

# EATING DISORDERS AMONG GIRLS AND WOMEN IN CANADA

# Report of the Standing Committee on the Status of Women

Hélène LeBlanc Chair

NOVEMBER 2014
41<sup>st</sup> PARLIAMENT, SECOND SESSION

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# STANDING COMMITTEE ON THE STATUS OF WOMEN

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# THE STANDING COMMITTEE ON THE STATUS OF WOMEN

has the honour to present its

# **FOURTH REPORT**

Pursuant to its mandate under Standing Order 108(2), the Committee has studied eating disorders among girls and women and has agreed to report the following:

# TABLE OF CONTENTS

E	XECUTIVE SUMMARY	1
E	ATING DISORDERS AMONG GIRLS AND WOMEN IN CANADA	5
	INTRODUCTION	5
	UNDERSTANDING EATING DISORDERS	6
	STATISTICS ON EATING DISORDERS	7
	A. General Data	8
	B. Eating Disorders among Boys and Men	9
	C. Mortality Rates	10
	D. Importance of High-Quality Data on Eating Disorders	10
	FACTORS CONTRIBUTING TO THE DEVELOPMENT OF AN EATING DISORDER	11
	A. Genetic Factors	11
	B. Biological and Psychological Factors	12
	C. Culture and Body Image	13
	D. Mainstream Media and Advertising	15
	E. Social Media	16
	F. Public Health Messages about Weight	
	G. Prevention	19
	OBSTACLES IN ADDRESSING EATING DISORDERS	23
	A. Awareness	23
	B. Community-Based Support	26
	C. Stereotypes and Stigma	28
	D. Bias in the Health Care Field	30
	E. Financial Roadblocks	34
	F. Concurrent Disorders	36
	G. Producing Research and Tracking Information	38
	H. Marginalized Populations	40
	CHALLENGES IN ACCESSING TREATMENT	42
	A. Inadequate Training for Health Care Providers	42
	B. Lack of Treatment Programs	43

C. Inappropriate Treatment Programs	45
D. Wait Times	46
E. Insufficient Research	46
F. Additional Observations	47
G. Suggested Approaches in Treatment	48
PROMISING TREATMENT PRACTICES	48
A. Cognitive Behavioural Therapy	49
B. Family-Based Therapy (Maudsley Approach)	50
LIST OF RECOMMENDATIONS	53
APPENDIX A: LIST OF WITNESSES	59
APPENDIX B: LIST OF BRIEFS	63
REQUEST FOR GOVERNMENT RESPONSE	65
DISSENTING OPINION OF THE NEW DEMOCRATIC PARTY OF CANADA	67
DISSENTING OPINION OF THE LIBERAL PARTY OF CANADA	71

# **EXECUTIVE SUMMARY:**

# EATING DISORDERS AMONG GIRLS AND WOMEN IN CANADA

At any given time in Canada, as many as 600,000 to 990,000 Canadians may meet the diagnostic criteria for an eating disorder, primarily anorexia nervosa, bulimia nervosa, or binge eating disorder. Approximately 80% of individuals with eating disorders are girls or women. Eating disorders are a serious form of mental illness, "characterized by a persistent disturbance of eating or eating-related behaviour that results in the altered consumption or absorption of food and that significantly impairs physical health or psychosocial functioning." The devastating symptoms of an eating disorder lead to serious consequences: an individual's mental and physical health are compromised, personal relationships may suffer, current and future education and employment opportunities may be jeopardized, financial security is put at risk, and overall quality of life deteriorates.

Furthermore, these disorders can be deadly. Individuals with eating disorders can develop life-threatening medical complications and often have debilitating concurrent disorders, such as depression. In particular, anorexia nervosa has the highest overall mortality rate of any mental illness, estimated at between 10% and 15% of individuals with the illness; and the mortality rate for individuals with bulimia nervosa is about 5%. Combined, these two disorders kill an estimated 1,000 to 1,500 Canadians per year, with this number likely higher as death certificates often fail to record eating disorders as the cause of death.<sup>3</sup>

In the report *Eating Disorders Among Girls and Women in Canada*, the House of Commons Standing Committee on the Status of Women ("the Committee") examines this potentially deadly mental illness, the factors contributing to eating disorders, and the obstacles in addressing them and seeking treatment. The Committee was disturbed to learn that despite the suffering and high mortality rates among individuals with eating disorders, it was difficult for these individuals to acknowledge their disorder, to seek the support of family and friends, as well as the greater community, to receive an official

Dr. Gail McVey, Ph.D., C.Psych., Community Health Systems Resource Group, Ontario Community Outreach Program for Eating Disorders, The Hospital for Sick Children of Toronto, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Brief submitted to the House of Commons Standing Committee on the Status of Women*, 4 March 2014.

<sup>2</sup> American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition* (DSM-5), American Psychiatric Association, Arlington, 2013, p. 329.

<sup>3 &</sup>lt;u>Evidence</u>, 28 November 2013, 1530 (Dr. Blake Woodside, M.D., FRCPC, Medical Director, Program for Eating Disorders, Toronto General Hospital).

diagnosis from a medical professional, and to gain access to treatment and follow-up support services.

As outlined in the report, the obstacles to addressing eating disorders among Canadians are numerous. They include a lack of awareness of eating disorders; a need for greater community-based supports; entrenched stereotypes and stigma associated with eating disorders; bias in the health care field against patients with these disorders; financial roadblocks; the challenges of concurrent disorders; difficulties in producing research and tracking information; and particular challenges faced by marginalized populations.

As discussed in the report, there are also many challenges to accessing treatment for individuals with eating disorders. These barriers include health care providers with inadequate training in the field of eating disorders; lack of treatment programs; inappropriate treatment programs; lengthy wait times; and insufficient research into potential treatments. The report also examines promising treatment practices, such as Cognitive Behavioural Therapy and Family-Based Therapy (the Maudsley Approach).

The report's findings are based on testimony from the Committee's study on eating disorders among girls and women in Canada, which began in November 2013. The study commenced with briefings from officials from Status of Women Canada, Health Canada, the Public Health Agency of Canada and the Canadian Institutes of Health Research. Testimony was provided by 27 witnesses – 4 appearing as individuals and the remainder representing 20 organizations – over a total of 9 meetings held from November 2013 to March 2014.

The Committee recognizes the important contributions of the witnesses who appeared, many of whom shared their personal experiences of struggling with their own eating disorder or helping a loved one to cope with the disorder. One witness shared the words of her daughter, who is living with an eating disorder:

You keep saying this time last year I was dying, and although I'm not in the same immediate danger, my head is as ever, if not more, in the deepest darkest rabbit hole. I feel impending doom, the same impending doom I felt when I was alone at my lowest weight and bingeing purging 24/7. It's 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 one-third that recovers. I may even be in the 20% that die [sic]....

There is nowhere to go in the emergency. There are so few who understand. I still wake up dreading the day. How will I get through it? What will I eat or not eat? How will I control myself from eating trigger foods? I can't focus on anything. 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.<sup>4</sup>

2

<sup>4 &</sup>lt;u>Evidence</u>, 10 February 2014, 1640 (Wendy Preskow, Founder and Chief Advocate, National Initiative for Eating Disorders).

Furthermore, the Committee acknowledges that while this report examines eating disorders from the perspective of girls and women, as approximately 80% of individuals with eating disorders are female, many boys and men also suffer from these disorders, and they also face challenges in receiving both diagnosis and treatment.

Lastly, members of the Committee and witnesses would like to highlight the importance of this study, as it shines a spotlight on an often marginalized and misunderstood mental health disorder that affects hundreds of thousands of Canadians, as well as their families. As one witness explained, "the establishment of [the Committee's study] has given me so much hope that we can work together in partnership to save lives from this horrible and lethal illness." Another witness noted:

As many leaders have now said in public in the last few years... there is no health without mental health, and that breaking the silence and opening a dialogue is critical when living with a mental illness – more specifically, an eating disorder....<sup>6</sup>

The Committee hopes that its report will play a role in breaking this silence, opening a crucial dialogue and leading to substantive improvement in the awareness and treatment of eating disorders in Canada.

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Evidence, 3 March 2014, 1610 (Elaine Stevenson, co-administrator, Alyssa Stevenson Eating Disorder Memorial Trust).

<sup>6 &</sup>lt;u>Evidence</u>, 3 March 2014,1535 (Ms. Patricia Lemoine, as an individual).

# EATING DISORDERS AMONG GIRLS AND WOMEN IN CANADA

# INTRODUCTION1

The House of Commons Standing Committee on the Status of Women ("the Committee") agreed in November 2013 to study eating disorders among girls and women in Canada. The Committee adopted the following motion:

That, pursuant to Standing Order 108(2), the Committee conduct a study of eating disorders amongst girls and women, including the nature of these diseases, what treatments are providing the most relief to patients and where they are available, how family physicians can learn more about eating disorders and how to treat them, what roadblocks exist to better serve girls and women with eating disorders, and what resources relevant stakeholders need to improve the lives of these patients.

The Committee was briefed by officials from Status of Women Canada, Health Canada, the Public Health Agency of Canada and the Canadian Institutes of Health Research. The Committee received testimony from 27 witnesses – 4 appearing as individuals and the remainder representing 20 organizations – over a total of 9 meetings held from November 28, 2013 to March 5, 2014. In addition, the Committee received briefs from a number of organizations, many of which had also appeared before the Committee, along with follow-up responses to questions by Committee members.

This report summarizes evidence gathered during the study on eating disorders and examines a number of themes that emerged during the Committee's meetings. These themes, in turn, serve to underpin the report's recommendations included at the end of certain chapters in the report.

The importance of this study was recognized by both Committee members and witnesses. The study shines a spotlight on an often marginalized and misunderstood mental health disorder which affects approximately 600,000 to 990,000 individuals, plus their families, at any given time in Canada. As Dr. Blake Woodside, Medical Director for the Program for Eating Disorders at the Toronto General Hospital, explained:

[Y]ou need to know that the work of the committee is very important in a whole other arena, in that it offers hope to both those who suffer and their families, hope that change can occur in our system of care, hope that the discrimination and stigmatizing attitudes can be reduced, and hope that the suffering associated with these conditions can be eliminated.<sup>2</sup>

The evidence cited in this document is from the <u>House of Commons Standing Committee on the Status of Women (FEWO)</u>, 2<sup>nd</sup> Session, 41<sup>st</sup> Parliament, unless otherwise noted.

<sup>2 &</sup>lt;u>Evidence</u>, 28 November 2013, 1540 (Dr. Blake Woodside, M.D., FRCPC, Medical Director, Program for Eating Disorders, Toronto General Hospital).

### UNDERSTANDING EATING DISORDERS

The Committee learned that eating disorders are a form of mental illness "characterized by a persistent disturbance of eating or eating-related behaviour that results in the altered consumption or absorption of food and that significantly impairs physical health or psychosocial functioning."<sup>3</sup>

Witnesses spoke of three specific eating disorders:<sup>4</sup>

- Anorexia nervosa, which is characterized by distorted body image and severe dietary restriction that lead to significantly low body weight in the context of age, sex, development and physical health, accompanied by an intense fear of gaining weight.
- Bulimia nervosa, which is characterized by recurrent episodes of eating an
  excessive amount of food and losing control during that episode, which is
  called a binge, followed by purging behaviours, such as self-induced
  vomiting or misuse of laxatives, in order to avoid weight gain.
- Binge eating disorder is characterized by recurrent episodes of consuming an excessive amount of food in a short period of time, without purging behaviour, and is accompanied by feelings of embarrassment, selfdisgust, loss of control and distress.

The Committee was provided with statistics on the number of individuals with eating disorders, as highlighted in the section below, and was also told about the immeasurable toll taken on individuals with the disorder and on their families. Witnesses stated that research indicates it takes between two and seven years to "recover" from an eating disorder, but that only 50% of individuals will fully recover. As Joanna Anderson, Executive Director of Sheena's Place, an eating disorder support and resource centre in Toronto, told the Committee, eating disorders involve "relentless pain, self-loathing, isolation, sadness, hunger, disgust, and self-contempt," and the eating disorder is "the first

American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition* (DSM-5), American Psychiatric Association, Arlington, 2013, p. 329.

Evidence, 24 February 2014, 1540 (Dr. Giorgio A. Tasca, Ph.D., C. Psych., Research Chair in Psychotherapy Research, University of Ottawa and the Ottawa Hospital, Canadian Psychological Association); American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5), American Psychiatric Association, Arlington, 2013; and American Psychiatric Association, "Feeding and Eating Disorders", Fact sheet, 2013.

<sup>5 &</sup>lt;u>Evidence</u>, 12 February 2014, 1635 (Dr. Monique Jericho, M.D., Psychiatrist and Medical Director, Calgary Eating Disorder Program, Alberta Health Services).

<sup>6 &</sup>lt;u>Evidence</u>, 24 February 2014, 1530 (Dr. Wendy Spettigue, MA, M.D., FRCPC, Psychiatrist, Canadian Academy of Child and Adolescent Psychiatry).

thing [those with the disorder] think about when they wake up in the morning and the last thing they think about before they go to bed."<sup>7</sup>

Psychiatrist Dr. Wendy Spettigue, of the Canadian Academy of Child and Adolescent Psychiatry (CACAP), described the experience of some of her young patients who have anorexia nervosa:

I want you to imagine a patient with severe obsessive-compulsive disorder, who has the constant thought, "There are germs on my hands," and the only thing that makes it better is if that patient goes and washes their hands, and then the anxiety decreases. But that patient sits down and the thoughts appear again, "There are still hidden germs on your hands. You didn't get them all. They're going to get inside you. They're going to make you sick. They're going to make you die." You can't stand the agitation, and the only thing that makes it better is washing your hands. Individual treatment would be like trying to get the person to choose not to wash their hands. Even if they're motivated to do that, they probably can't tolerate the severe urges.

Anorexia nervosa in youth is the exact same kind of illness where they can't tolerate the severe anxiety and agitation that goes with the thoughts that have taken over their minds that constantly say, "You're eating too much. You're gaining too much weight." They feel compelled to restrict or purge, or whatever, to get rid of that. You can't just talk them into not doing it. First of all, they're not motivated because they're afraid of gaining weight.<sup>8</sup>

While witnesses spoke of the difficulties of living with an eating disorder, the Committee was impressed by the strength of witnesses in the face of such a debilitating condition. Patricia Lemoine spoke of her personal battle with an eating disorder:

My diagnosis with a mental illness did not define me. Eating disorders have the highest mortality rate of any psychiatric diagnosis. I am alive in front of you today. I am 32 years old and I am recovered.<sup>9</sup>

#### STATISTICS ON EATING DISORDERS

Many witnesses suggested that eating disorder data collection is insufficient, that the data are out of date, and that too little is known about the incidence and prevalence of eating disorders in certain populations, including children and youth, ethnic and visible minorities, First Nations people, and sexual and gender minorities.<sup>10</sup> Better data,

<sup>7</sup> Evidence, 12 February 2014, 1540 (Joanna Anderson, Executive Director, Sheena's Place).

<sup>8 &</sup>lt;u>Evidence</u>, 24 February 2014, 1610 (Dr. Wendy Spettigue).

<sup>9</sup> Evidence, 3 March 2014, 1535 (Patricia Lemoine, as an individual).

Evidence, 5 February 2014, 1625 (Merryl Bear, Director, National Eating Disorder Information Centre); Evidence, 10 December 2013, 1620 (Marla Israel, Acting Director General, Centre for Health Promotion and Chronic Disease Prevention Branch, Public Health Agency of Canada); Evidence, 24 February 2014, 1700 (Elizabeth Phoenix, Nurse Practitioner, Canadian Federation of Mental Health Nurses); Evidence, 12 February 2014, 1610 (Joanna Anderson); Hasan Hutchinson, Ph.D., Director General, Office of Nutrition Policy and Promotion, Health Products and Food Branch, Health Canada "Follow up to Standing Committee on the Status of Women", Written Response, 21 March 2014; Evidence, 10 December 2013, 1635 (Dr. Joy Johnson, Ph.D., RN, FCAHC, Scientific Director, Institute of Gender and Health, Canadian Institutes of Health Research); Evidence, 10 February 2014, 1610 (Dr. Leora Pinhas, M.D., FRCPC, Department of Psychiatry, The Hospital for Sick Children of Toronto).

witnesses suggested, would help raise awareness and provide proof of the severity and pervasiveness of eating disorders. The Canadian Institute for Health Information (CIHI) indicated that "while CIHI's current data holdings provide some information on eating disorders for women and girls in Canada, there is the opportunity to do more." The Committee was told that eight jurisdictions report eating disorder data to CIHI, and that estimated emergency department coverage is at 59% for all of Canada.

#### A. General Data

Witnesses nonetheless provided the Committee with the most relevant or up-to-date data available. The Public Health Agency of Canada (PHAC) told the Committee that in 2006, 0.5% of Canadians aged 15 years and over had been diagnosed with an eating disorder in the previous 12 months, and that 1.5% of Canadians reported symptoms that met criteria for an "eating attitude problem." Dr. Blake Woodside, Medical Director for the Program for Eating Disorders at the Toronto General Hospital, reported that anorexia nervosa occurs in about 0.5% of the population, meaning that about 150,000 Canadians have or have had this illness. About 15% to 20% of individuals with anorexia nervosa develop a chronic form of the illness, which is often unresponsive to treatment. Dr. Woodside reported that bulimia nervosa occurs in nearly 1% of the population, which is about 300,000 Canadians.

The data that Dr. Gail McVey, of the Hospital for Sick Children in Toronto and Director at the Ontario Community Outreach Program for Eating Disorders (OCOPED), provided to the Committee suggest that as many as 600,000 to 990,000 Canadians meet the diagnostic criteria for an eating disorder at any given time, with an even larger number of individuals reporting symptoms that are seriously debilitating, but insufficient for diagnosis. Other witnesses noted that among adolescents, onset peaks between the ages 19 and 20 for anorexia nervosa, between the ages 16 and 20 for bulimia nervosa, and between the ages 18 and 20 for binge eating disorder.

Dr. Carla Rice, Canada Research Chair in Care, Gender and Relationships and M.Sc. candidate Andrea LaMarre, both of the Department of Family Relations and Applied

Dr. Gail McVey, Ph.D., C.Psych., Community Health Systems Resource Group, Ontario Community Outreach Program for Eating Disorders, The Hospital for Sick Children of Toronto, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, Submitted Brief, 4 March 2014.

Brent Diverty, Vice-President, Programs, Canadian Institute for Health Information, "Brief to the Standing Committee on the Status of Women", *Submitted Brief*, 2 April 2014.

<sup>12</sup> Brent Diverty, "Brief to the Standing Committee on the Status of Women", Submitted Brief, 2 April 2014.

<sup>13 &</sup>lt;u>Evidence</u>, 10 December 2013, 1540 (Marla Israel).

<sup>14</sup> Evidence, 28 November 2013, 1530 (Dr. Blake Woodside).

<sup>15</sup> Ibid.

Dr. Carla Rice and Andrea LaMarre, University of Guelph, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014.

Nutrition at the University of Guelph, suggested that the recent change in the Diagnostic and Statistical Manual's (DSM-5) classification of eating disorders will likely lead to changes in eating disorder diagnosis, which could affect prevalence and incidence calculations. They also warned that statistics often represent only the cases of individuals who sought medical intervention, meaning that actual incidence of some disorders may be higher; in the case of Canadian children with eating disorders, the actual incidence was estimated to be two to four times higher than what is reported in the literature. Further, certain populations may be less likely to seek treatment, particularly if they do not meet the stereotypical eating disorder patient profile. Men and boys, members of ethnic and visible minority groups, and members of sexual and gender minority groups might be less likely to seek treatment out of shame or fear of stigma, and health professionals may not recognize eating disorders as readily in these populations as they would for young white women. On the professionals are added to the professionals are populations as they would for young white women.

