House of Commons
Chambre des communes
CANADA

Standing Committee on the Status of Women

FEWO • NUMBER 016 • 2nd SESSION • 41st PARLIAMENT

EVIDENCE

Wednesday, March 5, 2014

Chair

Ms. Hélène LeBlanc

Standing Committee on the Status of Women

Wednesday, March 5, 2014

● (1530)

[*Translation*]

The Chair (Ms. Hélène LeBlanc (LaSalle—Émard, NDP)): Good afternoon everyone. Welcome to the 16th meeting of the Standing Committee on the Status of Women. I would also like to welcome Ms. Carly Lambert-Crawford and Ms. Lisa LaBorde, who will be providing testimony by videoconference.

[*English*]

Welcome. Thank you for being here. You will each have 10 minutes for your presentation followed by questions from the members.

I will start with Mrs. Lambert-Crawford, for 10 minutes, please.

Ms. Carly Lambert-Crawford (As an Individual): Thank you for having me here today.

I am a psychotherapist treating anxiety, depression, and eating disorders in Burlington, Ontario. I am also a proud member of the steering committee of the National Initiative for Eating Disorders.

I am here representing the voice of my clients along with my own voice as a survivor of anorexia. I'm proud to say that I'm one of the people that were able to get through our system despite its flaws.

As a therapist I often see people who the system didn't work for, the people who are waiting. I treat the most desperate of individuals and the sickest of the sick. They are lonely and desperate. I have only been a therapist for five years, and in my early career I have seen one of my clients die from anorexia. That is one client too many. She was bounced around, kicked out, and misunderstood. She struggled with OCD in addition to her eating disorder, and this left her paralyzed with fear. She was 20 years old when she died.

I have since known three more women who I was in treatment with who have all died from complications of their eating disorder. They were all under the age of 30 and were part of our system of care.

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.

Prior to my work as a private practitioner, I worked as the program director at Danielle's Place, an eating disorder and support resource centre in Burlington, similar to Sheena's Place. Throughout my three years directing the centre, we had a terrible time getting funding to keep our doors open. Our aim was to provide services that were free of charge and would be free of waiting lists and were able to support the hundreds of men and women each year. Unfortunately, when I left the centre, they had to close their doors. This was devastating for a number of clients who saw the centre as their regular safe haven.

The inability to recognize the severity of the illness is one of the diagnostic criteria for anorexia nervosa, and this was me. I was one of the ones who had no idea that this was happening to me. Before I was diagnosed with anorexia, I was diagnosed with severe depression and anxiety. I suffered so badly that I really and truly did not know how to live without being on a myriad of different drugs to calm me down.

My eating disorder probably started when I was 16 years old. It was at this time that my family had gone through an extremely traumatic event, which is very typical for the onset of mental illness. Anorexia was one of the greatest gifts because it numbed my brain and it really helped slow these thoughts down.

Things went downhill pretty quickly, as they do, and all of a sudden things were getting harder for me to do. My doctor told me that I was underweight because I was a competitive athlete. He put me on a myriad of antidepressants that left me feeling a confused mess. I never weighed myself. This also surprises people. When I first weighed myself, it was the first thing that scared me enough to go to a specialist for assessment.

The next couple of years of my life are the hardest for me to talk about. These were the years that I was battling the system and myself. I had no idea what was happening to me. My world was falling apart. I was defeated. After years of loving the anorexia I let it take me.

From here I have a hard time remembering why, but I ended up on a psych ward in another city. I was the only anorexic patient within their whole entire program. My illness took over at this point and I was asked to leave that program. I was hospitalized in the ICU at my local hospital. I have had many doctors tell me they don't know how I survived.

I'm telling you this not to make you feel sorry for me, but for you to understand that my story is not unique. This happened all while I was waiting for an assessment with a local treatment centre. This happened while my parents were begging for someone to talk to me and for someone to understand. This all happened because I was kicked out of the psych ward because they did not know how to help me and my weight kept dropping. They asked me to leave their program at ... pounds at 20 years of age. [*Pursuant to a motion passed on April 30, 2014, a portion of this testimony has been deleted. See* Minutes of Proceedings] They discharged me from hospital at that weight because they told me I was being non-compliant.

From that moment on, I had no will to live or fight. My weight went down significantly and I ended up in the ICU surrounded by individuals who were three, four, or five times my age and dying of heart failure, cancer and other terminal illnesses.

My name happened to come up for an assessment at the Toronto General eating disorders program after waiting for four months for the assessment. They would not let me do the assessment over the phone and did not have the resources to send their specialist to me while I was in the hospital so I had to go by ambulance from Burlington to Toronto, hooked up to IVs, a tube that was feeding me and a heart monitor making sure I didn't go into cardiac arrest, just to prove that I was sick enough for their program. I actually remember lying there in bed completely out of it while a team of doctors asked me questions.

● (1535)

Does this seem right?

There is something wrong with our system. Would they make a child who was sick with cancer travel that long distance to prove they needed radiation or chemotherapy or to prove they needed to see an oncologist? From here I was put on a waiting list. I waited for four more months in a hospital where I endured the most disgusting abuse from the staff, which gave me the courage and the passion to do what I do today.

I don't want anyone to have 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.

