BC Children's Hospital
Provincial Health Services Authority

Compass Mental Health
Supporting Providers

2022

Guidelines for the assessment and management of behavioural escalation in children and youth with developmental disabilities* in the emergency room.

The assessment of children and youth with developmental disabilities who present to the emergency room in behavioural crisis can be challenging for families, patients, and medical staff. The goals of these guidelines are to assist medical staff in helping the assessment run smoothly, and to help in the decision making process. The guidelines address how to differentiate between chronic and acute behavioural symptoms, and how to assess for common psychiatric disorders.

**The term "developmental disabilities" in this document refers to individuals with intellectual disabilities and/or autism spectrum disorders.*

Provincial Health Services Authority
British Columbia
BC Children's Hospital Foundation

CONTENTS

DECISION FLOW SHEET

Assessment and Management of Behavioural Escalation in Children and Youth with Developmental Disabilities in the Emergency Room

CONDUCTING THE EMERGENCY ASSESSMENT

The ER can be a stressful environment for any patient, but especially those with developmental disabilities. The following suggestions are helpful ways to moderate the impact on the patient.

Conducting the Interview:

- Minimize the wait time if at all possible.
- Try to find a quiet, private place for the patient and caregiver to wait until the assessment begins.
- **Meet with the caregiver to inquire about:**
  - The patient's primary methods of communication
  - Sensory sensitivities
  - Suggestions from previous emergency visits which would help the patient feel more at ease
  - Any existing crisis plans
  - Existing protocols for procedures, bloodwork, etc.
- **For the assessment:**
  - Find a quiet and private exam room.
  - Keep sensory stimulation in the form of bright lights, rough materials, interruptions and unfamiliar people to a minimum.
  - Be sensitive to your means of communication. Individuals that do not speak usually still hear what is being said. Be aware of speaking slowly, using simple words and monitoring your non-verbal cues in addition to the patient's responses.
  - Ask permission to proceed before entering patient's personal space
  - Explain procedures to the patient through simple drawings and words.

ESTABLISHING BASELINE LEVEL OF FUNCTIONING

Areas of Inquiry around Baseline Level of Functioning:

- **Communication:** usual level of expressive and receptive language.
- **Cognitive Capacity:** psycho-educational testing, school history, individual educational plan.
- **Adaptive Functioning:** degree of support needed in areas such as personal hygiene, dressing, toileting, eating and medication taking. Capacity of patient to transport self independently and be in the home without caregiver.
- **Activities:** extracurricular activities including sports, arts, areas of interest and degree of support needed for this. How does the patient spend their day: at home, in school, or in a day program?
- **Peer Relationships and Social Functioning:** Presence of friendships, degree of social interest, ability to engage in social reciprocity, attachment to support workers.
- **Residential Arrangement:** living at home with family or in a group home.

REVIEWING POTENTIAL CAUSES OF BEHAVIOURAL EXACERBATION

A systematic approach to the assessment is especially important for individuals with developmental disability. The presenting complaint is likely to have multiple contributing factors and the patient's ability to interpret their own internal cues, both physical and emotional, and explain their symptoms, may be quite limited.

Areas of Inquiry around Contributing Factors:

- **Physical Illness:** Examples include constipation, urinary tract infections, musculoskeletal complaints, ear infections, dental concerns. It is important to ask when the most recent hearing and vision tests have been done as decreased capacity in these areas may result in behavioural changes.
- **Drug Interactions or Medication Side Effects:** For example, benzodiazepines and some anticonvulsants may cause paradoxical reactions in individuals with autism. EPS from antipsychotics, and even allergy medications with their antihistaminic or anticholinergic properties can affect the patient's presentation.
- **External Supports and Individual Expectations:** Examples include changes in staff at group homes or individual support workers, changes in work or school routine, and unrealistic expectations around developmental milestones such as higher education goals or romantic relationships.
- **Distressing Events:** Examples include siblings going to university or getting married, co-residents or staff leaving group homes, anniversary reactions to losses, changing living situation, abuse, financial or medical stress in the family.

