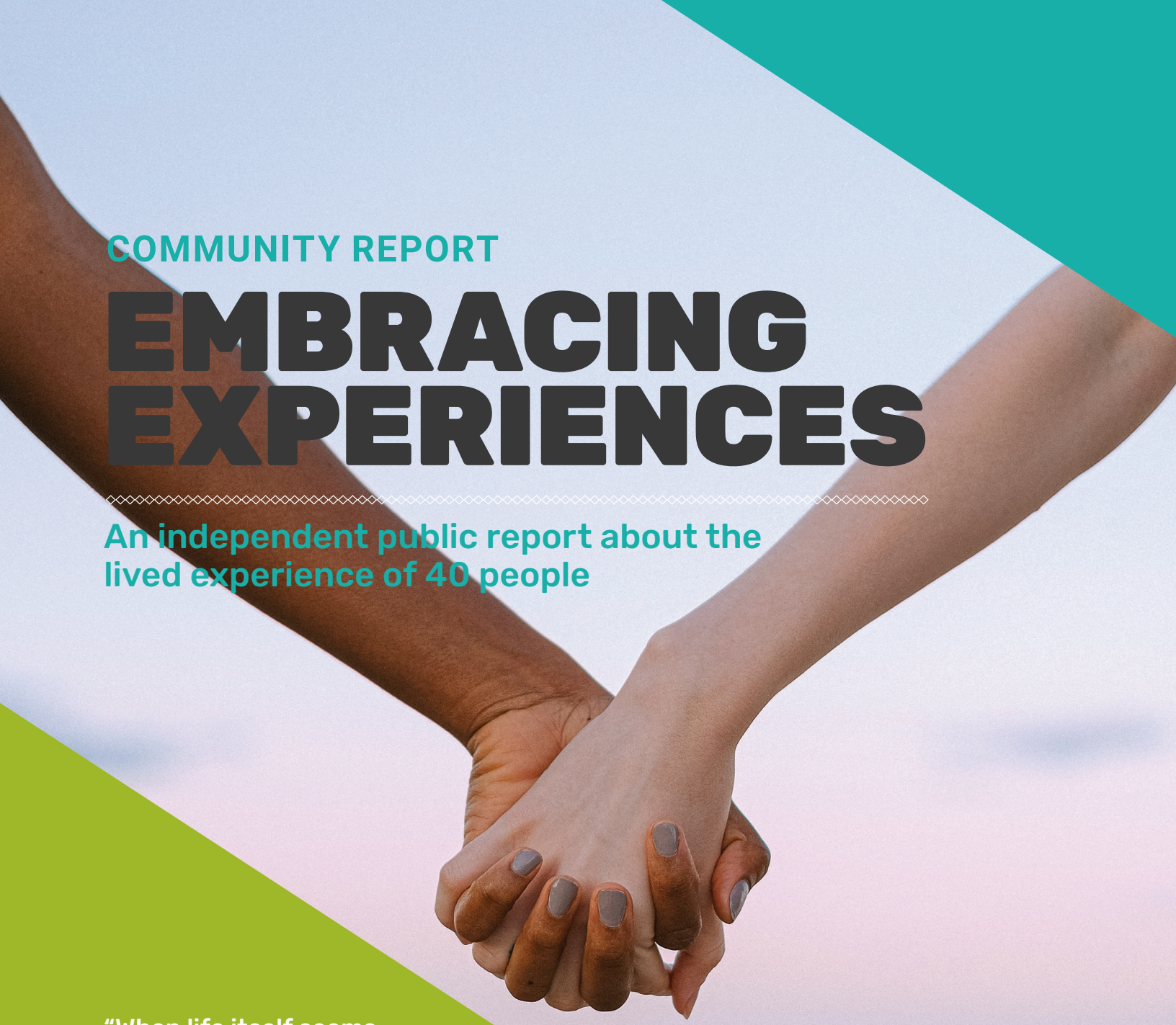


COMMUNITY REPORT

EMBRACING EXPERIENCES

An independent public report about the lived experience of 40 people

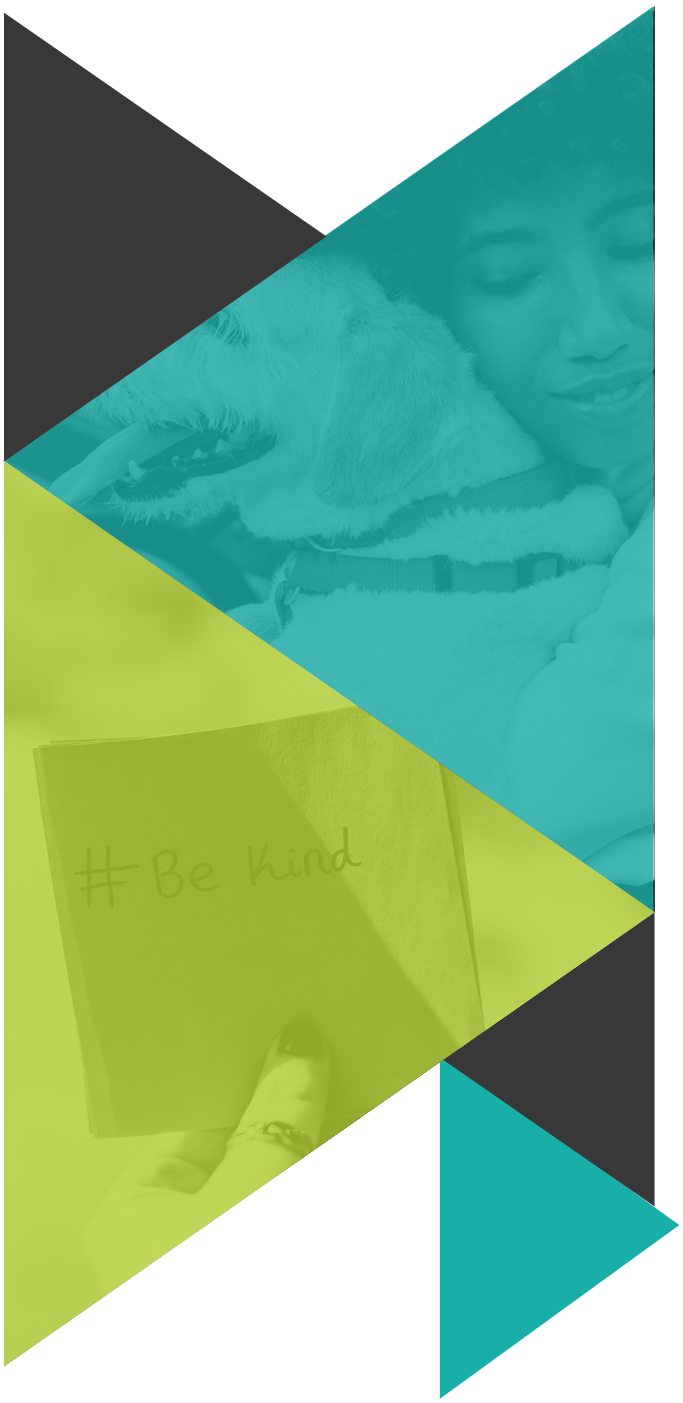
"When life itself seems lunatic, who knows where madness lies? Perhaps to be too practical may be madness. To surrender dreams, this may be madness… Too much sanity may be madness and maddest of all, is to see life as it is and not as it should be."

- Miguel De Cervantes Saavedra, Don Quixote

Canadian Mental Health Association
Newfoundland & Labrador
Mental health for all

WHY THIS REPORT?

At some point in life, many of us will struggle with our mental health or with addictive behaviours. That's why mental health and addictions services – like counselling, support groups, and rehabilitation programs – are so important. These services can help people through all kinds of life struggles. Lots of dedicated people work hard to make these services accessible and helpful, but they can always be improved.



Most evaluations of healthcare focus on the numbers, things like how many people accessed a service, how often people were admitted to hospital, or what it all cost. This is really valuable information, but it isn't the whole story.

People's stories matter. They tell us what's working and what isn't. That's why we at Canadian Mental Health Association, Newfoundland and Labrador (CMHA-NL) want to listen to those stories. CMHA-NL is a provincial branch of the nation-wide leader and champion for mental health. Our mission is to facilitate access to the resources people need to maintain and improve mental health and community integration, build resilience, and support recovery from mental illness. CMHA-NL wrote this report because we wanted to gather and amplify the voices of people who have used mental health and addictions services in the province. We want to spotlight the perspective of people with lived experience (PLE) so we can be an ongoing public voice to support change in the NL mental health and addictions system.

