Emergency Management and Resources to Support Children and Youth with Developmental Disabilities in the ER

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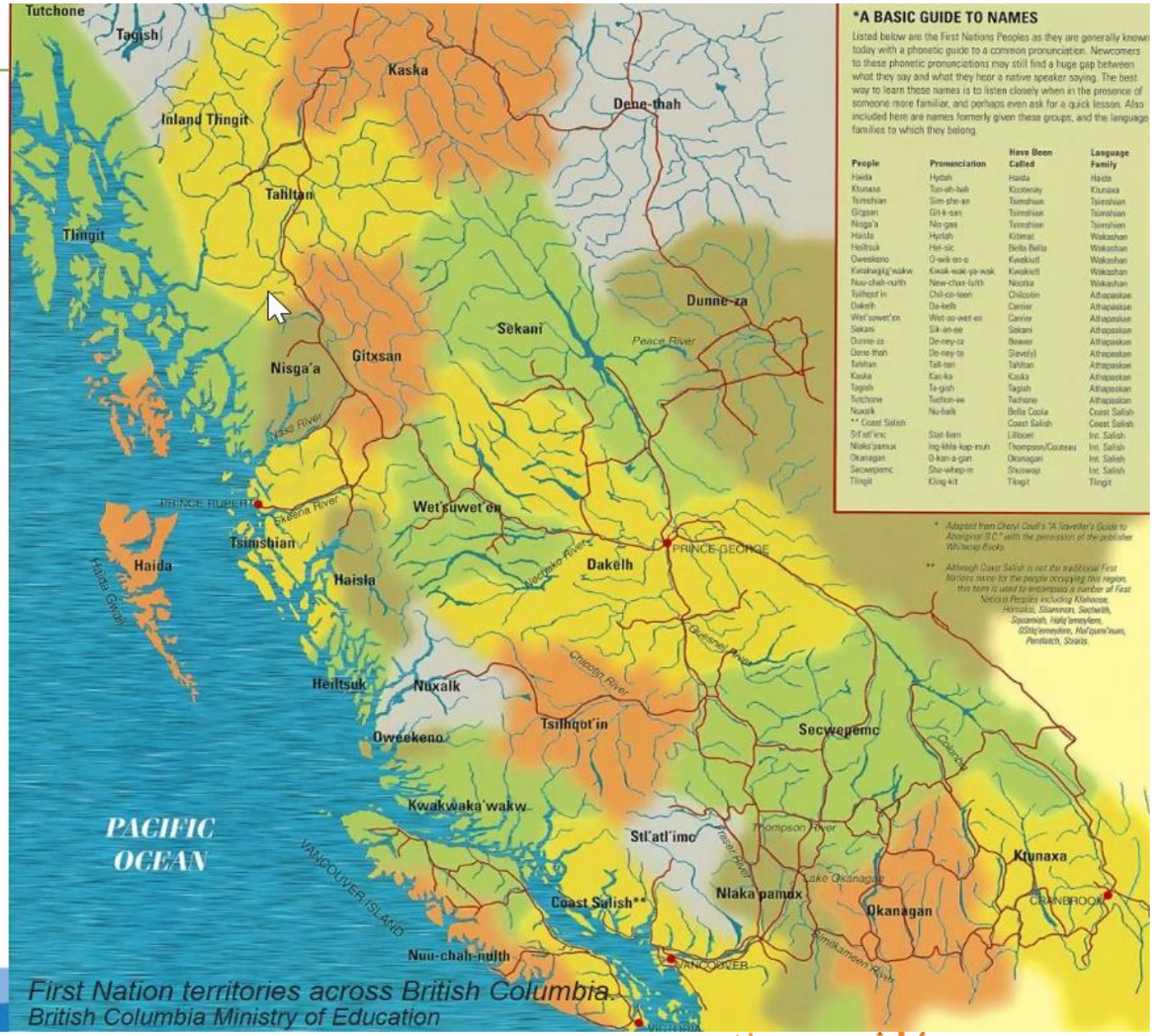
We acknowledge that today we are coming together from a number of locations from across BC. Collectively we acknowledge these homelands and recognize and respect the indigenous peoples presence, reminding us of the importance of establishing healthy and reciprocal relationships that are key to reconciliation.



First Nation territories across British Columbia.
British Columbia Ministry of Education

Housekeeping

- Attendees are automatically muted and cameras are turned off
- Please submit questions for the speakers through the “Q&A” function and vote for the questions you want answered
- Please submit technical questions through the “Chat” function
- The webinar will be recorded and made available at compassbc.ca
- Specialist learners may apply for MOC Section 2 self-learning credits and family physician learners can apply for Mainpro+ self-learning at their respective colleges.

Disclosures

- Dr. Russel has a private consulting business
- Dr. Susan Baer has no disclosures or conflicts of interest to declare
- Erika Ono has no disclosures or conflicts of interest to declare

Speaker Introduction

Susan Baer, MD, PhD

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Speaker Introduction

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Social Worker,
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Overview

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History of the Guidelines

- Initially developed in 2013 in response to high levels of hospital admissions for children with developmental disabilities and behavioral issues
- Recognizing that the assessment of children with developmental disabilities who present to the emergency room in behavioural crisis can be challenging for families, patients, and medical staff.
- Collaboration between Neuropsychiatry Task Force, BCCH Neuropsychiatry Clinic, BCCH Emergency Dept
- Guidelines revised and updated in 2022, with expanded section on resources

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Goals of the Guidelines

1) How to help the emergency assessment run smoothly
2) How to differentiate between chronic and acute behavioural symptoms
3) How to assess for common psychiatric disorders in children with developmental disabilities
4) Help with management of aggression/agitation in ED
5) Help with decision-making around disposition
6) Help with navigating resources

