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## Disabled Canadians face uphill struggle for regular care as COVID-19 drains resources

**EMILY FAGAN**

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Heather Morgan, a disability advocate, in her home in Barrie, Ont. on March 8, 2021.

FRED LUM/THE GLOBE AND MAIL

There's a lot Heather Morgan has figured out on her own to ensure her family's well-being. She spends 10 to 30 hours a week as a caregiver for her Ontario-based family of four, helping manage their multiple disabilities in addition to looking after her own health. Her husband is autistic, while she and her two young adult children have an undiagnosed muscular condition that requires them to use power wheelchairs.

With what little time remains, she's pursuing her master's degree. It's an uphill battle.

Since the start of the COVID-19 pandemic, that hill has become a mountain. The support workers the family relied on to help them shower, clean and prepare meals have not been allowed in their home for most of the past year. During lockdown, Ms. Morgan says she's seen her pharmacist more than her extended family, and is now facing steep new costs for medical essentials that aren't covered by the Ontario Drug Benefit program.

"Living life when you're disabled relies on a network of people, and we've had to do without almost all of those people for most of the last 11 months," Ms. Morgan said. "It's taking a huge toll on all of us."

Ms. Morgan's words have been echoed by advocates and disabled Canadians across the country during the past year. Those with disabilities – an estimated 20 per cent of Canadians – continue to face high financial barriers to affording basic needs in a

pandemic that experts say has left them doubly disadvantaged.

The Speech from the Throne in September announced the country's first Disability Inclusion Action Plan, including a new Canadian Disability Benefit, an employment strategy for Canadians with disabilities and an improved process for determining eligibility for disability programs and benefits.

In the first months of the pandemic, Carla Qualtrough, Minister of Employment, Workforce Development and Disability Inclusion, created a COVID-19 Disability Advisory Group to give her advice on what Canadians with disabilities were experiencing during the coronavirus crisis.

The group released a final report in December that detailed the disproportionate toll of the pandemic on disabled people, including the loss of access to critical services and support, difficulty adhering to distancing protocol, loss of employment and increased expenses. Among its recommendations was income support for people with disabilities during the pandemic.

“We know the COVID-19 pandemic has highlighted long-standing barriers and systemic gaps,” said Marielle Hossack, a spokesperson for Ms. Qualtrough, after the report's release.

However, when asked by The Globe and Mail, Ms. Hossack declined to provide a timeline for when Canadians can expect the rollout of the Disability Inclusion Action Plan.

Financial hardships faced by people with disabilities aren't unique to the pandemic. According to the 2017 Canadian Survey on Disability, 1.5 million Canadians aged 15 years and older with a disability said they weren't able to get a medical aid or device they needed. Of that group, one million – 17 per cent of all Canadians with disabilities – reported the reason was cost. Although data from the pandemic are not yet available, experts expect the situation has worsened because of COVID-19.

“Disadvantaged groups become doubly disadvantaged when an emergency comes about,” said Mary Ann McColl, academic lead of the Canadian Disability Policy Alliance, a group of academics, policy makers and advocates who aim to improve policies that affect disabled Canadians. “This has been shown to be the case for people with disabilities and COVID, especially in terms of employment, financial security and health care access.”

Brooke Pinsky, an Alberta-based board member of the Canadian Autism Spectrum Disorder Alliance, says current pandemic measures fall short in considering the out-of-pocket expenses that those in the disabled community have taken on.

“There’s an assumption amongst the general population that ‘[universal] health care must cover that,’ ” she said.

Housing that meets accessibility needs is expensive and hard to come by, and utilities are costlier. Child-care rates are significantly higher for children with disabilities. Ms. Pinsky’s daughter has an intellectual disability and isn’t able to wear a mask because of sensory issues, so Ms. Pinsky decided it was unsafe for her to attend in-person classes. To ensure her daughter can still learn from home and not fall behind, Ms. Pinsky privately hired a teacher’s aide for \$2,500 a month.

At a time when collective efforts are focused on protecting the vulnerable, she is shocked at the lack of support available for those in her daughter’s situation. Ms. Pinsky’s family isn’t the only one facing these issues. The COVID-19 Disability Advisory Group’s report mentions instances such as this as some of many new barriers for those with disabilities arising from the pandemic.

Nearly 33 per cent of Canadians with severe disabilities live in poverty, and working-age Canadians with disabilities are twice as likely to live below the poverty line, according to Health Canada. Those with disabilities are more likely to be employed short-term, part-time, independently or as part of the informal economy.

Before the pandemic, about 60 per cent of disabled Canadians were employed, compared with 80 per cent of Canadians without disabilities. According to Employment and Social Development Canada, COVID-19 has further lowered employment rates and raised financial pressure for those living with disabilities.

To relieve some of the economic pressure on Canadians with disabilities, the government announced a one-time, non-taxable \$600 emergency payment for those with a valid Disability Tax Credit Certificate and those getting disability pension benefits. An estimated 1.7 million received it, about 10.5 per cent of all Canadians with disabilities.

But advocates say that \$600 was not enough.

“Many people said it was too little too late in light of all of the existing barriers that disabled people face to survive in Canada, and then additional ones that were created by the pandemic,” said Vivian Ly, an organizer for 300 to Live, a B.C.-based group formed in response to the pandemic to advocate for increased financial support with people with disabilities.

From April, 2020, to December, 2020, the B.C. government provided \$300 a month to those on disability and income assistance, a move that Mx. Ly and their group have advocated for the province to make permanent. On March 17, B.C. announced that starting in April, it would raise these rates by \$175, which has been criticized for falling short of the temporary COVID-19 benefits.

Another hurdle is that eligibility for the Disability Tax Credit is focused primarily on physically restrictive disabilities, which can make it hard for those with invisible disabilities to be accepted. Mx. Ly said it can be difficult to get documentation needed, especially for those who are low income, racialized, trans, non-binary or women.

After obtaining the tax-credit certificate, those with lifelong disabilities must continue to renew their application, typically every three to five years. If the renewal is denied, all related services and access are stopped until a months-long appeal process is wrapped up.

Complaints about the Disability Tax Credit are not new, Mx. Ly said. “The federal government has been criticized for years for discriminating against disabled people and denying eligible people for support.”

Justin Trudeau’s government has promised to improve processes such as this in the Disability Inclusion Action Plan, but Ms. Hossack, the spokesperson for Ms. Qualtrough, declined to provide details when asked.

While those with disabilities were disproportionately affected by the pandemic, some have seen the lives of able-bodied people transformed to more closely resemble their own.

Diagnosed with cystic fibrosis, Lilia Zaharieva has lived her whole life between hospital visits. She practised physical distancing and spent days alone in her home long before the pandemic. In 2018, she was among the loudest voices urging Canada to cover the costs of Orkambi, the \$250,000-a-year drug she calls “life saving.”

“People with cystic fibrosis have been living in COVID conditions for a lifetime. We’ve always been terrified, waiting for a drug company to save us,” said Ms. Zaharieva, whose average lung function was between 30 per cent and 40 per cent for most of her life.

“After this year, I hope that people can look at health care spending with more empathy. I would love for people to imagine how they would feel after 30 years of this.”

COVID-19 has proved revealing of Canada’s capacity for responding to a health crisis. Ms. Morgan said she wishes the same level of efficiency and resolve could be put to supporting the millions of Canadians in need of life-saving support.

“We’ve proven just how agile and flexible and responsive we can be to an emergency,” she said. “We just have to decide that this one is important enough to do something about it.”

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351 King Street East, Suite 1600, Toronto, ON Canada, M5A 0N1

Phillip Crawley, Publisher