

What we heard

Roundtable Dialogue with People with Lived Experience

Abbotsford, June 4, 2018

On June 4, 2018, the Honorable Judy Darcy, British Columbia's Minister of Mental Health and Addictions, met with 32 people with lived experience using drugs for a roundtable dialogue in Abbotsford.

This dialogue was part of the Ministry's engagement process for developing a strategy for a seamless, coordinated mental health and addiction system that is free of discrimination and stigma, culturally-safe and focused on a path forward. The initial stages of the process include engagement with a broad spectrum of individuals, communities, and Indigenous peoples from across the province. In addition, we are encouraging people to share their feedback on mental health and addiction services on the B.C. Government Engage [website](#). What we learn from this engagement process will help inform the mental health and addictions strategy and be incorporated into a final report.

The Ministry recognizes that B.C.'s mental health and addictions service system needs reform in spite of the best efforts of service providers who are working hard every day to serve people's needs. Hosted by the Honourable Minister Darcy and facilitated by Simon Fraser University's Morris J. Wosk Centre for Dialogue, the roundtable provided an opportunity to listen and learn from the experiences of people with lived experience—so B.C. can build from the strengths and approaches that are successful.

Following opening remarks from Minister Darcy, participants were invited to introduce themselves and to share what brought them to this dialogue. After the opening circle, participants met in small breakout groups supported by a table facilitator to discuss what—based on their experiences or observations—has worked or is currently working in the mental health and addictions system, and what challenges they have encountered or observed. Next, participants discussed what changes would make a difference. In a closing circle, participants shared what gives them hope and what needs to change in the mental health and addictions system.

Participants' experiences and specific suggestions were captured by note-takers and through worksheets.¹ This report summarizes participants' input and suggestions by themes, illustrated with selected individual responses recorded in participants' own words. The themes listed in this report are ideas or suggestions mentioned in at least two participant worksheets. This means that the list does not indicate an order of priority.

¹ The testimonies and suggestions recorded in this report do not necessarily reflect the views of the Ministry of Mental Health and Addictions or its staff. Individual statements reproduced in participants' own words are identified as such through quotation marks.

Many participants with lived experience expressed a strong sense that the system of care is not serving them well, with the exception of peer-led services and certain harm reduction and overdose prevention measures, as well as low-cost housing where available.

Addressing the many forms of discrimination and stigmatization that people with lived experience face, was the most prominent theme among the changes and improvements called for. In particular, judgmental behaviour and stigmatizing practices or language that cause harm and create significant barriers for drug users who are trying to access critical health and social services was highlighted. Addressing discrimination is related to another theme that emerged around ensuring access to government assistance and social services, such as long-term disability assistance, which drug users are often denied.

The second most frequently mentioned theme was addressing the housing crisis. As one participant put it: “The root is homelessness. Drugs are a mechanism to cope with a problem, it’s not a problem in itself.” Several participants argued that if everyone cannot be housed appropriately, tent cities should be supported as they provide safety and a sense of home.

Participants called for empowering communities by involving them in shaping and planning the services that meet local needs. Increased support and recognition for peer groups and peer services was another change participants called for as a means of providing non-stigmatizing services to people with lived experience and as a way to illustrate one pathway to hope.

Participants also frequently mentioned the negative impacts of by law and bylaw enforcements in their calls for change. Several participants stressed, for example, that warrants create barriers for accessing services while others cited how bylaw enforcement officers affects drug users on a daily basis and forces them into humiliating and life-threatening situations. Providing safe access to the drugs that people need either through prescriptions or supervised consumption services (not limited to injectable drugs) was another important theme.

The full list of themes² for suggested changes and improvements includes:

- Addressing discrimination and stigmatization
- Addressing the housing crisis
- Empowering local communities to shape the services they need
- Ensuring access to government assistance and services
- Support for and recognition of peer work
- Stopping harm inflicted by law and bylaw enforcement
- Providing safe access to drugs
- Education about drugs and drug users

² Themes are listed in the order of the number of times they were mentioned in participants’ worksheets, which does not necessarily represent participants’ order of priority.

1. What has brought you here?

Please note: some quotes below may contain explicit and triggering content

“There is still a lot of work that needs to be done downtown to deal with the state of emergency.”

“I’m too scared to break [out of] the prison without doors (to go outside of the Downtown Eastside).”

“It’s so nice to have a life back.”

