Alberta Council of Disability Services

Advocating for, supporting, and elevating the Community Disability Services sector in Alberta

ACHIEVING SUSTAINABILITY

Recommendations from ACDS for Addressing Challenges in the PDD Program

Background

In December 2019, senior leaders from the Persons with Developmental Disabilities Program (PDD) presented PDD program data and trends to the Service Provider Partnership Committee, the ACDS Board of Directors, and subsequently, with community disability service providers. After the presentation, we were invited to submit written responses to the following questions:

- How can the PDD program create room for caseload growth?
- What can be done to address pressures associated with the exceptional growth of individuals with complex needs?
- Is there merit to encouraging particular service models (e.g. FMS) or exploring new, innovative delivery approaches (e.g. hybrid models)?
- How can we reduce "red tape" and maximize operational efficiency to ensure investments support desired outcomes?

These questions reflect issues and concerns that ACDS and others have voiced numerous times, including at the 2018/19 PDD program review. We once again emphasize the imperative need to take a systems approach and urge the government to avoid ad hoc quick-fix solutions.

In this document, we propose a framework for a systems conversation. Recognizing that such work takes time, we also suggest ways in which some pressures can be addressed quickly, to achieve immediate, meaningful progress while working towards a systemic solution.[1]

We believe there is strong alignment between the government's goals to make Alberta the best place to live and ACDS' vision for vibrant communities where all citizens are safe, healthy, connected and valued. We also believe that through ongoing conversation and collaboration, ACDS and the Government of Alberta can help people with disabilities have excellent lives.

[1] Our response is informed by our ongoing consultations with ACDS members, service provider networks, ACDS surveys, government reports, and conversations with other stakeholders. Much of the information in this document was presented in *Moving Forward: A Vison and Framework for Impact,* originally submitted to the 2018 PDD Program Review Panel.

A Framework for a Systems Approach

How can the PDD program create room for caseload growth?

1. Complex supports program

One of the reasons for caseload growth is the massive increase in the PDD program of individuals with complex and "ultra-complex" support needs.

We suggest

Create a separate program for individuals with complex and "ultra-complex" support needs (see next section).

2. Flexible, sustainable funding

Despite significant increases to the PDD program, community service providers have been chronically under-funded. Time and again, evidence has shown that funding to agencies has not kept pace with inflation,[2] not fully recognized the indirect and administrative costs associated with quality service delivery and accountability demands, and created a chronic issue of low staff wages and high turnover.[3, 4] Service providers are forced to reduce expenses, pull from other resources, and seek additional revenues. These activities impose stress on agencies, divert energy from service delivery and have significant impacts on the quality of life of individuals.[5] An overburdened program is not sustainable.

We suggest

Provide predictable, responsive and sustainable funding through long-term, flexible contracts that reflect the full costs of providing quality supports.

✓ This aligns with government's recognition of the vital role of community organizations in delivering government-mandated services and its promise to "expand civil society efforts" and "be a champion of civil society groups" (UCP Platform, p.73).

3. Organizational collaborations

There is a perception by some in PDD that there is unnecessary duplication of services and processes by service providers. Although a proper assessment of this depends on a clear sense of program intent, scope and design, it may be beneficial to support agency leaders to engage in honest self-reflection about the merits of creative collaborative arrangements (from combining administration functions to creating formal mergers), and exploring barriers preventing such initiatives.

We suggest

Support agencies to engage in exploring collaborative initiatives and alliances as potential solutions to achieve their mission goals and increase their own effectiveness and impact as well as sector sustainability and outcomes.

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[2] Funding for administrative costs has not increased since 2014; equating to 7.4% inflation-related erosion in the past 5 years. Statistics Canada CPI data for Alberta 2014 and 2019: http://inflationcalculator.ca/alberta/

[3] Funding contracts have not provided wage increases for five years. Compensation for all staff has been below market value for decades. Alberta Ministry of Labour. March 2018. *2017 Alberta Wage and Salary Survey (AWSS)*

[4] In 2017, turnover in Community Disability Service Workers was 31.7%. Alberta Council of Disability Services. 2018. *ACDS 2017 Annual Workforce Survey. Provincial and Regional Workforce Profiles.* Calgary, AB: ACDS.

