Excluded:

Increasing Understanding, Support and Inclusion for Children with FASD and their Families

APRIL 2021

REPRESENTATIVE FOR
CHILDREN AND YOUTH

April 15, 2021

The Honourable Raj Chouhan
Speaker of the Legislative Assembly
Suite 207, Parliament Buildings
Victoria, B.C., V8V 1X4

Dear Mr. Speaker,

I have the honour of submitting the report *Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families* to the Legislative Assembly of British Columbia.

This report is prepared in accordance with Section 20 of the *Representative for Children and Youth Act* which gives the Representative authority to make special reports to the Legislative Assembly if the Representative considers it necessary.

Sincerely,

J Charlesworth

Dr. Jennifer Charlesworth
Representative for Children and Youth

pc: Ms. Kate Ryan-Lloyd
Clerk of the Legislative Assembly

Ms. Susan Sourial
Committee Clerk, Legislative Assembly

Contributors

The Representative would like to acknowledge with gratitude the children, youth and families who shared their perspectives and made this report possible. The Representative also thanks all who participated in interviews and community dialogues, as well as expert reviewers Dorothy Badry, Michelle Stewart, Dr. Christine Loock, Dawn Johnson and Richard Willier for their contributions.

In addition, the Representative would like to acknowledge the project team for this report:

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Territorial Acknowledgment

The Representative and staff, who do their work throughout the province, would like to acknowledge that we are living and working with gratitude and respect on the traditional territories of the First Nations peoples of British Columbia. We specifically acknowledge and express our gratitude to the keepers of the lands on the traditional territories of the Lheidli T'enneh peoples (Prince George) and the Songhees and Esquimalt Nations (Victoria), where our offices are located.

We would also like to acknowledge our Métis and Inuit partners and friends living in these beautiful territories.

Executive Summary

Fetal alcohol spectrum disorder, or FASD, is a life-long disability that is often misunderstood and accompanied by significant stigma for those affected by it. The goal of the Representative for Children and Youth (RCY) in undertaking this project was to illuminate the experiences of children and youth with FASD and their families and, through these experiences, to offer insight into how these children and families can be better supported through assessment, diagnosis and in their day-to-day lives.

One of the great challenges RCY faced in completing this work was to do so without reinforcing stigma. This includes the mistaken assumptions that FASD is an *"Indigenous problem"* and that it is *"100 per cent preventable"*, both of which ascribe blame and shame to mothers, families and communities without giving consideration to the multiple factors that can contribute to fetal exposure to alcohol, which is what leads to a person being born with this disorder.

The evidence is clear, FASD is not a diagnosis that is specific to a particular population or group of people; nor is it necessarily the result of a woman knowingly consuming alcohol while she is pregnant. However, it is often stereotyped as either or both of these and the resulting shame and blame can lead to harmful consequences, including a general lack of empathy and understanding about the disorder and an undeniable lack of supports and services for children and families who clearly need them.

This report aims to help break through the stigma and to shine a spotlight on significant issues with assessment, diagnosis, support and services related to FASD. It points out tremendous inequities in supports for children, youth and families with this disorder and makes recommendations on how those can be improved.

RCY's project team employed a mixed-methods approach to gathering and analyzing information for this report, including ongoing engagement over several months with nine children and youth with FASD from across B.C., as well as their parents and/or caregivers. The project team was co-led by Myles Himmelreich, an adult with FASD who has 15 years experience working in the field and who was a tremendous help in bringing forward a clear understanding of these children and families, their strengths and challenges.

Other sources that informed the report included interviews with 48 professionals and service providers working in the field; a review of injuries and deaths of children and youth with suspected or confirmed FASD that were reported to RCY over a 16-month period; RCY dialogue sessions involving families and service providers with three distinct First Nations groups and one involving Urban Indigenous people; an extensive literature review guided by the themes that emerged from RCY's work with the families involved in the research; and input from external subject matter experts.

RCY also invited key decision-makers to Sharing Experiences for Change, an October 2019 forum that brought together participants from provincial government ministries, health authorities and First Nations organizations to hear stories and watch presentations from the participating children and youth and their parents about their experiences at home, at school and in their communities.

Among the nine key findings made by this report is a foundational finding pointing out that structural racism toward First Nations, Métis, Inuit and Urban Indigenous people appears to lead to assumptions that can influence referral and assessment processes.

Clinicians and service providers involved in those processes described to RCY researchers a noticeable trend with First Nations, Métis, Inuit and Urban Indigenous children and youth being referred for FASD assessments, while other children presenting in a similar manner are more commonly being referred for other assessments such as autism spectrum disorder (ASD) or attention deficit hyperactivity disorder (ADHD). Participants in the First Nations community dialogues recounted similar experiences, saying that racist stereotypes about alcohol use in general can skew First Nations, Métis, Inuit and Urban Indigenous children toward FASD assessment. These observations are also reflected in research literature.[1, 2]

RCY sought data from B.C.'s Ministry of Health and the Ministry of Children and Family Development (MCFD) to further explore the issue of racial bias in streaming for assessments of FASD and other conditions, but the provincial government does not collect the disaggregated data necessary to do this. Nevertheless, the Representative observes that all available indicators – from interviews with family members, clinicians and service providers, from the First Nations community dialogues, and from literature reviewed – point to the troubling conclusion that FASD continues to be falsely framed and practically experienced as a predominantly Indigenous issue.

As previously mentioned, FASD is also often claimed to be completely preventable, a message that supports the narrative that FASD is solely the fault of biological mothers.[3, 4] This dominant public discourse ignores systemic factors that can contribute to birth parents' alcohol use (e.g., experiences of trauma that go unsupported) and also disregards the instances of alcohol use by women before they are even aware they are pregnant. This narrative perpetuates false and harmful stereotypes that RCY researchers were repeatedly told ultimately affect the services received by children and youth with FASD, which some community dialogue participants referred to as a *"loaded diagnosis."* These participants continuously highlighted the importance of eliminating stigma and blame directed at biological mothers and stressed the necessity of *"embracing birth moms with understanding and empathy."*

The stigma and lack of empathy experienced by families with FASD are accompanied by a general lack of understanding about the effects of FASD, which is an "invisible disability". This lack of understanding can lead to exclusion from community and peers, and result in social isolation for children and parents. Said one parent whose family was part of this research project: *"You don't get invited to birthday parties; you don't get invited to go to somebody's house. Hey, we didn't even have a birthday party for three or four years, because there wasn't anyone to invite."*

RCY research shows families with children with FASD receive meagre supports and services compared to those whose children have other special needs. RCY repeatedly heard that this lack of services is a direct result of Children and Youth with Support Needs (CYSN) eligibility criteria that is based on diagnosis rather than functional need.[5] FASD has been left undefined in the B.C. special needs service delivery model – meaning that, as a diagnosis, children, youth and families living with this disability can, and do, slip through the cracks of almost every program stream. As RCY's recent report *Left Out: Children and*

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[1] Emily Bell et al., "It's a Shame! Stigma Against Fetal Alcohol Spectrum Disorder: Examining the Ethical Implications for Public Health Practices and Policies," *Public Health Ethics* 9, no. 1 (April 2016): 67, https://doi.org/10.1093/phe/phv012.

[2] Nina Di Pietro and Judy Illes, "Closing Gaps: Strength-Based Approaches to Research with Aboriginal Children with Neurodevelopmental Disorders," *Neuroethics* 9, (2016): 248, https://doi.org/10.1007/s12152-016-9281-8.

[3] Peter Choate and Dorothy Badry, "Stigma as a dominant discourse in fetal alcohol spectrum disorder," *Advances in Dual Diagnosis* 12, no. 1/2 (2019): 36-52, https://doi.org/10.1108/ADD-05-2018-0005.

[4] Michelle Stewart, "Fictions of Prevention: Fetal Alcohol Spectrum Disorder and Narratives of Responsibility," *Journal for the Anthropology of North America* 19, no. 1 (May 2016): 55-66, https://doi.org/10.1111/nad.12040.

[5] The CYSN program was formerly known as Children and Youth with Special Needs.

youth with special needs in the pandemic, clearly showed, services for B.C. children with special needs are insufficient overall, and families with FASD often struggle to get any tangible help.

In addition, this report finds that the FASD assessment and diagnostic process is complex and resource intensive; that children and youth with FASD are not sufficiently supported in the public school system, often leading to their exclusion from full-time participation; and that children and youth in government care who have FASD may not receive a diagnosis or proper supports and can face significant hurdles and limited supports as they enter adulthood and transition out of care.

Problems with how children and youth with FASD are supported have been identified long before this report. In fact, more than 12 years ago, the B.C. government released a cross-ministry plan, *Fetal Alcohol Spectrum Disorder: Building on Strengths, A Provincial Plan for British Columbia (2008-2018).* Three goals were stated in this plan, including that "*People living with FASD are supported to reach their full potential in healthy and safe communities.*"[6] A strategic objective called for: *"Children, youth and adults living with FASD and their families and support networks [to] have access to comprehensive and lifelong intervention and support."*[7, 8]

More recently, a report released by the Select Standing Committee on Children and Youth (SSCCY) in October 2019 entitled *Children and Youth with Neuro-Diverse Special Needs* emphasized that access to supports for children and youth with FASD and their families or caregivers was inadequate and inequitable. And RCY's own *Left Out* report in December 2020 also raised concerns. One parent responded in a survey administered as part of the *Left Out* report: *"Because my child's diagnosis is FASD, we do not qualify for any support, yet my child needs one-to-one, 24/7 supervision as well as mental health support, occupational therapy, special therapy. We continue to be denied essential services."*

It has been well-established that children, youth and families with FASD need better support. This report makes 11 recommendations toward that goal, including a call for MCFD to fully fund and implement its new CYSN framework and to ensure that the new framework is fully inclusive of children and youth with FASD. That includes ensuring that children and youth with suspected or diagnosed FASD – based on an assessment of functional needs – are fully eligible for CYSN services.

The Representative also recommends that the Ministry of Health take steps to examine systemic bias with regard to referral pathways for FASD and other assessments and to reduce wait times for assessments at B.C.'s complex developmental behavioural conditions (CDBC) diagnostic clinics.

Other recommendations call for a review of, and improvements to, FASD awareness training for appropriate workers in the education, health, mental health and child welfare sectors as well as the development of a cross-government plan to routinely collect high-quality demographic and service data that allows for disaggregation.

The Representative would like to honour the children, youth, families and communities who shared their experiences to help inform this report and thereby foster a deeper understanding of FASD and the strengths, challenges and needs of those who feel its effects.

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[6] Ministry of Children and Family Development, *Fetal Alcohol Spectrum Disorder: Building on Strengths, A Provincial Plan for British Columbia (2008-2018)*. (Victoria, British Columbia: Ministry of Children and Family Development, 2008), 13.

[7] Ministry of Children and Family Development, *Fetal Alcohol Spectrum Disorder*, 14.

[8] FASD awareness and prevention initiatives; services provided by private agencies; youth justice services; and youth older than 19 were all out of scope for this research project.

Scope and Methodology

Scope

The goals of this review were to develop an understanding of the needs of young people with FASD and their families and caregivers, with a focus on how supports to children and youth with FASD can be improved and expanded. With these goals in mind, the following activities were within scope of this project:

- A review of MCFD and Ministry of Health policy documents related to FASD diagnostic, assessment and support services;
- A review of publicly funded FASD assessment, diagnostic and support services provided by government agencies and contracted service providers;
- Identification of gaps in support services to children and youth and their families or caregivers
- Identification of strengths and challenges in the Key Worker and Parent Support Program; and
- Examination of the lived experience of children and youth with FASD and their caregivers.

A Community-Based and Mixed Methods Research Approach

A multi-method approach was used to gather information and data for this report to ensure a broad understanding of FASD, its impacts on children, youth and their families or caregivers, and how the lived experiences of children and youth with FASD connect to B.C.'s social support system (see Appendix A for more detail).

A primary goal of the research was to gain a deeper understanding of systemic challenges and how they impact the lives of children and youth with FASD and their families or caregivers – an understanding that is necessary to address service and support needs. To explore this, RCY researchers used a qualitative methodology that centres on the principle of lived experience – the Mosaic Approach (see Appendix A for a description of this approach).

Informing the Research Through Lived Experience

Myles Himmelreich, a researcher with FASD lived experience, joined the project team to help ensure the research design and implementation were ethical and appropriate. RCY researchers learned about some of the impacts of FASD through their relationship with Myles. In addition, because FASD is often invisible, isolating and discussed in negative terms, having the opportunity to work with an adult with FASD positively impacted the young people involved.

A Message from Myles Himmelreich:

"In this report, you will read many examples of how lack of support, understanding and proper care lead to isolation, exclusion and loss of potential for children and youth with FASD in our province.

As you will notice, the struggles that the families in this report faced seemed to be similar. I can share with you from being a professional in the field of FASD for over 15 years, and more importantly as an individual with FASD, I have found that the story for one person with FASD can be the story for many people with FASD.

The general public's lack of FASD knowledge leads to our behaviours being seen as "bad." The lack of support leads to failure. The lack of care leads to low self worth. I often refer to the saying "I'm not the only one" as what individuals with FASD say when they have the opportunity to interact with others with the same diagnosis. It is said when talking about not being the only one to struggle in school or to be misunderstood or to have sensory issues or to struggle with showing correct emotions and much more. In doing this project, I got to see these children and youth saying, "I am smart," "I do try," "I care."

The lack of understanding and incorrect information is what has led to so much shame, blame and stigma when it comes to FASD. We can't talk about and focus on upgrading and employment options if we don't first understand how FASD plays a role in our ability to have success. My inability to keep a job wasn't due to my lack of effort and lack of care, it was because I was dealing with sensory overload in my environments, memory issues leading to mistakes and struggling with abstract concepts, like time, causing me to come across as lazy or not caring. Those are just a few of the things needed for an individual with FASD to know about so they can deal with them and learn to self-advocate for support in these areas.

FASD is caused when there is alcohol intake during the pregnancy. This can happen for a number of reasons but please know statements like "FASD is 100 per cent preventable" just leads to more shame and blame. Statements like "The child's mother should have cared enough to not drink" lead to stigma for the mother and child. My mother drank; I have FASD. This is what I HAVE – not who I AM. This is what the children and youth in this report HAVE – not who they ARE.

We would not understand the full impact of what's happening for children and youth in our province with FASD if we didn't speak with them firsthand. To truly know what is or is not working for these children and youth in our systems, we need to go to the source – children and youth with FASD. I am a strong believer in "nothing about us, without us." Don't say this is what "they" need, or that "they" need to change this or that. It is our society that needs to change and allow our voices to be heard.

I have seen the strength in every one of the young people in this report – to face every difficult day, every judgment and to continue fighting. All they are asking for is care, understanding and support. They – like all children and youth – deserve that."

The Children and Youth Involved in the Research

RCY had the opportunity to work closely over several months with a group of children and youth in completing the research for this report. RCY researchers spent time with eight young people, while a ninth youth contributed through written work submitted, with his permission, by his parent. The children and youth ranged from age eight to 18 and live throughout the province, including in both urban and rural communities in northern, southern and central B.C. Three of the young people identify as female, five identify as male, and one identifies as non-binary. All these children and youth have a diagnosis of FASD, or a diagnosis under the FASD spectrum depending on the year of their diagnosis, and some have additional diagnoses.[9]

Collaboration and Community Dialogues with First Nation Communities

During the initial scoping stage of the FASD research project, RCY often heard the concern that FASD is framed as occurring mainly in First Nations, Métis and Inuit communities, as well as the claims that systemic racism could be leading to bias in identification, referral pathways and assessment of First Nations, Métis, Inuit and Urban Indigenous children and youth with FASD.

RCY approached a number of First Nations communities to express interest in co-facilitating community dialogues in order to gain insight into how the general perception of FASD impacts First Nations children and youth with FASD, their families and their communities. RCY is aware of the historical and current practices in which research is done *on* First Nations communities rather than *with* communities. Upon receiving invitations to each Nation or community, RCY came with open ears and hearts to engage in dialogue.

Each dialogue was co-designed with the Nation government or community, ensuring it was distinct and responsive to the community where it was held (see Appendix A for descriptions of each dialogue). Community dialogues included a broad range of voices: Elders, families, young people, service providers and leaders. These dialogues were vital to the research and, in particular, to allowing RCY to hear the voices and experiences of birth mothers and biological families.

RCY committed to each Nation and community to return upon completion of the analysis to present the findings and ensure that voice and lived experience were captured appropriately. Unfortunately, the COVID-19 pandemic meant that the report-back sessions had to be held virtually and not all who attended the dialogues were able to attend the report-backs. RCY incorporated feedback from the report-back sessions into this report. In addition, the leaders for each Nation or community who developed the dialogues was provided an embargoed copy of the report to review, with the opportunity to offer further feedback prior to release.

Data Collection Methods

The Mosaic Approach engages with children in research by bringing together *"different pieces or perspectives in order to create an image of children's worlds."*[10] RCY engaged with nine children and youth between the ages of eight and 18 and their parents from across the province over several months.

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[9] Prior to 2016, individuals could be diagnosed under the following categories: FAS with and without a confirmed history of alcohol exposure; partial FAS; alcohol-related birth defects (ARBD); and alcohol-related neurodevelopmental disorder (ARND). In 2016, the new Canadian diagnostic guidelines were published changing the categories for which individuals could be diagnosed. These categories now include: FASD without sentinel facial features; FASD with sentinel facial features; and At risk for FASD.

[10] Alison Clark, "Ways of Seeing: Using the Mosaic Approach to Listen to Young Children's Perspectives," in *Beyond Listening. Children's Perspectives on Early Childhood Services*, eds. Alison Clark, Anne Trine Kjorholt and Peter Moss (Bristol: Bristol University Press, 2005), 13.

Semi-structured interviews were held with six parents of the children and youth who participated in this research, as well as with 48 professionals and service providers working in the field of FASD and two parent support networks.

To further inform this report, RCY conducted a literature review guided by the themes that emerged in the work with the children and youth and their families, and reviewed injuries and deaths of children or youth with suspected or confirmed FASD that were reported to RCY in the 16-month period between April 2018 and July 2019.

When the data-gathering stage for the family research portion of this project was complete, RCY invited decision-makers and leaders to a forum to share themes and open a conversation on FASD. Sharing Experiences for Change, held in Victoria in October 2019, brought together participants from key government ministries, health authorities and First Nations organizations to hear stories and watch presentations from the children and youth and their parents about their experiences at home, at school and in their communities.[11] Many participants expressed that they had not fully understood what day-to-day life was like for a person with FASD. Forum participants committed to identifying and exploring ways to improve the provincial supports for children and youth with FASD.

Gathering data through child, youth and family voice, community dialogue voice and interviews with professionals and service providers provided a broad look at FASD and uncovered common themes and connections between lived experience and societal systems. Nine key findings were identified in the research and confirmed through feedback sessions with families and the First Nations communities who participated in the dialogue sessions.

External Reviews

RCY engaged with external researchers and expert reviewers to identify gaps in literature or information and to receive feedback on unintentional harm or consequences that this report might potentially cause.

FASD in the Context of Human and Child Rights

RCY is a rights-based organization and its work is situated within the frameworks and context of human and child rights. It is critical to consider the implications of international treaties that align with and value the lives of people with disabilities and highlight the need to continue to advocate for human rights.

When reflecting on available programs and the issue of access to services for children and youth identified as having a disability, including those with FASD, it is important to consider individual rights in the context of international treaties that have been ratified in Canada. The *United Nations Convention on the Rights of the Child (UNCRC)*, ratified in 1991, and the *UN Convention on the Rights of Persons with Disabilities (UNCRPD)*, ratified by Canada in 2010, both provide context for children and youth in B.C.

The *UNCRC* speaks specifically to the rights that all children hold: to grow and develop to their full potential (Article 3), to special education and care for children with a disability (Article 23), and to help from the government for children who are in need (Article 26).

The *UNCRPD* provides an additional imperative around the rights of children with disabilities specifically. Article 7 explicitly defines the importance of *"all necessary measures to ensure the full enjoyment*

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[11] Participants included decision-makers from the Ministries of Children and Family Development, Education, Health, Mental Health and Addictions, the Select Standing Committee for Children and Youth, and leaders from the First Nations Leadership Council, the DAA Directors' Table Secretariat, and the First Nations Health Authority.

by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children." In addition, as outlined under Article 8 (awareness raising) of the *UNCRPD,* ratifying countries must "…*undertake to adopt immediate, effective and appropriate measures:*

> *a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;*
>
> *b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;*
>
> *c) To promote awareness of the capabilities and contributions of persons with disabilities.*

Further, Article 24 of the *UNCRPD* describes the obligation that ratifying states have to ensure access to inclusive education at all levels for children with disabilities to develop to their full human potential, develop a sense of dignity and self-worth, develop their personality, talents and creativity, and fully develop their mental and physical abilities to their fullest potential. In realizing an inclusive education system, states must ensure:

> *a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;*
>
> *b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;*
>
> *c) Reasonable accommodation of the individual's requirements is provided;*
>
> *d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;*
>
> *e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.*

Human and child rights have provided both the inspiration and a foundation for inclusion. That foundation requires the recognition of all children as full members of society. It also requires the removal of barriers that might prevent the enjoyment of rights and requires the creation of appropriate supportive and protective environments. These environments need to minimize and ultimately remove barriers to children's full participation and the realization of their potential.

RCY's work is also guided by the *Calls to Action* of the Truth and Reconciliation Commission.[12] FASD is addressed in *Call to Action* numbers 33 and 34. The Representative points to *Call to Action* number 33:

> *We call upon the federal, provincial, and territorial governments to recognize as a high priority the need to address and prevent Fetal Alcohol Spectrum Disorder (FASD), and to develop, in collaboration with Aboriginal people, FASD preventive programs that can be delivered in a culturally appropriate manner.*

This is the context in which the remainder of this report should be placed – the obligation that society has to all children and specifically those with disabilities, including FASD.

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[12] Truth and Reconciliation Commission of Canada, *Truth and Reconciliation Commission of Canada: Calls to Action* (Winnipeg: Truth and Reconciliation Commission of Canada), 2015, 1-11.

Background

What is FASD?

FASD is a diagnostic term that describes the life-long effects that can occur as a result of prenatal alcohol exposure. *Fetal Alcohol Spectrum Disorder: A Guideline for Diagnosis Across the Lifespan,* published in 2016, identifies two FASD diagnoses: FASD with sentinel facial features, and FASD without sentinel facial features.[13] A third category known as *"at risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure"* was developed as a designation to indicate that prenatal alcohol exposure was identified, but other FASD criteria were not met (see Appendix B).[14] FASD is captured in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* as a neurobehavioural disorder associated with prenatal alcohol exposure.

In B.C., diagnosis can occur at any point in an individual's life and is a life-long diagnosis.[15] An assessment for FASD is conducted by a multidisciplinary team and involves a comprehensive assessment of functional abilities (i.e., the ability to perform everyday tasks). Early diagnosis and ongoing support services may lessen the impact and prevent co-occurring conditions from arising later in life (e.g., depression, anxiety, mood disorders).[16, 17, 18]

Prevalence

The prevalence of FASD in Canada, nationally and provincially, is difficult to determine for a number of reasons. First, the stigma associated with alcohol consumption during pregnancy discourages biological families from seeking assessments which leads some researchers to believe that FASD is being under-diagnosed and under-reported.[19, 20] Second, access to referrals and assessments is also a challenge as RCY found that wait times for assessments vary by region but range between one and two years. Third, the assessment process itself is complex and dependent on factors that may be impossible to determine, such as receiving confirmation of alcohol consumption during pregnancy, bolstering the suggestion that the prevalence of FASD may be greater than current research estimates.[21] Finally, tracking criteria

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[13] Jocelynn L. Cook et al., "Fetal Alcohol Spectrum Disorder: A Guideline For Diagnosis Across the Lifespan," *Canadian Medical Association Journal* 188, no. 3 (2016): 191, https://www.cmaj.ca/content/cmaj/188/3/191.full.pdf.

[14] Jocelynn L. Cook et al., "Fetal Alcohol Spectrum Disorder," 191.

[15] Cook et al. "A Guideline For Diagnosis Across the Lifespan,"

[16] Heather Carmichael Olson and Rachel A. Montague, "An Innovative Look at Early Intervention for Children Affected by Prenatal Alcohol Exposure," in *Prenatal Alcohol Use and FASD: Diagnosis, Assessment and New Directions in Research and Multimodal Treatment*, eds. Susan A. Adubato and Deborah E. Cohen (Washington: Bentham Science Publishers, 2011), 64-107.

[17] Christie L.M. Petrenko and Michelle E. Alto, "Interventions in Fetal Alcohol Spectrum Disorders: An International Perspective," *European Journal of Medical Genetics* 60, no. 1 (January 2017): 79-91, https://doi.org/10.1016/j.ejmg.2016.10.005.

[18] Nguyen Xuan Thanh and Egon Jonsson, "Life Expectancy of People with Fetal Alcohol Syndrome," *Journal of Population Therapeutics and Clinical Pharmacology* 23, no. 1 (March 2016): 53, https://jptcp.com/index.php/jptcp/article/view/240/196.

[19] Katherine Flannigan, Kathy Unsworth and Kelly Harding, *The Prevalence of Fetal Alcohol Spectrum Disorder* (Vancouver, B.C.: Canada FASD Research Network), 2018. https://canfasd.ca/wp-content/uploads/2018/08/Prevalence-1-Issue-Paper-FINAL.pdf.

[20] Data provided by Provincial Health Services Authority's STAR B.C. BCAAN/CDBC database on Nov. 4, 2020.

[21] Svetlana Popova et al., "Population-based Prevalence of Fetal Alcohol Spectrum Disorder in Canada," *BMC Public Health*, 19, no. 1 (June 2019), https://doi.org/10.1186/s12889-019-7213-3.

and diagnosis vary considerably across jurisdictions. However, there have been a number of attempts to determine prevalence:

- In 2006, Health Canada estimated that nine in 1,000 (0.9 per cent) infants in Canada are born with FASD.[22] If this is accurate, then it would be expected that nearly 395 infants of the approximately 43,878 births in B.C. in 2019 were born with FASD.[23] Other studies have indicated that the prevalence of FASD may be higher than this.
- A recent study with Greater Toronto Area elementary school students (seven- to nine-years-old) estimates prevalence of FASD at two to three per cent of that population.[24, 25]
- Based on a review of the most current literature, the Canada FASD Research Network estimates that as many as four per cent of Canadians have FASD.[26]

It is also important to note that prevalence estimates vary with methodologies used, such as individual self-reported questionnaires (which produce lower estimates) and Active Case Ascertainment (which produces higher estimates).[27, 28]

A Promising Resource

The national FASD database through the Canada FASD Research Network (CanFASD) aims to provide national prevalence statistics, key insights and comprehensive quantitative data related to individuals with FASD. The database strives to provide a more comprehensive understanding of the FASD population in Canada in order to identify distinct needs and gaps in services while simultaneously ensuring best practices within diagnostic assessments. The database is also meant to help parents and families feel less isolated and give them a deeper understanding of how FASD affects the brain and impacts behaviour. Currently, there are more than 3,000 records in the database from over 29 participating assessment clinics across Canada. One of the main goals of this database is to inform policy decisions and resource allocations pertaining to health services provided to those with FASD and their families or caregivers at a national level. Another focus is to provide data to each diagnostic clinic to help inform and support its work. Additionally, the database provides opportunities for national education and training to improve services for individuals with FASD.*

* Vanessa Hrvatin, "Canadian Fetal Alcohol Spectrum Disorder Database Demonstrates International Leadership in FASD Research," Kids Brain Health Network, last modified Aug. 15, 2019, https://kidsbrainhealth.ca/index.php/2019/08/15/canadian-fetal-alcohol-spectrum-disorder-database-demonstrates-international-leadership-in-fasd-research/.

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[22] Health Canada, *Fetal Alcohol Spectrum Disorder* (Ottawa, ON: Public Health Agency of Canada), 2006.

[23] "BC Vital Statistics Agency Births by Local Health Area," Ministry of Health. https://www2.gov.bc.ca/assets/gov/birth-adoption-death-marriage-and-divorce/statistics-reports/birth-reports/births-by-lha-2019.pdf.

[24] Ministry of Children and Family Development, "Fetal Alcohol Spectrum Disorder," 2.

[25] Svetlana Popova et al., *World Health Organization International Study on the Prevalence of Fetal Alcohol Spectrum Disorder (FASD): Canadian Component* (Toronto, ON: CAMH Publications) 2018, 2.

[26] Canada FASD Research Network, *2016-2017 Annual Report*, accessed July 31, 2020, https://canfasd.ca/wp-content/uploads/2017/07/CanFASD_AnnRpt_2017_WEB.pdf.

[27] Katherine Flannigan, Kathy Unsworth and Kelly Harding, *FASD Prevalence in Special Populations*, (Vancouver: B.C.: Canada FASD Research Network), 2018, https://canfasd.ca/wp-content/uploads/2018/08/Prevalence-1-Issue-Paper-FINAL.pdf.

[28] Active Case Ascertainment is a research method that focuses on a specific population such as within a geographical area or a school. This method actively seeks and recruits children with FASD in the particular population under study.

Effects of FASD

When a child is born with FASD, a constellation of effects can occur. Alcohol can interfere with the growth and development of all fetal body systems; however, the developing central nervous system, encompassing the brain and spinal cord, is especially vulnerable to the effects of alcohol.[29] These effects, which can vary from mild to severe, may include physical, mental, behavioural and/or learning disabilities with life-long implications.

"Lots of personal space helps my FASD. FASD makes my family work hard sometimes. FASD makes it really difficult to think hard enough … FASD feels like your brain is switched around the wrong way. For example, it's sometimes hard to make choices about what you would want. Even which kind of juice. Sometimes when you are trying to celebrate, FASD gets in the way."

– ASHLEY

Executive Functioning

These cognitive processes include a person's capacity to regulate attention, affect and impulse. Further, executive control allows an individual to integrate newly obtained information with memories, make decisions, solve problems and link behaviours to their consequences.

Executive functioning deficits can be significant, including difficulties with organization, planning and cognitive flexibility that are important for adapting to the demands of daily life into adulthood.[30] One youth who was part of this research described some of the effects of FASD as "*learning difficulties, mood swings, hyperactivity, lack of focus and poor judgment*." This youth further explained that, like everyone with FASD, it affects him in a number of ways:

> *"It causes me a few social difficulties. I have difficulties communicating verbally with others. When I do it's in places I feel extremely safe, like at home with my family, but I am unable to talk at school and other crowded places. Some people think I do this by choice or that I'm playing tricks. Someone even offered me 20 dollars to speak, but I couldn't do it."*

In addition, FASD is typically not a standalone disorder and often includes other comorbid conditions.[31] For example, other diagnoses that the children and youth in RCY's research project have include attention deficit hyperactivity disorder (ADHD), selective mutism and autism spectrum disorder (ASD).[32, 33, 34] Between FY 2016/17 and FY 2018/19, 37 per cent of children and youth diagnosed with FASD in B.C. were also diagnosed with an additional co-occurring diagnoses.[35] Similar to variations in

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[29] "Fetal Alcohol Spectrum Disorders (FASD)," Centre for Addiction and Mental Health, accessed May 15, 2020, https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/fetal-alcohol-spectrum-disorder.

[30] Carmen Rasmussen, "Executive Functioning and Working Memory in Fetal Alcohol Spectrum Disorder," *Alcoholism: Clinical and Experimental Research* 29, no. 8 (2005): 1361-1362, https://doi.org/10.1097/01.alc.0000175040.91007.d0.

[31] Svetlana Popova et al., "Comorbidity of Fetal Alcohol Spectrum Disorder: A Systematic Review and Meta-Analysis," *The Lancet* 387, no. 10022 (2016): 1. https://doi.org/10.1016/s0140-6736(15)01345-8.

[32] Selective mutism is predominantly a childhood anxiety disorder that is diagnosed when a child consistently *does not speak* in some situations but speaks comfortably in other situations.

[33] Attention-deficit/hyperactivity disorder (ADHD) results in a persistent pattern of inattention and/or hyperactivity–impulsivity that interferes with functioning or development.

[34] Autism spectrum disorder (ASD) is a complex developmental condition that involves persistent challenges in social interaction, speech and nonverbal communication, and restricted/repetitive behaviors. The effects of ASD and the severity of symptoms are different in each person.

[35] Note provided by Provincial Health Services Authority on Feb. 6, 2020.

fingerprints, each child and youth with FASD has a different combination of effects and symptoms, as we see with the children and youth who participated in this report.[36] There are also commonalities across the FASD spectrum, with children and youth experiencing shared challenges, often expressed in different ways. This is the reason that FASD is considered a spectrum disorder.[37]

Dysmaturity – A Definition

Dysmaturity occurs when chronological age does not match brain function age, resulting in an inability to meet age milestones. This can result in a mismatch between expectations and abilities – in school, in the community, in extended families and in social and peer relations – and can lead to exclusion and isolation.

Definition provided by Myles Himmelreich as part of an FASD Myth Buster created for RCY's October 2019 FASD forum.

For example, all the young people in this report experience challenges with transitioning and processing, regardless of age. In addition, they all spoke of difficulties with sensory overload and extreme emotional responses or shutting down. Challenges with dysmaturity and resulting impacts with difficulties in maintaining friendships is another example of commonalities across the research participants.

Research with the report participants highlighted how the effects of FASD translate to impacts (see pages 17 and 18). The Representative notes that these common effects are not the sum of a child or youth with FASD. However, understanding the reality of FASD's effects and how they can manifest in a child's life can lead to better ways of providing support to ensure that these challenges do not result in poor outcomes. Each of these challenges can be supported once it is understood. As one youth explained:

> *"The message I want you to take … is that there are ways to help me. Continue to include me, don't leave me out … you can support me by explaining things to me and offering help even when I don't ask for it. Understand when I withdraw, it's not something against you but something to help calm my anxiety and fears … try not to judge people before you get to know them."*

All the parents who participated in this report talked about tools and strategies they have developed to work with their children and youth to help them mitigate the impacts of FASD in their day-to-day lives. Some of these strategies include: avoiding things that can cause sensory overload, giving time to process, transition and respond, setting expectations and safety planning.

Staddon's Story

A chance newspaper photo of a school band performance captured the image of 13-year-old trumpet player Staddon intently watching the fingers of the young trumpet player next to him.

His mom later asked him what that was all about. Staddon told her that when he tried to read sheet music, the notes *"danced all over the place."* So he'd figured out a better way to learn the song: He studied his bandmates' finger motions instead.

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[36] Svetlana Popova et al., "World Health Organization International Study on the Prevalence of Fetal Alcohol Spectrum Disorder (FASD)," 1.

[37] Christine Loock, Elizabeth Elliott and Lori Cox, "Fetal Alcohol Spectrum Disorder: Evidence, Theory, and Current Insights," in *Handbook of Social Work and Addictive Behavior*, eds. Audrey L. Begun and Margaret M. Murray (New York: Routledge, 2020).

The anecdote demonstrates what the RCY heard over and over again while gathering information from families for this report. Children with FASD face many challenges in their daily lives, but they are also remarkable at figuring out new ways to learn, participate and adapt to a world that's not set up for them.

RCY worked closely over several months with nine young people in B.C. ranging in age from eight to 18 in completing the research for this report. All have a diagnosis of FASD. A primary goal of this research and data-gathering was to gain a deeper understanding of the systemic challenges impacting the lives of children and youth with FASD, and their families and caregivers.

Staddon jumped into the project with enthusiasm after learning of RCY's plan to follow five families affected by FASD for its report. *"This could be our chance to make a difference!"* he told his mom.

Staddon lives with his mother, Jocelyn, and grandmother, Lynn, in a small B.C. community, where they run a home-based business. His family works hard to buffer the difficult reality of growing up with a misunderstood and stigmatized condition – one that's largely invisible even though the impact on a child's social skills, emotional responses, school experiences and differences in learning can be significant.

Families participating in the RCY project were asked to keep a journal, and some of Staddon's entries are painful reminders of how difficult it is to live with a disorder that's commonly and wrongly interpreted as a behaviour or attitude problem.

"It was hard walking to the climbing gym," reads one of his journal entries. *"Teacher yelled at us to keep up. Feel worried and stressed when they talk to me like that."*

Another day, he wrote that his camp coach got mad at him when he hadn't cleaned up the arts and crafts area. *"They said I'm lazy and not helpful. I was upset about the new coach."*

Eager to be involved in the world around him, Staddon is beloved by those closest to him for his playful nature and striking empathy.

"Everything that he goes to do is all in, all the time. I love that!" says his mom. *"At one point, the biggest concern at school was that he was too empathetic. He couldn't actually take care of himself because he was so worried about everybody else."*

But he's also the child who ended up eating his lunch alone at music school day after day when none of the other kids wanted to sit with him. (Asked if that was hard on him, Staddon told his mother, *"No … I am there to do music, and it's exciting.")* He's the child who can't always find the words to express the emotions welling up inside him, a frustration that leads him to pick at his skin and act out.

Like many parents of children with FASD, Jocelyn spends much of her time advocating for the supports Staddon needs but doesn't receive. While there are some publicly funded supports in B.C. for children with an FASD diagnosis, eligibility requirements often focus only on those with IQs below a certain level. That shuts out Staddon and most other B.C. children whose FASD doesn't manifest as an intellectual disability. Of the 925 children and youth in B.C. diagnosed with FASD in the two-year period 2016/17 and 2018/19, approximately 75 per cent did not receive an intellectual disability diagnosis.[38]

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[38] Data provided by Provincial Health Services Authority's STAR B.C. BCAAN/CDBC database on June 22, 2020.

Jocelyn knows to walk a fine line in her advocacy. It angers and saddens her to hear that a coach or a teacher called Staddon stupid or lazy, but she takes care to *"handle it in a way that's going to be positive, so that the coaches understand that we can't talk like this."* Get too angry and you risk push-back from whoever you're angry at that only ends up hurting your child more, she adds.

Her own journal entries reflect her ongoing struggle to ensure Staddon has the supports he needs to thrive.

"Feeling frustrated trying to figure out how to handle safety things for Staddon when gymnastic camp changed plans," reads one of her entries. *"Do I find someone to support him, or not let him go and deal with the upset from Staddon not understanding? So expensive to ask someone to do extra support."*

Family support is critical in helping children with FASD grow into adults able to manage life's many challenges. Staddon sees the effort his mother and grandmother put into helping him, and wrote them this poem as thanks:

> *You put your own time aside*
> *You're always there to give me a ride*
> *Like a roof that covers a house up above*
> *Your heart covers all of me with love*

Challenges & Effects of FASD[39]

Sensory integration

Difficulties processing and integrating one or more senses. A common effect of FASD, but each affected child experiences the impact differently.

> *"My kids don't like loud noises … we [went] to the fireworks one time … it was too much, and they don't like crowds. I can't even take them to the mall."*

> *"She is most comfortable in pajamas and switches into pajamas sometimes a couple of times a day."*

What It May Look Like or Translate Into

- Physical discomfort and pain when experiencing sensory overload
- Difficulty concentrating and focusing
- Difficulty in learning
- Aggression
- High pain tolerance
- Exclusion because of behaviour that is a response to sensory overload
- Isolation because of exclusion
- Emotionally overwhelmed, presenting internally or externally
- Running away from spaces that cause physical, emotional, spiritual or mental discomfort (referred to as "bolting" by the parents in this report)

Cognitive

Not all children with FASD experience all challenges, while some can experience a combination of challenges:

- Difficulty with memory
- Confabulation[40]
- Impaired executive functioning
- Difficulty setting and reaching goals
- Diverse learning abilities, limited attention span, hyperactivity
- Diverse processing speeds
- Difficulties in abstract thinking
- Impaired language skills
- Inability to understand cause and effect

> *"He has a speech problem, and they noticed it at the school too. His speech is not right."*

What It May Look Like or Translate Into

- Impulsivity
- Difficulty with social interactions, leading to exclusion and isolation
- Immaturity
- Difficulties with transitions and change
- Emotionally overwhelmed, anxiety
- Perceived as unreliable, hard to engage, lazy
- Difficulty retaining information
- Inability to complete tasks
- Depression
- Not remembering all the steps in project assignments for school
- Difficulty forming attachments
- Perceived as lying when they are in fact confabulating

Behaviour and Mood

Behavioural disabilities include an assortment of actions, reactions, voluntary and involuntary activities. Children and youth with FASD frequently experience challenges with judgment and connecting actions with consequences. This often gets interpreted as poor behaviour:

- Dysmaturity[41]
- Trouble understanding social cues
- Impulsive actions
- Can struggle with social skills

> *"She has no tether … I've found her two kilometers from our cabin in the woods picking flowers. She'll go as far up a tree as she can and never gets scared … she has no sense of danger."*

What It May Look Like or Translate Into

- Inability to express emotions or emotional response may appear to be misaligned with the context of the situation
- Labeled as bad – others focus on the behaviour rather than brain differences
- Legal trouble
- Exclusion and isolation
- Targeting and pressure by peers to do "bad" things
- Frustration by parents and service providers
- Difficulty maintaining relationships
- Labeled as not caring
- Emotionally overwhelmed and mood swings

Physical

Can include delayed motor development; challenges in fine and gross motor control; delayed growth; underweight bone, joint or muscle problems; repeated ear infections; hearing, eye, kidney problems; heart defects; sleep challenges.

