

PONDA Annual Meeting Minutes

November 22nd, 2019, Novotel Hotel, Toronto

Minutes taken by Nicky Jones-Stokreef

Welcome and transition of leadership (6 pm)

Chair: Alvin Loh
Vice Chair: Mohammad Zubairi
Secretary: Jennifer Saltzman-Benaiah
Treasurer: Jennifer MacLean
Past Chair: Nicky Jones-Stokreef

Alvin Loh: Ministry of Health – Mental health meetings (6:15)

- **Aug 13, 2019**, with Emily Beduz, senior policy advisor, who referred to Mr. MacGregor
- **October 8, 2019**, with Matthew MacGregor, director of policy for MOH-MH, Minister Tibollo
- Panel of experts including Liz Grier, Alvin Loh, Mark Lachmann, Anupam Thakur, Yona Lunsky, Jonathan Weiss, Vikram Dua,

Highlights of the Oct 8th meeting:

- Addressing Gaps in health care for adults with DD – Yona Lunsky
- Increased utilization of health care services and premature mortality
- Areas of policy concern:
 - 1.Higher prevalence of mental health conditions in children/youth and adults with NDD. Increasing complexity of supports and health care needs
 - 2.Limited experts
- Excellent research informed work being done in ON
- Creation of a centre of excellence on mental health and addictions
- PONDA offered potential policy solutions, including acting as a resource to government
- Government passed legislation in summer 2019 and are waiting for a provincial centre of excellence in Mental Health, across the lifespan, to become established
- Ministries such as MOH and MCCSS are working together

Invited Speaker - Dr. Anupam Thakur, Psychiatrist, CAMH & Surrey Place (6:30)

● Reflections across the pond

Here in Toronto for 5 years, things have changed a lot, used to work in North-east England

- **Child & Adolescent Mental Health Services (CAMHS) in the UK**
 - Sectorial distribution by postal code: tier 3
 - Community teams: not based in hospital, at times next to family health teams
 - Tiered approach to care
 - Waitlists were a huge problem, wait for 8 – 9 months,
 - asked to bring it down to 13 weeks (pretty easy), then 5 weeks (difficult):
 - CAPA (Choice and Partnership Approach) model (also in Halifax)

- too few psychiatrists for too many patients
- **Tier 1: non-mental health specialists**
 - A primary level of care: midwives, health visitors, school nurses, counsellors
 - Identify early signs of mental health problems, Offer general advice
 - Mental health promotion
- **Tier 2: CAMHS specialist working unidisciplinary model**
 - community and primary care settings in e.g. GP practices and schools
- **Tier 3: multidisciplinary and multi-agency specialist CAMH professionals working as a team**
 - offering assessment and treatments, usually from a community base
- **Tier 4: essential tertiary level services: day and inpatient units**
- **Various models of care in CAMHS**
 - CAPA choice and partnership approach, (specialists need to let go)
 - CYP-IAPT (Children and Young People's Improving Access to Psychological Therapies)
 - improved access to psychological based services in the community
 - THRIVE (it is a framework): goals, Evidence Based Practice, measure outcomes
 - <http://implementingthrive.org/about-us/the-thrive-framework/>
 - It **conceptualises need in five categories**; Thriving, Getting Advice and Signposting, Getting Help, Getting More Help and Getting Risk Support.
 - Emphasis is placed on prevention and also the promotion of mental health and wellbeing across the whole population.
 - Children, young people and their families are empowered through active involvement in decisions about their care through shared decision making, which is fundamental to the approach.
 - Models such as CAPA, CYP-IAPT and THRIVE have been studied and published in adult population, not necessarily youth side, cost effectiveness established
 - **Building Capacity** for Mental health in IDD, through training of SW and nurses supported by university for 2 years
- overlaps between paediatrics and child psychiatry: opportunities for collaboration
 - neurodevelopmental disorders e.g. autism
 - eating disorders
 - juvenile diabetes
 - deliberate self-harm
 - and many others (but less collaboration)
 - opportunities for creative problem solving: improving collaboration
 - prioritizing and targeting areas needing inter-sectorial coordination
 - proactive outreach from frontline clinicians
 - innovative use of resources – special Interests and service level agreements
 - effective leadership needed to support
 - shared learning: informal and formal
 - winner is young person and family