DIFFERENTIATING CHRONIC BEHAVIOUR/PSYCHIATRIC SYMPTOMS VERSUS ACUTE SYMPTOMS

Chronic symptoms need to be differentiated from new onset symptoms. This is an important point of distinction as inpatient management is directed towards addressing NEW psychiatric disorders. Chronic psychiatric conditions are managed in the outpatient setting.

Common Chronic Behavioural/Psychiatric Symptoms:

While an escalation in any of these areas may result in an ER visit, it is important to determine the baseline presence of these symptoms. This, in addition to baseline level of functioning and contributing factors, will help delineate an exacerbation of a chronic psychiatric symptom from the new onset of a psychiatric condition.

- Self-injurious behaviours
- Aggression
- Stereotypes
- Obsessive thoughts and compulsive behaviours
- Tics
- Inattention, hyperactivity and impulsivity
- Anxiety, fears, phobias

The most frequent causes of acute emergency presentations are aggression and self-injurious behaviour, neither of which is necessarily an indicator of psychiatric illness. Proceed to Management of Aggression and Self-Injurious behaviours for strategies around addressing an escalation in chronic behaviours (SEE PAGE 10).

PRESENTATION OF PSYCHIATRIC DISORDERS IN INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Common new onset psychiatric disturbances include mood disorders, anxiety, and psychosis.

To determine if the psychiatric disturbance is of new onset:*

1. Determine usual behaviour including baseline level of chronic psychiatric conditions and baseline level of functioning.
2. Determine whether:
    a. A **significant change** in behaviour has occurred lasting **one week AND there has been a deterioration in level of functioning in at least 2 of the following areas:** self-care, interest and involvement in school or work, play or leisure, social relationships, initiative and need for change in supervision or placement.

    Or

    a. Evidence of new onset psychotic or mood symptoms.

**Adapted from: Bolton, Patrick &Rutter, Michael. (1994). Schedule for the assessment of psychiatric problems associated with autism (and other developmental disorders) (SAPPA): Informant version. Cambridge, U.K.*

Psychosis:

Diagnosing psychosis in individuals with developmental disabilities is difficult. Sometimes, what appear to be psychotic symptoms are actually a reaction of a person with limited cognitive capacity to stress. Thoughts can become more confused and ideas may appear delusional as the individual struggles to cope with feeling overwhelmed. Imaginary friends and talking to oneself may be developmentally appropriate, particularly if this is longstanding and does not cause distress.

Psychotic Symptoms in Patients with Developmental Disabilities can include hallucinations (visual, auditory), delusions, disorganized speech or behaviour (more than baseline), and negative symptoms including a decrease in speaking, pursuit of interests, and facial expressions.

Mood Disturbance:

Individuals with developmental disabilities are sometimes unable to describe cognitive symptoms of mood disturbances (e.g. I feel depressed), but their mood changes may be expressed in other ways.

Depression Symptoms in Patients with Developmental Disabilities can include sad affect, irritability, crying episodes, changes in sleep, loss of interest in preferred activities, changes in energy or concentration, decreased appetite or weight loss, psychomotor agitation or retardation and social withdrawal.

Manic Symptoms in Patients with Developmental Disabilities can include sleeplessness, talkativeness, excessive involvement in pleasurable activities (e.g. hyper-sexuality), distractibility, disinhibition and increased risk-taking behaviours.

Anxiety Disorders:

Similar to Mood Disorders, individuals with developmental disabilities are sometimes unable to describe cognitive symptoms of anxiety. Anxiety can present as insomnia, fearful affect, irritability, hyper-arousal, increased startle response, new onset compulsive rituals, panic attacks, and aggression.

MANAGEMENT OF AGGRESSION OR SELF-INJURIOUS BEHAVIOURS IN THE ER

1. **Ensure safety of patient, caregivers and hospital staff as per usual ER procedures.** This may have to include chemical or physical restraint, although a sensitive approach to the individual's experience in the ER may avert this.

2. **Review list of Contributing Factors to rule out situational causes for behavioural escalation.** Rule out medical and dental causes.