> *"He's tired [after school]. He's not that physical. He's been under weight at times. So, he's not a strong kid."*

> *"[He] said that his body … moves a lot and he's tired quite often … he said that he does sometimes sleepwalk …"*

What It May Look Like or Translate Into

- Difficulty in using fine motor skills (e.g., difficulty writing)
- Illness
- Chronic fatigue

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[39] This table was developed by examining a combination of literature outlining the effects of FASD and then using examples from parent interviews that highlight practical examples of how the particular effect impacts the children and youth in the research.

[40] Confabulation occurs when the brain unconsciously takes pieces of information from the day and weaves it all together to form a new memory. To an outsider, this can sound like lying, fabrication or stories. To the person with FASD, it is a real and true memory. Definition provided by Myles Himmelreich as part of an FASD Myth Buster created for RCY's October 2019 FASD forum.

[41] When chronological age does not match brain function age, resulting in an inability to meet age milestones. This can result in a mismatch in expectations and abilities in school, in the community, in extended families and in social and peer relations and lead to exclusion and isolation. Definition provided by Myles Himmelreich as part of an FASD Myth Buster created for RCY's October 2019 FASD forum.

Pathways to Services in B.C. for Children and Youth with FASD

The primary services available for those diagnosed with FASD and their families or caregivers are diagnostic and assessment services administered by health authorities and MCFD's Key Worker and Parent Support Program (KWPSP), which offers support to families in accessing education, health, emotional and practical support.

The FASD assessment process begins with a referral from a pediatrician or child psychiatrist (or family physician in regions where those professionals are not available) to the Complex Developmental and Behavioural Conditions (CDBC) program under the Provincial Health Services Authority (PHSA). An FASD assessment is funded through the Ministry of Health for children up to age 19 – after that, publicly funded assessment services are no longer available. Multidisciplinary teams that assess children and youth are housed in four health authorities across B.C.[42] The assessment process requires many hours of testing with multiple clinicians who must come to an agreement before a diagnosis is made.

Other provincially designated services that support children and youth with disabilities typically exclude young people with FASD and their families or caregivers (see Appendix D). These services include CYSN Services, Developmental Disabilities Mental Health Services (DDMHS), and the Community Brain Injury Program.

The only province-wide, FASD-specific program available to parents or caregivers is the KWPSP. This program is low barrier, in that a child does not need a formal FASD diagnosis for a parent to access the program, it is publicly funded, and families can self-refer. However, the KWPSP is not meant to provide any direct FASD-informed mental health or social supports for a child or youth.

Parents involved in this study told the Representative that being the parent of a child with FASD means always being *"on"* to manage the effects of the disorder. This has a huge impact on parents' mental health, their relationships with their children and their relationships with others outside of their immediate family. The parents also told RCY that the lack of supports leaves them feeling exhausted and isolated.

Improvements are required to services for children and youth with FASD and their families or caregivers. Currently, the Ministry of Education is updating its *Inclusive Education Policy* and related resources and MCFD has been developing a new *Children and Youth with Support Needs Service Framework*. These processes hold some potential for addressing the many inequities experienced by children and youth with diverse needs as found in this report, but only if they result in fulsome, accessible and effective services and programs across the province.

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[42] The CDBC assessment team at Sunny Hill Health Centre – BC Children's Hospital handles the assessments for Fraser Health Authority and Vancouver Coastal Health Authority. The Interior, Northern and Island Health Authorities also have assessment teams. These teams are located in Kelowna, Prince George and Victoria, respectively.

Lulu, Fredrick and Owen – Their Stories

Music, art and mom. Life would be very different for three Lower Mainland siblings with FASD were it not for those all-important things helping everyone hang in.

The youngest child, Lulu, got into drumming at age 10 after her much-admired older brother declared it *"cool."* She's 16 now and in two different bands at her school.

Middle child Fredrick, 18, isn't in the band but goes along to many of Lulu's practices anyway, to help her remember the verbal instructions from her teacher that she struggles to retain. Older brother Owen isn't a musician, but he writes slam poetry and loves to write in general.

As for the importance of mom Maeve and her own mom Helen in the children's lives – well, they're the ones who keep it all together. Maeve's children are all at an age when most parents can think about stepping back a bit to let their child start finding their own way into young adulthood, but that's not something Maeve is able to do.

She knows her children just aren't there yet, and that she will still have to be *"there"* for them indefinitely as they slowly figure their lives out. *"Realizing I go through a range of emotions every day, and I ride the waves of my unique life,"* the busy mother noted in the journal she kept for the RCY project.

FASD affects every child uniquely, and Maeve's family is certainly proof of that. Lulu is diligent and conscientious, but her inability to hold onto verbal instructions leaves her teachers and others thinking that she's not paying attention or is lazy. Fredrick is *"a ray of sunshine"* at school and does very well academically – which is sometimes a disadvantage because it makes teachers and support staff miss seeing that Fredrick still needs help to stay on task and complete assignments.

Owen has social anxiety, to the point that he participated in the RCY project only through his writing and his mother's comments about him.

"We worry about Owen and school, because he doesn't fit in. Basically, for the last year of school he was hardly there all year because he just didn't fit," says Maeve. *"But eventually, I'm going to have to stop worrying about the systems failing him and still have the hope of them changing. However, at this time, we just need to support him where things are at."*

The school environment can be an unsettling place for young people with FASD. Not being able to take in verbal instructions well means there are many points in the school day when it's all just too much, says Maeve.

"I think anxiety is huge, and the not knowing. The constant changes that are part of the school system, especially for Lulu and Owen," she says.

"Any changes in their environment, they just get really anxious, like around exam time, a brand new school. 'Who's my homeroom teacher? Where's my mom going to be? Where's my locker? Can you phone them? Can you phone them because I need …?' " There are so many things that can cause the anxiety.

Maeve has always been honest with her children about their FASD diagnoses, though Lulu still struggles to understand the ways the condition impacts her. All three have been in Maeve's family since they were infants, and the benefit of being able to grow up together in a loving, stable home simply can't be overstated, says Maeve.

She sees herself as an *"outside thinker"* for her children, and worries about how to find the right balance of being there for them while also nurturing their independence. She describes Owen as her *"learning experience"* – the one whose early school experiences clarified for her that the only person who was going to give him the extra support he needed was her.

"I learned that the system is going to fail. That's not me trying to be pessimistic, it's just how it is," says Maeve. *"So you have to adjust your expectations of the individuals, adjust your expectations of the system."*

Parents of children with FASD also face having to take on the world on behalf of their young family members. Maeve sometimes finds herself trying to catch a cruel word from someone before it reaches one of the children, to deflect it before it can hit home.

"I think I have taken a lot of the hits for them – of, like, trying not to have the negativity come toward them," acknowledges Maeve. *"For instance, like stopping people before the kids hear it, or when they do hear it, I'll say, 'You know what, they just don't know anything about FASD. They don't understand you. So that's their issue, not yours.' "*

Findings and Analysis

Finding: *Structural racism, stereotyping and bias lead to assumptions that can influence the referral and assessment processes for FASD*

FASD Occurs Across all Demographics

FASD is caused by prenatal exposure to alcohol and alcohol consumption, which occurs across all demographics. Canadian society embraces the consumption of alcohol as a social norm and alcohol is widely used by Canadian women of reproductive age.[43, 44] Research shows that the impacts of alcohol exposure vary depending on the time during the pregnancy that alcohol exposure occurs and the amount of alcohol exposure.[45, 46, 47] It is well documented that in the early stages of the first trimester, when a woman may not yet know she is pregnant, alcohol can have a significant impact on development. A large number of pregnancies in Canada are unplanned, and many women often do not know they are pregnant during the beginning stages of a pregnancy. In addition, there are a range of reasons that a woman may consume alcohol during pregnancy.[48] In a study attempting to estimate the prevalence of consumption during pregnancy, researchers found that, between the years 2003 and 2010, approximately one in every 10 pregnant women in Canada consumed alcohol.[49] FASD is not limited to one particular demographic or individual situation. It is a diagnosis that is found throughout our society, and across all demographics.

> "We don't blame her mom for drinking when she was pregnant because her mom did not receive the supports that she needed to get through her trauma and her mental health piece …"
>
> —Parent

> "There are tons of reasons why people may consume alcohol during pregnancy, including dealing with traumatic events, friends and family celebrations, lack of awareness, unplanned pregnancy or pressure from their partner to drink."
>
> —Youth participant

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[43] Svetlana Popova et al., "Maternal alcohol use, adverse neonatal outcomes and pregnancy complications in British Columbia, Canada: A population-based study," *BMC Pregnancy and Childbirth* 21, no. 74 (2021): 1-13. https://doi.org/10.1186/s12884-021-03545-7.

[44] Alexa Norton, "Discourses of Motherhood and Stigma Production: FASD Public Awareness-Raising in British Columbia, 1979-2015." (MA Thesis, University of British Columbia, 2013), 1-192.

[45] Philip A. May et al., "Maternal alcohol consumption producing FASD: Quantity, frequency and timing of drinking" *Drug and Alcohol Dependence* 133, no. 2 (2013): 502–512. https://doi.org/10.1016/j.drugalcdep.2013.07.013.

[46] Clemens Kiecker, "The chick embryo as a model for the effects of prenatal exposure to alcohol on craniofacial development," *Developmental Biology*, 415, no. 2 (July 2016): 314-325. https://doi.org/10.1016/j.ydbio.2016.01.007.

[47] Natalie Zizzo and Eric Racine, "Ethical challenges in FASD prevention: Scientific uncertainty, stigma, and respect for women's autonomy," *Canadian Journal of Public Health* 108, no. 4 (2017): 414-417. https://doi.org/10.17269/CJPH.108.6048.

[48] Zizzo and Racine, "Ethical Challenges in FASD Prevention," 414-717.

[49] S. Lange et al., "Alcohol use and self-perceived mental health status among pregnant and breastfeeding women in Canada: A secondary data analysis," *An International Journal of Obstetrics and Gynaecology* 123, no. 6 (May 2016): 900-909. https://doi.org/10.1111/1471-0528.13525.

Parents, caregivers, community dialogue participants and service providers all expressed frustration about the blame and shame placed on birth mothers, echoing what the research literature says: some women do not realize they are pregnant and may continue to drink without this knowledge.[50] Other women may be survivors of trauma and/or may be experiencing trauma during their pregnancy and may address this trauma by using substances if they are unable to access supports to address their deep mental/emotional pain.[51] There are also indications that some women continue drinking alcohol while pregnant because they have limited knowledge or awareness about how alcohol can potentially harm their fetus.[52]

Popova et al. conducted a recent population-based study of the estimated prevalence of FASD in the Greater Toronto Area.[53] The study sample included students in the public school system in the Greater Toronto area from September 2014 to June 2017. The students were ages seven- to nine-years-old and the study involved two phases. Students in the first phase who were identified as having growth deficits, behavioural or learning challenges and/or at least two of the three facial feature characteristics of FASD were selected for phase two. In phase two, selected students completed a neurodevelopmental assessment for suspected FASD alongside a random control group of children. This phase included interviews with biological mothers in which 74.6 per cent of the mothers interviewed *"reported consuming alcohol (any amount, at any frequency) prior to pregnancy recognition."*[54] The study found that *"students with suspected FASD did not differ from typically developing children in terms of demographic characteristics, specifically sex, age and ethnicity."*[55] Given the diversity within the sample of the study, the findings highlight FASD as a diagnosis that is likely prevalent across all demographics in Canada.[56]

> "When you say, 'My kid has FASD', whether your child is your biological child, or adoptive child/foster child, you are blamed. So, the black and white statement is *'Don't drink alcohol if you're pregnant, you won't have a baby with FASD.'* [But] when do people know they are pregnant? It's the first trimester where those foundational, structural changes happen ... it's the most dangerous time ... not knowing [you're pregnant]."
>
> —Key Worker

Racism and Stereotypes – In Canada, FASD is framed as an *"Indigenous-only Problem"*

Although the reality is that FASD affects people across all demographics, in Canada FASD is overwhelmingly framed as an *"Indigenous problem."*[57, 58] Research for this report found a consistency, both in statements from participants and in the literature: historic and current racism surrounding FASD results in societal assumptions that FASD is connected to First Nations, Inuit and Métis children, and that these children are identified more readily as requiring an FASD assessment.

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[50] Anna Maria Abadir and Abel Ickowicz, "Fetal alcohol spectrum disorder: Reconsidering blame," *Canadian Medical Association Journal* 188, no. 3 (February 16, 2016): 171, https://doi.org/10.1503/cmaj.151425.

[51] Choate and Badry, "Stigma as a dominant discourse in fetal alcohol spectrum disorder," 36-52.

[52] Abadir and Ickowicz, "Fetal alcohol spectrum disorder," 171.

[53] Popova et al., "Population-based prevalence of fetal alcohol spectrum disorder in Canada," 845.

[54] Popova et al., "Population-based prevalence of fetal alcohol spectrum disorder in Canada," 845.

[55] Popova et al., "Population-based prevalence of fetal alcohol spectrum disorder in Canada," 845.

[56] Popova et al., "Population-based prevalence of fetal alcohol spectrum disorder in Canada," 845.

[57] Centre for Addiction and Mental Health, "Fetal Alcohol Spectrum Disorders (FASD)".

[58] Alexa Norton, "Discourses of Motherhood and Stigma Production", 1-192.

RCY repeatedly heard stories of communities and families experiencing stigma and racism connected to FASD. Community dialogue participants shared their views that stigma and racism were often a result of a lack of understanding within society including others in their own communities. They related stories of experiencing the framing of FASD as "*an Indigenous problem.*" Participants shared their thoughts about how First Nations, Inuit and Métis people have generally been stereotyped as alcoholics or substance users, how harmful these assumptions have been for their children in school, and the blame and shame they experience. Many participants referred to FASD as a *"loaded diagnosis"*.

Where Does This Framing Come From?

It is impossible to separate colonialism and systemic racism from the current framing of FASD and societal and governmental responses to the disorder. Colonization is an ongoing process and its outcomes are felt today by First Nations, Métis, Inuit and Urban Indigenous peoples. In examining FASD, specifically, one can start with colonizers' introduction of alcohol to Indigenous peoples. Alcohol was used as currency in the fur trade and the introduction of alcohol was a way to attempt to control Indigenous people during early settlement in order to facilitate taking over their lands.[59, 60] Alcohol has since symbolized colonialism to many Indigenous communities, and has contributed to an ongoing legacy of harm, racism and stigma against Indigenous peoples and communities.[61] The importance of alcohol as a representation of colonization in many Indigenous communities is "*reflected in Aboriginal literature, painting[s] and other forms of artistic expression.*" [62] An important piece to this puzzle is how the use of alcohol has become overwhelmingly constructed as a problem for First Nations, Métis and Inuit peoples, whereas it has generally been constructed as socially acceptable for other populations.[63]

The introduction of alcohol and the subsequent framing of alcohol in relation to First Nation, Métis and Inuit peoples intersects with harmful colonialist policies and practices that aimed to assimilate, control and govern Indigenous peoples and communities.[64] These policies include residential schools, the *Indian Act*, the child welfare system (e.g., the sixties and millennial scoops), and medical and social services.[65, 66] The "*view has always [been] that Aboriginal peoples' 'future' is best served under*

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[59] Steven Koptie, "Alcohol as a great destroyer: A call for insight on ceremonial approaches for coping with FASD," *First Peoples Child & Family Review* 8, no. 1 (2011): 17-24.

[60] Caroline Tait, "The Tip of the IceBerg: The Making of Fetal Alcohol Syndrome in Canada," (PhD diss., McGill University, 2003), 191, http://www.namhr.ca/media/docs/lega4eb233149a533-tait-2003.pdf.

[61] Judy Iseke, "Indigenous Storytelling as Research," *International Review of Qualitative Research* 8, no. 4 (2013): 559-577.

[62] Tait, "The Tip of the IceBerg," 190.

[63] Wanda Phillips-Beck et al., "Confronting Racism Within the Canadian Healthcare System: Systemic Exclusion of First Nations from Quality and Consistent Care," International Journal of Environmental Research and Public Health 17, no. 22 (2020): 8343. https://doi.org/10.3390/ijerph17228343.
See also: Government of Canada, "The Chief Public Health Officer's Report on the State of Public Health in Canada 2015: Alcohol Consumption in Canada," (Ottawa, Ontario, Public Health Agency of Canada, 2016), 1-72. https://www.canada.ca/en/public-health/services/publications/chief-public-health-officer-reports-state-public-health-canada/2015-alcohol-consumption-canada.html.

[64] Tait, "The Tip of the IceBerg," 170-180.

[65] Tait, "The Tip of the IceBerg," 170-180.

[66] Robert Henry, "Moving Beyond the Simple: Addressing the 'Misuse' of the FASD-Gang Link in Public Discourse," *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health* 11, no. 2 (2013): 241-254. http://www.pimatisiwin.com/online/wp-content/uploads/2013/10/07Henry1.pdf.

the control and regulation of the dominant society." [67] Indigenous peoples have been constructed as a problem *for* the Canadian government, and as having problems that need government intervention, as evidenced by these harmful policies.[68, 69] Indigenous women, in particular, are affected by these policies as they have created and reinforced the dominant narrative that Indigenous women are unable or unwilling to care for their children. Adding this to the colonial stereotype that Indigenous people cannot consume alcohol responsibly, and that alcohol is an Indigenous problem, the intersection of these racist assumptions has very real and harmful consequences to Indigenous women, their children and their communities.[70, 71]

RCY also heard stories in community dialogues about the stereotyping of First Nations children even when a diagnosis of FASD was not made. One community member spoke of an experience in which a teacher assumed "*his mom drank with him, and that's why he is the way he is*," despite the reality that his mother had not consumed alcohol for more than three years prior to her pregnancy.

The lived experience shared with RCY from community dialogue participants is echoed in research literature. Michael Oldani (2009) looked at the difference in diagnoses between ADHD and FASD among First Nation, Métis, Inuit and Urban Indigenous children in Manitoba, concluding that the diagnosis of *"FASD and ADHD often follow a racialized script."* [72] In particular, the research noticed that *"white passing"* children were more often screened and assessed for ADHD, whereas First Nation, Métis, Inuit and Urban Indigenous children, whose symptoms presented as ADHD, were more likely to be screened and assessed for FASD, a finding echoed by other researchers.[73, 74]

Caroline Tait notes, "*My fieldwork experience suggests First Nations persons are most commonly labelled as having FAS in the absence of a medical assessment. Generally, non-medical labelling involves an 'assessment' based on the opinion of one or more persons, and involves consideration of the person's body, specifically their facial characteristics, possibly consideration of their height and weight, and an 'assessment' of their intelligence, cognitive abilities, and behaviour."* [75]

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[67] Caroline Tait, "Disruptions in Nature, Disruptions in Society: Aboriginal Peoples of Canada and the Making of Fetal Alcohol Syndrome," in *Healing Traditions: The Mental Health of Aboriginal Peoples in Canada*, eds. Laurence J. Kirmayer and Gail Guthrie Valaskakis (Vancouver: UBC Press, 2009), 198.

[68] Tait, "The Tip of the IceBerg," 167-186.

[69] Tait, "Disruptions in Nature", 198.

[70] Tait, "The Tip of the IceBerg," 1-392.

[71] Henry, "Moving Beyond the Simple," 241-252.

[72] Michael J. Oldani, "Uncanny Scripts: Understanding Pharmaceutical Emplotment In the Aboriginal Context," *Transcultural Psychiatry* 46, no. 1 (March 2009): 135, https://doi.org/10.1177/1363461509102291.

[73] Oldani, "Uncanny Scripts," 135.

[74] Norton, "Discourses of Motherhood and Stigma Production," 1-192.

[75] Caroline L. Tait, "Simmering Outrage During an 'Epidemic' of Fetal Alcohol Syndrome," Canadian Woman Studies 26, no. 3-4 (2008): 73.

The link between FASD and First Nations, Métis and Inuit communities developed across Canadian society because of the ongoing effects of colonialism and structural racism, as well as the focus of FASD research on First Nations, Métis and Inuit communities – research that has subsequently been cited to support claims that FASD is an *"Indigenous-only problem."*[76] For example, researchers note that the high prevalence of FASD among First Nations, Métis and Inuit populations is due to the fact that studies on alcohol use during pregnancy in Canada *"have disproportionately and almost exclusively focused on Indigenous women."*[77, 78, 79, 80]

Structural racism is *"the totality of ways in which societies foster racial discrimination through mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, health care, and criminal justice."*[81] Structural racism can be seen in how the underlying racist connection between alcohol use and First Nations, Inuit and Métis populations creates a bias that ripples into the identification of developmental concerns in children, the referral and assessment processes, societal responses to an FASD diagnosis, and the fact that FASD research has focused primarily on Indigenous communities.[82, 83, 84, 85]

Structural racism shows up in our economic, social and political institutions.[86] It emerges when a dominant group is established and its power is reinforced through inequitable laws, policies, rules, regulations and access to resources.[87] In Canada, European colonialists established their dominance – and continue to maintain it – through the ongoing process of colonialism. Mi'kmaq academic Marie Battiste describes the discrimination against First Nations, Métis, Inuit and Urban Indigenous peoples that results from systemic racism:

"Systemic discrimination dominates political and policy making spheres, creating massive discriminations against Aboriginal persons, whether as groups or as individuals. It operates through inaction, silence, neglect, and indifference to the aboriginal, human and treaty rights, stifling the talents and opportunities of individuals

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[76] John Aspler et al., "Stigmatisation, Exaggeration, and Contradiction: An Analysis of Scientific and Clinical Content in Canadian Print Media Discourse About Fetal Alcohol Spectrum Disorder," *Canadian Journal of Bioethics* 2, no. 2 (2019): 23-35. https://doi.org/10.7202/1058140ar.

[77] Deborah Rutman, "Voices of women living with FASD: Perspectives on promising approaches in substance use treatment, programs and care," *First Peoples Child and Family Review* 8, no. 1 (2013): 108. https://fpcfr.journals.publicknowledgeproject.org/index.php/FPCFR/article/view/204/32.

[78] Colleen Anne Dell and Gary Roberts, *Research update, alcohol use and pregnancy: An important Canadian public health and social issue* (Ottawa: Public Health Agency of Canada), 2005, 24. https://www.researchgate.net/publication/235747443_Alcohol_Use_and_Pregnancy_An_Important_Canadian_Health_and_Social_Issue/link/55b2666008ae9289a0854fb6/download.

[79] Amy Salmon, "Aboriginal Mothering, FASD Prevention and the Contestations of Neoliberal Citizenship," *Critical Public Health* 21, no. 2 (June 2011): 171-173, https://doi.org/10.1080/09581596.2010.530643.

[80] Nina Di Pietro and Judy Illes, "Closing Gaps", 248.

[81] Zinzi D. Bailey et al., "Structural racism and health inequities in the USA: evidence and interventions," *Lancet* 389, no. 10077 (April 8, 2017): 1453. DOI: https://doi.org/10.1016/s0140-6736(17)30569-x"10.1016/S0140-6736(17)30569-X.

[82] Stewart, "Fictions of Prevention: Fetal Alcohol Spectrum Disorder and Narratives of Responsibility," 58.

[83] Salmon, "Aboriginal Mothering, FASD Prevention and the Contestations of Neoliberal Citizenship," 171-173.

[84] Amy Salmon, "It Takes a Community: Constructing Aboriginal Mothers and Children with FAS/FAE as Objects of Moral Panic in/through a FAS/FAE Prevention Policy," *Journal of the Association for Research on Mothering* 6, no. 1 (2004): 112-123.

[85] Colleen M. O'Leary and Carol Bower, "Guidelines for Pregnancy: What's an Acceptable Risk, and How Is the Evidence (finally) Shaping Up?" *Drug and Alcohol Review* 31, no. 2 (2012): 170-183, https://doi.org/10.1111/j.1465-3362.2011.00331.x.

[86] Andrew Leyland et al., "Health and Health Care Implications of Systemic Racism on Indigenous Peoples in Canada: Fact Sheet," (Canada: The College of Family Physicians of Canada, 2016): 2.

[87] Charlotte Reading, *Social Determinants of Health: Understanding Racism* (Prince George, B.C.: National Collaborating Centre for Aboriginal Health) 2013. https://www.nccih.ca/495/Understanding_racism.nccih?id=103.

while sustaining poverty and malaise and affecting diverse social, cultural, political, economic, spiritual and physical outcomes among Aboriginal peoples."[88]

Researchers argue that the framing of FASD as an *"Indigenous-only problem"* results in professionals and community members alike being conditioned to seek a diagnosis of FASD for First Nations, Métis or Inuit children and youth – a phenomenon that results in screening and assessment bias.[89]

Screening and Assessment Bias

RCY heard multiple stories suggesting that the referral pathways for children and youth are influenced by systemic bias – based in racism and classism. These allegations came from multiple sources, including community dialogue participants, service providers and health professionals involved in the assessment and diagnosis processes, and they are also reflected in research literature.[90, 91] This apparent bias may influence screening and assessment and may result in First Nations, Inuit, Métis and Urban Indigenous children being diagnosed with FASD while other children presenting with similar developmental and behavioural characteristics are more likely to be diagnosed with ASD or other behavioural disorders.

Implicit Bias

Stereotypes about race, gender, age, socio-economic status and other factors automatically and unconsciously influence actions, behaviours and decisions. This "implicit bias" is sometimes referred to as "unconscious" or "non-conscious" bias. These biases often do not reflect one's explicit beliefs.

Elizabeth N. Chapman, Anna Kaatz and Molly Carnes, "Physicians and Implicit Bias: How Doctors May Unwittingly Perpetuate Health Care Disparities," *Journal of General Internal Medicine* 28, no. 11 (November 2013): 1505, doi: 10.1007/s11606-013-2441-1.

Clinicians who work within the regional health authorities' CDBC assessment network expressed concerns to RCY researchers about patients being referred for an FASD assessment based on implicit racial bias. These clinicians indicated that there appears to be a tendency for First Nations, Inuit, Métis and Urban Indigenous children and youth to be referred for an FASD assessment, whereas other children are referred for an ASD assessment. As one assessment centre clinician said, *"It would be rare for an Indigenous child to go through [an] autism [assessment] and, yet, it's so prevalent in the rest of the population … that's weird, right?"* Another clinician said they had cases where a referring physician would provide notes about the child being First Nations and that they suspected FASD, even though the physician did not have any information about prenatal alcohol consumption or other information to support this suspicion.

This concern was widespread and echoed by families, Key Workers and other support workers. As one First Nations Health Authority worker said, "*There's the tendency that we hear about for Indigenous families to be diagnosed with FASD and non-Indigenous families to be diagnosed with [ADHD] or autism. I think there can be some racist and colonial assumptions that families might face.*"

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[88] Marie Battiste, "Editorial Commentary: Systemic Discrimination Against Aboriginal Peoples," *Canadian Race Relations Foundation Directions* 5, no. 1 (2008): 4, https://www.crrf-fcrr.ca/images/stories/pdf/directions/directionsVol5No1-Sys_Racism-AboriginalPeoples.pdf

[89] O'Leary and Bower, "Guidelines for Pregnancy", 170-183.

[90] Bell et al., "It's a Shame! Stigma Against Fetal Alcohol Spectrum Disorder," 67.

[91] Nina Di Pietro and Judy Illes, "Closing Gaps," 248.

Although alcohol consumption during pregnancy occurs across a diverse range of women regardless of socioeconomic status (SES), other research has found that caregivers with First Nation, Métis, Inuit and Urban Indigenous children were consistently asked if the biological mother drank alcohol during pregnancy.[92, 93]

CDBC diagnostic assessment clinicians told RCY they have seen referrals that appear to be related to the mother's socioeconomic status (SES) and substance use history. One clinician said:

> *"We also get referrals that might say mom was really marginalized or mom was a drug user and so we suspect alcohol use. It's very rare that we have confirmed alcohol exposure at the point of referral. So often there's a bias in that sense."*

One clinician shared their experiences conducting ASD intakes, observing that many of the parents of these children and youth are *"higher functioning"* and non-Indigenous. In these cases, the clinician said that historical information about alcohol consumption is not as well assessed by the referral source, indicating that assumptions may be being made based on a family's race and socio-economic circumstances that then influence a child's referral pathway.

RCY attempted to determine whether these community and professional observations of bias are reflected in actual referral and diagnosis rates. RCY requested data on First Nation, Métis, Inuit and Urban Indigenous heritage from the CDBC assessment network, but were informed that Indigenous heritage is not recorded in CDBC's data.[94] However, RCY's recent report, *Illuminating Service Experience: A Descriptive Analysis of Injury and Death Reports for First Nations Children and Youth in B.C., 2015 to 2017,* examined the care plans of 200 First Nations children and youth and found that 43 per cent carried a label of FASD, while only two per cent had a diagnosis of ASD. In addition, RCY's Care Plan Review, which examined 66 child service files, found that 27 per cent (n=18) had qualitative evidence of diagnosed or suspected FASD. Of these, 78 per cent were for Indigenous children (n=14/18) as compared to 16 per cent which were for non-Indigenous children (n=4/18).[95]

RCY also requested data from MCFD regarding children and youth in care (CYIC) who have been diagnosed with FASD, further disaggregated by First Nation, Métis, Inuit and Urban Indigenous identity. However, MCFD replied that there are "*no records available for 'confirmed diagnosis'* " of FASD. The Representative finds it troubling that MCFD does not track FASD diagnosis to inform service planning for all children and youth and consequently is unable to link that diagnosis to Indigenous heritage in order to identify potential biases. In September 2020, B.C.'s Office of the Human Rights Commissioner released *Disaggregated Demographic Data Collection in British Columbia: The Grandmother Perspective,* which described disaggregated data as a tool that can be used to reduce systemic racism and oppression and achieve equity.[96]

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[92] Popova et al., World Health Organization International Study on the Prevalence of Fetal Alcohol Spectrum Disorder (FASD)," 33.

[93] Oldani, "Uncanny Scripts," 135.

[94] The CDBC assessment network consists of five regionally based FASD assessment teams. When a child or youth is in need of an assessment for FASD, they will be assessed at the closest location to their home community.

[95] This sample was drawn from MCFD's audit sample that was used for the MCFD Provincial Care Plan Audit. Notably, MCFD's audit sample only includes a review of files with care plans uploaded to ICM within policy range and with an in-care legal status. Therefore, the RCY sample drawn was not random. From MCFD's audit sample of n=228, the Care Plan Audit drew a random sample of n=76 child service files.

[96] British Columbia's Office of the Human Rights Commissioner, *Disaggregated Demographic Data Collection in British Columbia: The Grandmother Perspective* (Vancouver, B.C.: British Columbia's Office of the Human Rights Commissioner) 2020.

Finding: *Shame, blame and stigma result in a misplaced focus on the origins of FASD rather than on the support needs of children and youth with FASD*

In an overview of FASD on its website, the Centre for Addiction and Mental Health says: *"Fetal Alcohol Spectrum Disorder (FASD) … describe[s] the range of effects that can occur in an individual whose mother consumed alcohol* during pregnancy. When a woman drinks alcohol while pregnant, her fetus is exposed directly to alcohol through her bloodstream."[97]

This statement is an example of common discourse that continues to place responsibility for FASD on the shoulders of mothers consuming alcohol during pregnancy.[98] Dominant messaging that blames biological mothers for their child's FASD diagnosis allocates all responsibility to the individual and shifts the focus away from the main issue: providing resources and supports for the child or youth and their family or caregivers. Research that analyzed Canadian print media articles on FASD from 2002 to 2015 found a dominant narrative of hopelessness and struggle for individuals with FASD, and a perpetuation of the cycle of maternal blame that places increased strain on the whole family.[99]

In addition, FASD is often claimed as being 100 per cent preventable, a message that supports the narrative that FASD is a biological mother's fault.[100, 101] It is harmfully implied that "*good, responsible mothers will stop drinking as soon as they know they are pregnant, while bad, irresponsible mothers will continue to drink and knowingly harm their child.*"[102] First Nation, Métis, Inuit and Urban Indigenous and low-SES birth mothers become the most frequently targeted by this claim because it feeds into the idea that Indigenous or impoverished mothers are unable or unwilling to care for their children.[103, 104]

The dominant public discourse ignores the systemic factors that facilitate conditions for birth parents' alcohol use (e.g., experiences of trauma that are unsupported) and thus perpetuates false and harmful stereotypes that RCY researchers were told over and over again affect the services received by children and youth with FASD. A Key Worker shared her experience at a community and practitioner meeting she attended with MCFD:

> "*They asked us for feedback and all of us at our table … said 100 per cent of birth moms [to babies born with FASD] … [in research] from South Africa, Sweden, Russia, Japan, all over the world, rich women, poor women, 100 per cent of birth moms … had a personal history of trauma, and most of them unsupported.*"

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[97] Centre for Addiction and Mental Health, "Fetal Alcohol Spectrum Disorders (FASD)."

[98] In contrast, messaging on FASD can be created in a non-blaming way. For example, FASD is a diagnostic term that describes the life-long effects that can occur as a result of prenatal alcohol exposure.

[99] Aspler et al., "Stigmatisation, Exaggeration, and Contradiction," 23-35.

[100] Choate and Badry, "Stigma as a Dominant Discourse in Fetal Alcohol Spectrum Disorder," 36-52.

[101] Stewart, "Fictions of Prevention," 55-66.

[102] Emily Hellard, "From Blaming to Belonging: Re-examining Our Approach to Fetal Alcohol Spectrum Disorder," *International Child and Youth Care Network* 237 (2018): 51-65. https://www.cyc-net.org/cyc-online/nov2018.pdf.

[103] Gemma Hunting and Annette J. Browne, "Decolonizing Policy Discourse: Reframing the 'Problem' of Fetal Alcohol Spectrum Disorder," *Women's Health and Urban Life* 11, no. 1 (2012): 35-53. http://hdl.handle.net/1807/32417.

[104] Deborah Rutman et al., *Substance Use and Pregnancy: Conceiving Women in the Policy-Making Process*, (Ottawa, ON: Status of Women) 2000. http://publications.gc.ca/collections/Collection/SW21-47-2000E.pdf.

In listening to the voices of young people, their families, community dialogue participants and interviewees, RCY heard that the shame, blame and stigma associated with an FASD diagnosis create secondary harms to the children and youth with FASD and their families that are sometimes more impactful than the effects of the disorder itself.

The concerns around blame and shame were particularly poignant in the community dialogues, where one community member said, "*There is stigma around the issue; people think it is self-inflicted and shame comes with that, then society bans people for that.*" Another community dialogue participant said, "*My experience as a mother is impacted by whether or not my kids [with FASD] are perceived as biological or foster.*"

> "Because of the stigma and because of the bullying that still continues to take place and the marginalization that still continues to take place, one of the things I find … is many parents are hesitant to tell their kids they have FASD because they're afraid of what will come out of that for their kid. They are afraid of how they will internalize that, what their friends will say, what their teachers will say … this whole topic of FASD is still loaded…"
>
> —Key Worker

In community dialogues, participants continuously highlighted the critical importance of eliminating stigma and blame directed at biological mothers and stressed the requirement to "*[embrace] birth moms with understanding and empathy*."

Blame associated with an FASD diagnosis has also led biological parents of children with FASD to fear the system. This is strongly linked to MCFD's legacy of removing First Nations, Inuit and Métis children and youth from their families. RCY researchers heard during dialogues with First Nations communities, as well as in interviews with professionals working in child-serving systems, that one of the greatest barriers to a mother seeking help or support while pregnant or in a child's early years is the fear that a child will be taken away because a parent is perceived as being incapable of caring for their child, or neglectful because they consumed alcohol during pregnancy. This same fear has been noted in other research.[105] As one Key Worker interviewed for this report said, "*You have to understand, people do not … want to come see you [MCFD] because they are afraid that if they admit they are vulnerable, you will take their kids away.*"

> "We all said [to MCFD], what needs to change – attitude, attitude, attitude. You cannot deal with a client by saying *'How many times a week do you drink, what's wrong with you?'* What you need to sit down and say is, *'Oh my, tell me your story. What has happened to you?'*"
>
> —Key Worker

Further, a Tribal councillor in one First Nations community explained that there is "*a huge fear of MCFD for obvious reasons because of [child] apprehension,*" and that, in their community, there are many cases where families chose not to go through the FASD diagnostic assessment process because they were afraid that their child would be taken away. The councillor said the fear was so intense that there had not been an FASD assessment conducted in their community for more than 10 years, despite families in the community verbally acknowledging that their child may have FASD.

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[105] Nancy Poole et al., "Prevention of Fetal Alcohol Spectrum Disorder: Current Canadian Efforts and Analysis of Gaps," *Substance Abuse* 10, no. 1 (2016): 1-11. https://doi.org/10.4137/SART.S34545.

Finding: *The lack of knowledge and understanding about the impacts of FASD have long-term, negative consequences for affected children and youth*

A child with FASD is born into a world that has a general lack of understanding of FASD, its effects and impacts on family, community, education and support systems.[106] This situation influences all aspects of a child's life outside of their immediate family. In fact, the knowledge gap and resulting lack of understanding of FASD and its effects – socially, emotionally, physically and cognitively, across different ages and stages of childhood and adolescence – underpins all findings in this report.

This general lack of understanding exists within the community and also in front-line service delivery.[107] The impacts of these misunderstandings can be traced to poorer outcomes in education,[108] justice,[109] and health care with implications for delivery of services.[110] Research shows that a lack of understanding tied to limited professional development and education on FASD – combined with personal opinions about FASD and those who have it – impacts how professionals deliver front-line services to individuals diagnosed with FASD.[111, 112]

The lack of understanding is partially due to the shame, stigma and blame surrounding the disorder that is generally focused on the biological mother's personal responsibility.[113] Stigma directed toward mothers and their children results in discriminatory practices.[114] Research from Canada and Australia notes that FASD *"exists against the backdrop of colonization"* and systemic racism.[115, 116] Such a backdrop continues to perpetuate the myth that FASD is an "Indigenous-only problem," despite the reality that FASD

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[106] Melissa Fond et al., *Seeing the Spectrum: Mapping the Gaps Between Expert and Public Understandings of Fetal Alcohol Spectrum Disorder in Manitoba* (Winnipeg, MB: FrameWorks Institute) 2017. https://canfasd.ca/wp-content/uploads/2017/05/Manitoba-FASD-Strategic-Meeting-Report-May-2017.pdf.

[107] Kerryn Bagley and Dorothy Badry, "How Personal Perspectives Shape Health Professionals' Perceptions of Fetal Alcohol Spectrum Disorder and Risk," *International Journal of Environmental Research and Public Health* 16, no. 11 (2019): 1936. https://doi.org/10.3390/ijerph16111936.

[108] John Aspler et al., "Stigmatization, Exaggeration, and Contradiction," 23-25.

[109] Michelle Stewart, "FASD & justice: The ethical case for effective training and knowledge mobilization practices for frontline justice professionals in Canada," in *Fetal alcohol spectrum disorders in adults: Ethical and legal perspectives* (Springer, Cham: 2016), 191-206.

[110] Bagley and Badry, "How Personal Perspectives Shape Health Professionals' Perceptions of Fetal Alcohol Spectrum Disorder and Risk," 1936.

[111] Michelle Stewart, "FASD & Justice: The Ethical Case for Effective Training and Knowledge Mobilization Practices for Frontline Justice Professionals in Canada.

[112] Bagley and Badry, "How Personal Perspectives Shape Health Professionals' Perceptions of Fetal Alcohol Spectrum Disorder and Risk," 1936.

[113] Bell et al., "It's a Shame! Stigma Against Fetal Alcohol Spectrum Disorder," 65-77.

[114] Patrick W. Corrigan et al., "The Public Stigma of Birth Mothers of Children with Fetal Alcohol Spectrum Disorders," *Alcoholism: Clinical and Experimental Research* 41, no. 6 (2017): 1166-1173. https://doi.org/10.1111/acer.13381.

[115] Robyn D. Williams, "Understanding Fetal Alcohol Spectrum Disorder (FASD) through the Stories of Nyoongar Families and how can this Inform Policy and Service Delivery" (Doctoral dissertation, Curtin University, July 2018). https://espace.curtin.edu.au/bitstream/handle/20.500.11937/70736/Williams%20Robyn%202018.pdf?sequence=1&isAllowed=y.