“I’ve lived two blocks from Main & Hastings since 1990. I’m so pissed off and angry at stepping over dead bodies. It feels like we have these small victories and then just tons of tragedy. Just let us know really bluntly: What are the limitations of the Ministry? Tell us what they are, and we’ll go tear them up.”

“I hope to find out, who do we go to when the people who are perpetrating the violence against us have the authority? Who do we go to for safety when the ones that are supposed to protect you are the ones who hurt you?”

“I’ve known what homelessness was since I was four years old, and I never thought it would happen to me.”

“I’ve been in and out of homelessness. I’m a recovering addict of 15 years. I’ve seen a lot of good friends die through horrendous situations. It has to stop. We have to figure out a way to stop the whole situation, especially with homelessness. Being a recovering addict and then being homeless and then having a home and then being homeless is depressing and you think about going back [to using].”

I want to learn how to spread awareness with other young people. A lot of young people now think it’s almost wrong to go and help yourself. You’re a loser if you do that. That’s a really negative mindset to be in. I’m an advocate for recovery and I think that in order to really get through everything you’ve got to really live everything.”

“Organizing a group around inclusion rather than around some abstract thing like recovery or abstinence.”

“I’m a board member of VANDU [Vancouver Area Network of Drug Users] and a member of the Mayor’s Task Force for Addictions. I’m here to make sure that we stop criminalizing people who use drugs. It’s the number one predictor of overdose.”

“I’m here as a potential person who could overdose. Thankfully, I haven’t, but I’ve lost a lot of friends and family. Since they took away the methadone, it’s what changed my life.”

“As the mother of a substance user, I’ve lost a lot of hope. I’ve been dealing with the systems for two decades and see how people are stigmatized, and how people who are already stigmatized find it almost impossible to move forward because of these barriers. There are cops who hate my son ... it makes it hard for him to have hope in himself.”

“By the end of the day, I want to feel like that sense of hope has really increased in me, moving away from helplessness because that’s where I get my power from.”

“I get to spend time with some of the most amazing people, who are in this room. I’m here for several reasons and what keeps me going every day is that I’m a woman who had a long-term history with opiates. I was in what I would call a healthy relationship with drugs and then an

unhealthy relationship with drugs. I've lost so many people, I can't even count—almost every other weekend I'm going to a funeral. If I decide to pick up my drug of choice, I know that I will die.”

“This discourse of disposal of people—instead of pulling us closer when we're suffering to push us away and isolate us. I want to see something different. A lot of times we have these meetings and it's 'they talk we die.' The health perspective and disordering people is also harmful. We just need to remember we're humans.”

“I lost my dad last year to 'fentanylity' [fentanyl + fatality]. The Minister said she had opened a lot of safe injection sites, but you should have safe consumption sites (for people who smoke or snort, who can't go to safe injection sites). You gotta make it so it's not illegal.”

“VANDU is a powerful model: bringing people with lived experience together as models for others and to do activism. It's the community that amazes me when it comes to a crisis like this. Everybody just gets up and takes care of what they can. Whether they're homeless or not, they carry naloxone.”

“Over 55,000 people come through an overdose prevention site (that's for 6 spots). It was a lot for us. The burn out rate is high. It's been over two years, but we're still going strong.”

“I'm here because of the systems that are surrounding us are failing us. I'm also sitting here as a homeless person who's at risk of losing my job. I haven't slept in two days—hard to get any sleep when you're getting pushed around. It's been proven that this kind of displacement causes health impacts (huge stress). The answers are within us if the people would just listen to us. If they don't know the answers, they should leave our community alone.”

“I'm a drug user, it doesn't mean I'm not human. The stigma is incredible. You don't catch it—you end up in this circle and there's no way out: you can't get on welfare if you can't comply; you can't comply if you've got no sleep.”

“Some people have lost all hope because they were given no hope. There's a good chance that one of us around this circle won't be here next year...next week.”

“I found out people were dying in my backyard, that people were left to die in the ditches. I found that unacceptable. What was going on back then is a lot of what is going on right now. We still have private police officers, who seem to think they can take the Chief Justice's ruling and enforce it as they see fit, decide who they enforce it with. We, at the BC/Yukon [Association] of Drug War Survivors, are continuing this fight wherever we can and however we can.”

“I got into this fight because I couldn't believe that humans were doing this to other humans. We all have feelings and desires. These guys are not bad people. They've got good hearts and good desires.”

