

Hands, not Hurdles:

Helping Children with FASD and their Families

KEY MESSAGES FOR COMMUNITY SERVICE PROVIDERS



REPRESENTATIVE FOR
CHILDREN AND YOUTH



A Message from the Representative

Fetal alcohol spectrum disorder (FASD) is one of the most common neurodevelopmental disabilities in the Western world and yet it remains a highly misunderstood, multi-faceted brain and body disability that affects many people in our communities.

This lack of understanding about the complexities of FASD leads to blaming, shaming, stigma, discrimination and racism that causes harm to people with FASD and their families. It also leads to people with FASD getting almost no supports or services.

We all need to be more informed, understanding and supportive of children and youth with FASD and their families. This short, illustrated report follows RCY's more detailed report *Excluded, Increasing Understanding, Support and Inclusion for Children with FASD and their Families*, released in April 2021.

Excluded showed that, while there are differences across B.C. jurisdictions, many of the challenges for those with FASD are the same. Families of children and youth with FASD are too often isolated and desperate for support.

The idea behind this report is to offer a more condensed version of what we learned about FASD while producing *Excluded* – a product that is useful and easily digestible for practitioners who work with children and families in B.C. Through this more accessible report, we also hope to continue to raise awareness about the need for improved supports and services to these children and families as there has been little progress on this front since *Excluded* was released.

As with the previous report, this publication was co-led by Myles Himmelreich, an adult with FASD who has more than 16 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. Also helping to communicate those challenges – as well as the supports that can help children, youth and their families – was artist Sam Bradd, who provided the illustrations. I am grateful to them both.

It can be alarming and discouraging to learn about the negative experiences that people with FASD have in school, recreation, work and community, but there is a lot that can be done to improve things right now. Included in this report are suggestions on how you can take meaningful action to inform yourself about FASD and to better help children and families.

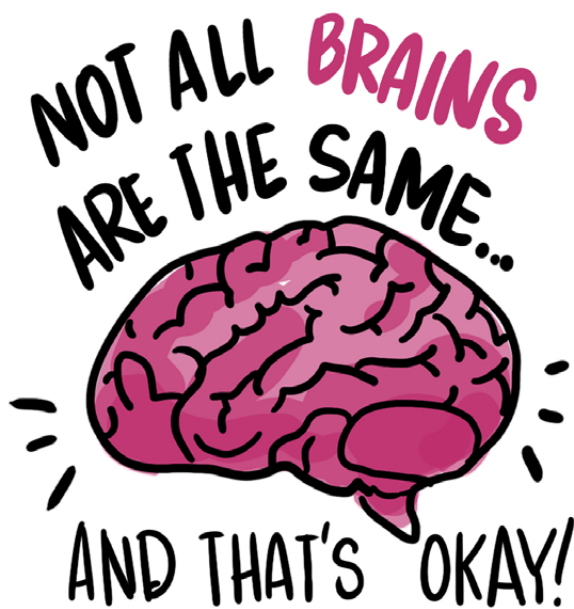
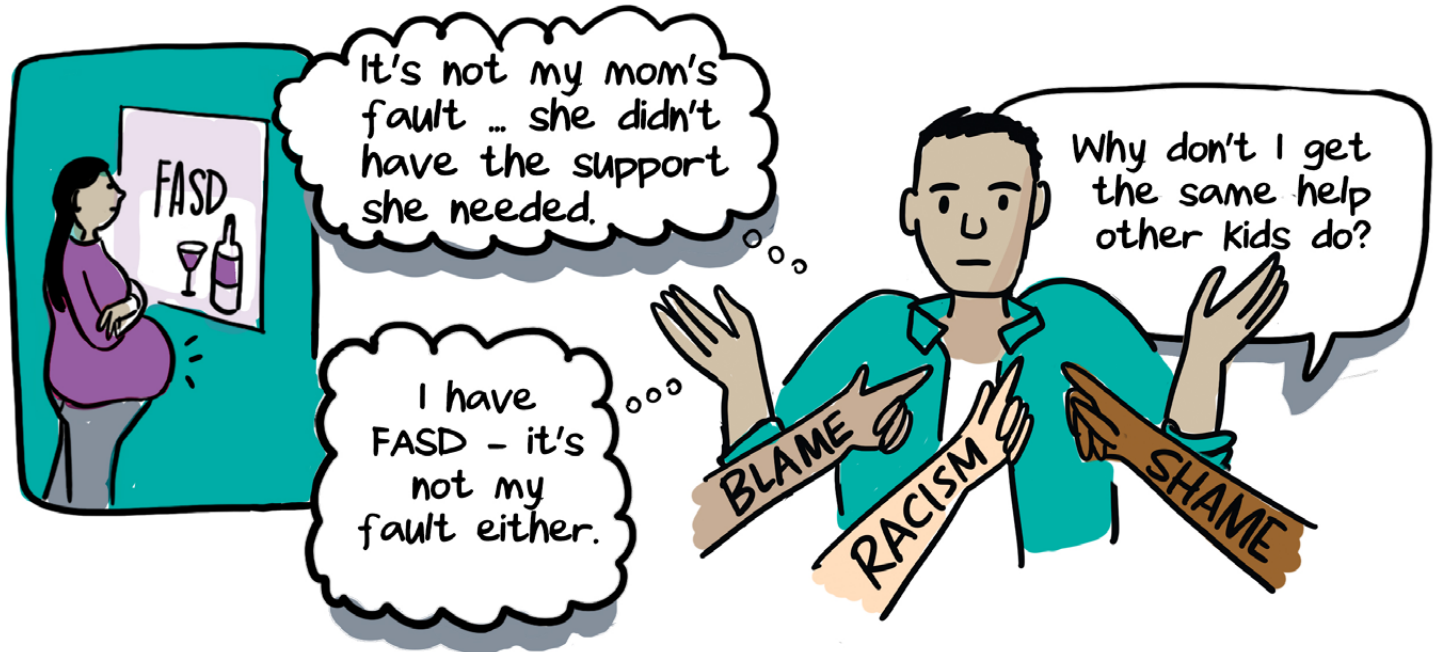
People with FASD are resilient, have many strengths and can thrive when understood and supported well. It is my hope that this report helps to foster that understanding and advocate for the support that is so greatly needed.

