

# Persons with Developmental Disabilities (PDD) Steering Committee Report

December 16, 2021

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Community and Social Services, Government of Alberta  
Persons with Developmental Disabilities (PDD) Steering Committee Report – Accessible Version

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ISBN 978-1-4601-5292-8

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# Letter from committee chair

Minister Luan,

Thank you for letting our steering committee present ideas and recommendations to you on how to make the Persons with Developmental Disabilities (PDD) program better for the future.

We know that there are many challenges and that change is needed soon. Self-advocates have shared their voice through the PDD Review, and shared their ideas with the Steering Committee about being included in the community and improvement ideas for the program.

The steering committee is a group of people who all know about different parts of the PDD program, and we came up with 30 suggestions related to:

- People making their own decisions and being included in the community
- Government and the community making sure that people's needs are met
- Making sure that services meet people's needs and how people get services is fair
- Using technology to help people
- Being flexible in how services are delivered

Making changes to PDD will take time and we will need to make changes as we learn what works. Any changes that happen need to be thoughtful, based on what works well, and focused on people.

We look forward to working with you and your staff to promote a good life for Albertans with disabilities.



Dr. Dorothy Badry  
PDD Steering Committee Chair

# Background

The PDD program helps about 12,000 people with developmental disabilities in Alberta get support to be active citizens in their communities.

The Government of Alberta wanted to hear ideas on how to make the PDD program better. The Government chose a group of nine people, called the steering committee, to do this.

The steering committee's job was to understand how the PDD program can be better, and come up with answers to these questions:

- Who should get help from the PDD program and how?
- How can PDD understand what kind of help a person needs and how much help a person needs?
- How do people want to be supported in their homes?
- How can services be easier to get?
- How can Family Managed Services be better for everyone?

## Who was involved

The steering committee was made up of family members, service providers, advocates and government staff who know about PDD.

Albertans Advocating for Change Together (A-ACT) asked self-advocates and self-advocacy groups around Alberta how PDD can help Albertans with developmental disabilities have good lives and shared what they said with the steering committee.

Four smaller groups of family members, supporters of people with disabilities and government staff called working groups, were set up to talk about specific topics.



## Process

The steering committee and working group members learned about what Albertans with developmental disabilities, their families and their supporters liked about the PDD program and what they would like to see changed to make it better.

# What government can do to make PDD better

The steering committee came up with 30 ways government can change the PDD program to make it better for Albertans with developmental disabilities, their families and their supporters.

Most of the steering committee's ideas focused on five main things.

1. People accessing PDD need to be involved in decisions about their life, how they receive help, and the need to be included in the community.
2. Government and the community should both play a role in helping Albertans with developmental disabilities have a good life.
3. Services should be meaningful to the people who need them and help to meet their goals.
4. Using technology to help people.
5. It should be easy to get help when you need it.

## 1. People making their own decisions and being included in community

The steering committee agreed that it is important to make sure people with developmental disabilities are treated well and the same as people without disabilities.

They also agreed that it is important for everyone to be

included in their communities, and that people should have a say in decisions about their life and their future. This should continue to be the purpose and focus of PDD.



It is important that people with disabilities are listened to and are given choices about where they live, how they spend their time, and who supports them.

## 2. Government and the community working together with Albertans with developmental disabilities

Government, service providers and community organizations, families and people with developmental disabilities must work together to make sure people are included in their communities.

The steering committee thinks that it is **important for everyone to know what their role is to support people with developmental disabilities** and for government to support service providers and other community organizations to take the lead on helping people get

services. People who work in the community often know more about what help is available and know people and their families better than government does.

The steering committee thinks that planning for support should happen as early as it can and that it should match what people's goals are for their life.



One way to get services is by managing them yourself or having a family member help. This is called Family-Managed Services (FMS). **The steering committee thinks that more people would choose FMS if it were easier to do, and thinks the community should play a bigger role in helping make FMS easier for people to access.**

Some people get help from lots of different government programs. This can be confusing. The steering committee thinks government programs should work together to make it easier for people to get the help they need when they need it. This could include people who have health issues, or may be involved with the law, or are getting closer to their senior years.

Government should make sure people with disabilities can get education and training so they can get jobs that pay a good wage.

### 3. Supports and services should be meaningful to people who need them and help to meet their goals

The government should provide money to community organizations who are doing a good job at providing care and helping people with disabilities have a good life. Community organizations and service providers should be helping people have happy lives, understand their rights, make choices, participate in activities they enjoy and have healthy relationships.

