



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

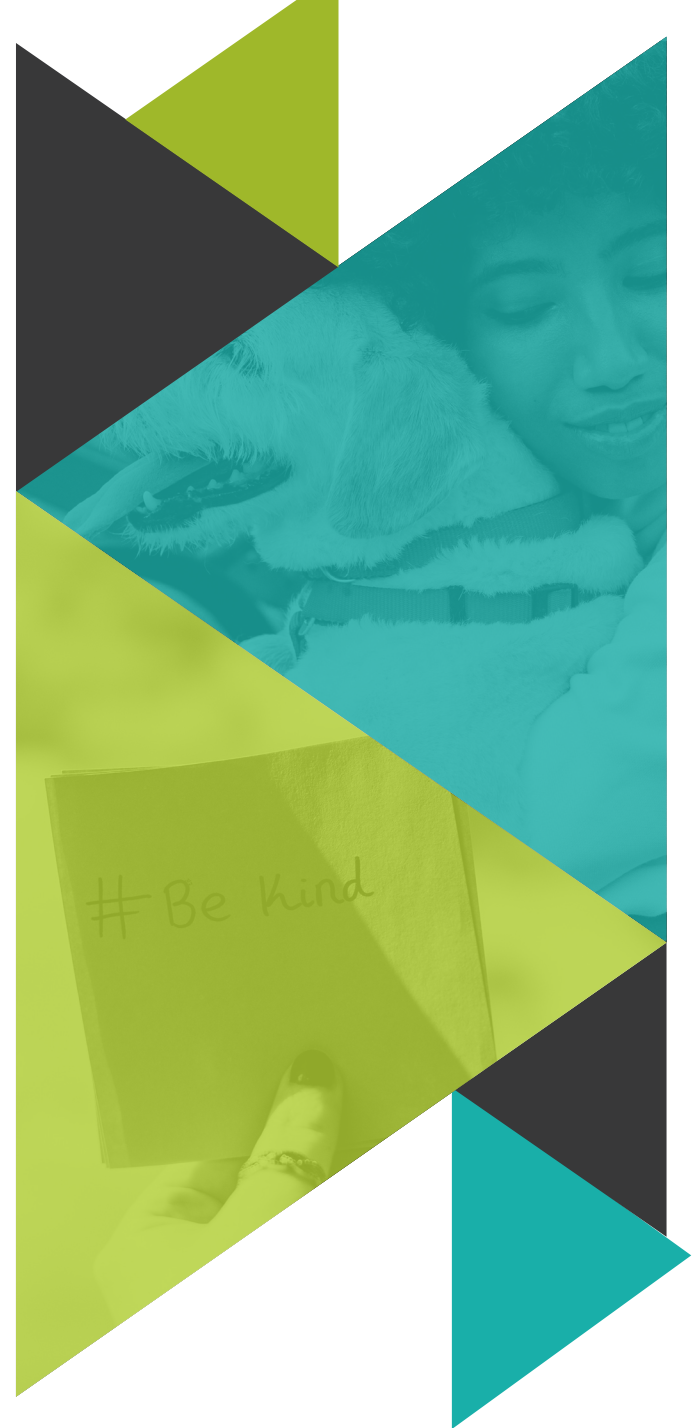
ABOUT THIS REPORT

'Embracing Experiences' is an independent public report, sponsored and funded by CMHA-NL. At its heart are the words of 40 people with lived experience who were interviewed about their experiences with mental health and addictions services in Newfoundland and Labrador.

This report is part of a growing movement to reconsider how we develop and use tools to monitor mental health and addictions (MH&A) system performance. By encouraging the use of storytelling, narrative, and personal experience to provide a richer understanding of MH&A services, 'Embracing Experiences' is building momentum to involve people with lived experience and healthcare providers in the co-evaluation and assessment of MH&A systems. There is a long history of people, whether identifying as (ex) patients, clients, or service users who have been striving to have their voices heard in public discussions about their healthcare. In the spirit of that history of empowerment, 'Embracing Experiences' aims to amplify the voices of people with lived experience, also known as PLE.

Other collaborations also made this report possible, including an advisory committee that provided support and direction to the project team. This advisory committee included PLE and executives from Stella's Circle, The Gathering Place, Choices for Youth, CHANNAL, Empower, Thrive, Newfoundland and Labrador Centre for Health Information (NLCHI), Newfoundland & Labrador Centre for Applied Health Research (NLCAHR), and Conne River First Nation. Using CMHA-NL capacity, the reporting team consisted of a project manager, researchers, and writers with backgrounds in social work, anthropology, psychology, and public health. Importantly, CMHA-NL contracted a PLE – recruited directly from one of our interviews – who will remain anonymous. This person was centrally involved in reviewing the interviews and in writing this report – a process that moves PLE out of the illness identity and narrative that often dominate discussions of mental illness, into active involvement as co-evaluators of the very systems they engage with. Through this inclusive approach, 'Embracing Experiences' emphasizes collaboration, community participation, and the considerable expertise of people with lived experience.

Notably, NLCHI has also supported the 'Embracing Experiences' reporting team. NLCHI's legislated mandate includes preparing health reports and conducting research and evaluation. Offering qualitative analysts for coding our many



interviews, CMHA-NL and NLCHI worked together on establishing common codes and definitions along with developing a standardized table to log codes and associated quotes. We thank them for their technical support.

We also appreciate the open communications we had throughout the reporting process with the NL Government's Towards Recovery Provincial Action Plan team, as well as representatives from the Eastern, Central, Western, and Labrador-Grenfell Regional Health Authorities.

CMHA-NL extends our sincere thanks to all partnerships in the maintenance and delivery of this report.

ABOUT CMHA-NL

The Canadian Mental Health Association, Newfoundland and Labrador (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, 2020). Our core values include embracing the voices of people with lived experience of mental illness, working collectively, influencing the social determinants of health, and using evidence to inform work. These principles lay a strong foundation for participatory practice which involves vulnerable and marginalized groups in **co-production**: a relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities (Slay & Stephens, 2013).

CMHA-NL is increasing capacity and developing resources to improve access, quality, and safety of mental health services in Newfoundland and Labrador. Our belief in innovation, collaboration, and participation, have brought us to this report: a living document where people with lived experience of mental illness and addiction tell their stories. These brave testimonies have been shared with the hope of influencing policy and initiating change. This report is one where inclusion, evidence, and transparency are applied. We will endeavor to produce these reports – independent of government – on a bi-annual basis to benchmark and provide comment on the state of MH&A related services in Newfoundland and Labrador.

The purpose of this report is to identify gaps in services, identify opportunities for quality improvements based on emerging and best practices, and to be an ongoing public voice to support change in the Newfoundland and Labrador MH&A system, both for persons with lived experience and those yet to experience mental health and addiction-related challenges.

DISCLAIMER

This report shares the experiences of PLE in the province of Newfoundland and Labrador. The results of this work do not claim to be research evidence that is transferable or generalizable to any other province or population within or outside of Canada. The qualitative content of our report is meant only to provide contextualized information to local MH&A professionals, policy makers, policy analysts, and other interested parties.

Recruitment was not representative; participants who signed up were mainly from the metro-area, were white Canadian-born with relatively high education and wealth status. Despite our efforts, we know we have under-represented populations; like Black, Indigenous, and People of Colour (BIPOC), homeless, rural, new-Canadian, and non-English speaking. We believe these under-represented populations may be more likely to lack access to safe, quality, and effective MH&A services. We recognize this is an important limitation of this report. CMHA-NL has begun work on the next edition of the report, including relationship-building with populations under-represented in this evaluation. In the spirit of inclusion and diversity, CMHA-NL will endeavor to represent all people with lived experience in the ‘Embracing Experiences’ reporting project. We want to be a platform for all voices to be heard.

A description of the project design and detailed participant demographics are provided at the end of the document.

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MENTAL HEALTH & ADDICTIONS SERVICES
IN NEWFOUNDLAND & LABRADOR

STRENGTHENING SYSTEM PERFORMANCE

Our belief in innovation,
collaboration, and participation
have brought us to this report:
a living document where people
with lived experience of mental
illness and addiction tell
their stories

We are not an island unto ourselves in evaluating MH&A system performance, but part of a greater whole. MH&A system performance is a national concern.

Pan-Canadian collaboration on our shared goals and priorities for the MH&A system is the starting point for implementing performance standards and measuring progress. Health Canada, in partnership with the Canadian Institute for Health Information (CIHI), is developing common indicators to measure pan-Canadian progress on the agreed priorities of MH&A system performance, to be reported on annually to Canadians.

There are many challenges in measuring MH&A performance nationally as the provinces differ in service delivery and system measurement. Standardization may not be entirely possible or desirable as each province has its own unique needs. This leaves us here in Newfoundland and Labrador responsible for the assessment and improvement of our own provincial MH&A system. Public reporting for ongoing monitoring and change is essential: it supports our province in being transparent and accountable to the public and improves our understanding of people's lived experience with mental health and addictions services throughout the province. Public reporting provides people with an opportunity to share power, encouraging action, innovation, and change for the improvement of the MH&A system in this province. Public reporting is therefore key to supporting Newfoundlanders and Labradorians in an honest assessment of the province's progress in meeting health system challenges, and on identifying issues of priority concern to PLE.

