



---

## Report on the Testimony on Eating Disorder Treatment and Prevention in Canada

Carla Rice  
*University of Guelph*

Andrea LaMarre  
*University of Guelph*

---

**Recommended citation:**

Rice, C., & LaMarre, A. (2014). *Report on the Testimony on Eating Disorder Treatment and Prevention in Canada*. Submitted to the Standing Committee on the Status of Women, Study on Eating Disorders Amongst Girls and Women. Ottawa: Government of Canada.

## **Speaking Notes for Presentation to the Standing Committee on the Status of Women- Eating Disorders Amongst Girls and Women**

**February 12<sup>th</sup>, 2014**

Dr. Carla Rice: Thank you very much for inviting us here today. My name is Dr. Carla Rice and I am a Canada Research Chair in Care, Gender, and Relationships at University of Guelph, where I research problems of embodiment, including eating disorders and obesity. Andrea LaMarre: a M.Sc. student whose research focuses on individuals' experiences of eating disorder recovery.

Dr. Carla Rice: In my 20 plus years experience working in this area—formerly as program manager at the National Eating Disorder Information Centre, later as a clinician at Women's College Hospital and now as a researcher—I have been in contact with hundreds of individuals, family members and health providers dealing with these problems. **While I have witnessed many changes in the delivery of services over this period, one thing has remained constant: a “revolving door” scenario where many individuals cycle in and out of treatment without finding solutions.** Many families and friends, too, still feel helpless in the face of these complex concerns; caregiver burden is high even though caregivers are resilient and desire the best for their loved ones. As the existence of this study shows, there is a growing interest in developing federal policy in support of eating disorder prevention and treatment in Canada. We fully support this development. **We are here today to advocate for a strategy that acknowledges, honours, and welcomes in individuals' complex lived experiences of eating disorders. We want to make a case for centering those experiences in any strategy.**

Andrea LaMarre: Obtaining specific information about programs, including the number of beds available, reliable estimates on wait list timing, and specific types of therapy offered remains extremely difficult despite efforts to devise online service directories. Individuals and families may also struggle to obtain information about services across Canada. This difficulty can be exacerbated when seeking services in a province other than one's home province, for example while attending university. Patients and families may be left trying to navigate a difficult system of referrals and waiting. There is certainly a dearth of available and affordable services for those whose health may be at serious risk if appropriate and timely treatment is not provided.

Dr. Carla Rice: I do not think it is about changing the entire system or about re-inventing the wheel: rather than overhauling a system that may be helping many individuals and that is based in evidence, **we recommend developing an alternative**

**system of community-based treatment and support.** This system would focus on prevention and on counseling people before they developed chronic conditions. As well, alternative approaches to care may be more appropriate for individuals for whom mainstream approaches have not worked. While we have accurate statistics about individuals who obtain diagnosis, our research shows that there are others who remain undiagnosed. These unnamed and unheard others may face stigma or be dismissed by community, family, medical providers, and others on the basis of body size, race/ethnicity, and gender among other factors. To better match services to complex needs, **we envision a system with multiple points of entry and multiple approaches to care and support tailored to the needs of these different groups.**

Dr. Carla Rice: A number of barriers may prevent individuals from seeking needed care, not least of which is how we *talk* about eating disorders. Though we are starting to see some shifts, a number of stereotypes persist. Among these, we may still “expect” eating disorders to be a problem of young, White, middle to upper class, heterosexual women with hyper-emaciated bodies. Those who do not fit this stereotype may feel that their disorder is NOT legitimate in the face of this “single story.” This perception may be magnified by negative experiences with medical professionals, family members and others.

Dr. Carla Rice: Let me give you an example: Individuals from minority groups in particular may face a system that disbelieves in their disordered eating, while also feeling that to seek treatment is to broach their ethnic/racial identity. For example, in researching body image and eating concerns among diverse groups of Canadian women, I spoke with a number of racialized women (Asian, South Asian and African Caribbean) whose eating disorders were misdiagnosed or dismissed by health care providers—an experience that complicated their recovery and that they attributed to race. Andrea has heard similar stories from her research participants.

Andrea LaMarre: In my research, I spoke to young women who faced strong familial and cultural norms around “problems” in the family: these things were not to be spoken about outside of the home, for fear of bringing shame and embarrassment onto the family unit. For individuals faced with such cultural and familial discourses, asking for help can be extraordinarily difficult. There is still a great deal of stigma that surrounds help seeking among individuals with eating disorders from minority and non-minority groups alike.

Dr. Carla Rice: For those whose bodies do not fit neatly into the stereotypes, help seeking can be met with confusion and assumptions. Taking the example of the women involved in our studies, significant struggles went unrecognized as doctors read their bodies as “normal.” This suggests that behaviours considered extreme, for example multiple workouts a day and extremely restrictive eating, may only be read

as “disordered” once one’s body crosses the line to “extreme thinness.” Those whose bodies were classified as “overweight” or “obese,” too, were sometimes advised to restrict their diets and increase their exercise even though these recommendations actually triggered or fueled their disordered eating. These practices are prescribed in doctors’ offices and gyms across the country, as we fight against an apparent obesity epidemic. Yet fat-shaming tactics offer few “solutions” and may even perpetuate behaviours detrimental to women’s health. **In my research, for example, every single woman I interviewed who experienced themselves as fat in childhood developed an eating disorder due to people’s attempts to regulate her weight.**

Andrea LaMarre: Not occupying a body that is easily understood to be suffering from an eating disorder may also complicate recovery. Weight restoration and normalized eating are generally considered pillars of eating disorder treatment programs. New instructions are given to help individuals develop new patterns of behavior around food and exercise; these are often in direct opposition to the prescriptions for health offered to the general population. Recovery in such a context can be extraordinarily difficult. To borrow one of my participants’ words, “for people who already feel so alone and want to belong, to ask them to do something counter-cultural can be really scary.” Recovery itself is poorly understood; while individuals may see recovery as a process, rather than an outcome, clinicians may require biomedical criteria through which to gauge recovery. More funding for research in this area would help to explore individuals’ and families’ understandings of recovery and the resources required to achieve it.

