

Report on Spring 2013 Persons with Developmental Disabilities Community Conversations

ASSOCIATE MINISTER'S MESSAGE

During the past several years, a much-needed transformation has been underway in the Persons with Developmental Disabilities (PDD) program.

The PDD program must function as one provincial program that provides services equitably, based on need, and evaluates those services by the outcomes they are achieving for the individuals they support. Meeting these goals requires the use of a consistent assessment tool to determine what people's needs are, as well as a consistent survey tool to measure the outcomes of the services we provide. It also means moving away from the tedious administrative task of tracking hours of service, and focusing on the *results* of those services.

We are also looking at moving PDD to a more modern "employment first" approach, where paid employment is a key goal of services for every person with a developmental disability who is willing and able to work.

I understand that this is a significant change for many service providers, families, and individuals who receive PDD supports, and I felt it was critical for me to be on the ground talking with people who may be affected by these changes.

During May and June 2013, I visited 23 communities across Alberta to talk with individuals, families and service providers who are involved with the PDD program. I was pleased to have many local MLAs join these conversations. I wanted to discuss why we were making these changes and share the vision for disability services in Alberta. I also wanted to hear about people's hopes, fears and ideas.

What I said to them was that I want to see an Alberta where people with developmental disabilities are truly included in meaningful ways, with jobs and friends and decent incomes, living with the independence and dignity that they deserve. I also said that I wanted to remove the barriers to disability supports, because many Albertans have told me that there are people who need our help, but cannot get it because they do not meet the PDD eligibility criteria. People with autism, Fetal Alcohol Spectrum Disorder (FASD), brain injury and other challenges are struggling, and we are currently not meeting their needs. That is not acceptable. We must make sure our disability support system is fair and sustainable so that we can help everyone who needs our support. If you would like to see a full account of my concerns with the current program, and our vision for the future, please see my [Minister's Statement](#), which I shared with my government colleagues during the Spring sitting of the Alberta Legislature.

What the people at the community sessions told me was that they agree with our vision. They share our goals of independence, employment and greater community inclusion for people with developmental disabilities, and they agree that there are some problems in the system that we need to fix. However, they also said that we need to slow down. They told me that we need to take the time to work more closely with families, individuals and service providers to ensure that PDD services and supports are in place to make this transition go smoothly. And they told me that they need funding to remain stable while we do that.

The sessions were emotional, passionate and, to my mind, incredibly productive. I have heard the concerns, and I commend everyone at the sessions for their commitment and advocacy on behalf of Albertans with developmental disabilities. This report is a summary of those community sessions.

Before I close, I would like to thank the Honourable Dave Hancock, QC, Minister of Human Services, for his support – not just for these extensive consultations, but for the transformation that we are undertaking in PDD. Minister Hancock shares the vision of delivering services that are fair, inclusive and focused on outcomes.

Frank Oberle
Associate Minister of Services for Persons with Disabilities

BACKGROUND: IMPROVING THE PDD PROGRAM

Many reviews and consultations have been done over the past few years around changing the PDD program. This previous work has laid the groundwork for the current PDD transformation.

In 2008, the PDD priority actions were established to improve the effectiveness and efficiency of the PDD program. They were based on previous consultations with families and service providers, and focused on creating clarity and consistency across the program, increasing flexibility for families, and improving supports to people with complex needs.

Then in 2011, an administrative review of the PDD program was completed at the request of stakeholders. Following this review, former Minister Mary Anne Jablonski gave specific directions to the Community Boards to address the issues identified in the review. The Minister's directions were combined with work that was already underway from 2008 to form the current PDD Change Initiatives.

