

## EXECUTIVE SUMMARY

### INTRODUCTION

Family Managed Services (FMS) is a current funding option available to families who have an adult child in The Persons with Developmental Disabilities (PDD) Program within the Ministry of Seniors and Community Supports. It allows families to manage, direct, and hire the supports required by their family member.

The PDD Program understands that families are a critical component of service delivery and the purpose of this study is to explore and recommend comprehensive program policies that strengthen the role of families and individuals with developmental disabilities who want to direct and manage their services. The focus is on allowing families to have the appropriate level of autonomy, while ensuring accountability, and the achievement of positive outcomes for individuals receiving supports. This study was commissioned by the PDD Program to examine current practice in FMS to determine what is working and where the challenges lie so that recommendations regarding policy changes can be made for the PDD Program. The information gathered within this study will be provided to all key stakeholders in a summary document.

### RESEARCH DESIGN

A qualitative study was designed to: 1) gather a province-wide perspective of families involved in FMS, and 2) provide the PDD Program with information to assist them in the development of policy recommendations for consideration by the Minister and the PDD Program.

The research design included consultations (focus groups and phone interviews) with families engaged in FMS, PDD staff providing support to those families, and service providers who provide services to families through FMS.

The objective of the family consultations was to gather information on such topics as:

- aspects of FMS that are working for families,
- aspects of FMS that are not working for families, and
- support needs that should be made available to assist families in the operation and management of FMS.

The objective of the PDD staff consultations was to gather detailed information about:

- the monitoring and accountability supports, requirements, and processes that should be made available to manage FMS; and
- how families are equipped to understand processes such as service standards, contracting, monitoring, and reporting.

The objective of the service provider consultations was to gather information on such topics as:

- the types of challenges that service providers face when working with families who are engaged in FMS;
- the positive and negative experiences of service providers who work with FMS; and
- the kinds of quality assurance standards (i.e., accountability processes) that should be in place for families who hire and manage their own staff.

There were 124 families, 47 PDD staff members, and 6 service providers who participated in this study. Qualitative data analysis was conducted on the information provided by participants and key themes and subthemes were identified. Key themes and subthemes were:

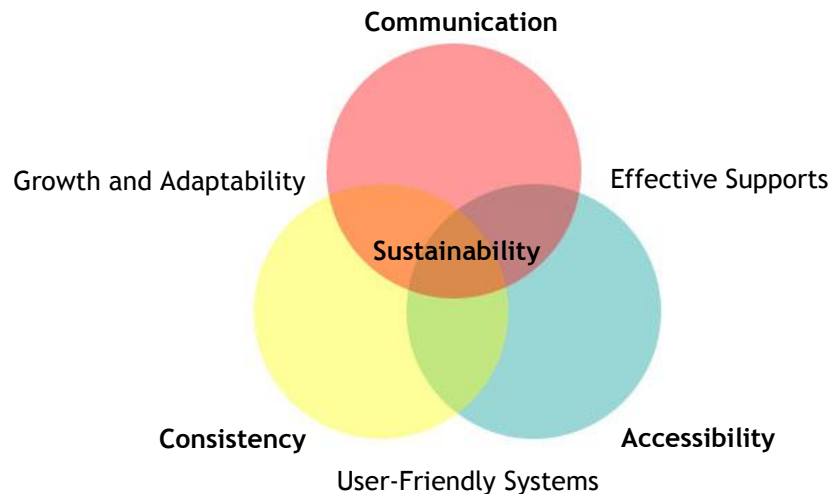
- Coded across regions with unique aspects within a region identified (e.g., use of a payroll company in Edmonton).
- Coded as *positive* (things that are working), *negative* (things that are not working), or *needed* (things that would improve effectiveness or efficiency).

- Coded into systemic themes that ran across multiple subthemes.

## RESULTS

### Overarching Themes

Conversations with families, PDD staff members, and service providers resulted in three key overarching themes: 1) Communication, 2) Consistency, and 3) Accessibility. Where each of these three themes overlapped, three overarching subthemes were identified: i) Growth and adaptability, ii) User-friendly systems, and iii) Effective supports. In addition, at the core of all these themes and subthemes, the central theme of Sustainability was identified.



