Canadians relying on ODSP facing constant struggle to make ends meet

Written By KIRA WRONSKA DORWARD

Those lucky enough to be in ignorance of how the Ontario disability (ODSP) program works easily can shrug it off with the notions of ?free money? and ?limitless benefits?. However, there are many unpleasant realities to this essential social service system that only ensures a maximum monthly stipend of $1,169 - well below Canada's official poverty line.

Margaret Barstow, a 20-year ODSP recipient with Fibromyalgia, Degenerative Disc Disease, and inoperable Spinal Stenosis (along with anxiety and PTSD), sums it up well when she says that if it weren't for her mother who clothes her, and a sister who helps her buy medication not covered by the program, she would have no money to eat.

?My 85-year old mother? helps me so I can cut my hair and buy food, and that is wrong in so many ways,? Margaret said. ?I am on several meds they won't cover that keep me alive and add up to $400 a month.?

The wheelchair-bound Barstow, who lives alone, also added, ?I have to beg for extra money for incontinence and special diet [food] because I have IBS. Now they (the provincial government) tell me they won't pay for new/old frames I need for my glasses to see and read. All I have to entertain myself are e-books and TV, and they keep rising in price each year. They told me my phone is a luxury item. I need it to call 911 for the hospital when the pain gets really bad.?

Ontarians dependent on this program, such as young Sara Boudreau of Bolton, have reached beyond limits of frustration and endurance with the bureaucratic process, well before the recent changes that have made life even harder for those already facing hurdles to literally get out of bed in the morning.

Boudreau suffers from a myriad of conditions that severely limit her quality of life and prevent her from holding down full-time work or study due to accessibility issues. As if Cerebral Palsy wasn't enough, just before the pandemic hit, Boudreau also suffered from a ten-year misdiagnosis involving uncontrollable fainting spells. Although doctors now think she also suffers from cataplexy, a form of narcolepsy, Boudreau has been unable to schedule the necessary tests to confirm the diagnosis due to the limitations of COVID.

?Unfortunately,? says Boudreau, ?it is a process you have to go through [to be diagnosed], so I was in the hospital when Ontario declared the State of Emergency. Since then I have not been able to get any tests done? It could be upwards of 11 to 12 years before I am diagnosed. It's the reason I can't handle school, and I can barely do projects on my own.?

Boudreau relates more frustrations navigating the bureaucracy of the medical system, stating that during her hospitalization process, test results were even lost.

?I've been told by therapists to go for a walk to calm myself. I literally cannot walk,? Boudreau said. ?You don't have doctors on your side, and ODSP is definitely not accommodating. The Brampton [ODSP] office isn't even accessible. I literally walk in there with a cane and a service dog. This ?ableism? has been following me all my life, and I just feel worthless all the time.?

Despite her limitations, Boudreau continues with projects she is passionate about to keep her mind and body occupied, such as designing a video game in memory of a deceased friend, and hands-on carpentry, as well as making household products such as pillows.

However, recent changes made by the provincial government before and during the pandemic have the Boudreau family outraged, as Sara struggles to get through each day on existing limited resources.

?Doug Ford did a lot of changes without our notice,? comments her mother, Egle Boudreau, who also takes care of her disabled husband. ?I only found out [about these changes] on the online support pages for ODSP, and we were like, ?where did this come from?' People are confused about what's been going on.?

In early 2020, the Ford government quietly outsourced the running of both ODSP and Ontario Works to for-profit Australian-based company WCG, the same company that had been hired and fired by the McGuinty Liberal government in 2007 when the program was concluded to be unsuccessful. So far, the change has only been implemented across the Region of Peel, but was met with opposition by NDP MPPs Catherine Fife and Lisa Gretzky.

Gretzky was quoted as saying, ?An independent report following the Liberal privatization pilot found that it was both ineffective, and did not save the government money. The result? The Liberals were forced to abandon the plan.?

When asked why WCG had been rehired under Ford's government, a spokesperson from the Ministry of Children, Community, and Social Services, Palmer Lockridge, maintains that ?our government is committed to ensuring individuals have the support they need to break free from the cycle of poverty. As Ontario's Auditor General has highlighted, only one percent of people on social assistance are finding employment every month. That's why we have launched three pilots as we move forwards with our work to strengthen employment services for those on social assistance. We are building a system that will be easy to use, more localized, and will provide the training necessary to help individuals find meaningful employment. The competition was led by the Ministry of Labour, Training and Skills Development and overseen by Supply Chain Ontario and adhered to the principles of fairness and transparency. Under Premier Horgan, British Columbia also moved to an outcomes-based model. They also awarded contracts to a mix of non-profit and private providers, including the same organization that Ontario has selected for Peel Region.?

