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# Official Report of Debates (Hansard)

**Wednesday 17 June 2009**

## Select Committee on Mental Health and Addictions

Mental Health
and Addictions Strategy

Chair: Kevin Daniel Flynn
Clerk: Susan Sourial

Assemblée législative
de l’Ontario

Première session, 39e législature

# Journal des débats (Hansard)

**Mercredi 17 juin 2009**

## Comité spécial de la santé mentale et des dépendances

Stratégie sur la santé mentale et
les dépendances

Président : Kevin Daniel Flynn
Greffière : Susan Sourial

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

# SELECT COMMITTEE ON MENTAL HEALTH AND ADDICTIONS

# COMITÉ SPÉCIAL DE LA SANTÉ MENTALE ET DES DÉPENDANCES

Wednesday 17 June 2009

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*The committee met at 0901 in the Sheraton Hamilton Hotel, Hamilton.*

## MENTAL HEALTH AND ADDICTIONS STRATEGY

### MENTAL HEALTH RIGHTS COALITION

**The Chair (Mr. Kevin Daniel Flynn):** Okay, if I could ask the members to begin taking their seats, we can get started by calling forth the first delegation, the Mental Health Rights Coalition, Frances Jewell. Frances, if you'd like to come forward to the end of the table. Make yourself comfortable; pour yourself a glass of water, if you'd like.

As we travel across Ontario, everybody is being given 20 minutes, so you can use that any way you see fit. If you could leave some time at the end of the presentation for any questions and answers, that would be good, but it's not necessary. Apparently, the mikes work better when you're about a foot away from them. Other than that, the time is yours, and welcome.

**Ms. Frances Jewell:** Thanks very much. I'm delighted to be here this morning. My name is Frances Jewell. I'm the executive director with Mental Health Rights Coalition here in Hamilton. I'm also very happy to be the first presenter, hoping that you'll be nice and fresh. I'm sure that by the end of the day it's an awful lot of information for you. I did bring a PowerPoint presentation; however, I brought a memory stick, and wasn't advised to bring a computer. So I'll have you refer to this; it's probably easier on your eyes.

Again, I work for the Mental Health Rights Coalition here in Hamilton, and we are a consumer-survivor initiative, also known as a CSI. That CSI is not "crime scene investigation"; it is consumer-survivor initiative. Perhaps you've already heard that term. The Mental Health Rights Coalition has been, I believe, incorporated since 1991. Our goals are to reduce stigma, reduce isolation, increase accessibility, support integration and promote participation.

And what do we have? We provide peer support. That means that our operation is run by peers for peers, by people with mental illness for people with mental illness. We provide direct peer support for people. A person can drop in to see us; they can give us a telephone call and receive counselling, support, help with finding transportation—all kinds of different things. We are also the only CSI in the area that provides training for peer support workers. St. Joseph's Healthcare here in Hamilton has made it policy that all of their peer support workers are trained by us at Mental Health Rights Coalition. We have a drop-in centre, we have various committees, volunteer opportunities, jobs available as well—job postings, etc.

Still on page 1, under stats, we had 3,765 individual visits for a total of 5,671.7 hours with 2.8 full-time employees, and my budget—please note the budget—is $133,000, shockingly low.

If you go to page 2, what is peer support? I've touched on that already. Peer support means that a peer provides support, and through various studies it has been proven that a person with mental illness likes to connect with someone else who has experienced mental illness. Again, we have a drop-in centre. We're open Monday to Friday, 11 till 4. How will peer support help? It gives people exactly that: support within the community and a connection with someone else who has experienced perhaps the system, perhaps recovery—all of those things.

Community partners: We are in partnership with a number of people in the Hamilton area. We are part of the Hamilton Addictions and Mental Health Network. You'll see a number of people listed there: COAST, CAMH, St. Joe's and Good Shepherd.

The rest of the PowerPoint really talks about some statements that recently came up from people who have experienced mental illness. We ran some focus groups to gather some information to report back to the LHIN and the Ministry of Health. You'll see a number of quotes here, and I would like to read them to you because I find that they are pertinent to today.

The first one is: "If I had cancer there, I would be treated with respect. But I have depression so the government does not care about me."

"I want you to know that mental illness is a major part of today's society."

"Illness is not the enemy ... ignorance is."

"We are all gifts from God. It doesn't matter how sick we are, we are special."

"Mental illness ... make it go away? I can't make it go away."

"Get to work and provide funding to help us recover."

"I want the government to provide money to those of us with mental illness so we will have a better standard of living beyond subsistence."

"I would like to have more fun activities on the weekend so I don't feel so alone."

"Empower diversity. Help me get well."

"Please increase the funding for mental health services and also reduce stigma issues for us."

"I need you to listen."

"How many more times will the government ask us what they can do to help before they actually do something? How many more people will die from mental illness?"

"A peer worker in every emergency room in the province."

"Don't stigmatize mental health consumers. Give them adequate support."

"We need more money for seniors with mental illness."

"We need a peer support worker in every emergency room in Ontario."

"Don't stigmatize people with mental illness. Give people adequate financial support."

"Peers (who are experts in mental illness) need to be involved in all aspects of a person's recovery and paid accordingly."

"I deserve the opportunity to recover from mental illness as much as I would from cancer."

"Peers who are experts in mental illness need to be involved in all aspects of recovery and paid accordingly." I apologize; I think that was a repeat.

So that's my presentation in a nutshell, and I would like to ask you if you have any questions.

**The Chair (Mr. Kevin Daniel Flynn):** That's great. You left a lot of time for questions, so we'll sort of rotate it and start with France.

**M$^{me}$ France Gélinas:** Good morning. I'll start by apologizing for missing a part of your presentation. I came with short sleeves, and it was way too cold in here to stay with short sleeves so I had to run back.

I had a chance to read through the slides that I missed. When you talk about peer support, are you putting the focus mainly on mental health survivors or are you putting it more broadly to include families of people who have lived with mental illness etc.?

**Ms. Frances Jewell:** Peer support, where I am, is geared to people with mental illness. However, we do have family members who come in to access information, and they often identify that they are in need of peer support. So we certainly wouldn't send someone away. We also have people who come in with addictions issues, but again, we are not an addictions-focused group; we are more mental health and mental illness. But people will come in and ask for assistance.

**M$^{me}$ France Gélinas:** I don't know if I missed it, and if I did, I apologize again, but can you explain a little bit to me what peer support would do and also what they don't do?

**Ms. Frances Jewell:** Certainly. For instance, if you're a physician, your peer is another physician. With our agency, a peer is someone with lived experience of mental illness. We provide training for peers, for people who have experienced mental illness, to become peer support workers. So a peer support worker could provide anything from one-on-one counselling to helping a person navigate a computer system to finding, perhaps, affordable housing or transportation. They would do many things.

**0910**

**M$^{me}$ France Gélinas:** You said you don't turn anybody away. But it would be mainly people who have a diagnosis of mental illness?

**Ms. Frances Jewell:** We're not interested in whether they're diagnosed with mental illness. They come in. A person would identify themself as having mental illness, but we don't talk about diagnosis and we don't talk about medication. Sometimes medication would come up, but we certainly don't advise on medication or whatnot.

**M$^{me}$ France Gélinas:** Does your agency do any work in what I would describe as health promotion or illness prevention?

**Ms. Frances Jewell:** With a budget of $133,000, no.

**M$^{me}$ France Gélinas:** You focus your attention?

**Ms. Frances Jewell:** We certainly try to model healthy behaviour. I would be delighted to do something on health promotion, absolutely delighted to do that. But with a budget of $133,000, there is no budget for that. There's no room for that.

**M$^{me}$ France Gélinas:** Okay. Let's say a francophone person comes to your agency. Are you able to meet their linguistic needs?

**Ms. Frances Jewell:** No. We do have someone who speaks Spanish, but I don't have a French-speaking staff member. Again, I would be delighted to have resources to afford to hire an additional person. That would be wonderful.

**M$^{me}$ France Gélinas:** Where does your funding come from?

**Ms. Frances Jewell:** The Ministry of Health, LHIN 4.

**M$^{me}$ France Gélinas:** Thank you.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, France. Helena?

**Ms. Helena Jaczek:** Thank you for your presentation. You're actually reinforcing some of the issues that we've heard already. In fact, we heard peer support referred to as peer navigators, which I really liked, giving that sense of helping people navigate their way through the system.

I have a question about the funding as well. Would you have also received, then, a Trillium Foundation grant?

**Ms. Frances Jewell:** We did for peer support training. That's actually how we developed the peer support training program. So the Ministry of Health doesn't actually pay for that; we paid for that through Trillium.

**Ms. Helena Jaczek:** If you had more funding—obviously, you've said no wait time. What would you do with more funding? There was the comment from one of the survivors related to activities on weekends. What would you do if you did receive more funding?

**Ms. Frances Jewell:** I would do a number of things; one of them would be to put myself in a building that was secure, safe and appealing. Again, my budget is so small that I'm in a building that's not really suitable. I don't have wheelchair access, and I've tried to accommodate that. I do accommodate that in some way, but with some difficulty.

I would probably expand my hours. Again, we're open 11 to 4. That's midday. Many people who come to visit us live in second-level lodging, so at 9 o'clock, after they've received their breakfast, they are given a little brown bag with maybe a 99-cent horrible—you know, those dried noodles—and often they're told, "Don't come back until dinner." So people come in to see us. I would like to provide all kinds of groups for people to attend, whether it be—I'm not even really sure. I don't know that resumé writing is what people want, but they're looking for additional training in all types of things. I would provide training, I would expand my hours and I would put us into a safe, clean, welcoming environment. People with mental illness are often going to substandard locations for services.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you. Any other questions from that side? Maria?

**Mrs. Maria Van Bommel:** Please. You left us with this as well.

**Ms. Frances Jewell:** Yes.

**Mrs. Maria Van Bommel:** If you could explain what—I'm just reading through the foreword. That's about as far as I got before we got started.

**Ms. Frances Jewell:** Certainly. The peer primer was part of a Trillium Fund project with the Hamilton Program for Schizophrenia. With that project, we trained peer support workers and seconded them to mainstream agencies throughout Hamilton with great success. So we're very pleased.

**Mrs. Maria Van Bommel:** What types of agencies did you place them in?

**Ms. Frances Jewell:** The Hamilton Program for Schizophrenia, St. Joseph's hospital—sorry, they call themselves St. Joseph's Healthcare now—WPOP, the Canadian Mental Health Association. We had tremendous feedback from that. Part of the peer support primer was also an art project, and that was—

**Mrs. Maria Van Bommel:** Yes. I saw the art pieces in the back.

**Ms. Frances Jewell:** There were a few people who received colour photocopies of that. I thought there were five people showing up today, so there were five colour and the rest are black and white. But if you get a chance to see the colour—

**Mrs. Maria Van Bommel:** Even in black and white, they're quite impressive.

**Ms. Frances Jewell:** So the art program was part of the recovery program as well. That would be something I would love to see us connect with as well. We have a very big arts community here in Hamilton, and I would like to see the art program expanded into mental health and mental illness and recovery.

**Mrs. Maria Van Bommel:** Thank you.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you. Sylvia?

**Ms. Sylvia Jones:** Thank you. Good morning. When you talk about peer support, with your 2.8 full-time equivalents, are your staff training the peer support workers? Tell me more about the process. Is it one on one? Is it group peer support? Because I see on page 16, where you talk about a brief history, that you mention support groups, but I'm not sure if that's directly related to what you're doing or just generally.

**Ms. Frances Jewell:** Well, we do run support groups at our centre. However—

**Ms. Sylvia Jones:** And that would be in that 11-till-4—

**Ms. Frances Jewell:** Yes, that's right. However, the training part of it—if a person identifies that they're interested in becoming a peer support worker, they would come in to see us. We interview them and make sure that they're a suitable candidate in many different ways. We try to run three training sessions per year. They are 12-week training programs and they are offered free to people, to the potential peer support worker.

**Ms. Sylvia Jones:** In that 12-week period, how many hours of training would you give before that peer support worker would be ready to go out and assist?

**Ms. Frances Jewell:** It's 24; however, they don't just simply go out and assist then. We ask them to do practicum, hands-on hours. We ask them to do that within our agency, if possible, and if not, then we certainly would support them if they told us that they were doing a practicum for someone else, for another agency. We would say, "Absolutely, we support that." They then come back for a final interview, and they're graded and passed. Certainly, not everyone is suitable as a peer support worker.

**Ms. Sylvia Jones:** Do you keep in contact throughout the subsequent months or years, in terms of upgrading, touching base? What kind of support does the peer worker have?

**Ms. Frances Jewell:** That's a good question, because peer workers often do have a lot of stress or burnout when they go into mainstream agencies. We invite them back several times a year, not necessarily for training but more of a support—a debriefing.

If we could train all of the peer workers in Hamilton and second them out to programs, to other agencies, that would be ideal, because we do have a concern that what happens is, when peers go to work for mainstream agencies they lose the peer focus and they become much more of the agency focus, which, in our opinion, doesn't support recovery in the same type of way.

**Ms. Sylvia Jones:** Okay. One final question, and this comes from—we're in the third day of our committee travelling. We are hearing more and more about people who have a dual diagnosis: They have a mental health issue but they also have an addiction—whatever starts first; it doesn't really matter. And yet, at the beginning of your presentation, you mentioned that it's challenging for your organization to deal with the double.

**Ms. Frances Jewell:** Well, I think that, really, it has been very much a separate issue—or not that it is a separate issue; it's not. But it has been sort of played out as a separate issue—addictions over here; mental health over here—and it is not the case. We're very interested in collaboration and we do work with other agencies that have more addictions experience. For instance, there's a fellow in town who runs a number of houses here and he has suggested that he would like to hook up with us in some way to really promote the mental health and addictions piece. It's really a traditional thing. It's been more mental health, but without a doubt we have many people who have addictions problems, all types of things. We're aware of that. Again, it comes down to funding for many of us.

**Ms. Sylvia Jones:** Sure. Do I have time for one more question?

**The Chair (Mr. Kevin Daniel Flynn):** Unfortunately, you don't. Thank you, Sylvia, though, anyway. And thank you for coming today, Frances. We really appreciated that.

**0920**

## RAISING OUR CHILDREN'S KIDS

**The Chair (Mr. Kevin Daniel Flynn):** Our next delegation this morning is Barbara LaFleshe from Raising Our Children's Kids. Barbara, if you'd come forward.

*Interjection.*

**The Chair (Mr. Kevin Daniel Flynn):** Okay, there are four of you. We have four seats and four microphones. This will all work out. Now, the thing is, when you do speak—is somebody listening? Yes. When you do speak, you need to identify yourself for Hansard so they'll know which one of you is speaking. So before you speak, if you would identify yourself, that would be great.

Like everybody we've seen before us, you have 20 minutes. You can use that any way you see fit. It is better, we've found, if there is some time left over at the end, but it's not necessary. You don't have to do that if you don't want to. You can use the whole 20 minutes yourself if you want to.

Having said that, the time is all yours.

**Ms. Barbara LaFleshe:** Good morning. My name is Barbara LaFleshe and I'm with a group called ROCK Canada. We are located here in Hamilton. We're a support group. The name ROCK is Raising Our Children's Kids.

To my right is Beverly McIntosh, who will be talking on the fetal alcohol syndrome story. Next to her is Christine Joseph-Davies, a grandmother with our group who is raising a grandchild who has autism. On the end is Diane Chiarelli, our president, who is going to introduce the double-decker sort of phase of our lives, where she is raising her child and her grandchildren and is looking after her extended family.

Just to start off, I could tell you a huge, long story about my daughter and her mental health situation. We thought she was just a rebellious child. I have four children, so I figured one of them would give me a run for my money. Initially, I thought she was just a hippie child, because she was into the environment and all of this, but it went on further. Her life was just chaotic. She was just running from thing to thing to thing. I was trying to keep up, take her to doctors' appointments.

Literally, I found out that at that range, at 16 years old, family physicians will not give you any information about your child without that child's permission. Then, when it led to her trying to take her life, which she did try to do four different times, it was so severe that she had a security guard at the foot of her bed for days on end. She was placed in bubble rooms. She's run away from the hospitals and been pulled out of our house and thrown on the front lawn with a policeman's knee right in her back. She has been handcuffed and put in police cars and taken back to hospitals.

Literally, I realized at that point—because we were proving that we were parents who cared about this person, this child of ours, this sister—we could not get information because of patient rights. It was at one point a social worker for the city of Hamilton told our family that they were going to place her in a lodging home and that they were going to help her. What really happened was that she was placed in a lodging home, and a lot of the lodging homes in this city are privately owned and run. A lot of money is being made by private entrepreneurs. They're not fed well but there is a cook who does care, and she is the cleaner, she doles out the medication. Yes, you do see the owners sometimes, but they're not in the picture, and there is no pressure on these people to participate in any programming to help them recover.

Literally, they visit other members of the psychiatric community in various lodging homes. This is where she met up with the father of my grandchild. He was out of the jail system, and no doubt he has mental illness as well.

It's from 16 years up to 88, even street people; there was an 88-year-old woman in the same lodging home. No locked doors; men and women together, using the same bathrooms. It's just a free-for-all. It wasn't just one lodging home; I've been in many.

She brought many people to me to help or give lunch or a few dollars to. It was just an ongoing, chaotic, horrendous situation that our family has endured. But out of that came our granddaughter, and she actually—my daughter is very clever. I was told by a psychologist that she's retarded, and I said, "That's impossible." She's very manipulative at the same time, and was smart enough to get a midwife and actually have the baby come right to my apartment, that I was going to help her raise this child. But within 10 months, she became very ill again and went back into the hospital.

