



Physicians of Ontario Neurodevelopmental Advocacy

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## Presentation to MCCSS March 22, 2019

Nicky Jones-Stokreef, MD, Chair  
Ronit Mesterman, MD

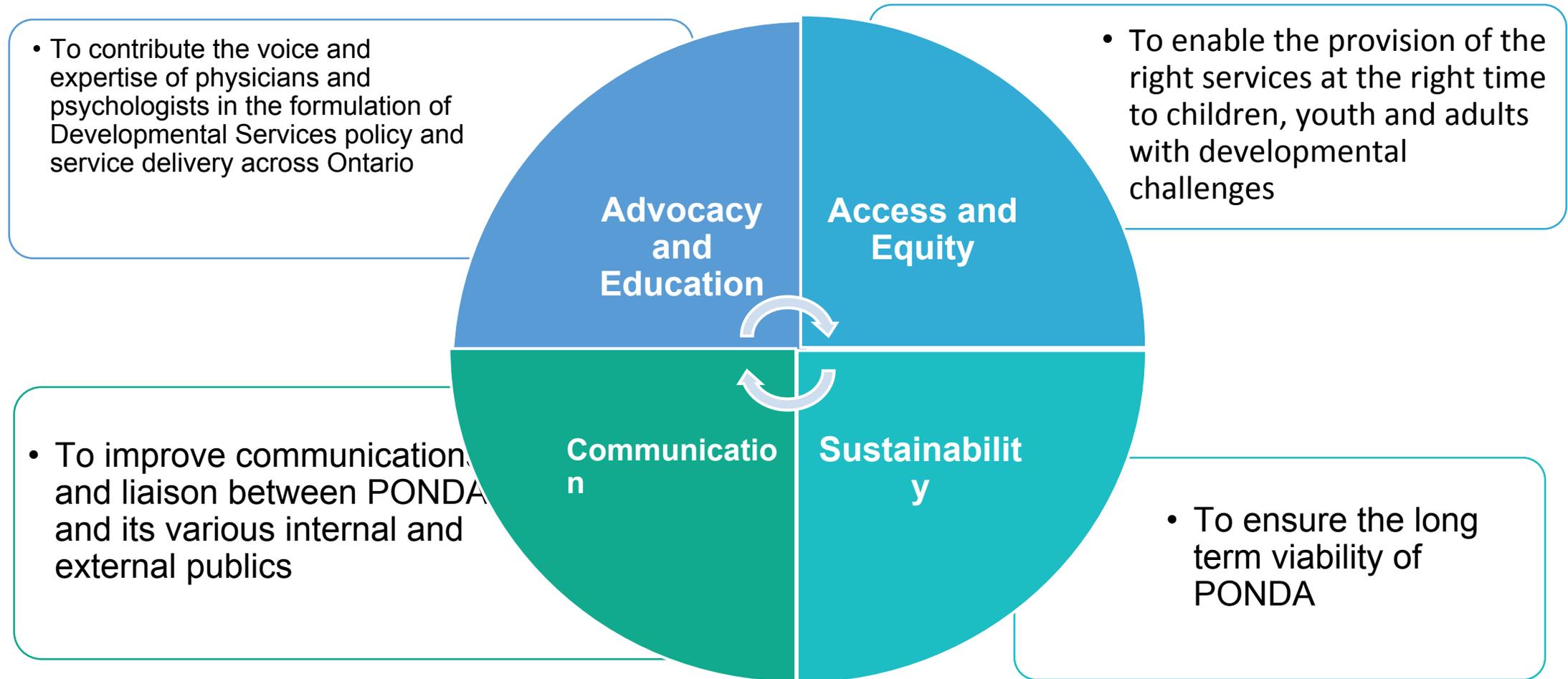
Alvin Loh, MD, Vice Chair  
Liz Grier, MD