The capacity of FMS to be a sustainable service option is strengthened through enhanced communication, increased consistency, and improved accessibility. Through developments in these key areas, FMS can become more adaptable and responsive to growth, more user-friendly, and can provide more effective supports for families. Simplifying processes and supporting families to manage services could reduce errors, increasing time for family and PDD staff members to dedicate to expanding programming opportunities for consumers and to monitoring these services, improving the overall quality of services provided. Through program planning and discussion of future service options, families and PDD staff can plan for lifestyle transitions faced both by the consumer and the family as they age. With appropriate planning to prepare for and accommodate changes in consumer and family needs and circumstances, PDD can help to ensure consumers have access to services despite these changes. By identifying how feedback from families influences system changes, PDD can maintain or increase families' motivation to share their experiences and provide suggestions for improving FMS. Overall, improvements in communication, consistency, and accessibility ultimately relate to ensuring FMS is a sustainable program that will continue to grow and improve in years to come.

### Specific Themes

Participants discussed what is working well, what is not working, and what they would like to see changed regarding FMS. These included:

**Family Managed Services Agreement (FMSA).** Additional detail added to the FMSA outlining accountability requirements and roles and responsibilities reduces liability risks for families and PDD. However, the complexity of the agreement makes it inaccessible, confusing, and overwhelming for families. Families identified that frequent changes to already complicated contract obligations and accountability processes create misunderstanding which can lead to invoicing errors and payment delays. The Individual Service Plan (ISP) created during development of the FMSA allows families to create a program that is in line with their goals and values but can be a difficult process for families who have little experience with programming

and require more assistance than is provided by their Client Service Coordinator (CSC). Inequities in funding received by families with consumers of similar need create dissatisfaction as families: 1) struggle to identify available service options, and 2) feel family advocacy is required to receive and maintain adequate service for the consumer. Inequities also exist between families who are approved to hire family members under an exemption policy and those who have been denied or are not aware an exemption policy exists.

Changes identified regarding the FMSA included:

- Simplification and consistency of the FMSA (e.g., plain language, multi-year contracts).
- Simplification of contractual obligations to make them less time consuming and more appropriate for families (e.g., insurance requirements, monthly invoicing).
- Additional support for program development.
- Standardization of FMSA contracting processes to increase equality and reduce the need for family advocacy and funding appeals (e.g., exemption policy).

**Funding.** FMS has provided some families the level of funding and flexibility to allocate funding to best meet the needs of the consumer (e.g., transportation). This level of funding and flexibility is beneficial, but is not consistent across families. Some families believe their funding is minimal and falls well below what a service provider would receive to support the same consumer, while others are frustrated they are not able reallocate funding based on changing needs or program costs. Families also worry about the stability of their funding and are concerned that if the consumer's needs increase, they will not receive the additional funding needed to provide services to meet these needs.

Changes identified regarding funding included:

- Consistency in level of funding and the ability to allocate funding as needed for services (e.g., wages, transportation).
- More equality between funding provided to service providers and FMS families.
- Increased security of funding outlined in the FMSA.

**PDD Roles and Responsibilities.** The short timeframe in which FMS policy and procedure changes have been implemented have created confusion and inconsistencies within regions. Participants feel these inconsistencies in policy and procedures within regions, as well as those between PDD regions, reduce the effectiveness of FMS. Regional differences in interpretation of PDD Program policy changes create multiple variations of one policy that may or may not be in line with PDD Program's original intention.

Communication between families and PDD is strongest through the CSC-family relationship. The information provided by PDD to families (e.g., mail-outs, guidebooks), however, can be daunting, especially if it is overly technical. Communication within PDD can be limited, leading to inconsistencies and incorrect information being provided to families by staff members who are uninformed of system and policy changes. There is also a lack of communication between PDD and other parties involved in FMS, such as service providers or other government departments. This creates additional challenges for families who must explain FMS to these government representatives (e.g., Worker's Compensation Board, Canada Revenue Agency).

Many families are extremely pleased with their CSC and feel secure because they receive high quality supports. Concerns exist surrounding family perceptions that CSCs are gatekeepers of PDD funding and may put the interests of PDD above the needs of families. Specialized CSC positions have been developed in some regions. They are seen by some participants to be beneficial because the CSCs can focus their knowledge on FMS; on the other hand, it can be a disadvantage if specialist CSCs are not located in the same area as the family or consumer. High turnover in CSC positions or caseloads is disruptive both to services and to the CSC-family relationship. PDD staff are also concerned that their time involved with financial accountability decreases the time CSCs have to interact with families and monitor services.

