

Inclusion Alberta

PDD Program Review

Suggested Issues and Recommendations

Inclusion Alberta has drafted this document to assist Albertans in their participation and contribution to the government's PDD Program Review. As per previous communications, we would like to remind everyone that you can participate directly by attending community conversations in your part of the province, completing the online survey, and/or submitting your ideas in writing, via video or other media.

Information on how to participate and when and where community conversations are occurring can be found at [PDD Program Review](#). We think it particularly important that parents of young children with developmental disabilities participate as this Review provides an opportunity to influence the shape of supports and services you will likely require in the near future for your son or daughter to have a meaningful and inclusive life.

We understand the issues and recommendations in this document do not cover the full breadth of experiences or concerns individuals with developmental disabilities and their families have relative to PDD. You should raise those issues and recommendations that are important to you, including those that arise from personal and direct experiences with PDD.

The term "PDD Community" used in this document refers to individuals with developmental disabilities, their families, those who provide supports and services and community allies.

The 10 issues and their recommendations are:

- 1) The Need for an Overarching Vision and Future Plan
- 2) PDD Provincial Advisory Committee (PAC)
- 3) Eligibility
- 4) Indigenous Albertans with Developmental Disabilities
- 5) Family Managed Supports Resource Centres (FMS)
- 6) A Trained and Certified Workforce
- 7) Inclusive Employment
- 8) Inclusive Post-secondary Education
- 9) Complex Needs
- 10) PDD Program Disparities

At the end of the document is a list of all the Recommendations.

1) The Need for an Overarching Vision and Future Plan

For some time now, government has not had an overarching vision and plan with respect to the future development of PDD; particularly not one developed in collaboration with the PDD Community. We do not see this Program Review as the appropriate means by which an overarching vision and plan would be developed but as the means to recommend to government that it engage in a process with the PDD Community to develop and implement a vision and bold plan for the future.

The government states it has increased PDD funding by \$150 million in the past few years, but this has been done without a known plan or future vision, particularly one developed in conjunction with the PDD Community. We do not know how these funds have been expended given a lack of transparency and consultation with the PDD Community. Many substantial PDD program elements are 50-year-old constructs, such as group homes and day programs, and it is possible new funding rather than enabling more progressive options is still sustaining outdated concepts. Just as Albertans without disabilities want a government committed to continuously improving and advancing health care and education, Albertans with developmental disabilities and their families should demand and expect no less with respect to PDD.

Existing outdated service and support models may continue but any new government funding should be dedicated to service delivery and support models that are individualized and personalized while promoting and enabling individuals with developmental disabilities to be fully included in community life. In the future, individuals with developmental disabilities should be supported to live in their own homes and be active and participating members of their communities and not limited in life by being congregated and segregated in where they live and how they participate in community. Advancing inclusion to a greater degree will require a multi-year plan with clearly articulated goals, means and measures.

Recommendation

That government, in collaboration with the PDD Community, initiate a process to develop an overarching plan and future vision for the delivery of supports, services and funding that will lead to increasingly inclusive life outcomes for individuals with developmental disabilities and their families.

2) PDD Provincial Advisory Committee (PAC)

For decades, government departments responsible for services for persons with developmental disabilities established and engaged a PDD Provincial Advisory Committee (PAC). This Committee was made up of individuals with developmental disabilities, family leaders from across the province, service provider representatives and senior government officials responsible for PDD. PAC met regularly and provided an opportunity for family members, individuals and providers to be in dialogue with policy makers, provide feedback on existing PDD policies and practices and make recommendations as to future needs and actions.

PAC ceased to exist when, without any consultation, the current government eliminated the Committee approximately 18 or more months ago. Families and individuals with developmental disabilities were never informed of the government's intention and no reasons were ever shared. However, the Provincial Parent Advisory Committee for Family Support for Children with Disabilities (PPAC) continued, so it is confusing as to why the PDD Provincial Advisory Committee was unilaterally terminated. The Premier's Council on the Status of Persons with Disabilities continues to exist, but it does not serve anywhere near the same purpose as PAC and is entirely government appointed individuals, many of whom have no relationship, experience or expertise relative to PDD.

