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Falling through the cracks: How service gaps leave children with neurodevelopmental disorders and mental health difficulties without the care they need

Four clinical vignettes illustrate the challenges faced by families of children with a dual diagnosis in British Columbia and demonstrate the need for a wraparound approach to service delivery.

ABSTRACT: Children with neurodevelopmental disorders are at increased risk of developing mental health difficulties, and when neurodevelopmental and psychiatric disorders do co-occur, children and their families frequently face multiple barriers as they try to access services and resources. A literature review indicates that there is a lack of specialized mental health services for patients with a dual diagnosis, and the resulting inadequate level of community supports has placed the burden of care on families. Services for children in BC with a dual diagnosis are delivered by different agencies and programs, primarily under the Ministry of Children and Family Development and the province's health authorities. Depending on the specifics of the diagnoses, children may be eligible for community support services, outpatient mental health services, and inpatient psychiatry services. However, because of system fragmentation and insufficient collaboration and communication, obtaining these services can be challenging and many children are falling through the cracks. Four clinical vignettes illustrate how children and their families trying to access support face barriers, including bureaucratic processes, lack of respite, out-of-home service obstacles, and limited specialized training for care providers. Policy changes are needed to ensure a wraparound approach to care based on integrative interagency and cross-agency practices.

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The *Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition)* defines neurodevelopmental disorders as "a group of conditions with onset in the developmental period. The disorders typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational function-

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ing. There is a wide range of developmental deficits that vary from very specific limitations of learning or control of executive functions to global impairments of social skills or intelligence."[1] Major neurodevelopmental disorders include intellectual disability (ID), autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD), and genetic conditions such as Prader-Willi, fragile X, and Down syndrome. Children with neurodevelopmental disorders are at increased risk of developing mental health difficulties, with 39% of children with a neurodevelopmental disorder requiring mental health services compared with 14% of children in the general population.[2]

Children with a dual diagnosis and their families frequently face multiple barriers when trying to access support services. Service delivery in BC is fragmented, with the health authorities and different agencies, programs, and contractors providing various kinds of care and funding, primarily through the Ministry of Children and Family Development (MCFD). Service gaps have resulted from this model, similar to those seen across Canada (oral communication from V. Dua, psychiatrist-in-chief, Surrey Place [Toronto, Ontario], 7 July 2017).

Literature review

In BC before the 1990s, children with neurodevelopmental disorders received services through three institutions: Woodlands, Tranquille, and Glendale. In 1981 the BC government announced plans to close all three institutions. This plan was implemented over the next 15 years, with Woodlands[3] officially closing in 1996.

Following deinstitutionalization, services became de-medicalized and more importance was placed on integrating individuals with intellectual disabilities in the community. In this process specialized psychiatric care diminished.[4] Individuals with a co-occurring neurodevelopmental disorder and mental health difficulties could only access generic mental health services in a system not set up for easy access to these services. The "generic [mental] health care model, combined with no national guidelines and provincially determined services shared by two distinct ministries has translated into poorly coordinated care for individuals with intellectual disabilities and mental health needs in Canada."[5] These systemic issues have "led to misdiagnoses, inappropriate treatments and over-reliance on psycho-pharmacological interventions."[6] As Ouelette-Kuntz states, "Individuals with mental health problems and ID experience 'double stigma'. . . . Persons with ID and mental health issues are often considered inappropriate for traditional ID community integrated services because of their psychiatric difficulties but are also considered inappropriate for usual mental health services because of their low IQ. Adding to this stigma is the lack of knowledge of mental health professionals with regard to this population because of deficiencies in training and the existing barriers to practice in this area."[6]

The attempt to integrate individuals with neurodevelopmental disorders into their communities has led to them being "segregated once again by a failure to address their specialized medical needs."[6] Social marginalization cannot be addressed solely by a shift to community care. The "work of deinstitutionalization does not stop at transferring participants into the community. . . unless relocation brings with it a fundamental change in the [quality of life] of participants, it creates only an illusion of deinstitutionalization."[7]

In addition to making access to specialized mental health services difficult, the inadequate level of community supports in general has placed the burden of care on families. "Caring for a child with a disability can be a demanding experience, taxing both the physical and emotional capacities of the caregiver, as well as the material resources of the family."[8] Challenges include increased caregiver physical and psychological stress, family distress, reduced marital satisfaction, and inadequate social supports for parents of these children.[9] Research indicates the need for adequate respite ("short-break residential services"); availability of additional respite services in emergencies; accessible out-of-home placements; flexibility in eligibility and service delivery; shorter waiting lists; psychoeducational support groups for parents; peer mentoring; on-site health clinics for caregiver accessibility, cultural sensitivity; and streamlining, coordination, and centralization of services.[10-12] Furthermore, as Goddard and colleagues note in their study of stories collected from parents, "Perhaps the most persistently troubling system for these parents was that of the bureaucracy. . . . Parents expressed their frustrations about how they have received the bureaucratic 'runaround,' especially from the social welfare system. . . . They described a system that compartmentalized, that regularized, and that fostered fear, confusion, and frustration."[13]

Current services

Services for children in BC with a dual diagnosis are delivered by different agencies and programs. Children may be eligible for a variety of community support services, outpatient mental health services, and inpatient psychiatry services, depending on the specifics of their diagnoses.

