# "We are First Responders":

# How Parents Caring for a Substance Dependent Child Experience a Trauma Resiliency Training Designed for Professional First Responders

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March 14, 2021

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# Acknowledgments

We respectfully acknowledge that this project took place on the traditional territories of the WSÁNEĆ and ləkwəŋən peoples. We recognize with great gratitude the Indigenous individuals and communities that have cared for this land for thousands of years before us. By acknowledging the history of choices made and actions taken, we glean the wisdom needed to interrupt the perpetuation of harm and make tangible steps toward equity.

Thank you to my colleague Chantal Brasset and the Parent Collaborators who inspired this project and risked venturing into this project. Thank you for all you do to champion your child's care. You are essential. I hope that this endeavour has shed some light on the complexity of your caregiving journey and illuminated ways that we can care for you and create space for your voices.

Thanks to Dr. Tim Black for graciously giving of his time, energy, and knowledge. You have gifted us with knowledge that will continue to benefit families at Foundry Victoria and beyond.

Thanks to my Supervisory Team, Dr. Jennifer White, Dr. Janet Newbury, and Amy Schactman whose compassion and expert knowledge, on both personal and professional levels, guided me through this endeavour.

Thank you to Barb Thompson and the Victoria Youth Clinic Society whose understanding, encouragement, and financial support made this project possible.

I would like to make special mention to these extraordinarily patient community members who amid their own rich, busy lives, provided their feedback and suggestions: Emma Rai, André Serzisko, Elena Henwood, Sean Frey, Lorna Mace, Neely Hourigan, and Sylvia Storry. And to Dr. Martha Haylor, my treasured friend and mentor, thank you for everything, and for insisting that I trust myself.

#### Introduction

"We are the **first** First Responders." - Parent

In British Columbia, the opioid poisoning epidemic continues to end the lives of hundreds of young people and ravage the lives of the families that love them. In 2021, Victoria was declared one of the three communities in BC with the highest increase in opioid poisonings. Across the province, three hundred and fifty-five youth under the age of 30 died from illicit drug toxicity in 2021 (BC Coroners Service, 2021). Currently, this age group is the fastestgrowing population for opioid-related hospitalizations in BC. Young people are often supported by families<sup>1</sup> and communities that have felt the ripple effects of caring for a child dependent on substances. I have come to learn through my role as Family Support Worker at Foundry Victoria that these effects include witnessing their child be exposed to overdose, injury, death, and other traumatic events related to substance dependence. Families tirelessly working to support and care for their child are then personally impacted by the witnessing of these varied traumatic events and often adopt myriad roles including that of first "First Responders" for their children. These families I have come to recognize as essential to the survival of their children are the advocates and inspiration for this project. It is through the generosity and courageous sharing of their lived and living experiences, and their unrelenting hope that other families in similar circumstances may be spared of pain and isolation, that this project came to fruition.

"You're only doing as well as your sickest child is doing." - Parent

<sup>&</sup>lt;sup>1</sup> The definition of "Family" in the context of this project and other definitions can be found in the glossary of this report.

In this report, I will describe a research project that was initiated by an extraordinary group of 13 parents who were caring for children who were chronically dependent on opioids and other substances. The parents participated in the *TRT* or *Trauma Resiliency Training* which was initially designed for professional frontline medical personnel and veterans by Dr. Tim Black, who passionately and generously served as facilitator for the training. Seeking to reach the highest rung on "Hart's Ladder of Participation" (Hart, 1992), the parents were active collaborators throughout the entirety of this project, assessing the TRT for their context of parenting, co-designing this report, and recommending strategies for mobilizing this knowledge and sharing what was learned. This study demonstrates how non-profit organizations, service users, and the academic community can work together to generate collective wisdom and meaningful results.

"It's important for research to be informing practice. Usually there's a gap between when the research is done and when it develops into something. Because we're doing this together that gap won't be there." - Parent

My intention as Research Coordinator for this project was to organize this report to make it accessible to a wide audience. My hope was that the journey undertaken by these families would inspire reflection and action within the healthcare community and recognition by the academic community as knowledge worthy of expanding upon. I felt the weight of responsibility of doing this well, meaning I hoped to honour and dignify the breadth of experiences of both the participants and the facilitator.

<sup>&</sup>lt;sup>2</sup> A description of Hart's Ladder of Participation can be found in the glossary.

"I'm hoping this won't be really messy, but it might be." - Parent participant at beginning of first TRT Session

I fully acknowledge that the totality of this project only scratches the surface of conveying the complexities that parents face in caring for a substance dependent young person. Arguably, only someone that has cared for a loved one who is addicted to substances could possibly understand what is required of these families to get through the day. As well, the families' experiences can only truly be recognized by considering the larger context of psychosocial, societal, and cultural factors that have shaped their circumstances and influenced their choices, not to mention the compounding stress of Covid-19 and the surging numbers of opioid overdoses occurring during the time of this research. It is also essential to note that although many references are made to opioids throughout this report, the substances used by the young people cared for by these families is not confined to opioids (and tragically, poisonings are increasingly being associated with polysubstance use) (BC Coroners Service, 2021). Hence, this project and final report is limited in many ways and was not intended to solve these immensely complex societal problems. My intention was that this project be responsive to a population that has faced unthinkable barriers in trying to find adequate help for themselves and their children. In my experience and supported by this research, families who care for an addicted child are not only essential to their child's well-being, they are also expected by systems of care to step into specialized roles that can impact the life and death of their children. Their extraordinary capacities and resiliencies and the need for specific supports to prepare and sustain them in these roles requires illumination.

"I feel that this group and this content and the relationships being developed are greater than the sum of its parts. And that there are many to come that will greatly benefit from what is being wrought here." - Parent after first TRT session

This report is divided into three sections: The first section will answer why this project was pursued which includes our hopes, intentions, and the questions guiding the process. The second section will speak to the process by detailing who collaborated to produce this knowledge and how the project and themes were determined. The final and third section will provide a description of what we learned and hope to share with systems of youth and family care, the academic community, and other families who could benefit from this knowledge. A glossary is also included to provide some context for the many terms and concepts referred to throughout this project.

#### Section 1: A Brief Background of this Project

"If you're a First Responder you maybe could change your job. I can't. I don't want this job.

The only thing keeping me here is love." - Parent

The 13 parents who collaborated in this research were diverse in many ways, but they all had one thing in common: they were drawn to this project by the love for their children. The parents were all caring for young people (between the ages of 15 and 24) who struggled with chronic substance dependencies, and they had all accessed support from the Family Support Team at Foundry Victoria, comprised of myself and my colleague, Chantal Brasset. The majority of the parents participating in this project were long term members of a parent support group at Foundry, where they met bi-weekly alongside the Family Support Team to share their stories and offer the kind of compassion that only another parent living in similar circumstances could

provide. Parents and caregivers referred to the group as, "The one place I don't feel alone".

During meetings, parents commonly offered updates of their journeys, which not being my stories to tell, I will not divulge here. What I will share (with the families' permission) is what I frequently witnessed in those meetings: parents creatively and tenaciously riding the unpredictable and persistent waves as they researched, trained, adapted, problem-solved, compromised, and sacrificed to help keep their child alive. With the gradual increase in opioid poisonings across the city and the compounded pressure from the onset of Covid-19, it was not uncommon to hear these parents refer to themselves as the "First Responders" for their children. When asked what they could possibly need to help support them to keep going, one request was made: "Could you find someone to help us deal with the trauma?".

# The Context of Parenting a Child Dependent on Substances in BC

"I didn't sign up to be a First Responder." - Parent

Families caring for a child dependent on substances are faced with extraordinary responsibilities. They demonstrate significant resiliency and take on multiple roles that are unimaginable for most of us. The current opioid poisoning epidemic in British Columbia has increased the pressure on parents to adapt and adopt the role of First Responder in addition to the traditional responsibilities of parenting. Often, these parents are exposed to the threat of overdose, death, injury and/or traumatic events related to their young person's mental and physical health challenges (McCann et al., 2017; McCann et al., 2019). In addition to this, families caring for a child dependent on substances are forced into isolation due to the stigmatization and hopelessness associated with having exhausted all available resources that could help their child and/or themselves (Frye et al., 2008). The repetitive experience of crisis

and the associated trauma can leave parents at high risk for chronic stress and other threats to emotional, physical, and psychological well-being, adding further burdens to coping and resilience resources.

"Big difference between being a parent going through this and someone with less connection, I can't build up the same emotional barriers – it's wired. I should feel responsible because I am the parent." - Parent

Supportive programming designed to bolster the resiliency of professional First Responders is considered an essential intervention in treating repeated exposures to trauma (Quevillon et al., 2016). Although the literature on individuals caring for a family member dependent on substances reveals comparable impacts of trauma, supportive programming tailored to the context of families is minimal (McCann et al., 2019). As a Family Support Worker at Foundry Victoria, my experience is that there are currently no consistent, affordable, or widely accessible programs to address symptoms of trauma for families who care for a substance dependent child. As well, families exposed to trauma associated with caring for their young person are rarely recognized for their extraordinary and essential, life-saving contributions, nor are they enlisted to inform suitable systems of support (Soklaridis et al., 2019). In fact, "insider" knowledge is rarely privileged or acknowledged within academia, limiting the design of programming and policy and its' effectiveness in addressing the complex needs of those directly impacted (Gitlin et al., 2002; Kothari et al., 2017). The lack of current, accessible, and affordable trauma-specific resources for families, the identified gap in knowledge, and the express wishes of the parents themselves all served as driving forces behind this project.

"I also believe that the situation and emotions become more complex when it is your child." - Parent

## The Intentions of This Project:

- Respond to a request made by parents that are long-term members in a bi-weekly peer support group at Foundry Victoria who requested help addressing symptoms of trauma associated with caring for their substance dependent children.
- Honour their voices and experiences by co-creating the space for them to experience the Trauma Resiliency Training (TRT) and to assess its relevance and value for them.
- Invite families to serve as collaborators in knowledge creation and to the development of accessible and relevant family centred healthcare.

# **Guiding Questions for this Project:**

What aspects of a TRT geared to professional First Responders apply to the context of these families?

What do the experiences of families encountering the TRT materials tell us as service providers about the unique needs and resiliencies of families caring for a substance dependent child?

How can we leverage the expertise of university scholarship to support grassroots initiatives and privilege family's voices as valid contributors to systems of knowledge?

### **Section 2: The Collaborators and Our Process**

This section requires an introductory word of caution to the reader and a short explanation on what is meant by "trauma" in the context of this project. According to the Diagnostic and Statistical Manual, (5th ed.; DSM–5; American Psychiatric Association [APA], 2013) a traumatic event is defined as "being exposed to: death, threatened death, actual or

threatened serious injury, or actual or threatened sexual violence". "Exposed" refers to one or more of the following ways:

- Direct exposure
- Witnessing the trauma (in person)
- Indirectly, by learning that a close relative or close friend was exposed to trauma
- Indirect exposure to disturbing details of the event(s), usually in the course of professional duties (i.e., First Responders, Firefighters)

Using the DSM-5 standard to classify the parents in this project as traumatized raises a number of issues. Namely, to deem the parents as "traumatized" is at the same time validating and pathologizing. On one hand we dignify feelings of guilt, shame, self-doubt, and exhaustion by naming these as typical responses to having been traumatized. On the other, we locate the pathology *within* the parents, as "being traumatized", "having trauma" or PTSD, and we risk identifying their child as the sole cause of their trauma. The latter of these two has repercussions, such as perpetuating a loop in healthcare in which a condition is medicalized, where problems and remedies are sought without understanding the larger context (Netherland & Kaye, 2012). As Menakem (2020), esteemed educator in the realm of anti-racism practice reminds us, "Trauma decontextualized in a person looks like personality." (14:11). If we aspire to care adequately for youth dependent on substance and their families, we must take a comprehensive, holistic, and thoughtful approach that considers the larger social context in which we are active participants.

