Building Better Bridges

Final Report on Programs and Services in Support of Persons with Developmental Disabilities

Prepared by
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January 24, 2000

Honourable Halvar C. Jonson, Minister
Alberta Health and Wellness
228 Legislature Building
Edmonton, Alberta

Dear Minister Jonson:

As requested, I am pleased to provide you with my Final Report, *Building Better Bridges: Final Report on Programs and Services in Support of Persons with Developmental Disabilities*, and recommend that, after you have reviewed it, you consider making it available to the public as soon as possible.

In providing this comprehensive Report, which reflects extensive public input and comment, research, observations, and official recommendations, I am confident it contains the basis upon which future decisions can be made regarding PDD.

Issues regarding PDD recipients and others involved with the PDD system are enormously varied and complex. Therefore, ongoing consultation with all stakeholders is essential, particularly since the PDD community governance model is still in its infancy.

In conjunction with the greater PDD community, I believe it is the Province's role to help maintain and improve an already excellent program, and to establish a more stable, predictable, and accountable PDD system that responds to those in need. The PDD community and others are counting on our leadership and I believe that, collectively, we have the tools, knowledge, and capacity to deliver.

In closing, I especially want to thank you, Minister Jonson, for your leadership in this regard, and for your personal and professional commitment to this important area.

Sincerely,

Gene Zwozdesky
Associate Minister
Alberta Health and Wellness
MLA, Edmonton Mill Creek

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Section One: Introduction and Background

Primarily in response to financial difficulties encountered by some Persons With Developmental Disabilities (PDD) Community Boards in June 1999, Honourable Halvar C. Jonson, Minister of Alberta Health and Wellness, announced the immediate infusion of an additional $10 million and requested that a Review be done regarding PDD. I was asked to conduct this Review and determine, among other things, why and how these financial difficulties had arisen.   (David Steeves, Special Advisor to the Deputy Minister of Alberta Health and Wellness, Lynne Duncan, was appointed to assist me with the Review.)

Significant concerns were being expressed by PDD recipients, their families, caregivers, service providers, and others about potential reductions in programs and services. This was particularly perplexing, given that the Province of Alberta's 1999/2000 budget reflected an increase of $22.7 million (or 8.5%) for PDD.

This Review, then, sought answers to countless questions aimed at deriving a better and more complete understanding of the circumstances that led to these difficulties. In the process, however, I soon discovered there were many other issues impacting PDD which were beyond just the financial aspect.

An independent and private consulting firm was engaged to conduct confidential interviews with various stakeholders, and an independent and private accountant was engaged to help review financial-related materials.

I began the Review by attending numerous meetings during July and August to better acquaint myself with all PDD issues and to meet with several recipients, their families, caregivers, service providers, PDD Boards, staff members, government officials and others. One meeting that I attended with Minister Jonson on August 12, was with PDD recipients and some service providers at the Disability Action Hall in Calgary. Hearing directly from PDD recipients early in the process helped identify and shape many of the issues and set the tone for the Review.

Additional meetings and/or telephone conference calls with all PDD Boards and the Premier's Council on the Status of Persons with Disabilities also provided valuable input and direction, and set the stage for each step of the Review process.

On September 3, I issued a News Release and announced the details of the comprehensive Review, including programs, services, funding and accountability of PDD Boards. A copy of this News Release is included in Appendix 1, along with other announcements regarding PDD.

Review Process

The Review process involved several key steps, including:

- meetings with the PDD Provincial Board, including an additional meeting with the Executive Committee;
- meetings with the six local PDD Community Boards, the Michener Centre Facility Board, and the PDD Foundation Board;
- meetings with the Premier's Council on the Status of Persons with Disabilities;
- meeting with the CEOs of all PDD Boards;
- visiting each of the six regions to hear and receive public presentations from PDD recipients, funded agencies, service providers, parents/guardians, PDD Boards, and the general public;
- conducting focus groups with stakeholders (facilitated by Alberta Community Development staff);
- conducting over 200 one-on-one interviews;
- reviewing financial information relative to the PDD system;
- receiving, reviewing and responding to several hundred letters regarding PDD; and,
- analyzing and organizing information, and preparing this Final Report.

As part of the process, I visited a number of PDD Program sites, met and/or talked with many individual PDD recipients, their families and service providers, and responded to letters received. Appendix 3 provides a list of some of the program sites I was able to visit.

Another important part of the Review process was a series of public meetings held in each PDD region. These meetings were advertised from September 3, and were held between September 27 and October 22, 1999 at locations and venues determined by each local PDD Community Board. Appendix 2 provides the dates and locations of these meetings, a list of organizations and individuals who presented, and the locations represented. In total, 170 public presentations were made by about 300 presenters.

In addition to these public meetings, I received and reviewed about 300 communications/submissions in the form of letters, faxes, phone calls, personal presentations, reports, cassettes and videotapes.

Section Two of this Report, *Summary of Comments from Public Presentations*, provides a detailed summary of what was heard and/or submitted in this regard.

Input from all these Review components provided the basis for my Final Report.

Terms of Reference for the Review

The Review focused on the following specific terms of reference:

1. To review the mandated responsibility, authority and accountability, roles and practices of those involved in the design, delivery and maintenance of PDD Programs including the PDD Provincial Board, the PDD Community Boards, the PDD Facility Board and the PDD Foundation; to provide advice and recommendations regarding responsibilities, authority and accountability.

2. To review the current mandate, caseloads, definitions of eligible clients and the scope/level of service of the Boards and advise on areas of change in policy or practice, if required.

3. To review the business plans of the Boards, including an assessment of any perceived gaps in the current standards, measures and outcomes and to make recommendations in this regard.

4. To review the financial statements, the budgets, the system of funding and the allocation of resources by the Boards (including an assessment of how contracts are awarded, monitored and the specification of deliverables), and to provide advice and recommendations regarding changes, if required.

5. To review and make recommendations regarding the process of the PDD Boards for the establishment of policy and procedures regarding financial decisions and provide comment on how Board policies impact the financial outcomes of the Boards.

6. To review and assess the provision of support services to the PDD Board, including consideration of the Shared Services Agreement in existence between the PDD Boards and the Government of Alberta and make appropriate recommendations where necessary.

7. To review and make recommendations as to funding issues relating to support for individuals with brain injury living in the community.

8. To provide advice and recommendations on these and any other relevant matters regarding the PDD Boards.

Section Two: Summary of Comments from Public Presentations

Over the past six months, the PDD Review process has involved literally hundreds of Albertans who provided their input and advice. Through public meetings organized across the province, individual meetings, visits to various programs, letters and submissions, one message is very clear. People involved in programs for disabled Albertans – whether they are disabled themselves, are family members, service providers or Board members – all care passionately about the quality of life and future opportunities for people with developmental disabilities. They speak strongly of the leadership Alberta has shown in providing services to people with developmental disabilities. Their objective is to ensure that Alberta maintains its leadership role and maintains an environment where disabled Albertans have the opportunities they need to live productive lives and contribute to their communities to the maximum of their potential.

"Let the ideal of true community inclusion be the guide for community governance that lies within the grasp of the Persons with Developmental Disabilities Act. Let the vision that is the preamble to the Act be the goal for all of us."

- Lethbridge Organization

Summarizing the ideas and advice of hundreds of individuals and organizations within the time allotted has been a huge task; however, the key themes that emerged were very consistent across the province, although there were different ideas about how the various issues should be addressed.

This section summarizes the key themes, concerns and suggestions provided in public meetings, personal meetings, submissions and letters.

1. Roles and Responsibilities of PDD Boards

Many participants commented on the roles, responsibilities and membership of the various PDD Boards.

> "I was thrilled when the Government announced the movement to a community governance model. I was excited that the Government was visionary in putting this model in place. However, I have been very confused with how the model has been implemented across the province and how in reality the model is working."
>
> *- Calgary Individual*

Overall, there was strong support for the current community model that began in April, 1998. Many said they were pleased when government announced the move to a community governance model. However, they also said that, while the model began with much promise and enthusiasm, its implementation has led to some difficulties. In many regions of the province, there appears to be a positive working relationship among PDD Community Boards, parents and guardians, PDD recipients, and service providers. In other cases, there are concerns and some confusion about roles, relationships and communication.

In many cases, communication and relationships were at the heart of concerns expressed. People suggested there should be improved communication and consultation among Boards, agencies and service providers, PDD recipients and parents/guardians. The process should be more transparent, all meetings should be open, and people at the community level should be asked for their input before important decisions are made. Some suggested there should be a planned process for expanding the ability of volunteer agencies to participate as partners with the PDD Boards.

Looking to the future, most said that the governance structure is new and more time is needed to develop relationships and sort out how the PDD Provincial and Community Boards will operate. Most argued for "giving the Boards a chance" before major changes are made. Some also said that limits on resources and the challenge of addressing budget shortfalls has had a negative impact on some of the PDD Boards, particularly on their ability to develop strong relationships with PDD recipients and service providers. On the other hand, other people suggested that the model of Provincial, Community, Facility, and Foundation Boards should be reconsidered.

Specific comments on PDD Boards centered around structure, roles and membership on Boards.

On the **structure of the Boards**, comments included the following:

- Do we need six Regional Boards, a Provincial Board, a Facility Board, and a Foundation Board to serve 8,000 recipients?
- Too much money is being spent on administration instead of front-line services.
- Board membership should be reduced.
- The Boards provide another layer of bureaucracy between the parents/guardians, agencies and PDD recipients, and the government.
- There is a need for clear boundaries between the legal responsibilities of Community Boards and the legal responsibilities of contracted service providers.
- Some felt the Foundation Board should be disbanded and the funding used to support direct services. Concerns were expressed about the direct competition between the Foundation Board and various agencies in fund-raising. Others noted that many other foundations already contribute to the PDD cause. On the other hand, some suggested that the Foundation Board should be given an adequate endowment by government and those funds should be used to support pilot projects, new initiatives and innovation. Either way, a speedy decision was urged regarding the future of the PDD Foundation.
- Some asked if the duties of the Michener Centre Facility Board could be performed by the PDD Central Community Board, or by the PDD Provincial Board, and questioned the need for a separate Facility Board. They also noted that the Facility Board used to report directly to the Minister responsible.
- There should be a process for evaluating the effectiveness of Boards after a certain period of time.
- The Boards should be more independent from the provincial government.
- The Boards should be accountable to their community first.

> "We would like to suggest that the role of the PDD Board is not … to be the gatekeeper. We need people who are independent and neutral – to make objective decisions – to respond to individuals in a fair and equitable manner. "
>
> *- Slave Lake Organization*

On the **roles and responsibilities of PDD Boards**, comments included:

- Government's role should be to set broad policy directions, not to manage the PDD Boards.
- The relative roles and relationships between the Provincial Board and Community Boards should be examined and clarified.
- The role of the Provincial Board should be to provide a shared vision, province-wide leadership, and consistent

policy direction. People felt that common direction and consistency were lacking, especially as the Community Boards took steps to accommodate budget deficits.

- Concerns with the Provincial Board focused on communication, the need for direction on policy and procedures, and expanded opportunities for agencies and organizations to bring forward ideas and suggestions.
- Many people suggested that the Community Boards should act as advocates for parents/guardians and PDD recipients rather than as the voice for government. People also expressed concerns that the Community Boards do not represent or act on behalf of community members.
- Several said the Boards were too involved in micro-management. There is a need to clarify the role of Boards and the role of Management.
- Community Boards need to continue their efforts to develop strong linkages with the community.

On **representation and membership on PDD Boards**, comments included:

- Parents/guardians, family members and people with developmental disabilities should make up the majority of Board members. On the other hand, some people said it was a conflict of interest for family members to be appointed to PDD Boards, and that emotions may impair objectivity. In their view, Boards make decisions on individual service contracts and this would put parents/guardians on the Board in a conflict of interest position. Supporters wanting parents/guardians on the Boards said this would be no different than other situations, such as parents being on school boards.
- Members-at-large on the PDD Provincial Board should come from people nominated by provincial associations serving the disabled community. Others flatly said no to this idea.
- At least one member of the PDD Provincial Board should be a developmentally disabled person.
- At least one member of every PDD Board should be a developmentally disabled person.
- Members of the PDD Community Boards should be elected by the developmentally disabled community.
- Each Board, including Michener Centre, should have a First Nations or Metis representative. The Provincial

Board should represent the diversity of Aboriginal communities.

- The criteria for membership on PDD Boards should be clearly established and made public.

In addition to comments on PDD Boards, several people also commented on the need for improved coordination among government departments responsible for providing services to people with developmental disabilities and other disabilities. They pointed to fragmentation in services among Regional Health Authorities, PDD Boards, Children's Services Authorities, and Mental Health Advisory Boards.

2. Funding and Forecasting

> "It is our hope that the result of your review will be recommendations for much greater rigor and clearer parameters for funding. We believe that these factors are required to protect funding and to predict much better in the future."
>
> - *Edmonton Organization*

The majority of concerns expressed by the participants in the Review process centered on funding. People are worried about potential reductions in funding available to support programs and services. Steps, such as cost containment strategies, that were taken to accommodate budget deficits have caused uncertainty and anxiety among parents/guardians, service providers and PDD recipients. (Specific comments on cost containment strategies are included in the next section.)

Many presenters said Alberta is widely known to have the best system in the country for supporting PDD recipients. They do not want a limit on resources which, in turn, might put programs and services at risk.

> "We need to recognize the need for stable funding to persons with exceptional needs, whose requirements may never change and who, if they are to remain in the community, need the stability of setting and staff to succeed to whatever extent they are able."
>
> *-Grande Prairie Organization*

The most consistent comment was a call for stability. People want a stable system and a predictable base of funding. Several suggested multi-year contracts, three-year budgets and lifeplans for individual PDD recipients rather than dealing with the uncertainty of year-to-year funding.

Some participants said that there is a need for greater clarity and predictability in the PDD system. Some find that the system is fragmented and difficult for families to understand, and pointed to numerous idiosyncrasies, exceptions and inconsistencies between regions. Several participants suggested that PDD recipients should be able to receive the same level of service no matter where in the province they live.

On the one hand, some called for clearer parameters for funding, while on the other hand, others called for more flexible funding approaches. Examples of where more flexible funding is needed included cases where PDD recipients move from one community to another, where they choose to leave an institution such as Michener Centre and live in a community, or where there is a change in service providers. Some suggested per capita funding should be provided to the regions or funding models similar to the education system should be considered. (Comments on funding models – individual, contracted and clustered – are included in later sections of this Report.)

"The system that is in place right now is very pro client and family and it is one of the best, if not the best, systems for people with developmental disabilities in the world.
… I'm very proud of what we have here and I would hate to see programs and services disappear because of a lack of funding."

