

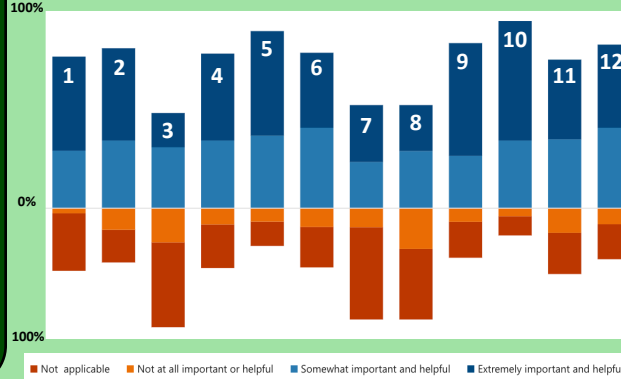
MENTAL WELLNESS FOR PEOPLE WITH DISABILITIES FORUM

Summary Report - Focus Group and Survey Data, November 28, 2023

RESOURCES & ACTIVITIES (% of responses)

1. Professional counseling/therapy
2. Doctor-prescribed medication
3. Non-prescribed substances
4. Peer support (individual or group)
5. Social interaction: gatherings, game nights, community events
6. Education: courses/seminars
7. Employment: career counseling, job programs, volunteering
8. Religion/spirituality
9. Home environment: a space that is clean, organized, clutter-free
10. Food security: eating wholesome, filling meals on a regular basis
11. Creative expression: arts/crafts, making music, writing groups
12. Fitness/Recreation: organized sports, exercise, hiking, etc.

Importance of Resources & Activities in Managing Mental Wellness



90
people with disabilities responded to our survey

50
people with disabilities took part in focus groups

12
focus groups held in English, Farsi, Dari, Arabic and ASL

WHAT DOES MENTAL WELLNESS MEAN TO YOU?

"Feeling like myself again. I remember what it was like before all these things happened in my life: becoming disabled, the car crash, my husband dying of cancer. I want to feel like my true self without fear of being judged or feeling unsafe. When my physical health issues are exacerbated, my mental health will decline because you can't feel well if you can't breathe, right?"

"I tremendously improved my mental wellness when I was able to contribute to society. That means holding down a job, having people say, 'Oh, well done, you really contributed to the team.' That feedback was missing when I was living in group homes and just surviving. By choosing to work, I lost all my benefits, supported housing, disability pension, supports from care teams, whatever perks I had. I'm not saying it's for everybody. I have nothing to fall back on so I still have fear of not having a safety net. When you work, you get money so to get coffee, buy your own art supplies, go on a vacation, all of that. I've done and still do a lot of volunteering. But actually getting a paycheck does wonders for my mental wellness."

"I spent a good five years after my accident in survival mode. For me, mental wellness is about getting past that and deriving some joy from life. Not only being able to vacuum my floor, but also have an enjoyable activity or two every day to give me a sense of purpose. Even just to eat healthy and exercise, there has to be a reason behind it. When you lose purpose, you don't care about diet, exercise, fulfilling relationships, because what's the point? So it's just a little step above survival mode."

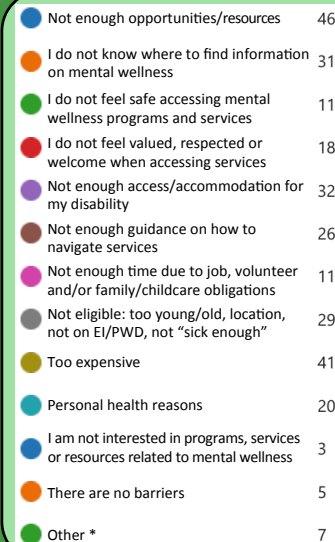
"I've had suicidal thoughts and learned not to share them with people. Someone told me once that suicide is a permanent solution to a temporary problem. It's a thought, it doesn't have to lead to action. It's not who I am. Yeah, life is crap right now. I think about it, but I just need to have someone to talk to without having the police knocking on the door. That's a weakness in our system."

"I shared in a group that I was not doing well and the first response was 'Have you talked to your doctor?' That is such a shutdown! What needs to be more available is inexpensive or free counseling."

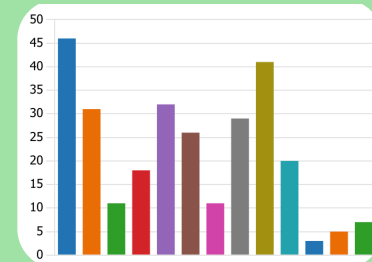
FEAR OF MENTAL ILLNESS

"I don't feel I can say, 'I'm having a panic attack right now,' if I'm at work. I may look like I'm having a normal day but inside my heart is racing. It would be nice to just speak freely and say, 'Hey, I'm not doing good right now. I'm experiencing high anxiety and I need to go in a quiet room for 20 minutes and calm down.' I don't know how it would be met and it doesn't feel safe to do that. It would be nice to actually be able to say how I'm really doing without judgment or fearing someone will call a psychiatrist on me and do a psychiatric assessment just because I'm having a panic attack, which I know how to handle. I've had them my whole life."

"Being able to listen versus shoving it off onto a professional would make it easier for people to talk. I mean, suicidal thoughts are different than suicidal planning. It's important to let people know you take them seriously but don't jump the gun. Be willing to listen more and don't react out of fear."



Barriers preventing access to mental wellness-related programs, services and resources



* Other barriers include lack of trauma-informed practice, language barriers, lack of follow-up, long wait lists, ableism, transphobia.