She has introduced three different men as fathers to my granddaughter—the biological father, the chosen father and the new father. Literally, all of these people are on ODSP and have mental problems themselves. But it's her lack of choices that has caused us a great deal of stress and concern.

We're coming to you because we're now raising grandchildren in this story. We've had difficultly with the custody stories. On ODSP they have free legal aid, and they are taking us down financially as well. We need intervention. We need our government to know that there are caring parents out there. We need parents' rights in the situation of raising these children, as well as grandparents' rights.

I'll introduce Bev McIntosh.

**Ms. Beverly McIntosh:** I'm a grandmother of two fetal alcohol children. Rosina was nine months old when I got her. She was born in Toronto. I didn't even know that she had been born until children's aid called me and wanted to talk to me because the mother couldn't handle her. She was also two pounds when she was born and was in the hospital for four months. She has had major problems since she was a baby. She had problems drinking, swallowing Pablum. She wasn't on food until she was two years old. It was just Pablum and milk and vitamins to try and keep her up, because she just couldn't chew; she couldn't eat. Now she can eat, but she's still very picky—very small, soft stuff. She doesn't like anything hard still.

But she has many, many problems other than that as well. She's developmentally delayed by three years. In school she's in grade 4 but she's doing grade 2 work in grade 4 because she can't handle any higher. Each year she moves up. It depends. She might still be in grade 2 next year when she moves up.

Besides that, she is a very volatile child now. She's 10. She just gets very angry and she'll kick somebody or bite them. She gets very, very violent when she gets angry. It's because if she can't sit down and play her videogame or she can't watch the TV—"You've got to do some homework"—she just blows up. Other times, she just blows up for no reason at all. She just picks on me because I'm her parent per se, even though I'm her grandmother. She actually misses out on a grandparent because I can't be a grandparent either. I have to be the one that has to tell her, "You've got to do this," you know?

She's a beautiful little girl, although she's tiny. She's only 42 pounds and she's 10. But she's never going to be very big because of the—her fetal alcohol is more severe than her brother's because the mother drank at the beginning. She has the features and is very developmentally delayed.

**0930**

Now, when Austin was born, the mother had moved to Hamilton. He was born and taken to McMaster to have his hair tested, and he had alcohol in his hair follicles, although the mother, to this day, says that she didn't drink. He doesn't have the full one; he has the behaviours, and he can't control his behaviours either. So when the two of them get together, it's like a fighting match in a ring sometimes, and I have to get in between and separate them.

He, right now, is going through a large problem. The school called me, and I went in to see this picture: It has a bat on this wall, and the story was that the bat came in the house, the father took a knife and stabbed the bat, and the blood's running down on the wall, and then he chased the kids out.

So he's now back in Lynwood Hall. This is his second time to go up there. The lady's coming tomorrow to talk to me and see what we can do for him. Dr. Calvert, the pediatrician that they are with right now, has upped his meds, doubled them from what they were before, trying to keep him calm. Hopefully, it doesn't put him to sleep, because he's on Concerta, 56 milligrams twice a day, plus Strattera, plus risperidone. So he does get a large dose of medicine to try to help him when he's in school. Mind you, when he comes home, the medicine is not working and I get the brunt. He's slow too; he's a year behind in his schooling. He's developmentally delayed, but just a little bit.

They both are very volatile, and for me it's very frustrating to try to deal with this and to try to help them to get through all these little nitty-gritties that they're doing all the time. It's hard for me to do it by myself. I do get a CCAC worker for one hour a night so I can cook their supper. She helps them a bit with their homework and then I finish it with them later. I get that hour break so I can cook, because I can't cook very well with them around. They are always running in, and I'm afraid of them—because they're not afraid of anything, they might pick up the frying pan or whatever I'm doing, boiling water, so I have to be very careful with them.

I'm told I have to stop now. Sorry.

**Mrs. Christine Joseph-Davies:** I'm Christine Joseph-Davies, and I'm raising my grandson. My stepdaughter is mentally challenged and she had a child, and the children's aid called us and told us that if we didn't take him—go through the kinship care program and take the child—that he would be put up for adoption. There's nobody else who would step forward, so we did, and we had to jump through all the hoops that the children's aid put up, fast-track into the kinship care program. We're the first family in Hamilton to go from kinship to foster care and become foster parents.

We left the children's aid because of our grandson being diagnosed with autism. One of the problems of having an autistic child is getting the diagnosis. There's a two-year waiting list to see a doctor who can say if he is or isn't autistic.

I know that in other cities the grandparents get financial support. In Hamilton, some of us do, some of us don't. I don't. People assumed that he was fetal alcohol; they also assumed that he was my child. I have a lot of prejudice against me, being native. I'm getting it from both sides. In the native community, we believe it takes a village to raise a child, but a child belongs with his parents, so my culture, my people, have kind of pushed me aside because I'm going against my traditions by raising my grandchild.

My "baby" is 24 years old, and I didn't think that I would ever be raising somebody else's child at this age. It's almost like being 16 and finding yourself pregnant and stuck. My life is over in a sense, but my life is beginning again. My life revolves completely around my grandson. We haven't been out together in four years, because nobody can take care of him. He doesn't talk, and he won't go to anybody but us.

After we finished the kinship care program and he came to live with us, he was about three months old, and about three pounds also. He was addicted to crack and his intestines didn't grow. There are all kinds of physical ailments wrong with him. He stayed in the custody of the children's aid but lived with us until he was nine months old, and they pushed us and pushed us and pushed us to get custody of him, and then once we got custody they dropped us like a hot tomato. There was no financial help whatsoever.

We were 44 years old, both of us, when we got him. Brandon will be five in December. We didn't have a crib or a diaper or a toy, because our children had grown up and moved away. There was no help, nowhere.

So you're kind of on your own. There's no help, nowhere. The mother is in the HOMES program in Hamilton—it's for mentally challenged adults—and she doesn't have a care in the world. She has her freedom and her life is great.

One of the things that I feel I'm always yelling and screaming about, maybe: She goes to these mental health support group meetings and she meets men. I believe that they should be segregated. There should be males and females. One of the side effects from the antipsychotic drugs that she has to take is a higher libido, so you have all these females who are mentally challenged and these men are looking at them, and if you look at a mentally challenged woman for more than three minutes, obviously you love her, and she's going to sleep with you. That's what's going on, and that's how Brandon was born. I just think those meetings should be separate.

Help should be available. We've gone through our savings. Having an autistic child, they don't automatically get diagnosed. You're put on a waiting list. We're on a waiting list for—I think we have two more years before he can see an autism spectrum disorder team in Hamilton. So it's a long process, and it's hard. We need support: financial, mental and emotional.

**Ms. Diane Chiarelli:** Good morning. Our organization, ROCK, recognizes the huge impact that mental illness and drug and alcohol addiction have on our community. It's quite serious; it's like a huge ball of wax that you can't unravel. There are just so many directions and places that these addictions and mental illness cause valuable resources to be just used up immediately, leaving the community almost bankrupt.

We are very active in our community, not just with the fact that we raise our grandchildren, our extended family, or have struggles. We all have huge struggles; they're not insurmountable, but they certainly are difficult. We lobby the government. We truly feel that change starts with each of us within our community. We make certain that we have people made aware of resources that are available to them and get them there.

Part of the problem within our organization is that many of the grandparents are raising what you would call children who have been born as a result of mental illness or drug addiction. A lot of them do have significant disabilities. So you have a grandparent who is trying to deal with a parent who is mentally ill and challenging you at Family Court, or a mentally ill parent who is on a supervised access program, and then you have a child who is suffering as well.

We truly believe that there's a cycle as well with mental illness. A lot of the individuals are incarcerated and then either are released into a lodging home or become homeless, which causes a circle, because then they commit a crime if they are not on their drugs and are either rehospitalized or back incarcerated. It's a very difficult cycle to break.

We feel that there are not enough supports in place, or maybe not the right supports. We feel that these individuals truly are suffering. They have a daily battle with depression and addiction, okay? Nobody wakes up one morning and says, "Jeez, today I choose to be mentally ill." This person does have an illness and they're suffering. It's the same with a drug-addicted person.

**0940**

I think we feel, the whole membership in our group, that we must make a concentrated commitment at all levels of government to support and create new programs and continue funding good programs to help these suffering individuals. We can't allow them to fall into the cracks, because when we do that, we have significant problems within our community that could have been prevented. We have to focus on the very real fact that their human status must be restored. These people are suffering. They need that support and help and need to realize that there is hope in life for them. We have to allow them to step out of their shadow of despair and hopelessness and step into the light of hope.

As members of our community, we must be accountable. If we're not mentally ill, if we're not drug-addicted, if we have the intelligence, we have to be accountable to bring programs and assist these members of our community. It is vital to the community. Some people say nothing changes; however, it does when all members of the community and all levels of the government come up with a vital and viable solution to these problems.

I believe that it exists. There are solutions. I believe that we can find the right solutions and programs for these individuals, that we must to protect the future generations that follow. You can have chaos like this: communities losing all their funding; homelessness; crack addicts like we have in Gore Park, and the mentally ill going there because they're out of the lodging home. It creates such a mix, it creates significant problems for the community as a whole. I believe that we will find a solution if everybody remains committed. Thank you very much.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Barb, Bev, Christine and Diane. Unfortunately, you've used up all your time, but you gave a wonderful presentation.

## MADHURI AND KRIS RAMAKRISHNAN

**The Chair (Mr. Kevin Daniel Flynn):** If we could have the next delegation come forward, Kris and Madhuri Ramakrishnan.

**Ms. Madhuri Ramakrishnan:** He's just trying to hook up the computer.

**The Chair (Mr. Kevin Daniel Flynn):** Okay. Well, if you can make yourself at home there.

**Ms. Madhuri Ramakrishnan:** Okay, I will do that. Thank you. Good morning.

**The Chair (Mr. Kevin Daniel Flynn):** Do we know if the computer works?

**Ms. Madhuri Ramakrishnan:** Our computer works. We are just waiting for it to be connected.

**The Chair (Mr. Kevin Daniel Flynn):** Just while we have a second, for those members who are checked into the hotel, we need to all be checked out by 1 o'clock.

**Ms. Madhuri Ramakrishnan:** Maybe I can start.

**The Chair (Mr. Kevin Daniel Flynn):** That's fine. If this is only going to take a second, we can wait. If I was doing it, it would take about a half of an hour. That stuff—

**Ms. Madhuri Ramakrishnan:** That's why he's doing it.

My name is Madhuri Ramakrishnan and that's my husband, Kris, working on the computer there. Kris is a retired engineer and I'm a retired banker. Our son, who is very bright, when he was going to high school initially was a very popular kid and had a lot of friends. As he grew up, near the senior years, we noticed that he was losing his friends and was becoming more of a recluse. We kind of attributed it to the teenage years, growing up, hormonal changes, and figured he would grow out of it. So that was our assumption at that point. He went to the University of Waterloo in 2000 on a math scholarship and he went through university on and off, changing subjects.

In the summer of 2004, he came home for the summer. He could not hold on to a job, and we noticed that there was a great difference in his behaviour. We were getting concerned. We had him checked out. Physically he was fine. He was sleeping erratically. He would pace all night and sleep during the day. His behaviour was not consistent with who we thought he was. Our son is a very gentle, sensitive person, and he was violent towards my husband, pushed him a couple of times and swore at me. It was totally uncharacteristic of him, and we were getting quite worried. I spoke at the time to St. Joseph's, spoke to a resident psychiatrist because I didn't know what I was dealing with. We spoke to our GP and even spoke to COAST in Hamilton, which was the only one available at that time, but since we live in Burlington we could not use any of those services. Based on all the recommendations, we took him to Joe Brant Hospital in August 2004.

When we took him to the hospital, he was admitted first on form 1, which allows them to keep him for 48 hours, and then on form 2, allowing them to keep him for 10 days. We found that the nurses in the psychiatric ward weren't very knowledgeable. They said, "If these people just took the medicine, they would be fine." They didn't seem to have any compassion or any empathy towards the consumers, as the patients are called. We found that there was no information on mental illness. We had to look around to find even a pamphlet on SSO, which is the Schizophrenia Society of Ontario. When our son was put on form 2—they get legal rights, as the earlier person talked about, so they get a lawyer and they go through a review panel. He was allowed to come home. However, I was given the authority to administer the medicine, which really doesn't work. The psychiatrists there, again, were pushing pills, were not telling us what it was all about and not explaining what it was to our son, which does not help them because then they don't adhere to the treatment. They relied on the case managers to tell them what is going on, and the case managers are not always available. So when we came home and we needed the case manager, if they were not available they told us not to call police if it could be helped because only two police officers in Halton were trained to deal with mentally ill patients; otherwise, they might be handcuffed or tasered, and that was not a desirable situation.

With his medicine, there were many side effects. There was weight gain, which is a common side effect. When we would go to the psychiatrist, the appointment was given every six weeks and he would only spend about 10 minutes with our son and really did not ask him about his symptoms. His symptoms were, apart from weight gain, that he had erratic leg movements, he was pacing, his eyes were blinking and the anxiety was tremendous; he was very anxious at all times. This meant that we as caregivers were pretty well house-bound. We don't have any other family here, so there was no other help, and because of the stigma attached to mental illness, it's not always easy to start admitting this to your friends; you have to weigh the pros and cons. We had to be home all the time, constantly comforting our son. That meant there was no respite.

Then we attended the strengthening families together program with the Schizophrenia Society and found out that another set of parents had a similar experience with Joe Brant in Burlington. They were not happy with the medical team there. They told us that they took their son to CAMH, the Centre for Addiction and Mental Health, and their FACT Peel clinic in Mississauga, to the psychiatrists there. With great difficulty, Kris got our son into the early psychosis program there. Again, because we were in Burlington, it was difficult because they did not deal with Burlington; when we did get in, we found that the psychiatrist's whole approach was different. He and his case manager spent an hour and a half with our son and spent an hour with us. Even now, with all our appointments, they make sure that we are also heard and they talk about the medicine, they talk about why they're doing what they're doing. They also provide other help to the consumers. They have games day there, they take them out to different activities and they have counselling for parents. So the help that is provided by them is quite exceptional and was a lifesaver for us.

Now I'm going to let my husband do the balance of the presentation.

**0950**

**Mr. Kris Ramakrishnan:** The one great advantage our son has is his desire to study, which helped him immensely to realize that he wasn't doing well, and he went to the University of Waterloo. At Waterloo, he didn't take his medicine because he didn't believe it would help him.

CAMH has a remarkable case manager who went to Waterloo on her own time, along with a professor who took great interest in our son and the disability services in the hospital. They convinced him to go to the Kitchener-Waterloo hospital. We didn't realize how bad he was at that time because he was off the medicine. With schizophrenia particularly, or any mental illness, if you stop the medicine, it attacks you with a vengeance.

The hospital doctor, without checking anything, sent him back to the residence, saying, "You can walk there," which is about three kilometres. We didn't realize at that time that our son had a habit of thinking he could stop cars by crossing the street, holding his hand out and touching the car. He was a danger to himself, but the doctor discharged him. We went there because we talked to him and we found that he was incoherent. We went rushing there, and we couldn't find him. Then we called the police; they couldn't find him either.

We called the hospital and they said, "We won't do anything till 8 o'clock. That's when he's supposed to come back." But we said, "He's not in a position to go anywhere. He thinks he can stop traffic by going and standing in front of cars." Luckily, our daughter was a crown attorney at that time in Toronto, working for the ministry. She has a master's in neuroscience from McMaster University, so she's familiar with mental illness. She spoke to the police because we were concerned about what the police would do, because very few are trained in how to handle mentally ill people. They could taser or shoot them. She spoke to them, and the police were just going to put his picture on the local television. Then we phoned the hospital. He was back, which they were supposed to tell us, but they never did. We went to the hospital and saw him. We were shocked at the condition he was in, and the doctor had sent him out of the hospital. Then we spoke to the doctor. She realized her mistake and then kind of apologized. She put him on form 1, which is to keep him there for 24 hours. He refused to take the medicine. It's different than at Joe Brant, in the sense that they were all given rooms. I've worked for a lot of industries, travelled around the world. That's the worst thing you can do: put people in rooms with telephones. They never came out of their rooms. They monitored all their calls using voice mail. You couldn't talk to them and neither could they; they only came out when it was necessary. The whole thing was like a jail set-up with big fences and other things. Joe Brant is at least on the lakeshore here; you could walk around on the nice grounds. This reminded you of a jail.

Then we moved heaven and earth to move him to CAMH in Toronto, which is on College Street, because our doctor was from CAMH. We found there, again, that in the medical system all are not equal. Some of the nurses there were very good; some just sat in their office and never came out. Our son thought they were the best nurses because they never bothered him with medicine.

Our son fought tooth and nail. We are very proud of the way he behaved with all the form 1, form 2, form 3, form 4—all this to keep him to get him to take the medicine, because he refused again. Then the medicine he was on wouldn't work. That meant he went to a third medicine. At that time—even now, almost—in Ontario there are only four approved medicines for mentally ill people. The first one, in Joe Brant, had side effects. Number 2 was working well, then he stopped taking it; it didn't work in CAMH. Then he was on number 3, which caused high anxiety. He was curled up in the fetal position most of the time in the hospital; we didn't know what to do.