I was eventually able to get a bed at the Toronto General eating disorders program. I spent four months there and left prematurely. I relapsed immediately, and from there I was facing outpatient treatments and very expensive individual therapy.

I worked tirelessly with my family and my husband to get where I am today. Many things that happened in my life were very influential in my recovery. Those seven years were the hardest of my life as I battled that system, but I truly believe my eating disorder has made me a better person. However, I will never ever underestimate the power this has on any individual that is diagnosed.

What I am here to get across today is that eating disorders are truly deadly illnesses. They take your life away and destroy families. As is the case with many other mental illnesses, people just do not understand. They feel an eating disorder is something you can just fix, something you need to address and get over. What we know now is that this is an illness of the brain, a psychological illness that takes away all logic and reasoning. I cannot believe how lucky I am to be sitting here right now, and how close my life came to ending. I have a very hard time making sense of it. I have a hard time making sense of it because there is no sense to make.

People die from this illness because there aren't adequate resources to treat it. Doctors misdiagnose and minimize the struggles, and people end up feeling enabled and blamed for something they do not understand. The prognosis for eating disorders is not very good. We know that it is hard to recover, and the longer the eating disorder goes on, the lower the chances for a full recovery.

We need help to make sure that when people are ready, there is treatment available. We need to put eating disorders on the radar and help people correct their misinterpretations of this illness and erase the stigma.

There are three aspects that I feel are most important to focus on at this time.

First is funding. As others who have spoken at this forum have said, I believe there needs to be equitable funding for eating disorders and other related illnesses. There need to be more beds and spots available so that waiting lists are shortened.

Second, I believe there needs to be an equitable amount of OHIP coverage for youth and adults who are struggling with eating disorders. OHIP is quite easily convinced to send anyone under the age of 18 to programs in the United States for specialized and timely care; however, anyone older is told to make use of our resources here.

Third, I believe there needs to be mandatory training for medical professionals to be able to properly screen and diagnose eating disorders. There needs to be more awareness and consistency among general practitioners, nurses, psychiatrists, and other professionals to ensure that this illness doesn't continue to be swept aside.

At this time, I am happy to answer any questions to help you understand my perspective and to offer any insight I may be able to bring to the study.

Thank you.

● (1540)

[*Translation*]

The Chair: Thank you, Ms. Lambert-Crawford.

I will now give the floor to Ms. LaBorde for 10 minutes.

[*English*]

Ms. Lisa LaBorde (As an Individual): I would like to thank the committee for giving me this opportunity to present to you. I'm grateful to be able to give you a sense of what it is like for a family to navigate the system and care for a child with an eating disorder.

The field of eating disorder research and treatment has changed significantly in the last 10 years. The view of parents and their role has changed dramatically. There is now a current, effective, evidence-based treatment for adolescents, and it relies heavily on family involvement. We now know that families don't cause eating disorders and that families are in fact vital to their children's recovery.

My family's story is in many ways a version of a best-case scenario in the current treatment landscape. I say this for the following reasons.

I recognized that something was wrong with my daughter very early on. I was prepared to take immediate action. I managed to find up-to-date, evidence-based information quickly. I was ultimately connected to stellar hospital treatment, and I worked to link myself to support. My family's case is one example of "as good as it gets", and still the experience was devastating. It took nine months from my first recognizing that something was wrong with my daughter to her being admitted to the hospital and beginning treatment. It took another year from the beginning of treatment until she was firmly in recovery.

It's an arduous and long journey. Caring for a child with a life-threatening illness is difficult; there's no getting around that. However, misinformation, stigma, and lack of accessible resources added to our burden. My daughter was diagnosed with anorexia when she was 10 years old. With this illness, early intervention is key. Early treatment correlates with better outcomes. Often, what parents see first are actually late-stage symptoms. I first noticed something was amiss in September 2010. What I first noticed were not eating disorder related changes but rather a change in her temperament. I had a 17-year-old and a 10-year-old, and both were happy and healthy. An eating disorder was not on my radar.

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, she got an eating disorder.

My daughter was a funny, independent kid. She was socially comfortable and had many friends. She loved school. She took piano and choir, not dance or gymnastics. She was affectionate and goofy and she was 10. Who gets an eating disorder at 10?, I thought. The fact that she did not fit the stereotypical image of an ED sufferer worked against us. It allowed me to question my instincts and to unthink what I saw. It allowed me to miss what I now know were clear signs.

Between January and the end of April 2011, I took her to the doctor three times. I expressed that something was wrong, that she was not eating, that she was complaining of a tummy ache, and that she seemed to be losing weight and was not herself. No alarms were sounded. By May, however, I knew that we had a serious problem. On May 15, I met her at school and I took her for lunch, for pizza, and I told her she had to finish. She took two bites and something washed over her and she said, "Mommy, I can't eat." I went from the lunch to the school and I told them we would not be returning, and then I went straight to the doctor. The doctor spoke to her and finally said, "Yes, there's a problem." He made a referral to the pediatric ED program at our local children's hospital. The doctor also told me, "Don't try to make her eat. You're not going to be able to. Don't be the food police."

I was told nothing else at that time. I was given no information on eating disorders and no direction. I went home and I tried to get her to eat, and when I couldn't, I went on the Internet and I started searching. I remembered I had read a *New York Times* piece a few years earlier about a new treatment for anorexia called Maudsley. I searched for that piece and I was linked to information on family-based treatment, and I started to educate myself.