Changes identified regarding PDD roles and responsibilities included:

- Increased consistency in implementation of provincial policy and processes.
- Simplified written communication to ensure information is accessible for families.
- Increased communication between PDD and other parties involved in FMS (e.g., involvement of service providers in the FMSA when families are contracting services, WCB,).
- Redefined CSC roles to focus on facilitating a trusting relationship and monitoring services (e.g., decrease focus on financial accountability, decrease caseload turnover).

**Employer Responsibilities.** In recruiting and retaining both program workers and respite or coverage workers, families appreciate the flexibility to hire workers through their social networks, people they trust and that the consumer is familiar with. The flexibility that FMS provides to families allowing them to increase job satisfaction (e.g., accommodating schedule changes, providing direct contact with the family and including them in goal planning, etc.) has allowed families to retain their workers, maintaining consistent staffing which improves the service provision. While this flexibility exists, families still have a hard time recruiting and retaining qualified workers who are willing to work only part-time hours or for the pay that can be offered with no benefits, especially for those with smaller social networks. It is even more difficult for families to find qualified respite or coverage workers and families often provide service when their regular worker is unavailable, often at the expense of their personal wellbeing or their career. Staff retention also becomes difficult for families who do not have management experience; they can either be over-demanding of staff, or detrimental to the family and service provision by being over-accommodating to their workers out of fear they will quit. While training that families have been able to access has increased the workers' skills and helped make the workers more independent in service provision, there are very few training opportunities available and families struggle to maintain service provision for the consumer during training sessions as funding is not often incorporated in their FMSA.

For families with accounting or finance experience, payroll administration responsibilities are straightforward and undemanding; it is perceived as a positive responsibility as they are aware of how funding is being distributed. However, for those without experience, it is intimidating, complex, and overwhelming. Many of the deductions and requirements are confusing and families do not receive the necessary information to help them understand the process.

In the Edmonton region, a payroll service (ERAPS) was implemented for families. A majority of the families in the focus groups are currently using ERAPS to manage their payroll. Many families feel the service that ERAPS provides decreases the time they spend on monthly administrative work. Families believe ERAPS makes FMS more accessible for families who feel they do not have the skills to manage payroll responsibilities on their own.

Some families, however, experience issues with ERAPS. Errors in reports from ERAPS require families to learn about payroll, deductions, and the CRA in order to find the errors. Families also find it difficult to contact ERAPS and often are unable to speak with a representative to determine the source of the error.

In the Central region, a pilot study regarding use of a payroll service was being implemented just prior to data collection in the region. While most families were unaware of the pilot study, they feel that having access to a payroll service would be a benefit to those who do not have the skills to manage payroll.

Changes identified regarding employer responsibilities included:

- A staff directory where families can post job descriptions and workers can post resumes and indicate if they are available for respite or coverage.

- A family network to facilitate shared staffing to provide full-time hours for workers and to facilitate connections where families could find respite or coverage workers.
- Access to information resources and training regarding recruitment practices (e.g., writing job ads, recruitment resources), management, labour standards, and payroll.
- Flexibility to pay family members for respite or coverage when workers are not available.
- Competitive salaries, group benefit plans, and casual illness pay need to be available for families to be able to recruit and retain workers.
- Increased professional development and training opportunities as well as funding to be able to provide these opportunities to workers and still be able to maintain service provision.
- Templates and tools for families to use in payroll administration (e.g., spreadsheets, checklists).

**Transition into FMS.** When families have support through various sources (e.g., PDD, FSCD, education professionals) and are able to plan ahead, the transition into FMS becomes easier. However, many families do not have the support or do not obtain information early enough in the process and the transition is difficult, overwhelming, and stressful. The transition is also more difficult when the family does not have the capacity to manage service provision or when FMS is the only option available for families. The transition into FMS is also more difficult when the family is coming from FSCD to PDD as the systems and terminology differ.

Changes identified regarding the transition into FMS included:

- The need for FMS to be a service choice, not the only option available.
- Accessible information regarding FMS and the transition process needs to be available through multiple sources (e.g., doctor, education system).
- Families need support and training through PDD or other sources (e.g., families) before the transition in deciding whether FMS is the right service option to meet consumer and family goals as well as during the transition.
- Families would like to see more collaboration between FSCD and PDD to create a smoother transition.