One intention of this project was to be responsive to the request of the parents for trauma support. Decontextualizing this project and the people involved risks separating them

from significant, crucial elements, leaving them open to a narrow interpretation. Hence, here I have made space to consider the wider contextual features of the key players within this project before presenting the findings in Section 3.

#### The Collaborators

In response to the request from families for trauma-related supports, my colleague,
Chantal Brasset (Parent Peer Support Worker at Foundry Victoria) and I approached Dr. Tim
Black, Associate Professor of Counselling Psychology at the University of Victoria. We proposed
that he facilitate his signature program prepared expressly for veterans and professional First
Responders, the *Trauma Resiliency Training* or *TRT*, to the parents in Foundry's parent support
group. In the absence of available trauma-specific training designed for families, our hypothesis
was that a training originally developed to bolster resiliency for professional First Responders
would hold some relevance for trauma-exposed parents. Seeing the potential benefit for
families, Dr. Black enthusiastically agreed, with the stipulation that the parents not only
participate in the training but also collaborate throughout the duration of the project.

Not a parent myself but having worked in the helping profession with youth and families for almost two decades, I was strongly guided by the social justice principle of "nothing about us without us" (Yeo & Moore, 2003, p. 587). This principle speaks to the widespread exclusion of marginalized individuals in the creation of research and policies that affect them. In alignment with Dr. Black's values of collaborative practice, I believed the meaningful involvement of the parents was required for this initiative to hold any weight in shaping the development of trauma-specific programming relevant to their context. Hence, the parents were enlisted from the onset to inform the delivery of the program, participate in the training,

assess the TRT's suitability for their unique context of parenting, and decide how to interpret and disseminate the results. As the Research Coordinator, my commitment was to do the *administrative heavy lifting*, cognizant of the high cost that people within marginalized groups typically bear in educating the broader public about their specific and unique difficulties (Dulay et al., 2018). Most importantly, I hoped that the TRT would provide some mental, emotional, physical, or spiritual respite to the parents who wanted to be a part of the project while caring for their children and families.

#### The Parents

Dr. Black: What do you hope to get out of today? [beginning of first TRT session]

Parent: Address the common experience we have of constantly feeling like something bad is about to happen – and the effect on our behaviour.

Parent: How to manage guilt and disappointment when I'm reflecting on my actions and thoughts.

Parent: I want joy in my life again.

Recruitment for this project was targeted at parents who had taken part in the Parent

Peer Support Group and/or had accessed support from the Family Support Team. In all, 13

parents took part in the project and all but one parent was a member of the Parent Peer

Support Group. Each of the families lived in Victoria, British Columbia and had more than one

year of experience caring for a child (ranging in age from 15-24) addicted to substances.

To remain within the scope of this project, demographic information was not taken from

participants. The individual identities of the parents were not considered central to the

project's purpose. Having witnessed the experiences of these families over time, I have come to

know some details that I have been granted permission to share in order to paint a picture of the group's diversity.

"You can have all the money in the world, but you can't stop this shit. Drug addiction is the grand equalizer." - Parent

The participants included both single parents and parents who were coupled. They all referred to themselves as a "parent" to their child and most of the participants were mothers. Some of their children were adoptees. Their economic status varied as did their levels of education. As is common with those who are primary caregivers for a substance dependent young person, each of them had spent an inordinate amount of time learning strategies to support their child (i.e., communication training, substance use and mental health education, parent groups, individual and family counselling). Their level of expertise in system navigation and advocacy was exemplary, so much so that some of them had developed informational workshops for other families and service providers. In fact, it has been my experience that families who care for a substance dependent child are remarkably skilled and industrious, exceedingly humble and generously natured people. Despite the challenges they persistently navigate including the judgement and rejection directed at them and their children from all levels of society, they are the first to donate their time and energy if it will ease the emotional load on another parent who is suffering. Hence, providing them with the TRT experience was not intended to dismiss their capacity, rather it assumed their capacity. I hoped the families would acquire some additional insights into their situation that would help sustain them in their ongoing journey.

Based on the TRT's definition of trauma (from the DSM-5), not all of the parents identified themselves as having been traumatized. However, all of the parents acknowledged they had been exposed to traumatizing situations in caring for their child. They all resonated with the descriptions of the physiological impacts associated with trauma and many of the families described their children as having been traumatized. Hence, although they may not all have self-identified as *traumatized*, they all encountered experiences in caring for their young person that would be considered *highly stressful*, *repetitive*, *and unrelenting*. Overall, the love for their child and commitment to bolstering their child's health far outweighed any negative impacts they endured associated with caring for their child. Their willingness to participate was one way they were seeking to regain and sustain a sense of well-being.

"I don't know if I have been suffering emotions from trauma, but more from chronic stress, fear, sadness, and frustration with varying moments of peaks and troughs. Dealing with addiction has been an evolving process - not simply one tragic event from which I need to heal. It is still on-going. I need to find a way to manage these often overwhelming emotions to live a happy, productive life."- Parent

#### Dr. Tim Black and the Trauma Resiliency Training (TRT)

"People are being traumatized unnecessarily because they don't understand what's happening to them" – Dr. Black

The TRT manual states that the program is a group-based training, designed to assist professional First Responders,

"... learn the fundamentals of how individuals in trauma-exposed workplaces become traumatized, how to best deal with traumatic responses in the moment and how to assist

members who may be dealing with the impact of traumatic exposure find the help they need." (Black & Sterling, 2020, p. 3)

The TRT is built upon the assumption that every First Responder will either encounter a potentially traumatizing incident in their lifetimes or are connected to someone who has. The training was created by two trauma experts at the University of Victoria, Dr. Tim Black and Alex Sterling, and was intended for those who had been exposed to trauma while working in a professional capacity, such as military personnel, and frontline medical staff such as first responders. The TRT is intended to provide a group learning experience in which participants who have experienced trauma can learn about the effects of trauma and obtain relevant and practical strategies to help lessen those effects. Learning about trauma and its impacts can have a validating and de-stigmatizing effect on individuals who are struggling with traumatic and post-traumatic stress responses (Menakem, 2017; van der Kolk, 2015).

The format of the TRT was carefully constructed with intentionally sequenced core components aligned with a trauma-informed approach<sup>3</sup> (Poole, 2014). The materials were designed to be compassionate to learners that were arriving to the training having been impacted by trauma and in some cases, Post Traumatic Stress Disorder (PTSD). Hence, key components of the training such as the physiological impact of trauma on the brain and corresponding behavioural responses were all delivered without the use of exclusive, theoretical language that could impede cognitive processing. Complex concepts detailing neurological functioning and the limbic system were explained in accessible and relatable language, using popular concepts (i.e., Window of Tolerance, Dan Siegal's Hand Model of the

 $<sup>^3</sup>$  Please see the glossary for a definition of trauma-informed approach in the context of the TRT.

Brain), and metaphors. In one instance, Dr. Black related the feeling associated with holding accumulated trauma in the body to the experience of holding a beach ball underwater. In another example he used a food analogy to explain the overloading effect of trauma on the limbic system, our physiological reactions, and the expanse of time and complex internal processes happening while the body "digests" the trauma:

"You can eat a whole pizza in 5 minutes but how long does it take to digest? It can take up to 30 days for one [trauma] to digest. We have to digest it. The body is flooded with chemicals. You can't think yourself through that."

A key principle from the TRT was that we naturally disassociate from our bodies in order to cope and tolerate trauma (Conti, 2021; Menakem, 2017; Ogden et al., 2006). As a result, the TRT places a major emphasis on recognising emotional states and developing the ability to modulate the body's state of arousal in reaction to highly stressful situations. As described in Section 3, the TRT experience was both affirming and empowering for caregivers who are prone to finding fault in themselves. They learn to reclaim control and choice in the midst of chaos.

"It's not a tool to take away your pain. It's to get into a place that's more tolerable." – Dr.

Black

Although the content of the TRT was standardized to maintain the integrity of the program, the facilitation of the material with trauma-exposed individuals required a skillful approach. A co-developer of the TRT, Dr. Tim Black has delivered the TRT to trauma-exposed professionals (i.e., healthcare professionals and emergency personnel, firefighters, veterans) for the past five years. He is a highly skilled trauma counsellor and group facilitator, and an accomplished academic at the University of Victoria. Throughout the project, Dr. Black was

consistently inclusive and collaborative, insisting that parents' needs and voices were centred at each stage of the endeavour. He was invested in the participants' learning experience being of value to them and was adamant that creating effective programming for a specific demographic required their participation. He took into consideration the families' everyday realities and prioritized collaboration and trust building as a starting point. Dr. Black was sensitive to the extreme pressure that families were facing as caregivers for substance dependent children amid an opioid poisoning epidemic and a global pandemic.

Although not intended as therapy, during the sessions Dr. Black's skill as a trauma counsellor was invaluable in co-creating and maintaining a safe and cooperative learning environment. He was transparent, identifying the boundaries of his knowledge, and sharing his own history of trauma while acknowledging the parent's expert knowledge as a key element in the learning space:

What I hope to portray is that I have zero expertise in what they [the parents] live with...But I was the expert in terms of the information around trauma...if you take two groups of experts, you're bound to do better than one group on their own.

Following the TRT, Dr. Black reflected that his teaching approach with the families was similar to that which he employs with First Responders and veterans. Tim had never served as a front-line medical professional or in the military, nor had he parented a child dependent on substances. Respecting each of these groups as experts in their own circumstances, their experiences of trauma, and in directing their own journeys of healing, his focus was on presenting the core components of the TRT and supporting participants to integrate the learnings that they found useful in their lives.

# The Parents as Unique Participants:

In a post-TRT interview, Dr. Black indicated that a unique aspect to this TRT was the focus of his audience. This was the first time he guided the TRT with a group of people who had experienced trauma associated with caring for their child. Dr. Black interpreted how the parents were engaging with the material as "Dual Processing":

"...that's very unique to this [group], because for some people they were like, 'This is about me. I'm now realizing something about me in this that I never thought about.' And for some other people, I could see what where they were going was, 'How do I take this and deal with my kid?'"

He also indicated that he had not delivered the TRT to participants whose experiences of trauma were ongoing.

"And also, almost everybody that I work with the traumas over, it's done. And that's in terms of treatment. You count on that. Like you count on the fact that the trauma is over, because then if the trauma is over, then you can start the healing process. So, the really unique part of this was that it's an ongoing thing, where their kids aren't safe and their kids are struggling."

Dr. Black took the approach of being realistic about what the content could provide for the parents, careful not to "over promise". He also saw the urgency in their situations given their constant stressors in real time. Above all, he intended to regard the parents as experts in their own lives, leaving them to determine what was most meaningful and applicable in light of their circumstances: "Let's get the information to you so that you can decide how best to use it."

# My Approach as Research Coordinator

"What is my intention? ...something useful for families which means that their voices are at the centre all the time." – Personal Journal Entry

A key responsibility in my role as Research Coordinator was to coordinate the Parent Collaborators and document the process to move together as smoothly and safely as possible towards a variety of positive outcomes. With this being a novel endeavour, my hope was this project would be a productive and impactful learning experience for everyone involved. I also strongly believed that this rare gathering of expert voices needed to be chronicled in order to uncover the benefits of merging the often divergent worlds of academia, frontline practise, and lived experience.