[116] Michelle Stewart, "FASD, Justice, Decolonisation, and the Dis-ease of Settler Colonialism," in *Decolonising Justice for Aboriginal youth with Fetal Alcohol Spectrum Disorders*, eds. Harry Blagg, Tamara Tulich, Robyn Williams, Raewyn Mutch, Suzie Edward May, Dorothy Badry and Michelle Stewart, (Routledge, 2020), 154.

occurs across all demographics. These perceptions and attitudes contribute to a substantial lack of – and inequitable access to – supports for children and youth with FASD.[117, 118] FASD is a life-long disability in which access to early supports and services is understood to be critical in the development of child.[119, 120] Taken with the knowledge that stigma can impact the delivery of front-line supports and services, one can trace the link between stigma, adverse childhood experiences, lack of timely and accessible supports and life-long impacts.

RCY researchers heard consistently – from all sources in compiling this report – about the lack of knowledge and understanding of FASD that factors into most interactions experienced by these children and youth. On a daily basis, children, youth and their parents describe having to explain themselves, particularly with regard to behavioural concerns, to extended family members, community members and professionals. And even after the effects of FASD are explained, it does not necessarily mean that they are fully understood on a day-to-day basis.

Most individuals with FASD have no outward signs of the diagnosis. However, their brains work differently due to prenatal alcohol exposure. Because of this, FASD is often referred to as an *"invisible disability,"* which contributes to both the lack of understanding of FASD and the way in which children and youth with FASD are perceived by others. Co-researcher Myles Himmelreich has developed the chart below, which takes some common misunderstandings and labels regarding children and youth with FASD and explains what may really be going on for the young person based on some effects of FASD.

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[117] Courtney R. Green et al., *Stigma as a Dominant Discourse in Fetal Alcohol Spectrum Disorder* (Vancouver, B.C.: Canada FASD Research Network), 2016. https://canfasd.ca/wp-content/uploads/2016/05/Stigma-and-FASD-Final.pdf.

[118] Choate and Badry, "Stigma, Discrimination and Fetal Alcohol Spectrum Disorder" 36-52.

[119] Gail Andrew, "Diagnosis of FASD: An overview," in *Fetal alcohol spectrum disorders: Management and policy perspectives of FASD*, eds. Dr. Edward P. Riley, Dr. Sterling Clarren, Dr. Joanne Weinberg and Dr. Egon Jonsson (Weinheim, BW: Wiley-Blackwell, 2011), 127-148.

[120] Susan Ryan and Danielle L. Ferguson, "The Person Behind the Face of Fetal Alcohol Spectrum Disorders: Student experiences, family and professional perspectives on FASD," *Rural Special Education Quarterly* 25, no. 2 (March, 2006) 124-142, DOI: 10.1177/875687050602500106.

Table 1: Busting FASD Labels[121]

Social Label	Lived Reality	Busting FASD Labels
Liar	**Confabulation**	**Confabulation** occurs when the brain unconsciously takes pieces of information from the day and weaves it all together to form a new memory. To an outsider, this can sound like lying, fabrication or stories. To the person with FASD, it is a real and true memory.
Poor listener	**Information-processing Deficit**	**Information-processing deficits** can occur in four domains: when information is recorded, interpreted, stored (memory) or retrieved. A person with FASD may take longer to process information, they may not be able to process it at all, or they may not be able to retain the information. When a person's information processing is impacted, others may perceive them as a "poor listener."
Inattentive	**Sensory Overload**	People with FASD can be very sensitive to sensory information. **Sensory overload** is caused when the amount of noise, light, smells or touch makes someone feel so uncomfortable that they are overwhelmed, cannot focus, and may even "shut down." It becomes difficult to calmly express themselves, and others may perceive them as "inattentive."
Immature	**Dysmature**	When someone's chronological age is 12, but the age their brain functions at is seven, they are unlikely to meet the milestones of someone else the same age. This is often the experience of someone with FASD. When a person has difficulty meeting a developmental milestone, outsiders may view them as immature and not acting their age.
Impulsive	**Cause and Effect**	Someone who struggles with **cause and effect** means they struggle with connecting their actions to the possible consequences. They may not understand what their options are in a social situation, how their actions impact others, and what the outcome of their actions will be. When someone struggles with this, they may be labelled as "impulsive."
Don't you get it?	**Abstract vs. Concrete**	Concepts such as time, money, sarcasm and metaphors are considered abstract, and are sometimes confusing or difficult for people with FASD to understand. It is best to explain things using plain language and concrete examples.

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[121] Created by Myles Himmelreich

Having a basic knowledge of FASD does not necessarily mean that a person – for example, a teacher – fully understands what the effects look like on a day-to-day basis, however. There are constant challenges and frustration for children and parents when the disability goes unrecognized and misunderstood. This experience has far-reaching impacts on the everyday lives of children and youth with FASD, and on their parents and caregivers.[122, 123]

Invisible Disability

In simple terms, an invisible disability is a physical, mental or neurological condition that is not visible from the outside, yet can limit or challenge a person's movements, senses or activities. Unfortunately, the very fact that these symptoms are invisible can lead to misunderstandings, false perceptions and judgments.

Experiences with Extended Family

Parents who participated in this report shared stories with RCY of judgment and exclusionary practices from extended family members – including grandparents, aunts and uncles – who did not understand the effects of FASD on their child. RCY heard these same sentiments during the community dialogues. One biological mother spoke of her need for help in "*teaching her family how to support her child,*" saying that she needs assistance in helping them change perspective, reframe their understanding of FASD and teach them skills to support her child. This feeling was echoed in other community dialogues where the need to increase the level of understanding in extended families was a key theme.

One parent of a child participant described an event that impacted both her and her child's mental health and contributed to isolation of their family:

> *"Last summer, my niece was going to stay with us … they had come over to have a visit and [Staddon] had a meltdown that day … and he escalated. And we [were] working to get him calmed down. And then all of a sudden, my brother says, "No, she [niece] can't stay here with you; it's not safe – she doesn't need to be a part of any of this." [But] … [Staddon had not] hurt anybody. And they wouldn't let [her] stay. [Staddon] knew because he had had a meltdown that now, his cousin that he was so excited to spend a whole week with … and then they just like shoot it right down. And we explain [FASD] all the time. And it's breaking my heart because I know he's having a hard time, but they don't get that piece … but it's hard with family."*

Experiences in the Community

Families, professionals, service providers in the field and community dialogue participants repeatedly told RCY researchers that children and youth with FASD and their families or caregivers often experience challenges in their community and in public spaces. Participants spoke about judgment and labels applied to children and youth with FASD, and that they are "*only seen as their behaviour.*" Some participants linked this misunderstanding directly to these young peoples' experiences of isolation in community and schools.

"If you're in a wheelchair, you have a right to that ramp … FASD doesn't [have] that ramp piece … It's basically because our children look typical."

—Parent

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[122] Christie L.M. Petrenko et al., "Prevention of Secondary Conditions in Fetal Alcohol Spectrum Disorders: Identification of Systems-Level Barriers," *Maternal and Child Health Journal* 18 (2014): 1496-1505. https://doi.org/10.1007/s10995-013-1390-y.

[123] Jason Brown et al., "Expectations of youth with Fetal Alcohol Spectrum Disorder in Adulthood: Caregiver Perspectives," *Journal of Developmental Disabilities* 24, no. 2 (2019): 30-31. https://canfasd.ca/wp-content/uploads/publications/41028-JoDD-24-2-v11f-30-42-Brown-et-al.pdf.

When the public sees challenging behaviour in public, it is difficult to link that behaviour to an invisible diagnosis. Most individuals with FASD have no outward signs of the disorder. This invisibility has an impact on how children and youth with FASD are perceived and labelled. RCY also heard from parents and in community dialogues that lack of knowledge and understanding of FASD often translates into judgment regarding the tools and strategies that parents use with their children. As one parent said:

> *"There's no off time. The only time it's off is seriously if he's laying beside you on his electronics. And I know people judge. We bring out the electronics in the restaurant. And he sits in the corner, throws up his hoody, barriers himself in there, plugs his nose and plays on his electronics. And … I'm like, do not pass judgment. I have been on for 11 hours. This is my one-hour break. He's fine … because people pass judgment all the time."*

"I will tell you that I have lied and said she is autistic, because people get it. In fact, when she called 911, that's what I told the operator, I'm like, 'She is autistic, and she doesn't understand. We're learning the rules of the phone. It's new to us,' and they were fine with that, because it's just easier."

—Parent

In addition to the lack of understanding by the public, the children and youth who participated in this report regularly experience a knowledge gap and lack of understanding of their disability by community program staff (e.g., swim instructors, summer camp coaches). When community program staff do not understand FASD, it can be extremely difficult, and sometimes unsafe, for children and youth with FASD to participate in programs. This means children and youth are either excluded from opportunities for recreation and personal growth (e.g., learning how to swim) or parents have to provide very direct support – such as getting in the pool with their child – in order for their children to participate.

RCY researchers heard similar experiences regarding the lack of understanding and lack of access to community programs in community dialogues and from service providers, and also heard that children and youth with FASD can experience a lack of understanding within their peer group. For example, community dialogue participants spoke about how children with FASD are often considered "*dumb*," and are "*ridiculed, left out and shamed*" at school by peers. As a result, children and youth with FASD often experience social isolation, which can directly impact their mental health.[124]

Max and Sophie – Their Stories

Home is where the love is for Sophie and Max. School is hard, and the community where they've lived for the past four years still feels all wrong. But everything's okay when they're all at home together.

Grandma Evelyn and her sister June are raising Sophie, Max and three other siblings born to Evelyn's daughter. All the children have FASD. Sophie, 14, and Max, 10, were the two siblings from this family who participated in RCY's research project.

FASD affects each of Evelyn's grandchildren differently, but the way that the world reacts to all of them is depressingly the same. They've all experienced being bullied, excluded and made fun of. Evelyn can't count the times she has quietly looked in on Max at school only to find him sitting outside in the hall again, or forced to sit apart from everyone else in class.

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[124] Timothy Matthews et al., "Social Isolation and Mental Health at Primary and Secondary School Entry: A Longitudinal Cohort Study," *Journal of the American Academy of Child & Adolescent Psychiatry* 54, no. 3 (March 2015): 225. http://doi.org/10.1016/j.jaac.2014.12.008.

"None of my kids have friends here," says Evelyn, who still feels guilty about moving the family away from Vancouver after seeing that some of the older children were being drawn into trouble. *"Me, I hate it, too. We all struggle here, but the kids are troopers and willing to keep going."*

Sophie is outgoing and bold, even jumping onto the stage at a school event to do an impromptu powwow dance in front of classmates who knew very little of First Nations culture. She once went on a two-month camping trip in the Yukon that included three nights of sleeping solo in the wilderness. Evelyn's favourite time of day is the evening, when she and Sophie have time to just enjoy each other's company.

But Sophie notices the way her classmates take in that her school papers are being graded differently than theirs. She knows that her anger can flare up fast and sometimes gets her in big trouble, like the time when the kids laughed at her after her lunch spilled and she *"saw red"* and put her hands around one girl's throat.

"She'd come home from school all the time and be really upset, talking about her papers and the kids seeing that she was different," says Evelyn. *"She asked me if there was something wrong with her. I've talked to her about it."* (Responding to this new knowledge, Sophie writes in her life book for the RCY, *"If I have FASD, I have it. It doesn't matter. We're all human.")*

Max is a quiet boy who is happiest when sticking very close to home, where he feels safe. He's a good reader at home, but feels so much stress at school that he shrinks away from any participation – to the point that his teacher concluded Max couldn't read.

"Oh my goodness, in school he struggles," says Evelyn. *"He hates being there. I was like, 'How could you hate it? You're in Grade 3.' But he hates it."*

Max's two oldest siblings dropped out of school for similar reasons. A third child scraped through high school only by enrolling herself in summer school so she could get the support she needed. Evelyn says the school system doesn't understand FASD, and isn't set up to do the slow, patient work that children with the disorder need.

"*They may show Max one time how to do something, but with kids like mine, you have to show them and show them. Like, if it's 50 times that's needed, then show him 50 times,"* says Evelyn. "*They're going to get it eventually. But schools don't have the time, they don't have the patience, they don't … you know, they just don't know how to look after him."*

Evelyn takes every chance to get educated on FASD. But the resources aren't there to help her children even when she knows exactly what's needed.

"Every single one of my kids, you're going to have to tell them maybe 100 times a day what to do – and when they get, they get it," she says.

"But it might take you that long every day to say, 'No, you have to do it like this or like that.' So that's what we do. We don't get frustrated. But at school, they think, 'You should know this.' No, they shouldn't. They're different than those kids over there."

On bad days, Sophie and Max feel the weight of being different from their classmates, and of being judged unfairly by people who don't understand FASD. On good days, Sophie pushes back on the judgment and recites her favourite quote, from Dr. Seuss: *"Be who you are and say what you feel, because those who mind don't matter, and those who matter don't mind."*

Experiences in the Education and Support Systems

Research participants also expressed frustration about a lack of understanding of FASD in the public school, medical and social support systems – including MCFD's Child and Youth Mental Health (CYMH) and child welfare services – directly impacting policy and program development and service delivery. This systemic misunderstanding is also identified in the research.[125]

> "I think it's safe to say in all departments of the ministry [MCFD] there's a very low [FASD] awareness ... doesn't matter which department we're talking about."
>
> —Key Worker

> "When [he] acts out at school or doesn't want to do [anything], maybe they could learn how to talk to him instead of saying ... he's defiant, he's this and that. Because he's not, he's not a bad kid and he does listen if you take the time ... "
>
> —Parent

Report participants recounted many challenges in schools that stemmed from a lack of understanding of FASD. Participants at one community gathering said the lack of understanding within their public school system was a critical barrier that meant appropriate support was not provided to children with FASD to allow them to participate more fully in their educational experience. One community member said, "*Teachers are relatively unaware of the context of children's lives and children are labelled as 'bad kids'.*" Another parent recounted that because her daughter doesn't process directions the same way other students do, she does not appear reliable and capable, and therefore misses opportunities. This focus on deficits, rather than fostering strengths, impacts the well-being of these children and youth and their families or caregivers.

The experience of having to provide a school with information so that teachers and support staff were more aware of how to address the needs of their children was echoed by all research participants. Parents said they offered free informational handouts, books and courses to the people who work with their children. One parent spoke of printing and sharing cards with school staff that highlighted techniques to de-escalate conflicts. For another parent, the situation became so stressful at school that the child's Key Worker offered to make a presentation to staff, but this opportunity was turned down by the principal: "*It was like, wow, why wouldn't you [accept the offer] to learn? Because my kids are struggling at school here.*"

When parents were able to find professionals and service providers with a strong understanding of how FASD impacts the brain (Key Worker, doctor), the result was very positive, but generally this was not the case. One community dialogue participant summed up the situation by saying: "*… more understanding about FASD is needed from educators, policy makers and funders.*" Further, in speaking specifically about CYMH, one Key Worker explained:

> "*I think a lot of it's fear, myths, mythmaking … 'People with FASD can't learn, why would I even bother?' Or, [a] 13-year-old boy with FASD who's been physically violent at school. The acting out at school is simply a result of what's brewing and stewing underneath, and the poor fit – right? If Child and Youth Mental Health … doesn't get FASD – that's a big barrier …*"

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[125] Jenelle Marie Job et al., "Toward Better Collaboration in the Education of Students with Fetal Alcohol Spectrum Disorders: Integrating the Voices of Teachers, Administrators, Caregivers, and Allied Professionals," *Qualitative Research in Education* 2, no.1 (February, 2013): 38-64. https://files.eric.ed.gov/fulltext/EJ1111952.pdf.

Experiences in the education system are often tied to stigma and a lack of knowledge about FASD.

The gap in knowledge and the subsequent lack of understanding of FASD, how it can affect children and youth, and how to appropriately support someone with FASD is a profound issue. RCY heard during community dialogues, and from all other research participants, an overall need to de-stigmatize FASD. Specifically, it was recommended that more education and training be provided to foster parents, educators, mental health practitioners and for those who are diagnosed with FASD. As one community member said, "*Programs [need to be created] that help them [the child/youth] understand FASD so they can advocate for themselves.*"

This finding is supported in research literature as well. In 2021, a group of researchers conducted a retrospective file review of 161 individuals diagnosed with FASD through the Asante Centre in B.C.[126, 127] These researchers found high rates of psychological conditions, learning differences and behavioural responses among the population studied.[128] Researchers stated:

> "*This points to the importance of increasing knowledge and understanding among service providers and professionals working within settings such as schools, child welfare, the justice system, hospital psychiatric departments, and family medicine regarding the unique challenges of FASD and how to support individuals, families. Including materials about the importance of screening, diagnosis, and treatment for FASD in the educational curriculum for these professionals may assist in earlier identification and mitigate some of the adverse health and social outcomes for individuals with FASD.*"[129]

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[126] The Asante Centre is a non-profit organization that provides assessments and diagnosis for FASD and CDBC.

[127] Svetlana Popova et al., "Health, social and legal outcomes of individuals with diagnosed or at risk for fetal alcohol spectrum disorder: Canadian example," *Drug and Alcohol Dependence* 219, (2021): 108487–108487. https://doi.org/10.1016/j.drugalcdep.2020.108487.

[128] Popova et al., "Health, social and legal outcomes of individuals with diagnosed or at risk for fetal alcohol spectrum disorder," 108487–108487.

[129] Popova et al., "Health, social and legal outcomes of individuals with diagnosed or at risk for fetal alcohol spectrum disorder," 108487–108487.

Finding: *The FASD assessment and diagnostic process is complex and resource intensive and leaves families with little or no supports or services*

In B.C., publicly funded child and youth assessments for FASD are overseen by the Provincial Health Services Authority (PHSA) and completed by the CDBC program. Four multi-disciplinary assessment teams conduct assessments in the five health authority regions – Northern Health Assessment Network, Interior Health Children's Assessment Network, Queen Alexandra Hospital (Island Health) and Sunny Hill Health Centre (Fraser Health and Vancouver Coastal Health).[130]

A child or youth can be referred for an FASD assessment by a pediatrician (or family physician in regions where pediatricians are not available), who completes a referral form indicating the assessment stream the child or youth is being referred to (i.e., ASD, complex developmental concerns or FASD). Once the referral is accepted, the assessment team begins to collect information from the family to help inform the assessment process (e.g., medical records).

An assessment team must complete a complex physical and neurodevelopmental assessment to determine whether a child or youth has FASD (see Appendix B).[131] Impairment in three or more neurodevelopmental domains – often referred to as "brain domains" – is a requirement for an FASD diagnosis. Impairment is determined if a child has severe challenges with: motor skills; neuroanatomy/neurophysiology; cognition; language; academic achievement; memory; attention; executive function, including impulse control and hyperactivity; affect regulation; and adaptive behaviour, social skills or social communication.[132], [133]

Adaptive Functioning

Adaptive functioning refers to coping with everyday environmental pressures and includes daily living skills that people perform to care for themselves and to interact with others. The measurement of an individual's adaptive behavior reflects their competence to perform daily activities required for personal and social sufficiency. The terms adaptive functioning and adaptive behaviour are often used interchangeably. Adaptive functioning is defined by typical performance, not ability. The components of adaptive functioning identified by the American Psychiatric Association are communication, self-care, home living, social, community use, self-direction, health and safety, academics, leisure and work.

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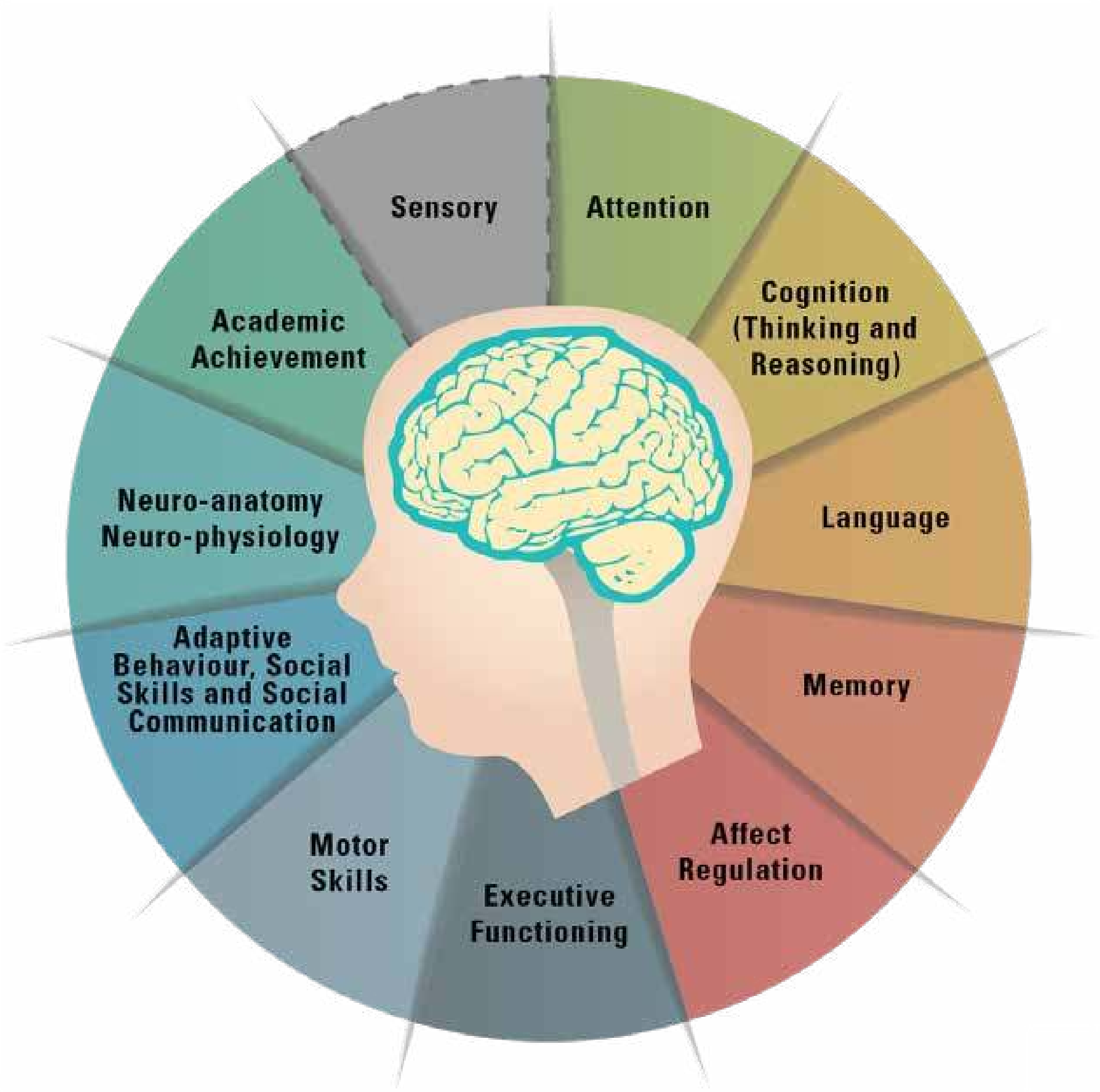
[130] Private and not-for-profit organizations also offer FASD diagnostic assessment services. Private and not-for-profit FASD assessment clinics were not reviewed or included in this scope of this research as they do not fall under the definition of "designated service" or "reviewable service" within the *Representative for Children and Youth Act*. Therefore, these services are deemed out of mandate for the Office to monitor.

[131] Cook et al., "A Guideline For Diagnosis Across the Lifespan," 191.

[132] Severe impairment is defined as a global score or a major subdomain score on a standardized neurodevelopmental measure that is two standard deviations below the mean.

[133] Cook et al., "A Guideline For Diagnosis Across the Lifespan," 193.

Figure 1: The 10 Brain Domains Examined in FASD Assessments



Source: New Directions for Children, Youth, Adults and Families. Developed in Partnership with New Directions for Children, Youth, Adults and Families, Manitoba FASD Centre, Manitoba government.

To assess each of these brain domains and depending on the needs and challenges of the child or youth being assessed, the composition of the multidisciplinary assessment teams can vary slightly. Teams can range in size and may include a combination of professionals including pediatrician, psychologist, psychiatrist, speech-language pathologist, occupational therapist and a social worker. After each clinician has conducted their assessment, the team discusses the results and comes to a consensus about whether an FASD diagnosis should be made. In complex cases where a team cannot reach a consensus, they may consult the Provincial Medical Director or the lead pediatrician, or they may defer the diagnosis until more accurate results can be obtained.

Upon determining the results of an assessment, the team puts together a report that includes the child or youth's diagnosis, the technical information (i.e., assessment scores), the child or youth's strengths and challenges, and recommendations to support the child. This information is provided to the family in a meeting with one or more clinicians from the assessment team.

Challenges and Barriers to Completing the Assessment

Despite the possible benefits of an FASD assessment and diagnosis for children and youth and their families or caregivers, barriers and challenges can make it difficult for families to seek out an assessment and complete the process.

Stigma

RCY heard from professionals and community dialogue participants that the stigma that comes with an FASD label can dissuade families and young people from pursuing a diagnosis or completing the assessment process. For example, a DAA social worker relayed a story about a youth who refused to be assessed and used stigmatizing words such as "*stupid*" to describe those with FASD. A community dialogue participant told RCY there is a sense of denial in families that their children have special needs due to the fear of stigma related to diagnosis.

Biological Mother's History

Canadian FASD diagnosis guidelines indicate that a confirmation of prenatal alcohol consumption is most often required to diagnose a person with FASD.[134] Reviewing a biological mother's prenatal history is one of the most complex and controversial aspects of assessing a child for FASD. The only time an FASD diagnosis can be made when prenatal alcohol exposure is unknown is if the three sentinel facial features are identified and there is evidence of impairment in three or more of the identified neurodevelopmental domains or, in infants and young children, there is evidence of microcephaly (a condition where the head circumference is smaller than normal).[135] A diagnosis of this nature represents a small proportion of cases as sentinel facial features develop as a result of prenatal alcohol exposure at a very specific time in a pregnancy.[136] In a recent study of files of children and youth diagnosed with FASD, just under 13 per cent were diagnosed with FASD with sentinel facial features.[137] Otherwise, confirmation of prenatal alcohol consumption is required.

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[134] Cook et al., "A Guideline for Diagnosis Across the Lifespan," 193.

[135] Cook et al., "A Guideline for Diagnosis Across the Lifespan," 195.

[136] Bernardino Petrelli, Joanne Weinberg, Geoffrey G Hicks, "Effects of prenatal alcohol exposure (PAE): insights into FASD using mouse models of PAE," *Biochemistry and Cell Biology* 96, no. 2 (2018): 5. doi:10.1139/bcb-2017-0280.

[137] Popova et al., "Health, Social and Legal Outcomes of Individuals with Diagnosed or at Risk for Fetal Alcohol Spectrum Disorder," 108487–108487.

For biological mothers, discussing prenatal alcohol use can be upsetting, stressful and traumatizing – and particularly so if a social worker, physician or someone else in a position of power is asking the questions. RCY repeatedly heard from service providers and community dialogue participants that systemically oppressed populations – especially First Nations, Métis, Inuit and Urban Indigenous peoples, people who use substances, people with mental health concerns and those who are socio-economically disadvantaged and/or racialized – are fearful and distrustful of the health care system and this fear and distrust trickles into the FASD assessment process. The recent *In Plain Sight* report found that *"widespread Indigenous-specific stereotyping, racism and discrimination exist in the B.C. health care system"* and that *"racism limits access to medical treatment and negatively affects the health and wellness of Indigenous peoples in B.C."* [138, 139] Families who made submissions to the *In Plain Sight* review process reflected some additional concerns about connecting to the programs and services offered by MCFD because of the ministry's power to apprehend children.

Some clinicians and service providers interviewed said that if mothers did not trust the person gathering the information, they were sometimes unable to talk about their prenatal history out of fear of shame, blame or the removal of their children. As one clinician said, "*If you dig too far, especially with birth parents, they will be incredibly traumatized by that question and some of them will have lied to their community doctors.*"

Unfortunately, the parent's fear of disclosing alcohol use during pregnancy may prevent a child or youth from receiving a diagnosis. As a Tribal councillor for one First Nation told researchers:

> *"I know a lot of the cases, though, you have mothers … [who] know that they were consuming alcohol … during pregnancy and they are struggling and they see that their kids are struggling … and they'll confirm to people in the community and even … go to an assessment and then when it comes to it, the shame is too big and they'll deny it … at the assessment centre, where they're with people who they don't know.… with someone asking questions … and very personal questions and there will be a denial … we have had several instances where that happened … it's actually … very uncommon now to have someone [from the community] go to an assessment centre."*

If a biological mother is unavailable to provide confirmation of alcohol consumption, or if it is not recorded in a child's birth records, clinicians may gather input from others who had a relationship with the birth mother while she was pregnant. For example, if a close family member is able to provide reliable information and offer details about the frequency of alcohol consumption, that information can be used to help determine a child's diagnosis. However, collecting this information and determining its accuracy can be challenging and raises ethical concerns.

Time-intensive Process

Given the multidisciplinary nature of the FASD assessment process, individual specialized clinicians each conduct their own assessment of a child, often resulting in a very lengthy process for families as a child moves from clinician to clinician. Some assessment teams stagger the assessments over the

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[138] Hon. Dr M.E. Turpel-Lafond, *In Plain Sight: Addressing Indigenous-Specific Racism and Discrimination in B.C. Health Care* (Victoria, B.C.: Ministry of Health) 2020, 20.

[139] Turpel-Lafond, "In Plain Sight," 25.

course of one to three months. Other assessment teams must condense assessments into one or two full days because they have a limited number of available clinicians or they want to minimize the number of times families from rural communities have to travel for assessments. Lengthy assessments can pose a challenge to children being assessed. As one parent described:

> *"We saw an occupational therapist. She spent about three hours with [our daughter] until [she] couldn't safely be in the room anymore. They push you, so they had just elevated [her] and she was … under a desk and had pushed over a bookcase. Yeah. It was long."*

Similar sentiments were echoed by community members who participated in the dialogue sessions. Meeting with multiple clinicians who are unfamiliar to a child or youth, in a new, strange location, and for several hours at a time can be strenuous and overstimulating for many children and youth.

In addition to the assessment itself, an onerous and time-consuming part of the FASD assessment process is gathering historical and current social, functional and medical information about a child, much of which is provided by the family. Some assessment centres support this process through a social worker or an assessment coordinator, or a family's Key Worker may assist. One parent felt the information-gathering and endless paperwork were among the most difficult tasks to complete. She said she did not have a lot of support with this process and was asked several times to fill out the same information.

Age of a Child

Most of the children or youth who participated in this research were diagnosed at a young age – some as young as four or five. This raises some important questions about the apparent tension between early diagnosis and access to services.

> "You can't get a diagnosis before the kid is seven, second grade basically, because CDBC wants to know how the kid is reacting to school structure and support, you know, and difficulty."
>
> —Key Worker

Assessment clinicians involved in our research told RCY that it was best to assess a child after they turned five. As noted in *Fetal Alcohol Spectrum Disorder: A Guideline for Diagnosis Across the Lifespan,* and in interviews with assessment centre clinicians, the guidance is that assessments are not as reliable when children are younger than six.[140] For example, clinicians assess memory and cognitive profiles, but these aspects of a child's brain generally do not develop until a child is older, making it difficult to obtain accurate results if a child is assessed too young.

At the same time, if a child does not have a diagnosis until they are six or older, they are not eligible to receive funding or supports during their critical early years in the public school system – potentially leaving them without supports between Kindergarten and Grade 1 or beyond. Not only is the school district unable to designate the child to receive supplemental funding, but children and youth with FASD often do not qualify for MCFD's CYSN Family Support Services unless they meet other diagnosis-based criteria (discussed later in this report). Clinicians indicated that an early diagnosis allows for more time to implement the appropriate FASD-informed interventions. If the assessment process is delayed until a child is six or older, they could be left without appropriate interventions that could address their needs and help build their skills.

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[140] Cook et al., "A Guideline for Diagnosis Across the Lifespan," 195.

Wait Times and Assessment Team Capacity

Current data on wait times, interviews with assessment teams and discussions with community dialogue participants point to significant challenges in wait times for assessments.[141]

Wait times to have an assessment completed vary from one health authority to the next and were described by a community member as an "*eternal wait list*." Where one region may have an average wait time of 53 weeks (just over a year), another may have a 116-week wait time (over two years) (see Table 2).[142] Assessment team capacity is a factor in the regional variation in wait times, with some assessment teams having challenges recruiting and retaining qualified clinicians. For example, the northern region experiences capacity issues and must rely on clinicians to fly into the region to support assessments, impacting the length of time that it takes to complete an assessment and provide final results and feedback to families.

RCY Wait Time Recommendations

In December 2018, RCY released *Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family*, which includes the following recommendation: *"That the Ministry of Health take steps to incrementally decrease the wait times to three months for completed assessments of autism* ***and complex behavioural developmental conditions [CDBC] across the province****. Wait times to be reduced to nine months by Sept. 30, 2019; to six months by Sept. 30, 2020; and to three months by Sept. 30, 2021."*

Despite this recommendation, the CDBC assessment provincial average wait times increased from 63.5 weeks in 2017/18 to 64.4 weeks in 2020/21. (see Table 2), nowhere near meeting these targets.

As explained by one Key Worker:

> *"We've got a child say in Grade 1 where they're flagged … [for] an assessment, then you go through the process to wait for a pediatrician. Once the referral is made for an assessment, the wait list can be up to 18 months,, so we're talking about three years of schooling that's basically lost and the child by then may be flagged as having as a behavioural issue. The child's school day may be reduced to one to two hours, they miss the whole socialization … there are big implications on that child's future at that point."*

Table 2: Average CDBC Assessment Wait Times (Weeks) Per Fiscal Year[143, 144]

Health Authority Region	2017/18 FY	2018/19 FY	2019/20 FY	2020/21 FY[138]
Interior	53.5	53.1	53.6	71.6
Fraser	64.1	58	54.0	59.4
Vancouver Coastal	67.4	65.4	50.0	53.1
Island	62.9	78.1	97.0	116.9
Northern	70.1	63.6	79.1	89.9
Provincial Average Wait Time	**63**	**62**	**58.00**	**64.36**

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[141] Wait times measure the time between the date of referral to the date of diagnosis (in weeks).

[142] Data provided by Provincial Health Services Authority's STAR B.C. BCAAN/CDBC database on Nov. 4, 2020.

[143] Wait time data is for children and youth referred for complex developmental conditions and/or FASD. Average wait times may vary based on the condition(s) that a child or youth is referred for. In cases where a child has been identified for an FASD, ASD or complex developmental condition, a child may be assessed through the BCAAN assessment stream, which is not presented above.

[144] Data from 2020/21 fiscal year is provided as of Oct. 15, 2020.

Families in Rural Communities

Families located in rural communities may be required to travel several hours to access an assessment clinic. Many community dialogue participants expressed frustration about making this journey, citing this as a common barrier to an FASD assessment. For example, someone in Bella Coola may drive either to Kelowna (nine hours) or Vancouver (12 hours) to have their child assessed. Costs incurred include taking time off work, paying for lodging, food and fuel or flights. This travel can impose financial stress on families, especially for those families experiencing socio-economic barriers.[145] In addition, children and youth with a neurodevelopmental disability can find travelling lengthy distances to an unfamiliar place stressful, overstimulating and dysregulating.

Some assessment teams do travel to communities, so families do not have to make the lengthy trip to an urban centre. For example, the assessment team at Queen Alexandra Centre for Children's Health in Victoria has done outreach trips to Port Hardy, Comox and Port Alberni, among other communities, where they complete multiple assessments within the span of a few days. While this helps to alleviate travel costs and stress for families, these outreach trips are infrequent, creating a further delay in the assessment process and the opportunity for families to learn more about their child's well-being and how to best support them.

Diagnostic Report, Feedback and Building Understanding

Upon completion of the diagnostic assessment process, families meet with the assessment team to discuss the results. An assessment report typically provides feedback about the results, along with recommendations of ways in which a child can be supported with strategies to lessen impacts of the effects of FASD. It highlights a child or youth's strengths and abilities, as well as the areas in which they experience challenges, thereby ensuring the family and support network (e.g., Key Workers, therapists, teachers, doctors) have a more complete understanding of the areas to cultivate and build upon. The assessment report also provides suggestions to address potential areas in which challenges may arise for a child or youth, such as working with an occupational therapist to address motor skills or sensory challenges.

Generally, children do not participate in the meeting to discuss results unless families determine it is appropriate, or if a child or youth has asked to participate. Families may also request that their Key Worker, a teacher or other support person be present, so everyone receives the information at the same time. In some cases, families may request a meeting with the child's school to share the results, especially if the child is experiencing significant challenges in the classroom.

Families, Key Workers and service providers interviewed for this report had mixed feelings about the usefulness of the assessment reports. Some indicated that the medical jargon can be difficult for families to understand , particularly when English is not their first language, and that, in schools, the reports just sit, meaning that a child will not benefit from information provided in the report.

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[145] Some families can access funding through the provincial Travel Assistance Program (TAP) or charitable organizations such as the Children's Health Foundation of Vancouver Island (accessible to Vancouver Island residents). TAP B.C. helps alleviate some of the transportation costs for eligible B.C. residents who must travel within the province for non-emergency medical specialist services not available in their own community. TAP is a corporate partnership between the Ministry of Health and private transportation carriers, whereby the parties agree to waive or discount the regular fees. FNHA offers funding to cover medical transportation for clients to access medically necessary health services not available in their community of residence.

Key Workers shared how the assessment report is a vital resource for families and, with some guidance, the feedback can make a world of difference in supporting their child. One Key Worker said that one of the most important roles they can play is helping a family interpret the report. By helping a family and a child's support network interpret an assessment report, the Key Worker can co-create a starting point for the family to build their knowledge and understanding of their child's unique needs, challenges and strengths. Another Key Worker said the "*lightbulbs start going off*" when they use the report as a tool to foster a process of learning and understanding FASD symptoms.

> "So, for example, Johnny's score in processing speed was well below average … so then I tell [the parent] what they actually mean by 'processing speed' [and what to do]. You ask him to do something, wait five seconds … before you expect a response. One mom, she's like, 'Five seconds changed my life.' … And she wouldn't have wanted to do it unless I could string the connections together."
>
> —Key Worker

It is evident that the assessment reports contain valuable information that can help the family and the child's support network. However, it is important to note that many families need guidance from the Key Worker or the assessment team to understand what the report says and how to utilize this information. If families or support staff are unable to interpret and effectively use the information, there is a risk that the child will not benefit from the learning what is in the report.

Beyond the comprehensibility of the reports, another point of contention and frustration for families is the lack of follow-up after the diagnosis and report are completed. As outlined in *Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis, "The diagnostic profile is dynamic and may change over time; thus, individuals affected or suspected to be affected may require several assessments over time."*[146] One clinician said the lack of follow-up was a critical concern because a child or youth's strengths and needs change over time as they grow and develop:

> *"It doesn't have to be a full FASD assessment but there has to be follow-up at some point with a professional who's familiar with FASD and then can guide things further … we make recommendations and they often need to be adjusted as the child matures or clinical situations or social situations change."*

Bright Spot:
Revamping Assessment Reports

To address the challenges that families experience with interpreting reports, assessment teams have taken steps to improve their reports. One assessment team held a focus group with parents to gather feedback. As a result, the assessment team now provides a short executive summary explaining the results in plain language.

Another assessment team writes an accessible *"family friendly summary"* that does not use a lot of medical terminology, to complement the more medically based report. This same team writes a report specifically for youth attending feedback meetings to learn about their strengths and challenges and it includes recommendations to encourage the youth to build their skills.

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[146] Albert E. Chudley et al., "Fetal Alcohol Spectrum Disorder: Canadian Guidelines For Diagnosis," *Canadian Medical Association Journal* 172, no. 5, (March 2005): S10. https://www.cmaj.ca/content/cmaj/172/5_suppl/S1.full.pdf.

Benefits of FASD Diagnosis

The research did reveal examples where, despite the noted challenges in the assessment process, some benefits came with a confirmed FASD diagnosis, including increased clarity and awareness and understanding of FASD within a child or youth's family and support network, as well as fostering a child or youth's sense of identity, self-understanding and self-awareness.

While an FASD diagnosis can bring difficulties, it can also be helpful for children and youth to gain a better understanding of themselves and why they experience things differently from their peers who don't have FASD. RCY heard this sentiment from youth research participants and community dialogue attendees, with one youth expressing desire for "*learning about myself*."

Participants told RCY that self-understanding must be supported through programs and services, such as programs that teach children and youth with FASD how their brain and bodies can be impacted, so that they are better able to understand how FASD can affect daily living activities. In turn, this knowledge can help them to explain the challenges they face and allow them to better advocate for themselves. Parents in the family research saw the importance of linking self-understanding with self-advocacy and called for the creation of mentor groups so that children and youth can learn from those older than them who have lived FASD experience.

