



STRONGER TOGETHER

COMMUNITY PRIORITIES TO ADDRESS ISSUES RELATED
TO SUBSTANCE USE AND ADDICTION IN FRASER HEALTH
AUTHORITY

INDINGS FROM FAMILY-LED DIALOGUES IN SURREY, BRITISH COLUMBIA

*Fraser Health's unceded Coast Salish territories,
including the Semiahmoo, Katzie,
Kwikwetlem, Kwantlen, Qayqayt and
Sawwassen First Nations.*

March 5-9, 2019

TABLE OF CONTENTS

- INTRODUCTION 2
 - Background** 2
 - Host Agencies** 3
 - A Note on the Definition of “Family”** 3
 - Limitations of the Report** 4
- ACKNOWLEDGEMENTS 4
- PARTICIPANTS 1
- PROCESS 2
- FINDINGS 3
 - THEME 1: Navigating the Health System – “Where to begin?”** 3
 - THEME 2: The Silos Between Systems** 3
 - THEME 3: Confidentiality - It’s Complicated** 4
 - THEME 4: Public Perception of the Crisis** 4
 - THEME 5: Finance, Refinance and Repeat** 5
 - THEME 6: Down With The Flop Houses** 6
 - THEME 7: Grief Support** 6
- ELDER’S INSIGHTS 6
- SUMMARY OF POSITIVES 7

Stronger Together: Navigating the Personal Impacts of Substance Use
COMMUNITY DIALOGUES SUMMARY REPORT
Surrey, BC | March 5- March 9, 2019

We gratefully acknowledge the communities and nations on whose unceded territories these events took place, including the Semiahmoo, Katzie, Kwikwetlem, Kwantlen, Qayqayt and Tsawwassen First Nations.

INTRODUCTION

Background

In the context of the provincial illicit drug overdose crisis over the past two years, too many communities have been personally and tragically affected by drug-related harms. There is an urgent need for stakeholders impacted by a public health crisis of this magnitude to lead and inform overdose response and substance use treatment initiatives. The family members of people who use drugs, in particular, are an important, but undervalued, resource for the health system. They hold a wealth of knowledge on how the system can be improved to support their loved ones, particularly those who are at highest risk of fatal overdose (people using alone due to stigma). Similarly, bereaved families have substantial insights on what systemic improvements could have prevented their loved ones' deaths. However, families have historically been excluded from key decision-making in our province, particularly around substance use services.

Stronger Together is a series of family-led dialogue and learning sessions taking place in seven communities across British Columbia in 2018-19, in partnership with local and regional stakeholders. The primary objectives of the project are to:

1. Mobilize family and service provider knowledge to identify local challenges and barriers for people who use drugs, inform service provision, and improve pathways to treatment and care in Island Health and across British Columbia.
2. Build resilience and increase family members' capacity to support their loved ones by offering tools and resources and fostering local connections.
3. Build local community capacity to support families impacted by addiction and the overdose crisis through the delivery of learning sessions for people interested in running support groups.

In collaboration with Fraser Health Authority (FHA), Surrey, BC was selected as one of the seven host communities. FHA contributed additional funds of \$2,060.80 to support the expansion of Stronger Together to Mission, BC to engage the urban Indigenous community supported by Mission Friendship Centre Society. These sessions will be hosted in Fall of 2019.

This report is a culmination of the wisdom and insights offered by families and service providers in Surrey, BC. We hope that what follows will lead to the development of locally-relevant, actionable solutions within each of your systems, in partnership with these key knowledge holders.

Host Agencies

The **British Columbia Centre on Substance Use (BCCSU)** is a provincially networked resource in British Columbia with a mandate to develop, implement and evaluate evidence-based approaches to substance use and addiction. The BCCSU's focus is on three strategic areas including research and evaluation, education and training, and clinical care guidance. With the support of the province of British Columbia, the BCCSU aims to help establish world leading educational, research and public health, and clinical practices across the spectrum of substance use.

The **British Columbia Bereavement Helpline (BCBH)** is a provincial leader in providing education, support, advocacy, networking, and information resources for the bereaved, their caregivers, and professionals. The BCBH is committed to assisting the bereaved and their caregivers in coping and managing grief, and recognizes the unique factors that come with a sudden death due to substance use. In addition to a helpline, the BCBH provides support programming for the bereaved and training for community members to establish support groups.

Parents Forever is a professionally supported, mutual support group for parents and other family members of adults (18 years of age and up) suffering from addiction. The group meets two times per month in Vancouver, BC (unceded Coast Salish territories) for the past 19 years.

Moms Stop the Harm (MSTH) is a network of Canadian families whose loved ones have struggled with substance use or have died from drug-related harms. MSTH aims to advocate, educate, and expand supports for families affected by substance use. They call for an end to the failed war on drugs and embrace an approach that reduces harm and respects human rights.

