Views of the Persons with Developmental Disabilities (PDD) program: Successes, Challenges and Opportunities

Report of the PDD Review Panel

July 2019
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Message from co-chairs

On behalf of the PDD Review Panel, we wish to thank all self-advocates, families, community disability workers, service providers, Government of Alberta staff, other organizations and members of the public who came forward to participate in this review. You shared details of your life circumstances – of basic needs and relationships that can be both difficult and rewarding. You also told us about your hopes for the future. We were humbled by your open, honest discussions with us.

We were inspired by your ideas and deep commitment to improving the lives of those with developmental disabilities. For that we thank you.

The PDD program impacts a broad, deeply invested community and requires a strong network of effective partnerships in order to work well. We heard about individuals, families, service providers and PDD staff working together to build areas of strength across the province, with many people well served by the program. Albertans also told us they want changes and improvement to what is not working in addition to celebration and protection of what is working well.

Everyone who participated in the engagement activities had ideas of what could be done to improve the PDD program. While people acknowledged the overall value of the PDD program to Albertans with developmental disabilities and their families, they see opportunities to improve the PDD program and want to be fully involved in that change.

We also want to thank the provincial government technical and support staff who provided so much advice and logistical assistance to us – in the community conversations, survey delivery and preparation of materials. Your help allowed us to offer people safe and inclusive ways to participate. This was reflected through positive feedback on the community conversation sessions. Without the dedication and commitment of staff this would not have been possible.

Again, thank you to everyone who participated and supported us in the engagement activities for the PDD program review.

Dorothy Badry
Ann Nicol
Dick Sobsey

PDD Review Co-Chairs
Background

Established in 1999, the Persons with Developmental Disabilities (PDD) program provides staffing and supports to approximately 12,000 Albertans in four areas of life – home living, employment, community access and specialized community supports. The program’s vision, as set out in the preamble to the *Persons with Developmental Disabilities Services Act*, includes honouring and respecting the dignity and equal worth of adults with developmental disabilities, supporting their self-determination and inclusion in community life and providing services based on equitable opportunity, funding and access to resources.

Why a PDD review?

On January 19, 2018, the Minister of Community and Social Services announced a review of the Persons with Developmental Disabilities (PDD) program. A review of the program was recommended as part of previous work done on the PDD Safety Standards to explore ways to improve supports for persons with developmental disabilities. This report will be of particular interest to Albertans with disabilities, their families and professionals working in the disability sector.

The review panel

A community-led panel was appointed to oversee the review. For the PDD Review Panel, careful consideration was given in selecting a diverse range of individuals with varying skill sets, experience and background who would best represent the intent of the review. The panel includes self-advocates, family members and service provider representatives (a complete list of panel members can be found in Appendix A).

Focus of the review

The key areas addressed in this review were developed through a pre-engagement process that included an online survey and conversations with Albertans. Pre-engagement feedback indicated Albertans wanted the review to focus on:

- eligibility
  - examining eligibility criteria to access the PDD program’s services and supports
- access
  - examining access to services and supports to meet individual needs and goals
- service delivery
• responding to the needs of individuals and families and providing clear lines of accountability and oversight

• workforce
  ○ evaluating access to training and supports to enable a skilled and well-trained workforce

• communication and connections
  ○ ensuring engagement with the disability community at both the system level and individual level has clarity of purpose and outcomes.
Engagement process

The engagement set out to encourage involvement and participation from the disability community and interested public. Offering a variety of ways to provide input to the review allowed participants to choose the format best suited to them.

The panel welcomed input from everyone with an interest in the PDD program. This included people receiving PDD services, their families and guardians, community disability workers, service providers, Government of Alberta staff, other organizations and interested members of the public.

Community engagement took place between October 22 and December 7, 2018. Albertans were invited to share their ideas in a variety of ways, including:

- attending a community conversation
- responding to an online questionnaire
- hosting a self-directed discussion
- sending a written, art or video submission
- providing a presentation to the panel.

A discussion guide described the topic areas and asked questions about what is working well and what could be improved. A public website provided an overview of the process as well as summaries of what the panel heard at the community conversations. A total of 1,115 people attended community conversations held in St. Paul, Grande Prairie, Fort McMurray, Red Deer, Lethbridge, Medicine Hat, Calgary and Edmonton.