Government, Albertans with developmental disabilities and their families should be able to say if service providers and support staff are not doing a good job of providing care or helping people to meet their goals.



## 4. Using technology to help people

Sometimes technology can help Albertans with disabilities live more independently in their homes by making it easier to do simple activities. Work should be done to learn more about what kind of technology is most helpful for Albertans with developmental disabilities and their supporters.

The steering committee also thinks it should be easier for people to give information to and get information from PDD on their computers, tablets or phones.



## 5. It should be easy to get the help you need when you need it

The steering committee agrees that people with developmental disabilities should be able to share the same experiences as people without disabilities, like learn new skills, have a job, or live with friends. There should be more options for how people with disabilities are supported throughout their lives.

The amount of help a person gets should be fair and based on a person's strengths, not just needs. The steering committee also said PDD should learn about what kind of help a person needs by understanding what a good life means to them. The help a person needs will change over time, and their supports and services should be able to change with them. There should be plans in place in case an emergency happens.

The steering committee said there should also be more choice in how people use their PDD money to get help. For example, some people like hiring their own staff, but also like going to service providers for other kinds of help. There should be fewer rules about how a person gets the help they need.

## What will happen next



The steering committee said the PDD program is really important. People with disabilities, their families, agencies and staff should be part of any future changes to make it better. Ideas should be tried out to make sure they make things better for people with disabilities and their families before any changes are made.

The steering committee will give this report to the government. The government will decide where to start and form groups with people with disabilities, families, agencies and staff to plan and try out changes.

# Recommendations for change

## A. What the PDD program does

1. Change the *PDD Services Act* to show that the Government of Alberta, service providers and the community as a whole share responsibility for helping adults with developmental disabilities.
2. Make individuals with IQs between 70 and 85 who have similar support needs eligible for PDD services.
3. Have the PDD program and other Government of Alberta ministries work together and share costs to help individuals with developmental disabilities have a better life, so PDD does not have to pay for everything.
4. Use technology to help support individuals with disabilities to be more independent where it makes sense.
5. Improve employment supports to help persons with developmental disabilities get and keep good jobs.
6. Work with Alberta Health Services and other partners so that as individuals with developmental disabilities get older, they can access a range of aging-related supports available to individuals over 65.
7. Measure the outcomes of PDD services in a way that helps make services better.
8. Fund service contracts based on outcomes that are important to individuals with developmental disabilities.

## B. Alternative home living supports

1. Reduce barriers to make it easier to change the kind of home they live in and how they get support to live there. Changing from one kind of living situation to another can be hard, and help making the transition is an important support to have.
2. Provide ways for service providers and families (through Family Managed Services) to share resources and work together.

3. Make the purpose of respite supports clear.
4. Have more shared living (e.g., support home and supportive roommate) options for people with disabilities.
5. Allow a lot of different home living options to be funded.
6. Look at how assistive technology can add to other supports to help people be more independent.
7. Make service provider funding and support rules more flexible so they can try new things that work better for the individuals they support.
8. Have rules that support caregivers to plan for local and global emergencies before they happen.

#### C. Assessment of needs approach

1. Develop an Alberta-made planning-based assessment that is person-centered, strengths-based and changes when people's needs change.
2. Try out an Alberta-made assessment and planning process that shares responsibility between government, individuals, families, service providers and community.

#### D. Delivery models, roles and responsibilities

1. Define government, service provider and community roles so they are clear and separate with service providers and community taking more roles in support planning.
2. Fund a lot of different ways to support individuals with disabilities so there is flexibility to support changing needs as individuals grow up and get older.
3. Use technology to make getting help easier and work better for people.
4. Actively involve individuals with developmental disabilities, families, service providers and government in planning changes to PDD. Make sure we continue to try new things and check whether they work well.

#### E. Family Managed Services

1. Give community organizations the money and support needed to help Albertans with disabilities who use Family Managed Services and their families.
2. Government should be clear about how it shares responsibility of monitoring and overseeing of Family Managed Services to minimize risk and improve outcomes for everyone involved.

F. Other recommendations

1. Create a group that meets regularly to advise the PDD program.
2. Raise wages for community workers in disability services.
3. See if there is technology available that could be used consistently throughout the province (because it is cheaper if you can buy in bulk and all use the same thing).
4. Review the rules used for group living situations (i.e., SLALA) to make sure they fit the community living goals and values of PDD, and if they don't fit, change them.
5. Figure out how to fairly work out if an individual's services need to be changed due to changes in his or her life.
6. Identify ways to make overnight staffed homes more efficient and effective, and cheaper to run.