

## Moving Forward: A Vision and Framework for Impact

*This document was originally prepared as a submission to the Persons with Developmental Disabilities (PDD) Program Review Panel*

### ABOUT ACDS

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ACDS is a not-for-profit network of over 145 community disability sector organizations, representing 80% of agencies funded by the PDD program. Our members employ 15,000 people to provide supports to over 12,000 Albertans with developmental disabilities.

Since our origin in 1973 as the Alberta Association of Rehabilitation Centres, we have been regarded as a trusted and respected partner, collaborating with the Government of Alberta and community allies to strengthen services and develop supportive policies to

benefit Albertans with developmental disabilities and the community disability services sector as a whole.

**Our Vision** People with disabilities live full lives as citizens supported by a vibrant network of services in their communities

**Our Mission** To be the collective voice of our members, advancing excellence and best practices, advocating for effective public policy, and championing professional disability services

### ABOUT THIS SUBMISSION

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#### Approach

We first present our vision and framework for vibrant communities and quality services. We then discuss specific topics that are of concern to our members, and provide our recommendations for solutions based on three guiding principles:

1. Respectful relationships
2. Prudent investment
3. Seamless and integrated systems

Unless specified, all quotes are from our Spring 2018 Membership Engagement Sessions, attended by 100 sector leaders representing over 65 organizations,<sup>1</sup> or from our 2018 Annual General Meeting.

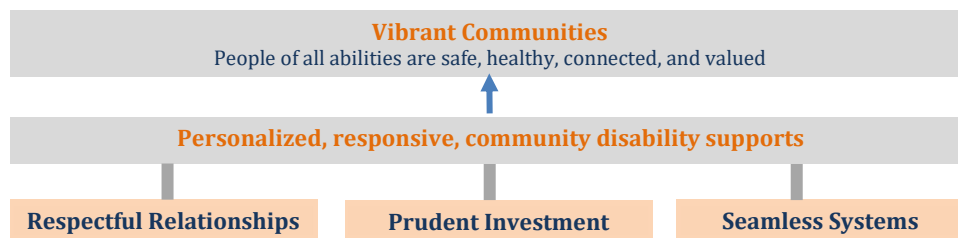
#### Sources

The content in this document draws on:

- **Realities and perspectives of our members**, obtained from diverse vehicles including membership consultations, forums, committees, and connections to regional service networks.
- **Information from ACDS surveys and periodic pulse checks**, which provide key sources for trends, demographics and state of Alberta's CDS sector.
- **Government reports and publications**, which provide data or context from previous conversations on disability services and policies.
- **Conversations with allies and partners** who share our vision and goals, including: the Alberta Disability Workers Association; the self-advocacy group, Disability Action Hall; ALIGN Association for Community Services; and others with whom we collaborate within and outside the disability sector to address systemic issues.

## ACDS VISION AND FRAMEWORK FOR IMPACT

Vibrant communities thrive when all citizens feel safe, healthy, connected, and valued. Community disability services facilitate the citizenship of Albertans with disabilities by providing essential personalized supports. We believe three foundational pillars are necessary for community disability services to achieve our vision for vibrant communities with maximum impact. These pillars are also our guiding principles for quality services.



### GUIDING PRINCIPLE 1: RESPECTFUL RELATIONSHIPS

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The delivery of government mandated supports by contracted agencies thrives when the relationship is built on a common vision, shared values and principles, and a foundation of trust.

- Maximizing the impact of this partnership requires shared vision and values, genuine commitment to collaborative problem-solving, timely access to information, transparency in decision-making, role clarity, and the reasonable allocation of accountability across the partners.

### GUIDING PRINCIPLE 2: PRUDENT INVESTMENT

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Investing in community disability services has high returns. It benefits the individuals receiving services, the people who support them, their communities, and the provincial economy. It saves public funds by helping people become contributing citizens, creates employment, establishes resources in communities, reduces risk, and strengthens the social fabric.

- Maximizing the impact and value of this investment requires supporting the real costs of community services, encouraging innovation, promoting a culture of continuous improvement, and fostering the development of a highly-skilled, professional workforce.

### GUIDING PRINCIPLE 3: SEAMLESS AND INTEGRATED SYSTEMS

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The lives of individuals with disabilities intersect with multiple programs and service, and are shaped by a broad range of policy areas. These intersections provide natural opportunities to leverage efficiencies and effectiveness.