Sincerely,



Dr. Jennifer Charlesworth
Representative for Children and Youth

FASD IS MISUNDERSTOOD, LEADING TO BLAME, STIGMA and RACISM.



1. FASD is misunderstood, leading to blame, shame, discrimination and racism.

Fetal alcohol spectrum disorder (FASD) is a term that describes the life-long effects that can occur because of prenatal alcohol exposure. Common effects may include physical, mental, behavioural and learning disabilities. FASD is a prenatal brain and body injury, and there may be no outward signs of the disability. As a result, FASD is often referred to as a “hidden disability” and it is misunderstood by service providers, educators, and even family members and caregivers.

Racism surrounding FASD results in harmful and inaccurate assumptions that FASD is more common among First Nations, Inuit and Métis children. Those who work in child-serving systems report that First Nations, Inuit and Métis children are sent for an FASD assessment more often than non-Indigenous children who present with very similar challenges or support needs. These assumptions are not only harmful, they are discriminatory and may lead to misdiagnosis and mismatched supports.

Anyone can have FASD. It is not limited to any racial, ethnic, cultural or geographic group. It is a disability that is found across all demographics throughout the world. It is a complex and multi-faceted disability and affects people differently – this is why it is described as a “spectrum disorder.” Because it is misunderstood, people with FASD are often blamed for the challenges they face in daily living and excluded from services, supports and community throughout their lives.



Intelligence and executive functioning are different. Children and youth with FASD can be very intelligent and still struggle with “executive functioning,” which includes capability in areas such as organization, planning and cognitive flexibility. All of these elements of executive function are important for adapting to the demands of daily living including typical expectations in schools, community programs and support services. Children and youth with FASD may also experience dysmaturity, which means their chronological age does not match the age at which their brain functions – something that can lead to a mismatch between expectations and abilities, especially in school.

“This is what I HAVE – not who I AM.”

