Canadian Eating Disorders Strategy

2019-2029

This Strategy has been developed by representatives of the Eating Disorders Association of Canada-Association des Troubles Alimentaires du Canada (EDAC-ATAC), Eating Disorders Foundation of Canada (EDFC), National Eating Disorder Information Centre (NEDIC), and National Initiative for Eating Disorders (NIED). Its purpose is to scan and describe the field of Eating Disorders in Canada and facilitate ongoing dialogue and broad engagement with a range of stakeholders interested in improving health and social outcomes of people living with and affected by EDs in this country.

Citation: "Canadian Eating Disorders Alliance (2019).
The Canadian Eating Disorders Strategy: 2019 - 2029.

November 2019

Eating Disorders
Association of Canada
Association des Troubles
Alimentaires du Canada

EDFC
Eating Disorders
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of Canada

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National Eating Disorder
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NIED
NATIONAL INITIATIVE FOR
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Awareness. Understanding. Action.

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Canadian Eating Disorders Strategy: 2019 - 2029

Preface

In 2016, EDAC-ATAC, EDFC, NEDIC and NIED[1] joined together to articulate a national strategy for Eating Disorders (EDs). Our four organizations agreed to first describe the field of Eating Disorders in Canada and start a process of creating actions involving many stakeholders that could improve outcomes for people affected by EDs. These actions appear as 'Recommendations' (grouped under 6 pillars) throughout this Strategy.

We welcome the opportunity to discuss these recommendations with stakeholders across Canada to determine how we can best improve health and social outcomes for people living with or recovering from EDs in Canada.

Introduction

Approximately 1 million[2] Canadians meet the diagnostic criteria for an Eating Disorder (ED), such as Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge Eating Disorder (BED), Avoidant Restrictive Food Intake Disorder (ARFID)[i] and Otherwise Specified Feeding and Eating Disorder (OSFED)[3]. EDs are serious but treatable mental illnesses that can affect anyone regardless of gender, age, racial and ethnic identity, sexual orientation or socio-economic background[ii].

Unfortunately, research data indicate that the majority of people with EDs do not seek or receive treatment, and that those who do experience lengthy delays[iii]. Many people with an ED are never diagnosed, do not receive any treatment, and suffer significant personal and family distress. The social and economic costs of untreated EDs are similar to those of depression and anxiety, with debilitating physical and mental health effects comparable to psychosis and schizophrenia[4].

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

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

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[1] Eating Disorders Association of Canada – Association des Troubles Alimentaires du Canada (EDAC-ATAC); National Eating Disorder Information Centre (NEDIC); Eating Disorders Foundation of Canada (EDFC); and National Initiative for Eating Disorders (NIED).

[2] 2016 calculation based on prevalence rates cited in Langlois, K.A., Samokhvalov, A.V., Rehm, J., Spence, S.T. and Gorber, S.C., *Health Descriptions for Canadians – Mental Illnesses* (2012): 39-42, Statistics Canada surveys and statistical programs – Documentation: 82-619-M2012004, https://www150.statcan.gc.ca/n1/en/pub/82-619-m/82-619-m2012004-eng.pdf?st=gRt3lMry

[3] In the United States, it is estimated that 30 million Americans live with an ED and that only 1 in 10 receive treatment (National Eating Disorders Association (NEDA), https://www.nationaleatingdisorders.org/statistics-research-eating-disorders). In 2012, it was estimated that there were 913,986 people with an ED in Australia.

[4] The Butterfly Foundation, *Paying the price: The economic and social impacts of eating disorders in Australia* (2012), https://thebutterflyfoundation.org.au/about-us/information-and-resources/paying-the-price/

About the Canadian Eating Disorders Alliance (CEDA)

CEDA is a dedicated group of stakeholders and volunteers whose main goal is to improve health and social outcomes for people living with and affected by EDs. CEDA includes the:

- Eating Disorders Association of Canada-Association des Troubles Alimentaires du Canada (EDAC-ATAC);
- Eating Disorders Foundation of Canada (EDFC);
- National Eating Disorder Information Centre (NEDIC); and
- National Initiative for Eating Disorders (NIED).

Purpose

To be the national collective voice for Canadians affected by Eating Disorders, including people living with an Eating Disorder, loved ones, as well as treatment providers and researchers, and to advance the field of Eating Disorders in Canada.

Mandate

1. We will support the collaborative relationship between the National Initiative for Eating Disorders, the Eating Disorders Association of Canada – Association des Troubles Alimentaires du Canada, the National Eating Disorder Information Centre and the Eating Disorders Foundation of Canada on all matters that pertain to the collective national field of Eating Disorders in Canada.

2. We will establish national goals and collaborative activities as determined to be helpful for the advancement of the field of Eating Disorders in Canada.

3. We will determine the level of commitment and financial investment required of each organization prior to the undertaking of any joint activity.

4. We will also value the input and participation of provincial and territorial stakeholders as well as other groups of relevance to the field of Eating Disorders.

5. We recognize that speaking with one united voice has a stronger impact and will increase the likelihood of successful outcomes. Therefore, we commit to seek out the input of our partner organizations prior to engaging in national communications or advocacy initiatives focused on Eating Disorders in Canada.

6. Collaborative activities could include, but are not limited to, the articulation of a national strategy on Eating Disorders, inter-organizational fund-raising activities, other activities of national prominence requiring the support of the field of Eating Disorders.

7. We will evaluate the effectiveness of our inter-organizational activities on a regular basis.

Acknowledgements

The Alliance is grateful for the leadership, time and expertise of the many passionate caregivers, health care professionals, people with lived experience, social service providers and researchers who provided insights and input to reviewing or writing significant sections of this Strategy and its recommendations.

We are also grateful to Dr. Angela Grace, Heather Lilicco, R.H.N. and Dr. Karen Patte who researched and wrote the first version of the Prevention Pillar.

The authors of the strategy, who are representatives or former* representatives of the Canadian Eating Disorders Alliance, takes full responsibility, though, for the final version of this Strategy and any oversights or errors.

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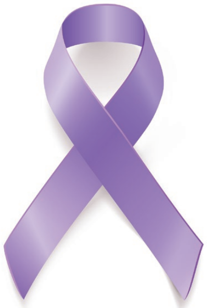
Vision

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



The Canadian Eating Disorders Strategy

This strategy contains 6 key pillars and 50 recommendations aimed at improving outcomes for people living with and recovering from EDs and related mental illnesses.

Each pillar is co-chaired by respected researchers, clinicians, caregivers, health care professionals and social service providers from across Canada who conduct research on EDs and related illness, and/or treat and support people directly affected by EDs.

We believe that we can successfully implement many recommendations in this Strategy over the next 10 years by adopting a highly collaborative approach involving multiple stakeholders, including people with lived experience, caregivers, health and social services providers, researchers[xiii], existing health care, mental health and social services organizations, policymakers, governments and other stakeholders[5]. The successful implementation of several recommendations will require, among other activities, the creative exploration, modelling and selection of highly collaborative approaches to working across different stakeholder groups regardless of service and professional boundaries[xiv].

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[5] Mental Health Commission of Canada; CAMIMH members; psychiatrists, physicians, psychologists, registered dietitians, social workers, psychotherapists/counsellors, dentists, occupational therapists, physical therapists, nutritionists, naturopaths, acupuncturists, chiropractors, massage therapists, dentists, osteopaths, and other health care professionals; family caregivers including parents and siblings; employers, researchers, teachers, first responders and other professionals.

1 Prevention

OBJECTIVE

1.1 To reduce the prevalence and severity of EDs in Canada.

Introduction

Prevention efforts need to target the time period before someone develops an ED to help divert developing cases and to reduce the severity of a disorder if it does develop.

Canadian Context

Programs and messaging for ED prevention have been developed in the past, but information on effective resources/programs is scattered and research evaluating the effectiveness remains limited. Limited funding is available to conduct research to fill evidence gaps regarding which types of programs or what core components are most effective for prevention (e.g., The Body Project, feminist-informed approaches, social justice, media literacy programs, media activism).

Moreover, relatively few researchers within Canada are focused on ED prevention given the lack of funding support. Many initiatives targeting other health-related conditions (i.e., obesity) are often given priority over ED prevention, yet anti-obesity messaging has been implicated in the unintended development of ED symptoms[xv].