- Maximizing the impact of these opportunities requires intentionally designing integrated systems, providing seamless access and transitions, and taking into consideration how changes in one area might impact other area

## SUMMARY OF RECOMMENDATIONS

### GUIDING PRINCIPLE 1: RESPECTFUL RELATIONSHIPS

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**A shared vision** We recommend that the Government of Alberta collaborate with individuals, families, community disability service providers, and related stakeholders to articulate a shared vision, common values, and a cohesive plan for quality supports to achieve the full citizenship of individuals with disabilities.

**Permanent forums for dialogue** We recommend that the Government of Alberta establish permanent provincial and regional forums for ongoing dialogue between government, ACDS and community disability service providers, individuals and families to inform planning, policy development, issue identification, and joint problem solving.

**Charter of Engagement** We recommend that the Government of Alberta engage with ACDS to collaboratively draft a Disability Services Charter of Engagement that has a framework with common vision and principles, well-defined rules of engagement, commitment to transparency, and a clear statement of the distribution of roles and responsibilities.

**Open portal for disability data** We recommend that the Government of Alberta, upload and provide full access on the government's open data portal to accurate and comprehensive information related to the PDD program, including demographic projections, current service usage and waitlists, funding, and regional profiles.

**Contracting framework** We recommend that the Government of Alberta, collaboratively with community disability service providers, develop a comprehensive framework to guide the creation of consistent contracting processes, including transparent funding formulas, clear budgeting approaches, and tools to streamline reporting and evaluation protocols. The core aspects of such a framework have already been identified by the Agency and Human Services Procurement Advisory Table in 2016.

### GUIDING PRINCIPLE 2: PRUDENT INVESTMENT

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**Flexible, responsive funding model** We recommend that the Government of Alberta provide predictability and sustainability through contracts that: are spread over at least 3 years; are indexed to inflation; incorporate all administrative and indirect costs associated with providing quality supports (true cost of service); and, allow service providers the flexibility to re-allocate funds to accommodate the changing needs of the individuals receiving supports.

**Innovation Fund** We recommend that the Government of Alberta set aside an annual envelope of funding dedicated to support community disability service providers to pilot, evaluate, share, and scale up innovative, successful service models and approaches.

**Comprehensive human resource strategy** We recommend that the Government of Alberta, in collaboration with community disability services, post-secondary institutions, and community training providers develop a framework and plan for a comprehensive human resource strategy, that includes adequate and sustainable funding for staff compensation, training, and professional standards designation applicable to all community disability workers regardless of employment context (service providers and FMS).

## GUIDING PRINCIPLE 3: SEAMLESS AND INTEGRATED SYSTEMS

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**Broader eligibility and improved assessment** We recommend that the Government of Alberta expand the eligibility criteria for PDD programs to include individuals who may otherwise fall through the cracks, including those transitioning from Family Support for Children with Disabilities (FSCD) with broader access to services and to widen the involvement of people who know the individual in the assessment process. Any expansion to the criteria must be accompanied with proper resources to community disability service providers to meet these increased demands, including enhanced funding for staff training.

**Program and Systems Access** We recommend that the Government of Alberta review areas of overlap between PDD and other systems and programs, and address barriers, and inconsistencies in access criteria and approaches by ensuring people with development disabilities are able to access appropriate systems outside PDD, consistent with other Albertans.

**Disability-based analysis** We recommend that the Government of Alberta review all government policies, programs, and initiatives to assess and address their potential impact on individuals with disabilities in the same way that the government has committed to conduct analysis of its policies, programs and processes for other frequently impacted groups.

## Guiding Principle 1 - Respectful Relationships

### ISSUE 1: A SHARED VISION

#### CONTEXT

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Time and time again, through various engagement processes—whether these are driven by members of the community disability sector or government-initiated community consultations as part of program reviews such as this one—we consistently hear that there is a lack of a common and overarching vision for supports for Albertans with disabilities.

The PDD program states as its mission: “to support adults with developmental disabilities to be included in community life and to be as independent as possible.”<sup>2</sup> However, there is no articulation of what that looks like. What do inclusion and independence mean for PDD? Are these definitions the same as what individuals receiving PDD supports or their families would consider inclusion and independence? What are the resources and support strategies necessary to achieve these goals in the community? How are individuals with complex needs best supported to live inclusively in community in a way that honours and protects human rights and balances the safety of individuals, community disability workers and community members?

