

Persons with Developmental Disabilities Program Review



Discussion Guide

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Background

Context

The Persons with Developmental Disabilities (PDD) program currently provides staffing supports for over 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.

On January 19, 2018, Community and Social Services Minister Irfan Sabir announced a review of the PDD program to explore how the program can be improved to better serve Albertans with developmental disabilities. The PDD program review is being led by an appointed review panel. The review panel is seeking input from Albertans through a number of activities, including in-person Community Conversations, an online questionnaire, and individual submissions. Albertans can attend in-person Community Conversation Sessions in their communities and share their ideas with panel members about what's working well and how to improve the PDD program. The locations and times for the sessions and other information related to the review are listed on the [PDD Review Website](https://www.alberta.ca/pdd-review.aspx) at <https://www.alberta.ca/pdd-review.aspx>.

Community Conversation Sessions will ensure Albertans have an opportunity for their unique perspectives to be heard by the review panel.

The PDD program review will be guided by the disability sector's overarching principle of **Nothing About Us, Without Us**. To reflect this principle, engagement with Albertans will be:

- **Inclusive:** every person is respected, acknowledged to have insight, and has an opportunity to be heard.
- **Adaptable:** stakeholder involvement will reflect the scale of issues and the potential impact.
- **Transparent:** stakeholders will understand the process and how their input will affect policy or decisions.
- **Diverse:** stakeholders are diverse and have multiple perspectives across the lifespan, disability type and lived experience.

Meet the panel members

Dorothy Badry: Co-chair

Dorothy is an associate professor with the faculty of social work at the University of Calgary, where she teaches courses and conducts research related to social work, child welfare, Fetal Alcohol Spectrum Disorder (FASD), Indigenous issues, human behaviour and disabilities. Her research work, much of which is focused on FASD, has earned her numerous awards and accolades over the years. She is the author of a wide range of publications that address the societal impacts of FASD at provincial, national and international levels. Dorothy serves on numerous boards and committees related to her work in the social work and disability sector. She is also the parent of a young adult with developmental disabilities.



Dick Sobsey: Co-chair

Dick Sobsey is an emeritus professor of educational psychology at the University of Alberta, where he taught courses and conducted research related to the lives of people with severe disabilities and their families. He formerly served as the Director of the John Dossetor Health Ethics Centre and The J.P. Das Centre on Developmental and Learning Disabilities. He is the author of a wide range of books and articles that address the health, education and human rights of children and adults with disabilities. Dick is also the father of a 28-year-old son who has severe and multiple disabilities.



Ann Nicol: Co-chair

Ann Nicol has over 35 years of experience in front-line and senior management roles with the Government of Alberta social services and non-profit community disability services in Alberta. She worked directly with, and on behalf of, children, youth, families and adults with disabilities. Ann was also the executive director of a provincial human service organization providing community-based supports for persons with developmental disabilities and complex behaviour needs, and CEO of the provincial association representing community disability service providers. Ann holds bachelor's and master's degrees in social work and received the Queens Diamond Jubilee medal for her community work. Recently retired, Ann volunteers as a member of the Premier's Council on the Status of Persons with Disabilities and the Community and Social Services Citizen Appeal Panels.

Krista Carr

Krista Carr is the executive vice president of the Canadian Association for Community Living (CACL), where she brings a perspective on disability supports and services from across Canada. Krista has extensive experience in the not-for-profit sector working with people with developmental disabilities, their families, governments and systems to accomplish the mission of full inclusion and citizenship for persons with developmental disabilities and their families. She also sits on a number of disability-related boards and committees provincially and nationally. She currently resides in New Brunswick with her husband and two daughters.



Ryan Geake

Ryan Geake has extensive experience in the non-profit sector working with people with disabilities. He is the chief executive officer of the Calgary SCOPE Society, a non-profit charity that helps people with disabilities live successful lives in the community. He's held numerous positions with SCOPE, where he worked to develop a stronger local disability community through the creation of programs like disability arts and film festivals, community gardens, kitchens and more. He presently sits on a number of disability-related non-profit boards and councils. Ryan also shares his expertise as a sessional instructor at Bow Valley College and the University of Calgary.