"How am I going to carefully and thoughtfully do this in a way that centres their voices and doesn't cause harm and nurtures healing?" – Personal Journal Entry

In reading this quote, I remember the combination of fear and hope that I experienced in beginning this project. To ground myself, I needed to stake my approach in guideposts that I could frequently return to throughout the project: respect for the autonomy and leadership of the parents, the intentions and guiding questions identified in Section 1, and commitment to a reflexivity practice. The last of these guideposts involved a weekly journaling practice and consultations with a skilled supervision team<sup>4</sup> which included both academic and community representation. Along the way, I relied heavily on their experience, insight, and guidance to

<sup>&</sup>lt;sup>4</sup> Dr. Jennifer White and Dr. Janet Newbury, Professors in the Department of Child and Youth Care (CYC) at the University of Victoria served as Academic Advisors and Amy Schactman, Clinical Coordinator at FV, served as Community Advisor.

understand the impact of my beliefs, perceptions, and values. As well, they were essential in helping me ethically navigate my dual role as Foundry's Family Support Worker and Research Coordinator for this project. Honouring my relationship with the families, I felt the immense ethical responsibility to communicate both the risks and the potential benefits to them in participating in this project. With knowledge of the parents' living experiences and aware of my own lack of experience as a parent, I approached with great confidence in their inherent abilities as well as much humility and hope.

# **Documenting the TRT Experience**

Session 1 (4 hours)	Trauma Basics, BETR Model and the PRO-STEP method
Sessions 2, 3, 4 (1.5 hours)	Debriefing the TRT tools, coaching, reviewing, and adapting

I observed the four TRT sessions and documented the parents' experiences based on their verbal and nonverbal responses. Included in my observations was Dr. Black's presentation of the material and his engagement with the families. I was aware of how documenting and reflecting on this unique collaboration could benefit the university community, and community service users and providers in the future.

I generated and collected four types of "data":

- **1. Researcher generated field notes taken during TRT sessions:** Throughout the TRT sessions I took field notes, recorded my own observations, and accounted for what I observed as valuable contextual information (Phillippi & Lauderdale, 2017);
- **2.** Written responses from electronic TRT session reflection e-surveys: At the end of each TRT session, participants were invited via e-survey to reflect on three questions ("What about the material today fit for you?", "What was not a fit?", and "What was missing?");

- **3. Two interviews with Dr. Tim Black, facilitator of the TRT:** I interviewed Dr. Black at the mid-point of the TRT sessions and once again to include his insight in the data analysis process after a summary of themes had been completed. In these interviews I explored his experience of facilitating and learning alongside the families;
- **4. Audio recordings from two Parent Working Group sessions:** After the completion of the TRT sessions, the parents were invited to participate in two 1.5 hour audiotaped sessions to finalize themes, collaborate on the final report, and decide how to disseminate the findings. My intentions were to offer every opportunity to ensure the results and outcomes represented their experiences rather than mine.

# Reviewing and Understanding the Data

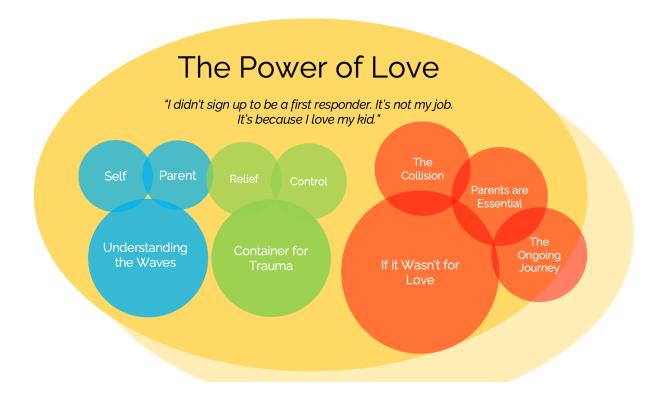
Reflexivity Practices

Here, I have included a visual summary of the steps taken to collaboratively generate the themes and subthemes. These will be discussed in more detail in Section 3. For a complete description of methods, please see Appendix 2 at the end of this report.

#### Steps of Data Analysis: > Dr. Black was presented with Themes and Subthemes for his Reflexive Thematic Analysis (RTA) Two Parent Working review and input. (Braun and Clark, 2019) Group Sessions took place at Step #4, and This research method #5 to discuss and finalize Themes and was a good fit: It is flexible and helps Parents provided Subthemes. their input and answer questions about direction on the people's experiences and views of a particular final report. phenomena. a report about what > RTA is not a neutral process: To address the impact of my subjectivity on developing themes, I Research Coordinator used three guideposts completed the first for deciding on three steps of RTA Themes: which resulted in "The Data" · Parent Autonomy three Themes each Research Questions with Subthemes. and Intentions

Section 3: What We Learned

"I feel like that's [love] what keeps everything emotionally and physically sustainable." —
Parent



In discussion with the parents, three themes with corresponding subthemes were developed, each of which reflect the language they used and represent significant points of learning throughout the TRT process. The themes fell under two key questions: What resonated from the TRT? and What was missing or needed to be expanded from the TRT?. Throughout our discussions, a recurrent concept surfaced which the parents identified as an essential unifying force behind their commitment to the learning: the love for their children. As a result, this driving force, "The Power of Love" became the central concept for understanding all of the other themes and patterns.

The TRT provided the parents with crucial information which helped them make sense of the chaos they were experiencing. One parent described how they were feeling at the first session as, "Going down the toilet bowl and I want to change the story." By the end of that session, there was significant movement in how the parents described their state of being. With a broader understanding of trauma came new insight and their narratives describing themselves and their relationships were shifting:

Parent: Understanding the brain and understanding my own self as a parent, it felt like the foundation was a little bit stronger.

Parent: I have more peace around the word trauma.

Parent: Increased self-awareness and understanding to meet my daughter where she's at.

There were also times during the TRT sessions when aspects of the parents' unique circumstances were not specifically addressed by the material, as evidenced by this question posed by one of the parents, "How does the power of love affect my trauma response?". As the following theme descriptions will convey, the parents made significant contributions throughout the sessions suggesting that the core material could be expanded to suit the context of families caring for a young person dependent on substances.

"In these times of crises and terror, we need new theories to guide our work in safeguarding the natural resiliency of families. To assess both diversities and commonalities in how families stay strong, we need more inclusive theory to analyze data and guide interventions for easing the family stress and trauma." (Boss, 2007)

#### The Power of Love

"Love is as love does. Love is an act of will - namely, both an intention and action. Will also implies choice. We do not have to love. We choose to love." Scott Peck, The Road Less Travelled, p. 97

Given the infinite possibilities of interpretation, the introduction of the word "love" needs to be contextualized to accurately reflect the meanings of love conveyed by parents whose voices are represented in the names and descriptions of the themes. According to bell hooks, love is both a noun and a verb (hooks, 2000), a significant truth in the context of these families. Within the context of family life, their love is a continuous expression of action evident in all the ways they stand alongside their children bearing the personal and social brunt of internal and external judgment. Standing alongside a child who is dependent on substances carries internal experiences of worry, grief, and trauma, feelings often arising from their own critique of what they *hoped for* their child and family, a critique grounded in self-blame and a perceived "failure" to make the "right" choices as their parent.

"The only thing keeping me here is love." - Parent

Loving a child through cycles of dependency and recovery generates uncertainty, tumult, and unpredictability in daily life, experiences that spill out from the confines of immediate family into the social world of friends, school, employment, and extended family. The practice of loving their children also means standing alongside them in the face of social judgment, shame, and expectations of what it means to be a "good parent". Despite these isolating social forces, parents participating in this project were propelled by the belief that a meaningful life for themselves and their children was possible. When other family members, friends, support

services, the community, and the young person themselves could not or would not hold on to this belief, these parents *do* and they fervently sought new information that would support this end. Love in the context of these parents is the driving force or "the power" that is necessary for them to *hang in there*. Who, if not them would remain despite the waves, to be there for their children?

#### What Resonated from the TRT?

Theme #1: "Understanding the Waves"

**Subthemes:** 

- a. Understanding of Themselves
- b. Understanding of Themselves as a Parent

"Understanding the Waves"

"I am understanding the waves of dealing with trauma". – Parent

"...once people understand the body's reaction to it, like from the limbic system, it's that whole feeling of, 'Oh, so it's not me'". - Dr. Black

The turbulent stories of strife and resourcefulness described by parents caring for a substance dependent young person are widespread across social media, websites, and newspaper articles. (Anonymous, 2020; Edwards, 2017; Ethridge, 2017; FAR Canada, n.d.; Moms Stop the Harm, n.d.). Traumatizing situations in the present, such as an overdose, or in the past, such as flashbacks of painful occurrences, and the fear of one day losing their child to a poisoned drug supply are common in their stories. Compounded by the stigma attached to addiction, parents caring for a substance addicted child frequently face feelings of guilt, grief, and shame (Anonymous, 2020; Menakem, 2017). Learning to cope with the "waves" of extreme

stress and the associated stigma can be isolating, profoundly impacting the body and how the brain processes information.

The TRT program reflected what experts working with trauma exposed individuals suggest is often the first step in healing trauma: "Educating people on what trauma is." (Menakem, 2017, p. 21). For trauma-exposed individuals, gaining a better grasp of the physiological mechanics and consequences of trauma on behaviour can be a liberating experience, freeing them from crippling self-blame and humiliation (Conti, 2021). With a greater understanding of trauma and its impact on body, the way parents experienced themselves and their child's circumstances made a noticeable shift:

"What I want to take [from the TRT experience] is more self-awareness of what I'm feeling – and able to share this info with my husband and my son – and try to help us all move forward or understand what's going on." – Parent

Two subthemes were identified to accompany this theme: *Understanding of Themselves* and *Understanding of Themselves as a Parent*. In deciding on two subthemes, the parents were asked whether they considered their "parent identity" separate from that of themselves as individuals. The consensus was that the two were separate with essential points of overlap.

"Maybe [splitting these into 2 categories] is a good reminder that there is a separation even if it doesn't feel like it. Perhaps that would give us a reason to help ourselves so we could become a better parent." - Parent

Dr. Black also commented on this "split" as one of the factors that set the parents apart from past TRT cohorts, referring again to dual processing:

"The major difference in this group, I couldn't always tell if they were responding because of something they learned about their kid, or something they learned about themselves....

How do you only take it for yourself and not apply it to your kid?... It's someone you love and someone you care about." – Dr. Black

# a. Understanding of Themselves

"I process in my head – not in my body – and I need to pay attention to emotions and my body." – Parent

"In order for us to transform we need to be connected to it [emotion]. We are training you to widen your Window with Tolerance<sup>5</sup>." – Dr. Black

The TRT experience increased the parents' understanding of their own body's interaction with stress and trauma, the accumulative effect of trauma on the brain, and how this was translating to their behaviours. The TRT sessions included exercises to help participants reconnect with their bodies in the present moment, guide them through mindfulness practices, and shape their awareness and ability to identify their emotions. One parent described this experience as "Understanding how my body worked and put[ting] words to it." According to the advice of acclaimed professor of psychiatry, Dan Siegel (2012), it is essential that we "name it to tame it" (p. 27). The ability to notice and identify one's feelings in response to a stressful episode can neutralize anxiety and calm an overactivated nervous system. The TRT also described the purpose of emotions and how getting stuck in a reflexive cycle of ignoring, not

<sup>&</sup>lt;sup>5</sup> The Window of Tolerance (NICABM, 2021) is a concept developed by Dan Siegel and used in the TRT to provide a language for recognizing fluctuations in our nervous systems.