In addition to a clear, collaboratively developed vision statement that all stakeholders agree on, there is a need for a clear articulation of the shared values underpinning this vision. Values demarcate the line between what cannot and will not be undermined to achieve the vision, and other areas where there may be room for negotiation or compromise. What are these most fundamental values? What will it take to uphold these values regardless of shifting economic pressures or competing visions of society?

The answers to these questions are necessary pre-requisites for shaping the policies, programs, funding levels, contractual obligations and accountability mechanisms for government-mandated, community-based supports for Albertans with disabilities.

Currently, however, there is an overwhelming sense that there is no commonly understood vision or a coherent plan. In the daily lives of service providers, this manifests as inconsistencies in processes, confusion around goals and outcomes, and ever-shifting accountability requirements.

“The focus of the vision and philosophy has shifted from quality of life to custodial care. We’re expected to support community inclusion, but given resources to provide basic care.”

“Accountability is very important. But we need to know what exactly the government requires to ensure accountability. ...[PDD doesn’t] know what is actually important.”

#### RECOMMENDATION

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**A shared vision** We recommend that the Government of Alberta collaborate with individuals, families, community disability service providers, and related stakeholders to articulate a shared vision, common values, and a cohesive plan for quality supports to achieve the full citizenship of individuals with disabilities.

## Guiding Principle 1 - Respectful Relationships

### ISSUE 2: COLLABORATION AND MEANINGFUL ENGAGEMENT

#### CONTEXT

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The partnership between government and community disability service organizations in Alberta dates back to the 1970s, as policy makers, program administrators, community agencies and families collaborated closely to support deinstitutionalization.

Since the 1990s, the relationship between government and service agencies has become largely transactional and prescriptive, reflecting more acutely its contractor-vendor aspect than its origins as a true partnership.<sup>3</sup>

However, even as this relational shift has occurred, there have been examples of structures and processes to facilitate engagement and collaboration. These include various provincial and regional advisory committees, some which have provided spaces for general dialogue and feedback, while others which have been more program or issue-specific. For reasons unknown, these forums have been unilaterally disbanded by government.

The result is an uneven landscape, creating barriers to collaboration and meaningful engagement across the PDD program. In some regions, communication between agencies and PDD staff is absent, infrequent, or involves people without decision-making authority. In other regions, PDD staff inform service providers of changes and developments, but provide little direction or support to address the resulting implications or

issues. Some service providers feel that even when PDD does include them, the process is not collaborative: agendas are set and conversations are top-down, driven by government and its needs and priorities rather than bottom-up, driven by individuals or those responsible for supporting them. In most cases, this results in service providers having to be reactive to changes, rather than working proactively with PDD to develop effective strategies.

Unless there is a strong, embedded culture of collaboration, meaningful engagement requires intentionally created structures, mechanisms and processes. For these to function in ways that can build trust over time, there needs to be a clear framework articulating the common vision, goals, and mutually agreed upon rules of engagement.

“We want government to engage with us at all stages: from the development stage, to the implementation stages.”

“People who meet frequently seldom differ.”

#### RECOMMENDATIONS

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**Permanent forums for dialogue** We recommend that the Government of Alberta establish permanent provincial and regional forums for ongoing dialogue between government, ACDS and community disability service providers, individuals and families to inform planning, policy development, issue identification, and joint problem solving.

**Charter of Engagement** We recommend that the Government of Alberta engage with ACDS to collaboratively draft a Disability Services Charter of Engagement that has a framework with common vision and principles, well-defined rules of engagement, commitment to transparency, and a clear statement of the distribution of roles and responsibilities.

## Guiding Principle 1 - Respectful Relationships

### ISSUE 3: INFORMATION AND TRANSPARENCY

#### CONTEXT

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Just as there is an uneven landscape in the extent of collaboration and meaningful engagement across the PDD program, so too are there inconsistencies in the sharing of information. Service providers cite numerous examples, encompassing the full range of the service delivery process.

- Demographic projections of people expected to need disability supports in the future are not available, restricting the ability to plan
- Accurate data about individuals in services and on waitlists is also not available to service providers
- There are regional differences in funding processes and expectations, including how contracts are awarded, what costs are included, how these are calculated, and what outcomes and reporting standards are expected. Service providers describe the contracting process as “convoluted and cumbersome,” one that changes depending on the PDD staff and their relationships with the service provider or the family advocate.
- Complete information about individuals moving from one service provider. It appears that full disclosure is not occurring in some instances, especially for individuals with complex needs.