[5] Friedman, C. 2018. Direct support professionals and quality of life of people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 56*(4), 234-250.

4. Create trust and buy-in

Although the extent varies across regions, in general, service providers and families don't trust PDD and PDD demonstrates lack of trust through rigidity and micromanagement.

Lack of trust has cost implications.

For example, there are individuals who have historically been allocated high annual funding but whose current needs do not warrant the high amounts. Families and agencies are reluctant to request reduced funding out of fear that the funds may not be restored if the individual's needs unexpectedly increase.

One way to create buy-in to reduced funding may be by pooling the allocations for these individuals and assuring families and agencies that: (i) funding levels would respond to the individuals' evolving needs over time, and (ii) the "savings" would be allocated to individuals who need funding but are not getting any (e.g., those on the waiting list).

A responsive and trusted funding mechanism relies on having a fair, consistent and objective assessment of supports needs. Implementation of the *Supports Intensity Scale* in the mid-2000s failed due to lack of transparency about its intentions and because PDD, rather than an arm's length body, was conducting the assessment. The rationale for the tool for fiscal management versus needs assessment was therefore questioned. However, such a tool could be successful if there was genuine assurance it would be used to respond flexibly and fairly to individuals' changing needs, and the process was seen as unbiased.

We suggest

Explore ways to assure families, individuals and agencies that funding for supports will be responsive, flexible and evolve in tandem with an objective assessment of the individual's changing needs over time.

- Review historically-high funding contracts and explore if funds can be pooled to generate savings, ensuring individual funding will be responsive to evolving needs.
- Implement a proven tool to objectively assess evolving support needs and allocate accordingly, with the assurance that such a tool would not be used to justify unwarranted funding cuts.

5. Program structure

Explore efficiencies within PDD structure and roles. This includes exploring if eliminating the PDD regional structure will save costs and achieve consistency in policy application and processes. It also includes examining the roles of PDD staff, particularly caseworkers, and assessing if service providers or external contractors could fulfil the roles more effectively. The considerations must ensure unique regional needs (e.g., urban vs rural) are addressed and "out-source" parties are properly compensated.

We suggest

Review PDD program structure to determine if its design achieves program goals and outcomes efficiently and effectively.

- In the near-term, examine the allocation of roles and responsibilities in PDD staffing to assess effectiveness.

What can be done to address pressures associated with the exceptional growth of individuals with complex needs?

1. Complex supports program

Over 1,700 individuals (14% of the total PDD caseload) each receive over $120,000 in supports annually, reflecting the complex and "ultra-complex" needs of these individuals, many who also have histories (or co-existing issues) of chronic substance abuse, addiction, homelessness and criminal behaviour.

Most individuals with complex needs currently in the PDD program are relatively young; they will require services and create cost pressures in the program for a long time. In addition, their involvement with multiple systems more frequently and intensely than most other individuals in service creates costs that are borne by PDD or duplicated across systems. Unless a separate, targeted program is created, burgeoning costs for PDD are inevitable.

We suggest

Examine whether individuals with complex and "ultra-complex" support needs belong in the PDD program. Creating a separate program will create significant room for intake of individuals who are the intended target population for PDD.

2. Seamless access; no duplication

Several supports that could be available to people with developmental disabilities through existing programs are being provided by duplicate processes within PDD. This "parallel system" is financially inefficient and prevents individuals, especially those with complex needs, from receiving supports from programs with the right mandates and expertise to best address their needs.

In some cases, neither PDD nor other external systems have successfully delivered the right supports for individuals with complex needs. External systems see people with disabilities as a PDD responsibility; meanwhile, PDD has not done enough to provide these systems with the proper tools and resources to respond to the needs of individuals accessing those programs.

In essence, what has manifested as a resource or a cost issue is a problem rooted in a failure in policy and program design. Over time, one after another band-aid solutions have prevented the development of a thoughtful and sustainable systemic response. The result is a program that costs $1 billion, in part, because it provides supports to individuals it was never intended for, while disproportionately bearing costs that should be apportioned to other programs and systems.