Assessment services for neurodevelopmental disorders

Regional health authorities in partnership with Provincial Health Services provide multidisciplinary assessments for autism spectrum disorder and fetal alcohol spectrum disorder through the BC Autism Assessment Network (BCAAN) and the Complex Developmental Behavioural Conditions (CDBC) program (Figure 1). In addition, a small number of children are assessed at BC Children's Hospital through the outpatient medical psychology department. Some psychological assessments are also conducted in child and adolescent inpatient psychiatry units across the province, and a smaller number in the BC Children's Hospital outpatient psychiatry clinics. Assessment for intellectual disability is done mainly through psychoeducational assessments at schools; however, these resources are limited and many children with intellectual disability are not assessed during childhood. The other option for assessment is private fee-for-service psychology clinics. Assessments for genetic conditions are undertaken by hospital-based services, including pediatrics, medical genetics, metabolic diseases, and neurology.

Community support services

The Ministry of Children and Family Development provides community support services for a range of neurodevelopmental and psychiatric disorders (Figure 2).

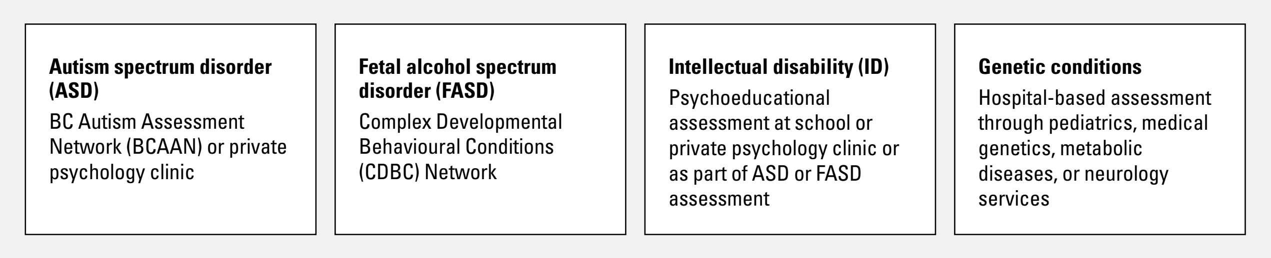


Figure 1. Assessment services for neurodevelopmental disorders.

