



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 – April 3, 2019

Happy Spring! There are lots of changes happening to Ontario services, almost on a daily basis. We will update you on what you need to know, and how PONDA is advocating for individuals with neurodevelopmental conditions.

What's New

PONDA presentation to MCCSS

Steering committee members have been busy meeting with MCCSS staff and participating in roundtable discussions to inform a renewed ODSP process. We have presented our ideas about how the service system could be improved. Our goal is to advocate for all individuals with neurodisabilities, rather than specific groups. You can see our presentation [here](#). Our main points can be summarized:

1. PONDA would like to offer our expertise in ongoing discussions to make the Ontario service system better
2. Ontario should develop a functional approach to service delivery for children and adults with neurodevelopmental disorders, independent of diagnosis
3. Ontario should support broad diagnostic assessment clinics rather than single diagnosis e.g. ASD
4. Provincial regulation of behaviour therapy is needed to ensure quality evidence informed intervention
5. Physicians are an important part of an integrated multidisciplinary team: developmental specialists should be part of every CTC
6. MOHLTC and MCCSS should support capacity building and better integration of networks of specialized care (CNSC) and health care teams for adults with complex needs (continue to fund the DD Primary Care Program)
7. Strong evidence based interventions should be mandated where they exist e.g. Direct Instruction for reading impairment in all schools
8. Unnecessary assessments should be avoided where clear functional impairment exists e.g. Developmental Services Ontario

PONDA now has a parent advisory group

- Two parents of children with special needs have agreed to meet with us regularly to ensure we are grounded in advocating appropriately for people with neurodisabilities.

New members of our steering committee

- Dr. Liz Grier, family doctor in Kingston
- Dr. Jennifer Saltzman-Benaiah, neuropsychologist with Children's Treatment Network

Improving Health Care Capacity in Adults with Neurodevelopmental Disabilities

- Alvin Loh and Liz Grier have been meeting with HCARDD lead, Dr Yona Lunsky, and other IDD family physicians to develop priorities for this working group. Come to the June meeting share your priorities and find out more, or contact Alvin.Loh@SurreyPlace.ca if you have questions about the group.

Ontario government policy initiatives

- [Autism Services](#): MCCSS is doubling the funding for autism hub diagnostic clinics to move children off the waiting list for assessment more quickly.
 - Funding of services will be based on a written diagnosis of autism by a qualified professional and age of the child (up to 18 years old), but family income will no longer be a factor.
 - More services now qualify including behaviour services, speech language pathology, occupational therapy and physiotherapy.
 - These changes came into effect April 1st.
 - Children already involved in a behaviour plan through the OAP will be allowed to complete their plan and have it renewed for a further 6 month period at the current intensity.
 - Starting in May 2019, the government will engage in public consultations through an online survey and telephone town halls. These consultations will help inform how the government can better support children and youth with autism who have complex needs, including through additional direct funding.
 - A new advisory panel will be made up of parents with lived experience, autistic adults and experts from a range of disciplines like psychology, behavioural analysis, rehabilitation services, education, developmental pediatrics and research.
- [Education](#): EDU is making several changes including increasing classroom sizes for Grades 4 and up, banning cellphones in the classroom, and making a number of changes to the curriculum affecting math, health and STEM subjects.
 - Some of these changes are based on the public consultation which ended in December 2018. Implementation will start in the fall 2019.
 - For an update on what services will look like in the next academic year, please read the Learning Disabilities Association of Ontario April 2019 SEAC Circular available [here](#).
 - The **Minister's Advisory Committee on Special Education** has been on hold for the past year. We have just heard that the committee will reconvene in June,

where various interest groups are represented to advise the government on special education policy. PONDA has a representative on the committee.

- **For physicians:** please complete the [attached survey](#) to provide input on how special education services are/are not working for your patients and fax to Nicky Jones-Stokreef at 705-323-9279.
- **[Disability Support:](#)** ODSP is being redesigned, with stakeholder consultation currently taking place on how to define severe disability, minimize reporting requirements, and encourage employment where possible. Representatives from PONDA are at the table.