# B. Eating Disorders among Boys and Men

Eating disorders are far more common among women and girls than men and boys. Dr. Blake Woodside of Toronto General Hospital testified that about 80% of individuals living with eating disorders are women.<sup>21</sup> Dr. Joy Johnson, Scientific Director of the Institute of Gender and Health at the Canadian Institutes of Health Research (CIHR), told the Committee that boys are increasingly being diagnosed with eating disorders. 22 As Dr. Woodside noted, however, the manifestation of eating disorders in boys and men may be different than in girls and women. For instance, he reported that while some men may pursue weight loss, others may also seek to increase their weight through weight lifting.<sup>23</sup> Dr. April Elliott, Chief of Adolescent Medicine with the Alberta Children's Hospital, suggested that young men face additional challenges as they must often seek treatment through programs designed for young women.<sup>24</sup> Finally, Laura Beattie, Co-chair of Families Empowered and Supporting Treatment of Eating Disorders (F.E.A.S.T.) Canada Task Force, urged the Committee not to forget that young men develop eating disorders too, because in her view, failing to acknowledge this population only perpetuates "the stigma and myths attached to this illness."25 Witnesses focused mainly on women due to the mandate and purview of the Committee, but did ensure that the Committee knew about the manner in which men and boys suffered from eating disorders.

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<sup>18</sup> Ibid.

<sup>19</sup> Ibid.

<sup>20</sup> Ibid.

<sup>21</sup> Ibid.

<sup>22 &</sup>lt;u>Evidence</u>, 10 December 2013, 1545 (Dr. Joy Johnson).

<sup>23</sup> Evidence, 28 November 2013, 1545 (Dr. Blake Woodside).

<sup>24 &</sup>lt;u>Evidence</u>, 5 February 2014, 1635 (Dr. April S. Elliott, M.D., Paediatrician, Chief of Adolescent Medicine, Alberta Children's Hospital, Calgary Eating Disorder Program).

<sup>25 &</sup>lt;u>Evidence</u>, 3 March 2014, 1550 (Laura Beattie, Co-chair, Families Empowered and Supporting Treatment of Eating Disorders Canada Task Force).

### C. Mortality Rates

Some of the most disturbing statistics about eating disorders are their mortality rates. Many witnesses noted that eating disorders, particularly anorexia nervosa, have the highest mortality rate of any mental illness. The high mortality rates are a result of life-threatening medical complications and the frequency of suicide among people with eating disorders. Researchers have estimated that 10% of individuals diagnosed with anorexia nervosa will die within 10 years of diagnosis. The overall mortality rate for anorexia nervosa is estimated at between 10% and 15%, while mortality for bulimia nervosa is estimated at about 5%. Together, these two disorders kill an estimated 1,000 to 1,500 Canadians per year. Some witnesses noted, however, that death certificates often do not record eating disorders as the cause of death, but instead record the medical complication that killed the patient or, if applicable, suicide, as the cause of death, thus hiding the true lethality of eating disorders.

# D. Importance of High-Quality Data on Eating Disorders

In addition to hearing about problems with Canadian data on eating disorders, the Committee heard why high-quality data are so important for people working in the field of eating disorders. Elizabeth Phoenix, a nurse practitioner with the Canadian Federation of Mental Health Nurses (CFMHN), argued that strong data are necessary to inform practice decisions.<sup>32</sup> Jarrah Hodge of Women, Action and the Media Vancouver explained that not-for-profit and community organizations working with or on behalf of people with eating disorders struggle to secure funding for their programs without having accurate data to demonstrate the need for their services.<sup>33</sup>

31 <u>Evidence</u>, 28 November 2013, 1530 (Dr. Blake Woodside); <u>Evidence</u>, 5 February 2014, 1625 (Merryl Bear); <u>Evidence</u>, 3 March 2014, 1550 (Elaine Stevenson, co-administrator, Alyssa Stevenson Eating Disorder Memorial Trust).

<sup>&</sup>lt;u>Evidence</u>, 5 February 2014, 1635 (Dr. April S. Elliott); <u>Evidence</u>, 5 February 2014, 1650 (Dr. Debra Katzman, M.D., FRCPC, Professor of Paediatrics, Division of Adolescent Medicine, Department of Paediatrics, University of Toronto); <u>Evidence</u>, 5 February 2014, 1535 (Merryl Bear); <u>Evidence</u>, 10 February 2014, 1640 (Wendy Preskow, Founder and Chief Advocate, National Initiative for Eating Disorders); <u>Evidence</u>, 10 December 2013, 1545 (Dr. Joy Johnson); <u>Evidence</u>, 24 February 2014, 1530 (Dr. Wendy Spettigue); <u>Evidence</u>, 12 February 2014, 1535 (Noelle Martin, RD, Professor, Brescia University College, Western University, and President, Registered Dietitian Services); <u>Evidence</u>, 3 March 2014, 1535 (Patricia Lemoine).

<sup>27 &</sup>lt;u>Evidence</u>, 5 February 2014, 1635 (Dr. April S. Elliott); <u>Evidence</u>, 24 February 2014, 1530 (Dr. Wendy Spettigue).

<sup>28</sup> Evidence, 12 February 2014, 1535 (Noelle Martin).

<sup>29 &</sup>lt;u>Evidence</u>, 28 November 2013, 1530 (Dr. Blake Woodside).

<sup>30</sup> Ibid.

<sup>32 &</sup>lt;u>Evidence</u>, 24 February 2014, 1555 (Elizabeth Phoenix).

<sup>33 &</sup>lt;u>Evidence</u>, 10 February 2014, 1700 (Jarrah Hodge, Women, Action and the Media Vancouver).

Carly Lambert-Crawford, a therapist and survivor of an eating disorder, told the Committee, "I can tell you right now that the statistics on eating disorders are downplaying this issue a thousand times over and millions are suffering in silence." 34

# FACTORS CONTRIBUTING TO THE DEVELOPMENT OF AN EATING DISORDER

Although the exact causes of eating disorders are not fully understood, <sup>35</sup> research suggests that they are complex illnesses with a biological or neurobiological basis influenced by a multitude of genetic, psychological, social and cultural factors. <sup>36</sup> The relative influence of contributing factors might vary between males and females with eating disorders, <sup>37</sup> and possibly across age groups. <sup>38</sup> This section of the report discusses some of the known or suspected factors contributing to the development or maintenance of eating disorders without attempting to rank them in order of their relative contribution.

#### A. Genetic Factors

Developments in genetic research are advancing our knowledge of the causes of eating disorders.<sup>39</sup> The Committee heard that the heritability for anorexia nervosa is about 75%, which is higher than many illnesses commonly understood to be genetically determined, such as schizophrenia, with a heritability of about 50% and type II diabetes, at about 70%. According to Dr. Blake Woodside, Medical Director for the Program for Eating Disorders at the Toronto General Hospital, in the case of anorexia nervosa, "genetics loads the gun; environment pulls the trigger." Bulimia nervosa is also believed to have a strong genetic basis.<sup>40</sup> Noelle Martin, a professor at Brescia University College, Western University, and President of Registered Dietitian Services, described the genetic predisposition of certain individuals to eating disorders as a "ticking time bomb," waiting to be triggered by any of a complex array of social, cultural, and environmental factors.<sup>41</sup>

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<sup>34</sup> *Evidence*, 5 March 2014, 1530 (Carly Lambert-Crawford, as an individual).

<sup>35</sup> Evidence, 5 February 2014, 1635 (Dr. April S. Elliott).

Evidence, 10 December 2013, 1545 (Dr. Joy Johnson); Evidence, 10 December 2013, 1535 (Marla Israel); Evidence, 12 February 2014, 1715 (Dr. Monique Jericho); Evidence, 5 February 2014, 1645 (Dr. Debra Katzman); Evidence, 5 February 2014, 1635 (Dr. April S. Elliott); Evidence, 5 March 2014, 1610 (Carly Lambert-Crawford); Evidence, 10 February 2014, 1630 (Jarrah Hodge); Evidence, 12 February 2014, 1540 (Joanna Anderson); Evidence, 28 November 2013, 1530 (Dr. Blake Woodside); Evidence, 12 February 2014, 1535 (Noelle Martin).

<sup>37 &</sup>lt;u>Evidence</u>, 28 November 2013, 1545 (Dr. Blake Woodside).

<sup>38</sup> Evidence, 5 March 2014, 1555 (Lisa LaBorde, as an individual).

<sup>39 &</sup>lt;u>Evidence</u>, 5 February 2014, 1635 (Dr. April S. Elliott); Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014.

<sup>40</sup> Evidence, 5 February 2014, 1635 (Dr. April S. Elliott).

<sup>41 &</sup>lt;u>Evidence</u>, 12 February 2014, 1535 (Noelle Martin).

# B. Biological and Psychological Factors

An in-depth discussion of the physiology of eating disorders is beyond the scope of this report, but many witnesses emphasised the biological nature of eating disorders. For instance, Dr. Joy Johnson, Scientific Director of CIHR, noted that factors such as early puberty or obesity in girls could predispose them to eating disorders. Merryl Bear, Director of the National Eating Disorder Information Centre (NEDIC), noted that emphasising the multiplicity of factors is important because it moves away from "blaming" parents for "causing" eating disorders in their children by mentioning their child's weight or eating habits. It might also help parents understand the reason for their child's disturbed behaviour:

I understood what was happening in the brain. This made it easier for me to exhibit patience. My daughter was exhibiting a typical fight-or-flight response to an anxious situation. From a neurobiological standpoint it made sense. 45

Some witnesses emphasised the complex interplay of biological and psychological factors. Therapist Carly Lambert-Crawford noted that while certain psychological factors may predispose individuals to eating disorders, the starvation of the brain that results from food restriction negatively affects cognition. The lack of nutrition associated with food restriction can lead to increased obsessiveness, which in turn fuels the perceived need to diet, exercise or purge. Thus, eating disorders function in a manner similar to obsessive compulsive disorder, where the obsessive thought is a meating too much, I'm gaining too much weight and the compulsive behaviours used to alleviate stress are restricting food, purging and/or exercising. Dr. Blake Woodside of Toronto General Hospital noted that chronic dieting – which has biological and psychological implications – can predispose individuals to developing eating disorders.

From a psychological perspective, witnesses described certain personality traits or mental health problems as being factors that predispose individuals to eating disorders. For instance, high levels of anxiety may predispose children to eating disorders, as can depression and mental illness generally. Young people with obsessive, perfectionist or anxious personality style might also be predisposed. Acting Director

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42 Evidence, 5 February 2014, 1645 (Dr. Debra Katzman).
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49 Evidence, 28 November 2013, 1530 (Dr. Blake Woodside).

<sup>43</sup> Evidence, 10 December 2013, 1545 (Dr. Joy Johnson).

<sup>44</sup> Evidence, 5 February 2014, 1615 (Merryl Bear).

<sup>45</sup> Evidence, 3 March 2014, 1555 (Laura Beattie).

<sup>46 &</sup>lt;u>Evidence</u>, 5 March 2014, 1610 (Carly Lambert-Crawford).

<sup>47</sup> Evidence, 24 February 2014, 1530 (Dr. Wendy Spettigue).

<sup>48</sup> Ibid.

<sup>50 &</sup>lt;u>Evidence</u>, 5 March 2014, 1610 (Carly Lambert-Crawford).

<sup>51</sup> Evidence, 5 February 2014, 1635 (Dr. April S. Elliott).

General of the Centre for Health Promotion and Chronic Disease Prevention Branch of PHAC, explained that inadequate coping mechanisms in some children – meaning their inability to respond appropriately to stressful situations – could contribute to the development of eating disorders. Dr. Wendy Spettigue, psychiatrist with CACAP, described food restriction as a means that patients use to cope with intolerable feelings of fear, sadness, worry, guilt, anger and stress. Dr. Monique Jericho, a psychiatrist and Medical Director of the Calgary Eating Disorder Program with Alberta Health Services, cautioned that despite their presentation, eating disorders are not in fact about food; the food restriction and other behaviours associated with eating disorders are symptoms of more complex underlying issues. Several witnesses noted that physical and sexual abuse might predispose individuals to eating disorders.

# C. Culture and Body Image

Although witnesses generally discussed cultural influences on body image and social pressures to conform to a particular ideal as triggers, rather than causes, of eating disorders, they emphasised that these pressures can be huge burdens for women, and young girls particularly. Factors such as a pervasive acceptance of an unrealistically thin ideal, a rise in celebrity culture, and society's tendency to objectify women, ocntribute to girls' development of unhealthy expectations about their own body. One potentially damaging message that girls receive is that if they try hard enough, they can all attain a particular body type, when in fact some girls' genes may dictate a different body type. Witnesses also noted that societal pressures to be thin can mask the symptoms of eating disorders because people are encouraged to lose weight or praised for losing weight. Further, because society equates beauty with power, and the predominant beauty ideal

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<sup>52</sup> Evidence, 10 December 2013, 1535 (Marla Israel).

<sup>53</sup> Evidence, 24 February 2014, 1530 (Dr. Wendy Spettigue).

<sup>54 &</sup>lt;u>Evidence</u>, 12 February 2014, 1715 (Dr. Monique Jericho).

Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014; <u>Evidence</u>, 10 December 2013, 1545 (Dr. Joy Johnson); <u>Evidence</u>, 28 November 2013, 1545 (Dr. Blake Woodside).

<sup>&</sup>lt;u>Evidence</u>, 3 March 2014, 1720 (Dr. Valerie Steeves, Ph.D., Associate Professor, University of Ottawa); <u>Evidence</u>, 3 March 2014, 1555 (Laura Beattie); <u>Evidence</u>, 26 February 2014, 1600 (Bonnie L. Brayton, National Executive Director, DisAbled Women's Network of Canada).

<sup>57</sup> Evidence, 3 March 2014, 1545 (Dr. Valerie Steeves); Evidence, 10 February 2014, 1630 (Jarrah Hodge).

<sup>58</sup> Evidence, 28 November 2013, 1550 (Dr. Blake Woodside).

<sup>59 &</sup>lt;u>Evidence</u>, 24 February 2014, 1530 (Dr. Wendy Spettigue)

<sup>60 &</sup>lt;u>Evidence</u>, 12 February 2014, 1655 (Dr. Carla Rice, Ph.D., Canada Research Chair in Care, Gender and Relationships, Department of Family Relations & Applied Nutrition, University of Guelph).

<sup>61</sup> Evidence, 12 February 2014, 1625 (Joanna Anderson).

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014; *Evidence*, 10 February 2014, 1630 (Jarrah Hodge).

implies thinness, it may be difficult for some individuals to fully appreciate the potential danger of pursuing thinness.<sup>63</sup>

In addition to the societal pressure to be thin, there is an even greater pressure to avoid becoming fat. Some witnesses described a "moral panic" that has led to the stigmatization of fatness. People perceived as being fat face discrimination and stereotypes; they may be considered unattractive, unhealthy, immoral or lazy. The Committee heard that even preschool-aged girls have internalized society's collective rejection of fatness; when presented with fat or thin figures, girls aged three to five years were more likely to describe the thin figures as "nice, smart, cute, neat and quiet, while heavier figures were characterized as mean, stupid, friendless, sloppy, ugly and loud." In the words of Jarrah Hodge of Women, Action and the Media Vancouver, if the pursuit of thinness acts as a carrot, the policing and shaming of fatness acts as a stick.

These dangerous messages are affecting young girls and women.<sup>68</sup> Dr. Wendy Spettigue, psychiatrist with CACAP, cited a study in which researchers found that 61% of Canadian girls in grades 7 and 8 were trying to lose weight. She cited another study of 700 children in Edmonton in grades 5 to 7, in which researchers found that 15% were purging or over-exercising, 16% were binge eating, and 19% were restricting their food intake to one meal per day or less.<sup>69</sup> Adult women are also vulnerable to pressures to be thin; research shows that as many as 87% of adult women are dissatisfied with their bodies and 70% are dieting to lose weight.<sup>70</sup>

Witnesses characterised schools as potentially toxic environments for messaging about weight and appearance. Dr. Spettigue noted that many teenaged girls do not eat lunch at school out of fear that they would be judged by other students, particularly boys. She also noted the popularity in schools of apps that allow users to rate images of girls and women. Dr. Valerie Steeves, associate professor of the Department of Criminology at the University of Ottawa, noted the focus in high schools on "thigh gap"; girls with a gap between their thighs are envied and subjected to jealous taunts, while girls without them are considered fat and ugly. Because many young people spend more time with their

66 Evidence, 10 February 2014, 1630 (Jarrah Hodge).

68 <u>Evidence</u>, 24 February 2014, 1640 (Dr. Wendy Spettigue); <u>Evidence</u>, 10 February 2014, 1630 (Jarrah Hodge); <u>Evidence</u>, 10 December 2013, 1615 (Marla Israel).

71 Ibid., 1640.

72 Evidence, 3 March 2014, 1630 (Dr. Valerie Steeves).

<sup>63 &</sup>lt;u>Evidence</u>, 12 February 2014, 1635 (Dr. Monique Jericho).

Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014.

<sup>65</sup> Ibid.

<sup>67</sup> Ibid.

<sup>69 &</sup>lt;u>Evidence</u>, 24 February 2014, 1530 (Dr. Wendy Spettigue).

<sup>70</sup> Ibid.

peers than with their families, parents may struggle to counteract this barrage of negative messages in the time they have with their child. Witnesses explained that this was yet another area where parental support and communication is key. Witnesses had repeatedly explained that fostering good body image and confidence, and helping people through eating disorders, is more effective with familial support.

The Public Health Agency of Canada works to counteract some of the negative messages that witnesses warned against. The agency advised the Committee that fostering a positive sense of self, with feelings of control and self-esteem among girls and boys can protect against eating disorders.<sup>74</sup>

# D. Mainstream Media and Advertising

As specific examples of cultural influences that could trigger behaviours related to eating disorders, witnesses discussed the fashion and entertainment industries, as well as advertising in general, and the advertising of diet products in particular. These industries convey "very specific messages about what [young women's] bodies should look like." The images of beauty that the entertainment industry presents are quite unrealistic; although an average healthy body mass index (BMI) for a young woman is about 21, typical models and celebrity actresses have a BMI closer to 16 or 17. Dr. Giorgio A. Tasca, Research Chair in Psychotherapy Research at the University of Ottawa and the Ottawa Hospital, noted that as television and the Internet were introduced into communities that had previously had little access to these forms of media, rates of eating disorders increased dramatically. Merryl Bear, Director of NEDIC, commented that many behaviours associated with eating disorders – such as highly restrictive eating, excessive exercise and guilt about eating – are highlighted or even "glamourized" by the media. Further, meta-analyses of studies on eating disorders suggest that increased media consumption is associated with eating disorder symptoms.

Elaine Stevenson, long-time advocate on behalf of people with eating disorders and co-administrator of the Alyssa Stevenson Eating Disorder Memorial Trust, expressed dismay that negative images in the media are fuelling the "very powerful, multi-billion dollar" diet industry.<sup>81</sup> This industry promises that thinness will bring "health, happiness,

<sup>73 &</sup>lt;u>Evidence</u>, 3 March 2014, 1725 (Patricia Lemoine).