**Consumer Programming.** FMS provides the flexibility to meet the consumer's needs and interests within their own community. This flexibility of FMS also allows for the program to change on a daily basis so that it meets the consumer's current needs. Staying within the consumer's community helps the consumer develop friendships and social networks. Consumers also benefit from social connections with their peers. FMS has allowed families to provide learning opportunities and lifestyle changes (e.g., independent living) that allow the consumer to grow, develop, and gain independence. While the consumer is able to benefit from this increased independence and control, the family also gains a sense of security, especially where independent living situations have been set up, so that if something changes in the family situation, the consumer's living situation will not be impacted as severely.

Unfortunately, community opportunities and social connections with peers are limited, and families struggle to find the time to be able to continuously search for and schedule activities. Because of this, families struggle to prevent the consumer from being socially isolated. Few resources are available to set up employment, education, and independent living opportunities. Also a concern of many families is that FMS is hinged on their motivation and ability to manage the service provision. Many do not have immediate or extended family to take on the responsibilities involved. If the funds administrator falls ill or has an accident, the program cannot continue.

Changes identified regarding consumer programming included:

- Access to resources to assist in providing opportunities to consumers, including a list of community activities, education opportunities, and employment opportunities.

- A family network would allow families to share knowledge about available activities in their community and to connect with other families when looking for roommates.
- More social, post-secondary education, and employment opportunities need to be made available.
- Families would like to see planning for the future of their FMS program. This would include: i) transition planning for a new funds administrator, ii) simplification of FMS processes so that a new funds administrator can step in easily, iii) long-term care options if there is no one available to take over as funds administrator, and iv) independent living supports need to be provided.

**Quality of Services.** FMS, in some instances, has allowed for consistent services and staffing and a more 'normal' lifestyle which has led to increased consumer health, happiness, and confidence. However, there is some concern that family burnout will lead to poor decisions when hiring a worker, reducing consumer safety.

In monitoring, families feel that the close connection they are able to have with their workers allows them to better monitor their performance. Unfortunately, when issues do arise, there are few resources for families to turn to. PDD staff also have limited opportunities to interact with families, making it difficult for them to monitor the families and provide assistance.

Changes identified regarding quality of services included:

- Resources available for families so they can better monitor workers and conduct performance evaluations and when issues arise, families need to have external assistance.
- PDD systems regarding monitoring need to be developed for families.
- Increased time for CSCs to be able to interact with their families to monitor them and provide them with assistance.

**FMS Community.** Connecting families within FMS allows them to share their experiences, mentor others, and interpret PDD information in a family context. A network functions as a source of moral support to prevent families from becoming isolated. Efforts to connect families have been unsuccessful as the time commitment required to develop and maintain a family network exceeds what families can contribute. Many families are also hesitant to connect with others out of fear funding inequities will result in their services being challenged and potentially reduced.

In contracting a service provider, families are able to reduce the amount of administrative work. Families and service providers tend to have positive relationships because they work together more closely on service planning. While families are able to have more involvement, they do not have as much control and do not always understand the roles of each party involved, sometimes leading to conflict. In providing services to families through FMS, service providers do incur additional administrative costs and encounter some additional human resourcing challenges. At the current levels, service providers are able to handle the additional costs and challenges. They are, however, concerned if the number of families purchasing their services through FMS increases; they will need to pass the costs on to the families, and with no administrative funding provided in the FMSA, will decrease the amount of services that can be provided to the consumer. It is for this reason as well as concerns that families could withhold payments for services that the service providers believe so few service providers are willing to provide services through FMS; without a third party to act as an arbitrator, service providers feel they would be incurring additional risk.

Changes identified regarding FMS community included:

- Multiple networking options available for families within communities as well as across the province (e.g., internet, community groups).
- Organization of and funding for family networking through a third party (e.g., PDD, advocacy organization).

- Administrative funding available in the FMSA so that service providers are able to offer this option without assuming additional costs they do not have the resources to accommodate.
- PDD involvement so that service providers can be comfortable that they are not assuming additional risks in providing this option to families.

**Family Engagement.** Although families appreciate the ability to provide feedback on FMS processes and policies, many are frustrated that they are not compensated for their time and are not informed of how their input contributes to FMS systems changes.

