

## EDITORIAL

### Living with care, support, and an intellectual disability during COVID-19

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**Winnipeg, Manitoba, Canada** –This is an editorial from the Executive Committee of People First of Canada (PFC) in response to the situation that is happening in Markham, Ontario, at a facility for people with intellectual disabilities called Participation House.

People First of Canada members have always said that living in the world of intellectual disability is not easy. People with disabilities are often called the most vulnerable of our society. But those with disabilities often call themselves the 'left behind.' And in the disability world, people with intellectual disabilities are the 'left behind of the left behind.' Since the beginning of the COVID-19 crisis in Canada, we have definitely been feeling that – left behind.

It's hard to keep up with the amount of news and media that keeps coming every day. It's hard to know what to do when there is little information in plain language. It's hard to prepare when you live in poverty. It's hard to buy extra when you can't really afford enough. It's hard to have any control when you have very little power.

But that's not surprising given our history is mostly a horror story of institutionalization, neglect, abuse and social exclusion. Our fight is always for inclusion and our full human rights. Our victories are small and hard-won. We protect those wins because even our victories can be threatened.

The smallest of things can have a big ripple effect on us. A change in funding at the legislature can mean a real change in our daily lives. A change in government can mean a change in focus and we can easily find ourselves out of the fight for rights – again.

Part of this is because the lives of people with intellectual disabilities can be complicated. Many of us get home care or personal care services. Many of us have a personal support worker. We depend on these services. We need this support to help us live our lives. And our supports are often made up from different programs and involve different people. Our personal safety net is usually fragile and full of holes at the best of times.

We also often live in different spaces and situations than people without intellectual disabilities do. Some of us live in ordinary homes and apartments. Some of us live with our family. But many of us live wherever there is a free bed, or wherever we can get the supports that we need.

This means we live in group homes, or personal care homes or residential homes like Participation House in Markham, Ontario.

Participation House is a facility for adults with developmental and physical disabilities. There are 42 people living there and about 80 staff work there. Late last week, all but 4 of the staff walked away from their jobs when they were told about an outbreak at the facility. There were 10 residents and 2 staff with COVID-19.

By the end of the weekend, the numbers had risen and 12 residents and 6 staff that tested positive for the virus. By Tuesday evening, 37 of the 42 residents had tested positive and 4 were in hospital with one in critical condition. There are now 12 staff members who have tested positive.

The alarm bell for senior's homes began ringing across the country in mid-March. It is only now, four weeks later, that it is finally being rung for the places where many people with intellectual disabilities live. Why didn't we start protecting people with intellectual disabilities sooner? It's not like we don't know that COVID-19 spreads quickly in close quarters.

The government of Manitoba has issued a new directive around COVID-19 precautions that take effect this week. It requires staff who work with people with intellectual and other disabilities to wear personal protective equipment.

We can only hope that the rest of the provinces and territories follow along. But this is still a full month since our country started its COVID-19 lockdown, social distancing and extra precautions for many places. A full month.

Is this a signal to us that we will once again be left behind?

To **all** the governments of Canada, if you believe we are among the most vulnerable in society then you **MUST** have a coordinated effort to protect us. We can't do it ourselves.

And we will not settle for being the 'left behind of the left behind' this time.

Because being left behind during COVID-19 might mean being left behind for good.

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Kory Earle, President; Gordon Fletcher, Treasurer; Dewlyn Lobo, 1<sup>st</sup> Vice President – on behalf of the membership of PFC

People First of Canada is the national voice of people who have been labelled with an intellectual disability. The vision of People First is to see all citizens living equally in the community. For further information contact Shelley Fletcher, Executive Director for People First of Canada Phone: 204-784-7362 or by Email: [sfletcher@peoplefirstofcanada.ca](mailto:sfletcher@peoplefirstofcanada.ca) Find out more at [www.peoplefirstofcanada.ca](http://www.peoplefirstofcanada.ca)