What I needed was better information and I needed more informed first-line treatment. I needed my family doctor to have the skills to identify earlier and to provide me with accurate information so that I could take action. Everything I found that was helpful to me I found on my own, and that should not have been the case. I should have been told, "Your daughter has a biological brain disorder. It's treatable. There are evidence-based practices for this age group." I should have been told to feed my child, and I should have been supported in doing so.

To treat this illness, parents have to build a new skill set quickly. Understanding how the illness works and effective treatment methods early helps with this. What happens when you don't get that information is that you lose time, your confidence is undermined, and all the while your child is getting sicker. I often think about how things might have been different if I hadn't lost those early months.

● (1545)

During the time that we were on the wait list for the assessment, I tried to find community help. I phoned everywhere I could, and I felt like I was screaming in the wind. There was no help in the community for a 10-year-old. I knew that nutritional rehabilitation should be my focus, but I needed help. I felt like I was watching my child die slowly.

I took her to the emergency room at Sick Kids every single day, and two weeks later she was medically unstable and she was admitted. She spent seven weeks in-patient at the Hospital for Sick Children. On the ward at that time there was another 10-year-old and two 8-year-olds. We moved from in-patient to outpatient, and outpatient consisted of a clinic appointment and a family-based treatment appointment once a week. The other six and a half days of the week her care was in my hands.

This phase of treatment is called outpatient, but the work of treatment is not happening during the clinic visits. The work of treatment is happening at home. She gained 20 pounds in the hospital and she gained another 30 pounds at home.

With family-based treatment, the majority of work is happening at home and it is done by families. Treatment consists of feeding and interrupting symptoms. Food is medicine. It sounds easy, but getting an anorexic child to eat is anything but. My daughter will now say that it felt like I was pushing her out of an airplane without a parachute six times a day. What we were doing was exposure therapy, and cajoling, and bribing, and forcing. Nothing made it easier. The only thing that worked was making not eating not an option. If she ran and hid under the bed, I had to pull her out. If she threw the food, I had to plate it again. If she just sat there, I had to sit with her for as long as it took.

Quite simply, parents have to be stronger than the eating disorder. They 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. She 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.

I focused on her recovery. I made that my number one priority. I took time from work and I took out a line of credit. My daughter was back at school in the fall with support. I met her every day for lunch for the entire school year. By the end of the school year, she was in true recovery. This past September, we saw a flare-up of symptoms due to anxiety that she was experiencing over a move to a new school. I knew what to look for this time and I addressed it right away. I got her plugged back into treatment and she's doing wonderfully now.

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.

Thank you.

I'll take any questions.

The Chair: Thank you very much.

We'll start the questions with Madam Truppe, for seven minutes.

Mrs. Susan Truppe (London North Centre, CPC): I'd like to welcome you to our committee. Thank you for coming and sharing your personal experiences.

We've heard so many stories from individuals who have had eating disorders, as well as all the people who are treating them. It's amazing how many people have to do everything on their own, as if there was nothing out there. I've heard the Maudsley family-based treatment mentioned several times. Interestingly enough, everyone is finding it on their own on the Internet, because certainly, for all the work that they've done and how much help it has given everyone, it doesn't seem there's a big awareness of it. Everybody simply seems to use Google and Maudsley comes up. It seems to be doing wonders for many people.

Ms. Crawford, maybe I will start with you.

I think you said you were 16 when it was determined you had an eating disorder. How long did you say that you felt you had the eating disorder before they put you on the psychiatric ward?

● (1550)

Ms. Carly Lambert-Crawford: The question is, how long after I was diagnosed was I in the hospital?

Mrs. Susan Truppe: You were 16 at the time and then you felt that there was a problem. If you were only 16, were your parents—

Ms. Carly Lambert-Crawford: No. I'll clarify that, absolutely.

Looking back now, I can see that my eating disorder started when I was probably about 15. Nobody started talking about it until my very late teens, early twenties.

Mrs. Susan Truppe: How did someone recognize that you had the eating disorder? Was it through an awareness program and someone realized that you had a problem, or did you or your family realize that?

Ms. Carly Lambert-Crawford: I think my family realized it first and pushed me into getting an assessment. Then from there it took years for me to be....

Mrs. Susan Truppe: Once your family thought you should get an assessment then, did you go to the psychiatric ward?

Ms. Carly Lambert-Crawford: Yes.

Mrs. Susan Truppe: And you weighed only ... pounds when they let you go? [*Pursuant to a motion passed on April 30, 2014, a portion of this testimony has been deleted. See* Minutes of Proceedings]

Ms. Carly Lambert-Crawford: Yes.

Mrs. Susan Truppe: That's amazing.

Ms. Carly Lambert-Crawford: I was 20 years old, so....

Mrs. Susan Truppe: Were there any awareness programs at the time that would have helped you to identify you had this type of problem?

Ms. Carly Lambert-Crawford: Yes, I think in relation to Lisa, I was an adult, so my family was very aware; however, they were helpless because I wasn't ready to make that connection. You've heard from Sheena's Place. There was Danielle's Place at the time, but I was seeing my family doctor weekly until the point of my hospitalization. He thought it was because I was an athlete and things like that, so there was no support there.