"finishing" or completing emotional responses, can alter brain function and negatively impact behaviour (Conti, 2021; Menakem, 2017; van der Kolk, 2015).

Ascribing to the Triphasic Model<sup>6</sup> of trauma treatment (Herman, 1992), Dr. Black suggested that in supporting trauma-exposed individuals, it is not as important to ask, "What happened?" as it is to ask, "Where are you feeling it in your body?". This dissociation with the body is supported by trauma expert Bessel van der Kolk (Tippett, 2021, 50:56): "I'd say the majority of the people we treat at the trauma centre and in my practice have very cut off relationships to their bodies. They may not feel what's happening in their bodies." The TRT was rich with accessible concepts, metaphors, and techniques that gradually invited participants into brief moments of body-reconnection. The TRT was useful to parents in providing them with the tools to be aware of when they were being exposed to trauma, the language and concepts to describe the impact on their bodies and reactions, and accessible options for returning to a regulated state of being.

"I realized that what I was experiencing was a grief response and I needed to ride it through. My body was shaking. I was doing the BETR<sup>7</sup> steps." - Parent

As a result of living in a state of protracted uncertainty and unpredictability, parents caring for a child dependent on substances are commonly plagued with fear, self-doubt, and grief (Edwards, 2017; Frye et al., 2008). The TRT was a validating experience, verifying reactions and responses that they had previously questioned and regretted.

<sup>&</sup>lt;sup>6</sup> A description of the Triphasic Model can be found in the glossary.

<sup>&</sup>lt;sup>7</sup> The BETR Model is a TRT concept that provides an understanding of the impact of trauma on the body, emotions, thoughts, and relationships.

"Your response is not a problem. Period. It's a natural response when someone you love is suffering." – Dr. Black

For a community of people living with the daily pressures and societal stigma of having a child who is a chronic substance user during an opioid poisoning epidemic, Dr. Black's thoughtful and compassionate responses were relevant, de-pathologizing, and as one parent described, "normalizing". The TRT experience inspired fresh perspective and self-awareness, where parents could reinterpret the meaning and significance of their decisions and prioritize their own health to participate in the learning.

"Once we learn and understand the waves of dealing with trauma, we recognize it in ourselves. That allows us time to let go a bit or leave that spot of being frozen in trauma and then be more present for our children. It helps us directly be present for our kids when they're in crisis. That's my goal." - Parent

# b. Understanding of Themselves as a Parent

"I find I'm not just thinking about myself. I'm also thinking about how my child is experiencing it." - Parent

Although parents had distinctly requested trauma support for themselves, there was no doubt that they were also benefitting from the information to better understand their child. Parenting a substance dependent child includes witnessing their child in an onslaught of seemingly destructive decisions that keep them trapped in the cycle of addiction. The parent-child relationship becomes hijacked by attempts to reclaim power and control over the child's behaviour. As their dependency grows, it is excruciating for families to watch as their child pulls back from activities that once brought them joy. Attempts to connect and communicate

with their young person are either disregarded or treated with animosity (Manning, n.d.). This disconnection is "crazy-making" for parents who feel helpless and powerless to alleviate their child's suffering.

Parents sought understanding and often asked questions that could help them better understand their child's feelings and behaviours under the influence of substances:

Parent: How does this happen with kids who use drugs?

Dr. Black: Drugs work to not feel that stuff.

Parent: If someone's using opioids, would it be different?

Dr. Black: Opioids tamp down emotion.

Sometimes feeling trapped within a destructive push-pull relationship with their child, a greater understanding of the limbic system introduced elements that invited the potential of new meanings behind their child's behaviour. The neuroscientific elements in the TRT provided concrete, physiological explanations for their child's behaviour enabling parents to reframe their own experience, and increase compassion for their child's experiences:

"I can see where my daughter acted as she did. It softened it for me. I know that wasn't my daughter." - Parent

"I have more peace around the word trauma and what my son is going through." – Parent Some parents differentiated their experiences as "themselves" from their identification as "parents." In one example, a parent contrasted her own mental health with that of her daughters' who entered a period of recovery: "My daughter is out of it [addiction] and I'm doing the worst I've ever done." She had expected that her well-being would improve in the wake of her daughter's recovery. During the second TRT session, this parent had what she

called an "aha moment", realising the backlog of thoughts and emotions she had been unable to access while stuck in her limbic system's hypervigilant cycle while her daughter was using. It was deflating for her to realize that her daughter's recovery had not meant complete relief. As opioid poisonings increase, it is understandable that these parents become emotionally and cognitively consumed by the day-to-day fluctuations connected to their child's addiction and recovery. However, they are having their own experience that may not resolve in tandem with their child. The TRT section on *transforming trauma into memory* was extremely helpful in assisting this parent in prioritizing her own healing and connecting with "hope" for resolution.

"... [I have] Hopeful thinking that what's traumatic will eventually become a memory. That gives me a lot of hope, especially if the crisis and trauma ends at some point that things could become a memory – things won't always be so scary and painful." - Parent

#### Theme #2: "Container for Trauma"

### **Subthemes:**

- a. "Relief"
- b. "Control"

#### "Container for Trauma"

"Provided a container for trauma unlike what I had before." - Parent

"However, it requires a leap of faith that inviting people to step out of a crisis to reflect rather than simply react will be beneficial in the long run." (Madsen & Gillespie, 2014)

The TRT sessions were designed and facilitated with great forethought and intention, prioritizing safety and a sense of belonging in the learning space. In the context of the TRT, I consider a "container" one result of "Structuring Safety" (2014) a practice developed by Cathy

Richardson/Kianewequao and Vikki Reynolds who worked therapeutically alongside Indigenous survivors of residential schools. Knowing that most of the parents identified themselves as having been traumatized, ways to develop and maintain safety was of the highest priority.

There were many factors that contributed to the creation and ongoing negotiation of a container in the TRT sessions. Within the scope of this report, I have identified three factors that contributed to a trauma-informed, contained space:

1. Co-creation of clear and realistic intentions for the sessions: The parents collaborated with Dr. Black on session dates, times, purpose, and guidelines for the sessions which included a strict coherence to sessions having an educational foundation rather than being "group therapy". In accordance with educational objectives of the TRT, both the families and Dr. Black agreed that sharing personal stories would not be wise or necessary. All but one of the parents were regular attendees at the parent support group and therefore were well acquainted with one another's stories. To compliment the agreed-upon educational focus, Dr. Black was adamant that the goals of the sessions be realistic and reflect the expressed needs of the families. He was cognizant not to "overpromise" and verbalized his intentions in a way that took into account the reality of the parent's circumstances. His commitment was modest and clear: "Trauma is pure chaos – this will put some structure on pure chaos." 2. Recognition of parent's capacity and unique circumstances: Dr. Black introduced the first session with transparency and conveyed his confidence in the TRT tools: "I use these tools to prevent myself from going down. Keep myself healthy." Although a parent himself, he differentiated his experience from theirs: "It's [trauma] not happening all the time in my

house. Context is different, but mechanism is the same." He consistently validated the

parent's struggles including their unimaginable challenge to find ample support: "There is more emphasis on the people hurt than those caring for those that are hurt." Dr. Black also recognized that the demand on these families could not be overstated referencing their choice to participate in the TRT whilst their children's lives were regularly at stake. "We're under constant threat all the time". Aware of the pressure on the parents, Dr. Black persisted in prioritizing the family's input and direction from the planning stage to the delivery of the TRT. He consistently opened space for families throughout sessions to share their thoughts on the TRT material and their perspective of its' suitability to the context of their lives.

"When it's your family it's not the same. You love them. You care for them. If it's affecting you, that's not a pathology. That's what we're designed to do when we love people." – Dr. Black

3. Community: As mentioned, all but one of the parents had been members of Foundry's Parent Peer Support group. Hence, they participated in the TRT amongst their peers, and had some inkling of one another's personal circumstances. The unifying factor was that they all had intimate experience caring for a substance dependent child. These parents typically exist under the immense weight of stigma, both societally and self-imposed. Peers lift one another from the confines of isolation by relating to each another's journeys and in the midst of suffering, they return to one another to be reminded that they were not alone in their experience:

"The power of feeling taken care of and feeling believed, and that it's possible to survive just about anything, as long as you have the people who are important to you are on your

side. And that synchronicity between us and other people is much at the core of resistance through trauma." Bessel van der Kolk (Tippett, 2021, 30:24)

One parent suggested that future discussion focus on the relationship between belonging to a community and learning integration:

"Further conversation about how good community (like we have in the group) engenders an environment where we feel safe and understood which I suspect allows us to go further into dealing with the trauma using all the tools and techniques Tim has presented us with." – Parent

The thoughtful, shared development of a "container" would generate what one parent called, "... a little bit of control, in an out-of-control situation." The following two subthemes were products of having collaboratively created this contained space to listen, experience, and learn together. The first represents a feeling that was commonly expressed as "Relief", and the second, "Control", will describe where shifts occurred in the parent's narratives.

# a. "Relief"

"4 hours of stories will be challenging." - Parent

"Relief" for the parents meant not going through the TRT experience having to relive their stories of trauma. Parents wanted the freedom to put the emotionally charged memories and fears aside to focus on learning and discover ways out of what they felt powerless within.

"We got very clear information from them, which I was super happy with, which is 'No, we don't need another support group. No, we don't need to get into our stories. Just give us the information and allow us to be here.' ... I almost felt like it was a break [for them] to just learn." Dr. Black

The containment was impactful, enabling the parents with a sense of relief to settle into the training and be emotionally and cognitively present to engage with teachings and broaden their skillset. Exposure to the TRT's accessible tools and self-nurturing practices introduced ways they could approach highly stressful situations differently.

Dr. Black: What will you take from this experience?

Parent: Relief. I have more tools.

Parent: The Rhodo Breaks<sup>8</sup>.

Parent: It's OK to have a nap every two hours because I'm overwhelmed.

At the close of the first session one parent stated that they would like to leave behind "Any illusion [that] I can fix my situation. I can only cope with my reactions." Having given themselves the permission to take time away from caring for their children, settle into the session, and absorb the material, parents were gaining a nuanced understanding of where they had opportunity for control within the complexity of their situations.

#### b. "Control"

"I'm giving her 100% control and in the meantime, I'm losing myself." - Parent "I cannot fix him, his addiction. I am trying. I will continue to try. What I do doesn't make a difference. What I can do is fix how I live with it." – Parent

By fully engaging with new learning on the physiology of trauma and awareness of its impact on the body and on their child, and having received validation alongside the learning, the parent's ideas of where they had control in their lives were transformed. They began to

<sup>8</sup> Rhodo Breaks were mindfulness prompts intentionally situated throughout the slides in the first TRT session that invited participants to reflect on how they were feeling, and practice bringing an image of beauty into the moment.

describe the locus of control within themselves and investigated their experiences with curiosity, identifying alternate choices. Hence, as Dr. Black had stipulated, the TRT would not take away their suffering, rather, it may provide them with the awareness to differentiate between "productive" or helpful suffering and "unproductive" suffering where their "lizard brains" dominated. The TRT provided options that could help address trauma as it arose without the weight of the pathologizing narrative that often accompanied their experiences and responses.

"Learning to take control and not allow your body to go there when it doesn't have to be.

You can't afford to live there all the time – and you can't be there for others." – Parent

Parents who participated in the working group sessions reflected on the uniqueness of
their situations in the realm of parenting and their shift in awareness as "empowering",
recognizing areas in their lives where they had control.