Service providers generally have good working relationships with PDD staff, characterised by mutual respect and recognition that we are all working toward

the same goals. However, systemic constraints, by design or otherwise, are creating information barriers, resulting in suspicion and distrust. Without shared understanding of the needs and realities of the system and program, community can not engage in shared solutions with government.

The solution, as suggested previously, is to create intentional structures to enhance information exchange and transparency. These include making available PDD information on the government’s open data portal to a much greater extent, and developing a comprehensive framework to guide and streamline contracting decisions and processes, much like what was proposed by the Agency and Human Services Procurement Advisory Table (2016).<sup>4</sup>

“Engagement requires that everyone has the information to contribute meaningfully.”

“Data-based decision-making requires data; accessible and transparent to all stakeholders. Engagement is meaningless without commonly accessible data.”

#### RECOMMENDATIONS

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**Open portal for disability data** We recommend that the Government of Alberta, upload and provide full access on the government’s open data portal to accurate and comprehensive information related to the PDD program, including demographic projections, current service usage and waitlists, funding, and regional profiles.

**Contracting framework** We recommend that the Government of Alberta, work with ACDS and service providers to develop a comprehensive framework to guide the creation of consistent contracting processes, including transparent funding formulas, clear budgeting approaches, and tools to streamline reporting and evaluation protocols. The core aspects of such a framework have already been identified by the Agency and Human Services Procurement Advisory Table in 2016.

## Guiding Principle 2 – Prudent Investment

### ISSUE 1: REALISTIC AND RESPONSIVE FUNDING

#### CONTEXT

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Funding community disability services to deliver government-mandated supports is, and should be treated as, an investment that strengthens local communities and benefits the provincial economy. To maximize its return and impact requires treating it like any valued investment: ensuring contributions keep up with inflation, addressing real costs, and being responsive to changing needs and pressures.

#### Inflation and economic pressures

Despite significant increases to the PDD program over time, funding to community agencies has not kept pace with inflation or recognized other economic pressures. The historical lag in funding impacts the entire organization, but manifests most acutely in the chronic, decades-long issue of low staff wages, a topic discussed in more depth later in this document.

#### Administrative and indirect costs

**Contracts do not take into account all of the administrative and operational costs associated with running sound and sustainable organizations.** Service providers tell us that funding for these costs has not increased since 2014. This alone equates to 5.75% erosion in funding based on the inflation over the past 4 years.<sup>5</sup>

Contracts also do not cover indirect costs associated with providing quality supports. These include time and costs associated with submitting service proposals, getting to know the individual, consulting specialists

and professionals, developing community relationships to optimize the individual's participation opportunities, arranging service review meetings, and navigating bureaucratic processes for changing services.

Service providers are forced to fund these costs by reducing expenses, pulling from other internal resources, and seeking additional revenues. These activities impose significant stress on services, and divert energy from providing quality care.

#### Paperwork and accountability

Accountability pressures have increased significantly over time. Prescriptive and stifling processes of oversight and micromanagement, manifested through an overload of paperwork, have become a necessary part of service provision. These are not funded, nor is it clear what purpose they serve.

“Why isn’t there enough funding for community services given that the PDD allocation keeps increasing? Where is the money going? How much is going to PDD?”

#### RECOMMENDATIONS

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**Flexible, responsive funding model** We recommend that the Government of Alberta provide predictability and sustainability through contracts that: are spread over at least 3 years; are indexed to inflation; incorporate all administrative and indirect costs associated with providing quality supports (true cost of service); and, allow service providers the flexibility to re-allocate funds to accommodate the changing needs of the individuals receiving supports.



## Guiding Principle 2 – Prudent Investment

### ISSUE 2: SUPPORTING INNOVATION

#### CONTEXT

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There have been numerous initiatives in the past to support community disability service providers to implement innovative service models and try new concepts. However, these typically have ended with little to show for any lasting impact.

Service providers feel that there is no support for wide-scale implementation of successful projects, or for sharing knowledge and learnings from these projects more broadly.

The Achieving Better Outcomes Initiative (ABOI) was cited as one such example of a promising initiative which ended before any dissemination or impact could be achieved.<sup>6</sup>

Initiated by PDD, ABOI began with then Minister of Seniors and Community Supports, Hon. Greg Melchin hosting a day-long brainstorm session in May 2007 with PDD stakeholders to identify innovative ideas to achieve better outcomes for individuals. From as many as 52 ideas presented, 10 priority projects were eventually supported.