<sup>74 &</sup>lt;u>Evidence</u>, 10 December 2013, 1540 (Marla Israel).

<sup>75</sup> Evidence, 10 December 2013, 1615 (Dr. Joy Johnson).

Body mass index is one's weight divided by one's height. See, for example, Health Canada, "Body Mass Index (BMI) Nomogram", Food and Nutrition.

<sup>77</sup> Evidence, 24 February 2014, 1640 (Dr. Wendy Spettigue).

<sup>78 &</sup>lt;u>Evidence</u>, 24 February 2014, 1700 (Dr. Giorgio A. Tasca).

<sup>79 &</sup>lt;u>Evidence</u>, 5 February 2014, 1545 (Merryl Bear).

<sup>80 &</sup>lt;u>Evidence</u>, 10 February 2014, 1630 (Jarrah Hodge).

<sup>81 &</sup>lt;u>Evidence</u>, 3 March 2014, 1610 (Elaine Stevenson).

sexiness, and acceptance by society," when in fact, she argued, pursuing thinness may cause serious harm.<sup>82</sup>

Witnesses expressed particular concern about marketing specifically aimed at girls. Dr. Valerie Steeves, associate professor, noted that there has been a significant change in her lifetime; when she was young, adolescents and children were off-limits for most advertisers, but this market now appears wide open.<sup>83</sup> Further, advertisers may be specifically targeting young women with potentially dangerous messages. Dr. Steeves shared her experience of visiting educational websites on eating disorders with sponsored links; the advertisements were for plastic surgery and diet products.<sup>84</sup>

#### Recommendation 1

The Committee recommends that the Government of Canada consider supporting research on the impact of media messaging and marketing directed toward children and the impact and consequences of society's current, narrow definition of beauty.

#### Recommendation 2

The Committee recommends that the Government of Canada encourage academic institutions to promote media literacy for young children to help them to view media content critically and question the messages therein.

#### E. Social Media

Our society appears to be increasingly focused on individuals' appearance, and this focus is particularly strong in the online context. This emphasis on image can lead to a perception that one's identity – which might otherwise comprise personality, intellect and other aspects of oneself – is "reduced to our physical identity." In turn, this can cause people to distance themselves from their bodies and to judge their visual identities while knowing that others are judging their visual identities too. Witnesses pointed to Facebook and social media to help explain this phenomenon.

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<sup>82</sup> Ibid.

<sup>83 &</sup>lt;u>Evidence</u>, 3 March 2014, 1550 (Dr. Valerie Steeves).

<sup>84</sup> Ibid., 1540–1545.

Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014; *Evidence*, 12 February 2014, 1705 (Dr. Carla Rice); *Evidence*, 3 March 2014, 1700 (Dr. Valerie Steeves).

<sup>86 &</sup>lt;u>Evidence</u>, 12 February 2014, 1705 (Dr. Carla Rice).

<sup>87 &</sup>lt;u>Evidence</u>, 3 March 2014, 1700 (Dr. Valerie Steeves).

Facebook allows users to construct their visual identities.<sup>88</sup> It also allows other people to comment on a user's visual identity.<sup>89</sup> Dr. Valerie Steeves, associate professor, described some of her recent research in which she interviewed young women about their Facebook practices.<sup>90</sup> She described girls dieting then posting images of themselves in lingerie, and waiting to see if they received enough "likes" for their picture in the short time after they posted an image. If they did not receive enough "likes" in that time, they felt humiliated and took down their picture. Dr. Steeves explained that while social media "provides a snapshot of teen life" because of its public-private nature, the emphasis on body image and the pressure to be thin are not unique to social media. Rather, she argued, they arise from media and culture generally.<sup>91</sup>

# F. Public Health Messages about Weight

The Committee was told that although public health messages about weight and healthy eating may be "very well-intended," they may be dangerous for certain populations. There are widely publicized campaigns to fight a childhood obesity "epidemic," but some witnesses questioned whether such an epidemic exists. Dr. Gail McVey, of the Hospital for Sick Children and OCOPED, told the Committee that research indicates that childhood obesity and eating disorders are actually linked and that public health "attention to preventing one does not have to mean neglect of the other."

The Committee heard that adults are unintentionally "transmitting a kind of panic" to children about obesity. Psychiatrist Dr. Wendy Spettigue, of CACAP, told the committee that public health messaging about obesity actually increases the incidence of eating disorders. Dr. Leora Pinhas a psychiatrist from the Department of Psychiatry at the Hospital for Sick Children, noted that studies show that children would rather lose an arm, be hit by a truck or have a parent die of cancer than be fat.

Some witnesses warned against the current approach to education about eating disorders in schools (discussed in greater detail later in the report). While these awareness-raising messages may be well-intentioned, they can act as triggers for eating

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88 <u>Evidence</u>, 12 February 2014, 1705 (Dr. Carla Rice).
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Ibid., 1720.

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<sup>89 &</sup>lt;u>Evidence</u>, 3 March 2014, 1545 (Dr. Valerie Steeves).

<sup>90</sup> Ibid.

<sup>92 &</sup>lt;u>Evidence</u>, 10 December 2013, 1615 (Dr. Joy Johnson).

<sup>93</sup> Evidence, 10 February 2014, 1605 (Dr. Leora Pinhas).

<sup>94</sup> Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014.

<sup>95 &</sup>lt;u>Evidence</u>, 24 February 2014, 1535 (Dr. Wendy Spettigue).

<sup>96 &</sup>lt;u>Evidence</u>, 10 February 2014, 1605 (Dr. Leora Pinhas).

disorder-related behaviours.<sup>97</sup> Joanna Anderson, Executive Director of Sheena's Place, shared the following experience:

I worked with a young 13-year-old boy who was hospitalized after someone had come into his class to educate them about healthy eating. In that talk it had been said that fat was bad, that fat should be cut out of diets. Within six weeks this child was in a tertiary health care centre on a heart monitor after he had lost so much weight as a result of receiving that message.

Certain children may be especially vulnerable to these messages. Witnesses remarked that a single comment from a teacher, a coach or a family doctor, or information from a health class or school project could trigger dangerous behaviours. Dr. Pinhas noted that these messages are particularly unhelpful for younger children because they may not be able to process all the nutritional information that is being conveyed, and further, they have limited control over their diets because their parents buy food and make meals.

When Jadine Cairns, President of the Eating Disorders Association of Canada (EDAC-ATAC), mentioned to one of her clients with an eating disorder that she would be appearing before this Committee, they discussed public health campaigns about weight. The patient said "yes, please tell them that it's really hard on us." Dr. Spettigue shared similar concerns:

[T]here are a lot of very compliant, self-conscious, perfectionistic, anxious little girls who are trying to be very, very good, and avoiding all the bad foods. Many of them get to the point where they're hospitalized for medical instability because they're only eating vegetables because they've heard so many messages about the bad foods: the fats, the sodium, and the sugar. We somehow need to create an atmosphere that's more about moderation and balance that applies to everybody. We also need to figure out how to treat obesity without causing eating disorders because for all of the patients who are getting the messages about the need to diet and watch your eating and all of that, they're creating a whole bunch of young patients who are coming into our hospital terrified of eating, terrified of gaining weight.<sup>101</sup>

A representative from Health Canada noted that the department's nutrition messaging emphasises health and well-being rather than weight and calorie counting, 102

<sup>97 &</sup>lt;u>Evidence</u>, 24 February 2014, 1535 (Dr. Wendy Spettigue); <u>Evidence</u>, 12 February 2014, 1540 (Joanna Anderson); <u>Evidence</u>, 5 February 2014, 1535 (Merryl Bear); <u>Evidence</u>, 10 February 2014, 1625 (Dr. Gail McVey, Ph.D., C.Psych., Community Health Systems Resource Group, Ontario Community Outreach Program for Eating Disorders, The Hospital for Sick Children of Toronto).

<sup>98 &</sup>lt;u>Evidence</u>, 24 February 2014, 1535 (Dr. Wendy Spettigue); <u>Evidence</u>, 12 February 2014, 1610 (Noelle Martin).

<sup>99</sup> Evidence, 10 February 2014, 1550 (Dr. Leora Pinhas).

<sup>100</sup> Evidence, 26 February 2014, 1620 (Jadine Cairns, President, Eating Disorders Association of Canada).

<sup>101</sup> Evidence, 24 February 2014, 1625 (Dr. Wendy Spettigue).

<sup>102 &</sup>lt;u>Evidence</u>, 10 December 2013, 1540 (Dr. Hasan Hutchinson, Ph.D., Director General, Office of Nutrition Policy and Promotion, Health Products and Food Branch, Health Canada).

and witnesses supported this approach; this approach is also an important part of prevention, as discussed below. 103

#### Recommendation 3

The Committee recommends that the Government of Canada collaborate with the provinces and territories to consider adjusting medical criteria for defining normal weights beyond quantitative measures such as Body Mass Index.

#### Recommendation 4

The Committee recommends that the Government of Canada review the information it provides on nutrition to encompass greater sensitivity in its guidelines on "good" and "bad" foods with the goal of helping to prevent unintended consequences, such as children as young as five years old developing eating disorders, which have been alleged to arise from the current guidance.

#### G. Prevention

The Committee was told that the development of effective prevention strategies is a critical step in reducing cases of eating disorders. Effective prevention initiatives must address the range of contributing factors described above with the goal of changing the circumstances that promote, initiate, sustain or intensify eating disorders. Noelle Martin, professor at Brescia University College and President of Registered Dietitian Services, highlighted the importance of prevention strategies:

Eating disorders are mental illnesses related to one's relationship with body, food, and others. We know that there's often a genetic link... Then, we have social, cultural, and environmental factors that may cause the gene to be expressed. For example, it could be a comment from a parent, friend, coach, or teacher that triggers a new thought in one's mind. It could be an article in a magazine, a commercial, or the content of a movie or a show. It can be obvious, or it can be very subtle. We cannot pinpoint just one thing that is the cause for eating disorders. Because of this, we need to look at prevention strategies that target a variety of areas. <sup>105</sup>

Prevention strategies can be targeted (aimed at a subset of a population) or take a more universal approach (e.g., national or school-wide level). Witnesses stated that prevention campaigns with a more universal approach can address more than just eating

103 <u>Evidence</u>, 10 February 2014, 1605 (Dr. Leora Pinhas); <u>Evidence</u>, 10 December 2013, 1615 (Dr. Joy Johnson).

Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014.

<sup>105 &</sup>lt;u>Evidence</u>, 12 February 2014, 1535 (Noelle Martin).

Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014.

disorders; such campaigns can have the wider goal of changing society's attitudes about weight and appearance and reducing stigma for individuals at risk of developing an eating disorder. From a public health perspective, such a widespread prevention campaign can promote the development of a solid foundation in terms of mental well-being, self-confidence and self-esteem. As well, such universal prevention efforts can focus on healthy eating and balanced nutrition, without discussing dieting, calorie-counting and weight. Self-esteem.

For example, Dr. Hasan Hutchinson, Director General of the Office of Nutrition Policy and Promotion at the Health Products and Food Branch of Health Canada, said that "nutrition promotion policies, programs, and messages such as those developed by Health Canada, which focus on health and well-being and not on weight and calories, play an important role in the prevention of disordered eating." <sup>110</sup>

Among targeted prevention strategies, the Committee learned that prevention can focus on the general promotion of healthy eating, with the goal of stopping eating disorders before they develop, or prevention can focus on assisting individuals who may be showing eating disorder symptoms, with the aim of providing early identification and early treatment.<sup>111</sup>

Among prevention campaigns geared to adolescents, the population at greatest risk of developing an eating disorder, the Committee was informed that organizations should be cautious when designing campaigns to teach youth about eating disorders. Research indicates that poorly-designed campaigns can provide "how-to" information and can trigger an eating disorder among individuals at risk. <sup>112</sup> Dr. Gail McVey, of the Hospital for Sick Children and OCOPED, explained that having speakers present on the topic of eating disorders to youth is "ineffective as a prevention strategy" and can "glorify eating disorder symptoms among impressionable youth." She noted: "For example, it is well documented that following such presentations youth are at risk of adopting dangerous [eating disorder] techniques including laxative use, starvation, self-induced vomiting." <sup>113</sup>

<sup>107 &</sup>lt;u>Evidence</u>, 24 February 2014, 1640 (Dr. Wendy Spettigue); Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014.

<sup>108 &</sup>lt;u>Evidence</u>, 10 December 2013, 1540 (Marla Israel).

<sup>109 &</sup>lt;u>Evidence</u>, 12 February 2014, 1540 (Joanna Anderson); <u>Evidence</u>, 10 December 2013, 1615 (Dr. Joy Johnson); <u>Evidence</u>, 10 February 2014, 1625 (Dr. Gail McVey).

<sup>110 &</sup>lt;u>Evidence</u>, 10 December 2013, 1540 (Dr. Hasan Hutchinson).

Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014.

<sup>112 &</sup>lt;u>Evidence</u>, 24 February 2014, 1645 (Dr. Wendy Spettigue).

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014.

As well, as discussed above, the Committee was told that obesity prevention campaigns can be equally harmful; for example, programs that measure youth's BMI end up stigmatizing different body sizes and creating a sense of fear over weight gain. 114

The Committee was told by Dr. McVey that prevention strategies can adopt a "lifespan approach" which is "heavily anchored in mental health promotion designed to foster healthy coping skills to fend off stressors that lead to eating disorders."115 Prevention campaigns can also include long-term media literacy components, which help youth to build confidence and resilience, combat social pressure and improve critical thinking related to media messages. 116

The Committee was informed that while evidence indicates that prevention targeted at adolescents is most effective, there is "a total absence of targeted prevention for Canadian adolescents" and "this gap in service, or death valley, coincides with the highest period of risk for the development of eating disorder symptoms and their associated mental health concerns."117

Josée Champagne, Executive Director of Anorexia and Bulimia Quebec (ANEB Quebec), said that prevention programs in schools should be more prevalent, and she recommended training "peer helpers" to assist students at risk of developing eating disorders. 118 However, Dr. McVey recommended that only qualified mental health experts be responsible for leading eating disorder prevention as they have the appropriate knowledge and expertise to "deliver high quality, sophisticated, clinically-sensitive prevention programming."119 Prevention strategies targeted at children, often with the aim of providing nutritional information, have begun to shift towards targeting parents and other adult role models or authorities, as these people have direct control over the lifestyles and eating habits of the children. 120 Dr. Leora Pinhas, psychiatrist at the Hospital for Sick Children, said that teaching children about nutrition can have a limited impact, as it is the parents who prepare meals; she suggests instead creating "a lunch program" to ensure children are eating balanced meals. 121 Laura Beattie, Co-chair of F.E.A.S.T. Canada Task

<sup>114</sup> 

Evidence, 28 November 2013, 1625 (Dr. Blake Woodside).

Evidence, 10 February 2014, 1540 (Dr. Gail McVey). 115

Evidence, 10 February 2014, 1635 (Jarrah Hodge); Evidence, 3 March 2014, 1705 (Dr. Valerie Steeves); 116 Evidence, 24 February 2014, 1645 (Dr. Wendy Spettigue).

Evidence, 10 February 2014, 1540 (Dr. Gail McVey). 117

<sup>118</sup> Evidence, 26 February 2014, 1545 (Josée Champagne, Executive Director, Anorexia and bulimia Quebec).

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community 119 Outreach Program for Eating Disorders, Submitted Brief, 4 March 2014.

Evidence, 10 February 2014, 1625 (Dr. Gail McVey); Evidence, 10 February 2014, 1550 (Dr. Leora Pinhas). 120

<sup>121</sup> Evidence, 10 February 2014, 1550 (Dr. Leora Pinhas).

Force, recommended that schools provide adequate time and supervision for lunch and nutrition breaks to promote healthy eating. 122

The Committee also heard about certain types of prevention<sup>123</sup> that should be targeted primarily at parents, health care professionals, teachers, coaches and any other adult who may recognize early onset symptoms of an eating disorder. Dr. McVey explained that evidence indicates the effectiveness of targeted prevention in the early identification of disordered eating habits, and that this serves to stop early onset symptoms from escalating into full eating disorders.<sup>124</sup> These programs must have consistent messages that are directed at multiple levels, across sectors in health, education, sport and more.<sup>125</sup>

A challenge in the creation and delivery of prevention programs and strategies is the need for funding. Ms. Beattie suggested the diet industry be financially responsible for the cost of certain prevention programs. 127

Dr. McVey suggested establishing a "prevention strategy" for Canada. 128 However, the Committee was informed that efforts to prevent eating disorders are valuable, but not always sufficient. As was explained by Lisa LaBorde, parent of a daughter with an eating disorder:

Our home environment was probably as close to an experiment in eating disorder prevention as one could get. There was no scale in our home. We did not have cable. I'd never been on a diet in my life, and I grew up in a culture that did not internalize the thin ideal. I worked to pass that on to my children also. We consciously spoke about healthy bodies of any size, and I raised them to be conscious and critical of media messages. Still, [my daughter] got an eating disorder. 129

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Laura Beattie, Co-chair, Families Empowered and Supporting Treatment of Eating Disorders Canada Task Force, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", Submitted Brief, 3 March 2014.

<sup>123</sup> Evidence, 10 February 2014, 1600 (Leora Pinhas).

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014.

<sup>125 &</sup>lt;u>Evidence</u>, 5 February 2014, 1720 (Dr. Debra Katzman).

<sup>126</sup> Evidence, 5 February 2014, 1610 (Merryl Bear).

Laura Beattie, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", Submitted Brief, 3 March 2014.

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014.

<sup>129</sup> *Evidence*, 5 March 2014, 1540 (Lisa LaBorde).

#### Recommendation 5

The Committee recommends that the Government of Canada collaborate with the provinces and territories to consider developing a health and well-being education and awareness campaign, including both in-school and social media content, to foster a positive sense of self to protect against eating disorders, and to include media literacy components to counteract images portrayed in mainstream media.

### **OBSTACLES IN ADDRESSING EATING DISORDERS**

The Committee heard about a number of obstacles that make it difficult for individuals with an eating disorder, their families, health care professionals and others to recognize, receive or provide diagnosis, seek treatment and access other forms of support for the condition. This section discusses some key obstacles, which include low levels of awareness and understanding of eating disorders, a lack of community-based support, existing stereotypes and stigma, bias in the health care field, financial roadblocks, difficulties producing research and tracking information, and specific challenges for marginalized populations. The Committee was also informed of the challenges in accessing treatment for individuals with eating disorders; because of the importance of this problem, it is covered in a separate section.

In order to address the aforementioned roadblocks, some witnesses asked for the development of a national eating disorder strategy, using an approach that includes all levels of education, practice and research, and that provides support to all provinces. 130

#### Recommendation 6

The Committee recommends that the Government of Canada consider developing a federal framework supported by an online public resource that would serve to collect from, and provide to, all provinces and territories information, statistics, best practices in recognizing symptoms, diagnosis, and treatment, and to raise awareness about the prevalence of eating disorders in Canada. This would close gaps in data collection and analysis regarding eating disorders and ensure a comprehensive picture of the incidence and prevalence of eating disorders and corresponding services in Canada.

#### A. Awareness

The Committee heard that greater awareness of eating disorders is needed to counter stigma, misinformation or lack of information, and stereotypes (issues which are examined later). Witnesses were encouraged by progress in recent years in the realm of

Evidence, 5 February 2014, 1540 (Merryl Bear); Evidence, 24 February 2014, 1600 (Elizabeth Phoenix); 130 Evidence, 26 February 2014, 1600 (Bonnie L. Brayton); Evidence, 5 February 2014, 1715 (Dr. April S. Elliott).

mental health; there is improved understanding of mental health problems and greater ability to talk about these conditions publicly. However, witnesses raised concerns that eating disorders are not being included under the mental health "umbrella," and are being excluded from mental health campaigns, programs or agendas. Eating disorders need to be invited to round table discussions and incorporated into the mental health community. Health community.