The host agencies partnered closely with **Fraser Health Authority** and **Surrey Community Action Team (CAT)** to plan, implement, and/or identify recommendations and next steps following these sessions, as well as the **Canadian Mental Health Association – BC Division (CMHA-BC)** in funding and promoting these sessions.

A Note on the Definition of “Family”

We acknowledge that not all families are biological or nuclear, but rather, “family, specifically family in relation to outpatient substance use service, was in all cases understood as being **defined by the person accessing services.**”¹

¹ McCune S., Pauly B., VanBoven, S. (2017). Disrupting Standard Mode: A Big Picture Story of Family Inclusion in Substance Use Services. Retrieved from: <https://www.uvic.ca/research/centres/cisur/assets/docs/report-family-inclusion-substance-use-services.pdf>

Limitations of the Report

This is a report-back of what we heard from **some** family members and service providers living and working in Surrey, BC. Please note that this is not a generalization of the entire community.

We also wish to note there was a lack of attendance from racialized populations, which could be representative of a larger, systemic problem in Surrey – for example, in relation to stigma and how it might affect people of colour differently. In particular, Surrey is one of the largest concentrations of South Asian residents in North America, yet this group was underrepresented at the dialogue sessions. There was also a disproportionate representation of Indigenous peoples at the dialogue sessions.

ACKNOWLEDGEMENTS

BCCSU, BCBH, MSTH and Parents Forever would like to sincerely thank the Province of BC through the Overdose Emergency Response Centre and Community Action Initiative for their significant contribution of \$75,000 to make these events possible across British Columbia. Thank you also to Canadian Mental Health Association – BC Division for their additional contribution of \$1,500 to support the continued capacity-building of communities.

In particular, we express our sincere thanks to Frances Kenny, facilitator of Parents Forever, for her many in-kind hours dedicated to planning and facilitating the “Supporting Families” Learning Session, travel, and ongoing support to participants across BC.

The organizers also wish to thank the following individuals for their key contributions to these events in Surrey, BC: Anthony Neptune, Len Polak, and Wendy Stevens from Fraser Health Authority for their in-kind and financial contributions, commitment to utilizing community feedback in their work and leveraging recommendations to leadership, and serving as a regional resource; Tracy Steere from First Nations Health Authority for their leadership, guidance, and partnership; Frances; Parm Matharu for additional facilitation and meeting support; Marsha Drake from Valley View Funeral Home for donating refreshments to nourish our bodies through these difficult conversations.

Most of all, thank you to the participants who shared their deeply personal stories of struggle, grief, and loss, and inspiring us with your visions of a better system.

PARTICIPANTS

Total number of participants: 78

General demographics

Dialogue session: Families with loved ones in active addiction

Date: Tuesday, March 5, 2019

Participants: 19

Identified as:

- Parent (x7)
- Grandparent (x1)
- Sibling and person who uses drugs (x2)
- Support worker/ally (x9)

Dialogue session: Service providers supporting families

Date: Thursday, March 7, 2019

Participants: 28

From a variety of service organizations, including:

- Ministry of social development and poverty reduction
- Fraser Health Authority
- Corrections
- Provincial agency for front-line provider wellness
- Provincial non-profits for mental wellness
- Local non-profits for community support
- Family addictions counselling
- OAT clinics
- Indigenous services agency
- Funeral homes
- Hospice and grief support agency

Dialogue session: Families who have lost loved ones to substance use

Date: Wednesday, March 6, 2019

Participants: 10

Identified as:

- Parent (x7)
- Sibling (x3)

Learning session: Grief and Loss Support Group Facilitation

Date: Friday, March 8, 2019

Participants: 13

Identified as:

- Service provider (x6)
- Undocumented (x7)

Learning session: Coping Families Support Group Facilitation

Date: Saturday, March 9, 2019

Participants: 14

Identified as:

- Parent (x5)
- Service provider (x9)

PROCESS

We convened five groups in Surrey. This included three dialogue sessions (2.5 hours each):

1. Families whose loved ones are actively using
2. Families who have lost a loved one to substance use
3. Service providers interfacing with people who use drugs and their families

And two learning sessions (6 hours each):

4. Family Support Group Facilitator's Learning Session – for people interested in hosting support groups for families who are coping with their loved one's addiction
5. Grief & Loss Support Group Facilitator's Learning Session – for people interested in hosting support groups for families navigating grief and loss due to substance use

Each group committed to a set of community guidelines for engaging in dialogue:

- Make space, take space.
- Take breaks to support your wellness.
- What we say here, stays here. What we learn here, leaves here.
- We listen to learn rather than to respond or react.
- We gather in a spirit of mutual support and respect.

Each dialogue session was guided by three questions

1. What's not working well?
2. What's working well?
3. What are your highest hopes and biggest wishes for your community?