3. **Medications:** Be cautious about changing routine medications in the emergency setting unless there is an immediate need for a change (e.g. intolerable side effect, new onset disorder, etc.). However, advice about medication options for the community physician to consider based on emergency assessment, can be invaluable, and should be included in a consult note.

4. See Child Health BC Provincial Least Restraint Guideline: https://www.childhealthbc.ca/initiatives/mental-health-and-substance-use

DETERMINING DISPOSITION

Inpatient Admission Required:

Inpatient admission is usually reserved for patients with a **new onset psychiatric disturbance AND who are at risk of harm to self, harm to others or deterioration in the community.**

An inpatient stay is often a stressful change of routine, caregivers and environment for the patient. **It should not be used to manage chronic psychiatric co-morbidities such as aggression, self injurious behaviours and difficult behaviours, unless there has been an acute exacerbation.** These are best addressed through crisis management in the ER and follow up outpatient treatment with development of a crisis plan.

Outpatient Management:

Hospitalization not required but an alternative environment to manage the crisis is needed:

Individuals with developmental disabilities and autism often present with difficult behaviours which result in the need for caregiver respite. Housing arrangements can be lost for other reasons or a caregiver may be unable to support a client temporarily due to medical illness, emotional burnout or other.

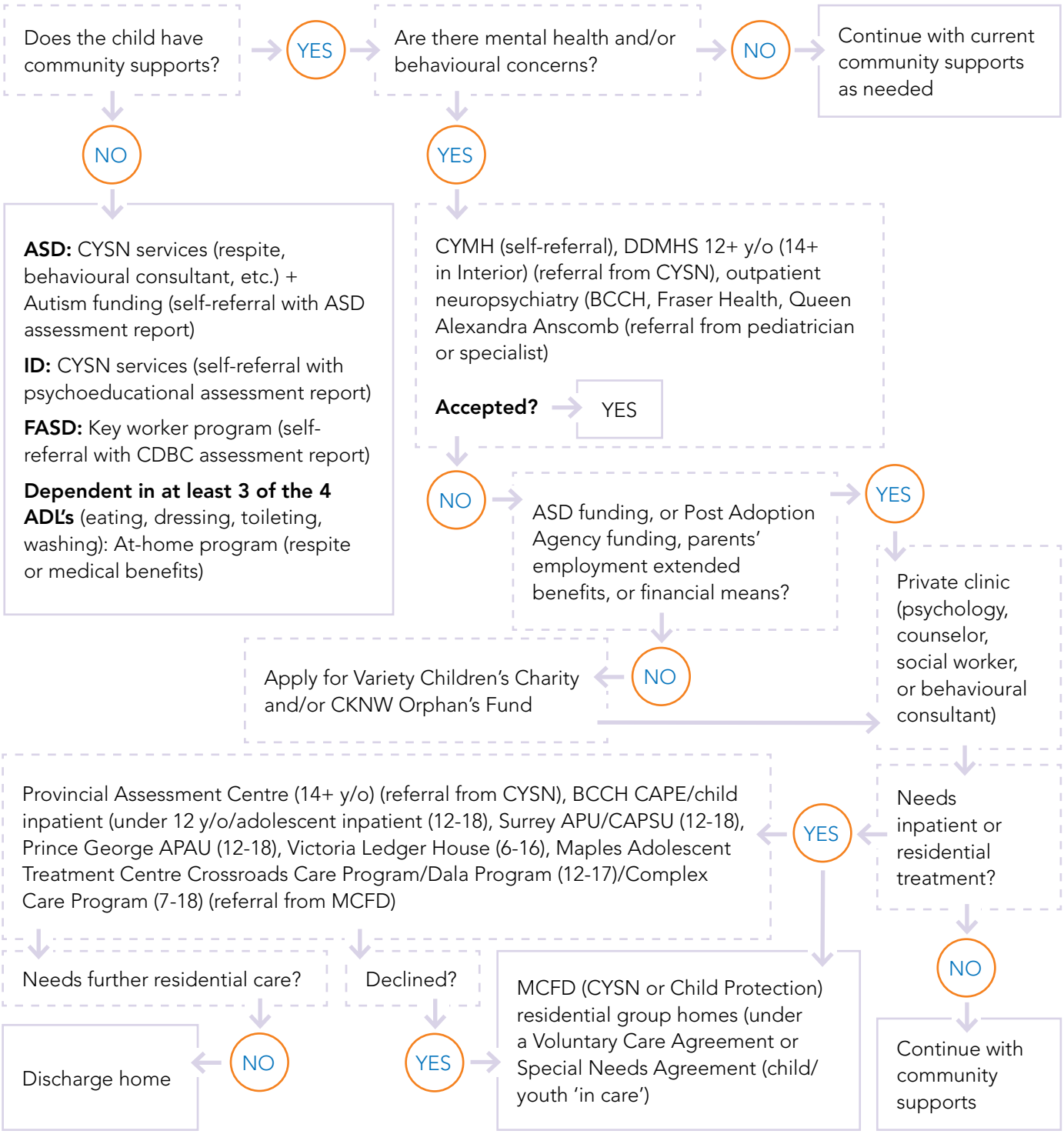
Return to home environment with Outpatient Supports:

Additional resources for support in the home and community needed, but caregivers willing to return home with patient if additional supports can be arranged (see below for contacts).

RESOURCES

APPENDIX: SERVICE NAVIGATION ALGORITHM

Erika Ono, RSW MSW PhD (c), 2022. Manuscript in Preparation



APPENDIX: SERVICE PATHWAY DIAGRAM

Adapted from: Ono, E., Friedlander, R., & Salih, T. (2019). Falling through the cracks: How service gaps leave children with neurodevelopmental disorders and mental health difficulties without the care they need. British Columbia Medical Journal, 61(3).

Assessments for neurodevelopmental conditions in British Columbia

ASD: BC Autism Assessment Network (BCAAN), private psychology clinics

FASD/CDBC: Complex Developmental Behavioural Conditions (CDBC) Network

ID: Psychoeducational assessment at school, private psychology clinic, part of ASD or FASD

General syndromes: Medical Genetics, Metabolic Diseases, Neurology

Community supports

Ministry of Children and Family Development (MCFD)

Child and Youth with Special Needs (CYSN)

FASD: **Key Worker Program**

Autism Funding (I.E. Behavioural intervention)

ASD or ID Services: I.E. Respite, Behavioural Consultant (BC), Child & Youth Care Worker (depending on need and availability of resources in community)

At Home Program: Child is dependent in at least three of four functional activities of daily living (eating, dressing, toileting, washing) (medical and/or respite resources)

Outpatient services for mental health and/or behavioural challenges

Examples: anxiety, depression, ADHD, aggression, self-injurious behaviours, safety concerns

MCFD

CYSN: Additional respite, overnight respite

Emergency respite: **Child Protection & Family Support Services** (if the child/youth is not eligible through CYSN)

Child and Youth Mental Health (CYMH)

Health Authorities

Developmental Disabilities Mental Health: Specific to Intellectual Disabilities

BC Children's Hospital Neuropsychiatry

Fraser Health Child and Youth Neuropsychiatry

VIHA Queen Alexandra Anscomb Services, Neurodevelopment Team

Private: BC's, psychologists, counsellors, psychiatrists, pediatricians

Inpatient/residential services

MCFD

Residential group homes: through contracted agencies, organized by **CYSN** or **Child Protection** under a Voluntary Care Agreement or Special Needs Agreement (child/youth 'in care')

Complex Care Unit at Maples Adolescent Treatment Centre: Residential treatment ages 7-18, for health, developmental, and/or behavioural needs that affect ability to function in the routine of daily life

Health Authorities

Hospitals: Child or adolescent inpatient psychiatry or psychiatry emergency (I.E. CAPE)

Community Living BC (CLBC)

Provincial Assessment Centre (PAC): 14 years+; ID and mental health, behavioural challenges

OUTPATIENT RESOURCES

Child and Youth with Support Needs (CYSN)

Family Support Services

For children/youth with ID and/or ASD, which can include: direct funded respite, contracted respite, respite relief, homemaker/home support, behavioural support, child and youth care workers, and parent support. Availability of services is dependent on what programs are running through contracted agencies, which differ depending on each community.