But I had read at that time—there is a book by Dr. Tory about mental illness. There are other medicines you could use to reduce anxiety and remove side effects. I asked the psychiatrist there, "Why don't you use them?" He said, "No. These people have trouble taking one medicine. How can they take three?" He forgot that there are caregivers who are begging for this.

If the Risperdal didn't work, there was only one medicine left, which very few people can use, and it has phenomenal side effects. So what are you going to do? There are only four medicines. At CAMH, being a research hospital, they said, "Don't worry. We can bring medicines from India on a research basis." There are 20 approved in India, 14 in the United States and about 12 in the UK. Here there are only four. Luckily, Risperdal worked and they discharged him home.

Then we went back to our FACT Peel illness outpatient ward, and there was what you call a CTO, a community treatment order. A community treatment order, we found out—we asked CAMH to give one, which makes the patient take the medicine. However, it's toothless in Ontario. You have no power. Ontario rights are very high. It's useless. He said, "There is no point in you having a community treatment order because you can't force him."

Consequently, our son had tremendous anxiety attacks caused partly by medicine and partly by illness. He would go around stomping his feet all along—we took long walks with him in Burlington, constantly comforting him. He would lie on our laps for hours, and we couldn't go anywhere. It was a bit worse than when it started in 2004. We were totally homebound. We both decided to retire and work from home only. I could rarely work at home. Sometimes he wanted me home; sometimes he didn't want me home. I went to every Tim Hortons you can think of with books when he kicked me out of the house, even the senior citizens' centre to sit and read because they have the nicest chairs in Burlington. He wanted constant comfort. He suffered from all these effects.

Then I became a volunteer for COAST in Burlington, which started with a guy in Hamilton. I phoned; it was a table like this in this meeting, an advisory council, and there were 23 agencies representing mental illness. There was no single forum to know what all these 23 agencies did—each one on its own—so I started on my own, collecting data on all these agencies and what they do. Nowhere was it published that there are 23 agencies in Halton which handle mentally ill people.

Our son then decided to take the medicine, after a lot of convincing, and he went back to the University of Waterloo. This time he was doing well, and every day we would drive him to the University of Waterloo. He was anxious on the way, so we had to constantly comfort him and give him additional medicine when required, when he decided to take it. When he was in school, we walked around all over the place. We made daily trips to Waterloo, regularly.

Then he decided to go to teachers' college, because he was associated with the teachers' college in North Bay. In North Bay, the teachers' college has a theoretical portion as well as a practical placement portion. The placement portion—it's like a union. I'm an engineer, my wife is a doctor, and all my colleagues are doctors, every one of them. But every disability department in the placement place there considers a mentally ill person the same as anybody else. They should do exactly the same thing as others regarding placement.

In North Bay, at Nipissing, there are no—the disability department is super, but the placement department sucks, and they didn't help him anyway. Later on, we found out that U of T, for those who are mentally ill, has a mentor as well as a mock setup to make them work. It seems that Brock, Queen's—everything is different. The McMaster disability department, the Waterloo department, they all have their own independent entities, and they all work totally differently.

Our son had constant panic attacks due to this placement dealing with kids who are not totally disciplined, and we had to start at 6 o'clock, phoning him and giving him encouragement to go do his schooling. We made many, many trips to North Bay.

As caregivers, we found there is really no help available, because we can't leave the house. We have to look after him. He's much, much better now. We can go now. Those days—for four years, we couldn't go anywhere or do anything, whereas in BC the law allows two hours of time for a psychiatric nurse to look after a caregiver. Saskatchewan also—the CTO has got power; Ontario's doesn't. And in Halton, those who have Alzheimer's disease can get two hours of respite care, paid for by Halton region, whereas there's nothing for mentally ill patients.

We have certain recommendations. Start with schools and universities. First, with schools, tell all the symptoms so that the teachers are aware of what symptoms to recognize, because the earlier you treat them, the better the chances are.

Bring proper disability standards to all universities. They vary widely. Some are good, some really suck. And there is a lot of stigma, so we couldn't tell the university or anywhere what was wrong with our son. We generally would say that it was non-physical, so of course they guessed. So that stigma—something must be done with PR or television.

There should be one centre established—I heard at a meeting that Peel is kind of trying to do this—which talks about training the nurses so they're aware of what medicine they use and how to use it. They don't know. I had to tell them sometimes, "You can't do that," what they were trying to propose, to cut the medicine and give it to two. It disappears in your own hand. The nursing supervisor said, "This is all we get. What can we do with them?"

**1000**

Then the psychiatrists, they are not the same. Some are good, some are just pill pushers. We need cognitive therapy to overcome anxiety, apart from medicine. So that is not freely available. There should be a one-stop centre where you can go and get all this help and this should be widely publicized. We need more medicines, at least as much as the United States, and use of multiple medicines must be promoted, which is what is helping our son. He's got a master's now in Waterloo, and then he wants to do a PhD. Luckily the professor is super-duper. Multiple medicines help, which a lot of psychiatrists are not using because they lack knowledge. They sit in their offices and push the pills. Provide a CTO with teeth for parents like us caregivers so that if the people don't take medicine, they should be helped. Additional help is required.

Ontario is the most liberal of all the provinces and the patients have all the rights. We fought tooth and nail in all these hospitals, how to get through the forms. CAMH has got it to a perfect art and a science. Without that help, we couldn't have done that. The CAMH psychiatric approach should be put into all the community hospitals. They are all low standard compared to CAMH Peel.

The rights have swung too much toward the patients. Once upon a time it was bad; they were in prison, they were treated rotten. Now it's gone the other way, and the caregivers are left holding the bag. And if you take the cost—where is all this cost going to come? An average mental health patient stays for 37 days in a hospital against three days—this is what I read in the Star—for a normally ill patient. So you can avoid a lot of these things and help us to help our children and others by providing more medicine, better schooling, better—this thing. At least people with mental illness like we are dealing with, it would help.

We're still not having vacations, but it's much better because we are one of the fortunate ones. We did a lot of research and fought with psychiatrists and everybody to help our son. And his great desire to study helped us.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you very much for your presentation. There really isn't time for any questions. There's a little bit of time left, but I think you got your point across very clearly.

**Mr. Kris Ramakrishnan:** Thank you.

**Ms. Madhuri Ramakrishnan:** We urge you to look at our recommendations and consider them very carefully.

**The Chair (Mr. Kevin Daniel Flynn):** I can promise you the committee will do that.

**Ms. Madhuri Ramakrishnan:** It will help all people with mental illness and their families. Thank you.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you very much for coming.

## BURLINGTON COUNSELLING AND FAMILY SERVICES

**The Chair (Mr. Kevin Daniel Flynn):** If we can call forward our fourth presenter of the day, somebody I know well, Susan Jewett, executive director of Burlington Counselling and Family Services. Good to see you, Susan.

**Ms. Susan Jewett:** Thank you.

**The Chair (Mr. Kevin Daniel Flynn):** Make yourself comfortable there. There is some water. Everybody in our hearings across Ontario is getting 20 minutes. You can use that any way you like. If there is a chance to leave any time at the end for questions from the committee members, that would be great, but it's not necessary.

**Ms. Susan Jewett:** Okay. Thank you very much for inviting me here today. I'm Susan Jewett. I'm the executive director of Burlington Counselling and Family Services. I'd like to acknowledge your Chair, Kevin Flynn, who represents Oakville. It's part of the community that we serve. I see Kevin frequently out at community meetings that deal with issues of poverty, mental health and addictions, and we really are delighted that he's chairing this committee. I think you're in good hands.

I've taken the time to review most of the presentations you've heard prior to today and I want to try only to add a few new points and build on others. There are almost 50 family service agencies across Ontario but I'm going to speak mostly about our own in Burlington.

We are what I would call a secondary level type of service. If you think of GPs as being primary care and some of the services that you just heard about as being more specialized and tertiary, we're more an entry point for the broader community who may experience any kind of mental health or addiction issue. People will come to us who have experienced trauma, depression, crippling anxiety, family separation, grief and loss issues, and abuse at some point in their lives. Some will suffer in silence while others will reach out for help; some will attempt suicide or high-risk behaviours; some will numb their pain with alcohol or drugs; some will be killed by their partner. Children are greatly affected by these types of family crises. They may be the invisible victims or they may develop problems of their own, and during a recessionary economy it only gets worse. Our services help get people back on track. We're part of the system that builds stronger families in the community, and I think family service agencies are part of the solution that this committee needs to consider.

We don't tend to use the words "mental health" or "mental illness"; we talk about counselling services. But in reality, most of the people we serve come with mild to moderate mental health problems. Our budget is just over $1.1 million—I'm going to tell you where it comes from, but I want you to listen for the silos as I describe our funding—of which 65% comes from the provincial government, 7% from the region of Halton, 7% from United Way, and the remainder is raised through client fees, employee assistance programs and other small grants. You will notice that we have no funding from the Ministry of Health and no funding through the LHINs, although most of the people we serve have mental health problems.

Over the past two years we participated in a study, and I've outlined a bit of it in my report, but what I want to highlight is that that study looked at 2,100 people served through family service agencies in Ontario and it demonstrated the impact of our service: 62% of the individuals served with moderate mental health problems demonstrated a significant improvement in their symptom reduction and their overall life functioning.

I'm sort of skipping, if you're following the report, because I'm afraid I'll run out of time. I want to emphasize a point about children and the need to improve mental health services for kids. You've heard that from a number of previous presentations. I support that 100%. But we must never forget that most kids live in families, and we can't have emotionally healthy kids without working with the families too. Depressed moms have trouble parenting; alcoholics make poor parents; families in which there is violence tend to raise kids who think that violence is acceptable. It's hard for kids to keep it together when their families are falling apart. So count on us, family service agencies, to provide these very needed services for the family.

One of our areas of expertise in Burlington is family violence. Again, let me tell you where our funding comes from and listen for the silos. We receive funding for counselling for women who are victims of abuse and their children—it's from MCSS. We have a partner abuse program, which is for people who perpetrate the violence; it's primarily men, but not exclusively men—that's from the Ministry of the Attorney General. We have a caring dads program, which is for fathers who have a history of abusive behaviours—it's from a grant through Halton region. Our supervised access program provides a safe place for children to visit with their non-custodial parent; many of these families are referred to us through the court and they have a troubling and lengthy history of family violence, severe mental health or addictions—again, funding is through the Ministry of the Attorney General.

Let me be clear: Family violence is not caused by mental health or addictions. However, there are significant links with these three issues. I hope you will have an opportunity to refer to the Ontario Domestic Violence

Death Review Committee reports and their many excellent recommendations, which address the connections between family violence, mental illness and addictions.

**1010**

Let me tell you about Sam; that's the name I'll give him. Please listen for the impact of funding silos. Listen for the stigma and the sense of shame, and lastly, listen for the entry point into the mental health system, if we want to call it that. Sam was referred to our partner abuse program; that means he was already accused and found guilty of abusing his wife. So he entered the system through the police and the courts. He arrived at our program, he was seen by a counsellor, and prior to that he completed what we call the OQ-45. It's an outcome measure tool where someone assesses themself on 45 variables. When he did that, he informed us that he considered taking his life frequently.

When we interviewed him, he denied that. We hadn't seen what he had written, and we always ask about suicide tendencies. He said he didn't have any. And so we moved on to talk about the abuse that brought him to our door and what the program had to offer. When he left, he was given a date to start the program a few weeks later. He didn't come and he didn't cancel. We followed up with a phone call, couldn't reach him and had to leave a message. We didn't hear from him again. A few weeks later, we learned that he had died by suicide.

So here's an example of silo funding. People don't come in the silos that we're funded in. They come with a multitude of problems. He could tell us in writing that he was suicidal, but we think the shame and the stigma—he couldn't tell us when we were asking him. And because we weren't really funded to deal with his depression, we proceeded with what we thought we had to do. We won't make that mistake again, but it's partly pushed on us by the way we're funded. We need funding that is flexible enough to respond to people's needs, not for one issue with the assumption that one size fits all. We work in silos because we're funded in silos. All of our provincial funding is to deliver a certain program in a certain way, no exceptions.

Let me say one other thing about the partner abuse program. It was designed to be an early intervention program, so people with a fairly mild, if you can use that expression, incident of abuse where the police have been involved. It's unfortunately the only program, so we cannot accept voluntary people, we can only accept people who are sent to us by the courts, and because it's the only program, even though it's early intervention, we will be sent everyone, whether he's an 18-year old who assaulted his date, whether he's an 80-year old who's been abusing his wife for years or, as in one case recently, whether he is a man who "accidentally" killed his wife. I don't call that early intervention, but that's the only program funded, and so they come to us.

Most of our funding from the province requires us to provide a certain number of services for people a year. That's understandable. It doesn't fund us to coordinate service, and we deal with people with complex problems. We need to be able to work with other service providers and coordinate our services. Let me give you an example: Joe Brant—and you just heard of them—had, a couple of years ago, a woman who was admitted. She had been shot by her husband. She lived. Her child died. They treated her physical wounds and they called us to say, "This has been a horrible tragedy for her family. She needs help, Susan. Can you take her? And oh, by the way, she only speaks Arabic." We were delighted that this was a good example of coordinating the service. Yes, we could do it; yes, we could do it in Arabic; and yes, we could do it today if she was able to come, and they sent her.

But we don't have funding that encourages us to coordinate, and people fall between the cracks. Most of our families are involved with justice systems, children's aid, children's mental health, the hospital, or some combination of all of those, and we need funding that allows us to work together with those other communities. Some communities have developed co-located services, buildings where a number of agencies work together out of one site. I'd encourage you to look at some of those innovative, community-based projects.

In another presentation, it was mentioned that we have a two-tier system for people with mental health issues. Certainly, in our community this is true. People living in poverty who have mild to moderate mental health problems have far less access to service than people who can afford to pay. I have this bumper sticker on my wall: "My Ontario includes the poor." I hope your strategy will include them too.

People who live in high-growth areas, such as Halton and the GTA 905, have far less access to service because funding is usually historical and does not address population growth or decline. The Auditor General spoke to this; I'm not going to go on about it. But every year in high-growth areas we fall further and further below the provincial average. There has to be some way of addressing these inequities so that people all across our province have equal access. The funding does not need to be based on population alone. It should be a combination of population and social indicators. But history doesn't work; we know that.

You've also heard from other presenters that 80% of people with mental health and addiction problems go to their GP for help. There is an innovative model of service that was recently developed in Waterloo region and is funded by the Ministry of Health. It's called Health-Connect Counselling Partners. I've included a brochure in my package for your review. Family doctors are able to refer any of their patients with mental health issues to this Health-Connect program. It's a group of six agencies that all provide different types of counselling, and there's one centralized intake. It helps the doctors deal with the issue that they don't have time to treat people for and allows them to focus on the areas that they do. It's connected to the family doctors, so it's a wonderful way for family doctors, who are seeing 80% of these people, to refer them on to a system that is community-based. I again encourage you to take a look at this type of model.

Remember Sam? He's the young man who was also suffering from depression and took his own life but who came to us for partner abuse. I often wonder what would have happened to him if he had entered the system earlier through his GP rather than through the justice system. If we had had this type of model in Halton, perhaps he'd still be with us today.

Dr. Gina Browne, who's a Burlington resident but works at McMaster, has done numerous studies which demonstrate that providing counselling along with a range of other services saves millions of dollars because it reduces the use of more intrusive services, more specialized services, and it reduces the length of time that people are financially dependent on the province. I've put some material in my package about her work as well.

In closing, let me make one more pitch for strengthening family service agencies across Ontario as part of your strategy. We are community-based. Most of us are open long hours and are available when families need us. Most of us offer services in a number of languages. We work with other service providers. We have a long history of serving families across Ontario.

**1020**

My recommendations, in no particular order:

We must reduce stigma.

The gross inequity in funding for mental health services versus physical health services must be addressed.

The inequity created by funding which is historical must be changed.

We must develop strong, community-based secondary level integrated mental health and addiction services.

We must address the funding in silos, which create barriers.

Finally, we do need a champion to move this work forward.

Thank you.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Susan—a very comprehensive presentation. You've left time for one, maybe two questions. Helena has the first question.

**Ms. Helena Jaczek:** Thank you for all your points, excellent recommendations. We've certainly heard some of the same themes. I'm impressed with this HealthConnect piece that you've drawn our attention to.

You make a point of saying that your counsellors are master's-prepared. Have you used peer support workers, peer navigators?

**Ms. Susan Jewett:** In our agency, no, but some other family service agencies may have.

**Ms. Helena Jaczek:** Is that because you don't need to or it doesn't fit or you—do you have a sense of the value of that program?

**Ms. Susan Jewett:** Yes. Partly what we provide is what we're funded to provide and all of our funding is program-specific. So it doesn't leave us room to expand or try new things. We must deliver—

**Ms. Helena Jaczek:** You don't have the flexibility—

**Ms. Susan Jewett:** We don't. Some are larger and they do. We don't.

**The Chair (Mr. Kevin Daniel Flynn):** There may be time for one more brief question. Sylvia?

**Ms. Sylvia Jones:** It will be brief. You mentioned a lot about the silos. Some of the presentations previously talked about the need for one ministry taking the lead. Do you have a comment on that and, if you do, a preference?

**Ms. Susan Jewett:** A preference of ministry? I can't speak to a preference of ministry but I do think that is an excellent solution, having one ministry or one lead in the ministry. One of the huge silos is that the ministry people at a program level don't connect with each other. So they have a barrier within the provincial government itself, which quite frankly ripples all the way down to the community. If there is any way to address that, I highly support it.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Susan, and thank you very much for coming today.