Andrea LaMarre: Although we can see the evidence base growing around mainstream approaches such as cognitive behavioural therapy, currently existing models may not resonate for all individuals. One size does not fit all in eating disorder treatment. Our knowledge base around treatment stems primarily from studies conducted at programs that are currently funded, generally in hospital contexts. It may be that other forms of treatment, for example narrative therapy, often employed in fee-for-service, community practice, are highly effective. “Evidence-based” sometimes only means that someone has been able to gather a large enough sample size to conduct a randomized controlled trial of the approach. Strong quantitative studies testing and comparing various **forms** of treatment are still lacking.

Dr. Carla Rice: This suggests that we need to develop stronger relationships with individuals with lived experience to truly understand what is working and what is not working. Centering the experiences of people who have and have not received treatment in a wide variety of settings would entail deeply engaging with individuals, and this requires good qualitative research. Greater dialogue between individuals,

families, and providers would also help to bridge significant divides between those who deliver and those who receive care. We cannot abstract individuals from the social context especially in the case of eating disorders where context is deeply implicated in girls' and women's disordered eating. Developing effective and supportive systems depends on an acknowledgment that neither "individuals" nor "systems" need "fixing" in isolation. We need to work at the interface of individuals and systems to better understand individuals' complex needs, as well as to expand possibilities for treatment and care. Our solutions must be grounded in a strong understanding of the social-situatedness and lived, embodied experiences of diverse individuals with eating disorders.

Thank you, we welcome questions from the committee.

**Contact Information:**

Dr. Carla Rice, Canada Research Chair in Care, Gender, and Relationships,  
University of Guelph, Department of Family Relations and Applied Nutrition  
[carlar@uoguelph.ca](mailto:carlar@uoguelph.ca)  
519-824-4120 x53921

Ms. Andrea LaMarre, MSc. Student, University of Guelph, Department of Family  
Relations and Applied Nutrition  
[alamarre@uoguelph.ca](mailto:alamarre@uoguelph.ca)  
519-824-4120

**Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada Prepared by: Dr. Carla Rice and Ms. Andrea LaMarre**

**Prepared for: the Standing Committee on the Status of Women, Study on Eating Disorders Amongst Girls and Women**

**Date: March 10, 2014**

---

## **Introduction**

We would once again like to thank you for the opportunity to appear before the Standing Committee on the Status of Women in support of the study Eating Disorders Amongst Girls and Women. As a follow up to the testimony we provided on Wednesday, February 12<sup>th</sup>, 2014, we would offer some additional information to be considered in this study and resultant report.

Ms. Young requested that we send in to the committee more information about (i) the context around eating disorders and whether eating disorders are increasing in the Canadian population; and (ii) interventions that addressed the broader social contextual factors surrounding eating disorders. In what follows, we respond to Ms. Young's inquiries and also address in greater depth questions asked at the Standing Committee Meeting, in particular those related to the (iii) "minimum standard of care" and (iv) recovery processes and relapse rates.

## **I. Prevalence and Incidence of Eating Disorders**

### *A. Numbers of Diagnosed Individuals*

Determining whether eating disorders are increasing in the Canadian context is a difficult task. The Diagnostic and Statistical Manual (DSM), which contains criteria for diagnosing eating disorders, has recently been released in its fifth iteration (American Psychiatric Association, 2013). The revision of the DSM has meant the "loosening" of diagnostic criteria for anorexia nervosa (AN) and bulimia nervosa (BN) and has entailed a revisioning of the "eating disorder not-otherwise-specified" (ED-NOS) category to "other specified feeding and eating disorder" (OSFED). A discrete category for binge eating disorder (BED) has also been established. Under the DSM-IV criteria (American Psychiatric Association, 2000), up to 60% of those receiving an eating disorder diagnosis received the diagnosis of ED-NOS (Fairburn & Bohn, 2005; Wade, Crosby & Martin, 2006). The new diagnostic criteria have meant that significantly fewer individuals are diagnosed with ED-NOS, with more of these individuals now falling into diagnostic criteria for AN, BN, or BED (Machado, Goncalves & Hoek, 2013). This provides evidence for the mutability of the diagnostic categories in the DSM, also reflecting its socially constructed nature. In terms of current numbers of diagnoses, American studies suggest that the incidence of anorexia nervosa has remained relatively static over the past 10 years, though diagnoses have increased among girls 15-19, and rates of bulimia nervosa have also remained relatively static, with a slight decline (Smink, van Hoeken & Hoek, 2012). Lifetime prevalence of all eating disorders is estimated at 1.01%; when sub-divided, *lifetime prevalence reports range from 1.92-3% for BED, 0.81%-2.6% for BN and 0.21%-0.93% for AN (Qian et al., 2013; Stice, Marti & Rhode, 2013; Preti et al., 2009). Among adolescents, onset peaks at 16-20 for BN, 18-20 for BED and 19-20 for AN (Stice, Marti & Rhode, 2013). The incidence of restrictive eating disorders among children under the age of 18 is estimated to be up to 2 times higher than type 2 diabetes; importantly, such statistics represent only*

those who present to pediatricians, and actual incidence may be 2-4 times higher (Pinhas et al., 2011). Eating disorders have been epidemiologically linked to heritability, gender (female), age (younger), history of abuse (both physical and sexual) and participation in certain sports (those oriented toward weight or aesthetics); such studies indicate that despite presumptions, eating disorders are not strongly linked to ethnicity, socioeconomic status, rural/urban dynamics, or education level (Mitchison & Hay, 2014).