All of the important work completed to date clearly indicates that Newfoundland and Labrador is dedicated to re-evaluating and improving MH&A services.



MENTAL HEALTH & ADDICTIONS SERVICES
IN NEWFOUNDLAND & LABRADOR

PERFORMANCE EVALUATION

Our vision is for PLE collaboration
to become central to how system
evaluation and reporting are
conducted in the province of
Newfoundland and Labrador

Several important evaluations of MH&A service in Newfoundland and Labrador have been undertaken. The Towards Recovery Action Plan Report (2017) by the All-Party Committee has done foundationally important work.

They engaged hundreds of service providers, members of the academic community, people with lived experience, and their families to capture as complete a picture of Newfoundland and Labrador's MH&A landscape as possible. They generated detailed and thorough recommendations for improved MH&A system performance. MH&A Programs Performance Indicators reports published by NLCHI are also a valuable source of statistical information, measuring system performance and tracking it over time. The various Health Authorities have engaged in efforts to measure PLE satisfaction with MH&A services through the regular administration of Patient Experience Surveys.

What CMHA-NL hopes to contribute to this growing body of work is an independent evaluation of how the system is working from the PLE perspective, in their own words. We aim to offer insight into the indicators that matter most to PLEs so these can be measured over time. Our vision is for PLE collaboration to become central to how system evaluation and reporting are conducted in the province of Newfoundland and Labrador. We believe that qualitative, narrative-based accounts produce a kind of rich, meaningful data that is not always captured through surveys and administrative data.

Qualitative methods have often been used to evaluate mental health and addictions services, as they offer "a depth of understanding to complement the breadth of understanding afforded by quantitative methods" (Palinkas, 2014, p. 852). Qualitative program evaluation is uniquely descriptive in a way that complements and contextualizes quantitative evaluation. In addition, open-ended qualitative interviewing

allows PLEs to define their own experience, rather than forcing them to fit into categories preconceived by interviewers. We recognize that a qualitative program assessment of this nature requires a lot of time, capacity, and resources. But it also generates rich, nuanced narratives for evaluation. We hope the contents of this report can inform health authorities and all their ongoing evaluations of client experience, programs, and service systems. Whether it is used for gathering statistics, designing surveys, or conducting interviews, we believe this report can positively inform the questions we ask and how we ask them.

Nothing in this report is intended to replace the other evaluative efforts underway, rather it is intended to complement them. As the reader will see, many of our recommendations align with those found in the above-mentioned reports.

All of the important work completed to date clearly indicates that Newfoundland and Labrador is dedicated to re-evaluating and improving MH&A services. CMHA-NL is committed to being a part of this collective effort, by amplifying PLE voices and serving as a liaison between PLE and health systems. We asked, ***"What do PLE have to say about their experiences with the MH&A system in Newfoundland and Labrador?"***

HERE'S WHAT WE HEARD.



OUR FINDINGS

STORYING EXPERIENCES

These are four key messages
from those with lived
experience of mental health
and addictions services in
Newfoundland and Labrador



FOUR KEY MESSAGES FROM PEOPLE WITH LIVED EXPERIENCE:

- » People with lived experience are concerned about **Access** to and **Navigation** through MH&A services, including those offered by the public system, private systems, and community-based organizations.
- » People with lived experience want **Continuity** in care, and stressed the importance of building trust in relationships with healthcare providers
- » People with lived experience see an important distinction between services that are **Proactive rather than Reactive**, and are concerned about feeling that one must 'perform' their mental health concerns in a certain way in order to receive timely services.
- » People with lived experience cited elements that impact **Confidence** that the MH&A system or individual providers will offer competent, compassionate care

These four areas of importance are discussed in detail below.

1. Access & Navigation

A major topic of the interviews was the experience of locating and navigating mental health and addictions services in NL. Many PLE felt that services are not organized in an easy-to-navigate fashion. Whether PLE found the process easy or difficult, they often framed their experience as depending on the resources at their disposal; both material resources such as education and employment, and internal resources such as stamina and resilience.

STREAMLINING

Some PLE had very smooth, timely access and transition experiences within the MH&A system:

It was smooth – it was streamlined. I saw the in-take person within a couple weeks. I had no issue. It was a lot faster than I thought. I was thinking it was going to be months (laughs). [...] It was absolutely streamlined. I had no glitches, they were organized. They made my appointments. I showed up – there was no issue. (Kim, W, 40s, \$80-100,000)

When I lived in [Labrador], it was very easy to access mental health services, addiction services, because [...] they're very good at advertising and reaching out and confidentiality and free services and all kinds of follow up. (Lucy, W, 30s, >\$100,000)

Other PLE felt that services could be more interconnected and streamlined. They found that healthcare providers were often unaware of the breadth of available services, failing to offer potentially appropriate referrals:

There was no CHANNAL phone number and those kinds of things weren't even available at the Recovery Centre. They didn't know who worked at CHANNAL or what CHANNAL was, necessarily. They knew there was something called the Warm Line – they had the Warm

Line number that someone had written beside the communal phone. [...] I imagine this thing in my head where, [what] if there were [community] liaisons who worked with Eastern Health or Government? (Mark, M, 30s, >\$100,000)

I wish that, you know, instead of [my GP] 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)

PLE thought that technology could be better used once referrals were made: to facilitate appointments, or to enable communication between service-users, individual healthcare providers, and co-operating organizations:

There is no 'transitioning between' services because there is no follow-up nor inter-department referrals; each experience with addressing the issues I have is 'fresh' to each department, with no data being shared to each other. [...] If I can rely on a private small business restaurant to fill my order using modern touch-screen pads, then why can't there be likewise for hospital staff, to facilitate a mentally ill person being able to physically move through the different levels of possible care without being made to sit in the same room for hours on end and repeat the same symptoms to different people, all of whom take physical notes on paper and pencil as if it is the 19th century, and then do not pass along their observations to the next person? (George, M, 40s, <\$20,000)

I think the main thing that really gets me frustrated is why on earth we're using letters. I just don't understand why we're using the mail for this kind of stuff. It boggles my mind. I don't know how it's more efficient. I don't know how it's less expensive. I don't know what the point is. I start to get these conspiracy theories that the point is to hopefully deter people from accessing services by making them either lose interest by the time the letter arrives, or potentially lose it. You know, is the idea that you want to make sure that only people who are 'really serious' are accessing services, and so you put a few hurdles in their way? (Beth, W, 30s, \$20-40,000)



Beyond organizational and logistical challenges, PLE found that they needed to muster many different material and internal resources in order to navigate their options.

SOCIOECONOMIC STATUS

PLE often recognized that a privileged social location improved their experience of accessing services:

[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 think in general 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)

I am, at the end of the day, a fairly privileged person. I'm sick and I'm trans, but I'm also white and highly educated and middle class and-, well, my parents are middle class. I'm still broke, but I have a support system. I have other people in my family who access mental health services and advocate for themselves. I'm concerned with how the system is failing other people. (Aster, non-binary, 30s, \$20-40,000)

I feel like a lot of times in Newfoundland services and institutions we get so married to, like this is the way things are. And that's it. You know, our way or the highway. Rather than thinking, OK, well, who is this not serving? How is this not meeting people where they're at and what their needs are? And how do we figure a way out? There's lots of creative, smart people in these institutions. It's not impossible. [...] I think that services should ideally be designed in a way where you take the person with the absolute least resources and you build it for them. And that means that everybody else who has more resources will also have no trouble getting it. (Beth, W, 30s, \$20-40,000)



EMPLOYMENT

PLE had access to more resources, and an easier time accessing them, depending on their employment. PLE had a better experience if they had employment that granted them services through employee assistance programs or private insurance packages, and/or they had compassionate management and could work a flexible schedule. When PLE worked low-paying or shift work without benefits, they struggled more to access and afford MH&A services.

I find it difficult now that I no longer have any insurance through work. I'm working part time right now but I don't have enough hours for benefits. My last job, that I loved, became very unsupportive when new management came in. I am now without those benefits. It's difficult to access things when medications cost quite a bit and I don't have any kind of coverage or supports that way. (Susan, W, 40s, <\$20,000)

It is a well-known, researched, and documented fact that the social determinants of health play a vital role in access and navigation of the mental health care system.