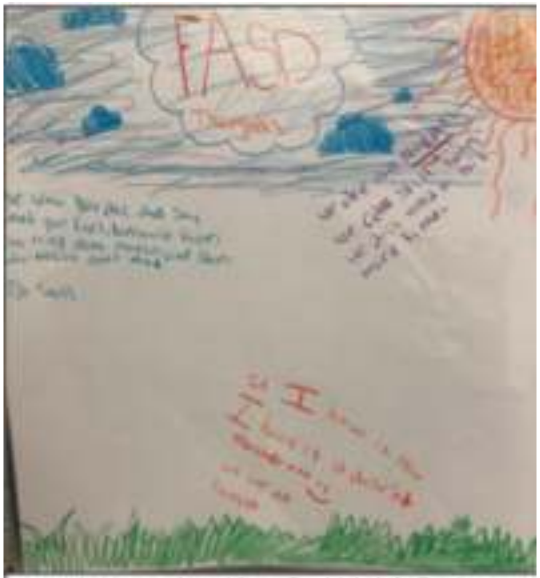

Image retrieved from Sophie's Life Book

In some cases, young adults may seek out a diagnosis for themselves to gain a better understanding of why they face various challenges. This may particularly apply to those who grew up in foster care who may have had multiple placements and social workers and for whom the diagnostic process was not initiated. For children and youth in care or formerly in care, an FASD diagnosis may provide an opportunity to develop a more enduring, informed and positive sense of themselves as they move into adulthood.[147]

STADD Program

MCFD's Services to Adults with Developmental Disabilities (STADD) program offers a personal Navigator to support youth and young adults (ages 16 to 24) with developmental disabilities and their families or caregivers throughout the transitioning process from child and youth services to adult services and supports. A Navigator's main role is to act as a primary point of contact for young adults and their families or caregivers to help coordinate and organize transition planning and access to community and government supports. It is important to note that most youth with FASD are not eligible for a STADD worker unless they are among the small proportion who have been assessed as eligible for Community Living British Columbia (CLBC) services.

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[147] Referred to as "identity permanency," the need to understand yourself has been described in the Representative's consultations with youth advisors as including access to information about their family, the circumstances that led to them being in care, what happened to them while in care, access to assessments so that they better understand the challenges that they might face in areas such as learning, mental health, health and employment and how they might be able to be more successful (such as through developing coping strategies or choosing certain learning or career paths).

> *"What I've learned is sometimes those labels for youth help. [They will say] 'Oh, that's why … I have challenges with showing up on time for appointments or that I don't remember stuff like my friends do.' And so, they can actually say, 'Okay, so now what do I need to do to get better at that?' "*
> STADD Team Leader

Another STADD Navigator described a former youth from care who experienced an immense sense of relief when he received his FASD diagnosis. Growing up, this youth was told that he was "*manipulative*," "*dramatic*," and that it was "*all in [your] head*." The confirmed diagnosis was a revelation for this youth, helping him gain a better sense of himself and his identity and dispelling the harmful labels created by others who did not believe him when he described the challenges he experienced. Input from the community dialogues echoed the ways that a diagnosis can support the understanding of FASD in relation to identity.

Building Understanding

While RCY heard many community members speak about how the diagnosis of FASD comes with barriers, stigma and exclusion, some highlighted how receiving a diagnosis can at times be positive because it also helps parents and support networks better understand a child or youth's strengths and needs, and how to make environmental adaptations to better support their needs.

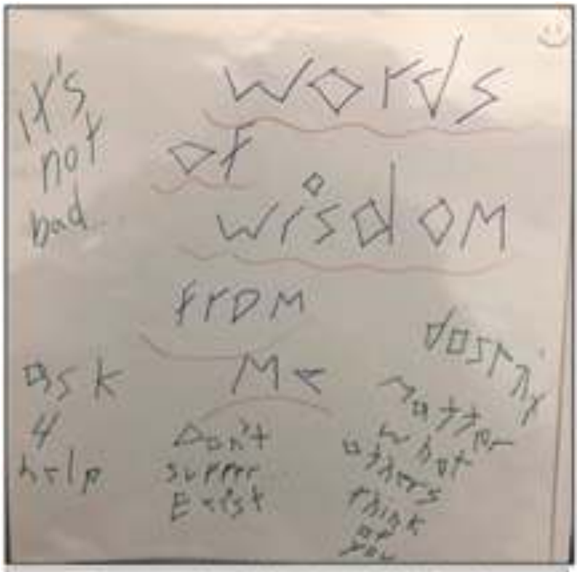

Image retrieved from Lulu's Life Book

The FASD assessment report that is provided to families is also seen as a benefit of an official diagnosis, as it provides recommendations and strategies for support from professionals such as occupational therapists and doctors. In some instances, recommendations are provided to schools so that a child's learning environment is more supportive and addresses their needs. However, while these reports can be a valuable tool, RCY heard from multiple sources, including parents, community dialogue participants and service providers, of examples where schools had not used the report in a child's planning.

Inadequate Supports Post Diagnosis

The assessment process is complicated, involves many clinicians and can consume a lot of a family's time and energy. In addition, there can be a sense of false hope with a diagnosis. Families and community dialogue participants shared how hopeful they felt when their child was being assessed, as they thought a confirmed diagnosis would help them access supports. Yet this was not the case.

> "The lack of services for children … diagnosed with FASD is very frustrating and difficult for families to understand. If you have the intellectual disability diagnosis or the autism diagnosis, you get supported by [the] Children and Youth with Special Needs [program]. But your child [with FASD] has the same needs and because it's FASD, there is no support."
>
> —Clinician

Other eligibility criteria must be met that most often prevents families from accessing provincially funded supports.[148]

The long road to an FASD assessment and diagnosis leads to few, if any, follow-up supports. This will be explored in the next finding.

Finding: *Inequity in B.C.'s special needs system leaves children and youth with FASD and their families without access to most support services*

Research shows that when supports for children and youth with FASD are appropriately tailored to their neurodevelopmental strengths and challenges, their skills can grow and adapt.[149, 150] Despite this, RCY heard from families, community dialogue participants and service providers that support services for children and youth with FASD in B.C. are nearly non-existent.

Families who participated in this report were exasperated with the lack of supports. Likewise, clinicians, Key Workers, service providers and community dialogue participants echoed their frustration with this issue. RCY heard time and again that the lack of services is directly connected to eligibility criteria based on diagnosis or other narrow criteria – rather than functional need. In addition, FASD has been left undefined in the B.C. service delivery model – meaning that, as a diagnosis, it slips through the cracks of almost every program stream.

A recurring issue expressed by families and community dialogue participants was the lack of funding for any available programs or services. Without essential funds, families struggle to meet their child's social, emotional, mental and physical health needs. The result is that children and youth are unsupported in their disability, limiting their abilities, quality of life and mental health and well-being.

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[148] Interviews were conducted with each publicly funded assessment team across the province. Non-profit and private assessment centres were not within the scope of this project. The objective was to gain a stronger understanding of the assessment process, reasoning for the complexity of the process, understanding of regional contexts and to hear about strengths, challenges and results for children and youth with FASD and their families or caregivers.

[149] Christie L. M. Petrenko, Mary E. Pandolfino, and Luther K. Robinson, "Findings from the Families on Track Intervention Pilot Trial for Children with Fetal Alcohol Spectrum Disorders and Their Families," *Alcoholism: Clinical and Experimental Research* 41, no. 7 (May 2017): 1340-1351. https://doi.org/10.1111/acer.13408.

[150] Christie L. M. Petrenko, "Positive Behavioral Interventions and Family Support for Fetal Alcohol Spectrum Disorders," *Current Developmental Disorders Reports* 2, no. 3 (September 2016): 199-209. https://dx.doi.org/10.1007%2Fs40474-015-0052-8.

RCY also heard about the impacts of intergenerational FASD during community dialogues and from service providers. Participants in one community said that FASD can sometimes exist across three generations – grandparents, parents and children. This can lead to increased involvement with the child welfare system as community dialogue participants described the lack of supports both for the parent and now also for the child. Some First Nations dialogue participants called for the provision of supports to the entire family in such cases, so that families can stay together in a healthy and safe way.

Developmental Disabilities

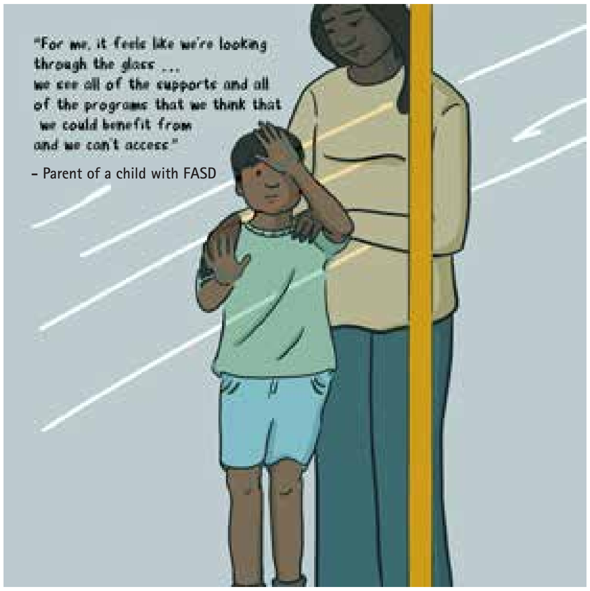
Developmental disabilities are understood as a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime. In B.C., this term is much narrower and is used to determine eligibility for services. The term is akin to the DSM-5 criteria for intellectual disability, meaning that an individual has significant impairments in intellectual functioning (an IQ score under 70) that manifest before the age of 18, which exist concurrently with impaired adaptive functioning.

In addition, a recent RCY report, *Left Out,* released in December 2020, details the on-going and severe challenges that many children with special needs experience when their diagnosis precludes them from accessing the scant resources and programs that are available. RCY's report *Alone and Afraid* (2018) also identified the inadequacies of services even for those who are eligible for services. The emphasis on diagnosis-based – rather than needs-based – eligibility creates significant inequality among families, children and youth with special needs, and results in hardship for families whose children's needs don't fit within a program's narrow criteria.

Exclusionary Eligibility Criteria

Families told the RCY that the inability to access services because their children do not meet specific program eligibility criteria is one of the greatest barriers to support that they face. Key workers at one agency described seeing this exclusion clearly because they work within an agency that supports children accessing CYSN supports. They describe the inequity they witness and the frustration when they can not link the family they are trying to support with services because their diagnosis does not open the right doors:

> *"The obvious gap … in an agency like ours, which has a lot of CYSN funded supports – families [can] access a whole range of services [when] their child has the diagnosis that opens that door [to services], and FASD isn't one of [those diagnoses]. So that's an obvious inequity that we struggle with."*



"For me, it feels like we're looking
through the glass …
we see all of the supports and all
of the programs that we think that
we could benefit from
and we can't access"

– Parent of a child with FASD

In reviewing eligibility criteria for services that support children and youth with disabilities, RCY researchers found that young people with FASD are typically excluded from them. These include CYSN, Developmental Disabilities Mental Health Services (DDMHS) and the Community Brain Injury Program (see Appendix D).

Children and Youth with Support Needs Services

CYSN services are available to families through MCFD. These services provide eligible children, youth and their families or caregivers access to a number of supports included in several streams of Foundational Programs for children who have – or are at risk for – a developmental delay or disability. Included in CYSN services are the Infant Development Program, Aboriginal Infant Development Program, Aboriginal Supported Child Development, Supported Child Development, the School-Aged Therapy program and Early Intervention Therapies (EIT). A confirmed diagnosis is not required to access these programs. While some of the families in this report accessed EIT, this support ended once their child turned six.[151]

In addition to Foundational Programs, CYSN offers Specialized Provincial Services. These include the Autism Funding Program, At Home Program medical benefits, At Home Program respite benefits, Provincial Deaf and Hard of Hearing Services, Provincial Outreach and Professional Support, Community Brain Injury Program, and Family Support Services.

To support their children with various interventions, families included in this research hoped to access funding, respite and behavioural supports through Specialized Provincial Services and Family Support Services available through CYSN service delivery. People who meet the eligibility criteria for these services can access a CYSN worker who helps with the following activities:

- Case management – Coordinate with the family and the care team
- Agreements – Administration of At Home and/or Direct Funding Agreements, Support Service Agreements and other agreements as needed
- Respite services – Families receive an interval of rest and relief, provided through either contracted respite or funding directly to families to purchase respite services
- Support services – A range of programs to support parents to care for their child or youth with special needs in the home. Examples of available supports include access to a child and youth care worker; behaviour supports; parenting skills training and support groups; counselling; household management services; and life skills activities or programs for children and youth
- Transition planning to support youth with support needs as they approach adulthood.

While these supports may seem potentially helpful, each service has highly restrictive eligibility criteria. Parents expressed a strong desire and need for Family Support Services. However, to be eligible, a child or youth who is a B.C. resident and under age 19 must meet one of three streams of eligibility:[152]

1. Developmental disability (DSM-5 criteria for intellectual disability and significant adaptive functioning impairments)
2. Autism/ASD (autism diagnosis)
3. At Home Medical Benefits Program.

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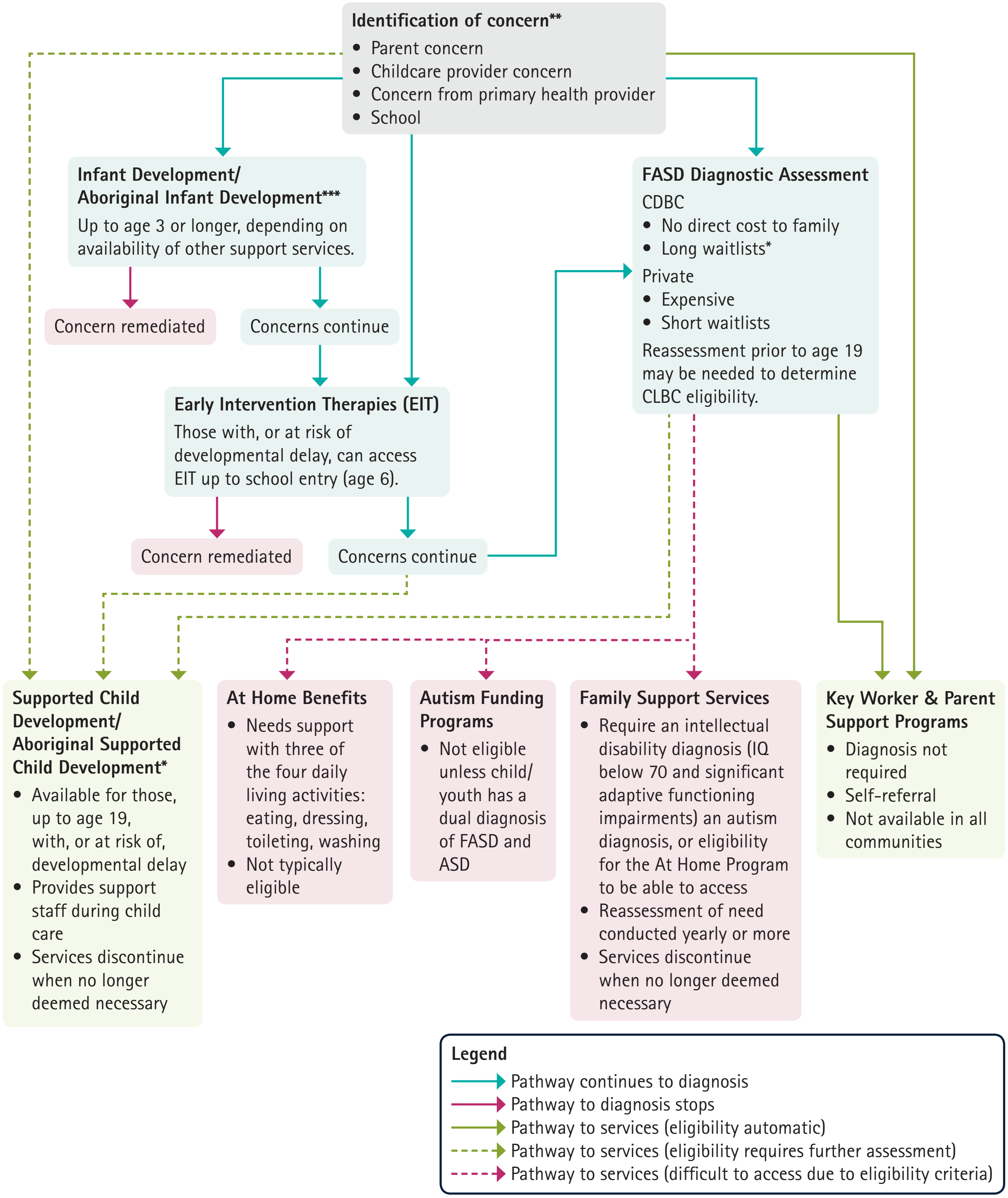
[151] It is unclear how many children with FASD and their families access EIT and how well these programs address the needs of children with FASD who do access these services.

[152] Children under five years of age who have been diagnosed with Global Developmental Delay (GDD) are eligible for CYSN Support Services. Children must be re-assessed at age seven to determine the child's ongoing eligibility for CYSN Support Services.

Figure 2. Pathways to CYSN Services – FASD Diagnosis



* Wait list for each service varies depending on agency delivering services and regional location.

** This pathway assumes identification for a young child. Services such as IDP/AIDP or EIT would not be available for children identified after the age of six.

*** For this research, it is unclear how often children/youth with FASD access IDP/AIDP as none of the families, Key Workers, clinicians or other interviewees spoke about accessing this service.

Most children and youth with FASD do not meet the criteria for the At Home Program, and very few children and youth with FASD are concurrently diagnosed with autism. This means that to access Family Support Services, a child's diagnosis must specify that they have an intellectual disability as outlined in the DSM-5, meaning the child's IQ score must be 70 or lower and they must also have significant deficits in general cognitive abilities that impact adaptive functioning (e.g., language, reasoning, social judgment personal care). While some children and youth with FASD may have an intellectual disability, the children and youth included in this research were all deemed ineligible for CYSN services because they did not meet this criterion.

MCFD was unable to tell RCY how many children and youth with FASD access CYSN services, as the ministry does not collect this data. However, anecdotal evidence from professionals and families interviewed for this report suggests that most children and youth with FASD are excluded from CYSN. As one clinician said, *"[Children and youth with FASD] fall through the cracks because the kids with FASD, upwards to 90 per cent will not have an intellectual disability."*

Of the 925 children and youth in B.C. diagnosed with FASD in the two-year period 2016/17 and 2018/19, approximately 75 per cent did not receive an intellectual disability diagnosis.[153]

In fact, of the 925 children and youth in B.C. diagnosed with FASD in the two-year period 2016/17 and 2018/19, approximately 75 per cent did not receive an intellectual disability diagnosis, making them ineligible for CYSN Family Support Services.[154] While most children and youth with FASD do not have an intellectual disability, many still require significant support to address some of their cognitive, mental, emotional and social challenges.

Multiple families involved in this research cited respite as a key support they wish they could access in order to help alleviate some of their stress. This need for respite for families was echoed by community dialogue participants and service providers. Families can receive funding for respite and support workers through Family Support Services. However, even if a family is able to access respite services, there are often lengthy wait lists, the funding only covers a few hours of respite, and appropriate caregivers are difficult to find.[155, 156, 157]

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[153] Data provided by Provincial Health Services Authority's STAR B.C. BCAAN/CDBC database on June 22, 2020.

[154] Data provided by Provincial Health Services Authority's STAR B.C. BCAAN/CDBC database on June 22, 2020.

[155] Representative for Children and Youth, *Left Out: Children and Youth with Special Needs in the Pandemic*, (Victoria, B.C.: Representative for Children and Youth), 2020, 1-68.

[156] Representative for Children and Youth, *Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family*, (Victoria, B.C.: Representative for Children and Youth), 2018, 1-124.

[157] As noted in the Representative's report *Alone and Afraid*, "RCY investigators were informed by MCFD that it does not centrally track the number of B.C. families waiting for respite services or the length of time they have been waiting. The extensive wait lists for respite are regionally managed by each service delivery area in the province on separate spreadsheets. Without any provincial oversight, it is impossible for MCFD to know how effective and accessible this program is or to determine the amount of funding that would be necessary to adequately support this program." (p. 67)

In the absence of respite funding, some parents spoke about their reliance on extended family members for support, although others were not as fortunate. Without the appropriate respite or assistance from a support worker, relationships within families who have children with FASD can become tense. As one parent shared, *"I would like to be her mom and I don't spend as much time being her mom as I would like. I'm her case manager and her at-home nurse and her support worker and her teacher … and a secretary and a medical transcriptionist … [and] I think that affects our relationship."*

MCFD CYSN Service Framework Update

MCFD is in the process of developing a new CYSN Service Framework that intends to move away from a diagnosis-based service delivery model to a needs-based model. The goal of the new service framework is to improve access to services that will address the specific needs of children and families, knowing these needs change during developmental stages or based on a child and/or family's life circumstances.

The new CYSN Service Framework will provide overarching guidance on how CYSN programs and services are delivered. This includes the Foundational Programs, Family Support Services and Specialized Provincial Services and includes families and caregivers involved with Special Needs Agreements.[158] The framework is intended to clarify MCFD's system of supports, guide planning and establish a service approach driven by the needs of a child and/or family while reflecting current research.

The Representative looks forward to the release of this framework and the steps that MCFD will take to revise policies, put plans into place and evaluate the efficacy of the changes. However, the Representative also notes that – as outlined in past RCY reports *Alone and Afraid* and *Left Out: Children and youth with special needs in the pandemic* – the current system of CYSN services does not come close to meeting the needs of children, youth and their families or caregivers who are already eligible for services. Therefore, a substantial investment of new resources will be required to provide adequate services to those who are currently eligible for services as well as to meet the needs of those who are currently ineligible, such as children and youth with FASD.

Developmental Disabilities Mental Health Services (DDMHS)

DDMHS is a program provided through the five regional health authorities. DDMHS offers multidisciplinary mental health community services to people who live with co-existing developmental disabilities and a mental illness. The multidisciplinary team may include a psychiatrist, counsellor, behavioural consultant and/or nurse, as well as other consultants (e.g., occupational therapists).

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[158] Special Needs Agreements are entered into when a child or youth with special needs must live outside their parents' home because in-home supports are not available to meet a child's or youth's special needs. (Source: Ministry of Children and Family Development, *Family Support Services and Agreements* – Chapter 2, (Victoria, B.C.: Ministry of Children and Family Development, 2020).

DDMHS is partially funded by MCFD and is available to children and youth between 14- and 18-years-old with a referral from a CYSN worker, a physician, a nurse practitioner or a paediatrician.[159, 160] For people ages 19 and older, referrals can be initiated by CLBC, the individual, a family member, a physician, or anyone else in the person's support network. To be eligible for these services, the person must meet the following criteria:

- be a minimum of 14-years-old
- 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 age 18
- meet CYSN or CLBC service criteria.

Since the majority of children and youth with FASD in B.C. do not have an intellectual disability, the eligibility criteria for DDMHS results in numerous children, youth and young adults with FASD being turned away from this service. Additionally, the people who are eligible to access this service must have a serious co-existing mental health challenge as well as their developmental disability. This means that children, youth and young adults must present severe challenges before accessing this service – the service is not available to help prevent mental health disorders from emerging.

Brain Injury Programs and Associations

FASD is often described as a brain injury or brain damage, because a child or youth's brain was injured due to exposure to alcohol while in utero.[161] Children and youth with FASD can face similar challenges to children and youth who acquired a brain injury after birth. While some children or youth who acquired a brain injury after birth may have physical disabilities, many of the effects of brain injury are "invisible disabilities," which is akin to the effects of FASD. These invisible disabilities may include challenges with learning, memory, attention, processing speed, problem-solving and behaviour/emotional regulation challenges.[162]

> "We would present it in a very non-judgmental [way] ..., 'You have a brain injury, and it's a permanent brain injury.' Then, when she would ask questions, 'I don't understand why this is so hard for me,'... we say, 'It's because of your brain injury.' "
>
> —Parent

> "You have a brain injury, my love, and so we will have to give you extra help to learn this thing. The reason you are struggling with this is because of your brain injury, baby."
>
> —Parent

The B.C. Centre for Ability (BCCFA) is contracted by MCFD to coordinate and fund the Community

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[159] The Fraser Health Authority region is the only health authority that offers DDMHS to children ages 12 and older.

[160] It is important to note that the age range, services offered, and referral streams vary slightly between health authority regions as it depends on the capacity of the DDMHS team in each region. For example, the Fraser Health Authority offers services to children starting at age 12, whereas other health authority regions start at 14 years old.

[161] Government of Canada "About Fetal Alcohol Spectrum Disorder (FASD)," Fetal alcohol spectrum disorder (FASD), last modified May 25, 2017, https://www.canada.ca/en/public-health/services/diseases/fetal-alcohol-spectrum-disorder/about.html.

[162] Brain Injury Canada, "Acquired Brain Injury: The Basics," accessed October 11, 2020, https://www.braininjurycanada.ca/wp-content/uploads/2019/02/ABI-The-Basics_PRINT.pdf.

Brain Injury Program.[163] The BCCFA contracts with local service providers to provide short-term (six months) intensive community-based rehabilitation throughout the province for children and youth with an acquired brain injury.[164] To be eligible for the Community Brain Injury Program, clients must meet the definition of acquired brain injury, meaning that a child or youth can only access services if they are diagnosed with a brain injury as a result of a fall, infection, tumour, stroke or other causes, and the child's injury or diagnosis must have occurred within the last 12 months.

While the Community Brain Injury Program is not a provincial service that parents of children and youth with FASD would typically turn to, one family who took part in this report spoke about FASD as a brain injury and described reaching out to her local Brain Injury Association as a last resort after being turned away from many other supports and services:

> *"I actually called the Brain Injury Association and they didn't – they were blown away that I called them. They said, 'I don't understand why you would be calling us.' I'm like, 'Because she has a brain injury.' They're like, 'No'."*

Since the eligibility criteria and definition of acquired brain injury are so narrow, children and youth with FASD are unable to access this service, either.

Child and Youth Mental Health Services

All the children and youth in this report experienced mental health challenges. In listening to the lived experience of families and community dialogue participants and the perspectives of service providers and clinicians, it appears that these mental health issues are at least partially related to the stigma, lack of understanding, lack of supports and the exclusion and isolation that children and youth with FASD experience.

"We're putting time and money on my child's well-being. So that piece is hard. You're telling me that he's not worth that time and money. And that ... you can't help him?"

—Parent

Findings in the literature highlight that mental health challenges, including anxiety, mood disorders and depression, are prevalent among people with FASD.[165, 166] One youth participant said:

> *"[A] difficulty I have as a result of my FASD is extreme anxiety. I'm easily overwhelmed when things come at me too fast or when I'm not sure what's going on. I'm bothered by a lot of noise around me such as people talking unnecessarily loudly and being in places with lots of people speaking at once. Too many work assignments all at once also makes me anxious. I need to have really clear instructions in advance because it is difficult for me to get started and it's really hard for me to ask for help. Sometimes I need things explained again because when I am anxious, I can't think clearly, and I forget things. When I'm stressed it may cause me to isolate myself and withdraw from certain situations or people."*

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[163] Community Brain Injury Program for Children & Youth in British Columbia, "Welcome to CBIPCY," Community Brain Injury Program, accessed August 28, 2020, http://mybrainonline.ca/?page=2#Accessing_Our_Services.

[164] A total of 139 and 126 children and youth were served through the Community Brain Injury Program during the 2018/19 and 2019/20 fiscal years, respectively. This data was provided to the Representative by MCFD on Oct. 23, 2020.

[165] Jacqueline Pei et al., "Mental Health Issues in Fetal Alcohol Spectrum Disorder," *Journal of Mental Health* 20, no. 5 (October 2011): 440-441. https://doi.org/10.3109/09638237.2011.577113.

[166] Popova et al., "Comorbidity of Fetal Alcohol Spectrum Disorder," 7.

Families stressed the need for FASD-informed mental health supports. Besides DDMHS that is delivered through health authorities, MCFD provides Child and Youth Mental Health (CYMH) services.[167] CYMH services are available on a referral basis to a child or youth experiencing mental-emotional health challenges. A variety of services and specialized programs are offered and can include the involvement of clinicians, clinical social workers, psychologists, nurses and outreach workers.

There are also approximately 100 CYMH drop-in intake clinics available throughout the province. CYMH services have a high volume of clients, often with wait lists and a limited capacity to deliver a full spectrum of services, which has been a serious concern raised by the Representative in the past. [168, 169] These service gaps were acknowledged by the Ministry of Mental Health and Addictions in its 2019 publication *A Pathway to Hope*.[170] When RCY asked MCFD to provide the numbers of children and youth with FASD who are accessing CYMH, the ministry said it was unable to. MCFD explained that a diagnosis of FASD is not captured systematically and that FASD diagnosis is not extracted for tracking purposes.[171]

Even if a child or youth with FASD is able to access CYMH, the support methods that are commonly used are not always appropriate to meet the needs of this population.[172] For example, CYMH commonly offers group drop-in counselling and cognitive-behavioural therapy, but families who took part in this research told RCY that these methods are seen by them as not suitable for a child or youth with FASD. As one parent shared:

> *"We went through the whole intake. We were there for five hours. They're like, 'All the programs we have either are too young for her', or she didn't need them … they didn't have anything, so they discharged us the same day."*

Families, Key Workers and clinicians described instances where a child or youth was turned away from CYMH because the workers did not know how to provide support. As one Key Worker shared:

> *"If the child had an FASD diagnosis I would immediately receive a phone call saying: 'Hey, can you see this kid? We [CYMH] don't work with kids with FASD … you know the way we do things isn't going to work with them.' I say, 'Well, if you're only talking about face-to-face, eye-to-eye … – you are right, it ain't gonna work. But my hope would be you would use whatever modality would work. And … nobody is referring a child to you so you fix their FASD; they are being referred to you because 80 per cent of people with FASD will also have a mental health issue, and those have been identified on the referral form. So … could we focus on some of those things? The FASD is just part of who the kid is – it's not something you're going to fix. Work with them the way they need to be worked with.'"*

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[167] Most CYMH core services are delivered by MCFD, except in Prince George where services are contracted, and Vancouver and Richmond where services are fulfilled by Vancouver Coastal Health.

[168] RCY staff heard anecdotally of long waitlists; however, the Representative has concerns on the quality of provincial data regarding waitlists for CYMH. For example, the Representative is seeking clarity from MCFD on how the information is captured, how those on the waitlist are defined (intake appointments, initial appointments, service streams), who is included (i.e., Aboriginal CYMH), and what regions are counted.

[169] Representative for Children and Youth, *Still Waiting: First-hand Experiences with Youth Mental Health Services in B.C.* (Victoria, B.C.: Representative for Children and Youth), 2013, 1-127.

[170] Ministry of Mental Health and Addictions, *A Pathway to Hope: A Roadmap for Making Mental Health and Addictions Care Better for People in British Columbia* (Victoria, B.C.: Ministry of Mental Health and Addictions) 2019, 1-35.

[171] Information provided by MCFD to RCY through a data request. This information was received on Aug. 20, 2020.

[172] Elizabeth Peadon et al., "Systematic Review of Interventions for Children with Fetal Alcohol Spectrum Disorders," *BMC Pediatrics* 9, no. 35 (May 2009): 2. https://doi.org/10.1186/1471-2431-9-35.

One parent recounted how the CYMH door was closed to her child after an FASD diagnosis:

> *"We'd been working with [the CYMH clinician] possibly three months, seeing her every week, working with her through all this anxiety. She said, 'Let me know how your IHCAN [Interior Health Children's Assessment* Network] goes.*' I phoned her that day, in tears … and said, 'He got an FASD diagnosis.' And she says, 'Yeah, I just wanted to let you know that we're going to close the file now and there's nothing else we can do to help you.' Literally shut the door that day. Never heard from her again."*

Parents, community dialogue participants, professionals and service providers indicated multiple times that there is a significant need to train mental health practitioners to be FASD-informed and to understand appropriate methods to use to support a child with FASD in their mental, social and emotional development. One clinician told RCY that the lack of specialized mental health support for children and youth with FASD in B.C. is a "*huge deficit"* and that children and youth with FASD who also have a mental health issue *"fall through the cracks."*

The Representative agrees with concerns about identifying and implementing appropriate mental health service modalities for these children. RCY has commissioned the Children's Health Policy Centre at Simon Fraser University to undertake a review of the literature in relation to the prevalence of mental health disorders amongst children with special needs – including FASD, ASD and developmental disability – and effective mental health interventions for the same. These reports will be released in the coming months.

RCY also heard that a major challenge with CYMH is that support is crisis-driven rather than preventative – for one child, this meant that they received only eight weeks of support to address their crisis. Families expressed that these time-limited supports are not appropriate for children and youth with FASD as these children require ample time to build a relationship with mental health clinicians to have consistency over time.

One of the potential issues affecting CYMH support for children and youth with FASD is clinicians' lack of training and understanding of FASD. MCFD informed the Representative that there is no dedicated training for CYMH clinicians that specifically addresses supporting a child or youth with FASD, but that there are three courses available that include some information pertaining to FASD that CYMH clinicians can access (Appendix F).[173]

Of the courses that are available, few CYMH clinicians enrol. MCFD course enrollment data indicates that, over a three-year period, only eight CYMH clinicians completed a course that included just one slide about FASD, while 49 clinicians enrolled in a course that contained just one paragraph about FASD (see Appendix F).

The *CYMH Service Framework* does acknowledge that some children and youth accessing CYMH will need specialized service, which includes those with co-occurring developmental disabilities (including FASD) and mental health.[174, 175] The framework says that assessment and treatment for this population occurs through partnership with other ministries and the various health authorities. The framework

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[173] Information provided by MCFD to the Representative through a data request. This information was received on Aug. 20, 2020.

[174] Ministry of Children and Family Development, *Child and Youth Mental Health Service Framework* (Victoria, B.C.: Ministry of Children and Family Development) 2019: 1-13. https://www2.gov.bc.ca/assets/gov/health/child-teen-mental-health/cymh_service_framework_2019-20.pdf.

[175] The service framework includes FASD in its definition of developmental disability.

acknowledges that providing such services requires specialized training, noting that it is not always possible to have such competencies on each CYMH team.[176]

While the MMHA's 2019 mental health and addictions strategy, *A Pathway to Hope*, includes a focus on child and youth mental health, it is silent on mental health supports for children and youth with special needs or diverse abilities, including those with FASD.[177]

Inequitable Distribution of Supports

This report shows that many services focus on providing support to children and youth based on their diagnosis and not on their needs (e.g., Family Support Services, Autism Funding Program, DDMHS, Community Brain Injury Program). The narrowly defined eligibility criteria results in an inequitable distribution of, and access to, supports for children and youth with disabilities and their families or caregivers.

On many occasions, parents described to RCY researchers how other children and youth with similar developmental, behavioural and functional needs as their child were able to access services because they had a diagnosis that fulfilled the eligibility criteria, but their own child was excluded from receiving any supports because they did not have the right diagnosis. Key Workers, clinicians, community dialogue participants and other service providers also expressed their frustration at the inequitable distribution of services.

The Autism Funding Program offered by MCFD was repeatedly used as an example to illustrate this disparity. Children and youth with ASD can face similar challenges to children and youth with FASD (e.g., strong sensory aversions, cognitive delays, executive and adaptive functioning challenges), yet children and youth diagnosed with ASD are offered guaranteed funding for services while children and youth with FASD and their families who participated in this research say they are struggling to find supports – an experience heard across the board, from community dialogue participants to the professionals working to try and find supports for these young people and their families or caregivers.[178]

The Autism Funding Program provides funding for children and youth diagnosed with ASD if they are residents of B.C.[179] Funding is renewed annually and can be used to assist with the cost of purchasing eligible autism intervention services that promote a child or youth's communication, social, emotional and functional life skills development.[180] Additionally, children and youth diagnosed with ASD are eligible to access Family Support Services, even if they do not have an intellectual disability.

> "And not everybody that has autism has an intellectual disability. Which makes me crazy because they have access to CYSN. … And there's so many similarities between FASD and autism. That's what makes me crazy."
>
> —Parent

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[176] Ministry of Children and Family Development, *Child and Youth Mental Health Service Framework*, 1-13.

[177] Ministry of Mental Health and Addictions, "A Pathway to Hope," 1-35.

[178] Somer Bishop, Sheila Gahagan and Catherine Lord, "Re-examining the core features of autism: A comparison of autism spectrum disorder and fetal alcohol spectrum disorder," *Journal of Child Psychology Psychiatry* 48, no. 11 (2007): 1112. https://doi.org/10.1111/j.1469-7610.2007.01782.x.

[179] Children diagnosed with ASD receive $22,000 per year from birth to five-years-old and children and youth from six to 18 receive $6,000 per year.

[180] Ministry of Children and Family Development, "Eligibility for Autism Programs Policy", Last modified June 2015.

One community dialogue participant gave an example of the tension this inequity creates, saying, "*I have a child who has autism and they have access to many more supports than my child with FASD. My child with FASD deserves support in a similar fashion to my child with autism.*"

Ashley's Story

Sometimes it's just easier for Maggie to tell people that her 11-year-old daughter Ashley has autism spectrum disorder, and leave out the part about her daughter also having FASD. She wishes she didn't have to, but sometimes it's just easier to go with ASD than try to explain a stigmatized and misunderstood condition like FASD, says the busy mom of five.

In fact, the increase in support that Ashley started getting after her ASD diagnosis a year ago has astounded Maggie, who had not been able to get anywhere near that level of support in the years when Ashley's sole diagnosis was FASD. Like every parent of a child with FASD, Maggie and husband Rick have had to fight hard to get help for their daughter – and talking openly and often about FASD is critical to that advocacy.

Ashley's interactions with others are both her greatest strength and her greatest challenge. In the journal she kept for the RCY project, she happily noted in one entry that *"I helped a little boy!"*, and marked that observation with a smiley emoji.

Her family admires and loves her for her bravery, kindness, creativity and boundless energy. "*She is not afraid to put herself back out there, so I'm really proud of that,"* says Maggie. "*Her interactions with people are very hard for her, but if she has made a bit of a mess of it, she is so good at going back and saying, 'I'm sorry that it didn't work out last time. Do you want to play?'* "

The times when she reacts impulsively and inappropriately in social settings and with family and friends pose an endless challenge, both for Ashley and her support circle. *"I was mean to Nana and sad,"* she wrote in her journal.

"When she has made mistakes and it's clear she has hurt somebody she loves, she really feels that deeply. I think that piece would be what is hardest for her," says Maggie.

Ashley loves being involved in activities and events, and can even get herself out of a burst of anti-social behaviour if somebody comes along to distract her with a task they need help with. But without sufficient support outside of the family home, the only people able to play that role are her parents, and they're sometimes just too tapped out with all of life's other demands.

"I would love to be doing more mother daughter things," says Maggie. *"I tried to take Ashley to clay classes with me. She just can't maintain. We would have to go so many times unsuccessfully before she would have a capacity to work in that environment and I don't have that capacity."*

Having a community support worker for Ashley – and respite for her family – would help immensely with that dilemma, Maggie adds.

"Ashley wants to be in dance class, she wants to be in tap. But she would need a support person to be there, just to keep her there because the flight risk is an issue. I expend so much energy prepping her that I then don't have energy to do all of that and come home and still be her mom. The amount of times we have to do something unsuccessfully – and the energy we expend just managing the environment – is more than I can often do. And so I have to let go of the activity."

The thought of Ashley involved in any activity without an adult to watch over her frightens her family. With her fearless nature and a high pain threshold, Ashley is at high risk of putting herself in unsafe situations, whether that's running into traffic after getting angry about something and bolting away from whoever she's with, or swimming into deep water beyond her capability.

"You know that tether that kids have, where it's like, 'I'm going to get angry and I'm going to stomp off, but I'm only going to go so far'? Ashley doesn't have that," says her mom.

"I've found her two kilometres from our cabin in the woods picking flowers. Two kilometres. She'll go as far up a tree as she can and never gets scared. She has no sense of danger, so it's a massive risk for us."

At the same time, Ashley's energy and independent nature are also her strengths. More support would mean more opportunities to build on those strengths.

"Ashley is very strong, very brave, very creative, very forgiving," says Maggie. *"I'm really proud of her empathy and her loving nature. She has a deep love of things and people."*

Connection to Culture and Community Involvement

Participants in each RCY community dialogue stressed the importance of community involvement in supporting their children, as well as the vital importance of connection to culture for First Nations children and youth with FASD. Although this importance was heard specifically in the context of the First Nation community dialogues, RCY acknowledges that connection to culture and community is a protective factor for all children and youth.

Dialogue participants emphasized that First Nations culture is traditionally strengths-based and recognizes the importance of an individual's history and context. Community dialogue participants shared how everyone was valued for the different gifts and roles they play and that there are "*historical ways of being in community where everyone is seen as having purpose*." Participants relayed that, in many First Nation cultures, "*People accept people for who they are … but when interfacing with the larger culture, they suffer*." It was evident in the community dialogues that support

Bright Spot:
Live-In FASD Education (LIFE) Sessions

Live-in FASD Education (LIFE) Sessions provided by the Whitecrow Village FASD Society is a strong example of a positive FASD-informed program. LIFE Sessions began in 1996 with a mother of eight children whose needs were not being met at mainstream camps. Frustrated by a lack of staff flexibility and knowledge to meet the needs of her kids, this passionate mother started her own camps, inviting families of children with FASD to attend and learn together. These LIFE Sessions provide a morning workshop for adults while staff work with the children and youth. Each day has a schedule, ensuring consistency and structure for participants. Most of the staff also have FASD and know how to work with children, youth and families with unique needs. While beneficial to attendees, the camps also benefit staff as they feel empowered and fulfilled by the experience of working with others with FASD.