At community conversations, the panel heard from:

- 462 people at sessions for families and individuals receiving PDD supports
- 335 people at sessions for service providers and community disability workers
- 188 people at sessions open to anyone with an interest in the PDD program.
  - attendees at these sessions were most often individuals receiving PDD supports, families and service providers, as well as individuals with disabilities who may not currently
receive PDD supports and their families

- 130 people at sessions for Government of Alberta employees
  - this included PDD service coordinators and contract specialists

An online questionnaire which focused on the same key topics as the community conversations was also available as a means to provide input to the review. The questionnaire was offered in two formats to ensure accessibility for all reading levels. It was completed by 1,163 Albertans, most identifying as persons receiving PDD services (7.5 per cent), their families or guardians (20 per cent) and community disability workers (36 per cent).

For further engagement, groups and organizations were invited to host their own discussions and share what was heard with the panel. A facilitation toolkit supported these discussions. A total of 10 submissions were received from organizations that hosted their own sessions. A further 62 written submissions, seven videos and 26 works of art were received from individuals. The panel was also provided with 13 presentations from advocacy groups and other interested organizations.
Summary of feedback

The information in this report is a summary of the feedback expressed through all methods of engagement. It is not a compilation of every comment received, but instead represents a thematic overview of what was heard.

Participants in community conversations were passionate and open in sharing their thoughts, ideas and suggestions for improvement. The value of the program to self-advocates, families and community members was reflected through the interest shown in this review not just by people with disabilities but interested stakeholders and the broader community. The community is deeply invested in the program and wants to be a part of change for the better. The questionnaires, submissions and presentations contributed additional input that was both thoughtful and powerful.

Participants shared varied perspectives and experiences, often differing on what they thought was most pressing or important or the exact nature of the problem. Despite this diversity, there was consensus across all groups that improvements can be made in each of the key topics under review. The response to the public engagement also suggested all five key topic areas are interconnected.

Before documenting the areas of concern, it is worth noting some of the things people said are working well for them:

- many individuals supported by PDD are living happy, fulfilled lives in their communities like all other citizens
- a number of self-advocacy organizations are making positive changes in their communities
- many positive, supportive relationships between community disability workers and the people they serve
- many collaborative relationships exist between PDD and a variety of service providers and communities throughout the province
- support and appreciation was expressed for Family Managed Services (FMS), a program which has grown in recent years
• support for the option of increasing the term of a contract or agreement from one year to up to three years
  o many people commented that longer contracts provide greater continuity for people receiving PDD supports, more flexibility for contractors who are planning services while freeing up PDD staff to respond to other needs.

“PDD has made it possible for my sons to find programs and workers that allow them to enjoy life, learn skills and use their strengths, and for me as an aging widow to feel more secure about their futures.”

- Family/guardian of a person receiving PDD supports
1. Eligibility

To be eligible for the PDD program, an Albertan must be 18 years old or older, a Canadian citizen or permanent resident and have:

- a significant limitation in intellectual capacity (an IQ score of 70 or below)
- a significant limitation in adaptive skills (needs help with daily living activities like making food)
- both of these limitations before 18 years of age.

Albertans expressed strong views about eligibility. At community conversations, many receiving PDD acknowledged the program as a key contributor to a good quality of life. Those ineligible expressed disappointment with not being able to receive the support they need.

Overall, there was broad consensus and strong support to change the PDD eligibility criteria so more people can get help. Many saw the IQ requirement as a barrier to eligibility and suggested PDD take a more holistic approach when assessing an individual's need for support. They pointed out people with Fetal Alcohol Spectrum Disorder (FASD), Autism Spectrum Disorder (ASD) and other disabilities may need help with daily activities even if they have an IQ over 70.

Some suggested removing the IQ requirement completely or keeping it as a consideration with more weight applied to an individual’s ability to perform the skills required for daily living. Many also questioned the need for a disability to appear before the age of 18 to get PDD support, citing those who experience brain injuries after age 18.

Others shared their challenges about differences in eligibility (e.g., the IQ criterion) between the Family Support for Children with Disabilities (FSCD) program and the PDD program. They noted families may only become aware of this difference as children “age out” of the FSCD program and look to PDD for support. Families find out their soon-to-be adult child might not qualify for PDD funding, even though their support needs have not changed, only their age.

