

Federal Government – Pre-Budget Submission – August 2020

From and On Behalf of Canada's Eating Disorder Community

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- **Recommendation 1:** That the federal government expand access to evidence-based prevention, early intervention and support through the creation of the National Eating Disorders Strategic Fund. This Fund will invest in:
 - i. critical community-based support programs that provide prevention and early intervention education and services for individuals across Canada who are struggling with eating disorders; and
 - ii. initiatives that enhance collaboration, research and knowledge exchange.
- **Recommendation 2:** That the federal government establish a national Eating Disorders Surveillance System, as part of the Canadian Chronic Disease Surveillance System, to ensure that important data about eating disorders in Canada are collected and reported.

Rationale, Recommendation 1:

- a) Community-based support programs fill significant gaps in eating disorder programs and services across Canada. Community organizations – charities that receive little or no government funding – supplement provincially-funded treatment programs administered by health authorities and affiliates. These programs and services have low barriers to entry, therefore reach and serve a broad population of individuals and caregivers.

Canadians who rely on publicly funded treatment wait, on average 2-3 years for care. In this time the disorder can worsen, necessitating much more intensive, costly, and life-interrupting care. Some research suggests that symptoms of anorexia nervosa worsen significantly after 3 years of the illness, increasing the likelihood that the illness remains debilitating, longstanding, and potentially fatal.

Eating disorders are the 3rd most prevalent mental illness in Canada and the 3rd most common chronic health condition among adolescents. The average age of onset is between ages 13 and 23. The incidence of eating disorders among adolescent girls in Canada is 18%. Approximately 10-25% of individuals with eating disorders are male.

Anorexia has the highest mortality of any mental illness excluding opioid addiction. 5-10% of those with anorexia die within 10 years of disease onset; 18-20% will be dead after 20 years, with 1 in 5 deaths by suicide.

With early intervention and rapid access to quality treatment, approximately 75% of people with eating disorders recover. Despite this, it is estimated that only 1 in 10 receive appropriate treatment and even fewer receive early intervention.

⇒ **When we refuse to intervene, we make a conscious decision to let people get sicker, sometimes leading to avoidable death.**

⇒ **Community-based organizations save lives. Yet we receive little to no government support or funding, and are now at real risk of closing our doors.**

⇒ **This request aligns with broader calls from the mental health and addictions community for a Mental Health Parity Act.**

- b) COVID-19: forced the closure of many in-person eating disorder treatment centres and support programs, and hospital resources have been diverted to address the pandemic. Extremely ill people were sent home – to people and circumstances ill-equipped to deal with serious mental and physical ailments.

Support options were lacking before the pandemic: a severe shortage of treatment beds across the country; waitlists for community programs and medical/care professionals; barriers to entry (restrictions on age, severity, co-morbidities).

COVID-19 has intensified the already pervasive problem of unmet support and treatment needs. Isolation is one of the greatest challenges – it decreases hope and negatively impacts recovery. Community-based support organizations have experienced a dramatic jump in demand for services. These organizations are underfunded and their resources are stretched.

⇒ **COVID-19 has exacerbated an already desperate situation for people struggling with eating disorders.**

⇒ **Our volunteers and staff are reporting that program participants have increased rates of anxiety and depression, and escalating harmful behaviours such as self-harm, substance misuse, and talk of suicide. People well along the recovery path have lost significant ground. Those are the people who reach out to us – what about those who are struggling in silence?**

- c) **Economic Reality:** Eating disorders are costly to treat, particularly as they worsen. They require expensive health care funding, and have negative economic impact on those who are suffering, their caregivers, and their employers.

In Ontario in 2012, there were 6,326 patients hospitalized for an eating disorder. Direct total costs were just under \$63 million.

Inpatient & outpatient eating disorder care is expensive – it is estimated that the mean total cost of a hospital admission, based on mean length of stay (~38 days) in Canada is \$54,932.

Eating disorders disrupt developmental trajectories, resulting in delayed or non-entry into the workforce and increasing dependence on social assistance.

⇒ **Prevention and early intervention save lives and dollars. Investment in the programs offered by community-based support organizations makes good economic sense.**

Rationale, Recommendation 2:

- a) Due to underfunding of data collection and research, we do not have statistics for the prevalence of eating disorders in Canada. However, data on the global prevalence suggests 7.8% of the population – approximately 2.9 million Canadians – are affected. Only 10% of individuals receive specialized treatment. Barriers include economic disparities and limited treatment options – compounded by stigma and shame.

A national Eating Disorder Surveillance System will enable us to plan – in a comprehensive, collaborative, effective way – systems of support for this chronically underserved and misunderstood population.

We do know that marginalized communities (e.g. low SES, BIPOC, LGBTQ2S+) are more likely to experience eating disorders/disordered eating and are more likely to experience negative health and economic consequences as a result of COVID-19. There are also significant disparities – for example, Black women are less likely than white women to be diagnosed and receive treatment/support. People who experience food insecurity are more likely to develop an eating disorder than those who do not.