LIFE Sessions occur across Canada, depending on the funding source, and families pay what they can. There is always a wait list to attend. Whitecrow keeps in touch with families who have attended the camps, and several families have come back multiple times – a testament to the success of the program. One participant described a tremendous feeling of safety and belonging at the camp, saying how much the camp changed their family's life.

rooted in First Nations ways of knowing and being are crucial to the wellness of children, families and communities affected by FASD – just as it is for those not affected. This includes connection to Elders, land, ceremony, cultural activities and language, and the need for cultural teachings to be embedded in any training about FASD. In addition, community dialogue participants emphasized that supports must be holistic, and delivery planning and the development of supports must include children and youth, their families and the community as a whole.

RCY heard from participants that First Nations governments and communities have the right to lead the development and delivery of programs for children and youth with FASD and their families, and that they are in the best position to determine the supports required by their Nation. Community dialogue participants were clear that the capacity to develop and deliver programs exists within their communities and that support and resources to sustain such programs is what is needed from the provincial and federal governments, rather than programs developed by government and then slotted into First Nations communities.

For example, one community dialogue included discussion about the Community Healing and Intervention Program (CHIP). Developed in the 1990s by the Nation, CHIP was researched and designed to provide a culturally sensitive, holistic approach to prevention, intervention and service delivery for children, families and communities impacted by FASD. The program was developed with a focus on learning how people experience living and learning with FASD. The goals of the program were to: raise community awareness of and willingness to prevent FASD; develop the ability of families, caregivers and the community to meet the needs of children and youth with FASD; and develop identification, assessment and intervention mechanisms.

Community dialogue participants told RCY that the CHIP program helped to remove the stigma and shame attached to FASD and promoted greater understanding, compassion and learning. The program was evaluated by researchers from UBC and found to be very effective. The program had a positive impact on individuals with FASD, mothers who consumed alcohol during pregnancy, teachers, families, employers and community leaders. However, the program was unable to continue when it lost provincial funding in the early 2000s, although community leaders are hoping to revive the program to fit current community needs.

In another example, RCY heard about the impacts of an ongoing camp and alternative learning environment that incorporates a First Nations approach to learning and an FASD-informed lens in its work with children and youth in one small, isolated community on the coast of B.C.

The program was developed as a response to a community crisis in which local youth were not graduating from high school – something that severely limited their future opportunities. The community responded by establishing a program in which the young people got the opportunity to board boats, sail up the inlet from the community, set up camp and live together in the wild. The focus was on building relationships with one another and developing plans for their future. Through collective planning with the young people, the community set up an alternative school that fit the learning needs of these youth. The community also set up small businesses in which the young people could work and learn skills. As a result, the program director says, *"those kids, a lot of them turned the corner. Many of them are now working in the band or have degrees and they're doing their own business and so on."*

Financial Barriers

Families shared with RCY how they address their children's various needs, especially sensory sensitivities and related overstimulation, anxiety or dysregulation. Some have noise-cancelling headphones for their children when in crowded spaces and others use weighted blankets to help relax their child's overstressed or overstimulated nervous system. These supports can make a dramatic difference to a child or youth's health and wellness, however they can be expensive.

In addition, RCY heard stories from families whose child or youth also experiences mental health challenges and the difficulty in accessing appropriate supports even when the young person and their family are at the height of a crisis. When families are unable to access mental health supports for their young person, some told RCY they pay out of pocket for private treatment. However, this is not an option for many families who cannot afford this option.

Those with FASD can also face various health challenges that may require financial support to address comorbid conditions. One study identified numerous comorbid medical conditions associated with an FASD diagnosis.[181, 182] These include language disorders, chronic middle-ear infections, heart malformations, hearing loss, visual impairment including blindness, bone and joint disorders, epilepsy/seizure disorders and ADHD.[183] Some of these ailments may go unrecognized or misunderstood, particularly as many of these comorbid medical conditions are not visible.

As a result, children and youth with FASD may also require medication to address comorbidities, which can become costly. One family participating in this research was paying $200 per month for just one of their child's medications, in addition to others. Other families use the support of a physiotherapist, occupational therapist or speech language pathologist. Although CYSN EIT services offer these supports at no cost and without the requirement of a specific diagnosis, once a child turns six, they are no longer eligible for EIT. There may be jointly funded services between the Ministry and Education and MCFD available through the school, but these services are limited and may be impacted by whether or not the child has a diagnosis. To continue accessing similar services, families who support children and youth with FASD must pay out of pocket. Families discussed with RCY researchers the various attempts they made to access funding to continue therapies, but noted there is nearly no provincial funding for families whose children have FASD, except in the unlikely event that they happen to qualify for one of the CYSN support streams, as discussed earlier.

I need lots of special tools to go out. I use weighted toys, fidgets, compression tools and familiar objects to combat anxiety and stay grounded.

i have Lots of Wheted Suff ys

In the absence of government-funded services and supports, families are left to figure out how best to meet their children's needs for therapeutic tools and items to manage sensory challenges, access to essential mental health supports, access to medications, physiotherapists, occupational therapists and speech therapists, as well as access to community recreational programs. These can add up to significant costs. For families living on low incomes or in poverty, such purchases are simply not feasible. This exacerbates the shame and stigma associated with FASD for both the families and children.

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[181] Comorbidity refers to the presence of more than one disorder in the same person.

[182] Popova et al., "Comorbidity of Fetal Alcohol Spectrum Disorder", 5.

[183] Popova et al., "Comorbidity of Fetal Alcohol Spectrum Disorder," 1-10.

One source of funding that can sometimes be accessed by families who have adopted a child with FASD is MCFD's Post Adoption Assistance (PAA). However, this is only available to families who have adopted children, effectively increasing the overall inequity for non-adoptive families.

In addition, how PAA can be used by those families who do qualify is limited in some cases. In one instance, a parent in this research was denied funding through PAA for a weighted blanket to help her child feel calm, safe and secure. This parent ended up paying out-of-pocket. As they explained:

> *"Post Adoption Assistance said they covered other things but not a weighted blanket. We have NO access to CYSN for anything. We also tried asking a couple of smaller programs that I had heard helped out with equipment, but everyone said to use CYSN funding … and then the standard answer, 'We're sorry we can't help out' and 'That's really too bad that you can't access CYSN funding.' "*

PAA is one of the only sources of provincial financial support available to the adoptive families of children with FASD. However, it is only available to families who have adopted a child, and that child must be designated for funding.[184, 185] There are limitations with PAA, as described by this family:

> *"We get post-adoption assistance of $914 a month … and then if we were going to do braces, I think they'll pay for that. And we can ask for – and we may not get it – but if we were doing some counselling or therapy and there was travel involved and if there's medication that's not covered, there's certain things that they will assist with. But, if you have a child that has really high needs, that [money] isn't going to begin to look after that child. But you know, if [MCFD] is serious about wanting to care for kids, then they should be doing that differently."*

Sometimes families reach out to other organizations to help alleviate the financial burden. Organizations that families in this research accessed for grants included Canadian Tire's Jumpstart program and KidSport Canada. These two charitable organizations provide grants to help families access sports and physical activity. While such grants can be helpful, it can be time consuming for families to complete the applications for a small amount of money, and those funds can only be used for specific programs that may not address the complex needs of a child or youth. As one parent said:

> *"You cut corners where you can, and you get every grant even if it's only $250 or $400 here or $100 here. And you fill out all that paperwork and you send it in hour after hour. You do it, because he's your baby and you would do anything for them, right?"*

Parents expressed that their reliance on charitable organizations has been unsustainable, stressful and full of uncertainty. There is no guarantee they will receive funding, even if they spend countless hours completing grant application forms. Dependence on grants from charitable organizations can result in financial and mental-emotional stress if funding is suddenly no longer available – as has been the case during the current COVID-19 pandemic, a situation RCY highlighted in the recent *Left Out* report.

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[184] Ministry of Children and Family Development, "Post Adoption Assistance Provincial Guidelines," last modified April 2019, https://www2.gov.bc.ca/gov/content/life-events/birth-adoption/adoptions/how-to-adopt-a-child/adopt-from-foster-care/post-adoption-assistance-program.

[185] To be designated, adopted children or youth must have a "special service need" or a "special placement need." Additionally, families must go through an income and asset test to determine how much funding they will receive. PAA can be used by adoptive families towards supports such as counselling, speech therapy, physiotherapy, occupational therapy, medical expenses and respite. Families who already access funding through CYSN are ineligible to access PAA, and there are some things that PAA will not cover, such as a weighted blanket.

Last Resort: Government Care

With so many barriers in place to access services and supports, families may turn to MCFD's child welfare services out of desperation. While none of the families involved in the research for this report took this path, Key Workers and community dialogue participants – including birth families and various service providers – indicated that they had seen multiple cases where families had to turn to MCFD child welfare services as a last resort to get support.

When one parent was asked what it would take to change the system, she responded: *"A big trumpet saying 'FASD exists, exists.' They [people with FASD] have had their rights squashed … Like, 'We [the Province of B.C.] apologize.' Actually – an apology to people with FASD."*

One Key Worker described how frustrating this was for her, and how traumatizing it is for families to make this decision. After months, and sometimes even years, of building a trusting relationship with families and expanding their capacity to support their children, this Key Worker has seen some families experience a breakdown or an inability to cope with the circumstances they face. As this Key Worker said: "*It hurts to have to be put into a position where I know how difficult life has been for this family, and all I want to do is get them a little help from the ministry, and it's impossible to breakdown the door, let alone knock on the door*." As this discussion between Key Workers during an interview with RCY showed, the only option left for some families is child protection.

Challenges During the COVID-19 Pandemic

One family who participated in the research whose child was diagnosed with both FASD and autism shared the following story with RCY, describing some of the challenges they faced during the COVID-19 pandemic:

"During the pandemic shut-down, our daughter with FASD experienced significant anxiety, depression and mental health trauma. This resulted in us accessing the hospital several times, two admissions to the pediatric psychiatric unit and multiple interactions with the RCMP. Our whole family has been traumatized and exhausted by these setbacks.

"Her needs became so high that we did discuss whether we could continue safely caring for her in our home. But we were able to access respite through our Post-Adoption worker, funds for in-home support through our foster agency, equipment and staffing through Autism Funding and counselling through PAA. None of this was available to us as an FASD caregiver home.

"Without her additional diagnosis of autism and her well-crafted adoption supports, we likely wouldn't have been able to meet her needs and her adoption placement would have been disrupted. I thought of this often, and the other families we know who are raising children with FASD, and how they were coping. We are a family with no economic, educational, societal or communication barriers. If we couldn't do it, I am not sure who could.

"This is an acute example of the lack of recognition and real investment for children and families affected by FASD. It would have been an even greater tragedy if we had been left to try to cope ourselves."

> ***Key Worker 1**: "We work in a system where if you have a child with autism or an intellectual disability and you say you're exhausted and need rest, you get put on a wait list for respite or you get respite funding. If you have a child with FASD and you're exhausted, you might have to go to the Child Protection door and …"*
>
> ***Key Worker 2**: "Basically, turn your kid over."*
>
> ***Key Worker 1**: "Until you feel like you're ready to say 'I'm going to hand my kid over,' you might get offered respite, maybe, maybe."*
>
> ***Key Worker 2**: "Such inequity."*

These disparities highlight the glaring inequities in provincial service provision for children and youth with special needs. Without the necessary supports, families struggle until they are no longer able to cope and then see no alternative but to place their children in voluntary care in order to access appropriate services.

In community dialogues, RCY heard the need for wraparound services and supports for the entire family. This was highlighted as a protective factor for biological parents who may have FASD themselves, although the emphasis was placed on the entire family receiving such supports regardless of whether there is intergenerational FASD. Developing such services and supports is particularly important as a way for families to remain together. Connections were made by participants in community dialogues and by Key Workers between a lack of respite services leading to parental burnout and child welfare involvement.

The dire need for supports and services was heard across all groupings of research participants for this report. Families and community dialogue participants identified a need for more appropriate programs for children and youth with FASD through which they can learn social skills, life skills and interact with peers. In addition, RCY heard from community dialogue participants about the need for culturally safer supports and programs, increased numbers of First Nations, Métis, Inuit and Urban Indigenous support workers and connections to mentors and youth workers with lived experience, with the need for connections to mentors echoed by the parents involved in this research.

Promising Practice – Youth Outreach Program

An example of a mentorship program was the Youth Outreach Program (YOP) (2008 to 2011), a three-year intensive outreach and support pilot program for First Nations youth with suspected FASD in Burns Lake that was funded by the federal government. YOP included one-to-one support via youth support workers and weekly after-school groups that provided opportunities for relationship-building, skill development and recreational activities. The program was designed to be flexible, available both on- and off-site, and individually tailored to each youth based on their needs, goals and abilities. An evaluation of the program showed a number of positive outcomes for participants, including improved self-confidence and self-esteem, improved school-related success, improved social relationships and support from peers, reduced substance use, improved life skills, healthier relationships with partners and improved knowledge and/or use of community resources.[186] However, this program was not renewed after the pilot funding ended.

Finding: *The Key Worker and Parent Support Program is inconsistently delivered, underfunded and lacks MCFD oversight and training*

The only province-wide FASD-specific program is the Key Worker and Parent Support Program (KWPSP), which is vital to supporting caregivers. MCFD established the program in 2006 with the goal of maintaining and enhancing the stability of families with children with FASD and similar neurodevelopmental conditions.

KWPSP is delivered by community-based agencies. As of May 2019, 54 community-based agencies across B.C. were contracted by MCFD to deliver the program (see Appendix D). By accessing KWPSP,

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[186] Carol Hubberstey, Deborah Rutman and Sharon Hume, "Evaluation of a three-year Youth Outreach Program for Aboriginal youth with suspected Fetal Alcohol Spectrum Disorder," *International Journal of Alcohol and Drug Research* 3, no. 1 (March 2014): 63-70. https://doi.org/10.7895/ijadr.v3i1.124.

families are connected with a Key Worker who acts as a navigator, educator and source of mental-emotional support for parents, caregivers, family members and others within a child's support network. There is no funding or respite for the families to access, nor is KWPSP meant to provide any specific FASD-informed mental, emotional or social supports for the child or youth.

One of the program's greatest strengths is that it is low barrier. The program is voluntary and there is no cost. Families can self-refer at any time between the birth of a child and their 19th birthday, with no requirement for a formal diagnosis in order to be eligible.

The KWPSP, as outlined in the 2009 *Key Worker and Parent Support Program Standards,* is specifically meant to support parents and caregivers – not their children or youth with FASD.[187] However, RCY found that, in practice, many Key Workers do provide direct supports to children and youth to fill the gaps left by the lack of services available to this population.

Some, but not all, of the families who participated in this report were connected to a Key Worker. Those who were connected often praised their Key Workers and shared examples of their positive interpersonal relationships with them:

> "*She's wonderful. She's an older Aboriginal lady that understands me and knows my family and, you know, she understands. She goes to bat for me and checks on me and, yeah, she's really one of the ones I feel safe with, that I could talk to."* – Parent

> "*She's a keener, she's actually helped tremendously even though she doesn't have the background of FASD. She's just hungry for [the work] and very passionate …"* – Parent

> *"My mom was blessed that in the mid 2000s, a Key Worker program came into place to support families. Through this, she could draw knowledge and strength that she was doing what her kids needed. She felt supported and was able to create a safe, supported environment and support networks for their needs, even when the 'outside' world, even though unintended, would or could not understand. She found that when her kids were supported, they would thrive, and when supports were not given or were pulled away when they were doing better, their world would become more chaotic and stressful."* – Owen

In its role as the only FASD-specific provincial service available to caregivers, KWPSP is critical for families. Multiple times, families shared how powerless and isolated they felt in their attempts to obtain school supports, CYMH services or access to additional funding, yet their Key Worker stood by them and pushed for the supports that the family needed. It was evident that the Key Workers who were interviewed for this report and engaged in the community dialogues were passionate about their work.:

> *"When we are getting to know families, we really work on building relationships with families and with the children. Just being mindful of different things they may have experienced; taking that time to get to know them and to know what's important to them."* – Key Worker

> *"These children and families are so resilient, so resourceful, have so much capacity, so much ability to grow and learn, and adapt to different things that are going on for them. I think that they are sometimes not given that space, or the credit that they're able to do that."* – Key Worker

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[187] Ministry of Children and Family Development, *Key Worker and Parent Support Program Standards* (Victoria, BC: Ministry of Children and Family Development), 2009, 1-21. https://www2.gov.bc.ca/assets/gov/health/managing-your-health/fetal-alcohol-spectrum-disorder/key_worker_program_standards.pdf.

Despite their pivotal role and their passion for helping families, Key Workers described several barriers preventing them from delivering consistent quality supports that meet the needs of the families they serve.

Regional Program Variations

The KWPSP Standards state that the program *"provides an opportunity for regional variation … within a provincial framework."* [188] While regional variation could be seen as a program strength, allowing contracted community agencies to tailor KWPSP to their unique context, the result is that the program is very different from one community to the next. This can be confusing for families, especially those who move to a new location. Variations are seen in the Key Worker's role, their support approaches, Key Worker education and skills, and program length.

"A certain amount of variation is okay … communities are different and it doesn't have to look exactly the same, but there are definitely some communities within our regional network who have taken the program and turned it into something completely different and completely unrecognizable."

—Key Worker

Key Workers interviewed for this report explained that social workers, counsellors and community-based service providers are unclear about the role of the Key Worker. Due to this confusion and a lack of supports for children and youth with FASD, Key Workers have received pressure from families and other service providers to focus on providing direct support to a child or youth, despite this being outside their role. Key Workers told RCY they repeatedly explain that they are a resource for parent support, and do not typically provide direct support to a child or youth.

Some contracted KWPSP agencies respond to pressures by supporting a child or youth's needs themselves, even though this is outside of the program standards. Multiple Key Workers expressed frustration about the absence of FASD-informed supports. Said one:

> *"There are a myriad of forces that want me to provide direct services to children and youth with FASD – because it is a recognized gap. There are not a lot of specific services for children and youth with FASD diagnosis only."*

Support Approaches

The Standards outline various approaches Key Workers can use to support parents, including support groups, information sessions and parent mentoring. However, Key Workers told RCY that approaches vary widely across agencies. For example, one agency may only provide assistance to a family during the diagnostic assessment process, while another provides a suite of supports that could include parent support groups, family-gathering opportunities, support with a child's Individual Education Plan process and general information for parents about making home or environmental adaptations to support a child's needs.

Families, community dialogue participants and service providers characterized these variations as inequitable. As one Key Worker said, *"I guess I worry about if they are moving … [KWPSP] is not standardized. So, depending on where they're moving, I guess I'm always uncertain of what service they are going to get when they move."*

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[188] Ministry of Children and Family Development, "Key Worker and Parent Support Program Standards," 5.

Key Worker Education and Skills

The level of education and skill set of each Key Worker interviewed for this report varied greatly. While some workers met the qualifications listed in the Standards (see Appendix E), others had no FASD-specific training prior to entering the Key Worker role and many said they had gained their knowledge about FASD from colleagues who mentored them once they stepped into the Key Worker role.

Recruiting Key Workers who possess all the qualifications outlined in the Standards is especially challenging for contracted agencies within rural regions, who have a very limited pool of candidates. To address this challenge, one community service provider suggested more flexibility around the qualifications be considered, with intensive training and mentorship offered for newly hired candidates to gain the FASD-specific knowledge required to do the job.

Program Length

Key Workers also raised the length of time given to families to access the KWPSP as a barrier for some families. Since the Standards do not outline how long families can engage in services, community agencies make this decision on their own. In some regions, the program can be accessed from the time a child is born to when they turn 19, while in others services are limited to one year, with the option to re-open a case. In areas of limited service provision, the KWPSP is regarded primarily as a support to parents through the FASD diagnostic assessment process and for three months thereafter to assist a family in implementing the recommendations from the assessment report.

MCFD Oversight of KWPSP

RCY found that the KWPSP lacks consistent evaluation and oversight, which likely contributes to the considerable regional variations. Multiple Key Workers said that standards are not always followed by community agencies, with some Key Workers indicating that they were not aware of the standards or had only ever glanced over them.

No system-wide program evaluations have been undertaken since 2009 to assess participant satisfaction, quality of services and, ultimately, whether program supports meet the needs of families.[189] While the program may be monitored by a local agency or region, there are no clear provincial evaluation measures that are applied to monitor program quality. The KWPSP has existed for 15 years, and one provincial evaluation has been undertaken. This was done by a third-party consultant in 2009, who provided MCFD with a Continuous Quality Improvement Plan in addition to the evaluation findings.[190] This plan includes templates and tools to use for annual evaluations, including a client satisfaction survey, community partners' survey and a Key Worker and agency questionnaire. MCFD confirmed to RCY that some tools were implemented at the regional level for varying periods of time, however these were never implemented across the province.[191]

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[189] Data provided to the Representative by MCFD on June 30, 2020.

[190] The purpose of this Continuous Quality Improvement Plan was "to enable MCFD to conduct ongoing evaluation of the Key Worker and Parent Support services and to support and ensure continuous quality improvement once the comprehensive, external formative and summative evaluation is completed in June 2009" (p.1). Sharon Hume and Associates, *Continuous Quality Improvement Plan Key Worker and Parent Support Services*, June 2009.

[191] Information provided to the Representative by MCFD on March 30, 2021.

Some Key Workers said that their interactions with MCFD were inadequate. One Key Worker said:

> *"There hasn't been a lot of adherence to program standards – other than the service director signing MCFD contracts in that service area – there's nobody checking up on [the KWPSP]. So, how that's impacting families now is that it's become a watered-down service."*

Additionally, when RCY requested data on the KWPSP, MCFD replied that it does not collect data on children and youth served by this program and had no records to share.[192] In addition, the KWPSP Standards have not been updated in 11 years, and the list of KWPSP agencies provided on MCFD's website had not been updated since October 2017 and contained broken or no website links to several agencies.[193] The lack of basic data, oversight, evaluation and review of Standards is concerning to the Representative as the KWPSP is the only generally available ministry-funded, FASD-specific support services for families and caregivers.

Need for Consistent Training

> "It's all fine and good to think, 'Oh yeah, we [MCFD] have a great response to FASD, because we have the FASD Key Worker Program'; but if half the province isn't doing the program as MCFD is assuming – then we have something else."
>
> —Key Worker

Key Workers require a strong foundational knowledge and understanding of how to work with children and youth with FASD and their families or caregivers, as well as access to emerging knowledge and practice guidance as the understanding of FASD and development evolves. However, there are concerns about the level of training Key Workers receive and whether they possess the education or knowledge to be sufficiently FASD-informed.

While the Standards indicate that contracted organizations can participate in provincial and regional training as opportunities arise, this does not guarantee consistent training for Key Workers, who offered RCY mixed reviews of the opportunities for ongoing training in order to fulfill the competencies as outlined in the Standards (See Appendix G). Some experienced Key Workers said that implementation training, mentorship and conference attendance were financially supported by MCFD during the first few years of the Key Worker program, however support diminished after initial implementation. Some agencies were able to pay for training, while others could not due to budget or workload constraints. In rural areas, additional time and costs associated with traveling to an urban centre to attend training was a barrier to ongoing FASD-specific learning. To address the lack of training, Key Workers in one region said they were attempting to have monthly virtual meetings to discuss key topics and share ideas related to their work.

Key Workers were pleased that MCFD supported training specifically for Key Workers at a provincial conference in Spring 2019. MCFD also provides bursaries for Key Workers to attend the *International Research Conference on Adolescents and Adults with FASD*, held annually in Vancouver. In addition, two-day provincial training was provided to Key Workers in February 2017 and again in January 2018. DAA staff were also in attendance at both events.[194] While opportunities for ongoing training have been sporadic, Key Workers told RCY they deeply appreciate the training that has been provided. Not only have these opportunities expanded their knowledge and understanding of FASD, they have helped them

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[192] MCFD Director, email to the RCY Executive Director of Monitoring and Strategic Initiatives, June 26, 2020.

[193] "Ministry of Children and Family Development, "Key Worker and Parent Support Agencies," last modified October 2017, https://www2.gov.bc.ca/assets/gov/health/managing-your-health/fetal-alcohol-spectrum-disorder/key_worker_parent_support_agencies.pdf.

[194] Information provided to the Representative by MCFD on March 30, 2021.

feel less isolated in their roles. Connecting with peers was viewed as highly beneficial and helpful in their work as this provided an opportunity to discuss challenges, promising practices and different ways of working with families.

Staff Turnover and Funding

One of the most critical aspects of the Key Worker role is to form strong relationships with families so they have someone to turn to if they have questions or require assistance. The amount of progress a Key Worker can make with a family can be affected by their capacity to cultivate a trusting relationship.

Key Workers interviewed for this report expressed how turnover in the Key Worker position, or the absence of a Key Worker in a community for an extended period, can result in an erosion of trust. Staff turnover is a particularly acute issue in rural or small communities. One program director reported that in their community that families would prefer to wait for the previous person in the position to return from an extended medical leave rather than form a relationship with a new Key Worker. One parent whose Key Worker left their position after working together for five years said, *"[Losing our Key Worker] was brutal. I still haven't quite gotten over that, yet, and what that's going to look like for school and [missing] that huge resource*."

Key Workers highlighted that staff turnover is often the result of a lack of funding to support more than just a part-time position. Not all Key Workers work part-time, but even Key Workers who work full-time indicated that their capacity was stretched thin. Many Key Workers told the RCY that they needed an additional Key Worker position or an increase in their hours so they could adequately serve families. RCY requested data from MCFD on caseloads for Key Workers in B.C, however MCFD responded that it was unable to provide such data.

Key Workers interviewed for this report said that MCFD's determination of which communities receive Key Worker program services and to what degree (i.e., full-time funding vs. part-time), have not changed since the KWPSP was first introduced in 2006. When RCY requested an overview of the funding formula and the rationale that MCFD uses to determine funding allocations for the KWPSP, MCFD responded that the funding allocation is distributed across five regions and is based on a socio-economic formula that was implemented in 2006/07 – more than 14 years ago.[195] The outdated nature of the funding model and limitations in Key Worker staff time underscore the need for a full program review of the KWPSP, including how to incorporate the program into the overall CYSN service framework.

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[195] Information provided to the Representative by MCFD through a data request on Aug. 20, 2020.

Finding: *Children and youth with FASD are often not sufficiently supported in the public school system, leading to their exclusion rather than inclusion*

The experiences of children and youth with FASD in the school system were a primary concern for most participants in the family research, community dialogues and service provider and clinician interviews. Experiences shared with RCY included common themes that suggest that policies designed to ensure inclusion in B.C. schools may not always translate into action.

The experiences young people have with their peers, teachers and the school system play a role in shaping their identity, sense of self, aspirations and mental health and well-being, with the impact of school on a child often staying with them throughout life. The children and youth in this research, parents and caregivers, community dialogue participants and service providers spoke about negative school experiences of children and youth with FASD. Their experiences point to the need for a fulsome review by the Ministry of its *Inclusive Education Policy* and funding structures – as well as best practice approaches in relation to the social and learning needs of children and youth with FASD – to ensure meaningful inclusion.

One Child's School Experience

One of the children who was part of the RCY research for this report is a bright 11-year-old boy who loves history, reading and politics. He is passionate and kind.

Although he is friendly and fun, he has a difficult time at school with peers and with school staff, mainly related to their lack of understanding about FASD. But this boy is resilient and is well-loved and supported at home. He very much wants to fit in and is full of hope that school can be good.

After presenting at the forum hosted by RCY, this boy created a presentation on FASD for his peers and staff at school. The presentation was well-received and, as a result, school improved for him for a short while. However, within weeks, things worsened substantially – he is bullied so much that he, his mom and his support worker do not feel he is safe.

The boy remains hopeful that things will change for the better:

"Do you think that the report will make changes? School is hard but it's always been hard for me. My mom is trying to get me into a different school but it's hard to have a spot for me."

Lack of Understanding

When asked by his school to describe what he felt to be his accomplishments in the Grade 10 to 12 years, one youth in this research wrote: "*I survived a system that wasn't user friendly to me … I worked with quite a few people who didn't understand me.*"

A general lack of understanding of FASD within schools was raised by research participants as the foundation to all the challenges they experienced. The effect of dysmaturity and the widening gap between these children and their peers in terms of social skills and expectations from the school system was cited as a major contributor to this understanding. This becomes a bigger issue as young people age and are moved up grade levels to match their age rather than their level of maturity or academic ability. One parent echoed the experiences widely shared by research participants:

> *"So, we get these e-mails that say … 'He's not acting 11'. 'I told you he's [developmentally] six.' I'm constantly saying that. 'Remember, he's six.' 'But he's not acting 11.' 'Because he's not 11. He's six' … I am so frustrated. How many times [do] we have to repeat the same kinds of things?"*

Community dialogue participants also spoke about children and youth with FASD in their Nation being pushed forward in grade when they are not ready to advance.

RCY heard from families, community dialogue participants and service providers about some cases where children's FASD diagnostic assessment reports have not been read or utilized by school staff in order to develop an understanding of strengths and support needs or better support them at school. A Key Worker noted that, in his many years of experience, the No. 1 recommendation on an assessment report is usually "*for the school to review the assessment*." However, RCY was told by parents, community dialogue participants and professionals that often a child's school does not use the diagnostic report or will not participate in the results meeting. One community member said, "*Even when they [children] receive a diagnosis with recommendations, educators still try to use their own ideas*."

Understanding the impacts of FASD and how to properly support and accommodate a child with FASD are important to a child's success in school.

The apparent lack of educators' knowledge and understanding of FASD is not necessarily due to a lack of available resources to engage in training or learning. The Ministry of Education funds a promising program that provides training and education to teachers in B.C. on how to best support children and youth with FASD in their classrooms (see textbox on POPFASD).

Despite this resource, RCY heard frequently that levels of understanding within schools varied, including variation in a willingness to engage in learning about FASD or to read and use a child's diagnostic assessment report. RCY also heard that the absence of a formal diagnosis affects how well children and youth with FASD are understood in the school environment. Without a formal diagnosis, children and youth with FASD can be defined as behaviourally challenging, rather than being understood as needing support and accommodation for brain differences.

Lack of Supports

The young people who participated in this report experienced a substantial lack of support in the schools they attended and, when supports were offered, they were often inconsistent or removed when a child appeared to be doing well. This lack of support leads some children and youth to remain lost in their learning experience. As one parent said, "*One time I went there and everybody was doing their work [but] there was [Max] playing with his pencil, because he didn't know what to do. He has no help.*"

> "FAS affects my ability to organize and my time management skills. I need much more time than most students to fully understand and process requirements and expectations of each assignment. I sometimes need help keeping track of assignments and due dates. To help with my organization, it requires adults to help me stay on track."
>
> —Owen

Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD)

POPFASD was established in 2006 and is funded by the Ministry of Education. The program's mandate is to *"increase educators' capacity to meet the learning needs of students with Fetal Alcohol Spectrum Disorder."* POPFASD offers webinar training, online workshops, and in-person workshops to train staff. POPFASD also liaises with school districts to support teachers in each district and offers a suite of publicly available videos and print resources.

POPFASD Goals:

- Provide support and training for educators of students with FASD
- Build district capacity to serve students in their home school districts by working with a district partner
- Provide online access to information, e-Learning videos, resources and training
- Synthesize and share current research and successful practices to support students with FASD
- Share knowledge and practice
- Liaise with school districts, MCFD, Health, and the multi-district steering committee

POPFASD has delivered a total of 153 workshops (face-to-face) across the province between fiscal years 2017/2018 and 2019/2020. A total of 979 classroom teachers (approximately three per cent of B.C. teachers), 574 resource workers (approximately 28% of B.C. resource workers), 1,852 pre-service teachers and education assistants, and 1,605 other education staff attended these workshops.* POPFASD also delivered a total of 82 FASDcasts (webinars) across the province between fiscal years 2017/2018 and 2019/2020. A total of 421 classroom teachers, 203 resource teachers, 593 pre-service teachers and education assistants, and 489 other education staff attended these FASDcasts.** Further, POPFASD began offering livestream learning opportunities in January 2020 which has included up to 1,228 participants in one session. While these numbers are promising, the Representative notes that they represent a fraction of the staff in the provincial public education system.

* This includes support staff, administration and district resource support.
** It is unclear if these counts include distinct individuals or if individuals took workshops and FASDcasts multiple times.

Source: "About POPFASD," The Provincial Outreach Program for Fetal Alcohol Spectrum Disorder, accessed August 2, 2020, https://www.fasdoutreach.ca/about#:~:text=The%20Provincial%20Outreach%20Program%20for,57.

RCY heard frustration from families, community dialogue participants and service providers about continual requests for supports at school that were either denied or ignored. For example, one parent told RCY:

> *"We've been [to the school to address] so many problems [with how they treat] my kids and nothing ever changes, nothing … Well, what kind of school is this? I'm going to have to fight these schools and fight and be there every day to watch my child. I'll go sit there every single day outside the class and if he needs help, I'll help him. But I shouldn't have to do that … but I will, I will."*

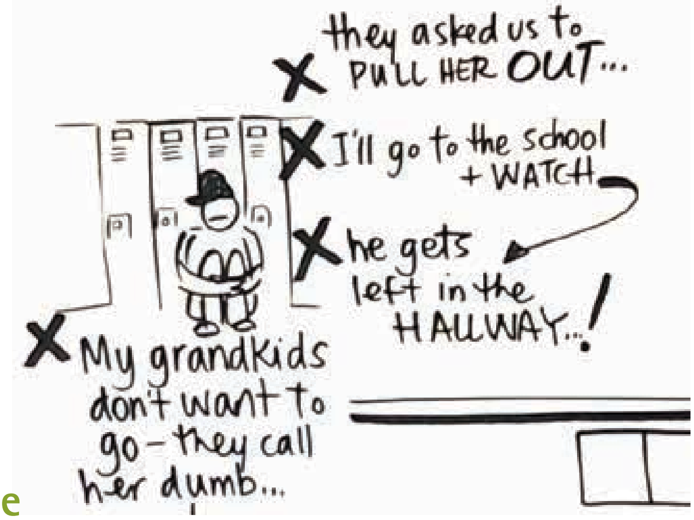
Despite frequent frustration, parents highlighted the importance of building strong relationships with staff at schools in order to advocate for their child's needs. However, these relationships tended to be delicate and parents found themselves balancing between advocating and maintaining co-operative relationships. For some biological parents, advocating for their child or youth in the school system can be difficult because of the blame that can be placed on them. RCY heard in community dialogues that parents can sometimes experience blame from the school system while also not feeling heard by school staff.

Gaps in the Learning Environment from an FASD-Informed Perspective

"It's the nature of education and the way in which the system operates that often creates the liability for children with FASD."

—Parent

Parents, caregivers, professionals and community members told RCY researchers that one major challenge with the public school system is the *"one size fits all"* approach to learning that does not align with the needs of children and youth with FASD. For example, the schools that children were attending required much sitting and desk time, versus hands-on learning and active outdoor time. A community dialogue participant said, "*The education structure must change … after Grade 5 they start to fall behind due to the abstract parts.*"



One parent told RCY of the impact on her child and the inability of the school to adjust to his needs:

> *"School has a hard time. They keep bringing up medication. I'm like 'Sorry, you're going to have to learn to work around him … take him outside … Do something else with him. I don't know what you're going to do, but he has a right to be in school.'* "

Exclusion from full attendance

Not all the children and youth who participated in this report were able to attend school full-time due to various barriers. Parents, young people, community dialogue participants and professionals highlighted many instances of exclusion at school, including:

- Educators' raised expectations, based on age:

  "There's a number of my kids in high school right now that are literally on the verge of being kicked out and a lot of the reasons why are directly related to their brain. I think that's where I'm seeing the real gap, is high school … as the kids hit 13, 14, 15, the bar gets raised, the expectations get raised, and our kids can't meet those expectations because they're still dealing with what they were dealing with in elementary school." –Key Worker

- Students permitted to attend school only for short periods of time a day:

  "We have a lot of our children with FASD being [allowed in school for] one hour. I have a child who was in class for only 15 minutes of the day or half an hour for one week. Then when we came in and advocated for the child, the child was now put in for two hours." –Key Worker

- Children having a rough day often sent home from school:

  "I had never, ever given [the school] that cop-out of 'I'll pick him up at noon.' But I did at the end. And then, as soon as I had done it once, it was like every day they were calling me. And I'm like, damn. Everybody told me not to do that. But I did. And I went and got him. And [then] school was … every day … 'We're going to try and make it until noon but if you could come a bit sooner, that would be great.' And I'm thinking, did I just give you a cop-out?"

Promising shifts on the horizon: Update from the Ministry of Education

In 2019/2020, the Ministry of Education conducted a review of inclusive education policy and practice in B.C. public school districts to better understand the alignment of practices with ministry provincial policies. As a part of this review, school districts were asked to describe their practices in relation to school exclusions and part-time attendance/reduced hours.

The review found varying definitions and understanding of school exclusion among districts as well as in policies and procedures for tracking exclusions and part-time attendance/reduced hours and ensuring plans for returning to full-time attendance.

In response, the ministry has included the following in its draft *Inclusive Education Policy* Guide currently being updated:

- a clear definition of school exclusion, based on s. 91 (3) (5) of the *School Act*
- language requiring school districts to have policies or procedures describing inclusive education practices within the district
- outline of the legislated requirement of school districts to offer a full-time education program to all students residing within their school district boundary.

The Ministry has assured RCY that it is "committed to working directly with school districts to ensure school district practices are aligned with Provincial Policy."[196]

Lack of Meaningful Inclusion

RCY heard that there is a lack of meaningful inclusion at school for children and youth with FASD because they are often excluded from the classroom community, experience bullying from peers and lack engagement in meaningful learning. One parent described how this exclusion from the learning environment impacts her child, who at eight-years-old wanted to quit school: "*They're not doing anything, they're just letting him go there. He's too small just to say, 'Oh well, he's not going to go to school.' I can't do that.*"

FASD and the School Experience

The 2018 B.C. Adolescent Health Survey shows that youth with FASD were more likely to have been teased than youth without FASD (50% vs. 38%); more likely to have been physically assaulted at school or on the way to or from school (30% vs. 8%); and more likely to have been cyberbullied in the previous year (31% vs. 14%). The survey data also indicates that only 41 per cent of youth with FASD reported feeling a part of their school, compared to 60 per cent of youth without FASD.

Source: McCreary Centre Society, 2018 B.C. Adolescent Health Survey, https://www.mcs.bc.ca/about_bcahs.

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[196] Information received from the Ministry of Education on Oct. 19, 2020.

Parents reported continued exclusion of their child, even after they or other advocates had worked with the school on ways to adapt to their child's needs. The inability to adjust approaches in the classroom can result in challenging behaviour and can single out a child. For example, one child was not allowed to participate in the annual province-wide *Foundation Skills Assessment* test that assesses B.C. students' academic skills in Grades 4 and 7:

> *"We actually got a letter that said they were not allowing him to participate … he wanted to do this testing so badly because all the kids were doing it. And the teacher told him when they went to go do a practice class … he [the child] says, 'How come I don't get to go?' 'It's because you have a learning disability, sit down' … In front of the whole entire class, he sobbed and sobbed and sobbed. She told him to go to the bathroom to get himself together … And all he wants to do – he talks about it already, that in Grade 7 they have to write it again and he wonders if he'll be smart enough to write it … And he says, "Do I have a learning disability, mommy?' And I said, 'No, you just learn differently.' "*

Racism of Low Expectations

Racism of low expectations refers to the phenomenon of educators and school district staff having lower expectations of some students, based in biases stemming from social attitudes.* This is particularly evident with regard to First Nations, Métis, Inuit and Urban Indigenous children and youth.

An example brought forward by B.C.'s Auditor General involved School Completion Certificates (also called Evergreens), intended to recognize students with special needs who are not expected to graduate from high school.

The Auditor General found that Indigenous children and youth were more likely than other children and youth to be granted an Evergreen despite not having special needs.

As one educator notes,

"The most profound impact that I believe as an educator that is happening with Aboriginal learners is the soft bigotry of low expectations which is a racism perpetrated on Aboriginal students by educators who do not believe that they can achieve the same outcomes or the same level of understanding as non-Aboriginal students." **

For children and youth with FASD, who are also Indigenous, this means they may be exposed to two levels of low expectation – one based in racism and one linked to their diagnosis.