1. Prevention Recommendations

Consistent with Research recommendations made in this Strategy, a well-connected network to disseminate best practices to practitioners and the public is recommended given that Canada is geographically large. Where to focus prevention efforts (e.g., certain age or demographic groups) or when a tailored approach is needed (i.e. one size fits all messaging will not always work) must also be determined through a robust, ongoing research strategy.

PREVENTION RECOMMENDATIONS

1. Develop a common language or definition of what prevention means in the context of EDs and a culture influenced by weight bias[xvi].
2. Develop messaging for the general population about prevention.
3. Educate practitioners, educators, policy makers, medical and obesity professionals, and other relevant groups (e.g., fitness professionals; dance coaches; education professionals; dentists; media) on
    - early identification and identification of people at risk of developing EDs or related mental illness;
    - best practices for prevention;
    - appropriate messaging in specific settings (e.g. schools); and
    - timely referral to either information resources or appropriate care[6].
4. Identify gaps where no best practices exist, either for certain populations or disorder types.
5. Connect with researchers to fill evidence gaps, including looking to "success" stories in other countries.
6. Validate whether to use existing best practices repositories or the creation of a new central repository to share best practices for prevention-related materials.
7. Subject to R. 6, create a centralized repository to facilitate sharing of better ED prevention practices.
8. Consistent with R. 43, systematically measure efforts aimed at reducing prevalence of EDs in Canada.

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[6] This is important, as currently sometimes people with EDs are referred erroneously to obesity clinics, which cause delays in treatment and possibly unintended consequences on the individual being referred for treatment.

2 Public Education and Awareness

OBJECTIVES

2.1 To reduce stigma and shame associated with EDs; and

2.2 To better support ongoing awareness and education about EDs in Canada.

Introduction

Educational interventions targeting stigma and mental health literacy are needed in Canada to change misconceptions about EDs[xvii] held by the public as well as health professionals working with those who may be affected by EDs.

According to a 2015 public survey conducted by Ipsos Reid[xviii] (on behalf of NEDIC), "4 in 10 (40%) Canadians mistakenly believe that EDs are a choice while 21% believe they are genetic".

Moreover, a survey conducted by NEDIC in 2018[7] to gauge literacy about EDs in Canada revealed that among the professionals who participated, the group categorized as "health care providers with high levels of engagement with medical service users (general practitioners, nurse practitioners, and nurses)" did not score statistically significantly higher in ED literacy than the average for professionals as a whole. Also of note, fitness professionals scored lowest in ED literacy and highest in endorsement of stigmatizing beliefs, yet were most likely to agree that public education about EDs is "adequate". This is concerning, as we know that sociocultural factors, including weight stigma and diet culture, can significantly impact public health as they contribute to risk factors for the development of EDs.

Canadian Context

In Canada, a lack of education as well as misinformation about EDs are barriers to treatment and recovery from EDs. Moreover, low mental health literacy contributes to stigmatization of those with EDs[xix] and may also impede early detection, help-seeking, and appropriate treatment. However, public education can mitigate stigmatization and the barriers to treatment and detection.

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[7] NEDIC conducted an online survey of 1000 respondents across Canada to explore the Canadian public's experience with ED education, as well as to explore ED literacy across individuals employed in different professions.

Resources to support additional public education about EDs are scarce, and yet the need is great. A 2012 survey of Canadian teachers[xx] revealed a need for increased provision of education in schools to help teachers to address mental health challenges in students, including EDs:

- 38.8% of respondents strongly or somewhat agreed that EDs are a pressing concern relating to student mental health
- Yet 87% of agreed that a lack of adequate staff training in dealing with children's mental illness is a potential barrier to providing appropriate services for students in their school

While there have been efforts to better educate the public about EDs, a strategy including clear guidelines and standards to inform such endeavours does not yet exist. As such, certain approaches that have been identified as harmful for the target populations may be used in educational efforts by individuals or groups who are well-intentioned but not well-informed. Research suggests that the inclusion of direct information and media reports within ED education for young people contravenes the principle of "first do no harm" [xxi]

- Providing specific details about EDs results in increased knowledge, but may at the same time result in increased levels of dietary restraint and disordered eating behaviours[xxii]
- The use of media articles (e.g. those in magazines) may also serve as a 'how-to' or information source to adopt disordered eating behaviours due to the perceived glamorization of the disorders[xxiii]

Consequently, there is a need for a significant improvement in the access to and delivery of public education relating to EDs to support early identification, early access to treatment, and stigma reduction.

2. Public Education and Awareness Recommendations

Improved public education related to EDs can facilitate early identification and early access to appropriate treatment, which are actions associated with improved outcomes. Conversely, a lack of education and misinformation about EDs can create significant barriers for treatment seeking individuals and caregivers who are affected by EDs.

PUBLIC EDUCATION AND AWARENESS RECOMMENDATIONS

9. Seek champions in each province and territory to identify and summarize public education campaigns and best practices. This information will be used to inform the development of evidence-based educational and training materials.
10. Using findings from the 2018 NEDIC survey and academic research, further identify significant gaps in knowledge and effective educational programming that could be used to address these specific areas of need.
11. Develop and disseminate educational programming to fill gaps in knowledge for appropriate audiences. These tools could include, but are not limited to, webinars, pamphlets, PowerPoint® presentations, train-the-trainer resource kits, conferences, and panels. Materials are to be housed in a central location (NEDIC) to ensure streamlined access.

3

Treatment

OBJECTIVES

3.1 To improve access to appropriate care in Canada;

3.2 To reduce barriers to care across the country;

3.3 3 To reduce variation in continuum of care for EDs across Canada; and

3.4 To support outcomes evaluation of care and the development of indicators of recovery.

Introduction

ED treatment in Canada is focused on medical stabilization, nutritional rehabilitation, normalization of eating behaviours, and in some cases stabilization of psychiatric comorbidities. Appropriate assessment is required to identify treatment options.

Canadian Context

In Canada, there exist:

- a limited number of specialized, publicly funded EDs clinics or treatment centres[8], mainly concentrated in urban areas in the provinces of British Columbia, Alberta, Ontario, Quebec and Nova Scotia;
- Provincial, community and virtual ED networks in British Columbia, Alberta, Manitoba, Ontario, Quebec, Nova Scotia and Newfoundland to help guide people recovering from an ED through the system[9];
- private clinics and practitioners in most provinces; and
- little to no services in the Territories.

In Canada's publicly funded health care system, there are varying levels of care available across

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[8] See, for example, BC Children's Hospital Provincial Specialized Eating Disorders Program; the Provincial Adult Tertiary and Specialized Eating Disorders Program at St. Paul's Hospital; BridgePoint Center in Saskatchewan; the Ontario Community Outreach Program for Eating Disorders (OCOPED), which lists publicly funded programs across Ontario, including the UHN Eating Disorder Program; the Eating Disorder Program at the Douglas Mental Health University Institute; Le Programme des troubles des conduites alimentaires for adults at the Centre hospitalier de l'Université Laval; and the Nova Scotia Health Authority Eating Disorders Clinic.

[9] See, for example, Kelty Mental Health Resource Centre (BC); The Looking Glass Foundation (Vancouver); the Eating Disorder Support Network of Alberta; Eating Disorders Manitoba; Sheena's Place (Toronto); Hopewell (Ottawa); Body Brave (Hamilton); Anorexie et Boulimie (ANEB) Québec; Eating Disorders Nova Scotia; Eating Disorders Foundation of Newfoundland and Labrador; and F.E.A.S.T..

the country for people with EDs. Care provided is based on values that are patient- and family-centered, collaborative, interprofessional, evidence-based, and in support of a scientist-practitioner model. However, even when treatment is available, some individuals are not motivated to participate in treatment, which can lead to delays in accessing appropriate care.