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Case

9 year old boy with Autism and moderate intellectual disability

Brought into hospital by parents after he punched his father and broke down a door in the home

He is pacing and agitated in the ED, not responding to questions by nursing staff

Mom looks overwhelmed and exhausted

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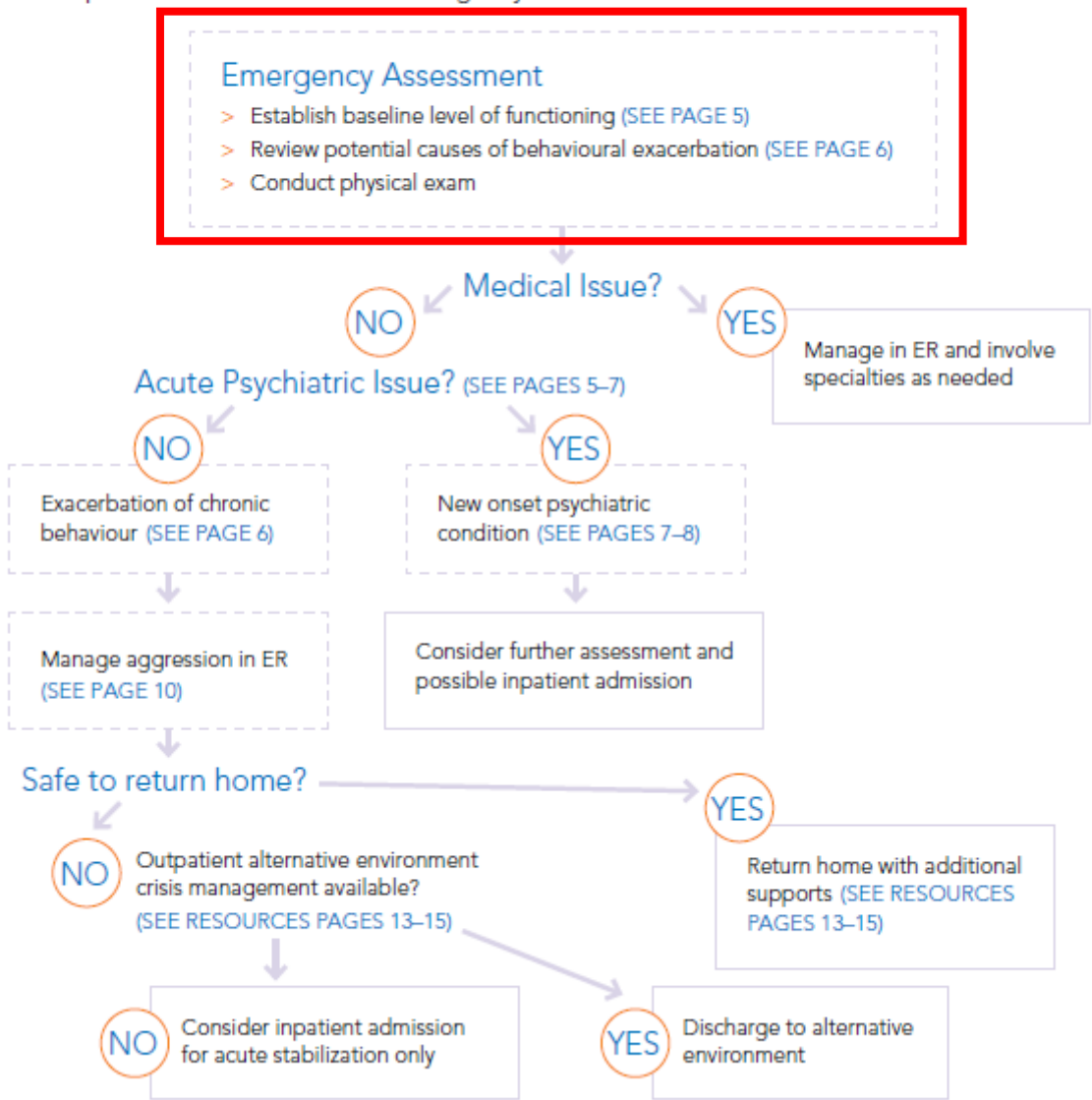
DECISION FLOW SHEET

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



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Conducting the Emergency Assessment

- **Minimize wait time** and find a quiet, private place for the patient and caregiver
- **Meet with the caregiver to inquire about:**
  - Patient's primary methods of communication
  - Sensory sensitivities
  - Suggestions from previous emergency visits which would help the patient feel more at ease
  - Existing crisis plans
  - Existing protocols for procedures, bloodwork, etc.
- **For the assessment:**
  - Find a quiet and private exam room.
  - Keep sensory stimulation (e.g. bright lights, interruptions, # of people) to a minimum.
  - Communication: speak slowly, using simple words. Watch non-verbal cues.
  - Ask permission to proceed before entering patient's personal space
  - Explain procedures to the patient through simple drawings and words.

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Establish Baseline Level Of Functioning

- Communication: usual level of expressive and receptive language
- Cognitive Capacity: psycho-ed test, school history
- Adaptive Functioning: support needed in toileting, dressing, eating, medication-taking. Can patient transport self independently? Can they be in the home without caregiver?
- Activities: How does the patient spend their day: home, school, day-program?
- Social Functioning: friendships, degree of social interest, social reciprocity, attachment to support workers.