This response failed to directly address questions posed as to why a program proven to be ineffective and detrimental, not only by a former Ontario government, but also Australia and the United Kingdom, was reinstated in 2020 in Peel.

The heart-breaking interview with the Boudreau family highlights the many ways that the system is failing Ontario's most vulnerable in so many ways. Sara frequently breaks down in panic attacks while describing her experiences, and it takes her sister Della, training in Ottawa to be a professional therapist, and her service dog Betamax, to help calm her. There is no treatment for Cerebral Palsy in adulthood, and massage therapy and chiropractors are not covered by the program. Physiotherapy is covered to an extent, but that does not help Boudreau with spastic muscles, which she suffers from frequently.

Boudreau also explained that ODSP did not ?cover a dime? for her service dog, despite her applying for funding ?through any place I could?, and would also not allow payment for her sister Della to become her official caregiver, as family members are not eligible.

?It's unbelievable, having an able-bodied sister wanting to help us, and she can't do anything,? Sara said.

Having Della return to Ottawa in the fall is a major area of concern for the family, as Sara is also having no luck finding suitable living accommodation with a built-in support network, essential for anyone with her conditions.

Her cataplexy means she must live with someone, but finding housing, another often insurmountable hurdle for the disabled, has become a dire need as her family prepares to move. Many assisted living facilities only specialize in certain conditions, and spaces on waiting lists are hard to come by.

?I've been calling,? says Boudreau, ?and people have been giving me resource list after resource list. Look, I just need a place to live where someone is there in case I faint.?

The possibilities of choking or hitting her head during a fainting spell are very real, but the endless run around of referrals and waiting lists is not anything new within the ODSP system.

Barstow echoes the struggle for housing, as she recounts first living in an apartment, which took up half her monthly stipend, in a busy, dirty, and unsafe neighbourhood. She has now moved into a basement apartment, despite suffering from dust and mould allergies. It took her ten years to be registered for the RGI (Rent Geared to Income Housing) program, a form of housing assistance that limits rent payments to 30 percent of income.

The fact that ODSP recipients live well below the poverty line was highlighted particularly during COVID-19, when CERB recipients, who received $2,000 a month, complained this was not enough to live on. Talk has now begun in earnest around a basic living income, but the reality remains that most disabled Ontarians, whose costs of living are usually higher than the average person due to their disabilities, have not had their government stipend adjusted for inflation since the 90's. Falling far below the imaginary poverty line, ODSP recipients receive about $12,000 annually.

A survey conducted in 2017 revealed that over a quarter of those on disability could not afford essential medications, medical devices, and equipment, while nearly 30 percent live below the poverty line. That is a rate three times higher than the average Canadian. To add to the hardship, the cost of living in Canada's major cities, such as Toronto, means that the provincial stipend falls well short of what is needed for the disabled person to survive in an expensive metropolis- where many need the access to hospital services not offered in cheaper communities.

The realities are that we are discussing a system that is so far behind in paperwork that proper orientations do not take place until more than a year after filing the necessary applications, itself an extremely onerous, potentially expensive, and time-consuming process. The system design itself is perhaps a half century behind what is needed in terms of upgrades to account for inflation and changes in the medical establishment.

Then there is the question of the claw backs on income, which start at 50 percent after a paltry $200. Although expenses are taken into account, breaking down percentages of phone bills and internet charges are impossible, meaning that for some people, being on ODSP can mean you end up paying to work.

This was made even more apparent after the CERB announcement, when after being advised by the federal government not to claw back essential income from those on ODSP eligible to draw on the program, the Ford government decided to do so anyways. This left one ODSP recipient with a grand total of $2.50 to live on a month, of which he was given no prior warning in applying for CERB or reporting it to his social worker.

Trudeau's federal government had implored the provinces not to claw back the pandemic income. When asked for an explanation as to why Ford's government chose to go against this advice, Lockridge responded, ?To support individuals during the COVID-19 outbreak, and following a productive conversation with Federal Minister Qualtrough, our government provided new direction to Ontario Disability Support Program (ODSP) and Ontario Works (OW) staff to ensure individuals on social assistance keep much more of the Canada Emergency Response Benefit (CERB) than they would have under previous rules. A number of other provinces took a similar approach.

