



Citizens With Disabilities – Ontario

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“Together We Are Stronger”

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Access Awareness Week 2020

Long term care home residents have been out of sight and out of mind from the general public for far too long. What they have endured represents the least and worst of what our society is willing to offer to people with disabilities.

On May 26, the Ontario government outlined key findings from the Canadian Armed Forces report on the five long-term care homes at which the military has been assisting. The report details serious concerns around infection prevention, safety, staffing and level of care.

As horrifying as these reports may be to the general public, we are not at all surprised. Many of us know from experience what it is like to live in a nursing home or an institution. Long-term care facilities of any description don't have sufficient funding to provide decent food for residents that respect to their individual preferences and cultural/religious observances. Institutions don't have sufficient funding to pay staff competitive wages, leaving many of them disillusioned, bitter, burned-out, indifferent or even hostile to the people in their care. Most of the front line staff dealing with residents have PSW training – a career often chosen because certificates can be earned quickly – but they don't necessarily have training in de-escalation techniques that are important to work respectfully with people with cognitive disabilities. This lack of sensitivity training leads to abuse because staff get irritated, angry or impatient with residents who act out in ways that they cannot control or simply because staff



have lost their patience with the system. The design of institutions sometimes purposely bars residents from certain areas – like barriers preventing a person with a wheelchair to get into a library. It also often requires people sharing rooms and bathrooms, eating areas and recreation areas in such a way that has proven to be impossible to deal with under COVID-19 conditions.

In our newsletter, we shared an article about a woman who said she was going to be choosing MAiD because she did not want to go to a nursing home because she should not get the care that she needed and she did not want to impose on her family. In short, you would rather be killed than go to a nursing home. No wonder.

Add to this now the COVID-19 reality whereby people are not allowed to have visitors. It is well-known that when a family has daily involvement, the level of care they get is better. Without access to these visitors, people will not be fed their meals – no one will have time and may just record that the person refused to eat, not that they were not given sufficient time to eat. Without these visitors, people don't have comfort care and additional personal care that staff don't have time to deliver – even at the best of times. People who have cognitive disabilities will deteriorate more rapidly. When they finally get to see their loved ones – if they live that long – they may not remember who they are. It is heartbreaking.

In April, the Ontario government established an Incident Management System (IMS) structure to coordinate operational support to long-term care homes. The IMS table meets daily to organize efforts across multiple providers and government to make rapid decisions that support long-term care homes in need. Homes identified for support are those struggling to control outbreaks, complete infection prevention and control assessments, ensure appropriate staffing levels, have access to personal protective equipment (PPE), and complete the testing of all long-term care home residents and staff. The government announced it was extending the mandate of this table the same day the Canadian Armed Forces Report was released.

Long term care home residents have been out of sight and out of mind from the general public for far too long. What they have endured represents the least and worst of what our society is willing to offer to people with disabilities. This is a shameful indictment on a society that has benefited for generations from being among the wealthiest in the



world. It is a reality that the rest of us with disabilities fight to avoid every day.

Access Awareness Week has always tried to push the positives of what has been achieved. But decades of pushing the positives have only served to shove the horrors many of us endure below the surface. Finally, it is beginning to show, and it is not pretty, it is not humane treatment and it is not a reflection of who we are or ought to be.

Change is needed. Change must happen. Let's be aware, but also let's act. Now.

A handwritten signature in blue ink that reads 'Tracy Odell'.

Tracy Odell
President