"Strengthening this ability to self-regulate - not allowing hypervigilance when it's not warranted. To anyone else who doesn't deal with this, it is warranted but once you are fully in this, you can't allow yourself to be operating from that limbic brain place all the time. Like Tim said, it can take three minutes to get there but days to come down." —

Privacy in Healthcare for Youth in BC and the Impact on Families Supporting Them

It is not uncommon for parents caring for a substance dependent child to feel completely removed from their child's health. At present, a doctor in British Columbia can treat a young person without their parent's consent or knowledge of treatment at any age as long as they consider the child "capable" to consent to their own healthcare

choices (Infant Act, 1996). Although these laws are intended to protect child rights and freedoms, they are also potentially problematic for parents who want to care for their children in the day-to-day tumult of substance dependency.

"I have found that sometimes things are set up so that you can't be an effective ally of a parents. Really, we are critical allies in this. For all the reasons we need to be aware of confidentiality, it's the starting assumption about the parents and their role. If you're not seeing them as an ally, you are going to alienate the parents and it's a loss for everyone." – Parent

There is no argument that families perform the bulk of care for their children and play a critical part in recovery outcomes (Cheng et al., 2020). Cleverley et al. (2018) looked at youth perceptions of parental influence on their motivation to seek treatment for problematic substance use. They found that parents often step in to overcome structural and pragmatic barriers to their child's accessing treatment such as inconvenient appointment times, lack of transportation, and care after hospital release. As well, the value of a parent's "gut feeling" and unscientific knowledge about their child's behaviour is also widely unrecognized (Soklaridis et al., 2019). These studies acknowledging parents' contributions to their child's health concluded that limited research has focused on the subjective views or needs of caregivers for youth with complex mental health and substance use concerns. For a population that has been dismissed, misunderstood, and stigmatized for being the parent of a child dependent on substances, lifting the weight of pathology and introducing areas where they have control are incredibly important factors in validating their worth and sustaining their resiliency.

The TRT experience, with Dr. Black as facilitator, clearly provided parents with significant skills, affirmation, and relief. One parent referred to the experience as feeling "like a break" and another called the program "highly relevant". The awareness of their experiences of trauma and their power to address trauma shifted in meaning which translated to more compassion for themselves and for their child. There was a tremendous amount of learning that took place, much that could continue to be discussed if the TRT is to be formally adopted as a training for families at Foundry Victoria.

If the TRT is to be formalized and repeated for other parents who are caring for a child dependent on substances, there is immense value in including the materials described in these two themes. And, during TRT sessions, key points reoccurred that revealed areas of question and distinctiveness within the parent's circumstances that require thoughtful consideration:

How does the TRT model apply when traumatic episodes are associated with someone you love?

What if the traumatizing incidents have happened in succession and are ongoing, making completing or "finishing" a trauma response seem impossible? And how can we, as service providers invest in parents as vital caregivers for their children and recognise that their journey of struggle and healing is a unique experience and not always in tandem with their child's? The next theme will expand on these areas of discussion.

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What Was Missing or Needed to be Expanded From the TRT?

Theme #3: "If it Wasn't for Love"

Subthemes:

a. "The Collision"

b. "The Ongoing Journey"

c. "Family is Essential"

"If it Wasn't for Love"

"I also believe that the situation and emotions become more complex when it is your

There are areas of overlap in the roles that parents and First Responders play, especially

child." - Parent

those working in small and rural communities that are relationally connected to their patients (Stanley et al., 2015). However, the realities of caring for a child dependent on substances differ in many ways such as the compounding elements of emotional connection between parent and child, and the accompanying emotional impact. As well, the duration of a parent's journey in caring for their child is ongoing and indeterminate, and in the case of substance dependency,

marked with repeated exposures to stress and trauma along the way.

"It's someone you love and someone you care about. Somebody you're worried about. So that was very unique in terms of working with this group". Dr. Black

In addition, a contention in healthcare relevant to these parents and their children is the age limit on many support systems and the unknowns connected to the duration and severity of their child's problematic substance use. Substance dependency is anything but linear and predictable, and in the case of chronic use such as with the children of the parents in this

project, supporting their loved one is commonly referred to as a "marathon, not a sprint".

When young people "age out" of a support system, their maximum hospital stay is reached, or when healthcare staff leave their positions, parents and caregivers are frequently the only genuine constants in their child's life, stepping up to care for their child despite lacking medical knowledge or training. As one parent referred to themselves: "We don't age out". In the absence of adequate support from youth-serving healthcare providers, parents are obligated to fulfill responsibilities that are often well beyond their scope and capacity. As one parent described her experience, "The system focuses on being finished and this doesn't finish. At least it doesn't feel like it finishes. There is no finishing date with the process. It's almost like when the crisis is at bay, all the other stuff creeps in and you don't have the supports."

#### a. "The Collision"

How caregivers respond to their child's needs is at the intersection of brain components
that are often at odds in the parenting context: the Mammalian and the Reptilian
components.

"For us to have to revive our child like a First Responder, it's so different from a professional First Responder who doesn't love the victim deeply. It's a whole other level of experiencing the trauma and why we wanted to do this [the TRT]. We're the First Responder. We're responding first and then calling 911." - Parent

The TRT's explanation of the physiological systems that drive behaviour was a key component and source of validation for the parents. Dr. Black explained that repeated exposures to highly stressful situations associated with someone they love was progressively wiring their brains to respond with hypervigilance, self-doubt, and chronic worry. However,

what never sat well with the families was how Dr. Black described a harsh limitation of the Reptilian (or "lizard") brain: "The lizard brain doesn't care about your kids". This description inspired contention from the parents which continued to grow as the sessions progressed. Why, the parents wondered, would they feel so compelled to protect their children if their lizard brain did not?

Parent: Can the lizard brain get triggered if we are seeing another in pain?

Dr. Black: We are a social species. When we are connected to someone else, our identity is linked to another. That person is a part of you. When something happens to that person, we feel it - the lizard brain starts to fire. Hearing about someone you love [being in danger] is still a traumatic event.

It was in response to this parent's question during the third TRT session that Dr. Black expanded the explanation of the brain's neurological mechanisms to introduce the mammalian area of the brain, the "bonding area, where we feel concern for one another". He spoke of the mammalian brain as a neurological force that would drive them to care for their child even if that meant putting their own well-being at risk, representing another contrasting element with professional First Responders.

"The distance is a buffer for professionals. When you're the First Responder and a family member, you have no buffer. It's not a case. It's your child. It's not the same as First Responders because of that attachment and mammalian brain piece. First Responders don't have that. If they do, that's what will traumatize them even more." – Dr. Black Neff (2021), a psychotherapist and prolific researcher on the subject of self-compassion, refers to the Reptilian brain reflexes as our "threat-defense response" (Ch. 3, 21:50), a natural

reaction to perceived danger. She explains how mammals have an evolutionary advantage over reptiles since they are born with complex neurology that allows for the extraordinary plasticity of the human brain. However, as mammals our offspring are born immature, with protracted growth periods during which sophisticated neurological wiring occurs, lasting up to 30 years. As a result, the bonding reaction, dubbed "the tend and befriend response" (Ch. 3, 24:14) by Neff, evolved to motivate parents and their offspring to establish safety during this lengthy developing phase. In fact, when a parent's care for their child is stimulated, the brain's hormonal system conspires to produce natural endorphins, or "feel-good opiates," which boost feelings of safety. Understandably, managing these two relatively sophisticated and instinctual regions of the brain, both vying for safety, would be extremely difficult and exhausting.

The competing reptilian and mammalian drives came to represent the parent's inner turmoil, coined by one parent as "The Collision". In practical terms, their child's safety took priority, even if their effort to keep their child safe seemed hopeless and was of great cost to their own well-being. The identification of these duelling brain components established a framework through which they could understand and identify a source of struggle and verbalize the emotional cost of sacrifice.

"We assume that the reptilian brain always wins, but what about the parents who sacrifice their own lives for their child's life? It's that collision that creates such chaos, grief, and pain as we realize that there is so little that we can do to save them." -

Also relevant to The Collision, one parent described the ways they experienced guilt being caregivers "with high-risk kids"<sup>9</sup>. As their children continue to engage in dangerous behaviours, parents naturally doubt their own decisions, harbour guilt for choices they have made, and ruminate over the "right" thing to do to help their child<sup>10</sup>. When this discussion arose, Dr. Black urged the parents to consider the limitations of their limbic brains: "You are probably going to feel bad about yourself, but you are fighting your lizard brain. Please don't do that to yourself."

Neff (2021) speaks to the potential of directing the natural caring instinct of the mammalian brain inward, learning to "tend and befriend" the self to nurture an internal sense of security and counteract the debilitating effects of self-judgement and doubt.

### b. "The Ongoing Journey"

- The experience of caring for a substance dependent child is fluid and everchanging; the
  associated cycle of trauma, guilt, and grief is ongoing and unique to parenting a
  substance dependent child.
- The context of addiction and associated trauma in caring for a substance dependent child means the TRT's concept of "finishing" was insufficient and needed expansion to accurately reflect the lives of these families.

"We're under constant threat all the time." – Parent.

The second theme the "Ongoing Journey" represented the continuous and unpredictable qualities specific to the parent's caregiving experience that made the TRT's concept of

<sup>&</sup>lt;sup>9</sup> "High Risk" corresponds to a score of 25 or higher on the Kessler Psychological Distress Scale (K10). K10 is completed by youth completing an intake when accessing Foundry's services for the first time.

<sup>&</sup>lt;sup>10</sup> The "right" thing to do or choice to make was a significant source of anxiety for parents caring for a child dependent on substances and a frequent topic of discussion with families in my role as Family Support Worker.

completing or "finishing" a trauma response ill-fitting to the family's context. As Dr. Black described, "The first rule of [trauma] treatment is that you're out of the water." Dr. Black's metaphor reflected the Triphasic Model (Zaleski et al., 2016) of trauma treatment, which prescribes that for safety to begin to be established, the traumatic episode must be in the past. For the parents who participated in this project, their child's continuous substance dependency suggested that traumatic experiences were likely to persist. In fact, in the current atrocity of poisonings, at ever-increasing risk of trauma are those young people whose substance use includes opioids and the ripple effect on those that love them.

"The process is fluid because sometimes recovery includes relapse. [You have] the idea that you're fine but the next overdose messes with your mind because it might feel worse or not as bad and then you're questioning yourself. Maybe you just start to get used to the process. I don't know." – Parent

As well, the fact that the past traumatising incidents experienced by these parents were numerous made the idea of finishing a single trauma response or transforming a past trauma into a distant, less harmful memory seem impossible.

"I'm not sure which of the 25 events is getting triggered. How does one start unpacking years of trauma?" - Parent

Conti, author of the book *Trauma: The Invisible Epidemic* (2021) suggests that multiple, successive exposures to highly stressful or traumatic events significantly reduces the body's ability to cope. Throughout the TRT, Dr. Black acknowledged in many ways that *"recovering from trauma is exhausting."* The pressure experienced by parents caring for a substance dependent child is reported in the academic literature as one of the most complex and

disruptive to a parent's emotional and physical well-being (Frye et al., 2008). With no linear path for coping or recovery, parents forge their own journey amidst the ambiguity of their circumstances to support their child, themselves, and the rest of their family, typically through cycles of trial and error. A common theme in these studies is the message that adequate support for parents to manage throughout the journey of caring for their child is necessary for better outcomes for all (Denomme & Benhanoh, 2017; McCann et al., 2017; McCann et al., 2019). However, what constitutes adequate support for families who have been subjected to multiple and ongoing exposures to trauma as a result of caring for their child is not a one-sized fits all and will be specific to the context of the particular young person and their family.