A principal means of valued communication whereby individuals with developmental disabilities, families and providers could and did meaningfully collaborate with government in the interest of continuously improving PDD simply ceased to exist when PAC was unilaterally ended. PAC needs to be re-established and the PDD Program Review is an excellent, but one-time-only, vehicle by which to advocate for its reinstatement.

Recommendation

Re-establish the PDD Provincial Advisory Committee (PAC), with representation of families, individuals with developmental disabilities and service providers, determined by the PDD Community itself. A revitalized PAC will be essential to ensuring an environment of trust and communication to enable the recommendations flowing from this PDD Review to be implemented successfully. This requires a commitment from government to listen and act in good faith on the basis of input from PAC.

3) Eligibility

Until August 2009 the PDD eligibility criteria allowed for the PDD Program to consider individuals whose IQ scores were above 70. Government budgeted and allocated resources accordingly and any existing waiting times for services and supports were comparable to what exists today. That is, a broader allowance for eligible individuals did not negatively impact the availability of resources and funding.

In the past, eligibility could be granted to those individuals who had serious limitations in adaptive abilities and executive functioning. For example, individuals with Fetal Alcohol Syndrome Disorder (FASD) may score above 70 on an IQ test but in fact given their compromised executive functioning and adaptive skills, function no differently or may function less well, than someone with a much lower IQ score. The same would be true for other disabilities that impact adaptive behaviours and thinking skills.

Where an individual was denied eligibility, they or their family could appeal the decision, including taking the matter to court.

However, in 2009, government changed the criteria with the substantive difference being the regulatory requirement for an IQ of 70 (within a confidence interval of 95%) with a psychological assessment to be completed within 5 years of the date of the PDD application. These criteria were incorporated into a government regulation. As Appeal panels and courts are bound by government regulations (unless they violate the Charter of Rights), there was no chance of an eligibility appeal being successful when an individual had an IQ score above 70. At times, PDD might tell parents they could appeal, which technically was accurate, but in fact no appeal would be successful as the Appeal Panel was bound by the Regulation.

This created and continues to create crises for families whose family members do not meet the current IQ requirement yet clearly need supports given seriously compromised adaptive abilities and executive functioning. These are individuals who typically have or are receiving extensive supports from Family Support for Children with Disabilities (FSCD) given the complexity of their needs and the risks they pose to themselves and others. These families and their children are left without any supports the moment their child turns age 18. It is very confusing for families as, in effect, government has acknowledged through Disability Services the complexity of their child by providing extensive FSCD supports but the same Disability Services then advises that on their child's 18th birthday they are not eligible for continuing supports. This places families and individuals in harm's way. At times, but not consistently and not currently, government had provided limited funding to some individuals given their serious limitations in adaptive skills and executive functioning, outside of PDD but within Disability Services. This sporadic and limited funding is neither fair nor just, as it only benefits some and only to some degree.

Further challenges emerged with the 2009 regulation when Alberta Education no longer required an IQ score for determining school supports. The necessity for IQ assessments diminished and children with developmental disabilities did not necessarily undergo these assessments as they moved through school. When the time came to apply for PDD a recently completed IQ test simply did not exist. Part of the reason for changes in education related to the irrelevance of IQ scores in terms of teaching strategies and classroom placement plus the negative stigma and assumptions associated with lower IQ scores.

Even if one holds to the standard definition of intellectual disability based on an IQ score of 70 or less before the age of 18, there is nothing to suggest that the IQ score is a measure of who needs or should be entitled to support. IQ scores are simply not a valid ethical or scientific criteria for determining who needs supports and funding and what those should be. An IQ score should not be a determinant in whether or not an individual qualifies for support. We are not suggesting that PDD extend beyond its original eligibility criteria, only that it returns to that criteria which allowed for reasonable flexibility and judgment to be applied with access to appeals when someone had significant limitations in adaptive skills and cognitive abilities.