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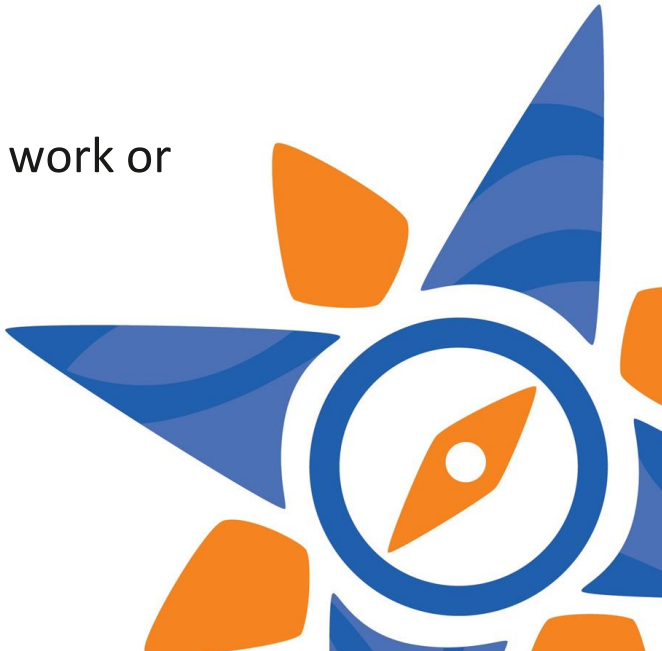
Review Potential Causes Of Behavioural Exacerbation

Physical Illness:
- e.g. constipation, UTI, ear infections, dental concerns, changes in hearing or vision

Drug Interactions or Medication Side Effects:
- e.g. benzodiazepines or anticonvulsants, EPS from antipsychotics, antihistaminic or anticholinergic allergy medications

Changes in external supports and/or expectations:
- changes in staff at group homes or individual support workers, changes in work or school routine, overly-high expectations of performance

Distressing Events:
- e.g. siblings going to university, staff leaving group homes, anniversary reactions to losses, changing living situation, abuse, stress in the family.



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Differentiate Chronic Vs Acute Behaviour/Psychiatric Symptoms

Chronic symptoms may result in an ER visit, but don't necessarily indicate acute psychiatric illness.

What is level of baseline behavioural/psychiatric symptoms?

- Self-injurious behaviours and Aggression
- Stereotypies
- Rituals/Obsessive-compulsive symptoms
- Inattention, hyperactivity and impulsivity
- Anxiety, fears, phobias

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Acute Psychiatric Illness In Individuals With Developmental Disabilities

- Psychosis:
  - Challenging! What appears like psychosis may be a reaction of a person with limited cognitive capacity to stress. Imaginary friends and talking to oneself may be developmentally appropriate.
  - Hallucinations, delusions, disorganized speech/behavior, decreased speaking, decreased pursuit of interests, loss of facial expressions.
- Mood Disturbance:
  - Fewer cognitive sx's
  - Depression: 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.
  - Mania: sleeplessness, talkativeness, excessive involvement in pleasurable activities (e.g. hyper-sexuality), distractibility, disinhibition and increased risk-taking behaviours.
- Anxiety Disorders:
  - Fewer cognitive symptoms
  - Insomnia, fearful affect, irritability, hyper-arousal, increased startle response, new onset compulsive rituals, panic attacks, and aggression

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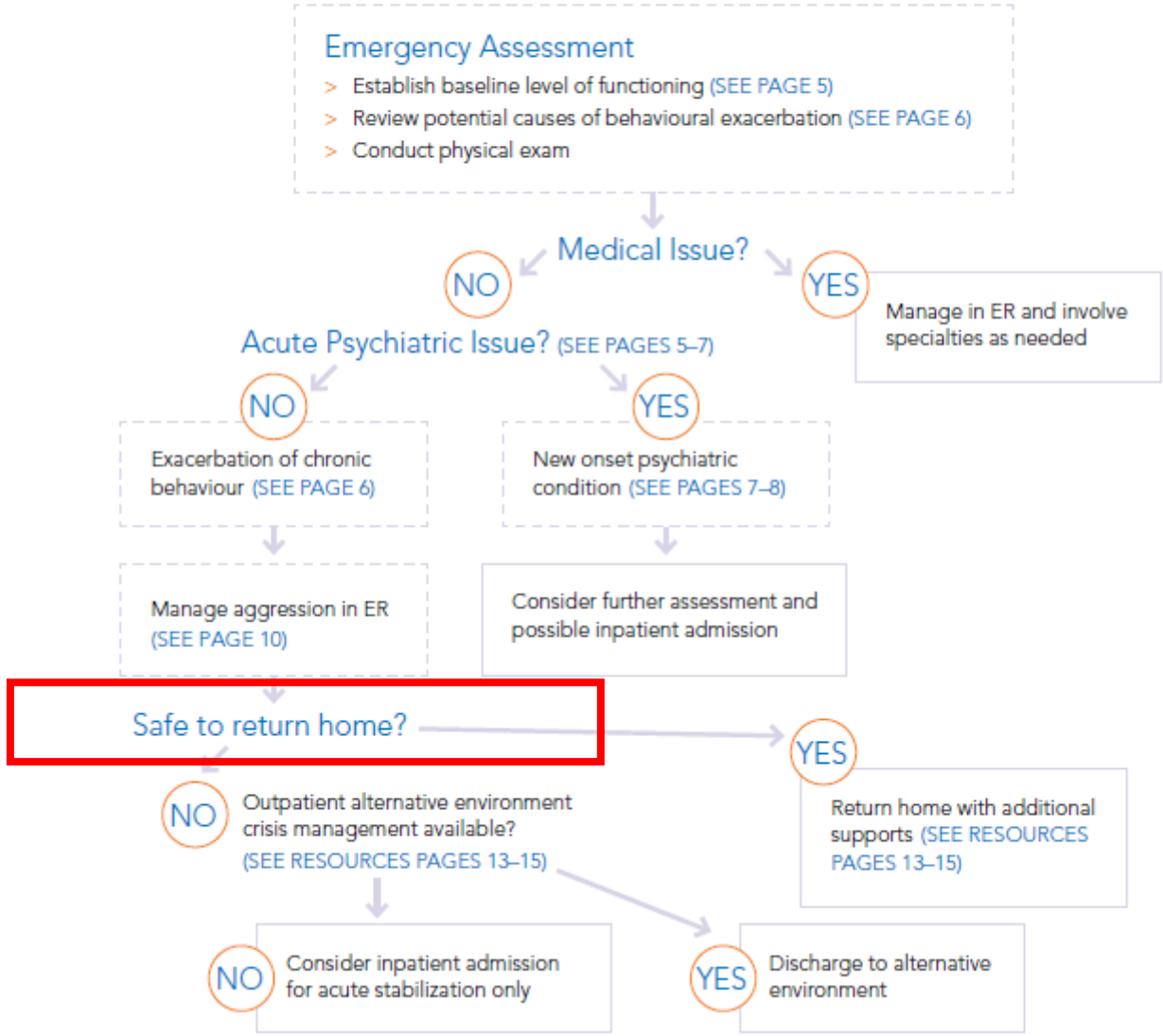