Busting FASD labels helps to improve understanding and reduce stigma. Social labels are incorrect assumptions that are often applied to different behaviours common for children and youth with FASD. These labels do not reflect the lived reality of children and youth with FASD and can lead to the blaming and shaming of the young person (or their family) rather than acknowledging that the behaviours are due to the disability. You can learn more about busting FASD labels on Page 33 of *RCY’s Excluded report*.

1. FASD is misunderstood, leading to blame, shame, discrimination and racism

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.

Created by RCY External Project Researcher Myles Himmelreich for *Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families*.



Public messaging about FASD tends to focus on prevention and FASD is often described as a preventable condition. However, vulnerability to FASD is highest in the early weeks of a pregnancy when someone may not yet be aware that they are pregnant. Also, some mothers need extra support during their pregnancy to prevent FASD, and such support is often lacking. This results in blame placed on biological mothers for their child's FASD. Such assumptions and misconceptions may result in discriminatory practices by service providers and service delivery systems and heightened child protection oversight. This not only contributes to feelings of shame and fear; it can discourage families and young people from pursuing a diagnosis or completing an assessment process that could lead to services and supports.

Blame and misconceptions are harmful to children and youth with FASD and their families. Together, they can result in discrimination or inappropriate supports being provided to children and youth with FASD. The challenges and life events experienced by individuals with FASD may lead to poorer outcomes in education, health, employment and justice. However, access to adequate supports and services can positively alter life-long trajectories for people with FASD.

"I survived a system that wasn't user friendly to me ... I worked with quite a few people who didn't understand me."

—Youth with FASD

So what can you do?

- Take time to learn about FASD and what it means to live with it. Check out this 1½-minute animated video on what it feels like to be misunderstood as a person with FASD www.cbc.ca/player/play/1465636931869 and this 20-minute podcast on *FASD Through a variety of lenses* www.fasdoutreach.ca/resources/all/f/fasd-through-variety-lenses-e02-himmelreich
- Explore the wealth of resources from the Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD at www.fasdoutreach.ca) and The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD at www.canfasd.ca).
- Take a free online course offered by CanFASD on Foundations in FASD to up your knowledge and awareness www.estore.canfasd.ca/foundations-in-fasd. Then consider going further with the range of courses available.
- If you are an educator or caregiver, check out the POPFASD video *Learning the Dance: Community Making a Difference*. This 46-minute film shares an "average" day in the life of two Winnipeg adolescents diagnosed with FASD and their parents. Video highlights include how school-based interventions are implemented, what families consider to be important for educators to understand, and how educators and administrators adapt their approaches to include the students. www.fasdoutreach.ca/resources/all/l/learning-the-dance
- Take the specialized FASD courses for professional groups offered by CanFASD e.g., www.estore.canfasd.ca/fasd-for-school-staff-level-ii and www.estore.canfasd.ca/fasd-for-judicial-professionals-level-ii or POPFASD's wide array of training for educators www.fasdoutreach.ca/training#fasdclass
- Read, print, post and share the FASD label busting resource that is included on Page 4 of this guide and be an ally who helps bust FASD labels.
- Share this simple but informative visual on 'reframing the behaviour' to help you re-assess a young person's behaviour from a place of understanding about FASD www.fasdoutreach.ca/resources/all/r/reframe-behaviour
- Be aware of the language you are using, and work to make it more inclusive and less stigmatizing. Check out CanFASD's Language Guide here: www.canfasd.ca/wp-content/uploads/2018/01/LAEO-Language-Guide.pdf
- Challenge your own assumptions about FASD and encourage colleagues to do the same.
- Connect with stories shared by people with FASD such as Myles Himmelreich, the External Project Researcher for RCY's *Excluded* report. To prepare, check out this article on having discussions with – not about – people with FASD: www.cheos.ubc.ca/research-in-action/why-are-you-talking-about-me-but-not-with-me-new-organization-launched-by-and-for-people-with-fasd
- If you enjoy podcasts, check out the FASD Success Show hosted by Jeff Noble, who brings a wide range of interesting folks who are highly knowledgeable about FASD – including people with FASD, family members, caregivers, researchers, counsellors, etc. A wide range of diverse and relevant topics are covered over more than 100 episodes: www.fasdsuccess.com

ALL CHILDREN and YOUTH,
INCLUDING THOSE WITH FASD,
HAVE THE **RIGHT TO THRIVE.**



2. All children and youth, including those with FASD, have the right to thrive.

Children and youth with FASD have the same rights as all other children and youth. They have the right to identity, culture, connection and safety; the right to access education, health care and disability supports; and the right to be heard and be free from discrimination – all of which help them to thrive. These rights are not being upheld by service providers and systems currently in place to support children and youth with FASD.