To do this, we interviewed 40 people and asked them what they thought about mental health and addictions services in the province. We listened to what they had to say, and then grouped their experiences into different themes. This is a summary of what we found. You can read the full report here.

We know lots of hardworking people in Newfoundland & Labrador care about mental health and addictions. We all want to make the system as good as it can be. That's why we asked people, ***"What do you have to say about your experiences with mental health and addictions services in Newfoundland & Labrador?"***

WE HEARD FOUR KEY MESSAGES:

1. **Access & Navigation:** PLE want services to be easy to find and easy to move through.
2. **Consistency:** PLE want to have consistency in the service providers they see, so that they can build trusting relationships.
3. **Prevention:** PLE want access to preventative services instead of receiving treatment when things have gotten really bad.
4. **Confidence:** PLE told us different things that make them more or less confident in the system or in service providers.

GET THE FULL CONVERSATIONS AND ALL THE RESEARCH IN OUR FULL REPORT.

DOWNLOAD HERE

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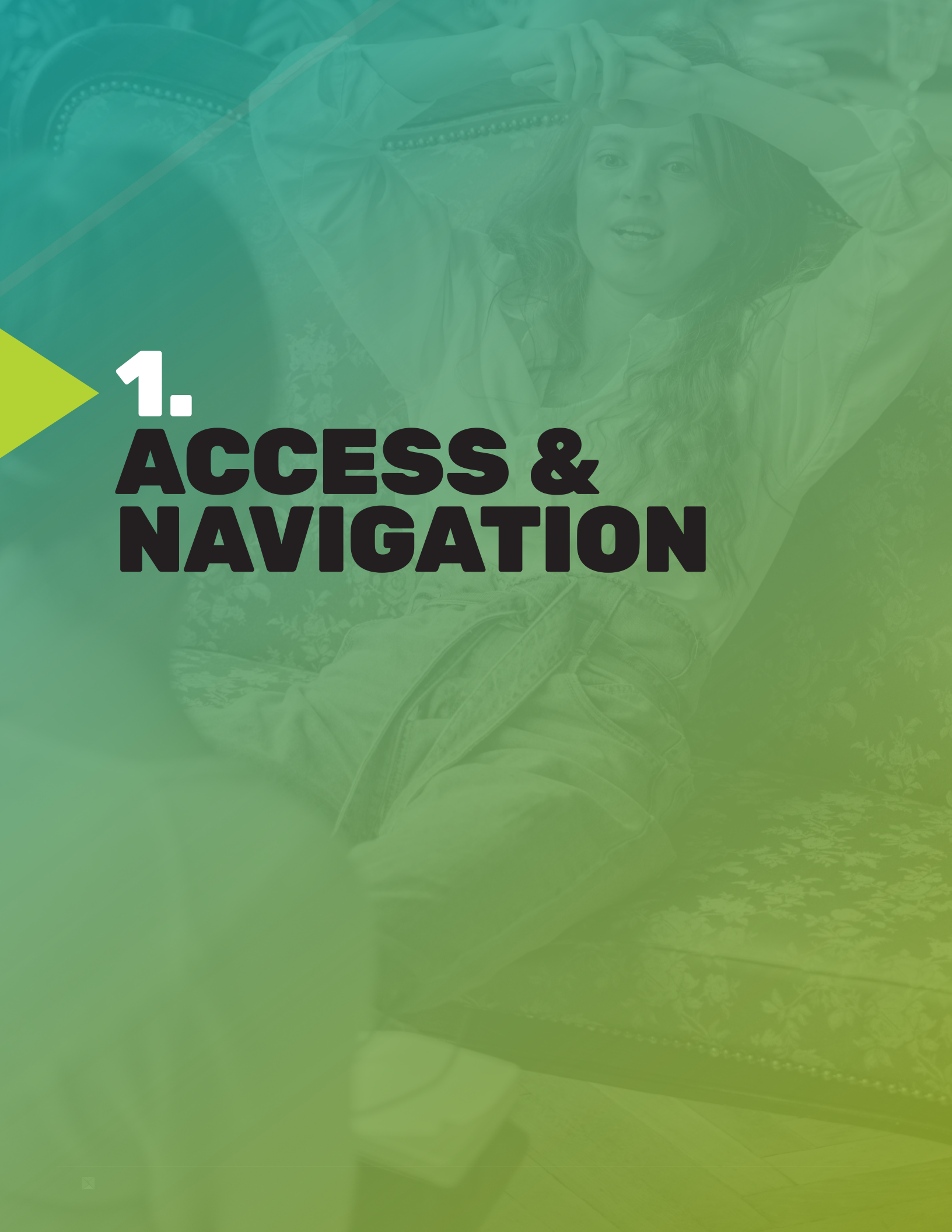

