



# News Release

---

## For Immediate Release

April 15, 2021

### **RCY report calls for improved, equitable supports to children with FASD and their families**

VICTORIA – The provincial government should take both immediate and long-term action to improve supports and services to children with fetal alcohol spectrum disorder (FASD) and their families, recommends a report released today by B.C.'s Representative for Children and Youth.

Children with suspected or confirmed FASD should immediately be made eligible for the Ministry of Children and Family Development's (MCFD) Family Support Services for Children and Youth with Special Needs (CYSN), based on functional need, thereby allowing these children and their families access to services that are available to those with other specific neuro-developmental conditions, said Representative Jennifer Charlesworth.

*Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families* examined the experiences of these children and families through their own eyes as well as those who support them. The report revealed significant inequities in services available to children with FASD and a general lack of understanding about this 'invisible disorder'. It also examined the structural racism that, those who work in the field say, skews the referral process for First Nations, Métis, Inuit and Urban Indigenous children toward an assessment of FASD.

"Our research shows that children and families with FASD receive meagre supports and services compared to children with other special needs," Charlesworth said. "FASD has been left undefined in the B.C. special needs service delivery model. Those living with FASD, whether diagnosed or not, can and do slip through the cracks of almost every program stream. That's unfair, and I'm calling on government to take much-needed action to rectify this."

In addition to making children with FASD eligible for CYSN Family Support Services, the report calls for MCFD to proceed with implementation of its new CYSN framework while ensuring that it fully includes children with FASD, based on their functional needs.

RCY's project team for the report was co-led by Myles Himmelreich, an adult with FASD who has 15 years' experience working in the field. The team employed a mixed-methods approach to gathering and analyzing information, including ongoing and extensive engagement over several months with nine children and youth with FASD from across B.C., their parents and caregivers. The Representative is deeply grateful to these young people and their families as they revealed not only the challenges that FASD presents but also the strengths, resourcefulness, creativity, kindness and love that the children and their families embody.

"It was important to me that this report be done to not only bring awareness to FASD but also to bring change," Himmelreich said. "It is important because, rather than focusing on the cause of

FASD, the report focuses on the needs of those children and youth with FASD here now who need support.”

Other sources informing the report included 48 professionals and service providers (through interviews); 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; community dialogue sessions involving families and service providers; an extensive literature review guided by the themes emerging from RCY’s work with the families involved in the research; and input from external subject matter experts.

“Previous RCY reports have shown that services in B.C. for children and youth with special needs are insufficient overall,” Charlesworth said. “And this report clearly indicates that families with FASD often struggle to get *any* tangible help.”

FASD is a life-long disability that is often misunderstood and accompanied by significant stigma for those affected. One of the great challenges RCY faced in completing this work was to do so without reinforcing that stigma, including the mistaken assumptions that FASD is an “Indigenous problem” and that it is “100 per cent preventable”. Both these assumptions 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 pregnant,” Charlesworth said. “It is often stereotyped as either or both of these, however, and the resulting stigma can lead to harmful consequences, including a general lack of empathy and understanding and an undeniable lack of supports and services for children and families who clearly need them.”

Among the report’s key findings is that structural racism appears to lead to assumptions that can influence referral processes for assessment of FASD. Clinicians and service providers involved in those processes described a noticeable trend of Indigenous children being referred for FASD assessments, while non-Indigenous children presenting in a similar manner are more commonly referred for other assessments such as autism spectrum disorder (ASD) or attention deficit hyperactivity disorder (ADHD). Participants in RCY’s First Nations and Urban Indigenous community dialogues recounted experiences that support this view, reinforcing the experience that racist stereotypes about alcohol use can push Indigenous children toward an FASD assessment.

Although government does not collect the disaggregated and FASD-specific data necessary to confirm such bias, information gathered for this project points to the troubling conclusion that FASD continues to be falsely framed as a predominately Indigenous issue, Charlesworth said.

“The stigma and a lack of empathy experienced by families with FASD are accompanied by a general lack of understanding about the effects of FASD,” she added. “This lack of understanding can lead to exclusion from community and peers, and result in social isolation for children and parents. With understanding, appropriate supports and greater acceptance, inclusion and belonging, children can thrive. We have the knowledge and we can do so much better.”

The report also 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; and that children in government care who have FASD may not receive a diagnosis or proper supports and can face significant hurdles with limited help as they enter adulthood and transition out of care.

The report 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 include the call for a review of, and improvements to, FASD awareness training for appropriate workers in the education, 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 would allow for disaggregation.

The full report is available here <https://rcybc.ca/reports-and-publications/reports/monitoring-reports/excluded/>.

**Media Contact:**

Jeff Rud

Executive Director, Strategy and Communications

Cell: 250-216-4725

Email: jeff.rud@rcybc.ca