Changes identified regarding family engagement included:

- Increased communication from PDD linking feedback from families to decision making and policy/systems changes.

**Future Directions of FMS.** In general, families are very pleased with the services they receive through FMS and believe FMS should continue to be developed and improved to ensure it remains a sustainable service option.

Changes identified regarding future directions for FMS included:

- Increased marketing and awareness of FMS within the disability services sector and across provincial jurisdictions.
- More service providers willing to contract services to FMS families who cannot sustain FMS through the direct hire option.

### **Summary of Regional Initiatives**

Several regional initiatives involving FMS were ongoing prior to data collection. PDD Program and PDD regional representatives provided a list of these initiatives to the researchers and they gathered any information identified by families about: 1) whether they were aware of the initiatives within their region, 2) whether they have accessed any of these initiatives, and 3) whether any of these initiatives have been helpful in assisting families. Families identified the following initiatives.

**Payroll Service.** In the Edmonton region, a payroll service (ERAPS) was implemented for families. A majority of the families in the focus groups are currently using ERAPS to manage their payroll. Many families feel the service that ERAPS provides decreases the time they spend on monthly administrative work. Families believe ERAPS makes FMS more accessible for families who feel they do not have the skills to manage payroll responsibilities on their own.

Some families, however, experience issues with ERAPS. Errors in reports from ERAPS require families to learn about payroll, deductions, and the CRA in order to find the errors. Families also find it difficult to contact ERAPS and often are unable to speak with a representative to determine the source of the error.

In the Central region, a pilot study regarding use of a payroll service was being implemented just prior to data collection in the region. While most families were unaware of the pilot study, they feel that having access to a payroll service would be a benefit to those who do not have the skills to manage payroll.

**Dedicated CSC Position for FMS.** In the South region, a designated CSC position for FMS was created. Many families feel that a designated CSC position allows the CSC to develop more expertise. They also feel that the single point of contact helps to increase the consistency of information and that the CSC is better able to stay up to date on changes within FMS. PDD staff members also feel a specialized caseload is beneficial as many CSCs have difficulties supporting a few families in FMS who comprised a small fraction of their caseload.

Concerns surrounding a specialist CSC position focus on a decrease in local representation and flexibility. Families feel local representation is important and believe when their CSC is located in another city, the quality of support decreases as the CSC is less familiar with community resources in the family's area and cannot meet with a family on short notice. Families also

worry a transition into or out of FMS will be more difficult because their case will have to be transferred to a different CSC.

While the Northeast and Northwest regions made the change to dedicated CSC positions just prior to data collection in those regions, families did provide information regarding this change, which mirrored that provided by the families in the South region.

**Family Newsletter.** In the South region, a newsletter was created by the CSC to improve communication between families and PDD. The newsletter was well received by families who appreciated information presented in a format they could access on their own time. Newsletters in the Northwest and Edmonton were also well received and Edmonton families particularly appreciated information on city programming (e.g., community recreation, DATS, etc.). One drawback to the newsletters is that the information presented has a PDD focus rather than a family focus. Families would like to see newsletters include family contributions to connect parents seeking shared staffing or roommates, or who have resources or equipment that another family could use.

**Information Resources.** The Central region developed a FMS handbook *Taking Charge: A Guide to Choosing Family-Managed Supports*. Unfortunately, while the families were aware of the handbook, they had been using IF prior to FMS and did not use the handbook when FMS was implemented as they planned to continue the service choice when the transition from IF to FMS was made.

**Family Managed Resource Centre.** At the time of data collection the Calgary region had hired a coordinator to operate a Family Managed Resource Centre (FMRC), but it was not yet open to families. As such, families could not provide information about the FMRC. The coordinator was present for some of the family focus groups and informed the focus group participants that Calgary was developing the FMRC (or a PDD representative when the coordinator was not present). When discussing their challenges and support needs, families commented that the FMRC would be a good place to get the assistance they required for many of the issues that arose.

## **CONCLUSION**

Although families are critical of some elements of FMS and believe changes are necessary, families are grateful for the support they receive and feel privileged to live in Alberta where FMS is available. Many families feel FMS provides a level of family input and individualized service unavailable through other service options, enhancing the lives of both consumers and families. It is for these reasons that families would like to see FMS grow and evolve to become a sustainable service option that is both available and accessible for current consumers and for those who will transition into PDD in future years.