- *Calgary Organization*

Several presenters stressed the need for better forecasts of the numbers of recipients to be served. More accurate forecasts would allow the PDD Provincial Board and the PDD Community Boards to project service demands and plan accordingly. They pointed to the lack of tracking systems and insufficient information. Some wanted school codes used to improve tracking. Forecasts should be more directly linked to information about school-aged children, demographics and population increases across the province.

Several presenters also called for improved accountability. They pointed to the need for clear standards to be in place, for monitoring to ensure standards are met, for consistent performance measures and consistent financial audits.

Specific comments related to funding for PDD programs included the following:

"Adequate and sustained funding must be assured to enable people with developmental difficulties to have opportunities comparable to Albertans without disabilities and secondarily to give community governance a valid chance to demonstrate its potential."

- *Province-wide Organization*

- Funding criteria should be based on the needs of the PDD recipients, not specifically on the type of disability a person has. In some cases, the ceiling for funding is too low and should be lifted.
- Chronic under-funding of PDD Programs leads to staffing problems, a sense of "valuelessness", and problems in sustaining a base of volunteers.
- Funding problems are more than a salary issue. Program costs are significant and they are increasing.
- The costs of operating facilities (including rent, utilities and maintenance) are high and are only funded at a minimal rate or not at all. Adequate support is needed for housing, transportation, adaptive equipment and specialized services such as speech, physiotherapy and occupational therapy.

> "A shortfall in funding will create a competition for dollars between communities. Our region has had a long history of sharing resources and partnering to the benefit of the person served. This has arisen often because very small rural communities cannot support several providers."
>
> *- St. Paul Organization*

- Minimal cost-of-living adjustments make it difficult to accommodate increasing costs.
- The current funding models do not support the costs associated with administering complex community-based programs.
- There should be increased funding available for research, and it should be equally available to all organizations – not just one or two. Several presenters suggested that research is needed into innovative ways of addressing PDD recipients' needs but research was being cut back because of limited funds.
- Because budgets are capped, it is difficult to accommodate a new person who moves into the community. This means that services to existing PDD recipients may be reduced.
- In some rural communities, the shortfall in funding has led to competition among communities where there used to be more co-operation and shared services.
- Many agencies are experiencing difficulties with fundraising. There is intense competition for fundraising dollars and it is difficult to compete with the major fundraising initiatives that support other benevolent causes. In smaller communities, fundraising is a problem because there are small numbers of people to draw from and many different projects to support.
- AISH funding levels should be reviewed. Some suggested there should be increases in the limits on how much people can earn before their income is deducted from AISH payments. Others wanted a more extensive benefits package and said AISH should recognize the higher costs of living in northern Alberta and other isolated areas.

3. Cost Containment Strategies

> "The current deficit in PDD is due to the increased number of individuals requiring services and the problem should be treated as such and not be used as an opportunity to eliminate clients from access to services."
>
> *- Calgary Organization*

Many of the concerns expressed during the Review process related specifically to steps taken by the PDD Provincial and Community Boards to implement cost containment strategies in order to accommodate projected budget shortfalls.

Many presenters said that budget shortfalls were not the result of bad management or inefficiencies. They were the result of an increasing population of developmentally disabled people. Several agencies pointed to significant increases in PDD recipients. Many presenters indicated that the funding shortfalls were not new; the Boards inherited deficits and, in the past, shortfalls had been made up by the former Department of Family and Social Services.

People were particularly concerned about how the cost containment strategies were implemented. Many of the comments related to proposed operational guidelines in regions such as Edmonton that, in fact, were not implemented. Many said there were inconsistencies across the different regions. Because each region appeared to manage cost reductions in a different way, the result was confusion among parents/guardians and communities. Some said it was a top-down approach, and that agencies and service providers were not properly consulted on how savings could be achieved. However, several PDD Community Boards indicated they had extensive consultations with service providers in their area and were working co-operatively with them.

"It concerns me when I hear that non-direct services may be cut. … It is not enough to be kept warm, dry and fed. It is not enough for my daughter or anyone, disabled or otherwise."

\- *Calgary Individual*

"Change needs to occur but not as a result of budget panic."

\- *Edmonton Organization*

In addition to those general comments, the following specific concerns were identified:

- Mandate – Narrowing the mandate for eligibility for PDD Programs is leaving some people without services. (Additional comments on the mandate issue are included in the next section.)
- Ratios – Several presenters expressed concerns that proposed ratios might compromise services and could jeopardize the well-being of PDD recipients. Specific concerns were raised with the proposed ratios for vocational programs. Most, although not all, said a proposed 6:1 ratio was not workable. They suggested that a 1:1 ratio may be necessary in the initial stages when a person is placed in a vocational situation, then the ratio could be progressively increased to possibly 3:1 or 4:1. Similar concerns were expressed by agencies that provide services to PDD recipients with severe, multiple disabilities.
- Group homes – Several presenters expressed concerns about proposals for increasing the number of people in group homes, although not everyone agreed. Many said they would not want to see eight to ten people in a group home because it would take away from the family atmosphere. Some also commented that municipal bylaws do not allow for group homes of more than three or four PDD recipients while some PDD Boards were encouraging group homes with larger numbers.

"…we believe we have implemented the necessary actions and strategies to maintain a high level of fiscal accountability without sacrificing quality of service delivery."

\- *High River Organization*

- Support for community living services – Many participants expressed concerns about the possibility of limiting or eliminating support for community living services. These services allow PDD recipients to participate in their community, expand their quality of life, and increase their feeling of self worth. This includes: recreation programs, respite and day programs, psychological and counseling services; rehabilitation, occupational, and leisure skills; preventive programs, and services provided by agencies in matching an individual PDD recipient's needs to different community programs. If funding for these services is reduced, the result will impact the quality of life for PDD recipients and only their essential food, shelter, health and personal care needs would be met. A reduction of such services could also lead to increased long-term costs.

4. Mandate and Scope

"The implementation of a narrow mandate for PDD puts a burden on the individual seeking service and on their family/guardian as they search out appropriate services, and … on the service provider who does not distinguish between potential service recipients based on diagnosis."

\- *Province-wide Organization*

Consistent concerns were raised about the need for support for individuals who do not fit within the revised mandate of PDD.

In the past, a number of individuals who were not developmentally disabled received support through the Services to Persons with Disabilities Program operated by the previous Department of Family and Social Services. However, the mandate of PDD has been narrowed to focus more specifically on support for individuals with developmental disabilities. A number of individuals who previously received support but are not developmentally disabled have been 'grandfathered'. However, in the longer term, support for these individuals appears uncertain, with some inconsistencies across the province, and there is no clear source of support for people who fall outside the definition of developmentally disabled.

"It doesn't make sense to me that I should have my supports disrupted because of a mandate. People need supports whether it is under PDD or homecare."

\- *Calgary Individual*

Specific concerns were raised about the following groups of individuals who fall outside the current mandate of PDD:

- brain injured adults;
- people with Fetal Alcohol Syndrome/Effect;
- some autistic individuals;
- some people with dual diagnoses;
- people with significant brain dysfunction either because of trauma or disease, or both;
- people whose IQs are marginally above 75 (the upper end of the eligibility criteria) but who are disabled and unable to function without support; and,
- some people who have physical or sensory disabilities.

> "It is difficult to fit the brain injured into the medical model. We are unable to meet their needs for socialization, job training and general life skills… Very few brain injured people require hands on personal care, rather they need guidance and constant reminders to complete tasks."
>
> - *Grande Prairie Organization*

A number of presentations and submissions focused specifically on support for people with brain injuries. Under the current guidelines, people who have or incur brain injuries before the age of 18 are likely to fit the criteria for developmentally disabled support, but those who become brain injured after the age of 18 are not. However, the needs of brain injured people may be very similar to the needs of people who are developmentally disabled. Currently, some support is available from home care through the regional health authorities, but people who provide home care are trained primarily to look after physical needs. There is little support available on an ongoing basis for adults with brain injuries. (People with brain injury may also have specific medical needs that cannot be met by social and/or rehabilitation workers.)

The same is true for people with fetal alcohol syndrome/effect or those with mental illnesses, dual diagnoses, or other types of brain dysfunction.

> "We believe that services to this population (FAS/FAE) should be funded through PDD and that PDD will need to plan for an influx of individuals with high support requirements."
>
> - *Lethbridge Organization*

Many people suggested that the mandate for PDD was being narrowed primarily as a cost containment strategy, and people who did not meet the strict criteria for PDD were falling through the cracks.

In terms of how to address this problem, opinions were divided. Many presenters said eligibility for support should be based on needs not on diagnosis. If a person with a brain injury, FAS/FAE, or other diagnoses had similar needs to a developmentally disabled individual, they should be eligible for similar support, programs and assistance. As one organization put it, "People with community rehabilitation service requirements, people with like needs (regardless of etiology) should be eligible for services through one entry point, PDD." Other service providers said they are having increasing problems trying to arrange services for people who "don't fit the mandate." Some said they were concerned about vulnerable people going from service to service trying to get the support they need.

> "New consumers should not be brought into service at the expense of existing consumers."
>
> - *Thorsby Individual*

On the other hand, some argued that the mandate for PDD should be expanded only if additional resources are made available to support a wider range of people with disabilities. If additional resources are not provided, the result of expanding the mandate would be to limit or reduce services currently in place for developmentally disabled Albertans. There needs to be adequate planning, forecasts, and resources in place before the mandate is expanded.

5. Increasing and Changing Service Demands

The population of people with developmental disabilities is increasing. Many presenters said their region had experienced much higher growth rates than had been projected. For some, the intake of new PDD recipients has doubled in the last two years. This is due to:

- Demographics – Alberta's population is increasing.
- Medical advances are allowing more babies with health problems to live and people with disabilities to live longer.
- Strong economic conditions mean more people are moving to Alberta.
- Aging parents/guardians are no longer able to meet all the needs of their disabled adult children and are looking for appropriate community assistance, including day programs, respite care programs, and residential placements.
- More people are moving from Michener Centre (and from other institutional facilities) into the community.

> "We cannot ignore the increasing needs of clients who age much faster than the norm, and have special needs beyond what we know among the majority of our population."
>
> - *Edmonton Organization*

The population of people with developmental disabilities is also changing. Like the rest of the population, people with developmental disabilities are aging. However, many presenters said that, depending on the nature of the disability, most PDD recipients face a number of symptoms of aging more quickly than other members of our community. Others stated that, as people with developmental disabilities age, some may face additional problems related to mental health.

In this regard, suggestions were made to develop better relationships between the PDD system and the broader mental health system; to educate PDD staff specifically about mental health issues; and to develop and implement strategies to prevent mental illness and/or at least reduce the impact of mental illness.

Several participants also said we should do more planning now to address the impact and changing needs of seniors with developmental disabilities. For example, this may mean there will be less need for employment skills programs for older PDD recipients, and more need for learning and recreational opportunities. Participants also said there is an increasing number of individuals with a severe and profound level of disability and more people with multiple disabilities.

In addition to people who are not eligible for services because of mandate issues, participants identified a number of PDD recipients who are not well served under the current system, including:

- PDD adults without guardians or support networks;
- persons with developmental disabilities on and/or off First Nations Reserves and Metis Settlements; and,
- new Canadians who are not aware of the PDD Program.

As noted in the funding section, many participants suggested that there should be better plans in place for forecasting and anticipating the needs of a growing and changing population of people with developmental disabilities.

6. Service Providers and Caregivers

Aside from funding, concerns about staffing issues were most frequently identified. Many presenters called for a comprehensive human resources plan to address staffing issues and ensure an adequate supply of trained personnel. Agencies pointed to difficulties in attracting and retaining qualified workers. PDD recipients and their parents/guardians expressed concerns about the impact a change in caregivers has on the individual PDD recipients involved.

> "The costs associated with turnover rates are immense both in organizational recruiting and orientation costs, and in the costs paid by the individuals receiving service, who must constantly adjust to new personal care givers (who provide very intimate care) and teach new staff what their needs are and how they communicate them."
>
> - *Province-wide Organization*

Specific concerns related to:

- Low salary levels. People appreciated the recent salary increases but said that salaries continue to be too low to attract and retain qualified staff.
- High staff turnover. At least partly because of low salaries, staff turnover rates are very high. Several presenters talked of turnover rates in the range of 30 – 40%. This results in uncertainty for PDD recipients and parents/guardians, and in additional training costs.
- Wage disparities between provincial direct service providers and community service providers. There were consistent references to discrepancies between salaries paid to service providers who work for provincial boards compared with those who work for community agencies. Many said the discrepancy in salaries was about 30%.
- Limited access to post-secondary training, limited access to direct training while people are employed, and a limited

connection between training and salaries. Many agencies and service providers pointed to problems with accessing training programs. Post-secondary programs have limited access. Agencies have difficulty arranging on-the-job training and compensating staff for training time. In remote areas, training costs are higher and access problems are greater. In addition, people with extra training do not necessarily receive higher pay.

- Low morale. The work of providers is often under-valued and under-paid. This makes it difficult to attract and retain staff.
- Burden of responsibility on staff. Many parents/guardians pointed to the burden of responsibility staff members have in caring for PDD recipients. This supports the need for additional training to assist staff in meeting their responsibilities. Parents/guardians also expressed concerns about possible changes in ratios of staff to PDD recipients. There is a concern that increasing ratios would lead to an even greater burden on staff and could compromise the safety, health, hygiene and community activities of PDD recipients.

7. Addressing Disparities

> "While there needs to be room for regional and individual differences in interpretation and implementation, people accessing the system need to be assured of fair and equal access to the system regardless of where in Alberta they live."
>
> - *Edmonton Organization*

As noted in other sections of this summary, participants in the Review pointed to a number of disparities across the province, including:

- disparities in funding provided to individual PDD recipients with similar conditions;
- inconsistencies in contracts provided to different agencies;
- disparities from one region to another – e.g. some regions were expected to reduce their budgets more than others;
- disparities between the rules for Individual Funding and Contracted Funding;
- gaps in salaries paid to provincial caregivers in comparison with community caregivers;

> "The patchwork quilt of funding mechanisms across the province in many communities reflects our lack of long term planning for a group of citizens who need it most."
>
> - *Medicine Hat Organization*

- disparities in funding reductions for community programs compared with reductions for Michener Centre; (Some indicated that while a significant number of residents had recently left Michener for one reason or another, the institution's budget was not reduced proportionately.)
- disparities in services available to those who fit the mandate of PDD compared with those who do not fit the mandate and are served in the broader health sector; and,
- disparities in support for group homes that are operated by funded agencies and those that are operated by proprietors.

Underlying these disparities is a call for more consistency across the province, for overall policy direction, and a common approach in the various regions.

8. Choice – Community Integration and Residential Options

> "Choice for people with developmental disabilities is essential. It is important for them to be able to choose a lifestyle, a community within which they wish to live, and then to interact in that community as completely as they are able."
>
> - *Rocky Mountain House Organization*

Those who advocate for community inclusion spoke strongly in favour of expanding programs and support for developmentally disabled people to remain in their communities with appropriate services in place. Many were parents/guardians who have worked tirelessly on behalf of their children to secure programs, support and an acceptable quality of life in the community. It was recognized that many individuals who live in institutional accommodation also experience a degree of community inclusion options through employment and recreational activities, including volunteering in the community.

