

Workshop Summary Report: A Family-Centered Approach to Substance Use in Alberta

Date of Report	July 4, 2017
Date of Meeting	March 9 2017
Title of Meeting	“A Family-Centered Approach to Substance Use in Alberta”
University Partners	Dr. Elaine Hyshka & Heather Morris (University of Alberta), Dr. Rebecca Haines-Saah (University of Calgary), Dr. Emily Jenkins (University of British Columbia)
Community Partners	Petra Schulz (Moms Stop The Harm); Donna May (mumsDU); Jennifer Woodside (The Voice of the Family)

In Alberta – as well as across Canada – bereaved parents and family members have been at the forefront of public discussions on the urgent public health issue of opioid misuse and overdose deaths. It has been through sharing their personal stories and experiences that they are continuing to challenge the social stigma of illicit drug use and addiction, contributing a much needed family-based perspective to public understandings of substance use. Parents are working to influence drug policy change around the prevention and treatment of substance misuse through voluntary efforts which have included lobbying governments, media engagement and other forms of advocacy. While research and policy initiatives have recently included people who use substances by emphasizing peer and patient engagement, the experience of parents and families has historically not been included. This is problematic due to the fact that family members are greatly impacted by a loved one’s substance use, are often a primary support, and have a unique lived experience that is important to consider when undertaking program planning, policymaking and research in substance use.

Public Forum

On March 9, 2017, our research team hosted a half-day public forum and workshop, the purpose of which was to focus on finding ways to leverage the wisdom and experience of families to mitigate the province’s overdose epidemic. The workshop was jointly funded by Campus Alberta Health Outcomes & Public Health (HOPH) and the Canadian Research Initiative on Substance Misuse (CRISM): Prairie Node. The day’s events began with a public forum that was moderated by Dr. Elaine Hyshka (UA School of Public Health) and attended by 106 individuals. Presentations by our community collaborators, all of whom have lost a child to substance use, were delivered by Petra Schulz (Moms Stop The Harm, Edmonton), Donna May (mumsDU, Toronto), and Jennifer Woodside (The Voice of the Family, Vancouver). Dr. Hakique Virani (Addiction Medicine and Public Health Specialist) spoke about the role of families in treating individuals with addictions and Ms. Marllis Taylor (Program Manager, Streetworks



and Member of the Steering Committee for the Canadian Drug Policy Coalition) provided us with an overview of harm reduction.

Roundtable Discussions

The afternoon roundtable discussion workshop was attended by 38 different stakeholders representing over 20 different organizations from both Edmonton and Calgary. Invited attendees included frontline health care providers (nursing, medicine, peer outreach), decision-makers from Alberta Health Services, university researchers, family advocacy/support groups, hospital and community organizations, Calgary & Edmonton Police, Edmonton Fire Rescue Services and City of Edmonton Community Services. The afternoon workshop began with opening remarks by Dr. Rebecca Haines-Saah (Community Health Sciences, University of Calgary) which was followed by a blessing by Elder Jo-Ann Saddleback. Dr. Emily Jenkins (School of Nursing, University of British Columbia) spoke on the concept of a family-centered approach to care. We then moved into our roundtable discussions which focused on four primary questions:

1. What does a family-centered approach to substance use look like to you?

Workshop participants expressed the importance of using a broad and inclusive definition of family, recognizing whoever is meaningful to the individual while also acknowledging that some people do not have families directly involved in their lives. Families have lived experience, similar to individuals, and thus acknowledging their experience and expertise is essential. Approaching families as partners and providing a meaningful voice for families in the prevention and treatment of substance use disorders as well as in policy-making and research was expressed as being important. A family-centered approach also means addressing the blaming, shaming and stigma that often accompanies substance use as well as providing education and support in ways that are innovative and affordable. Emphasizing family strengths and promoting resiliency while at the same time addressing system-level barriers that may impede a family-centered approach were highlighted by participants. Informed by Indigenous ways of knowing, participants suggested that it is important to 'see beyond the numbers,' in terms of reporting on individuals who have died, to see how the impact of a substance-related death extends to many more people in families and communities.

2. What challenges/barriers are present to involving families in the overdose response?

Challenges to providing support include the stigma associated with mental illness and addictions which can be attributed in part to the criminalization of drugs. A sense of embarrassment or shame imposed by many, may contribute to parents' and families' feelings of isolation and being unsure of where and how to seek help during times of crisis. This is only made worse by a health care system that has been characterized as being disjointed, expensive (e.g. counselling), episodic and inconsistent in its



approaches to substance use care. Participants expressed that it is at times difficult to find support – program space may be limited and wait times can be long with a corresponding lack of information of where to go and how to access support. It was also identified that we are in need of research to support evidence-based treatment options so that substance use care is effective and appropriate. Families sometimes feel excluded when guidelines prevent sharing information due to issues around patient confidentiality (i.e. FOIPP), or when their loved one had a preference that health information not be shared with their family during treatment. There was a recognition that healthcare providers are said to be overworked and the lack of providers who specialize in the field of addictions is discouraging, particularly as it relates to the intersection of substance use and mental illness.

