BRIEF REPORT

Supporting Youth and Young Adults Using Opioids:

Experiences of family members and loved ones







What is CRISM EHT Youth Project?

This interview study from the CRISM Prairie Node took place as part of a national project from the Canadian Research Initiative on Substance Misuse (CRISM), with funding from the *Emerging Health Threat (EHT) Implementation Science Program on Opioid Interventions and Services*. The Youth Project ran from 2018 and 2022 with researchers focused on mapping the landscape of prevention and treatment for Canadian youth aged 15-25 who were new or "at risk" users of opioids. Our research activity included regional youth focus groups, a national Youth Summit, a survey of youth treatment service providers, and a scoping review. All activities were carried out in partnership with CRISM research teams based in Quebec and the Atlantic provinces, Ontario, the Prairie provinces, and BC.

This report summarizes the findings of a smaller project embedded in CRISM's Prairie Node, covering Alberta, Saskatchewan and Manitoba. To compliment other youth engagement research in the CRISM EHT Youth Project researchers at the University of Calgary interviewed 17 family members and loved ones affected by youth or young adult opioid use and overdose death. Our aim was to understand family experiences when supporting a young person seeking healthcare and treatment for the use of opioids and/or other substances. While our discussions emphasized family members' roles as caregivers we also discussed their needs for support when supporting a loved one or dealing with grief following overdose death.



How did we recruit people?

We carried out interviews online and by phone in the spring and summer of 2020. Participants were recruited from researchers' local networks (i.e. "convenience" sampling) and many were affiliated with family support and advocacy networks (12 people). A few people were referred by social media posts and research email lists (3 people), and snowball (participant referral) sampling (2 people). We interviewed people who identified as women, and most (n=12) were mothers of young adults or adult children. The remainder of the sample (n=5) was made up of other family and close relationships (e.g., common-law partner, stepsibling, aunt, cousin). In addition to one-to-one interview discussions each person completed a brief survey about their background and family experience. Participants received an honoraria (\$50 CAD, in cash) as a token of appreciation and in recognition of their time.

This study was approved by the Conjoint Health Research Ethics Board at the University of Calgary, (REB19-0142).

Who participated?

Participants ranged in age from 20 to 60, with a mean age of 47 years; only five were 40 years old or younger. In terms of ethnicity, 13 participants self-identified as white and four as Métis or Indigenous. We recruited and interviewed 17 participants living in Alberta (n=13), and Saskatchewan or Manitoba (n=4).



What did we learn?

We categorized the topics discussed in the interviews under the following set of broad headings:

Positive Solutions	Examples of current programs or services for opioid and other substance use that could be scaled up or more widely accessible.
Failed Solutions	Programs that didn't work, or weren't "promising" or positive for youth and their families.
Barriers to accessing services	The barriers and challenges in accessing opioid and other substance use treatment and services.
Guiding Values	Desirable characteristics of interventions or treatments, e.g., youth-friendly, family-centered, trauma-informed, etc.
Knowledge of Supports	Knowing and learning where to get treatments and services; Understanding different treatment and support options available.
Polysubstance Use	Discussion of substance use beyond opioids and substance co-use; Substitution practices; Use of prescribed and non-prescribed substances.
Mental Health	Family member or loved one's mental health needs for support and counselling, as well as the intersection of youth/young adult mental health and substance use challenges.
Stigma	Families experiencing stigma when from service providers when accessing services, as well as stigma from law enforcement and friends/other family members.

Seeking care for a loved one using substances

The most prominent theme identified through the analysis of interviews was the challenges faced by family members in learning how to support their loved ones in accessing treatment for opioid and other substance use, and their subsequent difficulties in navigating a complex and disorganized array of services. As a result, family members often became advocates for more support and services, and many took on the role of navigating services for others in their networks and communities. The most significant barrier to care discussed was stigma, and our interviewees shared numerous, heart-breaking examples of encounters with stigma and discrimination towards people who use drugs they experienced when supporting loved ones seeking care in hospitals and in other treatment settings.

Many of those we spoke to reiterated that over time, and even with more experience in navigating the system, their perception of the situation was that the available options for addressing substance use had not substantially improved. The need for greater access to concurrent mental health services and trauma-informed care for addiction was also raised frequently, as well as housing and employment supports for young people using drugs who may become more disenfranchised or destabilized when aging out of youth services, or when leaving education and the family home.

Seeking care and support for their own needs

Families of youth or young adults using opioids and other substances faced numerous challenges to their mental health and well-being and all participants expressed their need for social and grief supports specific to the family experience of drug use and overdose death. Some found support in volunteer-run, informal groups online and in their communities, while others were motivated to start their own support groups. Some noted that while there were now more support groups for parents in Canadian communities, there are fewer supports for siblings, partners, and other family members. It was painfully clear from the interviews that family members have substantial unmet mental health needs, especially a lack of access to formal supports for coping with grief and bereavement.



What should be done?

In our interview discussions we heard loud and clear that families want:

- > Access to better information and resources for treatment system navigation.
- > Concrete strategies to address the stigma of substance use in healthcare.
- > Increased mental health support specific to family experiences of substance use.
- > Peer-based supports and family members as peer navigators in their communities.
- > Evidence-based approaches to family counselling that do not reinforce blame and shame.
- > "Youth-friendly" supports and services for those under 18 years old.
- > Access to a spectrum of services: detoxification, recovery, harm reduction, OAT, safe supply, concurrent mental health treatment, housing, employment and trauma-informed care.

We are grateful to the people who agreed to be interviewed and who shared their experiences with us.

Publication

The first publication from our project is available in a special issue of the *Canadian Journal of Addiction* from the members of the CRISM Youth EHT Project.

Khan F, Lynn M. Porter K, Kongnetiman L, and Haines-Saah R. (2022, July 15). "There's No Supports for People in Addiction, But There's No Supports for Everyone Else Around Then as Well": A Qualitative Study with Parents and Other Family Members Supporting Youth and Young Adults. *Canadian Journal of Addiction*.

Questions?

For more information, please contact : Dr. Rebecca Haines-Saah (rebecca.saah@ucalgary.ca)