### *B. Undiagnosed Individuals and Reasons for Non-Diagnosis*

The significant changes to diagnostic criteria under the ever-evolving DSM limit our ability to put specific figures to population trends in eating disorders. Determining whether these disorders have increased is also complicated by the large numbers of individuals who remain undiagnosed for any number of socio-contextual reasons. For example, cultural myths that circulate around the idea of who is “susceptible” can obscure the experiences of diverse individuals suffering from eating distress. Examining barriers to treatment seeking among ethnically diverse people, Becker et al. (2009) found that willingness to seek treatment (which would require obtaining a diagnosis) depends largely on social factors, including cultural practices and community norms, as well as stigma, shame, and fear that the eating disorder will be perceived to be indicative of a weakness or character flaw, and stereotypes about the profile of those who struggle with such problems. These stereotypes may be internalized due to prior misdiagnosis or dismissal of eating concerns. While individuals from non-minority groups (e.g. White young women) may be “expected” to suffer from eating disorders, those from minority groups (including racial/ethnic minority women, men, and queer women) may be considered by family, friends, and medical professionals to be immune (Becker et al., 2009; MacDonald, 2011). There is also a great deal of variability in health care professionals’ capacity to recognize complex disorders that do not fit stereotypes around eating disorders.

### *C. Numbers of Sub-Clinical Cases*

Eating disorder cases dubbed “sub-clinical” (i.e. exhibiting symptoms of AN and/or BN without yet meeting criteria for “full syndrome” disorders) also weigh heavily on the ability to devise accurate statistics and to differentiate between “clinically significant” (meeting cut-off points on measures commonly used to diagnose eating disorders, such as the “gold standard” Eating Disorder Examination Questionnaire- EDE-Q; Wade, Byrne & Touyz, 2013) and non-clinically significant disordered eating. *Rates of sub-clinical disordered eating vary widely depending on sample used, and range from 25-80% in some populations. For example, Schwitzer et al. (2001) reported sub-clinical disordered eating in up to 40% of college-aged women in a US study. A more recent study by Touchette et al. (2011) found a prevalence of around 3.5% for subclinical anorexia nervosa, 3.8% for subclinical bulimia nervosa, 10.8% for subclinical binge eating, and 13% for weight concerns among adolescent females in Quebec.* Subclinical cases may or may not be recognized as warranting treatment, concerning in light of suggestions that up to 70% of these will “cross the line” into clinically significant eating disorders within 30 months (Milos, Spindler, Schnyder & Fairburn, 2005).

## **II. Interventions Addressing the Social-Contextual Factors Surrounding Eating Disorders: Efficacy of Prevention Programs by Pedagogy, Content, and Scope**

Regardless of whether the incidence of eating disorders has increased in recent history, Ms. Young's question surrounding the socio-contextual factors surrounding eating disorders and whether there are steps that can be taken to reduce these risks is well received. In response to her query, we give an overview of what we identify as prevention "fundamentals" and then detail the types of eating disorder prevention strategies tested over the past few decades and their effectiveness in reducing risk factors and current or future eating distress in targeted populations.

### *A. The Importance of Attending to the Gendered Idealization of Thinness and Stigmatization of Fatness*

While we need to recognize that individuals with eating disorders are not simply sponges for cultural imagery, it is critical to attend to the interaction between individuals and environmental, socio-historical contexts. This includes not only an acknowledgement of the experience of being a woman in image-driven modern, Western society, but also how this context may make recovery from eating disorders extraordinarily difficult, particularly for those whose bodies do not fit the stereotypes surrounding eating disorders. Attending to the broader social context and the potentially harmful messages of anti-obesity/obesity prevention, including instructions for body management that circulate in society, may be crucial. Moral panic surrounding the fat body has led to an unhelpful stigmatization of fatness (Granberg, 2001; Saguy & Ward, 2011; Rice, 2014; Saguy & Riley, 2005). The fat body is constructed as unattractive and unhealthy, even immoral or lazy (Rice, 2007; Saguy & Riley, 2005). There is strong evidence that individuals with larger bodies are faced with discrimination in society, from the general public as well as medical professionals (e.g. De Brun, McCarthy, McKenzie & McGloin, 2014; Puhl & Brownell, 2001; 2006; Puhl & Heuer, 2009; Teachman & Brownell, 2001). Individuals whose bodies are read as "overweight" or "obese" are not imagined to be individuals for whom eating disorders might arise, unless this disordered eating is "overeating." Youth labeled as overweight may, however, be at increased risk of developing eating disorders (Eddy et al., 2007; Russo et al., 2011). Adolescents with a history of obesity may exhibit symptoms and behaviors concordant with eating disorders and yet be misdiagnosed, dismissed, or untreated (Sim, Lebow & Billings, 2013). Such studies bolster evidence pointing to the problematics of weight control tactics prescribed in doctors' offices, school physical education classes, and gyms across the country (for an exploration of these prescriptions for health for the general population, see Evans & Rich, 2011; Evans, Rich, Allwood & Davies, 2008; Rice, 2007; 2009; 2014; Rich, 2010; 2011). We would suggest that taking social context into account must necessarily acknowledge not only the reproduction of "the body beautiful" in media imagery but the ways in which strategies designed to be health promoting (i.e. obesity prevention and healthy weights messaging) may in fact perpetuate behaviors detrimental to women and girls' health.

