

Awareness. Understanding. Action.

Strategic Plan 2019-2021

About Eating Disorders in Canada

Approximately, 1 millionⁱ Canadians have a diagnosis of an eating disorder, such as anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), Avoidance Restrictive Food Intake Disorder (ARFID)ⁱⁱ and otherwise specified feeding and eating disorder (OSFED)ⁱⁱⁱ.

Eating disorders are serious but treatable mental illnesses that can affect anyone regardless of gender, age, racial and ethnic identity, sexual orientation or socioeconomic background^{iv}. Many people with an eating disorder are never diagnosed but suffer significant personal and family distress. The social and economic costs of untreated eating disorders are similar to those of depression and anxiety, with debilitating physical and mental health effects comparable to psychosis and schizophrenia^v.

While it is well documented that mental illnesses are a leading cause of premature death in Canada^{vi}, it is less known that eating disorders have the highest overall mortality rate of any mental illness, with estimates between 10-15%^{vii}. Suicide is the second leading cause of death (after cardiac disease) among those with AN^{viii}; 20% of people with AN and 25-35% of people with BN may attempt suicide in their lifetime^{ix}. For females aged 15-24 years old, the mortality rate associated with AN is 12 times greater than that ALL other causes of death combined.^x

Younger Canadians are also increasingly^{xi} engaging in dieting behaviour which may put them at risk of developing an eating disorder and other health-compromising conditions^{xii}. In Canada, between **12% and 30%** of girls and **9% and 25%** of boys aged 10-14 report dieting to lose weight^{xiii}. Moreover, the incidence of Eating Disorders in Canadian children is estimated to be 2 to 4 times greater than Type 2 Diabetes.^{xiv}

About NIED

When NIED was created in 2012, its main objectives were to

- 1. Promote awareness and education of eating disorders to the public;
- 2. Assist persons in coping with the effects of eating disorders by offering education and counseling and by establishing mutual support groups;
- 3. Carry out research for the benefit of the public into the lack of programs and funding relating to treatment and awareness of eating disorders; and
- 4. Expand the scope and variety of available treatment resources for persons living with an Eating Disorders.

Since 2012, NIED has

- 1. developed and delivered 63 Eating Disorders symposia for the public;
- interacted with over 10,000 individuals, families and caregivers to provide guidance, support and education regarding Eating Disorders, the health care system and social services across Canada;
- 3. participated in the co-design and development of a CIHR-funded research study aimed at identifying and prioritizing research related to Eating Disorders in Canada; and
- 4. surveyed, in 2016, approximately 400 organizations to identify gaps in care for people living with and recovering from Eating Disorders in Canada.

In support of these recommendations made by stakeholders across Canada in 2016, as well as caregivers and people with lived experienced in 2017 and 2018, NIED has updated its organizational strategy to focus exclusively on working with

- caregivers, healthcare professionals and social services providers to empower and help parents, families, individuals with Eating Disorders;
- a wide range of stakeholders to improve access to appropriate, evidence-based care.

In 2018, NIED adopted a 1 year strategic focus that focused on (1) **Supporting People** and (2) **Improving Access (Appendix A)**.

This focus has led to the identification of a select few initiatives that NIED believes will make meaningful changes to the way in which Eating Disorders are prevented and treated in Canada.

Today, with the publication of our updated 3-year *Strategic Plan: 2019-2021*, NIED is refining its strategic direction to fully support new partnership opportunities and the implementation of a new, co-designed pan-Canadian strategy focused on improving outcomes for Eating Disorders in Canada between 2019 and 2029. Initiatives in this strategic plan will continue to focus on (1) **Supporting People** and (2) **Improving Access** to appropriate care for people affected by Eating Disorders.

NIED Strategic Plan 2019-2021

Mission

NIED supports the creation and dissemination of informational and recovery-oriented resources aimed at treating and preventing Eating Disorders in Canada.