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Determining Disposition

- Inpatient Admission Required:
  - Patients with **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.
  - Not for management of chronic psychiatric problems such as aggression and self injurious behaviors, *unless there has been an acute exacerbation and caregivers are unable to cope.*
  - Chronic issues are best addressed through crisis management in the ER and follow up outpatient treatment with development of a crisis plan.

Determining Disposition, Cont.

- Outpatient Management:
  - Hospitalization not required but an alternative environment to manage the crisis is needed:
    - Chronic difficult behaviors may result in the need for caregiver respite, caregiver may be unable to support a client temporarily due to illness, etc.
  - Return to home environment with Outpatient Supports:
    - Additional resources for support are needed, but caregivers willing to return home with patient if additional supports can be arranged.

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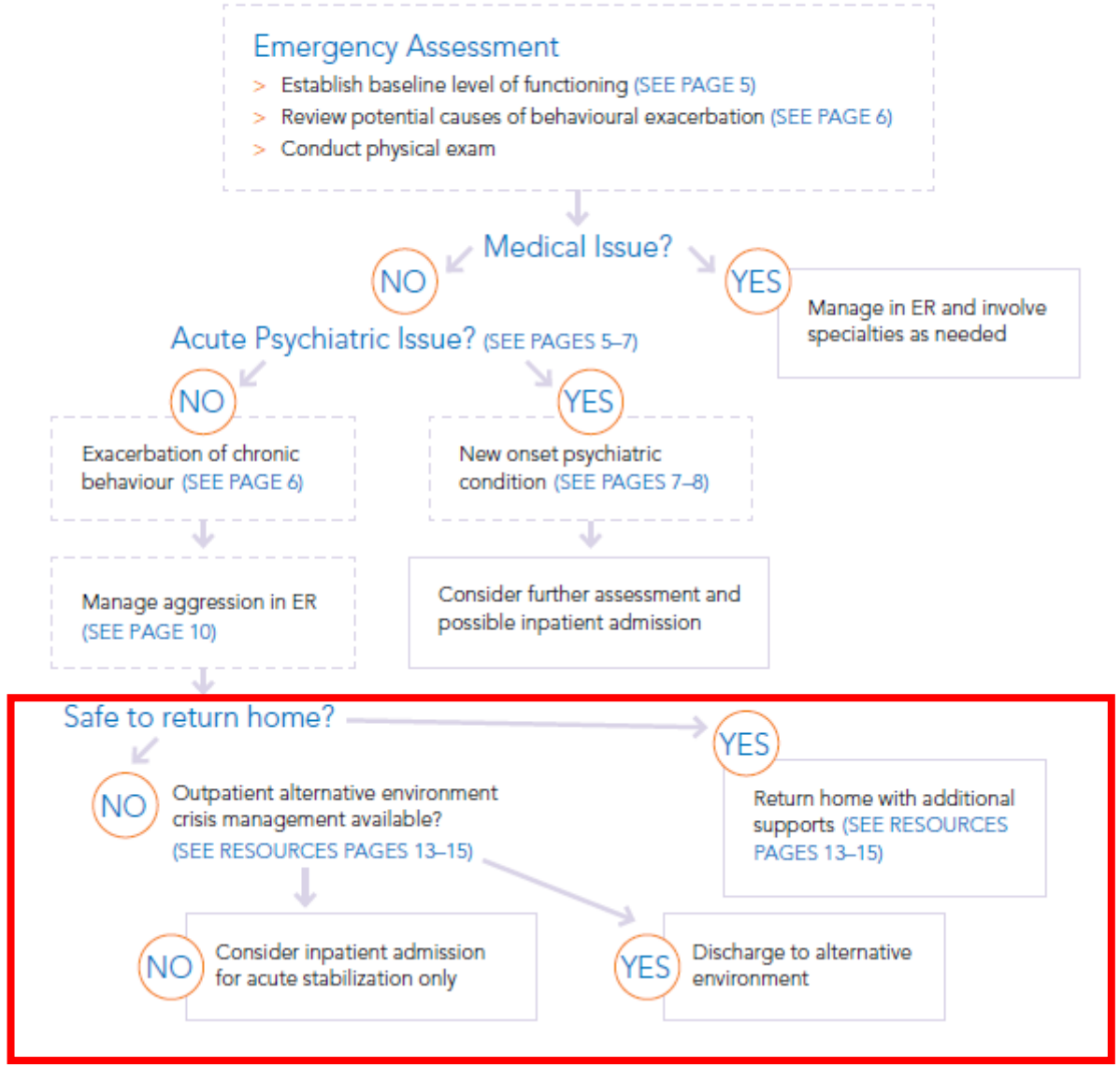