Since the beginning of the PDD Change Initiatives project, the PDD Community Boards and staff have continued to work with stakeholders to brainstorm, consult, and share information and best practices through a variety of avenues including:

June 2011	Focus groups on contracting
November 2012 – present	50+ regional engagement sessions for service providers and families Regional service provider council meetings Regional self-advocate meetings
February 2013	Complex needs consultations
March 2013	Service provider teleconference
March 13, 2013	Service Provider Summit webcast
April 15, 2013	Family Forum webcast
May 9-10, 2013	Symposium on Disability Innovations in Employment and Technology
June 25, 2013	Minister's teleconference with families
June 26, 2013	Minister's teleconference with service providers

A CATALYST FOR CHANGE

On March 11, 2010, the Government of Canada, with the support of all provinces and territories, ratified the Convention on the Rights of Persons with Disabilities at the United Nations headquarters in New York City.

The Convention on the Rights of Persons with Disabilities is intended to protect the rights and dignity of persons with disabilities. Parties to the Convention are required to promote, protect and ensure the full enjoyment of human rights by persons with disabilities, and to ensure that they enjoy full equality under the law.

Along with equality before and under the law, the Convention is meant to protect the right of persons with disabilities to:

- *Non-discrimination*
- *equal opportunity*
- *independent living*
- *full integration*
- *security*

CURRENT CONTEXT: ALBERTA'S SOCIAL POLICY FRAMEWORK AND RESULTS-BASED BUDGETING

In 2012, the Ministry of Human Services was created to ensure a more holistic approach to supporting Albertans. It brought together programs for children and families, people with disabilities and Albertans struggling with unemployment, homelessness and poverty. One of the ministry's first major initiatives was the development and release of Alberta's Social Policy Framework. This was one of the major steps along the road to ensuring all Albertans have an equal opportunity to achieve their potential. Albertans identified four key goals for social policy and community in the province: reduce inequality, protect vulnerable people, enable collaboration and partnerships, and create a person-centred system of high-quality services.

Alberta's Social Policy Framework has created a lens through which all programs and supports within the Government of Alberta could be evaluated using a consistent set of criteria. The most important of these criteria is that they produce the outcomes that are expected of them.

At the same time, the Government of Alberta is embarking on a results-based budgeting process. This process asks all programs within government to look at the services they are currently offering and how effective they are at achieving positive outcomes for the people they serve. This is a significant shift away from looking at cost and focusing on results instead. The intent is to use financial resources in the most efficient and effective way possible. Disability services is the first program "bundle" being reviewed through the results-based budgeting process.

CHALLENGES AND OPPORTUNITIES

When it comes to PDD, feedback from Albertans and preliminary analysis of support levels indicate that some individuals are being underserved or are not getting services at all, while others appear to be overserved. Furthermore, best practice shows that surrounding people who have low needs with formal services is not the best way to help them achieve independence and community inclusion, which is the mission of the PDD program.

It is clear that what is needed is a consistent process for assessing need and allocating funding to ensure there is equitable treatment of all people with developmental disabilities. This is particularly true when it comes to creating equity of service in urban and rural communities.

Time and time again, individuals with developmental disabilities have indicated that employment is a key goal for them. Employment is a very effective way to achieve independence and build natural relationships with others in the community.

60 per cent of PDD-funded individuals have been assessed as having low needs, and are likely employable to a certain degree. Yet currently, only a small portion of these individuals have some level of employment.

With PDD now residing under the same ministry as the [Alberta Works](#) employment programs, there is a tremendous opportunity to address this issue using the combined expertise and resources of the province's disability and employment support sectors.

SPRING 2013 COMMUNITY TOUR AND CONVERSATIONS

In each community, the regional PDD Community Board hosted a forum for stakeholders that began with comments from Associate Minister Oberle; Assistant Deputy Minister of the Disability Services Division, Brenda Lee Doyle; and the regional PDD CEO. After the opening comments attendees had an opportunity to ask questions. After the sessions ended, Associate Minister Oberle, Ms. Doyle, and the CEO were available to speak with any attendees who wished to stay and ask further questions. Wherever possible, Associate Minister Oberle also visited a local service provider in each community and met with individuals and families who receive services.