FINDINGS

The facilitated discussions surfaced a number of priority areas, challenges, and hopes for the future. What follows is a summary of key themes from the dialogue sessions. Insights from participants appear throughout the report in italicized quotes.

THEME I: Navigating the Health System – “Where to begin?”

There is no continuum of care for substance use and addiction, nor are there supports for caregivers who are helping their loved ones navigate the system. Like many, one participant felt like they were *“jumping through loopholes, all while being expected to deal with the emotional traumas of having a loved one struggle with addiction”*. Another described their experience as a *“never-ending chase for treatment”*, since *“you can’t rehabilitate until you’ve detoxed, but you have to call detox every single day for available beds”*. Many participants shared that when their loved ones were ready for treatment, they were stuck on a waitlist and felt there was no place to begin.

All participants of the Dialogue with Bereaved Families shared that their loved ones experienced mental health issues, including depression, ADHD, anxiety, and schizophrenia. It was clear that those families experienced a disconnect between mental health and addiction treatment services. One participant shared a story about an Indigenous couple that was not able to get into addiction treatment because the wife’s mental health issues was too severe. Another shared about her son, *“he spoke of suicide every day. Not a day went by where he didn’t do drugs. He hid behind drugs to mask his mental health challenges.”*

Service providers shared that they are stumbling across family support programs *“by chance”*, which impedes their ability to effectively refer their patients and families to services. They expressed experiencing *“disjointedness and inconsistencies across community services”*, like they were working *“on an island”*. There was a recurrent demand from both families and providers for a *“road map that should be provided for families and patients to help them navigate the system”*.

Peer and family navigators, funded and employed by the health system, may be an option to support communities through this experience, whilst enhancing social engagement and connectedness. Participants of the Dialogue with Bereaved Families shared that they would have preferred a family member with lived experience to show up at their door instead of Victim Services, as they found the human relatability more helpful than what they received at the time.

THEME 2: The Silos Between Systems

Participants noted the lack of housing and rehabilitation supports (i.e. employment) as a barrier for their loved ones and clients. Some families described that, despite all the shortcomings and lack of support within the criminal justice system, they would still prefer for their loved ones to be incarcerated because *“there are more supports in prison than when [they are] homeless”*. They also reported that their loved ones would intentionally offend for the purpose of entering corrections so that they could receive healthcare and housing.

Yet, the correctional system is not built to support people to rehabilitate and pursue wellness. While there have been improvements to the correctional system in recent years, including integrated mental health services, there is still a lot of work to be done to reduce harms. One participant shared that their child, who was addicted to fentanyl, was prescribed a low dose of Suboxone, which set them up for failure.

Furthermore, there is a reported lack of continuity between correctional and health systems. Families felt that corrections does not effectively support people – in particular people charged with petty drug crimes – to re-integrate into society. Intervention at the pre-trial judiciary stage was identified as a crucial need for non-violent drug offenders, as service providers felt strongly that these individuals have the potential to become well and develop life skills at the pre-trial stage. Service providers proposed that integrating more social justice services with probation processes would support the continuity of recovery for those living with SUDs and who are under custody.

Families also shared of how their loved ones are not supported during vulnerable periods, including after they transition out of the recovery home - *“What’s the point of sending kids back (to the streets) after relapsing?”* – and after they’re released from emergency – *“they sent him back out with a bus ticket and Naloxone ticket.”*

“It’s a postal code lottery because services are so disjointed across BC.”

THEME 3: Confidentiality - It’s Complicated

Patient confidentiality is a right, however, family involvement must also be acknowledged and supported. Several family participants shared that they felt excluded from their loved ones’ care plans despite the knowledge and patient history they have to offer. Some service providers expressed feeling torn between respecting patient confidentiality and effectively working with and supporting the family. For example, providers working in recovery homes that discouraged family involvement shared about their challenges to find a healthy balance between maintaining confidentiality and building a partnership with the family in order to support clients’ recovery.

THEME 4: Public Perception of the Crisis

Participants felt that there needed to be a paradigm shift in the public’s understanding of the overdose crisis, substance use, and addiction. They felt that the media does not currently portray the crisis accurately, which is causing harm and creating more silos between families, their loved ones, and agencies. One family member pointed out the lack of urgency felt by the public and decision-makers: *“The overdose crisis was declared a public health emergency in 2016, so why is it not being treated like one?”* Some bereaved families shared that *“there needs to be billboards on highways – that are visual and tangible – of our families who we’ve lost to overdose”*.

Participants expressed that the lack of public education is impeding families from accessing the help they need: *“We need phone numbers, not websites. Where’s the marketing for BC211?”*; *“Community response is still lacking. Think about the stigma from a child dying due to an overdose versus cancer. We need more education because overdoses have now become normalized.”* Participants suggested using Facebook Messenger as a means for connecting with struggling families.