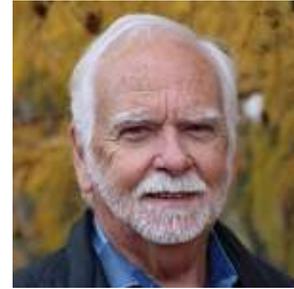
Lorelei Martin

Lorelei Martin is the executive director of the Drumheller and Region Transition Society, a rural community organization that provides individualized support to people with disabilities. Throughout her career, Lorelei has been involved with numerous disability-related initiatives, including a PDD persons centred planning pilot, a PDD funding demonstration model and building self-advocacy in the Drumheller region. She previously served on the board for the Alberta Council of Disability Services and continues to serve as a member of the board of the Community Services Benefits Trust. She holds great enthusiasm and passion for the future of community disability services.



Norman McLeod

Norman McLeod has over 50 years' experience in the disability field. He began his career at the Michener Centre in Red Deer where he was the assistant manager for 20 group homes. After moving to the provincial government in the Services to Persons with Disabilities (SPD) branch, he assisted non-profit organizations in developing community supports and provincial policies for people with disabilities to live inclusive lives in their community. Prior to his retirement, he served as chief executive officer of the SPD provincial board, where he managed the delivery of supports to people with disabilities through six regional boards. He now spends his time volunteering and is currently board president of the John Humphrey Centre for Peace and Human Rights.



Sahana Parameswara

Sahana has international experience working with people with disabilities. She has worked closely with people on the spectrum of ability and emotional health in the United States, India and Canada. She has worked in a number of roles throughout her disability career, from conducting social work research at the University of Calgary to counseling at the YWCA in Ottawa to working as a community disability worker in Sherwood Park. Her focus in the last 10 years has revolved around therapeutic communities and youth living with barriers in the child welfare system. Her experiences have given her the opportunity to help people with disabilities in a number of different ways, which led her to her current position as executive director of the Gateway Association for Community Living in Edmonton.



Johnathon Red Gun

Johnathon Red Gun is a disability employment coordinator for Community Futures Treaty Seven. Throughout his career, he has facilitated numerous workshops in the wellness stream to those impacted by the Residential School legacy and its intergenerational trauma. He has served in various advisory roles with the Province of Alberta and developed partnerships with several disability program agencies. With his judicial background (former member of the RCMP) and knowledge of Blackfoot culture and tradition, his research for Siksika Nation Chief and Council into the complex issues of disability makes him a valuable resource for individuals in the community and private sector. He continues to advocate for First Nations persons with disabilities.



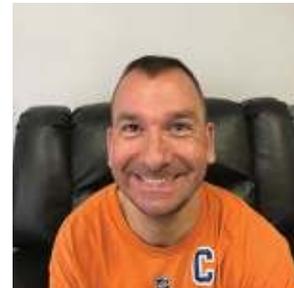
Lloyd Thornhill

Lloyd Thornhill brings a lived experience as someone with a developmental disability. He has been an active member of the Disability Action Hall for 21 years, where he enjoys the opportunity to help others with disabilities. As an avid volunteer, he lends his time to the Alex Community Food Centre and Bell Music Centre. He is also actively involved with the Calgary Scope Society and enjoys participating in social activities with his peers. Originally from Newfoundland, Lloyd lives independently in Calgary and receives supported independent living supports through the Scope Society.



Dan Huising

Dan Huising is a self-advocate with cerebral palsy who is also employed in the field as a community support worker assistant. He has been receiving PDD residential supports for close to 24 years. Dan has inspired others through his determination, perseverance and ability to overcome obstacles. In 2014, Dan successfully climbed Mount Kilimanjaro as part of a fundraising project for an orphanage in Africa. Dan has also been involved with Special Olympics since the early 1990s. He has competed numerous times at provincials and twice at nationals. Dan had previously served on the Board of Directors of the Loseca Foundation, a non-profit agency in St. Albert supporting adults with developmental disabilities.