It was recommended to the Committee that Canada establish a national awareness and education campaign on eating disorders to educate the general public, 134 as well as professionals in key fields, such as health care, the media, education and justice. 135 The Committee heard that an awareness and education campaign should include components to increase understanding of eating disorders, their symptoms, treatment options, and available support services. It was also suggested that media literacy could be a valuable part of any national awareness campaign. 136

Witnesses also suggested that such campaigns should emphasize the fact that an eating disorder is a "severe mental illness that has very high mortality rates," with the goal of relieving shame and denial, and also decreasing stigmatization and discrimination against individuals with eating disorders. 138

The Committee learned that awareness empowers prevention strategies, as people are more likely to recognize early onset symptoms of eating disorders and seek assistance; this leads to better population health. As early intervention leads to more successful treatment outcomes for eating disorder patients, witnesses recommended that awareness campaigns educate parents on the initial symptoms of eating disorders and on the first steps that should be taken to address the condition. Joanna Anderson, Executive Director of Sheena's Place, explained that it is critical to "have parents understand if suddenly their child is skipping meals, the lunch containers are coming back with food still in them, there is a problem and it needs to be addressed."

134 <u>Evidence</u>, 12 February 2014, 1610 (Joanna Anderson); <u>Evidence</u>, 28 November 2013, 1620 (Dr. Blake Woodside); <u>Evidence</u>, 5 February 2014, 1550 (Merryl Bear).

138 <u>Evidence</u>, 5 February 2014, 1530 (Merryl Bear); <u>Evidence</u>, 26 February 2014, 1540 (Josée Champagne).

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<sup>131 &</sup>lt;u>Evidence</u>, 10 December 2013, 1625 (Marla Israel); <u>Evidence</u>, 10 February 2014, 1545 (Dr. Gail McVey); <u>Evidence</u>, 12 February 2014, 1545 (Joanna Anderson).

<sup>132</sup> Evidence, 10 February 2014, 1640 (Wendy Preskow); Evidence, 10 February 2014, 1535 (Dr. Leora Pinhas).

<sup>133</sup> *Evidence*, 10 February 2014, 1545 (Dr. Gail McVey).

<sup>135</sup> *Evidence*, 5 February 2014, 1535 (Merryl Bear).

<sup>136</sup> Evidence, 12 February 2014, 1625 (Joanna Anderson).

<sup>137</sup> Ibid., 1605.

<sup>139</sup> Evidence, 10 December 2013, 1625 (Marla Israel); Evidence, 5 February 2014, 1530 (Merryl Bear).

<sup>140 &</sup>lt;u>Evidence</u>, 5 March 2014, 1555 (Lisa LaBorde); <u>Evidence</u>, 12 February 2014, 1620 (Joanna Anderson); <u>Evidence</u>, 3 March 2014, 1700 (Patricia Lemoine).

<sup>141</sup> *Evidence*, 12 February 2014, 1620 (Joanna Anderson).

Some witnesses spoke of the role that the federal government should play in raising awareness about eating disorders, through methods such as providing the public with reliable information online about eating disorders or highlighting services that assist individuals with eating disorders. 142

According to witnesses, awareness campaigns should also focus on teaching school staff the appropriate strategies for dealing with eating disorders among their students, and this would include information on preventive measures, possible "triggers," and symptoms. Wendy Preskow, founder and chief advocate of the National Initiative for Eating Disorders (NIED), suggested that school boards check their curricula to remove "triggers" such as excessive emphasis on healthy eating and obesity concerns. He Committee heard that children are overwhelmed with information about nutrition and health; schools should be aware that children think in concrete terms, and therefore educators should not teach what is "right" and "wrong" to eat or attach guilt to certain food items. He

The Committee was told that beyond awareness of eating disorders, the general public should be educated on the ideal healthy body. People should be aware of the "normality of differences between all bodies, and the importance of nourishing our bodies respectfully," and should promote body confidence in children and youth. Witnesses indicated that greater understanding of healthy bodies should be accompanied by a critical examination of the possible damage done by messages that promote dieting, tracking of BMI and the monitoring of obesity. As Dr. Hasan Hutchinson, Director General of the Office of Nutrition Policy and Promotion at the Health Products and Food Branch of Health Canada, stated:

Nutrition promotion policies, programs, and messages such as those developed by Health Canada, which focus on health and well-being and not on weight and calories, play an important role in the prevention of disordered eating.<sup>148</sup>

147 <u>Evidence</u>, 12 February 2014, 1540 (Noelle Martin).

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Evidence, 28 November 2013, 1615-1620 (Dr. Blake Woodside); Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, Submitted Brief, 4 March 2014.

Evidence, 24 February 2014, 1645 (Dr. Wendy Spettigue); Wendy Preskow, Founder and Chief Advocate, National Initiative for Eating Disorders, "Testimony, Additional recommendations and answers," Written Response, 5 March 2014; Laura Beattie, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", Submitted Brief, 3 March 2014.

Wendy Preskow, "Testimony, Additional recommendations and answers", National Initiative for Eating Disorders, *Written Response*, 5 March 2014.

<sup>145 &</sup>lt;u>Evidence</u>, 10 February 2014, 1550 (Dr. Leora Pinhas); Laura Beattie, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", *Submitted Brief*, 3 March 2014.

<sup>146</sup> *Evidence*, 5 February 2014, 1600 (Merryl Bear).

<sup>148</sup> *Evidence*, 10 December 2013, 1540 (Dr. Hasan Hutchinson).

#### Recommendation 7

The Committee recommends that the Government of Canada, in collaboration with the provincial and territorial governments and the Mental Health Commission of Canada, consider including those living with eating disorders, their families, and stakeholders in discussions and round tables regarding mental health.

#### **Recommendation 8**

The Committee recommends that the Government of Canada should work with provinces, territories, and stakeholders to ensure that sufficient materials on eating disorders are incorporated into curricula for medical, nursing, psychology, psychiatry, and other health care professions to raise awareness and reduce stereotypes and stigma around eating disorders.

### **Recommendation 9**

The Committee recognizes that there is a need for an advocacy group, like the National Initiative for Eating Disorders, to advocate on behalf of those living with eating disorders and to raise public awareness.

# **B. Community-Based Support**

For many individuals with eating disorders and their families, there are scarce resources and information available in the community. The local resource and support centres that do exist have difficulty keeping up with demand. Joanna Anderson, Executive Director of Sheena's Place, reported that when successful programs are offered, groups fill up and have wait lists within hours of registration opening. The Executive Director of ANEB Quebec, Josée Champagne, spoke of the need to improve accessibility to specialized support services in the community in order to ensure appropriate and quick assistance for individuals waiting for support.

Witnesses also spoke of the shortage of community-level assistance geared to parents, siblings and partners of individuals with eating disorders. Laura Beattie, Co-chair of F.E.A.S.T. Canada Task Force, said that parents of children with eating

Evidence, 12 February 2014, 1545 (Joanna Anderson); Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, Submitted Brief, 4 March 2014.

<sup>150 &</sup>lt;u>Evidence</u>, 12 February 2014, 1545 (Joanna Anderson); <u>Evidence</u>, 26 February 2014, 1545 (Josée Champagne).

<sup>151 &</sup>lt;u>Evidence</u>, 12 February 2014, 1545 (Joanna Anderson).

<sup>152</sup> Evidence, 26 February 2014, 1545 (Josée Champagne).

Evidence, 5 February 2014, 1600 (Merryl Bear); Evidence, 10 February 2014, 1640 (Wendy Preskow); Laura Beattie, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", Submitted Brief, 3 March 2014.

disorders needed specific community help with certain aspects of treatment, such as refeeding and meal support. Lisa LaBorde, whose daughter had an eating disorder, said that families need community resources and support as children are developing symptoms at younger ages. States of treatment, such as refeeding and meal support.

Among community mental health agencies, the Committee heard that there is generally not enough time and funding to provide training in eating disorders. Merryl Bear, Director of NEDIC, explained that when her organization refers people seeking help to local mental health programs, often the staff at these mental health centres do not have specialized knowledge in eating disorders. Dr. Leora Pinhas, psychiatrist at the Hospital for Sick Children, said "we need intensive community programs and people who are trained to work with families where they live and provide them the supports they're entitled to in the way they do for any other mental health disorder."

A central challenge in developing and providing assistance at the community level is the lack of sustained funding for community-based resource and support centres. As witnesses explained, many of these centres currently receive little or no public funding and depend on fundraising efforts to keep their doors open. As a result, the Committee heard that these organizations spend their time and energy "looking for funding" and many of them "live month to month." Many witnesses specifically recommended the provision of sustained funding for community-based resources and programs. Noelle Martin, professor at Brescia University College and President of Registered Dietitian Services, suggested "federal funding... [be] offered to places that are maybe even outside of clinical settings, such as Hope's Garden or Sheena's Place, and other places like that across Canada."

If community-based resource and support centres received stable funding, the Committee was told these centres could expand preventive programs, provide support

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Laura Beattie, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", Submitted Brief, 3 March 2014.

<sup>155</sup> *Evidence*, 5 March 2014, 1625 (Lisa LaBorde).

<sup>156</sup> Evidence, 24 February 2014, 1535 (Dr. Wendy Spettigue).

<sup>157</sup> *Evidence*, 5 February 2014, 1600 (Merryl Bear).

<sup>158 &</sup>lt;u>Evidence</u>, 10 February 2014, 1605 (Dr. Leora Pinhas).

Evidence, 24 February 2014, 1545 (Dr. Lisa Votta-Bleeker, Ph.D., Deputy Chief Executive Officer and Director, Science Directorate, Canadian Psychological Association); <u>Evidence</u>, 12 February 2014, 1545 (Joanna Anderson); <u>Evidence</u>, 5 February 2014, 1530 (Merryl Bear).

<sup>160</sup> *Evidence*, 26 February 2014, 1545 (Josée Champagne).

<sup>161</sup> Evidence, 10 February 2014, 1600 (Dr. Leora Pinhas).

<sup>162 &</sup>lt;u>Evidence</u>, 12 February 2014, 1545 (Joanna Anderson); <u>Evidence</u>, 24 February 2014, 1545 (Dr. Lisa Votta-Bleeker); Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014.

<sup>163</sup> Evidence, 12 February 2014, 1605 (Noelle Martin).

services to underserved and isolated populations, assist clients who are navigating the health care system, and build resource databases to inform clients. 164

Dr. Carla Rice, Canada Research Chair in Care, Gender and Relationships, recommended the "development of an alternate system of community-based treatment and support" for individuals with eating disorders. <sup>165</sup> Wendy Preskow, founder and chief advocate of NIED, spoke of the need for community support, asking for specific community group homes, which she describes as "places of safety the same as provided for substance abuse, alcoholism, and drug abuse; there is absolutely nothing like this for eating disorder sufferers." <sup>166</sup> Ms. Preskow also suggested funding and training community crisis teams, which would be "teams of professionals – medical, mental, nutritional – who parents or sufferers can call on at any time during a crisis 24/7/365 for meaningful help and support." <sup>167</sup> It was also recommended that community-based support be offered in schools. Psychiatrist Dr. Wendy Spettigue, of CACAP, said there was a great need for "trained community health counsellors who can counsel students who suffer from depression, anxiety, self-injurious behaviour, eating disorders, and addictions." <sup>168</sup>

#### **Recommendation 10**

The Committee recommends that the Government of Canada recognize as a best practice the availability of navigators for eating disorders for the health and mental health care system to help identify quality services available in a timely manner, and help individuals and families navigate the system.

## C. Stereotypes and Stigma

Witnesses agreed that one of the most significant roadblocks to successful diagnosis of, treatment of, and recovery from eating disorders are the stereotypes and stigma attached to them. As with many mental illnesses, the reality for individuals with eating disorders, and their families, is not well understood and the disease tends to be viewed as taboo or a pseudo-illness. Elaine Stevenson, co-administrator of the Alyssa Stevenson Eating Disorder Memorial Trust, remarked that "eating disorders are cloaked in the three S's: shame, secrecy, and silence."

<sup>164</sup> Evidence, 12 February 2014, 1545 (Joanna Anderson).

<sup>165</sup> *Evidence*, 12 February 2014, 1645 (Dr. Carla Rice).

<sup>166</sup> Evidence, 10 February 2014, 1645 (Wendy Preskow).

Wendy Preskow, "Testimony, Additional recommendations and answers", National Initiative for Eating Disorders, *Written Response*, 5 March 2014.

<sup>168</sup> Evidence, 24 February 2014, 1535 (Dr. Wendy Spettigue).

Evidence, 12 February 2014, 1550 (Noelle Martin); Evidence, 10 February 2014, 1605 (Dr. Gail McVey); Evidence, 28 November 2013, 1540 (Dr. Blake Woodside); Evidence, 5 March 2014, 1535 (Carly Lambert-Crawford).

<sup>170</sup> Evidence, 5 March 2014, 1605 (Elaine Stevenson).

Witnesses described the common, erroneous stereotypes about eating disorders that are held by the general public and health care professionals, including:

- only young, Caucasian, middle- to upper-class, heterosexual girls have eating disorders: 171
- parents, mothers in particular, are to blame for their child's eating disorder; 172 and
- an eating disorder is merely a phase, is self-inflicted, and is an attempt to get attention. 173

These stereotypes are so engrained, so persistent and so powerful that some witnesses referred to them as mythologies. 174 The consequence of these stereotypes is that they feed into stigma, which fuels shame among individuals with eating disorders, making it more difficult for them to acknowledge they have the disorder, to seek diagnosis and to accept and maintain treatment. As well, this stigma can lead to discrimination by the public and health care professionals, which will be discussed in the next section on bias in the health care field. 175

The Committee heard that an individual with an eating disorder may sometimes be told "she's just looking for attention," "it's her mother's fault," or "she's a spoiled rich girl." 176 These characterizations reinforce the stigma; those with an eating disorder are afraid of admitting to the disease and of being judged. Witnesses noted that it is even difficult for these individuals to confide to their closest family and friends. As a result, many individuals have difficulty seeking diagnosis and accepting treatment; instead, they suffer in silence. 177

Furthermore, the Committee was told that for individuals who do not fit the stereotype of a patient with an eating disorder, they may not recognize their illness or feel that their disorder is serious or legitimate. 178 As well, parents, friends and health care

<sup>171</sup> Evidence, 12 February 2014, 1645 (Dr. Carla Rice); Evidence, 5 February 2014, 1535 (Merryl Bear); Evidence, 10 February 2014, 1620 (Dr. Leora Pinhas); Evidence, 12 February 2014, 1540 (Joanna Anderson).

<sup>172</sup> Evidence, 24 February 2014, 1650 (Dr. Wendy Spettigue); Evidence, 3 March 2014, 1720 (Laura Beattie); Evidence, 5 February 2014, 1615 (Merryl Bear); Evidence, 28 November 2013, 1535 (Dr. Blake Woodside).

<sup>173</sup> Evidence, 5 February 2014, 1535 (Merryl Bear); Evidence, 28 November 2013, 1535-1540 (Dr. Blake Woodside); Evidence, 12 February 2014, 1635 (Dr. Monique Jericho); Evidence, 10 February 2014, 1620 (Dr. Leora Pinhas).

Evidence, 5 February 2014, 1535 (Merryl Bear); Evidence, 5 March 2014, 1550 (Laura Beattie); Evidence, 174 10 February 2014, 1620 (Dr. Leora Pinhas); Evidence, 12 February 2014, 1640 (Dr. Carla Rice).

<sup>175</sup> Evidence, 5 February 2014, 1535 (Merryl Bear).

<sup>176</sup> Evidence, 12 February 2014, 1535 (Noelle Martin); Evidence, 28 November 2013, 1535 (Dr. Blake Woodside).

<sup>177</sup> Evidence, 28 November 2013, 1600 (Dr. Blake Woodside); Evidence, 26 February 2014, 1545 (Josée Champagne); Evidence, 12 February 2014, 1540 (Joanna Anderson).

<sup>178</sup> Evidence, 12 February 2014, 1645 (Dr. Carla Rice); Evidence, 5 March 2014, 1540 (Lisa LaBorde).

professionals may not believe an individual has an eating disorder if he or she does not match the stereotype; this situation can arise among young children, among boys and men, or among ethnic and visible minorities. 179

As discussed in the previous section on awareness, the Committee was told that Canada should establish a national awareness and education campaign on eating disorders to educate the general public, in part with the goal to fight stigma, stereotypes and discrimination against those with eating disorders. 180

#### D. Bias in the Health Care Field

Some witnesses indicated that patients with eating disorders, and the patients' families, feel discriminated against by health care professionals and the health care system in general. The Committee was told that a central example of such discrimination is the limited access to treatment and lengthy wait times for admission to eating disorder programs across the country. Dr. Blake Woodside, Medical Director for the Program for Eating Disorders at the Toronto General Hospital, compared the treatment wait times for patients with anorexia nervosa versus prostate cancer:

If there were waits like this of four to six months for prostate cancer treatment, there would be a national outcry. There would be marches in the streets. The marches would be attended by middle-age men like me, but of course prostate cancer is a disease of middle-age men just like me, and older, so there is a clinic for prostate cancer in every hospital in this country. Compare that with the situation for anorexia nervosa where, in the province of Ontario... there are only three treatment centres that have in-patient beds for a population of 12 million. If this isn't discrimination, I don't know what is.<sup>182</sup>

Dr. Leora Pinhas, psychiatrist at the Hospital for Sick Children, spoke of her frustration because these disorders are not considered as a priority within health communities, and her persistent advocacy and work is dismissed by colleagues. In addition, witnesses expressed frustration that eating disorders are marginalized within the mental health care system, and are rarely included in mental health programs, campaigns or research agendas. For example, Dr. Pinhas explained that in Toronto, all

<sup>179 &</sup>lt;u>Evidence</u>, 26 February 2014, 1545 (Josée Champagne); <u>Evidence</u>, 5 March 2014, 1540 (Lisa LaBorde); <u>Evidence</u>, 12 February 2014, 1640 (Dr. Carla Rice).

<sup>180 &</sup>lt;u>Evidence</u>, 12 February 2014, 1610 (Joanna Anderson); <u>Evidence</u>, 28 November 2013, 1620 (Dr. Blake Woodside); <u>Evidence</u>, 5 February 2014, 1550 (Merryl Bear).

<sup>181 &</sup>lt;u>Evidence</u>, 28 November 2013, 1535 (Dr. Blake Woodside); <u>Evidence</u>, 10 February 2014, 1535 (Dr. Leora Pinhas).

<sup>182</sup> *Evidence*, 28 November 2013, 1535 (Dr. Blake Woodside).

<sup>183</sup> Evidence, 10 February 2014, 1535 (Dr. Leora Pinhas).