"We decide what it means to thrive. It is personal."

—Person with FASD

Rights Matter. Canada is a signatory country to three important international agreements: the *United Nations Convention on the Rights of the Child (UNCRC)*, the *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)* and the *United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)*. As a ratifying country, this means that Canada is obligated to ensure that the rights set out within each are respected, protected and fulfilled.

Here are some examples:

Under the *UNCRC*, children have the right to grow and develop to their full potential, the right to special education and care if they have a disability, and the right to help from the government when they are in need.

Under the *UNCRPD*, ratifying countries are expected 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 develop their mental and physical abilities to their fullest potential.

"If you are 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

Finally, under *UNDRIP*, Indigenous children and youth have the right to all levels and forms of education without discrimination, and to the continual improvement of their social, economic, environmental and physical and mental health conditions, especially if they have special needs or disabilities. And most

importantly, Indigenous children and youth have the right to have their cultural connections, language, traditions and practices protected, respected and nurtured.

In reality, these rights are too often not experienced by children and youth with FASD and their families. Caregivers often feel that FASD is seen as an *"undeserving disability"* and is frequently a diagnosis that leads to nowhere. Services and supports are few and far between and access to government-funded supports is often based on complicated processes and eligibility criteria through which those with FASD rarely make the cut. Families sometimes look to charitable organizations for bits of help, but the paperwork to get any support is often daunting, and many caregivers do not have the capacity to jump through all the hoops. Even when they spend countless hours seeking services and completing paperwork, there is no guarantee these families will get any support and, if they do, it is rarely consistent or sustainable.

"Children only get one childhood."

—Cindy Blackstock



The right to education is denied to many children and youth with FASD. Because of insufficient supports in schools, many children and youth with FASD are only allowed to attend school for short periods of time. Others are sent home if they are having a rough day or if they cannot sit still. Even when supports are offered, they can be inconsistent or removed when a child or youth appears to be doing well.

So what can you do?

- Raise your own awareness of the rights of children and youth under the *UNCRC*, *UNCRPD* and *UNDRIP* – especially for those children with disabilities – and consider how these rights should be upheld for people with FASD.
- Ask yourself: How does what I do – and what my program/organization does – respect the rights of children and youth with FASD and their families? Can we do better? What might be possible?
- Engage your colleagues in a discussion about ways to support the rights of children and youth with FASD to thrive. What are you already doing well that you can keep doing or expand? What should you stop doing? What could you try?
- Take a look at your policies and practices through a rights-based, FASD-aware lens. Pay special attention to policies and practices that may result in exclusion and disconnection, rather than understanding, adaptation, inclusion and belonging.
- Learn more about good practices and ways that other jurisdictions are making a positive difference and consider what you can apply locally. Alberta stands out with a strong and coordinated approach. CanFASD features many helpful resources, including Towards Healthy Outcomes for Individuals with FASD – a strengths-based 'roadmap' to foster lifelong thriving www.canfasd.ca/wp-content/uploads/publications/Final-Towards-Healthy-Outcomes-Documents-with-links.pdf
- Advocate to funders, policy-makers and leaders for equitable and timely access to services and supports.

CHILDREN and YOUTH WITH FASD ARE **EXCLUDED** IN **EVERY** ASPECT OF THEIR LIVES.



3. Children and youth with FASD are excluded in every aspect of their lives.

Children and youth with FASD are excluded in their schools and their communities. When educators and service providers do not understand the disability, children and youth with FASD are only seen as their behaviour because they are not supported in the ways they need. They might be seen to be disruptive and uncooperative rather than dysregulated and in need of additional guidance to understand what is being asked of them.