Families and service providers alike suggested that media outlets must play a more active role in engaging the public in the fight against bad drug policy and increase awareness about support services in the area. Families recommended that the Fraser Health Crisis Line and BC211 be advertised ubiquitously. *“This needs to be in our faces constantly so when we need it later on, we’ll remember this.”* A common hope in all dialogue sessions was for Fraser Health to work on bridging communication gaps through advertising and promotional efforts.

Gendered approaches to crisis response was reported as a priority. The majority of illicit drug overdose deaths in Canada are of men, which leaves many women in grief (in a hetero- and cis-normative context, which is currently what we are seeing at our dialogue sessions). Similarly, participants noticed that it was mostly women who showed up for the dialogue sessions (cis-normative context), and attributed both observations to the way society socialize men to not be vulnerable.

THEME 5: Finance, Refinance and Repeat

Families experience great financial hardship when caregiving for a loved one with active addiction. While a two-tiered health system for recovery is necessary due to the lack of available publicly-funded beds, participants shared the impact this has had on their financial well-being. Families urged health authorities to invest more in the *“individual steps for their clients since most of them seem to get lost in the shuffle”*, and that there be more regulation on *“shutting down flop houses that take money”*. Some families felt it was problematic that recovery homes keep the funds even when their clients are released early due to an offense, because it incentivizes businesses to make money off the turnover of their residents.

Families reported that the costs of supporting their own wellness – even grief supports after death – were also breaking the bank: *“While my son was in rehab, I did a 3-day workshop to learn self-awareness and self-kindness. It was helpful but it cost me \$3,500.”* For families who had lost a loved one to substance use, it was found that *“There wasn’t enough support during [our child’s] addiction and right after death. We had to refinance [to pay for counselling]”*.

Participants felt that the availability and accessibility (i.e. financial) of family support programs was lacking. The primary focus is usually on the person who uses drugs (PWUD), but they called for more support for the family, recognizing that by building resiliency of the family system, it improves protective factors for the PWUD. Many family participants who are volunteering their time to do support work also expressed the toll this has on their well-being and livelihood: *“As much as I love doing this, I still need to feed my children. I do a lot for free. A lot.”*

THEME 6: Down With The Flop Houses

Families who have lost loved ones to substance use and with loved ones in active addiction expressed hope for their community as having more regulatory bodies overlooking recovery houses *and “shutting down flop houses charging exorbitant fees”*. Several times, parents mentioned being unaware of *“how bad the recovery homes were”*, with one parent stating *“I wouldn’t let a rabid animal in that home. No one checked on him (son). They found his body at 4pm and who knows, he might’ve started using at 5am. I would’ve rather he died in his home than in filth.”*

THEME 7: Grief Support

Grief support is often seen as separate from mental health support and overdose prevention. However, in the context of the overdose crisis, it’s become clear that the grief of losing a loved one to substance use is closely interrelated to the bereaved person’s own mental health and risk of overdose. Participants who identified as siblings shared that they carry a heavy burden in supporting their parents’ grief while navigating their own. However, their grief was not well-supported or as recognized. Similarly, participants who did not share a biological relationship with their lost loved one expressed that *“it was hard to know where to put my grief because friends would try to comfort me by saying, ‘at least he was your stepson’.”* More also needs to be done to support grandparents who are left with grandchildren after the death of the parent.

ELDER’S INSIGHTS

We were honored to have Elder Rosie Trakostanec from the Fraser Region Aboriginal Friendship Centre Association (FRAFCA) to co-facilitate the dialogue sessions. The wisdom and support she offered to families helped ground families through the difficult conversations. Culture is treatment, and in the context of a colonially-driven overdose crisis, *“if [Indigenous people living with SUDs] get their culture back, they get their lives back.”*

SUMMARY OF POSITIVES

Guided by the question “What’s working well?”:

- BC211: A champion in the thick of chaos, connecting most families to appropriate resources such as recovery homes and counselling services
- Existing support groups in Surrey, including: GRASP, Moms Stop the Harm, Narcotics Anonymous, GriefShare - *“Coming to a group once a month helps because everyone feels the same.”*
- Family therapy at Phoenix Society and SOURCES
- Surrey Safe Schools
- Valley Oak Clinic: Client-centred model
- Community Action Teams (CATs) establishing new connections between agencies
- Increased distribution and use of naloxone kits across BC
- Normalization of conversations about substances: *“The provincial ministry of health have done a good job in lessening stigma and opening the conversation.”*
- Shift in how parents are talking about their children’s drug use, from: *“How do we stop kids from using?”* to *“Where do we get naloxone kits?”*
- Social justice programs in schools are working to unpack stigma around drug use
- Peer connections and mentorship: *“The realness of my story allowed kids to see things differently. Playing a mentorship role works.”*
- Volunteering to help other families was healing; activism and advocacy