At the end of 2008, the Advisory Committee's final report showed that many of the priority projects had achieved positive outcomes. The Committee

recommended PDD to: (i) continue to invest in innovation; (ii) commit to implementing the successful projects, and (iii) invest in sharing the learnings from the projects. However, for reasons unknown, the initiative was discontinued.

One example of the many innovative practices that community disability service providers develop to provide quality supports can be found in the Appendix.

"The ABOI project was, I believe, the most positive and full of opportunities for positive change that has been initiated by the GOA in a very long time. Unfortunately, the recommendations from the advisory committee were not followed up on, nor were the positive results achieved by many of the pilots widely shared. Celebration and sharing of the information was to have been the final phase of this project. All this was dropped by the government people..."

#### RECOMMENDATION

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**Innovation Fund** We recommend that the Government of Alberta set aside an annual envelope of funding dedicated to support community disability service providers to pilot, evaluate, share, and scale up innovative, successful service models and approaches.

## Guiding Principle 2 – Prudent Investment

### ISSUE 3: COMPREHENSIVE HUMAN RESOURCE STRATEGY

#### CONTEXT

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Human resource issues are the top concern for community disability service providers, and have been so for over two decades. Issues revolve around recruitment and retention challenges related to the intractable gap in compensation between public sector employees and community-based staff, the closure of post-secondary disability programs, the training burden that agencies have consequently been forced to bear, and the lack of access to training to support individuals with increasingly complex and specialized needs. There is also a need for a formal system that recognizes the qualifications of staff in a way that is comparable across organizations.

#### Compensation

Compensation for frontline staff has been below market value for a long time compared to similar jobs in other sectors, such as nursing, homecare, and teaching aides. Compensation is also lower for other positions compared to their counterparts in the public and private sectors. Despite this, funding contracts have not provided any wage increases for five years.

According to Alberta Labour's Alberta Wage and Salary Survey (AWSS),<sup>7</sup> the overall average hourly wage in 2017 for all occupations in non-profit social service organizations was \$23.59, compared to \$27.09 in the for-profit sector and \$37.64 in the public sector (p.7). Occupations classified as care providers (NOC-44) had an average hourly wage of \$19.49 in the non-profit social services sector, compared to \$26.30 in the public sector, a differential of 35% (p.8).

The 2017 ACDS Annual Workforce Survey,<sup>8</sup> which contained wage information for over 4,500 workers in community disability services province-wide, reported the average hourly wage in 2017 for all positions at \$21.06, ranging from \$18.73 in the South region to \$22.26 in North West (p.25). Frontline hourly wages started at \$13.60 and topped off at \$33.00 for workers supporting individuals with complex needs (p.26).

These numbers do not take into account benefits, which generally tend to be better in the public and private sectors than in the non-profit sector. Nor do they reveal wage compression issues caused by increases in minimum wage without concurrent increases in funding to provide commensurate raises for staff earning more than minimum wages.

High wage differentials coupled with less competitive benefit packages make recruitment and retention of qualified staff a perennial issue for service providers. In 2017, overall turnover in Alberta's community disability sector was 23.9%, and as high as 32.8% in the South region and 36.6% in Central (p.28). Turnover was highest for Community Disability Service Workers (CDS-W) at 31.7% province-wide (p.34).

Recruitment and turnover costs are not adequately recognized in funding contracts. Turnover also has a significant impact on the quality of life of individuals receiving services.<sup>9</sup> Addressing recruitment and retention, thus, is an ongoing and stressful activity for community disability service providers.

#### Post-secondary programs

Low wages and demanding work have made the sector less attractive to post-secondary students. Expected wages are insufficient to justify the costs of certificate, diploma or degree programs in disability studies. Since 2008, nine post-secondary disability programs have been discontinued in Alberta due to low enrollments. As older workers retire or reduce their work, service providers have few qualified young people to hire.

"Wages. It boils down to wages. Until the wage gap is addressed, recruitment and retention will be ongoing issues."

## Training

When new staff are hired, many often need training in some of the most basic skills to work in this sector. This includes the range of mandatory technical training, and also imparting the values for supporting individuals with disabilities to achieve citizenship and full participation in the community. In addition, the growing number of aging individuals and individuals with complex needs has expanded the scope of training needed, including the need for specialized training in medical supports and technical skills such as patient lifting and transfer as well as mental health and addictions.

