

Statement

Oct. 29, 2019 For Immediate Release

A unique forum on Fetal Alcohol Spectrum Disorder (FASD) that saw children, youth, caregivers and key decision-makers come together recently in Victoria has highlighted the need for impactful and positive change to the system of supports for a population of young people that has generally been underserved.

The Oct. 25 forum, *Sharing Experiences for Change*, is one component of an extensive RCY research project designed to understand the current system of supports and the gaps, challenges and opportunities to improve that system for children and youth living with FASD and their families. A public report will be released in spring 2020 that will also reflect input from community dialogues, policy analysis, literature and jurisdictional reviews and service provider interviews.

Participants from several government ministries and Indigenous organizations heard heart-wrenching stories from nine children and youth living with FASD and their parents/caregivers about their experiences at home, at school and in their communities. Key themes that arose again and again throughout the day – and in RCY's research to date on this project as well – included isolation and exclusion, lack of understanding about the effects of FASD, lack of support in school, inconsistent or non-existent community supports, and problems with the assessment process.

Many of the decision-makers – representing the ministries of Health, Children and Family Development, Education and Mental Health and Addictions, as well as the First Nations Leadership Council, the First Nations Health Authority and the Select Standing Committee on Children and Youth (SSCCY) – expressed that they had not fully understood what the life of a person with FASD was like on a day-to-day basis. Each decision-maker attending the forum committed to identifying and exploring ways to improve the experiences of those living with FASD.

RCY expects the forum and upcoming public report to provide another opportunity for government to address the needs of this population as it designs a new Children and Youth with Special Needs (CYSN) framework and responds to recommendations from RCY's 2018 report *Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family*. The forum and RCY FASD report could also complement SSCCY's look at CYSN supports, now in completion.

The forum reminded everybody who attended – decision-makers, RCY staff, parents and caregivers – that we all want the same thing: for all children and youth to have every chance to succeed. Collaboration is the key to amplifying the need for change and those with lived experience are best positioned to help us understand how to design the most effective interventions and policies.

RCY has deep gratitude to the children, youth, parents, caregivers and decision-makers for saying "yes" to participating in this forum, and for their openness and willingness to share and question. Your contributions will hold us up as we move ahead on this project, with the ultimate goal to ensure that the inequity in supports and services provided to children and youth with FASD is addressed.

Sincerely,

Jennifer Charlesworth

Representative for Children and Youth