



PRIORITIES IN EATING DISORDER RESEARCH AND SERVICE PROVISION: RECOMMENDATIONS FROM YOUNG ADULTS AND CAREGIVERS

ABOUT THE NATIONAL INITIATIVE FOR EATING DISORDERS

Since 2012, the National Initiative for Eating Disorders (NIED) has supported individuals with an eating disorder and their caregivers through education, people-first research, awareness-raising initiatives, and taking action to address the needs of Canadians impacted by eating disorders. Through the Initial Point of Contact program, calls and e-mails from thousands of Canadians have been met with confidential, empathetic support from individuals with lived experience and expert guidance in seeking professional support. In September of 2022, NIED was certified as a Canadian registered charity.

RESEARCH QUESTION

What are the main priorities for research on disordered eating from the perspectives of young adults with lived experience, and their caregivers / parents?

STUDY OVERVIEW

In collaboration with NIED and Mental Health Research Canada (MHRC), Dr. Gina Dimitropoulos (University of Calgary) and Dr. Jennifer Couturier (McMaster University) identified research priorities and recommendations for eating disorders from the perspectives of young adults with lived experience and their parents / caregivers.

Conducting two group discussions between April and May of 2023, individuals with lived experience of eating disorders prioritized 10 recommendations. Balanced participation was encouraged using a Nominal Group Technique, ensuring findings reflected sentiments of the entire group.

WHAT IS AN EATING DISORDER?

Eating disorders (EDs) are debilitating behavioural conditions characterized by severe and persistent disturbances in eating behaviours associated with distressing thoughts and emotions about one's weight, shape, or size.¹

“**Generating research priorities in partnership with people with lived experience is critical in order to ensure that new knowledge generated is relevant and aligned with the needs of those most impacted.**”
— AKELA PEOPLES (CEO, MHRC)

STUDY

TOP PRIORITIES

**STUDY 1:
YOUNG ADULTS
WITH LIVED
EXPERIENCE**

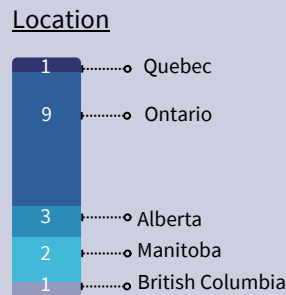
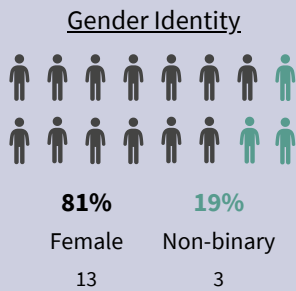
1. Focus on underlying psychological / mental health concerns
2. Emphasize diversity and inclusion in research
3. Improve current education and training for ED care providers

**STUDY 2:
CAREGIVERS /
PARENTS**

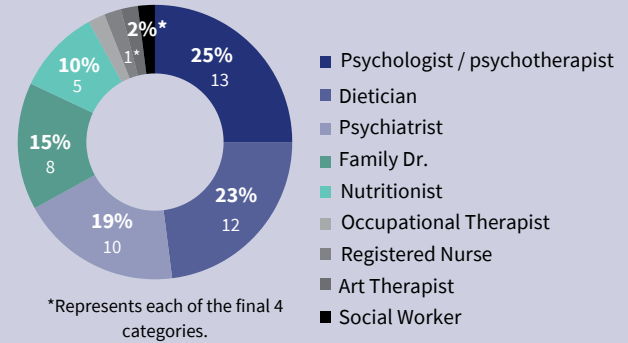
1. Adopt standard operating procedures and protocols for ED
2. Examine current best practices for ED treatment and care
3. Improve current education and training for ED care providers

YOUNG ADULTS: DEMOGRAPHICS

16 young adults with lived experience participated



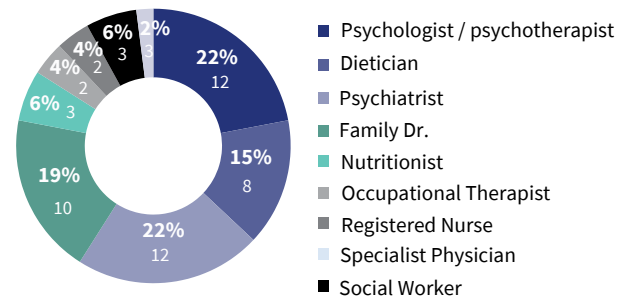
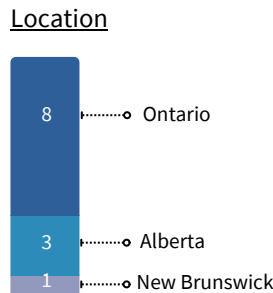
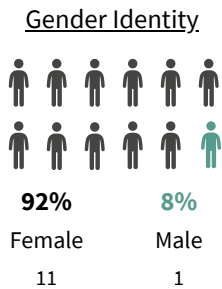
Treatment Providers Used



CAREGIVERS / PARENTS: DEMOGRAPHICS

12 caregivers/ parents of young adults with lived experience participated

Treatment Providers Used



OTHER RESEARCH PRIORITIES

While the recommendations above represent the top three most important research priorities for the participants, they also discussed numerous other recommendations, including (but not limited to):

- Exploring which harm reduction strategies would be beneficial in the treatment of individuals with ED symptoms
- Exploring alternatives to BMI to accurately assess weight and/or successful treatment outcomes
- Examining the impact of childhood weight loss and/or management programs on the development and maintenance of EDs
- Examining the impact of healthcare provider-related factors
- Ensuring that individuals with ED symptoms are not (re)traumatized when sharing their stories with different healthcare providers and during treatment
- Examining access to care for individuals with ED symptoms and their families (e.g., in rural vs. urban areas, in specialized ED care, out-of-province care, and waiting for treatment)