Some called for no new placements in Michener Centre or the complete closure of the Centre. Some also asked if expectations for reducing costs might create pressure to place more developmentally disabled people in institutions. Others said institutions should be reserved for medically fragile individuals only and wanted to know how many institutionalized residents would meet such criteria. For those individuals leaving Michener (or some other institution) to reside in the community, concern was expressed that insufficient monies from that institution were accompanying the individual to help cover his/her community inclusion needs. Therefore, they felt that PDD Community Board budgets were being pressured unfairly.

On the other hand, parents/guardians of people in Michener Centre and other institutional settings such as the Eric Cormack Centre made passionate pleas on behalf of their children, many of whom are severely disabled and require 24 hour total care. In their view, these placements provide the best option for their children. They said, because of the highly trained personnel at hand, they feel secure, confident and at ease that their children are being personally cared for in a safe environment. They also said there have been tremendous improvements in the quality of institutional care and that institutions must remain because there will always be those who require such facilities.

"The Eric Cormack Centre has been labeled an institution but … those familiar with the Centre submit that it is an 'attitude' not size that defines an institution."

- Edmonton Organization

Others said there should be a clear and straightforward statement on the future long-term plans for Michener Centre and other institutions.

Many presenters talked about the need for choice – the ability of parents/guardians and caregivers to make informed choices and to have those choices supported. Rather than a "one size fits all" approach, they should have information, assistance and the ability to make choices on behalf of their children. As one presenter said, "No people with developmental disabilities should have to leave their family, friends and community to live in institutions in order to receive proper care. But nor should people who have called an institution home for 30 years have to leave if it is meeting their family's needs and it is their choice to stay."

9. Administration and Processes for Boards

A number of comments and concerns were expressed about administrative aspects of PDD including contracts and individual funding, monitoring and reporting, administrative burden, appeals and shared support centres.

Several participants suggested there should be annual business plans within the context of a three or five year funding commitment. Discussions on business plans and budgets should be open to the public.

Several concerns were expressed about an increasingly cumbersome administrative burden, micro-management, and the need to streamline the process. Some presenters suggested that the systems for accessing funds have become more complex and there is a need to "de-mystify" the process. Suggestions were made for more electronic systems for billing and payments to save time and management, and to provide better tracking of services and the inflow and outflow of PDD recipients. Several presenters indicated that some volunteer boards and agencies did not have the financial expertise and experience to meet the growing expectations for accounting, monitoring and administration. (However, PDD Community Boards do have access to the Director of Finance at the PDD Provincial Board level.)

Comments were made that the intake process is sometimes drawn out, complex, and creates apprehension for some families. Some people wanted a single assessment tool and other steps to simplify the process and prevent backlogs in assessments. Others commented on a single point-of-entry system and expressed concern that, if not properly designed, it could cause bottlenecks in accessing services.

Many presenters commented on the benefits of and/or problems with individual funding vs. contracted or clustered funding. Views on the most effective funding approach varied and included the following:

- Individual Funding.[*] Many supported individual funding because it provides individual PDD recipients with the best access to programs and services they need. Individual funding also has the advantage of ensuring that funding is available to each PDD recipient and is not re-directed if another PDD recipient moves into the community and needs services.
- Multi-year individual funding. Some said there should be multi-year individual funding agreements since the needs of most PDD recipients do not change much from year to year. This would streamline the process and reduce administration.
- Clustered Funding.[*] Some supported clustered funding of individualized services to streamline administration but wanted to retain the ability of consumers to control services.
- Contracted Funding.[*] Some advocated that contracted funding (or block funding) should replace individual funding primarily because of the ease of administration. These agencies suggested that an overall contract should be in place to set the standards, expectations and number of PDD recipients to be served, then it would be up to the

> "Our group has several questions or concerns… The first is that when an agency receives block funding, what mechanisms are in place to ensure how many clients actually are registered and receiving service, and for what length of time each week?"
>
> - *Duchess Organization*

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[*] For definition refer to Appendix 4

"We have to be careful about interfering directly in community agency operations, but we must not be slaves to historical funding (methods), i.e., continue to fund agencies (the way and) because we 'always have'. We must be prepared to look at new and innovative ways to provide services through our funding."

\- *Lethbridge Individual*

agency to provide services within the budgeted amount. Others said contracted funding should be cancelled in favour of individual funding.

- Several people suggested there should be equal access to the different types of funding models. Information packages should be developed on each of the funding models so people are able to assess the options and make appropriate choices.
- Some suggested that agencies should be merged. The number of agencies is growing and this adds to the administrative burden and overall costs. While some suggested a straight merger of agencies, others suggested there should be a cap on the number of new agencies allowed to operate in a region.
- People also suggested the need for consistent financial reporting methods for both individual funding and contracted funding so there are comparable cost figures available.

In addition to comments on funding arrangements, there were suggestions for a review of the appeal process because the current process is too complex and time consuming. Some suggested that Community Boards should be required to have an initial appeal at the local level before the appeal goes to the Provincial Board. Local citizens should be involved in appeals at the local level. On the other hand, others said the process is fine, but better communication of the process is needed. For example, all PDD Community Boards have a voluntary dispute resolution mechanism which can be accessed prior to the provincial appeal process; however, very few knew the details of this mechanism. (Most disputes/challenges are resolved locally and do not proceed to the provincial level.)

Only a few comments were made about Shared Support Centres. Those comments generally related to the need for PDD Community Boards to have their own financial, information technology and communications support.

10. Implementing Standards

> "One set of standards being implemented through a partnership with one recognized accreditation body in the province provides an accountable, cost effective mechanism for monitoring the provision of quality rehabilitation services throughout Alberta."
>
> - *Province-wide Organization*

Many participants in the Review suggested that there is a need to ensure that all service providers meet provincial standards for the development and delivery of services to people with disabilities. Presenters frequently referred to work already done on *Creating Excellence Together*. This document was jointly prepared by the Alberta Association of Rehabilitation Centres, PDD staff, and others, and sets out provincial service standards. Presenters suggested that this work should be supported and fully implemented. To date, all of the recommendations have been adopted but not all have been implemented.

> "If our organization could suggest nothing more for consideration by PDD we would suggest the need for planning and review of the methods in which all providers deliver service."
>
> - *Edmonton Organization*

Some also suggested we need a definition of an acceptable service. Others called for standardized assessment tools to ensure consistent service standards in assessment of providers. Many presenters called for improved monitoring of agencies and services, especially in residential settings and group homes. Some suggested there is a need for more outside staff and consultants to monitor programs.

11. Support for Parents/Guardians, Especially During Their Children's Transition to Adulthood

Throughout the Review, many parents/guardians talked passionately about the struggle they faced in finding the most appropriate placements, programs and services for their developmentally disabled family member. Many spoke about difficulties in finding out what is available, how to access services, and how to navigate the system. Some have difficulty making informed choices. They need support and good information.

> "I am the expert on my children. I realize today that I am not only an expert about being my children's mother but on what life is all about living with disabled children. In fact, I don't know anything else."
>
> - *Red Deer Individual*

Others wanted the Departments of Health and Wellness, Learning, Human Resources and Employment, and Children's Services to create a transition requirement mechanism to help prepare a smooth cross-over from childhood to adulthood.

Many suggested there should be workshops and seminars for parents/guardians to provide them with access to the most current information. Others suggested there should be:

- an umbrella organization for parents/guardians;
- a “hot line” information source for parents/guardians;
- a direct line to PDD staff for questions or concerns;
- networks with others who have had similar experiences; and,
- an ombudsman.

Several parents/guardians were concerned that, as they become older they may no longer be able to advocate on their child’s behalf. Others requested more support and services to help them keep their PDD child at home for as long as possible. Without this support some felt pressured to place their child in a group home just to get the basic minimum of services.

> “Many parents breathe a sigh of relief when their children turn 18 as their children are then considered independent adults who can care for themselves. I could not have this freedom. In fact, after 18, the long, painful and seemingly cold journey into the unknown began.”
>
> - *Edmonton Individual*

Some suggested there should be greater recognition for the role of family members. Several suggested that family members should be able to be paid as workers or caregivers under the individual funding model. Several agencies commented on the need for expanded respite programs to give family members and caregivers a break.

Support for parents/guardians and family members is a particular concern when a young person turns 18. Many pointed to problems in the transition of services for people before and immediately after they turn 18, and the lack of coordination between agencies, and inconsistencies in eligibility for programs and support. To use a football analogy, some suggested there should be a planned hand-off from one type of support to the next, not a scrambled play or a dropped pass. Some were concerned about the guardianship requirements once their children turn 18, and said better communication is required. Others said they were planning to move their children out of their homes before they turned 18 so there would be a better transition of services.

To ensure a smooth transition, it was suggested that children who turn 18 continue to be funded until they are appropriately placed and funded as adults. Others suggested that workshops about available options should be provided to parents/guardians before their children leave the school system.

Some concerns also were expressed by PDD recipients who are parents themselves and need help with parenting skills.

12. Supports in the Community – Transportation, Housing, Volunteer and Job Opportunities

A number of concerns were raised about the lack of adequate transportation. This problem is even greater in rural communities. Specific concerns related to the length of time PDD recipients spend on a handibus or other forms of transportation. Some said PDD recipients can spend more time on the bus than they do at their destination. These lengthy rides can increase the possibility of behaviour problems. Others expressed concerns about the need to book transportation three days in advance and the lack of flexibility this provides. Transportation is a particular problem for PDD recipients attending medical appointments, for example or who volunteer or work in employment situations where punctuality is required.

> "We strongly encourage government to address transportation issues affecting services to persons with developmental disabilities."
>
> - *Wainwright Organization*

A key problem is that the approach to transportation for PDD recipients was developed at a time when institutional care was more common than community integration. As a result, transportation for individuals with disabilities often reflects a system designed for groups rather than individuals. To respond to this, many agencies are buying their own vans; however, this is expensive and can create liability issues.

Concerns were also expressed about the lack of affordable housing, especially in Calgary and Edmonton. With a strong and growing economy and current market conditions, the challenge of finding affordable housing goes beyond PDD recipients. However, in the case of PDD recipients, the challenge is particularly difficult since those who are living on their own cannot afford to pay high rents for accommodation. When market forces put a squeeze on available space, rents tend to increase. This forces PDD recipients to seek other accommodation, but there are very few low-cost options available.

In some cases this has resulted in a very high proportion of group homes in low-income neighbourhoods. This has caused some municipalities to restrict the placement of group homes. Some suggested that a strategy be developed between Municipal Affairs and Municipal Councils to have future neighbourhoods designed to accommodate group homes and other suitable accommodation. Others said the lack of affordable housing was a serious barrier for those wishing to leave an institutional residence to live in the community.

The search for adequate housing is becoming more of a challenge with the loss of many publicly funded housing programs. The costs of housing are taking up a greater proportion of the monthly AISH funding. Some landlords also have negative perceptions about renting space to certain PDD recipients. One presenter suggested there should be a "Multiple Listing Service" for housing for people with disabilities so parents/guardians and service providers would have easier access to information about what types of housing are available. Others suggested that housing subsidies should be provided to individuals rather than assigned to the housing units, and that housing and land trusts should be established to ensure the long-term availability of special needs housing.

"PDD should be working with employers to create employment opportunities, improve their capacity in hiring people with developmental disabilities, and sustain employment; working with … community organizations to facilitate the participation of adults with developmental disabilities as volunteers and members…"

- Province-wide Organization

Several presenters focused on the need to maintain and expand programs in the community where people with developmental disabilities can volunteer their time, continue learning, work or develop on-the-job experience. People mentioned the need for university programs to help developmentally disabled adults participate in classes and volunteer for certain activities. Some asked if Alberta Learning could contribute toward this purpose. Others mentioned the need to encourage more employers (possibly through appropriate tax incentives) to provide opportunities for developmentally disabled people to work and expand their employment experience, while others suggested that Government should increase its role as a model employer.

"Everybody knows someone with a disability and everybody wants to help, so why don't we just get out there and do it!"

- Fort McMurray Individual

13. Transfer of PDD to Alberta Health and Wellness

Many presenters expressed concerns about responsibility for PDD Boards and Programs being placed within the Ministry of Alberta Health and Wellness.

Concerns related to:

- The predominant medical model in the Ministry of Alberta Health and Wellness is one which may not fit the needs of developmentally disabled people.
- Persons with developmental disabilities are not sick and they cannot be cured; therefore, they should not be included in the mandate for Alberta Health and Wellness.
- Rules and criteria for access to health related programs are different. In health, assessments are based on diagnosis and

treatment while for PDD recipients, assessments should be based on their abilities and interests.

- If similar approaches to home care were used, some felt it could result in people being placed in long-term care facilities once the cost of their care reaches established limits.
- There are significant pressures for funding in Alberta Health and Wellness particularly to support acute care hospitals. Some felt it may be difficult to compete for necessary funds if PDD budgets are part of this Department.
- Others appeared relieved and satisfied that PDD Programs were included under the ‘Wellness’ side of Alberta Health and Wellness, and indicated that many PDD recipients do have medical needs which are not able to be met by the current PDD system. Some suggested a cost-sharing approach in areas like physiotherapy, speech therapy, and occupational therapy, for example. They noted that these services are covered in institutions but not necessarily in the community.

Several presenters suggested that responsibility for PDD Boards, programs and services should go to Children’s Services for continuity purposes, and that the mandate for that Department should be expanded to include families, children and adults with disabilities. On the other hand, a few presentations suggested that the move to Alberta Health and Wellness was an opportunity to expand the PDD Program to include and coordinate support for individuals who do not meet the PDD eligibility requirements but have similar needs.

Section Three: Observations and Official Recommendations

Introduction

After an extensive Review process, I wish to acknowledge and thank the hundreds of PDD recipients, parents/guardians and family members, agencies and service providers, volunteers and Board members who took time to present their views, listen to others and contribute in a very constructive way to the overall PDD Review.

Having listened intently to each public presentation and having carefully read several hundred submissions, I am deeply impressed with the commitment and dedication of everyone involved in caring for persons with developmental disabilities.

There is no doubt that people have worked hard and are proud of the leadership Alberta has shown in developing programs and supports for persons with developmental disabilities. As one Grande Prairie organization put it, "It is unfortunate that presentations to reviews such as this seem to focus always on what is deficient, what is lacking, what is negative. Too often we fail to communicate that actually, in the bigger picture, much is better than it was."

In that regard, people clearly want a community governance model to work. They want choice and community inclusion to remain and be emphasized as the cornerstones of the PDD Program. They want to be involved and continue to play a role in making a good system even better. They want stability and predictability; and, they want to be assured that people who need PDD services will receive them when and where they are needed.