Below is a summary of the communities visited and the approximate number of people who attended the stakeholder sessions.

Date	Location	PDD Region	Approximate # of attendees
May 11	Grande Prairie	Northwest	70
May 13	Fort McMurray	Northeast	25
May 16	Lethbridge	South	320
May 22	Olds	Central	120
May 22	Red Deer	Central	200
May 23	Wetaskiwin	Central	120
May 23	Camrose	Central	200
May 24	Sherwood Park	Edmonton	300
May 29	Edmonton	Edmonton	500
May 30	Lloydminster	Central	40
May 30	St. Paul	Northeast	60
May 31	Falher	Northwest	40
May 31	Peace River	Northwest	80
June 3	Calgary (South)	Calgary	200
June 4	Calgary (North)	Calgary	150
June 4	Cochrane	Calgary	100
June 6	Drumheller	Central	45
June 10	Brooks	South	20
June 10	Medicine Hat	South	300
June 17	Whitecourt	Northeast	35
June 18	Edson	Edmonton	45
June 18	Barrhead	Northeast	120
June 26	St. Albert	Edmonton	200
June 28	Vegreville	Northeast	20
Total: 3310			

Associate Minister Oberle also visited a number of homes, work sites and centres operated by community service providers across the province and spoke with several local family and self-advocacy groups:

- Accredited Supports to the Community, Olds
- Bea Fisher Centre Inc., Lloydminster
- Blue Heron, Barrhead
- CentraCam Vocational Training Association, Camrose
- Central Alberta Residence Society, Red Deer
- Chrysalis, Edmonton
- DARTS, Drumheller
- Falher Friendship Corner, Falher
- Family Voices, St. Paul
- Horizons Training Centre, Wetaskiwin
- In-Definite Arts Society, Calgary
- Newell Community Action Group, Brooks
- Optional Rehabilitation Services, Calgary
- REDI, Medicine Hat
- Robin Hood Association, Sherwood Park
- Southern Alberta Community Living Association, Lethbridge
- South Region Self Advocacy Network, Medicine Hat
- VALID, Vegreville
- Whitecourt CARE, Whitecourt
- W. J. Stelmaschuk and Associates Ltd., Fort McMurray

COMMUNITY CONVERSATIONS – KEY ISSUES AND MOVING FORWARD

Issue: The Pace of Change

“The goals and vision are good, but the timing is too short.”

Generally, there was broad support for the vision. Participants said that they want families to have a more active role in service planning, and they agree that PDD should focus on better outcomes for individuals and take a holistic approach to supporting each person. They agree that change is needed, but asked government to work more closely with service providers, individuals who receive services, and their families to make sure we get it right. They felt that the pace of the change along with the funding reduction in the community access category of services were too much, and too fast. Rather, they thought that at least one year is needed to align funding with assessed need. Service providers indicated they need a longer transition, to support them move forward with the new approach.

Many families feel that PDD is a good program that makes a difference, and they do not want disruption to set back the gains that many individuals have made towards independence. Safety is a key concern, and they want more time to understand how the changes will affect their loved ones and plan services going forward.

Some older parents are particularly concerned about change, saying that this creates uncertainty for them as they age and try to plan for the future of their adult child when they are no longer able to support them.

Participants indicated better communication is needed, and parents, self-advocates and service providers need to be more involved in planning for the future of the PDD program; communication materials should be clear and easy to read for everyone.

Moving Forward

Associate Minister Oberle heard the concerns of participants around the timeline and the need to work more closely with individuals, families and service providers through the transition. PDD has extended contracts to allow for more planning conversations to take place with individuals and families.

Service Planning

Over the course of 2013/2014, PDD staff will meet with individuals, families and agencies to develop a [service plan](#) for each individual. This will help create a clear picture of what services will look like for each person that PDD supports.

A funding allocation for each individual will be based on their individual goals, their assessed needs as determined through a Supports Intensity Scale (SIS) interview, as well as existing natural and community supports.