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INSIGHTS FROM FOCUS GROUP AND SURVEY DATA

- Mental wellness programming should reflect the wide diversity of clients, based on mobility, level of functioning, severity of disability, disorder or illness, hours of availability, language barriers, poverty, etc.
- Due to the enormous demand for free or low-cost counselling, peer support is commonly seen as a low-cost alternative. Compassion, sensitivity, active listening and facilitation skills are considered as important (or more) as trained mental health professionals.
- Due to limited knowledge about programs and services and how to access them, a dire need exists for peer navigators and more centralized information.
- To reduce stigma, program and service promotion can be framed around a specific issue rather than a diagnosis, e.g. "for those grieving the death of a loved one" or "for those who have difficulty getting out of bed."
- People with disabilities place a high priority on raising awareness about their own disability, condition or disorder. They want the general public to gain a better understanding of what their everyday lives are like.

"Frankly, we're sick of being treated with pity, infantilized and sidelined from life. We're not going to put up with it. We want meaningful lives and community. Nobody is perfect out there. We all have weird stuff happening in life, different boats and different storms on the same ocean."

"I'd love to see a brochure of Do's and Don'ts, just to eliminate the toxic positivity: 'It'll get better,' or 'You'll be OK.' Something that says: 'Top Ten: Do not ever say this to somebody struggling with disability and mental wellness. Here's what you could say instead.' We've lost so much of our life, those of us who weren't born with a disability, we're navigating that transition and on top of it, we're expected to be positive and put on a happy face. It's nauseating!"

FAMILY & FRIENDS

"I have no family here so I rely on friends who are often busy with their work and life. When it comes to my needs, I still have pride, unfortunately, so it's hard to ask for help even though everyone says, 'Let me know, I'll be there for you.' When I get sick I just fall off a cliff. I don't pick up phone calls. I feel exhausted. I don't want to get out of bed. I don't want to exist in this world. People knock on my door and I don't answer. Not that I don't care about people, I do, but at that moment I have no feeling, I'm numb. So my friends call the police to do a safety check. The police come and I'm all smiles. I'm very good at putting up a good face. 'Oh, I'm fine! Thank you. Bye!'"

"I had no idea how judgmental and ableist my family were until I became disabled. One completely alienates herself based on my physical illnesses like long COVID, emphysema and COPD. She's like, 'You're insane, nothing is wrong with you, you weren't exposed to anything, go away!' It's almost emotional abuse that I suffer daily with the ableist comments. They try to motivate me to be well, even though I have an incurable illness. I cannot make them care, I cannot make them understand, I cannot force them to learn the science behind my autoimmune and genetic conditions. They have no idea how deeply it hurts me. Emotionally, it's completely undermining the positive self-talk I need to do to keep my mental health from crumbling."

"I'm deaf and all my family is hearing. I'm often left out of the loop. At any kind of family event, I am not involved and don't find out until much later, which I think is wrong. I should be included equally and know what people are saying but I'm often just ignored. It makes me very sad; I go home afterwards crying. I would like to be with my family and understand what's going on with them."

"I spend most my time cooking, cleaning, going out with friends, and watching movies that are family friendly and helpful for mental health. I don't like to read a lot. I spend my time with my pet birds and they are beautiful. For me to be peaceful, I think about my family, my mom and my two sisters who are still in Afghanistan, and they are not safe there. My sister used to be a general in the Afghan forces. My brother used to be a journalist and his life was in danger in Afghanistan. He had to move to Pakistan, where Afghans are not being treated well. If my family is safe, that would be a huge help for my mental wellness."

NOT SICK ENOUGH

"I'm a first generation immigrant in Canada, I speak Mandarin and Cantonese and I am diagnosed bipolar. It's invisible and because I'm considered high functioning and well educated, I don't get mental health support. Peer support is so important, but apparently I'm not qualified because I'm not with any mental health team. It creates a lot of barriers and stress for people like us. There are just no services. I have to check myself into a hospital in order to be connected with services."

"I'm high functioning at times and then certain things trigger me and I can't function at all for one week to a few years depending on what it is. To me the system says, 'If you can communicate well, if you're somewhat intelligent, go home, talk to your GP and figure it out.' There are psychiatrists who write prescriptions but none that do therapy, and that's inadequate. We need more homes similar to Venture House (a short-term crisis intervention facility). If someone is in a really serious mood state they shouldn't be alone but sometimes there's no place for them. A person shouldn't have to go into emergency and act and perform that they're sick enough so they can go somewhere. It's ridiculous."

PREFERENCES FOR FINDING SERVICES & RESOURCES

Our survey compared methods for finding mental wellness-related services and resources. Results showed a preference to receive more information from family doctors and mental health professionals. This was confirmed by the focus group comments.

Category	Prefer to find	Usually find
Disability Organizations	46	48
Email	44	36
Internet & Social Media	38	42
Family Doctor	38	21
Mental Health Organizations	35	33
Mental Health Professional	34	23
Word of Mouth	31	34

Vancouver Disability Solutions Network (VDSN) Steering Committee: David Fong, Disability Foundation; Helaine Boyd, Disability Alliance of BC; Karen Lai, City of Vancouver; Chris McBride, SCI BC; Adrienne Fitch, Disability Foundation (Project Coordinator).

With gratitude to Ruby Ng of Canadian Mental Health Association, Vancouver-Fraser Branch, and her excellent team for their generous sponsorship and collaboration in organizing this forum.