Access to training varies greatly. Although basic and mandatory training are readily available, often through train-the-trainer programs and local community partners, specialized training opportunities in rural areas and in the remote northern locations are either not available or expensive. In addition, staff are increasingly diverse in background creating cultural and language challenges in traditional training mechanisms.

The costs for training staff is a real and considerable issue. Costs include course fees, travel expenses, staff pay, and coverage for people who are away at training. In addition, there is the cost of recertification of some courses. In some cases, there is duplication of resources as staff who work for more than one agency often repeat their training (e.g., medications administration) with their different employers.

Training is also needed for agency leaders and Boards. In recent years, large numbers of senior executives have started to retire, creating a leadership gap in many organizations. Executive leadership and Board governance training are both needed as the sector witnesses a churn in these positions.

The inadequate funding in the sector has created a vicious cycle of recruiting untrained and inexperienced workers, providing core training, and then losing to higher paying jobs once they are trained and qualified. Time to train staff impacts directly on service provision and quality of life of individuals in service. Staff who are not properly qualified can result in poor support, or create a safety risk for individuals, staff and public.

“Post-secondary institutions have washed their hands of developing the next generation of workers. We are absorbing all the costs of educating the workforce. No other industry has to hire workers and train them from scratch.”

## Certification

Service providers have a difficult time assessing credentials of workers as most new workers do not have formal disability service qualifications when they enter the field, and different organizations and training bodies have different competency criteria. There is a call for a formal professional designation for positions in the community disability sector. Two mechanisms that can support the implementation of this already exist and need to be supported to achieve widespread adoption: (i) the ACDS Workforce Classification System, which identifies in great depth the competency criteria for each position, and (ii) ADWA’s worker certification process currently being piloted.

Human resource issues in the sector are chronic and urgent. Addressing them requires a comprehensive strategy encompassing wages, training, and development of the workforce.

## RECOMMENDATION

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**Comprehensive human resource strategy** We recommend that the Government of Alberta, in collaboration with community disability services, post-secondary institutions, and community training providers develop a framework and plan for a comprehensive human resource strategy which includes adequate and sustainable funding for staff compensation, training and professional standards includes adequate and sustainable funding for staff compensation, training, and professional standards applicable to all community disability workers regardless of employment context (service providers and FMS).,

## Guiding Principle 3 – Seamless and Integrated Systems

### ISSUE 1: ELIGIBILITY CRITERIA

#### CONTEXT

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Community disability service providers have mixed feelings about changing the PDD eligibility criteria.

##### A question of resources

The minority are unsure, or not in favour of changing the criteria. They feel that other ministries and programs that have mandated responsibility to provide supports to people who are not in the PDD program should be properly resourced so that people do not fall through the cracks. They also feel that there should be no changes to legislated and regulated criteria until there is a multi-ministry discussion to ensure there is a clear distinction of responsibility and enough resources to meet the responsibilities if there are any changes.

##### Broader criteria and a better tool

The majority favour expanding the criteria to include individuals who have received supports in the past through the Family Supports for Children with Disabilities (FSCD) program, or who need supports to cope despite having an IQ higher than 70, e.g., individuals with FASD or on the autism spectrum. These individuals typically fall through the cracks and could be accommodated within the PDD program.

Those in favour of broader criteria would like a better tool to assess ability to function in the community, not just IQ or the functional abilities currently measured.

##### Improved assessment process

The assessment process is lengthy and excludes people who may know the individual the best. There are too few professionals to do the assessments, which results in a long time to access PDD supports or to appeal the decision. One suggestion is an intake panel that includes people with a prior support relationship with the individual, e.g., FSCD and agencies that provided supports before the individual turned 18 years old, for a more holistic assessment of eligibility.

##### Cross-ministry barriers

Different programs have different criteria and approaches. Individuals eligible for supports under FSCD may suddenly lose them the day they turn 18 years of age. If a person is eligible for PDD but also needs mental health supports, accessing the latter is not automatic. When programs operate in silos, navigating these become challenging, resource intensive, and may create a crisis for the individual and potential risk in the community.

It is prudent to expand criteria so that people do not fall through the cracks. However, as an advocate for community disability services, we want to ensure that service providers are adequately and sustainably funded to support individuals who may not have accessed their services in the past. This means additional resources including funding, proper training for staff, and more seamless and consistent cross-ministry connections.