Individuals and families always have the right to appeal any change in funding.

Service Provider Transition

PDD is committed to working with its funded service provider agencies on their transition to the new model. The PDD regions are working directly with their service provider councils and individual service providers to develop transition plans.

Communication

Human Services is committed to better communication on the PDD transformation. Teleconferences were held with service providers and families at the end of June. The first issue of a monthly Human Services newsletter went out in July to all stakeholders. The newsletter contained articles about individuals who receive supports from PDD, and provided information about SIS, service planning, outcomes and program demographics. Associate Minister Oberle will also be speaking with stakeholders later in the year to hear their thoughts on how the transition is going.

Issue: Supports Intensity Scale

Many participants asked questions and voiced concerns about the Supports Intensity Scale (SIS). They wanted to know if it was well-researched, how accurate it is and what kind of training the SIS assessors have. People voiced concerns about whether the SIS was being done consistently across the province. Some families reported that they were not asked to participate in their family member's assessment.

Some felt that it is a conflict of interest for PDD staff to be administering the SIS assessment, and suggested that this be contracted to an independent third party.

People wanted to know how the SIS could capture the nuances of a person's needs, particularly around individual safety.

Some felt that their SIS assessment was not accurate, and wanted to know if reassessment was possible, and the process to have a reassessment done.

People were unsure of how the SIS assessment is related to funding, how funding will be assigned, who will decide on an individual's funding, how an individual will find out what their funding is, and whether the process is fair and transparent. There was concern that funding will be assigned using a mathematical formula that is not people-focused. They felt a person's history, goals and individual needs should be an important part of any decision about their funding. People also questioned how funding will be assigned when not all SIS assessments have been completed.

Participants wanted to know more about how SIS is tied to planning an individual's services, what the planning process will look like and how PDD will be involved.

Moving Forward

The [Supports Intensity Scale](#) is only one of the tools used to determine the needs and supports of an individual. The person's geographic location, existing natural supports (such as family, friends and community) and most importantly their individual goals will also be used to determine the needs and supports of an individual. PDD will complete a service plan (see previous page) that will help to determine the person's goals and what they need to achieve them.

PDD staff are working on completing all SIS assessments as soon as possible, and reviewing the SIS results of those who have concerns about their previous assessment. This review will examine whether there has been a significant change in the individual's needs since the SIS was completed. If there has been no change, but an individual or family member disagrees with the original SIS results, PDD staff will discuss their concerns with them and determine if the SIS results are accurate or not. If the results are not accurate, arrangements will be made to do the SIS interview again as soon as possible.

Issue: Community Access

Participants are concerned about the \$42 million reduction in community access that was identified in this year's budget. This is a significant reduction, they said, so how can it be achieved without a significant reduction in services?

Families are concerned about the future of day programs and felt that these programs keep their family members safe during the day, so they do not have to worry about them while they are at work. Families expressed concern that they would have to leave their jobs to care for family members if they lost their day program.

People stressed that not everyone is able to work, and some people will always need day programs and community access programs.

Participants in rural areas stressed that their options are limited, and in some cases, there is only one service provider in the community.

The role of the community is also important when it comes to community access, participants said. Fitting in is not always easy. The community needs to accept people too. They suggested that Alberta's Social Policy Framework could be used to engage communities to be more welcoming of people with disabilities.

People were interested in learning more about how PDD will measure outcomes, and how it was possible to measure abstract concepts such as community inclusion.

Moving Forward

Community Access

Community access services have not been eliminated. PDD is working with service providers to determine how community access will be provided in each region. Where appropriate, PDD will work with service providers to move their programs to an employment focus. People will be supported to work as much as they are able and as much as they want in order to meet their individual goals.

PDD recognizes that everyone is different. Each person will receive services based on their unique needs and goals. For those who need it, their service plan will include meaningful activities to help them be included in community life.

