



PREBUDGET SUBMISSION AUGUST 6 2014

The Key Issue. Eating Disorders carry the highest mortality rate of any mental health disorder in adolescent females. We lack a National Strategy for Eating Disorders.

Quotes from parents with lived experience:

Wendy Preskow – Founder of NIED. Our daughter, Amy (29) has been suffering with her chronic Anorexia and Bulimia for over 14 years. In Amy’s words...excerpts from her journals (with her permission):

*I am cross-eyed with rage toward myself for being alive, toward everyone else who is functional. I want to take a knife and slash my body. Carve off the fat places until only bone remains and everything is quiet. I want to cry, which only infuriates me further.
I want to kill myself but don't have the courage, which again ignites the anger.*

My head is as ever - if not more - in the deepest darkest rabbit hole. I feel impending doom. Its the sense of profound fear that I'm not going to make it out of this eating disorder - I'm not going to be the 1/3 that recovers; I may even be in the 20% that die. You are changing the ED world in Canada and perhaps the only reason I ever existed was for you to create colossal change. But what about me, now? I can barely read or write or find joy in anything because I'm constantly paralyzed with fear and anxiety. Consumed with indecision and yearning to be numb.

JPP: As parents, it was difficult for us to understand and is still difficult for us to explain to others. So perhaps Laura herself can explain it best through excerpts from the letter she wrote to us to say goodbye...

“I don’t think anyone who hasn’t gone through it can fully appreciate the extent of what it is like to live trapped in an anorexic mind. I don’t want to live a life struggling with food and weight and body image...to battle those demons every day, every meal, every moment. I don’t want to live the rest of my life in constant fear, panic, anxiety and guilt. It’s not that I won’t tolerate it....it’s that I feel it is impossible to tolerate it. I can’t express how much I love you all and care about your well-being. But I just can’t stand living like this anymore and being such a burden to you all. You did absolutely everything to help me get through this and, in the end, I just couldn’t handle it and help myself. Thank you so much for all of the love and support that you have given me and shown me throughout my life, especially in these last 6 years. You have stood by me through the good times and the bad and have never given up on me, even when I have given up on myself.”

From a Dad JV: *My Amanda was diagnosed with Anorexia Nervosa four years ago at age 12. Amanda was too sick to wait or get treatment here in Canada for her chronic Anorexia . She left us for 12 months living 3000 kms away at a USA treatment center at \$1200.00 per day at the tender age of 14. We have 3 other children. We had to drive countless times to visit Amanda in treatment. The financial stress and strain on us was almost to the point of selling our home to avoid bankruptcy. How can this be happening here in Canada where Parents cannot see their kids because they are too sick to get the help they need to save their lives? We are forever grateful to her residential treatment in the USA. We almost lost our daughter to her Eating Disorder. Please don't let me lose her again..."*

About the National Initiative for Eating Disorders (NIED)

NIED is a “for purpose” not-for-profit coalition of parents with children (including adult children) challenged by Eating Disorders, sufferers, healthcare professionals and counselors.

Recognizing the gaps in current services, delays in treatment, lack of pan-Canadian data and medical training, inadequate information and education in all levels of government, healthcare, professionals, schools, and public, NIED aims to increase awareness and education of EDs to create change in the understanding, treatment and funding of the disease in Canada.

Since NIED was launched February 2012, we have hosted 34 monthly free symposia. We will continue these informative and helpful evenings to bring communities together for support, education and empowering confidence to speak out and overcome the stigma and discrimination against eating disorders. However, much greater efforts need to take place to ensure we make a significant difference in the lives of those affected.

FEDERAL CONTEXT

In its 2002 report entitled, *A Report on Mental Illnesses in Canada*, published by Health Canada, co-authors¹ identified several priority needs related to eating disorders:

- “Incidence and prevalence of each of the eating disorders by age, sex and other key variables (for example, socio-economic status, education and ethnicity).
- Impact of eating disorders on the quality of life of the individual and family.
- Access to and use of primary and specialist health care services and community programs.
- Stigma associated with eating disorders.
- Attitude toward body image in the general population.
- Access and use of public and private mental health services.
- Access and use of mental health services in other systems, such as schools.
- Treatment outcomes.