Eligibility: Provide assessment with diagnoses of ASD or ID.

Autism Program

Children with ASD receive additional services under the Autism Program, which includes funding for Autism intervention services ($22,000 per year for under age six and $6000 per year for ages six to eighteen).

Eligibility: Provide assessment with diagnoses of ASD or ID.

Respite and Group Homes

When families are not able to care for their children in the community due to increasing safety concerns and challenging behaviours, they may be able to access out-of-home respite through CYSN. This is a shorter-term and part-time option. The only other option is to place their child in a group home, which would also be arranged through CYSN (or MCFD child protection). To do so, they need to sign a Special Needs Agreement (SNA) or Voluntary Care Agreement (VCA), which places the child/youth under the care of MCFD. Parents remain legal guardians under a SNA or VCA.

Eligibility: Determined by CYSN. Parent/caregiver to discuss with CYSN worker.

Referral: Self-referral, contact a local CYSN office.
https://www2.gov.bc.ca/gov/search?id=3101EE72823047269017D08E55AF6441&tab=1&q=special+needs

Website: https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs

At Home Program

Part of CYSN, although eligibility and the referral process are separate. This program provides medical and/or respite benefits and is intended to assist parents with costs of caring for a child with severe disabilities at home.

Eligibility: Dependent in at least three of four functional activities of daily living (eating, dressing, toileting, washing), has a palliative condition.

Referral: Form to be completed by a physician.
https://www2.gov.bc.ca/assets/gov/family-and-social-supports/children-teens-with-support-needs/at_home_program_application.pdf

Fax to the regional At Home Program office, list:
https://www2.gov.bc.ca/assets/gov/family-and-social-supports/children-teens-with-support-needs/at_home_program_regional_offices.pdf

Website:
https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs/complex-health-needs/at-home-program

FASD Key Worker Program

Key workers assist families in understanding FASD by providing education and information specific to the needs of the child and family. Their role is to assist families in accessing support, health, and education services. Parent support services include local parent and grandparent FASD training, parent mentoring, and parent support groups.

Eligibility: Provide assessment with diagnosis of FASD

Referral: Self-referral, contact community key worker program, list below.
https://www2.gov.bc.ca/assets/gov/health/managing-your-health/fetal-alcohol-spectrum-disorder/key_worker_parent_support_agencies.pdf

Website:
https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs/fetal-alcohol-spectrum-disorder-fasd

Ministry of Children and Family Development (MCFD) Family Support Services

Separate from child protection services, MCFD family support services can offer assistance for families struggling to care for their children through voluntary services. These may include respite or other family support programs, depending on the availability of resources in the region that the family resides.

Referral: Self-referral, centralized screening is 1-877-387-7027.

Recommendation: Service provider to call with parent to advocate for a support file.

Website: https://www2.gov.bc.ca/gov/content/governments/organizational-structure/ministries-organizations/ministries/children-and-family-development

Child and Youth Mental Health (CYMH)

The Ministry of Children and Family Development's Child and Youth Mental Health (CYMH) teams located across B.C. provide a range of mental health assessment and treatment options for children and youth (0-18 years of age) and their families at no cost. Their clinics are staffed by mental health clinicians, psychologists, and psychiatrists. CYMH does not provide specialized services for children and youth with neurodevelopmental disorders and co-occurring mental health challenges. However CYMH may still be appropriate if the child/youth has mild ID and/or 'high functioning' autism. Children, youth and families can attend their local CYMH intake clinics for an intake interview. The intake interview will take about 45-90 minutes.

Eligibility: Children and youth (0-18 years of age) with mental health concerns.

Referral: Self-referral, intake days/times different at each CYMH office. https://www2.gov.bc.ca/gov/content/health/managing-your-health/mental-health-substance-use/child-teen-mental-health/mental-health-intake-clinics#intakeclinics

Recommendation: Service provider to call CYMH and fax medical documentation outlining the need for CYMH.