“I identify as someone with lived experience at many different levels. I was homeless, heroin-addicted, a sex worker. I'm thankful to the people in this room, for meaningful inclusion, community, and the determination of people to not give up and throw my life away, that's why I'm here in this room. I made it off the streets. I have friends who are still there now. I have been followed by my ancestors and kept alive so that I can come into this room and fight with my brothers and sisters.”

“There are unnecessary deaths—lives being thrown away. There's no pathway to hope, there's not even a path. Somebody gets two steps forward and the system says, 'Fuck you' and there's a wall there and then if you get through, there's another wall. Even with all of our advocates doing this amazing work, it is still almost impossible to get what we need: a place to crap, a place to eat, a place to sleep.”

“Without reconciling with the natural world, there is no reconciliation. We need to protect what sustains us in British Columbia. You talked about the colonial oppression that created this relationship—cultural genocide was real. It’s going to be very important to include in the strategy, to do what is necessary to restore our languages and our cultures and our spiritual beliefs. When we have that good relationship to the land, for everyone, not just Indigenous people, we can heal.”

“I’ve worked in the DTES [Downtown Eastside] for five years and then was put into the position of being manager of an Overdose Prevention Site. I’m just about homeless now. I have a daughter who is a former user and I had her children for ten years. And I honestly don’t have the means to keep them, but I always just wanted to help the people in my community on the DTES.”

“VANDU: While I did my service, I became disillusioned with myself and my people and sort of lost myself and lost hope. Hope is everything, there’s nothing without hope. I’m forever indebted to VANDU because it gave me my hope back. I owe my life to VANDU. I can never really give back, I can only help give back to other people. Nobody woke up in the morning and decided ‘I want to be an addict.’ Things happened.”

“I’m here because I still have hope and I want what we say to be used in a good way because we’ve been talking for years and we’re still going around these circles.”

“I’m homeless, but I’m not unhappy, I’m uncomfortable. We don’t need a hand out, we need a hand up.”

“I am an Indigenous mother and grandmother. It would make me feel safer to have a separate Indigenous caucus to deal with all of the complex issues we face. The second overdose that I responded to was my daughter in my basement. She stopped breathing, she was non-responsive; she didn’t have a heartbeat. And when I leaned over to try to breathe life back into her, her whole life flashed before my eyes and it reminded me of the first time I kissed her after she was born. They worked on her for 90 mins and got a heartbeat. My daughter is alive today and she is a walking and talking miracle, but she is falling between the cracks all the time. The message that she wants me to bring here today is that in the clinics where people are going, they should be able to inject fentanyl two to three times a day and they should be able to go home with a fentanyl patch. That is the true meaning of harm reduction. Harm reduction is any route that you want to take. The first practice of harm reduction is housing.”

“My 8-year-old grandson said to me: ‘The doctors at the hospital have the good medicine, right? And the fentanyl on the street is the bad medicine? So why are they not giving us the good medicine? Is that because it’s ‘us,’ grandma?’—I’m asking, what does it tell you that our children can figure this out—and what will it do to them to know this?”

“I’ve watched a transformation happen through the Fraser Health mental health services.”

“The Canadian government has now lifted a lot of the restrictions on the prescription drugs. Right now, we’re importing from Switzerland, we need to start manufacturing it here to overcome some of the barriers to getting it.”

“We’re not going to enforce our way through this, we’re not going to get away with it. You’ve got to give people what they want—if people want fentanyl, if that’s what they’re doing and that’s what’s working for them, let’s give it to them.”

“There has been 17 years of sustainability in Switzerland through their model.”

“The bylaw officers are a big problem. They get away with murder. I wish I was exaggerating when I say that.”

2. What is working

The most frequent participant response to this question was that the system is not working and fails to serve people with lived experience using drugs well. The list below includes themes for aspects of the system that participants identified as effective.

- **Peer-led services**

“Peer-run organizations such as VANDU. Even though VANDU is not a service provider like so many other organizations in the DTES, we are activists fighting for human rights and social justice. It has made me the man I am today. I’ve been out of jail for 10+ years.”

“Peer Witnessing Pilot Program”

- **Safe-consumption sites**

“For the addiction services I think the openness for giving supplies is great how there is no discrimination for your use is good. The places like “Positive Living” and their safe consumption room which I work in is awesome. To have a place you can use without someone looking down at you. It is located in Abbotsford by the Sevenoaks Mall.”

- **Overdose prevention sites**

“The peer-led overdose prevention site at St. Paul’s Hospital”

“Overdose prevention sites – for harm reduction – a clean place to use.”