### *B. The Importance of Attending to Factors Found to Mediate the Efficacy of Prevention Efforts*

Prevention that focuses on the promotion of positive body image within individuals may inadvertently promote ideals of the body beautiful (O'Dea, 2002), especially when interventions do not critically address the harmful effects of such ideals. Further, campaigns must be carefully designed in order to avoid reproducing common stereotypes around eating disorders and those who



suffer from them (Schwartz, Thomas, Bohan & Vartanian, 2007). Poorly designed prevention campaigns may risk exacerbating the very behaviours and attitudes they are designed to prevent, for instance dietary restraint (Carter, Stewart, Dunn & Fairburn, 1997), unhealthy weight loss, and other eating disorder symptoms (Mann et al., 1997). Some studies conclude that attending to social environment beyond body image may be more effective in promoting wellness. While movement toward a broadening of socio-cultural body imagery, for example through limiting the use of Photoshop and featuring models of more diverse sizes is encouraging, there is a need to recognize that eating disorders are not the sole purview of body image distortions or passive receipt of cultural imagery. Eating disorders may be very effective coping mechanisms through which individuals experience comfort and empowerment, at least for a time (Warin, 2010). It is also important to recognize that while over 60 prevention programs have been evaluated using controlled trials, very few of these have led to long-lasting improvements in eating disorder behaviour (Stice, Becker & Yokum, 2013). Drawing on existing quantitative and qualitative data, we discuss the necessity of attending to efficacy of prevention efforts on the basis of three factors found to mediate their effectiveness: i) pedagogy (teaching and learning techniques), ii) program content, and iii) scope of interventions.

### **i. Pedagogical Approaches**

Eating disorder prevention programs have taken several different forms over the past few decades, including: a. didactic or information-provision (public education campaigns, curricular resources), b. interactive (emphasizing experiential learning and audience engagement), c. empowerment-relational (such as empowerment programs for girls), and d. dramatic-theatric interventions (plays and puppet shows for children and youth). Drawing on the evidence, we recommend endorsing teaching and learning techniques that:

- *Avoid taking a didactic approach:* Psychoeducational/ information-only programming has been less effective in driving long-term change (Pearson, Goldkang & Striegel-Moore, 2002; Stice, Shaw & Marti, 2007). Because information-based programs do not result in attitudinal and behavioural changes, many researchers have concluded that pure information is highly insufficient in terms of prevention. Further, emerging research suggests that information intended to be health-promoting can be internalized by audiences in unhelpful ways (e.g. triggering unhealthy behaviours around food and exercise) particularly when the overall message is “healthy eating” (Larkin & Rice, 2005; Pinhas et al., 2013). In contrast to information-only general messaging, prevention delivered by interventionists trained in eating disorders and those inducing cognitive dissonance for thin-ideal internalization (inviting audiences to question dominant cultural attitudes about weight) have been shown to be moderately successful (Stice, Shaw & Marti, 2007).
- *Encourage active participation in lessons:* Research evaluating school-based prevention programs suggests that rather than simply providing students with information about “healthy eating” or media literacy, programs with a prevention aim should *actively involve students in lessons* (e.g. Stice, Rohde, Gau & Shaw, 2009). Ideas for experiential learning include group work, teamwork, games, play, and drama. Participatory approaches that provide space for body image work have also been shown to increase body esteem, self-esteem and resistance to teasing (Dahlgren Daigneault, 2000; Friedman, 1996; Piran, 1999; Rice & Russell, 2001). These programs could be run as focus groups within schools and community organizations,

directly addressing body image determinants such as peer influence and competition, and body based harassment (negative verbal commentary targeting the body).

- *Use creative and age appropriate activities.* Creative prevention interventions are clearly needed for children, who as young as age 6, are developing appearance-related prejudices and body image concerns. Although theatrical interventions have shown success for this and older age groups, there remains little research on the efficacy these methods.

## ii. Content

To date, prevention programs have focused primarily on improving body image and increasing media literacy. Yet there has been only mixed evidence for the effectiveness of such campaigns. In a meta-analysis of eating disorder prevention interventions, Stice, Shaw & Marti (2007) conclude that interventions that are specifically targeted toward those “at risk” for eating disorders and those that induce a disconnect between knowledge about unrealistic body image ideals and food and weight-related behaviours have been shown to be effective in reducing *individuals’* negative body image. However, interventions aimed at changing the individual may leave in place the socio-contextual factors, for example body-based harassment, that perpetuate negative body image and disordered eating behaviours in some populations (girls and young women) (Larkin & Rice, 2005; 2006; Rice, 2014). To improve the efficacy of eating disorder prevention efforts, we recommend that the committee considers endorsing content that:

- *Seeks to not only bolster body image but also enhance other life skills and the environmental conditions:* Rather than focusing solely on issues of body image and thin-ideal internalization, interventions should also address other potential predisposing risk factors, including self-esteem (e.g. McVey et al. 2004) and body-based harassment and stigma (Larkin & Rice, 2005, 2006; Rice, 2014). This is particularly important given that interventions oriented toward promoting positive body image in individuals have demonstrated only limited long-term success (e.g. McVey et al., 2002); it is also important in light of recognition that targeting body image and thin-ideal internalization may not be effective alone in preventing eating disorders. As other witnesses have also suggested, eating disorders have multi-causal etiology, and are not simply the result of poor body image or diets “gone too far.”
- *De-emphasizes nutritional information:* Nutritional information should not be included, nor should moralistic messages about food be given. Children and youth at risk for eating disorders may internalize messages about “healthy eating” in ways that lead to restriction and other unhealthy behaviours (Pinhas et al., 2013); messages around healthy eating must be carefully tailored to avoid iatrogenic (counter-indicated and intervention-triggered) effects.
- *Avoids specific discussion of eating disorders:* Particularly for younger children, messages specifically discussing eating disorders may be ineffective or counter-productive. Interventions may inadvertently normalize or glamorize eating disorders (e.g. through case studies of recovering peers), reinforce stereotypes about eating disorders (Schwartz, Thomas, Bohan & Vartanian, 2007) or promoting the very behaviours they intend to counteract (Carter et al., 1997).
- *Carefully tailors representations of bodies and bodily abilities:* Programs should avoid suggesting that there is one “normal” body to which students should aspire. Instead, depictions