"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

In school, children and youth with FASD are often ridiculed, left out and shamed by their peers, leading to social isolation and poor mental health. They can also be excluded inadvertently by their teachers, who may not have the knowledge or capacity to support their unique learning needs. Additionally, without a formal diagnosis, children and youth with FASD can be perceived as behaviourally challenging rather than being understood as needing supports for their brain injury.

"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. But eventually, I'm going to have to stop worrying about the systems failing him and still have the hope of them changing."

—Parent

In community, children and youth with FASD are often not invited to participate in programs or events and, when they are invited, they are often not provided with the supports they need to engage in meaningful ways.

Inclusion requires that everyone be supported to participate and that no one feels left out. Inclusive environments are supportive and adaptive to different needs, strengths and abilities.

Government ministries supporting children and youth with special (support) needs have established funding priorities but children and youth with FASD are not often included. Some

financial support is available for extracurricular activities, therapeutic services and caregiver respite, but most children and youth with FASD do not qualify. Paying out of pocket for these activities and supports is not an option for a lot of families, so many children miss out on participating, and caregivers miss out on much-needed breaks.

Inclusion is not optional. It is a basic right, and it is essential in order for a child to thrive. An inclusion statement or policy may result in positive changes down the road, but children and youth cannot wait. Immediate steps must be taken to ensure children and youth with FASD have opportunities to participate at the same level as their peers.

So what can you do?

- Ask children and youth with FASD and their families what inclusivity looks like for them. Get creative and try new things. To get inspired, check out this blog post on “The Golden Rule of providing support in inclusive classrooms: Support others as you would wish to be supported” www.wrap2fasd.org/2022/08/29/the-golden-rule-of-providing-support-in-inclusive-classrooms-support-others-as-you-would-wish-to-be-supported
- Think ahead about how you make spaces and experiences more inclusive. It is not enough to address this in the moment; preparation will go a long way to make a young person feel included.
- Read up on inclusivity for people with FASD. Community Living BC has a helpful resource, *Supporting Success for Adults with Fetal Alcohol Spectrum Disorder* that offers ideas and suggestions relevant to a range of ages www.communitylivingbc.ca/wp-content/uploads/Supporting-Success-for-Adults-with-FASD.pdf. And the Alberta government funds Wrap2.0 – FASD Coaching Partnership Project offering a wealth of resources that support understanding and inclusion, with a special focus on what educators can do. www.wrap2fasd.org
- Curious about inclusive education? Check out Inclusion BC’s work in this area and gather information, good practices and ideas designed for parents as well as educators www.inclusionbc.org/resource-types/inclusive-education
- Be inspired and find community at the Inspire Kids – FASD Support Services of BC Facebook network www.facebook.com/InspirekidsFASDBC. This evolving and supportive network for families of young people with FASD was established by Bonnie McBride – who was a family participant and advisor for RCY’s *Excluded* report.

FAMILIES of CHILDREN and YOUTH WITH FASD ARE ISOLATED AND DESPERATE FOR SUPPORT.



4. Families of children and youth with FASD are isolated and desperate for support.

Families whose children have FASD receive limited supports

compared to those whose children have other support needs. They are often excluded and alone in their journeys supporting their children. Some feel as though they are being punished because of the blame that is placed on parents of children with FASD. Many families do not have access to FASD services in their communities such as the FASD Key Worker Support Program; and the majority of families do not have access to respite at all – which is unique to families of children with FASD, as other neurodiverse diagnoses qualify parents for greater respite funds.

“Even within the special needs community ... we are isolated ... from the community of people who are supporting individuals with intellectual deficits.”

—Parent

Parents are left alone to take on the role of caregiver, system navigator, administrative assistant, respite worker, classroom support worker and more, leaving them stretched thin and in many cases having to leave their employment to fulfill these roles. Without funding, support and compassion, families struggle to meet the social, emotional, mental, cultural and physical needs of their children, not to mention their own needs.