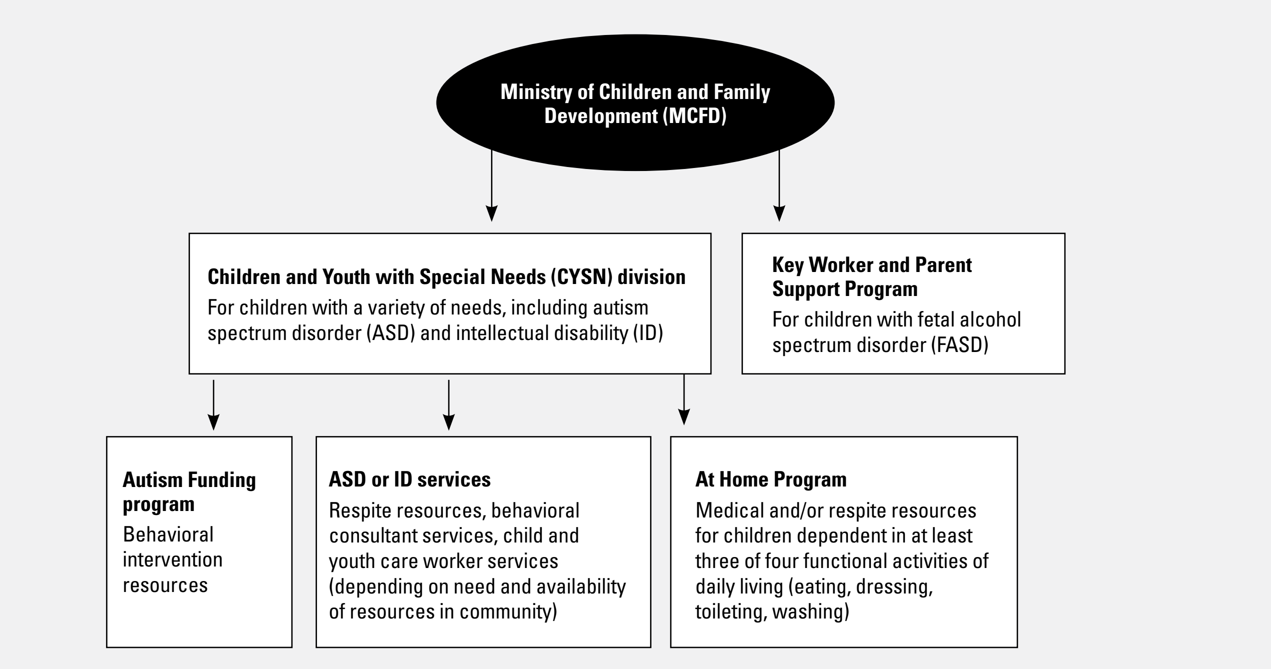


Figure 2. Community support services.

Children and Youth with Special Needs (CYSN). Most of the services for children with autism spectrum disorder and intellectual disability are delivered through the Children and Youth with Special Needs division of MCFD.[14] Services are often delivered by contracted agencies or individual care providers. Families receive support services for children with autism spectrum disorder and/or intellectual disabilities, which can include direct-funded respite, contracted respite, respite relief, homemaker/home support, behavioral support, child and youth care worker support, and parent support. The availability of services is dependent on which programs are running through contracted agencies, which varies from one location to another. Children with ASD receive additional services under the Autism Funding program, which provides support for intervention services: $22 000 annually for children under age 6 (early intervention) and $6000 annually for children age 6 to 18.

At Home Program. The At Home Program provides medical and/or respite benefits to assist parents with the costs of caring for a child with severe disabilities at home. To be eligible for the program, children must be dependent in at least three of four functional activities of daily living (eating, dressing, toileting, washing), have a palliative condition, or meet the requirements for direct nursing care provided by provincial Nursing Support Services.

Key Worker and Parent Support Program. Key workers help families understand fetal alcohol spectrum disorder by providing education and information specific to the needs of the child and family. They also help families access support, health, and education services for the child. Local parent support agencies provide parent and grandparent FASD training and parent mentoring sessions, and sponsor parent support groups.

Outpatient mental health services

Outpatient services are provided primarily by divisions of the Ministry of Children and Family Development and the province's health authorities (**Figure 3**). In addition, some services are provided by private practitioners such as psychologists and counselors.