TRANSPORTATION

A lack of transportation was also brought up as a barrier to accessing services. PLE may be fully aware of available resources, but unable to physically get to them:

I don't have a vehicle and buses suck. So I've been unable to actually physically get to half of the places I could actually go to. (George, M, 40s, <\$20,000)

I have a long term chronic illness too. So just getting my body from place to place is very tough sometimes. And the fact that I was sort of putting my body in this problematic space was really difficult. (Aster, non-binary, 30s, \$20-40,000)

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)

I know we have drop-in services that are kind of intended to be low-barrier to get people in. Which is great, except that Doorways is in the middle of nowhere. And if you don't have a car like me, you know, how are you supposed to get there? Maybe there's a bus every hour. Maybe they can get you up there, but then you're stuck there. So all of our low-barrier services are not really low-barrier in a lot of ways. (Beth, W, 30s, \$20-40,000)

For this reason, some PLE noted how positive their experience with virtual services – use of which increased due to the COVID-19 pandemic – had been for enabling easier access:

I loved [accessing services over Zoom]. I thought it was absolutely amazing. [...] I don't have to leave to access something. It's right there in my home. I sincerely hope that some services would be offered [online] after the pandemic is over. (Brenna, W, 50s, >\$100,000)

Many PLE had also availed of the virtual Bridge the gapp service, outside of the contexts necessitated by “Snow-mageddon” (the major 2020 winter storm that immobilized parts of the province) and COVID-19. PLE reported largely positive experiences in regards to its ease of access, its usefulness as a systems navigation tool, and the self-directed programming – for example, many reported positive experiences using TAO (Therapy Assistance Online) specifically. Some noted that while Bridge the gapp was not adequate for in-depth, ongoing, or complex MH&A needs, it can be considered part of an essential circle of care.

HOUSING

PLE also described how lacking basic housing diminished their capacity to access MH&A services, or to make good use of them if they were available:

Seven years of being denied [housing] took a bad toll on me and made me feel abandoned, left behind, dismissed, and fallen through the cracks. I could no longer handle the system of NL Housing's denial process and it made me bitter, cynical and contributed to similar feelings that I engendered towards other government institutions. It was and remains a terrible period that added to my mental health anguish a thousand-fold. (George, M, 40s, <\$20,000)

I was homeless, for a very short period. [...] Housing, that was a whole different level of anxiety for me. Because with all the things that I've had my life, having a home to go to is always [...] the anchor to hold onto. [...] When you don't have a home, where's that anchor? Is it something you can hold onto, or is it tied to your neck now and you're drowning? (Connie, W, 50s, \$40-60,000)

This PLE described how all of these broader circumstances – education, employment, and so on – must be considered when creating accessible services:

There are a lot of models of mental health that put the onus on the individual for making their lives better while at the same time, particularly relevant now, we see that there are social conditions that affect someone's mental health. If you happen to be trans, you probably are more likely to be unemployed, and unemployed often because you are trans. And no amount of like, hey, this is gonna be OK is actually going to change those circumstances. [...] Connecting mental health conversations with those larger like socioeconomic conditions that end up affecting mental health, I think is an important step for making mental health services more useful. [...] Racism exists and transphobia and homophobia exists and classism exists, and poverty goes a long way in fucking your life up and you know, unless there is reasonable conversation between mental health services, physical health, and other segments of services that are working on these larger problems, then I think we're going to see mental health services continue collapsing in on themselves because of the individual focus that is sort of necessary to keep them going on the very, very few resources that they have. (Aster, non-binary, 30s, \$20-40,000)

RESILIENCE

PLE acknowledged that the longer they spent time in the MH&A system, the easier navigating services became. Previous experiences helped them know what was available and what to expect. This knowledge improved coping and enabled PLE to navigate services strategically and creatively. In confronting these challenges, PLE developed their capacity for resilience.

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)

The longer I was in the system [...] it became significantly easier [...] I had people that I identified [...] as people I could trust, people who had got things done. [...] So that entry could be challenging, but once you're in, there's [...] a wealth of things that open up. (Mark, M, 30s, >\$100,000)

On the other hand, many PLE expressed difficulty in locating and accessing services when first encountering the MH&A system, or when feeling overwhelmed:

I didn't know where to go to even begin to navigate the system to see what resources were there for me. [...] 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)

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

This PLE described how impactful it was to receive supportive guidance when seeking services during a difficult time:

I went to the clinic and I was like, there's something wrong, I can't think clearly, I'm really depressed. And then they kind of laid out a path for me, like, we'll put you in touch with this person. They'll contact you. You can set up your own schedule. And then we'll have an appointment for you with this doctor on this date. And it just felt very refreshing and very easy. (Lucy, W, 30s, >\$100,000)

Making our MH&A system easier to access and navigate is a fundamental concern for system improvement by both PLE and healthcare providers (HCP). We have shared PLE insights about the need to streamline services by improving technology and referral procedures, and by expanding both provincial and community mental health care knowledge among PLE and HCP. PLE described the need for resilience and self-advocacy skills – an immense expenditure of internal energy – to receive quality care at a time when they are the most vulnerable. They also evoked how the social determinants of health have impacted their experience of accessing and navigating services and their receipt of quality care. Our MH&A system favours the most privileged; those with access to transportation, safe housing, employee benefits, compassionate workplaces, high education status, social support, et cetera.

It is a well-known, researched, and documented fact that the social determinants of health play a vital role in access and navigation of the mental health care system. This is why a combined community and provincial initiative and effort is required, one that recognizes the linkages between mental health and socioeconomic well-being, and adequately resources community level services that are low and no-barrier. This could include services with no access criteria (such as sobriety requirements), mobile services, no-cost services, and increased liaisons between MH&A services and food security, housing, childcare, employment, and other healthcare services. Based on what we heard, these are CMHA-NL's recommendations:

Making our MH&A system easier to access and navigate is a fundamental concern for system improvement by both PLE and healthcare providers.

RECOMMENDATIONS TO IMPROVE ACCESS & NAVIGATION

Streamline Services:

1. Streamline services by having HCP take the initiative in regards to outreach and follow-up
2. Ensure community mapping of available services is thorough, up to date, and properly utilized
3. Ensure patient-navigator is connected to all who could benefit from this service
4. Improve use of technology (electronic health records, scheduling services, etc.) to streamline transition between services, communications between HCP, and coordination of care between service providers

Social Determinants of Health:

1. Acknowledge the social determinants of health such as education, employment, housing, et cetera, and work interprofessionally including with community partners to address them
2. Service providers should evaluate their own services to determine all potential barriers and reduce them as much as possible through, for example, virtual, free, non-referral based, or mobile services
3. Adopt a Housing First approach as a foundational element of mental health and addictions services



2. Continuity

The issue of trying to access long-term care versus short-term solutions was a major point of discussion in our interviews. When PLE reported the MH&A care they received was effective, it was often associated with having a consistent provider they felt was the right match for them. However, it was difficult to create such a relationship because of system limitations: PLE reported being offered only drop-in/same-day counselling, given limited opportunity to choose if a care provider was a good fit for them, unable to change providers if they felt it was not a good match, and pressured to only access a limited number of sessions.

SAME-DAY & DROP-IN SERVICES

Several PLE reported that drop-in or rapid access counselling, as provided by Doorways and the Women's Centre, was an essential service in terms of ensuring accessibility in times of crisis.

[Doorways] were professional and efficient. Everyone there was nice from reception until when you leave. It was positive. (Kim, W, 40s, \$80-100,000)

You get out [of hospital] and there's – it's almost like there's nothing. So I guess the Doorways would be filling that gap. (Tanya, W, 40s, >\$100,000)

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)

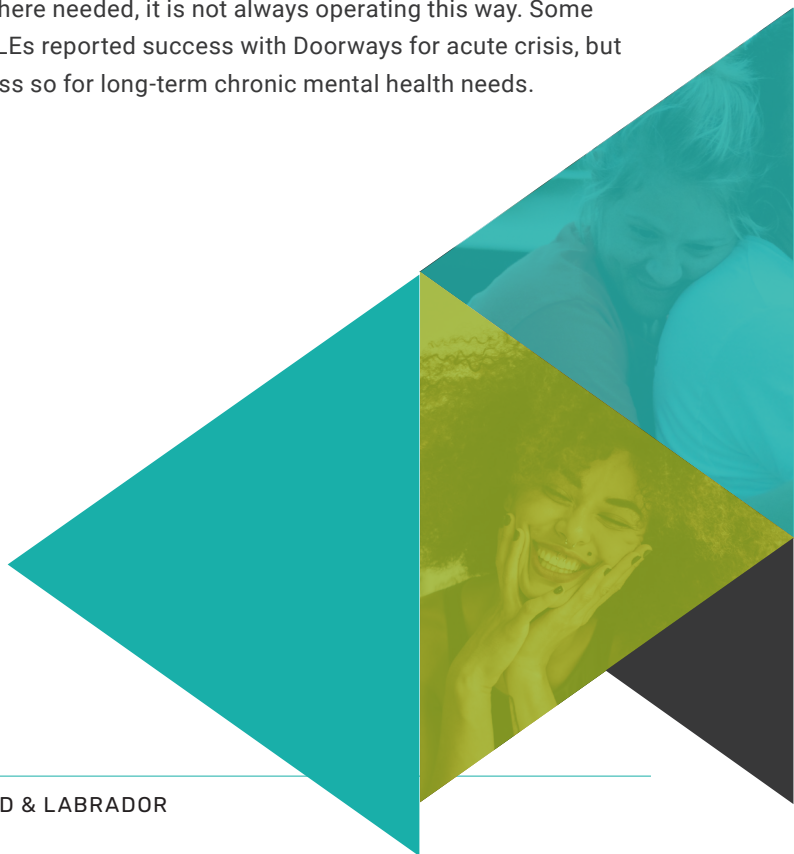
However, many also felt that an over-reliance on this model outside of crisis scenarios proved frustrating:

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)

If I just wanted drop-in counseling, I could go to Doorways, I could go to the Women's Centre. But I wanted continuous care of the kind of trust and scheduling that allows you to prepare in advance for talking about something triggering, to be able to know that you're going to see the same person every time. [...] I was just really disheartened by it, it felt like what was the point of all that stuff I went through? To get this: basically a phone number for drop-in? So I gave up on Eastern Health at that point. (Beth, W, 30s, \$20-40,000)

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. [...] So that was limiting. Their desire was there and they were really trying to be helpful. But I personally found that wasn't going to be terribly helpful, because I wasn't able to build any kind of establishment, any kind of rapport with one person. (George, M, 40s, <\$20,000)

Doorways have been an essential and life changing service to Newfoundlanders and Labradorians where entry into the MH&A system can be easily accessed. While the Towards Recovery plan envisioned Doorways drop-in services as an entry-point for people to be connected to sustained care where needed, it is not always operating this way. Some PLEs reported success with Doorways for acute crisis, but less so for long-term chronic mental health needs.



ASSIGNMENT

PLE also noted that when they sought services, they had little to no choice in who they would work with. While practical from a systems perspective, PLE argued that this impedes the effectiveness of the care relationship:

I just feel like every psychiatrist and every health professional kind of has their own style. And if their style doesn't suit you, it can be really frustrating – and likely for both parties. But I understand that there's only so many people who you can see. (Michelle, W, 20s, \$60-80,000)

I don't think you have any option or choice. I think your referral is picked up by the triage nurse or whatever, and then it's just assigned to the next available counselor. (Roxanne, W, 40s, >\$100,000)

[Throughout] my history with mental health, I've been passed around a lot. I've had thirty-three or thirty-five-ish admissions to hospital here. And every time, whatever you're admitted under, that's your psychiatrist. I think that was the most difficult part of it all, is that every time I was admitted it would be someone new. (Christine, W, 40s, >\$100,000)

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SUSTAINED RELATIONS

PLEs preferred to build sustained relationships with care providers. They sought follow-up and after-care from providers they connected with during treatment. When follow-up was not instigated by healthcare providers, PLE would sometimes initiate it themselves. PLE also reported that switching to a new person could set them back in their treatment/recovery. Sometimes a switch was forced by system circumstances. For example, because this PLE had been assigned to someone hired on a temporary basis to replace someone on leave, their care was discontinued when the original employee returned to work:

Then the counselor that I had been seeing was no longer in that role. So I was not able to continue seeing the counselor that I had developed a rapport with and who knew my story. (Emily, W, 40s, \$60-80,000)

On the other hand, when PLE were able to establish a sustained relationship with a care provider, this was very beneficial to their recovery. PLE had positive experiences when they were able to avail of continuous programming:

The trauma program was a lifesaver [...] It helped me unpack the trauma that had happened and really helped me identify where all my negative coping mechanisms were coming from. (Meg, W, 30s, \$60-80,000)

When I went to the Grace Centre it was an absolutely amazing program [...] You're put into a bubble and it's a very safe bubble and is very nice. And everything is attended to, where it becomes a real program of being selfish for the right reasons. So it's all about you. (Lorne, M, 40s, \$80-100,000)

PLE described working hard to maintain relationships with care providers, as this allowed them to build trust, made therapeutic sessions more productive, and assisted PLE in reaching out and accessing additional support when needed.

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)

[Having a consistent healthcare provider] is super useful because I'll be talking about an issue that I feel is new and she's like, well, actually, we started talking about this five years ago. So really valuing that longer-term picture of things. Because as a lot of the research shows, if you have an issue, you will probably deal with it in spirals for your whole life. And having that continuation is so helpful. (Aster, non-binary, 30s, \$20-40,000)

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)

PLE acknowledged that when care providers adapted services to meet their needs – which sometimes necessitated pushing against common practice – they were able to build trusting, sustained relationships that promoted recovery:

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)

I used – I guess they call it Doorways, but I didn't go through the drop-in on Wednesday. I called and said I wasn't really comfortable doing that, so they made an appointment for me to go in and see someone for intake. [...] Then I went back and I saw a counsellor after that. I've been seeing her since. (Kim, W, 40s, \$80-100,000)

Quality relationships between HCP and PLE are an essential factor in care and recovery. The sense of connection based on shared humanness can offset feelings of isolation and vulnerability for PLE, as well as improve confidence and safety in care. In order to promote the creation and maintenance of quality relationships with HCPs in our MH&A system, we must address the barriers as outlined above. While we cannot control all circumstances – such as a

service provider leaving a role and ending the care relationship – we can ensure all clients are well-connected to support and referred out when necessary. Thorough case transfers should always be completed. Continuity of care through a trauma-informed perspective should assist in the development of effective policy and practice.

PLEs preferred to build sustained relationships with care providers. They sought follow-up and after-care from providers they connected with during treatment.

Many HCPs are already committed to trauma-informed care and understand the impact of retraumatization caused by PLE having to re-tell their stories or relaying medical/social histories to different professionals. We commend those who remain flexible and attuned to the needs of their patients and community users. PLE shared that it was these efforts made by dedicated and caring professionals that made all the difference in their experience with the MH&A system. This is an example of how appreciated and valued health care professionals are by PLEs and how warmth in care truly matters, is felt, and transferred from person to person. Programs should be evaluated for administrative, bureaucratic, and other system barriers that prevent the maintenance of quality care relationships.

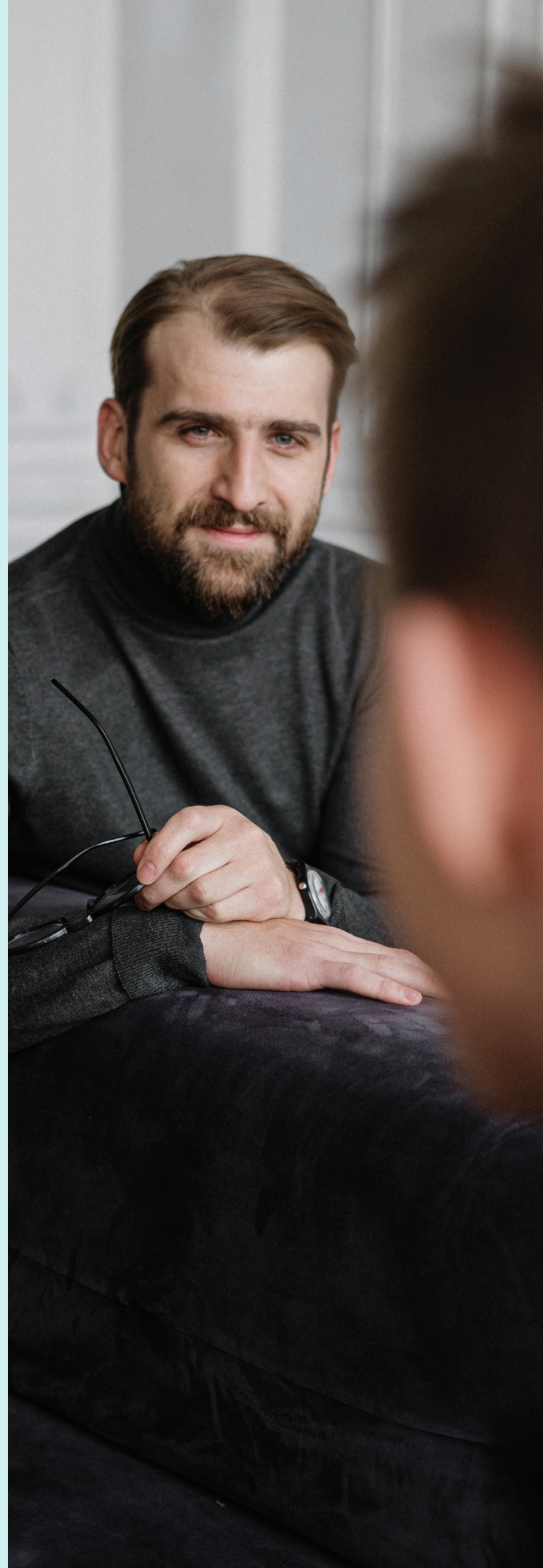
RECOMMENDATIONS FOR CONTINUITY OF CARE

Doorways

1. Improve communications to HCP, PLE, and the broader public around the breadth of services offered at Doorways, such as therapy modalities and referrals to appropriate long-term care
2. Enable flexible Doorways staff to case manage interim periods while PLE wait for long-term services to begin
3. Continue to evaluate Doorways services through PLE and public engagement

Improving Sustained HCP-PLE Relationships

1. Adopt a Trauma-Informed perspective to guide reform
2. Improve HCP assignment by developing better ways to best match PLE to providers
3. Lower the barriers to switching providers if a match is deemed inappropriate by PLE
4. Per recommendation 1.4 above (re: electronic health record), use technology to improve communications between providers to reduce problems associated with inconsistent HCP
5. Foster sustained relationships by prioritizing sustained care relations where possible
6. Increase HCP-instigated follow-up
7. Limit changes in providers mid-treatment
8. Institute and ensure thorough case transfers
9. Reconsider maximum appointment cut-offs on a case-by-case basis



3.