Mrs. Susan Truppe: Then you opened Find Your Voice Counselling? Was that your initiative?

Ms. Carly Lambert-Crawford: Yes, I'm a private practitioner now.

Mrs. Susan Truppe: How do you make young people or families aware of Find Your Voice Counselling? How do they know to come to you so you can share your experiences?

Ms. Carly Lambert-Crawford: A lot of my awareness is through the National Initiative for Eating Disorders, NIED. That's really where I want most of the focus to be.To find a private practitioner, we have NEDIC, an information centre based out of Toronto. That has all the eating disorder specialists and is like a database, so I know that's how a number of people come to find care. It's just that the care listed there is so limited at this point.

Mrs. Susan Truppe: Do you have a best practice that you would like to share, something that really works to help either the individuals who have the eating disorder or to help the families?

Ms. Carly Lambert-Crawford: I use the evidence based, so I am trained in the Maudsley approach. I did my training with Daniel Le Grange in the United States. With adults we're really working with cognitive behavioural therapies; dialectical behavioural therapy is used a lot more now. It's very interesting that the treatment for adolescents and the treatment for adults is very different, so it's navigating those two systems.

Mrs. Susan Truppe: Thank you.

Ms. LaBorde, thank you for sharing your story about your daughter. I think you said she was 10 when you noticed a change in her temperament. How old is she now?

Ms. Lisa LaBorde: She's 13.

Mrs. Susan Truppe: It has been going on for three years now.

Ms. Lisa LaBorde: She was diagnosed. She's in recovery now. She's not ill at the moment.

Mrs. Susan Truppe: What was the best thing that came out of the Maudsley family-based treatment? What was the thing that helped you most? You seem to have had to do a lot of it on your own.

Ms. Lisa LaBorde: Focusing on getting her weight restored, and having that be the first and most important focus was very helpful to us.

● (1555)

Mrs. Susan Truppe: After everything that you experienced with your daughter, probably first not getting help and then having to look on the Internet to see what else you could do, is there anything you would recommend that might help as public awareness for kids at school who have eating disorders or for families?

Ms. Lisa LaBorde: I think what would be very helpful is to have first-line physicians—primary care physicians, doctors, psychiatrists, psychologists in the community—be aware of eating disorders, the current evidence around eating disorders, and the evidence-based treatments, so that when parents notice something's wrong with their children, they actually get up-to-date information early. That would be helpful. In terms of public awareness, the focus seems to be on the environmental aspects, media and things like that. What would be more helpful is to have more of a public awareness around the biological and genetic factors that contribute, because those are, I think, what parents can see first.

Had I known that hereditary factors are so important and that a history of eating disorders in your family raises a child's possibility of being diagnosed with an eating disorder, it would have been helpful information for me to know. As I said, she wasn't really influenced by the media. She was 10. There wasn't a lot of thin-ideal internalization on her part, but we did have a history of eating disorders in our family. I'm adopted and I found that out later.

The Chair: Thank you very much.

[*Translation*]

Thank you very much, Ms. Truppe.

Ms. Ashton, you have the floor for seven minutes.

[*English*]

Ms. Niki Ashton (Churchill, NDP): Thank you very much, Ms. Lambert-Crawford and Ms. LaBorde, for joining us today for such an important study and for sharing your personal experiences as a survivor and as a mother.

Ms. Lambert-Crawford, you spoke of your experience. In your experience as a counsellor, when someone is living with anorexia nervosa, depression and anxiety, when that person has the multiple illnesses at once, could you speak to the challenges that person faces in dealing with the system the way it's set up?

Ms. Carly Lambert-Crawford: First and foremost, eating disorders don't exist in a vacuum, so generally speaking there's always going to be.... It's an anxiety-based illness, so there's anxiety, depression. There's a very high level of comorbidity that is happening.

To answer your question in terms of challenges, it is very challenging because you 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.

From FBT, family-based treatments, the Maudsley approach, if the family doesn't have the resources to take time off work to do the work that you need to do with your child.... I have worked with many families for whom that's very challenging. A particular family that I worked with had five kids in the house, so it was very hard for them to not have the eating disorder affect the rest of the children. They were scrutinized and really made to feel that they were bad parents through their program because they couldn't take that time to help their daughter through the way that FBT or the Maudsley approach needs to happen.

It's a very big problem in terms of lots of doctors finding that eating disorders are too complex to treat because they are so multi-faceted.

Ms. Niki Ashton: Thank you.

I'm wondering if you could share with us, perhaps briefly, so I can make sure I get to Ms. LaBorde as well, in your experience, why do you feel that many people end up leaving treatment before it's over or maybe don't even stick around to start treatment?

● (1600)

Ms. Carly Lambert-Crawford: I think our treatment here is very black and white. The treatment here for eating disorders hasn't changed in the last 20 years. If you're not able to comply completely, you're not given any chances. There are very strict criteria in terms of how much weight you have to gain. I'm talking about the adult system; I should clarify. There are very specific criteria. The short answer is that the biggest barrier is there's no flexibility. For someone with very high anxiety, that's very challenging.

Ms. Niki Ashton: Thank you very much.