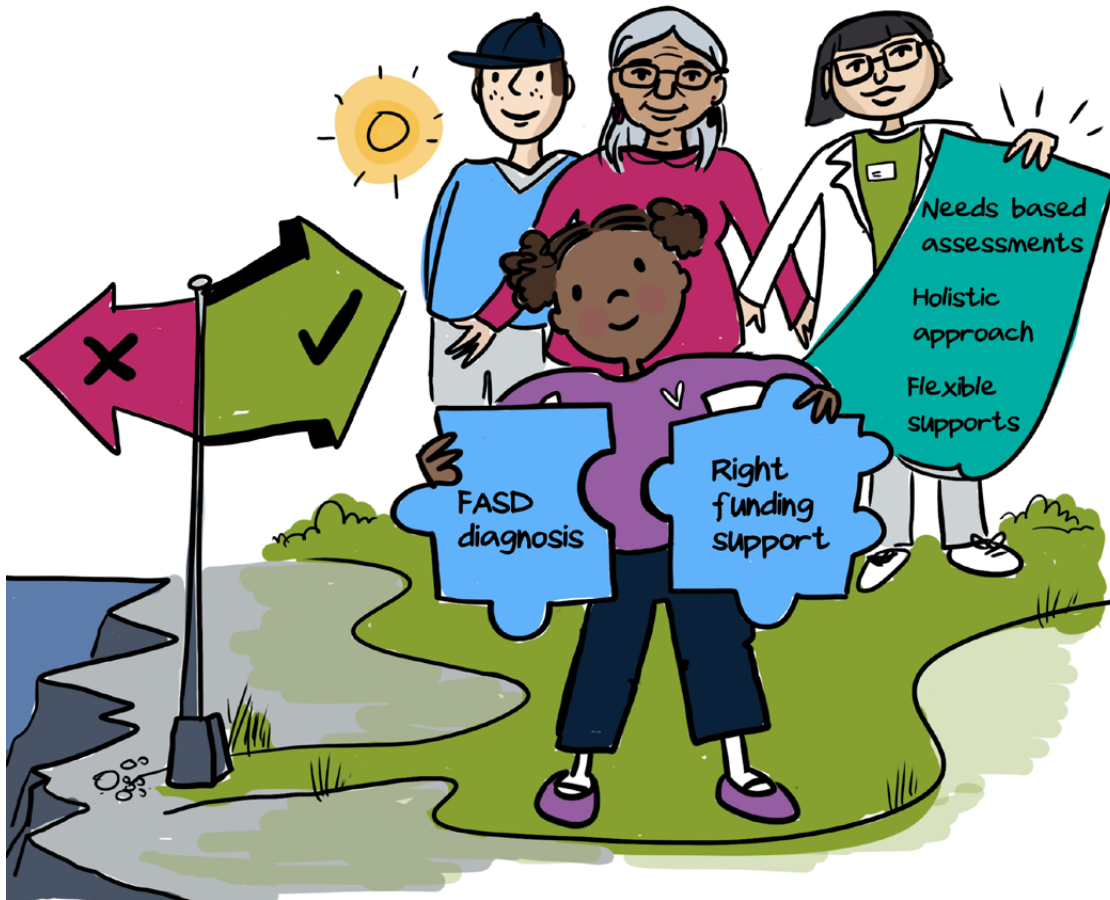
Fear and judgement: Parents of children with FASD express fears about having their children taken away from them if they tell someone they need help, further reducing their access to supports and leaving them to parent in isolation. Because of the fear and stigma, they do not seek the limited funding that is available to them. They also describe feeling judged by others regarding the diagnosis and for the tools and strategies they use with their children.

“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.”

Parents of children with FASD are desperate for community understanding, peer-to-peer relationships and a safe space to seek support where they are understood. Without strong social networks, many parents must navigate the challenges of raising children with FASD on their own.

Families need support, and they need breaks. They constantly have to be the experts who educate everyone else about FASD, in addition to being full-time advocates and caregivers for their children. It is exhausting. Families get offers to put their children in care when what they really need is support at home and in community. Without support and without breaks, families face burnout, which can have negative impacts on the child, the family and the community.

FASD CAN'T BE A DIAGNOSIS TO NOWHERE...



So what can you do?