Proactive VS Reactive

In many ways, PLE described the available services – particularly from the public system – as more reactive than proactive. Timely services were more available following some form of crisis, for example, after a suicide attempt or after having been arrested.

On the other hand, PLE described having been denied services because they were considered ‘too unstable’. This created a difficult scenario where one needs to be in a precise degree of distress to be both a priority and treatable by the system.

CRISIS REQUIRED

These PLE described accessing services more readily after some type of crisis had occurred:

I did find a difference in that 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)

We need to do better because if I came in with a broken arm, they would treat it then and there. If I came in with a cardiac problem, based on severity, you might be admitted right away. But if you go in with a mental health issue, they can't see it unless you're acting out. (Connie, W, 50s, \$40-60,000)

[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)

It sort of took me getting to my breaking point in order to access the services that I needed. [...] There is that super long wait time unless you're like really, really dire, which is messed up because we know that once you're at the dire point, it takes that many more resources to get you back to where you actually need to be. (Aster, non-binary, 30s, \$20-40,000)

This was particularly the case with accessing psychiatry:

Getting to see a psychiatrist was not easy at all [...] Up until being admitted as an inpatient [due to an adverse reaction to SSRIs] I couldn't get outpatient psychiatric service. (Meg, W, 30s, \$60-80,000)

The only way I got psychiatry was from being in hospital overnight. I don't know if I was ever referred. (Christine, W, 40s, >\$100,000)

Some PLE saw this situation, and the wait times attached to seeking care outside of a crisis, as a ‘Band-Aid’ approach:

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)

Nothing is really immediate. I felt like a lot of times I needed immediate help, and then I had to wait months and months and I would get a lot worse. And then by the time the waitlist came around [...] I just wouldn't go. Part of me was like, I don't deserve help. Part of me was just like, I don't want to get out of bed. [...] If I'd gotten there a bit sooner, I think maybe I would have gone to some of those intakes. (Mallory, W, 20s, <\$20,000)

CRISIS PHONE LINES

Regarding the provincial crisis phone line specifically, when PLE felt they were attended to with warmth and compassion, they reported positive experiences.

The interaction [with the crisis line] was excellent, it was quite helpful. It was productive for sure. (Mark, M, 30s, >\$100,000)

But the person that I did speak [mental health crisis line] with, I remember being quite understanding. [...] By the time I hung up, I was feeling better and I didn't feel like I was in such a crisis. [The crisis line worker] said, well call back tomorrow if you still feel like you need us. [...] So the person I spoke with was quite helpful. (Emily, W, 40s, \$60-80,000)

In other instances, PLE felt the crisis line was evaluative and cold, rather than compassionate and helpful:

I absolutely hate calling [the crisis line]. It feels like they're just trying to assess whether you need to go to the hospital or not. (Mallory, W, 20s, <\$20,000)

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. (Susan, W, 40s, <\$20,000)

This PLE also noted that the crisis line's tendency to involve the RNC was a deterrent to using it:

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)

Other PLE reported positive experiences with the Mobile Crisis Response Team, noting that training of RNC in de-escalation techniques, and the wearing of plain clothes instead of police uniforms, improved these encounters:

What a help that program was, to just do training of the RNC officers [...] Previous to that, they would [be] violent [...] [After training] it was a much better relationship and it didn't escalate into anything. (Gertrude, W, 60s, >\$100,000)

[When the crisis unit came] I think it was a psychiatric nurse and a police officer, I'm not sure. But they came in and just sat down, just had a chat with me and everything, just to make sure everything was good. I didn't know the young girl was even a police officer [because she was in plain clothes]. [...] Talking to an officer [is] kind of intimidating, you know, because they can put the cuffs on you and take you against your will almost, right? [...] [But] I didn't even realize they were police officers. So it's a good thing, I guess. Because that would kind of bring your anxiety up. (Janet, W, 50s, \$20-40,000)

The establishment of community supports such as the Warm Line were viewed by many PLE as filling an important gap, providing low-barrier care before a crisis had been reached:

It's either you were in crisis and you should go to the Waterford hospital right away, or it wasn't really the right place to go. [...] I think that after the Warm Line was set up, it kind of gave us another option for people just looking to talk to somebody in a mental health, not necessarily crisis, but you know, before a crisis occurred. (Michelle, W, 20s, \$60-80,000)

Either PLE were not believed because they were not 'crazy enough'... Or they were denied care because they were 'too crazy.'

THE 'RIGHT KIND OF CRAZY'

Throughout our interviews, PLE described many ways in which they needed to express the 'right' kind of mental health issue in order to be treated. Either they were not believed because they were not 'crazy enough':

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)

Or they were denied care because they were 'too crazy':

I didn't get accepted [to Stella's Circle] then because I was too unstable. They wanted me to not be hurting myself all the time and be stable enough to complete their program. And then I didn't get accepted. (Mallory, W, 20s, <\$20,000)

PLE thus felt they had to perform a certain way to be treated compassionately. They attributed this to continued stigma and mistrust, in part due to the 'invisible' nature of mental health and addictions issues:

I have felt an overall, low-level sense of not being taken seriously by my GP and especially by the Waterford Hospital PAU. I have found myself being forced at times into a pattern of over-explaining my symptoms, my mind-set, my mental health issues and their impact on my well-being [...] If it wasn't physical, if it wasn't something he could diagnose or visually diagnose, it didn't exist. (George, M, 40s, <\$20,000)

I think if someone was having a relapse with cancer or another disease, there's more empathy available for it. So if someone had a relapse, then people tend to gather around and services are quickly available, it seems. But if someone has a relapse from addiction, it's a lot less so. That's where I felt and I see the stigma most. (Brenna, W, 50s, >\$100,000)

PLE reported that many of the province's MH&A services routinely required them to be in crisis as criteria to gain access, however what constitutes a crisis was determined by MH&A professionals rather than PLE themselves. Many felt that access to psychiatry, counselling, crisis lines, and inpatient treatment came at the expense of being treated according to outdated, evaluative, judgemental frameworks. For decades, PLE have been labelled 'histrionic', 'attention seeking', or 'medication seeking', reduced to symptoms and DSM labels without acknowledgement of their suffering or affirmation of their dignity. We must acknowledge that stigma and sanism¹ exist not only at the social-community level, but is also embedded within MH&A institutions and disciplines. When MH&A services are reduced to a medical model, we can lose sight of our shared humanity.

The adoption of social perspectives toward mental illness and addiction are necessary to transform institutions and policies that violate human rights. Many HCPs hold and adhere to anti-oppressive frameworks of practice, but are constrained by antiquated perspectives and policies entrenched in our systems which limit their ability to practice new and inclusive approaches.

From the PLE perspective, there is a need for more prevention services that offer substantive, practical support, rather than 'anxiety 101' educational groups or volunteer-run phone lines. Instead, we could consider more PLE-led education programs, group services, and barrier free spaces in which to relate and connect. We also need to improve access to psychiatry and create more opportunities for interprofessional work between psychiatrists and community MH&A services. While we do not yet have all the answers, little by little we are coming closer to finding them. All services are encouraged to evaluate their programs from the PLE perspective, and ideally to do so using the principles of participatory action by involving PLE in those evaluations through volunteer and/or paid opportunities. PLE-led service evaluations allow PLE to shed the illness identity, and can help us create innovative solutions in the provision of proactive care.

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).

RECOMMENDATIONS FOR PROACTIVE VS REACTIVE CARE

Increase the availability of preventative services

1. PLE-led education programs
2. PLE-led therapeutic groups with no specific assessment criteria
3. Informal barrier-free spaces for PLE to relate and connect
4. Evolve the Warm Line to increase capacity and specialized knowledge
5. Provide interim services during wait times, such as regular phone check-ins to give updates on wait times, assess for present needs that can be met through appropriate referrals, and offer brief emotional/psych interventions; and by continuing to refer PLE to the Warm Line, Bridge the gap, and other phone line, online, and self-directed services

Crisis Service Reform

1. Undertake training of crisis line operators in cultural humility/safety, social issues, and the provision of compassionate care
2. Establish PLE-led and staffed community crisis beds

Institutional Reform

1. Improve access to psychiatry by incentivizing and increasing hires
2. Eliminate police as first responders to mental health crisis events. If police presence is required, ensure they are unarmed, trained in mental health, and arrive in plain clothing
3. Fight sanism in the MH&A system through the implementation of open-door policies and less criterion-based evaluation and access thresholds



4. Confidence

Several interviews demonstrated a lack of trust in MH&A services. Some PLE expressed doubt in the MH&A care system generally, or that specific MH&A providers were competent in their practice and dedicated to acting in PLEs best interests.