#### RECOMMENDATION

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**Broader eligibility and improved assessment** We recommend that the Government of Alberta expand the eligibility criteria for PDD programs to include individuals who may otherwise fall through the cracks, including those transitioning from FSCD with broader access to services and to broaden the involvement of people who know the individual in the assessment process. Any expansion to the criteria must be accompanied with proper resources to community disability service providers to meet these increased demands, including enhanced funding for staff training.

## Guiding Principle 3 – Seamless and Integrated Systems

### ISSUE 2: SEAMLESS ACCESS AND TRANSITION

#### CONTEXT

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Like all Albertans, individuals with disabilities come into contact with and are impacted by a wide range of programs, services, and systems such as income supports, health, justice, housing and seniors. As well, the scope of supports that agencies need to provide has expanded as individuals with disabilities are living longer and participating in the community in more diverse ways. In addition, many individuals with disabilities receiving community-based supports have complex, and in some cases increasingly ultra-complex, behavioural and medical support needs.

#### The parallel system

For individuals with complex needs, the intersections with certain systems and policy areas are more frequent, intense, and demanding than most other individuals in service. It is important to note that the costs of these transactional interactions are borne by PDD. As the number of people with complex and ultra-complex needs increase, the cost of this parallel system will keep burgeoning.

Furthermore, a number of supports that should be available to people with disabilities through existing

programs are instead being provided by duplicate processes within PDD, creating, in effect, a “parallel system.” Therefore, there is the risk of potential financial inefficiency, or even gaps if one system believes the other is covering off responsibilities.

Although many social service programs are under the Ministry of Community and Social Services, there are significant differences across departments. Interactions between departments are often incongruent, with each having 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 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 natural opportunities to leverage efficiencies and effectiveness. Designing intentionally integrated systems, with seamless access and transitions, and addressing how changes in one area might impact others can maximize the impact of these opportunities.

#### RECOMMENDATIONS

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**Program and systems access** We recommend that the Government of Alberta review areas of overlap between PDD and other systems and programs, and address barriers, and inconsistencies in access criteria and approaches by ensuring people with development disabilities are able to access appropriate systems outside PDD consistent with other Albertans.

**Disability-based analysis** We recommend that the Government of Alberta review all government policies, programs, and initiatives to assess and address their potential impact on individuals with disabilities in the same way that the government has committed to conduct analysis of its policies, programs and processes for other frequently impacted groups.

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### Vision

People with disabilities live full lives as citizens supported by a vibrant network of services in their communities

### Mission

ACDS is the collective voice of our members, advancing excellence and best practices, advocating for effective public policy, and championing disability services

## APPENDIX

### Innovation story submitted by Blue Heron Support Services Association

Blue Heron Support Services Association (BHSSA) purchased a Duplex in 2015. This duplex was intended to be a transitional home for new individuals with dual diagnosis. (Developmental Disability, Mental Illness and Addictions). These are generally complex individuals that transition into service with Blue Heron and may come from other service providers, the justice system, Alberta Hospital etc. Up to three individuals can reside in the duplex at a time and these individuals require staff trained to complex needs supports as well as harm reduction training.

**The innovation story below is based on one of these individuals:**

Peter (name changed) was accepted into service in January 2015. He had a history of substance use, developmental delay, and drug induced psychosis/ schizophrenia. Peter spent quite a few years within the justice system due to the substance use and criminal activity that he participated in to continue to support his substance use.

When Peter arrived to the program, he was on probation as a result of charges he received due to an incident where he had forced his way through a drywall covered wall (both sides), looking for the hallucinations that he was experiencing. Through this, he had caused fear and anxiety for his family members. Peter's family found support services with BHSSA to meet his needs. Peter was admitted into the Addiction Recovery Program. These services provided Peter with a flexible structured program that provided 24-hour awake support staff. The program was double staffed for 18 hours per day. Although recovery based, this program was not specifically associated with sobriety. The approach was harm reduction in all aspects of the program.

In March 2016, he finished his probation, meeting all the requirements of the order. In July 2017, we started the process of transitioning the style of supports that his staff used into a more reflective and relapse prevention focus. Every day, in every circumstance, staff engaged Peter in the reality of the world around him, and focused all their efforts in empowering him to take an active role in his own sobriety. We slowly started fading supports and shifting supports from a process of walking him through things step, by step, to having him work through situations with his peers, supervised and guided by staff. Services were designed to provide Peter with opportunities and resources where he could focus his needs through more natural community supports.