* Auditor General of British Columbia, *Progress Audit: The Education of Aboriginal Students in the B.C. Public School System* (Victoria, B.C.: Auditor General of British Columbia), 2019, 13.

** Directions Evidence and Policy Research Group, LLP, *BC Antiracism Research* (Vancouver, B.C.: Directions Evidence and Policy Research Group), 2016, 21, https://www2.gov.bc.ca/assets/gov/education/ways-to-learn/aboriginal-education/abed-antiracism-research.pdf.

Based on the information heard from some families, community dialogue participants and service providers, *"meaningful inclusion"* in schools varies across the province. An assessment clinician explained that this variance impacts how they communicate with a family regarding an FASD diagnosis:

> *"In some school districts, if you have an FASD diagnosis you are automatically going to be getting services and supports. In other school districts, no … we have to be really careful when we're meeting with parents not to be promising them something, not leading them to believe that 'I'm going to take this summary report to the school and now [your child] is going to get funded support and have an EA with him all the time.' We need to … under-promise at best, because we're not in control of those situations and, we don't want to also set them up to be in an adversarial situation with the school."*

To illustrate this variability, one family in the research shared their experience of moving between schools and the immense difference between them. The family had experienced great understanding of FASD and support in one school district and was greatly impacted by the change to a school that was on the other end of the spectrum:

> *"It really put a shocker into all of us, being here … I didn't know anything about the school. I just assumed it was all the same. Like, why wouldn't it be? We got a really big shock [and] when it was school time, my kids cried. Oh man, it just discouraged them from everything … One quit. He should be in Grade 12 right now, graduating, but he quit [in Grade 10], he couldn't do it, he wasn't getting any help. Coming from [his previous community school he] had all the help he needed … did his work at his pace. Here, they just give you the paper and tell you to do it."*

To help children with FASD stay focused on tasks, the special education teacher in one northern B.C. community brought 50 rocking chairs into the school, painted them in bright colours and placed them in classrooms: *"So, the kids rock and then they do their work, and then they rock and then they do their work. They don't jump up and leave the room, they don't jump up and run around the room."*

"That's another thing I like to see; adapt the whole school because it works for everybody; don't single out the kids."

—Key Worker

In another B.C. school, a behavioural specialist worked with a teacher to adapt her whole class in order to support a child with FASD. Among other tactics, this school instituted a visual schedule that was posted on the wall for all students in the class to see. The schedule used written and visual cues for the students in which the activity would be written (e.g., library, math) and a photo of a digital clock telling the time that corresponded to the activity. The teacher would prepare the entire class for transition by pointing to the schedule and giving a 10-minute warning before a change in activity.

> *"[Children and youth with FASD] perseverate, and they don't want to … change gears, they don't want to transition because it gives them anxiety, and not knowing what's next gives them anxiety. So, you fix all of that with this visual schedule, so then they can look at it all day and know what's next."*
>
> –Key Worker

The positive examples and promising practices that emerged in the sharing of lived experiences are hopeful and could help to inform a review of the social and learning needs of children and youth with FASD for meaningful inclusion in B.C. schools. In addition, cross-jurisdictional research highlighted that there are promising practices B.C. can learn from other provinces, as seen in Alberta's FASD Success Coach program (see textbox).

Oshluc and Richard – Their Stories

On a peaceful rural property in northern B.C., two brothers are making the most out of the great outdoors when RCY researchers come calling. The oldest, Richard, is tending a bonfire. His younger brother, Oshluc, tells stories of skating on the nearby lake in winter and swimming in the summer.

Richard and Oshluc have FASD, as do most of the 50 other foster children who have been raised by the boys' mothers, Robin and Rose, over the years. It's a special place, and a special family. Even a visiting researcher can't help but feel the warmth and love everywhere.

Richard is 13 now, and his younger brother is just a year behind him. Life with an FASD diagnosis brings many challenges for the boys, but their parents make sure to celebrate the boys' many talents, and marvel at their energy and spirit. Robin and Rose know how hard it is to manage life with a permanent condition like FASD.

Richard has been part of their lives since he was a week old, giving Robin and Rose the rare opportunity as foster parents to provide him with stability and support from the time he was born.

"There's a world of difference between a child coming in later, even a couple of years old versus right away," says Rose. *"He has had that ability to attach, you know, feel safe.*

"He's been able to trust – to trust us. He knows all the limitations he faces, knows what people say about a kid being in care. But at the heart of hearts, he doesn't feel that."

Oshluc is an inventor – builder of mosquito traps, popcorn poppers and even a specialized chair for gaming. His family and teachers know him as a *"tender child."* He won the Best Helper award at his school, and has a big heart for anyone he senses is in distress.

Richard is the energizer bunny, his body restless and active even in sleep. *"Body moves a lot, makes me tired,"* he noted in the journal he kept as part of RCY's research project. He has won awards at school as well – for citizenship and athletic leadership.

School has not been easy for the boys, though Oshluc's most recent year going to school at his home First Nation marked the first time he had continued to attend for the entire year. "*School is better when you do activities,"* says Oshluc. *"It is boring when you have to sit and listen."*

Rose says there are times when her heart aches for Oshluc. *"I think every day is challenging for him. A lot of times, I think life is kind of a mystery to him. But he gets up every day and he goes to school, even though it's hard."*

Richard has been teased at his school for having a birth mother who drank while pregnant, but works hard to manage the many difficulties of school. He dreams of going to college one day, and of being an NBA star.

"There are times when Richard is shy, but there are times when he's even a little cocky," laughs Robin. *"He's confident. He could get up and speak in front of 400 people."*

The world can be a harsh place for a young boy with FASD. Robin and Rose recall *"many, many nights"* of kneeling beside Richard or Oshluc at bedtime, rubbing their backs to help them calm down and let go of their day. *"That was the way we handled it,"* says Rose. *"That and going to get fries."*

Fries?

"There are times when the best thing you can say is 'Let's go get some fries,' " Rose says, recalling one such time a while ago when Oshluc was heartbroken after his birth mother didn't show up for a planned get-together.

"We fully understand why that happened for the mother, and all the reasons for why they don't have many of these visits as well. But at the end of the day, you've got this kid who was expecting a visit and didn't get it," she says. *"So what do you do? You ask, 'Would you like to go get some fries?' And sometimes, that's enough to be able to move on."*

Promising Practice from Alberta: FASD Success Coach

The FASD Success Coach is funded by the Northeast Fetal Alcohol Network (NEAFAN) but directed by the Fort McMurray Public and Catholic School Boards. The success coach primarily serves as a school consultant for capacity building, personal development and offers mentorship to students with either confirmed or suspected FASD. The success coach provides child-specific classroom observations and subsequent strategies, general education and awareness for capacity building, participation in program design and transition planning, and also helps develop Individual Education Plans.

Broad capacity building can involve school- and district-wide professional development presentations. Individual capacity building involves consulting with service providers who are working with the students and their families to ensure that these service providers are FASD-educated and understand the disability. If not, the success coach provides education to these service providers.

Mentorship is adapted to the age of the child and is more limited to adolescents who are not currently connected to services and supports. The overall goal is to build the relationships that wrap around students with FASD, the schools, community, support services and caregivers. The mentorship component is also highly valuable when a child is new to the province and needs additional support to help integrate them to the new surroundings.

The success coach is also a member of the NEAFAN children's assessment and diagnostic clinic multidisciplinary team. Specifically, they support the families through the process and ensure timely sharing of information between the family, clinic and school before, during and after the assessment and diagnostic process.

There are several key features regarding this unique role. First, the role is specialized for a social worker. A social work background allows for delegation of supports needed for the child and can offer more involved mentorship. A social worker is also able to take on the ongoing challenge of stigma and shame associated with FASD and can expose the role of patriarchy, racism and classism in the perpetuation of that stigma and shame. Furthermore, the success coach role needs to be creative and adaptive in approach but not rigidly committed to existing structures or practices.

Second, while the referral process is seated in the school system, the success coach role is available to offer supports within the classroom setting, with teachers, educational assistants or students themselves, or with caregivers beyond the school environment. This provides the advantage of supporting the student wherever their need is most pressing. Support priorities are also adaptive and can vary over time depending on circumstances such as onboarding new school staff or adapting the environment to support a new behavioural symptom.

Third, a core element in the role is to develop and maintain long-term stability, relationships and trust with the child, their family and school supports. The success coach can develop one-on-one supports with the children and caregivers.

Fourth, working with the success coach is voluntary for families and by their invitation. Caregivers can decline participation. The success coach will meet with the families in their own space and context.

The role is founded on a neurobehavioural approach with a trauma-informed lens. In contrast, a behaviour modification approach can be inappropriate for students with FASD as this perspective does not take into consideration adapting the circumstances to suit the brain and brain injury. The success coach also challenges the paradigm to support those with FASD in a similar way as systems currently support those with physical disabilities: to provide accommodations and environmental supports with the same level of understanding. A guideline for the success coach is to provide solutions, not focus on the problem. An axiom that supports the style of the success coach is to "think Brain and not Behaviour."

Finding: *Children and youth with FASD and their families experience exclusion from their community and peers that results in social isolation*

Experiences of exclusion and isolation are a dominant theme in the lived experience of all the families who participated in this report. Also echoed in the community dialogues and service provider interviews, isolation is often a result of a lack of understanding of FASD and is very directly tied to systems – for example, the inability to attend school, or being excluded at school. In addition, RCY heard of multiple instances within extended families where the family of a child with FASD was excluded because of their child's challenges.

Community Isolation

Children and youth with FASD are faced with multiple barriers to participating in community programs and recreational activities. Challenges with sensory integration make it difficult to participate in community events with crowds and loud noises. In addition, families feel isolated from the larger special needs community and other families with a child or youth with FASD. As one parent shared, "*We don't have special needs programming, so we have to fit into these other programs and they're under no obligation to adapt them [for young people with FASD].*"

Families experience challenges when they approached private practices for support, such as mental health services, or community programs. Generally, they said staff do not understand how to appropriately support children and youth with FASD and are unfamiliar with using an FASD-informed approach in their programming. Despite such challenges for children and youth, RCY heard that the young people still wanted to attend these programs.

> "I know I'm isolated here, I feel it, I [only do things] … with my kids. Whereas when I was in [the previous community] when my kids were with other kids [with FASD] … and they could have friends over … to me, I felt safe, I felt safe over there in that community. Here … my kids have no friends … So, yeah, we're isolated here."
>
> —Parent

What is an FASD-informed approach?

An FASD-informed approach starts with the understanding that FASD is a brain-based permanent disability that has wide ranging effects and affects an individual in various aspects of life including physically, behaviourally, cognitively, socially, emotionally and spiritually.

An FASD-informed approach recognizes that children, youth and adults with FASD may struggle to follow certain rules or behaviour expectations and, in order for them to achieve success, a system, service provider or program needs to make accommodations to fit their specific needs.

Key practice principles of an FASD-informed approach

- understanding FASD and recognizing that every individual will have unique strengths and challenges
- Making person-centred accommodations and individualizing one's approach to need
- Using a strengths-based framework to highlight an individual's skills and support them in finding solutions to challenges.

At the core of this approach is developing trusting, positive relationships and creating supportive environments in which a person feels physically and emotionally safe to express their needs and can experience success.

However, there were numerous instances where families have been unable to access special needs programs or events because they were only available to children and youth with a certain diagnosis. A parent explained it this way:

> *"Even within the special needs community … we are isolated … from the community of people who are supporting individuals with intellectual deficits. They don't consider [her] diagnosis a disability that qualifies for their services. We'll be at something … maybe it's a foster thing, so there's a ton of people that have special needs kids and they all know each other, and we don't know anybody because … we don't go to bowling on Thursdays … we're not part of therapeutic riding. It's $450 a session … autism funding pays for that, but we can't afford it, so we don't meet any of those families. We don't carpool with anybody. Our kids know nobody."*

Children with FASD and their families or caregivers can be left feeling as though they're looking through glass – they see all the activities and programming that children with certain special needs are able to access, but they are excluded from participating. Without this ability to participate, they are unable to build stronger relationships with other children in their community. Since parents are left without a strong social network, they often have to navigate the challenges of raising children with FASD on their own.

> "Our kids … need to see other people with brain differences and how they're thriving. Some are artists. Some are working at banks. Some are selling cars. You need to meet other people living with it"
>
> —DAA social worker

In addition, for children and youth with FASD there are few opportunities to connect with adults with FASD who can mentor and support young people. In October 2019, RCY hosted a forum that brought together the young people in the research and their families with government decision-makers and community leaders. The excitement of the children and youth who attended was evident in their interactions with one another and in how they responded to Myles Himmelreich (the external co-researcher) and the other supportive adult team with lived experience. This excitement illuminated the critical need for children and youth living with FASD and their families to have meaningful inclusion in community supports, education and programming. It also illuminated the need to demystify FASD and build mentorship and connections across the lifespan.

Social Isolation

Social exclusion leading to isolation is a common experience for most of the children and youth in this report. At the same time, parents told RCY of many impacts to their children's social relationships based in the effects of FASD and the lack of awareness, inclusion and understanding. RCY researchers heard stories about difficult social interactions in which the young person thought they had *"done something wrong"* socially and wanted desperately to make up for it. Caregivers often mentioned how challenging it is for their children to maintain positive friendships because their child is either being bullied, manipulated or excluded by their peers at school or during extracurricular activities.

> "You don't get invited to birthday parties; you don't get invited to go to somebody's house. Hey, we didn't even have a birthday party for three or four years, because there wasn't anyone to invite."
>
> —Parent

Making friends and maintaining strong connections were viewed as challenges for a few reasons. Some caregivers described how their children's social skills or interactions are not always viewed as appropriate, so their peers don't know how to respond or react negatively. Sometimes, their child's energy is perceived as being "*just so much*" or "*disruptive.*" As one parent described:

> *"I think for [our daughter] the biggest challenge is probably the connection piece, because the connections she does have she damages frequently and the connections she wants she can't maintain, so she has very, very few peers, very few peer interactions that are positive and she is getting to an age now where the kids are not as forgiving."*

The families of the children and youth in this report also face social isolation. Parents told RCY that it is difficult to maintain their own friendships in addition to raising their children because "*you don't fit into other peoples' normal.*" Few parents are connected to people outside of their immediate family as they have little time for themselves after attending to the multiple needs of their children. Some parents said that this isolation sometimes stems from a lack of understanding of their child's behaviours and the resulting judgment from others. Families told RCY that, given the difficulty in being judged, they simply cocoon to protect their children.

"[He] can talk the talk, he just can't walk the walk all the time. But he can talk, and he makes people laugh ... he can go into a group of people and bring everybody together and talk. But he can't keep a friend."

—Parent

It is important to note that some of the young people involved in RCY's research also described positive friendships and connections they have with their peers, and the value of these. For example, some of the young people included images of friends in their life books or spoke about things they did with friends. In talking about an international trip taken with the school, one youth described a highlight as *"fun to travel with friends."* Another young person wrote in a poem that she *"loves to play with friends"*, while another child spoke about making new friends after changing schools.

Bright Spot: Family Together Night – BC Centre for Ability

Families who participate in the Key Worker Program at the BC Centre for Ability are able to access a supplementary support program – Family Together Night, a social get-together that occurs once every two months. Each event offers a different theme and is free to attend. At these events, families are encouraged to eat together and participate in live music, crafts, games and outdoor activities. It is an opportunity for children to meet other children and for parents to connect and network with other parents. The venue is not restricted to BCCFA's facility and can take place in community settings such as community centres, bowling alleys or sporting venues. Families can bring their wider family and siblings rather than just one child. This removes a participation barrier for families who would otherwise need to find childcare in order to attend the event. A primary goal of Family Together Night is to foster connections for the children and their families that extend beyond the agency and into their personal lives.

A distinct highlight of Family Together Night is its inclusiveness. Families feel no obligation to be at their best or achieve certain outcomes. Support staff are informed and understanding of children experiencing meltdowns and the origin of these behaviours, and these meltdowns do not prohibit or bar participation. Furthermore, the Family Together Night program can be adapted and modified to best suit the needs of the children. Family Together Night is designed to create a safe place for all participants and encourages continual participation despite challenging circumstances.

One of the indicators of success of this program is that many families have been attending for years. No one feels obligated to attend; it's a space for them to go if or when they need it. Families have often told program staff how much they appreciate the opportunity.

Finding: *Children and youth with FASD who are in government care may not receive a diagnosis or proper supports despite their challenges*

When children and youth are brought into government care, it can be a traumatic experience and result in attachment issues related to being removed from their families.[197, 198, 199] The consequences of the experience for children and youth with FASD can be amplified.[200]

Although, as noted previously, MCFD does not collect quantitative data specific to B.C. regarding the number of children and youth with FASD in care, various studies from other jurisdictions have found a much higher prevalence of FASD among children and youth in care than in the general population.[201]

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[197] Jessica Dym Bartlett et al., "The impact of a statewide trauma-informed care initiative in child welfare on the well-being of children and youth with complex trauma," *Children and Youth Services Review* 84 (November 2017): 110-117. https://doi.org/10.1016/j.childyouth.2017.11.015.

[198] Megan Miranda, Elizabeth Molla and Eman Tadros, "Implications of Foster Care on Attachment: A Literature Review," *The Family Journal* 27, no. 4 (March 2019): 394-403. https://doi.org/10.1177/1066480719833407.

[199] Caitlin Papovich, "Trauma & Children in Foster Care: A Comprehensive Overview," *Forensic Scholars Today* 5, no. 4, (April 2020). https://1q5krviw73e3rlh854lufacx-wpengine.netdna-ssl.com/wp-content/uploads/2020/04/csp_fst_vol5_issue4_trauma-and-children-in-foster-care.pdf.

[200] Anne M. Koponen, Mirjam Kalland and Ilona Autti-Rämö, "Caregiving Environment and Socio-Emotional Development of Foster-Placed FASD-Children," *Children and Youth Services Review* 31 (2009): 1050. https://doi.org/10.1016/j.childyouth.2009.05.006.

[201] Janine Hutson, "A Prenatal Perspective on The Cost of Substance Abuse in Canada," *Journal of FAS International* 4 no. 9 (2006): 2. https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.542.4210&rep=rep1&type=pdf.

Data collected by the Provincial Health Services Authority shows that approximately 45 per cent of patients assessed with FASD over the past three fiscal years (2016 to 2019) are currently under the care of MCFD via a foster family or other care home.[202] One international study estimated the prevalence of FASD among children and youth in care to be 16.9 per cent.[203] In a Canadian-based study, researchers determined that the prevalence of FASD among children and youth in care is, at minimum, between three and 11 per cent in Canada.[204, 205]

While there are differences in reported prevalence between studies and jurisdictions, it is important to note that all of these studies found that the prevalence of FASD is far higher among children and youth in care than in the general population. It is imperative that B.C.'s child welfare system, as parent to these children and youth, provide appropriate supports to ensure they have the opportunity to meet their full potential.

To fulfill this obligation, concerns raised by those interviewed for this report, RCY's data, and findings in the literature warrant further investigation by MCFD. These concerns include:

- lack of data regarding diagnosis for children and youth in care
- lack of training for MCFD social workers, staff at contracted residential services and foster parents regarding FASD
- missed opportunities for diagnosis while a child or youth is in government care, and
- the challenges young people with FASD experience as they transition out of government care.

Lack of Data

While research indicates that there is a high number of children and youth in care with FASD, MCFD informed RCY researchers that it can't disaggregate its data to obtain the number of children and youth in care or receiving services and who also have an FASD diagnosis. Yet, the ministry's Integrated Case Management (ICM) information system – used by child protection workers to document information related to the children, youth and families they work with – includes fields to record an FASD diagnosis. These fields are not mandatory and may remain empty even if a child or youth has a diagnosis, thus limiting MCFD's ability to understand the prevalence of FASD or other diagnoses.

The failure to record, track and disaggregate data regarding FASD diagnosis impacts the ministry's ability to identify or assess areas of need for children in care or receiving services and develop policy and programs to appropriately support them.[206] As stated by Fuchs and Burnside:

> "*These data on prevalence are necessary to ensure that child welfare authorities are prepared to meet the needs of children and youth in care (and transitioning out of care) with FASD with appropriate*

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[202] Note provided by Provincial Health Services Authority on Feb. 6, 2020.

[203] Shannon Lange et al., "Prevalence of Fetal Alcohol Spectrum Disorders in Child Care Settings: A Meta-analysis," *Pediatrics* 132, no. 4 (October 2013): 6. https://doi.org/10.1542/peds.2013-0066.

[204] B.C. social workers use an Integrated Case Management (ICM) system to record client information. There are fields available in ICM to record diagnosis information, however these fields are not mandatory to complete. A child's *Care Plan* form includes a *Current Health Information* section where this information can be added including any support requirements and medications prescribed. However, this information is not easily retrievable as MCFD would need to go through each individual Care Plan to determine the diagnosis. As a result, MCFD does not track or report out on diagnosis.

[205] Dorothy Badry and Kelly Harding, *Fetal Alcohol Spectrum Disorder in Child Welfare* (Vancouver, B.C.: Canada FASD Research Network), 2020, 1. https://canfasd.ca/wp-content/uploads/publications/FASD-and-Child-Welfare-Final.pdf.

[206] MCFD was able to provide the number of children and youth in care who have been diagnosed with ASD, however the only reason this is tracked is because the child or youth will be accessing the Autism Funding Program.

> *resources, programs, supports to caregivers, training to staff, and policies that facilitate their development into adulthood and emancipation from care.*" [207]

RCY Data – Children and Youth in Care with FASD

Care Plan Review

RCY's Care Plan Review team is conducting an audit of MCFD care plans for children and youth in care. Overall, the team reviewed care plans within a non-randomized sample of 76 Child Service (CS) files.* This sample was limited to looking at child and youth files that had a care plan completed between Sept. 1, 2017 and Feb. 28, 2018, with in-care legal statuses and did not include files held by DAAs. Of the 76 CS files, 66 had care plans within this scope. Of the 66 files sampled, each file had two to three care plans that were analyzed for quality, totalling 163 care plans audited overall.

Of the 66 CS files sampled, to date the team has found:

- Overall, 27 per cent (18) had qualitative evidence of FASD, including specific reference to suspected FASD, requests for assessment and confirmed diagnosis. This includes notes stating that prospective foster caregivers wished for a FASD assessment, FASD was suspected or there was an FASD diagnosis.
- Of the 27 per cent of files (18/66) that indicate the presence of FASD, 78 per cent (14/18) of the children and youth in this sample are First Nation, Métis, Inuit or Urban Indigenous
- 16 per cent (4/18) of the children and youth in this sample are not First Nation, Métis, Inuit or Urban Indigenous

Reviews and Investigations Data

Overview of injuries and deaths reported to RCY between April 1, 2018 and July 31, 2019 (16 months) for children or youth with suspected or confirmed FASD:

- During this time period, a total of 1,441 critical injuries were reported for 996 children and youth receiving reviewable services. Five per cent of these cases were identified as involving children and youth with suspected or confirmed FASD.
- Of these children and youth, more than one-third (35 per cent) were living in a staffed residential resource at the time of injury.
- Nine youth with FASD died during this time frame. All but two youth who died had previous injuries reported to the RCY. All but one youth were in care of MCFD when they died.
- Of 200 care plans for First Nations youth analyzed by the Reviews and Investigations team from 2015 to 2017, 43 per cent (n=86) of the young people had diagnosed or suspected FASD.**

* This sample was drawn from MCFD's audit sample, that was used for the MCFD Provincial Care Plan Audit. Notably, MCFD's audit sample only includes a review of files with care plans uploaded to ICM within policy range and with an in-care legal status. Therefore, the RCY sample drawn was not random. From MCFD's audit sample of N=228, the Care Plan Audit drew a random sample of n=76 CS files.

** This was a separate care plan review than the current care plan audit mentioned in the first bullet. These care plan reviews used different samples.

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[207] Don Fuchs and Linda Burnside, "Prioritizing Children in Care With FASD: Why Prevalence Matters," in *Transforming Child Welfare: Interdisciplinary Practices, Field Education, and Research*, eds. H. Monty Montgomery, Dorothy Badry, Don Fuchs, and Daniel Kikulwe (Regina: University of Regina Press, 2016), 139.

FASD Training Gaps

Like all children with diverse abilities, children and youth with FASD require additional considerations when it comes to in-care placements. Research indicates that early diagnosis and identification of FASD, as well as education on supporting a child or youth with FASD, are critical to arranging appropriate placements, facilitating better preparation and improving caregiver capabilities in meeting a child or youth's needs.[208] Awareness of FASD can increase understanding among caregivers and caseworkers and assist in appropriately supporting a child or youth in care.

FASD-specific training was emphasized by parents, caregivers, community dialogue participants and service providers as being of utmost importance to ensure that the needs of children and youth with FASD in care are being adequately supported and to prevent placement breakdown. As a DAA social worker said:

> *"Our foster parents get no formal training … then we can't figure out why these placement breakdowns occur. That is a travesty and is unethical. Why do we place kids [with FASD] in peoples' care and they have no training?"*

Those interviewed also discussed the gap in training for MCFD child welfare social workers and staff at contracted residential services. Overall, interviewees shared that there is minimal training for those who support children and youth in care with FASD – claims that were substantiated by MCFD's response to an RCY request for information regarding specific FASD training available for these workers.

Training currently available to MCFD staff offers very minimal information specific to supporting children and youth with FASD. An online course focused on youth justice and FASD is the most comprehensive FASD training available, however just one social worker took this course between 2017/18 and 2019/20 (see Appendix E).[209]

MCFD informed RCY that CYSN training is in development for child protection social workers which "*will generally address working with and communicating with children and youth with a variety of special needs"* and will include *"some examples related to children/youth with an FASD diagnosis*." [210]

MCFD also confirmed that it does not provide any mandatory training or curriculum specific to FASD to foster caregivers or staff at contracted residential services. Until December 2019, B.C. required foster parents to complete the *B.C. Foster Care Education Program,* which included three hours of introductory FASD training. This training program was replaced by new mandatory pre-service training in January 2020 titled *Parent Resources for Information Development and Education pre-Service Training*. This course does not include any specific information on supporting children and youth with FASD.

MCFD informed RCY that various agencies across the province offer FASD training specifically for foster parents, and that some staff from contracted residential services also attend this training. However, FASD training is not mandatory or consistently offered across service delivery regions, nor is attendance at training sessions regularly collated by MCFD.[211] It remains unclear how well caregivers, staff at contracted residential services and MCFD child welfare social workers understand FASD and whether they have the skills to work appropriately with children and youth with FASD.

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[208] Badry and Harding, "Fetal Alcohol Spectrum Disorder in Child Welfare," 3.

[209] Information provided by MCFD to RCY through a data request. This information was received on Aug. 20, 2020. MCFD did not specify if this social worker was a child protection, adoption, guardianship or resource social worker.

[210] Information provided by MCFD to RCY through a data request. This information was received on June 2, 2020.

[211] Information provided by MCFD to RCY through a data request. This information was received on Aug. 20, 2020.

Social Worker Turnover, Placement Changes and Missed Opportunities for Diagnosis

The Representative has noted in recent reports that social worker turnover and inappropriate placements leading to breakdowns or placement changes are pervasive, systemic issues that impact B.C.'s children and youth in care.[212] Throughout the research for this report, RCY heard from parents, service providers and community dialogue participants that the impacts of transitions between homes and a lack of consistency in child protection social workers are especially difficult for children and youth with FASD due to its effects, which include heightened anxiety and emotional responses.

Research has found that children and youth in care who have FASD need consistent caregivers who understand that FASD is a complex, invisible disability and can provide constant supervision, structure and support. Otherwise, placement changes or breakdowns can result.[213, 214, 215]

Research participants told RCY that the number of transitions between homes and lack of consistency in a child's life can result in a child or youth in care remaining undiagnosed, as the referral and follow-through required for an FASD assessment can be lost through transitions between social workers or homes – particularly since MCFD does not consistently track whether a child is suspected of having FASD. One Key Worker shared the challenges of obtaining a diagnosis for a child or youth in care when there are many transitions and no follow-through for an assessment:

> *"[Children and youth in care] don't have a family always constantly advocating for them and then they're in this residential home where you have different staff coming, dropping them off at school. So, nobody's actually following up to know if this child really needs a diagnosis."*

Service providers and professionals working in the field also pointed out that obtaining a diagnosis for a young person in care can be especially difficult during their teenage years when they become more aware of the stigma and some of the labels associated with an FASD diagnosis. One DAA social worker underlined this challenge by relaying a story about a young man she worked with:

> *"He had been in care all his life, since [age] three. He had not had an assessment up to [age] 11 … he transferred to the DAA when he was 11. At 11, 12, what happens? Kids can be involved in their Plan of Care and he said he did not want to be assessed. So, I get him at 16, 17. He has never been assessed, and [is] immovable, short of me dragging him to an assessment. He is going to age out in December and if that isn't heartbreaking … "*

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[212] Representative for Children and Youth, *Broken Promises: Alex's Story* (Victoria, B.C.: Representative for Children and Youth), 2017; Representative for Children and Youth, *Caught in the Middle* (Victoria, B.C.: Representative for Children and Youth), 2019; Representative for Children and Youth, *From Marginalized to Magnified: Youth Homelessness Solutions From Those With Lived Expertise* (Victoria, B.C.: Representative for Children and Youth), 2020.

[213] William Pelech, Dorothy Badry and Gabrielle Daoust, "It takes a team: improving placement stability among children and youth with Fetal Alcohol Spectrum Disorder in care in Canada," *Children and Youth Services Review* 35, no. 1 (2013): 121. https://doi.org/10.1016/j.childyouth.2012.10.011.

[214] Dorothy Badry, Deborah Goodman, and Jamie Hickey, "The Caregiver Curriculum on FASD: Transforming Practice Through Knowledge And Education," in *Transforming Child Welfare: Interdisciplinary Practices, Field Education, and Research*, eds. H. Monty Montgomery, Dorothy Badry, Don Fuchs, and Daniel Kikulwe (Regina: University of Regina Press, 2016), 274.

[215] Nazeem Muhajarine et al., "Phase One Evaluation: Improving Outcomes for Children with FASD in Foster Care Final Report" (Regina, SK: University of Saskatchewan), 2013. https://cuisr.usask.ca/documents/publications/2010-2014/Improving%20Outcomes%20for%20Children%20with%20FASD%20in%20Foster%20Care%20-%20Final%20Report.pdf.

Building Connection: An FASD and Trauma-Informed Approach in Action

Foster parents for more than 20 years and to nearly 50 children and youth, most of whom have FASD, relayed how they built trust and connection with one of their children who participated in this research. By exercising patience and meeting the child where he was at, they helped their child learn tools over time for self-regulation and showed him that it is okay to let others help him.

> *"He would go to his room and he would trash his room, you couldn't go anywhere near him. And yet, he's in there hurting and … in pain … emotional pain. So, we had a graduated approach we used with him. We'd start [outside his room] and just throw the occasional comforting word at him. Try not to set him off. And then we'd just get a little closer to his door. It took many times. So, you're getting to, 'I'm just outside your door but I'm not going to come in. I'm just going to be here' … then he'd rail at us. And then … if you could get in the door, in the room, looking down, don't look at him, get to the end of the bed – until finally he would be able to shorten that [process] up, because initially it's pretty long. And then he would let you comfort him … you could get to where you could [comfort him], usually just by patting his back. But he learned from that. He was able to take the feelings that he was having and process them down to a manageable level … with support. You know, you could leave a kid in their room and they're going to get there eventually, I guess. But it's very hard and it's very painful and [they] feel all alone."*

Without diagnostic information and final report recommendations, caregivers may struggle to understand how to best support the needs of a young person in their care. In addition, without a diagnosis, the root of a child's unmet needs that lead to sometimes challenging behaviours cannot be understood for what they are and this can lead to breakdown in placements. Further, without a diagnosis, a young person may be deemed ineligible for adult services, such as those provided through Community Living BC (CLBC), or Persons With Disabilities (PWD) financial assistance, ultimately impacting the young person's future.

Transitioning out of Government Care into Adulthood

Transitioning out of government care at age 19 is challenging, and young people with FASD can become especially vulnerable during this transition period.[216] One mental health practitioner spoke about the mental-emotional challenges young adults with FASD can encounter when they age out of foster care because of the uncertainty of their future living situation. This practitioner reflected on their experience with a client diagnosed with FASD and other concurrent disabilities who was in the process of leaving foster care:

> *"She's six months away from her 19th birthday and she was told that she's transitioning but they don't have … CLBC doesn't have a home for her … and she's just totally dysregulated because she has no idea. She's currently living in the safest [home] in a very, very long time and now she doesn't know if she can stay there with all these connections that she's made with her caregivers. Just because she's turning 19 her life is in a huge upheaval and she can't manage it. She can't handle the emotions around it."*

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[216] Linda Burnside and Don Fuchs, "Bound By The Clock: The Experiences of Youth With FASD Transitioning to Adulthood From Child Welfare Care," *First Peoples Child & Family Review* 8, no. 1 (2013): 40-61. https://fpcfr.com/index.php/FPCFR/article/view/200.

Once a young person turns 19, they no longer have the support of their social worker or caregivers. If a young adult has an FASD diagnosis and appropriate transition planning has taken place before they leave government care, there may be a few supports available for them to access. However, these supports are limited and often require the applicant to meet additional eligibility criteria (see Appendix D).

For young people who leave care without an assessment or diagnosis, the challenges become more difficult since the supports that are available are accessible only if a person meets specific eligibility criteria, which often require a diagnosis rather than being needs-based. If a young person wishes to pursue an FASD assessment after turning 19, they must pay out of pocket as these assessments are not publicly funded for adults, unless they are among the small proportion of individuals with FASD who are screened in as eligible for CLBC. CLBC can then refer for an assessment which is funded either by the Ministry of Health or CLBC. As one service provider said:

> *"There are a lot of people that don't get diagnosed when they're under 19 and then it gets very expensive and hard to get diagnosed. And some people say, 'Oh, well why does a diagnosis matter …' But I think it does matter for people in terms of getting disability benefits."*

A recent report by RCY, *A Parent's Duty: Government's Obligation to Youth Transitioning into Adulthood,* documented in detail the profound problems with existing systems supporting youth in care as they transition to adulthood, especially those with mental health issues and special needs.[217]

Finding: *Youth with FASD face serious hurdles and limited supports as they enter adulthood, impacting their futures*

Some of the children and youth who participated in this research are approaching young adulthood. Their families are concerned about their child's future in a world where, without supports, life would be challenging.

Like all children, they dream of a future where they are able to pursue things that make them feel happy, empowered and energized. Some of the children and youth dream of attending university, playing professional basketball or becoming a real estate agent. To give these aspirations a chance, appropriate life-long supports are necessary through young adulthood.

Unfortunately, the supports for youth with FASD transitioning into adulthood are limited. RCY heard consistently across all research participants, including parents, community dialogue participants, service providers and clinicians, that young adults with FASD need far more support than what is currently available in B.C.

"I like school, I will finish school, and then college, and then university, and then NBA."

Image and quote from Richard's Life Book

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[217] Representative for Children and Youth, *A Parent's Duty: Government's Obligation to Youth Transitioning into Adulthood* (Victoria, B.C.: Representative for Children and Youth), 2020, 1-89.

Some parents worry whether their child would be able to maintain income, employment or housing if the parent was no longer around to support some of their child's executive and adaptive functioning needs. This fear was also expressed by community dialogue participants while highlighting the gap in services for youth with FASD who are transitioning into adulthood. For example, FASD can affect a child or youth's memory and ability to complete daily living tasks. Since this type of ongoing support is not easily accessible for young adults with FASD through CLBC, parents feel extremely concerned about their children's futures.

Transitioning into adulthood also concerns families of children with FASD because of dysmaturity – the gap that often exists between the child's chronological age and their developmental age. Dysmaturity is one of the invisible effects of FASD, which can result in support workers, community members and others reacting negatively to adults with FASD if their behaviours are not considered *"acceptable"* for an adult. These negative reactions can sometimes result in serious consequences when someone with FASD is misunderstood, including loss of employment or housing.

One parent tried to focus on the positives and being "*grateful for the day that we have*" but also voiced her concerns about her child's future saying, *"Will he drive? Will he be able to hold down a job of any kind? … it's a scary thing. We try not to think, actually, that far in advance*." Another parent explained that their family is already going to great lengths to ensure their young daughter will have stable employment and housing as an adult:

> *"One of the reasons that we opened our store is because it would be a place that [she] could work, so we could transition over a 10-year period and create an employment opportunity for [her]. That's tucked in our back pocket in terms of employment. We have also begun saving for … and I have planned to have supported housing, so we will purchase a home and retrofit it. [She] will have a suite and we will rent out the upstairs and the upstairs income will pay for [her] living expenses."*

While this family has the financial resources to create the foundation for supporting their daughter into adulthood, this is most often not the case for families and their children with FASD. Those who do not have similar resources may seek government-supported solutions to secure housing, income and employment.

FASD's Effects Pose Challenges to One Youth's Post-Secondary Goals

One youth who was part of this RCY research is an academically gifted student in their last year of high school. They are described as a bubbly, outgoing, intelligent ray of sunshine who gets along with everyone.

As they excel in their high school courses, they are eager to pursue a degree at the University of British Columbia. However, they face various executive functioning challenges, such as remembering to complete different tasks for a class (memory) or understanding multiple instructions for an assignment (processing speed). They can also become very anxious if there are sudden changes to their schedule for which they are unprepared. This youth's mother supports them with these functioning skills and mental health challenges on a daily basis to help them succeed in high school.

While this youth is a passionate learner, their mother is concerned about sending them to university on their own. Will they be able to adapt to the intense course structure and assignments? Will they remember to complete daily living activities such as grocery shopping or household cleaning? Will they be able to navigate university life and some of the stressors on their own, without the appropriate mental health supports or their mother to support them?

This young person's high hopes, goals and aspirations could potentially remain unmet without the adaptive functioning and mental health supports they require to pursue their educational goals. As their mother, who has three children with FASD, said, *"What we know about FASD, period, is that I would say 100 per cent of my children … will probably need support until their late 20s."*

Support Programs and Eligibility

An RCY review of available government services indicated only a few supports that young people with FASD can apply for as they turn 19, and the eligibility criteria are extremely narrow (see Appendix D). These include:

- CLBC – Developmental Disabilities or Personalized Supports Initiative eligibility stream
- MCFD – Services to Adults with Disabilities
- Ministry of Social Development and Poverty Reduction (MSDPR) – Persons with Disabilities income assistance.

CLBC Supports

Young adults who are eligible through the Developmental Disability stream can access residential support, behavioural support, respite, employment support, skill development, homemaker support or further development of support networks. The Personalized Supports Initiative augments, rather than replaces, existing support. Where necessary, PSI will provide funding for supports such as those listed above.

Developmental Disabilities and Personalized Supports Initiative

Those diagnosed with a developmental disability can apply to CLBC for services through the Developmental Disability (DD) eligibility stream.[218] The eligibility criteria are similar to MCFD's CYSN services and specify that the individual must have significantly impaired intellectual functioning (IQ below 70) and significantly impaired adaptive functioning, and that these impairments started before age 18.

However, the vast majority of young people with FASD will not qualify for the DD stream as they do not have an intellectual disability.[219] RCY requested data regarding the number of young adults with FASD accessing the DD stream, however, like MCFD, CLBC does not track diagnosis through this eligibility stream.

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[218] Children and youth who received CYSN services through MCFD may be able to transition to adult services offered by CLBC once they turn 19 if they meet the specified eligibility criteria. CLBC is the provincial Crown corporation that funds services to adults with developmental disabilities, or individuals who have a diagnosis of Autism Spectrum Disorder (ASD) or Fetal Alcohol Spectrum Disorder (FASD) and also have significant difficulty completing day-to-day activities. These services are voluntary with various supports contracted to community service providers to assist clients with community inclusion, employment, behavioural support, respite for families and residential supports.

[219] PHSA's data provided to the Representative indicates that of the 925 children and youth with a confirmed FASD diagnosis between the 2016/17 and 2018/19 fiscal years, 692 (74.8 per cent) did not receive an intellectual disability diagnosis.

The Personalized Supports Initiative (PSI) eligibility stream was established in 2010 specifically to support adults with FASD or ASD who do not meet the IQ below 70 requirement.[220] To be eligible for PSI services, individuals with FASD must be confirmed as not having an intellectual disability, otherwise they would be eligible for services through the DD stream. The two eligibility criteria for PSI are a specified diagnosis of FASD or ASD and an adaptive functioning score of at least three standard deviations below the mean, both of which must be confirmed by clinically qualified professionals.[221]

Psychologists interviewed for this report said that it is "*exceedingly rare*" for someone with FASD to meet such a low adaptive functioning score – only about 0.13 per cent of the general population would receive a score that is three standard deviations below the mean, the equivalent of approximately 1.3 out of 1,000 people. One parent said, "*When they're saying for … adaptive functioning, three deviations under, it's really a wrong score for somebody with FASD,*" and one FASD assessment clinician went as far as to say that it is statistically "*almost impossible*" to meet this criteria.

