



Improving Services for Children and Youth with Neurodevelopmental Disorders and Psychiatric Comorbidities

Erika Ono MSW RSW PhD candidate

Robin Friedlander MD FRCPC

Learning Objectives

By the end of this presentation, learners will be able to:

- Identify the service needs of children with neurodevelopmental disorders and psychiatric comorbidities.
- Describe caregiver burden in families of children in neuropsychiatry.
- Discuss ways to improve service delivery to this population.

“Neuropsychiatry”

Comorbid mental health and/or behavioural issues in the presence of a NDD or neurological condition, such as:

- Autism Spectrum Disorder
- Fetal Alcohol Spectrum Disorder
- Intellectual Disability
- Cerebral Palsy
- Traumatic Brain Injury
- Genetic Disorders, such as Prader Willi, Fragile X, Down Syndrome
- Tic Disorders
- Stereotypic Movement Disorders
- Seizure Disorder

Neuropsychiatry at BC Children's Hospital

- Children/youth (6-18) with NDD and psychiatric co-morbidities.
- Have not responded to community treatment resources.
- Services: consultation, assessment, diagnosis, limited treatment, education/family support.
- Interdisciplinary team: psychiatrists, social workers, psychologists, an occupational therapists, and a speech and language therapist.

BCCH Neuropsychiatry Program Review

Current State:

- Significant variability in the extent to which these patients receive community services.
- Extremely limited provincial tertiary clinic services outside of the neuropsychiatry clinic at BCCH.
- Discharge is often difficult because of limited community capacity and skills to follow up on treatment recommendations.

Problem Statement:

- Multiple gaps in services, system barriers to accessing support, and a lack of provider knowledge about these conditions result in long waitlists for assessment and treatment at the BCCH Neuropsychiatry Clinic, as well as limited resources in the community for follow-up.

BCCH Neuropsychiatry Program Review

- Despite a provincial mandate, less than 7% of patients are from outside the Lower Mainland.
- The major cause of caregiver burden, parent burn-out and placements of children and youth with NDD outside the family home is challenging behaviors such as aggression.
- This requires accessible and specialized services to support and implement treatment.
- Pediatricians, GP's and schools are often the main service provider for these children/youth when they are not eligible for CYMH or CYSN.
- When crises arise for these families, emergency rooms, acute psychiatry, and MCFD emergency placements in foster/group homes serve as the only options.

Program Review Objectives

- Develop a community of practice with Pediatricians.
- Provide training to other professionals to build community capacity.
- Review other neuropsychiatry programs in Canada and the US.
- Complete a retrospective referrals review of the past 3 months.
- Clarify/define the social work clinician role in the clinic due to high case management, care coordination and discharge needs of the neuropsychiatry clinic patients.
- Create resources about service pathways and systems navigation for patients, the neuropsychiatry clinic, pediatricians, clinicians, and the Kelty Mental Health Resource Centre website.

Program Review

- Key informant interviews
- Environmental scan
- *Retrospective referrals review*
- Social Work scope/role (survey, referral tracking tool, priority setting tool)
- *Community of practice (with BC pediatricians)*
- BC pediatric society newsletter
- *Developed Service Pathway diagram and System Navigation algorithm*
- *Challenging Behaviours conference*
- Presentations
- Article

Retrospective Referrals Review

Data collection:

- Accepted and declined BCCH neuropsychiatry clinic referrals from April to July 2017.
- Review of the accepted referrals contained only neuropsychiatry documents.
- Declined neuropsychiatry referrals were gathered by reviewing all declined BCCH Outpatient Psychiatry Department referrals from this time period.
- A total of 51 referrals were used for analysis.

Retrospective Referrals Review

Objectives:

- Who are the patients being referred (NDD diagnoses, presenting concerns, reasons for referral)?
- What is needed (i.e. medication review, services, diagnostic clarification)?
- Who is referring (common pediatricians, ratio of GP to pediatricians to other medical specialists)?
- What is the percentage of referrals that are declined?
- What is the percentage of referrals sent from central intake to the clinic for review?