In June 2018, Peter transitioned into an independent living situation. He currently resides by himself in a basement suite, although there are other individuals that the association supports living upstairs in the house. This living situation helps to create another level of security and risk management for the transition. He currently receives 8hrs per day of support and he manages everything in his life including his own finances. Peter has had no further incarcerations or hospitalizations for his mental health. He is currently employed as a compassionate care worker, where he supports seniors with recreation and building relationships. Peter's family is no longer scared of him and he is flourishing in his new life!

Peter's success was attributed to the following efforts and supports over the last 3.5 years.

1. Strong, qualified leadership that understood and were trained to understand the specific issues that Peter faced
2. Collaboration with community supports and other professionals. This included everyone in the community that Peter may come into contact with prior to receiving his service including: RCMP, AADAC, Mental Health, Probation, Edmonton Remand Center. Everything for Peter was planned on a "just in case" situation.
3. Specialized training for every staff in the home, including training in; schizophrenia, harm reduction, experiential support training, legal navigation, trauma informed care, Mental Health First Aid, how to support individuals with hearing voices, how to have conversations around addiction, drug training, what it is like to be homeless, the prison system, just to name a few. This training was over and above the numerous mandatory



## APPENDIX

### Innovation story continued

4. training courses that the association required these staff to do as well. These specialized training required considerable time and resources by the team lead to implement.
5. Consistent crisis management support, being able to respond to every situation, while the program was built.
6. Training for Peter himself, such as recovery, relapse and learning all the resources in town.
7. Flexible Support staffing structure. Meet Peter and his roommates where they were at, and how they were that day.
8. "Sneaky structure" programming developed where the individual did not feel programmed. Natural learning experiences and situations that were pre-planned for success. For example, doing counselling sessions that met his needs. With previous trauma, office visits and structured counselling was not accepted. So we would "accidentally run into one of the addictions counsellors at a local restaurant or store each week, until Peter's interest was there to talk with this person more.
9. Started small, staff worked to complete the counselling tasks that were assigned to staff with Peter each week, without them being formal assignments.
10. RCMP relationship building strategy. Helping Peter build a relationship with RCMP in a positive way before he had a negative experience. Started with simply waving to them on the street, then "dropping off papers to them," and finally having coffee at the local restaurant.
11. Everything was pre-planned and risk managed as much as possible.
12. Slowly... very slowly giving more responsibility to Peter. For example, he started with 10 minutes without support at a time in the community, then 20 minutes, and eventually made his way up to 5 hours per day.
13. Building and practicing skills for independent living while being in a supported environment. I.e. Financial: he had no freedom with his own finances at the start of services and over time he controlled his own spending money each month. Once he could manage that, we added 1/2 of his grocery money, and then his other expenses. An account with previous savings was developed in the event that he failed (set up with trustee). This prevented Peter from losing his home, utility services, or going without groceries.
14. When Peter transitioned into his independent living situation, he kept the same staff and the same program coordinator to ensure consistency.
15. Making it OK to talk about everything, at all times. Talking about his past drug use, cravings, thefts, criminal activity, and homelessness and structuring these conversations as learning opportunities, each and every time they came up.

With this type of program many challenges arose including:

1. Obtaining and retaining qualified staff
2. Obtaining staff that understood and were comfortable being nonjudgmental in this complex situation. As the conversations were always challenging and the content, often shocking, staff struggled with being ok with the previous lifestyle choices such as prostitution and theft.
3. Training for staff. This was a new adventure for the association and a lot of training needed to be developed.
4. Awake overnights- these are always hard to staff.
5. Staff burnout rates are high in this program as everything can be intense. Staff are not only dealing with individuals with complex needs, but navigating friends and supports of Peter that also had complex needs, including active drug use, prostitution or incarceration and managing the risks this presented for Peter.
6. Buy-in with community members/professionals on how to support individuals with developmental disabilities with mental health and addiction concerns. The individuals did not fit into a "mold" for counselling and professionals felt that they were not equipped to help individuals like Peter.
7. Creating partnerships in local businesses the individual frequents, to be another level of support if needed.
8. Acceptance: Training RCMP about FASD. Accepting that the association could provide support and knowledge to RCMP and that we could actually be supporting them through situations.
9. Fluctuating Mental Health Supports required due to periodic drug use.

Thank you for sharing Peter's story.