

Persons with Developmental Disabilities (PDD) Review: what Albertans told us Report of the PDD Review Panel

Plain language version
July 2019



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Persons with Developmental Disabilities (PDD) Review: what Albertans Told us -- Report of the PDD
Review Panel (Plain Language version)

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Community and Social Services

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Letter from co-chairs

The Persons with Developmental Disabilities (PDD) Review Panel wants to say thank you to everyone who shared their ideas about the PDD program.

People told us what they liked about the PDD program and how it helps them be active in their communities.

People also told us what they want to change about PDD to make it better.

We learned a lot from everyone.

Most people told us they want to be part of making changes to PDD.

Thank you again for telling us your stories and writing to us with your ideas.

Dorothy Badry

Ann Nicol

Dick Sobsey

PDD Review Co-chairs



About the PDD program review

The PDD program helps about 12,000 people with developmental disabilities in Alberta get support to live in their communities and be active citizens of the province. PDD helps pay for staff to help with 4 areas of people's lives:

1. home living – things like meal planning and cleaning
2. employment – getting a job and keeping it
3. community access – things like volunteering in your community and going to activities you like
4. specialized community support – extra help when a person is having trouble.

The Government of Alberta heard people wanted to make the PDD program better. The Government chose a group of 11 people, called a panel, to hear people's ideas about this.

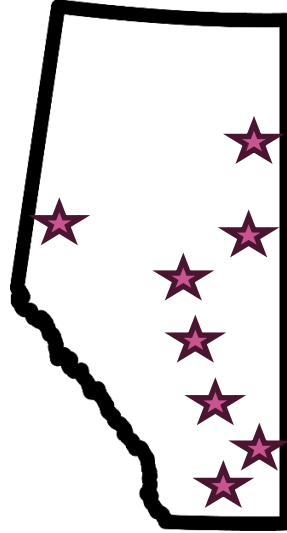
The panel's job was to learn what people thought about the PDD program and to get their ideas on how to make the PDD program better.

Who the panel heard from

The panel went to 8 places in Alberta to talk with people about PDD.

This is a list of places the panel went:

1. Fort McMurray
2. Grande Prairie
3. St. Paul
4. Edmonton
5. Red Deer
6. Calgary
7. Medicine Hat
8. Lethbridge



Over 1,000 people came to talk with the panel.

Most of the people who came were people who have PDD supports and their families.

A lot of staff and people who work at agencies came too.

Some PDD workers and other government staff also talked to the panel.

People with disabilities who do not have PDD supports and their families also came to talk with the panel.



Over 1,000 people filled out a survey. Most of the people who did the survey were people who have PDD supports, their families and staff.

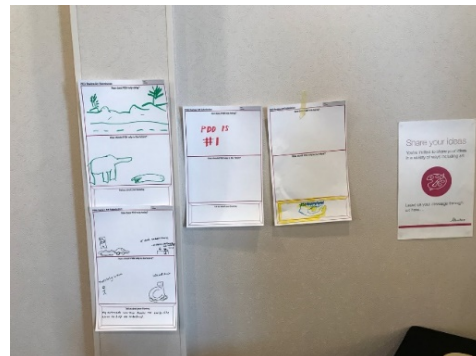


Many people wrote letters and emails to let the panel know what they thought.

Some people made videos and art.