# What is PONDA?

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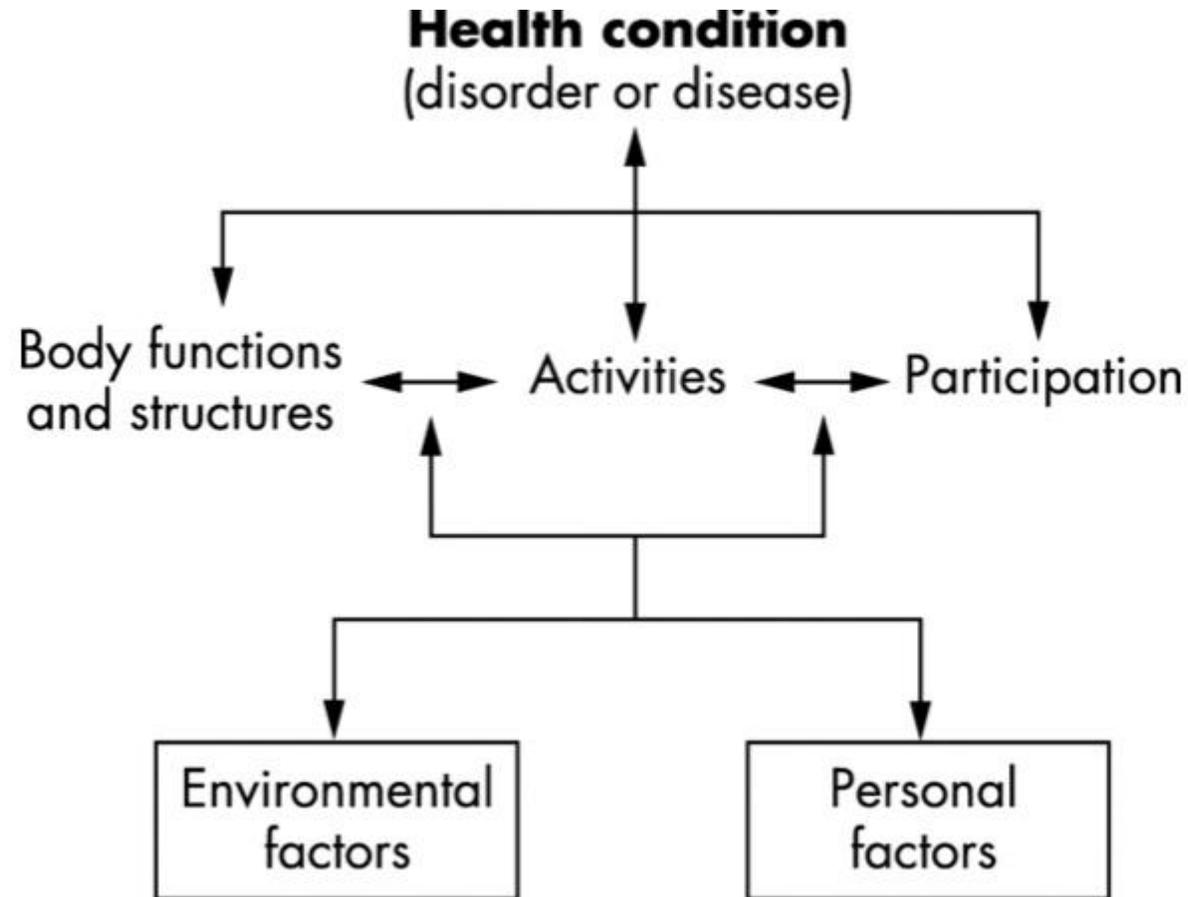
- Physicians and psychologists, front line providers to people with NDD developmental specialists, researchers, university leaders, educators, community physicians, psychiatrists, psychologists, international collaborators
- Relationships with Canadian Paediatric Society, Ontario Medical Association, Pediatric Alliance of Ontario, Empowered Kids Ontario, Dyslexia Canada, AODA Alliance
- Established in 2011