1. ACCESS & NAVIGATION

When mental health and addictions services were easy to find and move between, people had a really good experience. But many people told us they had difficulty knowing what services were available and how to access them. Sometimes they could not schedule convenient appointments or had trouble travelling to services. As Alexia told us:

> ***The MUN walk-in counseling was pretty inconsistent. And I didn't have a vehicle. I'd take the bus there. And it was first come, first served. So if you didn't get there soon enough, they were all filled up with people waiting. (Alexia, W, 20s, $40-60,000)***

Other times they simply didn't know services even existed. Emily told us she wished her doctor had explained more options for talking about her drinking:

> ***I wish that, you know, instead of [my Doctor] just saying,* have you tried AA? *That I would have been given the options that are available, that I would have been made aware of The Recovery Centre or The Grace Centre. She never even told me about addictions counseling. That came from a friend, you know? So I wish doctors had some sort of information package that when a patient starts to talk about these difficulties, that they're given all the options that are available. (Emily, W, 40s, $60-80,000)***

People felt they had an easier time getting help if they had things like more education, more money, better housing, access to transportation, and supportive jobs, friends, and families. They also felt that being white, straight, cisgendered, and male worked in their favour. Here, Mark explains:

> ***[I am a] university-educated, heterosexual, white male. And that has worked in my favour. Absolutely no question. And that's been said to me in so many words by different people. It's been said to me sometimes by care providers. It's,* Oh my goodness it's so much easier dealing with you, where you are [educated]. Oh my gosh, it's so much easier where you have this, or you have that. *Other times it's a bit more subtext, where I see other people really struggling getting access to things I'm accessing […] I come from a place of a lot of privilege. I know that has probably gotten me access and gotten to me things quicker than others have in my position. (Mark, M, 30s, >$100,000)***

Guidance and support can make a huge difference. Several people talked about how it's overwhelming and difficult to find help when you are feeling badly. Like Emily, who said

> ***I know the patient has to advocate for themselves and I know sometimes the onus is on the patient to find what resources are out there. But in the same breath, when you're so down and out and when you're in such a level of despair and hopelessness, it's really hard to go find those resources for yourself. (Emily, W, 40s, $60-80,000)***

Or as Danielle said,

> ***Navigating the system is really exhausting for someone who's already sick. (Danielle, W, 30s, $40-60,000)***

When people gained more experience using services, they had an easier time knowing where to go:

> ***Now that I'm in the system, I feel like I can just go here, here, here, and they get me in. (Angelina, W, 30s, >$100,000)***

We all want people to be able to get the mental health and addictions services we need, especially when we're going through a crisis. The people we spoke with are very resilient – but we shouldn't have to exert so much energy to get services when we're already feeling unwell. We need to make sure services are easy to find, easy to get to, and affordable or free. We can streamline services by making better referrals and using technology. We can improve access by making sure that all healthcare providers know about the different mental health and addictions options in the province.

