

Supporting children and adults with developmental disabilities for 60+ years

Background to the Forthcoming Budget

THIS BACKGROUND INFO IS FOR YOU, THE CORRESPONDING ONE PAGE LIST OF ACTIONS IS FOR YOUR MLA

Despite consistent messaging from government to the contrary, reductions to the supports and services available for children and adults with developmental disabilities are already underway in Alberta. The fact that families are facing these funding cuts during an unprecedented global pandemic suggests that further reductions are likely in the coming 2021 budget, a reality that threatens the lives of individuals with developmental disabilities across the province. While current economic circumstances require all Albertans to access public resources responsibly and equitably, it is unreasonable to ask children and adults with developmental disabilities and their families to shoulder this burden when they have begun on such an uneven economic playing field. By cutting into supports and services for persons with developmental disabilities and their families – some of the most impoverished and marginalized people in the province – the government is compounding existing inequities and pushing families and individuals to the brink of collapse if not complete crisis. No province should seek to overcome its financial challenges on the backs of children and adults with developmental disabilities and their families. The very necessary and human needs of children and adults with developmental disabilities do not disappear by withdrawing funding and supports; by pushing families into crisis by inadequately supporting them, we only increase the cost by shifting the responsibility to child welfare, health care or government care.

With significant cuts coming and multiple competing priorities, only you can impress upon MLAs and government that investing in children and adults with developmental disabilities and their families is as valued an investment in Albertans as the billions being allocated for reductions in corporate taxes, infrastructure and pipelines.

Suggested Actions to Impress Upon Your MLA

1. Sustain and improve existing cost-effective supports to children and adults with developmental disabilities and their families that enable them to grow up at home and live in the community.

Investing in families to be strong and well is an investment in Alberta and the economy. When individuals and families have access to needed supports, they are able to care for each other, sustain employment, stay healthy and contribute to their communities. Without necessary funding for supports, families will be pushed into crisis, forced to take more time off of work, require expensive health care, potentially lose employment altogether and require social assistance, contributing to the very unemployment the government claims to want to reverse. For some, the

lack of support will result in no longer being able to care for their children, requiring far more costly government care.

The most cost-effective ways the government has of supporting children and adults with developmental disabilities is through the Family Support for Children with Disabilities Program (FSCD), Family Managed Supports (FMS) for adults with developmental disabilities and PDD funded service providers who provide individualized support while capitalizing on community capacity to enable inclusion and natural supports to the greatest degree possible. Yet these proven cost-effective programs are being increasingly denied to families which will lead to families and individuals requiring more expensive supports. The government needs to cease being short-sighted and recognize an investment in families and community supports provides a substantial return on investment, while cutting may save the government a small amount at best in the short term, while increasing costs massively in the long-term.

Ask your MLA to ensure the integrity and purpose of FSCD, FMS and PDD are restored and that program delivery aligns with existing provincial legislation. The government should not be considering balancing the budget on at the expense of families and their sons and daughters with disabilities. The assistance previously available through these programs needs to be restored immediately. The cutting of supports and diminishment of families, needs to stop.

2. Move to community-based determination of supports

Currently access to FSCD and FMS funding is determined by government workers. These government workers often lack the knowledge and skills to assist families in capitalizing on community supports and in utilizing program funding cost-effectively. Our province is expending funds on government workers who repeatedly require families to meet with them going over the same ground with no apparent ability of achieving progress, as if this is not costing either government or families. They consistently deny families assistance until in desperation after months, families agree to whatever little support the worker is willing to consider, with no guarantee that this support will even be approved.

The costly function the Alberta government incurs in determining family and individual supports can be delivered at lower cost and more effectively by community organizations. Staff employed by a community organization have the knowledge and capacity to assist families in developing a plan that maximizes natural supports through community inclusion while minimizing paid supports to the degree possible. In this way the always finite public funds can be expended in more direct assistance to families rather than investing in a cumbersome, costly government bureaucracy.

Personal supports are among the greatest costs incurred by these programs and these cannot be offset without harm unless families and individuals are provided with the means to engage

community to provide natural assistance as much as possible. Government funding currently expended on its own staff and operations should be reallocated to community organizations to provide personal planning to individuals and families that can engage community resources. This will achieve improved and more sustainable outcomes.