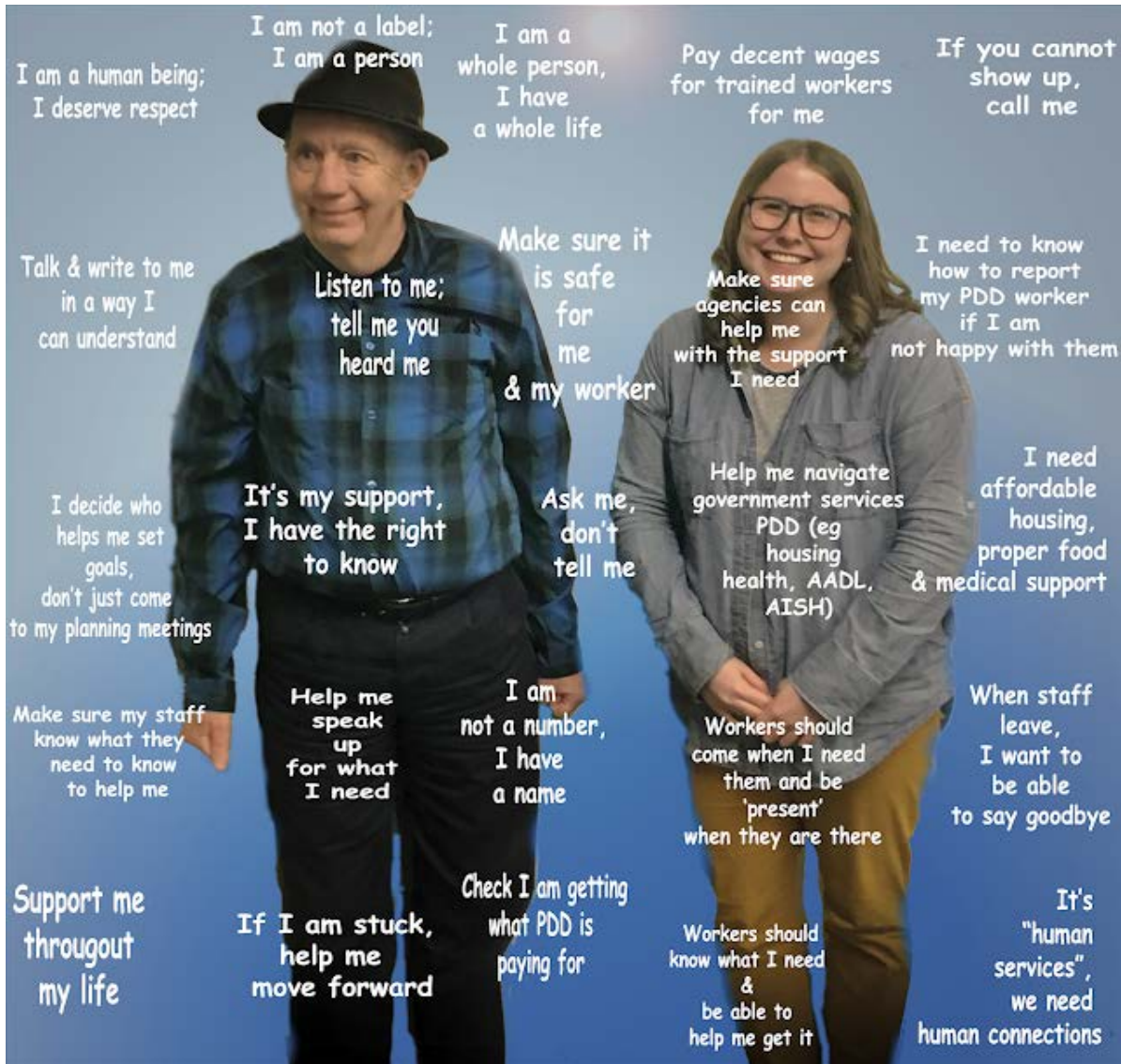


Collen Honish, artist



Art made at places the Review Panel had in-person sessions

A few groups, including a self-advocate [ad-vo-cat] group, gave presentations [pres-ent-a-tions] to the panel. The picture below is one of the ways the self-advocate [ad-vo-cat] group told the panel how PDD should help people with disabilities.



"Whole People, Whole Lives" puzzle included in the Disability Action Hall and Albertans Advocating for Change Together presentation to the panel

What people told the panel

People told the panel about 5 main things.

1. Who can get help from PDD

Only some people get help from PDD.

A person can get help from PDD if they are an adult. That means they are 18 or older.

Before the person turned 18, they must have:

- an IQ score of 70 or lower
- a hard time with daily living skills. This might be things like making food and shopping.

Almost everyone said more people should be able to get help from PDD.

A lot of people said a person's IQ should not be so important. They said whether or not someone needs help should be the most important thing when deciding if someone should get PDD supports.

