and so long as the inequity continues, the policy will disadvantage and limit the rights and opportunities of children with any other disability.

The government needs to ensure that the advantages being afforded to children through the OAP are equally available to children with any other disability in Ontario.

(2) A system of age-based funding is wrong.

We all know that a birthday doesn't change someone's level of need. The funding assigned to an individual needs to be based on the recommendation of a clinician, not some arbitrary date on a calendar. Children, youth and adults with any disability should receive the services they need when they need it.

(3) Children, youth and adults with disabilities need to receive a clinically appropriate amount of therapy to live to their full potential.

No two people with disabilities are the same. Some are verbal, some aren't. Some have intellectual disabilities, others don't. Some need intensive physical therapy, others don't. Ignoring these differences and giving everyone the same amount of funding isn't right. Giving everyone a subclinical amount of therapy is wrong. Equitable funding means considering the needs of each individual in service. This results in optimal funding for each child with disabilities, efficient use of government funds, and best outcomes for all individuals with disabilities. Equality is not equity

(4) Families are in financial crisis.

The cost of private therapeutic services, specialty diets, camps and assistive devices is crushing. Ensure they keep in mind that research tells us that the financial and emotional burden incurred by these families can be substantial, and devastating, especially among families who care for a child with a severe disability. Families who care for a child with a disability have thousands of dollars of non-reimbursed expenses for disability related supports. Families who are not in poverty will slip into poverty. (Donna Anderson PHD. The personal Cost of Caring for a Child with a Disability: A review of the literature)