As a result, many adults with FASD are not provided support to help them meet some of their basic needs. Various service providers indicated that, without the appropriate supports to transition into adulthood, many of these young adults have difficulty securing housing and employment and may become homeless and entrenched in poverty.

What is an Adaptive Functioning Assessment?

To assess adaptive functioning, a psychologist or someone trained in administering adaptive functioning tests will examine various domains related to communication (e.g., how one talks and understands others), daily living skills (e.g., home and personal care), conceptual skills (e.g., planning and organizing), socialization (e.g., interpersonal relationships, coping skills) and sometimes motor skills (e.g., gross and fine motor skills). There are different adaptive functioning assessments that can be used by qualified and trained practitioners to determine an individual's score.

Parents, community dialogue participants and service providers emphasized the need to change the CLBC eligibility criteria so more young adults with FASD can access PSI services. With more support, young adults with FASD could have better opportunities to thrive into adulthood, rather than slip into a cycle of poverty and/or homelessness. Eligibility for CLBC is governed and defined by the *Community Living Authority Act* (CLAA) and *Community Living Authority Regulation*, which would need to be amended to provide access to the Personalized Services Initiative (PSI) for more people.

Services to Adults with Developmental Disabilities (STADD)

STADD is an MCFD service that offers a personal navigator to support youth and young adults (ages 16 to 24) with developmental disabilities and their families or caregivers throughout the transitioning process from child and youth services to adult services and supports. STADD navigators are available in 145 communities across B.C., and their main role is to act as a primary point of contact for young adults

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[220] The guardian of a young man with FASD, Pervasive Development Disorder (now referred to as ASD) and ADD and an IQ of 79 challenged CLBC's decision to deny her son adult services and won the case. In response to this case, the Ministry of Housing and Social Development created the Personalized Support Initiative (PSI) eligibility stream in 2010, specifically intended for people with FASD or ASD who do not have an intellectual disability. People who are eligible through PSI can access funding for supported living, respite, employment support, skill development, homemaker services and development of support networks.

[221] *Community Living Authority Act: Community Living Authority Regulation*, B.C. Reg/231-2005, s. 2-2.5, https://www.bclaws.ca/civix/document/id/complete/statreg/231_2005.

and their families to help coordinate and organize transition planning and access to community and government supports. Navigators do their best to ensure that a young adult is set up for a successful transition into adulthood.

This critical service is only available to those youth and young adults who meet CLBC eligibility criteria. This means youth with FASD either need to meet the PSI criteria, or the DD eligibility criteria. Once again, these stringent criteria exclude the majority of young adults with FASD from being able to access this support.

Although STADD is intended to be available only to those who meet CLBC criteria, navigators interviewed for this report indicated that they are doing their best to support young adults with FASD and their families when their eligibility for services has not been determined. Further, a youth's adaptive functioning score may be too high as the youth may have developed their adaptive functioning skills and created various shortcuts to help them get by on their own. An adaptive functioning score that is too high automatically disqualifies an individual from CLBC services with no other services to turn to. As one navigator explained:

> *"For some of the youth I see, they're two standard deviations below … or close to three, but not quite … which means that they're still falling really low . . . [they are often] without family and a lot of times homeless or precariously housed, all of those kind of psycho-social factors . . . and [they] don't meet criteria because [they're] functioning [too well]. To me, it doesn't translate into what you see in how they're functioning . . . they're homeless."*

CLBC PSI Fast Facts

As of March 31, 2020, a total of 1,199 clients between the ages of 19 and 24 were accessing CLBC supports through the PSI eligibility stream.

- Of these clients, 316 (26.3 per cent) have a diagnosis of FASD, 870 (72.6 per cent) have a diagnosis of ASD, and 13 (1.1 per cent) have both an FASD and ASD diagnosis.

During the 2019/20 fiscal year, there were a total of 295 new PSI applicants between the ages of 19 and 24.

- Of these applicants, 248 (84.1 per cent) were determined to be eligible for services. The majority of these new clients had an ASD diagnosis (67.7 per cent), whereas a smaller proportion had an FASD diagnosis (31.9 per cent). One person (0.4 per cent) had both diagnoses.
- Of those who were determined to be ineligible, 39 (83 per cent) applicants were determined ineligible for services due to their adaptive functioning score being too high. Diagnosis was not provided for these ineligible applicants, so it is unclear how many had either an ASD or FASD diagnosis, or both. Eight (17 per cent) of the applicants were determined to be ineligible because they did not have an ASD or FASD diagnosis.

Source: Data provided by CLBC and sent to RCY on July 15, 2020 and Sept. 4, 2020.

Persons with Disabilities (PWD) Disability Assistance Program

PWD is a category of disability assistance provided by MSDPR. This program provides financial support to low-income individuals who have severe physical and/or mental health impairments and require

> "[My mom] recognizes that her children will need interdependence into adulthood and for the rest of their lives … FASD does not just disappear when the children become adults, it stays with them through their entire life and it is important to have supports in place for them as well."
>
> —Owen

assistance with their daily living activities from another person, animal or assistive device.[222] Considering the lengthy list of eligibility requirements (see Appendix D), which is only a portion of the application process, PWD can be extremely challenging for young adults to access and sustain.[223]

A DAA social worker interviewed for this report emphasized how difficult it is for young adults with FASD to access PWD, especially because successful applicants who have another source of income other than PWD are required to report to MSDPR by the fifth day of every month: *"Tell me why the PWD process is so mindboggling and complex. I have a degree and I'm like, 'Are you kidding me?' That process, that reporting every month, that remembering …"* This monthly reporting required for those who have an additional source of income poses an incredible barrier to people with FASD because they may have memory difficulties, which can result in them forgetting to submit the monthly report. In addition, this reporting requirement presupposes comprehension of the need to complete the reporting requirement, stable circumstances to do so, organizational skills such as retaining and storing records, access to a computer and computer skills and reading and numeracy skills. If the report remains incomplete, then the applicant may not receive the funding.

Duty to Accommodate

While the Representative predominantly heard that people with FASD struggle in their interactions with the PWD program, the Ministry of Social Development and Poverty Reduction (SDPR) advised RCY that for PWD clients who cannot submit monthly reports, the ministry has a policy to make all reasonable efforts to assist PWD clients in reporting. If a recipient is unable to complete their monthly report due to any special needs (e.g., physical, developmental, psychiatric, language and/or literacy barriers), the client can make an appointment to meet with an EAW or outreach worker to complete the report. In addition, the ministry has a Duty to Accommodate policy that requires staff to review cases individually to determine an individual's accommodation needs. The duty to accommodate applies to all points of contact with the applicant or recipient.

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[222] The amount that an individual receives for PWD financial assistance is dependent on the size of the applicant's family. As of May 1, 2021, disability assistance for a single person amounted to $1,358.42; up to $2,423.06 if an applicant and their spouse had PWD designation; and up to $1,784.08 for a single-parent family with two children. If an applicant has another source of income, they can only earn up to a certain amount per year, otherwise the monthly amount will change. For example, a single applicant can earn an additional $15,000 per year, a family with two adults where only one person is PWD-designated can earn an additional $18,000 and a family where both adults have a PWD designation can earn an additional $30,000. Source: Information received from The Ministry of Social Development and Poverty Reduction on March 16, 2021.

[223] The Ministry of Social Development and Poverty Reduction (MSDPR) provides a Simplified Application Process to eligible clients. Clients who access Community Living BC, MCFD's At Home Program, BC PharmaCare Plan P – Palliative Care Benefits, or Canada Pension Plan Disability Benefits can give MSDPR permission to confirm eligibility for PWD. This means that the client does not need to complete a full PWD application. The Simplified Application Process is also available to young people who are 17.5 to 19 years old and have a confirmed intellectual disability, upon submitting an existing psychological assessment and diagnosis.

Implications of Limited Supports and Opportunities for Change

Young adults who are unable to access CLBC support services, PWD or STADD may struggle to meet their needs into adulthood. STADD navigators, DDMHS workers and community dialogue participants have all seen people with FASD struggle with securing stable housing and employment and living in poverty or having run-ins with the criminal justice system (youth and adult). As one Tribal councillor from a First Nation shared:

> *"It's pretty disheartening for a lot of our people who have a brain injury, you know … they need support in ways that are not available to them here. And so, what has to happen and has largely been happening for a long time, is the community does what it can, so, you know, providing food and renting a room and like, providing just really that very foundational community support. It's sad, because if they had the correct supports in place, they could have a full and beautiful life. And instead they're really condemned to poverty. And to a very substandard quality of life."*

Justice-Involved Youth With FASD

Youth with FASD who are involved with the justice system were out of scope for this report because they are subject to distinctive processes through the courts and also have access to specialized services and supports not available to those who are not justice-involved. For example, MCFD Youth Justice Services has an FASD screening and referral tool for youth probation officers developed by the Asante Centre for FASD and also contracts for assessments through that clinic. As well, there are separate and specialized services and supports such as mental health services through Youth Forensic Psychiatric Services (YFPS), dedicated community residential substance use treatment programs (Full Time Attendance programs, or FTAPs), and intensive support and supervision (ISSP) workers.

While out of scope of this report, the services and supports available to justice-involved youth with FASD are still a matter of significant concern. Research has found that there is a great over-representation of persons with FASD in the criminal justice system,* including research in B.C. Fast et.al (1999) found that 23.3 per cent of youth admitted to the YFPS inpatient assessment unit were diagnosed with FASD, while more recently Popova et.al.(2021) found that 30 per cent of 161 cases diagnosed with FASD by the Asante Centre between 2015 and 2019 were involved with the criminal justice system.**

Of particular concern to the Representative are justice-involved youth with FASD who are transitioning to the adult system. Since criminal justice is governed by federal law, youth are subject to adult criminal court at age 18 and fall under the jurisdiction of the provincial or federal adult correctional systems yet, due to their cognitive impairments, these young "adults" with FASD are typically developmentally and functionally a much younger age. They have unique vulnerabilities and warrant special services and considerations, which are not supported in the current justice system model.***

* Flannigan, Katherine et.al., "Fetal Alcohol Spectrum Disorder and the criminal justice system: A systematic literature review", *International Journal of Law and Psychiatry,* 57(2018) 42-52

** Fast, Diane K., Julianne L. Conry and Christine A. Loock , "Identifying fetal alcohol syndrome (FAS) among youth in the criminal justice system." *Journal of Developmental and Behavioural Pediatrics,* 25 no.5, (1999),370-372. Popova, Svetlana et.al., "Health, social and legal outcomes of individuals diagnosed or at risk for fetal alcohol spectrum disorder: Canadian example", *Drug and Alcohol Dependence,* Vol.219 (2021), 1-9

*** Green et al., "FASD and the Criminal Justice System", CanFASD: Canada FASD Research Network, 2017/02

Recommendations

Building on Past Reports and Recommendations

This report builds on RCY's observations and recommendations in two past reports, bringing a more intentional and specific focus to the experience of children and youth with FASD.

In the 2018 RCY report *Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family*, the Representative recommended:

> *That the Ministry of Children and Family Development undertake a comprehensive assessment of the actual need for CYSN services across B.C. and the capacity of the current system to meet those needs. This assessment to examine funding, staffing levels and workloads, program delivery and wait times. Findings to be used to inform comprehensive service improvements so all eligible children with special needs and their families receive culturally respectful, appropriate and timely services and supports.*
>
> **MCFD to complete the comprehensive assessment and plan by the fall of 2019, seek necessary funding enhancements and begin implementation of changes by April 2020.**

As reported in the Representative's follow-up to this recommendation in fall 2020, MCFD has completed its assessment but has not yet begun implementation of changes as recommended by RCY and, therefore, is well behind the timeline laid out by that report. The ministry has developed a draft "service framework," which commendably proposes that CYSN service eligibility be determined on the basis of assessed functional needs rather than solely on the basis of diagnosis, which is consistent with the findings of this report.

MCFD intends to begin implementation of this new CYSN service framework in April 2021 but there is still, as yet, no sign of the substantive funding increase that is so essential to ensuring an effective transition to this new approach and to an accessible array of services for all CYSN families, and specifically including those with FASD. Although the Representative's recommendations in *Alone and Afraid* did not expressly identify children and youth with FASD, it is clear that they, too, fall under the rubric of children and youth with special needs.

Furthermore, in a more recent RCY report, *Left Out: Children and youth with special needs in a pandemic (December 2020)*, the Representative noted that the influence of historically inadequate CYSN supports were impossible to separate from the pandemic's impact on CYSN services:

> *The lack of equity in how CYSN families are served in B.C. is a source of tremendous frustration for families and Community Partners. They note that many families of children and youth with special needs are not able to access any supports. These include children and youth with complex behavioural needs such as attention deficit hyperactivity disorder and fetal alcohol spectrum disorder – children with presenting needs or diagnoses that do not meet CYSN eligibility criteria but whose behaviours can be extraordinarily challenging for families to manage in isolation.*

In *Left Out*, the Representative urged government to immediately re-engage with Community Partners on the design, development and implementation strategy for the new CYSN framework, with special attention to several problem areas including:

- *The absence of needs-based assessment processes and eligibility requirements in all CYSN services and supports, including for children and youth with FASD;*
- *Significant inequity in supports/services based on arbitrary lines that discriminate against children who do not fit into the restricted eligibility categories for support, including children and youth with FASD;*
- *Chronic delays in assessment and diagnosis;*
- *The exclusion from funding supports of families of children and youth with support needs solely because their diagnosis/need is not recognized by the current CYSN funding structure; and*
- *The disproportionate impact on CYSN families who are also Indigenous, Black, of colour, newcomers and refugees, and low-income or single parents.*

The Minister of Children and Family Development has acknowledged the inequities and has noted the need to ensure that the new CYSN framework supports the broad range of families who require these supports. MCFD has committed to establishing an advisory council to hear these voices and lived experiences.

RECOMMENDATIONS PREFACE

This report shows that improving the well-being of children and youth with FASD and their families requires a whole-system approach, involving actions across multiple ministries: MCFD, Health, Education, Mental Health and Addictions, Social Development and Poverty Reduction, and Citizens' Services. It also requires comprehensive engagement with organizations that specifically serve children and youth with special needs.

In addition, as B.C. works toward meaningful reconciliation with First Nations, Inuit and Métis peoples – prioritizing decolonization and resumption of jurisdiction over child and youth services – the expertise of First Nations, Inuit, Métis and organizations that represent Urban Indigenous peoples must be included in the planning and implementation of the response to this report.

Further, it is critical that MCFD co-lead, with DAAs, to collaboratively articulate culturally safe approaches to delivering supports and services for First Nations, Métis, Inuit and Urban Indigenous children and youth with FASD and their families. This process must include the ministries of Health, Education, Mental Health and Addictions and Social Development and Poverty Reduction, as well as First Nations and Métis governments.

The Representative acknowledges that the context of Indigenous self-government is changing rapidly. In this report, we have used language and an interpretation of child welfare for Indigenous children that reflects structures and processes that exist currently. As Indigenous governance bodies are constituted and assume their appropriate responsibilities, we anticipate that they will play an important role in guiding action on the recommendations in this report.

RECOMMENDATION 1

That the Ministry of Children and Family Development (MCFD) fully fund and implement a CYSN service framework and plan, fully inclusive of children and youth with FASD. The formation of the service framework and plan must extensively engage Delegated Aboriginal Agencies (DAAs) and all appropriate partners. This framework must articulate a comprehensive and accessible array of CYSN services, delivered based on both an assessment of functional needs and diagnosis and, therefore, fully including children and youth affected by FASD.

MCFD to begin implementation by Sept. 30, 2021 and complete full implementation of the CYSN service framework and plan over a three-year period ending March 31, 2024.

RECOMMENDATION 2

Pending full implementation of Recommendation 1, that MCFD immediately include suspected or confirmed FASD, based on an assessment of functional needs, in the eligibility criteria for CYSN Family Support Services, thereby allowing children and youth with FASD and their families to access services available to others with specific neuro-developmental conditions. The ministry should seek appropriate funding to expand the capacity of these services to adequately support the number of newly eligible FASD families so that this recommended expansion of service eligibility does not lead to reduced services or longer wait lists for other CYSN families.

MCFD to secure immediate funding enhancements and begin implementation of the expanded eligibility criteria by Sept. 30, 2021.

RECOMMENDATION 3

MCFD to complete a comprehensive review of evidence-based and promising practices specific to serving children and youth with FASD, including from the Key Worker Parent Support Program, for integration into the CYSN framework. In the meantime, MCFD to take immediate action to ensure that the KWPSP has consistent quality service across all regions of B.C. and is accessible to all families of children and youth with FASD.

MCFD to take immediate action to ensure equitability and accessibility of the KWPSP by Sept. 30, 2021 and complete the best practice review by March 30, 2022.

RECOMMENDATION 4

As a first step toward realizing fundamental changes in practice that address racism, stigma and bias, MCFD, in collaboration with DAAs, community service agencies and caregivers, to conduct a review of existing FASD awareness training and the training needs of all front-line staff working with children and youth with FASD.[224] MCFD, working with DAAs, to use this review to support the development of evidence-based, culturally attuned and regularly updated training materials that ground a required training program for current staff across the range of MCFD service lines and, in particular, CYMH, CYSN, child welfare and youth justice. This awareness training should then be incorporated into basic entry training for newly hired staff and made accessible to community service agencies and caregivers.

MCFD to complete the reviews and curriculum development and begin training by March 31, 2022 and complete training of all relevant ministry and agency staff by March 31, 2023.

RECOMMENDATION 5

That the Ministry of Mental Health and Addictions (MMHA), in collaboration with MCFD, DAAs and the Ministry of Health, lead a review, and develop and implement a plan, to provide effective and accessible mental health services for children and youth with special needs, including FASD. This should include a review of evidence-based, culturally attuned and promising practice models of therapy, intervention and care for children and youth with special needs including FASD, who have mental health impacts, as well as an assessment of current resourcing and resource gaps. The findings of this review and planning should be prioritized and built into MMHA's *Pathway to Hope* for implementation.

MMHA to complete the review and plan by March 31, 2022, with MCFD and Health beginning the implementation of new service approaches and enhanced services by Oct. 1, 2023, and completing implementation by March 31, 2024.

Preamble to Recommendation 6: *The RCY report* Alone and Afraid (December 2018) *recommended that the Ministry of Health* "take steps to incrementally decrease the wait times to three months for completed assessments of autism and complex behavioural developmental conditions [CDBC] across the province … to nine months by Sept. 30, 2019; to six months by Sept. 30, 2020; and to three months by Sept. 30, 2021." *The Representative notes that CDBC assessment provincial average wait times actually increased from 63.5 weeks in 2017/18 to 64.4 weeks in 2020/21, meaning that the ministry has not come close to meeting the timelines of the* Alone and Afraid *recommendation. While the Representative acknowledges that the COVID-19 pandemic has created more difficult conditions for the ministry she also notes that, even before the pandemic, these wait times had increased.*

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[224] The Representative acknowledges that the context of Indigenous self-government is changing rapidly. In this report, we have used language and an interpretation of child welfare for Indigenous children that reflects structures and processes that exist currently. As Indigenous governance bodies are constituted and assume their appropriate responsibilities, we anticipate that they will play an important role in guiding action on the recommendations in this report.

RECOMMENDATION 6

That the Ministry of Health incrementally reduce wait times for complex developmental behavioural conditions (CDBC) diagnostic clinics, and also secure additional resources to provide for periodic follow-up assessments, at key development stages from infancy through to adolescence.

The Ministry of Health to reduce wait times to nine months by March 31, 2022; to six months by March 31, 2023; to three months by March 31, 2024; and thereafter increase capacity to provide for follow-up assessments.

RECOMMENDATION 7

That the Ministry of Health, in collaboration with the First Nations Health Authority and with guidance from the Task Team formed as a result of the *In Plain Sight* report, apply learnings from the review of systemic bias to referral pathways and assessment processes for CDBC diagnostic clinics. The changes/improvements should specifically address the issue of bias with regard to the referrals of First Nations, Métis, Inuit and Urban Indigenous children and youth for FASD assessments and ASD assessments.[225]

Ministry of Health to complete the review and implement recommended improvements by March 31, 2022.

RECOMMENDATION 8

That the Ministry of Health conduct an assessment of existing FASD awareness training and the training needs of appropriate front-line staff working with children and youth with FASD, leading to the development of evidence-based, culturally attuned, Nation-specific and regularly updated training materials that ground a mandatory training program for current staff across the range of health services.

Ministry of Health to complete the assessment of existing FASD awareness training by March 31, 2022. Sequentially, the Ministry of Health to identify appropriate priority front-line providers to receive training, by Sept. 30, 2022, and develop training and access to training by Sept. 30, 2023.

RECOMMENDATION 9

MCFD together with the Ministry of Citizens' Services to initiate the development of a cross-ministry plan, in collaboration with the ministries of Health, MMHA, Social Development and Poverty Reduction, and Education, and in association with DAAs, health authorities and Community Living BC, to routinely collect high-quality demographic and service data that allows for disaggregation, providing an essential foundation for more effective policy development, program provision and service monitoring for children and youth with special needs and their families, including those with FASD who are receiving services from these public bodies.

The cross-ministry plan to be completed and implemented by April 1, 2022 and fully implemented by March 31, 2024.

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[225] FNHA is mandated by a number of health agreements and direction given by B.C. First Nations leadership. Given this mandate, the Representative trusts that FNHA will work with B.C. First Nations as appropriate through its mandate and those relationships. Source: https://www.fnha.ca/about/fnha-overview/mandate.

Preamble to Recommendation 10: *The explicit focus of this report is on understanding the direct lived experience of children and youth with FASD, and their families. Details about the experiences of children and youth in the education system, and an analysis of school-based supports and approaches was outside the scope of this report, and yet these emerged as a significant area for further attention. The Representative is aware that the Ministry of Education is investing in improving services and supports for children and youth with disabilities or diverse abilities, and encourages this direction, specifically with a focus on FASD.*

RECOMMENDATION 10

That the Ministry of Education update its *Inclusive Education Policy* and supporting documents and incorporate information to increase awareness and understanding of the specific learning needs of children and youth with FASD and related disorders into the supporting documents.

Ministry of Education to update *Inclusive Education Policy* and supporting documents and incorporate information to enhance awareness of FASD and related disorders by Sept. 1, 2021.

RECOMMENDATION 11

That the Ministry of Education work with the British Columbia Council for Administrators for Inclusive Supports in Education (BC CAISE) to support staff training and development needs for educators and school staff who work with children and youth with FASD or suspected FASD, and their families, and build on evidence-based and promising practice approaches to better support inclusion and improved learning outcomes for children and youth with FASD.

Ministry of Education to work with BC CAISE and partners to support the implementation of staff training and development to better support inclusion and improved learning outcomes for children and youth with FASD and related disorders by Sept. 1, 2022.

Conclusion

This report provides ample evidence of the challenges – the fragmentation, gaps and barriers – experienced by children and youth with FASD and their families. What is reported here through RCY's FASD research is echoed in many previous reports by the Representative and also in other reports such as the SSCCY report *Children and Youth with Neuro-Diverse Special Needs,* which emphasizes the inadequacy and inequity in access to supports for children and youth with FASD and their families or caregivers. The need to address these issues is urgent and pressing – the past year of the COVID-19 pandemic has shone an even stronger light on the many shortcomings of the system when it comes to children and youth with FASD and their families.

The imperative to make necessary change is driven by another theme that emerged through our research – the profound strength and capability of the children and youth whose experiences and stories have informed this report. Through the time we spent with them, through their story books, and in their connections with our co-researcher, Myles Himmelreich, what we came to see was the great potential each child and youth possesses, and their hopes for a future in which they can be seen, be connected and contribute. They are aware of their own unique experiences and challenges in a system that does not address their needs and they simply want to be seen and involved, as all children do. They are creative, loving, helpful, intelligent, athletic and they have big dreams for their futures. At the decision-makers forum that formed part of the research for this report, the courageousness, resilience and strength of the children, youth and families had a profound effect as they described their lived experience.

FASD Forum for Decision-Makers

RCY Researcher: *"What do you hope will happen with this story we are telling about FASD and about your and your family's experiences?"*

Youth Participant: *"I want the people who make decisions about us to hear us; to really listen so that they can understand."*

Youth participants in the FASD project expressed curiosity to RCY researchers about what could happen through sharing their experiences more widely. They had a keen desire to be heard by the people who make decisions. The RCY decided to find ways that the young participants and their families could share their truth with decision-makers and influencers.

On Oct. 25, 2019, a small group of senior leaders from the public bodies and organizations with significant responsibilities for assessing, diagnosing, supporting and caring for young people with FASD spent a day with the youth participants and their families. They were invited by RCY to come with an open mind, open heart and be prepared to be surprised, challenged and moved to action.

At the forum, the children engaged decision-makers through skits, stories, simulations and activities. Their creative presentations throughout the morning illuminated their experience: the many ways in which FASD is misunderstood, the lack of supports available to young people and their families, and the exclusion that they feel within school and community.

Parents and caregivers spoke eloquently and powerfully in the afternoon about their children's many strengths and challenges, how misunderstood FASD is, and how this affects their children. They spoke about how they support their children, what works and does not work, and how much harder it is to raise their children when practitioners and educators don't understand FASD. They spoke about the lack of meaningful, accessible and relevant services and supports. They described the heartache of being marginalized, looking into what is available for other children and youth with support needs but not being able to access what their own children and families need to thrive.

In the Collaborative Action discussions that followed, decision-makers were asked to consider what they could do, within their organizations and circles of influence, to effect change in four key areas:

1. Enhancing understanding of the effects of FASD and ways to support children and youth with FASD in the health, education and social services sectors;
2. Addressing the policies, program eligibility requirements and practices that result in the exclusion of children and youth with FASD from access to services and supports, and enhance inclusion;
3. Enhancing timely access to school, mental, physical and emotional health supports; and
4. Improving the assessment and diagnostic process and follow-through.

As the forum ended, participants acknowledged how little they had understood about FASD prior to the event. They could see that widespread lack of awareness and understanding contributed to a lack of empathy, supports and services.

They appreciated how frustrating it is for families to have an assessment and get a diagnosis, only to find that no doors to service or support open up. They acknowledged the inequities in access to services and supports that were revealed and agreed that these need to be addressed: youth with FASD should receive the services and supports they need to thrive.

They wrestled with the stigma, shame, bias and judgment attached to FASD and wondered how the professional and public discourse could be changed and how might broader awareness and understanding be fostered.

There was agreement that a whole-of-government approach was needed, that greater awareness and understanding of FASD and its impacts is essential, and that engagement and support with young people with FASD is necessary.

At the end of the day, commitments that were made are captured in the graphic below.

It is with deep gratitude that the Representative honours the young people and their families, the adult supporters and the decision-makers who brought so much to the discussions.

The forum clearly demonstrated the resilience and strength of he children and youth profiled in this study, as they led the event with pride and confidence. Their demonstrated determination to advocate for themselves and to request the support they need moved all of those present, culminating in a concrete commitment to do much more to support children and youth with FASD. The public partners attending the event acknowledged that the experiences of children and youth are not fully understood in government and committed to improving provincial supports for children and youth with FASD and their families.

A second imperative made evident through our research is that, while an adequate and appropriate response to the needs of children and youth with FASD and their families has not been mounted by B.C. ministries to date, there are examples of initiatives and programs that hold great promise: within these there are seeds for us to learn and build from. The CanFASD Research Network has built a substantial f**oundation of research and information** that can ground on-going evidence-based supports and services. In some regions, professionals have addressed issues related to the complexity of **diagnostic assessment** reports by preparing family-friendly versions that can act as a positive support for families in addressing the needs of their child or youth and advocating for them. The LIFE Sessions developed by the Whitecrow Village FASD society demonstrates the potential of **programming with families and their children together and does so through an FASD-informed lens** to empower and fulfil participants. To address issues related to **exclusion in schools**, the FASD Success Coach program, directed by the Fort McMurray Public and Catholic School Boards in Alberta, provides a school consultant to support capacity building, personal development and mentorship to students with either confirmed or suspected FASD. This program also supports a child's navigation through the school system through child-specific classroom observation, development of IEPs, and school-wide awareness raising and capacity building. In community and addressing issues of social isolation, the BC Centre for Ability brings together children, youth and their families for Family Together Night, **building social connection and support** through an environment that is inclusive and supportive.

A third imperative rests in our ethical commitments, under a variety of international, national and provincial treaties, agreements and frameworks – to mount an equitable and fulsome response to the rights of children and youth with FASD and those who care for them. Children with disabilities and special needs, and those with FASD specifically, have a right to the support and resources they need to develop to their full potential. They also have a right to the care and nurturance of trained and capable caregivers. And, importantly, we have an obligation as a society to ensure that we address long-standing and pernicious racism and bias that creates even more significant harm for some children, youth and their families.

The stories of children and youth in this report inspire great hope that, through addressing the many challenges they and their families experience, it will be possible to see them thrive, realize their full potential, and contribute substantially to the communities in which they live. Their stories of ability and resilience are inspiring.

Glossary

Term	Definition
Abstract vs. Concrete	Concepts such as time, money, sarcasm and metaphors are considered abstract, and are sometimes confusing or difficult for people with FASD to understand. It is best to explain things using plain language and concrete examples.
Adaptive Functioning	Adaptive functioning refers to coping with everyday environmental pressures and includes daily living skills that people perform to care for themselves and to interact with others. The measurement of an individual's adaptive behavior reflects their competence to perform daily activities required for personal and social sufficiency. The terms adaptive functioning and adaptive behavior are often used interchangeably. Adaptive functioning is defined by typical performance, not ability. The components of adaptive functioning identified by the American Psychiatric Association are communication, self-care, home living, social, community use, self-direction, health and safety, academics, leisure, and work.
Adaptive Functioning Assessment	Assessment of an individual's ability to function – at home, at school, and in the community – in order to determine what types or services and supports they need. There are various tools that exist for assessing adaptive functioning, which include *Scales of Independent Behaviour Revised, Vineland Adaptive Behaviour Scales,* and the *Adaptive Behaviour Assessment System.*
Attention Deficit Hyperactivity Disorder (ADHD)	ADHD is defined as a persistent pattern of inattention and/or hyperactivity and impulsivity that interferes with daily function or development.
Autism Spectrum Disorder (ASD)	Autism Spectrum Disorder is characterized by persistent deficits in social communication and social interaction, as well as restricted and repetitive patterns of behaviour, interests or activities with symptoms displayed from a young age.
Child	A person under 19 years of age, as defined under the *Representative for Children and Youth Act*.
***Child, Family and Community Service Act* (CFCS Act)**	Legislation enacted in 1996 governing child protection in British Columbia.
Children and Youth in Care (CYIC)	A child or youth who is in the custody, care or guardianship of a director or a director of adoption.
Community Living Authority Act	Legislation enacted in 1994 governing supports and services for adults with developmental disabilities, fetal alcohol spectrum disorder, pervasive development disorder and autism spectrum disorder who are 19 years of age and older.
Comorbidity	A person having more than one distinct condition or diagnosis.
Confabulation	The spontaneous or provoked use of inaccurate information to fill in memory gaps, without intention to deceive but rather believing it to be true.

Term	Definition
Developmental Disability	Developmental disabilities are understood as a group of conditions due to an impairment in physical, learning, language or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime. In B.C., this term is much narrower and is used to determine eligibility for services. The term is akin to the DSM-5 criteria for intellectual disability, meaning that an individual has significant impairments in intellectual functioning that manifests before the age of 18, which exist concurrently with impaired adaptive functioning.
Dysmaturity	Developmental dysmaturity looks like immaturity but it is really a brain-based challenge that can impact social situations, communication, and life skills. As children get older, they are expected to act certain ways for their age – they should be responsible, act appropriately and understand social cues. For someone with FASD, these expectations can be unrealistic as they are based on the belief that behaviour should reflect chronological age.
Executive Functioning	These cognitive processes include the capacity to regulate attention, affect and impulse. Further, executive control allows an individual to integrate newly obtained information with memories, make decisions, solve problems, and link behaviors to their consequences.
FASD-informed	An FASD-informed approach starts with the understanding that FASD is a brain-based permanent disability that has wide ranging effects and affects an individual in various aspects of life including physically, behaviourally, cognitively, socially, emotionally and spiritually. This approach recognizes that children, youth and adults with FASD may struggle to follow certain rules or behaviour expectations and for them to achieve success, the system, service provider or program needs to make accommodations to fit with their specific needs.
Fetal Alcohol Spectrum Disorder (FASD)	FASD is an umbrella term for a group of conditions associated with prenatal alcohol exposure. FASD is characterized by difficulties with thinking and memory, behaviour challenges and challenges completing activities of daily living. In Canada, the specific diagnoses within the spectrum include: (1) FASD with sentinel facial features and (2) FASD without sentinel facial features. A third category known as "at risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure" was developed not as a diagnosis, but as a designation to indicate that prenatal alcohol exposure was identified, but other criteria for an FASD were not met.

Term	Definition
Identity Permanency	The Representative's informal consultations with youth advisors have led to the exploration of a fifth dimension of permanency – identity permanency – defined by youth as the opportunity to develop a more enduring, informed and positive sense of themselves as they move into adulthood. Youth have expressed a desire to have access to information about their family, the circumstances that led to them being in care, what happened to them while in care, access to assessments so that they better understand the challenges that they might face with respect to learning, mental health, health, employment, etc. and how they might be able to be more successful (such as through developing coping strategies or choosing certain learning or career paths).
Impaired Adaptive Functioning	Means adaptive functioning that, when evaluated by a qualifying practitioner, is determined to be a contributing factor in making a diagnosis, in accordance with DSM-5, of intellectual disability (intellectual developmental disorder), or in making a diagnosis, in accordance with DSM-IV-TR, of the disorder that has been replaced in c5 by intellectual disability (intellectual developmental disorder.
Implicit Bias	This is the way in which stereotypes about race, gender, age, socio-economic status and other factors automatically and unconsciously influence our actions, behaviours and decisions. This implicit bias is sometimes referred to as "unconscious" or "non-conscious" bias. These biases often do not reflect one's explicit beliefs.
Information-Processing Deficits	Can occur in four domains: when information is recorded, interpreted, stored (memory) or retrieved. For a person with FASD it may take them longer to process information, they may not be able to process it at all, or they may not be able to retain the information. When a person's information processing is impacted, others may perceive them as a "poor listener."
Intellectual Disability	As defined by the DSM-5, intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.
Intergenerational Trauma	The cumulative and historical effects of colonial violence that are transferred across generations. In the present day, these harms interact with and are compounded by contemporary aspects of colonization such as racism. This results in emotional and psychological wounding over the lifespan and across generations.
Invisible Disability	In simple terms, an invisible disability is a physical, mental or neurological condition that is not visible from the outside, yet can limit or challenge a person's movements, senses, or activities. Unfortunately, the very fact that these symptoms are invisible can lead to misunderstandings, false perceptions, and judgments.

Term	Definition
Mother Blaming	Motherhood is embedded in a complex network involving internal and external factors including child development, family development, gender roles and society, and the economic and social climate of the cultural environment. Failing to consider these complexities results in mother-blaming, which is the tendency to hold mothers entirely accountable for their child's physical, mental and cognitive well being, challenges, and behaviour.
Sensory Processing Disorder	A condition where the brain has trouble receiving, misinterprets, has trouble responding to information that comes from the senses.
Socioeconomic Status (SES)	The social standing or class of an individual or group. It is often measured as a combination of education, income and occupation. Examinations of socioeconomic status often reveal inequities in access to resources, plus issues related to privilege, power and control.
Trauma	Trauma, often conceptualized as extreme stressors and individual psychological responses, is in reality much more complex. Trauma is embedded within cultural attitudes, behaviors, and systems that influence both stressors and outcomes.
Young Adult	A person who is 19 years of age or older but is under 24 years of age, as defined under the *Representative for Children and Youth Act*.
Youth	A person who is 16 years of age or older but is under 19 years of age, as defined under the *Representative for Children and Youth Act*.

Appendices

Appendix A: Detailed Methodology and Methods

Study Objective

Preliminary RCY research indicated that there is a lack of supports in B.C. for children and youth with FASD and their families. The objective of this research was to identify what the provincial social service system currently provides for children and youth with FASD, understand where the gaps exist in this system and understand what type of services are needed. Lived experience was determined to be the best way to create a deep and accurate understanding of the gaps and the service needs of children and youth with FASD and their families or caregivers. The Representative believes that, by listening to lived experience, recommendations for change can better reflect such needs. In addition, RCY learned early in the project scoping process that FASD has been largely seen as an Indigenous issue, and therefore RCY sought to understand this lived experience and the implications for First Nations, Métis and Urban Indigenous peoples. Further, this research sought to understand the two provincial programs available that directly relate to FASD: the Key Worker Parent Support Program, funded by MCFD, and the CDBC assessment process funded through the Ministry of Health.

FASD awareness and prevention initiatives, services provided by private agencies and youth older than 19 were all out of scope for this research project.

Study population

Children and Youth Research

Nine children and youth participated in this research, ranging in age from eight to 18. Participants live in communities throughout B.C., including urban, rural, north, south and central communities. Three young people identify as female, five young people identify as male and one young person identifies as non-binary. All participants have a diagnosis of FASD, or a diagnosis under the spectrum – depending on the year of their diagnosis. Some of the young people have additional diagnoses. All the child and youth research participants are First Nations or Métis. In addition, all children and youth were either adopted, living in a kinship arrangement or living with foster parents. RCY also interviewed six parents of the young people who engaged in the research.

Key Workers

Twelve people participated in semi-structured interviews about the KWPSP. Interviewees represented urban and rural communities across the four MCFD Regions (Coast Fraser, Interior, North and Vancouver Island), chosen because MCFD contracts agencies to deliver the KWPSP. The objective was to interview a Key Worker in each of the selected areas, however, the Key Worker role had been vacant for a long period of time in some communities, especially in rural areas. In these instances, professionals involved in community child development or family services were interviewed, helping gain an understanding of the community history and Key Worker vacancy.

CDBC Assessment Centres

Sixteen staff in all four CDBC Assessment Centres were interviewed for this report. Staff included executives, clinicians and other team members.

Service Provider Interviews

Thirty service providers were interviewed for this report. Service providers included a wide array of professionals such as social workers, case managers, counsellors, executive members of service organizations and service navigators. Service providers came from a variety of organizations, including community-based and government-based. Organizations represented a mixture of non-Indigenous, First Nations and Métis organizations.

Parent Networks

RCY researchers were invited to interview parents attending two separate support networks. One network was specific to parents of children and youth with FASD. This network also acted as a network for children and youth. The second network was specific to foster parents.

Methods

Research with Children and Youth with FASD and their Families

RCY had the opportunity to work closely over several months with a group of children and youth in completing the research for this report. RCY researchers spent time with eight young people. A ninth youth contributed through written work submitted, with his permission, by his parent.

Engaging deeply the young people and their families, alongside a co-researcher with lived experience, meant that RCY researchers learned about FASD through relationship. For example, researchers shared meals and stories with families, examined photographs that the young people took of what was important in their lives, created life books with the children and youth, played basketball, built fires and played in playgrounds. Researchers met with families in their homes, in restaurants and even in a campsite, and were invited to attend a family network meetup with one of the families where more lived experience was shared by this group of parents. Researchers started their journey to understanding FASD by listening to what young people with FASD and their families shared; they learned about the children and youth first and their FASD diagnosis second.

In designing the methodology for this report, flexibility was necessary to encompass the unique engagement needs of all participating children and youth. For example, while RCY worked directly with eight of the young people, the ninth young person submitted his thoughts to RCY researchers virtually because he experiences intense social anxiety.

RCY chose to use the Mosaic Approach in the research with the young people. The Mosaic Approach brings together different perspectives, research tools and types of data to understand young peoples' perceptions and views.[226, 227] This is a multi-method approach that combines

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[226] Alison Clark, "Ways of Seeing: Using the Mosaic Approach to Listen to Young Children's Perspectives," in *Beyond Listening: Children's Perspectives on Early Childhood Services*, eds. Alison Clark, Anne Trine Kjorholt and Peter Moss (Bristol: Bristol University Press, 2005).

[227] Cheryl Greenfield, "Personal reflection on research process and tools: effectiveness, highlights and challenges in using the Mosaic Approach," *Australian Journal of Early Childhood* 36, no. 3 (September 2011): 110.

observations and interviews with participatory research tools.[228] The elements of the Mosaic Approach include:

- focused on children's lived experience
- multi-method
- participatory
- reflexive
- adaptable
- embedded into practice.

Given these elements, the Mosaic Approach was a fit with the objectives of this research, particularly because of its focus on children's lived experience. The multi-method approach allows for the use of multiple tools for collecting data and worked with RCY's desire to obtain a wholistic understanding of the research participants' lived experience while also allowing for flexibility in adapting to their needs.

To understand what daily life could entail for the families involved in this research, researchers asked both the young people and the parents to keep daily self-reflection logs. The two-week logs recognized that not all participants were likely to fill out the full log. Cameras were also provided to the children and youth, and the resulting photos they took were used to co-create life books that also included writing and other items the participants deemed important in their lives.