Ms. LaBorde, in this committee we've heard from others that families really struggle in terms of resources and information. Given your involvement with F.E.A.S.T., do you feel that federal funding would be important to an organization like F.E.A.S.T., and if so, what would F.E.A.S.T. be able to do with federal funding: awareness, support, counselling for families?

Ms. Lisa LaBorde: All of those, in short. F.E.A.S.T. provides advocacy and education to parents or any caregiver of an individual with an eating disorder. What provided me with the most assistance through the entire process of caring for my child was on-the-ground support, but it was virtual on-the-ground support. F.E.A.S.T. has a forum and it's international so there's always somebody online. Because it's a 24/7 day in, day out type of care that's needed through the acute phases, that was vital.

I think because the community is lacking in resources, parents are left adrift. F.E.A.S.T. provides that; it fills some of those gaps in terms of providing parents with a road map for how to do FBT. It complements the family-based treatment that they're getting in their communities. With federal funding for something like that.... They exist as a touchstone for parents. They operate to fill some of the gaps. I think with awareness and with peer support, a lot of parents would have the additional resources.

Ms. Niki Ashton: Thank you very much.

Just quickly, Ms. LaBorde, we've heard from others that treatment often is blind to issues of diversity, or perhaps people in the field are, whether the diversity is in girls of colour, LGBT girls or boys, or disabled girls. I'm wondering if you could speak a bit to the importance of recognizing these factors.

Ms. Lisa LaBorde: The narrow view of who is affected by this illness affects families deeply because the illness is very isolating. Caring for your child and the level of focus that takes means that families are often quite practically isolated during the care period. Also, it's isolating in that if you fall into one of the groups that you've mentioned, the understanding isn't there. The awareness isn't there. So you are educating as you are caring for your child. The burden of that is quite onerous. I think that public awareness that shifts how the public understands eating disorders is helpful.

[*Translation*]

The Chair: Thank you very much.

Ms. O'Neill Gordon, you have the floor for seven minutes.

[*English*]

Mrs. Tilly O'Neill Gordon (Miramichi, CPC): I want to thank both of you for being with us today. Congratulations and thank you for all the work you do. We realize it is a disorder that requires a lot of work and understanding. We also want to thank you for sharing your personal stories. That is not easy for anyone to do. We certainly appreciate it because our focus and our study on this disorder have certainly given us a lot of information.

My first question is for Ms. Crawford. We have been told many times about the lack of community help. How large is your community of fellow professionals who specialize in this disorder? Are there enough? Should more be available? Or is it something that we find very common when we go to our regular doctor, a lack of that, I mean?

Ms. Carly Lambert-Crawford: That's a really good question. I know that for myself in particular, I practise out of Burlington and people travel hours and hours to get to me. I don't know how many exactly specialize in this field, to be honest, but I think that in my small city of Burlington, there are only two of us who will even take anybody with an eating disorder.

In larger cities like Toronto, there are more therapists out there, but the challenge with private therapy is that it's very expensive. Individuals, if they want to have a therapist in Toronto, are paying upwards of $200 an hour. It's not very feasible for most families.

● (1605)

Mrs. Tilly O'Neill Gordon: We have heard about the financial struggle parents have had in order to obtain information and get help for their children.

Although we've known this has been existing now for some time, do you see many positive or negative changes? Do you see changes being implemented in today's system that are bringing parents more awareness that this disorder really is a sickness, that it's something out there and something we need to be aware of and be ready to face?

Ms. Crawford.

Ms. Carly Lambert-Crawford: I wish I could say yes. I think the work that we've done through NIED in the last two years has been pretty incredible. One of the biggest doctors in the field, Dr. Woodside, said that he'd seen more change in the last year than in the last 30. That's positive in terms of bringing awareness. But the awareness isn't necessarily making the changes that need to happen. I think that one of our goals is to get the awareness out so that parents and supporters can be the advocates for the sufferer, to make up for the lack of understanding, unfortunately.

Mrs. Tilly O'Neill Gordon: Yes, and we did hear that too, that many times we think it's not really a disorder, that it's something they have to get over. This issue has to be brought forward to parents who are hit with that all of a sudden.

My next question is for Ms. LaBorde. Thank you for sharing your personal story.

We can be safe in saying we need changes out there to make people more aware of the disorder. What would you like to see change for others who are seeking help in our current system?

Ms. Lisa LaBorde: I think a focus on early intervention is very important for families. Often there's a gap between diagnosis and getting treatment. There's a wait-list time. There's much that can be done during that time in terms of education, in terms of support. Even linking parents to peer support during that time would be helpful so they could start with the process of treatment. Really to demystify treatment, much of it is around feeding your child, but how to do that is what parents need education on. I think if we focused on early intervention and got to families at the very beginning of the diagnosis, a lot of change could happen.

Mrs. Tilly O'Neill Gordon: What specific barriers did you face when you attempted to get treatment?

Ms. Lisa LaBorde: There wasn't anything available in the community. The barriers I faced were my doctor didn't notice it, identify it, and label it as such right away, so my child got much more ill than she needed to be. Then when I tried to find community treatment, there was nobody in the community practising FBT.

There were clinicians linked to the hospital program, but I wasn't able to access them prior to being in the hospital program. I don't think that has changed much. I think there is one therapist dealing with pediatrics privately in Toronto. That was an issue.