- **Access to low-cost housing**

“Rain City Housing in Vancouver”

“The ‘Hearthstone Building’ that is providing low cost rent of \$375.00 so that people on welfare can afford a nice place to live. They are a little too controlling, but it still is a nice place to live.”

- **Other aspects:**

“Health Emergency Management BC is working. One of the things they provide is trauma counselling.”

“Women’s shelters—‘Lifeskills’ was popular because women felt safe there.”

“Safety of the tent city”

3. Themes for suggested changes and improvements

- **Addressing discrimination and stigmatization**

- Addressing judgment and discrimination of drug users within the service system
- Increase education and accountability of doctors and medical assistants to ensure respectful and effective treatment
- Removing barriers resulting from stigma around drugs and drug use, such as requirements for supervision while taking prescription drugs
- Removing stigmatizing language from government forms
- Ensure facilities support people who use drugs (e.g. availability of toilets, clean spaces)
- Increase education and knowledge about drug use, addictions and various paths to healing

"Fentanyl poisonings' are not overdoses!!"

"The judgement of other people and how they look down on drug users needs to change."

"We need to treat everyone like people. The children of people with mental illness and addictions are seeing how people are treated. How are they supposed to have a pathway to hope if they see us treating people like this?"

"My challenge is that I feel I am unable to receive what I truly need to get. I have to be monitored by someone while taking prescriptions three times a day. This makes it difficult for me to work, which would help me to feel good about myself."

"Medical health assistants can cause more harm than doctors. They bring stigma, they deny access even though they don't have the authority to do so. They need to be educated. They need to be accountable for bad behaviour."

"I have a prescription of diacetylmorphine, but I'm missing my shot today because I'm seeing the Minister. I'm being told that it needs to be at a certain time and it needs to be witnessed. And then I'm being told that I need to watch my attitude."

"No more punitive systems that continue to criminalize and victimize our affected populations. Effective social systems that support people in their journey, no matter where they are at."

"Shelters serve only those who will support their system, NOT us! WE complain, WE get banned. Homeless BUSINESS! We are invalidated to shut us up!! because our ethics/values do NOT fit in with THEIR corrupt business. [...] YOUR PSYCHIATRIC SYSTEM quilts us, impedes us, shuts us down, makes us feel unworthy and worthless. BAD. WE are not bad. WE are not crazy and WE are not criminals. YOUR rigged systems design us to be all that."

"There are many places that exclude people who use drugs. Toilets are not readily available in most communities."

"I personally have had nothing but negative experiences trying to access medical help within the emergency departments of hospitals. This is due to having been labelled an addict on my medical"

records. Once they see that they instantly assume the only reason I am there is to obtain narcotics. And no matter what I do to try to have them treat me like a person, they continue to treat me with disrespect and disgust.”

- **Addressing the housing crisis**

“The problem is not mental health and addictions—the root is homelessness. Where there is housing, there is possibility. Drugs are a mechanism to cope with a problem, it’s not a problem in itself.”

“Housing is the most important thing.”

“Housing: If we can’t house the poor then we need to support tent cities.”

“There are people who choose to live on the street. But they don’t choose to live in chaos and in horrible conditions. They live there because of the community, because it feels like home. Why can’t we provide places for them, like tent cities? We provide spaces for our children to be, why can’t we do that for adults who choose to live on the streets.”

- **Empowering local communities to shape services they need**

- Supporting local communities of people with lived experience (including funding)
- Enabling drug user groups to make connections and collaborate
- Creating regional strategy groups of service providers to plan and coordinate services that meet local needs

“All regions need strategy groups of service providers. Problems and solutions can be very regional. In the Downtown Eastside one problem is no access to washrooms and phones. Other places have a handful of physicians and they are all prescribing different treatments.”

“Having people with lived experience involved in everything—every level of everything.”

“We just had 6 months of funding from Fraser Health for a Drug War Survivors Group. It has brought together a steering committee that meets twice a week, where people have built community. And people are connecting and dreaming things they wouldn’t dream otherwise: someone says ‘I’ve rented a house’ and inspires another person to think: ‘I can do that.’”

“When you get people together and you create community around them they will innovate. When people feel safe and supported, they can take the risks to innovate and solve problems.”

“I have been waiting to get health care for a long period of time from institutions, when really it should be in the community.”