We suggest

An appropriate policy response ensures: (1) individuals who need supports do not fall through cracks (i.e., there are no "eligibility" gaps in criteria or actual practice); (2) individuals are channelled into the program or system best able to provide appropriate supports; (3) access and transition across various programs and systems is seamless and barrier-free; and (4) a disability-lens assesses and addresses the potential impact of policies, programs and initiatives on individuals with disabilities.

✓ This aligns with government's promises to "enact policies that support the desires, dignity, and choices of Albertans with disabilities" (UCP Platform, p.77), and to review systems to reduce duplication, maximize effectiveness, and improve outcomes (p.56).

Is there merit to encouraging particular service models (e.g. FMS) or exploring new, innovative delivery approaches (e.g. hybrid models)?

1. Innovations support

There are merits in all service models; no single service model is the best for all individuals. Depending on their level of complexity of needs or lack of natural supports there will always be people who do not want or fit into the FMS model or a hybrid model.

Government must support service providers to test new approaches and share learnings for success. Regardless of approaches used, all models (FMS or otherwise, current or innovative pilots) must have the same expectations for staff training, safety and standards of care. They must also be evaluated by the same standards for quality assurance via the same or equivalent accreditation processes.

We suggest

Set aside annual funding to support community disability service providers to test innovative approaches.

✓ This aligns with the government's promise to create a $20 million Civil Society Fund to support innovative programs delivered by community groups (UCP Platform, p.73).

2. FMS Analysis

Although the FMS portion of the PDD caseload has almost doubled from 10% in 2009 to 19% in 2018, some service providers are seeing more FMS families approaching them to provide services instead of managing their own supports. Reasons for this include: families unable to find or retain qualified staff; family members aging or ailing; or Public Guardian seeking services after family member or guardian passes away.

Some agencies have started services to respond to these needs especially in remote locations with few or no service options. However, just as FMS is not the answer for all individuals, not all organizations are the right fit for all individuals or families.

Service providers are willing to support FMS families, and in all likelihood, hybrid models will become more attractive to families. Cost efficiencies can be realised if service providers have accurate data about FMS usage and demographic trends so that they can forecast and plan service demands.

We suggest

Undertake a deeper analysis of FMS usage and demographic trends, specifically to identify and monitor shifts from FMS to agency-based supports so that agencies can forecast and plan services to address anticipated demands.

How can we reduce "red tape" and maximize operational efficiency to ensure investments support desired outcomes?

1. Flexible contracts

"Red tape" issues manifest in the PDD program at various levels, and create financial inefficiencies, administrative burdens, and negatively impact individuals' access to supports and their quality of lives.

At the micro level, service providers struggle with stifling micromanagement and an overload of paperwork with an unclear purpose or rationale. Contracting processes and funding models create unnecessary inefficiencies.

One significant issue with the contracting approach is the differential between (1) the funding amount stated in the agency contract at the start of the year (i.e., a budgeted amount based on number of individuals anticipated during that year), and (2) the actual number of individuals approved by PDD to receive supports during that year (i.e., approved referral agreements, which may take several weeks for new intake or for program changes for existing clients). Since agencies plan their staffing and service delivery based on budgeted (contract) amounts, any gaps or delays in referral agreement approvals have significant cost implications for agencies.

The burden on agencies is further compounded since most individuals receive supports through shared staffing models (e.g., four or five individuals simultaneously supported by one or two staff). When an individual exits a program, their funding goes with them; the agency is forced to cover the revenue shortfall in order to maintain the staff still needed to support the remaining individuals. While this might seem logical from the funder's perspective, it results in unsustainable downloading of costs to service providers, only addresses direct costs on a per unit basis and does not consider impact on outcomes for the individuals.

We suggest

Collaborate with ACDS via the "red tape" and the contract sub-groups of the Service Provider Partnership Committee to identify solutions that can be implemented relatively easily to make processes more efficient for agencies, enhance service delivery outcomes, with no additional costs to PDD.