of individuals with diverse bodies (e.g. individuals with diverse abilities, race/ethnicities, and sizes) should be shared. It should be made clear that such depictions are not aspirational images; varied body imagery might be presented in conjunction with messages about the differences between “controllable” (e.g. multi-faceted identity development) and “uncontrollable” (e.g. weight and shape) aspects of self and self-presentation. Equally, programs should acknowledge the varied body image concerns that circulate in diverse groups. Prevention programs should thus discuss not only the links between sexism and body image, but also the effects of race/racism, classism, and ableism on body image and eating (Larkin, Rice & Bennett, 2000; Levine & Smolak, 2001, Piran, 1996, 1998; Rice & Russell, 2001). Addressing these cultural and systemic factors may help to build children’s confidence in what their diverse bodies can do and mitigate the types of body-based harassment and bullying that fuel body distress in children and youth. When physical activity is promoted, efforts should be made to emphasize pleasure and enjoyment rather than weight loss.

### iii. Scope

When considering the tailoring of prevention programs it is important to consider how, and to whom, these interventions are directed. Current debates focus on whether interventions should be universal (targeted at all members of a population, such as national or school-wide prevention campaigns) or targeted (aimed at a specific, at-risk subset of a population, e.g. young girls). Universal prevention has the benefit of reducing stigma for those at risk (e.g. McVey et al., 2004). More targeted interventions may be more effective, however, as they directly address those at elevated risk (Stice, Shaw & Marti, 2007). With regard to the scope of prevention programs, we recommend that:

- *Interventions address not only children and adolescent’s body concerns, but also those of others who affect their lives:* Policy makers in health and education, teachers and other educators, and all those who develop and/or deliver prevention programs are not immune to social messages around body weight and shape (Piran, 2004). Providing better training for thought leaders at all levels and for teachers in particular may help to improve the admittedly limited impact of prior teacher-implemented prevention programs (McVey et al., 2009; Rice, 2014; Stice, Shaw & Marti, 2007). Encouraging others in children’s lives to explore their own body biases (e.g. parents, grandparents, siblings, coaches) may also help to bolster the impacts of more individually-oriented interventions.
- *An ecological approach may be used to promote body-positive environments:* As Pinhas et al. (2013) suggest, in order to successfully promote health and reduce the negative impacts of weight stigmatization, all members of an “ecology” (system, such as a school) should be sensitized to messages of non-dieting, weight acceptance and health. Approaches to prevention should thus permeate children’s social worlds by including teachers, peers, and parents alike (Larkin & Rice, 2005).
- *Males should not be left out of prevention programs:* Programming should also address the unique and often unexamined beliefs and behaviours of male audience members. Encouraging all individuals, regardless of gender, to explore and critically examine beliefs about weight and shape may help to foster environments that reduce body biases and body-based harassment (Larkin & Rice, 2005).

### III. Minimum Standards of Care: Beyond One Size Fits All

#### A. *Listening to Individuals Living with Eating Disorders*

Further, we would like to explore in greater depth some responses to questions asked at the Standing Committee Meeting. Among these, we would like to address the “minimum standard of care.” *We would suggest that a minimum standard of care should take into account listening to the needs and desires of individuals with eating disorders.* While this may seem like a simplistic recommendation, we must be careful not to downplay the importance of grounding any strategy designed to help individuals with eating disorders, at least in part, in lived experience. Though it is not possible to provide all types of care, we need to recognize that CBT is a mainstream approach to treatment that may *not* be personally or culturally salient for all (e.g. Muroff, 2007). Despite the evidence base surrounding CBT-E in particular (e.g. Byrne, Fursland, Allen & Watson, 2011; Fairburn et al., 2008), engaging with mainstream approaches such as CBT may constitute, for some, a broaching or breaching of ethno-cultural identity (e.g. Becker et al., 2009). Hospitalization, too, should *not* be considered the first course of action or the *only* appropriate response to eating disorders. Though it may be a useful step in matching resources to the scale of the issue, simply providing more hospital beds will do little to bolster the support systems available to and useful for all individuals with eating disorders.

#### B. *Centering Individuals’ Needs and Interests in the Provision of Care*

Patients and individuals with eating disorders in general are often constructed as untrustworthy, manipulative or deceitful (Lester, 1997; Malson et al., 2011). Thus, their wishes/desires may be left out of a full consideration of research around, as well as approaches to prevention of and care for eating disorders. While in some cases individuals may not know what they need or want, or may wish to be told what to do, not all individuals will be in denial of the existence or seriousness of their disorders, and may be fully aware of what they desire and require to recover. We cannot neglect these voices when seeking to match services to needs. While it is not possible to meet all needs for recovery, establishing a “minimum standard of care” would at least acknowledge individual complexities in a number of areas, including but not limited to:

##### **i. Individuals’ Income and Social Status and Social Support Networks**

This includes the support individuals are able to access from family and/or friends, their living situation, and their socioeconomic status (e.g. are they reasonably able to afford care, or will this care need to be subsidized?). *A minimum standard of care would recognize that individuals should not be financially compromised in any way by accessing care that contributes significantly to their health.*

##### **ii. Availability of Appropriate, Relevant, and Effective Treatment/Care**

If past treatment has proved unsuccessful, it is essential not to assume that the problem lies within the individual but instead look at the factors that may have contributed to a lack of fit between the individual and the treatment. This might include issues of therapeutic alliance (which could range from a lack of meshing between client and therapist to experiencing discrimination, stereotyping or stigma in therapy), treatment setting (e.g. if the location is a hospital and the individual feels

discomfort in this setting), and geographic barriers, among others.