- **Ensuring access to government assistance and services**

- Increasing accessibility of social services and assistance for active drug users.
- Stopping the Ministry of Social Development & Poverty Reduction from denying assistance to people with a warrant
- Providing disability assistance to everyone who uses drugs via Ministerial Order
- Supporting children of parents who were poisoned and killed by fentanyl

- Ensuring people have access to food
- Providing housing support

“We need further help with getting people welfare, housing and then work on programs geared to providing clean drugs to everyone.”

“HELP, NOT denial, NOT hindrance. WE paid our way—EI, Income Assistance for example are our right—we earned those insurances!! WE worked to PAY/SAVE for those INSURANCES. It’s OUR money NOT the Government’s!!”

“Why on earth do you have to disclose when you have a warrant? Why is that in there? It kills people! If you really have a warrant for killing someone, you don’t look for welfare. The people who get shut out because of warrants are people who have missed a court date.”

- **Support for and recognition of peer work**

- Involving people with lived experience in service positions
- Supporting peers so they can continue to raise uncomfortable questions—often they have difficulty to address issues within the organization that pays them for fear of losing support
- Developing a provincial curriculum, best practices and guidelines for peers
- Peer workers at emergency rooms, detox, treatment centres
- Paid peer witness programs
- Peer involvement in schools, hospitals to help increase understanding of drugs and respect for drug users
- Funding for drug user groups across B.C. including rural communities
- Involving people not only from recovery programs
- Funding a provincial network of drug users

“Recognize peer-work. Avoid tokenism and exploitation. I have worked up the knowledge equivalent of a Master’s degree, but there is still stigma. We can’t overcome stigma until we challenge the policies.”

“People with lived experience can’t just be 12 step people.”

“We need to really consider increased funding for organizations. We have been working on pennies and we’re feeling exploited for the work that we are doing.”

“We need to pardon people so they can support others as peers.”

- **Increased and more varied service options / reduced wait times**

- Reducing wait times
- Treatment options beyond abstinence-based services
- Individual counselling services
- Safe spaces for women, such as transition houses, detox, treatment, healing centres
- Specific services and centres for men
- OATS (Opiate Addictions Treatment Services) programs expanded nationally

“Each person's needs and their road to recovery is different. We need more accessible detox treatment, with less waiting time. To an addict, timing is everything. Most won't wait two- five days to get in. Many won't wait two – five hours.”

“We need more recovery/treatment centres that work with you, giving what each person needs to be successful with their recovery. Not ones that tell you what you need.”

“As diverse as the addicts, so are our needs. At the beginning of my homelessness and drug use, I needed a lot of care. There are 22 different clinics, and they are all offering the same thing, but you have to fit their model. I only need 1.5 minutes. We gotta stop saying ‘this is the model, you gotta fit the model.’ Stop saying all addicts have gotta do it this way.”

“We need a safe house for young male hustlers. We still don't have one.”

- **Increased access to services in rural areas**

“Services in rural communities need to be in line with Vancouver services.”

“Bring what is working from urban areas to rural areas. We need heroin prescription, hydromorphone, opioid agonist treatment. Need third-line treatment. Once we hit 200 mg, the treatment options stop. Nelson has three physicians, Castlegar has one and they are all doing things differently. One is abstinence-focused, one is interested in third-line treatments, the other ones are in between. Physicians need to be consistently educated, connected to peers who are prescribing on a regular basis so they know what's happening. Doctors are reading about it in journals but flying by the seat of their pants.”

- **Stopping the harm inflicted by law enforcement and bylaw enforcement**

- Legalization and regulation
- Decriminalization
- Including police and the justice system as part of the anti-stigma campaign
- Providing legal assistance and advocates to drug users

“I've been out of the criminal system for 10 years but still have a criminal record and I am still suffering from this when I apply for housing. Can't afford to go for a pardon because it would mean not paying my rent. I still carry this judgment and the barriers from it.”

“No more punitive systems that continue to criminalize and victimize our affected populations.”

“Two of the biggest problems are homelessness and criminalization and the ongoing cycle of policing, arrest, institutionalization and then they come back from a few days, they've been sick and miserable when locked up and what are they going to do when they are coming back?”

“Ministry needs to support parents, not take children away (apprehension of children is another form of punishment/criminalization of parents).”

“Get an organized committee together to ensure police stop arresting people for possession of drug charges and the many ‘failing to comply’ charges that ensue. Do not wait for the Feds. Make

a ministerial order if necessary. This is a public health emergency. Forty per cent of criminal cases in B.C. are for failing to comply. Blomley and Damon published a study called 'Setting people up to fail.'