By the numbers¹

69 per cent of questionnaire respondents disagreed with the statement that PDD eligibility criteria should remain the same.

79 per cent said eligibility should be changed to include more people. Those most strongly in agreement were families with children under 18, people with disabilities who are ineligible and advocacy groups.

¹Percentages represent a combination of questionnaire respondents who indicated they agree and strongly agree or disagree and strongly disagree.
Some respondents expressed concerns about expanding eligibility because “it is already difficult to meet the demand for PDD services.” Without additional resources, they questioned the system’s capacity to support more people and expressed fear that services would be reduced if more people are served.

“I have an IQ of 76 but have cognitive problems. I need help with employment because I can’t keep a job very long.”

- Person not eligible for PDD
2. Access

Individual circumstances vary. As circumstances or needs change over time, an individual’s ability to access supports and services may be impacted. Availability of information, transition between programs, changing needs over time and geographic location (e.g. rural areas) were cited as challenges related to accessing supports.

**Information and transition support**

Some families reported they had a good experience transitioning from one program to another (e.g., FSCD to PDD) and were pleased with Government of Alberta efforts to streamline PDD processes with related programs such as Assured Income for the Severely Handicapped (AISH). Despite these improvements, numerous people indicated it is difficult to access PDD services.

Many people seem unclear about what services and supports are available and how to access them. This may be due to the fact some individuals and families indicated they did not know who their PDD worker was or did not have a strong relationship with the PDD staff in their community. A number of people expressed concern for individuals who do not have a family member or advocate to help them navigate the system.

Those directly providing services to individuals – community disability workers – said they need a clearer understanding of how the system works so they can better support the people they work with. As noted in the eligibility section, moving from youth (FSCD) to adult (PDD) disability services can be particularly challenging. Many families noted a difference in the level of funding and services provided by the FSCD and PDD programs and suggested better transition planning as people move between these program areas.

**Timely access and changing needs**

Many people shared a perception that there are inconsistencies across the province regarding access to supports and services, the types of services provided and the role of PDD in delivering supports and services.

Many families and community disability workers expressed concerns about the length of time it takes to access PDD supports and services. Some commented PDD policy, which prioritizes services for individuals where there are known health and safety concerns, may mean people with less urgent needs wait longer for services. There were mixed opinions, including among families of individuals receiving PDD supports, in how well the program responded to an individual’s changing needs.

In community conversations, a number of people stated the PDD program and other disability services need to be more flexible and respond to needs as they arise or change across a
person’s lifespan as they age. Self-advocates recommended funding follow the individual when they leave a service provider. A general sentiment expressed was there should be more opportunities to “reassess, try, fail and learn.” This opinion was particularly relevant for service providers who stressed the importance of receiving full information at the time of referral and the ability to change funding after an individual enters service if other support needs are identified.

Others expressed concern about the lack of coordination and collaboration between the PDD program, services offered through Alberta Justice (e.g., the Office of the Public Guardian and Trustee) or health-related services. It was noted a lack of clarity about mandates or poor coordination across these sectors may result in ineffective support for individuals with multiple, changing needs.

**Accessibility and inclusion**

A lack of affordable and accessible housing and transportation options were cited as barriers to accessing PDD supports and services. Absence of these resources, along with limited personal income, were identified as significant challenges to full community inclusion. Many engagement participants, particularly those in rural areas, said transportation options are limited, expensive and can be exacerbated by the cancellation of bus services. Even when transportation services are available, users shared their frustration about the timing of service and the need to book well in advance. A few people noted some transportation services are unable to accommodate wheelchairs.

While there are innovative housing models in some areas of the province, participants generally agreed more affordable housing is needed for individuals receiving PDD services. Many expressed concerns regarding a lack of housing, trained workers and structured programming for individuals with complex service needs.

There was strong commitment to the rights of people with disabilities and ensuring these rights are respected. Self-advocates, including those not eligible for PDD services, and their families

> "It didn’t take my daughter long to be able to work without support. She has become a valued, competent employee and has now worked part-time for the same employer over three years. I don’t know if this would have been achievable without a service provider being able to get the initial opportunity with an employer. My daughter’s pride in being a productive employee is immense and this has given her confidence to achieve other goals."

- Parent of individual receiving PDD services
want more community inclusion in the form of supports to obtain employment, as well as inclusive post-secondary education and vocational opportunities.