In addition to services available in publicly funded organizations, there are several types of specialized services for EDs in Canada, including the following:

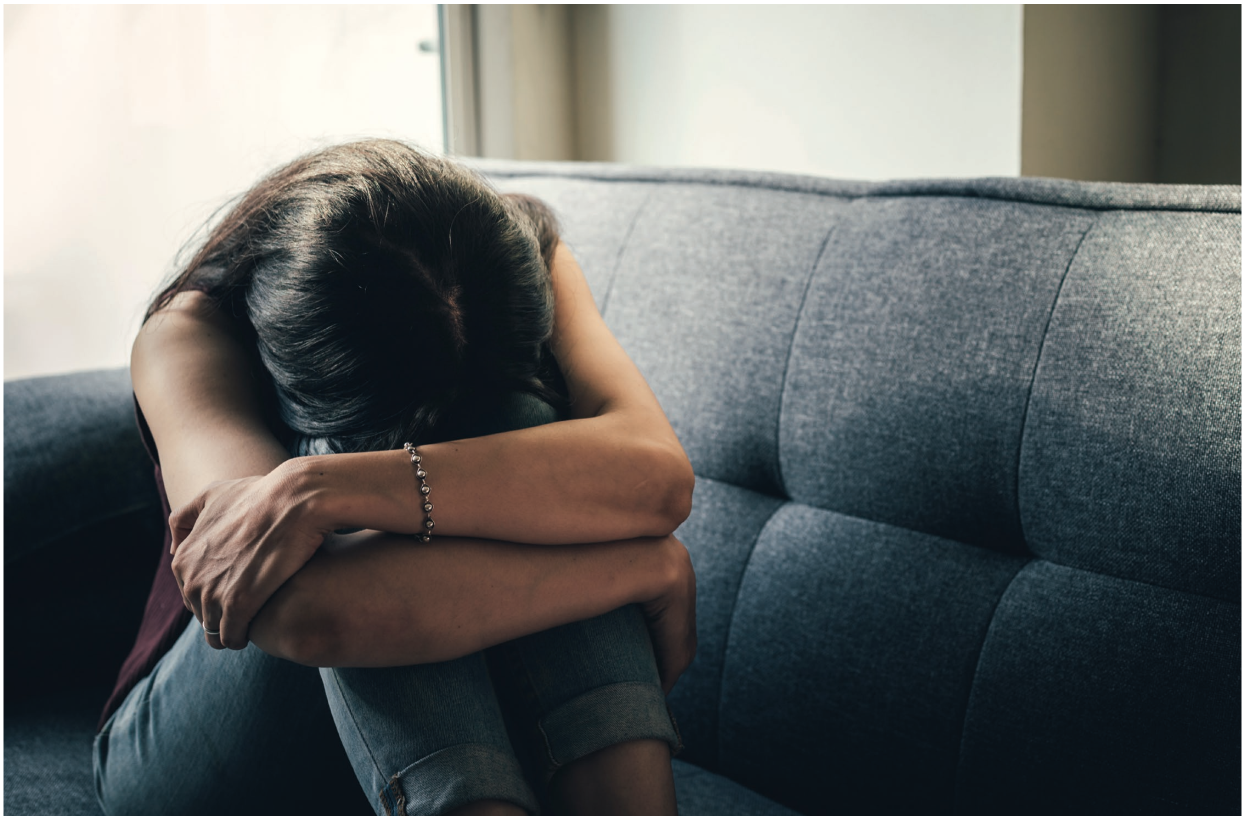
- **Residential**: Only a small handful of publicly funded residential facilities exist across Canada. Facilities in Ontario and British Columbia (BC) are intended for those with severe and unrelenting EDs who have tried other treatment options with little to no success. These facilities generally provide services that are short-term in nature, including meal support and around-the-clock care for individuals who are medically stable but who require intensive levels of service to try to combat the ED. BridgePoint Center for Eating Disorders in Saskatchewan also provides publicly funded residential care. However, it is different from the residential centres in Ontario and BC in that it is open to all clients with EDs, not limited to individuals who have achieved little or no success with previous treatment.

- **Inpatient units**: These types of services are available in tertiary care facilities, and house those with an ED who are medically unstable, extremely underweight and those who require intensive support to interrupt their symptoms and/or initiate weight restoration. Inpatient beds can be housed on specialized ED units or are embedded within general medical units. The care received while an inpatient on a unit involves medical support, nutritional rehabilitation, psychological and psychiatric support and 24-hour care.

- **Day Treatment Programs**: Also housed in tertiary care facilities, day treatment programs, also known as partial hospitalization programs, are services for those who are medically stable but who require intensive levels of support in order to try to recover from an ED. These intensive programs require individuals to commit to participating in treatment for 6-10 hours every day for 4-5 days per week, and constitute meal support, nutritional rehabilitation, psychological treatment, and addressing comorbid psychological issues. For those who initiated their treatment on an inpatient unit, these programs are often offered and serve as a step down from intensive levels of care. These are group-based programs that usually have 6-10 individuals in care simultaneously.

- **Intensive Outpatient Programs (IOPs)**: These programs are relatively new to Canada. They are generally offered outside of hospitals and may involve visits with different providers or professionals (in a centralized location or different locations). IOPs are intensive programs that provide multiple hours of treatment in a given week. IOPs aim to support those who require less intensive treatment than a day treatment program but more services than one treatment contact per week. These services usually involve one psychological group-based service and one meal provided during each interaction.

- **Outpatient programs**: These programs tend to be housed in hospitals and provide group-



based and individual therapy. Treatment is provided by an interdisciplinary team and includes group-based psychological treatments, and medical, nutritional and psychiatric monitoring.

- **Step-down outpatient services**: These programs that are housed in hospital are a step-down service for inpatient and day treatment programs and offer individuals on the path to recovery further treatment in the form individual psychological therapy and medical/dietetic monitoring at a frequency of once/week.
- **Transitional/Supportive Housing**: There are very few transitional housing opportunities in Canada where individuals, who have completed more intensive training, reside until they are able to return to their home communities. Sometimes these services are adjacent to more specialized ED programs that continue to provide treatment allowing patients a supportive living environment to further their recovery.

General, pediatric and adult ED programs differ not only in location, availability of appropriate interprofessional teams, and services offered, but also in treatment philosophies, modalities used, the involvement (or not) of families, and treatment inclusion and exclusion criteria.

This fragmented system results in individuals having unequal access to care; and when they do, it is often not matched to their developmental or symptom level needs. Alarmingly,

“Chronic ED patients often have complex health histories. Many of the community resources cannot accommodate complex cases. In fact, these are excluded from many of their mandates. In our experience, only the fully implemented inter-disciplinary ED specialty teams were effective.”

patients fall through the cracks entirely because their co-morbid symptoms exclude them from admission or their age at presentation of treatment does not match the available services in their geographical region.

Regarding age, **transition from child/youth to adult services** is also challenging and/or disconnected. It is known that treatment transitions within the system are disjointed and often difficult for the patient and their caregivers to navigate, let alone access, or even know about.

There are also an alarmingly high number of **under-resourced populations** (e.g. rural, LGBTQ people, males, indigenous and Northern communities, cultural and ethnic minorities).

Moreover, some treatment facilities do not treat Binge Eating Disorder (BED). In some cases, patients are referred by some primary care providers to a weight management clinic, which focuses on weight loss, and not treating the actual ED, a situation which may further perpetuate the problems associated with BED.

Finally, there is a lack of programming to address commonly occurring comorbidity issues for people with an ED. This in turn results in treatment provided in silos and patients having to move back-and-forth between service providers, leading to ineffective and disjointed care.

> “Chronic ED patients often have complex health histories. Many of the community resources cannot accommodate complex cases. In fact, these are excluded from many of their mandates. In our experience, only the fully implemented inter-disciplinary ED specialty teams were effective.”[10]

Sometimes, individuals with an ED seek services away from their hometown, and sometimes in other countries, notably the United States.

Therapeutic Approaches and Treatments

There are a number of different treatments that have been proposed for individuals with EDs.

Early treatment of EDs, such as rapid early intervention programs, has been shown to lead to better recovery outcomes, particularly in the length of illness and likelihood of recovery[xxiv]. Similarly, professional educational interventions have been shown to positively change the attitudes of clinicians towards specific EDs therapy[xxv].