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Resources

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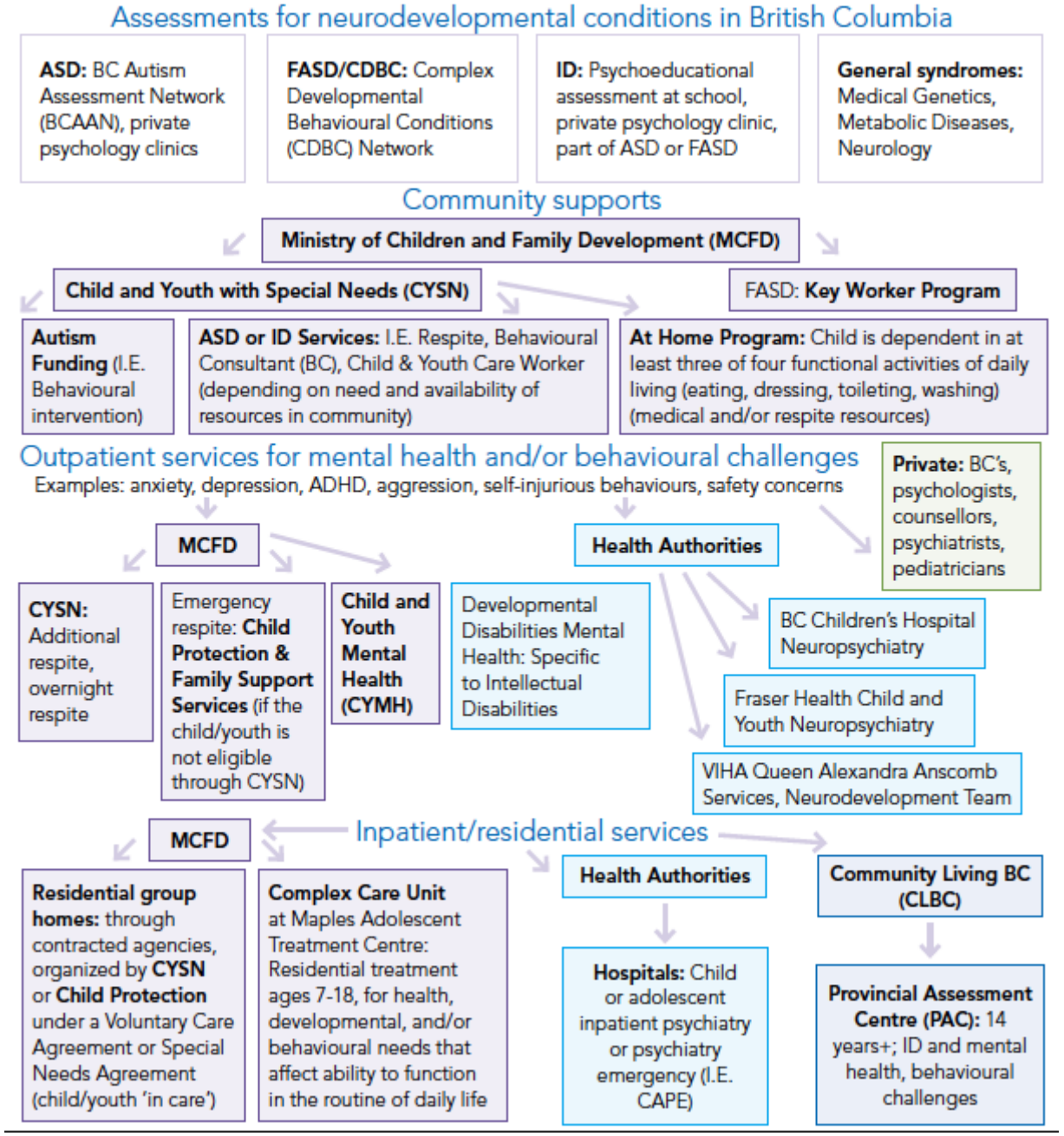