2. CONSISTENCY

Sometimes, short term supports are all we need. Other times, our mental health and addictions struggles require care over a longer period of time. We need time to develop trust so we can open up to the person offering us support. A lot of the people we spoke with talked about how they wanted to be able to work with the same person over time, build a strong relationship, and have the ability to switch things up if the match wasn't a good fit. For example, there were times that a one-off drop-in counselling session was exactly what people, like Janet, wanted and needed:

> ***I've only been there [to Doorways] once and it was under [crisis] circumstances. I say it was a good experience. I was in a bad place [...] But we sat for an hour, so that helped a lot. (Janet, W, 50s, $20-40,000)***

Other times, people like Mallory and George shared that they were frustrated if same-day counselling was all they were offered:

> ***Same-day counseling isn't something that was really helpful to me. I'm very slow to open up to people and so having something where you're given a different counselor potentially every time [isn't helpful]. (Mallory, W, 20s, <$20,000)***

> ***I know that [walk-in counselling] is available to me, but I haven't felt compelled to go back because I realized I would have to explain myself again and again and again and I would have to narrow my focus, like a drive-thru, like, OK, well, here's what I'm in for today. [...] [When I was doing walk-in counselling] I was repeating myself. I couldn't develop any kind of rapport with somebody because I'm not seeing the same person twice. (George, M, 40s, <$20,000)***

On the other hand, when people were able to build strong, consistent relationships they found their treatment was much more effective. Christine shared about having the same counsellor for a long time:

> ***It's been a good experience for me because I have this ongoing relationship with my therapist where she knows me and she's used to me. Like she can read my voice if I'm not doing well or whatever. She knows me so well. (Christine, W, 40s, >$100,000)***

And Tanya shared how her counsellor knew her well and so was able to also help her access other resources:

> ***My counsellor has been phenomenal. He's been pretty easy to access for me. He set up my inpatient treatment at the Grace Centre. He's helped me all along the way, and he kind of steered me in the direction of different groups that could help. [...] When I came out of the Grace Centre, I was still with the same addictions counselor. I stayed with the same one. That was good because he already knew everything. (Tanya, W, 40s, >$100,000)***

Aster's therapist also advocated for them, pushing for a longer-term relationship than was typically allowed:

> ***Overall, [my experience] was good. Especially because I felt like my therapist was really advocating within the system for me and to keep me. I have a feeling that she was doing a little bit more behind the scenes than I could see, because we were involved in a long-term therapy, which I know is sort of not always acceptable under the Eastern Health model of like, six sessions, get him fixed and get him out the door so that we can get the next person in. (Aster, non-binary, 30s, $20-40,000)***

Mental health and addictions issues are rarely resolved in just a few counselling sessions. Programs and services that allow for longer term relationship-building help people to open up and trust their care provider, without having to reintroduce themselves over and over. Telling the story of our suffering can be painful, so the less often we need to do it, the better. Consistent care promotes a sense of shared humanity, which reduces feelings of isolation and vulnerability. It can also improve PLE confidence and safety in care. The people we spoke with shared that when healthcare providers were flexible in responding to their needs, it made all the difference in their experience. This shows how appreciated and valued healthcare professionals are by PLEs and how warmth in care truly matters.

3. PREVENTION

Some of the people we talked to felt like they could only access services – especially psychiatry services – after they had some kind of crisis. These people felt that if they had been able to get service sooner, they might not have gotten to the point of crisis. For example, Meg talked about how she was offered more care after she was arrested than before:

> ***Services were better after being arrested than they were trying to prevent it from happening in the first place. [...] [My case manager] got in contact with JHS [John Howard Society] and got me into counselling that way. Because I had gotten probation, and that's the only way I ever got back into addictions counselling. It wasn't straightforward. But once I had a case manager and got probation, I was able to get something. (Meg, W, 30s, $60-80,000)***

Similarly, Cynthia got more support after a suicide attempt than she received beforehand:

> ***[Help] wasn't out there for me to know it existed, unless something major happened. So most of my help that I received was due to a suicide attempt, rather than it being before the situation got to that. (Cynthia, W, 30s, $40-60,000)***

On the other hand, mental health services could also be hard to get if people were not experiencing crisis or 'acting crazy enough'. As Aster explained, they can struggle to be taken seriously because they seem stable:

> ***Some GPs don't take my mental health problems seriously because I'm very articulate about them and I seem like I have a really good grasp on my life and I am a high performing individual. (Aster, non-binary, 30s, $20-40,000)***

George called this focus on crisis a 'band-aid' approach to mental health and addictions care:

> ***My experience, essentially, in waiting for access to mental health service is demoralizing, embarrassing, and has opened my eyes to the unconcern of our medical system towards mental health. It seems to be treated as a band-aid that seeks to purely 'stop the bleeding' of the moment without any regard for long-term consequential care. I have been given broken promises, casual assurances, and stop-gap 'solutions' that do nothing whatsoever. I have indeed waited for hours, days, weeks, months, at various times and for various services. (George, M, 40s, <$20,000)***

When it came to crisis phone lines, some people had very positive experiences, and some people had very negative experiences. For Emily,

> ***By the time I hung up, I was feeling better and I didn't feel like I was in such a crisis. [...] So the person I spoke with was quite helpful. (Emily, W, 40s, $60-80,000)***

Others said that when they called the crisis line they felt they were just being judged and assessed rather than supported. As Susan explained, some crisis lines also lack awareness of Indigenous issues and are quick to call the RNC, so she prefers to use community-based lines:

> ***The crisis line here in Newfoundland, I've had nothing but terrible experiences with. Horrible, terrible experiences. But I found other hotlines that I like to call, the CHANNAL Warm Line is a nice one. The Hope for Wellness, which is a national one specifically for Indigenous peoples, is a really nice one that I've called […] They seem to be much kinder, much kinder. The crisis line here seems to be very abrupt, very rude. The crisis line here is very quick to call RNC, and RNC is brutal and not well equipped. [With] the mental health Mobile Crisis Team, at least one of them is a social worker [and] one of them is an officer, but when they send just an officer it's been awful. (Susan, W, 40s, <$20,000)***

Many people felt that they had to be in crisis in order to get care, and then they were judged as 'attention-seeking' or 'hysterical'. Stigma and sanism[1] are ingrained in a lot of mental health and addictions institutions. When these services focus too much on the medical model, we can lose sight of our shared humanity. We need to understand mental illness and addiction as both a social and medical issue. We need to make sure the system supports treatment that is anti-oppressive, respectful, and uplifting.

1. "Sanism describes the systematic subjugation of people who have received 'mental health' diagnoses or treatment" (Poole et al., 2012, 20). It is more than mere stigma, but rather a belief system rooted in a "pathological view of madness" (22).

4. CONFIDENCE

Trust is a really important part of feeling safe to use whatever resources the mental health and addictions system has to offer. Many of the people we spoke with admitted that bad experiences had made it hard for them to trust certain services. For example, talking about the Waterford Hospital, Tanya said that:

> ***The Waterford staff were really good. I found them supportive and kind and legitimately seemed to want to help you. (Tanya, W, 40s, >$100,000)***

Whereas Mallory had not had such positive experiences:

> ***I've gone to the [Psychiatric Assessment Unit] about a million times. I've no idea how many times. It's been a lot, and I've been admitted to short stay a bunch of times and never been admitted to acute care or anything. I absolutely hate it there. There's just no structure, anything, so it's almost worse than being at home. […] It's not the best place but it's not the worst either, I guess. I'm safe while I'm there, but other than just being safe, it's not like anything is really happening. (Mallory, W, 20s, <$20,000)***

As Aster here explains, sometimes good people are just doing their best within badly-designed systems:

> ***I have a pretty deep distrust of the health care system in general. I believe in the goodness of people and the good people that I find are always working upstream and always working against sort of crappy things that are binding their hands in some ways. (Aster, non-binary, 30s, $20-40,000)***

Oftentimes, trust was gained when people felt they were being treated as full human beings, rather than, as Emma said, "just being a chart":

> ***You need to get back to people being there and not just a chart. You've got to have some kind of connection there with them. (Emma, W, 30s, >$100,000)***

Michelle similarly shared about her time at the Recovery Centre,

> ***[It] was more of a personal experience that wasn't as clinical. You know, they spoke to me like a person and I wasn't being talked down to. (Michelle, W, 20s, $60-80,000)***

Not being "talked down to" was important for a lot of people we spoke to. They wanted to be involved in making decisions about their care, rather than just told what to do.

We talked to several people who felt that care providers did not have expertise in really important parts of their experience. For example, Susan told us about her experiences of anti-Indigenous racism when trying to access care.