Recommendation

That the PDD eligibility criteria prior to August 1, 2009 be reinstated and the current eligibility criteria based on a fixed IQ score be rescinded. In turn, any impact related to additional Albertans being eligible for PDD supports needs to be taken into account by government in the allocation of its resources, as was true prior to 2009.

4) Indigenous Albertans with Developmental Disabilities

PDD funding and supports are not available to First Nations Albertans living on reserve. This means First Nations Albertans with developmental disabilities and their families can only access needed supports and services by leaving their First Nations communities. If they choose to remain within their First Nations, they and their families sacrifice access to the supports and funding that could make an invaluable difference to their lives. If they choose to leave in order to obtain supports, often feeling that this is not actually a freely given choice, they sacrifice culture, community and friends.

Although this issue has been raised for years, no action has been forthcoming in contrast to the fact that FSCD is available on reserves. The same multi-government agreement that enables FSCD to be offered on reserves includes provision for PDD to be similarly available but for reasons that are unclear, no action has ever been taken.

In addition, Indigenous Albertans with developmental disabilities and their families access PDD supports and services at a disproportionately lower rate than population demographics would indicate the rate of access should be. This is partially due to a lack of Indigenous operated or culturally knowledgeable resources within the PDD Community and Program.

Recommendations

The Alberta government should immediately negotiate with First Nations and the federal government to ensure the availability of the PDD Program on reserves.

In collaboration with Indigenous Albertans, a plan needs to be created to develop culturally relevant supports and services, including access to FMS, to better ensure Indigenous Albertans are accessing PDD.

5) Family Managed Supports Resource Centres (FMS)

The number of families interested in and utilizing Family Managed Supports (FMS) continues to grow, however, significant regional disparities exist and needed community resources have not been developed to keep pace with the growth. In some regions, families are well-informed by PDD as to the merits of FMS and often advised to contact Inclusion Alberta for more information and or assistance. In other regions, families may not even be told about FMS or are actively dissuaded from pursuing it as a funding option. FMS, as an approved provincial funding option, should be readily accessible as a choice.

It is a well-established reality, from decades of practice and experience locally, nationally and internationally, that more families will want to and be able to access FMS and realize its benefits when family-driven community resources are available to assist parents and individuals in utilizing FMS. The existence of Inclusion Alberta's Family Managed Supports Resource Center in Calgary, which has worked with over 500 families to-date, helps to explain why the uptake of FMS in Calgary is so much greater than in Edmonton; cities with comparable populations.

The Resource Centre was developed with the input of over one hundred Calgary families and created in partnership with Calgary PDD. Today it provides a wealth of services, from regular training events for families and FMS-funded staff to assistance with staff recruitment and employer responsibilities to costing and staffing arrangements. Most importantly, it works with families and individuals to create a vision and a plan for a meaningful and inclusive life and then assists with the implementation and refinement of that plan.

The Centre offers online resources and information, currently being updated and added to thanks to one-time funding from Community and Social Services. These online resources can be accessed by families across the province. However, these are still supplemental resources to the most critical and essential form of support which is a skilled and knowledgeable individual who can work directly with families guiding, mentoring, navigating and advocating as necessary.

For years, families in communities outside of Calgary have been meeting with government and respective MLAs, asking for Inclusion Alberta resource centres to be established in their community. Families in St. Paul, Grande Prairie and Medicine Hat have submitted formal proposals to government through Inclusion Alberta with operational descriptions and costs but have yet to have a formal response. Whenever families are given the opportunity to learn about the existent Resource Centre and the difference it makes, they become advocates for similar resource centres in their communities.

Recommendation

That government approve the funding of the three current FMS Resource Centre proposals it has received from St. Paul, Grande Prairie and Medicine Hat families and plan for the development and funding of additional FMS resource centres in Edmonton, Lethbridge, Red Deer and Lloydminster over the course of the next two years.