Retrospective Referrals Review: Analysis

Accepted referrals

- Neurodevelopmental disorder diagnoses
- Other psychiatric diagnoses
- Presenting concerns
- Reason for referral
- Decision by intake or clinic
- Reason for clinician review
- Region
- Referring physicians
- Referral form

Declined referrals

- Decision by intake or clinic
- Reason for clinician review
- Reason for decline

Neurodevelopmental Condition



■ ASD

■ Epilepsy or Seizure Disorder

■ FASD (including ARND, NDD in context of prenatal exposure)

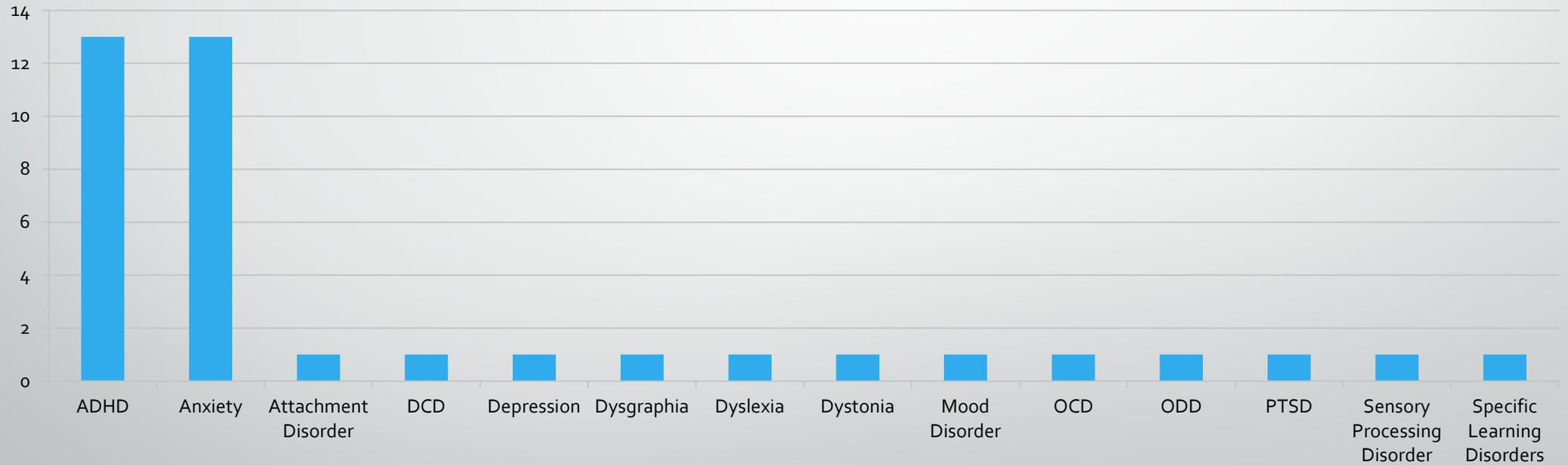
■ ID (including GDD)