The financial burden was an issue. I had to take time off work. I took out a line of credit. It was very difficult during that time.

I would say education and finances were the biggest burdens.

Mrs. Tilly O'Neill Gordon: How can we equip children with the tools to resist the pressure to conform to beauty norms? We've heard much about this and that girls especially are being pressured into conforming to these beauty norms. What are some ways we can help these young girls to resist this strong pressure?

● (1610)

Ms. Lisa LaBorde: How can we help them resist it? By teaching them to be critical consumers of media. I think the schools are doing work in that aspect. I think there is a difference between eating disorders and disordered eating. I think we have to differentiate between the two. My experience, and I know the experience of many parents, is that they will say they don't feel the media actually contributed to their child's eating disorder in the sense that they feel they didn't start it, that it wasn't the precipitating factor. It may have contributed to maintaining the eating disorder once their children became ill, but they didn't see it as a precipitating factor. I think actually teaching our children how to be critical and how to understand the images and the media messages that they're receiving is important.

[*Translation*]

The Chair: Thank you very much.

I now give the floor to Ms. Murray for seven minutes.

[*English*]

Ms. Joyce Murray (Vancouver Quadra, Lib.): Thank you very much, both of you, for coming and sharing your stories. I can only imagine how difficult it is to be wrestling with a disorder and deadly illness of the brain that is not easily understandable and there aren't that many road maps for, and to work with your child and not know if you're going to succeed or not. I just want to honour your courage and strength, both of you.

I'm new to this committee so I haven't been through some of the other testimony and panels, so I'm going to ask a couple of questions to better understand.

In calling this a deadly illness of the brain, do the brain changes result from the reduced eating, or is it a brain illness that contributes to the reduced eating?

Ms. Carly Lambert-Crawford: Who would you like to answer that?

Ms. Joyce Murray: Whoever has some thoughts on that can answer.

Ms. Carly Lambert-Crawford: It's both. It's very much both. We know there are predisposing factors in terms of genetics and biology if there's anxiety, but we also know that when the brain is starved, it's very difficult to have cognition and to even be able to have therapy when you're that underweight. The newest research that they're doing out of Toronto will tell us that it's very much both, and that we have to rule out one in terms of how a lot of the treatments will make you get to a certain weight before they will even engage you in any sort of therapeutic intervention. Then they will see what it's like in terms of how to engage them in any sort of therapeutic intervention, as I've said.

Ms. Joyce Murray: I think Ms. LaBorde mentioned precipitating factors. Is there always or usually a precipitating factor? Is trauma a part of this, or is it not necessarily but sometimes?

Ms. Carly Lambert-Crawford: It can be. Not necessarily but sometimes would be the answer.

I think what we know is that certain personality types may be more predisposed. If you're an anxious child, or if you have a lot of worry in your family, or as Lisa mentioned, any sort of mental illness in itself, we notice there can be a genetic component. It doesn't have to just be an eating disorder, but if there's depression or if there's anxiety, that can play a role.

Ms. Joyce Murray: I'm interested in understanding more, partially because the testimony you've given so far is so similar to what I've been hearing for six months in the national defence committee study of ill and injured soldiers with respect to PTSD.

Some 30% of people get an operational stress injury, but the other 70% don't appear to, and 15% appear to suffer from PTSD from similar situations, while the other 85% don't. There's some predisposition even when there's a trauma is what I'm hearing, so that's a deadly illness of the brain as well, which is often accompanied by depression, anxiety, and addictions. It just sounded so familiar. Also, the impact on families and the absolute need to consider the family's well-being and to support the families are so parallel as well.

Of course, there is the issue of stigma and how we reduce the stigma. What would you recommend in terms of a societal shift in seeing this as a brain injury and not as something to hide? Are there some principles you would suggest for how to continue moving forward in our society to accept, support, and not stigmatize eating disorders?

● (1615)

Ms. Lisa LaBorde: In terms of removing the stigma, everybody thinks they know what an eating disorder is. I think it's about shifting that perception from the sort of after-school special idea of the eating disorder to the reality of what it is. I think shifting it so that we understand that any of our children can be affected by this, that it is a biological brain disorder, that it is not something children choose, that it is not something families create.... You can't give your child an eating disorder.

I think the notions that exist now lead to the stigma. I think there's a distancing, because people think they understand it and they think it's something that doesn't happen to them or won't happen to them. I think we do have to change that.

On the new evidence that's coming out now, I think the public perception lags behind what we know now about eating disorders. Some of this is about making that trickle down to the general public, what the clinicians know, what the researchers know now, today, in 2013, and having that widely disseminated in a way that reaches the general public.

Ms. Joyce Murray: Are the general practitioners and the medical community an important place to start with that? How do we contact 36 million Canadians with education about a misunderstood biological brain injury?

Ms. Carly Lambert-Crawford: I personally think the other part of it is that it's an illness that is seemingly about food, which most people don't even think about. That makes the general population think that it's very simple. I often think that if people found out that I went to rehab for a drug addiction they would sympathize with me a lot more. However, because it's food they think, “Just eat,” or “Just stop eating,” or whatever your challenge is.

The other part of that, too, is that eating disorders are very rarely seen under the umbrella of mental illness. When we do all of these mental illness campaigns in terms of Let's Talk Day, or anything like that, eating disorders are very rarely profiled. I know that all mental illness needs to have more awareness, but that would be one place where I would like to see it shift as well.