A few people were worried that PDD did not have enough money and staff to help more people.

They thought it would be okay to help more people as long as there was enough money and staff to do it.

2. Getting help when you need it

Lots of people said it was hard to find out about PDD. They said it is hard to understand the rules to get PDD supports too.

Some families worried PDD would not be able to give their children with disabilities help when they turned 18 years old.

Many people said it takes too long to get PDD supports.

Lots of people said it should be easier to change PDD funding if you need to – like if you want to change agencies, move to a different place in Alberta or need more help.

The panel was told that sometimes people with disabilities who live on First Nation reserves have to leave home to get PDD supports.

People said government workers should talk to each other more and work together when they are helping someone. They said this is the best way to help people who have complex needs and need help from a lot of different people.

People with disabilities told the panel about things that make it hard for them to be included in their communities and do things that are important to them.

For example, lots of people said it is hard to find a place to live that they can afford.



People with disabilities said it is hard to find ways to get around. Many people said they do not have enough money to pay staff to drive them places. There are also problems with taking a bus. Sometimes a bus does not come when it is supposed to and some buses cannot take wheelchairs. People said there should be more places to live and more ways to get around.



Many people said they want more help getting jobs and going to school.

Some people told the panel it is hard to get certain services if you have PDD supports. For example, sometimes it is hard to get mental health and addiction services.

3. How PDD helps

PDD pays agencies or families to hire staff who help people:

- live in their homes
- get jobs
- do things in their community, like volunteer

Sometimes PDD will pay to hire staff when a person needs extra help to stay safe or healthy.

Many people said it takes too long to get help from PDD and they did not understand how PDD decided what to pay for.

People with disabilities and their families said PDD needs to get to know them better before PDD can decide what kinds of help they need.

People with disabilities told the panel they want to be listened to and have more choice in where they live, who their roommates are and who their staff is.

People with disabilities want to choose if their family or an agency helps them get staff.



*People with disabilities
want to be listened to*

Agencies said PDD did not pay for all the things agencies need to do, like staff training and paperwork. They said it should be easier to do PDD paperwork.

Agencies told the panel they want more choice in how they use PDD money to help people. Agencies said it would be good if they could give a little more help or a little less help depending on how the person with a disability was doing.

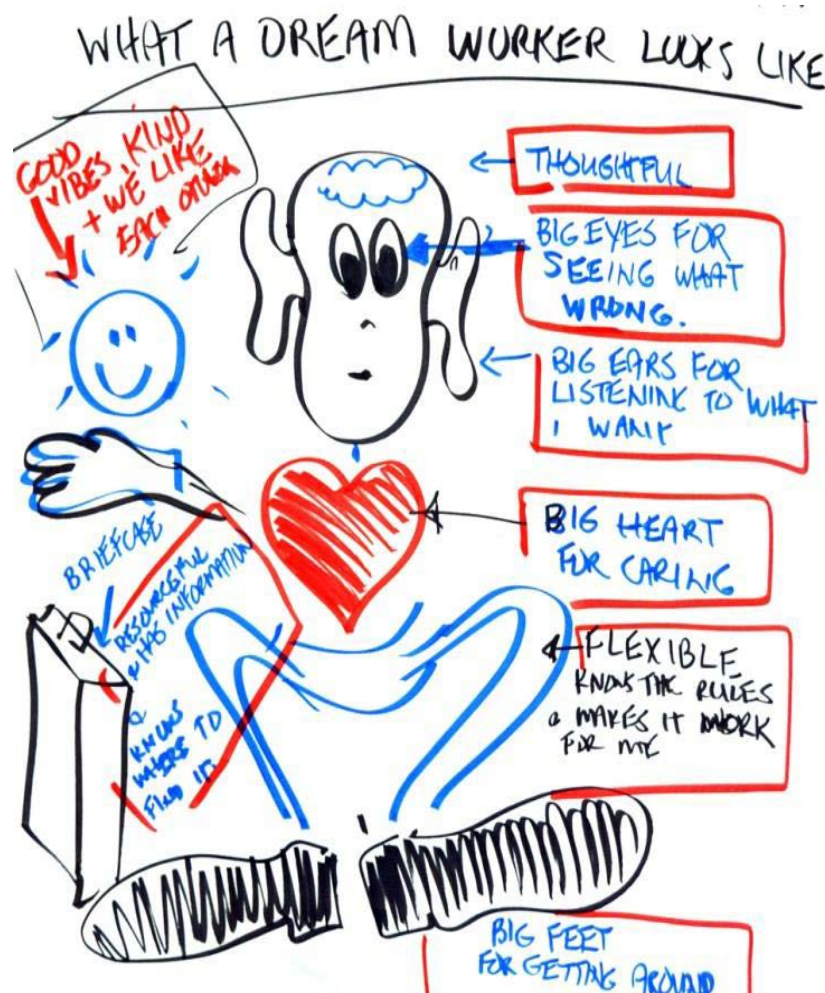
Many families who use Family Managed Services said they liked the program because they want to choose who their staff is and the kinds of help staff give. These families said they want more help to use Family Managed Services. Families want help finding staff and doing PDD paperwork.