Some people receiving PDD services who have additional disabilities, such as individuals who are deafblind, want these needs better accommodated. PDD service providers, families and Government of Alberta staff shared examples where individuals have experienced barriers accessing publicly available services such as addictions and mental health due to their eligibility for PDD supports and services.

**Services for First Nation communities**

Several people in the community conversations noted there are no provincial PDD services available on First Nation reserves. As a result, some First Nation individuals living on reserve may leave their communities to access PDD services or may not be able to access the supports they need.
3. Service delivery

The PDD program provides funds to service providers or Family Managed Services (FMS) administrators to hire staff to help individuals with developmental disabilities achieve the outcomes and goals identified in their plans. Outcomes may include living in one’s own home, finding and keeping a job and participating in the community. In some circumstances, the program also funds short-term supports when people or their caregivers need extra help, including counselling services or behavioural supports.

**Individualized services and choice**

One of the most common criticisms from engagement participants related to funding decisions. Some people noted it is not uncommon for individuals with similar support needs to receive different levels of funding, adding to a perception the program is not administered equitably. Self-advocates, families and service providers all agreed that, in many cases, service and funding decisions are made by people who have limited knowledge of the individual receiving services. This may contribute to a belief PDD services are inadequately tailored to an individual’s needs and vision for their life.

Related to this, people receiving PDD services want more input and choice in where and with whom they live, who provides their services, and who administers their funds. Both self-advocates and their families said they should be the primary "voice" when service planning is done and service providers are selected.

Most people agreed more clarity is needed on who makes decisions, what factors are considered in decisions, how funds are allocated and timely communication when decisions are made. They suggested a more transparent process for determining needs and supports – one that is understood by everyone involved and ensures the voice of the individual being supported is heard.

“PDD should not decide what my goals are or if I should have goals – I want to decide.”

- Individual receiving PDD services

Only 35 per cent of survey respondents thought the PDD planning process effectively identifies an individual’s service needs.

Only 14 per cent agreed with the statement “it is easy to understand PDD funding decisions.”

24 per cent thought PDD funding covers the cost of providing services.
Contracting, monitoring and accountability

Feedback regarding the contracting process for services and supports suggested there is confusion about the contract model and roles and responsibilities when administering and reporting on contracts.

Many community disability workers, service providers and families share a perception that PDD program funding does not allow service providers and families to offer workers employment opportunities that are competitive with other sectors - an issue further explored in the workforce section. Numerous service providers commented they do not receive enough funding to meet their administrative obligations, such as fulfilling reporting requirements or making changes to respond to occupational health and safety standards. Both families and service providers expressed concern regarding insufficient funding related to staff training, transportation costs and housing repairs or modifications.

Service providers said contracts do not compensate for the expertise, liability and administrative burden they take on. Service providers indicated they absorb fixed and uncontrolled costs, as well as those related to inflation. Conversely, Government of Alberta PDD program staff said, in some situations, they have little room to negotiate contracts due to a lack of qualified service providers willing or able to provide supports and services.

Most respondents support PDD’s recent shift to contracting for and reporting on outcomes, while some still see value in the previous approach of billing for the number and type of support hours spent with each individual. There was consensus that flexibility needs to be built into future approach so supports and funding can adapt to changes in an individual’s needs or circumstances.

Also related to accountability, some community disability workers and families said there is a need to clarify the responsibilities of all parties involved in the PDD program. They also said adequate mechanisms are needed to monitor how contract funds are being used and the quality of supports delivered. Some noted the accreditation process could be used to support enhanced accountability for quality services.

Support for families

The Family Managed Services (FMS) model is valued and appreciated by many families who said it gives them greater control, flexibility and choice over the supports their loved ones receive. Many families indicated administering the program is onerous and they need more support. Families stated a lack of information, tools and support necessary to fulfill their roles and responsibilities under the program was causing stress. Some families noted that family resource centres were one source of support and suggested additional centres in other locations may be
helpful. Aging parents and guardians were especially concerned about the responsibilities involved with FMS care.

While some self-advocates and families said FMS was not presented as a service option, others suggested they chose FMS to avoid long waitlists or to compensate for a lack of services in their community. Some indicated it was the only option available. Others said they chose FMS to avoid services driven by the needs of a large organization rather than by those of the individual. Many self-advocates noted it was important for them to remain involved in decisions about their supports, including when their families are using a FMS agreement.

