



Mission Statement

PONDA is a volunteer network of physicians and psychologists advocating to optimize the well-being of individuals with neurodevelopmental needs in Ontario by promoting evidence informed policy in the systems of care.

Newsletter – December 6, 2018.

It looks like winter is setting in, and the holiday season is just around the corner. I hope you are all keeping warm and looking forward to some time off over the holidays.

We had another great meeting on November 19 at the Empowered Kids Ontario (formerly OACRS) annual PONDA dinner. We continue to be very grateful for the partnership with this organization and their support of our work.

What's New

Advocacy Toolkit for Language Based Learning Disabilities/Dyslexia

Version 5.0 is now available on our website www.ponda.ca with updated info including

- Consensus guidelines on assessment and diagnosis of LD by the Ontario Psychologists Association
- Independent review of assessment and reporting in Ontario
- Ontario Human Rights Commission policy on accessible education for students with disabilities

Letter sent to Ministry of Education advocating for evidence-based interventions for reading difficulties with multiple signatories (see attached)

Plenary session at annual meeting of CPS scheduled to discuss advocacy for LDs

Investigations for Global Developmental Delay/Intellectual Disability

This topic was reviewed at our meeting, led by Dr. Pam Frid and Dr. Melissa Carter. There are significant differences in recommendations for investigating global developmental delay/intellectual disability from different sources, including a recent CPS statement published in Paediatrics and Child Health. Lack of consistency of recommendations and availability of evidence to support recommendations was discussed, as well as costs to government and individuals.

Next steps being considered are a letter to the editor of Pediatrics and Child health highlighting the concerns from an evidence and economic stand point and exploring the possibility of a prospective study of the investigations for global developmental delay/early developmental impairment.

Physicians at all Children's Treatment Centres

This continues to be an issue that PONDA is promoting. A presentation was made at the Empowered Kids Ontario (formerly OACRS) annual meeting in November on how physicians bring value to CTCs. Four different models were presented, including Children's Treatment Network – Simcoe, Lansdowne Centre – Brantford, Ottawa Children's Centre/CHEO – Ottawa, and Grandview Children's Centre – Oshawa. It is clear there are many ways in which physicians can play an important role in order to improve care for children and youth with neurodevelopmental disabilities at CTCs in Ontario. We are looking at outreach to northern centres like Firefly. We hope our presentation gave centres ideas on how to attract and support physicians.

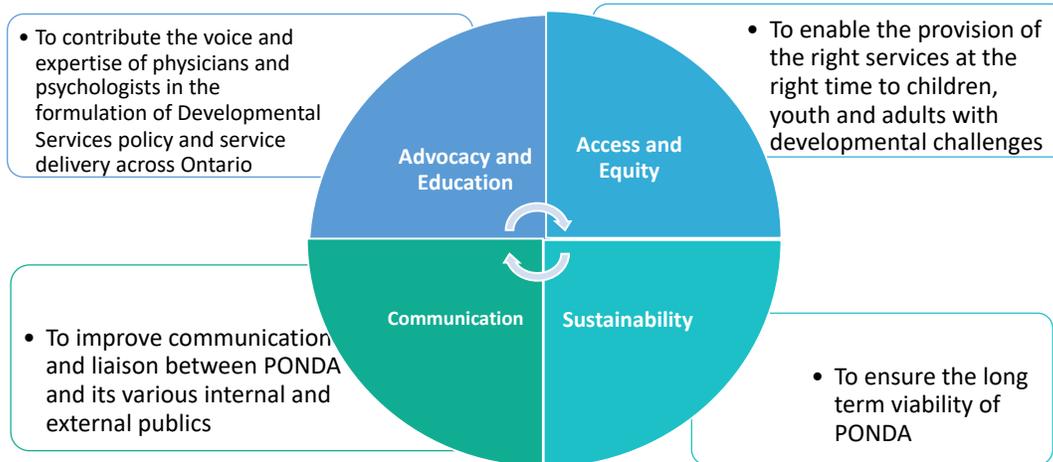
Bill C-81, Proposed Accessible Canada Act

This bill has passed unanimously in the House of Commons and is now at the Senate stage of the parliamentary process. Many of the amendments proposed by 34 disability organizations in Canada in [an open letter](#) drafted by AODA Alliance leader, David Lepofsky, were not accepted. There are now 91 disability organizations supporting the proposed amendments. PONDA was a cosignatory on this letter and continues to support this work. To stay up to date on this issue and many more accessibility issues affecting Ontarians, sign up for the AODA Alliance [newsletter](#).

Strategic Plan

Our Strategic Plan can be summarized in the infographic below, along with our goals for the next five years. We may have energy to add more things along the way, but we are committing to these things at the very least.