<sup>184 &</sup>lt;u>Evidence</u>, 10 February 2014, 1640 (Wendy Preskow); <u>Evidence</u>, 10 February 2014, 1605 (Dr. Leora Pinhas).

acute adolescent mental health beds do not accept patients who have a primary diagnosis of an eating disorder, even if they have a concurrent disorder such as depression.<sup>185</sup>

Witnesses spoke of being treated with disrespect and blamed by health care professionals when they sought assistance for themselves, or for someone else who had an eating disorder. <sup>186</sup> Joanna Anderson, Executive Director of Sheena's Place, described an experience where she sought assistance for a client:

She was having chest pain, and I was very nervous for her, and I accompanied her to emergency. I did that because I knew that she was going to be treated terribly in the emergency department. When I mentioned to the [Emergency Room] doctor that... she had been struggling with an eating disorder for many years, he said to tell her the waiting list was six months long, and then proceeded to not really treat her with the same kind of respect or care that you would get if you were just having chest pain and someone didn't know that you had an eating disorder. So I think our clients are discriminated against on the understanding that this is something that people do to themselves, that it's a bad choice that they make, whereas what we're trying to educate... the public about is that this is a mental illness that is very based in genetic and biological functions.<sup>187</sup>

In other circumstances, the Committee heard of general practitioners or doctors in hospital emergency departments who had little knowledge of the disorder, provided misguided advice such as "gain some pounds," or who focused on body appearance and weight. Carly Lambert-Crawford, a therapist and survivor of an eating disorder, told the Committee:

I don't want anyone [with an eating disorder] ... to be told that there are a lot of other people there who are sicker than them and to just eat and stop taking up a bed, or to be told that they are too sick to talk to anyone and to not be given a voice to even try to understand. 189

The suggestion of bias in the psychiatric field was also made to the Committee. Ms. Anderson said that "because this is a long-standing, entrenched illness, a lot of psychiatrists don't want to take eating disorder clients on. They view them as high-risk – their mortality rates are very high – and they view it as a very long commitment." <sup>190</sup>

The Committee was told that patients may not receive appropriate diagnosis and treatment because of doctors who rely on stereotypes and misinformation. Witnesses suggested that some doctors may dismiss eating disorder symptoms because

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<sup>185</sup> *Evidence*, 10 February 2014, 1605 (Dr. Leora Pinhas).

<sup>186 &</sup>lt;u>Evidence</u>, 12 February 2014, 1600 (Joanna Anderson); <u>Evidence</u>, 5 February 2014, 1720 (Dr. April S. Elliott); <u>Evidence</u>, 5 March 2014, 1535 (Carly Lambert-Crawford).

<sup>187 &</sup>lt;u>Evidence</u>, 12 February 2014, 1600 (Joanna Anderson).

Wendy Preskow, "Testimony, Additional recommendations and answers", National Initiative for Eating Disorders, *Written Response*, 5 March 2014; <u>Evidence</u>, 3 March 2014, 1630 (Patricia Lemoine); <u>Evidence</u>, 26 February 2014, 1625 (Arthur Boese, as an individual).

<sup>189 &</sup>lt;u>Evidence</u>, 5 March 2012, 1535 (Carly Lambert-Crawford).

<sup>190</sup> Evidence, 12 February 2014, 1615 (Joanna Anderson).

the patient does not fit the expected body size, race or ethnicity, or gender. For example, some doctors have an established idea of the "ideal body" and hold the common perception that "thin" is healthy and extra weight is not. In particular, witnesses indicated that many health care professionals are misguided in diagnosing eating disorders based solely on weight or BMI; rather, health care professionals should examine an individual's relationships with food and his or her body. Josée Champagne, Executive Director of ANEB Quebec, spoke of doctors who had not diagnosed an individual as being anorexic, because the patient was "not thin enough." Some health care professionals allow racial stereotypes of patients with eating disorders to limit their diagnosis, as will be expanded upon in the upcoming section on marginalized populations. Dr. Carla Rice, Canada Research Chair in Care, Gender and Relationships, explained:

[I]n researching body image and eating concerns among diverse groups of Canadian women, I spoke with a number of racialized women—Asian women, South Asian, as well as African Caribbean Canadian women—whose eating disorders were misdiagnosed or dismissed by health care providers, an experience that complicated their recovery and that they attributed to race. In other words, they attributed it to health providers' not being able to imagine, because of this dominant mythology, someone of their racial group struggling with an eating disorder. 195

Dr. Monique Jericho, psychiatrist and Medical Director of the Calgary Eating Disorder Program, cautioned against using the word "discrimination" as it implies deliberate neglect or harm; instead, she said it is an issue of lack of recognition, misunderstanding, stereotypes and stigma.<sup>196</sup>

The Committee was told that it was imperative that health care professionals – family physicians, nurses, emergency room doctors, and others – be educated about eating disorders. <sup>197</sup> It was recommended by a number of witnesses that eating disorders

<sup>191</sup> *Evidence*, 12 February 2014, 1645 (Dr. Carla Rice).

<sup>192 &</sup>lt;u>Evidence</u>, 24 February 2014, 1700 (Dr. Wendy Spettigue).

Noelle Martin, RD, Professor, Brescia University College, Western University, and President, Registered Dietitian Services "Additional Notes", *Written Responses*, 3 March 2014; *Evidence*, 24 February 2014, 1700 (Dr. Wendy Spettigue).

<sup>194</sup> *Evidence*, 26 February 2014, 1540 (Josée Champagne).

<sup>195</sup> *Evidence*, 12 February 2014, 1640 (Carla Rice).

<sup>196 &</sup>lt;u>Evidence</u>, 12 February 2014, 1700 (Dr. Monique Jericho).

Elaine Stevenson, co-administrator, Alyssa Stevenson Eating Disorder Memorial Trust, "Eating Disorders – Girls and Women", *Written Response*, 3 March 2014; *Evidence*, 5 March 2014, 1555 (Lisa LaBorde); *Evidence*, 5 March 2012, 1535 (Carly Lambert-Crawford); *Evidence*, 26 February 2014, 1545 (Josée Champagne); Laura Beattie, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", *Submitted Brief*, 3 March 2014.

be incorporated in the curriculum in medical schools, family practice residency programs and psychiatry residency programs. <sup>198</sup> Dr. Jericho suggested that:

[Health care professionals] need to be taught how to diagnose these conditions and generally how to manage them until people can access comprehensive specialized treatment centres ... they need to be prepared to deliver a diagnosis that the patient may not like or may deny.... They need also some preparation in how to talk to parents and partners about the condition.... 199

As director of the program, Dr. Gail McVey spoke of the Ontario Community Outreach Program for Eating Disorders, established in 1993, which receives its funding support from the Ontario Ministry of Health and Long-Term Care. She described this provincial training program:

[The program] identified champions who, with our support, showed an interest in specializing in the treatment of eating disorders and educating health care practitioners and educators to help out with identification and early intervention, where possible.... [As part of this program,] we [also] developed a first-of-its-kind provincial network of specialized eating disorder service providers.<sup>200</sup>

The program provides training on evidence-based care to these health care practitioners and educators, and incorporates the newest information about current practices in treatment and prevention.<sup>201</sup> Dr. McVey indicated that the program was very successful and recommended that it be "replicated in other provinces across Canada."<sup>202</sup> Other witnesses also spoke highly of OCOPED, and suggested implementing the same model elsewhere.<sup>203</sup>

#### **Recommendation 11**

The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to improve understanding of eating disorders in the health care field. One current model is the Ontario Community Outreach Program for Eating Disorders which delivers education and other supports to health care professionals and encourages and empowers health care professionals to treat people with eating disorders.

202 Ibid., 1625.

Evidence, 28 November 2013, 1555 (Dr. Blake Woodside); Evidence, 10 February 2014, 1645 (Wendy Preskow); Evidence, 10 February 2014, 1615 (Dr. Leora Pinhas); Laura Beattie, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", Submitted Brief, 3 March 2014; Evidence, 5 February 2014, 1640 (Dr. April S. Elliott); Evidence, 24 February 2014, 1550 (Elizabeth Phoenix).

<sup>199</sup> *Evidence*, 12 February 2014, 1635 (Dr. Monique Jericho).

<sup>200 &</sup>lt;u>Evidence</u>, 10 February 2014, 1545 (Dr. Gail McVey).

<sup>201</sup> Ibid.

<sup>203</sup> Evidence, 24 February 2014, 1645 (Dr. Wendy Spettigue).

The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to recognize that there exists in Canadian society, and within the medical community, a lack of understanding and a stigmatization of eating disorders.

#### E. Financial Roadblocks

There was broad consensus among witnesses that living with an eating disorder results in a significant financial burden for the individual, a partner, and family members. The Committee was told that private therapy ranges from \$80 to \$250 an hour, depending on the city and province, and individuals with an eating disorder can require multiple sessions each week. Individuals need a multidisciplinary team to assist in their recovery, which can include, but is not limited to, general practitioners, psychiatrists, psychologists, dietitians, and therapists. Witnesses suggested that the costs of this team are prohibitively expensive if an individual is required to pay for it with no assistance. While Sheena's Place provides free services and support, the centre's Executive Director Joanna Anderson explained the financial pressure:

Of the minority of [Sheena's Place] clients who are currently receiving other [eating disorder] services, 82% are paying for private sector individual therapy.... A young woman in Ontario has recently turned to crowd-funding \$60,000 to pay for life-saving treatment for her eating disorder.<sup>207</sup>

In addition, witnesses said that many mental health services, including those specific to eating disorders, are not funded by provincial health insurance plans and private insurance plans frequently provide insufficient funds for meaningful service. The Committee heard recommendations outside the scope of the federal government jurisdiction that private and provincial health care coverage be expanded to include greater and timely coverage for individuals with eating disorders when treatment is not available in Canada. 209

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014; *Evidence*, 5 March 2014, 1600 (Carly Lambert-Crawford).

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014; <u>Evidence</u>, 12 February 2014, 1545 (Joanna Anderson); <u>Evidence</u>, 5 March 2014, 1600 (Carly Lambert-Crawford).

<sup>206</sup> Evidence, 26 February 2014, 1535 (Arthur Boese); Evidence, 12 February 2014, 1615 (Joanna Anderson).

<sup>207 &</sup>lt;u>Evidence</u>, 12 February 2014, 1545 (Joanna Anderson).

<sup>208 &</sup>lt;u>Evidence</u>, 24 February 2014, 1545 (Dr. Lisa Votta-Bleeker); <u>Evidence</u>, 5 February 2014, 1530 (Merryl Bear); <u>Evidence</u>, 10 February 2014, 1650 (Wendy Preskow); Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, <u>Submitted Brief</u>, 4 March 2014.

<sup>209 &</sup>lt;u>Evidence</u>, 10 February 2014, 1640 (Wendy Preskow); <u>Evidence</u>, 5 March 2014, 1535 (Carly Lambert-Crawford).

The Committee was told that because of the debilitating nature of eating disorders, many individuals with eating disorders will at some point in their lives rely on disability or employment insurance for income.<sup>210</sup> One resource centre noted that only 44% of its clients are able to financially support themselves.<sup>211</sup> For other individuals, seeking treatment is not an option as they cannot afford the financial cost of leaving their jobs.<sup>212</sup>

In addition, witnesses informed the Committee that the shortage of publicly funded care and the long waiting lists leads many individuals to turn to expensive private treatment options, which they cannot afford. Patricia Lemoine, speaking of her personal experience with an eating disorder, stated "not only was [the eating disorder] ruining my life, but this was also ruining my finances."

Witnesses spoke of the great financial burden placed on families who are caring for someone, often children – young or grown up – with an eating disorder. Many parents will sacrifice their financial stability to pay for private treatment for their children; they will take out lines of credit, mortgage their houses, and sometimes end up bankrupt. In some cases, parents take leave without pay to regularly attend medical appointments or care for their children at home. Parents of adult children who rely on provincial disability benefits must often cover additional living expenses. Witnesses recommended providing greater financial support to parents of children with eating disorders. Two witnesses, in a written response, explained 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.

210 <u>Evidence</u>, 12 February 2014, 1540 (Joanna Anderson); <u>Evidence</u>, 10 February 2014, 1650 (Wendy Preskow); <u>Evidence</u>, 5 February 2014, 1650 (Dr. Debra Katzman).

213 <u>Evidence</u>, 12 February 2014, 1545 (Joanna Anderson); <u>Evidence</u>, 5 February 2014, 1530 (Merryl Bear); <u>Evidence</u>, 5 March 2014, 1600 (Carly Lambert-Crawford); Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, <u>Submitted Brief</u>, 4 March 2014; <u>Evidence</u>, 3 March 2014, 1700 (Patricia Lemoine).

214 <u>Evidence</u>, 3 March 2014, 1700 (Patricia Lemoine).

215 <u>Evidence</u>, 5 February 2014, 1600 (Merryl Bear); <u>Evidence</u>, 10 February 2014, 1640 (Wendy Preskow); <u>Evidence</u>, 5 March 2014, 1605 (Lisa LaBorde).

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014; *Evidence*, 5 March 2014, 1555 (Carly Lambert-Crawford).

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations," Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014.

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations," Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014; Laura Beattie, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", *Submitted Brief*, 3 March 2014.

Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014.

<sup>211 &</sup>lt;u>Evidence</u>, 12 February 2014, 1540 (Joanna Anderson).

<sup>212</sup> Ibid., 1600.

#### F. Concurrent Disorders

The Committee learned that the majority of individuals who have eating disorders also have a concurrent disorder, such as anxiety, depression, trauma-related disorders, obsessive compulsive disorder or a substance-abuse issue. Witnesses indicated that approximately 80% of individuals with eating disorders have one or more concurrent conditions.

A number of witnesses explained that having an eating disorder and a concurrent disorder creates additional challenges in terms of being diagnosed, being treated, and receiving other forms of support. The Committee was told that individuals with eating disorders who have concurrent disorders are passed between service providers who do not treat both conditions. They explained that most eating disorder treatment programs do not address concurrent conditions, despite the connection between the two health issues, and that many mental health programs refuse to accept, or are not equipped for, patients who also have an eating disorder.<sup>222</sup> Merryl Bear, Director of NEDIC, explained:

The biggest challenge is that very few treatment facilities will actually work with both of the concurrent issues... It's a revolving door where individuals who are ready for help actually find it exceptionally difficult to get in a door where they are going to be accepted as they are, as whole human beings with multiple difficulties.<sup>223</sup>

Carly Lambert-Crawford, a therapist speaking from past experience and from the experience of her clients, elaborated:

[Y]ou have to meet the specific criteria of whatever the program is. I was told that I was too sick for certain programs. Some of my clients who maybe are struggling with any sort of substance abuse or alcoholism, they are no longer eligible for these programs. A lot of programs don't treat binge eating disorder. There is a lot of criteria that you have to meet to be able to access the treatment that we have right now. That is really challenging.<sup>224</sup>

Many individuals with eating disorders are not capable of navigating this complex system of health care services divided into silos.<sup>225</sup> Wendy Preskow, founder and chief

 <sup>&</sup>lt;u>Evidence</u>, 24 February 2014, 1535 (Dr. Wendy Spettigue); <u>Evidence</u>, 12 February 2014, 1540 (Joanna Anderson); <u>Evidence</u>, 10 February 2014, 1545 (Dr. Gail McVey); <u>Evidence</u>, 5 February 2014, 1650 (Dr. Debra Katzman); <u>Evidence</u>, 12 February 2014, 1635 (Dr. Monique Jericho).

<sup>221 &</sup>lt;u>Evidence</u>, 12 February 2014, 1540 (Joanna Anderson); <u>Evidence</u>, 5 February 2014, 1650 (Dr. Debra Katzman).

Wendy Preskow, "Testimony, Additional recommendations and answers", National Initiative for Eating Disorders, *Written Response*, 5 March 2014; *Evidence*, 3 March 2014, 1610 (Elaine Stevenson); Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014; *Evidence*, 5 March 2014, 1555 (Carly Lambert-Crawford); *Evidence*, 5 February 2014, 1620 (Merryl Bear).

<sup>223</sup> *Evidence*, 5 February 2014, 1620 (Merryl Bear).

<sup>224 &</sup>lt;u>Evidence</u>, 5 March 2012, 1555 (Carly Lambert-Crawford).

<sup>225</sup> Evidence, 10 February 2014, 1640 (Wendy Preskow).

advocate of NIED, explained the difficulty that her 28-year-old daughter, who has an eating disorder, experienced:

There is no system in place to help our child... She is so paralyzed with anxiety and depression, and still expected to navigate the so-called system for help because of her age. <sup>226</sup>

Witnesses said that without coping strategies for concurrent problems, individuals do not feel in control and cannot focus on developing normal eating patterns. Ms. Preskow said she sought help for her daughter's anxiety, but that:

[B]ecause [my daughter] has an eating disorder she cannot be part of the Anxiety Clinic... [she] needs to go to an eating disorder treatment program first. But it's all wrapped up together. The anxiety fuels the eating disorder which fuels the anxiety. We believe if she could get strategies to control her anxiety, the eating disorder would be more controlled. 228

Some witnesses recommended that treatment programs consist of teams who can deal with the eating disorder, as well as the concurrent disorder. It was also suggested that there be greater cooperation between the health care professionals dealing with eating disorders, mental health problems and addictions. <sup>230</sup>

#### **Recommendation 13**

The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to encourage multidisciplinary care teams, which might include dieticians, psychiatrists, psychologists, and other necessary therapists, to ensure quality treatment, including for concurrent conditions.

<sup>226</sup> Ibid.

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014; Wendy Preskow, "Testimony, Additional recommendations and answers", National Initiative for Eating Disorders, *Written Response*, 5 March 2014.

Wendy Preskow, "Testimony, Additional recommendations and answers", National Initiative for Eating Disorders, *Written Response*, 5 March 2014.

<sup>229 &</sup>lt;u>Evidence</u>, 3 March 2014, 1650 (Elaine Stevenson); Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, Submitted Brief, 4 March 2014.

<sup>230</sup> *Evidence*, 10 February 2014, 1545 (Dr. Gail McVey).

#### G. Producing Research and Tracking Information

The Committee heard that there is a very active and dedicated group of Canadian researchers working on the subject of eating disorders, but that those researchers encounter serious challenges in developing and sharing research.<sup>231</sup> Members were informed that it is difficult to build specialized research in the field of eating disorders.<sup>232</sup>

Witnesses underlined the need for a nationally funded research strategy or agenda on eating disorders.<sup>233</sup> Dr. Blake Woodside of Toronto General Hospital suggested that the federal government examine the priorities and policies of the CIHI and of the Institute of Neurosciences, Mental Health and Addiction at the CIHR, with the goal of developing a national plan for research into novel treatments for eating disorders.<sup>234</sup>

Many witnesses highlighted the lack of dedicated funding available for research on the subject of eating disorders; they recommended increasing such funding. Other witnesses suggested that there is an uneven distribution of research funding in the health care field, with health conditions that are less or equally prevalent as eating disorders receiving much greater research funding. Dr. Woodside stated, "It is simply impossible in this country to do meaningful research on illnesses like anorexia or bulimia, given the amount of research money that's available."

According to some researchers, they face challenges in their work because of a lack of time, funds and resources, which limits their ability to share and collaborate with colleagues; this collaboration would serve to move the field forward. Dr. Monique Jericho, psychiatrist and Medical Director of the Calgary Eating Disorder Program, explained that these researchers end up "doing great things in pockets," rather than working in partnership. The Committee was told that collaboration with hospitals, general practitioners, psychiatrists, psychologists and counsellors would also benefit research in the field of eating disorders. A number of witnesses recommended the

<sup>231</sup> *Evidence*, 24 February 2014, 1645 (Dr. Giorgio A. Tasca).

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014.

<sup>233 &</sup>lt;u>Evidence</u>, 12 February 2014, 1545 (Joanna Anderson); <u>Evidence</u>, 24 February 2014, 1600 (Elizabeth Phoenix); <u>Evidence</u>, 28 November 2013, 1540 (Dr. Blake Woodside); <u>Evidence</u>, 5 February 2014, 1715 (Dr. April S. Elliott); <u>Evidence</u>, 5 February 2014, 1720 (Dr. Debra Katzman).