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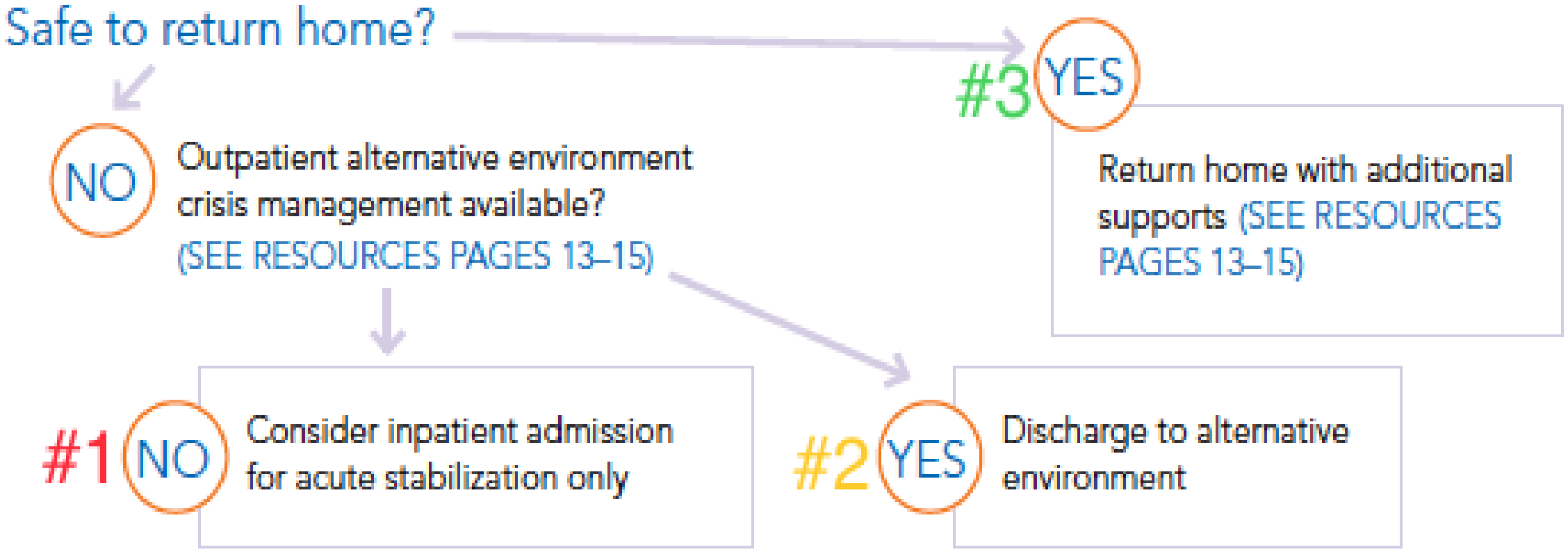
3 Scenarios for Discharge



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Supporting Parents/Caregivers

- When conducting the interview, meet with the parents/caregivers separately if possible.
- Empathic listening and validation.
- Ask them how they are doing. Do they have supports (formal and/or informal)?
- Are there other children in the home? How does this affect safety to return home?

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Caregiver Stress

"caregiver strain", "caregiver burden"

Vitale et al. (2022). Challenging behavior and parental depression: The effects of everyday stressors and benefit finding for parents of children with autism spectrum disorder. J*ournal of Autism and Developmental Disorders,* 1-13.

- Parenting stress mediated the relationship between challenging behaviours and decreased self-efficacy. Decreased self-efficacy partially mediated the relationship between parenting stress and increased depression/anxiety.
- The mental health and positive coping of parents of children with ASD is often not prioritized by providers as the focus of service provision is generally on the child.
- Parents have significant responsibility in facilitation and implementation of behavioral interventions, and their ability to perform such roles may be negatively impacted by accumulated daily stressors.

Yanagisawa et al. (2022). Needs assessment of caregivers of children with disabilities in resource-limited settings. *Journal of Rural Medicine, 17*(3), 143-150.

- 5 domains of caregivers' needs: health and medical, welfare, educational, social,and informational.
- Basic medical treatment was covered, specific support (i.e. referral to specialist or psychological support) was limited.
- Financial support and relief from the care burden were the main welfare needs.

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Safe to return home?

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No

Outpatient alternative environment crisis management available?

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Scenario #1

NO (no outpatient alternative environment crisis management available)

Inpatient admission for acute stabilization

- Dual Diagnosis: Provincial Assessment Centre (PAC) – *not direct from ER*
- Emergency Child/Adolescent Psychiatry – *direct from ER*
- Inpatient Child/Adolescent Psychiatry Units – *not direct from ER*

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Provincial Assessment Centre (PAC)

- Part of Community Living British Columbia (CLBC).
- Designated as a tertiary care mental health service under the Mental Health Act.
- 14+ with a developmental disability and “a concurrent mental illness or behaviour issue”.

Admission Criteria

- Voluntary or involuntary under MHA.
- All admissions are planned in advance.
- Dually diagnosed with a developmental disability, psychiatric and/or behaviour issue and be eligible for CLBC services.
- 14 years of age or older.
- Length of admission = 2 weeks to 3 months.

Who Can Refer?

- CYSN (14-18)
- CLBC (19+)

When to Refer?

- Broader-based intensive assessment is required to support the individual.

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Inpatient Psychiatry

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- Child & Adolescent Psychiatric Emergency (CAPE): 4 beds, ages 6-16.
- Child Inpatient Program (P1): 10 beds, ages 6-11.
- Adolescent Inpatient Program (P2): 10 beds, ages 12-17.

Island Health

- Ledger Program, Queen Alexandra Centre
- *Urgent Admissions,* Special Care Unit (SCU): 3 beds, ages 6-16
- *Planned Admissions,* Children's unit: ages 6-11; Youth unit: ages 12-16

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Inpatient Psychiatry (cont.)

Fraser Health, Surrey Memorial Hospital

- Child and Adolescent Psychiatric Stabilization Unit (CAPSU): 2-7 days, ages 6-17. Referrals from ER.
- Adolescent Psychiatry Unit (APU): 10 beds, approx. 4 weeks, ages 12-17. Referrals from CAPSU, CYMH, EPI.

Interior Health, Kelowna General Hospital

- Adolescent Psychiatry Unit (APU): 8 beds, ages 12-17.
  - "Not suitable for adolescents whose primary problems are severe behaviour disorders, substance abuse, significant developmental delay or eating disorders"

Northern Health, University Hospital of Northern British Columbia (PG)

- Adolescent Psychiatric Assessment Unit (APAU): 6 beds, crisis stabilization 72 hours or assessment 4-6 weeks, ages 12-17.