■ TBI

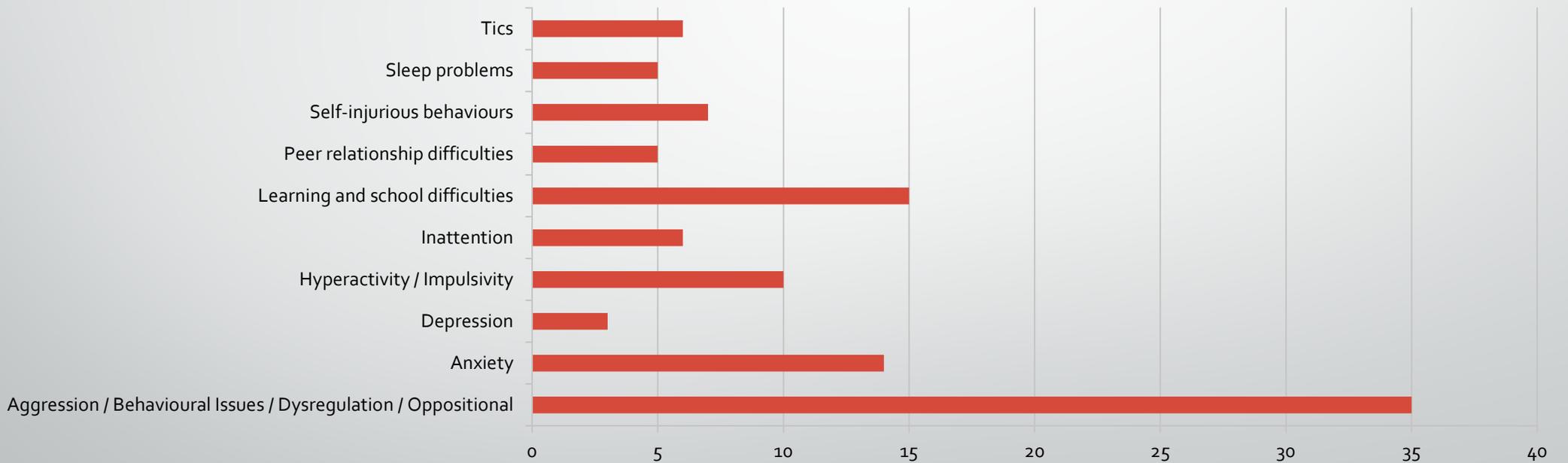
■ Tourette Disorder

■ Other

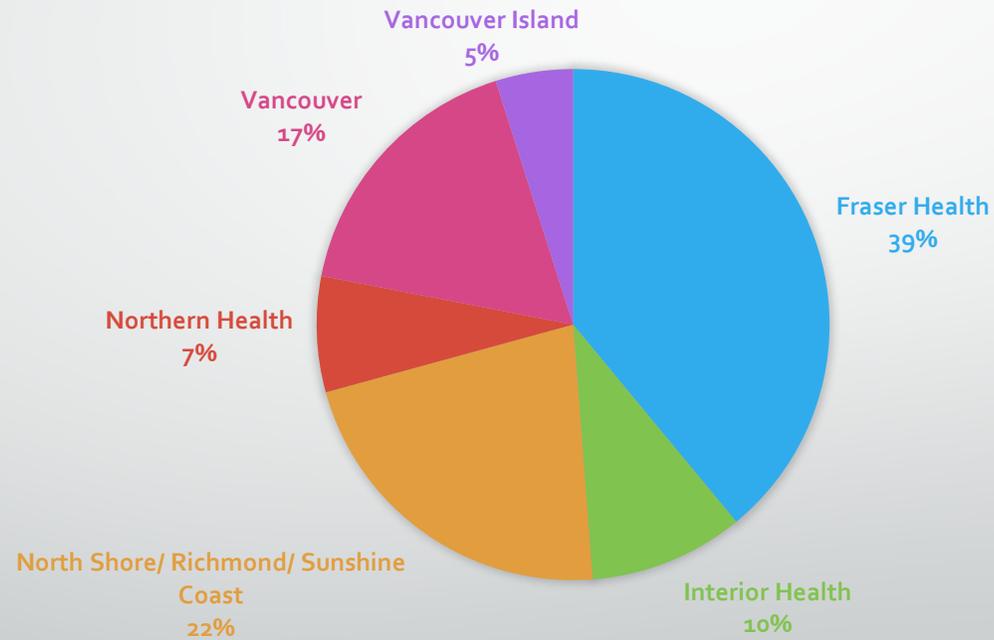
Psychiatric Co-Morbidities



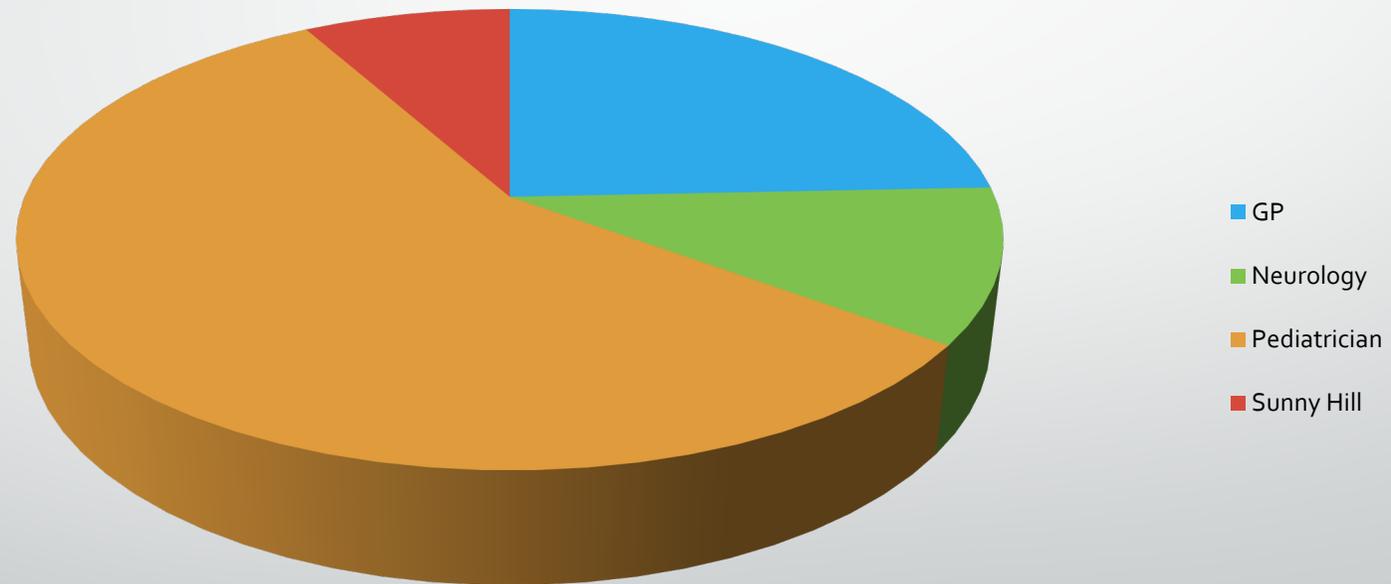
Top 10 Presenting Concerns



Region of Referral



Top 4 Referral Sources



3 Main Outcomes of the Program Review

- Neuropsychiatry service pathway diagram and system navigation algorithm
- Community of practice
- Challenging behaviours conference