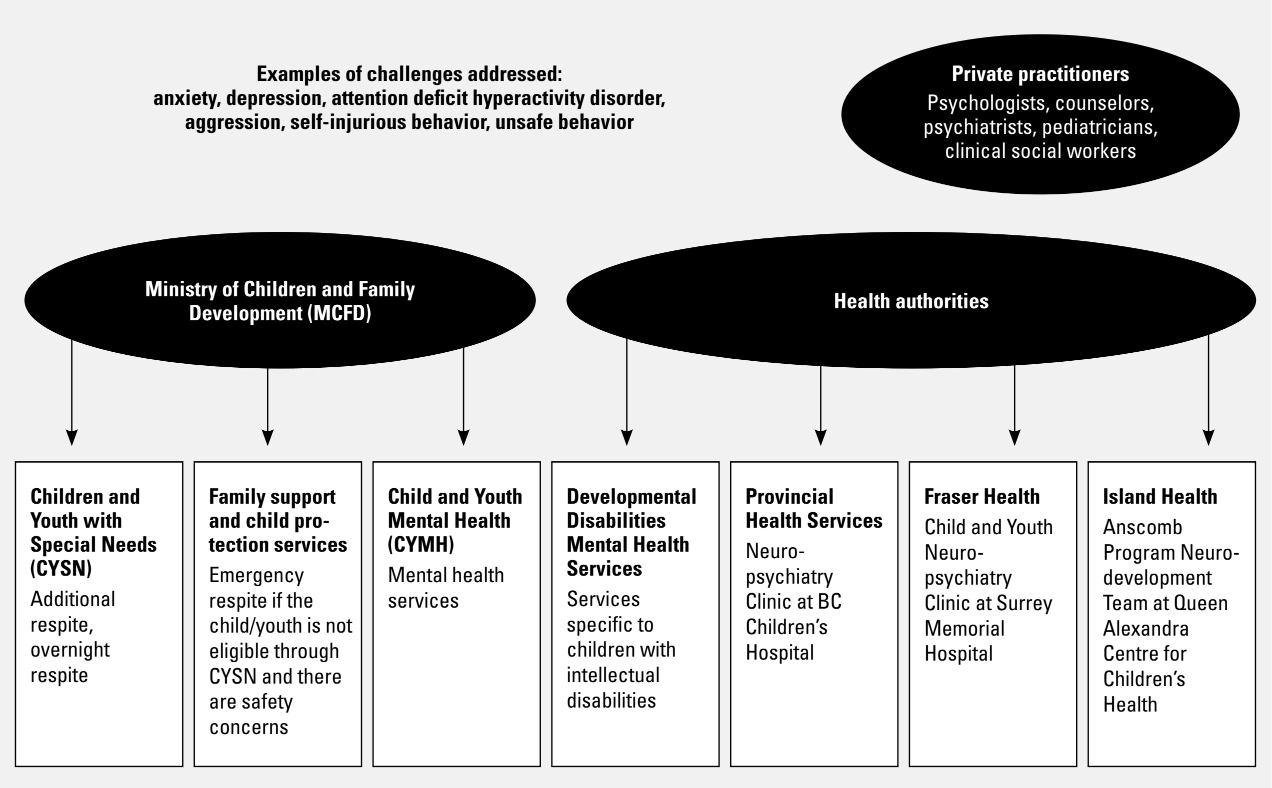


Figure 3. Outpatient services for patients with mental health and/or behavioral challenges.

Child and Youth Mental Health (CYMH). Child and Youth Mental Health delivers psychiatric services to children up to age 18. However, this service does not provide specialized care for children with a dual diagnosis. If children with neurodevelopmental disorders are assessed as "too severe" or "low functioning," they are often denied mental health services, regardless of mental health concerns or diagnosed psychiatric comorbidities. Since 2014 the referral process for Child and Youth Mental Health has changed to primarily self-referrals. Unfortunately, this has created obstacles for many families who are in crisis and find applying for services to be challenging. Moreover, most Child and Youth Mental Health offices offer drop-in intake sessions for only a few hours 1 day a week. This can create additional barriers for parents of children with neurodevelopmental disorders, families with English as a second language, working parents, single parents, and families without transportation.

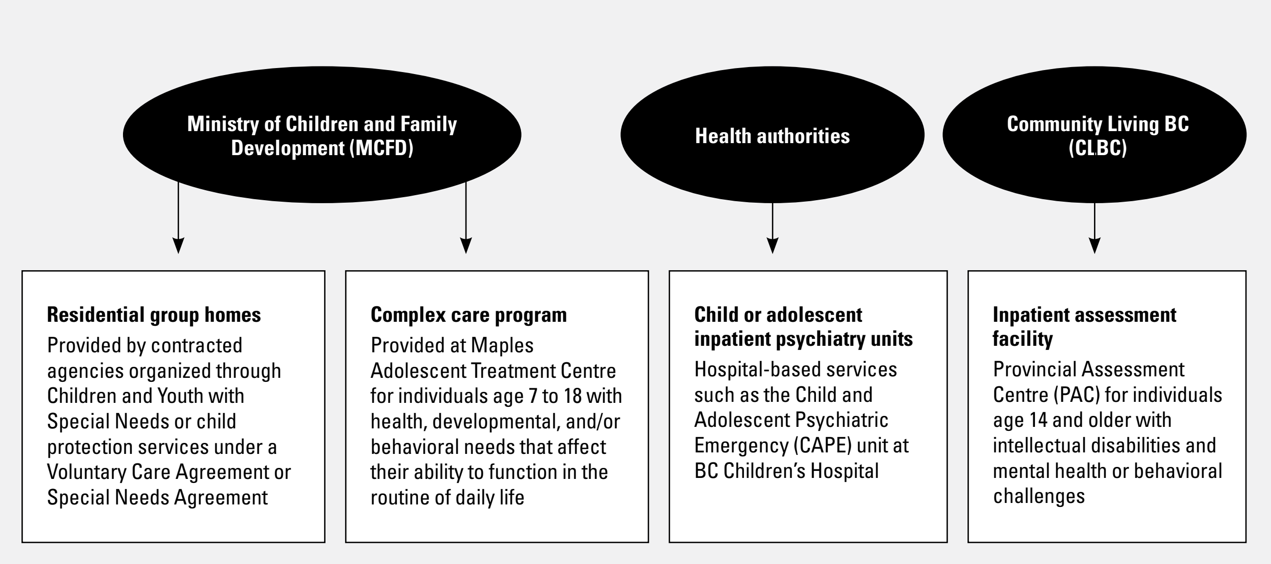
Developmental Disabilities Mental Health Services. Developmental Disabilities Mental Health Services is operated by regional health authorities to provide specialized mental health care for youth with co-occurring intellectual disability and mental health or behavioral challenges. This unique program offers psychiatric assessments and treatment, clinical counseling, music and art therapy, and case management. Eligibility requirements include a diagnosis of intellectual disability accompanied by severe mental health difficulties. Services are available to individuals starting at age 12 in the Lower Mainland and Vancouver Island and age 14 in the rest of the province.