- Exposure to known or suspected risk and protective factors.”

The same 2002 report went on to say that “existing data provide a very limited profile of eating disorders in Canada. The available hospitalization data needs to be complemented with additional data to fully monitor these disorders in Canada.”

We would add that this additional, upstream data is crucial to more effectively preventing and providing support for people and their families at the earliest possible moments in life when chances of recovery from eating disorders are higher. Despite the valuable insights on health system performance that can be gained through hospitalization data, these are of less use when trying to appropriately design prevention initiatives and access to recovery-oriented care for people affected by eating disorders.

Collecting relevant health data more closely linked to people within their communities (i.e. upstream data) will help. These upstream data will complement existing hospitalization, primary and specialist health services data.

CURRENT STATUS

Today, Canada still has limited means to effectively prevent or treat individuals affected by eating disorders. There are several reasons that explain this; one of them relates to what we still do not know (i.e. key basic data) regarding eating disorders in Canada.

While we recognize that Public Health Association of Canada (PHAC) reallocated \$2.2 million to develop mental health and mental illness indicators for Canada (announced in Budget 2012), and fully anticipate that efforts are being made to include appropriate indicators for eating disorders in a comprehensive, Canadian mental health and mental illness framework, we know that this work is focused on leveraging existing data sources.

There remains few, if any, existing relevant data sources related to eating disorders in Canada.

This is not a surprise given that eating disorders are complicated mental illnesses that affect a person’s sense of identity, worth, and self-esteem. Eating disorders are not just about food. They are often a way to cope with difficult problems or regain a sense of control. As such, eating disorders frequently escape appropriate characterization from an epidemiological perspective, particularly in Canada.

This lack of data is a challenge given that eating disorders are associated with “...serious physical problems that can lead to death, such as heart conditions, electrolyte imbalance and kidney failure. Suicide is also a possible outcome,” according to the 2002 report referenced above.

It is our opinion based on anecdotal evidence and discussions with clinicians that this affliction runs much deeper in Canadian society than most healthcare professionals

realize. We have given significant consideration as to how we can achieve our goals. The big issue facing most provincial healthcare ministries is simply a lack of data to support the development and funding of programs necessary to properly treat those who suffer from this mental affliction.

We are led to believe from discussions with many clinicians who practice in this area that there have been many studies and surveys completed but very few based on hard clinical data. Simply put, we need to uncover this data across Canada to develop treatment . We simply do not know what we do not know.

RECOMMENDATIONS FOR A PROPOSED SOLUTION

In order to overcome this important gap in public health, we recommend:

1. That the Government of Canada allocate \$3 million over 5 years to the Public Health Agency of Canada (PHAC) and/or the Canadian Institutes of Health Research (CIHR), to begin the development of indicators and a data collection framework related to eating disorders. The \$3 million could be devoted to a funding opportunity designed to support teams of researchers and decision makers interested in conducting epidemiological, applied health services and policy research specific to eating disorders that will be useful to health system managers and/or decision makers. This framework is fully aligned with the PHAC Objective 3 (Address gaps in information in autism, neurological conditions and mental health in Canada) in the *Preventing Chronic Disease Strategic Plan 2013-2016*.
 - The first stage will be to determine what data is available and what data we need and how best to access this data.
 - The second stage will be to collect the data we do not have but is needed to make decisions on treatment.
2. That an Advisory Committee reporting to the Minister of Health (Canada) be struck to contribute to this work, including membership from Health Canada, PHAC, NIED, the Canadian Mental Health Association (CMHA), the Eating Disorder Association of Canada (EDAC) and other national mental health organizations in Canada.

EXPECTED OUTCOMES:

Through this funding, the Government of Canada will determine:

- ✓ What data currently exists and what data needs to be collected to confirm the number of Canadians suffering from eating disorders.
- ✓ What barriers exist for people suffering from eating disorders and their families.
- ✓ What are the direct costs to the health care system and the indirect costs to our economy if Canadians don't have access to effective prevention, early intervention and specialized eating disorder treatment services.

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