Most people agreed families need to have choices in service delivery, and FMS is a desirable choice for families who have the time and capability to use this option. Some suggested FMS should minimize risk to individuals receiving services and their families by strengthening accountability processes. Some service providers suggested there may be merit in establishing accreditation standards (e.g. training for support staff) for families using FMS.

**Complex service needs**

People with developmental disabilities sometimes have mental health conditions, behavioural issues or complex medical needs. Service providers, Government of Alberta staff and other organizations report there are significant gaps in addressing these complex service needs within the existing PDD structure. They suggest PDD is becoming increasingly “crisis-driven” and a “catch-all” for services that should be delivered in a collaborative manner with other government departments such as Children’s Services, Justice and Health.

Some felt providing services to those with complex needs – without effective collaboration or adequate financial resources – can come at the expense of providing good supports and services to those without such needs. In response, some families said they feel the need to exaggerate the degree of risk their relative will experience so they can obtain the services they need.

Some families and service providers believe PDD’s current definition of complex service needs (which focuses on concurrent mental health conditions or significant behavioural issues) is too narrow and should be broadened to include those with complex medical issues in addition to a developmental disability.

Some families and service providers noted the PDD system was never “built for people with the types of complex needs we see now” and question whether the system can adequately accommodate them. The panel heard from several families who expressed concern at the prospect of their son or daughter living with someone with complex mental health issues or significant behavioural challenges, without adequate supports, resources and expertise.
4. Workforce

The disability services workforce includes community disability workers (employees hired by community service providers or FMS administrators) as well as Government of Alberta employees. Community disability workers provide a variety of supports to individuals with developmental disabilities in their homes and communities. Some examples of Government of Alberta staff in the PDD program include service coordinators and contract specialists.

Throughout the community conversations, self-advocates and families expressed appreciation and support for the community disability workers who provide services, as well as PDD program staff. These groups also shared stories of care and compassion, noting strong relationships are the foundation of the services provided. All groups spoke of challenges with recruiting community disability workers and the negative impact staff turnover has, especially for those receiving PDD supports.

“Dream Worker” from Albertans Advocating for Change Together submission
Wages and benefits

There was consensus among participants that relatively low wages for community disability workers contribute to an ongoing struggle recruiting and retaining staff. Many people raised concerns about wage and benefit disparities between community disability workers and similar positions in the public sector, as well as wages not keeping up with the cost of living. Community disability workers often work several jobs to earn a living wage, increasing the likelihood of staff burnout and potential safety risks. As well, while many community disability workers said they enjoy their work, it is demanding and other sectors may offer more competitive wages.

“Community disability workers need to work two or three jobs to cover their family needs. They may have knowledge and skills, but they often are burned out. It is difficult for agencies to control the number of hours they work in other jobs … a decent income would help a lot.”

- Community disability worker

Qualifications

People had mixed views as to whether community disability workers have the knowledge and skills to do the job. Individuals receiving PDD services and community disability workers rated the knowledge and skills of community disability workers most favourably.

There was broad support to establish qualifications and certification for working in the field, though it was noted Alberta lost many of its post-secondary programs in disability studies in recent years. The importance of a quality workforce was stressed by many participants at the community conversations. Some who shared negative past experiences wanted more safeguards in place as part of hiring processes.
Training opportunities
There was broad support for ongoing training for community disability workers. Many people believed community disability workers did not have adequate opportunities for education and training, while other workers indicated they do take advantage of existing professional development opportunities.

Community disability workers themselves had varied opinions on whether they have adequate education and training opportunities. Some service providers and families using FMS said they are not adequately funded to offer staff training. Many self-advocates indicated they want input on the kind of training their staff need.

Workload
Comments made by PDD staff, service providers, individuals and families throughout the engagement indicate the caseloads of PDD program staff are too large, preventing them from fulfilling their duties to a reasonable standard. It was also suggested there may be differences across the province in the caseload size and ability to meet expectations. Some suggested reviewing or clarifying roles and responsibilities within the overall service delivery system may be required to address the workload of PDD program staff.

“My personal experience with PDD staff for the past 20 years has been excellent in terms of the support we have received for our daughter. These people are in the difficult position of mediating between government policy, family dynamics and individual needs. For the most part, they do an excellent job as far as I can see.”