Website: https://www2.gov.bc.ca/gov/content/health/managing-your-health/mental-health-substance-use/child-teen-mental-health

Developmental Disabilities Mental Health Services

Provides specialized mental health services for youth who live with co-existing developmental disabilities and mental health/behavioural challenges. Offers psychiatric and behavioural assessments, diagnosis, psychiatric treatment, clinical counselling, speech/language assessment, music or art therapy, and therapies to address behavioural issues. These services include one-to-one support at home, case management, educational/ training/consultative services, and work in collaboration with existing community resources and support networks. DDMHS does not provide services to children under twelve or who have other neurodevelopmental disorders if they do not have a diagnosed Intellectual Disability.

Eligibility: Require the youth to be twelve (or fourteen in Interior Health Authority), have a psychological assessment indicating an IQ of 70 or below, have a mental illness and/or challenging behaviour, have developed the Intellectual Disability before the age of eighteen, and must meet CYSN criteria for services.

Referral: Through the CYSN worker.

Recommendation: Service provider to fax medical documentation to CYSN outlining the need for DDMHS.

Websites: https://www.fraserhealth.ca/Service-Directory/Service-At-Location/2/9/developmental-disabilities-mental-health-services---burnaby#.YVOQKPnMI2w

https://www.interiorhealth.ca/FindUs/_layouts/FindUs/info.aspx?type=Service&loc=&svc=Developmental%20Disability%20Mental%20Health%20Services&ploc

https://www.islandhealth.ca/our-services/mental-health-substance-use-services/mental-health-substance-use-teams-your-community/developmental-disability-mental-health-team

BC Children's Hospital (BCCH) Neuropsychiatry Clinic

The Provincial Health Services Authority provides specialized psychiatry assessments to children and youth (ages 6-18) with neurodevelopmental conditions that are also challenged by a combination of emotional, social, and cognitive behavioural concerns, and who have not responded to community treatment resources. Services include consultation, assessment, diagnosis, psychoeducation, family support, and limited treatment. The Self-Injurious Behaviour (SIB) Clinic is connected to Neuropsychiatry. The SIB Clinic provides a multidisciplinary team assessment of children and youth with neurodevelopmental disorders who present with severe SIB. Referrals to the SIB Clinic are made internally through the Neuropsychiatry Clinic, as such follow the same referral process as listed below.

Eligibility: Children/youth ages 6-18 with mental health issues in the presence of a neurodevelopmental disorder, such as: autism spectrum disorder, fetal alcohol spectrum disorder, intellectual disability, seizure disorder, cerebral palsy, traumatic brain injury, and genetic disorders (i.e. Prader Willi and Fragile X).

Referral: Referrals from pediatricians and specialists, with referral form and attached relevant assessments faxed to BCCH outpatient psychiatry department at 604-875-2099.

Referral form: http://www.bcchildrens.ca/health-professionals/refer-a-patient/outpatient-psychiatry-referral

Website: http://www.bcchildrens.ca/mental-health-services-site/Documents/Neuropsychiatry-referral-criteria.pdf

Surrey Memorial Hospital Neuropsychiatry Clinic

Provides specialized assessments, consultation, and short-term treatment for neuropsychiatry and neurodevelopmental child and youth disorders. The clinic provides the opportunity to help stabilize children and youth on medications and make referrals to appropriate community agencies and services as needed.

Eligibility: Children/youth ages 5-18 with neuropsychiatry and neurodevelopmental disorders who live in the Fraser Health region.

Referral: Family doctor or specialist referral.

Website: https://www.fraserhealth.ca/Service-Directory/Services/child-and-youth-services/child-and-youth-neuropsychiatry-clinic#.YVSjMy8r0lI

Anscomb Outpatient Services

Anscomb provides specialized services for children and youth up to and including age 18, who are having significant challenges in their daily functioning due to severe, complex and persistent mood, anxiety and/or behavioural conditions related to major psychiatric disorders such as depression, bipolar, OCD, generalized anxiety, panic, PTSD, complex trauma or schizophrenia. These may or may not be associated with co-morbid neuro developmental conditions such as ADHD, ASD, FASD, learning disabilities, or other developmental or intellectual impairments. The Anscomb program is located at the Queen Alexandra Centre for Children's Health in Victoria.