<sup>234</sup> Evidence, 28 November 2013, 1540 (Dr. Blake Woodside).

<sup>235 &</sup>lt;u>Evidence</u>, 12 February 2014, 1605 (Joanna Anderson); <u>Evidence</u>, 5 February 2014, 1720 (Dr. Debra Katzman); Elaine Stevenson, "Eating Disorders – Girls and Women", *Written Response*, 3 March 2014; <u>Evidence</u>, 24 February 2014, 1650 (Dr. Giorgio A. Tasca).

<sup>236</sup> *Evidence*, 10 February 2014, 1530 (Dr. Leora Pinhas).

<sup>237</sup> Evidence, 28 November 2013, 1535 (Dr. Blake Woodside).

<sup>238 &</sup>lt;u>Evidence</u>, 10 February 2014, 1545 (Dr. Gail McVey); <u>Evidence</u>, 12 February 2014, 1640 (Dr. Monique Jericho).

<sup>239</sup> Evidence, 12 February 2014, 1720 (Dr. Monigue Jericho).

<sup>240</sup> Elaine Stevenson, "Eating Disorders – Girls and Women", Written Response, 3 March 2014.

development of a centre of excellence or a national clearinghouse to promote collaboration.<sup>241</sup>

Researchers informed the Committee that another roadblock in their research programs is the limited data on several aspects of eating disorders in Canada. The Committee heard that this situation can be attributed, in part, to the lack of an established system to track such information; witnesses indicated a possible solution would be to develop a national registry, which could serve as a centralized database to track statistics related to eating disorders. Elizabeth Phoenix, a nurse practitioner with CFMHN, suggested tracking:

[T]he incidence and prevalence of eating disorders, the wait times for assessments and treatment, and the outcomes from the branches of services provided. It should also track dropouts from treatment and the state of wellness achieved by those who receive treatment.<sup>244</sup>

Witnesses also recommended that there be a method established (for example in coroners' reports) to properly record eating disorders as a "cause of death"; often cause of death is listed as another condition, such as heart failure or suicide, while the eating disorder is listed under the contributing cause of death (or sometimes not listed at all). However, properly recording "eating disorders" as a cause of death would help to understand the severity of the disease. <sup>245</sup>

The Committee was told that there are huge gaps in the field of eating disorder research in Canada, and as a result, practitioners are provided little information on evidence-based prevention, diagnosis and treatment.<sup>246</sup> As one witness said in response to a Committee member's question: "That's a very difficult [question], because I don't have

<sup>241 &</sup>lt;u>Evidence</u>, 24 February 2014, 1635 (Dr. Wendy Spettigue); <u>Evidence</u>, 12 February 2014, 1615 (Joanna Anderson); <u>Evidence</u>, 24 February 2014, 1600 (Elizabeth Phoenix).

Evidence, 5 February 2014, 1625 (Merryl Bear); Evidence, 10 December 2013, 1620 (Marla Israel); Evidence, 24 February 2014, 1700 (Elizabeth Phoenix); Evidence, 12 February 2014, 1610 (Joanna Anderson); Hasan Hutchinson, "Follow up to Standing Committee on the Status of Women", Written Response, 21 March 2014; Evidence, 10 December 2013, 1635 (Dr. Joy Johnson); Evidence, 10 February 2014, 1610 (Dr. Leora Pinhas).

<sup>243 &</sup>lt;u>Evidence</u>, 10 February 2014, 1535 (Dr. Leora Pinhas); <u>Evidence</u>, 24 February 2014, 1635 (Dr. Wendy Spettigue); <u>Evidence</u>, 12 February 2014, 1545 (Joanna Anderson); <u>Evidence</u>, 24 February 2014, 1555 (Elizabeth Phoenix); <u>Evidence</u>, 26 February 2014, 1640 (Jadine Cairns); Dr. Gail McVey, Ph.D., C.Psych., Community Health Systems Resource Group, Ontario Community Outreach Program for Eating Disorders, The Hospital for Sick Children of Toronto, "National Prevention Strategy Group: Linking eating disorders and obesity", The Hospital for Sick Children of Toronto, *Written Response*, 20 February 2014.

<sup>244</sup> *Evidence*, 24 February 2014, 1555 (Elizabeth Phoenix).

Wendy Preskow, "Testimony, Additional recommendations and answers", National Initiative for Eating Disorders, *Written Response*, 5 March 2014; Dr. Gail McVey, "National Prevention Strategy Group: Linking eating disorders and obesity", The Hospital for Sick Children of Toronto, *Written Response*, 20 February 2014.

<sup>246 &</sup>lt;u>Evidence</u>, 24 February 2014, 1705 (Dr. Wendy Spettigue); <u>Evidence</u>, 10 February 2014, 1550 (Dr. Leora Pinhas).

enough research to answer. ... I might have some opinions, but I don't have facts." Witnesses suggested establishing a National Research Chair on the subject of eating disorders who could be a champion in the field of research. According to psychiatrist Dr. Wendy Spettigue, of CACAP, this Chair could oversee a national registry and track the gaps in research in this field. Laura Beattie, Co-chair of F.E.A.S.T. Canada Task Force, suggested that Canada join other countries in participating in global research studies on eating disorders, such as the ANGI-Anorexia Nervosa Initiative, which is "a global effort to detect genetic variation that contributes to [anorexia]."

#### **Recommendation 14**

The Committee recommends that the Government of Canada should consider putting in place a centre of excellence or a national research chair in eating disorders, and increasing funding available for eating disorders research.

#### Recommendation 15

The Committee recommends that the Government of Canada should work with the provinces, territories and stakeholders to ensure that all jurisdictions send eating disorder data to the Canadian Institute for Health Information. Data coverage is estimated at 59% of overall visits across eight jurisdictions.

#### **Recommendation 16**

The Committee recommends that the Government of Canada should work with the provinces, territories and stakeholders to ensure that data on activities in primary care and community-based clinics is collected and sent to the Canadian Institute for Health Information.

#### H. Marginalized Populations

The Committee heard that access to information, diagnosis and treatment is very difficult for the majority of Canadians with eating disorders; and it is particularly challenging for certain marginalized populations. As an example, for individuals with eating disorders who live in remote and rural communities throughout Canada, support services and

<sup>247 &</sup>lt;u>Evidence</u>, 24 February 2014, 1620 (Dr. Wendy Spettigue).

<sup>248 &</sup>lt;u>Evidence</u>, 24 February 2014, 1635 (Dr. Wendy Spettigue); <u>Evidence</u>, 24 February 2014, 1600 (Elizabeth Phoenix); <u>Evidence</u>, 10 February 2014, 1545 (Dr. Gail McVey); <u>Evidence</u>, 26 February 2014, 1640 (Jadine Cairns).

<sup>249 &</sup>lt;u>Evidence</u>, 24 February 2014, 1635 (Dr. Wendy Spettigue).

Laura Beattie, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", Submitted Brief, 3 March 2014.

treatment centres are largely non-existent.<sup>251</sup> It was noted that simply moving individuals to treatment centres in urban areas is not an ideal solution, as this removes the individual from support networks and from familiar environments, thus reinforcing isolation.<sup>252</sup>

Dr. Blake Woodside of Toronto General Hospital recommended establishing "micro-agencies" with two or three employees who would receive training on eating disorder treatment, such as cognitive behavioural therapy, and who would be available in remote or rural communities.<sup>253</sup>

Among ethnic and visible minority communities, a central challenge to the treatment of eating disorders is countering the stereotypical idea that these disorders affect only Caucasian populations. Individuals in these communities may not recognize that they could have an eating disorder; they may feel their condition is less legitimate; or they may not know how to access the health care services. As well, doctors may dismiss eating disorder symptoms because the individual does not fit the stereotypical image of a patient with an eating disorder. Dr. Carla Rice, Canada Research Chair in Care, Gender and Relationships, explained that there tends to be "a singular representation of who is the woman who develops an eating disorder. In Canada's multiracial and multicultural society I think that image no longer fits the reality of who is actually developing eating problems in this country." Problems in the country."

In addition, while there is significant stigma attached to seeking help for eating disorders, this stigma can be reinforced in some families with cultural norms about family privacy and honour.<sup>257</sup> A final challenge for these communities is that there is little targeted research or culturally specific treatment for individuals of specific ethnic and visible minorities.<sup>258</sup>

Lisa LaBorde, parent of a child with an eating disorder, recommended direct collaboration with minority communities in order to address specific concerns related to

257 <u>Evidence</u>, 12 February 2014, 1650 (Andrea LaMarre).

<sup>251 &</sup>lt;u>Evidence</u>, 5 February 2014, 1530 (Merryl Bear); <u>Evidence</u>, 10 December 2013, 1645 (Dr. Joy Johnson); <u>Evidence</u>, 26 February 2014, 1540 (Josée Champagne); <u>Evidence</u>, 28 November 2013, 1615 (Dr. Blake Woodside).

Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014; *Evidence*, 3 March 2014, 1605 (Elaine Stevenson).

<sup>253</sup> Evidence, 28 November 2013, 1615 (Dr. Blake Woodside).

<sup>254 &</sup>lt;u>Evidence</u>, 12 February 2014, 1710 (Andrea LaMarre, MSc Candidate, Department of Family Relations & Applied Nutrition, University of Guelph).

<sup>255</sup> *Evidence*, 12 February 2014, 1645 (Dr. Carla Rice).

<sup>256</sup> Ibid., 1710.

<sup>258 &</sup>lt;u>Evidence</u>, 5 February 2014, 1550 (Merryl Bear); <u>Evidence</u>, 10 February 2014, 1635 (Jarrah Hodge).

mental health, and eating disorders in particular.<sup>259</sup> It was also suggested that awareness campaigns target these communities.<sup>260</sup>

Individuals who identify as a sexual or gender minority may also face unique struggles; their sexual identity may create different challenges than the rest of the population in recognizing, diagnosing and treating an eating disorder.<sup>261</sup>

The Committee heard that many marginalized populations face the same challenge:

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. <sup>262</sup>

#### **Recommendation 17**

The Committee recommends that the Government of Canada should work with the provinces, territories and stakeholders to ensure access to information, diagnosis, and treatment for Canadians living with eating disorders, and particularly for remote and rural communities, and marginalized populations.

#### CHALLENGES IN ACCESSING TREATMENT

The Committee heard about a very broad range of issues that act as barriers to treatment for individuals with eating disorders. Because of the severity of the illness and because of the benefit of early and appropriate intervention, witnesses stressed the importance of addressing these issues.<sup>263</sup>

#### A. Inadequate Training for Health Care Providers

One of the first (and often the most significant) impediments to accessing treatment is obtaining a diagnosis. In order to obtain a diagnosis, individuals exhibiting eating disorder symptoms must rely on their health care providers, <sup>264</sup> and, as the Committee

<sup>259</sup> *Evidence*, 5 February 2014, 1550 (Merryl Bear).

<sup>260 &</sup>lt;u>Evidence</u>, 5 March 2014, 1600 (Lisa LaBorde).

<sup>261</sup> Evidence, 10 February 2014, 1635 (Jarrah Hodge).

Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", *Written Response*, 10 March 2014.

<sup>263 &</sup>lt;u>Evidence</u>, 12 February 2014, 1640 (Dr. Monique Jericho).

Noelle Martin, "Additional Notes", Written Responses, 3 March 2014.

heard, health care providers are often inadequately trained to diagnose eating disorders.<sup>265</sup> For example, physicians and other health care providers:

- may not be screening for eating disorders in patients who are not underweight;<sup>266</sup>
- may not refer patients whose blood work appears normal;<sup>267</sup>
- may attribute eating disorder symptoms to other patient characteristics, such as low heart rate or athleticism: 268
- may not be aware of diagnostic tests that should be ordered for some eating disorder patients, such as bone density tests:<sup>269</sup> and
- may refuse to treat patients with eating disorders because of the complexity of their illness and the therapy time the patient and their family may need.<sup>270</sup>

Several witnesses also told the Committee that there is a lack of specialists trained to treat eating disorders.<sup>271</sup>

#### **B. Lack of Treatment Programs**

One of the most common concerns that witnesses raised with respect to treatment is the insufficient number of programs and the uneven distribution of programs across the

271

Evidence, 24 February 2014, 1535 (Dr. Wendy Spettigue); Evidence, 12 February 2014, 1635 (Dr. Monique Jericho); Evidence, 10 February 2014, 1610 (Dr. Gail McVey); Evidence, 28 November 2013, 1535 (Dr. Blake Woodside).

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community 265 Outreach Program for Eating Disorders, Submitted Brief, 4 March 2014; Noelle Martin, "Additional Notes", Written Responses, 3 March 2014; Evidence, 10 December 2013, 1655 (Dr. Joy Johnson); Evidence, 24 February 2014, 1625 (Dr. Wendy Spettigue); Evidence, 24 February 2014, 1550 (Elizabeth Phoenix); Evidence, 12 February 2014, 1650 (Dr. Carla Rice).

<sup>266</sup> Noelle Martin, "Additional Notes", Written Responses, 3 March 2014; Evidence, 24 February 2014, 1550 (Elizabeth Phoenix); Evidence, 5 February 2014, 1635 (Dr. April S. Elliott); Evidence, 26 February 2014, 1545 (Josée Champagne).

<sup>267</sup> Evidence, 24 February 2014, 1550 (Elizabeth Phoenix); Evidence, 24 February 2014, 1535 (Dr. Wendy Spettigue).

<sup>268</sup> Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, Submitted Brief, 4 March 2014; Evidence, 24 February 2014, 1535 (Dr. Wendy Spettigue); Evidence, 5 March 2014, 1530 (Carly Lambert-Crawford).

Wendy Preskow, "Testimony, Additional recommendations and answers", National Initiative for Eating 269 Disorders, Written Response, 5 March 2014.

<sup>270</sup> Evidence, 24 February 2014, 1540 (Dr. Wendy Spettigue).

country.<sup>272</sup> In fact, some witnesses said that patients sometimes have to be sent to the United States for treatment because the services they need are unavailable in Canada. Treatment in the United States, they noted, is significantly more expensive.<sup>273</sup>

Wendy Preskow, founder and chief advocate of NIED, shared the words of her daughter, who is living with an eating disorder:

You are changing the [eating disorder] world in Canada, and perhaps the only reason I ever existed was for you to create colossal change, but what about me now? It will be years before any such dream treatment facility will be brought to fruition in Canada.... They can check on my weight, and send me back into this world, and then I'm right back where I started as a little girl, scared of life and equally scared of death, scared of the unknown, and aging, and loss, and abandonment.<sup>274</sup>

#### **Recommendation 18**

The Committee recommends that the Government of Canada encourage provincial and territorial governments, due to the life-threatening nature of eating disorders and a shortage of treatment beds, to provide either in-patient care as needed for patients with eating disorders on a timely basis or to consider covering the cost of treatments available outside the province, including in the United States, with the goal that patients can access the critical care they need in a timely fashion.

Witnesses also expressed concern about the gap in services for individuals who are not "sick enough" to meet criteria for certain treatment programs, but who are nonetheless suffering.<sup>275</sup> Elaine Stevenson, whose daughter died of anorexia nervosa, has been involved in advocacy on behalf of people with eating disorders for many years. She remarked, "[t]o me, there is something inherently wrong with a public health care system that often only becomes available when someone is on death's door."

Evidence, 24 February 2014, 1625 (Dr. Wendy Spettigue); Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, Submitted Brief, 4 March 2014; Evidence, 10 December 2013, 1655 (Dr. Joy Johnson); Evidence, 5 February 2014, 1640 (Dr. April S. Elliott); Evidence, 10 February 2014, 1535 (Dr. Leora Pinhas); Evidence, 10 February 2014, 1615 (Dr. Gail McVey); Evidence, 26 February 2014, 1540 (Josée Champagne); Evidence, 26 February 2014, 1555 (Jadine Cairns).

<sup>273 &</sup>lt;u>Evidence</u>, 28 November 2013, 1535 (Dr. Blake Woodside); <u>Evidence</u>, 10 February 2014, 1615 (Dr. Gail McVey).

<sup>274 &</sup>lt;u>Evidence</u>, 10 February 2014, 1640 (Wendy Preskow).

Evidence, 5 February 2014, 1640 (Dr. April S. Elliott); Evidence, 5 March 2014, 1545 (Lisa LaBorde); Noelle Martin, "Additional Notes", Written Responses, 3 March 2014; Evidence, 24 February 2014, 1620 (Dr. Wendy Spettigue); Evidence, 24 February 2014, 1710 (Elizabeth Phoenix); Evidence, 10 February 2014, 1630 (Jarrah Hodge).

<sup>276</sup> Evidence, 3 March 2014, 1605 (Elaine Stevenson).

This gap in service for individuals with mild and moderate cases of eating disorders is particularly problematic because research indicates that early intervention leads to the best treatment outcomes.<sup>277</sup> Further, treating only the most severe cases places an undue burden on hospitals, when community treatment programs can be very effective for many patients.<sup>278</sup> Dr. Wendy Spettigue, psychiatrist with CACAP, told the Committee that in her work at the Children's Hospital of Eastern Ontario, the program received funding for "an in-patient program and a day treatment program," but received no funding "for an outpatient program" and "outpatient therapists" despite the recommended treatment being "outpatient family therapy." She spoke of the struggle for her program: "if we just treated patients in hospital who were medically unstable and we discharged them, they wouldn't get better" because "there are no community resources" to assist once they are released.<sup>279</sup> She elaborated: "if we're only treating the most severely ill patients, then who's going to treat all the others?"<sup>280</sup>

Andrea LaMarre, M.Sc. candidate at the University of Guelph, noted that in addition to a lack of programs, there is a lack of data about what programs are available.<sup>281</sup> Such data, if compiled and centralized, could help provide a more accurate picture of what services are currently available, and if they were publicly accessible, might assist people with eating disorders and their parents to find services.<sup>282</sup>

#### C. Inappropriate Treatment Programs

As discussed above, many witnesses noted that there need to be programs available to individuals with eating disorders of varying levels of severity. Witnesses also noted that treatment programs for patients with severe eating disorders should be geared to a specific population. For instance, Dr. Leora Pinhas, psychiatrist at the Hospital for Sick Children, described children as young as 6 who are admitted to in-patient treatment units along with 17-year-olds.<sup>283</sup> Dr. Carla Rice, Canada Research Chair in Care, Gender and Relationships, and M.Sc. candidate Andrea LaMarre argued that hospital care "should not be considered as the first course of action or the only appropriate response to eating disorders" because some patients might do better in other treatment settings. 284

Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community 277 Outreach Program for Eating Disorders, Submitted Brief, 4 March 2014; Evidence, 12 February 2014, 1540 (Joanna Anderson).

Evidence, 24 February 2014, 1605 (Dr. Wendy Spettique); Evidence, 12 February 2014, 1620 278 (Joanna Anderson).

<sup>279</sup> Evidence, 24 February 2014, 1605 (Dr. Wendy Spettigue)

<sup>280</sup> Ibid., 1630.

<sup>281</sup> Evidence, 12 February 2014, 1645 (Andrea LaMarre).

Evidence, 12 February 2014, 1645 (Andrea LaMarre); Evidence, 12 February 2014, 1545 282 (Joanna Anderson).

<sup>283</sup> Evidence, 10 February 2014, 1550 (Dr. Leora Pinhas).

