

PONDA Network  
Physicians of Ontario Neurodevelopmental Advocacy Network

November 29<sup>th</sup>, 2013

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To the Provincial Council of Maternal and Child Health,

Background: PONDA (Physician of Ontario Neurodevelopmental Advocacy) is a network of physicians across Ontario that has been meeting over the past two and a half years to discuss concerns about services for children and youth with a broad range of developmental challenges. The PONDA network is comprised of developmental pediatricians and community pediatricians whose practices include a large number of children with developmental problems.

At its most recent meeting, on November 4<sup>th</sup>, 2013, the PONDA network identified three areas of particular concern.

PONDA appreciates this opportunity to share those priorities with the PCMCH.

**Priority No. 1: Access to appropriate mental health services for children and youth with underlying neurodevelopmental problems.**

It has been well established by epidemiological research [1-3] that children and youth with developmental problems such as Cerebral Palsy, Developmental Coordination Disorder, Learning and Developmental Disabilities, Attention Deficit and Hyperactivity Disorder and Autism Spectrum Disorders are at increased risk for comorbid mental health problems. In practice these children frequently have difficulty accessing mental health services for a number of reasons:

1. They are denied access on the basis of their underlying developmental disorder. A diagnosis of a developmental disorder must not preclude access to mental health services.
2. In situations where services are available access is limited to those with the most severe symptoms such as psychosis or suicidality. We believe that intervention should be proactive and address emerging mental health disorders at any stage.
3. Expertise in the assessment and treatment of children with comorbid developmental disabilities and mental health disorders is lacking throughout most regions of Ontario.

As a result children and their families are pushed back and forth between different programs and agencies in their attempt to find help leading to further increases in family stress.

Possible Actions:

- Explore opportunities for integration of mental health services and developmental services.
- Build capacity among mental health professionals and community pediatricians for the assessment and management of mental health problems in children with developmental disorders.
- Establish programs/services to prevent the emergence of mental health problems in high-risk groups.

**Priority 2: Providing the right services at the right time to children and youth with developmental problems.**

There is considerable inequity in the services available to children in different diagnostic categories and in different regions of the province. Services for children with developmental problems are comprised of a patchwork of assessments and treatments offered by different agencies in different regions leading to a lack of standardization in care delivery across the province.

Many services are accessible only to children with specific diagnoses, causing families to seek those diagnoses in order to access treatments and supports. Follow up is often limited despite the chronicity of developmental problems and their changing impact over time.

The following case examples illustrates this issue.

Clinical presentation	Kevin is 7 years old. He is having difficulties at school, especially in Math. He is very frustrated and has frequent anger outbursts. Recently he has begun to avoid school. He is described as being a loner and has difficulties making friends although he does want to be with other children. His parents are wondering if he has Asperger Syndrome. They have heard that if Kevin is diagnosed with Asperger Syndrome he will receive more help at school.	Robert is 7 years old. He is having difficulty learning to print. He is also clumsy and uncoordinated. He is a quiet and shy child. He is often lonely during recess because he cannot keep up with his peers. Robert is referred by his family physician to a developmental paediatrician for diagnostic assessment.	Thomas is 7 years old. He has frequent meltdowns at home and school. He is fascinated by whales. His parents are wondering if he has Asperger Syndrome.
Access to assessment	Due to the referral diagnosis of suspected Asperger Syndrome Kevin is able to access a developmental paediatrician in his community.	Developmental paediatric services at Robert's local treatment centre are only available to children 6 years and under. Robert is redirected to a local community paediatrician	Thomas parents are directed by their family physician to call a CONTACT agency who directs them to mental health services, who then declines the referral as symptoms are not severe enough, but redirects him to the community pediatrician.
Assessment and diagnosis	Developmental paediatrician rules out Asperger Syndrome and suspects a Non Verbal learning disability (NVLD). Confirmation of this diagnosis requires psychometric assessment	Robert is diagnosed with DCD (developmental coordination disorder). His paediatrician recommends an occupational therapy assessment.	Thomas is diagnosed by his community paediatrician with Asperger Syndrome.

<p>Services</p>	<p>Kevin's school does not agree that psychometric assessment is warranted because he is maintaining relatively good grades. <u>Two years later</u> at age 9, assessment is completed and confirms the diagnosis of NVLD. NVLD is often associated with deficits in social skill development similar to those seen in children with Asperger Syndrome. Although Kevin's parents understand his diagnosis, they are disappointed as they are unable to access developmental services because Kevin is apparently too high functioning.</p>	<p>Robert is placed on a waiting list for OT at his school since the local treatment centre does not provide services to his age group. His mother is aware that children with DCD may have associated developmental and emotional problems. She feels unsupported, worries that Robert may also have an anxiety disorder and does not know what to do or where to go for help.</p>	<p>Thomas can access ABA (Applied Behavioural Analysis) services through his local treatment center. In addition, his school is well informed and now Thomas has received a specific individualized education plan (IEP). He is offered a social skills group, and his parents are offered 1:1 service with a behavioural therapist. Thomas' paediatrician diagnoses a comorbid anxiety disorder but Thomas is unable to access CBT (Cognitive Behavioural Therapy) from the local mental health program due to his diagnosis of Asperger Syndrome. The ASD service does not offer CBT.</p>
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Suggestions:

- Create a provincial framework for assessment and management of developmental services. This should include guidelines for access to primary, secondary and tertiary level services that is not diagnosis specific.
- Create a service model that will put more emphasis on pro-active assessments and supports and on longitudinal follow up.
- Move to a needs-based assessment and management model as opposed to services driven by diagnosis alone.

**Priority 3: Lack of expertise in the management of adults with neurodevelopmental disabilities - Expansion of subspecialty training of Family Physicians in developmental disabilities.**

In the past few years there exists increasing awareness of the needs for coordinated transition of patients with developmental disabilities from the pediatric to adult service system. This has been identified by patients, their parents as well as caregivers. The work done by the PCMCH Transition to Adult Healthcare Services work group provides a comprehensive summary of the needs of a broad range of youth with chronic health and/or developmental problems and outlines key recommendations for moving this aspect of care forward. We would like to propose an additional recommendation for consideration, highlighting the need for additional training for adult care providers who currently feel ill equipped to care for adults with neurodevelopmental disabilities.

Suggestions:

Establish a one-year fellowship training in developmental disabilities for family physicians. Queens University currently offers this program which could be expanded and offered more widely.

Advocate for special billing codes that would reflect the complexity of these patients and the time required to address their needs.

In conclusion:

The PONDA network hopes that PCMCH will endorse these priorities and offers its support towards the establishment of working groups to facilitate the system changes required to address them.



Ronit Mesterman  
Chair of PONDA Network

References:

1. Adamson, P., *Child well-being in rich countries - a comparative review - Innocenti Report Card 11*. 2013, UNICEF: Florence, Italy. p. 60.
2. Barnes, A., M. Eisenberg, and M. Resnick, *Suicide and self-injury among children and youth with chronic health conditions*. *Pediatrics*, 2010. **125**(5): p. 889-895.
3. Halfon, N., et al., *The changing landscape of disability in childhood*. *Future Child*, 2012. **22**(1): p. 13-42.