Health authority neuropsychiatry services. Outpatient child and youth neuropsychiatry services are provided at clinics in three tertiary care centres: BC Children's Hospital (Provincial Health Services Authority), Surrey Memorial Hospital (Fraser Health), and the Queen Alexandra Centre for Children's Health (Island Health). The neuropsychiatry and neurodevelopment teams working at these centres provide assessments and limited treatment.

Inpatient psychiatry and residential services

Inpatient psychiatry and residential services are provided by the Ministry of Child and Family Development, health authorities, and Community Living BC (CLBC) (Figure 4). Two child inpatient/day programs and several adolescent inpatient psychiatry units operate across the province. However, there are no specialized inpatient psychiatry units for children and youth with a dual diagnosis.

Residential group homes. When families are struggling to care for their children, placement in a group home may be required. To obtain residential care, parents must apply to the Ministry of Children and Family Development. They must then sign a Special Needs Agreement or a Volun-



Residential group homes
Provided by contracted agencies organized through Children and Youth with Special Needs or child protection services under a Voluntary Care Agreement or Special Needs Agreement

Complex care program
Provided at Maples Adolescent Treatment Centre for individuals age 7 to 18 with health, developmental, and/or behavioral needs that affect their ability to function in the routine of daily life

Child or adolescent inpatient psychiatry units
Hospital-based services such as the Child and Adolescent Psychiatric Emergency (CAPE) unit at BC Children's Hospital

Inpatient assessment facility
Provincial Assessment Centre (PAC) for individuals age 14 and older with intellectual disabilities and mental health or behavioral challenges

Figure 4. Inpatient psychiatry and residential services.

tary Care Agreement, which places the child in the care of the ministry. Families have no options for long-term out-of-home care that does not require going through Children and Youth with Special Needs or child protection services and giving up care of their child. Group homes typically do not have mental health staff.

Complex care program. The Maples Adolescent Treatment Centre offers residential care for children with mental health concerns and troubling behavior. A complex care program for children age 7 to 18 includes individual treatment and service plans.

Provincial Assessment Centre (PAC). The Provincial Assessment Centre is a designated tertiary psychiatric service under the Mental Health Act, mandated to provide multidisciplinary assessment and treatment for individuals age 14 and older with an intellectual disability and concurrent mental health and/or behavioral challenges. PAC is part of Community Living BC, the provincial Crown corporation that funds and supports services to adults with developmental disabilities, autism spectrum disorder, and fetal alcohol spectrum disorder.

Clinical vignettes

The following clinical vignettes are fictionalized amalgamations of patient symptoms and systemic barriers commonly seen at tertiary outpatient neuropsychiatry clinics in British Columbia. The vignettes do not represent actual patients. They have been included to illustrate the recurring issues and gaps in services that children with a dual diagnosis and their families experience.

Alex

Alex is a 13-year-old male with fetal alcohol spectrum disorder, attention deficit hyperactivity disorder, post-traumatic stress disorder, and a specific learning disorder in reading and written expression. Alex lives with his adoptive mother, who is a single parent and has her own mental health struggles. She currently receives income assistance as a person with disabilities. Over time, the behavioral difficulties stemming from Alex's multiple diagnoses (temper outbursts, aggression toward his mother and peers, stealing) have led to caregiver burnout.

There are two distinct patient populations: in one the children have few comorbidities and need limited specialized intervention and support, while in the other the children have significant mental health comorbidities and sometimes extremely challenging behaviors that require intervention for which funding is not readily available.

Services accessed and recommended. The family has access to a community key worker and a psychiatrist at a tertiary outpatient neuropsychiatry clinic. The psychiatrist has recommended Alex receive ongoing treatment in the community to monitor his medications and see a therapist for emotional regulation and a behavioral consultant to design an intervention program. The psychiatrist has also recommended respite care and counseling for Alex's mother.

Gaps in services. Multiple obstacles have made it difficult to move forward with the psychiatrist's recommendations. Because Alex has an IQ of 84 he is not eligible for services through Children and Youth with Special Needs, which requires an IQ of 70 or less when defining intellectual disability. Had he met this eligibility requirement, the family could have benefited from respite care and the services of a child and youth care worker and a behavioral consultant. Alex is also not eligible for care under Developmental Disabilities Mental Health Services because he does not meet that agency's requirements for intellectual disability either. Alex's mother, supported by the neuropsychiatry clinic, had previously called the Ministry of Children and Family Development and asked to be considered for respite and other support services. She was told that because there were "no child protection concerns" the ministry would not open a file, even though the MCFD does open files for family support services as well as child protection services. She then used the self-referral intake process for Child and Youth Mental Health to access required mental health services for ongoing therapy and medication management for Alex and was refused services. The reason given was Alex's diagnosis of fetal alcohol spectrum disorder. Because of this diagnosis, Alex's co-occurring mental health conditions were discounted.