- Remove, or accelerate, referral agreements.
- Create flexibility in contracts, giving agencies the latitude to redirect staff resources if an individual's support needs temporarily change instead of requiring contract amendments.

2. Regional efficiencies

At the regional level, some red tape issues are caused by poor communication or inconsistent practices by PDD staff across communities (within geographically large regions) or across regions. In some cases, these are due to frequent turnover in PDD staff; in other cases, they are due to differences in regional practices.

Some of these practices, such as eligibility determinations and intake processes, vary across regions yet can easily be standardised for province-wide consistency.

Communication and basic information about individuals and contracts can be made accessible by consulting on a mechanism and process to increase information accuracy and speed of access. This would mitigate inefficiencies due to turnover, provide continuity in information transfer when an individual moves to another agency, and reduce the need to compile and submit frequent reports. In the long-term, the development of a shared database could be a potential solution if issues of privacy, ownership and access are addressed.

We suggest

Examine regional processes and systems to identify ways to increase efficiencies:

- Implement standardised processes where relevant.
- Develop a mechanism to share accurate and consistent information between agencies and PDD on contracts and individuals in service.

3. Cross-system intersections

At the more macro level, red tape issues arise due to the significant differences across the many government departments accessed by individuals with disabilities.

Each program has its own access criteria, processes and service protocols. Many programs have been designed without intentional consideration of their impact on individuals with disabilities. Individuals receiving supports and their care providers may experience these programs in different ways than what they are accustomed to, or what might be optimal for their needs.

Although these intersections provide challenges, they also offer opportunities. Removing inconsistencies and identifying ways to increase seamless access and transitions will contribute greatly to maximizing efficiency and effectiveness.

We suggest

Review areas of overlap or barriers between PDD and other systems and programs to ensure individuals can access appropriate systems seamlessly and effortlessly. This includes reviewing policies, programs and initiatives to assess and address their potential impact on individuals with developmental disabilities.

Conclusion: The need for a systems approach

Time and time again, from various PDD engagement processes, one theme persists: the lack of a common and overarching vision for supports for Albertans with disabilities. This has prevented us from addressing the chronic issues that have become deeply embedded in the PDD program.

We urge the current government to forego the temptation to implement quick-fix solutions and invest, instead, the time and effort to engage with ACDS and the sector to develop a collaborative, systems-focused solution.

The first step in a framework for a systems approach is to articulate our shared vision and values.

The PDD program purpose is "to help adults with developmental disabilities get services to live as independently as possible in their community."[6] However, there is no clear understanding of what that means or looks like in practice.

- What do inclusion and independence mean for PDD?
- Do individuals and families agree with PDD's understanding of these concepts?
- What are the resources and support strategies necessary to achieve these goals?
- How are individuals with complex needs best supported to live inclusively in their community in a way that honours and protects human rights and balances the safety of individuals, community disability workers and community members?

There are also questions of values. Values demarcate the line between what cannot and will not be undermined to achieve the vision.

- What are our most fundamental values about our shared societal responsibilities to ensure people with disabilities have good lives?
- What will it take to uphold these values regardless of shifting economic pressures or competing visions of society?

Every single conversation intended to influence or impact the program of supports for Albertans with disabilities must begin by intentionally articulating our shared vision and values. Consultations, whether planned or ad hoc, that do not begin from this foundation are unlikely to result in the best and lasting interest of the very individuals the program is intended to support.

We recommend that the Alberta Government collaborate with the community disability services sector to articulate a shared vision and common values, as a foundation to the development of a cohesive plan to achieve the full citizenship of individuals with disabilities.

We recommend that the Alberta Government make a commitment to engage with ACDS and the community disability services sector stakeholders to take a systems approach to design a sustainable and impactful program of supports for Albertans with developmental disabilities.

✓ These overarching recommendations align with the government's desire that "the government should do more to help Albertans with disabilities" and its promise to "enact policies that support the desires, dignity and choices of Albertans with disabilities" (UCP Platform, p.77).

[6] Government of Alberta. Persons with Developmental Disabilities (PDD). https://www.alberta.ca/persons-with-developmental-disabilities-pdd.aspx

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