Caregiver Burden

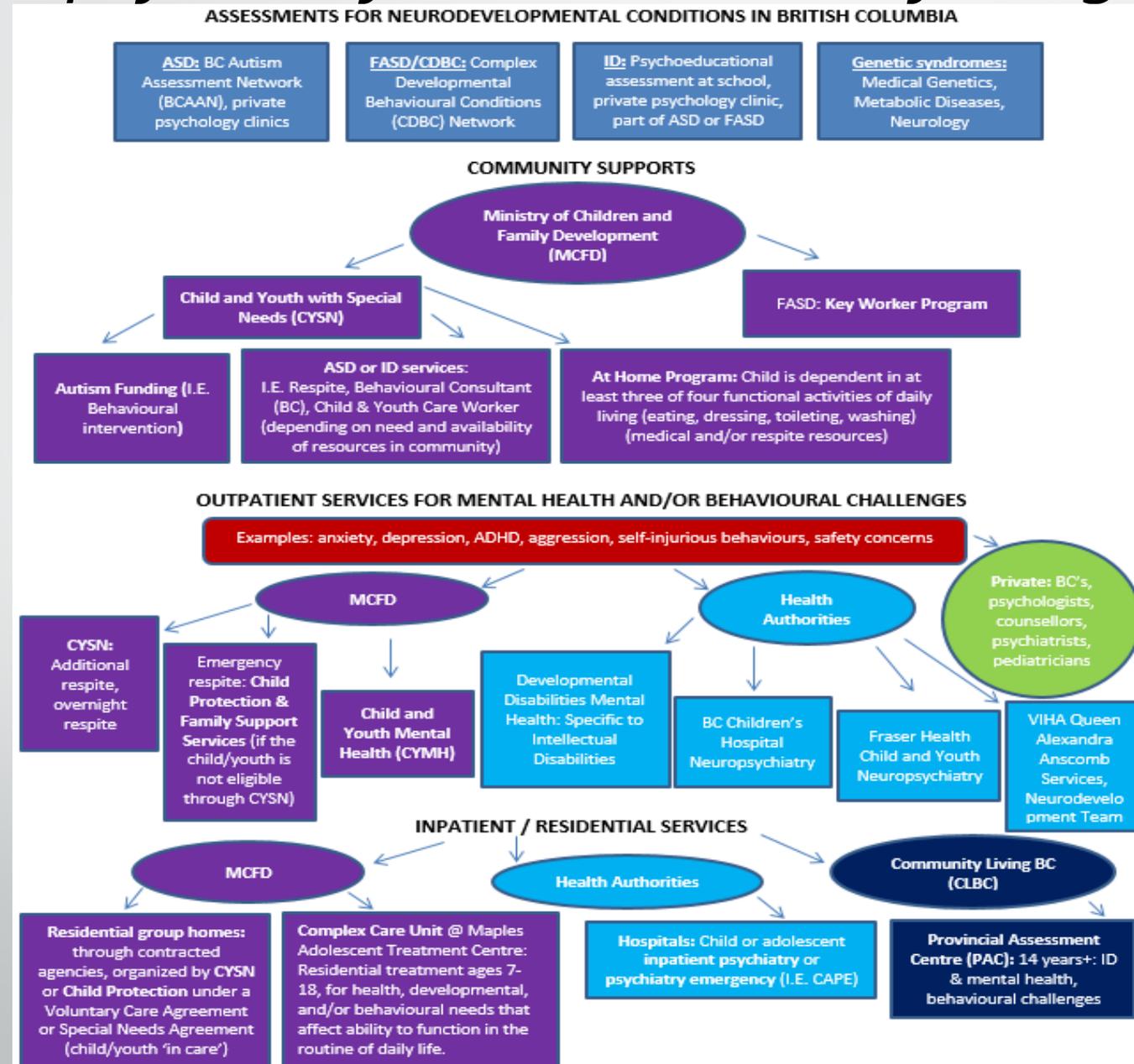
- Difficulties in accessing specialized mental health services and community supports has placed the burden of care on families.
- Studies have shown increased caregiver physical and psychological stress, family distress, reduced marital satisfaction, and inadequate social supports for parents of these children.
- Taxing on the economic/material resources of families.
- Parent-blaming: ““The only grief I ever had with the [local agency] was that everybody keeps pushing parenting courses at you. If your kid’s acting this way, take a parenting course. I’ve taken them all – the kid figures the stuff out before I do. All they’ve succeeded in doing is making me feel like an awful parent” (Goddard, Lehr, & Lapadat, 2000, p. 280).
- Difficulties with professionals and the bureaucracy of social and health services can add to parents’ stress, rather than provide supports to alleviate some of the challenges.