3. How can we better support families?

Workshop participants pointed to a variety of key strategies that are necessary to improving the support for individuals who use drugs and their families. Helping families navigate systems (e.g. making wait lists public; having detailed and clear directions on how to access support via internet) was deemed to be essential, as was disseminating evidence about best-practices in prevention and treatment of substance use disorders. While there have been recent advances such as family access to naloxone as well as overnight stays for family members being permitted at some hospitals, examples of additional supports mentioned include youth clinics, a “one-stop shop” offering a variety of support services, no or low-cost counselling, peer support programs, follow-up support post hospital discharge and more immediate access to treatment at the moment when it is required. Families need to be included in the development of new and innovative programs and services through meaningful participation on government task forces, commissions, quality councils, patient advisory groups and Alberta Health Services’ Strategic Clinical Networks. Fair compensation should be provided to family members who participate in such initiatives on their own time. Bringing positive stories of success to the mainstream was suggested as an important tool as well as offering a multi-pronged approach which includes the provision of easily accessible and reliable education on harm reduction for families and other members of the community. System-level barriers need to be considered such as addressing social determinants of health (i.e. poverty), enhanced training for health care providers and improved regulation and accreditation of treatment centres. Assistance for parent networks, support groups and advocacy organizations need to be provided. Providing care that is culturally appropriate, recognizes the generational impact of colonialism and which centers on Indigenous knowledge and experience was also identified as being essential to better supporting families.

4. What research questions are of utmost importance right now re: a family-centered approach to substance use?

A number of research questions were suggested for future study:



- 1) What is the family role in pain management and prescription opioid use?
- 2) What do parents know about substance use and harm reduction?
- 3) What are patient's/families perceptions of their health care providers and how do these perceptions affect engagement in treatment?
- 4) How does a family-centered approach change when a child transitions to adulthood?
- 5) How are families affected by loved ones' substance use disorders?
- 6) What is the impact on family members following a substance passing?
- 7) How does advocacy work which is conducted by families impact drug policy reform?
- 8) Are fathers more or less engaged in advocacy work than mothers?
- 9) What are family-centered approaches to care in substance use disorder prevention and treatment?

Other suggestions that were put forth that are more broad in nature (not specific to family) included research around public perceptions to the legalization of drugs, what factors contribute to resiliency, differences in best practice for opioid addiction compared to other types of addiction, economic analyses around treatment methods, school-based drug education programs and research which enhances our understanding of the experiences of front-line health care providers working in the area of substance use.

Media Coverage and Content Links

We received excellent media coverage of our public forum and would like to acknowledge the University of Alberta School of Public Health Marketing and Communications team for their support in promoting our event.

Print/Online

“Hardline approach to drug use costing lives, advocates tell Edmonton crowd.”
[Edmonton Sun](#) , [Edmonton Journal](#) , [Ottawa Citizen](#) (March 9, 2017).

Television

Health Matters segment on the Panel (March 9, 2017). [Global Edmonton](#)

Event Photos

[School of Public Health – Flickr Page](#)

Event Recording

[Adobe Connect Video](#)





Moving Forward

We wish to thank all of you who attended for your participation and would like to remind you to please contact us should you be interested in partnering in future research studies related to a family-centered approach to substance use. If you have any further suggestions around next steps or additional research projects, we would very much like to hear these from you.

Study Team Updates:

- Dr. Rebecca Haines-Saah presented an overview of this event at the Campus Alberta Health Outcomes and Public Health Annual Provincial Forum, May 16th
- Our research team met to follow up from the roundtable discussions on March 10/17 and will be undertaking a study this summer entitled ‘Mother’s stories of advocacy following their child’s substance passing: A qualitative interview study’.



- Two members of our research team have been named to the Alberta Health Minister's Opioid Emergency Response Commission – Dr. Elaine Hyshka as Co-chair of the commission and Ms. Petra Schulz who will be representing the perspective of family members.
- Petra Schulz will be giving a plenary presentation at the Ignite Change 2017 conference for Human Rights in Edmonton in August. She will be speaking about the lessons learned as a drug policy reform advocate.
- Through her NFP NGO, mumsDU-moms united and mandated to saving the lives of Drug Users, Donna May is continuing her national and international travels educating on the consequences ineffective drug policies have on families and loved ones. These efforts will culminate at the United Nations 2019 meetings in Vienna, Austria where there will be the opportunity to revisit global drug treaties to make amendments and revisions
- Jennifer Woodside, The Voice of the Family (VOF) participated in the *BC Overdose Action Exchange* held June 16, 2017 in Vancouver, BC. VOF continues to be a contributor on the *Joint Task Force on Overdose Prevention and Response* as well as the *BC Drug Overdose & Alert Partnership (DOAP)*. VOF will also be attending the *Recovery Capital Conference of Canada* which is being held on September 7th and 8th, 2017 in Vancouver, BC.
- As requested by participants at our workshop for access to research about evidence-based substance use treatment and prevention online, we have been working with our partners at CRISM (Prairie Node) who continue to upload new and relevant information to their website - <https://crismprairies.ca>

Sincerely,

Dr. Elaine Hyshka, Assistant Professor, School of Public Health, University of Alberta and Scientific Director of the Inner City Health and Wellness Program, Royal Alexandra Hospital, Edmonton

Dr. Rebecca Haines-Saah, Assistant Professor, Community Health Sciences, University of Calgary

Dr. Emily Jenkins, Assistant Professor, School of Nursing, University of British Columbia

Ms. Donna May, mumsDU

Ms. Heather Morris, PhD Student, School of Public Health, University of Alberta

Ms. Petra Schulz, Moms Stop The Harm

Ms. Jennifer Woodside, The Voice of the Family