Unfortunately, some approaches to treatment have mixed or limited evidence of effectiveness related to long-term outcomes[xxvi]. However, the evidence base available for ***Enhanced Cognitive Behaviour Therapy*** **(CBT-E)** – used to treat

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[10] Caregiver, *NIED 2018 Caregiver Needs Assessment Survey* (2018).

adults – and ***Family-Based Treatment* (FBT)** – used to treat adolescents – is strong. In addition to pharmacotherapy (iii), CBT-E and FBT are the two most commonly used approaches in treatment centres across Canada.

i. **CBT-E** or **Enhanced Cognitive Behaviour Therapy**: This approach is concerned with the processes that maintain ED psychopathology rather than those responsible for its initial development. Therefore, the focus is on maintaining mechanisms which help construct a formulation which is then used to target the features that need to be addressed in treatment. CBT-E is generally of fixed length i.e. 20 sessions over 20 weeks. It has 4 well defined stages: Stage 1 intensive initial stage, appointments are twice per week and it aims to engage the patient in treatment and change. Stage 2 is a transitional stage where we take stock, review and revise formulation. Stage 3 addresses main mechanisms that are maintaining the patient's ED. Stage 4 focuses on the future and minimizes the risk of relapse in the long term.

ii. **FBT** or ***Family-Based Treatment***: Maudsley FBT originated at the Maudsley Hospital in England. It involves intensive outpatient treatment in which parents play an active, positive role in their child's recovery from an ED.

- In addition, there are three guidelines, further developed by Dr. James Lock *et al.*, specific to treating a restrictive ED:

  - Phase 1: Parents are taught strategies to gain control over the youth's eating behaviours.
  - Phase 2: Family issues are discussed and addressed.
  - Phase 3: Getting the patient's healthy development back on track.

- FBT further stipulates that
  - the family take a compassionate stance toward the illness;
  - the clinician
    - raises anxiety about the illness in the parents as a means of inciting them to take action;
    - lifts blame and guilt that anyone caused the EDs;
    - empowers parents to be an active agent in recovery; externalizes the illness; and
    - places importance on the psycho-education of the illness for the whole family.

iii. **Psychopharmacology**: There is no specific medication meant to treat EDs directly. However, pharmacology can be used to address complex comorbid conditions and symptoms.

Complex Comorbidities

Common comorbidities of mood, anxiety, substance use, post-traumatic stress and personality disorders are often seen concurrently in those with an ED. Depression or mood symptoms have been found to be the most prevalent comorbidity in those diagnosed with anorexia nervosa (AN) or bulimia nervosa (BN), although recent estimates suggest that various comorbidities exist with EDs with alarmingly high rates: 93% of those with an ED will also experience a comorbid mood disorder; 56% will experience a concurrent anxiety disorder; and 22% will present with a comorbid substance use disorder[xxvii]. As a result of these complex comorbidities, treatments must target not only the symptoms associated with the ED, but also these other mental illnesses.

3. Treatment Recommendations

Canada has various, although limited, ED treatment facilities providing treatment as best as possible for individuals and families affected by an ED. Unfortunately, access to care is not equal across the country, and there are some provinces that have no treatment centres available for those with EDs. Emergency departments are sometimes used as a first point of entry into the healthcare system for many "and are considered a 'safety net' in response to the lack of other psychiatric services"[xxviii].

TREATMENT RECOMMENDATIONS

12. Consistent with principles in the Canada Health Act, publicly state that all Canadians, including individuals living with an ED, must have equitable access to medically necessary services to all Canadians – no matter where they live and without discrimination.
13. Create, fund and implement specialized services to address EDs across all levels of treatment intensity and for patients of all illness severities;
14. Support spread of leading practices aimed at better matching of treatment to patient needs (e.g. Short Treatment Allocation Tool for EDs (STATED))[xxix].
15. Improve communication and sharing of best practices and evidence-based care across professionals, providers / health care and social services.
16. Design networked services for EDs across Canada based on promising and evidence-based practices.
17. Establish networks in provinces and territories where they do not exist to coordinate resources and collaborative care.
18. Establish a pan-Canadian 'network of networks' to link together these networks across provinces and territories to further support dissemination of best practice and coordination of care.
19. Establish a Task Force to improve transitions from youth to adult services.
20. Develop stronger partnerships with primary care to ensure that individuals with EDs are identified early.
21. Develop bilingual, culturally appropriate and gender-sensitive[xxx] services for marginalized sub-populations.
22. Develop and deliver training in sensitivities regarding EDs in non-ED treatment environments (e.g. obesity clinics).
23. Encourage provincial health authorities to support participation of Eating Disorder clinicians in learning opportunities to enhance their treatment competencies (e.g. EDAC-ATAC conference).
24. Develop and deliver specialized training to optimize treatment planning for and the integration of treatment(s) that addresses complex comorbidities.

4 Caregiver Support

OBJECTIVES

4.1 To connect caregivers with evidence-based and evidence-informed resources and information to

- help them better navigate health care system and social services;
- support their own health;
- support the recovery of the person they are caring for; and

4.2 To develop and propose improvements to existing health, workplace and social policies and programs so that they are more responsive to caregiver needs.

Introduction

Caregivers, along with the person they are caring for, along with various professionals, providers and other family members, play an important role in supporting the treatment of a person diagnosed with an ED. This is consistent with clinical practice guidelines for EDs[xxxi], which promote team-based approaches to care.

Canadian Context

Informal caregivers are unpaid caregivers. They play an important part in improving the well-being of people living with a mental illness.

According to the Mental Health Commission of Canada (MHCC), "Caregivers often provide a variety of supports, including navigating the mental health system to access services, transportation, advocating for services, and social, financial, and emotional supports. Studies have shown that caregivers can experience a significant sense of personal growth, fulfillment, and purpose through the support they provide to a friend or family member with a mental health problem or mental illness. At the same time, the caregiver's own health — both physical and emotional — can be negatively affected by the day-to-day demands of long-term caregiving."[xxxii]

> "Caregivers often provide a variety of supports, including navigating the mental health system to access services, transportation, advocating for services, and social, financial, and emotional supports. Studies have shown that caregivers can experience a significant sense of personal growth, fulfillment, and purpose through the support they provide to a friend or family member with a mental health problem or mental illness."

However, this role is only starting to be understood by society. The MHCC acknowledges that "more needs to be done to support caregivers, both by acknowledging and addressing their needs, and by reducing the stigma they still experience".[xxxiii]

Although there are no comprehensive data sets or research in Canada regarding the role of caregivers of people affected by EDs[xxxiv], we know that caregivers of people living with a mental illness want to play a pivotal role in the recovery of the person they are caring for[xxxv]. We also know that multiple stakeholders, including caregivers of people living with a mental illness, have recently developed guidelines and standards to improve mental health services in Canada.

Caregivers of people living with an ED experience, as many Canadians with complex care needs, wait for appropriate care and do their best to cope while waiting: "The local children's hospital ED program currently has a 4 week wait list. Our family doctor is monitoring our daughter's vitals on a weekly basis but is unsure of what kind of advice to give. If the ED program or someone could provide a "so your child has an ED, and you're waiting for treatment - here's what to do", that would be so helpful. I am cobbling together a plan from online forums and published articles, and hoping it works ok."[xxxvi]

To help inform this Strategy, NIED surveyed caregivers of people living with or recovering from

EDs in 2018[11] to better understand their unmet needs as well as their successes in caring for themselves while they cared for someone living with an ED. Consistent with findings from various Statistics Canada surveys[xxxvii] on caregiving, caregivers who responded to this survey were more likely to be anxious, constantly worried, stressed, exhausted and/or depressed while caring for their loved one. Other caregivers experienced isolation, helplessness, poor sleep, mood swings, self-doubt and loss of autonomy as a result of caring for some affected by an Eating Disorder.

Understanding the relationship between the impact of caregiving on a caregiver's health status[xxxviii] is important, as the potential negative effects include an inability to care for their loved one, weaker attachment to the workforce, and increased use of health care services.

> "Findings relating increased family burden to increased presence of personal mental health difficulties conform to and extend existing research among caregivers. This further stresses the need for the investment of resources in the protection of the well-being of this group who perceive family burden, for moral and economic reasons or practical reasons, such as the impact of their mental health on their continued provision of care and the cared for person's outcome"[xxxix].