Eligibility: Children and youth up to and including age 18, who are having significant challenges in their daily functioning due to severe, complex and persistent mood, anxiety and/or behavioural conditions related to major psychiatric disorders. The Anscomb program serves all Island Health area children, youth and families

Referral:
South Island (Sooke, Westshore & Greater Victoria): Referrals to the Anscomb program are only accepted from Mental Health Clinicians through the Ministry of Child & Family Development - Child & Youth Health Clinics.

Duncan, Central & North Island: Referrals are accepted from physicians and mental health clinicians. It is recommended that children/youth be connected with their local Mental Health services prior to a referral to Anscomb.

Website: https://www.islandhealth.ca/our-services/mental-health-substance-use-services/anscomb-outpatient-services

Foundry Centres

Foundry offers young people ages 12-24 health and wellness resources, services, and supports online and through integrated service centres in communities across BC.

Website: https://foundrybc.ca

Assessment of Neurodevelopmental Disorders

Regional Health Authorities in partnership with the Provincial Health Services Authority (PHSA) provide multidisciplinary assessments for children and youth with possible neurodevelopmental disorders.

BC Autism Assessment Network (BCAAN)

BCAAN sees children with a query of autism spectrum disorder. BCAAN and CDBC assessments may include testing IQ and assessing for Intellectual Disability. The other resource for IQ testing is through psychoeducational assessments at schools; however, these resources are limited and not all children and youth easily receive assessments. The other option for assessments is fee-for-services through private psychologists. Chromosomal syndromes are generally diagnosed through Medical Genetics, Metabolic Diseases, and Neurology departments.

Website: http://www.phsa.ca/our-services/programs-services/bc-autism-assessment-network

Complex Developmental Behavioural Conditions (CDBC)

CDBC diagnostic assessment services are intended for children and youth who have significant difficulties in multiple areas of function, including development and learning, mental health, and adaptive and social skills, and those with known or suspected history of exposures to substances with neurodevelopmental effects.

Website: http://www.bcchildrens.ca/our-services/sunny-hill-health-centre/our-services/complex-developmental-behavioural-conditions

Reference: Ono, E., Friedlander, R., & Salih, T. (2019). Falling through the cracks: How service gaps leave children with neurodevelopmental disorders and mental health difficulties without the care they need. British Columbia Medical Journal, 61(3).

RESOURCES FOR PARENTS

Kelty Mental Health Resource Centre

Kelty helps families across British Columbia navigate the mental health system, connect with peer support, and access resources and tools to support well-being.

Website: https://keltymentalhealth.ca

Family Support Institute (FSI)

The Family Support Institute of BC (FSI) is a provincial not for profit society committed to supporting families who have a family member with a disability. FSI's supports and services are FREE to any family. Their Family Support Program connects families to trained volunteers referred to as "resource parents/peers". FSI also offers various groups.

Website: https://familysupportbc.com/

Autism Community Training (ACT)

ACT provides information and training, in accordance with international best practices. Their goal is to enable parents, professionals and para-professionals to support children and adults with autism spectrum disorder to live productive, satisfying lives within their families and communities. Based in British Columbia, Canada, ACT develops a wide-range of positive and practical information on everything from sleep problems and diet, to core issues such as diagnosis and aspects of intervention, including information on setting up intervention programs. These resources are free and are available online without a password requirement. ACT provides training through live events focused on a number of areas, and by providing free online videos available at the convenience of the user.

Website: https://www.actcommunity.ca

Pacific Autism Family Network (PAFN)

PAFN is a centre housing various service organizations and a province-wide network of support for all affected by autism spectrum disorder and related disabilities.

Website: https://pacificautismfamily.com

Registry of Autism Service Providers (RASP)

The Registry of Autism Service Providers (RASP) is a list of professionals who have the experience and education to offer programs for children with autism. If your child is under six and you want to use autism funding to pay for services, CYSN/MCFD requires parents/caregivers to choose service providers from the RASP.

Website: https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs/autism-spectrum-disorder/build-your-support-team/registry-autism-service-providers

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