Measuring Outcomes

Outcomes measurement is being done through the [Personal Outcomes Initiative](#). It is a survey that is done by adults with developmental disabilities who have had training on how to do the survey. They ask other adults with developmental disabilities to answer some questions about their life experiences in eight domains that are indicative of quality of life.

PDD is also integrating outcome measurement into its new contracting approach so we can better understand the quality of services that are being provided and the results that are being achieved for people. This outcome measurement will help PDD and service providers continue to improve community inclusion.

Issue: Employment

Participants were supportive of an increased focus on appropriate employment for Albertans with developmental disabilities. They had questions around what the definition of employment would be, and what the expectations were around how many hours people would work, etc. They wanted to ensure that people would have adequate supports to sustain them in their employment. They also stressed that PDD needs to monitor employment situations to make sure individuals are being treated fairly at work.

People suggested that employers need to be involved in any new employment initiatives. They voiced that it is hard to find employers who are willing to hire people with disabilities, and employers need to be educated and supported so they understand the skills that people with disabilities can bring to their business.

Rural residents said that the employment options in their communities are more limited, and that transportation to and from work is a challenge for people who are unable to drive.

Some service providers stated that they have higher rates of employment for the individuals they support than the provincial average that PDD is reporting. They expressed a desire to leverage work that is already being done and share best practices across the sector.

Participants also asked government to ensure that PDD and Assured Income for the Severely Handicapped (AISH) work together to streamline the administration around income and benefits. As individuals earn more money, their AISH benefits may be affected.

Moving Forward

Alberta Works

PDD will be working with Alberta Works to improve availability and access to employment supports for people with disabilities. Discussions are underway to explore the potential for policy coordination and integration between PDD and Alberta Works. Human Services also provides [Disability Related Employment Supports](#) (DRES), which funds supports and services to assist Albertans with disabilities to make successful transitions from school to work and from unemployment to employment. DRES also offers education and training, job search assistance and supports in the workplace.

In the Fall of 2013, the Youth Supported Employment Project will begin, providing peer support to youth (aged 15-19) with disabilities. Ten individuals with disabilities will be matched with a mentor of a similar age in order to provide peer supports on the job.

Employers' Council

Human Services is creating an Employers' Council to bring together Alberta's employers to discuss strategies for supporting, educating and encouraging employers to hire people with disabilities.

Employment First Strategy

A draft [Employment First Strategy](#) has also been created to gather input from stakeholders about the future of employment services for people with developmental disabilities in Alberta. This strategy was posted online as a wiki, and the feedback from stakeholders will be used to inform the next steps.

Issue: Workforce

Participants expressed their appreciation for the expertise and value of disability service workers. They were concerned about workforce issues such as turnover, wages and the lack of incentive for people to enter the field. Several people in different communities raised the issue of post-secondary institutions closing their disability studies programs.

Service providers shared their appreciation for government's commitment to increase agency wages over four years. They were pleased that government acknowledged that the wage problem requires a longer-term solution than just a one-time increase.

Some suggested that this year's wage increase, while very much appreciated, is not helpful if it corresponds with a decrease in funding resulting in staff layoffs. Job security is critical to maintaining a skilled workforce, they said.

Moving Forward

Government has committed to continuing to increase wages for the contracted agency sector over the next two years.

Human Services and representatives from across the contracted agency sector are working together on the Workforce Alliance committee to address the needs of the service provider sector. The Workforce Alliance will continue to plan, implement, monitor and evaluate the effectiveness and efficiency of short-, medium- and long-term strategies for a healthy, sustainable workforce.

Issue: Unmet Needs

Some participants expressed a need for PDD supports on First Nations reserves.

People talked about challenges finding supports for people with disabilities who currently fall outside of PDD's IQ criteria for eligibility (e.g., people with autism, FASD and brain injury). Participants expressed support for expanding services to this group of people with unmet needs, and wanted to know when that could happen and what funding supports there will be for these individuals.