Just over half of caregivers responded that they understood what they needed to do to support their family member recover from an ED. For those caregivers who were employed, about one-third (1/3) of caregivers said they were" very satisfied" or "satisfied" with the quality of support or care they receive from or through their employer.

Finally, caregivers provided a number of suggestions on how care and supports can be improved, including increased funding, a greater focus on the person requiring care, increased access to resources and financial assistance to help with daily living, better education for professionals and access to family or parent support groups, especially in rural and remote locations.

4. Caregiver Support Recommendations

The following recommendations are consistent with recommendations in the MHCC's *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses*[xl] and observations shared by caregivers with NIED and in various Statistics Canada surveys over the last 10 years. "*The Mental Health Strategy for Canada* recommends more help for family caregivers through better financial supports, increased access to respite care and more flexible workplaces. Planning a comprehensive approach to meeting the needs of family caregivers is not the sole responsibility of the mental health system and requires action on the part of many other system stakeholders, including governments and other organizations."[xli]

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[11] Qualitative responses to an online survey were received from 67 caregivers living in 9 out of 10 provinces.

Caregiver Support

> “The Mental Health Strategy for Canada recommends more help for family caregivers through better financial supports, increased access to respite care and more flexible workplaces. Planning a comprehensive approach to meeting the needs of family caregivers is not the sole responsibility of the mental health system.”

CAREGIVER SUPPORT RECOMMENDATIONS

25. Engage caregivers formally in the design and development of recommendations in this Strategy.
26. Validate and prioritize with caregivers and other stakeholders how this Strategy can support the implementation of recommendations in the *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses*.
27. Continue to work collaboratively with the MHCC’s Family Caregiver Advisory Committee and national and provincial caregiver organizations to support efforts aimed at improving caregivers’ access to resources and information about mental illness, involvement in system and program planning; navigating health care systems and social services; and engagement, when appropriate, as part of the care team.
28. Develop, with national and provincial caregiver organizations, new or adapted provincial and organizational policies and programs that will provide better support to all caregivers who need respite and/or who are trying to access appropriate care for their loved ones.
29. Further examine with caregivers and stakeholders the value and effectiveness of existing caregiver guides such as the *Mental Health Caregiver Guide: A Guide for Caregivers of Persons Living with Mental Illness or Experiencing Mental Health Challenges*[xlii].
30. Develop new or adapt existing workplace policies that can better accommodate periodic absences from work due to a need to fulfill caregiver responsibilities.
31. Work with employers to identify better practices that can be shared, spread and adapted in support of caregivers of people living with mental illness.

5 Training

OBJECTIVES

5.1 To identify post graduate and continuing professional development training pathways for EDs;

5.2 To develop clinical competencies related to the provision of health services to individuals with EDs and to their families; and

5.3 To encourage future graduates to pursue research careers in the area of EDs.

Introduction

Best practice ED treatment is interprofessional[xliii]. Medicine (Family Practice, Pediatrics [including Adolescent Medicine], Psychiatry), Psychology, Dietetics, Nursing, Advanced Practice Nursing, Occupational Therapy, and Social Work disciplines work closely with people, their caregivers and their family members to contribute to ED care. Other disciplines including Child and Youth Workers, Art Therapists, and Teachers may also work in ED care settings.

Professional training is integral to supporting advanced learning and practice related to the provision of high-quality care for EDs. Training can be used to support learning in several areas, including, but not limited to: research, early identification, prevention, health promotion, assessment, referrals, diagnosis, care planning and coordination, treatment selection, medication management, counselling, surveillance and more.

Through training, practitioners can acquire both foundational skills in post-graduate settings related to the provision of high quality, professional health care service delivery and ED specific competencies which are generally not available as part of graduate curricula across Canada.

Canadian Context

In addition to limited graduate course offerings specialized in EDs, Canadian professionals receive or acquire specialized skills regarding EDs from a variety of people and sources:

- Health care professionals who provide services to individuals with EDs are typically oriented, mentored and/or supervised by more seasoned providers working in those services.

- Service settings may also support these providers to seek continuing professional education to enhance ED knowledge and skills through a variety of on-the-job or intensive training experiences. These could include:
  - workshops and online learning modules offered by ED specialists or provincial discipline-based associations;
  - National/international conferences such as the Eating Disorders Association of Canada – Association des Troubles Alimentaires du Canada, the International Conference on Eating Disorders (ICED), the London Conference on Eating Disorders;
  - opportunities to job shadow another professional in specialized ED programs;
  - intensive training offered through supervised opportunities.

International Training

Canadian ED professionals may also have membership in the International Association of Eating Disorder Professionals (iaedp™), which provides certification of ED professionals to promote standards of excellence in the field of EDs. Professionals must demonstrate clinical expertise through education, experience and an exam to earn a certificate in a variety of discipline-based categories.

5. Training Recommendations

Despite having some clinical guidelines and evidence-based treatments available to guide practice, there is insufficient training in evidence-based treatments available across Canada and very few lead Canadian trainers in various treatments for mentoring purposes. This leads to few practitioners across the country having access to training in evidence-based practices.

TRAINING RECOMMENDATIONS

32. Coordinate and disseminate training in evidence-based treatments as they become available for current professionals.
33. Develop a continuing professional development webinar series by Canadian ED specialists with appropriately recognized learning credits.
34. Deliver training in sensitivities regarding EDs in non-ED treatment environments, which could include correctional settings and addictions.
35. Disseminate best practices via Telehealth for rural and remote areas.
36. Enhance training in Family Practice settings, primary care networks/health teams and integrated health networks to support ED screening and early identification.
37. Support professionals wishing to transition their practice into the field of EDs via intensive exposure within specialized ED settings.
38. Identify training/exposure opportunities to other healthcare professionals who come into contact with individuals with EDs (e.g., Gastroenterologists, Emergency Department staff, Paramedics, etc.).
39. Create a task force to identify minimum standards for graduate education in EDs within all health disciplines (including development of a standard curriculum for EDs).

39. Create a task force to identify minimum standards for graduate education in EDs within all health disciplines (including development of a standard curriculum for EDs).

6 Research

OBJECTIVES

6.1 To identify research priorities, needs and gaps in the field of EDs in Canada;

6.2 To enhance Canadian collaborative research and support for EDs research in Canada; and

6.3 To enhance ongoing surveillance, performance measures and data related to EDs.

Introduction

Ongoing research in the field of EDs is vital to better understand the etiology of EDs, as well as prevention and evidence-based treatment approaches. It is equally essential to effectively translate research findings to improve care and outcomes for those affected by EDs.

Canadian Context

A strength of the Canadian research landscape is the publicly funded healthcare system allowing for treatment to be determined by best practices and clinical guidelines as opposed to other factors. This should allow for the promotion and implementation of clinical research to inform practice. Accordingly, Canada has several clinician-scientists across the country who are promoting EDs research, and some provincial governments have invested meaningfully and supported research related initiatives in the field of EDs[12].

Unfortunately, the field of EDs research continues to be vastly under-funded, and consequently under-studied. Of the limited funding that exists in Canada, it is usually not available for the field of EDs. A 2014 reportli of the Standing Committee on the Status of Women suggests that across a 5-year period, $7.5 million has been spent on operating grants for EDs in Canada, while $86 million has been spent on operating grants for schizophrenia, despite EDs being as severe and more prevalent and deadly than schizophrenia. This same report also states that students, trainees and early career scientists are being coached to stay away from specializing in EDs to avoid career pitfalls resulting from this marginalized area of health. Practically, this means that there are few research mentors/supervisors/investigators available. There are many students across various disciplines interested in studying EDs, but there are few research training opportunities and few graduate