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Maples Adolescent Treatment Centre

- **Programs**
  - ***Bifrost*:** Home-based, intensive intervention for youth and their families.
  - ***Complex Care*:** For children/youth (aged 7 to 18) who have health, developmental and/or behavioural needs that affect their ability to function in the routine of daily life.
  - ***Connect Parent Group*:** 10-week program where parents and caregivers meet together in small groups with two trained leaders for one hour each week. Group sessions focus on maintaining and strengthening the parent's relationship with their teen.
  - ***Crossroads Care*:** Inpatient program for court-mandated youth, or youth with a severe conduct disorder or other mental health disorders that require care in a secure setting.
  - ***Dala*:** 3-month inpatient program for assessment and treatment of mental health disorders, i.e., depression, anxiety, schizophrenia.
  - ***Response*:** School program for children/youth in Maples' programs.

- **Referrals:** CYMH

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Scenario #2

YES (outpatient alternative environment crisis management available)

Discharge to Alternative Environment

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Ministry of Children and Family Development (MCFD): Service Lines / Service Delivery Structure

- Early Years Services (EY) (Early Childhood Development/Child Care) (ECD/CC)
- Children and Youth with Support Needs (CYSN)
  - CYSN Family Support Services
  - Autism Funding (AFU)
  - At Home Program
  - FASD Key Worker and Parent Support Services
  - Deaf, Hard of Hearing, Deafblind, Blind, and Partially-Sighted Services
- Child and Youth Mental Health (CYMH)
  - Maples Adolescent Treatment Centre
- Child Safety, Family, Youth and Children in Care Services (CS/CYIC)
  - Child Safety Service Teams
    - Child Protection
    - Family Support
  - Children in Care Guardianship Service Teams
  - Youth Service Teams
- Adoption Services (AS)
- Youth Justice Services (YJ)
  - Youth Justice Probationary Service Teams

With the exception of EY, some CYSN, and YJ that are administered centrally, services are delivered across the province in 13 Service Delivery Areas (SDA). Each SDA is divided into Local Services Areas (LSA).

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Children and Youth With Support Needs (CYSN)

(New service framework 2025)

Family Support Services

- Respite: direct funded, indirect funded (in-home, out-of-home, overnight respite).
- Behaviour consultant, child and youth worker, etc.
- Self-referral.
- Eligibility: Provide assessment with diagnoses of ASD or ID.

Autism Program

- Funding for Autism intervention services
- $22,000 per year for under age 6.
- $6000 per year for ages 6-18.
- Self-referral.
- Eligibility: Provide assessment with diagnosis of ASD.

At Home Program

- Medical and/or respite benefits to assist parents with costs of caring for a child with severe disabilities at home.
- School-Aged Extended Therapies (SAET) benefit when enrolled in AHP medical benefits, includes OT, PT, SLP, chiropractic and massage services.
- Physician referral.
- Eligibility: Dependent in at least three of four functional activities of daily living (eating, dressing, toileting, washing), or has a palliative condition. Assessed by MCFD, OT/nurse.

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Scenario #2

YES (outpatient alternative environment crisis management available)

Discharge to Alternative Environment

- MCFD emergency placement
  - Child protection worker arranges for child/youth to temporarily live with approved family member, foster parent, or contracted agency care provider.
    - Interim custody order, VCA

- CYSN respite
  - If already in place
  - Out-of-home respite
  - Indirect respite
  - MCFD respite cannot exceed 14 days/month, otherwise care agreement (SNA, VCA)

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Planned Alternative Environment Options

Special Needs Agreement (SNA) - CYSN

- When "in-home supports are not available or appropriate, and the parents are not able to meet their child's or youth's special needs".

Voluntary Care Agreement (VCA) – MCFD/Child Protection

- An assessment of the parents' current circumstances determines that they are temporarily unable to care for the child or youth.
- No less disruptive means and services are available and appropriate to assist the parents to care for the child or youth.
- SNA/VCA - maintenance agreement - parental financial contribution.

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Safe to return home?

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Scenario #3

YES (safe to return home)

Return Home with Additional Supports

- CYSN / AHP
- Key worker
- Public mental health services
- Private mental health services
  - Specialized service providers
  - Employment benefits plan?
- Schools
- Parent/caregiver support, system navigation, advocacy

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Key Worker and Parent Support Services

- 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.

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Assessment

- ASD, ID, FASD
  - BC Autism Assessment Network (BCAAN)
  - Complex Developmental Behavioural Conditions (CDBC)

- Mental Health:
  - BC Children's Hospital, Neuropsychiatry Clinic
  - BC Children's Hospital Self Injurious Behaviour Clinic
  - Surrey Memorial Hospital, Neuropsychiatry Clinic (Fraser Health)
  - Queen Alexandra Centre, Anscomb OutpatientServices (Island Health)

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Community Mental Health Services

- Dual diagnosis: Developmental Disabilities Mental Health
- Crisis response teams (CART, etc.)
- Child and Youth Mental Health / Indigenous CYMH

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Developmental Disabilities Mental Health

- Differs across health authorities (DDMHS/DDMHT)
- Provides specialized mental health services for youth who live with co-existing developmental disabilities and mental health/behavioural challenges.
- Psychiatric and behaviour assessments, diagnosis, psychiatric treatment, clinical counselling, therapies, one-to-one support at home, case management, groups.

- **Eligibility:**
  - Ages 12+ (or 14 @ Interior Health).
  - 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 18.
  - Must meet CYSN criteria for services.