The observations and recommendations I am presenting in this Final Report incorporate these views and, to the largest extent possible, reflect the advice and suggestions of hundreds of Albertans. Together, they comprise the starting point for *Building Better Bridges* – a starting point designed to address key issues and provide what everyone wants:

> **a stable, predictable and accountable PDD system that values, protects, supports and enhances the lives of individuals with developmental disabilities.**

1. ISSUE: Current Deficit Forecasts

Background

In July of 1999, the PDD Boards provided a deficit forecast of approximately $25 million for the current year. In response, Honourable Halvar C. Jonson, Minister of Health and Wellness, provided them with an infusion of $10 million to deal with cost pressures. The Boards were asked to work very hard at cost containment strategies and through that hard work they managed to reduce their deficits. In total, they have identified $10 million in savings through cost containment strategies. However, while the deficits have been reduced, they have not been eliminated.

Achieving this reduction in projected deficits has resulted in many concerns being expressed by PDD stakeholders. In fact, the PDD Community Boards still remain $5 million short in their projections, primarily as a result of new intakes; therefore, while constantly striving for efficiencies is important, I do not recommend any further cost containments that may lead to reductions in service delivery.

The current shortfall must be corrected immediately or the PDD Program will begin the new fiscal year (April 1, 2000) in a deficit position.

Recommendation

That the Province of Alberta eliminate the current PDD deficit by providing a further $5 million in the 1999/2000 fiscal year for the PDD Program to cover the projected shortfall and to enable the Program to begin the 2000/2001 fiscal year on a stable and deficit-free basis.

2. ISSUE: Future Funding Forecasts

Background

It must be recognized that the PDD community governance model is still in its infancy, having been established in April, 1998, and that our current information system needs improvement. Nonetheless, best efforts must still be made to forecast the anticipated needs and future growth of the PDD system.

With respect to intake, this will include projections regarding eligible individuals who:

- are in transition from childhood to adulthood;
- are moving into Alberta to become new residents; or,
- are already adults but have not yet approached the system.

(Ultimately, it may also include provision for those with similar needs but who are not receiving services because they are outside the current criteria of the PDD Program.)

With respect to programs, services, and delivery, this will include projections which address:

- the changing needs of PDD recipients;
- the capital, research, and project needs of the PDD system (which are covered under Issue 4);
- wages, staffing and training issues (which are covered under Issue 3);
- staff -to-client/recipient ratios;
- needs related to improving internal information systems; and,
- better communication and networking mechanisms for familiarizing future entrants and their parents/guardians about the PDD system.

Recommendations

That the 2000/2001 Provincial budget for the PDD system incorporate:

- *the $10 million infused in July, 1999; and ,*
- *the additional $5 million recommended in this Report (to eliminate the remaining PDD deficit)*

as part of the base budget for PDD;

That the 2000/2001 Provincial budget for PDD provide the additional funds necessary to meet projected increases in new intake of PDD recipients;

That the information-gathering, tracking, and accounting system for PDD be upgraded to provide more timely, reliable and accurate data for management purposes;

That PDD Community Boards review their local financial management needs and, if necessary, ensure that financial management expertise is available in their regional offices.

3. ISSUE: Wages and Workforce Retention

Background

About 90% of the approximately 12,000 rehabilitation caregivers in this field are employed by community and/or private agencies. They are paid an hourly wage ranging from $8.50 to $14.00 which is approximately 30% less than the Province pays for unionized caregivers doing similar work. While this wage gap has been acknowledged, there has not been a concerted effort to address it.

- From the perspective of PDD recipients – many of whom rely on caregivers for their health and safety, and for a very significant contribution to their daily quality of life – the main concern is the constant turnover of caregivers who leave for better pay in other rehabilitation programs, or who leave rehabilitation practice altogether because it does not pay well enough.

- From the parents' or guardians' perspective, they emphasize that it takes a long time for caregivers to learn about their children and the complex health, safety and social issues that affect them. Parents are rightfully concerned that health and safety must not be compromised, nor the quality of service undermined, because of frequent staff turnover.
- Service providers who hire rehabilitation workers are very concerned that constant staff turnover rates of 30% to 40% per year generate very high costs regarding hiring and training. They are also concerned that this could affect their ability to meet the certification and accreditation standards that are in the process of being fully implemented across the province.
- Rehabilitation practitioners and the community colleges that offer relevant diplomas are concerned that insufficient numbers of young people are being attracted to this field because of the low hourly starting wage, lack of benefits, and lack of opportunity for career advancement.

In the 1999/2000 PDD Program budget, a 4.5% increase was provided for these rehabilitation caregivers at the community level. However, the effect of this, while positive, did not help to reduce the wage gap between these workers and corresponding government workers (because of subsequent increases provided to government workers during the same period).

In the upcoming budget year, it has been proposed that a 3.2% wage increase be provided to front-line PDD agency caregivers. If accepted, this proposal should help keep pace with corresponding government caregivers, but it will not narrow the existing wage gap. It must be recognized that a well-trained workforce provides great stability to the PDD community and that annual staff turnover rates of 30-40% shake the confidence of the entire PDD delivery system. Since this is a field where continuity of care is vital, these turnover rates must be reduced because they compromise the service-providing agencies' ability to hire, retain, and train staff.

Recommendation

That the Ministry of Health and Wellness undertake the necessary steps to narrow the gap that exists in the PDD area between agency/service-provider staff wages and government-employee staff wages.

(It is acknowledged that the handling of this issue has the potential to impact wage rates for similar caregivers in areas other than PDD. Still, this wage gap must be narrowed.)

4. ISSUE: PDD Foundation and Ongoing Capital, Research, and Project Needs

Background

In 1997, the PDD Foundation Act came into force. The PDD Foundation was established to enhance the quality of life of persons with developmental disabilities in Alberta. To do this, the Foundation was given the ability to solicit and raise funds for granting purposes in support of capital, pilot, and research projects. While it was expected that the Foundation would generate some endowed contributions from the private sector, this has not happened for a variety of legitimate reasons. To date, the Foundation has received $2.5 million from the Province, which comprises its total and sole endowment (in addition to some interest revenue from investment of these monies). The Foundation's operating budget for 1999/2000 was about $270,000 which was provided by the PDD Provincial Board.

During the public presentation phase of the Review, many challenged the need to maintain the Foundation. They said its endowed base was too small to effectively fulfill the mandate, and that the Foundation would compete with local fundraising in communities if it tried to generate a larger endowed base through local fundraising. However, public presentations in the Review also confirmed there are real pressures in the system to address and/or to complement the quality of life needs for which the Foundation was established:

- affordable housing to support independent PDD community living;
- transportation of PDD recipients to community inclusion options such as work placements, volunteer activities, daily living needs, and recreational opportunities;
- innovative pilot projects to help determine best practices on an ongoing basis; and,
- research projects to provide valuable information for future directions and decisions.

During the Review it also became apparent that the ongoing capital needs of the PDD system are not being adequately addressed. The direct service sites operated by the Province (Michener Centre, Eric Cormack Centre, and others) are facing problems because these facilities are aging and unable to keep pace with the changing needs of those being served. These sites provide an important alternative for some PDD recipients and their families; consequently, they are needed and require a capital plan to be maintained.

In addition, community service agencies that provide day programs for developmentally disabled adults, such as respite care, are experiencing problems with their facilities. Some of these agencies are operating from older premises that have been retrofitted. The current provincial funding formula does not provide for new-building projects, nor for capital improvements or renovations to existing facilities in the community (which would help these agencies deal with basic needs such as roof repairs, healthier food preparation areas, improved washroom conditions, or expanded facilities to reduce crowding).

While the PDD Foundation has the legislated mandate to help fulfill these needs, its current endowment of $2.5 million is insufficient to do so in the long term. Furthermore, the expectation that the Foundation might grow its endowment through the receipt and subsequent sale of under-utilized provincial facilities (such as certain buildings on the Michener Centre site, for example) has not happened. Neither has the Foundation received any commitment for an additional cash endowment from the Province (which was presented as $15-25 million on a one-time basis and would have ensured the Foundation's long-term sustainability.) As a result, the Foundation's long-term viability is uncertain, the need for its existence as a stand-alone entity has been questioned, and clarification is required now; therefore, an immediate decision regarding the future of the Foundation is in the best interest of all PDD stakeholders.

In fairness, the PDD Foundation Board has tried to resolve this endowment dilemma and, to their credit, recently announced an initial community grants program of about $100,000 for eligible projects under the mandate. But without the anticipated inflow of sufficient new monies, the Foundation will not be able to significantly impact the purposes for which it was created. This is indeed unfortunate but it is the current reality.

Recommendations

Re: PDD Foundation

- *That the PDD Foundation be wound down in an appropriate and timely manner;*

- *That the central purpose of the PDD Foundation (being the provision of grants to assist PDD community initiatives) be assumed and continued as a separate function of the PDD Provincial Board;*

- *That monies and other assets held by the PDD Foundation be transferred to the PDD Provincial Board and be dedicated for community grant purposes;*

- *That, relative to its community grants function, the PDD Provincial Board not be allowed to solicit donations or engage in fundraising initiatives.*

Re: Ongoing Capital, Research, and Project Needs

- *That the Ministry provide the PDD Provincial Board with an ongoing annual allocation of $1 million to assist PDD community agencies/service providers with their capital (building, renovating, vehicle, and equipment), research, and project needs; and,*
- *That a funding mechanism be established by the PDD Provincial Board to facilitate the disbursement of these funds;*

- *That the PDD Provincial Board, as part of its business planning process, submit annually, a detailed capital plan for PDD.*

5. ISSUE: Support for Acquired Brain Injury Individuals

Background

The Terms of Reference for the Review provided an opportunity "To review and make recommendations as to funding issues relating to support for individuals with brain injury living in the community".

Including this within the Terms of Reference was widely supported both within and beyond the PDD community, and was applauded at all the public presentation sessions as well as in much of the correspondence received. The vast majority acknowledged that the types of services specifically required were similar to those provided through the PDD Program. The issues surrounding those with acquired brain injury have been discussed for many years but little has been 'actioned' to date. I support other findings which urge that a policy framework be developed first, and that there be some inter-ministry work undertaken to identify what roles and responsibilities existing ministries should take in this complex area.

I also want to emphasize that significant effort was made to obtain concrete information about this important area and, while some does exist, there is a further need for hard data to be assembled before specific policy directions, programs and services, and specific funding requirements can be determined. Organizations like the Brain Injury Association of Alberta, Edmonton Brain Injury Relearning Society, Northern Alberta Brain Injury Society, Central Alberta Brain Injury Society, Brain Injury Rehab Centre – Calgary, and other not-for-profit, volunteer-driven groups have done a good job in amassing some information but they will need help in solidifying and verifying it and, ultimately, in translating it into a clear action plan with corresponding policies, activities, structures, and funding.

I will recommend that new funding be allocated specifically for these purposes and in support of those with acquired brain injury. However, without sufficient hard data, it is not possible to specify an appropriate allocation at this time.

A relevant and very positive outcome regarding the transfer of PDD to Alberta Health and Wellness is that many key Provincial programs that could assist those with acquired brain injury are now incorporated under one Ministry, Alberta Health and Wellness. The challenge now is to respond appropriately to the immediate needs of brain-injured individuals while developing longer-term goals, strategies and expected outcomes surrounding their community inclusion. In fact, this challenge is actually an opportunity to provide much-needed assistance to a long-standing issue.

Recommendations

That the Ministry of Health and Wellness, in partnership with regional service providers and representatives of the brain injury community, proceed immediately to develop a response and a concrete action plan regarding the needs of those with acquired brain injury; and,

That this response and plan include:
- *an assessment to determine the scope of need;*
- *an analysis of regional service gaps;*
- *an inventory of existing services;*
- *an analysis of expected costs (from which a budget can be developed);*
- *a policy framework for future service delivery; and ,*
- *an implementation strategy; and,*

That the response mentioned above be completed by July 31/2000 and the plan be developed as soon as possible thereafter.

6. ISSUE: Mandate, Eligibility, and Scope of Service

Background

Much was said and many points of view were heard during the Review regarding these topics. Based on the public presentations, it is clear that the narrowing of the mandate (when the previous Services to Persons with Disabilities Program became the Persons with Developmental Disabilities Program) has caused some problems. The problems were compounded when recent funding concerns brought about unique regional strategies to address local cost containment issues.

- The commitment made to those who found themselves outside the new narrowed mandate (that their services would be ‘grandfathered’) was being eroded as budget pressures and cost containment strategies were imposed by PDD Community Boards in response to directives from the PDD Provincial Board.
- The new narrowed mandate excluded many individuals from the Program, including those with IQs that marginally exceeded the stated minimum; consequently, many were left without any services, even though they had legitimate on-going needs.
- Recreational services, arts and crafts classes, and other leisure activities are very important and beneficial to PDD recipients and, as such, must be part of the mix regarding ‘essential services’.
- The Handicapped Children’s Services program in the Ministry of Children’s Services, and education programs offered through the Ministry of Learning, acknowledge there are ongoing needs for all children with disabilities. The transition to adulthood, however, directs some of these young adults to treatment and/or long-term care

within the health care system, directs others to the community inclusion options within the PDD system, and unfortunately, leaves some with no place to go at all.

- Greater effort must be made to establish, co-ordinate and rationalize policies around the broader disabled community. For example, the acquired brain injury community, the FAS /FAE community, individuals with sensory disabilities, and others, who have ongoing needs and concerns must be addressed.
- Some groups and organizations established to assess needs and place potential recipients in contact with service-providing agencies have found themselves shut out of the system because they were advised they do not provide a ‘direct service’.
- Organizations that provide ongoing research regarding the developmentally disabled community have been told that historical funding will be reduced or phased out, because they do not provide a ‘direct service’ to recipients.
- Some PDD recipients and their parents/guardians have been advised that the type of service they have been receiving will be eliminated, or that the scope of their services will be reduced, or that the recipient-to-support-staff ratios they have previously received will be altered. In many of these cases, it was expressed that the proposed changes might seriously impact the health, safety, and quality of life of these recipients.

During the course of the Review, I visited many institutional settings and homes, and had discussions with many recipients, parents/guardians, caregivers and service providers. I visited with many recipients of PDD services who require intensive ongoing interventions provided by loved ones and dedicated caregivers. I visited individuals who experience ongoing seizures, require tube feeding, need assistance with personal hygiene and toileting, or require help with balance, and I saw others with communication difficulties, behavioral challenges, and so on. (Some of these individuals were ambulatory, some were not.)

In many cases, it was not possible to reasonably determine where the fundamental health need stopped and where the community inclusion need began, or indeed if there was any meaningful distinction between the two. In any case, I saw numerous caregivers trying their very best to attend to the needs of people in a holistic way.