[*Translation*]

The Chair: Thank you very much, Ms. Murray.

Mr. Young now has the floor for five minutes.

[*English*]

Mr. Terence Young (Oakville, CPC): First of all, thank you both for your time today.

I wanted to comment that if there was a vote here today for mother of the year, you would win that from this committee. We admire you very much.

I want to ask you a couple of things. When you talked about a new skill set for parents, do you have any ideas how that could be accomplished by way of training? You said you wanted to start working on healing the patient quicker, that is, getting the patient's training faster or with some kind of skill set.

Do you have any ideas how to do that?

Ms. Lisa LaBorde: Linking parents to other parents who have been successful in working through FBT is one easy way to do that. There are best practices out there among parents who have gone through this, and sharing those is a very simple way to do that. It's a learning curve that's steep, but it's one that I think you manage quite quickly.

Mr. Terence Young: I'm thinking of a class at a local clinic or a local hospital where they can say, “There's a class this month, it starts on Monday. If you can take five days off work, or your spouse can, or something, we can get you to be part of the solution as soon as possible.”

Is that possible? Would that make that work?

● (1620)

Ms. Lisa LaBorde: I think so. However, the way that caring for a child with an eating disorder works is that parents who are in the process of actually caring for their children would not be in a position to take five days away to sit in a classroom. The therapy or the treatment is actually feeding your child, and under FBT you're feeding your child six times a day. In the beginning a meal can take two or three hours or a meal could take an hour. Then you have to watch to make sure that certain things aren't happening after a meal. Having the parents out of the home for the training wouldn't work for that length of time. Linking parents to Internet training and having psycho-educational training for them that is easier to absorb in small bits is a possibility.

Mr. Terence Young: Thank you.

Ms. Lisa LaBorde: I was just going to say—

Mr. Terence Young: Go ahead.

Ms. Lisa LaBorde: Sorry, go ahead.

Thank you.

Mr. Terence Young: I'd like to ask Carly Lambert-Crawford a question.

We know that misdiagnosis is a problem with a lot of girls with eating disorders. You mentioned that somebody prescribed anti-depressants for you which created a confused mess.

Can you please describe how this off-label prescribing made your situation worse, or at least did not improve it?

Ms. Carly Lambert-Crawford: Part of it was I was diagnosed with the anxiety and the depression very early on, probably when I was around 15. The medications weren't coupled with any sort of therapy. They kept trying me on different medications because it wasn't working. The medications weren't making me eat and they weren't making me get better. It's hard for me to pass judgment, but I will; it wasn't done properly.

Mr. Terence Young: You mentioned that you were discharged from hospital—you weighed ... pounds at 20 years old—because you were non-compliant. Basically, they blamed you for your own illness. [*Pursuant to a motion passed on April 30, 2014, a portion of this testimony has been deleted. See* Minutes of Proceedings] You had to wait four months for an assessment at TGH, and you had to prove you needed therapy. You then did four months in the program and then, because you were released too soon, you relapsed.

Here's a big question. Could that happen to a girl who shows symptoms of an eating disorder now, or is the situation much better now?

Ms. Carly Lambert-Crawford: That's a good question. The situation is slightly better. We have another four beds since the time I was in treatment. We have a Credit Valley program now. But I have lots of clients who have been on waiting lists for months and months and who are very near being hospitalized.

Mr. Terence Young: Thank you. That leads to my next question.

If, within a single payer system, that is, with the Province of Ontario OHIP still paying, would you support the development of private clinics with specialists to treat girls and women with eating disorders now?

Ms. Carly Lambert-Crawford: I would. I have two clients who I'm working with right now who are paying thousands of dollars a day to go to the States, because we have nothing here.

Mr. Terence Young: You would. Thank you.

I first met this lady years ago. I think it's Danielle's mother who runs Danielle's Place in Burlington. Is that right? Danielle's story was just like yours, right?

Joseph Brant Hospital basically kicked her out because she wasn't eating. The nurses blamed her for her own illness. Are you saying that could still happen now?

Ms. Carly Lambert-Crawford: Absolutely, yes.

The Chair: Thank you very much, Mr. Young.

[*Translation*]

Ms. Sellah, you have five minutes.

Mrs. Djaouida Sellah (Saint-Bruno—Saint-Hubert, NDP): Thank you, Madam Chair.

First of all, I would like to thank our two witnesses for having shared their different experiences with us. One of them took care of her daughter, while the other is a survivor of anorexia nervosa.

I would like to mention that I am a health professional. I agree with you because after hearing from many witnesses who have appeared before our committee, we have understood that the health system has many shortcomings in terms of medical resources, infrastructure and family support.

I am also troubled by the fact that when people suffer from eating disorders, they are put on a waiting list before receiving treatment. I believe that is a problem that all levels of government should examine and try to solve.

In the medical field, there have always been diseases that resist diagnosis, such as depression for example. In the past, people who did not show up for work were simply called lazy. No one realized that they were suffering from a physical illness, like diabetes, which required treatment, support and follow-up.

In the case of people who don't have the necessary resources to pay for treatment in a private clinic and who don't have a mother who is as devoted as Ms. LaBorde who took care of her daughter, what should be done? I would like to hear your opinion on what the different levels of government could do to improve this situation so that other people do not have to go through the same process you went through.