**Ms. Susan Jewett:** Thank you.

## JUDY TYSON

**The Chair (Mr. Kevin Daniel Flynn):** Our next presenter this morning is Judy Tyson. Judy, if you'd like to come forward and make yourself comfortable. I don't know if there are any clean glasses left. There may be one down at that end of the table and I think there's some water left there if you need some. The trick is going to be making sure you pick up your own now.

**Ms. Judy Tyson:** It's true. We'll better the odds here.

**The Chair (Mr. Kevin Daniel Flynn):** Okay. Like everybody else, Judy, you've got 20 minutes to make your presentation. If you can leave some time at the end, that usually works better, but it's not necessary. The microphones work better when you're about a foot away from them.

**Ms. Judy Tyson:** Good to know.

**The Chair (Mr. Kevin Daniel Flynn):** It's all yours.

**Ms. Judy Tyson:** Thank you. Good morning, ladies and gentlemen. I come to you as a family caregiver whose family experiences have led me into some interesting adventures in non-profit groups and with the Mississauga Halton LHIN.

There was an advisory team that last year was called the detailed planning and action committee on mental health and addictions and this year morphed into SIGMHA, the system integration group for mental health and addictions. We put out a rather lengthy report, which is available on the Mississauga Halton LHIN website, on what we thought were the priorities in mental health and addictions integration.

I'd like to discuss a vision of good health care for mental health and addictions as I have experienced it and what I've grown to see as some of the obstacles. It's devastating to families—I'm sure you've heard that repeatedly—but what I don't see is a great deal of benchmarking for the care. I believe in bold policy and legislation, but I don't envy your job. I don't know where you start—it's a big job—but here are some priorities that families might put in higher priority.

No wrong-door access: Some of the organizations talk about one door. I don't know that that's possible, but where are the entry points to the system? It could be EMS, it could be a GP's office, a prison, long-term care, a school or a mobile unit police car. If you're thinking of education and training, that may be one place you should start to look. If you look at technology as a solution, the technology should connect a client to a service immediately upon intake. Even if it's a transitional service, I can't overestimate the necessity of having trust in the system right from the first encounter, both for the client and for the family. Navigation, as you've heard repeatedly, is a big issue.

Retelling a story could be eliminated by centralized systems, with a patient history that's accessible by all agencies, integrating primary care and mental health and addictions. What I don't understand is why we have to wait for six more years for the electronic health records to come on board. It's clearly going to be a big leap forward.

An inventory of services that's available on the web would assist providers and encourage a self-help strategy for people in crisis. We are capable of doing our own research to a certain degree, but we don't always know where to look.

Assessment and discharge: It's a critical first step that could save years of personal loss and avoid the revolving door. My business is marketing communications, and what we promise our clients is that it can be good, it can be fast or it can be cheap—two out of three—so we understand trade-offs, and I think clients and families do too. Trust is important, but nothing can get started without the proper assessment. The wrong assessment can set clients back years and lead to devastating effects. Discharge can't be into a vacuum. I think the importance of care coordinators or case managers can't be overestimated.

There also has to be a care path or a continuum of care, whatever the language is for that. The guiding principle here is to never abandon or isolate a client. Start with a plan that's flexible to fit individual needs, and then the go-to guy should communicate it to clients, agencies and families. There are agencies out there that don't know about each other, that run into each other anecdotally in a seminar or over lunch and learn or whatever, and that shouldn't be happening. I think there should be audits throughout the treatment to see if the treatment is working. If that care path is accessible electronically, it will encourage self-management, family participation and workflow planning with the agencies.

Collaboration and non-exclusionary criteria can prevent the "pong" effect—clients just bouncing back and forth between agencies.

**1030**

Counselling: One of our surveys on the DPA team said, "When you need a drink every day, you need counselling every day." Counselling is fundamental, but it's not a magic bullet. The weaknesses, of course, are long wait times—sometimes six months to get started with counselling. There are work complications, transportation issues, and some people are trying to manage a career and family life while managing their disease. What are the alternatives? Well, as we've discussed, peer support groups, online forums, phone conversations—that's not new technology—messaging. Some of our kids are managing three or four conversations at one time when they're messaging each other. That can possibly fill some gaps. I read a headline in the Globe and Mail about shrinks online. Why not? That delivers service when it's needed, not on a monthly or weekly basis, on a schedule.

Cognitive behaviour therapy was also cited as an important step in self-management, which is a goal for our group.

Family support, because families are the main caregivers. I put in more hours than any other caregiver in my father's and brother's care. But the ripple effect of the disease is devastating: the shock, the guilt, the confusion, fear and shame. It wipes out our assets, alienates kids, ruins marriages and careers.

What do caregivers need to know? In some cases it's the same that clients need to know. They need to know about the progression of their disease and what the behaviours are, and what the needs are short- and long-term.

A web link to a reliable source of information would be a good first step. I don't need to take time off work and go to a seminar where there may be people with a number of different mental health and addictions problems that aren't specific to my needs. An e-mail from a case manager keeping me in the loop, as a family caregiver, is a really important step. Communications—I can't overestimate—is a really powerful tool, and most of us have access to electronic communications.

Medication is also an important issue to me. Bad meds can cause more problems than they cure. An example is Paxil, which is an SSRI. It has a known high suicide risk, and the people I know who've taken it, for example, have had more complications from it than if they didn't. Evaluating the performance of pharmaceuticals should never stop. A pharmaceutical that comes onto the market should be on permanent trial and should be tracked, right from its first entry into the market. There may be issues of interactions, consistency and double-scripting, and hopefully the EHR will help with some of those complications.

Clients are holistic beings, and I think you have to look at their care in that way. Treatment has to be client-centric, not system-centric, which is not to say the system shouldn't be very strong in enabling that care. Clients need meaningful work, transportation, housing, financial assistance; these are all important to recovery.

Education and training: Working on the education and training group, I've put together an exhaustive list of target audiences, and I notice that the mental health committee, Michael Kirby's committee, has prioritized two groups. One of them was service providers, which includes GPs, because I understand that their training and education is very deficient. Someone told me it's only one month in six, seven or eight years of training, and they are usually one of the front lines. The other is the educational system. In the educational system you will reach teachers, who may be the first line of recognizing symptoms; curriculum administrators, who can put this information on the curriculum and start teaching children from an early age how to recognize or understand illnesses; future adult citizens, who are coming up through the educational system; and parents and school administrators. That hits a lot of people at one time. Prevention should be part of the message to address the stigma.

I think the key themes in this part of my address are innovation and initiative, management and logistics, integrating primary and mental health care, client-centric and holistic care, benchmarks, communication and collaboration. All of these terms are business terms; we use these terms in business. But from what I see of the service providers that I've had dealings with, they're resisting the business model. So the tail wags the dog, and then the system just spirals down with disconnect. Management of a complex organization is a science, and very few of us are skilled to do this; very few of us are successful at doing it. In mental health and addictions, there is an abundance of leadership. I am very impressed with the academic qualifications of the people I work with, many at the master's level, terrific at doing due diligence and analysis—and they do that to death. But there is no enterprise-wide operational management.

I propose seeking diverse skill sets. What about the logistics experts who bring bananas to our table from across the world exactly when they're ripe? I know you're going to think that's a ludicrous analogy, but there are some skill sets there in delivering service.

I'm very sad about the culture. Medical professionals are heroes and they're saving lives, but there's a toxic culture: entitlement, arrogance, competitiveness, skepticism of systemic change. The other edge of that sword is that they feel powerless, frustrated by bureaucratic blunders, indifference or lack of feedback. The only motivators are crisis and budget cuts. So they're not motivated to find efficiencies or they find the low-hanging fruit, like wait times, and the concept of creative destruction is a concept that presents a conflict of interest. They've got their head down the whole time.

I have asked questions: "Why are you doing things this way? Who's in charge? Why isn't there an execution plan?" and they say, "It's a slippery slope. Human factors are complex." Well, so is the internal combustion engine. "There's no money"—but I find that hard to believe, given that, what, 30% of GDP is for health care? "We need more due diligence. There's no feedback," and so on. But even a modest plan like co-location, which they're trying to do right now, was panned because they felt that the other agencies had no synergy or it was imposed upon them. The ministry hired consultants, but they feel that they weren't consulted on the changes. There is a disconnect with the LHIN. The disconnect with the LHIN is alarming, even anecdotally. When I see my surgeon friends, they say, "What is the LHIN? What is their mandate? What are they doing?" And that's coming from doctors, advisory teams and the public.

As far as finding efficiencies, I saw some simple ones in education. In the private sector, learning happens at our own expense, on our own time, nights and weekends, and we pay for it ourselves for the most part. But there are some easy things that can be done, like online courses. They test your comprehension as you go ahead, and they can be accessed at the convenience of the person studying, and that could be service providers or families.

**1040**

Record your seminars and put them on the Web so that people can see them, so you don't have to keep paying that consultant over and over again to do the same seminar. Transcribe your workshops and make them available on the Web. Lunch and learn: Bring all your PSAs or your health care workers together in your boardroom instead of sending them halfway across town and paying to substitute for them. Bring them all together at one time. Put in a DVD and train them all together; video conferencing. Online calendar was a solution that we felt would help all the service providers who are trying valiantly to do education and training but have no way to connect to people either in the community or in other agencies. But that was not accepted by the LHIN. These are technology-focused solutions. The other is trying to prioritize the target audiences, which was another problem for the LHIN.

The hockey analogy applies here. You've got to skate to where the puck is going, not where it is now. The workforce of the future is crowd-sourcing. You don't have to pay for everything. There are people like me who are willing to give our time, and truly collaborative work is constructive work. It's disappointing to find that work that you do is not accumulating toward a strategic plan. A plan has to have a dotted line to an executional plan. There have to be accountabilities and there have to be some shared goals.

That's all I have to say.

**The Chair (Mr. Kevin Daniel Flynn):** That was excellent time management. You hit the nail right on the head. Unfortunately, there is no time for questions, but I think we all got your point.

**Ms. Judy Tyson:** Thank you.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you very much for coming today, Judy.

## JEAN WIEBE

**The Chair (Mr. Kevin Daniel Flynn):** Our next presenter this morning is Jean Wiebe. If you'd come forward, Jean, and make yourself comfortable, we'll get you a clean glass of water. As we're travelling across Ontario, every delegation is getting the same amount of time—20 minutes. So you have 20 minutes and you can use that any way you see fit. If there is an opportunity to save some at the end for questions, that's usually pretty good. The microphones work better if you're about a foot away from them.

**Ms. Jean Wiebe:** Okay. How's that?

**The Chair (Mr. Kevin Daniel Flynn):** That's perfect.

**Ms. Jean Wiebe:** Okay. My name is Jean Wiebe, as has been announced. Those magazines that were handed out I got from Bill MacPhee, who is the publisher of the Schizophrenia Digest, and it's located and published out of Fort Erie. I got these from him free for our walk for schizophrenia, which was held in May. I had them left over so I thought you might get some education about mental illness. There is one there about depression, and there are two about schizophrenia.

I'm not a speaker, I'm a mother and a retired registered nurse, so I'm just going to read my presentation. I retired from being a registered nurse when I was 55, 10 years ago. I worked full time at the St. Catharines General Hospital for 31 years. I worked in intensive care and I worked in the recovery room, but I never worked in psychiatry.

My son Jim got sick right after he graduated from high school. He was 19 in 1994. That makes him 35 now. He became withdrawn, stayed at home, lived in the basement. He became afraid, paranoid. He had a cut-off hockey stick that he put in the window in his bedroom so you couldn't open it and he had a baseball bat at his bedside. That was to protect him. He had delusions. He wrote in a notebook about our family being superior, and I was excluded because I had divorced his father.

He also thought God was going to kill him, and in the beginning I had to lie on his double bed beside him, both of us fully clothed, so he could sleep, because God was going to kill him. If I was there to protect him, then it would be okay.

He did not hear voices—he has never heard voices—but he did have what they call auditory hallucinations, and he explained them to me as being poppings in his head. I got him to the psychiatrist and he was put on the old medication, Haldol, which made him dopey, but the doctor did not put him on the drug to counteract the side effects. The side effect was that you lose control over your ability to swallow and you lose control of your tongue, and it protrudes. Unfortunately, that happened to him. We got him on the drug that counteracts that and then he was all right.

Then I asked for a second opinion. We went to that psychiatrist, and he was put on one of the new medications, called Risperdal. Within four to six weeks, he improved slowly. But that took about six months. He got sick in July, and this was in January that we got to the new psychiatrist. But people are not diagnosed with a major mental illness until they are sick for at least six months.

He was diagnosed with schizophrenia. I don't know how many of you people know, but just to let you know, the definition of schizophrenia is "a mental disorder characterized by impairments in the perception or expression of reality and by significant social or occupational dysfunction." That's the definition of it.

During this time, my son became honest with me. He told me what he had done as a teenager. He started drinking when he was 14. He went on to use marijuana. He used LSD and he used magic mushrooms. He went to a rave in Toronto—I don't know if these raves are still going on; I haven't heard much of them lately—and he was given some sort of a sucker with some drug on it. He took it, and he didn't even know what that drug was. He just wanted to get high, I guess.

He didn't get any education at school about how bad street drugs and alcohol were, especially for young people, and I, as a parent, did not get any education about street drugs and how bad they are for young people, or alcohol either. We had no education in my nurse's training about addiction or alcoholism. And we had no education, during my 31 years of attending in-service education, about drugs and that. There was no in-service on drugs or alcohol, ever.

Doctors and nurses need more education about street drugs and alcohol abuse in young people especially. We need education for children starting in grades 5, 6 or 7, because the worst time to use marijuana especially is in grades 8, 9 and 10. This is when the brain is really developing, and marijuana has a negative chemical impact on that brain. This is from Dr. Archie, who is at the Hamilton Psychiatric Hospital now, or whichever hospital she's in—I don't know. She came and spoke to us in St. Catharines.

When my son Jim was 17, I thought that he was starting to drink. His father had a drinking problem. I started attending Al-Anon family groups. It was started along with Alcoholics Anonymous. These groups have been going on for over 50 years. Al-Anon family groups are for family, friends and co-workers of people who have a drinking problem. This group has helped me deal with my son's addiction to alcohol and drugs, and has educated me about the disease of addiction. The Journal of the American Medical Association defines alcoholism as "a primary, chronic disease characterized by impaired control over drinking, preoccupation with the drug alcohol, use of alcohol despite adverse consequences, and distortions in thinking."

**1050**

I went to a meeting of the Friends of Schizophrenics, as it was called then—it is now the Schizophrenia Society—in Welland shortly after my son was diagnosed. The doctor speaking was from the Hamilton Psychiatric Hospital. During the question period, I asked him—I remember specifically, and I quote—if he had "ever treated someone with schizophrenia and addiction to alcohol or drugs." His reply was—and I quote again, because it really stuck with me—that he had "but not successfully," because the treatment for addiction and alcoholism is a 12-step program, and people with schizophrenia do not like to be in groups.

So my son was sick. He had the disease of schizophrenia and the disease of addiction, and there was no treatment. Therefore, he lived at home with his stepfather and me for four or five years. He was put on ODSP, the Ontario disability support program, so his drugs were paid for. They ran, at that time, between $800 and $1,000 a month.

He was very attached to me. He would only go out of the house with me for quite a while. He would sleep all day and be up all night, pacing, pacing, pacing. He was upstairs, and we were trying to sleep downstairs. We were still working at the time, and it was difficult, to say the least.

He did share with me that he was angry all the time, so I got him into an anger management course. I took him and picked him up. That course did help. I could not find any counselling for him at that time, so he just went to a psychiatrist, and he ordered his medication and had a short talk. Thank goodness he liked his psychiatrist. They have gotten along well, and he has had the same one for 16 years. He is lucky in that respect, and so am I.

I paid for him to go to the YMCA. He always liked sports, and this helped him. He started to ride his bicycle again.

I paid for him to go to a martial arts school. The teacher—or sensei, in the martial arts world—was a friend of mine, and he accepted Jim. So did the group of people in his class. This really helped Jim. He had a place to go. He had a place to belong. He had people who accepted him. Jim got his black belt in kendo through that group. Now, if you don't know about martial arts, kendo is the Japanese art of fighting with bamboo swords. When he began, he said, and I quote, because again it stuck with me, "Mom, it's great. I get to hit somebody over the head with a stick and I don't get a penalty," because he played hockey all his life. But Jim was never violent. He was never violent in a psychosis, he was never violent at home, and he has never been violent to this day, in 16 years of having schizophrenia.

But mentally ill people are not accepted. There's a terrible stigma about being mentally ill. Educating the public about mental illness could help alleviate this stigma. Teachers should be educated; parents should be educated; ministers could be educated. Everyone should be educated, just like driving while impaired, just like stop-smoking education. Both these things have worked very well to educate everybody.

There is a program in the States called the clubhouse model. It's for people with mental illness, and it could be a room or rooms or it could be a building where people who are mentally ill can go and where they can be part of a group, where they can have things to do: games, crafts etc. They will have people to talk to. They could have tea, coffee, whatever. They would have things to be responsible for. They could be responsible for maintaining the grounds outside, for keeping the buildings clean, whatever they need to have in this organization. They take them on group outings etc. I could go on and on about what they do in these groups.