Moving Forward

It is estimated that there are about 330,000 Albertans who have disabilities, of whom less than 10 per cent receive supports from provincial disability programs. There will be further consultation with stakeholders about the unique needs of individuals who fall outside of PDD, and options for how best to meet those needs. The PDD eligibility regulation will also be reviewed over the next year.

Issue: Contracting

Service providers wondered about the future procurement strategy, and whether PDD would be adopting a competitive approach to contracting. They asked if PDD was looking to reduce the number of service providers by amalgamating services together under larger agencies.

Service providers expressed support for a multi-year contract to enable them to do more effective long-term planning.

Moving Forward

PDD worked closely with service providers to develop a new, outcomes-focused contract template. In July, service providers were given the choice to sign a contract using the new template, either at new or existing funding levels, or the old contract at the existing funding level.

Over the next few months, PDD will work with each service provider to develop a plan for what can be reasonably accomplished this year to align services and funding with individuals' assessed support needs.

Together PDD and service providers will also involve individuals and families in the planning process so that any impacts to individuals' services are understood. Through this planning process, the PDD region will translate each service provider's plan into a budget for the rest of the year.

Going forward, the PDD program will work with stakeholders to develop regional service delivery plans to ensure the continuity and availability of services across the province, including providing multi-year contracting options and procuring for needed services as required. PDD will be using a strategic procurement approach, which means the PDD program will be able to identify service areas for adults with developmental disabilities that could be enhanced and areas that are not yet in existence and could be developed. This strategic procurement approach will also enable the PDD program to understand the capacity of the service sector to provide these important supports and where the sector can be better supported to deliver new and innovative options for adults with developmental disabilities.

Issue: Transitions and Working across Government

Issues of transitioning from child to adult services were raised at some meetings. People also asked that we work to make transitions between PDD regions seamless.

Better collaboration across government was also suggested, including working with Alberta Health Services to create smoother transitions as people with developmental disabilities age and move into health care supports.

Participants also said that Human Services needs to work more closely with other areas of government, especially Education and Enterprise and Advanced Education, to look for more opportunities for inclusive schooling and job training.

Moving Forward

The PDD program is working together with other child and adult programs to ensure an integrated approach to planning to bridge from child to adult services. PDD staff will participate in planning with individuals as young as 16 to ensure that the needed supports are in place. Supporting this transition into adulthood aligns with Alberta's Social Policy Framework in ensuring collaboration between program areas and a person-centred approach to service delivery.

Issue: Future Role of Boards

Participants said that they agree that government must make sure PDD services are effective and efficient, and they expect PDD's own internal operations to do the same. Participants said that government needs to look at the board governance structure to ensure consistency and easier transition for people who move from one part of the province to another.

Several people asked what PDD's plans are with respect to the Community Boards, and whether the government would be implementing the 2010 KPMG recommendation to dismantle these boards.

Moving Forward

The department of Human Services is currently working with the Child and Family Services Authorities and PDD Boards on a new governance approach that provides a strong connection between community and government for the entire department.

GOVERNMENT'S COMMITMENT

At the community sessions, Associate Minister Oberle and his MLA colleagues heard the concerns of Albertans with disabilities and their families and supporters. All agree that there is room for improvement in the PDD program, but it needs to be done with care and caution. PDD is working together with individuals and their families and service providers to plan a gradual transition to an improved way of doing things. Associate Minister Oberle has committed to taking the time needed and deploying the right resources to ensure this transformation is successful.

Changes to the PDD program will be made with these concepts in mind:

- The PDD community must be engaged in an open discussion about the changes being made to the program.
- Changes must result in better inclusion in the community and create a greater degree of independence for people with developmental disabilities.
- Services must be responsive to the evolving needs of an individual over their lifespan.
- Different approaches may be needed for rural and urban communities.

The Government of Alberta thanks all participants at the 2013 PDD community conversations for their contributions. We will continue to work with you to plan the transformation of PDD into a program that meets the needs of people with disabilities in a way that is fair, efficient and sustainable.