Studies also demonstrate that transgender young adults are 15 times more likely than their cisgender peers to report being diagnosed with an eating disorder.

⇒ **Many of these individual face systemic barriers to care. Often, community-based programs are the only safe, affordable, and accessible options. We need to better understand and serve these populations.**

- b) To build a comprehensive picture of eating disorders in Canada, governments and health systems partners need to collaborate to collect and share data as part of community- and hospital-based mental health surveillance and performance measurement frameworks.

Building an Eating Disorders Surveillance System would align with steps already taken by the Canadian Institute for Health Information alongside federal, provincial, and territorial governments to improve mental illness data across Canada. It would be consistent with the Canadian Eating Disorders Strategy: 2019-2029.

⇒ **Evidence is needed to inform critical planning of programs, services, and research that support people across Canada who live with eating disorders. Benefits will extend to families, care givers, health system planners, employers, and beyond.**

⇒ **The lack of data results in significant gaps in the continuum of care for people with eating disorders, and there is unacceptable variability in the quality and accessibility of services for people across Canada. People are getting sicker, and dying, unnecessarily.**

Canada needs disease tracking data such that we are all equipped to deal with this escalating mental health crisis.

The financial impact of COVID-19, looking forward to 2021-2022, is deeply concerning to us:

- While temporary funding has been available during the height of the pandemic, fundraising options for 2021/22 are seriously impaired.
- The economic downturn across multiple sectors has a devastating impact on our finances.
- Fundraising events are being cancelled or budgeted to generate much lower income.
- As a result of COVID-19, demand for our services has increased exponentially, and the needs of those we serve are becoming much more complex.
- As our financial security worsens, we all fear we many have to cut services to those in crisis.

Testimonials received since the COVID-19 onset:

- *“I have been finding the current situation really hard to cope with, so being in a group with other people who have some shared experiences has been really helpful to be able to have some connection and seeing that I'm not alone in how the pandemic is affecting me.”*
- *“I appreciate using technology to keep connected and keep services running during this pandemic. Before this program I was alone in my struggles and was very ill. Having access to support makes me feel less alone, especially in this unprecedented time of isolation.”*
- *“Being able to access a network of support online is crucial to my recovery.”*
- *“Covid19 has been very hard on my eating disorder. If it were not for the online groups I do not know what I would have done for support.”*
- *“Thank you for saving my life” (a very frequent comment)*
- *“Having someone who I can talk to, who will not judge me and who understands how I feel, who provides support stemming from personal experience – is incredibly helpful. There are conversations and accountability that you cannot find in friends and loved ones who don't understand the eating disorder. Thank you to my mentor for showing me that it IS possible to heal and recover and for being my support through this journey.”*
- *“Night time is usually a very anxious time for me, so this chat group being at night and accessible from home is really nice. I feel like I have a lot more positivity and hope.”*
- *“As an advocate for many Canadians suffering from Eating Disorders in Canada for over 30 years I strongly urge the Federal Government to act on the proposals listed in this brief. For far too long I have witnessed and experienced the devastation that eating disorders have on too many lives. I am the mother of a 24 year old daughter who died after a 12 year battle with Anorexia in 2002. There were – and still are today – extremely limited resources available to treat and deal with this deadly illness. Eating disorder sufferers deserve equal treatment to those with other illnesses in the health care system in terms of reasonable access and availability to expert services. It is critical that the Federal Government collaborate with the eating disorders community by funding these recommendations.”*

Community-based Eating Disorder Support across Canada

- Collectively, we support over **55,000 people annually**. This barely scratches the surface of need.
- **Demand for services during COVID-19 has increased 20 – 50%**. We are adding programs when resources permit yet are overcapacity. Some of us have cut services due to financial constraints.
- **Waitlists, already unbearably long, have grown significantly**. One organization has a waitlist of 4 months for urgent medical assessments. **“We have a number of very ill individuals who will likely die if we are unable to provide more services for them. The situation is desperate.”**

1. Family Education
2. Family Support
3. Training for Family Supporters
4. Residential Treatment
5. Clinical Programs – Groups
6. Clinical Programs – Individuals
7. Peer Support – Groups
8. Peer Support – Individuals

9. Training for Peer Supporters
10. Education for Professionals
11. Education for Other Professionals
12. Web or Online Programs
13. Web or Online Education
14. Retreats or Camps
15. School Prevention Programs

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Alyssa Stevenson Eating Disorder Memorial	Advocates for Eating Disorder issues: wait lists; and lack of treatment and support programs, health care training, funding, research.														
Anorexia and Bulimia Quebec															
Body Brave															
Eating Disorders Nova Scotia															
F.E.A.S.T.															
Hopewell															
Jessie’s Legacy															
Looking Glass Foundation for Eating Disorders															
National Eating Disorders Information Centre															
National Initiative for Eating Disorders	Provides education, information, recovery-focused resource.														
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