Vision

That all Canadians affected by Eating Disorders and related mental illnesses have equitable access to high quality publicly covered health care and social services to support their recovery – no matter where they live in Canada.

Organizational Goals

To fulfill our mission, NIED works with dedicated volunteers and stakeholders on the implementation of the following priorities:

Organizational Goals	STRATEGIC PLAN PRIORITIES: 2019 - 2021
1. Supporting People NIED helps caregivers, patients and practitioners fill gaps in care through awareness building and educational activities and by highlighting better practices in prevention, health promotion and treatment in Canada and from around the world.	 Designing and Co-Delivering Educational Symposia and Workshops Co-developing a new e-learning Platform for Eating Disorders in Canada with Body Brave
2. Improving Access NIED is working with stakeholders across the country to address the gaps in current services, delays in treatment, lack of pan-Canadian data and insufficient training for clinicians, healthcare professionals and other providers who prevent and treat Eating Disorders.	3. Co-developing and finalizing a <i>Canadian Eating Disorders</i> Strategy with the Canadian Eating Disorders Alliance (CEDA) and external stakeholders to measurably improve Eating Disorders outcomes in Canada between 2019 and 2029.
3. Organizational Excellence and Sustainability Over the next 3 years, NIED will adopt new forms of governance across its 5 areas of operations aligned with Imagine Canada's Standards Program and seek accreditation as an Imagine Canada Accredited Charity.	 NIED will continue to engage openly and transparently with stakeholders through various media, fora and communications channels. NIED will launch a new comprehensive fundraising campaign in 2019 to support the implementation of its strategic goals and key initiatives identified in the <i>Canadian Eating Disorders Strategy</i>. NIED will launch a new evaluation matrix in 2019 to track its progress against organizational goals and key initiatives identified in the <i>Canadian Eating Disorders Strategy</i>.

NIED Strategic Focus 2018-2019

About NIED

NIED is the voice for Canadian families, caregivers and individuals who live with an Eating Disorder and other co-morbid and concurrent diagnoses.

We help caregivers, patients and practitioners fill gaps in care through education and by highlighting better practices in prevention, health promotion and treatment.

NIED is working with stakeholders across the country to address the gaps in current services, delays in treatment, lack of pan-Canadian data, and insufficient training for clinicians and healthcare professionals.

1. Supporting People

- NIED provides support and hope for eating disorder individuals and families
- NIED is working with caregivers, healthcare and social services providers to empower and help parents, families, individuals (including in rural and remote locations)
 - o recognize early signs and know how to seek help;
 - cope with the situation they find themselves in;
 - o navigate healthcare and social service systems.
- We know that early detection and intervention can result in full recovery from an Eating Disorder.

2. Improving Access

- NIED works with a wide range of stakeholders to improve access to appropriate, evidence-based care
- NIED is working with governments, statistical agencies, healthcare and social service providers
 to improve Eating Disorders education, reduce wait times, improve access to high quality care
 and improve patients' outcomes.
- We actively collaborate with stakeholders to overcome the following challenges:
 - Unfortunately, of the close to 1,000,000 Canadians (Statistics Canada, 2016) who meet
 the diagnostic criteria for an Eating Disorder, too few have reasonable access to timely,
 comprehensive and specialized treatment.
 - Many people with an Eating Disorder never get diagnosed and suffer significant personal and family distress.
 - Eating Disorders have the highest death rate of any mental illness; 1 in 10 will die because of their disorder.

Eating Disorders are serious mental illnesses associated with significant medical complications that affect every organ of the body.

Eating Disorders are not a choice and affect all genders, ages, racial and ethnic identities, sexual orientations and socio-economic backgrounds.