- Take time to listen to families and better understand their needs.
- Show up for families, support them in day-to-day tasks and respond to their needs.
- Demonstrate compassion and understanding toward birth mothers and caregivers.
- Advocate for enhanced resources to ensure equitable access to funding, services and supports, at home and in community.
- Support First Nations and Inuit families to access Jordan's Principle. For First Nations and Inuit children 18 and under anywhere in Canada, health and social service providers can apply to Jordan's Principle to facilitate access to FASD diagnosis and supports, including educational assistants, recreation programs, occupational therapy, child counselling, psychiatric services and special equipment. For information on Jordan's Principle: www.jordansprinciplehubbc.ca

CHILDREN and YOUTH WITH FASD LIVE
HAPPY AND HEALTHY LIVES WHEN
GIVEN THE RIGHT SUPPORTS.



WE NEED
HANDS
NOT
HURDLES.



5. Children and youth with FASD live happy and healthy lives when given the right supports.

Children and youth with FASD are remarkable at finding new ways to learn, participate and adapt in a world that is not set up for them. They want to go to school, or to a program, even when they know people will not understand them and they are unlikely to be supported. They persevere even after they stumble. Children and youth with FASD should not be responsible for navigating the obstacles constantly put up for them. They have the right to be supported and they have the right to succeed.

Provide helping hands, not more hurdles. Supportive adults, positive peer relationships and inclusive environments can help children and youth with FASD to feel safe, express their needs and experience success. When children and youth with FASD are supported in the right ways, they experience belonging and connection, and they actively participate in learning, social, cultural and recreational opportunities. They thrive.

Centre and explore strengths: Creating a supportive environment starts with understanding FASD, and the unique needs and abilities of children, youth and families who are affected by it. Check out [Me & My FASD](#).

"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

Providing support for the challenges requires us to ask about, explore and build on the strengths of children and youth with FASD. Thriving looks different for everyone, and therefore the strategies needed to support children and youth with FASD must be guided by children and youth with FASD and their families. There is no one-size-fits-all approach. It is important to take time to learn about their needs to support them. Creative strategies and a flexible and holistic system of care are essential. Early and ongoing supports are also critical and can prevent mental health challenges such as depression and anxiety later in life.

Promote active inclusion: It is not enough to simply invite a child or youth with FASD to participate if the supports are not in place to make participating enjoyable. Listen to children, youth and families who are affected by FASD, learn what belonging and inclusion feel like to them. Environments and settings must be set up to enable their success. Children and youth with FASD have the right to support, and they need support right now.

So what can you do?

From a youth with FASD: *"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."*

Resources on FASD

We encourage you to check out the following resources for more information about FASD and what you can do to support children, youth and families who are impacted by it:

Excluded: Increasing understanding, support and inclusion for children with FASD and their families
www.rcybc.ca/reports-and-publications/excluded

Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD)
www.fasdoutreach.ca

Canada FASD Research Network (CanFASD)
www.canfasd.ca

Me & My FASD
www.fasd.me

InspirekidsFASDBC – FASD Support Services of BC Facebook network
www.facebook.com/InspirekidsFASDBC

Language Guide: Promoting dignity for those impacted by FASD
www.canfasd.ca/wp-content/uploads/2018/01/LAEO-Language-Guide.pdf

FASD Success Show Podcast
www.fasdsuccess.com

Wrap2.0 – FASD Coaching Partnership Project (Alberta)
www.wrap2fasd.org

Inclusion BC's Inclusive Education Initiative
www.inclusionbc.org/resource-types/inclusive-education

To learn more about the rights of children, youth and people with disabilities:

United Nations Convention on the Rights of the Child (UNCRC)
www.ohchr.org/en/professionalinterest/pages/crc.aspx

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
www.ohchr.org/en/hrbodies/crpd/pages/conventionrightspersonswithdisabilities.aspx

United Nations Declaration on the Rights of Indigenous People (UNDRIP)
www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html

Thank you to the advocates and allies of the FASD community who participated on our advisory group to help create this community resource.

Contact Information

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Elsewhere in B.C.: 1-800-476-3933

Fax

Victoria: 250-356-0837
Prince George: 250-561-4624

Text (children and youth)

1-778-404-7161

Website

rcybc.ca


Chat (children and youth)

rcybc.ca/get-help-now/chat

E-mail

rcy@rcybc.ca

Social Media

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and RCYBC Youth

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