

Newsletter – July 23, 2019

We recently held our spring meeting which coincided with the annual Canadian Paediatric Society meeting in Toronto on June 6. Due to many time conflicts, some of our members were unable to make the meeting. If you missed it, this newsletter will get you up to speed.

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What's New

PONDA PODCASTS

Yes indeed! Our first podcast is launched and is available on Podbean and iTunes! You can also access it on our website, ponda.ca. A big thank you to Dr. Jacqueline Ogilvie for getting this project up and running so quickly, and hosting on the podcasts. We aim to release a podcast at least every quarter to coincide with our newsletters. The first two podcasts cover Literacy based Learning Disabilities and the Advocacy Toolkit, and feature school board superintendent Chris Samis, and OISE professor and clinical psychologist Todd Cunningham. If you have a topic which would lend itself well to a podcast and involves advocacy in the neurodisability sector, send us an email pondanetwork@icloud.com!

Every Canadian Counts Coalition

Bill Cowie, chair of the ECCC, and Bruce Bonyhady, economist in Australia and advisor to the ECCC, made excellent presentations to PONDA on the idea of a National Disability Insurance Scheme in Canada, similar to the NDIS in Australia. Please see Bill's presentation [here](#). This program would provide funding for people of all ages with a disability, based on their needs. It is a direct funding model which everyone pays in to, like disability insurance. In Australia, this has resulted in an increase in jobs in the disability service sector, and improved access to service for people with disabilities. It is not perfect, and Canada has the advantage of learning from some of the mistakes in Australia. ECCC is looking to have this issue on the Liberal Party platform in the upcoming federal election. If any of our members are interested in getting more involved in this initiative, ECCC is looking for more board members. Check out their [website](#).

Improving Health Care Capacity in Adults with Neurodevelopmental Disabilities

- This is a **Priority** for our patients as they age into adulthood !!

- 3 active members: Liz Grier (Family Doc); Yona Lunsky (Psychology); Alvin Loh (Dev Paeds), who are working at different levels in the system:
- **Local:** mentor a family medicine resident or practitioner (Transition Clinic: Paeds & Family Med at local CTC, ECHO Adults with IDD, Ont. College of Family Practice)
 - If it works for kids, why not adults? Advocate for access in adult hospitals to needed investigations and procedures
- **Provincial:** improve OHIP billing for Fam Med. for IDD consults & primary care,
 - Advocate at MOH and Ontario Health Team levels for funding for interdisciplinary teams for complex patients with IDD of all ages
- **Residency Education:** Start a local PGY 3 Family Medicine IDD training program
 - Improve PGY Psychiatry education in IDD; for youth and adults
- **What is one thing you can do?** Email alvin.loh@surreyplace.ca if you have other ideas or want to help with one of the above. [Presentation and Workgroup goals](#) are on PONDA website. Videoconf. meetings every other month to discuss progress & next steps.

Ontario government policy initiatives and Ministry news

- [Autism Services:](#) In the last newsletter we explained some of the changes to the OAP announced by the Ford government. Since then there have been further changes:
 - Cabinet shuffle with a new Minister of MCCSS, Todd Smith and Associate Minister of Children and Women's Issues, Jill Dunlop
 - Parliamentary Assistant, Children and Autism, continues to be Amy Fee
 - Ontario Autism Program Advisory Panel convened with first meeting on June 20 and 21- membership includes Mohammad Zubairi, PONDA steering committee member. The committee is considering a needs based approach to service delivery for children and youth with autism.
 - Recently, a [report](#) by MPP Roman Baber was leaked on Facebook, describing how the Ford government needs to reshape it's autism services policy. Among the recommendations is the restriction of ASD diagnosis to developmental paediatricians and psychologists. PONDA has responded to this idea with a letter to Ministers Smith and Dunlop, criticizing this idea which would create very long wait times for diagnosis. See PONDA's response [here](#).
- [Education:](#)
 - The **Minister's Advisory Committee on Special Education (MACSE)** has started meeting again. Nicky Jones-Stokreef is the medical representative on the committee. A summary of the latest discussion will be distributed soon, including information about the Empower pilot, (now in it's fourth year), a new policy for service dogs in schools, EQAO results, and more. Input from the physician stakeholder group is sought regularly through MACSE, which meets next in October. If you have something to say about how schools do or do not function, please complete this [form](#) with your comments and email to pondanetwork@icoud.com, attention: Nicky.

- Cabinet shuffle means a new Minister of Education, Stephen Lecce, MPP for King- Vaughan
- PONDA is teaming up with other advocacy groups to address how reading is taught in Ontario schools. Stay tuned for more in the coming months.
- The International Literacy Association has released a [Literacy Leadership Brief](#) advocating to:
 - Embrace early phonics instruction as integral to elementary literacy plan.
 - Incorporate explicit and systematic phonics instruction that directly addresses skills, follows a continuum of skill complexity, and includes a review and repetition cycle that leads to eventual skill mastery.
 - Assess phonics instruction to ensure key characteristics are in place, including blending, dictation, word awareness, and high-frequency words.

The David Onley Report: Accessibility for Ontarians with Disabilities Act (AODA)

The [2019 Legislative Review of the *Accessibility for Ontarians with Disabilities Act, 2005*](#), by the Honourable David Onley, was submitted January 31, 2019. It contains recommendations to prepare Ontario for the 2025 deadline for a fully accessible Ontario for people with disabilities. Sadly, Ontario is nowhere near ready for the 2025 deadline. Furthermore, the Accessibility Minister, Raymond Cho, and the Ford Government, have not responded to the recommendations in the report. The AODA Alliance and disability advocates, including PONDA, are advocating for full acceptance of the recommendations in the report. See the open letter [here](#).

Bill C-81

The Accessible Canada Act was given royal assent on June 21st, 2019, and is now the law of the land, including several amendments proposed by the disability community.

This law applies to federal jurisdictions such as:

- Banking
- Telecommunications
- Transportation industries
- The Government of Canada

The Act will create the Canadian Accessibility Standards Development Organization (CASDO)

The Canadian Human Rights Commission will then be responsible for monitoring and reporting our progress to the UN. There will be an accessibility complaints mechanism.

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Membership

Membership is open to all physicians and psychologists with an interest in improving the well-being of individuals with neurodevelopmental needs. We advocate for children, youth and adults with a wide variety of neurodevelopmental disabilities. Membership is informal with no fee. We simply add you to our mailing list if you are interested. Feel free to share our newsletter and advocacy tools. *The more members, the stronger our voice.*

Please email pondanetwork@icloud.com if you are interested in joining, especially if you are interested in joining one of our working groups!

SAVE THE DATE

The next face to face meeting of PONDA will take place in Toronto at the Novotel Hotel on Friday evening, November 22, 2019. This coincides with the [Child Developmental Update](#), a popular CME event with excellent speakers and topics put on by University of Toronto and Holland Bloorview Kids Rehab. Look for our sign up email in the fall!

Get Involved

Do you 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)
 - literacy based learning disabilities
- Attend an OMA workshop to improve your advocacy skills advocacy@oma.org
- Meet with your local MPP, and voice your opinion on a subject important to you
- 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
- Listen to our podcast

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

Sincerely,

Nicky Jones-Stokreef, MD

Chair of PONDA

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