How information will be used

The information provided to the review panel will be used to inform their final report and recommendations for improving the PDD program. The Panel will provide this report to the Minister of Community and Social Services.

Information shared with the Panel is subject to the [Freedom of Information and Protection of Privacy Act](#) (FOIP) regarding the collection, use and disclosure of personal information. Personal information provided to the panel will only be shared with the permission of the person providing the information.

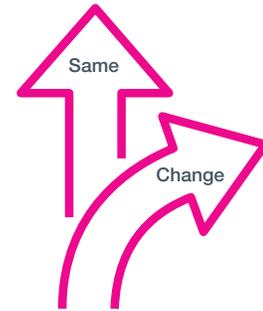
How to use this guide

This guide will help individuals and organizations have powerful conversations about what is working well and to share ideas about how to improve the PDD program. The guide outlines five key topic areas that the PDD review panel wants to learn more about. The questions in each topic area can be used as a starting point for reflection and discussion.

Input can be provided at in-person sessions, or through an online questionnaire available on the [PDD Review Website](https://www.alberta.ca/pdd-review.aspx) <https://www.alberta.ca/pdd-review.aspx>. Individual submissions can also be emailed to css.pddreview@gov.ab.ca, or mailed to PDD Review, PO Box 1020, Edmonton, AB T5J 2M1.

Discussion Topics

#1: Who gets help from the PDD program – 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 two limitations before 18 years of age

Some Albertans who need help in their daily lives may not have access to the PDD program, even though they may need similar kinds of supports and services. In some cases, they may not meet the eligibility criteria related to IQ score or they became disabled after the age of 18.

Conversation starters:

1. Should the current PDD program eligibility criteria be kept the same?
2. What changes should be made to the eligibility criteria? Why?

#2: Getting the help you need, when you need it - access



Access to services and supports to meet individual needs and goals

The review panel is interested in your experiences and ideas about getting PDD supports and services, including when services are first requested, as well as over time when circumstances or the need for services might have changed.

Key issues related to access may include:

- the application process
- needs identification and service planning
- getting the supports and services quickly when needed
- making changes to supports and services when needed (like moving to a new city, changing service providers, shifting from youth to adulthood, or an emergency or health issue)

Conversation starters:

1. How has PDD helped you get the help you need?
2. How could getting access to services be made easier? What could be improved?

#3: PDD now and in the future - service delivery



Albertans want a service delivery system that is predictable, accountable, easy to understand and responsive

Once an individual's support plan is created, the PDD program provides funds to service providers or Family Managed Services (FMS) administrators to hire staff that help individuals with developmental disabilities achieve the outcomes and goals identified in their plans. Outcomes may include things like living in their home, finding and keeping a job, and participating in their 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.

PDD supports and services are funded and delivered three ways:

1. Community service providers
2. Family Managed Services (FMS)
3. Direct operations (government owned and operated facilities)

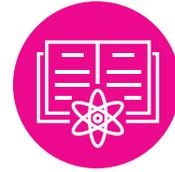
Key issues related to the service delivery system may include:

- ability to plan for the future (for individuals receiving PDD services, their families, service providers and government)
- reporting and monitoring requirements of FMS administrators or contracted service providers
- understanding how PDD funding is determined
- equity or consistency in how services are delivered across the province
- how the system supports individuals with complex service needs

Conversation starters:

1. Based on your experience with how PDD delivers services, what is working well?
2. What is not working well? How can this be improved?

#4: The people who help - a skilled and knowledgeable workforce



The disability services workforce should be skilled, knowledgeable and sustainable

For the purpose of this review, the disability services workforce is defined as 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. Examples of Government of Alberta staff include PDD Service Coordinators and Contract Specialists.

To be accredited, service providers must offer mandatory training for direct support staff in a range of areas, including First Aid, Abuse Prevention and Response, Positive Behaviour Supports, and others. Currently, there are no provincial minimum educational requirements for direct support staff working with persons with developmental disabilities.