<sup>284</sup> Dr. Carla Rice and Andrea LaMarre, "Follow Up Testimony on Eating Disorder Treatment and Prevention in Canada", Written Response, 10 March 2014.

For example, the Committee was informed that most patients with somatic disorders have a variety of treatment options to choose from, but for patients with eating disorders, there is often only one treatment available in their region, and if they do not respond to that form of treatment, they have no other options.<sup>285</sup>

#### D. Wait Times

Many witnesses addressed the protracted waiting periods for treatment that patients with eating disorders and their families face. Individuals can wait months between an appointment with their family doctor and a referral to a specialist, months for the results of an assessment, and again months for admission to a hospital program. Dr. Wendy Spettigue, psychiatrist with CACAP, explained that long wait times can have serious implications not only for individuals, but also for the viability of treatment programs:

For 14 years I served as the psychiatric director of the program at CHEO. Two years ago we were faced with a one-year waiting list, which is completely unacceptable, given the severe medical and psychological complications of eating disorders in young people. Out of desperation, given that you can't have a one-year waiting list for such sick kids, we just decided to close the program and all those one-year referrals on the waiting list were all sent back to their poor family doctors. We went through what's called a "lean review" to try to figure out what we were going to cut in order to be more efficient. We're not going to take mild or moderate referrals to our program anymore even though there's nobody out in the community who will do it. Even though it takes two years for these kids to recover, we're only going to offer them nine months of therapy.<sup>287</sup>

#### **Recommendation 19**

The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to reduce lengthy wait times for admission to eating disorder programs across the country.

#### E. Insufficient Research

Elizabeth Phoenix, a nurse practitioner with CFMHN, noted that the effective treatment of eating disorders depends on high-quality research. Such research can inform not only specific treatments, but also program development. On a related matter, Dr. Monique Jericho, psychiatrist and Medical Director of the Calgary Eating Disorder Program, remarked that there are few guidelines and no standards for drug treatment of eating disorders. She said that clinicians might try to treat some of their patients'

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Evidence, 10 February 2014, 1550 (Dr. Leora Pinhas).
Evidence, 10 February 2014, 1650 (Wendy Preskow).
Evidence, 24 February 2014, 1625 (Dr. Wendy Spettigue).
Evidence, 24 February 2014, 1550 (Elizabeth Phoenix).
Ibid.
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<sup>290</sup> Evidence, 12 February 2014, 1700 (Dr. Monique Jericho).

comorbid conditions such as depression and anxiety with medication, but that research is needed to determine if these treatments are effective or necessary.<sup>291</sup> Witnesses recommended conducting research with the goal of developing evidence-based national standards for appropriate clinical care.<sup>292</sup>

#### F. Additional Observations

Some witnesses raised additional challenges that present significant impediments to treatment. For instance, some witnesses argued that using weight as an admission criterion for treatment programs might exacerbate patients' obsessive thoughts about weight.<sup>293</sup> Other witnesses explained that the very nature of eating disorders makes it difficult for individuals to seek treatment. Witnesses described the great ambivalence that some people with eating disorders feel about treatment;<sup>294</sup> while some may recognize that they need help, they may resist seeking treatment because their disorder makes them want to continue their disordered eating. Noelle Martin, a professor and dietitian who survived an eating disorder, explained as follows:

For a client with an eating disorder, this choice is hard. It is difficult to realize that the disease is killing them, because at first it gives them such a sense of control. The loss of control that follows can give them a sense of despair, leaving them unsure about where to turn or what they can do. <sup>295</sup>

#### **Recommendation 20**

The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to overcome the challenges in accessing treatment, including a lack of a centralized database of treatment programs, undertrained health care providers, an insufficient number of programs, and uneven distribution of programs across the country, long wait times for treatment, inappropriate treatment programs, and a lack of pan-Canadian, evidence-based treatment standards.

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<sup>291</sup> Ibid.

<sup>292 &</sup>lt;u>Evidence</u>, 28 November 2013, 1540 (Dr. Blake Woodside); Laura Beattie, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", *Submitted Brief*, 3 March 2014.

<sup>293 &</sup>lt;u>Evidence</u>, 10 February 2014, 1630 (Jarrah Hodge); Noelle Martin, "Additional Notes," *Written Responses*, 3 March 2014.

<sup>294 &</sup>lt;u>Evidence</u>, 24 February 2014, 1545 (Dr. Lisa Votta-Bleeker); Dr. Gail McVey, "Existing gaps in eating disorder services and recommendations", Ontario Community Outreach Program for Eating Disorders, *Submitted Brief*, 4 March 2014; <u>Evidence</u>, 5 February 2014, 1640 (Dr. April S. Elliott).

<sup>295</sup> Evidence, 12 February 2014, 1535 (Noelle Martin).

The Committee recommends that the Government of Canada consider developing consistent standards on clinical care treatment and wait times for people with eating disorders.

#### G. Suggested Approaches in Treatment

Witnesses suggested solutions for many of the challenges that people living with eating disorders face in accessing treatment. Below are some examples:

- ensure that health care providers are well trained on how to recognize symptoms of eating disorders and how to refer or treat patients, as appropriate;<sup>296</sup>
- incorporate sufficient materials on eating disorders in curricula used for training medical, nursing, psychology, psychiatry and other students in health care professions;<sup>297</sup>
- establish national treatment standards for eating disorders;<sup>298</sup> and
- ensure that timely, evidence-based treatment is available to patients across the country.<sup>299</sup>

#### PROMISING TREATMENT PRACTICES

Eating disorders are very complex illnesses and witnesses suggested to the Committee that there is not yet a universally effective treatment for anorexia nervosa, bulimia nervosa or binge eating disorders. However, witnesses outlined some treatments that are showing promise in certain populations. Dr. Giorgio Tasca, Research Chair in Psychotherapy Research, summarized current treatment practices:

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<sup>Evidence, 5 February 2014, 1720 (Dr. Debra Katzman); Evidence, 10 February 2014, 1640 (Wendy Preskow); Evidence, 10 February 2014, 1545 (Dr. Gail McVey); Evidence, 24 February 2014, 1700 (Dr. Wendy Spettigue); Evidence, 24 February 2014, 1550 (Elizabeth Phoenix); Evidence, 12 February 2014, 1635 (Dr. Monique Jericho); Evidence, 5 March 2014, 1540 (Lisa LaBorde); Evidence, 26 February 2014, 1545 (Josée Champagne); Evidence, 5 March 2014, 1535 (Carly Lambert-Crawford).</sup> 

<sup>297 &</sup>lt;u>Evidence</u>, 10 February 2014, 1545 (Dr. Gail McVey); <u>Evidence</u>, 24 February 2014, 1550 (Elizabeth Phoenix); <u>Evidence</u>, 12 February 2014, 1640 and 1725 (Dr. Monique Jericho); <u>Evidence</u>, 5 February 2014, 1640 (Dr. April S. Elliott).

Laura Beattie, "The Study of Eating Disorders in Girls and Women for The Standing Committee on the Status of Women", *Submitted Brief*, 3 March 2014; *Evidence*, 28 November 2013, 1540 (Dr. Blake Woodside).

<sup>299 &</sup>lt;u>Evidence</u>, 10 February 2014, 1605 (Dr. Leora Pinhas); Elaine Stevenson, "Eating Disorders – Girls and Women", Written Response, 3 March 2014; <u>Evidence</u>, 5 February 2014, 1720 (Dr. Debra Katzman); <u>Evidence</u>, 12 February 2014, 1640 (Dr. Monique Jericho).

Psychological interventions have the best evidence base for treating eating disorders. Evidence-based psychological treatments are considered by most international treatment guidelines to be the first line of intervention for most eating disorders. Treatments can be provided on an outpatient basis for less severe cases. However, specialist care is required for more severe individuals in both day treatment and in-patient programs for those who are medically compromised.

Successful treatment of eating disorders depends on a comprehensive plan that includes ongoing monitoring of symptoms and stabilizing nutritional status; psychological interventions that include cognitive behavioural therapy, personal psychotherapy, and family counselling; education and nutrition counselling; and in some cases medications. 300

### A. Cognitive Behavioural Therapy

According to Dr. Blake Woodside, Medical Director for the Program for Eating Disorders at the Toronto General Hospital, cognitive behavioural therapy (or CBT) is the "gold standard" treatment for bulimia nervosa.<sup>301</sup> Witnesses testified that among adults, CBT is a first-line treatment for eating disorders.<sup>302</sup> The goal of CBT is to train patients to understand their thought processes, how their thoughts contribute to disordered eating, and how to change their thought processes in order to change their behaviours.<sup>303</sup> Some witnesses also noted that dialectical behaviour therapy may be used in conjunction with CBT, particularly for people with bulimia nervosa.<sup>304</sup>

The problem that CBT presents for many patients is that it is a complex treatment generally delivered by psychologists, whose services in private practice are not covered by provincial health insurance.<sup>305</sup> This means that unless individuals have private health insurance, they must pay out of pocket, which can be a significant barrier for many people.

Dr. Woodside explained the current theoretical basis for bulimia nervosa and anorexia nervosa treatment:

The binge eating of bulimia nervosa is not food addiction. It's actually a response to starvation in the same way that if you held your breath for a minute or two you would gasp for air because you were starved for oxygen. A certain percentage of the population, about 5%, will respond to hunger with these episodes of binge eating. That makes them different from everybody else.

301 <u>Evidence</u>, 28 November 2013, 1610 (Dr. Blake Woodside).

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<sup>300</sup> Evidence, 24 February 2014, 1540 (Dr. Giorgio A. Tasca).

<sup>302 &</sup>lt;u>Evidence</u>, 5 March 2012, 1550 (Carly Lambert-Crawford); <u>Evidence</u>, 24 February 2014, 1610 (Dr. Giorgio A. Tasca).

<sup>303</sup> *Evidence*, 28 November 2013, 1610 (Dr. Blake Woodside).

<sup>304 &</sup>lt;u>Evidence</u>, 12 February 2014, 1725 (Dr. Monique Jericho); <u>Evidence</u>, 5 February 2014, 1700 (Dr. April S. Elliott); <u>Evidence</u>, 5 March 2012, 1550 (Carly Lambert-Crawford).

<sup>305</sup> Evidence, 28 November 2013, 1605 (Dr. Blake Woodside).

To treat bulimia you have to feed people. In our day hospital we feed them lunch, afternoon snack, and dinner, and teach them strategies to resist urges to binge and to purge because these things get tangled up into stressors and stuff like that. The fundamental treatment is to feed people. You eat your way out of bulimia, oddly enough. People in our day hospital service will stop bingeing in a week or two if they are able to do what we ask them to do.

The treatment for anorexia nervosa is similar in some ways. Although most people with bulimia don't like binge eating, and they'll do whatever they need to do to get rid of it, for anorexia nervosa, the decisional balance is often much more finely balanced, because the illness has advantages to the person as well as disadvantages. The fundamental thing you have to do is help people to eat and gain weight. That's the behavioural change that has to occur first.

Then people have to address the underlying cognitive set, the way people think about weight, shape, food, and eating, which has to happen with bulimia as well. Then people have to deal with their other psychological problems that underlie or are associated with the illness. Depending on what those are, that could be the work of many years. 306

Although CBT has been promising, the Committee heard that there is no "one-size-fits-all" treatment for eating disorders. Dr. Giorgio Tasca, Research Chair in Psychotherapy Research, told the Committee that about half of bulimia nervosa patients "get better through cognitive behavioural therapy" while his estimate for anorexia nervosa patients was 25% to 30%. Dr. Woodside reported that with access to some form of treatment, about 65% to 70% of people with anorexia nervosa and about 70% to 80% of people with bulimia nervosa will eventually recover.

# B. Family-Based Therapy (Maudsley Approach)

Many witnesses told the Committee that the most effective treatment for children and adolescents with eating disorders is family-based therapy (FBT) or the Maudsley Approach, and after the Maudsley Hospital in London, England where the treatment was developed. Jadine Cairns, President of EDAC-ATAC, expressed great excitement about FBT because it "really does stop the progression" of certain eating disorders.

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306 Ibid., 1545.
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<sup>307</sup> *Evidence*, 12 February 2014, 1650 (Andrea LaMarre).

<sup>308</sup> *Evidence*, 24 February 2014, 1610 (Dr. Giorgio A. Tasca).

<sup>309</sup> Evidence, 28 November 2013, 1535 (Dr. Blake Woodside).

Evidence, 5 February 2014, 1700 (Dr. Debra Katzman); Evidence, 5 February 2014, 1720 (Dr. April S. Elliott); Evidence, 12 February 2014, 1725 (Dr. Monique Jericho); Evidence, 5 February 2014, 1625 (Merryl Bear); Evidence, 24 February 2014, 1635 (Dr. Wendy Spettigue); Evidence, 26 February 2014, 1555 (Jadine Cairns); Evidence, 5 March 2012, 1555 (Carly Lambert-Crawford); Evidence, 3 March 2014, 1720 (Laura Beattie).

<sup>311</sup> *Evidence*, 3 March 2014, 1655 (Laura Beattie).

<sup>312</sup> Evidence, 26 February 2014, 1550 (Jadine Cairns).

The treatment appears to be quite effective for many young people, <sup>313</sup> although witnesses cautioned that 25% to 30% of young people do not respond to FBT. <sup>314</sup>

Psychiatrist Dr. Wendy Spettigue, of CACAP, suggested that one advantage of FBT is that it is inexpensive compared to inpatient treatment.<sup>315</sup> Although the cost to hospitals may be significantly lower, parents who have used FBT to help a child through an eating disorder testified that the treatment imposed a high financial burden on them.<sup>316</sup> Despite their enthusiasm for the treatment's effectiveness, parents, including Lisa LaBorde, also discussed an even higher emotional burden:

[Parents] have to be non-negotiable brick walls of love and compassion and strength. It's a different type of parenting and nothing you've done before prepares you for it. It is counter-instinctual, rather than soothe them you have to stay steady with them through tremendous distress. Eventually you get compliance and the weight goes on, and as they get closer to health, you begin to see your child return. It takes constant vigilance. [My daughter] slept in my bed for eight months. I watched every meal go in for months. The learning curve is steep. It's hard on a family. Everybody feels it: siblings, partners, grandparents. It's a very isolating experience for families. There's stigma and shame, and most people simply don't understand. Your world becomes very small... Parents are able to do this, but they need rings of support around them. They cannot do it alone and they should not have to.

Another parent, Laura Beattie, Co-chair of F.E.A.S.T. Canada Task Force, described the re-feeding process, one of the most challenging aspects of FBT:

First, I'd like you to imagine your worst fear. You can probably avoid this fear and the anxiety that it creates. We were exposing our daughter to her worst fear, but she could not avoid food or she would die. Our daughter would cry, scream, spit, hit, punch, scratch, and yell that it was too much food, that her stomach hurt, that she wanted to die. Plates of food were thrown. My daughter would fall into a catatonic state. It was like a scene from *The Exorcist*. Meals could take hours, but food is medicine. We learned to separate the eating disorder from our daughter. Intuitively, you do not want to see your child upset and in pain, but when we're refeeding, there is no choice. There is no rationalizing with an eating disorder. This was not forced feeding, and it was not punitive. It was a requirement, using whatever leverage we had. Life stops until you eat. There is no option: food is your medicine. If meals are refused, then plan B is put in place: a trip to emergency for a [nasogastric] tube feed, or a call to the mobile crisis unit.<sup>318</sup>

<sup>313 &</sup>lt;u>Evidence</u>, 5 February 2014, 1700 (Dr. Debra Katzman); <u>Evidence</u>, 5 February 2014, 1700 (Dr. April S. Elliott); <u>Evidence</u>, 24 February 2014, 1605 (Dr. Wendy Spettigue); <u>Evidence</u>, 26 February 2014, 1555 (Jadine Cairns).

<sup>314 &</sup>lt;u>Evidence</u>, 5 February 2014, 1710 (Dr. Debra Katzman); <u>Evidence</u>, 24 February 2014, 1635 (Dr. Wendy Spettique).

<sup>315</sup> *Evidence*, 24 February 2014, 1605 (Dr. Wendy Spettigue).

<sup>316</sup> Evidence, 5 March 2014, 1605 (Lisa LaBorde); Evidence, 3 March 2014, 1550 (Laura Beattie).

<sup>317</sup> *Evidence*, 5 March 2014, 1545 (Lisa LaBorde).

<sup>318</sup> Evidence, 3 March 2014, 1550 (Laura Beattie).

Although Ms. Beattie was very frank about the stress linked to FBT, she was equally candid about her daughter's eventual success: "Our daughter was smiling and less withdrawn at school. She began to sing again. Over the next five months, with support from FBT, and then participating in a year-long, multifamily treatment program, we managed to get my daughter's weight restored and into recovery."

#### **Recommendation 22**

The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to help community programs offer integrated treatment approaches, as a recognized best practice, that include family members and people with eating disorders.

#### **Recommendation 23**

The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to examine as a best practice that patients be treated by multi-disciplinary medical teams with experience and expertise on treating eating disorders.

#### **Recommendation 24**

The Committee recommends that the Government of Canada consider improving research on treating eating disorders, such as deep brain stimulation and trans-cranial magnetic stimulation.

#### **Recommendation 25**

The Committee recommends that the Government of Canada work with the provinces, territories, and stakeholders to encourage relevant authorities to consider examining residential hospitalization treatment programs with the goal of ensuring that patients receive an adequate length of care in order to gain control of the eating disorder before being sent home, helping to improve conditions for a successful recovery.

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319 Ibid., 1600.