### **iii. The Need to “Treat” the Individual in/and the Context**

With respect to geographic barriers, it is important to recognize that simply transporting individuals from rural settings to hospitals in urban centers is unlikely to provide lasting and concrete solutions: this removes individuals from the contexts they are familiar with and does little to support their efforts to maintain recovery in their environment. Upon re-entering their environment (post-discharge), people may be faced with the same stressors they left. *Simply “changing” individuals is an insufficient approach; there is a need to look to the interaction between individuals and environments to provide effective care.*

### **iv. The Importance of Care for Individuals Along the Spectrum of Eating Distress**

Support and care for individuals with disordered eating and eating disorders should begin before diagnosis, not following diagnosis. For reasons articulated above, and perhaps for other reasons, not all individuals will obtain diagnoses. Obtaining a diagnosis should not be the only way to access support. As other witnesses have suggested, individuals may never feel “sick enough” to warrant help seeking; they may not feel as though their disorder is legitimate or worthy of attention. We need to work toward changing the culture of representation of eating disorders such that individuals’ needs and desires are met. *There is no “one size fits all” where eating disorder treatment is concerned; even those approaches “based in evidence” do not work for all (Strober & Johnson, 2012). Without an understanding of biology, rearing environment and larger social context, treatments will inevitably come up short, as “symptoms of psychological illness do not exist in an impersonal vacuum” (Strober & Johnson, 2012).*

## **IV. The Need for Research on Recovery**

We would also like to comment briefly on the idea of “recovery” where eating disorders are concerned. The construct of recovery remains poorly understood, and patient-articulated definitions of recovery may differ markedly from those of clinicians (Boughtwood & Halse, 2010; Darcy et al., 2010). Current treatment regimes do not necessarily provide the type of care that individuals experience to be helpful in the long term, and a “revolving door” scenario *continues* to exist. Relapse rates are estimated to be between 22-51%, around 36% for AN and 35% for BN; individuals may also cross-over between diagnoses rather than “recovering” (Keel et al., 2005). *Importantly, recovery must be conceptualized as more than simply the absence of symptoms. Drawing from the consumer/survivor movement, recovery entails self-determination, community integration and social justice (Nelson, Lord & Ochocka, 2001) among other factors. Recovery conceptualized as a process may allow for a recognition of diversity in experiences without imposing set parameters on the label of “recovered” which can serve as still more prescriptions for health and standards to which individuals must adhere.* Focusing solely or primarily on weight gain and normalizing eating may alienate individuals in “recovery” (e.g. Bardone-Cone et al., 2010; Boughtwood & Halse, 2010; Gremillion, 2003). More research into the complex and diverse experiences of individuals in recovery would help to illuminate key steps toward developing systems that embrace complexity and honour diverse experiences, ultimately helping individuals to achieve the “recovery” they desire.

## References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Bardone-Cone, A., Schaefer, L.M., Maldonado, C.R., Fitzsimmons, E.E., Harney, M.B., Lawson, M.A., Robinson, D. P., Tosh, A., & Smith, R. (2010). Aspects of self-concept and eating disorder recovery: What does the sense of self look like when an individual recovers from an eating disorder? *Journal of Social and Clinical Psychology, 29*(7), 821-846.
- Becker, A.E., Hadley Arrindell, A., Perloe, A., Fay, K. & Striegel-Moore, R.H. (2009). A qualitative study of perceived social barriers to care for eating disorders: Perspectives from ethnically diverse health care consumers. *International Journal of Eating Disorders, 43*(7), 633-647.
- Boughtwood, D. & Halse, C.. (2010). Other than obedient: Girls' constructions of doctors and treatment regimes for anorexia nervosa. *Journal of Community & Applied Social Psychology, 20*, 83-94.
- Byrne, S.M., Fursland, A., Allen, K.L. & Watson, H. (2011). The effectiveness of enhanced cognitive behavioural therapy for eating disorders: An open trial. *Behaviour Research and Therapy, 49*, 219-226.
- Carter, J.C., Stewart, D.A., Dunn, V.J. & Fairburn, C.G. (1997). Primary prevention of eating disorders: might it do more harm than good? *International Journal of Eating Disorders, 22*(2), 167-172.
- Darcy, A., Katz, S., Fitzpatrick, K. K., Forsberg, S., Utzinger, L. & Lock, J. (2010). All better? How former anorexia nervosa patients define recovery and engaged in treatment. *European Eating Disorder Review, 18*(4), 260-270.
- De Brún, A., McCarthy, M., McKenzie, K. & McGloin, A. (2014). Weight stigma and narrative resistance evident in online discussions of obesity. *Appetite, 72*, 73-81.
- Dahlgren Daigneault, S. (2000). Body talk: A school-based group intervention for working with disordered eating behaviours. *Journal for Specialists in Group Work, 25*, 191-213.
- Eddy, K.T., Tanofsky-Kraff, M., Thompson-Brenner, H., Herzog, D.B., Brown, T.A., Ludwig, D.S. (2007). Eating disorder pathology among overweight treatment-seeking youth: Clinical correlates and cross-sectional risk modeling. *Behaviour Research and Therapy, 45*, 2360-2371.
- Evans, J. & Rich, E. (2011). Body policies and body pedagogies: Every child matters in totally pedagogised schools? *Journal of Education Policy, 26*(3), 361-79.