There is only one place that I know of, and it is Welland, that's like this. It is called Oak Centre Clubhouse, and it functions very well. But we have none in St. Catharines or Niagara Falls or anywhere else in the Niagara area, and I'm not sure if there are any others in Ontario. I belong to the Schizophrenia Society in St. Catharines-Niagara, and we have monthly meetings. There are somewhere between 10 and 20 of our family members who come to our Schizophrenia Society meetings. Now, normally these are support meetings for the families of schizophrenics, but in our case our family members who are ill like to come to these meetings because they have nowhere else to go to meet and be with anybody. They are accepted even though we all know that they're mentally ill. It has been growing. Over the last five, six, seven years, more and more of our family members are coming. They come there and they share what medications they're on and they share that they're having hallucinations or delusions and what kind of medication worked. It's amazing, but there's nowhere else for them to go in St. Catharines except once a month to our meetings.

But we are just a volunteer organization in St. Catharines. We have no paid people in St. Catharines who work with these people. There are no programs for outings, for social events, for sports, for crafts, cycling; there's nothing. We need programs for our family members who have a mental health issue and are stable on their medication. We need education about drug and alcohol abuse in the schools and in the general public. We need education about mental illness to try to stop the stigma.

The other support we need is in help finding meaningful work. My son has had many jobs since he got sick, but he's afraid to tell his employer that he has a mental illness, let alone schizophrenia. If we could have government support to employers to hire people with mental illness issues, be it depression, manic depression, schizophrenia—or in my son's case, the final diagnosis that he has is that he has schizoaffective disorder, which means he has schizophrenia, anxiety and depression—all three. He's on medication for each one. But he cannot work full-time; he may not be able to work eight hours at first, or he may be one day a week or maybe only three or four hours at a time. Employers need to be educated about mental illness.

As I said before, the other people who need to be educated are police officers. Police officers need to be educated about how to deal with people who have a mental illness. My son Jim gets very anxious when he's around uniformed police officers. Last December, he was on his way to a hockey game—he was back playing hockey—when he came upon what he thought was an accident. So he tried to avoid it, but it turned out to be a RIDE check. So the uniformed police officer came running over, pounded on the window and told Jim to get out of the car. They gave him a roadside sobriety test and a breathalyser. He blew zero on the breathalyser, but he was shaking on the sobriety test. He told them he was on medication from a psychiatrist, but anyway they handcuffed him, took him to jail and put him in a cell. Then he had to give a urine sample in front of a female police officer. All this stress triggered an anxiety attack, so he failed some of the coordination tests. He was charged with impaired driving by drugs and then released to drive himself home at about 4 o'clock in the morning.

We got a legal aid lawyer, and we had to appear in court four times before we got the urinalysis test back, which showed all of the psychiatric medication that he was on plus one kind of marijuana. The lawyer found a precedent case, and the crown attorney withdrew the charges. This just happened last week. His final court date will be this Friday. We don't really have to go, but I'm taking Jim and we're both going to thank the lawyer very much.

**1100**

My son has been lucky to:

(1) have a nurse as a mother;

(2) find a good psychiatrist who cares;

(3) listen and take his medication always—now, he didn't always take it properly. One time I asked him why he was so sleepy, and he said, "Well, I didn't want to take those pills morning, noon and night, so I took all three in the morning." I said, "No, Jim, you can't do that. You have to spread it out over the day." So we've got things all straightened out now, and he has his medication in those blister packs where it says what time you're supposed to take them at;

(4) have help from my husband and me to rent to own his house, so his ODSP rent goes toward owning his own house eventually, in 20 years or 25 years or so;

(5) find a woman with almost the same diagnosis as he, and to be married to her for six years—quite happily, I must say;

(6) find out that he loves gardening, and now he has a garden to work in;

(7) have pets, which they've found is a very therapeutic thing for people with mental illness to have—he has two cats, which he loves very much;

(8) have taken a course last September in Guelph, which I drove him to, to be a minor hockey official; he passed his test, and he refereed hockey games all winter long;

(9) have a sister who helps him with his budget, with his money from ODSP;

(10) have in-laws that help both him and his wife;

(11) live in Ontario, where you get ODSP.

In closing, I'd like to say that we need education. We need education for children, parents, teachers, ministers, police officers and the public about drug and alcohol abuse and about mental illness. We need programs and clubhouse models. We need activities, sports, games, crafts etc. We need employment. We need help from the government so they can have part-time, graduated employment. The employers need to be educated, and the work needs to be meaningful. Thank you.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Jean. Thanks for telling your story. You've used up the whole 20 minutes to do it, unfortunately, but I think—

**Ms. Jean Wiebe:** I should have talked faster.

**The Chair (Mr. Kevin Daniel Flynn):** No, no. You talked at just the right pace. Do you know what? I'm not sure we need any questions. I think you got your point across very clearly.

**Ms. Jean Wiebe:** Thank you very much.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you.

## MARY ELLEN FREDERICK

**The Chair (Mr. Kevin Daniel Flynn):** Our next presenter is somebody I know very well as well. Mary Ellen Frederick, come on forward. Get yourself a clean glass, if you need one—there are some there—and some water. There you go. Good to see you again.

**Ms. Mary Ellen Frederick:** Good to see you, too.

**The Chair (Mr. Kevin Daniel Flynn):** Like everybody else in Ontario who's appearing before us, you get 20 minutes. You can use that any way you see fit. If there is any time left over for some questions of the committee, we'll try to get as many in as we can.

I'm not sure if you were here when I was saying that the mikes work better when you're about a foot away from them. Other than that, the time is all yours.

**Ms. Mary Ellen Frederick:** Okay, great. Thank you very much. Is that level good?

**The Chair (Mr. Kevin Daniel Flynn):** Perfect.

**Ms. Mary Ellen Frederick:** Okay. I'll also be reading my presentation. I wanted to thank all of you for giving me the opportunity to address the members of the Select Committee on Mental Health and Addictions.

My name is Mary Ellen Frederick, and I'm here with my husband, John, today. Our son, who is 27 years old, was diagnosed with paranoid schizophrenia three years ago. However, his mental health problems first emerged 11 years ago when he turned 17 years of age. It was at that time that our family embarked on a painful, frightening, confusing and isolated journey in search of answers, treatment and support for our son's increasingly escalating mental health and addiction problems. It is from those life experiences that I am making these recommendations. The following are key areas that a comprehensive mental health system needs to address.

Accurate diagnosis and treatment: It can take years for an individual to be accurately diagnosed, i.e., during the onset of psychosis. This delays effective and timely intervention in treatment and escalates the illness, the number of crises and the family challenges associated. There appears to be a critical shortage of psychiatrists and of professionally trained psychiatric support staff.

Stigma: Individuals and their families deal with mental health issues in isolation due to the stigma and ignorance surrounding this group of illnesses, creating even greater stress and, of course, delaying and often denying effective treatment. There needs to be a coordinated national, provincial and community education and information campaign utilizing the expertise of professional marketing to increase understanding and compassion within the general public for individuals and families battling these diseases.

Early intervention: Access to treatment should not be based on crisis and an escalation of mental illness; it should be through early intervention before illness becomes debilitating and life-threatening. There needs to be intensive, targeted education of professionals—i.e., teachers, police, general practitioners and HR staff of employers—on how, when and where to refer individuals for treatment. Once referred, access to professional psychiatric treatment and intervention needs to be immediate. Lengthy waiting lists result in an escalation in the severity of the client's mental illness, making treatment more difficult and contributing to the erosion of the client's family and friend support systems.

Currently, it would appear the only expedient way to receive treatment in both Ontario and Quebec is through emergency rooms. While living at home, our son called the crisis line several times when feeling suicidal and was brought to the hospital by police and then admitted to the psychiatric ward of our local hospital on a short-term basis. After a brief stay in hospital and with very little counselling or psychiatric diagnosis, he was put on powerful anti-psychotic medicines which were monitored by very brief 15-minute visits to a hospital day clinic. After discharge from the hospital, our son received virtually no psychiatric follow-up counselling or referral to any community-based programs.

Treatment focus: In general, mental health services, including professional treatment and community support services, are underfunded and are not available to individuals when needed. Access to treatment involves long waiting lists after individuals are assessed and referrals are made. Increased funding is required to train more professionals to provide treatment in the system, i.e., psychiatrists, psychologists, psychiatric nurses. We need to develop effective, multidisciplinary outreach community treatment teams.

Effective treatment requires much more collaboration between family, treatment teams, employers and educators. There is now a focus on early intervention, particularly for the high school population, which is to be applauded. However, there are many people in their 20s, their 30s and beyond who were diagnosed much later. There need to be resources and effective treatment strategies developed for this population as well.

Treatment focus on the whole family, not just the client: Counselling should include support for spouses, children or parents, if the clients are still living at home. Family needs to be a part of the treatment plan, especially before, during and after hospitalization. Families should be included in some of the therapy sessions and involved in discharge planning.

Privacy act: The privacy act should be reviewed and special provisions built into it for individuals and their families who are dealing with serious mental illness. Currently, in the name of privacy, sensitive diagnostic information is not shared with a client's family, so the counsellors speak to the client, not family, which can result in anger and isolation and create a very negative environment when the client returns home. This is completely counterproductive, as it is the family that the client depends on for long-term support.

**1110**

Concrete support services for spouse and children: Babysitting and transportation assistance should be available so that spouses can visit loved ones in the hospital and have free time to do necessary errands like groceries, banking, etc. Spouses at home shoulder all of the parental and living responsibility while a client is in the hospital.

Young children: Currently there appears to be no focus whatsoever on support for young children in families with one or more parent battling serious mental illness. Children suffer guilt and separation anxiety when a parent is hospitalized long-term. There is no support for them or the spouse. Clients and partners need parental coaching.

Medication issues: Treatment is too focused solely on medication. Once a client is stabilized, there needs to be more emphasis on life skills training and support for living purposefully in the community. Clients need step-by-step support towards re-engaging in family and community life, i.e. job preparation, training, re-education, parenting courses, skills development, specific individual retraining to get back drivers' licences, fitness re-engagement in healthy physical activities.

Medication education: Clients and families should be given full disclosure on the medication that a client is taking and its side effects, how they interact with other medication and food, etc. Excessive weight gain from many medications causes serious health and also mental health issues. People are depressed about their body image and the inability to do sports, work out—things that individuals were able to do before the weight gain. Currently, psychiatrists do not appear to address the serious physical side effects of prolonged usage of prescriptions for serious illness like psychosis.

Lack of coordinated treatment for concurrent disorders: In most cases, treatment for addiction and mental health operate in silos—different organizations, different philosophies, different counsellors—all working with one client who is suffering from both mental health and addiction. Concurrent disorders are non-divisible. They are intertwined and interactive, and the individual needs a holistic treatment approach in order to be effectively treated. The waiting list for any publicly funded facility offering treatment for concurrent disorders is unacceptably long. Treatment is only immediately available if payment is made privately, but the cost is prohibitive for most families.

Criminalization of mental health: Criminalization of persons suffering from mental health problems appears to be related to the current high level of negative stigma and ignorance in our country towards mental health. It is most prevalent with paranoid schizophrenia and the sensational coverage by newspapers when someone suffering from this disorder is involved in violent crime. This stigma permeates even the helping professions. A case in point: Our son voluntarily went to the emergency ward at the Gatineau hospital in Quebec and asked to be admitted when he felt his illness was out of control. After he was hospitalized for a week or so and had been sharing his paranoia, his conspiracy theories and violent thoughts with the psychiatrist in this hospital, the psychiatrist called the police and had him removed from the psychiatric ward and jailed. When our son appeared in court, the judge questioned why he had been arrested and referred our son back to the mental health system. This was a terrifying experience for our son, but ironically, by entering into and becoming engaged in the court system and, ultimately, the mental health court system of Quebec, the result was his receiving both psychiatric and outreach community counselling that is now monitored by the mental health court. This was a negative, a convoluted and a resource-wasting path to receive the treatment he required and should have received in the first place after he self-admitted to the hospital.

Universal health plan: non-existent. Provincial borders are really treatment barriers.

Disability allowance and benefits: There is a great disparity between services and treatment available from province to province. Disability allowances are in fact welfare benefits, and those battling mental illness and living on this allowance live in poverty. Their families and children need additional support—i.e. daycare, transportation and school nutrition programs—so that their children are raised in a healthier, supportive environment.

Provincial borders are treatment barriers. Our son lives in a common-law relationship in Gatineau, Quebec, so he now has a Quebec health card. He speaks no French. He is in close geographic proximity to Ottawa and all of the English services for mental health, but because he resides in Quebec and carries a Quebec health card, he can only receive health care services there. When he was being assessed by the psychiatrist for the courts, the psychiatrist had to have an interpreter. The inability to speak to a professional in your own language is a severe limitation to treatment. Our son cannot participate in any support groups in Quebec due to the language barrier. If we are to have an effective mental health strategy, provincial borders should not act as barriers to effective treatment. Clients and their families should be able to access the best treatment anywhere in our country.

Research: None of the above recommendations can be operationalized effectively and efficiently without well-organized and well-funded long-term and short-term research. Research is needed into the etiology of mental illness, genetics, environment, nutrition etc. to enable more accurate diagnosis and treatment. Research is needed on medications, developing new, safer, more effective meds and researching current medications more thoroughly—their short-term and their long-term effects on the individual's mental and physical health. Research is needed on treatment modalities: what works, what doesn't. The current need is so great that treatments need to be introduced based on anecdotal evidence, but eventually treatment concepts—i.e., community outreach teams and clubhouses—need their effectiveness evaluated by evidence-based research. The Canadian Cancer Society Research Institute provides a good existing model to replicate and improve upon for research into the mental health field.

That concludes my presentation. I don't know if there's time left for any questions.

**The Chair (Mr. Kevin Daniel Flynn):** There is; there's actually about five minutes, and I think it's Sylvia's turn to go first.

**Ms. Sylvia Jones:** Thank you, Mary Ellen. I have one question. You mentioned that your son is 27—

**Ms. Mary Ellen Frederick:** Yes.

**Ms. Sylvia Jones:** —and he was only diagnosed two years ago?

**Ms. Mary Ellen Frederick:** Three years ago.

**Ms. Sylvia Jones:** Three years ago. Why did it take so long? What did you see as the barrier?

**Ms. Mary Ellen Frederick:** From everything that I understand, psychosis increases in severity over time. When he first started showing symptoms, I had a colleague who was a psychologist, so we engaged him. For over a three-year period, he provided private counselling for our son. He thought he was dealing with an anxiety disorder, and my son received a lot of behaviour modification counselling. That was helpful in triggers and because he was suicidal. However, at the same time he was increasingly abusing and becoming addicted to alcohol and drugs, and became particularly addicted to marijuana. The addiction problem became the one that we as a family were more concerned about dealing with. It was out of control. The psychologist could not deal with the addiction, so Tim ended up in a detox centre. He ended up going to the Renascent centre in Toronto for addiction treatment, which he dropped out of. With the help of the psychologist, we got him in to a counsellor at CAMH and it was around that time he self-admitted to our local hospital and started receiving medication. At that time, the psychiatrist there said he wasn't sure whether he was dealing with psychosis or whether it was the short-term effects of prolonged use of marijuana, which he felt were the same, and until he was off of marijuana for a year, he felt he couldn't be properly diagnosed. However, he was put on anti-psychotic medicine at that time. It was an evolving situation, so it was not until he went to Quebec and entered into the system there that he was diagnosed as paranoid schizophrenic.

**1120**

**The Chair (Mr. Kevin Daniel Flynn):** France?

**M$^{me}$ France Gélinas:** Just a quick question, and it's personal so you don't have to answer if you don't feel comfortable, but does your son work?

**Ms. Mary Ellen Frederick:** No. He has been in and out of the hospital for stays in Quebec. He has two small children, one his partner had previously, so a four-and-a-half-year-old and a two-and-a-half-year-old—granddaughters—that they're caring for. His medications are being monitored by a psychiatrist. He does have an outreach worker but at this point in time he's not able to work, no.

**M$^{me}$ France Gélinas:** I realize the language barrier and the added difficulty that brings. Aside from his spouse, does he have any social support? If he doesn't work, what are his—

**Ms. Mary Ellen Frederick:** His only social support would be the friends that his spouse has, because his spouse is from that area, and she has a small amount of family. His main social support would be the outreach worker he sees. He's quite isolated because in the housing complex where he lives the language that is spoken is French.

**The Chair (Mr. Kevin Daniel Flynn):** Maria, a very short question?

**Mrs. Maria Van Bommel:** Very quickly, you talked about programs for children of mentally ill people and you mentioned you have two granddaughters.

**Ms. Mary Ellen Frederick:** I do.

**Mrs. Maria Van Bommel:** Are they getting any kind of programming in Quebec? You brought that issue up, so I'm just kind of wondering—

**Ms. Mary Ellen Frederick:** Yes, because I don't see a focus—the treatment that my son is getting is focused on him, so his family is not a part of that. So if he's in a hospital for six weeks, as he was last summer, he receives treatment; they don't. His spouse does have a counsellor to help with child rearing for our older granddaughter. We have provided support for her also to be in daycare, ourselves personally. But there is no focus whatsoever, in terms of his illness, on engaging the family and dealing with the family unit, and I think that's very important. Whether a person battling mental illness is in their original family, living with their parents, or whether they're in a marriage situation or whether they're living independently on their own, most of the time the support in their life is coming from their families, and there needs to be communication in the treatment process with them and support.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Mary Ellen. Thank you very much for coming today. We really appreciate it. Thank you, John.

## JUDITH FINK

**The Chair (Mr. Kevin Daniel Flynn):** Our next speaker after Mary Ellen is Judith Fink. Judith, make yourself comfortable; grab yourself a clean glass. I think you've been here for the other presentations.