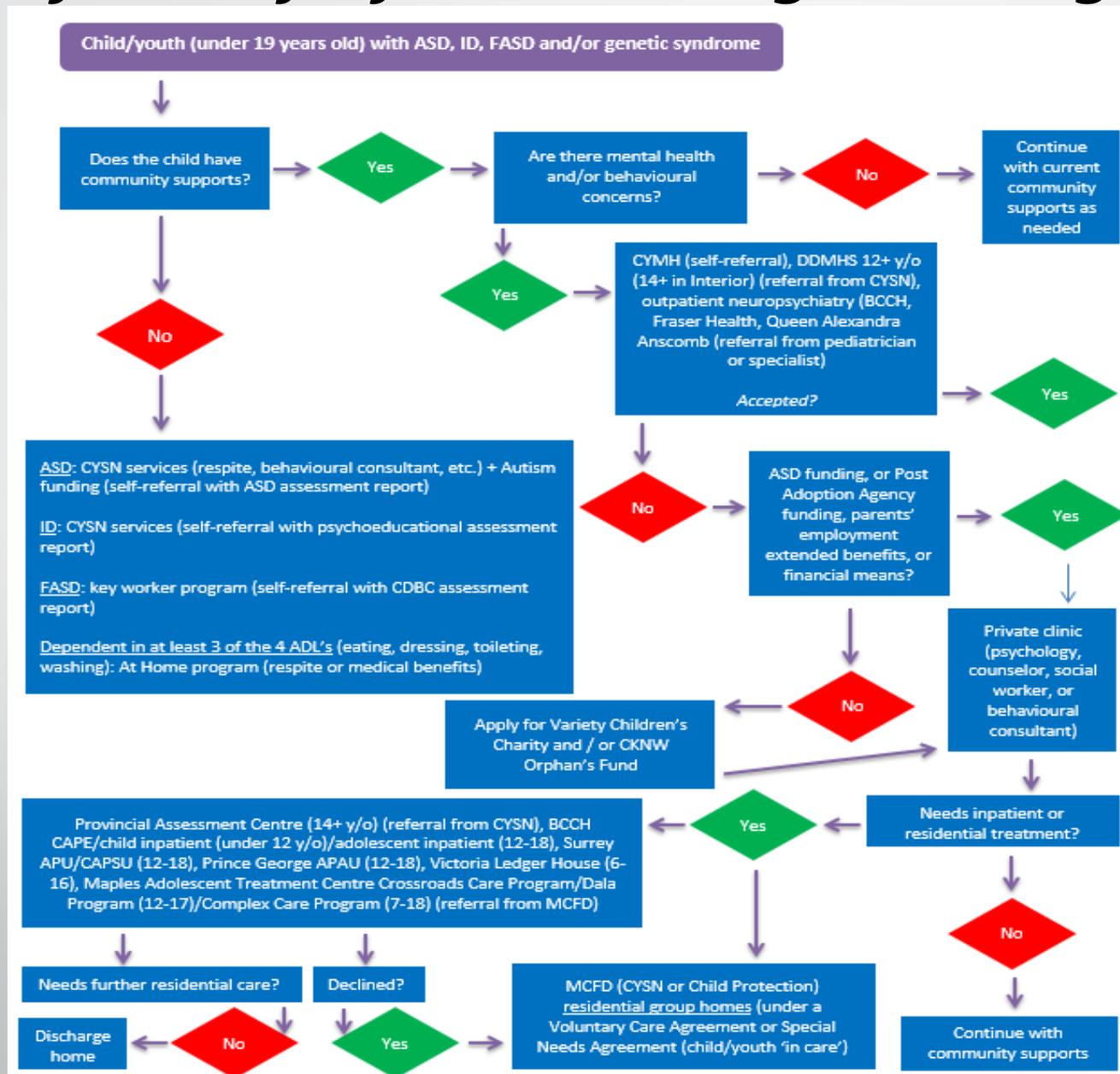
Resources

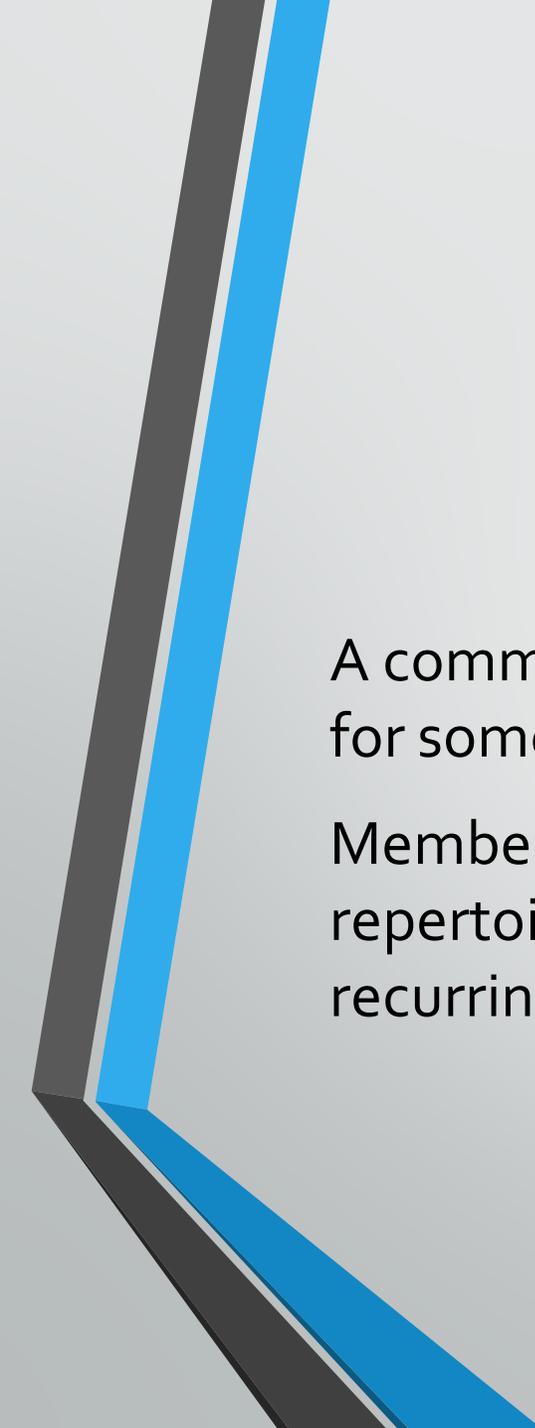
- Fragmented and complex service systems.
- Confusing for caregivers *and* service providers.

Neuropsychiatry Service Pathway Diagram