Leo

Leo is an 11-year-old male with Prader-Willi syndrome, a rare genetic disorder affecting chromosome 15. Individuals with this diagnosis commonly have insatiable appetite, developmental and cognitive delays, hypogonadism, and behavioral and psychiatric difficulties. Leo has an IQ of 67, placing him in the mild intellectual disability range. Leo engages in chronic skin-picking and self-harm, typical of the behavioral phenotype associated with Prader-Willi syndrome. He also inserts objects into his rectum and smears feces over his body, stabs his wounds with sharp objects, and fills them with dirt. His parents have often had to stay up all night to prevent him from worsening the multiple self-inflicted wounds on his body. Leo exhibits impulsive behaviors and is a flight risk. Leo's parents are overwhelmed by managing the difficult behaviors associated with his neurodevelopmental disorder and co-occurring psychiatric problems.

Services accessed and recommended. The family has access to Children and Youth with Special Needs services because Leo's IQ is less than 70. Leo has an education assistant at school and sees a psychiatrist at a tertiary outpatient neuropsychiatry clinic for consultation and short-term treatment. The psychiatrist has recommended that Leo receive support from a behavioral consultant and behavioral interventionist and be started on medication and monitored in the community.

Gaps in services. Because Leo does not have a diagnosis for autism spectrum disorder he is not eligible for the Autism Funding program, which would cover the cost of a behavioral interventionist to implement a treatment plan developed by a behavioral consultant. Leo cannot be referred to Child and Youth Mental Health to address his mental health concerns because his clinical needs require more than the services of a general mental health clinician, and he cannot access a psychiatrist through Child and Youth Mental Health without seeing a clinician first. In addition, he is unable to access a psychiatrist through Developmental Disabilities Mental Health Services because he is younger than 12, and a private child psychiatrist will not accept the referral.

Emily

Emily is a 9-year-old female with autism spectrum disorder, moderate intellectual disability, separation anxiety disorder, and Tourette syndrome. Emily must wear a helmet, gloves, and knee pads because of her severe self-injurious behavior. Her parents have had to stand by helplessly while Emily bruises and batters her head and face. Despite multiple trials of medication by several psychiatrists and community-based behavioral interventions, Emily's self-injurious behavior is worsening.

Services accessed and recommended. Emily is under the care of a psychiatrist at a tertiary outpatient neuropsychiatry clinic and receives benefits through the Autism Funding program. Previously, community-based consultants who were not experts in self-injurious behavior were contracted by Children and Youth with Special Needs to provide in-home behavioral consultation and intervention. These interventions did not change Emily's behaviors. For the past 2 years Emily's psychiatrist has been strongly recommending she see a behavioral consultant skilled in managing self-injurious behavior and be considered for placement in a residential facility specializing in challenging behaviors. As the behaviors continue and worsen, the mental health of Emily's parents is precipitously declining and their marriage is under heavy strain. One parent is unable to continue working because of the constant care Emily requires.

Gaps in services. Lack of communication from Children and Youth with Special Needs initially delayed securing appropriate supports for Emily. While her family now receives benefits through the Autism Funding program, the $6000 per year provided does not cover the interventions she needs. Also, despite the very obvious challenges Emily's parents face, they have had to continuously and tirelessly assert their needs and advocate for their child. An additional issue for this family has been the requirement to sign a Special Needs Agreement for residential treatment, which involves relinquishing care of their child to CYSN. This is a difficult step for the family to take, but is the only way to access a specialized residential program.

Harpreet

Harpreet is a 14-year-old female with moderate intellectual disability. Her comorbidities include epilepsy, anxiety, sleep disturbance, obsessive-compulsive disorder, and episodes of major depression that have recurred over the past 2 years. She has irregular periods, constipation, and anemia. Harpreet squeezes, pinches, and grabs peers, teachers, and her parents. She is nonverbal and gets very upset if people talk about her in her presence. Harpreet is only allowed to attend school for half a day as the school staff report that they cannot manage her behaviors for longer. Harpreet is on high doses of antipsychotic medications to manage her behaviors, keep her in school, and prevent her parents from becoming completely overwhelmed to the point where they can no longer care for her. Harpeet is an only child and her parents are immigrants who require an interpreter during appointments. Her mother suffers from depression caused by the stress of caring for Harpreet.

Services accessed and recommended. Harpeet sees a psychiatrist at a tertiary outpatient neuropsychiatry clinic. Her intellectual disability makes her eligible for services from Children and Youth with Special Needs, but she does not qualify for benefits under the Autism Funding program. Harpreet is eligible for the At Home Program and will be able to receive medical and/or respite resources once a referral from a physician is completed.