"First PWUD (persons who use drugs) need legal help. They are treated with stigma and discrimination and this will only stop if there are consequences for people who violate people's rights. And there needs to be education offered so they can become allies and heroes and excellent service providers. If PWUD (persons who use drugs) can call for an advocate to help in the many situations they face, we will at least be able to move forward."

"Bylaws steals all of our (homeless) personal belongings, bedding, food, clothing."

- **Provide safe access to drugs**

- Supervised consumption services (including inhalation)
- Safer access to different drugs (including fentanyl)

"Give people methadone if they prefer it and of course a whole raft of injectable and oral OAT [opioid agonist therapy] therapies. Get "ministerial order" if the College of Physicians and Surgeons - do not cooperate!"

"Expand heroin-assisted treatment. Look at the evidence – it's working, but we're not moving fast enough."

"Hydromorphone does NOT work for everyone."

"PRESCRIBE FENTANYL NOW."

"Guidelines for opiate replacement therapies have changed - the changes are not made clear for those who want/need them."

"I'm afraid I'm going to die because I am using Methadose after having been on Methadone. It's a government policy to move people from methadone to Methadose and it works for some, but not for others."

"Methadone and Methadose is like giving Aspirin for a car accident."

- **Education**

- Increased awareness and education about drugs and drug users

"Understanding, education on the way addiction actually is, and how it affects everyone differently. That each person's needs and road to recovery is different."

- **Other comments and suggestions**

- Supporting whistle-blowing:

“It’s very difficult to raise issues with government-funded services. If there is a clinic that is hedgy about their services and there is no one in it. It’s very difficult to go to the government and raise it. You will be hated. We need an ombudsman system where anyone can call.”

“They need to be able to tell the truth without the fear of being fired or held back.”

- Reviewing policies and rules that interfere with services:

“We have champions working at these locations that will admit that they are being hampered by restrictions in the services they can offer to people. People are not being allowed and supported to do effective work because of the mandates attached to the services.”

“A worker has gotten two weeks without pay for holding the arm of someone during an injection. There are so many rules and services get hung up in it.”

- Provincial pressure on local governments to provide services:

“Different levels of government need to work together, especially in hostile communities, where everyone who is wearing a backpack is seen as homeless. There needs to be a stance from the Provincial Government that this is how we are doing it and it’s not up for discussion.”

- Collaboration and connections among programs:

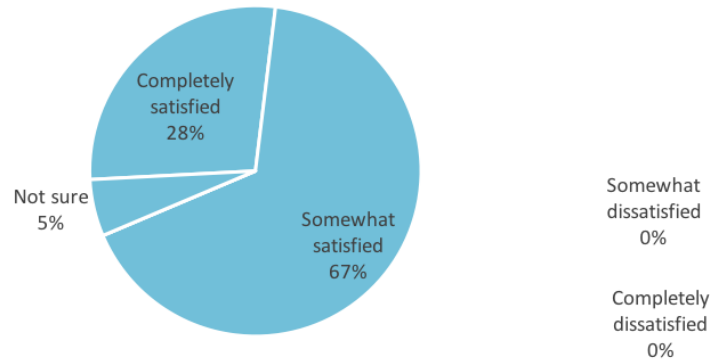
“We need all the programs to have connections to the other. We have to make sure people pick up the phone and talk to each other when a client needs something. Regional strategy teams could help with that.”

- Recognizing oppression of Indigenous people in strategy:

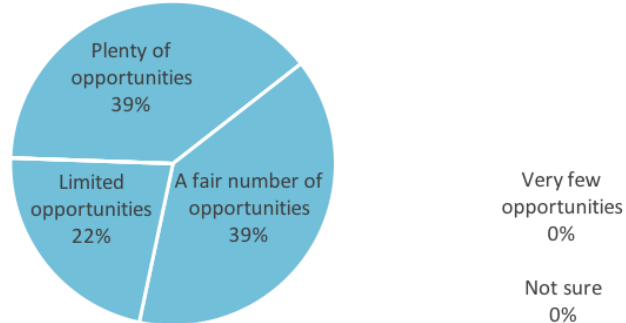
“It is very important to recognize the cultural genocide committed against Indigenous people in the strategy.”

4. Participant feedback about the session

Overall, how satisfied or dissatisfied are you with your experience as a participant of today's dialogue?



Did you feel you had enough opportunities to express your views in a way that felt comfortable to you?



To what extent did you feel your needs as a participant were taken care of ?