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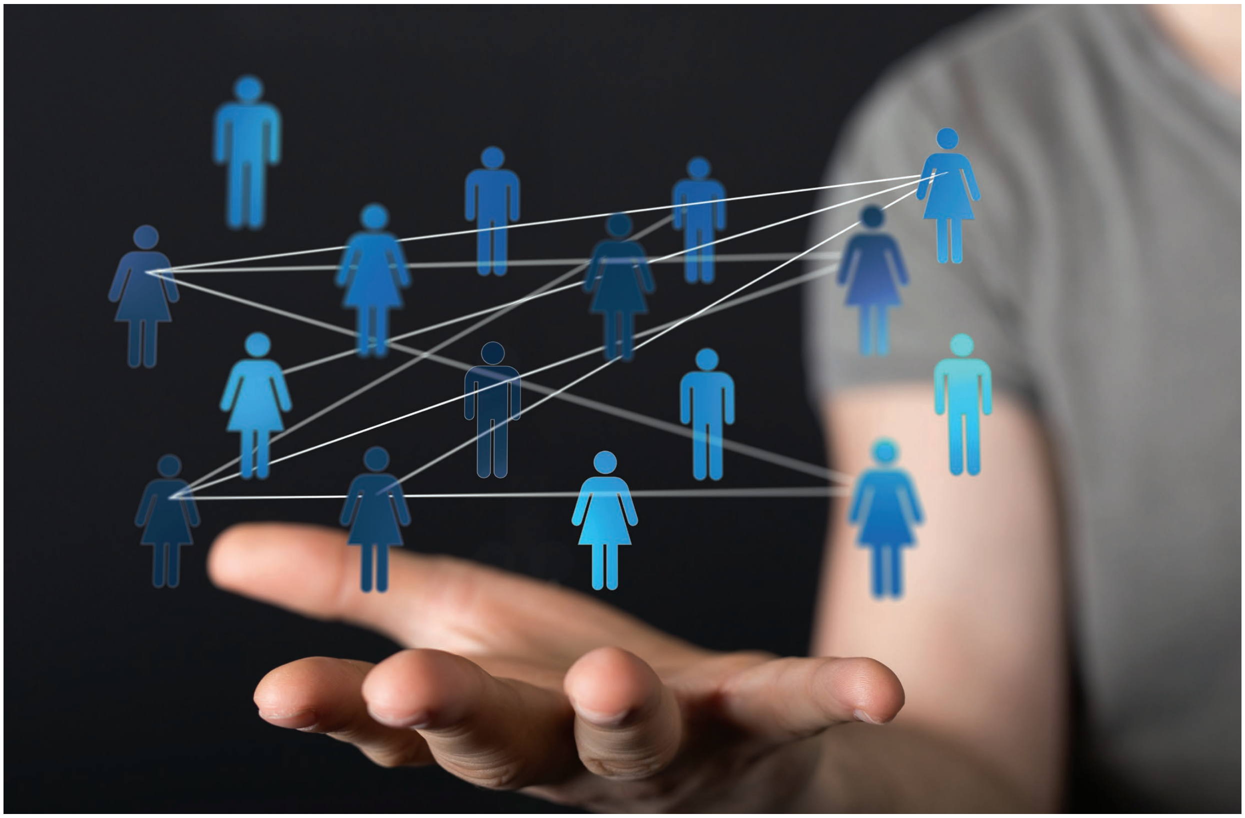
[12] For example, see notably, Ontario's investments in the Ontario Community Outreach Program for Eating Disorders (OCOPED) since 1994, http://www.ocoped.ca/ and the establishment of an integrated approach to addressing EDs in British Columbia, started in 2009, which resulted in the adoption of an *Action Plan for Provincial Services for People with Eating Disorders*, the adoption of *Clinical Practice Guidelines for the BC Eating Disorders Continuum of Services*, the creation of a Centre for Excellence for Eating Disorders and the expansion of the BC Eating Disorders Community of Practice (CoP).



program research supervisors able to support advanced research training across the country, limiting the emergence of new Canadian scientists in the field and advancement and innovation in the field.

With regard to research translation, clinical research findings are not reaching clinicians across the country, preventing individuals with EDs from benefiting from these areas of strength and innovation. There are no dedicated cross-country research bodies that exist in the field of EDs (e.g. peer-reviewed journals, clinical information service such as UpToDate[xliv]). Such a network is essential to engage in pan-Canadian research as well as with various cultural and indigenous communities to enhance collaboration, research possibilities and knowledge translation that can inform practice and improve outcomes.

Finally, in Canada, as elsewhere in the world, statistics related to EDs in primary care are generally regarded as poor[xlv] or woefully out-of-date.

On July 3, 2018, federal, provincial and territorial (FPT) health ministers endorsed CIHI's plans to "measure pan-Canadian progress toward improving access to mental health and addictions services and to home and community care"[xlvi]. Provincial and territorial governments' development of new mental health and community care indicators[13] represents a great opportunity for stakeholders to identify relevant or new data sources that can support comparable reporting of performance across Canadian jurisdictions.

The creation of these new methods of data collection and performance measurement will lead to improved knowledge exchange related to mental illnesses, including EDs. The use of comparable, pan-Canadian data sets and measures will also greatly enhance the potential for jurisdictions to learn from each other's successes and challenges and continuously improve the responsiveness and accessibility of existing mental health resources aimed at preventing and treating complex mental illnesses.

6. Research Recommendations

There is strong potential for research advancement in EDs from Canadian researchers, as strong collaborative research teams are emerging across the country and Canadian research is well-represented at international conferences. Greater investment could accelerate this exponentially. However, there are no research chairs in Canada for EDs research to increase the capacity of Canadian research. In 2018, a pan-Canadian patient-oriented research project[xlvii], funded by the Canadian Institutes of Health Research (CIHR), identified the top 10 research priorities from those with lived experience, their carers and clinicians. This project provides the field with a consensus-built understanding of where research efforts should be placed next. Canadian researchers are in a unique position to leverage this work and to advocate to research funders for more investment in these priorities.

It is relevant to broaden the scope of ED research, as it is fairly homogenous, in that research exists mostly for women with anorexia nervosa, whereas research in other diagnostic categories or in differing populations (e.g. adolescents, males) remains limited.

RESEARCH RECOMMENDATIONS

40. Continue to identify research needs and priorities by people with lived experience, caregivers, and health care professionals in the field so that research questions of most importance to those affected by an ED are carried out and widely promote these priorities[xiii].

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[13] Except Quebec and Ontario. "The federal government has agreed to an asymmetrical arrangement with Quebec, distinct from the Common Statement of Principles. In addition, given the transition to a new government in Ontario, the province cannot officially endorse the recommendations," https://www.newswire.ca/news-releases/a-canadian-first-cihi-to-measure-access-to-mental-health-and-addictions-services-and-to-home-and-community-care-687245651.html

RESEARCH RECOMMENDATIONS (cont'd)

41. Support a systematic approach to the identification of research priorities across the spectrum of EDs and affected populations.
42. Update[xlviii] existing EDs data and relevant indicators in Canada.
43. Update existing mental health performance measures[xlix] so that they include EDs[l].
44. Enhance uptake of available ED research by using various knowledge translation strategies and models.
45. Identify/create research training opportunities across all disciplines.
46. Encourage collaboration, organization and planning of research objectives and combination of expertise to attain federal (i.e., CIHR, SSHRC) funding to carry out pan-Canadian research.
47. Establish a Canadian Research Chair for EDs.
48. Establish a Canadian Research Network for EDs, modelled on the EDs Centres for Excellence in British Columbia.
49. Increase financial support for research related to EDs.
50. Create a national data repository for enhanced research capabilities that reflect the Canadian context.

Conclusion

How this Strategy Was Developed

In 2015, following the publication of a thoughtful report entitled[li] *Eating Disorders among Girls and Women in Canada* by the House of Commons Standing Committee on the Status of Women in 2014, EDAC-ATAC, EDFC, NEDIC, and NIED[14] discussed how we could collaborate meaningfully to improve outcomes for people living with EDs in Canada.

These conversations led to the development of a survey to systematically engage stakeholders across Canada to identify gaps that could be worked on to better support care and recovery for individuals and others affected by EDs.

Prior to the September 2016 EDAC-ATAC conference, NIED worked with stakeholders and volunteers, led by Andrea Lamarre, to develop and disseminate a survey to approximately 500 private and public organizations across Canada, including hospital programs, private practices, mental health organizations, and all those who participated in NIED's M.O.M. (Mothers & Others) March Against EDs on October 27th, 2015. Based on responses from 400 stakeholders, we identified 6 pillars: Training, Education, Treatment, Prevention, Advocacy and Research. Following the EDAC-ATAC conference, a 7th[15] pillar was added: Caregivers.