*Interjection.*

**The Chair (Mr. Kevin Daniel Flynn):** That's right; we need the seventh-inning stretch here.

You've been here for, I think, a few of the presentations, so you know you have 20 minutes. You can use that any way you see fit. If you can leave some time at the end, that'd be great; other than that, it's all yours.

**Ms. Judith Fink:** Thank you so much. It's a pleasure, and I truly appreciate being able to present to this all-party committee.

I'd like you to just join me for a minute in imagining something. Think of a young child; it could be your own child, grandchild, a niece or a nephew. Which words describe him? Is he curious, eager, affectionate, playful? Imagine sitting by the bedside of this child while he sleeps, knowing that he has a high fever, thinking about the recovery from his illness. The fever breaks, he opens his eyes and he looks at you. There is some recognition in his eyes, but he looks away. You speak to him, and he responds with a one-word answer, no interest in what you're saying. You reach out to him, but he doesn't want to be touched. No hugs, no smiles, no giggles, no laughter—that's what it's like to be a parent with a child who has schizophrenia.

I've divided my presentation into three sections: recognition of mental illness, support for the mentally ill, and promoting recovery. And I'm asking you as representatives of the people of the province of Ontario to improve health care for people with mental illness, to educate the public and professionals, and to provide service and information in all Ontario communities. You will notice I live in Newmarket, but I've had experience in Toronto, York region and Peterborough in dealing with my son's illness.

My son was a bright, normal, social child. He did well in school, participated in extracurricular activities and, when he was 21, moved to Peterborough to attend Trent University. He was very successful in his summer jobs, but in 1997 began to skip classes and be more involved with substances like alcohol and marijuana. He broke up with his girlfriend, or she broke up with him, and the onset of schizophrenia—we're not sure if there was any kind of cause-and-effect relationship. They just seemed to happen around the same time, which made it, of course, very difficult to recognize whether this was a normal response to a breakup or the onset of a mental illness. Anyway, the next couple of years he lived quite an isolated life, and in 1999 he recognized that he needed to make some changes. He left Peterborough and moved back to Toronto.

He could not find housing on his own, something that he'd been able to do previously. He could not hold a job for more than a couple of weeks, something he had been able to do previously. We realized it was a serious problem. We consulted our family doctor, and she was quite sure from speaking to him and observing his behaviour that he had developed schizophrenia. He absolutely resisted getting any kind of treatment. He was belligerent in psychiatrists' offices and absolutely refused medication. We know now that's part of the paranoia that accompanies the disorder.

We had to take on basic responsibilities, his dad and I, to find him a place to live; we paid for his rent and we gave him a living allowance. He agreed to work with a talk therapy psychiatrist for a couple of years, but that was very limited in its effectiveness. We struggled and struggled to get him to go to an appointment with a psychiatrist, and eventually he gave in and had a psychiatric assessment. The follow-up appointment was scheduled, and my son and his dad showed up for the appointment and were told that the appointment had to be cancelled because his psychiatrist had been called away on an emergency. At that point my son became incredibly angered and totally rejected all medical help.

What did we learn? We learned we need to recognize the symptoms of schizophrenia in early adulthood. We need to remove the stigma that's associated with mental illness. We need to overcome barriers to actually connect a patient to doctors for diagnosis. We need improvement in the general education through secondary school programs. The onset of schizophrenia, as you probably know by now, is usually between the ages of 14 and 25. We need to support media education which is accurate, and we need to recognize that with paranoia and a loss of reality, it is extremely difficult for the patient to advocate for himself.

**1130**

Please improve health care for people with mental illness. Shorten the wait time for psychiatric assessments. Encourage psychiatrists to work as part of a mental health team. If the original psychiatrist is unable to do the follow-up visit, there should be someone present who can take over and provide the services that are needed immediately. Promote psychiatry as a highly respected option for physicians. We absolutely need more psychiatrists in our province.

Educate the public and professionals. Initiate mental health issues education as part of the curriculum for students at the intermediate and secondary school level. Make mental health information part of teacher professional development for secondary school educators. Provide school guidance counsellors with relevant information regarding recognizing mental illness. Encourage teachers to refer students to guidance counsellors to assess the need for formal diagnosis.

Please provide education, service and information in all of our communities. Up-to-date information about mental health services should be available through a website with links. Institute 211 access to social services throughout the province. This is something I learned about last week. I had no idea; we don't have it in Newmarket. It's available other places; 24/7, you dial 211 and they are able to direct you to social services to take care of the issues that you're having. It's not available throughout the province. Publish mental health crisis phone numbers with other emergency numbers in telephone directories.

The second part of my presentation deals with support for the mentally ill. We continued to try to get our son to work with a different psychiatrist and to take medication, and after he rejected the offer from the Clarke to try medication for a short period of time, we made the very difficult decision to stop our financial support. We gave him some time to find some income, and then we stopped paying his rent as well. Of course, he was evicted from his apartment, by the police. We packed his belongings and put them into storage. This was an incredibly difficult thing—I mean, if we weren't weeping constantly, we were certainly brimming with tears—to pack up, clean up and move his things into storage, not knowing where he was going to go or what he was going to do.

He left Toronto, went back to Peterborough and moved in with a friend, got a job in a café, phoned his dad. The job didn't last, neither did the housing circumstances, and the next four years were extremely difficult. We could see that he was having delusions. He had extreme trouble with relationships and several jobs within the next few months. When things weren't working out for him in Peterborough, he took off for the family cottage. During the winter of 2004-05, he isolated himself there. We were very concerned for his welfare—how he would get food, how he would provide himself with heat and his inability to make judgments that were, we believed, essential. Occasionally, he would answer the telephone. One Christmas I went out and walked into the cottage; he wasn't home. I just left a bag of goodies on the doorknob.

In the spring, we moved him to an apartment in downtown Peterborough. He needed help from his parents to find the apartment and to make the move. He applied for ODSP finally in April 2005. He had refused previously because he denied that he had any mental health issues, but he was now physically injured, and so it was okay to apply for ODSP because it was a physical issue, not a mental issue. Regardless, it took 10 months—until January—for him to receive his first cheque. During this entire period there was tremendous deterioration—disconnection from reality, isolation, delusions, hallucinations and paranoia. In May 2007, he was evicted from his next apartment, this time for security reasons.

During the period of time when he was ill, we came to understand that survival is very complicated and difficult for a person with untreated schizophrenia. Family members require counselling to determine how and when to help the loved one, where to find services and how to preserve their own physical, emotional and mental health. My son suggested that we need to support food banks. That was one thing that was incredibly important to him: knowing that he could go to a food bank when necessary. We need to improve our financial support in housing through ODSP. We need to educate police and the justice personnel so that they master required skills and have the knowledge to interact with a mentally ill person.

So my recommendations are:

Educate the public and professionals. Provide training and more education for police and justice personnel in dealing with people who are mentally ill.

Provide service and information in communities. Make programs like the York region CMHA support group for families and caregivers available and accessible. Support and work with food banks to sustain individuals in need. Respect the need for privacy, but provide information to food bank personnel so that they can monitor, recommend and initiate contact with services when appropriate.

Make some modifications to ODSP by linking the recipients with caseworkers who are trained, have time and knowledge, and can refer their clients to appropriate services.

The next part of my presentation is the happy part: promoting recovery. After being evicted from his apartment in Peterborough—and let me remind you again that this act of packing the belongings, washing the dishes, moving everything into storage and not knowing what's going to happen is very distressing for the families. You have no idea what tomorrow is going to bring. You just know the police have escorted your son away again.

Police officers took him to hospital. Fortunately, he had a crisis worker with him who stayed with him, and after several hours he was finally admitted. The psychiatrist was on duty, which is not always the case. In a town like Peterborough, the psychiatrist—the psychiatrist—splits his time among at least two jurisdictions. Zyprexa was prescribed. He took it without resistance, and within days there was a significant change. He was discharged after two weeks, and received excellent help from his CMHA case worker.

He found an apartment on his own, continued to keep his appointments, and when the noise downstairs got to be unbelievable, he organized his own move to a different apartment. In September 2008, he went back to Trent, took a two-part computer course and did quite well. Now, as of the beginning of this month, he's attending the concurrent issues residential program in Penetanguishene, called Georgianwood. If you don't know about that, I'd like to tell you about it.

So in order to promote recovery, we need to:

—recognize that schizophrenia can be treated with medication;

—realize that there are many people in hospital admission staff who do not recognize mental illness or have training to deal with a person in crisis;

—understand that an independent, productive life is possible;

—provide support through existing community health programs; and

—expand and create special residential programs to help establish a normal lifestyle for a person in recovery.

Please, once again, improve health care for people with mental illness. Educate nurses and admission staff to respect the family, police or social workers who bring a person to hospital. Teach hospital staff to recognize the volatility of mental illness. A mentally ill person can pretend, for a short period of time, to need absolutely no help. Initiate a reasonable period of time for observation before sending a mentally ill person away.

Provide services and information in the community about recovery support programs. Tell the individuals receiving treatment, medical personnel, counsellors and families what is available, and maintain and update websites with current information.

For recovery support programs, work through community centres, libraries, adult education centres and the Y to initiate programs for those in recovery. Create provincial initiatives to hire those in recovery on a part-time, temporary basis, with supervision and support from mental health professionals. And, of course, involve the healed person in the recovery process, and perhaps even use them as mentors to others who are ready to build new and healthy lives.

To summarize, please improve health care, educate the public and professionals, provide service and information to the communities, and hopefully we will see more curious, eager, affectionate and joyful people in our province.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Judith. You mentioned Georgianwood?

**1140**

**Ms. Judith Fink:** Yes.

**The Chair (Mr. Kevin Daniel Flynn):** And you said that, if we asked you, you'd tell us about it. So why don't I start asking you, and then we'll—

**Ms. Judith Fink:** I found out about this through the York region support group for families and caregivers. Our team leader invited a young man who'd been at Georgianwood. It's a concurrent program and it's run at the mental health facility of Penetanguishene. It is for people with substance abuse and mental health disorders. It is a totally concurrent program. You must be off substances for a period of 72 hours before they'll admit you.

We were fortunate. Our son finished his courses in May and was accepted in June. He had one week from the phone call that came through to be ready to go, and it was great. I said to him, "I can't believe I'm washing your dishes and organizing your place and you're here, you're well and you're going to get help, that we're not taking your stuff into storage and the police aren't at the door."

The program is very comprehensive. It includes physical activity, eight different counselling support groups, some dealing with substance, some dealing with employment, some dealing with individual counselling, some dealing with group counselling. There is an Alcoholics Anonymous meeting that takes place. There are physical education resources that are shared with the correctional facility. There's a pool, tennis courts. It's located on a beautiful site right on Georgian Bay. The intake is 12.

**The Chair (Mr. Kevin Daniel Flynn):** Twelve beds?

**Ms. Judith Fink:** Twelve people for a three-month program, but it is comprehensive, if my son's experience is anything like that of the young man who came to talk to us or the way the social worker spoke to me when I was there last Tuesday.

**The Chair (Mr. Kevin Daniel Flynn):** Okay, and it's funded by OHIP?

**Ms. Judith Fink:** Yes.

**The Chair (Mr. Kevin Daniel Flynn):** That's wonderful.

**Ms. Judith Fink:** That's to the best of my knowledge. It's not costing us anything.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you. Let's start with France. We've probably got time for maybe two questions.

**Ms. Judith Fink:** Good. I got it down to 18 minutes.

**The Chair (Mr. Kevin Daniel Flynn):** One question each.

**Ms. Judith Fink:** I've been talking faster every day.

**The Chair (Mr. Kevin Daniel Flynn):** No, no, you've done a good job.

**M$^{me}$ France Gélinas:** We've had a few family members come and talk to us, and listening, there's this great divide as to family members wanting their loved one to get treatment and often the person with mental health refusing treatment. This is something we see in cancer treatment. There are people who have been diagnosed with cancer who refuse treatment, there are severely diabetic people who refuse treatment and there are quite a number of seriously mentally ill people who refuse treatment. Your son went through this phase for a long time and then finally accepted it. Do you have recommendations for us for that period of time where he refused treatment? How do you balance the right of a person to refuse cancer treatment etc., as well as mental health treatment, versus the good that can come of it?

**Ms. Judith Fink:** It's a very difficult issue, of course, and that's why the family counselling is extremely important, because, of course, the parents want their child, or the sister wants the brother, to receive treatment and take medication, and it's almost impossible to do that.

The people who came to the groups that I attended through the CMHA program were facing these issues of denial. I don't think our son ever would have gotten help if we hadn't pulled the plug on the finances. The reality has to be so bad that they have to want treatment. One of the things that the talk therapist said was, "There's no point in forcing him to take medication; he'll just go off it anyway," which is a major issue.

The family needs to know that they have to step back. One of the social workers said to us, "Don't forget the three Cs: You didn't cause it, you can't cure it and you can't control it." So the burden has to be on the individual. That's why I brought up this issue of food banks. During that period of time when a person is unmedicated and mentally ill, they need to survive.

My son did have a brush with the justice system, which turned out to be wonderful for us because he had an excellent probation officer who essentially said to him, "Go for a psychiatric assessment or we're putting you in jail. Meet with your caseworker or we're putting you in jail." He wasn't belligerent; he was very helpful. For some wonderful reason, he was able to stay in touch with myself and my son's dad on a monthly basis. The link through the justice system, through the mental health system in Peterborough at that time—they were able to be in touch with each other. So when we did have this issue of taking him to the hospital at the end, the mental health team and the justice team were on site and we got excellent help at that point, but—

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Judith. I'm going to have to end it there, unfortunately, but I think you got your point across very clearly at the end. So thank you for coming today.

**Ms. Judith Fink:** Thank you for instituting this inquiry.

## HALDIMAND-NORFOLK RESOURCE CENTRE

**The Chair (Mr. Kevin Daniel Flynn):** Our final presenter before we break for lunch is the Haldimand-Norfolk Resource Centre. Susan Roach is with us. Susan, come forward. You can probably find a clean glass there somewhere if you need one, and, like everybody else, you've got 20 minutes.

**Ms. Susan Roach:** Okay, thank you.

I'm a daughter, a friend, a program manager, a community volunteer, a colleague, a university graduate, a life skill coach and a suicide intervention trainer. I enjoy photography, I love to read and I bowl. And I am a person living with a serious and persistent mental illness.

Thank you for this opportunity to present today. I am Susan Roach. I'm the program manager of the Haldimand-Norfolk Resource Centre. We are a mental health drop-in program run by and for people living with a mental illness. We have a mandate to provide social recreation, education, peer support and advocacy. We are a program of Community Addiction and Mental Health Services of Haldimand and Norfolk. We are considered to be a consumer-survivor initiative, one of 61 similar programs across the province of Ontario.

I've taken the time to tell all of this about myself today because some of the greatest barriers for people living with mental illness, in treatment, in services and in our community, are the assumptions that people make about who we are and what we are capable of. Illness becomes the predominant way in which we are viewed by others, and services and supports narrowly assume that as long as they treat the symptoms of our illnesses, they have provided adequate care for our mental illness or our addiction.

Clearly, we must have access to doctors and psychiatrists, there must be an adequate number of hospital beds and programs dedicated to providing mental health and addiction treatment, and programs must be accessible without long waiting lists and without barriers and numerous hoops to jump through in order to get those services. These represent the elements of the medical model of treatment that need to be sustained, improved and enhanced. However, we must look at how we deliver these services and begin to recognize that these services alone do not provide all that is required in order for an individual to recover.

Recovery is not some elusive concept, and it's not founded on the premise of a total absence of symptoms. Rather, it is based on the principle that hope and meaningful life are possible despite the mental illness and/or the addiction. Recovery is a process by which the individual living with mental illness recovers self-esteem, dreams, self-worth, pride, choice, dignity and meaning. Recovery is a personal process, but it can either be supported and encouraged or undermined by the very design, development and delivery of our health care and social service programs.

Our system of care must first and foremost believe in, invest in and proceed as if recovery is always possible, because nothing will extinguish hope faster than an implied or direct message that while we may be able to achieve some symptom relief, thinking that we will ever achieve anything further is just a pipe dream.

**1150**

Toward recovery, we must be provided input through the whole process of our care and in the designing and development of programs and services. Systems and programs need to be person-centred. The system must begin to challenge us and empower us, not coddle us and do for us. We are capable, and the system needs to proceed as if we are, not as if we are not. Opportunities for recovery are enhanced when we are viewed as whole individuals, not just as a cluster of symptoms. Our culture, spirituality, meaningful activity, work, socialization and education are all components that need to be addressed to support our recovery.

Recovery is supported when the system works from a position of recognizing our strengths rather than focusing on deficits and weaknesses. Recovery is supported when those important to us are engaged in the process. Recovery is supported when services are available within our own communities and when opportunities to be engaged and involved in the community are provided and supported.

I want to take a few minutes to share with you comments offered by others living with mental illness who attend the resource centre where I work. We asked our members to share with us one important message that they believe the community needs to learn about mental illness. Some of their responses are as follows:

"People with mental illness can live a productive life and be as important to the community as someone who doesn't have an illness."

"We are capable of parenting, employment, self care and basically having a 'normal' life," just like anyone else.

"That people with mental illness are not lazy, sitting on their butts, smoking and drinking coffee. They lead very productive lives in the community," when given the opportunity.

"That people with mental illness can recover."