Other families would like to have an agency. In some places in Alberta, there are no agencies that can help families right now so they use Family Managed Services.

4. The people who help – support staff and PDD workers

People with disabilities and their families told the panel that their staff and PDD workers helped them a lot.

They said they were glad their staff and PDD workers were caring and smart.



"Dream Worker" from Albertans Advocating for Change Together submission

The panel heard low wages were a problem. Some staff have to work too much or work too many jobs to earn enough money. Staff get tired and stressed when they work too much.

Many people thought staff should be paid more. People thought staff would stay at their jobs longer if they were paid more. People said this would be better for everyone, especially for people with disabilities.

Many people thought it would be a good idea if staff had to learn about people with disabilities before they got a job.

Lots of people said staff should be able to take training for their jobs. People with disabilities want to be part of deciding the kind of training their staff need.

Agencies, families and staff would like PDD to pay for more training for staff.



5. Working together

PDD workers told the panel they have a hard time keeping up with all the parts of their jobs. People who have PDD supports, their families and staff said they would like to talk to their PDD worker more and meet with them more often. They want their PDD worker to have enough time to be able to get back to them if they leave telephone messages or send emails.



A lot of people said they were confused about how PDD works. They do not understand PDD rules or how PDD decides what to pay for. Even some PDD workers said they have a hard time knowing what the rules are. Many people thought it would be a good idea to get together to talk about this. People said it would be good if PDD talked with everyone before they changed any rules about how the program works.

PDD workers, agencies, families and people who have PDD supports said it would be good to talk about what each other's jobs are. Everyone could decide who would be the best at different jobs. For example, some agencies thought they would be good at making plans for the help people with disabilities need. Agencies thought they would be good at this because they know the people they work with better than PDD workers do.

Many people said if they understood what each other's job are, it would be easier to work together. People said everyone working together with the same goal is the best way to help people with disabilities.

One thing people really wanted to know was who they can talk to if services are not good. People said it is really important for people with disabilities to have staff and agencies that do a good job.

What will happen next?

The panel heard the PDD program is really important. People with disabilities, their families, agencies, staff and many other people want to be part of making it better.

The panel will give this report to the Minister. The Minister will decide what to do next.



The PDD Review Panel



Dorothy Badry
Co-chair



Ann Nicol
Co-chair



Dick Sobsey
Co-chair



Krista Carr



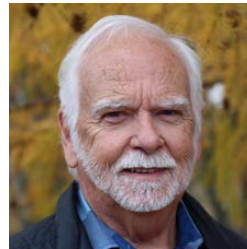
Ryan Geake



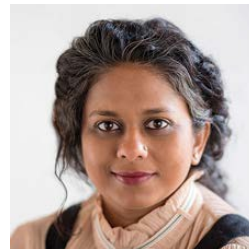
Dan Huising



Lorelei Martin



Norman McLeod



Sahana Parameswara



Jonathon Red Gun



Lloyd Thornhill