Gaps in services. Numerous obstacles are keeping Harpeet and her family from receiving sufficient support. Harpeet's pediatrician has not yet made the referral needed for her to receive At Home Program resources. Her parents have difficulty communicating in English and do not know how to navigate in a system unfamiliar to them or what services can be provided through Children and Youth with Special Needs. The parents are exhausted and need appropriate respite to avoid burnout. Previously, the neuropsychiatry clinic's social worker helped the family contact their Children and Youth with Special Needs social worker for assistance with direct-funded respite, which requires advertising for and interviewing respite providers. Given the parents' limited ability to communicate in English, these tasks were extremely challenging. While they did eventually manage to find someone, the caregiver quit after 1 week. The parents would still like to find out-of-home respite for a few days each month, but have been told their only option for more respite is to put Harpreet in care, which they do not want to do.

Barriers

As the clinical vignettes illustrate, children and families trying to access services for co-occurring neurodevelopmental and psychiatric disorders face a number of barriers caused by system fragmentation, bureaucratic processes, lack of respite, out-of-home service obstacles, and limited specialized training for care providers.

System fragmentation

Children with a dual diagnosis and their families often do not obtain the support they need because services are fragmented and there is insufficient interagency collaboration and communication. This system fragmentation means that many children fall through the cracks. As seen in some of the clinical vignettes, children are denied Child and Youth Mental Health services because of their neurodevelopmental disorder diagnoses, yet are not considered eligible for mental health services through Children and Youth with Special Needs. Even when families do manage to access some services, the care they receive does not always meet the complex needs of their children. These issues are particularly challenging when families are faced with long waitlists and do not have a case manager or care coordinator to help them navigate through the system and advocate for them. The situation is especially difficult for single parents and families who are already challenged by socioeconomic stressors, previous negative experiences with the Ministry of Children and Family Development, and language barriers.

Even when families do manage to access some services, the care they receive does not always meet the complex needs of their children.

Families new to British Columbia (or Canada) have a particularly difficult time with unfamiliar social service and health care systems.

Bureaucratic processes

Parents of children with a dual diagnosis often have to advocate for needed supports over many years in a system that is hard to understand and to navigate. They have to endure bureaucratic processes, jump through hoops, and wait for long periods of time for services. They often experience parent-blaming for the behavioral challenges their children exhibit. Coping mechanisms can fail and family breakdown becomes more likely when care is difficult to access. Adequate services are often put into place only after crises occur and families are overwhelmed.

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Lack of respite care

Many families of children with a dual diagnosis need respite to prevent caregiver burnout. Despite this common need, families still struggle to get sufficient respite. Difficulties include inconsistent offerings of respite hours for families and communities, long waitlists for contracted respite providers recruited and monitored by Children and Youth with Special Needs, the need for parents to independently recruit direct-funded respite providers, and the need for parents to advocate constantly for respite. When parents do obtain funding for respite, the amount that CYSN provides for an hourly wage is low and many families cannot afford to top this up to make a reasonable wage for the respite provider. The low wages, along with safety issues in many cases, make it very hard to retain respite providers. Additionally, there is a limited number of skilled respite providers with specialized training and an understanding of both neurodevelopmental disorders and mental health issues.

Out-of-home service obstacles

The routes to receiving out-of-home placement or residential treatment are confusing and fragmented. One route involves going through Children and Youth with Special Needs and signing a Special Needs Agreement or a Voluntary Care Agreement. In this case, parents relinquish care of their child to the Ministry of Children and Family Development for the duration of the placement. The placement can be in an existing group home or a home arranged specifically for the individual child. Generally, these homes are operated by agencies contracted by the ministry to provide care, and are staffed with group home workers who do not have mental health training. Another route to receiving out-of-home treatment involves going through inpatient psychiatry. There are currently no specialized pediatric neuropsychiatry inpatient units in BC. While the Provincial Assessment Centre can help individuals with intellectual disability and co-occurring mental health and/or severe behavioral concerns who are age 14 and older, PAC is focused primarily on assessment and stabilization and does not offer services for children younger than 14, nor does it offer services to youth with neurodevelopmental disorders other than intellectual disability. Many children with neurodevelopmental disorders who are referred to child or adolescent psychiatry units are declined service because the milieu in these units is not suitable for children with a dual diagnosis.

Limited specialized training

Specialized neuropsychiatry training is needed for those who provide care for children with neurodevelopmental disorders and mental health issues, but a limited amount of this training is currently available. More training is needed for psychiatrists, pediatricians, general practitioners, nurses, social workers, counselors, psychologists, behavioral consultants, respite providers, and group home workers.