Accessibility Standards in Education: AODA

- Two committees looking at accessibility standards in education have been on hold since the Ford Conservatives have been in office. The AODA Alliance continues to advocate for the resumption of these committees, with the goal of ensuring our schools, colleges and universities are compliant with AODA legislation by the deadline of 2025.
- The [2019 Legislative Review of the Accessibility for Ontarians with Disabilities Act, 2005](#), by David Onley, has been released. It contains the following recommendation:
Recommendation 4: Direct the standards development committees for K-12 and Post-Secondary Education and for Health Care to resume work as soon as possible.

Ontario Human Rights Commission

- *The OHRC has released videotapes of a training session on our new Policy on accessible education for students with disabilities. OHRC Senior Policy Analyst Cherie Robertson leads you through key elements of the policy, including:*
 - The vital importance of education to a person's social, academic and economic development– and the need for accessibility and accommodation in the process
 - A broad definition of disability
 - Up-to-date information about human rights and responsibilities for students, parents and educators
 - Practical guidance to education providers to meet their legal duty to accommodate
- Training sessions are presented in two videos (Part 1 – 48 minutes and Part 2 – 37 minutes) suitable for viewing on larger screens for group viewing. Wherever possible, audience questions and answers have been included.
 - The videos are available in English, with both English and French captioning options. As well, each video features ASL translation.
 - View the videos on YouTube: <http://bit.ly/2FAueV0>

Bill C-81

- The Accessible Canada Act passed second reading in the Senate and has been referred to the Standing Senate Committee on Social Affairs, Science and Technology.
- The AODA Alliance (David Lepofsky et al.) has proposed a number of amendments to strengthen the bill. See their brief to the Senate [here](#).

- PONDA is supporting these recommendations. If you would like to add your voice and share your views about Bill C-81, you can contact the clerk, Daniel Charbonneau, for more information: Daniel.Charbonneau@sen.parl.gc.ca or SOCl@sen.parl.gc.ca .

Coming Soon

Advocacy Toolkit for Language Based Learning Disabilities/Dyslexia

Version 6.0 will be posted on our website shortly. A poster has been accepted for AACPDm annual meeting in Anaheim, CA for September 2019. This will be a new venue to share evidence based information about intervention for reading disabilities and how to advocate for better intervention in schools.

Podcasts

Yes, podcasts are being produced by PONDA to share our message of advocacy! Thanks to Jacqueline Ogilvie, Shawn Kao, Jolene Huber and Jane Gloor for helping with this project. Look for our first podcast on our website in June when we launch at the Canadian Paediatric Society annual meeting in Toronto.

Spring Meeting: SAVE THE DATE!

We are planning a meeting in **Toronto, June 6, 2019**, to coincide with the Canadian Paediatric Society Annual Meeting. We hope to have a more national group of physicians and psychologists attending, to share ideas from across the country.

Location: Surrey Place, 2 Surrey Place, Toronto, ON M5S 2C2

Time: 6:00 pm to 9:00 pm

Cost: \$40 by e-transfer before deadline, \$50 after deadline, includes light meal/snacks

Early Bird Registration Deadline: May 29, 2019

Open to physicians and psychologists interested in advocacy for neurodevelopmental conditions. **RSVP** to Mohammad Zubairi m.s.zubairi@gmail.com

Topics for discussion will include:

- Needs based approach to service delivery including review of Australian experience with NDIS
- working group updates: improving health care capacities in adults with neurodevelopmental disabilities, new media, parent engagement
- review of changes in Ontario services

Membership Drive

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 130 members and are looking to expand.

The more members, the stronger our voice. Please email me if you are interested in joining, especially if you are interested in joining one of our working groups!

Get Involved

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

- Join one of our working groups:
 - Improving Health Care Capacity in Adults with Neurodevelopmental Disabilities
 - new communications strategies (podcasts)
 - parent engagement
- 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

Steering committee members:

Alvin Loh, Ronit Mesterman, Paige Church, Pam Frid, Jennifer McLean, Beth Macklin, Mohammad Zubairi, Olaf Kraus de Camargo, Ben Klein, Liz Greer, Jennifer Saltzman-Benaiah