



Supporting children and adults with developmental disabilities for 60+ years

The Honourable Jason Kenney
Premier of Alberta
307 Legislature Building
Edmonton, AB, T5K 2B6

March 19, 2020

Dear Premier,

Re: Action Needed Now in Support of Individuals with Developmental Disabilities and Their Families

We very much appreciate the recent and necessary actions you and your government have taken with respect to Albertans in general and services and supports for those with specific vulnerabilities, such as seniors and women and children who rely on shelters for safety. We support the Alberta Nonprofit Network (ABNN) in its request to have the government offer a broader array of assistance to non-profit supports and services. In this light we want to ensure the voices of families of children and adult sons and daughters with developmental disabilities, persons with developmental disabilities themselves and those who support them, is not lost.

The very vast majority of children and adults with developmental disabilities will only remain safe if they have personal supports in their lives. For as many as possible, this principally will come from families, but unsupported, families will still be at risk. And there are thousands who do not have family in their lives and require the support provided by agencies. Many individuals with developmental disabilities will not understand their degree of vulnerability, particularly as this population has a higher incidence of health challenges. They will not be able to take the necessary precautions on their own and some cannot communicate readily or independently when they are not feeling well and potentially symptomatic. Yet others have parents who fall within vulnerable categories themselves and are thus limited in providing for their sons and daughters safety without risking their own lives.

These are just a few of the challenges that require a coordinated and detailed response from government in collaboration with families and those who provide services and supports.

As families may not be able to find or retain personal support staff (as there will be less staff available to work in supporting individuals and families in their homes), they and those who support them require a greater degree of flexibility and accommodation by government. Right up until the advent of Covid19 many families were having their supports restricted, reduced or eliminated and based on families who have contacted us, this is still occurring. Fear and apprehension were growing across the province before Covid19 and now this is naturally growing even larger and deeper. At the very least government could be less rigid by increasing its flexibility in how funding is used and ensuring existing funding will continue and not be lessened.

As well, we are asking the government to assure each and every individual family and service providing organization that their funding will not be reduced or eliminated as a result of underutilization during Covid19. It would be even more helpful for government to provide incentives to attract and sustain personal support staff, whether employed by families or service providers. Currently, families are either unable to contact their government worker to get approval to utilize their funds differently and in other instances are being told they cannot. Each and every family should not have to attempt to personally get through to a government worker to adjust their utilization of funding under the current circumstances.

We are seeking greater flexibility in the existing funding that families and individuals already receive, in terms of:

- a) how they use their supports, for example, families of children with disabilities being able to utilize their supports during school hours when this is ordinarily not permitted, or being able to utilize under expended funding for additional hours of supports,
- b) being able to expend funds on other needs, for example, access to online software or the purchase of items their children can use at home while schools are closed, or their adult sons and daughters can use given the restrictions to being in community,
- c) being able to increase their staff's wages during the Covid19 public health emergency, within their allotted funding, and
- d) where an agency can no longer provide staff to support an individual, that families be funded directly or be able to charge the agency back if they are able to secure staff.

The above are example and not an exhaustive list of possible actions.

While many parents are struggling to cope with the closing of schools, the challenges are far more complex, intense and demanding for families who have children with disabilities. Families and their children with disabilities need teachers and schools to also be developing and providing materials and the means for parents to continue to have their children learn while at home. Our Inclusive Education Consultants would welcome the opportunity to assist schools and teachers and work with Alberta Education to ensure children with disabilities and their families are not left without options which can be pursued at home while schools remain closed.

As classroom assistants will not be working with children in school, we call upon the government to consider mobilizing this component of the workforce, with appropriate safeguards, to work in family homes and/or support adults where and when the personal support workforce has been compromised. We also believe the civil service, such as those working within Community and Social Services could be mobilized to provide direct support to families and individuals prior to a crisis occurring but certainly in the context of crisis management when personal supports are essential.

As the personal support workforce self-isolates or otherwise becomes compromised, this does not lessen the need for those supports but in fact heightens the risk for all. We need a coordinated provincial mechanism that mobilizes the pool of staff who typically work to support adults with developmental disabilities during the day and may not be doing so now that congregate programs are limited, to be on a roster to support individuals in their homes or housing. Part-time staff might also be added to this pool, but without a coordinated mechanism that families and providers can readily access, this potential resource might go unrealized. In addition to the usual precautions from washing hands and sneezing and coughing into elbows, some support staff require Personal Protective Equipment (PPE), particularly given they may be supporting small groups of adults with developmental disabilities and having to meet intimate care needs. To-date we are not aware that this need is being addressed.

We call upon government to work with us in reaching out to families of children with disabilities and those families actively supporting their adult sons and daughters with developmental disabilities, to ensure they are safe and to attempt to address any factors that are putting their lives at risk. We know there are service providers commendably doing this for the individuals and families they support, but there are thousands not attached to a provider. Specific measures will be needed given the particular challenges families face if they have a child with disabilities over and above the challenges many Albertans now face. For example, a parent of an adult son or daughter may not be taking time off from work in regard to their own personal safety or needs but in terms of their adult child's circumstances. And they may have to do this longer than would be true in other situations. The same

might be true of a parent of an older child who could be left at home while the parent works, but this wouldn't be the case if that older child has developmental disabilities. Without identifying these families and creating specific responses, they will experience additional hardships.

At the very least we are seeking an announcement from government that it recognizes the challenges families and individuals with developmental disabilities are facing, and that they will not be forgotten by Alberta in its response to Covid19. Even if the specifics are not yet known and to be worked out, families and individuals with developmental disabilities need the reassurance of government that it recognizes their unique circumstances and will be responding accordingly. For those families now reaching out for support we need a public shift in government's responsiveness from 'we have no resources or there is an indeterminate waiting list', to 'how can we help?'. There are multiple ways in which we can do this collaboratively with the Alberta government and are open to engaging immediately in how to best proceed.

We realize this is one additional vulnerable group of Albertans to take into account but in keeping with your appreciated actions and commitment to-date, this is about all of us being there for each other.

Thank you for your time and attention to this request and we look forward to hearing from you.

Yours sincerely,
INCLUSION ALBERTA



Trish Bowman
Chief Executive Officer



Barb MacIntyre
President

cc. Minister of Health Tyler Shandro
Minister of Finance Travis Toews
Minister of Community and Social Services Rajan Sawhney
Minister of Children's Services Rebecca Schulz
Minister of Education Adriana LaGrange