### **Grief and The Value of Peer Support**

The value of the relationships within the Parent Support Group at Foundry Victoria to address the impact of ongoing trauma cannot be overstated. As a Family Support Worker, I have seen countless expressions of unconditional love, understanding, and validation amongst the members of that group. These gestures of empathy and generosity are particularly impactful for families who in their Ongoing Journey find themselves in a perpetual state of loss, which one parent described as being "frozen in grief". The Group members hold space for one another to speak openly about the feelings and thoughts associated with the losses both they and their children experience throughout their journeys.

"My kid didn't get the milestones and I didn't get them for myself." – Parent

A prominent component of the TRT, titled Emotions as Information, introduced the connection between trauma and grief. Dr. Black described grief as an accessory to trauma:

"Trauma always takes – grief is the response of losing something that matters. Trauma takes

things that matter." Within the many statements made by the parents that conveyed the depth and profundity of their grief, it became evident that alongside the shame, disappointment, and frustration they experienced, grief was the constant companion throughout their ongoing journeys:

"In the first season of crisis with your kid whose using opioids, there's a lot of things in there to grieve and a lot of shame. It's very mucky in the first couple years. Then some of us have adjusted to a new normal – now I can't be ashamed anymore and you stay away from the those that shame you. You don't put yourself out there. You have adjusted. I haven't gone out for dinner in 5 years. This is just my life now. It's just sad." - Parent

This parent articulately depicts the continuous sequence of sacrifice, loss, and striving to adapt that are part and parcel of caring for a child using opioids. Another parent expresses the ambiguity of grieving for a loved one who is still alive, as well as the loss of a relationship ruptured by substance dependency:

"It's now coming to terms with the grief of what I had hoped for my daughter. The grief of the change in my relationship with my daughter, the grief day in, day out with the person still alive, for someone we are still primary caregivers for. If I could understand what I can and cannot control it would have made a huge difference." — Parent

#### **Ambiguous Loss and Grief**

According to Boss (2006) who developed the theory of *Ambiguous Loss*, grief is traditionally considered a pathology that we in the helping profession are trained to fix, heal, and eradicate. When trauma and grief are ongoing, the notion that there is a "fix" or a way to eradicate suffering is limiting and dismisses the complexity and cumulative impact of what the

families experience in caring for their child. Boss identifies Ambiguous Loss as the most stressful type of loss that one can experience because there is no access to closure or resolution. The theory of Ambiguous Loss is based on the idea that the ongoing uncertainty and the lack of control or information regarding the status of a loved one is traumatizing. In the case of the parents caring for a child who is substance dependent, their child's lifestyle is typically erratic and access to knowledge about their state of being is unclear or completely inaccessible.

"I feel like we were always on red alert. Kind of on standby." - Parent

Their child may be physically alive but psychologically and emotionally absent or at times,

unrecognizable. Adding to the ambiguity is the reality of a poisoned drug supply making the life

of a substance dependent child perpetually at risk.

Boss (2006) explains that the cost of living with constant ambiguity inherent to one's circumstances thwarts their ability to process grief and blocks higher level cognitive functioning which negatively impacts innate coping and decision-making capacities. Boss suggests a number of ways caregivers can survive Ambiguous Loss including identifying living with the ambiguity as the culprit and normalizing the anger, guilt, and sadness associated with living in ambiguity, rather than locating the deficiency within themselves. She also suggests that caregivers reconnect with some sense of mastery, to learn where they have control. Caregivers can also embrace the philosophy of "both/and thinking", which entails learning to accept the uncertainty that is inherent in their circumstances (i.e., sometimes their child is psychologically present, and other times, not). Above all, she suggests that those experiencing Ambiguous Loss develop relationships with others who can intimately relate to their situation, and others who cannot so that there is some space in their life, however small, not associated with the pain.

Once people can adapt to living in ambiguity by applying these coping strategies, Boss believes that they can process or transform (rather than "finish" or "fix") the feeling of being "frozen in grief".

"If that's where you can get to, that's what humans are amazing at – adapting, to getting relief. Physiologically, our body is always there – the things that always bring your body comfort can do so even in the worst of times." - Dr. Black

"You slowly start to rebuild some things – pieces of joy again. Try to find some moments of beauty. You have to make decisions from where you are now." - Parent

Between Covid-19 and a poisoned drug supply, the level of ambiguity has skyrocketed on a global level. In the context of parents caring for an addicted child, families are perpetually confronted with life-threatening issues related to their young person, with little to no control. Dr. Black was transparent with the families, ensuring there was no false hope of the TRT eliminating their suffering: "It's not a tool to take away your pain. It's to get into a place that's more tolerable." Judging from the families' responses after sessions, Dr. Black delivered on this promise. And, although the concept of "finishing" a trauma response offered some relief to the families, the mechanism may need to be broadened or reimagined with parental input, given that the parents' journeys are ongoing.

#### c. "Family is Essential"

• Family involvement in the care of substance dependent children improves treatment and recovery outcomes (Hogue et al., 2021).

- Unlike professional First Responders, parents exposed to repeated traumas associated with caring for their child are not provided with adequate training or supports that could bolster their competencies and sustain their resiliencies.
- Throughout the TRT experience, the significance of whole family impact and recovery became apparent, illuminating the unique recovery process for parents which is not always aligned with that of their child's.

"We are the first First Responders." - Parent

Parent

I have heard this statement uttered many times by parents seeking help for their child in my role as Family Support Worker at Foundry Victoria. It is one of the reasons I felt compelled to pursue this project, springing into action when a parent asked for "help dealing with the trauma". I am regularly witness to the immense pressure families experience by taking on a life-saving role for their children, with little guidance or shocked by what the role entails.

Compounded by the general public's lack of education and judgement around chronic substance use, the shame associated with having an "addicted" child is isolating and debilitating for the whole family. The genuine shame would be to dismiss the family's crucial contributions to their child's survival, or to disregard the fact that, despite their inherent abundance of capability, they too need acknowledgement, support, and inclusion.

"I have found that sometimes things are set up so that you can't be an effective ally as parents. Really, we are critical allies in this. For all the reasons we need to be aware of confidentiality, it's the starting assumption about the parents and their role, if you're not seeing them as an ally, you are going to alienate the parents and it's a loss for everyone." -

The surge in opioid poisonings in Canada compounded by contact restrictions associated with Covid-19 has necessitated an expansion of those taking on crucial life-saving roles. Public Health Ontario (2020) released a report showing that during the pandemic, naloxone was more commonly administered by a bystander than a professional First Responder. Supportive programming that recognizes the impact of trauma and bolsters the resiliency of professional First Responders (the TRT) is considered an essential intervention in treating repeated exposures to trauma. Although families caring for a substance dependent child experience comparable impacts of trauma, supportive programming tailored to their context is minimal.

"You don't fit anywhere." - Parent

There are efforts in healthcare to define ways where parents "fit" into the sphere of their child's care. However, if we expect parents to be effective caregivers for their children throughout the complexity and tumult of chronic substance use, we in healthcare need to critically reconsider what we mean by Family Centred Care. After their child overdoses, parents recount the isolation, feelings of ill preparedness, and lack of social support when their child is released from hospital and returns home to their care (Edwards, 2017). In the absence of adequate support from healthcare providers treating their children, families are obligated to fulfill responsibilities that are often well beyond their scope and capacity: "We need to stop expecting parents to double as psychologists and therapists and stop treating their homes as unfunded rehabs." (Anonymous, 2020, para. 14). There are alternatives to leaving families to fill in gaps in healthcare that require our consideration and exploration.

There is no argument that families perform the bulk of care for their children (Cheng et al., 2019). In fact, there is a positive correlation between a young person's health and well-being,

and meaningful involvement and engagement with their families (Coates, 2016; Stefanski et al., 2016). In the context of substance use, family involvement is proven to improve treatment and recovery outcomes among their children (Hogue et al., 2021). However, as has been extensively discussed, caring for a substance dependent child comes with a cost to the caregiver's well-being. The multiple layers of stigma, the extraordinary expectations placed on parents, (Soklaridis et al., 2019), and the everyday reality of attending to and caring for their child can culminate in "a never-ending cycle of trauma" (Ethridge, 2017, para. 22). My intention is not to minimise the emotional toll that First Responders face as a result of their jobs. Increased risk of PTSD is also identified in studies of First Responders working in small communities where they typically forge closer relationships with their patients (Brooks et al., 2016). As primary caregiver for a substance dependent child, the unfortunate cost of the emotional attachment to their young person is an increased risk of PTSD.

Within both the academic literature and online publications that spoke to the experiences of parents caring for a substance dependent child, the need for adequate support services addressing the trauma-specific complexities of this extraordinary subset of parents is clear. The few studies that feature the experiences of parents caring for a substance dependent child recommend that adequate treatment and social support is made available for parents in order to help sustain their essential caregiving duties (McCann et al., 2019). Bentley et al. (2013) showed that 69% of professional First Responders developed a range of PTSD symptoms and suicidal ideation without adequate time to recover between traumatic events. To recover from exposure to trauma, self-care practices such as getting adequate sleep, exercise and taking adequate breaks are recommended by resiliency programs designed for them (Quevillon et al.,

2016). In contrast, as primary caregivers for their child, parents are not allotted sick days or paid vacation time nor are respite services available that could allow time away from the home for recuperation after a traumatic episode. What adequate support looks like for families will vary based on many factors including culture and socioeconomic situation, severity, and longevity of their child's dependency, and whether there has been exposure to trauma associated with caring for their child. Regardless, the fact remains that gaps in healthcare mean families are a critical resource for their child's health and what they need to sustain themselves requires specific attention.

"According to the system, we're not the patients. Our kids are the patients so when their crisis is over then support stops." - Parent

# **Supporting Life in Recovery**

"Life after addiction isn't just possible, it's the norm". (Mann, 2022)

According to results from the Life in Recovery (LIR) (McQuaid et al., 2017) studies conducted in Canada and internationally, the possibility for recovery from substance dependency is extremely promising. The LIR study of 43,026 adults (18+) in the United States showed that 75% of people who identified themselves as having had a substance use problem were in recovery. Similar results were found in LIR studies in Australia (Best, 2015) and the United Kingdom (Best et al., 2015). These findings suggest that recovery is attainable even for substance users who are characterized as chronic and severe. As well, people who have transitioned from active use to recovery reported increases in life satisfaction including meaningful connections with family and community. The results of these surveys are a beacon

of hope for families who care for substance dependent young people and for frontline service providers and policymakers who are developing what defines "care" for this demographic.

"Once our supports in the system do stop, we need the education and the tools to support our own recovery." - Parent

This third subtheme, "Family is Essential" represents an unspoken assumption in healthcare that in my experience, requires illuminating. Namely, that parents who care for substance dependent children are expected to exist within a confounding ambiguity perpetuated by inconsistencies that we in healthcare must take some accountability for. It is critical that we consider ways to meaningfully engage parents in their child's care and provide adequate relief for them along the way, if we also ask that they remain a constant in their child's lives, catching their child as they move in and out of services, sit on waitlists, and "age out" of programming. Essentially, parents do not "age out" when their child's life is at stake. They do, however, *burn out*, and according to these parents, their own path of healing has often been incongruent with their child's.