6) The PDD Community Workforce

The vast majority of PDD community funding provides for the staff that individuals with developmental disabilities and their families rely upon for support from ensuring safety and well-being, to achieving and sustaining employment, to a home and a meaningful life in community. Yet this workforce remains underpaid, undertrained and uncertified with resulting inordinate turnover rates and poor outcomes that take an incalculable emotional and human toll on the very individuals that are at the heart of PDD. Over the years there has actually been a loss in available training at the college level for people wanting to work in the field of developmental disabilities. Post-secondary training opportunities have diminished as the government does not require a relevant post-secondary education or training for people to work in this field. Nor are community services funded to pay staff according to their training and position, as is true in other social sectors in this province.

Repeatedly, and for years, taskforces and committees established by PDD to address workforce issues have made the same consistent recommendations, but government has neither listened nor acted. In fact, even now the latest committee has recently made the same recommendations as past bodies, and their recommendation is currently before government. The consistent recommendation has been for government to repeat what the government of the day did when it made the decision to implement a planned approach for the training and certification of staff working in child care, with wages commensurate with certification and responsibilities. This was very successfully implemented over a period of a few years with training opportunities for certification provided for those currently working in the field. Today training and certification are mandatory for employment in the child care field.

A lot of work has already been completed by the PDD Community in alignment with this approach which could readily be utilized in the development and implementation of a plan similar to what was done to create a trained workforce in the child care field. This should include provision for ongoing staff development, applicable to FMS-funded staff as well. Currently there is little investment by PDD in supporting and enabling ongoing staff development.

On another related matter, there has not been a government-funded wage increase in more than four years for the community staff upon whom the majority of individuals with developmental disabilities and their families rely for their supports and services. The minimum wage increases only impacted a very small proportion of those working in the developmental disabilities field. As there has been no funded wage increase in years, the disparity in wages between those working in the government bureaucracy and those working in community continues to grow wider. A wage increase is needed to attract and retain qualified staff, which should include a benefits package for FMS funded staff.

Recommendations:

In collaboration with the PDD Community the government should accept the repeated requests from this Community to develop and implement a plan similar to that created for the child care field that will result in a trained and certified workforce with commensurate wages.

Provide an immediate and reasonable wage increase for PDD Community staff, including a benefits package for FMS-funded staff.

7) Employment

Only a small portion of the total PDD funding goes to support inclusive and competitive employment. This is part of the reason growth in the proportion of individuals with developmental disabilities being employed does not occur year over year. As no overarching plan exists, for example, to increase employment proportionally, government funding is not being allocated relative to this goal or, for that matter, in accordance with any overarching plan for more inclusive and individualized futures.

Two other factors contribute to the lack of proportional growth in employment outcomes. Funding for employment is not tied to growth. Year after year government funding remains effectively stagnant, even for successful employment initiatives with proven growth potential. When an employment initiative achieves the maximum number of individuals it can secure and sustain employment for with its existing funds, it is trapped. The initiative can only increase the number of individuals employed by failing to allocate its limited resource to sustaining the employment of those it has already found jobs for. As a result, employed individuals with developmental disabilities lose their jobs and often go back into the queue for a future job; which makes the system look like it is creating more jobs when in fact it is not.

Or a 'trapped' initiative choosing to sustain employment for the maximum number of individuals possible given its funding must forego creating additional employment opportunities for more individuals. As a consequence, potential employers who would hire more individuals with developmental disabilities are neglected and feeling abandoned, they lose interest in hiring. Again, the overall result is limited to no growth in the proportion of individuals employed, given stagnant funding year after year.

Lastly, the Government of Alberta, one of our province's largest employers and one supposedly committed to employment equity is grossly inadequate in creating jobs for individuals with developmental disabilities. Government, which is the recipient of public funds, should be an exemplary and leading employer. Instead, and admirably so, the business community vastly outperforms government in creating employment opportunities and does so with respect to its bottom line, not taxpayer dollars.