Some PLE described a general mistrust of MH&A services:

I did not have a great deal of confidence in the system in place to assist me or properly diagnose and form a firm grasp on my ongoing needs. It felt in some respects like lip-service and addressing only the mere basics, not as the lifelong process that it ought to be regarded as. (George, M, 40s, <\$20,000)

This mistrust was often accompanied by an understanding that there are individuals or professional fields doing their best to provide quality care, but who are thwarted by power struggles or system constraints:

Social workers and psychologists are picking up on a lot of what's been going wrong [in the MH&A system], but they're always stopped by the head people. [...] Why are they [psychiatrists] the boss? And how are they showing that they're effective? [...] There is a power imbalance because we've been to meetings and we've seen the psychiatrist at one end of the table and everyone else at the [other end of the] table. (Gertrude, W, 60s, >\$100,000)

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)

PLE often related lack of appropriate care to feeling that they were denied human compassion, genuine connection, and empathy from their care providers.

'WORSE THAN BEING AT HOME'

More specifically, several PLE felt that they had received less than adequate care, particularly at the Waterford Hospital's Psychiatric Assessment Unit [PAU]:

I've gone to the PAU 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)

We're supposed to live in Canada in 2020. Why am I going to this friggin Victorian hospital that's been around since my grandmother was young? I'm buzzed in and buzzed out and I'm in a room that might just as well be a confinement centre. Why was I left alone? It was not a very pleasant experience, and that kind of coloured how I approach things since that made me a little bit reticent to further explore other avenues. [...] It made me kind of draw back and realize that, boy, I'm not getting the level of care I think I deserve as a person. [...] I use the word disheartening. This is all I can say, because I thought if anybody should know how to handle mental health, it should be the Waterford Hospital and the staff of the Waterford Hospital. It's why they're there. (George, M, 40s, <\$20,000)

On the other hand, other PLE described more positive experiences at the Waterford:

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)

Things are changing at the Waterford, but it's slow [...] [My child in care there] is going to start music therapy this week. He communicates through music [...] So that's happening now, and it's all about getting the right person. (Gertrude, W, 60s, >\$100,000)

COMPASSIONATE CARE & CONNECTION

PLE often related lack of appropriate care to feeling that they were denied human compassion, genuine connection, and empathy from their care providers.

I've also had a lot of experience with going through the Health Sciences and St. Clare's, and sometimes the nurses can be very unprofessional, saying stuff at the nurses' station about me. Like last time I was there, they were talking to each other and talking about me and they called me an 'attention seeker' and it was so hurtful, and I cried for days about it. It was just so unhelpful. (Mallory, W, 20s, <\$20,000)

This is the same person who said I know your son and I, I've been working with him on and off for 5 years. I said, oh, what's his favourite song? What is a movie he likes?

Do you know any books he likes? I was like, How can you say you know someone when you don't know? You can't even answer that question. Why? That's a disconnect. (Gertrude, W, 60s, >\$100,000)

On the contrary, when PLE could make a genuine connection, they had a more beneficial experience:

When [my counsellor] would connect with me [she started with] just that little bit of, you know, Good morning. How was your week? How is the weather? And then we would jump into our conversation. So that made it more personal, opposed to me just being a chart. Because I know that happens regularly and it happens in our clinics. You know, with nurses and patients as well. 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)

[My latest care with my GP and the Recovery Centre] 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. And I don't know if that comes with being an adult and a professional myself. But I just felt more respected, I guess. [...] Not as much with psychiatry as I have with counseling and mental health nurses. (Michelle, W, 20s, \$60-80,000)

PATIENT INVOLVEMENT

One key element that determined if PLE felt respected and empowered was the degree to which they were involved in their own care plan. Many PLE described fulfilling, cooperative relationships with their healthcare providers:

I definitely find [treatment] works better if I have a little bit more control over it, because then I tend to follow through a little bit more. [...] [My psychiatrist] asks for my opinion and I feel valued and I think that's really great. Like if I change medications: she'll give me a few options about what she thinks would work for me, and I get the final decision. (Mallory, W, 20s, <\$20,000)

My relationship with my health care provider is absolutely outstanding. There's a great deal of respect and assurance that I'm not alone, we will make this better together. (Kathleen, W, 50s, \$40-60,000)

On the other hand some people felt they lacked involvement in their care:

They want you involved in your care, but they don't want to listen to your recommendations. [...] They were more concerned about how they wanted to do things, not how it affected me. (Janet, W, 50s, \$20-40,000)

PLE reported that when they were involved in decision-making, they felt more optimistic about recovery and more motivated to pursue their treatment plan. Family members of people in care wanted to be more involved in the design and implementation of treatment plans for their loved ones, and to have supports for the family alongside those for the person in care:

There is no family centered care. [...] If we were involved, then things would be easier. I think there's a fear within the medical system, and particularly with mental health, that family members shouldn't be involved or their input isn't valid. (Gertrude, W, 60s, >\$100,000)

I wish that there was something out there to treat the family unit, not just the individual person [...] I wish that there was family counseling, like the whole family would be part of that healing process, not just the individual. (Roxanne, W, 40s, >\$100,000)

We wish that there were more services there for parents. So that way then we could have somewhere or some resources. And maybe there is [...] We just don't know about it. But we wish that we had more resources that we could go to, to see what is it that we're doing right? What is it we're doing wrong? What can we improve on? You know, to be able to talk to other parents that are going through similar situations. So it would be nice if there was something there for parents. (Hugo, M, 40s, \$80-100,000)

SPECIFIC ISSUES & MARGINALIZED POPULATIONS

PLE expressed a lack of confidence that care providers were informed about their specific needs, either in terms of the issues they were seeking support around, or in terms of the populations they belong to.

FEEDBACK

If you have accessed MH&A services from the Health Authorities and would like to offer feedback in the form of a compliment, a comment, or a complaint, you can do so through the following 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**

Two PLE recounted ways that some local MH&A services can be culturally unsafe for Indigenous peoples. For example:

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)

This PLE went on to discuss having to spend time and emotional energy educating NL Mental Health Crisis Line operators around major Indigenous issues of importance to her call:

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)

Another PLE explained how unsafe local MH&A services can be for trans individuals:

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. You know, it's impacting my relationship with my body. And I'm getting signals from my body that are really confusing. 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)

They continued by pointing out that many other trans people known to them avoid accessing services for these same reasons:

A lot of trans people are afraid to go into mainstream mental health services because they don't feel like they'll be seen and read for who they are. Or that if they come with questions around their gender, then perhaps that will be used against them to undermine whether or not they are that gender in the first place. I hear that a lot. (Aster, non-binary, 30s, \$20-40,000)

This PLE described how she did not trust public MH&A services to be safe for people with sexually marginalized practices, such as sex work, consensual non-monogamy, and kink²:

I would love to see is 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 specialty], 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)

²Sex 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 polyamory 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'.

Other PLE noted that MH&A services and/or care providers were not well-suited to treat their specific mental health concerns. One PLE found a lack of suitable resources for eating disorder:

I had trouble finding somebody that worked for me because the issues that I deal with were particularly related to having an eating disorder. And for eating disorders, it's quite important to get a mental health professional who has experience with eating disorders. I found a lot of times if people didn't have experience, or the experience wasn't great, then it just wouldn't be a good fit between me and that person. So I had a lot of trouble for quite a while trying to find mental health support there. (Alexia, W, 20s, \$40-60,000)

A lack of specialized services is exacerbated in less resourced rural contexts, as this PLE also describes difficulty accessing MH&A services broadly and eating disorder support specifically:

So even though I was experiencing symptoms of depression and eating disorders when I was [age] and when I was still living in rural towns, that wasn't something that my doctor ever asked about. [...] There should be more emphasis on having those conversations as a GP in a rural setting, which is unfortunate because I know that that's not there. [...] That's not what they signed up for, but being a physician in a rural area, you kind of become the catch-all for everything. And I think there should be a little bit more emphasis on mental health for GPs in rural areas. (Angie, W, 20s, \$20-40,000)

Several others felt they, or people they knew, had received a lack of specialized care for addictions:

If I had been referred to the Recovery Centre, which knowing what I know now, I probably should have been from a health perspective, from a medical perspective [because] I went through major withdrawals in my first week. [...] I probably should have been hospitalized to get through that first week. But that wasn't even brought up to me. (Emily, W, 40s, \$60-80,000)

When my doctor sent me to the psychiatrist, he sent me to the right one because he sent me to a psychiatrist that understands addictions. Some don't, because again, I hear people in meetings talking about it and their psychiatrists: Not a clue. Or their family doctors: Not a clue. And so I fell in with the right doctor because he was so familiar with addictions. (Irina, W, 50s, \$40-60,000)

PLE expressed that GPs are sometimes quick to prescribe medications rather than making appropriate referrals to counselling or alternative services.