With the support of conference organizers, Dr. Heather Wheeler and Carly Crawford (Registered Psychotherapist), NIED brought together approximately 40 stakeholders from 9 out of 10 provinces (ED clinicians, researchers, frontline health care providers, parents with lived experience, caregivers and volunteers). Stakeholders participated actively in a workshop to define a focus for a pan-Canadian EDs strategy. Many volunteered to further refine possible actions we could take collectively to improve outcomes for people affected by EDs in Canada. We would like to sincerely thank them for their insights, expertise and encouragement, which have inspired us throughout this journey.

Following the conference, four national ED organizations — EDAC-ATAC, EDFC, NEDIC and NIED — agreed to work together to create a comprehensive set of actions that would fill gaps identified by stakeholders who participated in a national survey in 2016.

These actions appear as 'Recommendations' grouped under 6 pillars) throughout this Strategy. We believe these recommendations will improve outcomes for people living with or recovering from EDs in Canada.
This first Strategy will be used to expand our dialogue with stakeholders, refine specific recommendations and develop action plans for the Strategy's implementation starting in 2019.

We look forward to future dialogue with stakeholders to discuss how best to implement this Strategy's recommendations.

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[14] Eating Disorders Association of Canada – Association des Troubles Alimentaires du Canada (EDAC-ATAC); National Eating Disorder Information Centre (NEDIC); Eating Disorders Foundation of Canada (EDFC); and National Initiative for Eating Disorders (NIED).

[15] Since that time, 'Advocacy' is now seen as a separate but related step to implementing this Strategy and its recommendations. As such, it is not a pillar in this Strategy. Given that a wide range of stakeholders will be needed to take concrete actions to implement recommendations in this Strategy in jurisdictions across Canada, we cannot predict at this time how implementation, let alone Advocacy, will occur.

Annex 1

Why create a Canadian Eating Disorders Strategy?

Since the 1950s, the prevalence of EDs have been increasing around the world, and mainly in western and westernized countries[lii]. Moreover, governments around the world underinvest in EDs and mental health care compared to other services that serve relatively few people[liii].

Unfortunately, too many Canadians with EDs do not have access to timely, appropriate care, contrary to at least 2 out of the 5 principles of the *Canada Health Act* – universality and accessibility, which state that all Canadians are entitled to "the same level of health care" and have "reasonable access to health care facilities."

Based on a 2018 survey of caregivers, we know that navigating existing health care system and social service organizations and accessing timely, high quality specialized care remains a challenge for many people. One caregiver's frustration clearly illustrates the challenge they face when trying to find help: "I have been turned away from the hospital on several occasions even after being sent to [the emergency department] at the family doctor's request because her ECG showed that her heart was failing. Just this past winter we were at the hospital four times and turned away all four times, she is 24 and weighed 72lbs. We were terrified we were going to lose her! We finally got her into a private treatment centre and she was sent home because she was "too sick to be there". Too sick for a treatment centre, not sick enough for the hospital.... That is "extremely stressful". When you become solely responsible for your child's life with absolutely no support from the medical community the pressure is enormous, we are often expected to do what the system can't. The illness is often misunderstood by medical professionals and the resources for care are slim to none. Caring for someone with an eating disorder is an overwhelmingly stressful responsibly. We have been at this for eight years."[liv]

Suicide and suicidal ideation remain a challenge for many people struggling with an ED or related mental illness, such as depression, anxiety or an addiction. Members of the Alliance are actively working with the pan-Canadian Suicide Prevention Collaborative to reduce the rate of suicide for all Canadians and give life to the *Federal Framework for Suicide Prevention Act*[lv], adopted by the Parliament of Canada in 2012.

Regarding education and training, which we believe are foundational to achieving many of the recommendations contained within this Strategy, we aim to work collaboratively with health professionals, providers, caregivers and other stakeholders to design and develop new, evidence-based education and training courses to reduce risks, promote stronger health and speed recovery from EDs.

Based on survey responses of medical doctors[16], 70% of doctors receive 5 hours or less of ED-specific training while in medical school[lvi] and only 6.3% of psychiatry residents felt they had spent enough time with patients with EDs to work effectively with them in clinical practice[lvii].

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[16] In 2018, NIED worked with the Dietitians of Canada to better understand their educational needs related to the treatment of EDs. From this survey and ongoing engagement with dietitians and other professionals, we aim to develop and launch a similar survey with a wider group of health professionals in 2019 to better understand their needs for university training and continuing professional education (CPE) and continuing medical education (CME). The results of these training needs assessment surveys will complement what we expect to learn from a survey launched in July 2018 aimed at caregivers and non-professionals to better understand their knowledge and general educational needs associated with EDs.

This Strategy aims to update our understanding of learning needs of the general public and several professional disciplines. We aim to develop educational and training offerings that can fill knowledge gaps and improve practice.

Overall, multi-disciplinary research, education and training will help us to:

- reduce stigma associated with mental illness;
- avoid unintended harms associated with certain behaviours or practices in society and care; and
- better share and use evidence to guide specific interventions aimed at preventing or treating EDs and related mental illnesses.

Moreover, there are very few[17] examples of models of coordinated and continuous care for EDs in jurisdictions across Canada or around the world. In Canada, this has resulted in people seeking specialized medical and residential care for EDs outside of Canada, at great social and emotional expense to families and financial expense to Canadian health care systems[lviii]. We know that collaborative models are important to the timely identification of risk factors and referral to and use of appropriate support or care, all of which aim to prevent chronicity of symptoms, improve quality of life, improve chances of recovery and save lives through treatment.

Finally, the social and economic costs associated with EDs are large. In 2003, a study reported that provincial costs of people living with AN on long-term disability in British Columbia may be as high at $101.7 million/year (30 times the cost of all provincial specialized ED services)[lix]. Direct health system costs for treating EDs were estimated at $99.9 million in 2012 in Australia[lx] and productivity loss for society estimated at $15.1 billion[lxi]. While similar financial impact analysis is not available in Canada on a national scale, prevalence rates for EDs in Canada mirror those of Australia.

Based on recently published research regarding the cost effectiveness of prevention and treatments for EDs[18], as well as the value of spending on social services[lxii] in Canada, we are optimistic that we can explore options with stakeholders to better to allocate resources across health and social spending to achieve better outcomes for people affected by EDs and related mental illnesses in Canada.

Building on Existing Federal, Provincial and Territorial (FPT) Investments in Mental Health and Community Care

Multiple organizations, governments and individuals are already working together to prioritize research[lxiii] as well as increase awareness and education about EDs in Canada[lxiv].

We believe that we can successfully build on these foundational collaborations by exploring with stakeholders ways to better apply research to practice.

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[17] In Canada's most populous province, Ontario, the Ontario Community Outreach Program for Eating Disorders (OCOPED) is one example of a provincial network of specialized ED service providers.

[18] "Eating disorder interventions were mainly cost-saving or more effective and more costly compared to comparators; however, some results did not reach statistical significance": Khanh-Dao Le, L., Hay, P and Mihalopoulos, C. "A systematic review of cost-effectiveness studies of prevention and treatment for eating disorders," *Australian and New Zealand Journal of Psychiatry*, April 2018, Volume: 52 issue: 4, page(s): 328-338, https://doi.org/10.1177/0004867417739690

Annex 1

We are equally optimistic that new investments being made by provinces and territories in expanded community mental health programs and home care will have a positive impact on people with EDs and their caregivers, even though it is recognized that EDs require specialized, tertiary levels of care, which remain underfunded and under-resourced across Canada.

Over the last two decades, provincial and territorial governments have made important investments in community care, mental health and home care. In late 2016 and early 2017, the Government of Canada signed 10-year funding agreements totalling $11.5 billion with provinces and territories to specifically improve home care and mental health initiatives across Canada.

As provinces and territories continue to invest in community mental health and home care initiatives, opportunities exist to strengthen existing social support programs for caregivers of people affected by EDs and to support the integration of evidence-informed practices into existing and updated mental health programs.

Both collaboration and increased engagement with multiple stakeholders will lead to a more efficient and effective use of existing government resources invested in community mental health and health care across Canada.