Recommendations

PDD should immediately develop and implement a new funding model that funds employment growth so that the proportion of individuals with developmental disabilities employed will increase over time. This will contribute to more individuals with developmental disabilities being sustained in their employment and more individuals securing employment.

The government should commit to becoming a model employer of individuals with developmental disabilities and do so by learning from and partnering with proven employment initiatives that have established successful business and community partnerships.

8) Inclusive Post-Secondary Education

Inclusive post-secondary education has a proven track record over three decades in terms of beneficial and cost-effective outcomes, in addition to being formally recognized internationally as a world-leading innovation. While there have been recent increases in expanding inclusive post-secondary educational opportunities funded by Community and Social Services, there is no planned growth such that more individuals with developmental disabilities will gradually have access to a proven opportunity while maintaining quality. Given the known outcomes and benefits of inclusive post-secondary education, demand from individuals and families continues to grow. It is increasingly more common today to hear young people with developmental disabilities aspire to having the opportunity for a post-secondary education.

Inclusion Alberta is the principal developer of inclusive post-secondary education and the body responsible for developing quality assurance in inclusive post-secondary education. With a planned growth approach, we would have the capacity to expand existing initiatives and develop new partnerships with post-secondary institutions. There are more post-secondary institutions wanting to offer these opportunities, or expand them, but without a known government commitment these possibilities may not be capitalized upon and possibly lost.

Recommendation

PDD should develop a multi-year plan, in partnership with Inclusion Alberta, that optimizes growth in inclusive post-secondary educational opportunities while ensuring quality.

9) Complex Needs

Inclusion Alberta is continuously confronted with individuals across the province who are confined to psychiatric facilities when they should be living in community. Psychiatric facilities are confining individuals far longer than is to their benefit resulting in whatever gains were initially made through treatment evaporating and individuals regressing in terms of mental health and behaviour. They are being unnecessarily confined because there is not an effective partnership between PDD, mental health and community agencies to return individuals to community.

In other instances, individuals with developmental disabilities are released from psychiatric facilities without any PDD supports and services in place resulting in dangerous risks to their health and safety, at times to their families and communities. Efforts to secure supports fail because there are not community service providers able or willing to provide supports. These individuals needing support eventually end up in the criminal justice system and/or are readmitted to psychiatric facilities. And the cycle repeats itself.

There are as well individuals who are PDD-eligible with complex needs living in the community, both with and without families, who are unable to obtain supports and services as there is a lack of service provider capacity to support them. Part of the problem is the manner in which some PDD regions go about informing potential service providers about individuals with complex needs by painting them in the most negative light possible, usually by some cursory email. This leaves the individuals, their families and communities at significant risk with no resolution in sight.

Then there are individuals with complex needs being served by agencies that unilaterally terminate services with little notice resulting in crises given the time it takes to arrange a new service, should one even be available. An agency may have legitimate reasons for terminating services but doing so in a manner that leaves people on the streets or their families at risk is unacceptable. Agency termination of services should be permitted but this should necessitate an alternate plan and service being put into place so that the transition between supports and services is positive and successful.

While a number of other provinces have eliminated their large institutions for individuals with developmental disabilities and some continue active deinstitutionalization, the picture in Alberta appears stagnant. We believe Alberta should commit to closing its remaining large institution and at the very least ensure there is an active process to support and inform those who might choose to leave understanding the value and benefits of life in community.

Recommendations

PDD should develop a comprehensive, effective, responsive and supportive set of systemic resources to accommodate individuals with developmental disabilities and complex needs so that they: can live meaningful and safe lives in the community with minimally restrictive supports when these may be necessary; do not enter psychiatric facilities unnecessarily; and do exit psychiatric and institutional facilities in a timely and supportive manner.

Service providers should not be permitted to manufacture crises by terminating services without an alternative and positive arrangement being put into place and finalized.

PDD needs to alter the way it communicates the history and circumstances of individuals with complex needs and, second, initiate a plan to increase the number of community service providers with the capacity and willing interest to support individuals with complex needs.