The participatory nature of this methodology ensured that the children and youth were active in the research by helping to co-create meaning of their research outputs. This element of the research is not applied to the analysis of the findings but rather in ascribing meaning to how the children represent their lives. For example, rather than the researchers taking away the photos the children and youth took and ascribing meaning to their importance, the young people helped to create those meanings with the researcher through the creation of their life books. In addition, the young people were given the opportunity to ascribe meaning and emotions to the experiences they chose to share throughout their day in their self-reflection logs.

The reflexive element of the methodology encourages participants to reflect on themselves and their lived experiences, ensuring that the research does indeed capture lived experience. The principle of adaptability in this methodology allows the development of methods that can be adapted to the context of the research participants. The young people were encouraged to share in ways that they chose to share. In addition, the researchers did not wish to create an arduous or burdensome task and invited the participants to engage with the tools as much or as little as they wished. As a result, the amounts of information received from each participant varied.

Finally, the principle of embedding the findings in practice ensures the type of information collected can be used to develop policy and influence practice. The information collected through this research project has resulted in the public report with recommendations for changes in policy and practice based on the lived experience of the children, youth and their families.

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[228] Alison Clark, "Ways of Seeing: Using the Mosaic Approach to Listen to Young Children's Perspectives," in *Beyond Listening: Children's Perspectives on Early Childhood Services*, eds. Alison Clark, Anne Trine Kjorholt and Peter Moss (Bristol: Bristol University Press, 2005).

The Mosaic Approach includes two stages to research. The first stage uses observations and data collection employing various research tools (see below) and the second stage brings the data together through conversation, reflection and discerning meaning.

In developing the methods, researchers focused on the elements of the Mosaic Approach and developed tools that would appeal to a range of young people, taking possible FASD-related challenges into account. The design of this project was informed by the expertise of the project's co-researcher, Myles Himmelreich.

The following methods were engaged:

- observation and conversation through life tours
- photography and book-making tours
- self-reflection logs
- interviews with parents/caregivers and practitioners.

The researchers visited the families twice. On the first visit, the researchers spent a few hours with the participants on a life tour involving observation and open conversation to help the researchers understand what a day looks like for the participants. This first visit allowed for initial relationship-building and the opportunity to build trust. This approach had the additional benefit for RCY researchers to learn about FASD through relationship – invaluable for understanding the young people in relation to their diagnosis, rather than focusing on understanding a diagnosis on its own. During these visits, the researchers were invited into the homes of the families to share meals and stories.

In addition to the self-reflection logs and cameras, scrapbooks and semi-structured interviews with parents were used to capture lived experience. At the end of the first visit, if a child or youth decided to continue participation in the research, they were given two disposable cameras with instructions that included broad parameters/themes (i.e., take photos of things that bring you joy; what a typical day looks like; things that are challenging; things that calm or help) and, along with their parents, self-reflection logs with emoji stickers and space to record feelings and reflections throughout the day.

The purpose of the self-reflection logs was to help identify how the young people processed and reflected on their daily experiences, as well as to capture these lived experiences. The parents were given the logs to capture their lived experiences in supporting a child with FASD. The logs were also an opportunity to compare the different stressors or points of needed support.

Families were given a minimum of two weeks to work on their logs and photography. The second visit to the families focused on reflection and understanding and occurred over two days. Researchers brought a blank scrapbook, the developed photos from the participant and scrapbook making supplies. Researchers worked alongside the participant as they created a "map" using their photos and words. While all the youth engaged with the photography to a high degree, engagement creating life books varied. When a young person was less inclined to sit and work on their life book, the co-researcher would often get them active outside and have conversations with them which the researcher would record while they were engaged in the activity.

First Nations Community Dialogues

During the initial research stage and scoping of the FASD research project, the RCY was struck with the often-raised concern that FASD is framed as occurring mainly in First Nations, Métis, Inuit and Urban Indigenous communities, as well as claims that systemic racism could be leading to bias in identification, referral pathways and assessment of Indigenous children and youth with FASD.

To explore these concerns, RCY identified community dialogue sessions as a method to engage with First Nations communities. RCY began by reaching out to individuals in leadership positions in the child- and family-serving systems within First Nations communities and provided a description of the research project including the intent of the community dialogue sessions. Community leaders then spoke to either their governments or other community leaders (depending on the community context) to confirm interest in hosting RCY for such dialogues. Once interest was confirmed, initial conversations occurred to brainstorm how to proceed with the dialogues and address any questions or concerns from the Nation. RCY is aware of historical, and sometimes current, practices in which research is done *on* First Nation communities rather than *with* communities. RCY offered to enter into research agreements, following OCAP procedures. One Nation agreed that it would like a research agreement and developed one that RCY agreed to.

Each community led the creation and development of the community dialogues and RCY supported in whatever way the Nation requested. As such, each dialogue looked different, depending on how the Nation felt it best to host the community in such dialogue. All but one dialogue included a variety of participants including families, community members and service providers. Some of the dialogues included participants who are not Nation members but who work closely with the community (i.e., RCMP and service providers). All dialogue invitations were sent out by the Nation.

Although all dialogue sessions were different in their design, the following four topic areas were explored in each:

- supports for children and youth
- supports for parents, caregivers and families
- experiences with the education system
- cultural connection.

Upon completion of the dialogue sessions, RCY conducted an analysis of the themes raised in each session. These themes were compared against those that emerged from the child, youth and family research as well as service provider interviews. Unique themes and experiences were identified and brought forward in the report.

Dialogues were held with three distinct First Nations groups across B.C. and on the territory of a distinct Nation to connect with Urban Indigenous people.

Dialogue Session One

RCY was invited to a dialogue session hosted by the Nation. Members of four different communities attended the dialogue session – 85 individuals, including seven Elders. Participants in this dialogue included individuals with FASD, family members of those with FASD, community members, service providers, teachers and school board members, among others. The dialogue began with an opening prayer, a welcome and a presentation by a senior member of the Nation council. This presentation provided a history of the Nation and its work in the field of FASD. In this presentation, RCY staff also heard the role of family and community within this Nation – including an emphasis on children being at the centre and the understanding that, in order to support children properly, the entire family must be supported. RCY then made a presentation about the FASD project and its intentions asking to open a dialogue. The morning presentations were followed by a shared meal, after which small groups were formed within specific topic areas to accommodate smaller discussions. Four topics were presented for dialogue and two rounds occurred. This allowed individual participants to engage with two topic areas.

Participants who wanted to add to the discussion without speaking verbally into the circle were provided sticky notes and markers. RCY staff facilitated discussion at each of these smaller dialogues. At the conclusion of the small dialogues, each group presented the highlights of the discussion to the larger circle.

Dialogue Session Two

RCY was invited to a dialogue session hosted by a B.C. Native Friendship Centre. This dialogue was split over two days – the first day was intended for individuals with FASD, family members, and community members, and the second day was intended for service providers. Approximately 25 people attended each of the sessions.

The sessions included an overview of the research project and current findings. This was followed by a shared lunch and then small group discussions in the afternoon on participants' topic area of choice. In addition, poster sheets with topic areas were hung on the walls around the room and participants were provided sticky notes and markers so they could include their thoughts if they preferred not to share in the dialogue.

Each group then presented the highlights of their discussion to the larger group, where everyone had a chance to contribute additional thoughts/stories to the topic area.

Dialogue Session Three

RCY was invited to a dialogue session hosted by on the territory of a distinct Nation to connect with Urban Indigenous people. The dialogue session took place in the evening to ensure that families were able to attend. This large gathering included children, youth, families, caregivers and service providers – including several school board members and teachers. Approximately 40 people attended. The dialogue session was opened by the Chief and his son of the local Nation, who welcomed all participants to their territory. Prior to the dialogue all participants shared a feast – as it is necessary to share food prior to commencing work together. After the feast, RCY presented the FASD project and the goals of the dialogue session. The dialogue participants were then joined by pow wow dancers who performed and taught a pow wow dance.

Rather than having an open group dialogue session, RCY staff created a station for each topic area. Participants were free to walk around the space and engage in topic areas through dialogue or by adding thoughts and stories with sticky notes. This allowed for an evolving dialogue in which the conversation was continually updated and shifting based on those moving around the room.

Dialogue Session Four

RCY was invited to a virtual dialogue session that included service providers. This session was limited to two hours and included the same topic areas as the other dialogue sessions. Upon completion of the dialogue, RCY researchers provided the participants with the notes to validate what had been heard.

Interviews

Semi-structured interviews were conducted with a number of professionals and service providers to deepen RCY's understanding of the provincial system of care for FASD (see Study Population description on page 112).

Analysis

Report findings were arrived at through a themed analysis of information gathered from: the literature review; research of policies and programs; interviews with parents, professionals and service providers; the self-reflection logs, life books and community dialogues.

Common themes that emerged from the family-based research and the community dialogues were similar, however the context was at times slightly different. For example, the community dialogues brought forth lived experience of biological families. In addition, experiences around funding and the importance of connection to a child's culture emerged as important themes in the community dialogues that were not evident in the family research. Further, common themes that emerged from lived experience were also common themes that emerged from the professionals' and service providers' interviews.

Reporting Back

RCY made a commitment to each Nation or community to return upon completion of the analysis to present the findings and ensure that voice and lived experience were captured appropriately. Unfortunately, the COVID-19 pandemic meant that the report-back sessions had to be held virtually and not all who attended the dialogues were able to attend the report back. However, all leadership partners were able to attend. RCY took feedback from the report-back sessions and incorporated this into the report. One Nation was unable to schedule a report-back session, however all participants were given the dialogue session notes for review and each Nation or community was provided the report to review, with the opportunity for further feedback, prior to release.

RCY provided each family with a copy of the draft prior to an external review of the report. This allowed the families and young people to review the report and ensure that they were comfortable with what was shared of their experiences, as well as to validate the findings. RCY researchers then met with each family individually to receive their feedback and make any necessary changes to the report.

External Research Review

RCY contracted with two external researchers within the field of FASD – Dorothy Badry and Michelle Stewart. The external researchers reviewed the report and offered feedback on additional literature to include, searched for gaps in the research and provided feedback on disability justice and urgency.

Limitations

This research provides an in-depth look at lived experience. However, RCY was unable to hear the voices of all populations impacted by FASD, in particular biological families. Although RCY made a strong effort to include these voices, only one biological family participated in the in-depth research project.

Given the stigma, shame and blame associated with an FASD diagnosis, it is not surprising that recruiting biological families proved difficult. RCY was able to hear these voices through the shared dialogues with First Nations communities and from service providers.

In addition, all the children and youth who participated in this report are Indigenous. Most of the participants are connected to the B.C. child welfare system, which has had a well-documented over-involvement in the lives of Indigenous children, youth and families. However, it is important to note that epidemiological evidence is inconclusive about the incidence of FASD in Indigenous populations.[229, 230]

Researchers experienced challenges in collecting administrative data from MCFD and the PHSA. PHSA was able to provide the number of children and youth diagnosed with FASD, ASD and data on wait times, but was unable to report on the Indigenous status of children and youth diagnosed with FASD or ASD as such disaggregated data is not recorded. A data request directed to MCFD pertaining to CYSN, CYMH, the KWPSP and children and youth in government care was affected by timeline delays and the fact that MCFD does not record, collect or track diagnoses for children and youth in care or receiving CYSN and CYMH services at an aggregate level, and instead simply records this information in an individual child or youth's case file. In addition, the lack of administrative data regarding the KWPSP presented challenges in understanding who this program is serving, who is delivering this program, how the program is funded, reported high levels of staff turnover, and access challenges. Ongoing challenges in communicating with MCFD and the gaps in MCFD administrative data affected the completion of a fulsome analysis of services for children and youth with FASD.

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[229] These issues include: differences in how cases are ascertained across studies; misclassification of exposure and risk; a focus on specific geographic populations that do not allow for prevalence rates to be generalized to a broader population; a variety of different sources of data; timing of case identification and age of children/youth studied; and small sample sizes.

[230] Michael Pacey, *Fetal Alcohol Syndrome & Fetal Alcohol Spectrum Disorder Among Aboriginal Peoples: A Review of Prevalence* (Prince George, B.C.: National Collaborating Centre for Aboriginal Health), 2009. https://www.ccnsa-nccah.ca/docs/health/RPT-FASDAboriginalReviewPrevalence-Pacey-EN.pdf.

Appendix B: Canadian FASD Diagnostic Criteria

The following table outlines FASD diagnostic criteria as specified in the latest Canadian guidelines.[231]

FASD with sentinel facial features	FASD without sentinel facial features	At risk for neurodevelopmental disorder and FASD
• Simultaneous presentation of the three sentinel facial features • prenatal alcohol exposure confirmed or unknown and • evidence of impairment in three or more of the identified neurodevelopmental domains or, in infants and young children, evidence of microcephaly.	• Evidence of impairment in three or more of the identified neurodevelopmental domains and • confirmation of prenatal alcohol exposure, with the estimated dose at a level known to be associated with neurodevelopmental effects.	This is not a diagnosis; this is a designation that should be given to individuals when: • there is confirmation of prenatal alcohol exposure, with the estimated dose at a level known to be associated with neurodevelopmental effects • central nervous system criteria are not met • there is some indication of neurodevelopmental disorder and a plausible explanation as to why the neurodevelopmental assessment results failed to meet the criteria for substantial impairment (e.g., patient was too young; incomplete assessment). This designation may also be considered for individuals with all three sentinel facial features who do not yet have documentation or evidence of the requisite three or more neurodevelopmental domain criteria or true microcephaly. This designation should never be considered when prenatal alcohol exposure is confirmed absent.

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[231] Cook, Jocelynn L., Courtney R. Green, Christine M. Lilley, Sally M. Anderson, Mary Ellen Baldwin, Albert E. Chudley, Julianne L. Conry, Nicole LeBlanc, Christine A. Loock, Jan Lutke, Bernadene F. Mallon, Audrey A. McFarlane, Valerie K. Temple, and Ted Rosales, "Fetal Alcohol Spectrum Disorder: A Guideline for Diagnosis Across the Lifespan." *Canadian Medical Association Journal* 188, no. 3 (February 2016): 191-197. https://doi.org/10.1503/cmaj.141593.

Appendix C: Provincial Supports and Services for People with FASD and Their Families

Table 1: Provincial Supports and Services – Eligibility Criteria and Barriers to Access

Child and Youth Supports & Services (ages 0–19)				
Ministry	***Service/Support***	***Description***	***Eligibility Criteria***	***Barriers to Access***
Ministry of Children and Family Development	*Children and Youth with Special Needs Early Intervention Therapies (EIT)*	EIT provides occupational therapy, physiotherapy, speech language pathology and family support services to optimize children's growth and development and to support their families and communities. These services are contracted with community-based organizations, including health authorities. Family support professionals help families develop strong parenting, child development and advocacy skills, and address factors that may affect the caregiver's capacity to care for their child. EIT therapists provide: • screenings • referrals • assessments • family education and support • service planning • direct therapeutic intervention • consultations • monitoring • transition planning to schools and/or other services • training of community members.	Parents, physicians and community members can refer infants and young children up to school entry age who have – or are at risk for – a developmental delay or disability.	These services are only provided to children between birth and six-years-old. This age restriction prevents children from having continuity with their support person(s) into early adolescence and beyond. Since this is a free service, families may be required to pay out of pocket for similar supports beyond their child's sixth birthday if they are ineligible for CYSN Family Support Services, autism funding or the At Home Program.

Child and Youth Supports & Services (ages 0–19)				
Ministry	***Service/Support***	***Description***	***Eligibility Criteria***	***Barriers to Access***
Ministry of Children and Family Development	*Children and Youth Special Needs (CYSN) Family Support Services*	Those who meet the eligibility criteria for Family Support Services can access a CYSN worker who helps with the following activities: • case management: Direct support for the family and the multidisciplinary/care teams • agreements: Administration of At Home/Direct Funding Agreements, Support Service Agreements and other agreements as needed • respite services: Families • receive an interval of rest and relief, provided through either contracted respite or direct funding for the respite services that meet their needs. • support services: A range of programs intended to support parents who are caring for a child or youth with special needs in the home (such as behaviour supports, parenting skills, counselling, life skills, etc.) • transition planning to support youth who are aging out of government services • guardianship supports/services for children in care.	To be eligible for Family Support Services, a child or youth must be a B.C. resident under age 19 and meet the criteria of one of three streams of eligibility: 1) developmental disability: DSM-5 criteria for intellectual disability 2) autism/autism spectrum disorder (autism diagnosis) 3) eligible for the At Home Program (support needed with three of four daily living activities: eating, dressing, toileting, washing.)	Many children with FASD do not qualify for CYSN Family Support Services because they do not have an intellectual disability. Of the 925 children and youth in B.C. diagnosed with FASD between fiscal years 2016/17 and 2018/19, approximately 75 per cent did not receive an intellectual disability diagnosis, making them ineligible for CYSN Family Support Services.

Child and Youth Supports & Services (ages 0–19)				
Ministry	***Service/Support***	***Description***	***Eligibility Criteria***	***Barriers to Access***
Ministry of Children and Family Development	*Child and Youth Mental Health (CYMH) Community-based Services*	Community-based CYMH services provide a range of specialized mental health services. These supports and services range from mental health promotion and mental illness prevention to early intervention, treatment and support services for children with mental health problems from birth to 18 years of age, and their families/caregivers. These voluntary services are provided by clinicians with graduate degrees in disciplines such as psychology, social work, nursing, child and youth care and counselling, as well as by support workers with an undergraduate degree in similar fields – all with training and expertise in CYMH. CYMH practitioners provide services and supports including intakes, screenings and referrals, assessment and planning, treatment, case management and consultations.	No specified eligibility criteria.	The methods used to support children and youth with FASD have been cited as being "inappropriate" by multiple interviewees.

Child and Youth Supports & Services (ages 0–19)

Ministry	*Service/Support*	*Description*	*Eligibility Criteria*	*Barriers to Access*
Ministry of Health *(delivered by regional health authorities)*	*Developmental Disabilities Mental Health Services (DDMHS)*	DDMHS are provided by the five regional health authorities that are funded through the Ministry of Health. DDMHS offers specialized mental health community services for people ages 14 and over who live with co-existing developmental disabilities and a mental illness. Individuals may also struggle with behavioural challenges that are often influenced by their mental illness and developmental disability.	There are two streams of service that can be accessed: 1. core services for people with an intellectual disability, a developmental disability and a mental illness. This stream offers more thorough supports from a nurse and other practitioners when required. 2. a one-time consult for people who have been diagnosed with a developmental disability but have not been diagnosed with an intellectual disability. DDMHS is typically available to youth between ages 14 and 18, with referrals made by CYSN workers, physicians, nurse practitioners or pediatricians.[232] For adults 19 and older, referrals can be initiated by CLBC, the individual, a family member, a physician or anyone else in the person's support network.	Of the 925 children and youth in B.C. diagnosed with FASD between fiscal years 2016/17 and 2018/19, approximately 75 per cent did not receive an intellectual disability diagnosis, making them ineligible for DDMHS.

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[232] It is important to note that the age range, services offered, and referral streams vary slightly between health authority regions as it depends on the capacity of the DDMHS team in each region. For example, the Fraser Health Authority offers services to children starting at age 12, whereas other health authority regions start at 14-years-old.

Child and Youth Supports & Services (ages 0–19)

Ministry	*Service/Support*	*Description*	*Eligibility Criteria*	*Barriers to Access*
BC Centre for Ability *(funded by Ministry of Children and Family Development)*	*Community Brain Injury Program*	The BCCFA is contracted by MCFD to coordinate and fund the Community Brain Injury Program. The BCCFA contracts with local service providers to provide short-term (6 months) intensive community-based rehabilitation throughout the province for children and youth with an acquired brain injury (i.e., brain was injured as a result of a fall, infection, tumour, etc.).	• Children and youth from birth to 18 years and 11 months • Residents of B.C. • Primary diagnosis of acquired brain injury requiring acute rehabilitation • Referral to the program within 12 months post-injury	While children and youth with FASD are often described as having a brain injury and experience similar challenges as people with an acquired brain injury, they are ineligible to access the Community Brain Injury Program due to the narrow definition of "brain injury."
Ministry of Education	*Physical Disabilities or Chronic Health Impairments* *Funding Supplement for Unique Student Needs*	For schools to receive this funding to support children and youth with special needs, they must identify children and youth who fall within one of 10 special needs categories. Children and youth with FASD typically fall within the "Physical Disabilities or Chronic Health Impairments" category. If eligible, approximately $20,200 is provided to the school district per child that falls within this category for the "Unique Student Needs" funding supplement. The funding is pooled by the school districts and then redistributed amongst the schools to address the needs of children and youth.	A student is considered to have a physical disability or chronic health impairment based on the need for special educational services due to one or more of the following: • nervous system impairment that impacts movement or mobility; • musculoskeletal condition; and/or • chronic health impairment that seriously impacts their education and achievement. Students are only eligible for funding in this category if their functioning and education are significantly affected by their physical disabilities or chronic health impairments. In some cases, students diagnosed through the CDBC Network as having complex needs may be included in this category, including children and youth with FASD.	Families expressed that their children did not receive much support in school, despite funding being allocated to the school district based on their child's diagnosis. The funding is not allocated directly towards supports for the child since it is pooled into a school district-wide budget and redistributed across schools.

Supports & Services for Parents

Ministry	*Service/Support*	*Description*	*Eligibility Criteria*	*Barriers to Access*
Ministry of Children and Family Development	*Key Worker and Parent Support Program (KWPS Program)*	Key Workers: • use family-centred and culturally safe frameworks of practice • build on families' strengths • are a community resource on FASD • develop and strengthen community networks. Specific roles of Key Workers include: • finding ways that parents, family members, caregivers and service providers can adapt the child's environment • providing emotional and practical support for families along with education and information tailored specifically to their needs • referring families to resources such as training or support groups.	Children and youth with FASD or a similar neurodevelopmental condition and their family/caregivers are eligible for the program. An FASD diagnosis is not required to be able to access the KWPS program.	Access can be difficult for families who live in rural or small communities where the KWPS program is not offered. Families and/or Key Workers may be required to travel long distances to meet one another if the program is not offered locally.

Youth and Young Adult Supports & Services (ages 19 to 24)

Ministry	*Service*	*Description*	*Eligibility Criteria*	*Barriers to Access*
Ministry of Health (delivered by regional health authorities)	*Developmental Disabilities Mental Health Services (DDMHS)*	See first section *Child and Youth Supports & Services (ages 0-19) for a description*		

Youth and Young Adult Supports & Services (ages 19 to 24)				
Ministry	***Service***	***Description***	***Eligibility Criteria***	***Barriers to Access***
Community Living BC	*Personalized Supports Initiative (PSI)*	The PSI eligibility stream was established in 2010 specifically to support adults with FASD or ASD. The PSI meets client needs by coordinating existing community supports to help people maintain or increase their independence. PSI augments, rather than replaces, existing support. Where necessary, PSI may provide funding for supports such as supported living, respite, employment support, skill development, homemaker services and development of support networks.	• An IQ above 70 (otherwise the applicant would qualify for services through the developmental disabilities eligibility stream) • A specified diagnosis of FASD or ASD completed by a qualified professional • An adaptive functioning score of at least three standard deviations below the mean, completed by a qualified professional.	Only about 1.3 in 1,000 people in the general population would receive an adaptive functioning score that is three standard deviations below the mean (about 6,630 B.C. residents).
Ministry of Children and Family Development	*Services to Adults with Developmental Disabilities*	STADD is a service of MCFD that offers a personal Navigator to support youth and young adults (ages 16 to 24) with developmental disabilities and their families as they transition from child and youth services to adult services and supports. A Navigator's main role is to act as a primary point of contact for young adults and their families and to help coordinate and organize transition planning and access to community and government supports.	• Are between 16- and 24-years-old • Have a developmental disability, ASD or FASD.	If a young adult is not eligible for CLBC services, they are ineligible for support. However, STADD Navigators have supported young adults who believe they have FASD, but are seeking support to go through the assessment process to receive a diagnosis.

Youth and Young Adult Supports & Services (ages 19 to 24)

Ministry	***Service***	***Description***	***Eligibility Criteria***	***Barriers to Access***
Ministry of Social Development and Poverty Reduction (MSDPR)	*Persons with Disabilities (PWD)*	The BC Employment and Assistance Program for Persons with Disabilities provides disability assistance and supplements to provide greater independence for people with disabilities, including security of income, enhanced well-being and participation in the community.	A person may be designated as a Person with Disabilities (PWD) if they have reached 18 years of age and have a severe mental or physical impairment that meets all of the following criteria: • in the opinion of a *medical practitioner or nurse practitioner*, the impairment is likely to continue for at least two years • in the opinion of a *prescribed professional*, the impairment directly and significantly restricts the person's ability to perform *daily living activities* • the person requires an *assistive device*, significant help or supervision or the services of an assistance animal to perform daily living activities.	The various eligibility requirements have made it difficult for people with FASD to navigate and access PWD. Applicants who have another source of income other than PWD are required to report to MSDPR by the fifth day of every month, which can be challenging for someone with FASD if they experience memory difficulties. If the report remains incomplete, the applicant may not receive the funding.

Appendix D: MCFD Learning and Development Courses Containing FASD Content and Number of MCFD Workers Who Received Training (Fiscal Years 2017/18 to 2019/2020)

Course Descriptions and Number of MCFD Workers Who Received Training (FY 2017/18 to 2019/20)

Course Title	FASD Content Description	Intended Audience	Total # Social Workers	Total # of CYSN Workers	Total # CYMH Clinicians	Total # Youth Justice Workers	Total # Undefined	Grand Total
Foundations for CYSN Practice	No specific learning objectives for FASD. Only includes one PowerPoint slide referring to supports to adults with FASD.	Required training for CYSN new hires	69	152	8	2	26	257
Problematic Substance Use	One paragraph on addressing FASD with a link to the 2008 – 2018 Provincial Plan for FASD.	Required training for C6 social worker delegation, available to all staff	898	15	49	35	62	1059

Course Title	FASD Content Description	Intended Audience	Total # Social Workers	Total # of CYSN Workers	Total # CYMH Clinicians	Total # Youth Justice Workers	Total # Undefined	Grand Total
Youth Justice – 1114 Fetal Alcohol Spectrum Disorder	In this course the learner will: • Consider how FASD impacts the Youth Justice System • Develop basic knowledge of FASD and other neurodevelopmental concerns • Learn how brain functioning can be affected by prenatal alcohol exposure • Identify the risk factors and justice implications for youth with FASD and other neurodevelopmental concerns • Acknowledge your own values and beliefs related to FASD • Learn how a young person with FASD may present in your work setting • Examine the effectiveness of consequences for youth with FASD • Examine how to best obtain accurate information from a youth who has a language impairment. • Develop strategies to use when working with a youth with FASD or other neurodevelopmental impacts. • Understand the diagnostic process of an FASD assessment • Learn how to develop an integrated case management approach to address FASD in your workplace and community • Consider how to effectively advocate for youth with FASD in the legal system	Required training for Youth Probation Officer delegation, available to Youth Justice and Youth Custody staff	1	0	0	23	0	24

Appendix E: Key Worker and Parent Support Program Contracted Agencies and Regions Served, May 2019

The following list of contracted agencies and regions served was provided by MCFD to RCY through a data request. This information was received on May 8, 2019.

Agency Name	Regions Served
Alberni Valley Fetal Alcohol Spectrum Disorder Community Action Group	Port Alberni Valley
Arc Programs Ltd.	Kootenay
Arc Programs Ltd.	Okanagan
Axis Family Resources Ltd.	Kootenay
Axis Family Resources Ltd.	North Central - Quesnel
Axis Family Resources Ltd.	North Central Prince George catchment area
Axis Family Resources Ltd.	North East - Dawson Creek, Chetwynd and surrounding areas
Ayas Men Men Child & Family Services	Coast/North Shore
Beacon Community Association	South Island, Greater Victoria
British Columbia Centre for Ability Association	North Fraser
Campbell River and District Association for Community Living	Campbell River, Gold River, Tahsis, Sayward Quadra Island, Cortes Island & nearby areas
Cariboo Chilcotin Child Development Centre Association	Thompson Cariboo Shuswap
District 69 Family Resource Association	School District 69 (comprised of 10 communities), Parksville/Qualicum area
Fraser Region Aboriginal Friendship Centre Association	Surrey, Langley, Delta, White Rock
Fraser Valley Child Development (1982) Society	East Fraser Service Delivery Area (SDA)
Heiltsuk Kaxla Society	Coast/North Shore
Hiiye'yu Lelum (House of Friendship) Society	South Island, Duncan
Hollyburn Family Services Ltd.	Coast/North Shore
Inclusion Powell River Society	Coast/North Shore
Insight Support Services Inc.	Thompson Cariboo Shuswap
Insight Support Services Inc.	Thompson Cariboo Shuswap
Island Métis Family & Community Services Society	South Island, Greater Victoria
Kinsight Community Society	North Fraser
Kinsight Community Society	North Fraser
Lil'wat Nation	Coast/North Shore
Milieu Children & Family Services Inc.	Vancouver, Richmond, North Shore
North Island Crisis & Counselling Centre Society	Mount Waddington Region (Port Hardy and area)
North Okanagan Neurological Association	Okanagan
North Okanagan Neurological Association	Okanagan
North Okanagan Neurological Association	Okanagan

Agency Name	Regions Served
Nuxalk Nation	Coast/North Shore
OneSky Community Resources Society	Penticton
OneSky Community Resources Society	Penticton
Pacific Community Resources Society	Surrey
Pacific Community Resources Society	Vancouver/Richmond
Reach Child and Youth Development Society	Delta
Ridge Meadows Child Development Centre Society	North Fraser
Sea to Sky Community Services	Coast/North Shore
Shuswap Children's Association	Thompson Cariboo Shuswap
Sources Community Resources Society	White Rock, South Surrey
Sources Community Resources Society	Fort St John, Fort Nelson and district
Sunshine Coast Community Services Society	Coast/North Shore
The Bulkley Valley Child Development Centre Society	North West
The Cariboo Family Enrichment Centre Society	Thompson Cariboo Shuswap
The Centre for Child Development of the Lower Mainland	Langley
The Centre for Child Development of the Lower Mainland	Surrey
The Children's Foundation	Vancouver/Richmond
The Kermode Friendship Society	North West
Tla'amin Nation	Coast/North Shore
Touchstone Family Association	Vancouver/Richmond
Vancouver Native Health Society	Vancouver/Richmond
Victoria Native Friendship Centre	South Island, Greater Victoria
Wachiay Friendship Centre Society	Comox Valley
Young Women's Christian Association (YWCA Crabtree Corner)	Vancouver/Richmond

Appendix F: Key Worker Qualifications

The following qualifications were retrieved from MCFD's 2009 *Key Worker and Parent Support Program Standards*, page 11.

Qualifications of Key Workers

- Undergraduate degree in health or human services (social work, nursing, psychology, child and youth care) or equivalent education and experience
- Extensive understanding of FASD as a brain-based physical disability
- Education and training in child development
- Demonstrated skill in applying a family-centred strength-based approach when working with families of children and youth
- Demonstrated ability to use a cultural safety framework when working with Aboriginal families and communities
- Demonstrated ability to flexibly accommodate the communication, learning styles, and ethnocultural and socio-economic circumstances of all families
- Understanding of youth and women's addiction issues
- Good understanding of service delivery dynamics, including strengths and barriers at the community, regional and provincial level
- Demonstrated skill in working collaboratively with multiple community partners and service providers using diplomacy and excellent communication skills

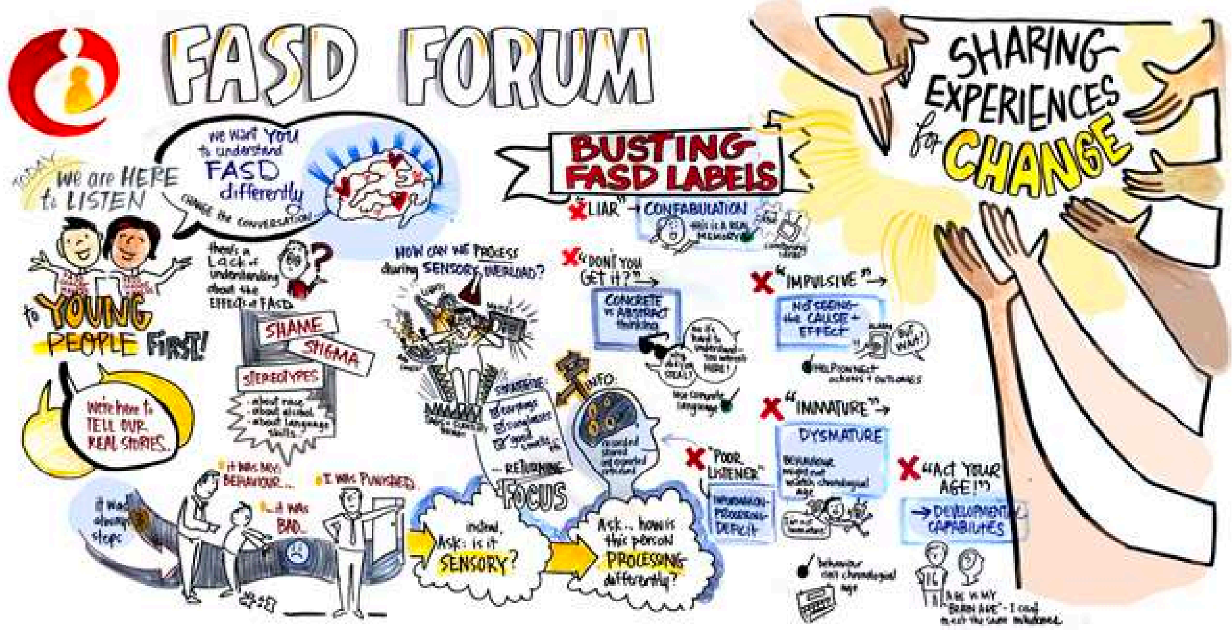
For Key Workers who also deliver Parent Support, these additional qualifications apply:

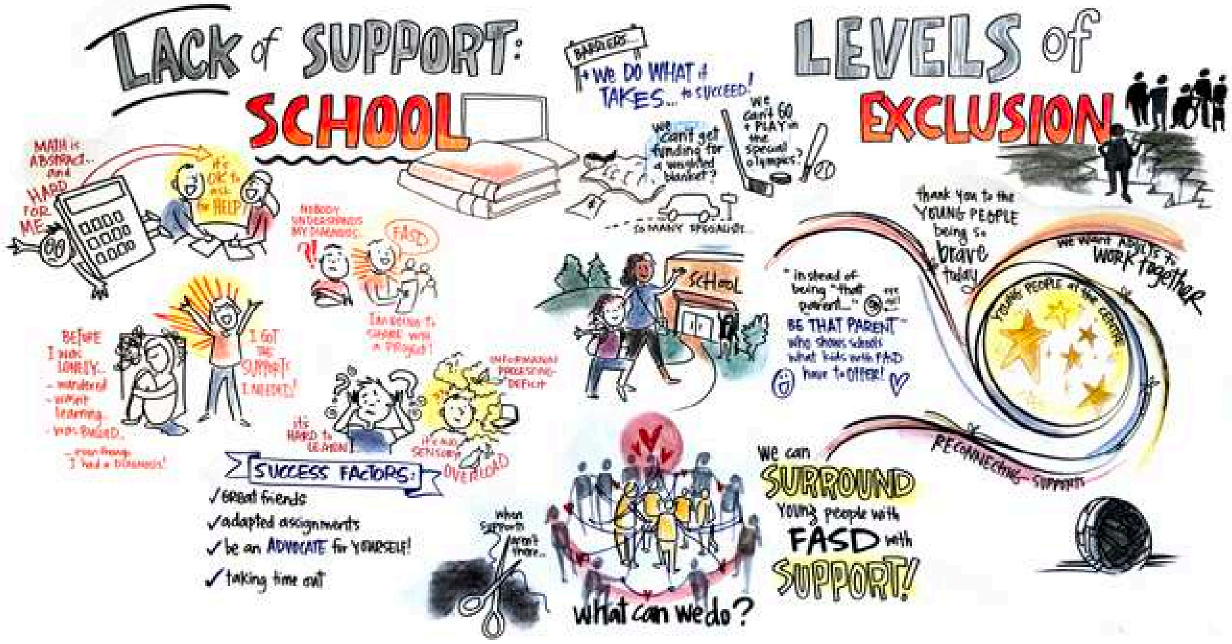
- Training on providing parent support for parents and caregivers of children and youth with FASD
- Experience in group organization and facilitation, and understanding of group dynamics

Appendix G: Sharing Experiences for Change: A Forum

RCY invited key decision-makers to Sharing Experiences for Change, an October 2019 forum that brought together participants from several provincial government ministries, health authorities and First Nations organizations to hear stories and watch presentations from the participating children and youth and their parents about their experiences at home, at school and in their communities.

Graphic artist Sam Bradd joined the day to capture graphical representations of the forum: the experiences shared by the children and youth, the parents' sharing circle, and the world café with the decision-makers. These are the graphics that emerged from that day.






PARENTS + CAREGIVERS
sharing circle
FUNNY
SMART
GIFT OF DETERMINATION
WE ♥ OUR KIDS' GIFTS
WE THRIVE when we're supported!
"Everyone told us NOT to Adopt - but they in foster - it was a ..."
There's so much ISOLATION
"I am a SUPER ADVOCATE - and YET I've NEVER met an adult with FASD - or an FASD community - until TODAY"
Fostering teenagers - no permanency
RURAL/REMOTE AREAS have long wait lists
advocacy
"Why didn't you come 3 years ago?"
"I'm planning for what will happen after I die..."
NO SERVICES
EVERY DOOR needs to be the RIGHT DOOR
OUR KIDS NEED an "external brain..." and care until 25
FASD = NO CAMPS, NO RESPITE, NO MENTAL HEALTH SUPPORT...
It's co-morbid diagnoses that get us SERVICES
$ SO EXPENSIVE
"hoping for autism diagnosis because we'd have SUPPORT"
AGING OUT
my 18 yr old is so SCARED
Lack of knowledge about FASD
my kid doesn't have an INTELLECTUAL Deficit → it's different
1:1 support
They asked us to PULL HER OUT
I'll go to the school + watch
He gets left in the HALLWAY!
My grandkids don't want to go - they call him dumb
SCHOOLS
the $ goes to the school but it's not ATTACHED to my kid
EQUITABLE
BULLYING is PERVASIVE
This group HERE has been my kid's FIRST FRIENDS
they told me to cut his hair - we're Aboriginal!
1:1 HELP in SCHOOL with INSTRUCTIONS + SUPPORT WORKERS
not all the 1:1 workers understand FAS
but we need HELP OUTSIDE school too
WE NEED
HELP because we don't have ANY
MORE SUPPORT
HELP with a worker to teach adaptive living skills
KEEP RAISING AWARENESS of FAS
MORE EDUCATION in schools
MEANINGFUL INCLUSION at school
to REMEMBER that our ADULT loved ones with FAS can succeed with SUPPORT


FASD FORUM: COLLECTIVE ACTIONS
- change takes TIME
TIMELY and APPROPRIATE SUPPORTS
reduce stigma
SUPPORTS based on NEED not diagnosis
FAMILY-centered! CHILD-centered!
supports needed EARLY
what's our GOAL - making this CHILD or family's life better
WE are the system and WE CAN DO BETTER
"I came here to scream from the MOUNTAINTOP THERE'S NO RESOURCES - BUT THERE ARE - and IT IS US."
OUR STORIES OF LOVE + RESILIENCE
We're NOT DOING ENOUGH
FASD
ENHANCING PROFESSIONAL + SYSTEM UNDERSTANDING OF FASD EFFECTS
we get frustrated - our kids DON'T FIT "the SYSTEM"
make the SYSTEM FIT US, INSTEAD
change the conversation to reach the WIDER PUBLIC
increase TEACHER TRAINING
"my mom drank - NOW WHAT? I'm RIGHT HERE"
not just a prevention message
ASSESSMENT should OPEN DOORS
A HELPFUL ASSESSMENT + DIAGNOSIS PROCESS
Diagnosis should mean SUPPORT IMMEDIATELY
SUPPORTS are inevitable - ... the justice system
FUNCTIONAL assessment can go with MEDICAL ones
right now support is based on CRISIS
It's amazing what can be HEARD when there's a PLATFORM
We're so GRATEFUL to the BRAVERY of young people HERE TODAY - thank you!
SUPPORT ADVOCACY capacity
INCREASE CONNECTIONS
• to the system
• between kids
• between caregivers
online
in real life
INCLUSIVE schools are better for EVERYONE
FUNDING + ONE INFO SOURCE to get HELP + NETWORKS
FROM EXCLUSION to MEANINGFUL INCLUSION
PARENTS are involved in creating POLICY
Lack of SUPPORTS leads to EXCLUSION + mental health issues

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