Inclusion Alberta's Family Managed Supports (FMS) Resource Centre in Calgary has demonstrated over many years the clear value of this approach. These family and individual plans are well designed and monitored for continuous improvement and quality. Government still retains the right to approve the dollars, but simple approvals of known quality practice consumes far less of costly government time while minimizing bureaucratic processes. While this government has stated, at some point yet to be determined, it will fund the expansion of these resource centres to other communities, this proposal extends that concept to be inclusive of children, not just adults and to the determination of individualized funding support costs.

Ask your MLA to have the government work with Inclusion Alberta and families to transfer the person-centered planning for the support provided by the FSCD and FMS programs to one or more community bodies and thus reduce government bureaucracy and inefficiency. As one proven example it should be possible to extend the successful FMS Resource Centre in Calgary to be available to families of children as well as adults and for it and/or other community entities to deliver at less cost than what government delivers now.

3. Inclusive Education: Ensuring access and quality

There is a wealth of research over decades that demonstrates access to inclusive early learning is an investment with significant value and benefit. Children with disabilities and their families who have access to early education experience developmental growth that can last a lifetime resulting in less need for supports across the lifespan. Reducing access to inclusive early learning, as has occurred in Alberta by changes to Program Unit Funding (PUF) will only contribute to more costs in the long term. The cost to children with disabilities in developmental gains lost is incalculable, as is the pain experienced by parents knowing the lost opportunities.

Although Standards exist that support inclusion, when the government does not hold districts accountable to them, they have little to no value. The message to school districts, intentional or not, is that students with disabilities do not count. In addition to failing to ensure existing Standards are upheld, education legislation itself is ignored. Children with disabilities are entitled to the supports necessary to have access to an education equivalent to that provided to children without disabilities. Yet in the midst of a pandemic, funding for educational assistants was eliminated with no means of knowing which children with disabilities were now without support or with insufficient support. With schools reopening, many children continue to be without appropriate in-class support and many children with disabilities who cannot attend school during the pandemic are at home without needed supports. Funding for therapists turned into general revenue for school

districts, and children with disabilities continue to be put into seclusion rooms without assurance the rooms and their use adhere to a Ministerial Order. Parents need government assurance that school districts are ensuring children with disabilities are valued and supported to equitably access an education equivalent to their non-disabled peers.

Ask your MLA:

- a) in conjunction with families and their representative organizations, to immediately engage in the development and implementation of adequate and readily available inclusive early learning, which is the most cost-effective and beneficial approach to early childhood development for children with developmental disabilities,
- b) to ensure school age children with developmental disabilities, particularly if they have to be educated at home during the pandemic, have access to the supports they require, including educational assistants where needed to receive an inclusive education, and
- c) to have the government take action to hold school districts publicly accountable with respect to the Standards for Special Education (Ministerial Order #015/2004), and the Standards for the Use of Seclusion and Physical Restraint in Alberta Schools (Ministerial Order #042/2019).
- 4. Increase access to FSCD supports for First Nations families who have children with disabilities both on and off reserve in partnership with First Nations and provide access to PDD supports to adults with developmental disabilities on reserve.

The systemic lack of supports to First Nations children and adults with developmental disabilities and their families living on reserve has been further exacerbated during the course of the pandemic. Efforts to address the lack of access to needed resources are long overdue. While FSCD supports are technically available on reserve very few families are comfortable negotiating and navigating FSCD, particularly given Canadian history. This contributes to children with disabilities being unnecessarily apprehended because their families cannot access needed disability-related supports and services. Partnerships with First Nations are required to ensure FSCD is both offered and accessed in First Nations communities.

Currently, families have to leave their First Nations homes, families and communities to access PDD related funding and supports or remain within their communities with no access to PDD funding and limited life opportunities. Individuals with developmental disabilities and their families should never be forced to leave their homes and communities to access vitally needed supports.

Ask your MLA to support the development of culturally relevant FSCD and PDD resources with First Nations communities, so that First Nations people on reserves have access to the supports and services ordinarily available off reserve.

Thank you for making a difference!