PSYCHIATRY & DRUG PRESCRIBING

PLEs reported having mixed thoughts and feelings around psychiatric drug prescriptions.

Many reported they felt psychiatrists prescribed drugs too readily. This parent expressed regret over allowing her child in care to be medicated, citing a lack of oversight around side effects and adverse reactions:

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)

For example, one PLE was prescribed a drug she had previously reacted poorly to:

The psychiatrist just kind of gives you drugs and tells you to go away. He ended up prescribing me the same drugs twice when I was allergic to one. (Delilah, W, 20s, <\$20,000)

On the other hand, many PLE explained that medications were a crucial element of their recovery plan. This PLE described how stigma around psychiatric drugs had made her hesitant to use them, but they were ultimately beneficial to her recovery:

I had been in denial about it as well, you know, before I got put on a daily medication. No, I don't need that. I can see through it. I've been there, done that. And no, you know what? It's OK. It's OK to seek help and to be medicated. (Emma, W, 30s, >\$100,000)

PLE expressed that GPs are sometimes quick to prescribe medications rather than making appropriate referrals to counselling or alternative services.

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

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)

On the contrary, this PLE describes how positive an experience she had because her GP was not solely focused on drug-prescribing:

I was very lucky to have met a remarkable doctor. His answer wasn't just pills, pills, pills, as I experienced in my younger days. It was about talking and getting to the root of where the high emotions were coming from. [...] I feel very safe using medication he may prescribe, as he always follows up on side effects, the lack or help it's proving or if it's not helping. I feel safe because I know he's not just throwing pills at me to fix my illness. Much talk comes before medication. (Kathleen, W, 50s, \$40-60,000)

Overall, PLE were concerned when healthcare providers prescribed medications when they were not adequately informed about possible adverse effects, when drugs were not coupled with other supportive therapies, and when there was a lack of trust in the healthcare relationship. On the other hand, when relationship building was the primary focus between healthcare providers and PLE, PLE felt more confident in the prescribing methods and other treatment plans suggested to them.

COMMUNITY SERVICES MORE TRUSTED

Community embedded services, especially peer-support and spiritually oriented models such as CHANNAL or 12 Step programs (Alcoholics Anonymous and Narcotics Anonymous), were generally trusted more than public services:

I would say [my 12 Step Program] is a 10 out of 10. Yes, absolutely. I belong to a recovery community and help is always available [...] It's because anyone who's recovering, our very lives depend on us helping someone else. That's the core of that philosophy [...] [that] in helping someone else, you're helped. It's not a medical model. It's a spiritual model, right? So help is always very quickly available, like within an hour. (Brenna, W, 50s, >\$100,000)

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

I've also been calling CHANNAL a lot lately and that's been great. [...] I think that's one of the things that's really helped me a lot. Probably helped me the most. (Mallory, W, 20s, <\$20,000)

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)

I feel like non-profit community organizations and advocacy groups have a better grasp on [mental health and addictions], and are better at coordinating services than medical institutions are. I feel like things are more current and there's maybe a better understanding of how we can try to address and look at complex mental health needs by people who have actually either lived and dealt with it. (Mark, M, 30s, >\$100,000)

General distrust of our MH&A system can result from the many issues and barriers outlined by PLEs in this report. The information shared with us here outlines the areas where we



can improve confidence in our MH&A system. PLEs describe a better experience and improved outcomes when they are able to build a warm and compassionate connection with HCP, and when they are afforded agency at all levels of decision-making about their treatment plan. This has the power to restore PLE's faith in the system and in themselves. Client and Family Centered Care have long been buzz words. While many HCP endeavor to follow these approaches, it is often institutional policy and procedure which make it difficult to do so. PLE acknowledge that HCP confront many institutional and bureaucratic barriers in their daily, dedicated efforts to provide quality care.

Ensuring client-centred care includes involving PLE in decisions around medication: PLE should be offered the full breadth of available options and be thoroughly informed of potential side effects. A collaborative approach to prescribing can improve drug safety by giving clinicians important individualized context with which to prescribe, while also increasing PLE faith and involvement in their care plan.

Many PLE felt that MH&A workers sometimes lacked an understanding of their communities that was essential to providing care: an awareness of both past and ongoing processes of colonization, and the impacts of intergenerational trauma and resilience among Indigenous peoples; an appropriately nuanced grasp of gender identity and expression; and a non-judgemental approach to sex work and non-traditional sex and relationship structures. Finally, some PLE felt their HCP did not know how to adequately treat addictions and eating disorders. HCP should be encouraged and incentivized to build competency in these areas, so that services are not only suited to PLE from the most dominant sectors of society. This includes ensuring more people from a variety of diverse communities enter into the field of MH&A.

In light of all these concerns, many PLE preferred to turn towards community services rather than those offered by private providers or the Health Authorities. Community-based services were generally considered more compassionate, trust-worthy, and tailored to specific community needs. Community models need to be supported, and can also inform how we evolve our provincial services.

RECOMMENDATIONS FOR CONFIDENCE IN THE SYSTEM

1. Support HCP in building trusting compassionate relationships, by evaluating the status of funding and staffing rates to address compassion fatigue, stress, and burnout; ensure HCP have support in accessing MH&A services themselves as needed; adjust policy to give HCP more agency in adapting care to specific PLE needs
2. Enhance client-centred care by involving PLE in the creation of their treatment plan; work collaboratively with PLE to establish personalized and descriptive treatment outcomes rather than simply prescribing services to be accessed
3. Enhance family-inclusive care when requested by PLE by creating space to involve families in treatment planning and amending policy where needed
4. Increase availability of supportive services for family members of PLE
5. Increase availability of care that is culturally safe for Indigenous peoples, 2SLGBTQIA+ people, and people with non-dominant sexual and/or relationship styles
6. Incentivize continuing education in specific mental health and addictions issues, and in the latest evidence around psychiatric drugs
7. Ensure potential adverse effects of psychiatric drugs are communicated clearly and transparently, and that non-pharmaceutical treatment options are discussed and made available
8. Develop a mental health advocate office to deal with grievances, ombudsman, etc.

PLE acknowledge that HCP confront many institutional and bureaucratic barriers in their daily, dedicated efforts to provide quality care.

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)*





FOCUS AREAS

PAVING THE PATHWAY TOWARDS RECOVERY

PLE-determined
focus areas for future
measurement

The above discussion illustrates the dominant concerns and key areas for improvement as defined by the PLE we interviewed.

The following series of questions is designed to enable continued review and evaluation of these issues. However, in the spirit of continual PLE-informed evaluation, this is by no means an exhaustive or definitive list. Rather, future evaluations must always remain open to hearing new voices and identifying new areas of importance as they arise.

1. Access:

- 1.1. Streamlining - How was the transition into and between services?
- 1.2. Socioeconomics - Do you feel your material circumstances (employment, income, housing, access to transportation, etc.) impacted your ability to receive MH&A services?
- 1.3. Resilience - How much energy do you feel you had to exert to access services?

2. Continuity:

- 2.1. Short-term vs long-term needs - Were you able to access immediate services when in crisis? Were you able to build meaningful relations with HCP over time when needed?
- 2.2. HCP appropriateness - When assigned to an HCP, do you feel it was a good match? Did you have any role in selecting your HCP? What was the intake process? If you wanted to or tried to switch HCP, what was that experience like?

3. Proactive vs Reactive:

- 3.1. The 'right kind of crazy' - Do you feel that the way you presented/behaved influenced the service (i.e. access, quality, and/or safety) you received? (e.g. not taken seriously; feared)
- 3.2. Crisis as criteria - Did you try to receive care and were denied? If so, what happened?
- 3.3. Did you engage in self-directed learning (i.e. Bridge the gapp, WellCentral.ca, or other online courses or reading content)? If so, what was this experience like for you?

4. Confidence:

- 4.1. Trust - Do you trust the MH&A system broadly/your HCP specifically?
- 4.2. Compassion - Do you feel your HCP cared about your recovery? Do you feel they tried to get to know you as a person?
- 4.3. Involvement - Do you feel you were adequately involved in developing your own treatment plan? Do you feel your family/caregivers were able to be involved in your treatment plan, if you wanted them to be?
- 4.4. Marginalization - Have you ever felt as though you were treated differently than other clients or treated unfairly due to your gender, age, sexual orientation, ethnicity, religious beliefs, ability, the type of service(s) you were seeking, or any other reason while accessing mental health and/or addictions services?
- 4.5. Pharmaceuticals - If applicable, what was your experience being prescribed medications? Were you fully informed of potential side effects, presented options, and given space to ask questions?