Neuropsychiatry Systems Navigation Algorithm





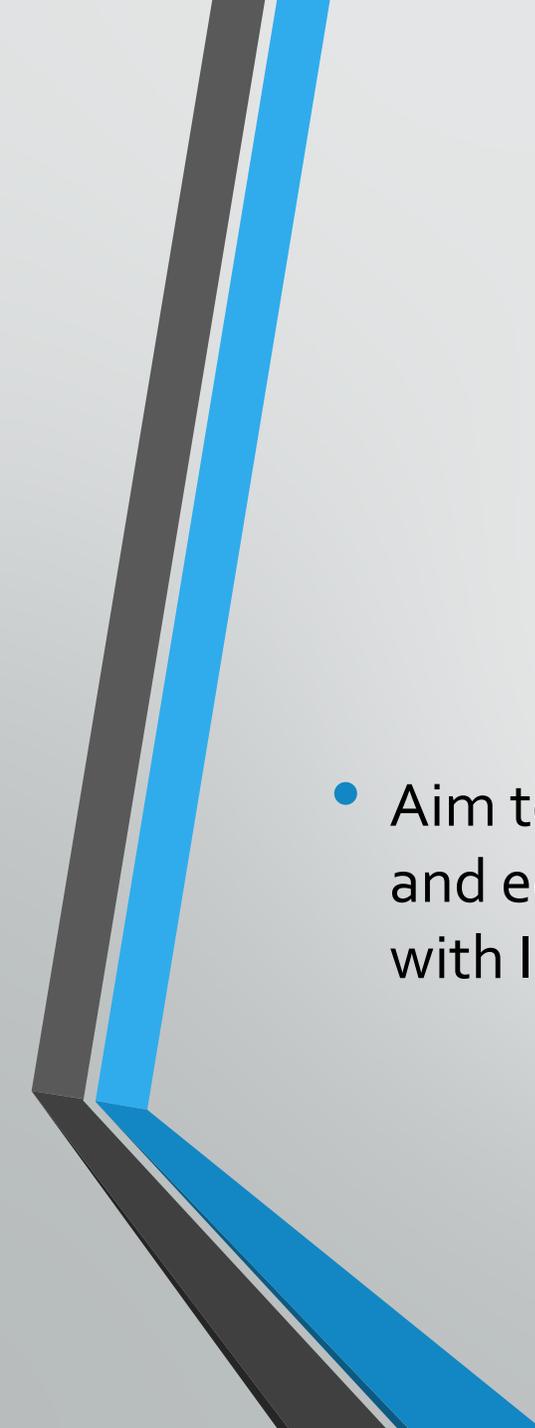
Community of Practice

A community of practice is a group of people who share a concern or a passion for something they do, and learn how to do it better as they interact regularly.