As recently as 28 years ago, Albertans had little choice. If there was a family member with a developmental disability, and the family could not accommodate the individual for whatever reason, the only choice was to send the developmentally disabled child to a large institutional home. In 1972, there were approximately 2,400 institutionally cared-for Albertans. At that time, 95% of the services provided to these Albertans was provided by Government workers in facilities owned and operated by the Government. Today, while the number of developmentally disabled Albertans has grown to approximately 8,000, less than 10% are in costly, full range-of-service institutional homes. While the current information system prevents individual tracking of some recipients under the Contracted and/or Clustered Funding models, it is estimated that an equal number of Albertans (10%) receive similar costly services through private sector service providers. These individuals with very significant needs account for less than 20% of the total PDD population and these high-end cases represent approximately 50% of the total PDD budget.

Over 60% of the currently trackable PDD recipients receive less than $2,000 a month in services. This is indicative of individuals living independently or continuing to live with a parent or a loved one with a modest level of community support services.

It appears there will always be a need for extensive services such as those delivered through institutional-like settings. These services are very expensive and will need to be monitored regularly to ensure quality and cost effectiveness. Services that support recipients' independence must also be encouraged where possible. These services, which support independent living and support individuals who choose to remain in their homes with the natural supports of their families, should be considered essential services. Services such as day programs that focus on abilities and interests, and respite services that help families to cope, are vital. They build independence, foster self-confidence, and enhance community inclusion and family wellness. These are necessary services that the communities want and, from a fiscal perspective, cost less to deliver.

In summary, the PDD vision is clear and in alignment with the purpose for which the Program was established in 1998. The PDD directions are also clear and long-range strategies chart their future for the next 10 years. The standards under which the Program operates are equally clear, widely circulated and well along the way to being fully implemented province-wide.

The current PDD Program is needs-based and demand-driven: if you meet the criteria, the Province must provide reasonable support for you through its PDD Boards, likely for the rest of your life.

Recommendations

That the PDD Provincial Board be advised that those individuals who were 'grandfathered' into PDD are to remain in the PDD Program with their services provided until such time as an orderly hand-off of responsibility to a more appropriate Provincial program is secured; and,
That the PDD Provincial Board develop strategies to resolve issues regarding PDD-funded agencies who have historically provided indirect services (such as assessments, counselling, facilitation and referrals) to the broader disabled community.

That the Ministry of Health and Wellness work in partnership with other Ministries to develop a policy framework around ongoing support needs for other disabled communities besides the PDD community; and,
That the first step be to coordinate and convene a broad policy and practices forum of representatives from the Premier's Council on the Status of Persons with Disabilities and from the Ministries of Health and Wellness, Learning, Children's Services, Justice, Community Development, Human Resources and Employment, and their relevant Boards and Agencies; and that this forum look at issues impacting on:

- *the orderly transition of children with special needs into adult programs, including early communication with parents/guardians about the process;*

- *those in the disability community with ongoing needs similar to, but currently outside, the PDD mandate (including FAS/FAE individuals, autistic individuals, and others);*
- *the vision and direction of the PDD Program in terms of community inclusion and how it might apply to those in the disabled community who have similar needs to PDD but are not receiving support (including those referenced immediately above);*
- *the current provincial delivery systems and ways to make them more effective in providing services to other members of our disabled community.*

That the PDD Provincial Board work with the PDD Community Boards to better define the scope of services offered in the PDD system and adopt a policy to include quality day program services and respite services as essential services within the PDD system.

That a component to provide for ongoing research regarding PDD be established by the PDD Provincial Board;

That, in the future, PDD Boards adopt policies that ensure recipients, parents/guardians and service providers are well informed and involved when changes in services are being contemplated.

7. ISSUE: Community Board Membership

Background

Board selection and membership were not topics about which I expected to hear significant comment during the Review. To the contrary, however, there were many views expressed. At the community level, many said that Boards should be composed of only parents/guardians, and some said Boards should be elected entirely from within the parent/guardian group. On the other hand, others said that having any parents/guardians on the Boards could lead to a conflict of interest situation.

In considering this issue, I reviewed the preamble to the Persons With Developmental Disabilities Community Governance Act which states:

“WHEREAS the people of Alberta honour and respect the dignity and equal worth of adults with developmental disabilities;

WHEREAS it is important that adults with developmental disabilities have opportunities to exercise self-determination and to be fully included in community life;

WHEREAS the individual needs of adults with developmental disabilities are most effectively met through the provision of services that are based on equitable opportunity, funding and access to resources; and,

WHEREAS the Government of Alberta recognizes, values and supports the ability of communities to respond to the needs of adults with developmental disabilities;…”

In order to maximize the delivery of this Act, Board membership must appropriately reflect society as a whole.

In my opinion, adopting an extreme position on either side of the Board composition issue would preclude valuable opinions, experience, and assistance of community leaders and advocates, which are necessary to achieve the vision of this Act. Exclusionary practices would be detrimental to this purpose and would not result in the balanced approach needed for effective and responsible governance. In support of this observation, and specifically regarding the potential of conflicts of interest in having parents or guardians of those receiving PDD services sitting on PDD Boards, the following points should be noted:

- PDD Boards are governance boards, not operational boards. They should not be involved in day-to-day decision-making relative to specific needs of any particular recipient.
- Each of these Boards has spent significant time developing conflict of interest guidelines which have been formally adopted and are included in their operating by-laws.
- Many of the individuals receiving PDD services are simply unable to articulate their needs and/or concerns.
- PDD is a needs-based program meaning that, if an individual qualifies (i.e. the provision of service needs is demonstrated), then services are provided. It is not unlike the provision of health services or the provision of educational services. We do not preclude parents/guardians from sitting on regional health authority boards because their children are receiving a health service, nor do we preclude parents/guardians from serving on local school boards because their children are enrolled in the education system.

Recommendations

That exclusionary practices not be adopted regarding PDD Board membership; and,
That, in accordance with existing guidelines, parents/guardians of PDD recipients continue to be eligible to serve on any of the PDD Boards;

That the existing criteria for PDD Board membership adopted by Alberta Health and Wellness remain in place;

That the Ministry continue to ensure that a balanced community perspective reflects the composition of every PDD Board.

8. ISSUE: Strategic Resourcing for Community Governance

Background

This Review clearly pointed out that strategic resourcing is a priority issue and is absolutely required to make community governance work. To date, adequate resources have not been made available to accommodate projected budgets, which address new intake, annualized growth, changing needs, expanded services, some increased staffing, wages, and other relevant matters. As a result, PDD Program deficits have been a frequent occurrence. While many other factors have impacted, perhaps impeded the community governance concept, three primary points need be highlighted:

- The management information system is inadequate and incomplete.
- PDD Provincial and Community Boards do not have line responsibility for their human resources.
- During the public presentations, recipients, parents/guardians, agencies, service providers, and others indicated that: there was scant and sometimes contradictory information provided on cost containment strategies; the implementation of those strategies seemed hastily planned and poorly executed in some areas; and, there was a lack of understanding regarding the need for cost containment measures and the role of PDD Community Boards within the delivery system

In spite of these concerns ("growing pains", as some said), community governance is a good concept that dovetails very well with the principles around which the PDD Program was established. But regardless of how well the concept lines up with the principles, community governance will only succeed if it is supported with adequate strategic resources and appropriate systems that enable effective governance.

Although it was not the purpose of this Review to delve into specific institutional settings (such as Michener Centre or other similar sites), the Facility Board which oversees Michener Centre was included in the Terms of Reference. It is understood that Michener Centre is to be maintained as a quality facility that delivers a full range of services for recipients who need this complex level of care. However, it also must be recognized that, today, more recipients and their families are choosing to have these services provided by agencies in their home communities. Therefore, statistically speaking, Michener Centre is likely to experience a continued decline in the number of recipients using the facility. Under these circumstances, the issue of maintaining a separate governance structure for Michener Centre remains a question. Preserving the site itself is not in question since it remains an important option with respect to the issue of choice.

In summary, PDD is approximately a $300 million Program that is currently meeting the needs of about 8,000 Albertans. A steady influx of eligible recipients is a certainty, and adequate preparation and planning are required now.

Recommendations

That a more concerted effort be made and appropriate resources be applied over the next year to build a data base that PDD Boards and the Ministry of Health and Wellness can rely upon for management information;

That adequate and appropriate human resources be available at the PDD Community and Provincial Board levels to provide them with the strategic capacity necessary to fulfill their governance responsibilities;

That similar human resources be placed at the Ministry level to provide for the creating and monitoring of strategic directions, goals, outcomes and standards of the PDD Program, and to ensure ongoing compatibility between the PDD Program and other Provincial programs;

That the ongoing responsibility for the governance of Michener Centre be studied jointly by the PDD Provincial Board and the Michener Centre Facility Board; and,
That a recommendation be provided to the Ministry of Health and Wellness by September 30, 2000, regarding the potential transfer of governance responsibility to the PDD Provincial Board.

That, in the future, with respect to any matters affecting issues such as governance, systems, and future directions for PDD, an improved strategy be developed by the PDD Provincial and Community Boards to communicate directly and in advance with recipients, their parents/guardians, and agencies/service providers.

9. ISSUE: Standards

Background

As noted in the *Summary of Comments from Public Presentations* section of this Report, the need for all service providers to meet provincial standards was well supported. The document, *Creating Excellence Together,* which was developed collaboratively by the Alberta Association of Rehabilitation Centres (AARC), the former Department of Alberta Family and Social Services, and numerous other partners and stakeholders, sets out provincial standards – but has not yet been fully implemented. It is vitally important for the PDD system to continue with and, as soon as possible, to complete the implementation of *Creating Excellence Together* which speaks to quality of service delivery, quality of life issues, and organizational framework matters.

From the perspective of recipients and parents/guardians, once fully implemented, these standards will help ensure that:

- the quality of service provided is maintained at a high level and is consistent throughout the province;
- services throughout the province are maintained at an equitable level; and,
- the types of services provided are appropriate to the degree of need.

For service providers, these fully-implemented standards will help ensure that:
- the quality of their programs and services measures up and is appropriate;
- staff are well trained in meeting recipients' needs and are performing their duties with the highest level of integrity; and,
- facilities are well maintained and meet recipients' needs .

For the Province, adherence to these fully-implemented standards will provide greater assurance that:
- policies are being followed;
- expected outcomes are being achieved; and,
- overall accountability has been strengthened within the delivery system to ensure PDD recipients' needs are being met.

I recognize that much has been done in this area over the past several years and that the development of standards is an ongoing, evolutionary process. The point now is to complete the implementation of what has already been identified as important and necessary.

Recommendation

That the Provincial and Community PDD Boards, together with service providers, proceed with further development and full implementation of Creating Excellence Together standards as a matter of priority.

10. ISSUE: Improving Stability and Predictability

Background

Arriving at a more stable and predictable PDD system was woven into nearly every presentation/submission made during the Review. Many different issues obviously impact these concerns; however, the fundamental factors that specifically impact PDD governance and management include:
- knowing who is entering the system, how they are entering, and in what numbers;
- assessing the needs, abilities, and interests of each entrant; and,
- allocating resources to meet the requirements of each entrant.

Intake and Assessment Process

The above-noted factors are the most critical part of the intake and assessment process. Individuals currently approach and/or enter the system in one of two ways: via an agency/service-provider, or via a PDD Community Board office. Both routes have their own reason for being and represent the initial step in building a partnering relationship among the PDD recipient, the parents/guardians, the service providers, and the relevant PDD Community Board.

The successful culmination of the intake and assessment process helps define the role each partner plays and the contribution each will make toward achieving the goals of the PDD program and the particular individual being considered. Therefore, the process must be fair, thorough, and applied in a consistent manner across the province.

It must also recognize the tremendous trust and goodwill that is necessary to make responsible decisions. Those charged with this responsibility and authority must realize that they can influence the outcome and potential of another individual’s life. Are there any decisions in society that need to be made more responsibly than those that exercise such influence over the lives of others? Therefore, intake and assessment personnel must be highly qualified and very well trained.

For the entrant, the intake and assessment process determines eligibility and the scope of services that will be tailored to complement and build upon his/her abilities. The process should also explore the individual’s interests, and identify suitable services that help advance each individual’s development.

Parents/guardians want an intake and assessment process that they understand, that is timely, and that will provide the best possible services and outcomes for the individual recipient. They also want assurance that the individual for whom they are responsible will be treated fairly and equitably within the process. Very few approach the PDD system with a solid understanding of what possibilities exist; as a result, many feel vulnerable.

Service providers, on the other hand, understand the system very well and in many cases are the initial point-of-contact for potential entrants. Having heard of a particular program from a friend or colleague, a parent/guardian may contact a service provider to begin exploring options. Since service providers have a deep understanding of the PDD system, they feel they have an inherent responsibility to help represent potential recipients during the intake and assessment process.

PDD Community Boards are fully responsible for ensuring: that potential recipients meet the eligibility requirements of the program; that the scope of services to be provided is determined fairly and equitably; and that the funding provided is sustainable within the resources allocated to each Board for its operations.

In summary, each of the partners has something to contribute and, therefore, each has a legitimate reason for being involved in the intake and assessment process. Each partner also has a responsibility to understand and respect the need for the other partners to be involved.

Recommendation

That the PDD Provincial Board establish an interim task force to review the intake and assessment process and report back to the Ministry of Health and Wellness by June 30, 2000; and,

That this interim task force be comprised of 12-15 individuals from the partnering group of recipients, parents/guardians, service providers, and PDD Community Board staff with representation from each region of the Province; and,

That this interim task force address the needs of each partnering member to be included in the intake and assessment process and arrive at recommendations that meet those needs within the overall PDD framework of predictability, sustainability, and accountability; and,

That the recommendations reflect province-wide uniformity and equity.

Models of Funding

Having been assessed and approved for entry into the PDD system, the recipient will receive services through one of three funding arrangements: Contracted Funding, Clustered Contracts, or Individual Funding. (Definitions of each funding model are provided in Appendix 4 of this Report.)

Since each of these models has evolved to meet unique circumstances within the PDD system, certain stakeholders strongly favour one model over another. In some cases, agencies/service-providers must accommodate all three models; others may deal exclusively with one. In turn, PDD Community Boards require different administrative and accounting systems to manage three models. As a result, there are many questions that need to be addressed carefully and more thoroughly, including:

1. Are all three funding models necessary to meet the requirements of PDD recipients?
2. Could one funding model adequately incorporate the needs of all PDD stakeholders?
3. Is it possible to arrive at one funding model that preserves the integrity of the PDD system without compromise?
4. How does each of these funding models impact predictability, accountability, and stability? (e.g., tracking, administration, and invoicing.)
5. How do funding models affect recipients in rural or remote areas?
6. Under what circumstances should family members (of PDD recipients) become contracted, paid care-givers for services they provide to a family member recipient?
7. How does the PDD system account for the rapid growth of many new agencies/service-providers?

