



Helping Kids with  
Physical Disabilities  
Succeed

# Easter Seals Ontario

## Parent Advocacy Kit 2019





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## About Easter Seals Ontario

Easter Seals Ontario was founded in 1922 with a vision to create a better life for children and youth with physical disabilities. Today, Easter Seals continues to offer programs and services to help these children achieve a greater level of independence and acceptance, such as funding for essential mobility and accessibility equipment, as well as owning and operating two fully accessible summer camps. Easter Seals also provides access to important information resources for parents and caregivers, as well as public education and awareness.

Easter Seals Ontario is a non-denominational, registered charity. The organization receives no government funding for its programs and services, which are funded entirely through donations by individuals, foundations, and regional event sponsors.

## Who We Serve

Easter Seals helps kids with a variety of physical disabilities and medical conditions, including cerebral palsy (CP), spina bifida, muscular dystrophy (MD), spinal muscular atrophy (SMA), spinal cord and brain injury as well as genetic abnormalities.

Regardless of the cause, these children share a common desire for independence, acceptance and achievement. Often children with disabilities live with feelings of isolation. Many spend most of their time at home or at school, with very little social interaction with others their age. For many of these children, camp or other recreational experiences are their only chance to establish independence, expand their personal boundaries, and explore their abilities.



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## Easter Seals Ontario Advocacy Activities

Easter Seals Ontario has been recognized as the voice for children with physical disabilities for over 97 years. Easter Seals has worked with the government and community partners to advocate for the following important issues:

- Pasteurization of milk to prevent food borne illnesses such as Salmonella, E. coli, and Listeria
- Bicycle helmets to prevent head injuries
- Folic Acid supplements to prevent and reduce incidence of spina bifida and hydrocephalus

Easter Seals Ontario continues to raise public awareness and advocate for issues that can improve the quality of life for children with physical disabilities and their families.

Current activities include:

- Public awareness of the impact of physical disability on children and their families through:
  - Direct Mail campaigns
  - Sharing information at Easter Seals Ontario's events
  - Making presentations to service clubs, community organizations and businesses about the needs of children with physical disabilities
  - Sharing about the impact of Easter Seals Ontario fully accessible camping program in reducing social isolation and building independence skills and self confidence
- Government meetings with key decision makers and policy advisors about:
  - Accessibility in homes, schools and communities
  - Funding for essential mobility and accessibility equipment
  - Changes to the Ontario Disability Support Program eligibility
  - Need for more children's rehabilitation services
- Special Education Advisory Committee (SEAC) Volunteers who advocate for students with physical disabilities to school board senior staff and Trustees.



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# Easter Seals Ontario Priority Advocacy Issues 2019

## 1. Key Issue: Cost of Equipment

A power wheelchair for a child with a physical disability can cost as much as \$35,000 – the price of a small car. When you add on the cost of other necessary equipment, such as lifts, ramps and bathing equipment, and escalating basic living expenses, the financial burden on families to care for their child at home is overwhelming.

Given that, of the families who requested financial assistance from Easter Seals in 2018, 63% reported a total family income under \$60,000, 48% had a total annual household income under \$40,000 and 25% had a total family income under \$20,000, it is difficult for most families with a child with a physical disability to financially manage on their own.

## 2. Key Issue: Accessibility Barriers

Many accessibility barriers still exist within public facilities, including schools, for individuals with disabilities. The Accessibility for Ontarians with Disabilities Act (AODA) does not require full compliance by all parties until 2025 and limited funding has been provided to assist with necessary accessibility modifications and renovations. In addition, there is no accountability being enforced on companies to ensure they comply with the mandated AODA standards. As a result, many facilities are still not accessible to individuals with disabilities and they are not able to participate fully in their communities.

## 3. Key Issue: Children's Rehabilitation Services

The children's service system is complex, given the involvement of multiple Ministries and organizations, making access to services and information extremely confusing and time consuming for families. Many services are inadequate with limited eligibility criteria and long wait lists. In addition, transitioning children and youth with physical disabilities between service providers can require duplicate assessments and result in long delays in service.