10) PDD Program Disparities

Regional and Individual Worker Disparities

Given the experiences of individuals and families, there are clearly substantive differences in how regional and individual government staff communicate to, and work with, individuals and families. The essence of this difference lies in individuals and families feeling they are heard and that PDD is an active ally in supporting them to have a good life in community. In other instances, individuals and families report that it felt as if they were going up against an enemy who treated them with disdain and indifference. This is exacerbated in those instances, which happens much too often, where PDD has not been accurate or transparent in terms of what is available to individuals and families and how this might be accessed. It should not be a matter of luck in terms of where one lives or which PDD worker is assigned as to whether an individual or family has access to a supportive ally and accurate information. It is upon the strength of those responsive regional leaders and allied PDD staff that PDD should build consistent supportive staff and accurate information delivery across the province.

As the PDD Provincial Advisory Committee (PAC) does not exist there are next to no avenues, other than complaints by really persistent individuals and families, by which the on-the-ground experiences of individuals and families trickles up to those ultimately responsible for PDD. As such, those at the most senior levels who could direct and improve practice are limited without the necessary feedback mechanisms being in place to hear from individuals and families.

Capacity to Assist Individuals and Families in Visioning and Planning for a Good Life in Community

No matter what part of Canada or the world one lives in it is clear that government is simply not the best body to assist individuals and families in determining needs and how those might be addressed in the pursuit of a meaningful and inclusive life in community. Government is far more likely to attempt to fit people into existing square holes no matter the nature of their unique individuality. Individualized and personalized planning support is best delivered by community, and government should be a partner in determining funding allocations to achieve the desired ends. Individual plans and aspirations for an inclusive life may not line up relative to government funding decisions but it is far better to have that plan articulated than to have government limit individual and family dreams. In other words, when government is both the planner and funder, plans are always limited to what government believes the funding should be.

Recommendations

Reduce the disparities in PDD responsiveness and accuracy and transparency in information sharing by establishing feedback mechanisms to be able to learn directly from the experiences of individuals and families. In addition to the re-establishment of the PDD Provincial Advisory Committee, this could entail the establishment of regional advisory committees, regular 'listening sessions' and/or opportunities for senior officials to engage directly and personally with individuals and families in their homes and communities.

In addition to increasing the number of family governed Resource Centres to assist families in personal and individual planning and the implementation of those plans when accessing FMS, similar supports can be created for those accessing supports through service providers. The combination of an overarching future-oriented plan for PDD to advance inclusion can be coupled with on the ground resources that would assist service providers and the individuals they support to be realizing an inclusive life to a greater degree than is currently the case.

Recommendations

1) The Need for an Overarching Vision and Future Plan

That government, in collaboration with the PDD Community, initiate a process to develop an overarching plan and future vision for the delivery of supports, services and funding that will lead to increasingly inclusive life outcomes for individuals with developmental disabilities and their families.

2) PDD Provincial Advisory Committee (PAC)

Re-establish the PDD Provincial Advisory Committee (PAC), with representation of families, individuals with developmental disabilities and service providers, determined by the PDD Community itself. A revitalized PAC will be essential to ensuring an environment of trust and communication to enable the recommendations flowing from this PDD Review to be implemented successfully. This requires a commitment from government to listen and act in good faith on the basis of input from PAC.

3) Eligibility

That the PDD eligibility criteria prior to August 1, 2009 be reinstated and the current eligibility criteria based on a fixed IQ score be rescinded. In turn, any impact related to additional Albertans being eligible for PDD supports needs to be taken into account by government in the allocation of its resources, as was true prior to 2009.

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The Alberta government should immediately negotiate with First Nations and the federal government to ensure the availability of the PDD Program on reserves.

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In addition to increasing the number of family-governed resource centres to assist families in personal and individual planning and the implementation of those plans when accessing FMS, similar supports can be created for those accessing supports through service providers. The combination of an overarching future-oriented plan for PDD to advance inclusion can be coupled with on-the-ground resources that would assist service providers and the individuals they support to be realizing an inclusive life to a greater degree than is currently the case.