> ***I usually wear a medicine bag, for First Nations spirituality, and I was treated very badly for that in St Clare's. […] [The staff] were actually discussing that I must've thought I was some kind of witch or something, because once again, they didn't understand the Indigeneity of it. (Susan, W, 40s, <$20,000)***

Susan also had to spend time and energy educating crisis line operators around major Indigenous issues that were important to why she was calling:

> ***The Hope for Wellness line is well aware of Indigenous issues. So I don't have to explain what a Residential School is and I don't have to explain what the National Inquiry for Missing Indigenous Women is, those kinds of things. Talking with the CHANNAL Warm Line and even the National Line, they seem much more versed in those topics too. But I've tried to call the local crisis line and if any of those sorts of issues came up, they had no idea what I was even talking about. I had to sit there and spend quite a bit of time educating them on what I was talking about. Which is frustrating, right? (Susan, W, 40s, <$20,000)***

Aster explained how services can also be unsafe for trans individuals, and that many trans people avoid accessing services for this reason. Of their own experience, they shared:

I went [to Memorial Mental Health] at the beginning of my transition as a space to be like, look, there's something like super funky going on with my gender. I really need a space to talk about it. *[...] And their response was to put me into a women's-only body image workshop, which is insane [...] Being in that space and being like, wow, this is not only useless, but it's actually really harmful […] I found out after seeing [a MUN therapist] for eight months or nine months that in all of my records she had written me as a 'she', and I found that to be just such a huge betrayal of everything that I was in that space working on. […] So that really destroyed my trust in her. (Aster, non-binary, 30s, $20-40,000)*

Another person felt that counsellors lacked awareness and understanding about sexually marginalized practices, such as sex work, consensual non-monogamy, and kink[2].

I would love to see a shift in the culture here where if a person has a specialty in various sex things, that that can be known. I went on the Newfoundland and Labrador Association for Psychologist and Psychiatrists [website]. […] There wasn't anything about non-normative relationship styles or the kinds of things that are important to me and communities that I'm close with. When you realize not only is there no one that specializes in your thing, [...] it's not even considered important [enough to list as a speciality], that communicates something to clients. And the idea of going into therapy and having to battle to explain why non-monogamy is a valid relationship style or to explain sex work. You know, I don't want to do that battle when I'm trying to move through trauma. [...] And I knew that pulling apart issues of sexual assault while being a person who is kinky, non-monogamous, and involved in sex work was going to take a certain kind of counselor. I'll admit I had zero faith that Eastern Health would be able to provide that. (Beth, W, 30s, $20-40,000)

Finally, there were people we talked to who felt that their care providers did not have enough education around eating disorders, addictions, or psychiatric drug safety. For example, Gertrude's son was given medication against his will. She explains:

I was a parent believing in a medical system. [My son] didn't want to take the drugs because it made him very sick. We need to be looking at [the side effects] and understand that those are real issues. They're not made up. You have to listen to the patient when they say they're having the side effects they're having […] Too many people are having problems because of only looking at a medical model approach. (Gertrude, W, 60s, >$100,000)

While many people explained that medications had a very positive effect on their lives, others thought that doctors were too quick to prescribe drugs. As Emily said:

My biggest recommendation is I wish family doctors, when a patient starts to disclose that they are having difficulty [with mental health] [...] that their first reaction is not to give them medication. I am on medication, I'm

2. Sex work refers to the consensual exchange of sexual services for money or other goods; consensual non-monogamy is an umbrella term for a variety of non-monogamous relationship styles (such as polyamoury or 'swinging') whereby those involved agree not to be sexually and/or romantically exclusive; kink refers to a variety of sexual practices involving the consensual and explicit exchange of power or other types of sexual play that might be considered non-normative or 'fetishes'.

on antidepressants. I'm not against antidepressants, it's been life changing for me. But I needed so much more than just a medication, like I needed to actually work on myself and until I worked on myself medications were only masking what was really happening. It wasn't an actual solution. (Emily, W, 40s, $60-80,000)

Overall, people wanted to know their medication options, but wanted to be involved in the choice and given all the necessary information – like about drug side effects – to make an informed decision.