Hence, as healthcare providers, if we see Family Centred Care as a practice that includes parents as essential contributors to their child's health, it is critical that we consider the elements that will sufficiently support our expectations of these parents. In the last five years, studies have shown that the majority of people dependent on substances recover, but the process can be slow after multiple relapses (Best et al., 2015). How can we in healthcare support parents to help their children hold on with enough chances to survive?

### Summary of Learning: "Connecting the Dots"

"It's erroneous to have a conclusion when this journey doesn't end." - Parent

This project began by recognizing a need: a gap in trauma-specific services for families who care for some of the most vulnerable children in Victoria, BC in a time being described as "the deadliest year for illicit-drug overdoses" (Radio-Canada.ca, 2021). As the parent's quote signifies, even as this report is finalized, each of the Parent Collaborators in this project will continue in their unique, ongoing journey to support their child struggling with substance dependency. In order to keep the discussion going, we have included a quick summary of our learning throughout the TRT, as well as a list of invitations that we hope will spark careful contemplation "on many levels".

"As you gather your thoughts, [consider that] this is from the 'subject matter experts'.

This made sense to them. I am not represented in the system so I'm thankful if the system themselves is making space for this document." - Parent

### **Brief Summary of Learning**

"Will they ever learn something that will protect them from all the suffering? Not a chance. Because it's a logical impossibility. When you love somebody, and they are suffering, and you cannot fix that suffering, you will suffer. To me, that's a truism. You can intellectually feel bad for people you don't know. But for your own children whom you love, if you feel responsible for their care and well-being, if you set the bar at, 'Are these people ever not going to suffer?' How? How, in what world, would it ever be the case if you're a regular human being?" – Dr. Black

The Trauma Resiliency Training designed for professional First Responders held resounding, immediate value and meaning for parents who collaborated in this project:

- The TRT teachings enriched the parents' understanding of trauma. This inspired a shift
  in the perspective of their own experience and their child's experience of trauma.
- Having begun the TRT feeling "ashamed", "isolated", and "frozen in trauma", following
  the sessions, parents reported feeling "seen", "validated", "normalized", and
  "legitimized".
- Many aspects contributed to a foundation of safety enabling parents to prioritize their own learning in the TRT: the learning took place amongst peers, the facilitator operated in a trauma-informed fashion, (i.e., focus was trauma-specific education, using relevant, accessible concepts, and offering tangible tools) and the parents were recognized as experts in their own lives and enlisted to serve as Collaborators throughout the project.

The TRT model, having been geared to professional First Responders, requires some expansion if it is to suit the reality of trauma in the context of intimate family bonds, the accompanying emotional impact, and the ongoing, repetitive exposures to trauma for parents caring for a child who is substance dependent:

- How parents caring for a substance dependent child respond to their child's needs is at the intersection of brain components that may be at odds in the parenting context: the Mammalian and the Reptilian components.
- The caregiving experience is fluid and everchanging; the associated cycle of trauma,
   guilt, and grief is ongoing and unique to parenting a substance dependent child.

Parents and caregivers who care for a substance dependent child play essential roles
 (i.e., vital advocates, counsellors, coaches, legal navigators, case managers) that
 contribute to their child's survival, only one of which is First Responder. The extent to
 which they are essential is not automatically recognized by the various systems that
 support their children.

# "Connecting the Dots"

Treating the individual without family involvement may limit the effectiveness of treatment for two main reasons: it ignores the devastating impact of substance use disorders on the family system leaving family members untreated, and it does not recognize the family as a potential system of support for change.

(Lander et al., 2013, pp. 194-195).

Turning to the families for their direction in compiling concluding thoughts, I asked them, "How do you think this report should end?", and "What do want the reader to take away from this?". Seven of the parents reviewed the final report and graciously provided their thoughts. Among their thoughts included a parent's suggestion for a conclusion that "...connects the dots in terms of the big picture (opioid crisis, system-level impacts of addiction and trauma on caregivers, benefits of the TRT to help prevent burnout and collateral PTSD and keep parents functioning as partners helping to keep their kids alive)." Another parent thought that this report could have impact on "future funding decisions around programming and supports". With their direction, the following is organized as a series of invitations accompanied by quotes from the Parent Collaborators and Dr. Black. We hope that by asking helping

<sup>&</sup>lt;sup>11</sup> Dr. Black's quotes were drawn from the two one-on-one interviews that I conducted with him.

professionals, policymakers, funders, researchers, and other parents to consider these invitations, we can inspire contemplation and a transformation in how we regard and engage with families who care for young people who are substance dependent.

### An invitation to recognize the family as an essential part of their child's care:

"As a parent of a child using substances, I have been excluded from a lot of important medical conversations and yet I am holding so much of the information to help other experts connect the dots." - Parent

"... creating space for the people [the parents] that created this project is essential. You can end the isolation by making space for them." - Parent

"To not include the family from the beginning is to do a disservice to them and the young person because they are a wealth of information. And to approach them in a trauma-informed way is to uphold and honour that information." - Parent

"Come from a place of 'Hey, how can we work together?' rather than, 'The youth hasn't consented. You're not allowed to know'. Automatically it puts you in a box when you're an essential part of your child's care. If parents are not currently factored into care, there is room there for tweaking." - Parent

An invitation to consider what it means to sustain families in their caregiving roles:

"...traumatic exposure to events of traumatic nature is endemic to the human condition.

All of us are exposed, but not all of us are traumatized. And we have to get away from this language of PTSD, and disorders and psychiatric diagnoses to understand that every person, if you live long enough, will be exposed to a traumatic event. And if they don't understand how their limbic system responds, (and for families like this they're continually

being exposed to traumatic events) and don't have the information about what their brain does with that, what are we doing?" – Dr. Black

"This [project] is about caring for the caregiver." - Parent

"This [research] adds empirical support for a program that helps parents/families to not burn out, to keep going in the marathon of addiction support. I guess it's what harm reduction is all about, trying to keep someone alive in hopes that they reach recovery." -

"....this notion that you're in a lifeboat, and someone's drowning, and you congratulate them for how strong they're treading water. No, you don't do that. ...Pat people on the back, encourage them to keep treading water and tell them how resilient they are.

Because their heads not underwater yet. Help them out of the water and get them out of a situation where they're treading water and then say, 'It's amazing how long you treaded water. I'm so glad you don't have to do that anymore.' Somebody's got to be there to provide something at some level, so that people aren't drowning." — Dr. Black

An invitation to partner with families in research to develop relevant and effective programming that recognizes their expert wisdom and adequately reflects their unique contexts:

"It was a reciprocal learning opportunity." - Parent

"If you ignore what they know, well, you're doing it to them, not with them. And anytime you do something to a community of people, you're bound to get it wrong....But if you do it with the community, they will find the places where it fits. They will find the things that they need." – Dr. Black

"The reader might be left to consider that each parent and each community is unique, so the audience for any future TRT programs must be consulted and have opportunities to actively engage in many different formats (not everyone will be comfortable participating in the same way)." - Parent

An invitation to parents who can relate to the ongoing journey, those sitting on long waitlists while their child is *ready* for treatment, or who have been told that their child is no longer eligible for services based on their age, or that they do not have the right to know the details of their child's medical condition:

"Find your people. You do have people. You do not have to be isolated." - Parent

Next Steps

"This whole project is really Step One." – Dr. Black

I am fortunate to be serving as this project's Research Coordinator while still working as a Family Support Worker at Foundry Victoria. As advised by the Parent Collaborators, a TRT specific to families is being developed at Foundry, designed and facilitated with parents from this project. It has been my immense honour and privilege to work alongside the parents and Dr. Black in bringing this project to fruition. I am deeply grateful to have had the opportunity to share in the delivery of this collective wisdom and hope that it can used to inspire more projects and partnerships of this kind. After reviewing this report, one parent remarked, "I know that changes in the system take time and there is so much work to do." I hope the words of this parent will urge us all to keep moving forward in bringing together our perspectives and agendas to co-create a more robust and inclusive system of care that addresses lethal gaps in healthcare and evolves to nurture families as the vital resource in their child's care.

#### **Appendix 1: Glossary**

**Family:** The definition of "Family" in the context of this project will reflect that developed by Foundry's Provincial Family Peer Support Team. Family, "parent", or "caregiver" is considered to be an important part of a young person's circle of care. Family, whether natural or chosen, holds a significant role in supporting a young person, by creating a sense of belonging and connection through their shared experience.

Family Centred Care (FCC): Historically, and within the context of health, "family" has been viewed through a child-centered lens, meaning the family was considered an obstacle to the child's progress, and often the source of the child's pathology (Garfat, 2004; Allen & Petr, 1998). Families refuted this reputation and generated pressure which prompted a gradual shift towards inclusion in service delivery. A more recent acknowledgement of the family as an interconnected unit expanded its conceptualization and supported the development of FCC. Both the grey and academic literature identified a wide spectrum of attributes associated with FCC (Family Mental Health and Substance Use Task Force, 2015; Chovil, 2019) including: caregiver participation in care decisions, shared responsibility for the child's care, and supports in place for the entire family (Family Mental Health and Substance Use Task Force, 2015; Chovil, 2019; Cleverley et al., 2018). In healthcare settings, FCC has been incorporated into policy (Chovil, 2019) and families are regarded as essential caregivers for young people struggling with various mental health and substance use concerns (Ambikile & Outwater, 2012). However, at present there is a general disagreement of what constitutes FCC in the healthcare literature and consequently, in practice (Institute of Families, 2014). In an analysis examining FCC in acute healthcare settings, the lack of a widely accepted working definition of FCC was associated with

inconsistent implementation in hospitals (Cheng et al., 2019). Although the concept of FCC has been in development for over 30 years, there remains a gap in research and a wide variability in practice and implementation (The Institute of Families, 2014).

Hart's Ladder of Participation (1992): Hart's Ladder is a scale that can be used to assess the participant's level of engagement in a project or initiative. It ranges from the bottom rung "Manipulation", where participants are unaware of the purpose behind activities, to the top rung where participants are the initiators and shared decision-makers. Achieving the top rung on Hart's Ladder requires an adjustment to seeing youth and families as essential co-creators of knowledge (rather than only service recipients) thereby acknowledging their agency and honouring the relevance of their contributions.

**Recovery:** Recovery is subjectively determined. Generally, recovery is enhanced health, function, and quality of life (McQuaid et al., 2017).

**Resilience:** The concept of resilience in the context of the TRT is having the knowledge, skills, and social support to move through adversity. In the words of Dr. Black, "People are resilient when they don't push beyond their Window of Tolerance" (Ogden et al., 2006).

**Substances:** Based on the substances that were in frequent use by the young people whose families collaborated in this project, there are many references made to opioids. However, the substances used by the young people were not confined to opioids.

**Substance Dependence:** While "addicted" or "addict" is commonly used, in an effort to destigmatize substance use, the Collaborators of this project opted to use first-person language. Therefore, the children of the parents in this project are described as "a substance

dependent young person" or "substance addicted child". This term "addict" is limiting as a label for young people whose totality cannot be defined solely by their dependency on substances.

**Traumatic Event:** According to the DSM 5<sup>th</sup> Edition a traumatic event is considered "being exposed to death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence" (APA, 2013).

Trauma-Informed Practice: Trauma-informed practice in the context of this project is based on the teachings within the TRT developed by Dr. Tim Black and Alex Sterling (Black & Sterling, 2020). A trauma-informed practitioner understands how people become traumatized (taking into account the broader psychosocial and cultural influences), comprehends the physiology of trauma, and can integrate and/or teach useful strategies to cope.