- Issues in Toronto
 - IDD and comorbid mental health issues, Waitlists
 - Transition points, Inter-professional working
- Surrey place
 - Transitional Age Youth clinic for BTClinic
 - TIP Clinic: telemedicine to support primary care provider
 - ECHO AIDD (Adults with Intellectual DD) Coming soon
- Next Steps to Improve Access and Build Capacity - Alvin
 - Improving Access to Mental Health Assessment and Treatment
 - Collaborate with Psychiatry and Paediatrics or Primary Care
 - Mental Health Lead Agency & Ontario Health Team collaboration
 - Improve capacity of paediatricians, developmental paed, primary care
 - Webinars
 - Collaborative Mentoring Networks (Ontario College of Family Physicians),
 - ECHO with focus on IDD and/or ASD with Mental Health issues
 - Increase exposure during residency to people with IDD + Mental Health issues

BREAK (7:10)

Liz Grier: OMA Special Interest Group - Neurodevelopmental Disorders (7:20 pm)

- which would include paediatricians, family physicians and psychiatrists, and others who are interested (genetics, internal medicine, gynecology etc.)
- We don't want the government to miss our population when they define complexity
- Facilitate networking of physicians who care for individuals with NDD across the lifespan
- Act as a resource for broader OMA initiatives that are relevant to our patients
- Jennifer Churchill from EKO commented that this highlights that Neurodevelopmental disorders are not just a social services but a health issue, which has funding implications from MOH and medical groups
- **ACTION: Attendees agreed that PONDA should support this application**
 - we need at least 50 signatures
- **ACTION: PONDA will ask our members to support this initiative in next newsletter – a separate email will be sent out for this.**

Olaf Kraus de Camargo: National Disability Insurance Scheme - principles (7:25 pm)

- [Link](#) to his presentation in dropbox

- Excellent Podcast on NDIS and ECCC (Every Canadian Counts) done ahead of PONDA meeting by Jacqueline Ogilvie, with Nicky, Bruce Bonyhady, and William Cowie
 - see [PONDA Podcast](#) page for the episode
- 475,000 out of 4.3 million people in Australia with disabilities get individualised supports under the NDIS, the most severely impaired group
- If you have a diagnosis that is not on the list, you must prove with functional assessment that your needs are significant and permanent
- Under 7 years of age, only the list of needs is required, and access is to early intervention. Does not have to be a permanent disability
- Integrated measure of functioning needed: however, this does not exist
- Assessing complexity: intersection between individual and the environment
- Buying services: what is therapy? In Australia there has been a proliferation of direct therapy, need for evidence-based treatment (how to define)
- **Comments:** how to measure needs: adds to our job in diagnosis, who can help families navigate, who can advocate if services are missing, many paediatricians may not feel they have the skills to know what their patients' needs are

Jan Willem Gorter: Transition to Adulthood Initiatives (8:10 pm)

- AACPDM group on Aging with CP and Transition to Adulthood
- Child Health Hub In Transition: continuation of the community of practice (CAPHC)
- Survey, 60 people have registered, includes health professionals, researchers, parent, policy decision makers, adults with condition and 1 trainee
- Physicians, nurses, pts, psychologists, occupational therapist, social workers
- Primarily paediatric driven
- 3 areas of interest:
 - promotion of skills of self-management including assessment
 - system navigation
 - supports that youth and families need across the spectrum of abilities
- Recurrent theme: There is a need to develop tools to measure needs
- **ACTION:** Message from Dr. Gorter:

Thanks to everyone who have expressed interest in joining the network. As we move forward with the Child Health Hub in Transition, we want to compile a complete list of interested members, as well as collect a bit of information about you. To do so we would like to ask that you please fill out a brief survey (see link below).

<https://canchild.mcmaster.ca/surveys/?s=EYNL4Y7NYK>

Mohammad Zubairi: Autism Advisory Panel report (8:30 pm)

- A huge thank you to Mohammad for his massive effort as a member of this panel
- Reviewed panel mandate: individualized needs-based approach to optimize outcome
- Main aspects of the report were reviewed ([see report](#))
- Mental health needs were incorporated and emphasized, including crisis response
- Family supports, care coordination, respite

- Working with other ministries: EDU and MOH
 - Does PONDA want to contribute ideas on how to assess needs and the interface between the clinician and the care coordinator process?
 - ACTION: PONDA to tweet recommendations from report intermittently