A lot of people put more trust in community groups or services led by their peers. This included different 12-Step fellowships and organizations like CHANNAL. Delilah described how CHANNAL had helped her:

CHANNAL has definitely met my needs and definitely helped me develop who I am now. Definitely helped me through some big crises. (Delilah, W, 20s, <$20,000)

These resources were often used alongside other supports like doctors, psychiatrists, or counselling offered by the Health Authorities. For example, Irina said:

Absolutely Amazing […] AA helps keep my thinking straight. You know, in a different way than my psychiatrist. (Irina, W, 50s, $40-60,000)

There are a lot of reasons that people might not trust the mental health and addictions system. Listening to these reasons can help us improve the care we give. PLEs described having better experiences when they could build a warm and compassionate connection with their healthcare provider, and when they were involved in making decisions about their treatment plan, including medications. PLE understood and appreciated that healthcare providers face many institutional barriers in their dedicated efforts to provide quality care.

Some PLE felt that healthcare workers did not understand things about their communities that would have improved their ability to provide care. Some PLE also felt that healthcare providers did not understand enough about their specific conditions. We need to encourage the training and hiring of mental health and addictions workers from these communities and backgrounds. We also need to encourage all healthcare providers to learn about these issues.

LUCK

Many participants believed that most people in the province do not receive effective mental health and addictions care. They expressed their positive experiences as the result of being 'lucky':

I can tell that I've had a very, very positive experience compared to some others. […] I don't believe in a higher power, but just by luck, I guess, and through medication compliance and through medications that are working for me, I feel like if it wasn't for that, I would have been one of these people [who was turned away from services and completed suicide]. (Michelle, W, 20s, $60-80,000)

Q: Do you feel that the mental health and addiction services that you've accessed in your community have been effective?
A: Yes, I have. I definitely consider myself one of the lucky ones for sure. (Tanya, W, 40s, >$100,000)

Cause I was lucky. Luckily for me, I was already set up with the mental health support that I needed. So I didn't have to try and navigate the system throughout all this [COVID-19 lockdowns]. (Alexia, W, 20s, $40-60,000)

I think it's just luck that I didn't have a relapse in between early sobriety and getting in to see a professional. (Emily, W, 40s, $60-80,000)

[I did not feel] terribly involved [in my care]. I felt like the ones that were working and were good for me, I just kind of lucked into. Do you know? So I can't say that I had informed choices or anything like that. (Susan, W, 40s, <$20,000)

CONCLUSION

The COVID-19 pandemic has pushed everyone to adapt how we do things. We have proven that when our wellbeing is threatened, we can change systems and lower barriers. And it is the entire system that needs to change. As the Health Council of Canada reported, "It is clear that tackling individual components of the health system is not sufficient. A broader and balanced *transformation* of the system is required" (2013, p. 4, our emphasis).

We hope this report will motivate others in the mental health and addictions community to centre people with lived experience when they are evaluating programs and making decisions about what needs to change (Slay & Stephens, 2013). As the Towards Recovery report says, "Redesign of the system to prioritize peoples' needs is essential" (2017, p. 13). We hope this report will support the ongoing assessment of our mental health and addictions system as we reimagine it. In order to ensure our mental health and addictions system performance is the best it can be, we need to consider both system-level and PLE-defined indicators. Please see our full list of PLE-defined indicators here.

Thank you to those who told us their stories, with courage and hope for a brighter future in mental health and addictions in Newfoundland and Labrador. Across cultures human beings are known for valuing the richness of stories. Perhaps it is time to include these narratives to deepen our understanding of NL health system performance.

FEEDBACK

If you have accessed mental health or addictions services from the Health Authorities and would like to given them feedback, you can use these Client Relations phone lines or emails:

Eastern Health:
709-777-6500
Toll Free: 1-877-444-1399 or
client.relations@easternhealth.ca

Western Health:
1-833-784-6802 or
clientrelations@westernhealth.nl.ca

Central Health:
1-888-799-2272 or
clientrelations@centralhealth.nl.ca

Labrador-Grenfell Health:
1-833-505-1178 or
client.relations@lghealth.ca

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For all references, acknowledgements, and project design information, please see our full report here.

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NEED HELP NOW?

Crisis Text Line: Text 'TALK' to 686868

Mental Health Crisis Line: Call 1-888-737-4668

CHANNAL Warm Line: Call 1-855-753-2560