I've included these particular statements because we need to be aware that, even in 2009, we still have people living with a mental illness who every day feel misunderstood, devalued, minimized and stigmatized. They know that they can and do have much to offer, that they are not violent, stupid, lazy or non-contributing. But how long does that hope and belief remain alive if it is not nurtured, supported and endorsed? How do we continue to believe when so much energy and personal resources are needed to be put into just sustaining ourselves and surviving?

Mr. Kirby raised an interesting point when he presented to this committee: that there is no single point of responsibility for providing mental health and addiction services. Mental illness and addiction will never be fully addressed if we focus only on having doctors, hospital beds or community clinical services. Yes, they must be present and they must be recovery-focused, and the recovery focus begins with accepting that the majority of challenges that we face will begin when we are discharged from hospital or when we leave the clinician's office—basically, when life begins.

The Ministry of Health and Long-Term Care, the Ministry of Community and Social Services, the Ministry of Transportation, the Ministry of Community Safety and Correctional Services and the Ministry of Municipal Affairs and Housing need to begin to work together to develop comprehensive solutions to the life challenges, the barriers that are inherent in their programs, which serve to undermine—and which can thwart—recovery. The time has come to end the "Oh, yeah, that's an issue, but it's not our responsibility." Everyone has historically been very good at passing off responsibility, leaving individuals with incomplete and fragmented services. Pieces of some programs are built on a foundation, which are generally assumptions, that the pieces are in place somewhere else. We need to make concepts like "seamlessness" and "comprehensive" a reality.

Again, I'd like to share with you the stories, challenges and experiences of the members from the centre. One of the programs of the Ministry of Community and Social Services is Ontario disability. It's there, supposedly, to provide financial help for people with disabilities who are in need, and it's supposed to help pay for living expenses like food and housing. Over 90% of our membership at the resource centre is on ODSP. While we appreciate that we have a system which financially supports those with disabilities, the current system is fraught with difficulties that begin right at the application stage.

Unfortunately, it's generally accepted by those who apply for benefits that no one will be accepted in their first application for ODSP. Virtually all will need to attend a tribunal hearing before they will finally be approved to receive benefits. One gentleman needed to attend seven hearings before he was finally approved to receive support and required legal counsel at the tribunal hearing in order to make that a reality. This can result in an elapsed time of three to five years between when people apply and when they are finally accepted to receive ODSP benefits. One member expressed that you are automatically suspect if your application is for mental health versus physical health problems.

Once in receipt of ODSP, the financial support an individual receives falls far below the poverty line. Disabled people in Ontario are falling more than $5,000 below the poverty line. Benefits are based on an allotment for housing set at $454 per month. I would challenge anyone to try to find housing anywhere in this province for $454 a month. Unfortunately, in part, it's based on the premise that individuals who are on ODSP are going to be eligible for subsidized or geared-to-income housing. Unfortunately, the reality of that system, as it's currently operated by the Ministry of Municipal Affairs and Housing, is that the waiting list can be in excess of two years to receive an offer of housing, and where, in the area I come from, Haldimand-Norfolk—and we have absolutely no public transit—offers of housing may in the end be for an apartment that's far removed from your own community and away from all supports and resources. Turning down a housing offer can cause you to lose your place on the waiting list.

Additionally, if you're on benefits because you have a disability and by chance you get sick and are hospitalized, the potential exists to have your benefits suspended.

You will then only receive $112 a month, which is considered a personal needs allowance, and an individual may lose their housing. Then all your belongings have to go into storage, and if you've been in subsidized housing, you can't get reconsidered for housing until you can pay the back debt that you owe. If you're only getting a thousand dollars a month, trying to clear a back debt in order to put yourself back into a position of eligibility is extremely difficult.

More than 40% of our members currently report that they are paying more than half of their income on rent, with many of those also paying utilities. Members are left with an almost daily challenge of deciding what will get paid and what, for the moment, has priority. One member was recently confronted with making the decision whether her child's over-the-counter medication or food would receive priority.

Although indicated as required by the physician, over-the-counter meds are not covered under the drug benefit, and individuals who, in addition to their mental health diagnosis, may also be attending to a range of physical issues are often faced with stretching an already over-extended budget in order to meet those needs.

Further changes to ODSP have made the process of obtaining additional funding for special diet needs difficult to access and far below the previous rates allotted to meet these needs. One individual reported that where previously they received $52 per month to assist with their medical dietary needs, this amount was cut to just $10 per month—although, as you can appreciate, the cost of food has only risen, it has not gone down.

**1200**

As I've already mentioned, Haldimand-Norfolk is a community without any public transportation. Our program serves a community equivalent, geographically, to half the size of Prince Edward Island. Members are scattered throughout this rural area. Although peer support programs such as ours are identified by the Ministry of Health as a best practice, which means they contribute to an individual's overall health, well-being and quality of life, it's not equally recognized by the Ministry of Community and Social Services, which is in a position to provide for transportation. Although medical transportation can be covered by ODSP if an individual is going to a peer-run AA or NA meeting, it's not covered if they're coming to a peer-run mental health meeting. Daily, we face the challenge of how to enable people to even get to the centre and access the supports that we have to offer. While we do operate two vehicles, these are not funded in our base Ministry of Health budget, because transportation is not deemed to be a health issue. So we fundraise to cover vehicle operations. Individuals struggle to get to the centre for support, but transportation as a health issue extends even further for the majority of our members.

We recently did a survey and 41% of our members reported that their family doctor was not located in the same community in which they themselves resided, and that, in addition, 65% have further need to travel to attend to see a medical specialist. The significant outcome of this survey that is of great concern to us is that 38% of the individuals we surveyed indicated that, based solely on a lack of transportation, they had missed a scheduled medical appointment, and that, as an outcome, had ended up using the services of either a walk-in clinic or the emergency room in order to attend to their medical needs. Additionally, it should be noted that for those few who may be able to operate a vehicle while on ODSP, ODSP approves a reimbursement rate of only 18 cents per kilometre for transportation.

Individuals with a serious and persistent mental illness continue to want to be engaged in meaningful activity. This may mean attending programs such as the centre, volunteering in the community or working. Participation can be negatively impacted by a lack of available transportation, lack of opportunities, program design and/or stigma.

Individuals have lost jobs when evidence of their mental illness became known to the employer. One individual lost their job of nine years when they were diagnosed, as concerns were raised suddenly about their ability to be productive. Others have had their opportunity for employment compromised when their police record check disclosed Mental Health Act information. One individual, where the police had been involved to transport them to hospital when they were suicidal, had noted on their police record check that they were "the subject of a mental health investigation." Embarrassment and fear of public scrutiny kept that individual from pursuing the position because they didn't want to hand their police record check to their potential employer. Others have sought and begun work under the revised ODSP work incentive program, which offers individuals $100 per month as a supplement. However, for one individual who did that, they got the $100 benefit and they lost the $160 transportation allowance that they had originally received in order to get to work.

**The Chair (Mr. Kevin Daniel Flynn):** You have about 30 seconds left, if you just want to summarize.

**Ms. Susan Roach:** Basically, we have challenges in running the program as well. We are woefully, as consumer initiatives, underfunded. We have an operating budget of around $200,000 per year, and yet last month alone we provided 2,222 hours of member support between our two sites in Dunnville and Simcoe.

**The Chair (Mr. Kevin Daniel Flynn):** Thanks for being here today, and I didn't mean to cut you off, but we are trying to be fair to everybody, and I think we got your point.

**Ms. Susan Roach:** Can I just finish my last sentence on here?

**The Chair (Mr. Kevin Daniel Flynn):** Sure.

**Ms. Susan Roach:** So what is it that we do? Consider the response of one member, who said, "Before I found this place, I was on a suicide mission. Now I have reason to be alive."

**The Chair (Mr. Kevin Daniel Flynn):** That's a great way to end. Thank you.

**Ms. Susan Roach:** I have left you with a copy of our most recent newsletter, for anyone who would like to take a look at it. I also did provide—

*Interjection.*

**Ms. Susan Roach:** Yes, that's the newsletter you're holding up. I also provided a copy of the transportation survey that we did. My final report is not yet really final, but it should give you a good overview.

**The Chair (Mr. Kevin Daniel Flynn):** Perfect. Thank you very much for coming today.

For the committee members, checkout of the hotel is at 1 o'clock. The lunch is at Windows on King, which is above the lobby, next to where you had breakfast this morning. The luggage needs to be on the bus at 4. We're going to eat here, and we're going to leave here just before 6. Okay?

We're adjourned.

*The committee recessed from 1206 to 1332.*

## CARLA

**The Chair (Mr. Kevin Daniel Flynn):** Okay, ladies and gentlemen, if we can call to order for the afternoon, I'm sure we'll be joined in progress by France in a few minutes. Our first presenter of the afternoon is Carla, if you'd like to come forward. Make yourself comfortable. As I've explained as we've been travelling throughout Ontario, everybody has been taking 20 minutes and they've been using that as they see fit. So if you want to make that all presentation, that's fine; if you want to leave something at the end, that's fine too.

**Carla:** Thank you for this opportunity to speak before you today. My name is Carla. I am a resident of Burlington, Ontario, where I live with my husband of 20 years. I am here as the sister of a 46-year-old man affected by serious mental illness.

Our family first became aware of my brother's illness in 1991 when he was 28 years old. A graduate of McGill University, my brother was in the early stages of what appeared to be a promising career in the field of computers. He had been married for two years, had purchased a home in Burlington and barely one month earlier had welcomed an infant son into his life.

Our parents, who emigrated from Italy over 30 years earlier and who raised us in a small French-speaking community in northern Quebec, had recently retired and moved to Burlington. I will never forget the day that changed our lives forever. It was a Friday and a day off for me. Our mother informed me by phone that my brother had been fired from his job. I pondered the shocking news, trying to make sense of this event. My brother was an intelligent, responsible and capable person. What could have gone wrong? But there had been signs, things that hadn't always made sense and which we naively attributed to stress.

I decided to visit my parents for some probing and later confirmed with my brother that he was mentally unwell. He shared details of improbable things that had happened at the grocery store, in his house, with practically everyone in his environment. Our conversation ended with a loving hug. I did not think to get my brother to a hospital. I was in shock and also in denial. Mental illness was just not part of our family.

When I talked with his wife, it became apparent that she had been suffering in silence, afraid for herself and in fear of her husband's unpredictable behaviour and erratic disposition. She described that he had been physically, verbally and emotionally abusive based on paranoid ideas. He had isolated her from friends and family during what should have been the happiest time of their lives. He was suspicious, secretive and protective of himself and his family. She asked me to call her parents. It was her father, a physician in Montreal, who directed me to take my brother to a hospital.

My brother came willingly and agreed to be hospitalized. My sister-in-law and I visited my brother's employer, the one who had fired him—again, more evidence that he was in serious trouble. I asked the employer if he would grant my brother sick leave or extend his health benefits given that he was ill. I pointed out that his wife was not working and that they had a newborn son. The answers were unequivocal noes. The employer was not interested in helping in any way.

That first hospitalization lasted about one month. We were told that it was premature for a diagnosis; time would inform us.

That next year was not without its challenges. My brother attempted to return to work. Despite being heavily sedated, he went for interviews and was not successful. Some time that fall, he stopped taking his medication. He was feeling better and did not think he needed it. Life soon became difficult again for his wife. She left him in February 1992, taking their young son with her to Montreal, eventually settling in Ottawa. The house was sold, and my brother moved in with our parents. The family convinced him to attend a program at Homewood in Guelph, which soon set him back on course.

Over the next 10 years, my brother was mostly but not entirely compliant with treatment. He would periodically take liberties. We could tell by his discourse, behaviour and disposition when he cut back his dosage. Paranoia and hostility aimed at family, friends, co-workers and even strangers became a hallmark. The hostility was expressed verbally and sometimes physically. There was evidence of auditory and visual hallucinations, and we would find ourselves accused of things that we had not said, done or witnessed. Getting him back on medication was never an easy task. His illness seemed to progress in severity with each breach of treatment. It was usually through the authority of our father that my brother would reluctantly begin to take treatment again.

Only once did an employer assist with this process by referring him to a psychiatrist for evaluation. Out of that assistance at Women's College Hospital in Toronto, my brother was placed on olanzapine, a drug with fewer and milder side effects than any other drug he had previously taken. Most surprising, the employer welcomed him back to work. My brother was able to function well enough on medication to be able to work in the computer industry, albeit in a diminished role to the ones he had previously assumed. He also lost jobs along the way when he went off his meds. It was difficult for him to see less-qualified workers being promoted while he was routinely passed over.

In January 2002, we lost our father to leukemia, leaving my brother to live with our mother. Two years later, in February 2004, my brother received notice of layoff from his employer of five years. He was initially poised to look for a new job, hopeful that he would find one closer to home, but things soon changed. My brother had put on quite a bit of weight as a result of taking olanzapine and he had become alarmingly hypertensive. Rather than work with his doctors to figure out a solution, he decided to go off olanzapine. Not only was our father no longer around to exert authority over my brother, but the external pressure of being able to function in a work environment had also been removed by unemployment. There was no one with any level of meaningful authority to intervene in my brother's harmful decision. Our attempts to get him back on track were met with hostile insults and stubborn opposition as the illness tightened its grip.

**1340**

My brother has never worked since. Our mother, my husband and I tried repeatedly to help him realize that he wasn't functioning properly and that he needed help. I turned to organizations and professionals for guidance on what to do, only to be reminded that the only way to get him to hospital was if he was a danger to himself or others. Verbal and emotional abuse did not meet the required criteria.

By September 2004, my brother's hostility had escalated to the point that our mother feared for her safety. For the first time, we went to the police for assistance. Later that day, they apprehended him and took him to hospital. It was traumatic, especially for our mother, who feared he would be hurt in the process. Fortunately, he went willingly in handcuffs. He was admitted to hospital for approximately two weeks. Conversations with him while he was in hospital informed us as to just how ill he had become. He had totally lost touch with reality. He stubbornly refused treatment and the overseeing doctor had to let him go untreated. He returned home calmer, at least for the time being.

My brother embarked on a friendly relationship with a female patient during this hospitalization, adding a new element to the situation. She became a frequent visitor to our mother's home. Although she seemed nice enough, our mother did not feel comfortable having her around the house with my brother. They disregarded our mother and engaged in inappropriate behaviour in her home. Tensions ran high. Our mother also worried about this young woman: Her son could hurt her.

The next hospitalization was in January 2005, following an incident in which my brother damaged some vehicles outside an ex-girlfriend's complex. The police were called. My brother was given the option of avoiding charges by going to hospital. We took him to Oakville Trafalgar, where his former psychiatrist now practised. There he denied his behaviours, accused us of making things up and again refused treatment. He was released in short order.

By this time, my brother's hostility towards our mother had become a daily occurrence. He had developed what appeared to be tics and physical hallucinations for which he angrily blamed others. For example, he thought people had their fingers in his ears or that someone was attached to his leg. He sometimes felt people inside him or that he was being stabbed repeatedly. He searched for the culprit and blamed whoever came to mind, including people from his past, people who lived miles away and even people who were dead. He began to focus on our mother as the one responsible for these physical things that were being done to him. He threatened to slap or kill her, and would ask her to leave the house or to give him her money. He even locked her out one day in sub-zero weather. Anything our mother said or did was somehow connected to my brother and his perceptual experiences. Even when she sat quietly, she was accused of saying or doing things according to his aberrant thoughts and perceptions. The hostility turned to everyone and anyone who came to his mind. He visited, telephoned and left phone or written messages for family friends, acquaintances, past bosses and co-workers, companies he dealt with. He was rude and insulting.

It became difficult to hide my brother's illness from others. He quickly lost remaining friends and even our mother's friends stopped coming by the house. We were left to deal with this alone. Our mother slowly succumbed to the stress of the situation. She became depressed and afraid to leave the house because she worried he would get rid of or damage items he thought were somehow interfering with his well-being. She became a prisoner in her own home. She lost her smile and turned into a different person. The effect was profound.

During this time I became a nervous wreck, worrying about our mother's well-being. I called her several times a day at every opportunity I got. I was checking in to see that she was okay and trying to judge whether I needed to take action. I wasn't sure that I could always trust her answers: Our mother protected both her children. My husband and I were over as much as we could so she would not be alone with him. We were on call around the clock. I went to bed fearful of what the night might bring. My cellphone was always on, and I was afraid to venture far from Burlington. I gradually began cutting back my time at work.

In January 2006, the police showed up at our mother's door. My brother had written some disturbing e-mail to a couple of politicians and they had been asked to check things out. With their help, the newly available COAST service came to our mother's home to assess my brother. They found enough evidence to take him to hospital, but we would need to get his physician involved. The police picked him up three days later following a visit with his doctor that we had arranged. He was admitted to Joseph Brant hospital yet again.

It was at this point that I saw an opportunity to get my brother out of our mother's home if he refused treatment. I explained to our mother that he had to go or she would lose me, her only support. I could no longer deal with how this was affecting our lives. He was ill and we were suffering. I asked for a family meeting, during which I told my brother that he could not return to our mother's home. He was characteristically hostile. I helped him look for an apartment, since the social worker told us this was not her role.

My brother finally applied for CPP disability and moved into a small apartment in Hamilton where the rent left him under $200 per month for other expenses. He chose to have Internet service but no phone. He cooked gourmet meals and entertained his girlfriend. He purchased gym equipment to furnish his living room, and placed aluminum foil on walls and windows to keep radioactive waves from entering the apartment. He installed additional venting fans and became obsessed with smells, bugs and mould.