A key area of focus in the review is sustaining a workforce that has the skills and knowledge they need to do their jobs well. This includes meeting the needs of those accessing the PDD program as well as fulfilling the mandate of the PDD program.

Key issues related to the disability services workforce may include:

- knowledge and skillset of both community disability workers and government staff
- training opportunities, especially to support individuals with complex service needs
- ability to recruit and retain staff to ensure effective service delivery
- organizational support for staff to do their jobs well

Conversation starters:

1. What is the most important quality or factor of the workforce?
2. What is working well or what are the current strengths of the workforce?
3. What can be improved to ensure a well-trained, knowledgeable workforce?

#5: Working together – connections and communication



Communication between PDD and the disability community has clarity of purpose and defined outcomes

The PDD program currently connects and communicates with the disability community in a variety of ways. They do this at the system level through advisory councils or committees, and at the individual level through individuals' and caregivers' connections with PDD program staff and service providers.

This review focuses on how government connects and communicates with the disability community at both the system level and individual level, and seeks to identify ways to improve how information is shared, issues are addressed, and relationships are strengthened.

Key issues related to connections and communication may include:

- roles and responsibilities of the PDD program, service providers, individuals receiving PDD services and families/guardians
- shared understanding of program goals and purposes
- ways of sharing information between individuals receiving services, families/guardians, service providers and PDD program staff
- ways to resolve concerns between individuals receiving services, families/guardians, service providers and PDD program staff (for example conversations, appeals or other processes)
- ways for self-advocates, families and guardians and service providers to voice issues and be included in discussions about the PDD program at a provincial level

Conversation starters:

1. Based on your experience with how you receive and share information, what has worked best for you?
2. Are current roles and responsibilities clear? How could relationships among the PDD program, service providers and others be improved?
3. What is working well with how issues related to PDD supports and services are resolved? How can this be changed?

Appendix A - PDD Program Snapshots

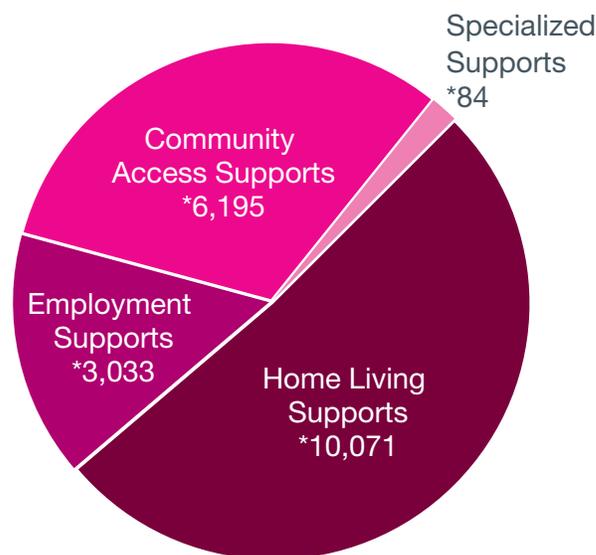
Facts about the PDD program

Mission

The PDD program works with others to support adults with developmental disabilities to be included in community life and to be as independent as possible.

Types of PDD services

- **Community Access Supports** – helps promote community connection and social inclusion
- **Employment Supports** – employment training and workplace support for maintaining paid employment
- **Home Living Supports** – support staff helps with living in your own home
- **Specialized Supports** – helps caregivers and support staff, when additional support is required.



* number of Albertans accessing services

PDD supports and services are delivered through



Service Provider
Contracts



Family Managed
Services



Direct Operations
(Government)

Since 2009-10

- The number of people using PDD Family Managed Services has increased by 132%
- The number of people accessing contracted service providers has increased by 26%
- The number of people being supported by government operated facilities (e.g.: Michener Centre) has decreased by 57%

In fiscal year 2017-18

- More than 12,000 Albertans receive supports and services from the PDD program
- The year's operating budget is nearly \$947 Million
- Number of people served by the PDD program since 2009-10 has increased by 30%

Facts about eligibility for the PDD program

To be eligible for PDD services, a person must:

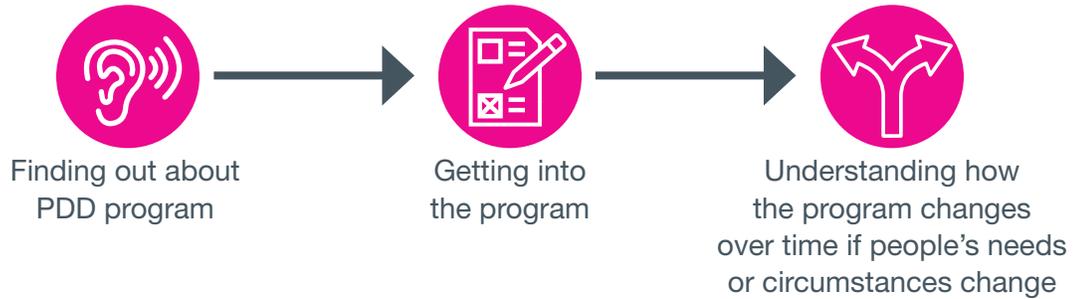
- be at least 18 years old
- have a developmental disability (*significant limitations in intellectual capacity and adaptive skills)
- have had the developmental disability before turning 18 years old
- be a Canadian citizen or permanent resident
- live and plan to receive services in Alberta
 - *A significant limitation in intellectual capacity is defined as an IQ score of 70 or lower.
 - A significant limitation in adaptive skills is defined as the inability to perform daily living tasks such as self-care, communicating with others and taking part in community activities.

55%

of youth with disabilities accessing the Family Support for Children with Disabilities (FSCD) program transition into the PDD program as an adult.

Facts about access to the PDD program

Access includes:



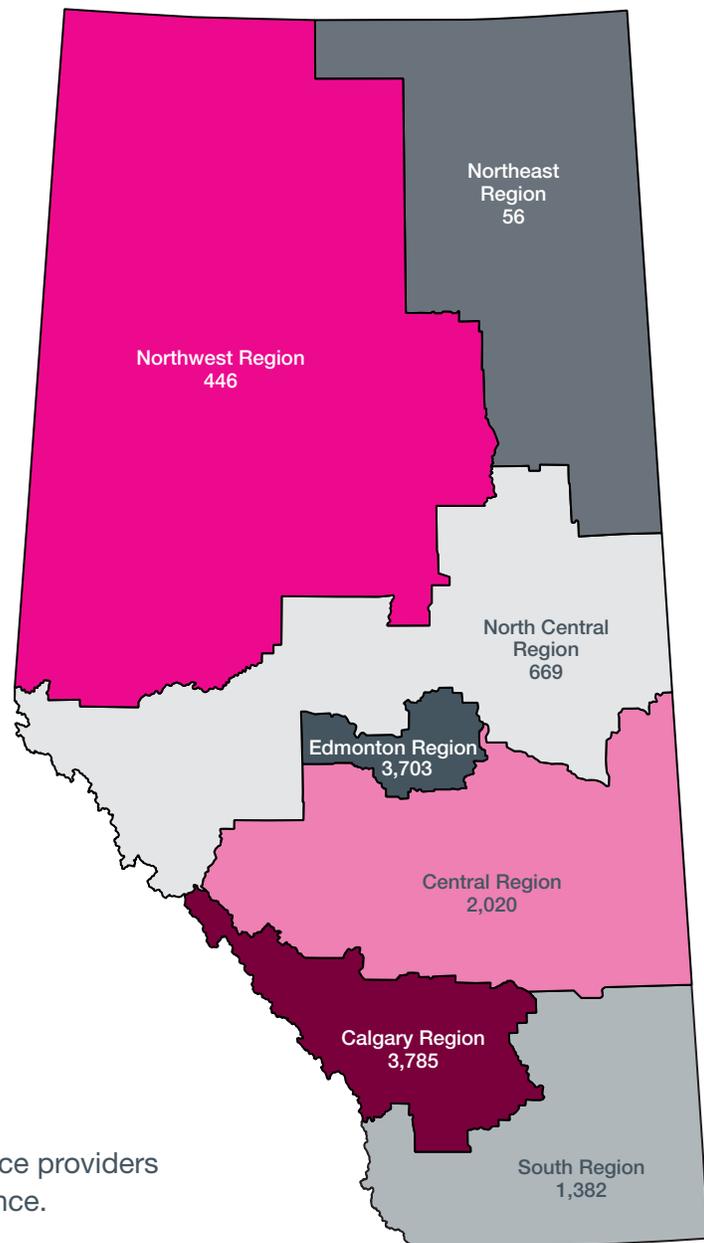
How PDD relates to other programs:

- 55% of children and youth supported through Family Support for Children with Disabilities go on to receive supports through PDD
- 87% of people accessing services and supports through PDD also access Assured Income for the Severely Handicapped
- 11% of people accessing services and supports through PDD are represented by the Public Guardian and 2% are represented by the Public Trustee
- 48% are represented by a private guardian and 3% have a private trustee, usually a family member fulfills these roles
- 38% do not have a substitute decision maker and make personal and financial decisions on their own or with informal help.

Facts about PDD program service delivery

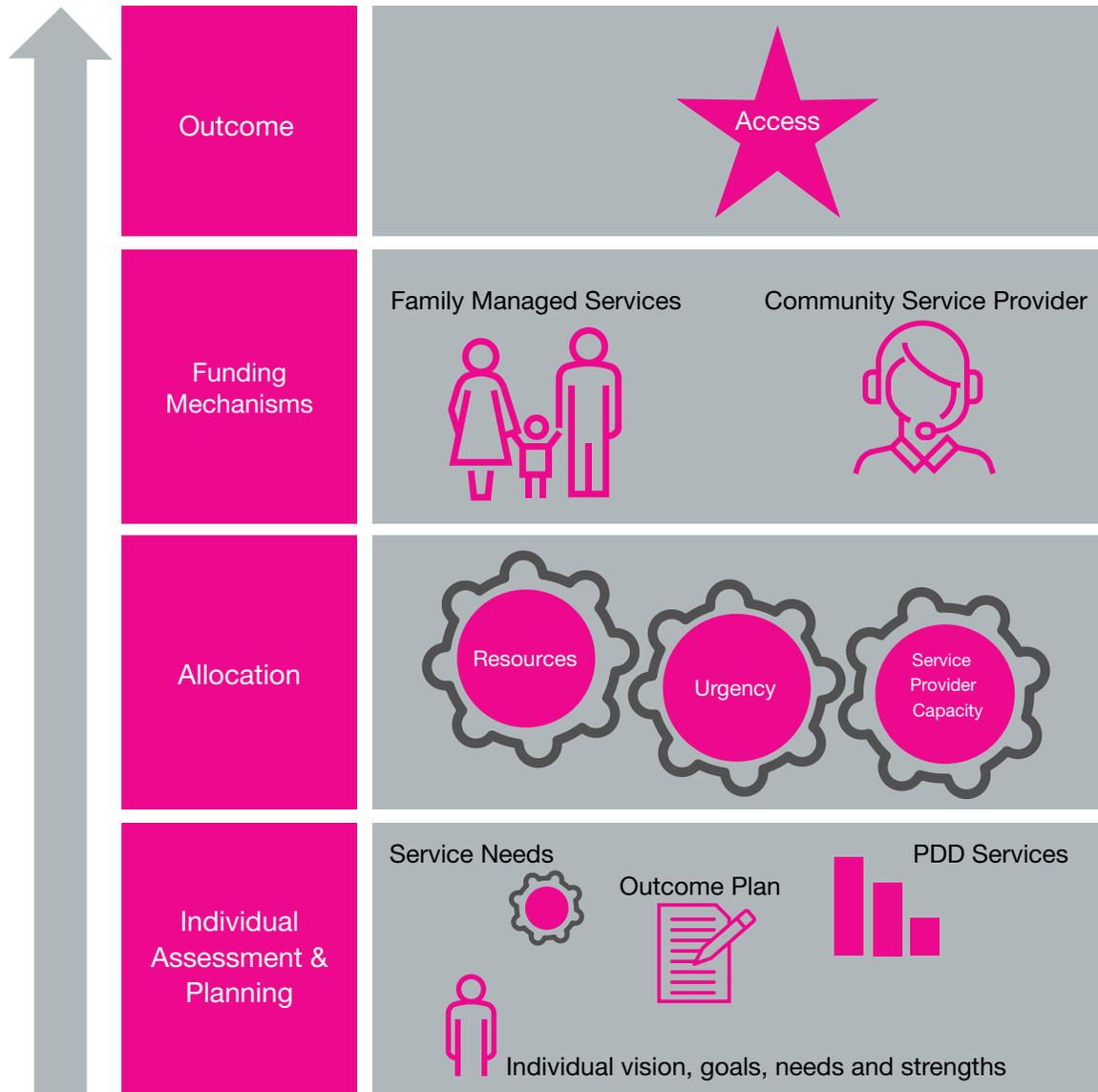
- Service delivery includes how government funding is decided and monitored as well as the outcomes the funding is intended to achieve.
- The Ministry of Community and Social Services delivers PDD programming across seven service delivery regions:

Region	# of Service Providers
Northwest	18
Northeast	2
Edmonton	45
Central	35
Calgary	34
South	24
North Central	15



157 community service providers across the province.

After eligibility is determined, there are several steps before accessing PDD supports and services:



Facts about the disability services workforce

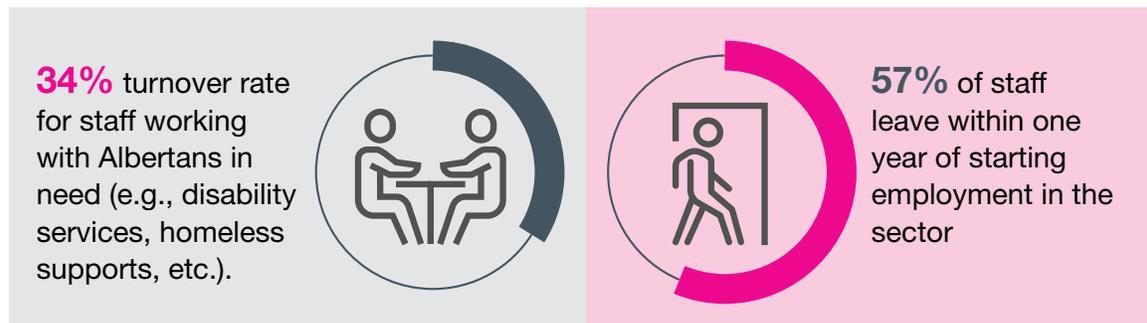
The disabilities services workforce includes community support staff hired by service providers or Family Managed Services administrators, as well as Government of Alberta employees working in the PDD program. PDD staff include service coordinators and contract specialists.



The Creating Excellence Together (CET) Accreditation Standards outline the following mandatory training for all direct support staff:

- First Aid & CPR
- Medication Administration
- Crisis Management
- Abuse Prevention & Response Protocol
- Positive Behaviour Supports
- Universal Precautions (e.g., hand washing)
- Training that addresses the needs & safety concerns of the specific people the staff will be working with

Workforce statistics:



Workforce demographics:

- Almost half (47%) have a high school diploma and slightly more (48.7%) have a diploma or degree
- Just over half (53%) work full-time
- Most of community disability workers are female (79%)

Facts about communication and the PDD program

The PDD program works and communicates with the disability community in a variety of ways, through established provincial councils and committees and through individuals' and family/guardian connections with Government of Alberta (PDD) staff, support staff, and service providers.

Provincial councils and other key organizations include:

- Premier's Council on the Status of Persons with Disabilities
- Alberta Council of Disability Services
- Alberta Advocate for Persons with Disabilities
- Provincial and Regional Parent Advisory Committees
- Resident and Family Councils
- Alberta Disability Workers Association
- Self-Advocacy Organizations