My question is for both of you.

● (1625)

[*English*]

Ms. Carly Lambert-Crawford: I think that's a really loaded question.

To answer the first part of your question, if you can't afford therapy and there's nowhere for you to go, you get sicker. I think Lisa raised a really good point in that you have to have early intervention, and it's during that time when you get diagnosed that, if you're not doing anything, you get sicker. I'm an example of that; Lisa's daughter is an example of that. It happens all the time. That's why our system is broken. There is no simple way to put it.

People go home from the doctor's appointment and they think, “I'm not sick enough,” and then they spiral.

[*Translation*]

Mrs. Djaouida Sellah: Ms. LaBorde, do you have something to add on this subject?

[*English*]

Ms. Lisa LaBorde: No, I agree with that. I think early intervention is key. I think supporting the community to be able to support the families.... We're seeing presentation in younger and younger children, but I also wonder if that's a matter of its being caught and addressed earlier. Some of it is to ensure children don't languish at subpar health for a very long time. Yes, support community resources.

[*Translation*]

Mrs. Djaouida Sellah: Ms. LaBorde, when you told us how you took care of your daughter, I was very surprised. I congratulate you for your sacrifice and for having had the courage to quit your job and to take on debt. I assume that you took on this fight by yourself and without the means to try to save your daughter.

In your opinion, what would you have liked the community or various governments to do for your daughter or for you as a caregiver?

[*English*]

Ms. Lisa LaBorde: I think part of the reason I had to do this is she was acute by that point. That was nine months from when I noticed something was wrong.

Had my family doctor been able to provide me with information earlier on, I may not have had to take time off work. I may have been able to address the issue in a much easier way, but we were some eight or nine months along in the illness. I think that is an example of what happens when you leave it too long. The cost to the individual, the cost to the family, the cost to the taxpayers is much higher. I think supporting me earlier on would have been beneficial to us all.

● (1630)

[*Translation*]

The Chair: I would like to thank the witnesses for being with us today. You have greatly enriched our study.

We will suspend for a few moments so that we can go in camera to discuss the committee's future work.

Thank you very much again, ladies.

[*Proceedings continue in camera*]

Published under the authority of the Speaker of
the House of Commons

SPEAKER'S PERMISSION

Reproduction of the proceedings of the House of Commons and its Committees, in whole or in part and in any medium, is hereby permitted provided that the reproduction is accurate and is not presented as official. This permission does not extend to reproduction, distribution or use for commercial purpose of financial gain. Reproduction or use outside this permission or without authorization may be treated as copyright infringement in accordance with the *Copyright Act*. Authorization may be obtained on written application to the Office of the Speaker of the House of Commons.

Reproduction in accordance with this permission does not constitute publication under the authority of the House of Commons. The absolute privilege that applies to the proceedings of the House of Commons does not extend to these permitted reproductions. Where a reproduction includes briefs to a Committee of the House of Commons, authorization for reproduction may be required from the authors in accordance with the *Copyright Act*.

Nothing in this permission abrogates or derogates from the privileges, powers, immunities and rights of the House of Commons and its Committees. For greater certainty, this permission does not affect the prohibition against impeaching or questioning the proceedings of the House of Commons in courts or otherwise. The House of Commons retains the right and privilege to find users in contempt of Parliament if a reproduction or use is not in accordance with this permission.

Also available on the Parliament of Canada Web Site at the following address: http://www.parl.gc.ca

Publié en conformité de l'autorité
du Président de la Chambre des communes

PERMISSION DU PRÉSIDENT

Il est permis de reproduire les délibérations de la Chambre et de ses comités, en tout ou en partie, sur n'importe quel support, pourvu que la reproduction soit exacte et qu'elle ne soit pas présentée comme version officielle. Il n'est toutefois pas permis de reproduire, de distribuer ou d'utiliser les délibérations à des fins commerciales visant la réalisation d'un profit financier. Toute reproduction ou utilisation non permise ou non formellement autorisée peut être considérée comme une violation du droit d'auteur aux termes de la *Loi sur le droit d'auteur*. Une autorisation formelle peut être obtenue sur présentation d'une demande écrite au Bureau du Président de la Chambre.

La reproduction conforme à la présente permission ne constitue pas une publication sous l'autorité de la Chambre. Le privilège absolu qui s'applique aux délibérations de la Chambre ne s'étend pas aux reproductions permises. Lorsqu'une reproduction comprend des mémoires présentés à un comité de la Chambre, il peut être nécessaire d'obtenir de leurs auteurs l'autorisation de les reproduire, conformément à la *Loi sur le droit d'auteur.*

La présente permission ne porte pas atteinte aux privilèges, pouvoirs, immunités et droits de la Chambre et de ses comités. Il est entendu que cette permission ne touche pas l'interdiction de contester ou de mettre en cause les délibérations de la Chambre devant les tribunaux ou autrement. La Chambre conserve le droit et le privilège de déclarer l'utilisateur coupable d'outrage au Parlement lorsque la reproduction ou l'utilisation n'est pas conforme à la présente permission.

Aussi disponible sur le site Web du Parlement du Canada à l'adresse suivante : http://www.parl.gc.ca