**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.



**STRATEGIC PLAN**

**PONDA**



International Classification of Functioning, Disability and Health

# What we believe

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- Functional/Needs-based approach to service delivery
- Environment is the context in which disability is experienced:  
Individuals are embedded in their family and community
- Goal: Optimize well being and long term outcome
- Participation = The F Words in disability
- Equitable access to services
- Accountability comes from evidence informed service delivery

# Neurodevelopmental Disorder

## *Definition*

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- Neurologically based
- Congenital or acquired
- Functional impairment in one or more domains
  - cognition; posture, movement and dexterity; communication; social relatedness; behavior and emotions
  - neurosensory processes of vision and hearing
- Trajectories in skill development and behaviour vary substantially from neurotypical peers
- Lots of functional and diagnostic complexity
- Examples: autism, learning disabilities, Tourette's Syndrome, Intellectual Disability, Cerebral Palsy, etc.

# Disability: definition

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Disability is a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors." (Leonardi, 2006)

# What are the concerns

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- Uneven access to support services for individuals with NDD, often contingent on a diagnosis and where they live
- Increasing complexity of habilitation and health care needs for individuals with NDD
- Quality concerns: No regulation of behaviour therapy services
- Privatization of developmental services needs to ensure availability and quality of services
- Evidence informed interventions are not consistently available

# Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities (DD) in Ontario - February 2019 <sup>(1)</sup>

**The problem:** A study of ICES data on ~ 65,000 adults with DD living in Ontario between ages of 19 - 65 over a six-year period (2010-16) found greater:

1. 30 day repeat emergency departments (34.5% vs 19.6% (age matched general population))
2. 30 day repeat hospitalizations (7.4% vs 2.3%)
3. Long Term Care (LTC) stays (3.5% vs. 0.2%)
4. Alternate Level of Care (ALC) stays (4.6% vs 0.7%)
5. Premature Mortality (death before age 75) (6.1% vs 1.6%)
6. High Cost Health Care Use (patients were 4 x as likely to have health care costs falling in the top 5% and remained in this high cost bracket after one year of study)

**Conclusion:** There is an **identifiable subpopulation** of adult patients with DD, (~40%), that are at high risk of **sustained, nonoptimal and costly use of health care** resources associated with detrimental impact on patients' **quality of life**

1. Lunskey et al. Health Care Access Research and Developmental Disabilities, February 2019

## Report Recommendations:

- An **integrated, province-wide infrastructure** to identify patients with DD as well as their special health care and social service needs.
- New initiatives subject to small, well designed and time-sensitive **evaluations**.
- Initiatives to include **education for all stakeholders** as well as availability of individuals with **specialized expertise in DD**.

## Where to start - Existing Resources requiring continued/enhanced MCCSS investment:

1. **Ontario Developmental Disabilities Primary Care Program** - internationally renowned clinical practice guidelines and tools tailored for both health professionals as well as developmental service workers
2. **MCCSS Community Networks of Specialized Care** - invest in integration of case management service with “champion physicians”, (**Family MDs with specialty in DD**), along with **Health Links Ontario**
3. **Health Care Access Research and Developmental Disabilities** – ongoing evaluation of ICES data

## Deliverables:

Interventions that are accountable through measurable outcomes including:

- 1. Reduced inappropriate, nonoptimal and costly** use of health care resources for adults with Developmental Disabilities in Ontario
- 2. Increased value for funds spent** by redirecting resources towards strengthening integrated, community-based health care and social service delivery
- 3. Improved quality of life indicators** for patients and their caregivers

## Contacts:

Dr. Liz Grier, MD, CCFP, Family Physician and Senior Advisor, Developmental Disabilities, Department of Family Medicine, Queen's University – [liz.grier@gmail.com](mailto:liz.grier@gmail.com)

Dr. Alvin Loh, MD, FRCPC, Developmental Pediatrician, Surrey Place Centre, Developmental Disabilities Primary Care Program – [Alvin.Loh@surreyplace.ca](mailto:Alvin.Loh@surreyplace.ca)

# PONDA's Proposal

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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

# PONDA's Proposal

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- 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 (DSO)