Recommendations

The way services for children with a dual diagnosis are currently structured in BC does not involve a wraparound system of care approach.[15] Such an approach supports children and their families by using integrative interagency and cross-agency practices to ensure collaboration and communication among child-serving agencies and programs. The current service delivery design in BC also fails to ensure a continuum of care by providing a comprehensive range of health services spanning all levels of intensity.[16]

Addressing the complex needs of children with a dual diagnosis will require ensuring a continuum of care, improving Ministry of Children and Family Development services, improving health authority services, and establishing a wraparound system of care.

Ensuring a continuum of care

- Provide timely access to various levels of care.
- Provide community-based programs and outreach.
- Provide intensive in-home support (nurse, behavioral consultant, etc.) for both prevention and step-down care when children and youth are discharged from inpatient psychiatry or residential treatment.
- Provide more out-of-home temporary respite options for complex cases to prevent caregiver burnout and safety concerns.
- Provide dedicated neuropsychiatry beds in current child and adolescent psychiatry units.

Improving Ministry of Children and Family Development services

- Provide integrated cross-agency service delivery to families accessing mental health, special needs, child protection, and family support services.
- Hold joint meetings to determine the most appropriate services for referrals between each division, and regular meetings for all professionals involved.
- Designate a case manager for children with a dual diagnosis and complex care needs.
- Address limitations in specific service areas:

Child and Youth with Special Needs

- Provide a program with funding based on need rather than diagnosis—currently designated funding is only available to children with autism spectrum disorder, regardless of their level of functioning, mental health comorbidities, and support needs.
- Develop separate funding models for children and youth with autism spectrum disorder and/or intellectual disability alone versus those with dual diagnosis.
- If separate funding models are not feasible, allocate distinct funding for these complex cases to the health authorities that frequently treat these children and have more specialized training in psychiatric comorbidities and treatment.
- Include treatment teams (mental health, specialist health care, pediatrics) in Ministry of Children and Family Development decision-making processes such as residential placements.
- Help families find skilled respite providers and behavioral intervention services when they must do so under the terms of direct-funded respite and Autism Funding.
- Provide designated respite programs for families of children with dual diagnosis.
- Provide training in dual diagnosis to Children and Youth with Special Needs social workers.
- Provide more out-of-home respite options for dual-diagnosis cases before resorting to ministry placement.

Child and Youth Mental Health

- Provide services to children with dual diagnosis.
- Assign designated clinicians on teams for dual-diagnosis cases, similar to concurrent disorder clinicians on mental health teams.
- Provide more staff training in specialized therapy for dual diagnosis.

Family support and child protection services

- Have family support services more readily available when other supports are not yet put in place.

Improving health authority services

Address limitations in specific service areas:

Developmental Disabilities Mental Health Services

- Provide services for children younger than age 12.
- Expand eligibility for services to include other neurodevelopmental disorders such as autism spectrum disorder and fetal alcohol spectrum disorder rather than providing services only for youth with a diagnosis of intellectual disability.

Outpatient tertiary neuropsychiatry

- Ensure that every health authority has a neuropsychiatry clinic.
- Include a behavioral consultant on the neuropsychiatry clinic team.
- Provide outreach and more consultation to general practitioners and pediatricians in BC who are already prescribing extensively for children with a dual diagnosis.

Inpatient psychiatry

- Establish designated neuropsychiatry beds.
- Develop a specialized short-term (3 to 6 months) neuropsychiatry intensive assessment and treatment unit for children and youth staffed with mental health professionals, behavioral consultants, and behavioral interventionists.
- Provide more training on dual diagnosis.

Physician training

- Provide mandatory training on dual

diagnosis for family medicine, pediatric, and psychiatry residents to increase community capacity.

- Provide ongoing funded opportunities for general practitioners, pediatricians, and psychiatrists to increase their knowledge and skill set in this area.

Establishing a wraparound system of care

- Support children and families by using integrative interagency and cross-agency practices among child-serving services provided by the Ministry of Children and Family Development and the province's health authorities.
- Provide a case manager to help families of children with a dual diagnosis navigate the system of care.
- Provide care that is individualized and least restrictive.
- Ensure early identification and intervention.
- Organize transitions to adult services.
- Provide culturally safe, trauma-informed, and clinically competent services.

In British Columbia the current system of care for children with neurodevelopmental disorders does not appear to recognize there are two distinct patient populations: in one the children have few comorbidities and need limited specialized intervention and support, while in the other the children have significant mental health comorbidities and sometimes extremely challenging behaviors that require intervention for which funding is not readily available. Where this second population is concerned, vigorous family advocacy is required to access services and family breakdown can result. The Child and Youth with Special Needs division of the MCFD operates on an underlying assumption that parents are able and willing to take on a case manager role to access appropriate resources. This role is usually not appropriate for parents whose children have a dual diagnosis and require guidance and additional support to access specialized services.

BC needs policies and practices that recognize and address the complex needs of children with a dual diagnosis.

Competing interests

None declared.

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