We also believe that highly collaborative approaches to knowledge dissemination and mobilization better and promising practices on existing, well-used knowledge exchange platforms (such as the Canadian Best Practices Portal, managed by the Public Health Agency of Canada, the B.C. EDs Community of Practice, the Evidence Exchange Network for Mental Health and Addictions, or the Knowledge Exchange Network[lxv] maintained by Children's Healthcare Canada).

Annex 2

Summary of Recommendations

1. Prevention Recommendations

Objective	**Recommendations**
1.1 To reduce the prevalence and severity of (EDs) in Canada.	1. Develop a common language or definition of what prevention means in the context of EDs and a culture influenced by weight bias[xvi].
	2. Develop messaging for the general population about prevention.
	3. Educate practitioners, educators, policy makers, medical and obesity professionals, and other relevant groups (e.g., fitness professionals; dance coaches; education professionals; dentists; media) on • early identification and identification of people at risk of developing EDs or related mental illness; • best practices for prevention; • appropriate messaging in specific settings (e.g. schools); and • timely referral to either information resources or appropriate care[6].
	4. Identify gaps where no best practices exist, either for certain populations or disorder types.
	5. Connect with researchers to fill evidence gaps, including looking to "success" stories in other countries.
	6. Validate whether to use existing best practices repositories or the creation of a new central repository to share best practices for prevention-related materials.
	7. Subject to R. 6, create a centralized repository to facilitate sharing of better ED prevention practices.
	8. Consistent with R. 43, systematically measure efforts aimed at reducing prevalence of EDs in Canada.

2. Public Education and Awareness Recommendations

Objectives	**Recommendations**
2.1 To reduce stigma and shame associated with EDs; and **2.2** To better support ongoing awareness and education about EDs in Canada.	9. Seek champions in each province and territory to identify and summarize public education campaigns and best practices. This information will be used to inform the development of evidence-based educational and training materials.
	10. Using findings from the 2018 NEDIC survey and academic research, further identify significant gaps in knowledge and effective educational programming that could be used to address these specific areas of need.
	11. Develop and disseminate educational programming to fill gaps in knowledge for appropriate audiences. These tools could include, but are not limited to, webinars, pamphlets, PowerPoint® presentations, train-the-trainer resource kits, conferences, and panels. Materials are to be housed in a central location (NEDIC) to ensure streamlined access.

3. Treatment Recommendations

Objectives	Recommendations
3.1 To improve access to appropriate care in Canada; **3.2** To reduce barriers to care across the country; **3.3** To reduce variation in continuum of care for EDs across Canada; and **3.4** To support outcomes evaluation of care and the development of indicators of recovery.	12. Consistent with principles in the Canada Health Act, publicly state that all Canadians, including individuals living with an ED, must have equitable access to medically necessary services to all Canadians – no matter where they live and without discrimination.
	13. Create, fund and implement specialized services to address EDs across all levels of treatment intensity and for patients of all illness severities;
	14. Support spread of leading practices aimed at better matching of treatment to patient needs (e.g. Short Treatment Allocation Tool for EDs (STATED))[xxix].
	15. Improve communication and sharing of best practices and evidence-based care across professionals, providers / health care and social services.
	16. Design networked services for EDs across Canada based on promising and evidence-based practices.
	17. Establish networks in provinces and territories where they do not exist to coordinate resources and collaborative care.
	18. Establish a pan-Canadian 'network of networks' to link together these networks across provinces and territories to further support dissemination of best practice and coordination of care.
	19. Establish a Task Force to improve transitions from youth to adult services.

3. Treatment Recommendations (con't)

Objectives	Recommendations
3.1 To improve access to appropriate care in Canada; **3.2** To reduce barriers to care across the country; **3.3** To reduce variation in continuum of care for EDs across Canada; and **3.4** To support outcomes evaluation of care and the development of indicators of recovery.	20. Develop stronger partnerships with primary care to ensure that individuals with EDs are identified early.
	21. Develop bilingual, culturally appropriate and gender-sensitive[xxx] services for marginalized sub-populations.
	22. Develop and deliver training in sensitivities regarding EDs in non-ED treatment environments (e.g. obesity clinics).
	23. Encourage provincial health authorities to support participation of Eating Disorder clinicians in learning opportunities to enhance their treatment competencies (e.g. EDAC-ATAC conference).
	24. Develop and deliver specialized training to optimize treatment planning for and the integration of treatment(s) that addresses complex comorbidities.

4. Caregiver Support Recommendations

Objectives	**Recommendations**
4.1 To connect caregivers with evidence-based and evidence-informed resources and information to • help them better navigate health care system and social services; • support their own health; • support the recovery of the person they are caring for; and **4.2** To develop and propose improvements to existing health, workplace and social policies and programs so that they are more responsive to caregiver needs.	25. Engage caregivers formally in the design and development of recommendations in this Strategy.
	26. Validate and prioritize with caregivers and other stakeholders how this Strategy can support the implementation of recommendations in the National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses.
	27. Continue to work collaboratively with the MHCC's Family Caregiver Advisory Committee and national and provincial caregiver organizations to support efforts aimed at improving caregivers' access to resources and information about mental illness, involvement in system and program planning; navigating health care systems and social services; and engagement, when appropriate, as part of the care team.
	28. Develop, with national and provincial caregiver organizations, new or adapted provincial and organizational policies and programs that will provide better support to all caregivers who need respite and/or who are trying to access appropriate care for their loved ones.
	29. Further examine with caregivers and stakeholders the value and effectiveness of existing caregiver guides such as the Mental Health Caregiver Guide: A Guide for Caregivers of Persons Living with Mental Illness or Experiencing Mental Health Challenges[xlii].
	30. Develop new or adapt existing workplace policies that can better accommodate periodic absences from work due to a need to fulfill caregiver responsibilities.
	31. Work with employers to identify better practices that can be shared, spread and adapted in support of caregivers of people living with mental illness.

5. Training Recommendations

Objectives	Recommendations
5.1 To identify post graduate and continuing professional development training pathways for EDs; **5.2** To develop clinical competencies related to the provision of health services to individuals with EDs and to their families; and **5.3** To encourage future graduates to pursue research careers in the area of EDs.	32. Coordinate and disseminate training in evidence-based treatments as they become available for current professionals.
	33. Develop a continuing professional development webinar series by Canadian ED specialists with appropriately recognized learning credits.
	34. Deliver training in sensitivities regarding EDs in non-ED treatment environments, which could include correctional settings and addictions.
	35. Disseminate best practices via Telehealth for rural and remote areas.
	36. Enhance training in Family Practice settings, primary care networks/health teams and integrated health networks to support ED screening and early identification.
	37. Support professionals wishing to transition their practice into the field of EDs via intensive exposure within specialized ED settings.
	38. Identify training/exposure opportunities to other healthcare professionals who come into contact with individuals with EDs (e.g., Gastroenterologists, Emergency Department staff, Paramedics, etc.).
	39. Create a task force to identify minimum standards for graduate education in EDs within all health disciplines (including development of a standard curriculum for EDs).

6. Research Recommendations

Objectives	Recommendations
6.1 To identify research priorities, needs and gaps in the field of EDs in Canada; **6.2** To enhance Canadian collaborative research and support for EDs research in Canada; and **6.3** To enhance ongoing surveillance, performance measures and data related to EDs.	40. Continue to identify research needs and priorities by people with lived experience, caregivers, and health care professionals in the field so that research questions of most importance to those affected by an ED are carried out and widely promote these priorities[xiii].
	41. Support a systematic approach to the identification of research priorities across the spectrum of EDs and affected populations.
	42. Update[xlviii] existing EDs data and relevant indicators in Canada.
	43. Update existing mental health performance measures so that they include EDs[xlix].
	44. Enhance uptake of available ED research by using various knowledge translation strategies and models.
	45. Identify/create research training opportunities across all disciplines.
	46. Encourage collaboration, organization and planning of research objectives and combination of expertise to attain federal (i.e., CIHR, SSHRC) funding to carry out pan-Canadian research.
	47. Establish a Canadian Research Chair for EDs.
	48. Establish a Canadian Research Network for EDs, modelled on the EDs Centres for Excellence in British Columbia.
	49. Increase financial support for research related to EDs.
	50. Create a national data repository for enhanced research capabilities that reflect the Canadian context.

Endnotes

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