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June 7, 2019

Legislative Assembly of British Columbia
Select Standing Committee on Children and Youth
Parliament Buildings, Victoria V8V 1X4

Dear Members of the Select Standing Committee on Children and Youth,

RE: Special Project on Children with Neuro-diverse Special Needs (Assessment and Eligibility Process)

Thank you for the opportunity to submit our feedback and recommendations to the Select Standing Committee. The BC Pediatric Society is the professional society for pediatricians (and pediatric sub specialists), and as such, our members are caring for neuro-diverse patients.

We understand that the MCFD Inclusion Supports and Services (formerly CYSN) is working with researchers and will be engaging with the physician community in regard to changes or rethinking of how some services are provided. It is our thought that supports and funding should be based on need, not on outdated criteria (e.g. the At Home Program) or simply by diagnosis that does not take into account the needs of the patient and family. Additionally, services vary throughout the Province, leaving some patients and families without needed services simply because of their geographical location.

As examples of the current situation, patients with Down Syndrome:

- Are not eligible for MCFD CYSN services unless proven to have Intellectual Disability (ID), but no public agency (i.e. Sunny Hill/CDBC Clinics or schools) will do psychoeducational assessment to prove ID
- Schools will not do Psyched assessments until late in a youth's life (to qualify in time for a CLBC designation). Parents/ caregivers could have benefited at a much earlier age for CYSN eligibility and support. Therefore respite or behavioural intervention is not available until at least age 14
- Therefore there is no specific publicly-funded therapy after Early Intervention
 - No physiotherapy
 - No occupational therapy (very important to learn basic activities of daily living)
 - Minimal speech therapy in school
- Serious behaviour problems often emerge during school age years, and often a big need for respite, but not usually eligible for At-Home Program, so can't access any funds for respite.
- Basically no support unless the patient also has a diagnosis of autism
- 40% of kids with ID/Down Syndrome/Autism etc have huge problems, are not functioning at home or school or in the community and their needs are not met at all by the current system¹

Or patients with Fetal Alcohol Spectrum Disorder:

- Sometimes have Key Worker support, but access to a Key Worker and involvement/expertise of Key Worker is variable, and this does not provide funding for support
- Not eligible for respite, even if huge behaviour problems, unless also have ID

Or patients with a Rare Genetic Syndrome:

- Usually ID and physical and neurological disorders, but like Down Syndrome, the eligibility for assessment and funding – eg At-Home Program - is inconsistent

And generally, respite availability - both number and quality – is inadequate throughout the province and availability is very dependent on where one lives.

Often children with special needs also have complicating mental health disorders and/or behavioural conditions. These patients are not well served by the current system.

Further complicating these issues is the "gap year", when CYSN services end at age 18 and adult services don't start until age 19.²

¹ Falling through the cracks: How service gaps leave children with neurodevelopmental disorders and mental health difficulties without the care they need. Ono, Friedlander and Salih. BC Medical Journal, vol. 61 no. 3, April 2019

Our Recommendations

Early Identification:

- Earlier identification of developmental concerns means earlier diagnosis, investigation and intervention including medical treatment but also therapy and referral for developmental assessments at Sunny Hill/CDBC Clinics or locally where available. This would require increased surveillance by Primary Care Providers with referrals to Pediatricians or Pediatric Subspecialists. Increased funding for Infant Development Consultants, Public Health Nurses, and public awareness will be required.

Eligibility:

- Supports and funding be based on need, not on diagnosis
- Automatic eligibility for CYSN services without requiring psych-ed assessment to prove ID for infants, children and youth, especially Down Syndrome and FASD (as it stands now a child is only automatically eligible for CYSN services if she/he is palliative with a life expectancy of less than 6 months, or requires Nursing Support Services because of serious complexity)
- Automatic eligibility for At-Home program for infants, children and youth with Down Syndrome and other genetic syndromes that typically cause developmental disorders
- Review of outdated criteria for the At Home Program (we understand this review is being undertaken currently)

Assessments and Wait Times:

- Assessments- long wait times to get to IDP, Child Development Centres (Speech language therapists, Occupational therapists, Physiotherapists), and Pediatricians. Once concern is raised, referral to Sunny Hill/CDBC Clinics for Developmental assessments follows (again, with long wait times).
- Children with delays can sit on a waitlist at a Child Development Centre or Health Unit for Speech for 18 months. Referral to a Pediatrician may occur at that point (more waiting) then referral to Sunny Hill/CDBC Clinics which is often another 18 months.
- Not all children have equitable access to assessments at Sunny Hill/CDBC Clinics, i.e. children with Down Syndrome have not been eligible for assessments of cognitive function. Assessments and service provision should not depend on medical diagnosis; they should be function-based as in the case with children who have Down Syndrome.
- Many of the children with Developmental Disabilities are diagnosed prenatally, at birth or within the first 18 months. They still have to wait for assessments and therapies.
- More funding required for reducing waitlists

Service Specific:

- Improve quantity and quality of respite services/beds with dedicated funding and training, make respite available for the above-mentioned kids if needed for behaviour or mental health reasons, not based on IQ.
- Increased funding and equitable access for CYSN social workers which will open up access to respite, behaviour support
- Increased funding for respite care and geographically equitable access to respite care, and the burden for finding that care should not fall on the family
- Early intervention is so important! We would like to see increased funding for the Early Years Program and infant Development Consultants and for Child Development Centres
- increased behavioral support and therefore funding for children and youth who are not diagnosed with Autism Spectrum Disorder and who therefore do not qualify for Autism funding

In regard to comorbid mental health and behavioural conditions:

- Recognize that a significant minority of children with special needs such as Autism, ID, FASD, have complex comorbid mental health and behavioural conditions. These children need to be recognized as the most underserved and needing the most help. CYMH should see these children but typically do not. Developmental Disabilities Mental Health (DDMH) only sees children over 12 (over 14 outside the Lower Mainland) and is a very limited service. DDMH should also see children under 12 and be significantly better funded and/or CYMH need to see these kids.
- CYSN social workers should get training to recognize and advise families about complex comorbid mental health and behavioural conditions in children with special needs. So, for example, when a child has aggression or self-injury, they can advise the families about appropriate professionals to assess the child including paediatricians, child psychiatrists, and/or the Neuropsychiatry clinic at BCCH. Additionally, mental health conditions may only emerge as child grows older. Social workers should be trained to help families recognize that behavioural conditions that emerge with age may not be attributable to the Autism, ID, and FASD etc. and advise referral to clinicians for assessment.

² Nathan Shipley's Really Lousy Gap Year: [Aryn Strickland](#) 21 Jan 2019 | TheTyee.ca

Access to Pediatric Care:

- All kids with these difficulties need access to a Paediatrician to follow them long-term; this would mean a pool of interested Paediatricians with specific expertise who are paid through some sort of alternate funding model (and may work in a team-based setting) so that they do not necessarily need to be referred by a GP

Navigator Support to Assist Families (During the Child and Youth Ages and at Transition into Adult Services):

- Need Navigators to support families at all transition ages (this may be a CYSN SW role, but we do not see this role being carried out for our patients).
- Some patients will qualify for the STAAD program (which is not available in all communities), but qualification is based on eligibility for CLBC; we recommend that this eligibility requirement be waived for patients with neuro-diverse special needs
- For patients transitioning between CYSN and adult services, the “gap year³” needs to be changed so that continuity of care is achieved

Yours truly,

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On behalf of the BC Pediatric Society

³ Ibid.