- Evans, J., Rich, E., Allwood, R. & Davies, B. (2008). Body pedagogies, policy, health and gender. *British Educational Research Journal*, 34(3), 387–402.
- Fairburn, C.G. & Bohn, K. (2005). Eating disorder NOS (EDNOS): An example of the troublesome “not otherwise specified” (NOS) category in DSM-IV. *Behaviour Research and Therapy*, 43, 691-701.
- Fairburn, C. G., Cooper, Z., Shafran, R., Bohn, K., Hawker, D. M., Murphy, R., et al. (2008). Enhanced cognitive behaviour therapy for eating disorders: the core protocol. In C. G. Fairburn (Ed.), *Cognitive behavior therapy and eating disorders*. New York: Guildford Press.
- Granberg, E.M. (2011). Now my ‘old self is thin’: Stigma exists after weight loss. *Social Psychology Quarterly*, 74(1), 29-52.
- Gremillion, H. (2003). *Feeding anorexia: Gender and power at a treatment centre*. Durham: Duke University Press.
- Larkin, J., Rice, C. & Bennett, M. (2000). Body based harassment, body image and disordered eating patterns: Clinical and educational implications. Paper presented at the *Annual Conference of the Canadian Psychological Association*, Ottawa.
- Larkin, J., & Rice, C. (2005). Beyond “healthy eating” and “healthy weights”: Harassment and the health curriculum in middle schools. *Body Image*, 2(3), 219 – 232.
- Larkin, J. & Rice, C. (2006). Harassment and harmful body practices: Broadening the focus of body image education for girls. In F. Leach & C. Mitchell (Eds.) *Combating Gender Violence In and Around Schools: International Perspectives* (pp. 125-133). Stoke on Trent, UK and Sterling, USA: Trentham Books.
- Lester, R.J. (1997). The (dis)embodied self in anorexia nervosa. *Social Science Medicine*, 44(4), 479-489.
- Levine, M.P. & Smolak, L. (2001). Primary prevention of body image disturbances and disordered eating in childhood and early adolescence. In K.J. Thompson and L. Smolak (Eds.), *Body Image, Eating Disorders, and Obesity in Youth*. (pp. 237-260). Baltimore: United Book Press.
- Keel, P.K., Dorer, D.J., Franko, D.L., Jackson, S.C., & Herzog, D.B. (2005). Postremission predictors of relapse in women with eating disorders. *American Journal of Psychiatry*, 162, 573-578.
- MacDonald, D.E. (2011). Impossible bodies, invisible battles: Feminist perspectives on the psychological research on and treatment of eating disorders in queer women. *Journal of Gay & Lesbian Social Services*, 23(4), 452-464.
- Machado, P.P.P., Goncalves, S. & Hoek, H.W. (2013). DSM-5 reduces the proportion of EDNOS cases: Evidence from community samples. *International Journal of Eating Disorders*, 46,

60-65.

- Malson, H., Bailey, L., Clarke, S., Treasure, J., Anderson, G. & Kohn, M. (2011). Un/imaginable future selves: A discourse analysis of in-patients' talk about recovery from an "eating disorder." *European Eating Disorders Review*, 19, 25-36.
- Mann, T., Nolen-Hoeksema, S., Huang, K., Burgard, D., Wright, A. & Hanson, K. (1997). Are two interventions worse than none? Joint primary and secondary prevention of eating disorders in college females. *Health Psychology*, 16(3), 215-525.
- McVey, G., & Davis, R. (2002). A program to promote positive body image: A one-year follow-up evaluation. *Journal of Early Adolescence*, 22, 96-108.
- McVey, G.L., Davis, R., Tweed, S. & Shaw, B.F. (2004). Evaluation of a school-based program designed to improve body image satisfaction, global self-esteem, and eating attitudes and behaviours: A replication study. *International Journal of Eating Disorders*, 36, 1-11.
- McVey, G., Gusella, J., Tweed, S. & Ferrari, M. (2009). A controlled evaluation of web-based training for teachers and public health practitioners in the prevention of eating disorders. *Eating Disorders*, 17, 1-26.
- Milos, G., Spindler, A., Schnyder, U. & Fairburn, C.G. (2005). Instability of eating disorder diagnoses: Prospective study. *The British Journal of Psychiatry*, 187, 573-578.
- Mitchison, D. & Hay, P.J. (2014). Epidemiology of eating disorders: Genetic, environmental, and societal factors. *Clinical Epidemiology*, 6, 89-97.
- Muroff, J. (2007). Cultural diversity and cognitive behavior therapy. In T. Ronen & A. Freeman (Eds.), *Cognitive behavior therapy in clinical social work practice* (pp. 109- 146). New York, NY: Springer.
- Nelson, G., Lord, J. & Ochocka, J. (2001). Empowerment and mental health in community: Narratives of psychiatric consumers/survivors. *Journal of Community and Applied Social Psychology*, 11, 125-142.
- O'Dea, J. (2002). Can body image education programs be harmful to adolescent females? *Eating Disorders*, 10(1), 1-13.
- Pearson, J., Goldklang, D. & Striegel-Moore, R.H. (2002) Prevention of eating disorders: Challenges and opportunities. *International Journal of Eating Disorder*, 31, 233-239.
- Pinhas, L., Morris, A., Crosby, R. & Katzman, D.K. (2011). Incidence and age-specific presentation of restrictive eating disorders in children: A Canadian paediatric surveillance program study. *Archives of Pediatric Adolescent Medicine*, 165(10), 895-899. doi:10.1001/archpediatrics.2011.145
- Piran, N. (2004). Teachers: On "being" (rather than "doing") prevention. *Eating Disorders*, 12(1), 1-9. doi: MFDU3PA0C36HP5T9