These and other related issues need to be explored in a meaningful and consultative way with all stakeholder groups.

Recommendation

That the PDD Provincial Board coordinate a process to bring together senior staff from each of the PDD Community Boards, with equal numbers representing service providers and recipients/parents/guardians, to review various funding models and processes, and submit recommendations to the Ministry of Health and Wellness by August 31, 2000; and,

That stakeholders involved in this process address the needs from all perspectives regarding predictability, accountability, stability, and sustainability.

Concluding Comments

Choice and community inclusion are two fundamental commitments and cornerstones of Alberta's PDD Program which we must maintain and build upon.

In 1972, approximately 2,400 individuals lived in institutional care and Albertans had few options. Today, despite a provincial population that has nearly doubled, relatively few PDD recipients reside in institutional settings. However, the fact remains that, for some, their needs continue to be met best in an institutional setting.

Today, for the vast majority who receive care and services within their local community, many options exist.

With regard to accommodation, recipients (in many cases with guidance from their parents/guardians) can choose to live in:

- supported independent-living accommodations;
- their own homes with parents/guardians or other family members;
- supported-home accommodation; or,
- institutional accommodations.

With regard to employment and other community inclusion factors, there has been great progress as well. Many PDD recipients have already been welcomed into, and most can now choose:

- a more structured, and sheltered work environment;
- community volunteer work;
- cultural or recreational activities suited to their abilities; and,
- work in traditional employment settings.

In many instances, choices are limited not only by the disability but also by the realities of housing, transportation, access to public facilities, and other barriers.

Therefore, although excellent progress has been made, some struggles and challenges still remain within the PDD system, including:

- greater opportunities for choice in terms of living accommodation;
- improved access to work and volunteer opportunities (which are not easily found by developmentally disabled individuals, or by parents/guardians on their behalf);
- more adequate transportation systems;
- overcoming attitudes of some members of the general public; and,
- just being 'accepted'.

In conclusion:

- Recipients and parents/guardians want a program they can count on and one that respects and responds to their needs. They also want assurance that services will be there as long as they are required.
- Agencies/service providers have responsibilities to their recipients, and to their care-giving staff, and want to provide the best services possible. They also want a predictable, timely flow of resources to enable them to deliver the services they provide.
- PDD Boards want the information they require to properly direct the PDD Program in the best interests of the recipients, while effectively managing the resources for which they have governance responsibility.
- The Ministry of Health and Wellness wants assurances that the program is being well governed, that recipients are adequately provided for, that families are involved, that the Program is sustainable, and that every aspect of the system is accountable.
- And everyone wants meaningful involvement in achieving greater stability and predictability.

Community inclusion means having appropriate supports available to make choices possible; and, where possible, it also means actively including developmentally disabled individuals in the community where they can make a contribution, and be respected for their contribution. To achieve this, PPD recipients will require appropriate funding and other resources to access necessary programs and services.

During my many meetings, visitations and tours, I had an opportunity to observe persons with developmental disabilities working in front-line jobs in traditional employment settings. Those communities accepted and encouraged their presence and participation. Other communities are at various stages in this continuum of community inclusion and are reporting excellent progress as well.

We – the Government of Alberta and the community – must continue *"Building Better Bridges"* that strengthen and further the objectives of Alberta's PDD Program. In this regard, the responsibilities and choices relating to future directions of this important Program have been entrusted to us. Let us proceed wisely.

Section Four:
APPENDICES

APPENDIX 1

Announcements Regarding the PDD Review

- **News Releases**

- **Advertisements**

Alberta
HEALTH AND WELLNESS

News release

Edmonton, October 22, 1999

PDD Public Presentations Over

The public presentation portion of Associate Health and Wellness Minister Gene Zwozdesky's review of Persons with Developmental Disabilities has wrapped up. The presentations were part of Zwozdesky's comprehensive review of programs, services and funding for individuals served through six regional PDD boards throughout the province. More than 170 presentations were heard from PDD individuals, parents, guardians, advocates, groups, service providers, and PDD board members. Their input has provided excellent feedback to the government, as the review focuses on improving a program that already provides the highest level of financial supports for Persons with Developmental Disabilities anywhere in Canada. Zwozdesky expressed his gratitude to the many people who have taken the time to attend the hearings and make their views known publicly:

"I have been impressed by the high level of commitment Albertans have shown on these important issues" said Zwozdesky. "We have benefited from a wealth of knowledge and ideas provided by people who are keenly aware of the issues facing these special members of society. I share their commitment to the principle of community inclusion as well as individual choice. Our aim is to improve a system of supports that is already a leader in Canada and throughout the world."

The review now moves into its next phase, which will include careful consideration of all the written submissions that have been forwarded to the Associate Minister. In addition to forthcoming focus groups with stakeholders, Zwozdesky will also consult with his caucus colleagues as he seeks solutions to some of the challenges that have been identified.

The report will be completed by the end of December, 1999.

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For more information, contact:
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Edmonton Region
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Alberta
HEALTH AND WELLNESS

News *release*

Edmonton, October 21, 1999

PDD Meetings Wrap Up

Over 170 public presentations from clients, parents, guardians, agencies, community groups and PDD Board members have been heard by Gene Zwozdesky during a province-wide review of services to Persons with Developmental Disabilities which wraps up public hearings in Edmonton tomorrow.

The public meetings held today and tomorrow are the conclusion to a series of similar sessions that have taken place in each of the 6 Regional Board areas. The hearings are intended to provide public input into the review of the PDD program across Alberta. Groups and individuals have brought their ideas to the table, in order to share their suggestions in these public forums.

"We are fortunate in Alberta to have one of the most unique and effective programs anywhere in Canada, with the highest level of financial support of any province," said the Associate Minister. "One of the reasons for this review is to determine how we can build on this excellent foundation, and make it even better."

Advocates for the developmentally disabled have provided a wide range of suggestions that will be taken into consideration as the review continues over the coming months. Media who are interested in attending the final day of hearings are welcome to join the Associate Minister at Chrysalis Foundation (13325 St. Albert Trail) on Friday, Oct 22nd from 8:30 A.M. until 4:30 P.M.

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For more information, please contact:

Jerry Bellikka
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PDD Edmonton Region
(780) 422-3634 or (780) 990-8866

Note: This was released at 4:00 p.m., October 21, 1999.

Alberta
HEALTH AND WELLNESS

News release

Edmonton, September 3,1999

Details of PDD Review Announced

Associate Minister of Health and Wellness Gene Zwozdesky has announced the details of the comprehensive review of the programs, funding and accountability of Persons with Developmental Disabilities Boards.

Zwozdesky was appointed to conduct the review on July 8, 1999 by Health and Wellness Minister Halvar Jonson, in response to difficulties encountered by some PDD community boards in managing within their budgets and the resulting concerns by PDD clients and their families about potential reductions in programs and services.

Said Zwozdesky, “ The intent of this review is to ensure that we have in place high quality and sustainable programs to support Albertans with developmental disabilities over the longer term and to ensure that all Albertans with developmental disabilities have fair and equitable access to those programs”.

He added, “ The additional $10 million provided to the community PDD boards earlier this summer, coupled with good management, should enable them to provide the essential services to their clients while maintaining a balanced budget. The review will provide us with greater understanding and future directions so that appropriate support can be available to persons with developmental disabilities today and in the future”.

The review will look at the authority, accountability and practices of the provincial, community, foundation, and facility PDD boards, the caseloads and programs of the boards, the client eligibility criteria, the standards and measures for the programs, as well as the overall funding for the programs. The review will also include funding issues related to support for persons with brain injury who are living in the community.

Zwozdesky will provide a final report and recommendations coming out of the review to the Minister of Health and Wellness by the end of December, 1999.

As part of the review process there will be extensive consultation with PDD board members and staff, with clients and their families, and with service providers across the province. The consultation will include public meetings in each of the six PDD regions at which individuals will be able to make personal presentations directly to the Associate Minister. Written submissions may also be sent directly to Mr. Zwozdesky. The deadline for written submissions is October 22, 1999.

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Individuals wishing to make a presentation at one of the public meetings should contact their local PDD Community Board to register and to receive more details.

George C. Cuff and Associates, an independent consulting firm, will assist the Associate Minister in carrying out the comprehensive review. David Steeves, Special Advisor to the Deputy Minister of Health and Wellness, will work closely with Mr. Cuff in the coordination and implementation of the review.

Concluded Zwozdesky, "The involvement of PDD clients, their families, and service providers will be an essential part of this review since meeting the needs of those clients is the sole reason for our PDD programs. We are fortunate in Alberta to have one of the most unique and effective programs anywhere in Canada, with the highest level of financial support of any province."

He added, "Our government's intention is to ensure appropriate program support for persons with developmental disabilities in a financially responsible and sustainable manner, and to keep Alberta as a caring leader in that regard."

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For more information contact:

Gene Zwozdesky	Garth Norris
Associate Minister	Communications
Alberta Health and Wellness	Alberta Health and Wellness
780-415-4840	780-427-7164

Attachment: Schedule of Public Meetings

Persons with Developmental Disabilities (PDD) Review
Public Presentation Schedule

September 27-28, 1999	Calgary Region Community PDD Board Darlene Thompson (403) 297-5497 (Calgary)	Ramada Crowchild Inn 5353 Crowchild Trail NW Calgary,AB
October 4, 1999	Central Community PDD Board Sharon Turnbull 403-340-7765 (Red Deer)	Red Deer Lodge Red Deer Room 4311-49 Ave Red Deer, AB
October 15, 1999	Northeast Community PDD Board Michelle McPherson (780) 645-6416 (St. Paul)	Persons with Developmental Disabilities Northeast Community Board Office Room 242, 5025–49 Ave St. Paul, AB
October 18, 1999	Northwest Community PDD Board Laurie D. Kennedy (780) 624-6225 (Peace River)	Grande Prairie & District Golden Age Centre 10222–101 Avenue Grande Prairie, AB
October 20, 1999	South Community PDD Board Noel McGarry (403) 381-5777 (Lethbridge)	Ramada Hotel 2375 Mayor McGrath Drive S. Lethbridge, AB
October 21-22, 1999	Edmonton Community PDD Board Arlene James (780) 422-7511(Edmonton)	Chrysalis 13325 St. Albert Trail Edmonton, AB

Written submissions may be sent directly to:

Honourable Gene Zwozdesky
Associate Minister of Health and Wellness
Room 229
Alberta Legislature Building
10800 – 109 Street
Edmonton, AB T5K 2B6

Alberta
HEALTH

News *release*

Edmonton, July 13, 1999

Move strengthens Persons with Developmental Disabilities program

A change in senior management to more effectively focus on a priority area was announced today by the Alberta government.

David Steeves, currently Acting Deputy Minister of Children's Services, joins Alberta Health and Wellness on a two-year secondment as a special advisor to the Deputy Minister, effective July 19, 1999.

One of Steeves' assignments will be to play a lead role in the comprehensive review of the Persons with Development Disabilities (PDD) program announced last week. He will also have lead responsibility for the development of the transition plan for the transfer of PDD from the former Department of Family and Social Services to Health and Wellness. Steeves' personal experience with the issues and the community will be a valuable asset in his new role.

A national competition will be held shortly to fill the position of Deputy Minister of Children's Services. Paula Tyler, currently Assistant Deputy Minister, Community Input and Research, assumes the Acting Deputy Minister position in the interim. Tyler has extensive experience in the area of services for children and families, including policy and research and family and community support services.

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For more information:

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Bill Rice
Communications
Children's Services
(780) 422-3004

Alberta
HEALTH

News *release*

July 8, 1999

Additional Funding for Persons with Developmental Disabilities Boards

An additional $10.0 million is being provided to Community Boards for Persons With Developmental Disabilities across the province to address unanticipated growth in client numbers, Health and Wellness Minister Halvar Jonson announced today.

In announcing the additional funding Jonson stated, “The growth in client populations has put pressure on the programs and services provided to persons with developmental disabilities, resulting in projected deficits by the community boards. The additional resources, along with good management, will assist these Boards to continue to meet essential client needs within balanced budgets.”

At the same time Jonson announced that he has asked Associate Health and Wellness Minister Gene Zwozdesky to undertake a comprehensive review of the accountability, programs and financing of the province’s Community Boards for Persons with Developmental Disabilities.

“I have reviewed thoroughly the financial situation of the PDD boards and determined that transitional funding is required to help the Boards reach a manageable and sustainable funding level this year,” Jonson said. “For the longer term I have asked the Associate Minister to take on the task of the comprehensive review and to provide his findings and recommendations to me by December, 1999.”

Despite regular annual funding increases, some community PDD boards had indicated that they would not have balanced budgets this year and would require further funding increases due to growing client numbers. This had caused some concern that services to clients would be significantly impacted.

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PDD boards have already received an additional $22.7 million in this year's budget, for an increase of 8.6% and a 22% increase over the past three years. A total of $283 million is earmarked this year to serve more than 8,000 clients. The additional resources announced today will increase that to $293 million, or an increase of over 12% this year.

"Clearly, support for persons with developmental disabilities has been, and continues to be, a priority for this government," Jonson said. "The individual funding program is unique in Canada and the level of funding support is unmatched by any other province."

Jonson said the Provincial Board for Persons with Developmental Disabilities, which oversees the six community boards, has been playing a leadership role in helping community boards to balance their budgets. The government's longer-term review will include an assessment of the findings of a financial review currently underway by the Provincial Persons with Developmental Disabilities Board, to be completed by mid-July.

Jonson concluded, "My goal continues to be to meet essential client needs within available resources and ensure that programs and resources are responsibly planned and managed. The additional funding announced today will help ensure that clients continue to receive the essential services that they need when they need them."