LOOKING TOWARDS

FUTURE STEPS

We know the urgent
concerns facing PLE
using the MH&A system in
Newfoundland and Labrador

We know the urgent concerns facing PLE using the MH&A system in Newfoundland and Labrador. We have known them for quite some time.

We see parallels between the areas for improvement identified by this report and by previous MH&A system evaluations completed in the province: the need for a system that does more than tokenize but rather centres PLE as the decision-makers, innovators, and agents of change; the need for more streamlined services and interprofessional collaboration within and beyond the health system to include other sectors that impact the social determinants of health (e.g. housing, employment); and the need to support HCP and improve working policy so they have the time and resources – both internal and material – to nurture relationships and provide compassionate, empathetic care. We believe this requires a radical transformation of our perceptions of mental health and addictions. Beyond the medical model, we must adopt a social justice approach to ensure services are accessible, safe, and prioritize quality human relationships.

While some work is being completed to address these gaps and issues from within the provincial healthcare systems perspective, these changes are often slow and carefully measured. We must continue to support innovation and leadership that deviates from the norm and genuinely centres PLE as decision-makers. But these are not uncharted waters. PLE-led services have been imagined, developed and co-created before. Internationally, there are initiatives with years of experience and success, including some that have taken a revolutionary approach – non-medical, person-centred, non-directive and community focused.

The Leeds Survivor-Led Crisis Services Dial House in the UK has been in operation for approximately 20 years and is a thriving example of a PLE-led service that successfully addresses acute mental health crises. The organization's guiding principles and beliefs are empowering to PLE; a focus on connection, empathy and person-hood rather than diagnostic labelling or prescriptive treatment plans. This approach is taken because, as their website points out, "Many people are also re-traumatized in the mental health system, labelled and stigmatized as having a 'personality disorder' or 'psychotic', when in fact their 'symptoms' are understandable human responses to terrible things that've happened to them" (Leeds, 2020, para. 1). The Leeds Survivor-Led Crisis Service Dial House shares commonalities with our Newfoundland and Labrador CHANNAL Warm Line service, which received a great deal of positive feedback in our interviews. However, the Leeds Dial House offers a physical space, a sanctuary

for those in crisis after hours when many other services are closed. The parallels between CHANNAL and Leeds Survivor-Led Crisis Service are encouraging. Further development of and resources directed to CHANNAL or a similar project could help bring this approach to the province.

Beyond the medical model, we must adopt a social justice approach to ensure services are accessible, safe, and prioritize quality human relationships.

Sweden's Family Care Foundation has liaised with its Ministry of Social Affairs to deliver the Healing Homes initiative. Healing Homes is an alternative to foster care, where folks who have not been helped by traditional psychiatric approaches live-in with families in rural Sweden to begin a new life and promote recovery. Host families are chosen based on their belief in the power of loving connection. While not PLE-led, Healing Homes operates on person-centered principles, supporting individuals to recover through social inclusion by providing a therapeutic family environment and counselling supervision. With 20 plus years of experience this model has documented long term success. Our FACT (Flexible Assertive Community Treatment) teams in Newfoundland and Labrador take a more clinical and medical-model approach to community care. FACT or an additional alternative service could embrace the person-centred values illustrated by Sweden's Healing Homes initiative. In a society that screams *self-care! self-heal! self-direct!* we emphasize the value of community care, collective healing, and community direction.

Here at home in Newfoundland and Labrador, the group Mad Pride on the Rock advocates for Mad identity and Mad politics through events, knowledge-sharing, and the creation of PLE-produced publications such as "Cracked on the Rock". The reclaiming of the term Madness is a way of redefining the medical notion of "mental illness" and is part of a long history of activism stemming from the psychiatric liberation

movement of the 1960s. Mad Pride on the Rock welcomes folks who “identify as mad/consumer/survivor/ex-patient/service user [to] celebrate mad culture, identity and history and believe in [their] right to equality” (facebook.com/madontherock/). The ‘Embracing Experiences’ team have become aware that some members have formed a non-profit, the Phoenix Wellness Centre, Inc., whose aim is the creation of a peer-run crisis centre. The centre would operate on a self-referral basis with no exclusion criteria for anyone over the age of 16. It would be fully accessible, allowing for freedom of movement and opportunities for sociability or privacy, as needed. Priority in staffing would be given not to nurses and social workers but to those with lived experience, who could sit with distress in an accepting manner. The goal of this project is to avoid hospitalizations, provide short term support, determine other needed resources, and build community connections (Andrea White, personal communication, December 27 2020).

We must continue to support innovation and leadership that deviates from the norm and genuinely centres PLE as decision-makers.



CONCLUSION

The COVID-19 pandemic has compelled everyone to adapt and redesign how we do things. Collectively we have proven that when our wellbeing is deeply threatened, we find the resources needed to adapt systems and lower barriers. We muster the will to do what it takes to meet our immediate, life-saving needs.

Mental health and addictions services are also a life-saving need. As a province, we have the expertise, the creativity, and the drive to develop a MH&A system where no one is left behind - to support CMHA-NL's vision of Mental Health for All. We have proven to ourselves, time and again, that we are resilient and adaptable. Systemic adaptation is crucial, for, 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 MH&A community to embrace "co-production in the commissioning, design, delivery, and evaluation of services, in order to truly transform services across all mental health settings" (Slay & Stephens, 2013, p. 1). We need to meaningfully engage people with lived experience in system evaluation if we are to sincerely understand and identify where and how the system fails to meet our needs.

But most importantly, we hope this report will support the ongoing evaluation of our MH&A system as we reimagine it. In order to ensure our MH&A system performance is optimal we need both system-level and PLE-defined indicators to be considered. As the Towards Recovery report says, "Redesign of the system to prioritize peoples' needs is essential" (2017, p. 13). PLE-defined indicators such as those we have identified here can help us measure if and how this invaluable goal is being reached.



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PROJECT DESIGN & PARTICIPANT DETAILS

Design:

Our Project Design began with our Recruitment phase. We designed a Call for Participants to reach our target audience, people with lived experience (PLEs) who have navigated the mental health and addictions system in Newfoundland and Labrador and who were over the age of 18. The call was advertised on our website and social media and was sent out to multiple channels like our Advisory Committee member organizations, community and non-profit groups, MUN and regional health authorities.

Interested parties connected with the project manager for further information and to schedule an interview. They were then presented with an informed consent and demographic form powered by Qualtrics. Given that these interviews took place during the height of COVID-19, we offered the options of video, telephone, or written interviews to participants. This way participants could choose their preferred method to tell their story. Recognizing these methods would be a barrier for some, we also employed low-barrier interview methods, to connect with more marginalized PLEs. We went to The Gathering Place and hosted in-person interviews to help make the project more accessible. Finally, we offered compensation to participants to thank them for their time and effort. Compensation was offered in mailed cheque or Tim Horton's gift card, whichever was preferred by the participant.

Our interview guide questions were based on 10 person-centred indicators of Mental Health and Addiction System Performance such as access, navigation, effectiveness, relationships with healthcare providers and stigma in MH&A services. Our interview guide was reviewed by external stakeholders and PLEs prior to its use.

Once interviews were completed, we transcribed and coded the narratives. We took a mixed inductive/deductive approach: some thematic codes were established in advance through our literature review; others were added as they emerged from the narratives. CMHA-NL developed a coding definition guideline or key to assist with standardization. CMHA-NL and NLCHI then collaborated on establishing common codes and definitions along with developing a standardized table to log codes and associated quotes.

The project recruitment materials, consent form, interview guide, and relevant coding definitions are available from the online companion document.

Participants:

50 individuals responded to our call for participants. Ten did not interview, either because they could not be reached with the contact information provided, decided not to participate, or missed their scheduled interview. We completed 40 semi-structured interviews lasting between 30 minutes to 1h30.

Gender: Of the 40 completed interviews, the majority (n=33, 82.5%) identified as women (30 cis/3 trans), 6 as men (6 cis/0 trans), and one as non-binary.

Age: The majority of respondents (n=12, 30%) fell into the 40-49 age range, followed by 30-39 (n=10, 25%) and 50-65 (n=8, 20%). The remaining 6 individuals were evenly split between the 18-24 and the 25-29 categories (7.5% each).

Income: The income distribution among participants was as followed:

Income bracket	n	%
< \$20,000	10	25
\$20,000 - \$40,000	4	10
\$40,000 - \$60,000	9	22.5
\$60,000 - \$80,000	5	12.5
\$80,000 - \$100,000	3	7.5
> \$100,000	9	22.5

Racial identity: We allowed participants to self-identify their racial/ethnic identity in a text box. The majority (n=20) wrote 'Caucasian'; another 7 wrote 'white' or 'white/settler'. One each wrote 'Indigenous', 'Inuit', and 'Canadian mixed-blood'. The remaining responses, one each, were: 'Canadian', 'Caucasian Canadian', 'English', 'Irish-English descent', 'Earth being', and 'Other'. (*Total does not equal 40 as there was data missing for 4 respondents). These answers suggest that approximately 75% of our participants are white settler.



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