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## Parent Advocacy Kit How to Advocate Effectively

The voice of parents and family can be very powerful and can influence policy and decision makers. You can make your voice heard in a variety of ways:

**Contact your local MPP** - Members of Provincial Parliament are your representatives at Queen's Park, the legislature. Your MPP will be in office until the next election in 2022 and you can write to your MPP or request a meeting. For the name and contact information for your local MPP, check the Legislature list of MPPs website:

<https://www.ola.org/en/members/current>

**Contact the local media:** Sharing your story with the media can be an effective method of making people aware of the issues. There are a number of ways that you can get your story into the media. You can contact the local newspaper, TV or radio station and ask to talk to a reporter about your concerns, or you can write a letter to the Editor of your local newspaper.

**Join a parent advocacy group:** Organize or join a local parent group that shares your concerns.

**Attend workshops and information sessions on how to advocate effectively:** Many organizations provide information sessions on how to advocate at school or for services for your child.

The following pages contain tips on how to share your story and advocate effectively for change, including:

- Advocacy tips
- How to make effective phone calls about your child
- How to prepare for a meeting
- How to write an effective letter
- Sample letter to an MPP



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## Advocacy Tips

The following tips can help parents and OAFCCD members to be effective advocates for children with physical disabilities:

1. Know what you want to happen. Be clear about your goal and what action steps are needed.
2. Prepare a written profile of your child to take to meetings. Include a photograph to personalize the information. Provide a brief description of all the things your child can do and their achievements. Also provide information on the challenges and barriers that your child faces.
3. Educate your friends and relatives about physical disabilities and your child's needs. Most people do not know very much about the impact of physical disability or about the effectiveness of rehabilitation services. As taxpayers, your friends can help to advocate for adequate publicly funded services.
4. Share your story with local elected representatives, Council members, School Board Trustees and MPPs. These people are decision makers and it is by hearing your story that they will understand the importance of accessibility and rehabilitation services.
5. Connect with other parents. Talk to each other and listen to each other. Many parents report that they feel better when they share their feelings and find out that someone else has had the same experience and feelings.
6. Present your case politely and positively. Do not play the blame game. Describe what is wrong but focus on the solution and what can be done to fix the problem.
7. Respect the ideas and solutions proposed by others. Be prepared to find areas of agreement and consider whether you can compromise on your solution to find an outcome that improves the situation.
8. Be a good listener. Show that you are listening by paying attention to the speaker, looking at them and asking questions if you are not sure what they are saying. Avoid interrupting and let each person finish before you make a response.



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9. Be polite and respectful to everyone, even if you don't agree with what they are saying. Focus on the issues not on the personalities and behaviour of others.
10. Be persistent and continue to put forward your concerns and solutions.
11. Prepare to leave the meeting without a solution. Know when you feel everything has been said and nothing is changing. Stop the meeting and suggest next steps.
12. Ask who else you can speak to and how to contact the person.
13. Keep records of your phone calls, meetings and letters. Make sure you date and include the name of everyone involved.
14. If you feel too emotional, ask for a break or to set another meeting.



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## Making Effective Phone Calls About Your Child

- Identify who you are speaking with on the phone. . Keep a note of the name, and the date and time of the call.
- Identify yourself and specifically state the purpose of your call.
- Be prepared to offer basic facts about your child which are relevant to the agency you are calling.
- Have records available (with identification numbers, dates, etc.) and encourage immediate action.
- Be goal-orientated. Know exactly what you want. Focus on your goal until it has been achieved.
- Be direct and confident, yet positive and polite.
- If you are not satisfied, ask who else you may speak to about the issue.
- Convey a sense of cooperation. For example; “How can we work with each other?”
- Finish the call by recapping key information and identifying next steps or follow up action.
- Thank the individual for their time and attention to the matter.
- Make notes about the call including key information and next steps that have been identified.
- Send a thank you note or e-mail to recap the conversation and next steps.



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## Preparing for a Meeting

Be Informed About What You Need To Know!

1. What are your child's strengths and successes? Can you describe their:
  - Personality strengths
  - Academic strengths
  - Social strengths
2. What are you child's special needs?
  - Is there a diagnosis? Do you understand it?
  - What are your child's specific problems?
  - What areas are affected by these difficulties?
3. What would help your child or solve the problem?
  - Is there an existing service that could help your child?
  - Does the program need funding to reduce the waiting list?
  - Are there other ways the service can be improved?
  - Are there problems with transition in or out of the service?
  - Are there eligibility requirements that prevent your child from getting into the program?
  - Do you have suggestions for a new program or change to an existing program that would help your child?
4. How does the health and community service system work?
  - Research information about the government and community programs that are available to you and your child.
  - Create a document with the history of your participation in the program (the date you started, what services or supports were received, benefits and challenges of the program).
  - Record the names of key contacts in the program.
5. Deciding on your Goal
  - What do you want to achieve at the meeting?