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For further information, please contact:

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Alberta Health and Wellness
(780) 427-7164

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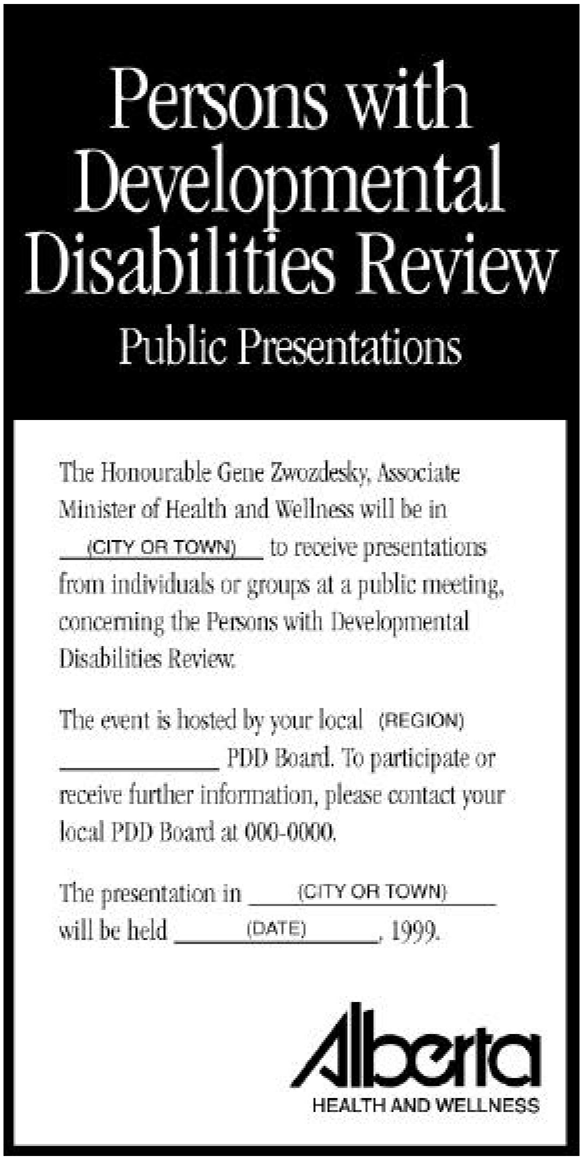

Persons with Developmental Disabilities Review

Public Presentations

The Honourable Gene Zwozdesky, Associate Minister of Health and Wellness will be in __(CITY OR TOWN)__ to receive presentations from individuals or groups at a public meeting, concerning the Persons with Developmental Disabilities Review.

The event is hosted by your local (REGION) ____________ PDD Board. To participate or receive further information, please contact your local PDD Board at 000-0000.

The presentation in __(CITY OR TOWN)__
will be held __(DATE)__, 1999.

Alberta
HEALTH AND WELLNESS

To help publicize the public presentation meetings, PDD Community Boards placed this advertisement (or a version of it) in many local newspapers throughout Alberta. In some areas, local PDD Boards used other means to publicize these meetings.

South Region Media Placements:

Brooks Bulletin
Crowsnest Pass Promoter
Fort Macleod Gazette
Lethbridge Herald
Medicine Hat News
Pincher Creek Echo
Taber Times

Edmonton Region Media Placements:

Edmonton Journal
Edson – Leader
Fort Saskatchewan Record
Hinton Parklander and Jasper Booster
Stony Plain Reporter and Spruce Grove Examiner
Strathcona This Week

Northwest Region Media Placements:

Beaverlodge Advertiser
Fairview Post
Falher/McLennan Smoky River Express
Fort Vermilion/La Crete Northern Pioneer
Grande Cache Mountaineer
Grande Prairie Daily Herald-Tribune
Grimshaw Mile Zero News
High Level Echo
High Prairie South Peace News
Manning Banner Post
Peace River Record-Gazette
Rycroft Central Peace Signal
Slave Lake Lakeside Leader
Valleyview Valley News

Central Region Media Placements*:*

Red Deer Advocate
(In addition, letters and/or newsletters were sent to PDD recipients, parents/guardians, agencies, district councils, health authorities, and others.)

Calgary Region Media Placements:

The public presentations News Release and a Community Notice were sent to PDD recipients, parents/guardians, service providers, partnering authorities and others.

Northeast Region Media Placements:

Barrhead – Town & Country
Bonnyville Nouvelle
Cold Lake Sun
Fort McMurray Today
Lac La Biche Post
St. Paul Journal
The Vegreville News Advertiser Ltd.
Vegreville Observer
Whitecourt Star

APPENDIX 2

Public Presentations - Participants

Public presentation meetings were held in each of the six PDD regions between September 27 and October 22, 1999. In total, 170 presentations were made by about 300 presenters at these public meetings. A list of the organizations represented, individuals who presented and locations they represented are outlined region-by-region. Approximately 300 additional representations were made in the form of formal submissions, letters, presentations, reports, cassettes and videotapes.

A number of MLAs and/or their representatives, and PDD Board members and staff also attended the public presentation meetings in their respective regions.

Public Presentation Participants

NORTHWEST REGION

Meeting held: October 18, 1999, at the Grande Prairie & District Golden Age Centre, 10222 – 101 Avenue, Grande Prairie. Members of the Northwest PDD Community Board who attended include Ms. Hildegard Campsall, Chair, Ms. Joyce Brooks, Mr. Michel Buitendyk, Ms. Helen Ficocelli, Mr. Denny Garratt, Ms. Mary Goede-Kohn, Ms. Dolly McArthur and Mr. Paul Renfree. Ms. Pearl Wilson attended the meeting on behalf of Mr. Wayne Jacques, MLA, Grande Prairie-Wapiti.

Organizations Represented:
1. Behaviour Outreach Services
2. Employment Enhancement Society
3. Falher Friendship Corner Association
4. Grande Prairie & District Association for the Mentally Handicapped
5. Independent Living Society
6. Marigold Enterprises Rehabilitation Services
7. Mistahia Health Region
8. Muskoseeta Independent Alternatives for the Handicapped
9. North Peace Community Living Society
10. Queen Elizabeth II Hospital
11. Specialized Employment Resources
12. Transitional Vocational Program, Fairview College

Individuals Who Presented:
1. Julie Anderson
2. Muriel Armstrong
3. Patricia Beckly
4. David Binnema
5. Jake Binnema
6. Barry Bucknell
7. Charlene Buziak
8. Gary Calliou
9. Marilyn Cramer
10. Dr. Phillip Cummins
11. Ruth Dutcher
12. Ross Gaehring
13. Gerry Hachey
14. Dianne Hammel
15. Kris Hvamb
16. Annette Jones
17. Joan Lalonde
18. Jane Manning
19. Kate McPhail
20. Joan McQuarrie
21. Marvin McMordie
22. Sharron McMordie
23. Tarah Patterson
24. Brian Reynolds
25. Angela Sather
26. Irene Sather
27. Alberta Sylvestre
28. Shannon Websdale
29. Brenda Williamson
30. Louise Zmaeff

Locations Represented:

1. Brownvale
2. Calahoo
3. Fairview
4. Falher
5. Grande Cache
6. Grande Prairie
7. High Prairie
8. Peace River
9. Slave Lake
10. Wembley

NORTHEAST REGION

Meeting held: October 15, 1999, at Persons with Developmental Disabilities Northeast Community Board Office, Rm. 242, 5025-49 Avenue, St. Paul. Members of the Northeast PDD Community Board who attended include Ms. Donna Desjardins, Ms. Johanne Hassey and Ms. Carmella Levesque. MLAs in attendance included Mr. Denis Ducharme, MLA, Bonnyville-Cold Lake; and, Mr. Dave Broda, MLA, Redwater. Ms. Theresa Cloutier, representative of Mr. Paul Langevin, MLA, Lac La Biche-St. Paul, also attended.

Organizations Represented:
1. Barrhead Association for Community Living
2. Blue Heron Vocational Training Centre
3. Blue Heron Support Services Association
4. Bonnyville-Cold Lake Community Council
5. Community Council of St. Paul
6. Empowering Citizens for Health and Opportunity Society
7. Friends of People First
8. Northeast Region Catholic Social Services
9. Positive People Society of St. Paul
10. St. Paul Abilities Network
11. Region 18 Child & Family Services Authority (Metis Settlements)
12. Vegreville Association for Living in Dignity
13. Westlock Independence Network

Individuals Who Presented:
1. Dorothy Baker
2. Tim Bear
3. Arno Birkigt
4. Richard Blyan
5. James Challman
6. Dale Clark
7. Janet Marchuk
8. Sharon Matheson
9. Greg Morris
10. Brenda Olson
11. Dee Palichuk
12. Ray Reidy
13. Lionel Remillard
14. Troy Siemers
15. David Szucsko
16. Mark Tremblay
17. Ken Tripp
18. Vivianne Widdifield
19. Henry Wierenga

Locations Represented:
1. Athabasca
2. Barrhead
3. Bonnyville
4. Elizabeth Metis Settlement
5. Neerlandia
6. St. Paul
7. Vegreville
8. Westlock
9. Whitecourt

EDMONTON REGION

Meetings held: October 21-22, 1999, at Chrysalis – An Alberta Society for Citizens With Disabilities, 13325 St. Albert Trail, Edmonton. Members of the Edmonton Community PDD Board who attended include Dr. Gerry Archibald, Chair, Mr. Rene Morrissette, Mrs. Jean Wilkinson, Mrs. Maria Seeber, Mr. Arnie Sprogis and Mr. Lawrence Wilson. Members-at-large of the Provincial PDD Board were also in attendance, including Ms. Barbara Stewart, Mr. Bill Hart, and Dr. Doug Fleming. Mr. Jim Killick, member of The Premier's Council on the Status of Persons with Disabilities, was also in attendance. Mr. Rob Lougheed, MLA, Clover Bar-Fort Saskatchewan, Mrs. Mary O'Neill, MLA, St. Albert, and Ms. Linda Sloan, MLA, Edmonton Riverview also attended.

Organizations Represented:
1. Canadian National Institute for the Blind – Alberta-NWT Division
2. Catholic Social Services
3. Chrysalis – An Alberta Society for Citizens With Disabilities
4. Community Rehabilitation Careers Project
5. Connect Society
6. Consumer Rights Advocacy Group
7. Council of Service Providers (Edmonton Region)
8. Edmonton Association for the Deaf
9. Edmonton Community PDD Board
10. Edmonton On Campus Adult Education Society
11. Edmonton Parent Living Services
12. Elves Special Needs Society
13. Employabilities
14. Eric Cormack Centre
15. Eric Cormack Centre Parent Association
16. Excel Resources Society
17. Goodwill Industries of Alberta
18. Grant MacEwan College – Rehabilitation Practitioner Program
19. Leduc Works Ltd.
20. Lo-Se-Ca Foundation
21. Northern Alberta Brain Injury Society
22. Official Opposition of Alberta
23. Robin Hood Association
24. St. Albert Association for People with Disabilities
25. Selections
26. SKILLS Training and Support Services Association
27. Society of Parents & Friends of Michener Centre
28. Strategies for Independence Inc.
29. Winnifred Stewart Association for the Mentally Handicapped
30. YWCA of Edmonton

Individuals Who Presented:

1. Justin Abel
2. Dr. Jerry Archibald
3. Trina Bandi
4. Karen Baum
5. Denis Bell
6. Larry Billings
7. Nancy Brine
8. David Campbell
9. Joan Charbonneau
10. Carol Chesney
11. Jodi Chesney
12. Randy Clark
13. Cheryl Crocker
14. Sharon Cyre
15. Fred de Souza
16. Mae Deans
17. Franciess Fay
18. Kirk Ferguson
19. Stan Fisher
20. Ann Marie Fortier
21. Nobert Frank
22. Paul Fujishige
23. Raymond & Jeanne Gaudet
24. Dave Glenhow
25. Bill Harper
26. Gail Hein
27. Fred and Verna Hochachka
28. Wendy Hollo
29. Marilyn Jones
30. Paulette Killam
31. Mairead Lavigne
32. Bernie Leins
33. Wendy MacKay
34. Neil & Linda Maki
35. Raylene Manolescu
36. Dr. Dave Mason
37. Bill Mathewson
38. John McGee
39. Cristina Molina
40. Nick Muntjewerff
41. Percy Nelson
42. Ken Nelson
43. Mitzi Okura
44. Dale Peterson
45. Cam Petty
46. Mitch Pogonowski
47. Dr. Gerry Raymond
48. Heather Rennebohm
49. Ed Riediger
50. Colleen Robinson
51. Eyla Rogers
52. Diane Satre
53. Iris Saunders
54. Kevin Seibert
55. Diane Sims
56. Mary Ann Sinclair
57. Kelly Sloan
58. Linda Sloan
59. Dennis Stockman
60. Jean Taylor
61. Margaret Teasdale
62. Grant Underschultz
63. Ralph Walker
64. Marlene Williams

Locations Represented:

1. Alberta Beach
2. Calahoo
3. Calmar
4. Edmonton
5. Leduc
6. St. Albert
7. Sherwood Park
8. Warburg

CENTRAL REGION

Meeting held: October 4, 1999, at Red Deer Lodge, 4311-49 Avenue, Red Deer. Members of the Central PDD Community Board who attended include Ms. Brenda Query, Chair, Ms. Gayle Moss, Ms. Margaret Emmett, Ms. Grace Higgins, Ms. Linda Moreau and Mr. Merv Rockel. Mr. Paul Gowans, a Michener Centre Facility Board member, Mr. Jim Pilson, Vice Chair, PDD Foundation Board, and Mr. Victor Doerksen, MLA, Red Deer South also attended.

Organizations Represented:

1. Accredited Supports to the Community
2. Central Community PDD Board
3. Community Behaviour Support Services
4. COPE, Rocky Mountain House Society for Persons with Disabilities
5. Cosmos Rehabilitation Society & Employment Access
6. Drumheller & District Special Challenges Council
7. Michener Centre
8. PDD Foundation Board
9. Padnoma Support Services
10. Parkland Community Living & Supports Society/Central Region Housing Committee
11. Partnership of Alberta Central Executives (PACE)

Individuals Who Presented:

1. Lily Breland
2. Russ Croft
3. Diane Cuts
4. Heather Emerson
5. Joanne German
6. Brenda Hansen
7. Lori Hallet
8. Barrie Heemeryck
9. Robin Johnson-Beeler
10. Carleen Jones
11. Sheila Kerr
12. Val Langevin
13. Diane Lehr
14. Tom Lindl
15. Carmel Maloney
16. Pat Marshall
17. Linda Maxwell
18. Barry Moon
19. Wayne Morrow
20. Maggie Nelson
21. Rita O’Connor
22. Susan Parkins
23. Jim Pilson
24. Brenda Query
25. Shirley Rockel
26. Janet Schmidt
27. Matt & Margaret Schoonderwoerd
28. Phil Stephan
29. John Terrenzio
30. Bruce Uditsky
31. Neil van Waas
32. Tim Vanderberg
33. Gary Vooys

Locations Represented:

1. Didsbury
2. Drumheller
3. Edmonton
4. Lacombe
5. Olds
6. Ponoka
7. Red Deer
8. Rimbey
9. Rocky Mountain House
10. Sylvan Lake
11. Wainwright

CALGARY REGION

Meetings held: September 27-28, 1999, at the Ramada Crowchild Inn, 5353 Crowchild Trail NW, Calgary. Members of the Calgary PDD Community Board who attended include Ms. Christine MacFarlane, Ms. Bonnie Pacaud, Ms. Simonne Walsh, Mr. Henry Eckert and Mr. Len Thorne. Mr. Blair Lundy, Chair of the Michener Centre Facility Board, and Mr. Don Hardy, CEO of the PDD Foundation Board also attended. Ms. Jocelyn Burgener, MLA, Calgary Currie, and Ms. Linda Sloan, MLA, Edmonton Riverview, also attended.