- Family member
5. Communication and connections

The PDD program currently communicates and connects with the disability community in a variety of ways, such as advisory councils or committees that support the overall disability system and at an individual level through the individual and caregiver connections with the Government of Alberta PDD program staff and service providers.

There were different opinions about the quality of communication and engagement with the provincial PDD program. At the system level, many expressed appreciation for recent engagement with the disability community, particularly the 2015–16 review of the PDD Safety Standards.

At the individual level, some people indicated they were generally satisfied with their relationships between PDD staff, service providers and families. For example, some people believed their involvement with the PDD program helped with access to other government programs such as AISH.

Others stated a need to improve communications and the quality of information provided, noting the need for more accessible materials and interpretation services. Many said they do not understand how the PDD programs works – its policies and processes – or how funding is determined and allocated. Some Government of Alberta staff indicated they were unclear about these same issues and believed more training, tools or other supports could help them to relay program information more effectively.

There was consensus amongst all groups in all forums that a cooperative relationship is desirable:

- individuals receiving PDD services and their families want PDD program staff to be accessible and responsive to their needs
- service providers and community disability workers want to feel their knowledge and expertise is valued and they are a full partner in the delivery of services
- everyone involved with the PDD program wants more collaboration – within and across ministries and with each other

Half of survey respondents indicated they share the same goal when working together. Advocacy groups had the lowest level of agreement with the notion that everyone is working toward the same goal. People receiving PDD services had the highest level of agreement with this idea.

47 per cent of respondents did not agree with the statement “I am satisfied with the information given to me about new initiatives that may affect the PDD program.”
• this is particularly important when serving individuals with complex service needs.
  • all groups want more input into the creation of policy and its implementation
  • individuals and families want more information about the types of services they should expect from PDD and a better understanding of the link between roles, responsibilities and authority in funding and service approvals
  • there was broad support for continued engagement with the disability community to review and refine the vision of the PDD program and ensure services align with this vision

All groups want clarity on the role of the PDD program with respect to monitoring and oversight of services. This was highlighted by some families who expressed uncertainty about how to effectively address concerns related to their family member’s quality of service.

Beyond the issue of funding and service approvals noted previously, there was general agreement the roles, responsibilities and expectations of all those with a stake in the PDD program need to be clarified and aligned with the mandate and purpose of the program. It was felt role clarity was critical, as it would go a long way to establishing trust and cooperation, as well as improving accountability for all parties and the overall effectiveness of the PDD program.

It was also noted that role clarity is intertwined with service delivery issues. For example, many service providers believe they are better positioned to lead the individual needs assessment and service planning process, given PDD program staff are often far removed from individuals requiring PDD services.

“We need ongoing mechanisms for communication and collaboration and change, true partnership based on a common vision. This can’t be a once only consultation process.”

- Service provider
Looking forward

The panel had the opportunity to meet with people from across the province. While the panel heard the PDD system faces many challenges, there was also genuine appreciation for the program. Those who participated in this review expressed dedication to people supported by the PDD program. This commitment and enthusiasm on the part of the community will undoubtedly be essential in responding to the challenges the system faces.
Appendix A: PDD review panel

Dorothy Badry (co-chair)
Associate professor with the faculty of social work at the University of Calgary, and a parent of a young adult with developmental disabilities

Ann Nicol (co-chair)
Former chief executive officer of the Alberta Council of Disability Services

Dick Sobsey (co-chair)
Emeritus professor of educational psychology at the University of Alberta, and the parent of an adult son with severe and multiple disabilities

Krista Carr
Executive vice-president of the Canadian Association for Community Living

Ryan Geake
Chief executive officer of the Calgary SCOPE Society

Dan Huising
A self-advocate with cerebral palsy who is employed as a community support worker assistant

Lorelei Martin
Executive director of the Drumheller and Region Transition Society

Norman McLeod
Board president of the John Humphrey Centre for Peace and Human Rights

Sahana Parameswara
Executive director of the Gateway Association for Community Living in Edmonton

Jonathon Red Gun
Disability employment coordinator for Community Futures Treaty Seven

Lloyd Thornhill
An avid volunteer in Calgary who brings lived experience to the panel as an individual with a developmental disability