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- Is it just about getting a service or support for your child? Or a group of children with similar needs?
- Do you have a plan B or an alternative solution you would accept?

6. Setting the meeting:

- Identify the person or people you want to meet with.
- Consider who else could be invited that would be able to provide helpful information.
- Contact the person you want to meet with and ask for a meeting by calling, writing a letter or sending an e-mail.
- Be flexible with the date and timing of the meeting.
- Follow up in writing to confirm the location, date and time of the meeting.

7. Gathering the meeting materials:

- Put a folder together with all of the materials and documents you might need at the meeting.
- Bring paper and a pen for making notes.

8. Preparing your presentation and questions.

- Put together a written summary of the issues, including the history and the goal of the meeting.
- Consider whether there should be formal presentation using slides and pictures to illustrate the issues.
- Make sure there are facilities available, such as a projector and screen, to show your presentation.

9. Take someone with you.

- Decide if you would like an advocate to accompany you, a friend or family member who could take notes or speak for you.
- Having a friendly face beside you will make the experience less daunting.

10. After the meeting, send a note or e-mail recapping the meeting and next steps.



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## Writing Effective Advocacy Letters

The most effective letters include the story about your child and how the issue impacts your child and family. To write an effective letter you need to:

- Organize the information about your child and the story you want to share.
- Share only the personal information that is relevant to the story, to protect your child and families' privacy.
- Put the facts in order of when they happened or what is most important.
- If possible, share a photo of your child or a photo to demonstrate the problem (lack of accessibility due to a step or steep slope).
- Personalize the letter by using your child's name and writing from your personal perspective (I was frustrated because....).
- Identify what action you want the person to take to fix the situation (contact the appropriate Ministry for you, vote on a key decision, change current legislation or introduce new legislation).
- Be polite and clear about your expectations and when you want a response (I look forward to hearing from you by the end of the month).
- Thank the person for considering the request and taking action.

### Sample Letter to your Ontario Member of Provincial Parliament (MPP)

This sample letter on the following page has been developed by Easter Seals Ontario to help you advocate effectively.

- Please feel free to edit this letter as necessary and send to your MPP.
- Adding your personal story and the challenges you and your child face will make the letter more powerful.
- Visit <https://www.ola.org/en/photo/members-provincial-parliament-mpps> to find contact information for all current MPPs.
- If you are sending the letter on behalf of an organization, please use your organization's letterhead.
- Send a copy of the letter to Easter Seals Ontario, Attn: Alison Morse.

Your Name  
Your Street Address  
City, Province Postal Code

Date

Dr./Mr./Ms Jane Doe MPP  
Address of MPP  
[For MPP addresses see <https://www.ola.org/en/photo/members-provincial-parliament-mpps>)

Dear Dr./Mr./Ms Jane Doe [if they are MPP] or Dear Minister [if they are a Cabinet Minister]:

I am writing to you as the parent of a child with physical disabilities to find out how you plan to support children and youth with physical disabilities and their families and improve their lives.

I would like to hear how you and your fellow MPPs plan to address the following key issues children with physical disabilities and their families currently face:

- The cost of caring for a child with physical disabilities at home includes thousands of dollars for equipment such as wheelchairs, home and vehicle modifications, accessibility aids, and specialized supports. How will you help me with the extraordinary cost of supporting a child with disabilities?
- The Accessibility for Ontarians with Disabilities Act (AODA) has introduced standards in several areas. However, there is a long way to go in creating an accessible Ontario. Many accessibility barriers still exist within public facilities, including schools, for individuals with physical disabilities. What are you doing to enhance accessibility in Ontario?
- Families are having difficulty accessing rehabilitation services for their children due to inadequate services and long waiting lists. How are you working to enhance rehabilitation services for children and youth with physical disabilities?

I look forward to hearing back from you with respect to what action plans you have to address these issues for children and youth with physical disabilities living in Ontario. Thank you for your time and consideration.

Sincerely,

[Your name and signature]

cc: Easter Seals Ontario, Attn: A Morse, One Concorde Gate, Suite 700, Toronto ON M3C 3N6