- **Referrals:** CYSN (CLBC for adults)

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Crisis Response Teams

VANCOUVER COASTAL HEALTH:

- Vancouver: CART Team (Child and Adolescent Response Team), ages 5-18
- Richmond: TRACC (Team Response to Adolescents and Children in Crisis), ages 6-18
- North Vancouver: Intensive Youth Outreach Service. ages 13-19

ISLAND HEALTH:

- South Island: Integrated Mobile Crisis Response Team, all ages
- Central Island: Central Island Crisis Response Team, all ages

FRASER HEALTH:

- START Team (Short Term, Assessment, Response, Treatment), ages 6-18.

INTERIOR HEALTH:

- Kelowna: Community Response Team, all ages

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Child and Youth Mental Health (CYMH)

- Ages 0/6 (depending on community) to 18.
- Does not accept all children/youth with developmental disabilities.
- Walk-in intake (days/times differ across offices).
  - Self-referral
  - Service providers can still refer
- Families can call first and schedule intake (sometimes).

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Foundry Centres

- Integrated health and social service centres for young people ages 12-24, including mental health care, substance use services, primary care, social services, and peer supports.

- Locations:
  - Abbotsford
  - Campbell River
  - Comox Valley
  - Kelowna
  - North Shore
  - Penticton
  - Prince George
  - Richmond
  - Ridge Meadows
  - Terrace
  - Vancouver
  - Victoria

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Schools

- Ministry of Education Special Needs Categories
- District inclusive education staff
- Education Assistants (EA)
  - Respite resource
- Individualized Education Plan (IEP)
- OT, SLP, PT, psychologist, counsellor, case manager
  - Varies across school boards and individual schools

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Parent/Caregiver Support

- Family Support Institute
- Family Smart
- Inclusion BC
- Autism Community Training (ACT)
- Developmental Disabilities Association
- Parent Support Services BC
- Pacific Autism Family Network (PAFN)
- Registry of Autism Service Providers (RASP)
- Kelty Mental Health Resource Centre

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Family Support Institute

Eligibility:
For anyone with a family member with a disability.

When to refer a family to FSI:

- Wants to connect with other families, needs support and encouragement from other parents
- Struggling and feeling overwhelmed
- Needs advocacy support and guidance, looking for support moving through systems

What can FSI volunteer Resource Parents do?

- Connect by phone, email or in person
- Guide families to community resources, attend meetings (take notes/debrief)

FSI mentors families to advocate for themselves:

- Help families build relationships with government/organizations/allies/services providers
- Work with families and community partners to problem solve together
- Help families to understand and move through systems (navigation)
- Help families to understand their rights and the rights of their family members
- Help families understand policy/resources to inform their own advocacy

Groups
(Next slide)

Phone: (604) 540-8374 ext. 523
Toll Free: 1-800-441-5403

24	25	26	27	28	29	30
7:00 pm - 8:30 pm Dads Supporting Dads	 4:00 pm - 5:30 pm Currents | Connecting families from Tofino to Sechelt and Port Hardy to Port Alberni  10:00 am - 11:30 am Self Injurious Behaviour 7:00 pm - 8:30 pm Journey Through Grief	12:00 pm - 1:00 pm Musical Explorations with Accredited Music Therapist, Emily Brown 1:00 pm - 2:00 pm Coaches Corner 6:30 pm - 8:30 pm Family Hang Out	 1:00 pm - 2:30 pm Currents | Connecting families from Tofino to Sechelt and Port Hardy to Port Alberni 11:00 am - 12:00 pm Music Group 1:00 pm - 2:00 pm Travel Around the World Through Music! 4:00 pm - 5:45 pm Understand our Cities 6:30 pm - 8:00 pm Complex and Challenging Behaviours	10:00 am - 11:00 am Zooming Around the World 11:00 am - 12:00 pm Peace Circle 1:00 pm - 2:00 pm Dance with Amanda! 6:30 pm - 8:30 pm Children in Care – Conversation for Families 7:00 pm - 8:30 pm FASD – Thinking Outside of the Box	 3:00 pm - 4:00 pm All About Anime 2:00 pm - 3:00 pm Coffeehouse 3:00 pm - 3:45 pm Music Bingo Karaoke 3:30 pm - 4:30 pm Newsroom with Henry	
31	**1**	**2**	**3**	**4**	**5**	**6**
7:00 pm - 8:30 pm Dads Supporting Dads		6:30 pm - 7:30 pm Single Parent Hangout 6:30 pm - 8:30 pm Family Hang Out	 6:30 pm - 8:00 pm Gender Marvelous: Parenting LGBTQ+ Children and Youth 6:30 pm - 8:00 pm	7:00 pm - 8:30 pm FASD – Thinking Outside of the Box 7:00 pm - 9:00 pm Housing Options		

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Connect 4 Care (C4C)

BC Children's Hospital & Sunny Hill Health Centre

- **Eligibility:** Children/youth with complex medical/behavioural/developmental and care coordination/support needs. Accessing 2+ services through BCCH psychiatry, medical, Sunny Hill.

- **Referrals:** BCCH/Sunny Hill Service Provider.

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Compass is a province-wide service that supports evidence based care to all BC children and youth (0-25) living with mental health and substance use concerns. This is done by supporting community care providers with the information, advice and resources they need to deliver appropriate and timely care to children and youth close to home.

Services include:

- Telephone advice and support
- Identification and help with connection to local and online resources
- Telehealth consultation when needed
- Tailored education, including **Compass Toolkits**

Thank you!

- Guidelines available on the Compass website: https://compassbc.ca/resources

- The slides and recordings will be posted on **compassbc.ca.**

- Please complete the evaluation survey that will be sent out about this series!