- Piran, N. (1999a). The reduction of preoccupation with body weight and shape in schools: A feminist approach. In N. Piran, M.P. Levine & C. Steiner-Adair (Eds.), *Preventing Eating Disorders: A Handbook of Interventions and Special Challenges*. (pp. 148-159). Ann Arbor: Edwards Brothers.
- Piran, N. (1998). A participatory approach to the prevention of eating disorders in a school. In W. Vandereycken & G. Noordenbos (Eds.), *The prevention of eating disorders*. (pp. 173- 186). London: Athlone Press.
- Piran, N. (1996). The reduction of preoccupation with body weight and shape in schools: A feminist approach. *Eating Disorders*, 4, 323-333.
- Preti, A., de Girolamo, G., Vilagut, G., Alonso, J., Bruffaerts, R., Demyttenaere, K., Pinto-Meza, A., Haro, J.M. & Morosini, P. (2009). The epidemiology of eating disorders in six European countries: Results of the ESEMeD-WMH project. *Journal of Psychiatric Research*, 43, 1125-1132.
- Puhl, R. & Brownell, K.D. (2001). Bias, discrimination and obesity. *Obesity Research*, 9(12), 793-805.
- Puhl, R.M. & Heuer, C.A. (2009). The stigma of obesity: A review and update. *Obesity*, 17(5), 941-964.
- Qian, J., Hu, Q., Wan, Y., Li, T., Wu, M., Ren, Z. & Yu, D. (2013). Prevalence of eating disorders in the general population: A systematic review. *Shanghai Archives of Psychiatry*, 25(4), 212-223.
- Rice, C. (2014). *Becoming women: The embodied self in image culture*. Toronto: University of Toronto Press.
- Rice, C. (2009). How big girls become fat girls: The cultural production of problem eating and physical inactivity. In Malson, H. & Burns, M. (Eds.) *Critical feminist approaches to eating dis/orders* (pp. 97–109). New York: Routledge.
- Rice, C. (2007). Becoming the ‘Fat Girl’: Acquisition of an unfit identity. *Women’s Studies International Forum*. 30, 158-174.
- Rice, C. & Larkin, J. (2000). What can a body know? Paper presented at the *Annual Conference of the Canadian Psychological Association*, Ottawa.
- Rich, E. (2010). Obesity assemblages and surveillance in schools. *International Journal of Qualitative Studies in Education*, 23(7), 803–21.
- Rich, E. (2011). “I see her being obese!” Public pedagogy, reality media and the obesity crisis. *Health*, 15(1), 3–21.
- Saguy, A.C. & Ward, A. (2011). Coming out as fat: Rethinking stigma.” *Social Psychology Quarterly*, 74(1), 53.

- Saguy, A.C. & Riley, K.W. (2005). Weighing both sides: Morality, mortality, and framing contests over obesity. *Journal of Health Politics, Policy and Law*, 30(5), 879-921.
- Schwartz, M.B., Thomas, J.J., Bohan, K.M. & Vartanian, L.R. (2007). Intended and unintended effects of an eating disorder educational program: impact of presenter identity. *International Journal of Eating Disorders*, 40(2), 187-192.
- Schwitzer, A.M, Rodriguez, L.E., Thomas, C., & Salimi, L. (2001). The eating disorder NOS diagnostic profile among college women. *Journal of American College Health*, 49(4), 157.
- Sim, L.A., Lebow, J. & Billings, M. (2013). Eating disorders in adolescents with a history of obesity. *Pediatrics*, 132, e1026-e1030.
- Smink, F.R., van Hoeken, D. & Hoek, H.W. (2012). Epidemiology of eating disorders: incidence, prevalence and mortality rates. *Current Psychiatry Reports*, 14(4), 406-414.
- Stice, E., Becker, C.B. & Yokum, S. (2013). Eating disorder prevention: Current evidence-base and future directions. *International Journal of Eating Disorders*, 46, 478-485.
- Stice, E., Marti, N. & Rohde, P. (2013). Prevalence, incidence, impairment, and course of the proposed DSM-5 disorder diagnoses in an 8-year prospective community study of young women. *Journal of Abnormal Psychology*, 122(2), 445-457.
- Stice, E., Rohde, P., Gau, J. & Shaw, H. (2009). An effectiveness trial of a dissonance-based eating disorder prevention program for high-risk adolescent girls. *Journal of Consulting and Clinical Psychology*, 77, 825-834.
- Stice, E., Shaw, H., & Marti, C.N. (2007). A meta-analytic review of eating disorder prevention programs: Encouraging findings. *Annual Review of Clinical Psychology*, 3, 207-231.
- Strober, M., & Johnson, C. (2012). The need for complex ideas in anorexia nervosa: Why biology, environment, and psyche all matter, why therapists make mistakes, and why clinical benchmarks are needed for managing weight correction. *International Journal of Eating Disorders*, 45(2), 155-178.
- Teachman, B.A. & Brownell, K.D. (2001). Implicit anti-fat bias among health professionals: Is anyone immune? *International Journal of Obesity*, 25(10), 1525-1531.
- Touchette, E., Henegar, A., Godart, N.T., Pryor, L., Falissard, B., Tremblay, R.E. & Côté, S.M. (2011). Subclinical eating disorders and their comorbidity with mood and anxiety disorders in adolescent girls. *Psychiatry Research*, 185, 185-192.
- Wade, T., Byrne, S. & Touyz, S. (2013). A clinician's quick guide of evidence-based approaches. Number 1: Eating disorders. *Clinical Psychologist*, 17, 31-32.
- Warin, M. (2010). *Abject relations: Everyday worlds of anorexia*. Piscataway, NJ: Rutgers University Press.

Wonderlich, S.A., Joiner, T.E. Jr., Keel, P.K., Williamson, D.A., and Crosby, R.D. (2007). Eating disorders: Empirical approaches to classification. *American Psychologist*, 62(3), 167-180.