Triphasic Model: Developed by Judith Herman in 1992, the intention of the Triphasic Model of trauma treatment is to reconnect the traumatized individual with a sense of power and control and re-establish the link to self and others that was fractured by the trauma. Herman's theory addresses the confounding effect of trauma on the brain's neurobiology and influence on behaviour. She suggests that our neurobiology becomes chaotic when our body's typical defensive responses to danger fail to keep us safe. The traumatized body responds to the chaos by amplifying and protracting the typical defense responses (i.e., fight, flight, freeze, and floppy) even though the threat has passed (Herman, 1992).

#### **Appendix 2: Research Framework**

In designing this research framework, my intention was to comply with the values and ethics that I return to as a practitioner working with youth and families over the past two decades. This framework was chosen to allow for the co-creation of a flexible, relationally sensitive, and collaborative research environment grounded in reflexive practices. Social constructionism provided a solid theoretical foundation and qualitative data analysis was carried out using Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2019).

Concurrently, as the Research Coordinator, I attended to ethical considerations throughout the project in an effort to minimize the potential risks to the wellbeing of participants who had experienced repeated exposures to traumatic incidents associated with caring for their substance dependent child. Reynold's and Richardson's principles of "Structuring Safety" (2014), their suggestions from working alongside Indigenous survivors of colonial genocide, were key to shaping my approach. My responsibility as researcher was to look for ways that this project could interrupt patterns of systematic oppression by centring the parents' experiences, prioritizing their autonomy, whilst trusting in their innate strengths and resiliencies that have sustained them.

The epistemological premise underlying social constructionism is that our understandings and agreement of how to function in society are constructed together through dialogue (Ness & Heimburg, 2020). "Truth" is a subjective phenomenon, and it is through sharing our individual truths that we collectively arrive at a shared language and understanding of how to operate in the world together. Having had prior relationships with the families who collaborated in this project, I knew that an incentive for parents to participate was the promise

that there was a "better" or alternative way for them to live and care for their child that was less depleting or disconnected from joy. Viewing the world from a socially constructed perspective opens to hope and the possibility of social change. For instance, if the way we as a culture construct "truths" about addiction implored us to empathize with substance users and their families, how we prioritised their care could have a tremendous impact on their path to health and well-being. In the words of one parent, "I wonder if we know as a society how hard it is to love an addict. But we don't value addicts. And it starts actually with valuing an addict."

Furthermore, both social constructionism and RTA describe knowledge design as a cumulative and generative "activity" which is facilitated through the participation and contribution of Collaborators (Gergen, 2020); knowledge is collectively constructed through a continual process of debate, negotiation, and eventual consensus. To construct knowledge that was relevant and applicable to the unique complexities of those caring for a substance dependent child in the midst of a global pandemic and ever-increasing opioid poisonings, I saw it as essential to enlist the voices of those who have experienced and navigated these complexities throughout the entirety of this project. One essential voice and invaluable source of expert knowledge was Chantal Brasset, Parent Peer Support Worker at FV; Chantal's awareness of Dr. Black's teachings, and her skilled leadership as facilitator of the Parent Peer Support at FV were a guiding light at each stage of the process.

With the aim to centre the voices of families in addressing this contentious societal phenomenon, the methods employed in this project were chosen to be flexible enough to enable the meaningful incorporation of parents' insight. For example, at the recruitment phase, various participation options were outlined in the letter of invitation. Parents could indicate

their consent to participate solely as participants in TRT sessions or extend their participation by collaborating in a "parent working group" to co-produce a final report and recommendations after the completion of the TRT. In addition, at the conclusion of each TRT session, all participants received an optional "Session Reflection E-survey" to assess the material for "fit" within the parenting context. These methods were designed to centre the voices of families and accommodate their busy and often fluctuating schedules by providing participants with ongoing options for collaboration throughout the entirety of the project.

The development of this project and formulation of results relied on the insight, guidance, and expertise of my supervisory committee: Dr. Jennifer White and Dr. Janet

Newbury, Professors in the Department of Child and Youth Care (CYC) at the University of

Victoria served as Academic Advisors and Amy Schactman, Clinical Coordinator at Foundry

Victoria (FV), served as Community Advisor. Supervisory team meetings took place at key points throughout the project providing invaluable direction and opportunities for reflexive discussion.

#### Methods

The methods employed in this project were informed by the recommendations identified in a scoping review that synthesized recent practices used to engage parents in healthcare research (Shen et al., 2016). Although the review found no clear guidelines within the studies on how to engage with parents as Collaborators, a summary of beneficial practices gleaned from these studies was provided. Invest time to build relationships with parents, address power imbalances, provide clarity and transparency on process, roles, and expectations, and offer monetary recognition for contributions were amongst the review's

recommendations. These suggestions were incorporated throughout participant recruitment, data collection, and analysis, and in anticipating potential outcomes.

# **Participant Recruitment**

The target audience for the TRT sessions included parents that had accessed services for themselves and/or their child at FV and/or were members of the established parent peer-led support group at FV. Parents in this group were all caring for a young person (ranging in age from 12-24) with moderate to severe mental health and/or substance use concerns, which correlated to "Step 3" and "Step 4" in Foundry's Stepped Care Model. As an integrated healthcare service for youth aged 12-24 years and their families, Foundry utilizes a robust, evidence-based Stepped Care Model where the type and intensity of a service is matched to the symptoms and needs of a client.

A cohort of 13 TRT participants were recruited to reflect the average number within Dr. Black's previous TRT programs. Parents were sent an invitation to participate via email which included detailed information about the project including a consent form with options for participation. The invitation also contained a list of potential benefits and risks, clarity regarding expectations and roles, and a description of how their contributions and identities would be anonymized. Measures to protect their confidentiality and privacy were explained (i.e. participants personal information would be automatically locked away in a secure location and given an alphanumeric code) as was their freedom to withdraw at any time throughout the project. I also included a statement of my positioning regarding my dual role as Family Support Worker and Research Coordinator, a rationale for this project from my perspective, and a candid account of my anticipated gains. Parents were compensated in the form of a cash

honoraria (\$25 per hour) as recognition for the investment of their time and effort as participants in the TRT sessions and as Collaborators in the Parent Working Group.

#### **TRT Sessions**

In total, 13 parents participated in the TRT and four sessions were offered. The first session provided the TRT's foundational principles and tools, was four hours in length, and was the only mandatory session. This session took place in-person at the parent's request. Due to covid-19 restrictions on maximum room occupancy at the time, the group of 13 participants was randomly split into two cohorts and the session was facilitated twice (in one of these sessions, one parent participated remotely via Zoom). The three remaining sessions were one and a half hours in length and took place via Zoom, enabling all 13 participants to join at once (in total, ten, nine, and eight parents attended Session 2, 3, and 4 respectively).

The series of four sessions took place during June and July 2021. The intention of each session was clearly stated, "To teach trauma fundamentals, the BETR Model of trauma and the PRO-STEP method including tools for identifying, tracking, and self-assessing the impacts of trauma for parents". Already members of a well-established Parent Peer Support Group at FV, parents participating in the TRT requested that the sessions provide "Education. Not therapy." In alignment with Dr. Black's intentions, the agreement that parents would not be asked to divulge their personal stories became the first collaborative agreement between facilitator and participants.

#### **Data Collection**

As Research Coordinator, I documented the parents' experiences of the TRT material presented by Dr. Black over the four sessions to determine its relevance and value for their

context. My intention was also to learn how to optimize university and community partnerships for the benefit of community service users and providers in the future. I generated and collected four types of data that comprised my dataset:

- 1. Researcher generated field notes taken during TRT sessions: Throughout the TRT sessions I took field notes, recorded my own observations, and accounted for valuable contextual information (Phillippi & Lauderdale, 2017).
- 2. Written responses from electronic TRT session reflection e-surveys: At the end of each TRT session, participants were invited via e-survey to reflect on three questions ("What about the material today fit for you?", "What was not a fit?", and "What was missing?").
- 3. Two semi-structured interviews with Dr. Tim Black, facilitator of the TRT: I interviewed Dr. Black at the mid-point of the TRT sessions and once again to include his insight in the data analysis process after a summary of themes had been completed. In these interviews I explored his experience of facilitating and learning alongside the families. My questions also were aimed at comparing and contrasting the experience of facilitating the sessions with families caring for a substance dependent child and professional First Responders.
- 4. Audio recordings from two Parent Working Group sessions.

### **Data Analysis**

As mentioned, I chose RTA (Braun & Clarke, 2019) as a guide for data analysis. Theme generation was a thoughtful, iterative, and collaborative process. To arrive at a complex explanation of the data and meaning-rich themes that accurately reflected the dynamic nature of the TRT experience necessitated the perspectives of all involved: TRT participants, facilitator,

and researcher (Nowell et al., 2017). Accessing the perspectives of multiple players is also a tool in ensuring a rigorous and accountable interpretation of the data.

Researcher subjectivity is a key aspect of the reflexive approach to thematic analysis and is particularly aligned with my intention to realize my impact on the data analysis and centre the voices of the parents. I began data analysis by considering the factors that affected, underpinned, and contextualised my experience witnessing the families in the TRT sessions. By journal writing throughout the project, I hoped to gain awareness of any biases, assumptions, hopes, and fears that would impact my engagement with the data. Key reflective questions I explored: "Within my awareness, what internal and external factors influence how I encounter and interpret the data?", "What are my hopes for this project's outcomes?", and "What actions can I take throughout this process to ensure that the themes accurately reflect the family's experience with the TRT?". I also relied heavily on my supervisory committee to regularly debrief, reflect, and return to the Guiding Questions to re-centre the process.

To honour the rich complexities existing within the parent's experience of the TRT, the ideal outcome of RTA was not simply to summarize the data; rather the aim of RTA "is to provide a coherent and compelling interpretation of the data, grounded in the data" (Braun et al., 2019, pp. 6). To achieve this outcome, I engaged in multiple readings of the data set, recording my initial thoughts and impressions along the way. Progressively I noticed patterns and areas of convergence across the dataset which became the framework for codes. To arrive at draft themes, the coding framework went through several iterations until the codes were meaning-rich, nuanced, and reflected my dynamic experience as witness of the TRT (Braun & Clarke, 2019).

#### Co-generation and Co-production: Expanding, Refining, and Finalizing Themes

The purpose of these sessions was to work alongside parents as primary authorities in determining the accuracy of the themes from the data collected and create space for their expert leadership in operationalizing the findings. These sessions were audio recorded and took place via Zoom three months after the completion of the TRT sessions. During the three-month period between the TRT and parent working group sessions, I engaged with the dataset using Braun and Clarke's Six-Step RTA (2019) as a guide to arrive at draft themes. Prior to the Parent Working Group meetings, parents were sent the draft themes to consider. During each session, parents shared their perspectives and themes were significantly arranged and enriched, and meanings were challenged and broadened through discussion. As each theme and subtheme was discussed, the family's shared their personal stories connected to the themes, grounding each theme in the context of their lives. These discussions revealed the expanse of complexities that their circumstances require they navigate, significantly greater than I was able to articulate in my interpretation of the data. The parents also made recommendations regarding how to operationalize the data collected and how to meaningfully share the learning materials they found relevant from the TRT sessions with other families encountering similar circumstances.

Dr. Black's perspective was also essential to co-generating relevant themes. He was provided with a summary of the themes for his input and for further refinement. His input was invaluable to voicing the mutual value of developing collaborative partnerships between academic and non-profit communities. Partnerships such as the one modelled in this project enable time for relationship development and a meaningful exchange of expert knowledge that results in shared understandings and the collaborative creation of academic knowledge and

relevant community programming. Section 3 in the report explores these and other outcomes of this project.

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