ENDNOTES

- iv Birmingham, C.L., Su, J., Hlynsky, J.A., Goldner, E.M. & Gao, M. (2005). The mortality rate from anorexia nervosa. *International Journal of Eating Disorders, 38*(2), 143-6; Girz L, Lafrance Robinson A, Tessier C. (2014). Is the next generation of physicians adequately prepared to diagnose and treat eating disorders in children and adolescents? *Eating Disorders: Journal of Treatment & Prevention, 22*(5), 375-85.
- ^v The Butterfly Foundation. (2012). Paying the price: The economic and social impacts of eating disorders in Australia
- vi Statistics Canada, Table 13-10-0801-01 (formerly CANSIM 102-0564).
- vii Arcelus, J., Mitchell, A.J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Archives of General Psychiatry, 68,* 724-731
- viii Berkman, N.D., Lohr, K.N., & Bulik, C.M. (2007). Outcomes of eating disorders: A systematic review of the literature. *International Journal of Eating Disorders, 40,* 293-309.
- ^{ix} Arcelus, J., Mitchell, A.J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Archives of General Psychiatry, 68,* 724-731
- * Smink, F.E., van Hoeken, D., & Hoek, H.W. (2012). Epidemiology of eating disorders: Incidence, prevalence and mortality rates. Current Psychiatry Reports 14 (40, 406-414
- xi See, notably, Roberts, K.C. "Overweight and obesity in children and adolescents: results from the 2009 to 2011 Canadian Health Measures Survey," Health Rep. 2012 Sep;23(3):37-41; and Lillico, H.G. et al. "The prevalence of eating behaviors among Canadian youth using cross-sectional school-based surveys" BMC Public Health. 2014; 14: 323; See also, Luongo, N.M., "Disappearing in plain sight: An exploratory study of co-occurring eating and substance abuse dis/orders among homeless youth in Vancouver, Canada," Women's Studies International Forum, Volume 67, March–April 2018, Pages 38-44, https://doi.org/10.1016/j.wsif.2018.01.003; and Godin, K.M., Patte, K.A. and Leatherdale, S.T. "Examining Predictors of Breakfast Skipping and Breakfast Program Use Among Secondary School Students in the COMPASS Study" Journal of School Health, yolume 88, Issue 2, February 2018, Pages 150-158, https://doi.org/10.1111/josh.12590.
- ^{xii} Raffoul, A., Leatherdale, S.T. & Kirkpatrick, S.I. "Dieting predicts engagement in multiple risky behaviours among adolescent Canadian girls: a longitudinal analysis" Can J Public Health (2018) 109: 61. https://doi.org/10.17269/s41997-018-0025-x
- ^{xiii} McVey G., Tweed S. & Blackmore E. (2004). Dieting among preadolescent and young adolescent females. *CMAJ Canadian Medical Association Journal*, *170*(10), 1559-61; McVey, G.L., Tweed, S., & Blackmore, E. (2005). Correlates of dieting and muscle gaining behaviors in 10-14 year-old males and females. *Preventive Medicine*, 40(1), 1-9; Bernier, C.D., Kozyrskyj, A., Benoit, C., Becker, A.B. & Machessault, G. (2010). Body image and dieting attitudes among preadolescents. *Canadian Journal of Dietetic Practice and Research*, *71*(3), e34-e40; and Gusella,

ⁱ Statistics Canada, 2016

ⁱⁱ See notably, Canadian Paediatric Surveillance Program, ttps://www.cpsp.cps.ca/surveillance/study-etude/avoidant-restrictive-food-intake-disorder

In the United States, it is estimated that 30 million Americans live with an Eating Disorder and that only 1 in 10 people living with an eating disorder receive treatment. In 2012, it was estimated that there were 913,986 people with an eating disorder in Australia.

J., Goodwin, J. & van Roosmalen, E. (2008). 'I want to lose weight': Early risk for disordered eating? *Paediatric Child Health*, 13(2), 105-110

xiv Pinhas, L., Morris, A. Crosby, R.D., & Katzman, D.K. (2011). Incidence and age-specific presentation of restrictive Eating Disorders in children. A Canadian paediatric surveillance program study. Archives of Pediatrics and Adolescent Medicine. 165, 895-899a