

'Parents like us. The unofficial survival guide to parenting a young person with a substance use disorder':

Process and outcomes of co-design methods used in the development of a parent handbook

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Background

The Canadian Centre on Substance Use and Addiction (CCSA) and Foundry Central Office partnered with Foundry Victoria to understand caregivers experiences and needs around opioid treatment services and co-design unique resources to improve their experiences.

Caregivers describe being on a never-ending roller-coaster trying to keep their young person safe and alive. Having to navigate multiple siloed systems left them feeling confused, frustrated, helpless, and hopeless.

As caregivers interacted with these systems, they began to build a community of other caregivers with lived/living experience which became a crucial form of support as they provide each other with different resources, ways of navigating the system, and emotional support.

To support others going through this journey, caregivers proposed a the development of *parent handbook* to provide caregivers with helpful information and resources.

Process Evaluation

The co-design meetings acted as a support group, where parents and caregivers could share their experiences and learn about new resources. Parents and caregivers described the experience:

"This is self-care for me, just to be able to put the knowledge that we've accumulated through this journey to good use makes me feel good."

"When we feel helpless for our kids, doing something like this really helps take that feeling away."

"I'm very pleased to be part of something like this, knowing that there's parents on the path that we were on a little while ago – how much it would have meant for me to be given a bit of a head start."

Implementation

The handbook was released on October 12th 2021 and is freely available online at <https://foundrybc.ca/parents-like-us-handbook/>

Hard copies were distributed to services in Victoria that serve parents and caregivers and are available for print-on-demand for external interest.

Co-Design Methods

Twelve parents and caregivers of young people with lived/living experience of substance use met regularly with the project team leads and community champions to co-develop and review the handbook's content, illustrations, and format/design (Figure 1).

The first meeting began with introductions, a review of the terms of reference, and the development of a community agreement. This was followed by a review of similar resources and the original handbook idea to kickstart the brainstorming session. Future meetings were spent prioritizing topic areas, which were developed in smaller breakout rooms with suggestive prompts.

Meetings were audio-recorded to ensure the content was portrayed in the caregivers' voices and the project team took verbatim notes from the live discussions.

Additional research and consultations with content experts took place to incorporate evidence-informed substance use information.

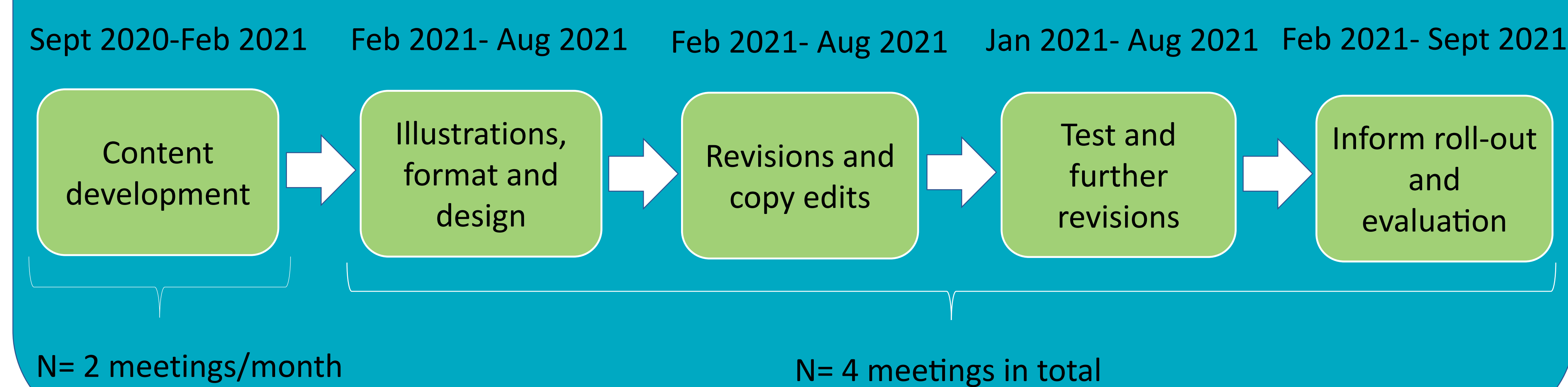
The handbook went through multiple rounds of revisions and was pilot tested with parents/caregivers and service providers in the community before being shared publicly.

The handbook is a collection of shared experiences and stories to help caregivers feel connected to others going through similar experiences. It consists of 8 chapters, in addition to a list of local resources. Chapters include:

- signs of substance use
- the science of addiction
- harm reduction
- overdose/drug poisoning
- navigating the system
- staying connected
- family dynamics
- support for yourself

Figure 1. Co-design meetings

Sept 2020 – Sept 2021



"This is excellent, I wish I had this at the beginning of this terrible road. Especially appreciate that it is written from parental experience."

