



**Family-Managed Supports
Project Report
March 22, 2006**

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Context for PDD's Work on Family-Managed Supports

Over time there has been a significant increase in the number of families wanting to personally hire and direct their own paid supports to assist their family member with a developmental disability. Persons with Developmental Disabilities (PDD) is committed to supporting this funding option and ensuring that it is readily accessible to families. A review of statistical data from PDD's Consolidated Service System (CSS) revealed that for the 2004/05 fiscal year, 234 families across Alberta exclusively used this option related to PDD funded supports.

PDD recognizes that the relationship between families, their family member with a developmental disability and paid supports they directly hire is distinct from that of service provider organizations, with staff hired to deliver services to multiple individuals. PDD wants to have accountability expectations that reflect this distinction, while ensuring that all parties meet core accountability requirements for the use of public funds.

Defining the Work

In April 2005, PDD engaged international consultant Michael Kendrick to help frame provincial policy considerations for guiding regional practices. Subsequent discussions with the Alberta Association for Community Living (AACL) led to the creation of an advisory team, comprised of paid supports from all PDD Community Boards and the Provincial Board, as well as AACL. The project charter identified the team's purpose, goal and guiding principles as follows:

Purpose:

To provide advice on the development of PDD operational policy for the option of individuals and/or their personal support network to hire and direct their own paid supports.

Goal:

To provide a clear understanding of the issues, identify core elements for policy parameters, identify operational risk factors of adopting the proposed approach and recommend implementation strategies for PDD provincial operational policy

Guiding Principles

To ensure core elements and recommended strategies align with PDD's values, principles, strategic direction and policy environment

To ensure policy parameters strike a balance between being family-friendly, while meeting government accountability requirements for the use of public funds

To ensure that the perspectives of all key stakeholders are considered in the development of the policy parameters and implementation recommendations

What the Advisory Team Found:

PDD's provincial operational policy focuses primarily on funding support options through the community service provider sector or government operated facilities, with

little reference to Family-managed supports. With the growing popularity of Family-managed supports, Community Boards have developed regional practices for responding to and overseeing such unique arrangements.

The result is significant variance across the province related to the scope of Family-managed supports that can be accessed, how readily and with what degree of administrative details. These factors were identified as potentially impacting how viable this option is viewed from a family perspective. Regional variances also were identified as posing challenges when families moved from one region to another.

As an organization, PDD is at risk by not having a rational provincial approach to funding such arrangements, applying clear and consistent accountability requirements across the province, that are both family-friendly and responsible from all perspectives.

What the Advisory Team Accomplished (Aug 2005 - Dec 2005)

Policy parameters:

Policy parameters were developed to guide consistency in regional practices. These parameters were developed through the identification of key characteristics for family-managed supports, principles of practice, and clear accountability roles for all parties. The parameters were reviewed to ensure align with PDD's Vision, Mission, Values and Principles for Determining Individual Support Needs.

Risks related to the Policy Approach:

Considering research, work from other jurisdictions and PDD's experience, the team reviewed risks and identified no operational impediments to proceeding with the development of a principle-based approach to family-managed supports. It was identified that while some regional adjustments may be required to ensure alignment of practices with the provincial policy, there are no significant risks identified in doing so.

Additional Areas of Consideration

The advisory team identified three additional areas for future consideration that extended beyond the scope of the project charter.

1. PDD Risk assessment

Assessing the risk in family-managed arrangements takes place at three levels:

- person focused - assessing risks on the balance between making personal choices in utilizing this option and associated risks to the individual and PDD
 - need to identify factors to be considered (recommended to be addressed by the Provincial Operational Managers)
- family focused – addressing concerns about the family history or ability to manage the supports within PDD's policy parameters
 - need to identify factors to be considered and mitigated (recommended to be addressed by the Provincial Operational Managers)
- system focused – identifying a family-friendly review process for family-managed supports arrangements that ensures that PDD is meeting accountability requirements for the use of public funds (recommended to be addressed in conjunction with the related work of provincial committees- Contracts and Legal Formats, Finance Managers, Provincial Operational Managers)
 - factors to be considered must align within PDD's risk management framework

2. Regional Resource Development:

The range and accessibility of relevant resources vary across the province. Each region needs to identify useful resources that are available or could be developed in their region for families, including family-to-family resources. Sharing of valuable resources and lessons learned is also key to strengthening resources to those involved in providing family-managed supports.

3. Strengthening Support to Families:

- Access to additional extra-structure/infra-structure resource supports, such as educational opportunities, access to payroll services, etc
- Bureaucratic buffers for families, which limits their need to know system details
- Development of an external system where families can express concerns– need to ensure adequate resources to address the concerns
- Families playing a role in teaching paid supports about the intrusiveness of their role in someone's life

Advisory Team Recommendations (December 2005)

The Advisory Team has provided the following recommendations for PDD's Provincial Board Administration:

- Gain endorsement for implementation from PDD's Provincial Operational Managers, Finance Managers and Executive Management Team for the proposed policy parameters
- Consider an implementation target date of April 1, 2006
- Work closely with the Risk Management Committee and the Alberta Association for Community Living to ensure that proposed risk management processes meet PDD's accountability requirements, while being sensitive to families.
- Work in conjunction with the Provincial Operational Managers to identify operational considerations for implementation and monitoring of the policy
- Consider action strategies to address additional areas of work identified as important by the Advisory Team

The work of the Advisory Team was completed in December 2005, having met all aspects of the Project Charter. Their work was shared with key PDD management committees for refinement in preparation for an April 1, 2006 implementation date. In addition, clarification advice was sought from consultant, Michael Kendrick.

Action Taken (Jan 2006–Mar 2006)

Opportunities were provided for feedback from key PDD management committees and Provincial Board Administration actively worked with the Provincial Operational Managers who supported the draft policy framework and identified areas for clarification, as well as operational considerations. The policy direction received endorsement from the AACL and was presented as a positive example of family-friendly policy development, in a Michael Kendrick workshop on Creating Responsive Alternatives.

Provincial Board Administration collaborated with the Provincial Operational Managers to address clarity issues and draft a workplan for addressing operational considerations and areas identified by the Advisory Team as needing further development.

Provincial Board Administration participated on the Risk Management Committee to develop a family-managed supports questionnaire. In addition, representatives from the

original advisory team collaborated to provide the context for the development of a provincial legal agreement, by the Contract and Legal Formats Committee.

Final project report and policy were released for an April 1, 2006 implementation date.