Recognizing these unprecedented times, and that the CERB was designed to replace employment income, our social assistance programs are treating it as such. This change has allowed existing clients to partially stack their CERB and social assistance benefits, while ensuring they continue to maintaining their health and other benefits. The majority of individuals on social assistance who receive the CERB see an increase in their monthly income as a result of this change.?

When contacted, Steven Del Duca, the new provincial leader of the Liberal party commented, ?Doug Ford has made life worse for those who have the least. The federal government explicitly asked him not to claw back CERB benefits from ODSP recipients - but Ford went ahead and did it anyway. Clawing back support from ODSP recipients during a pandemic is callous and cruel.?

The Boudreau family did not claim any CERB benefits, despite being eligible, because the claw backs from the Ford government would have put their income in jeopardy.

Not only did the CERB claw backs negatively impact those who depend on the regular monthly stipend, but the provincial government's four-time payments of $100 went unpublicized, with social workers failing to freely inform their clients of their $400 pandemic entitlement.

When contacted for comment, a Brampton Social Worker responded, ?I am unable to answer your question, as I do not make the decisions of how the program is run. Please contact your parliamentary representative for such questions.?

When questioned, Ministry representative Lockbridge responded that, ?This benefit operates like other social assistance benefits, in that clients are required to speak with their caseworker and identify any additional needs in order to receive it.?

In other words, one would have to know about the entitlement to ask - and many Ontarians did not know until it was too late.

It should be noted that while the budget for ODSP was cut in Ontario in the last year, deputy ministers were treated to a 12 percent raise, while the 2019-2020 Ontario budget for social assistance programs was cut by $1 billion.

In addition, Doug Ford gave a press conference in Ottawa on August 6th making his views on the issue abundantly clear, when he stated that disabled people should ?go get jobs?, adding that the ?best way to help people in Ontario Works or ODSP, if they're healthy and they're able to work, get them a job, help get them a job,? - despite the fact that being on ODSP in the first place means they are incapable of retaining full-time employment, and any money they make can be clawed back at a huge rate. These claw backs actually have the potential to put people who work in debt to the program, further increasing the cycle of poverty. Ford has subsequently failed to apologize for his remarks in August after backlash from advocacy groups, and multiple requests that he acknowledge his highly insensitive comments as unacceptable. Further, he repeated his ?if there are jobs out there- work, because we expect you to contribute to society? mantra at another press conference held on September 3rd, in the same breath where he pledged support for those whose conditions make it impossible for them to retain employment.

?It just digs a deeper and deeper hole,? remarks Boudreau, speaking on the financial burdens created- not alleviated- by the current system. ?I don't know what kind of future I have as a young adult.?

Ford's policies regarding those on disability amount to economic or low-income genocide by targeting a minority group that by definition is unable to hold full-time, long-term employment, if they can find or hold employment at all. During the pandemic, people with chronic disabilities have even been exploring assisted suicide, some publicly on social media, citing both lack of hope and the means to live and improve their health, although numbers will not be available until the spring. If Ford had made the comment about any other minority group, such as the Indigenous or elderly, one wonders how much notice would have been taken. But an unfeeling pot shot at the disabled and downtrodden in society went almost unremarked on.

?People with disabilities want to work,? emphasizes Sara Boudreau. ?But if work places aren't willing to provide accessible or accommodating environments, why should we be expected [to put ourselves in that situation]? Also there should be more understanding among employers and fellow employees. I love working with my hands and animation? but all I have been thinking for the past five years, is am I just wasting my time?? she says, finding it hard to catch her breath for crying. ?I so much believe in William Shatner's ?if you love what you do, is it really work?', and isn't that what everyone wants??

With the hashtag #ODSPoverty now making the rounds on Twitter, Boudreau believes that we, as Canadians, have to wake up to the increasing ?sink or swim? mindset, perpetuated by the Ford government, that leaves our most vulnerable behind.

?Everyone's already gotten a taste of it being on CERB,? comments Boudreau, ?and that's just the financial aspect. [Disabled people] aren't all that different. You're just one step away. People's stories are not being told properly, because the only ones who can explain it are the ones who are disabled. No one really sees the barriers [we face]. It's time to change the thought process of Ontarians.?