"This is a really excellent resource. It has changed the way I talk to our students and parents about substance use."

Outcome Evaluation

To support outcome evaluation, viewers of the handbook were asked to complete a pre-download survey, which collected basic demographic information and perceptions of the handbook (n=367; figure 2 and 3). We also asked participants to answer a follow-up survey (n=22; Figure 4). Since the release date, the handbook has had 1,779 views.

Figure 4. Follow-up survey

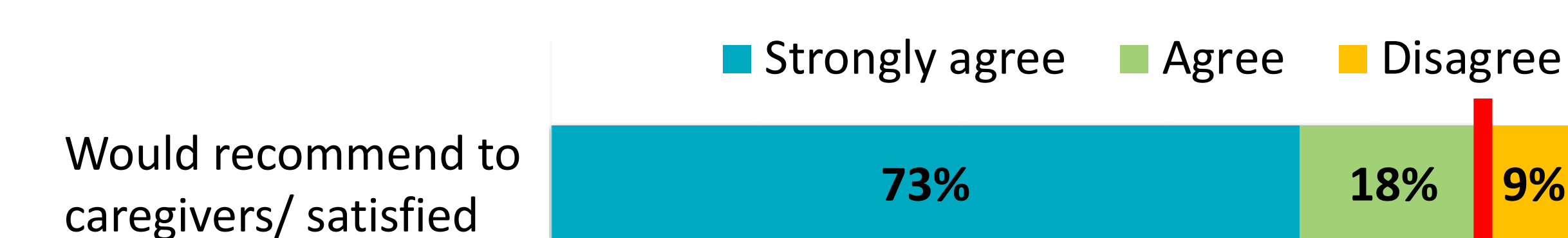


Figure 3. Self-identified role

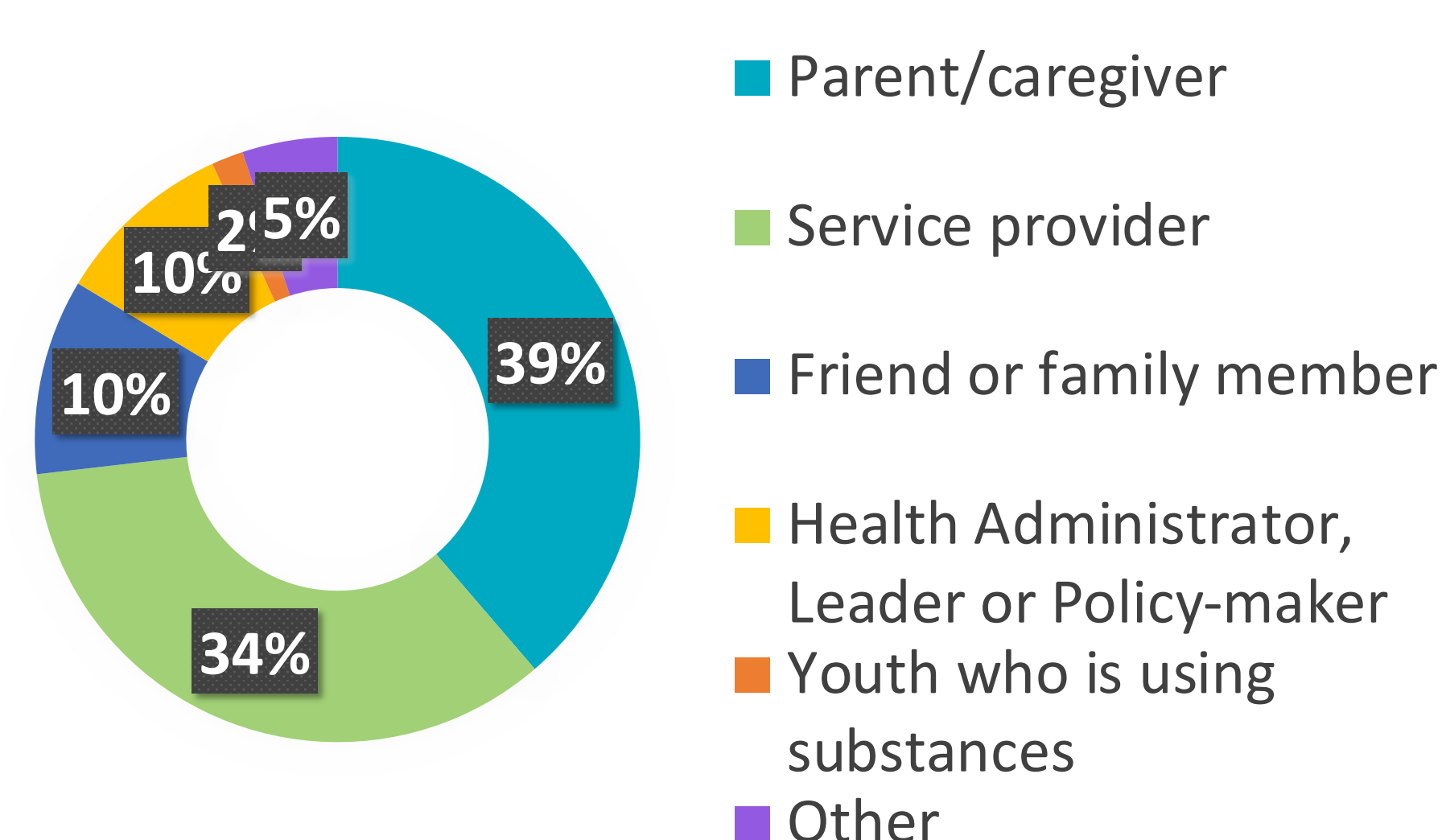
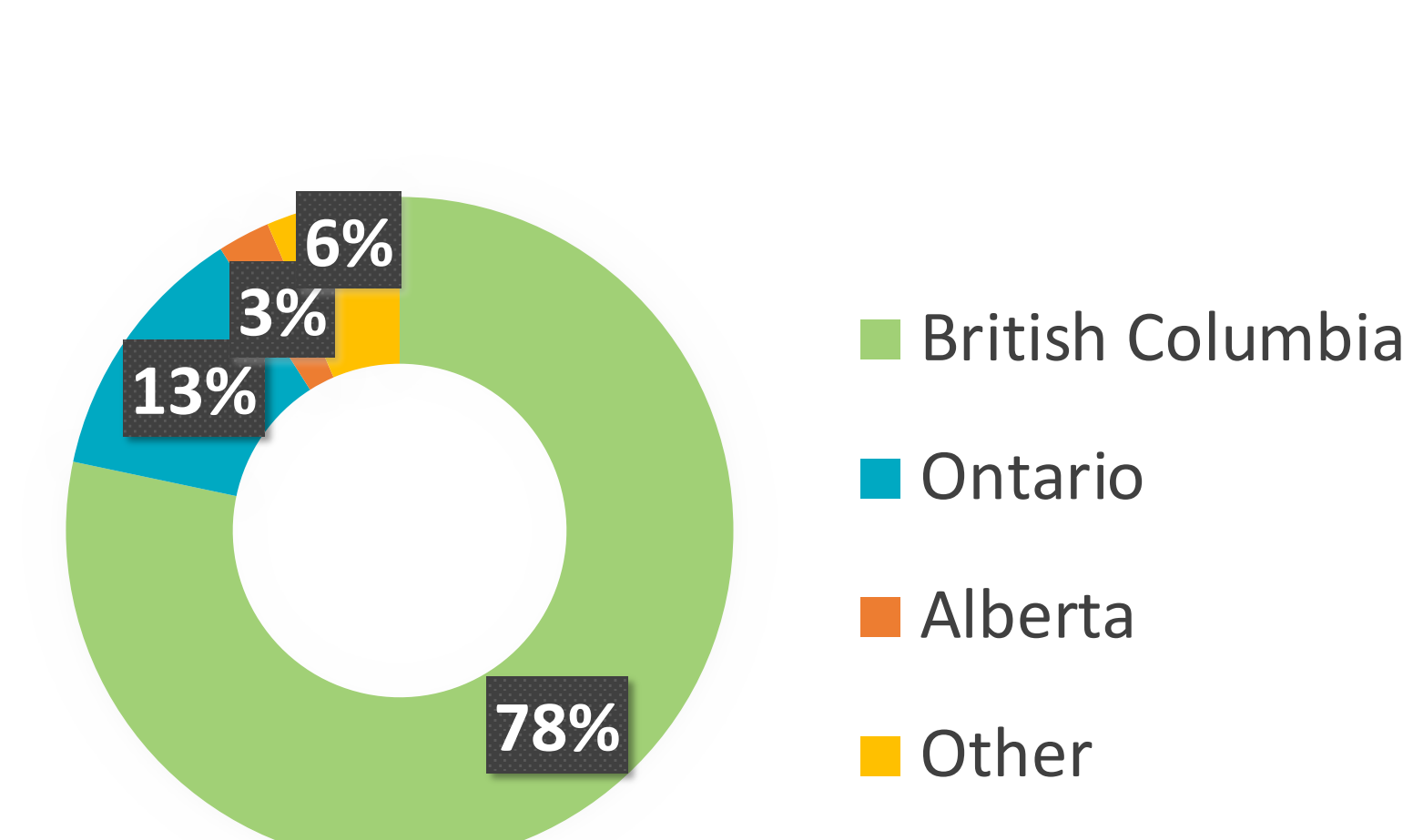


Figure 2. Geographic location



Parents like us.

THE UNOFFICIAL SURVIVAL GUIDE TO PARENTING A YOUNG PERSON WITH A SUBSTANCE USE DISORDER

written by parents for parents