Members of a community of practice are practitioners. They develop a shared repertoire of resources: experiences, stories, tools, ways of addressing recurring problems—in short a shared practice.

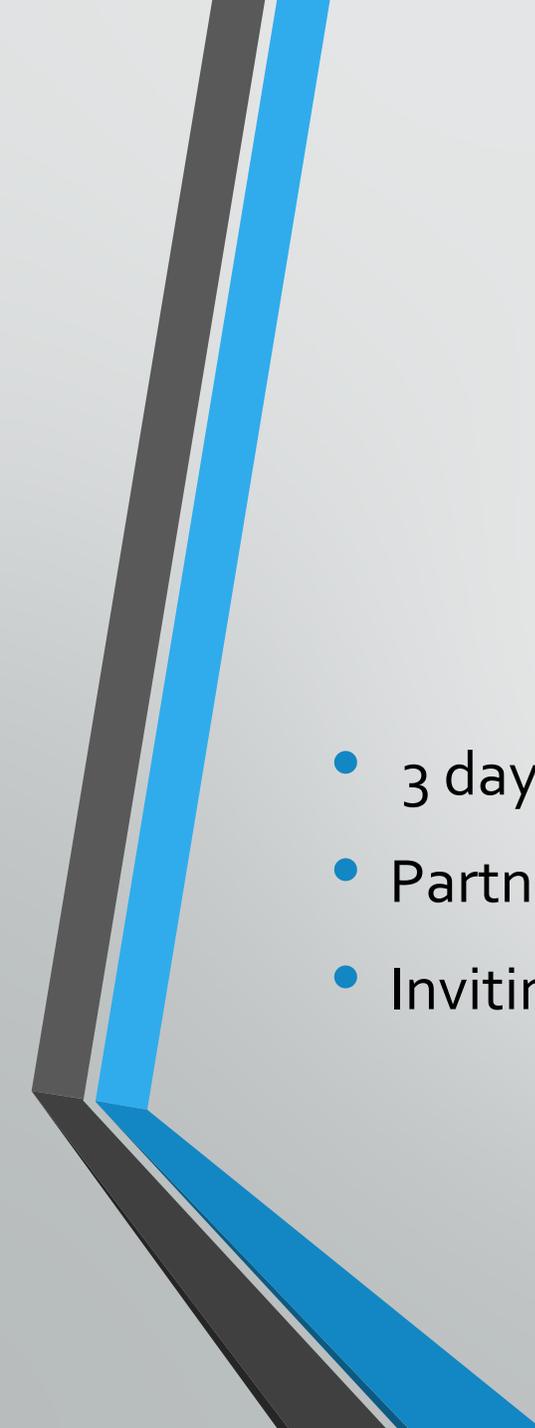
COP

- A partnership between the Pediatric society of BC and BCCH Neuropsychiatry Clinic with the aim of improving mental health support for children with Autism, ID, FASD, and challenging behaviors living in BC.
- Only 7% of our referrals come from outside Lower Mainland.
- Recognition of crucial role of community pediatricians.
- We have had one pilot COP and are seeking funding so this can be scheduled quarterly.



Challenging Behaviours Conference

- Aim to improve skill level of community clinicians, behavioural therapists and educators in addressing challenging behaviours in children and youth with ID, ASD, and FASD.



Challenging Behaviors Conference

- 3 day conference planned for May 10 – 13, 2018.
- Partnership between BCCH, PAFN, ABLE clinic, Surrey school district.
- Inviting out Glen Hanley PhD.



Discussion