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STRATEGIC PLAN

PONDA

Goals:

#1. Establish a working group to promote adult services for people with neurodevelopmental conditions

- The working group will be led by Dr. Alvin Loh, Alvin.loh@surreyplace.ca, who has already made connections with Dr. Yona Lunsky and Dr. Bill Sullivan. We would like to:
 - add a family physician to our steering committee
 - advocate for billing codes for GPs looking after adults with NDD.
 - create and promote local strategies for building health care capacity, and effective transitioning,
 - Collaborate with local community resources to increase meaningful engagement for individuals graduating to the adult system

#2. Meet with provincial government ministries

- Meeting set up with MCCSS Dec 14, 2018 to discuss physicians at all CTCs and a functional approach to service delivery for children and youth with NDD
- Working on meeting with MOHLTC Minister Christine Elliot to discuss funding of physicians at all CTCs

#3. Promote the use of a functional approach to care

- Presentation of FACT at OACRS November 20, 2018 by Dr. Ben Klein
- Further pilots of the FACT are being considered
- Interrater reliability study underway

#4. Establish a working group to develop new ways to share information such as podcasts and videos

- Dr. Jacqueline Ogilvie has volunteered to help with this
- More volunteers needed!
- Partnerships with PAO possible
- Looking to highlight advocacy stories and strategies for effective advocacy work

#5. Develop formal connections with representatives from the neurodevelopmental disability community

- Sara Pot, a parent of children with neurodisabilities, has agreed to help us on this journey and joined us for part of our Nov 19 meeting
- We are planning a Spring 2019 meeting to include parent representation: planning in early stages so far

#6. Obtain charitable organization status

- thank you to Doug Turner for offering legal services pro bono
- need to find affordable accounting help

Membership

Membership is open to all physicians and psychologists with an interest in improving the well-being of individuals with neurodevelopmental needs. Membership is informal with no fee. We will simply add you to our mailing list if you are interested. Feel free to share our newsletter and advocacy tools. We currently have approximately 120 members and are looking to expand. The more members, the stronger our voice. Please email me if you are interested in joining. And please contact me if you are interested in joining one of our working groups!

Get Involved

Are you already a member, but want learn more about advocacy or get more involved in our work? Here are some ideas:

- Join one of our working groups:
 - adults with neurodisabilities
 - new communications strategies
- Attend an OMA workshop to improve your advocacy skills advocacy@oma.org
- Meet with your local MPP
- Write an Op Ed and submit to your favourite print media
- Send a message to Queen's Park through twitter #onpoli
- Use the Advocacy Toolkit on our website to learn how to approach your local school board and encourage evidence based intervention for LDs

Don't forget to follow us on twitter: @pondanetwork and like us on Facebook!

Sincerely,

Nicky Jones-Stokreef,

Chair of PONDA

Nicolajs005@icloud.com

For The Parents Consultation

Open Letter

To the Honourable Lisa Thompson, Minister of Education;

Thank you for the opportunity to provide input into how the public education system in Ontario can be improved. Our society is rapidly changing, and it is important that our children receive the best possible education in order to be prepared for tomorrow. We also need to be fiscally responsible, and prevention is more cost effective than treatment.

The most important part of a good education is the ability to read fluently with excellent comprehension. Although Ontario has performed well in national and international measures of reading success ([PISA](#), [PCAP](#)), there is still a significant number of students who are not reading at the expected level. Reading ability is an important factor in predicting future success. Individuals who do not learn to read well have a higher rate of physical and mental disorders, have an increased chance of being abused, and are more likely to struggle with unemployment and incarceration. **Although the Ministry of Education has made many excellent strides towards helping children who struggle to learn to read, there remain significant gaps in our system that prevent success for all, with the fact that not all schools use evidence based strategies to teach children how to read.**

Research into how children learn to read has been clear; a structured, systematic, explicit, phonics based approach is most effective. Although all children benefit from a strong phonics based teaching strategy, 60% of the population require this in order to learn to read successfully, and 10 to 15% require systematic instruction with many repetitions. Ontario has a good policy on requiring schools to implement a tiered approach to reading instruction (ppm 8), but sadly it is not implemented consistently in all school boards. Balanced reading is still emphasized in many school boards with programs like Reading Recovery, which teaches guessing rather than a phonics approach. Research has been conducted in Ontario demonstrating the benefits of early (Grade one) direct instruction with a phonics approach and metacognitive strategies to help the 10 to 15% of children at risk for learning disabilities including Dyslexia. With early screening using free and simple tools, children at risk can be identified easily. They can then accelerate their reading gains, regardless of socioeconomic status or IQ ([Empower Reading](#)). In fact, the Ontario government has supported [research](#) showing the benefits of Empower as a tier two and three intervention. **The reality is that not all schools use such evidence based strategies and their students are therefore penalized compared to their peers. This sets them up for failure in school and in life.**

There is a strong emphasis on STEM subjects currently since EQAO testing has shown less satisfactory results in math achievement. My concern is that all children need a solid foundation in reading instruction in order to benefit from instruction in other subjects as they get further along in school. Much of math is understood in word problems. Reading is necessary to understand textbooks on science. We need to continue to focus on reading while also addressing STEM.

As you look to improve the education system in Ontario, **we strongly suggest you incentivize schools to implement evidence based reading instruction, and direct them to report on the funding spent on remediating reading disability, the number of students receiving it, and the average improvement after a year of intervention** PPM 8 has not been sufficient in ensuring all schools offer evidence based tiered intervention for learning disabilities, including Dyslexia. Programs like Empower or SRA Corrective Reading should be made available in every school so that children who struggle with the essential life skill of reading can have an equitable chance at success in tomorrow's economy. Not only will this be a good investment in our children, but **it will save money in the school system by avoiding the need for ongoing special education supports and mental health services for students who cannot read adequately.**

Sincerely,

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