Organizations Represented:

1. Accessible Housing Society
2. Alberta Association for Community Living
3. Calgary Alternative Support Services, Inc.
4. Calgary Association of Self-Help
5. Calgary Community Living Society
6. Calgary & District Adult Residential Service Providers
7. Calgary SCOPE Society
8. Columbia College
9. Community Rehabilitation Service Provider Council of Calgary
10. Deaf & Hard of Hearing Services
11. Developmental Disabilities Resource Centre of Calgary
12. Disability Action Hall
13. Dual Diagnosis Committee
14. Individualized Skills Training Program
15. Keeler Society for Independent Learning
16. L'Arche Calgary
17. Official Opposition of Alberta
18. Options – Optional Rehabilitation Services, Inc.
19. Progressive Alternatives Society of Calgary
20. Resicare Society of Calgary
21. Scenic Bow Association for the Multiply Handicapped
22. The Vocational & Rehabilitation Research Institute
23. Universal Rehabilitation Service Agency
24. University of Calgary, Community Rehabilitation & Disability Studies
25. University of Calgary, Community Inclusion Support Team
26. Universal Rehabilitation Service Agency

Individuals Who Presented:

1. Fred Aldington
2. Dawn Anderson
3. Bill Angus
4. Colleen Arndt
5. James Baker
6. Tom Boeda
7. Alan Bryant
8. Lorraine Bryant
9. Rosalie Buggs
10. Arron Butler
11. Marsha Carnat
12. Wayne Carrier
13. Lisa Casselman
14. Lisa Charleton
15. Sharon Cobb
16. Marg Cutler
17. Ann Dackers
18. Hans den Boer
19. Arlene Dickson
20. Elizabeth Dolman
21. Yolande Dolman
22. Henk & Hanna Dunnewold
23. Tanya Elston
24. Charlene Fairhurst
25. Pat Favaro
26. Bill Foreman
27. Shelley Gagnon
28. Susan Gagnon
29. Ryan Geake
30. Rick & Joan Godderis
31. Tania Gulley
32. Mary Jean Gustavson
33. Ian Habke
34. Carla Hamarsnes
35. Michele Hampton
36. Donna Haslam
37. Doug Hauser
38. Jan Heath
39. Dave Hughes
40. Anne Hughson
41. Tracie Jackson
42. Bonnie Jenkins
43. Maline Jenkinson
44. Michael Jorgensen
45. John Kazakoff
46. Ian Kershaw
47. Shelley Kinash
48. Terri Konoplenko
49. Sharon Korhonen
50. Jake Kuiken
51. Vivian Laprise
52. Steven Law
53. Ann Lewis
54. Loraine Luterbach
55. Kelly Lyons
56. Sheri Maclaren-Ross
57. Tom & Tara Mark
58. Nancy McDonald
59. Marion McGrath
60. Dr. Hal Medlicott
61. Earl Misfeldt
62. Nat & Mary Mitenko
63. David Mitenko
64. Isadore & Mary Moskwa
65. Aldred Neufeldt
66. Dianne Nickel
67. Helen Norton
68. Wendy Ogonoski
69. Melvin & Carla Pasternak
70. Susan Petch
71. Treena Peters
72. Steve Petingala
73. Dan Porteous
74. Jenny Ramsey
75. Debbie Reid
76. Jean Richards-Carter
77. Kelly Richmond
78. Evangeline Ring
79. Wendy Rodgers
80. Helen Rojek
81. Vicki Sannuto
82. Fran Sartison
83. Medina Shatz
84. Kim & Lisa Siddons
85. Linda Sloan
86. Carol Ann Smith
87. Dr. Tom Snell
88. Christina Stebanuk
89. Leslie Tamagi
90. Wendy Thompson

91. Len Thorne
92. Carol Urness
93. Myrna Vercaigne
94. Louise Vercaigne
95. Sue Webber
96. Dennis White
97. Dovie Williams
98. Norma Wisbling
99. Stephen Wright
100. Elaine Yost
101. Sjaune Zabel
102. Bonnie Zaboski

Locations Represented:

1. Calgary
2. Cluny
3. Edmonton

SOUTH REGION

Meeting held: October 20, 1999, at the Ramada Hotel, 2375 Mayor McGrath Drive South, Lethbridge. Members of the South PDD Community Board who attended include Mr. Jim Johnson, Chair, Mr. Roy Stelfox and Ms. Jackie Thornhill. Mr. Ed Maruska and Mr. Don Saunderson, members of the PDD Foundation Board, and Ms. Norma Berg, member of the PDD Provincial Board, also attended.

Organizations Represented:

1. Alfred Egan Home
2. Blue Fox Association
3. Chinook Health Region
4. Community College – Rehabilitation Services Program
5. Family Care (1997) Ltd.
6. Fetal Alcohol Syndrome Coordinating Centre
7. FAS/FAE Sub-committee – Adult Issues
8. Lethbridge Association for Community Living
9. Lethbridge Family Services
10. Medicine Hat Regional Association for the Mentally Handicapped
11. Medicine Hat Rehabilitation Society
12. Palliser Health Authority
13. Rehabilitation Society of South Alberta
14. Southern Alberta Community Living Association
15. Southern Alberta Individualized Planning Association
16. South Region Joint Planning Group
17. Speaking Out for the Disabled Actively

Individuals Who Presented:

1. Diane Alstad-Garriso
2. Murray Armstrong
3. Debbie Baggs
4. Mike Bodnar
5. Frances Bogle
6. Ron Burr
7. Tom Cain
8. Sharlene Campbell
9. Jeannie Chang
10. Shawna Churchill
11. Dave Czibere
12. Quinselle Duce
13. Elann Enger
14. Shirley Enger
15. Michelle Fiedler
16. Dr. Stan Gerhart
17. Ed Hinger
18. Sue Huffman
19. Andrea Ingraham
20. Rod & Ivy Kiddle
21. Dianne Kotkas
22. Sue Manery
23. Hazel Mitchell
24. David Moncrieff
25. Allan O’Byrne
26. Gordon Rhodes
27. Pat Robb
28. Elaine Roque
29. Bernie Sheahan
30. Darrell Shuell

31. Carol Simpson
32. Dr. Maurice Simpson
33. Roxanne Sissons
34. Marianne Ulrich
35. Pam Wagner
36. Lillian Westling
37. Sheryl Williams
38. David Zech

Locations Represented:

1. Bow Island
2. Champion
3. Lethbridge
4. Medicine Hat
5. Raymond
6. Vulcan

APPENDIX 3

Personal Visits, Meetings and Tours by Associate Minister of Health and Wellness

1. Alberta Association for Community Living (Eight Provincial Representatives) – Edmonton
2. Accessible Housing Association of Calgary (in consultation with Hon. Murray Smith, MLA) – Calgary
3. Alberta Association of Rehabilitation Centres – Edmonton
4. Barrhead Association for Community Living – Edmonton
5. Brain Injury Association of Alberta (conference call) – Edmonton
6. Camrose/Wetaskiwin PDD Groups (with LeRoy Johnson, MLA) – Edmonton
    - Catholic Social Services – Central Region
    - Centra Cam – Camrose
    - Wetaskiwin & District Association for Community Services – Wetaskiwin
    - Horizons Centre – Wetaskiwin
    - Camrose Association for Community Living – Camrose
7. Canadian Mental Health Association – Dennis Anderson, President of the Board, Alberta Division
8. Chrysalis – Edmonton
9. C.H.O.I.C.E.S. Employment Services – Dan Mullen – Ft. McMurray
10. Chrysalis – Edmonton
11. City of Calgary – Alderman Joanne Kerr and Frank Hoebarth (with Mark Hlady, MLA) – Edmonton
12. Community Rehabilitation Services Providers – Calgary
13. Developmental Disabilities Resource Centre (with Jocelyn Burgener, MLA) – Calgary
14. Disability Action Hall (with Hon. Halvar C. Jonson, MLA) – Calgary
15. Disability Action Hall Meeting (also attended by Mark Hlady, MLA and Gary Dickson, MLA) – Calgary
16. Disability Action Hall Rally at Provincial Legislature/Question Period – Edmonton
17. Edmonton Brain Injury Relearning Society – Edmonton
18. Employabilities – Edmonton
19. FAS/FAE support group from Lethbridge – Edmonton
20. Feika, Irene – Home visit with parents and service provider representatives – Edmonton
21. Foothills Advocacy in Motion (with Don Tannas, MLA) – High River
22. Friends of the Head Injury Association – Edmonton
23. Goodwill Industries – Edmonton
24. Leduc Works (with Albert Klapstein, MLA) – Leduc
25. Lo-Se-Ca Foundation (also attended by Mary O'Neill, MLA and Colleen Soetaert, MLA) – St. Albert
26. MacCabe, Margaret (Member of the Premier's Council on the Status of Persons with Disabilities) – Edmonton
27. Michener Centre (also attended by Victor Doerksen, MLA) – Red Deer

28. Michener Centre Facility Board (with Hon. Stockwell Day, MLA) – Red Deer
29. Northern Alberta Brain Injury Association – Edmonton
30. Osterman, Connie, re: Brain-Injured Individuals – Calgary
31. Options – Calgary
32. PDD Community Board, Calgary – Calgary
33. PDD Community Board, Calgary (conference call) – Calgary
34. PDD Community Board, Edmonton – Edmonton
35. PDD Community Board, Central – Red Deer
36. PDD Community Board, South (with Dave Coutts, MLA) – Cardston
37. PDD Community Board, Northeast – St. Paul
38. PDD Community Board, Northwest – High Level
39. PDD Foundation Board – Calgary
40. PDD Foundation Board, Chair and CEO – Calgary
41. PDD Public Presentations, Calgary (2 days) – Calgary
42. PDD Public Presentations, Central – Red Deer
43. PDD Public Presentations, Edmonton (2 days) – Edmonton
44. PDD Public Presentations, Northeast – St. Paul
45. PDD Public Presentations, Northwest – Grande Prairie
46. PDD Public Presentations, South – Lethbridge
47. Premier’s Council on the Status of Persons with Disabilities - Board Meeting – Edmonton
48. Premier’s Council on the Status of Persons with Disabilities - Open House (with Rob Lougheed, MLA and Chair) – Edmonton
49. Provincial Advisors on Disability Issues, Meeting – Edmonton
50. Provincial Advisors on Disability Issues (2 day Conference) – Edmonton
51. Strategies for Independence (with Albert Klapstein, MLA) – Leduc
52. Toward Universal Accessibility Conference (City of Edmonton) – Edmonton
53. Vocational Rehabilitation & Research Institute (in consultation with Hon. Murray Smith, MLA) – Calgary

TOURS

1. Drumheller Adult Resource Training Society (with Hon. Shirley McClellan, MLA) – Drumheller
2. Developmental Disabilities Resource Centre (with Jocelyn Burgener, MLA) – Calgary
3. Eric Cormack Centre – Edmonton
4. Foothills Advocacy in Motion (with Don Tannas, MLA) – High River
5. Goodwill Industries – Edmonton
6. Leduc Works (with Albert Klapstein, MLA) – Leduc
7. Michener Centre – Red Deer
8. Options – Calgary
9. Robin Hood Learning Centre (with Hon. Iris Evans, MLA) – Sherwood Park
10. Strategies for Independence (with Albert Klapstein, MLA) – Leduc
11. Voice Print – Calgary
12. Wetaskiwin & District Community Services (with LeRoy Johnson, MLA) – Westaskiwin

13. Winnifred Stewart Association, Assisted Living Project (also attended by – Hon. Ken Kowalski, MLA and Lance White, MLA) – Edmonton

APPENDIX 4

Funding Models – Definitions

(as provided by the PDD Provincial Board Office)

Contracted Funding

PDD Community Boards contract with agencies to provide services to groups of adults with developmental disabilities. The contract identifies the amount of funding the agency will receive and the level and quality of service to be provided. The contract stipulates that the agency must comply with the *Creating Excellence Together* standards and other government regulations. The contracted categories of support may include community living supports, employment supports, community access supports and specialized community supports. Monthly utilization reports are submitted by the agency. The contract is generally annual in nature. The agency also provides financial statements for annual review and re-negotiation. The agency is generally paid quarterly and in advance. Contracted costs are reported on the group average rather than on an individual basis.

Clustered Contracts

PDD Community Boards contract with agencies to provide services to groups of adults with developmental disabilities. These contracts incorporate some aspects of individual funding such as portability of funding and focus on the individual's support needs. The contract stipulates that the agency must comply with the *Creating Excellence Together* standards and other government regulations. The services purchased through an agency on behalf of an individual are the same as those available under contract. These contracts are generally annual in nature. Monthly utilization reports are submitted by the agency. Contracted costs are reported on the group average rather than on an individual basis.

Individual Funding

PDD Community Boards provide funding directly to the trustee or designate to purchase services on behalf of an adult with a developmental disability. The trustee, guardian, and individual with the developmental disability choose the agency who will provide services. Funding is portable in the event that the individual moves or wishes to change agencies. The types of supports provided and the annual costs are based on determination of the individual's needs, as identified in an individual support plan. Agencies supplying services through individual funding must comply with the *Creating Excellence Together* standards and other government regulations. The range of support categories available is the same as under contracted funding or clustered contracts. Monthly payments to the trustee or designate are based on an invoice for actual services provided during the previous month. Advance payment may be considered in exceptional circumstances. A policy is in place for the review of an agency's financial and program information. Costs are reported on an individual basis.

APPENDIX 5

Special Thanks and Acknowledgements

I want to sincerely thank everyone who contributed to, participated in, and/or was involved in some way with the PDD Review process, specifically:

- Honourable Ralph Klein, Premier, and his office staff;
- Honourable Halvar C. Jonson, Minister, Alberta Health and Wellness, and his office staff;
- Honourable Stan Woloshyn, Minister of Community Development and his Department staff;
- Honourable Iris Evans, Minister of Children's Services, and her Department staff;
- All MLAs and their staff;
- Peter Elzinga, Chief of Staff
- Lynne Duncan, Deputy Minister of Alberta Health and Wellness, and her staff;
- David Steeves, Special Advisor to the Deputy Minister of Alberta Health and Wellness;
- Premier's Council on the Status of Persons with Disabilities, Chair, Rob Lougheed, MLA;
- George B. Cuff & Associates Ltd.
- Bert Sparrow, Past Chair, PDD Provincial Board;
- Alan Anderton, Chair, PDD Provincial Board;
- Norm McLeod, CEO, PDD Provincial Board;
- Jim Menzies, Director of Finance, PDD Provincial Board;
- Maureen Murphy-Black, Policy Coordinator, PDD Provincial Board;
- Lena Rachmistruk, Executive Assistant, PDD Provincial Board;
- All PDD Boards, their Chairs and Board Members, CEOs and staff;
- All public presenters and others who made submissions during the PDD Review;
- Those who arranged and hosted the public presentation sessions; and,
- My Legislature and Constituency Office staff.