# LIST OF RECOMMENDATIONS

Recommendation 1
The Committee recommends that the Government of Canada consider supporting research on the impact of media messaging and marketing directed toward children and the impact and consequences of society's current, narrow definition of beauty
Recommendation 2
The Committee recommends that the Government of Canada encourage academic institutions to promote media literacy for young children to help them to view media content critically and question the messages therein
Recommendation 3
The Committee recommends that the Government of Canada collaborate with the provinces and territories to consider adjusting medical criteria for defining normal weights beyond quantitative measures such as Body Mass Index.
Recommendation 4
The Committee recommends that the Government of Canada review the information it provides on nutrition to encompass greater sensitivity in its guidelines on "good" and "bad" foods with the goal of helping to prevent unintended consequences, such as children as young as five years old developing eating disorders, which have been alleged to arise from the current guidance
Recommendation 5
The Committee recommends that the Government of Canada collaborate with the provinces and territories to consider developing a health and well-being education and awareness campaign, including both in-school and social media content, to foster a positive sense of self to protect against eating disorders, and to include media literacy components to counteract images portrayed in mainstream media

The Committee recommends that the Government of Canada consider developing a federal framework supported by an online public resource that would serve to collect from, and provide to, all provinces and territories information, statistics, best practices in recognizing symptoms, diagnosis, and treatment, and to raise awareness about the prevalence of eating disorders in Canada. This would close gaps in data collection and analysis regarding eating disorders and ensure a comprehensive picture of the incidence and prevalence of eating disorders and corresponding services in Canada.
Recommendation 7
The Committee recommends that the Government of Canada, in collaboration with the provincial and territorial governments and the Mental Health Commission of Canada, consider including those living with eating disorders, their families, and stakeholders in discussions and round tables regarding mental health
Recommendation 8
The Committee recommends that the Government of Canada should work with provinces, territories, and stakeholders to ensure that sufficient materials on eating disorders are incorporated into curricula for medical, nursing, psychology, psychiatry, and other health care professions to raise awareness and reduce stereotypes and stigma around eating disorders
Recommendation 9
The Committee recognizes that there is a need for an advocacy group, like the National Initiative for Eating Disorders, to advocate on behalf of those living with eating disorders and to raise public awareness
Recommendation 10
The Committee recommends that the Government of Canada recognize as a best practice the availability of navigators for eating disorders for the health and mental health care system to help identify quality services available in a timely manner, and help individuals and families navigate the system

The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to improve understanding of eating disorders in the health care field. One current model is the Ontario Community Outreach Program for Eating Disorders which delivers education and other supports to health care professionals and encourages and empowers health care professionals to treat people with eating disorders
Recommendation 12
The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to recognize that there exists in Canadian society, and within the medical community, a lack of understanding and a stigmatization of eating disorders
Recommendation 13
The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to encourage multidisciplinary care teams, which might include dieticians, psychiatrists, psychologists, and other necessary therapists, to ensure quality treatment, including for concurrent conditions
Recommendation 14
The Committee recommends that the Government of Canada should consider putting in place a centre of excellence or a national research chair in eating disorders, and increasing funding available for eating disorders research
Recommendation 15
The Committee recommends that the Government of Canada should work with the provinces, territories and stakeholders to ensure that all jurisdictions send eating disorder data to the Canadian Institute for Health Information. Data coverage is estimated at 59% of overall visits across eight jurisdictions
Recommendation 16
The Committee recommends that the Government of Canada should work with the provinces, territories and stakeholders to ensure that data on activities in primary care and community-based clinics is collected and sent to the Canadian Institute for Health Information

The Committee recommends that the Government of Canada should work with the provinces, territories and stakeholders to ensure access to information, diagnosis, and treatment for Canadians living with eating disorders, and particularly for remote and rural communities, and marginalized populations
Recommendation 18
The Committee recommends that the Government of Canada encourage provincial and territorial governments, due to the lifethreatening nature of eating disorders and a shortage of treatment beds, to provide either in-patient care as needed for patients with eating disorders on a timely basis or to consider covering the cost of treatments available outside the province, including in the United States, with the goal that patients can access the critical care they need in a timely fashion.
Recommendation 19
The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to reduce lengthy wait times for admission to eating disorder programs across the country
Recommendation 20
The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to overcome the challenges in accessing treatment, including a lack of a centralized database of treatment programs, undertrained health care providers, an insufficient number of programs, and uneven distribution of programs across the country, long wait times for treatment, inappropriate treatment programs, and a lack of pan-Canadian, evidence-based treatment standards.
Recommendation 21
The Committee recommends that the Government of Canada consider developing consistent standards on clinical care treatment and wait times for people with eating disorders48

The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to help community programs offer integrated treatment approaches, as a recognized best practice, that include family members and people with eating disorders.	. 52
Recommendation 23	
The Committee recommends that the Government of Canada should work with the provinces, territories, and stakeholders to examine as a best practice that patients be treated by multi-disciplinary medical teams with experience and expertise on treating eating disorders	. 52
Recommendation 24	
The Committee recommends that the Government of Canada consider improving research on treating eating disorders, such as deep brain stimulation and trans-cranial magnetic stimulation	. 52
Recommendation 25	
The Committee recommends that the Government of Canada work with the provinces, territories, and stakeholders to encourage relevant authorities to consider examining residential hospitalization treatment programs with the goal of ensuring that patients receive an adequate length of care in order to gain control of the eating disorder before being sent home, helping to improve conditions for a successful recovery.	. 52

# APPENDIX A LIST OF WITNESSES

Organizations and Individuals	Date	Meeting
Toronto General Hospital	2013/11/28	5
Dr. Blake Woodside, Medical Director Program for Eating Disorders		
Canadian Institutes of Health Research	2013/12/10	8
Dr. Joy Johnson, Scientific Director Institute of Gender and Health		
Department of Health		
Dr. Hasan Hutchinson, Director General Office of Nutrition Policy and Promotion, Health Products and Food Branch		
Public Health Agency of Canada		
Marla Israel, Acting Director General Centre for Health Promotion, Health Promotion and Chronic Disease Prevention Branch		
Status of Women Canada		
Sébastien Goupil, Director General Policy and External Relations		
Linda Savoie, Director General Women's Program and Regional Operations		
National Eating Disorder Information Centre	2014/02/05	10
Merryl Bear, Director		
University of Calgary Dr. April S. Elliott, Clinical Associate Professor of Paediatrics Chief of Adolescent Medicine, Department of Paediatrics and Psychiatry		
University of Toronto		
Dr. Debra Katzman, Professor of Paediatrics Division of Adolescent Medicine, Department of Paediatrics		
Hospital for Sick Children	2014/02/10	11
Dr. Gail McVey, Senior Associate Scientist Community Health Systems Resource Group, Director, Ontario Community Outreach Program for Eating Disorders		
Dr. Leora Pinhas, Psychiatrist Department of Psychiatry		
National Initiative for Eating Disorders		

Wendy Preskow, Founder and Chief Advocate

Organizations and Individuals	Date	Meeting
Women, Action and the Media Vancouver	2014/02/10	11
Jarrah Hodge		
Alberta Health Services	2014/02/12	12
Dr. Monique Jericho, Psychiatrist and Medical Director Calgary Eating Disorder Program		
Registered Dietitian Services		
Noelle Martin, President Professor, Brescia University College, Western University		
Sheena's Place		
Joanna Anderson, Executive Director		
University of Guelph		
Andrea LaMarre, MSc Candidate Department of Family Relations & Applied Nutrition		
Dr. Carla Rice, Canada Research Chair Care, Gender, and Relationships, Department of Family Relations & Applied Nutrition		
Canadian Academy of Child and Adolescent Psychiatry	2014/02/24	13
Dr. Wendy Spettigue, Psychiatrist		
Canadian Federation of Mental Health Nurses		
Elizabeth Phoenix, Nurse Practitioner and Clinical Nurse Specialist		
Canadian Psychological Association		
Dr. Giorgio A. Tasca, Research Chair in Psychotherapy Research		
University of Ottawa and the Ottawa Hospital		
Dr. Lisa Votta-Bleeker, Deputy Chief Executive Officer and Director Science Directorate		
Anorexia and Bulimia Quebec	2014/02/26	14
Josée Champagne, Executive Director		
DisAbled Women's Network of Canada		
Bonnie L. Brayton, National Executive Director		
Eating Disorders Association of Canada		
Jadine Cairns, President		
As an Individual		
Arthur Boese		
Alyssa Stevenson Eating Disorder Memorial Trust	2014/03/03	15
Elaine Stevenson, Co-administrator		

Organizations and Individuals	Date	Meeting
Families Empowered and Supporting Treatment of Eating Disorders Canada Task Force	2014/03/03	15
Laura Beattie, Co-chair		
University of Ottawa		
Dr. Valerie Steeves, Associate Professor		
As an Individual		
Patricia Lemoine		
As Individuals	2014/03/05	16
Lisa LaBorde		
Carly Lambert-Crawford		

## APPENDIX B LIST OF BRIEFS

### **Organizations and Individuals**

Canadian Institute for Health Information

Canadian Mental Health Commission

Canadian Psychological Association

Families Empowered and Supporting Treatment of Eating Disorders Canada Task Force

Ontario Community Outreach Program for Eating Disorders

WaterStone Clinic for Eating Disorders

## REQUEST FOR GOVERNMENT RESPONSE

Pursuant to Standing Order 109, the Committee requests that the government table a comprehensive response to this Report.

A copy of the relevant *Minutes of Proceedings* (Meetings Nos. 5, 8, 10, 11, 12, 13, 14, 15, 16, 26, 27, 28, 29, 30, 31 and 32) is tabled.

Respectfully submitted,

Hélène LeBlanc

Chair

#### **Dissenting Report re Eating Disorder Study- FEWO**

In the summer of 2014, a report from the Canadian Institute for Health Information was released proving that the rates of hospitalization for girls aged 10-19 has increased by 42 percent in just two years. Throughout the study of eating disorders at the Standing Committee for the Status of Women, the testimony has revealed that the prevalence and severity of this disease is on the rise in Canada for both women and men. Yet, treatment and prevention for eating disorders is badly underfunded, resulting in lack of awareness, under-diagnosis and unacceptable wait times for treatment. Too often these circumstances result in unnecessary fatalities. **New Democrats are concerned that eating disorder treatment in Canada is in a state of crisis and believe that action is required**.

#### **Absence of Federal Leadership**

Recognizing that jurisdiction over health care delivery is primarily a provincial responsibility, New Democrats believe that the federal government should work collaboratively with provincial and territorial governments to protect and expand our public and universal health care system. Our study revealed that almost no federal leadership is taken on behalf of the victims of eating disorders. No department or agency directs funding to awareness, prevention or treatment. Minimal funding, through the Canadian Institute for Health Research, has been provided for two research projects since 2006. In fact, so little federal initiative is taken that government departments and agencies were reluctant to appear before the committee, and had almost nothing to report during their testimony. It is clear that more can and must be done to improve access and supports for those suffering with eating disorders, the health care professionals who treat them, as well as the family members who care for them. New Democrats recommend that the federal government work with provinces, territories, Indigenous communities, patients, and relevant organizations to increase and improve resources dedicated to eating disorder treatment and awareness.

#### Gender based marginalization of women's health

New Democrats are concerned that the lack of resources dedicated towards eating disorders when compared with other illnesses that have similar rates of fatality could reveal the lack of targeted programs for women within the health care sector and society at large. We heard from Dr. Blake Woodside, a leader physician in the treatment of eating disorders and one of the committee's witnesses, who is quoted as saying: "If anorexia was an illness of middle aged men, there'd be a clinic in every hospital in this country but because it's a psychiatric illness of young women it's discriminated against."

The Conservative Government has shown its callous disregard for women's health on several occasions. In 2012 the Conservatives slashed all funding for the Women's Health Contribution Program (WHCP), thereby abolishing a potential source of funding support earmarked for diseases that afflict mostly women, such as eating disorders. As another example, in April 2012, The Minister for Health chose to unilaterally end funding directed towards Aboriginal women's health programs. New Democrats call for the government of Canada to reverse these cuts and take further actions through Health Canada, The Status of Women Agency and the Public Health Agency of Canada to ensure that women's health

benefits from adequate resource allocation, research initiatives, program funding and awareness campaigns.

Recommendation 18 is of particular concern to New Democrats. It encourages provincial and territorial governments to pay for the costs of treatments in the United States. Conservatives have cut billions in funding for health care services thereby forcing provinces to do more with less. It is reprehensible to consider encouraging provinces to send patients abroad, after such devastating cuts. These services must be available in Canadian communities. We need to work with provinces and territories to ensure that they have the resources they need to provide high quality and accessible care for eating disorders.

Furthermore, there is an acknowledged relationship between poor body image, harmful societal messaging and eating disorders. Several witnesses spoke with grave concern about multibillion dollar industries that prey on the insecurities and self-hatred of young girls and women. As well, it was recommended that federal healthy eating campaigns be updated to avoid the unintended outcomes of "fat shaming" young girls and boys who subsequently develop eating disorders. Media literacy must be integrated into education practices and be inclusive of racialized communities and Indigenous communities. New Democrats believe that the federal government must take a strong leadership role through the Status of Women Agency to address the root causes of eating disorders and gender inequality.

#### **Conservatives Fail to Act on Mental Health**

Eating disorders are psychiatric illnesses with extremely high mortality rates. However, as with all mental health disorders, the lack of government attention, combined with other factors like stigma, has isolated patients with eating disorders, and very few sufferers receive mental health services in Canada. The government's own Mental Health Commission created a Mental Health Strategy for Canada in 2012. The Conservative government has yet to fully implement its recommendations. New Democrats ask the government to take immediate action to implement the Mental Health Commission of Canada's 2012 Mental Health Strategy and to follow the six strategic directions that have been identified by the Strategy.

#### No Access. No Awareness

A complete lack of targeted, community based awareness, prevention and treatment for eating disorders was identified by several committee witnesses. Eating disorders afflict people from all ethnic backgrounds and socio-economic classes. Yet no services are geared towards Indigenous peoples, radicalized minorities, new immigrants or the LGBTQ community. Accessible treatment must be made available to all people in Canada regardless of identity or class. New Democrats recommend that all awareness, prevention and treatment programs be created with an awareness of the specific cultural needs of all minorities in Canada in collaboration with those communities with targeted outreach.

Too few resources exist for eating disorders outside of major urban centers in Canada. Particularly for lower income women or parents with small children this fact makes seeking treatment nearly

impossible. No treatment facilities exist in northern regions, Labrador or PEI. Access to health care is an essential service. New Democrats recommend that the federal government work in collaboration with provinces, territories and Indigenous communities to ensure that eating disorder services be made available in northern remote and rural regions as well as in all provinces.

# LIBERAL PARTY OF CANADA DISSENTING REPORT: EATING DISORDERS AMONG GIRLS AND WOMEN IN CANADA

Kirsty Duncan, Member of Parliament for Etobicoke North

#### INTRODUCTION

This dissenting report first thanks all the witnesses who had appeared before the Committee. Some of them were living or had lived with an eating disorder, and many of them were providing care. Many also shared often difficult information about their personal lives to contribute to a better quality of life for other Canadians. The report recognises their compassion, courage and deep desire for real change.

This report also thanks the many healthcare workers and organizations who appeared on behalf of the people they treat and work with to fight for more help for Canadians living with eating disorders.

It is regrettable that, from the very beginning, this study was a political exercise meant to appease a constituency – an effort meant to look like action was being taken. Canadians should ask why eating disorders were sidelined by the Government, which has the majority on the Standing Committee on the Status of Women. Eating disorders are serious mental health disorders, and they should have been studied at the Standing Committee on Health. The reality is that anorexia nervosa has the highest mortality rate of all mental health disorders. Women with anorexia are 12 times more likely to die than women of the same age without the condition.

Canadians should also know that, while young women are at high risk and tend to be more affected by eating disorders, an increasing number of boys and men also experience these conditions. In fact, one large American study of children aged nine to 14 years found that 13.4 percent of girls and 7.1 percent of boys showed disordered eating behaviours.

While the text accurately reflects witnesses' testimony, it is profoundly frustrating that the key recommendations that witnesses asked for remain absent from the main report, namely: (1) that the federal government should work with the provinces, territories and stakeholders to establish a pan-Canadian strategy to address eating disorders, including early diagnosis and access to the full range of necessary care, (2) that a national registry be established, and (3) that a robust research program be launched.

Moreover, this report might be better labelled a "consider, encourage, and recognize" report. Eight of twenty-five recommendations call on the Government to "consider"; and another six call on the Government to either "encourage" or "recognize". That is, 14 of 25-56 percent – of all recommendations call on the Government to undertake no action at all. This simply is not reflective of witnesses' testimony, which urgently called for real change.

Recommendation 4 is simply redundant, as it calls for the Government to do something of which officials were already cognizant. Recommendation 7 is also redundant, as I had informed the Committee that I personally called the Mental Health Commission of Canada (MHCC) this past summer, when I was informed that those with eating disorders were not included in consultative processes. The MHCC promised it would reach out to those organizations advocating on behalf of people with eating disorders, and did, in fact, follow up with calls. Recommendation 9 is purely political, as it recognizes merely one advocacy group. More disturbing still, the recommendation does not acknowledge that advocacy groups require funding, which we heard repeatedly.

This Government always uses the excuse of jurisdictional barriers not to act on matters of health, despite its ability to convene and bring the provinces and territories together for a discussion to act. And yet, it wants to: (1) encourage academic institutions to promote media literacy for young children, where it does not have jurisdiction (recommendation 2); (2) ensure that sufficient materials are incorporated into medical curricula (recommendation 8), where, again, it has no jurisdiction; and (3) improve understanding of eating disorders in the healthcare field (recommendation 11).

It is more than disappointing that recommendations 13, 23, and 25, each of which could really help those with eating disorders and their families, were weakened to do nothing more than "encourage", "examine", and "encourage…to consider," respectively.

That is, the report protects the *status quo* and fails to take up the recommendations made by witnesses. Hence, this dissenting report is necessary.

If, according to the Government, the *status quo* is acceptable and is working, why was such a lengthy study and report required? Why did I spend my summer addressing life-threatening eating disorder cases brought to me by advocacy organizations and parents who were desperate for help?

This report could have been so much more impactful if real recommendations had been made to address eating disorders – not merely "weasel words" that do not actually call for desperately needed action.

As it stands, a mere 6 of 25 recommendations (15, 16, 17, 19, 20, and 22) have the potential to move us past the *status quo* and trigger real change.

#### WHAT WITNESSES ASKED FOR

Canadians with eating disorders and health practitioners asked that the federal government work with the provinces, territories and stakeholders to develop a centralized database of treatment programs. They asked also that the government work with its counterparts to address challenges in treating eating disorders, such as an inadequate number and uneven distribution of programs across the country, excessive wait times, and the absence of pan-Canadian, evidence-based treatment standards.

Canadians living with eating disorders and their families asked for navigators to help steer them through the confusing and overwhelming world in which they are embroiled. Families and health practitioners asked for multidisciplinary care teams, and solutions to overcoming the steep financial costs for treatment.

Health practitioners and researchers asked for a pan-Canadian registry for eating disorders, and to close the gaps in data collection and analysis in order to ensure a comprehensive picture of the incidence and prevalence of these serious mental health disorders.

Families want an education campaign for healthcare professionals and other stakeholder-identified groups to promote awareness. Their goal is a better understanding of eating disorders and their challenges and conditions, and a reduction of associated stereotypes and stigma. Parents across Canada not only worry about their children's health, but also about their loss of employment and even their homes.

And all stakeholders called for a health and wellness education campaign, to foster a positive sense of self in order to protect against eating disorders, and media literacy to counteract unrealistic images of beauty and thinness.

Health practitioners and researchers also asked that the government consider putting in place a national research chair in the field eating disorders, and to increase funding for eating-disorders research.

In February, the Government of Ontario announced the first, long-term, publicly-funded residential treatment program in the Province--offering, at the moment, 12 beds for children and adolescents. This means at least some Ontarians with eating disorders may no longer be forced to go abroad for private health care, and return with little follow-up care. But, what about, for example, the Atlantic and Prairie Provinces?

#### **OUTSTANDING QUESTIONS**

Canadians should ask why the overwhelming human and economic costs of eating disorders (and how they compare to the meagre investment in research) are not included in the report. This includes the weekly uninsured costs of appointments to psychologists, nutritionists, and the cost of being unable to work or house oneself. What are the costs of eating disorders to the healthcare system?

Canadians should also ask why, of Canada's 4,100 psychiatrists, only 12 specialize in eating disorders. And why does each Canadian province not offer the full range of care for eating disorders -- from daily to long-term residential care?

#### CONCLUSION

Sadly, little has changed in the past twenty-five years. Canadians with eating disorders and their families still struggle. Boys and girls, young men and women are still told they have a choice and should "just eat". Parents continue to be blamed, and families still complain: where are the educational programs that allow frontline health practitioners to recognize eating disorders, the early intervention, and the access to care?

It is unconscionable that, today, families must still ask where the help is, when we know that early diagnosis and access to care will significantly enhance recovery. If eating disorders are not identified or treated in their early stages, they become chronic, debilitating, and even life-threatening conditions.

For these reasons, Canadians with eating disorders and their families eagerly awaited the Status of Women Committee report on eating disorders. They want to know that their pleas had actually been heard, and that there would be real recommendations to help struggling families — because the *status quo* is unacceptable.

Real progress on eating disorders requires the political will to act. Sadly, this report lacks the substantive recommendations to provide the Government with meaningful direction.