Although still worried about him, our mother enjoyed relief from no longer having to contend with threats and insults. She was smiling again, and we were able to take her out to places she enjoyed and to visit with her friends. In August, we were alarmed to discover that my brother had purchased a plane ticket to Italy. A few days before his scheduled departure, an incident occurred at the apartment which led to the involvement of the police and COAST. He was admitted to St. Joseph's hospital in Hamilton.

Our experience at this hospital was very different from our recent experiences at the other hospitals. For the first time in a long time, we were invited to attend a family meeting. Also for the first time, we were given a diagnosis. My brother, we were told, had paranoid schizophrenia, which is what we had suspected all this time. The physician judged him incapable of making decisions about his treatment and asked me to be the substitute decision-maker. I asked that a third party be appointed to support our cause.

My brother contested the decision that he should be treated and appeared before a review board. The board supported the need for treatment. It was looking as though we would finally be able to get him back on medication. My brother, however, appealed a second time and the case was destined for the Ontario Court of Appeal. We were told this could take months. The hospital found itself in a position to have to release my brother because he was no longer a threat to himself or others, and essentially this meant that the case would not go forward. We were also told that even if there were a court order forcing treatment, we would have a hard time finding a community physician who would take my brother on as a patient; it was too much trouble. We were disappointed, because for the first time in a few years there had been some hope that the system would ensure my brother would get the help he needed.

Following discharge, my brother could not go back to his apartment because he was convinced it was infested by mould and germs and that his physical health was being compromised. He stayed at a Burlington hotel for two months before moving into a furnished executive apartment where he seemed to have developed obsessive-compulsive-like behaviours. He disinfected everything that had been in his apartment with boiling water. His knuckles were red and raw. He treated tap water with iodine tablets, took oral medication for ringworm and also had an inhaler. He showered several times a day. I called COAST to come assess him. They cautioned him about his dangerous behaviour, but he was not enough of a danger to himself to be taken to hospital.

While in the executive apartment, my brother had a mild heart attack which required angioplasty and stenting. He was prescribed medication to keep the stent operational. He later discontinued that medication and complained that the stent was actually a communication device used to spy on or to bother him. He suggests to this day that he should have it removed.

My brother was asked to leave the executive apartment. Tenants had complained about him, and he had not paid his rent.

**1350**

It became clear that he would need a more permanent place to live. I made many phone calls looking for suitable accommodation. Summit Housing in Burlington had vacancies, and they said they would consider him for housing geared to income, even though he was not medicated, which was against protocol. His application was rejected, however. I was told that some of the staff knew him from working out in the field, and they did not want to be involved with him.

Having racked up a huge debt, my brother had no choice but to stay in shelters. Even they became suspicious and started asking for consent to review his medical records. He refused. He approached family friends for money. It became the one thing I kept from our mother.

When our mother came down with the flu in February, my brother offered to stay overnight to look after her. This is how he re-entered the home. My brother's behaviour toward our mother was surprisingly better. He continued to rant and rave, had angry outbursts and was hostile, but it was directed at others outside the home. It was still difficult to listen to day in and day out. Our mother started changing again, and I, in turn, began to withdraw. Our mother was admitted to hospital in December 2007 and died in May of last year.

My brother is now my responsibility. Because of our past experience, I have decided to keep our parents' house so that he can live in a familiar environment that limits his interactions with others. It is added work, responsibility and stress for me and my husband.

In March of this year, we took my brother out on his birthday to see his son, who now attends the University of Waterloo. He was in a hostile, angry mood from the time he got into the car and throughout dinner. At one point, he hit his son on the back of the head in the restaurant for no reason. Later, on the way back from the restaurant, he punched my husband in the face from the backseat of the car with no warning. Fortunately, my husband had just parked the car. The police were called and my brother was taken to Grand River Hospital in Kitchener, where he was admitted. They thought he was very ill and said that if he was their patient, he would not be allowed to leave their facility without treatment. We were once again hopeful that he would get the treatment he needed. The next day, however, my brother was transferred to Joseph Brant in Burlington. I knew this meant that he would walk out yet again, untreated.

**The Chair (Mr. Kevin Daniel Flynn):** Carla, you've got about a minute left. If you just want to kind of summarize—

**Carla:** I have how much left?

**The Chair (Mr. Kevin Daniel Flynn):** About a minute.

**Carla:** A minute? Really? Okay.

**The Chair (Mr. Kevin Daniel Flynn):** We're actually over time, but you have a minute.

**Carla:** Okay. So this latest aggressive incident changed our relationship with him, naturally, and we have been withdrawing a little bit, but we still need to keep an eye on him.

My request for this committee is to look at treatment and non-compliance with treatment. I'm fully aware of the history of people with mental illness and the horrible things that were done to them in the past, but I do feel that the pendulum has swung completely in the opposite direction at this time and we need to find some form of balance so that people can get the help they need.

My brother has something called anosognosia, where he has no insight into his illness. So how can he make decisions about what he needs when he can't see his illness? There are provinces in Canada, like Saskatchewan and British Columbia, which do enforce treatment, and I'm wondering why this isn't possible in Ontario.

Access to better drugs and availability of better drugs with government funding would also be a nice thing to have. Consent requirements, which keep the family out of the picture—my brother refuses to have us involved in his care, so we are completely isolated, not knowing what has happened in hospital.

Also, professional support and assistive services to persons who are ill and not in treatment: It would be nice for my brother to have a caseworker. It would be helpful for my brother to have a caseworker who could act as a consultant to us and who could monitor his situation.

My last request has to do with financial issues. I've given you a summary of them. You are welcome to read them. Essentially, getting my brother to apply for anything is very difficult. He is suspicious of everything. I can't even contribute to an RDSP for him right now, because he won't apply for the disability tax credit. So having some control in that area would be helpful as well.

Also, the financial institutions—my brother has a line of credit and multiple credit cards. I don't understand why that is the case. Trying to keep him living within his means is very challenging. Thank you very much.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you very much, Carla, for telling your story and for coming forward.

**Carla:** You're welcome. Thank you.

## HAMILTON ADDICTION AND MENTAL HEALTH COLLABORATIVE

**The Chair (Mr. Kevin Daniel Flynn):** Our next presentation this afternoon is from the Hamilton Addiction and Mental Health Collaborative. I understand we've got Brother Richard MacPhee and Dr. Lori Regenstreif with us, if you'd like to come forward. There are some clean glasses there with some water. Make yourselves comfortable. I think you were here at the start of the previous presentation, so you know you've got 20 minutes, and the 20 minutes is yours to use as you see fit.

**Brother Richard MacPhee:** And you're exact.

**The Chair (Mr. Kevin Daniel Flynn):** Yes, that's right. I'm mean. That's the only thing I'm mean about.

**Brother Richard MacPhee:** Thank you for allowing us to come here today to present to you.

Just a brief history of the Hamilton Addiction and Mental Health Collaborative: We originally were a subgroup of the previous district health council in which we were an advisory group around the issue of mental health. This group grew after the inception of LHINs and was a mental health group. Then, more recently, within the last year, it has added the addiction community to our table because we see the correlation and the incidences of addiction and mental health really present within the clients that we all serve. We are a number of member agencies, consumers and hospitals systems that are involved in the delivery of mental health and addiction services within the Hamilton community of LHIN 4.

My own background is that I work as the executive director of Good Shepherd Centres and Good Shepherd Non-Profit Homes. In particular, Good Shepherd Non-Profit Homes provides housing and support to almost 500 people who have serious mental health issues and are in need of housing and support. In addition, we provide wellness programs, social entrepreneurship programs in terms of work, and also dealing with the area of crisis intervention through the provision of crisis care beds.

Lori's going to introduce herself.

**Dr. Lori Regenstreif:** Hi. I'm a family physician with the Shelter Health Network of Hamilton. It's a member of the Hamilton Addiction and Mental Health Collaborative, and it's also quite a new organization in Hamilton primary care. It is a novel program in itself and it has been quite successful.

I'll just give you a little bit of background. I've been a physician for 13 years. My initial years were spent in Vancouver's downtown east side doing HIV primary care and HIV in-patient care. I then went up to Inuvik and spent the next nine years doing rural and remote care across Canada, in the Northwest Territories, Ontario and the Yukon, and ended up on Manitoulin Island. I was there for three years. So I have a significant amount of experience with primary care in aboriginal community settings and emergency rooms in rural and remote settings where resources are relatively scarce and where mental health services are also extremely scarce, and it falls on whoever the front-line workers are to provide a lot of that. All of that has really informed my work in the downtown inner city of Hamilton with the Shelter Health Network.

As a physician who just likes to do my front-line work and doesn't particularly like to spend a lot of time sitting on committees, I find it difficult to be able to speak broadly for the committee, but I did realize, thinking about it and discussing it with Richard this morning, that I don't have to speak for everyone in Ontario who has a mental illness, for example. What I would really like to speak to is those individuals who have severe mental illnesses that are disabling enough that they are rendered impoverished, without housing or precariously housed, and unwell—unwell physically and mentally. I think we have all heard quite graphically, vividly and poignantly about what that's like on the individual level. For us, as the front-line workers, which is what I enjoy the most, what we see are the successes and the failures of the individual and also of the systems that we're working with to try to connect that individual to meet their needs.

The Hamilton Addiction and Mental Health Collaborative, which we'll just call the collaborative, identified, as a group, primarily areas of concern and issue. Those areas are access to care, so access for people with severe mental illness—I'm not going to talk about mental illness in general, but people with severe mental illness, usually who are rendered impoverished and lacking in housing. Those are the individuals who don't get rostered to family health teams, who don't live in the suburbs, who don't have family doctors, who access emergency and urgent care services disproportionately, who have a disproportionate number of days of in-patient stays because they're homeless or because there's nowhere to discharge them to. As well, moving them from one service program to another can be very difficult because those people don't function that well. These individuals just aren't able to get themselves from A to B on their own; they can't necessarily function independently when they're unwell. So access and transition are issues that we've identified.

**1400**

Connecting them with primary care is a huge problem that—again, we work with the family health team of Hamilton, and the family health team of Hamilton has had a key role in providing mental health programming that's connecting elsewhere in the system. They're part of our collaborative. What the Shelter Health Network has is somewhat novel; we could call it a model in and of itself for provision of primary care to individuals with mental illness in Hamilton. I just very quickly will summarize it because it's only a couple of years old. It's a group of physicians, nurse practitioners, nurses, social workers, front-line workers, and shelter staff and shelter administrators in Hamilton. We started out as a table; we all sat at a table about three years ago and envisioned a way of bringing primary care into the sites where people are rendered homeless, so the shelters in Hamilton. We've had a wonderful co-operative series of meetings over the years, and we still have them, with the shelters.

I was telling Brother Richard that I like to describe our model as a "stone soup" model. The shelters give us a pot, the ministry gave us some water, and the water was funding just for the physicians, which is a special kind of funding that I think belongs in a setting like this where doctors are paid by the hour. This is really important. For people with mental illness, you cannot function in the fee-for-service system. They're not accepted by fee-for-service, and they don't work in rostered systems either because you can't roster someone who's drifting. So we've been funded as an APP, which means we're just paid sessionally, and we roughly decided how many family physicians we were going to need and what kind of services we needed. We knew we'd need psychiatry and we suspected we'd need some internal medicine support. As it turns out now, we also need chronic pain management support with anaesthetists. We're not getting that quite yet, but we're hoping that will come through.

We get called "oh, the best doctor ever," because we have a whole hour with somebody, but they've needed these hours from us and they get them. We become the point of contact for them. So if you're homeless or you have an addiction or a mental illness that's brought you to a shelter or it's brought you—we're also detox addiction services. Wayside House and Claremont House are all different forms of treatment programs and they're all points of contact for people with addictions and mental illnesses or at risk of one or the other, because if you have one you're at risk for the other. At that point, we bring them into the setting of primary care. We then coordinate with the family health teams. Once people have been stabilized, they're usually in our care for anywhere from six months to three years. We try to move them into a new program, a bridging program with bridging nurses and the family health team, which has agreed to take our patients as they become easier to care for.

Again, it's really hard for me to speak for the whole group. I'm speaking for what I do and what we do, but what we've managed to do is to address some of the issues that we've put into this brief in terms of areas that aren't necessarily being met. This is one area I think that has been successful. Richard's going to speak—

**Brother Richard MacPhee:** The Shelter Health Network is one of the areas in which our collaborative has come together. We've also come together around the formation of the HOMES program, which is housing with on-site, mobile, and engagement services. We've come together in terms of some of our addiction responses. We've also come together in terms of, for example, the COAST program that was cited earlier. It's a model that started in Hamilton and came from this network, which actually at that time was a network. It now is a collaborative.

We also recognize that as we've been working with people who have serious and persistent mental illness, or at least are in the beginning stages of that, we see a lot of young people in our community who are in need of services. They're being seen in the Shelter Health Network, they're seen by mental health clinicians who are working on the streets. We are also seeing them in the Cleghorn program, which was established for early intervention for young people with first-break psychosis and things like that.

I think the other part of it is that we really, as a community, have embraced and struggled to embrace the concept of recovery and how we as agencies centre around a recovery model which involves peer support, which involves consumers within the delivery of services, and also the whole issue of how we change some of the cultures within our organizations and hospitals that make us more recovery-oriented.

Another challenge that we've all been dealing with is the whole issue of concurrent disorders and the issue of mental health and addictions, and one of the ways that we as a community have responded to that has been the whole issue of cross-pollination. We've really spent a lot of time in terms of agencies hiring addictions specialists, addictions agencies having resources to mental health practitioners, addictions agencies having access to, say, the Shelter Health Network or other physicians within that. So there's some movement back and forth in which we've been able to help the clients we're serving.

One of the things, for sure, in what we worked on was the whole issue of emergency usage. Many of the folks we see are often seen as frequent flyers within the emergency health care system because they don't have access to primary care or they don't have access to mental health services. I think we have a really good crisis outreach team, we have a good crisis care centre in Hamilton, but I think some of the challenges are what happens to our clients when they come to the door of an emergency room, either with a practitioner or by themselves, and how long they sit and how often they have to become medically certified before they can even begin to see someone within the mental health system. We know that within our family health teams there has been a way to circumvent some of that stuff, and I really think there's a challenge for us to figure out how we can divert some of these folks away from emergency rooms and make sure they don't use some of those valuable services and can in fact have service in a different way that is less intrusive and less expensive.

The other issues are the social determinants of health. One of the things that we really see is that if you don't give people a place to call home, you can't even begin treatment. We hear time and time again, "What do people want?" They want a home, they want a job and they want a friend. To have a friend, you have to have a place to meet with them, a place to welcome them. One of the things that we've also seen is that as people get stable in their own housing, they also want meaningful activities and work, and we've seen time and time again their need for that. Particularly, we're also seeing that as people have been in programs for a long period of time, they age in those programs, so they have some of the unique issues of having a mental health issue and aging, and there are barriers to services that some of those folks are experiencing through either CCAC services or other services that may in fact allow them to live in their communities without some of the services that other people are entitled to.

Trauma is a big issue that we're seeing within our community. Within the province of Ontario, Hamilton is the second-largest welcoming point for newcomers. We're seeing a number of people who are coming from war-torn countries who are victims of trauma, women and children who are victims of domestic violence, and abuse in young people.

I think the other part of it is that we have really worked hard in this community to have consumer involvement within our programs. We've had consumers involved in peer support roles as clinicians, and that has been a real blessing for all of our programs in terms of how we've changed some of the cultures and some of the recovery models within our various programs and how we adapt to recovery.

I think I'm going to leave it there because I really would like to leave the floor open for questions instead of just talking at you.

**The Chair (Mr. Kevin Daniel Flynn):** That's great, Brother. Thank you. It's 2:09, and you've got until 2:14, so we've got time for probably a question from each party. Mike Colle?

**1410**

**Mr. Mike Colle:** I'm just very impressed with your commitment and this very innovative approach. Have you had any discussions with the Ontario Ministry of Health, which has an initiative under way right now to reduce the impact on emergency rooms and to find new strategies? Have you talked to the Ministry of Health?

**Brother Richard MacPhee:** To the local LHIN, yes. The LHIN has been responsive in terms of some of the stuff we've been doing and how we've been diverting people from emergency rooms. The Medical director, Dr. Myles Sergeant, and myself have been in contact with the local LHIN around what we're doing. We, right now, have a lot of the support from the physicians, but a lot of the other supports are coming from the agencies. They're getting piecemeal pieces of money, but in reality we are hoping that at some point in the future, the LHIN will see this as an emergency room diversion program and an ALC diversion program.

**Mr. Mike Colle:** Just as a follow-up, could you, along with the submission to the committee, and I'm sure you can give a copy to all the members here—

**Brother Richard MacPhee:** We have provided copies to the clerk.

**Mr. Mike Colle:** But just a one- or two-pager for a layperson on how this program works as a diversion. I will certainly give it personally to the Minister of Health and ensure there's a follow-up on it, besides the presentation you're making on mental health here. Because we've got serious problems in Toronto on this emergency backlog, because people who are in high need are coming there right now.

**Dr. Lori Regenstreif:** I just wanted to comment on something we didn't actually discuss that much, and that was the support of self-evaluation for the programs. For example, for us, we have to—and I didn't really finish my stone soup metaphor. We've actually been trying to piece together from—because an APP contract to pay physicians is only that. We were actually disappointed that that was all the ministry was willing to do at that point. So we have been piecing together with—

**Brother Richard MacPhee:** We were disappointed but grateful.

**Dr. Lori Regenstreif:** The shelters have become our transfer agencies for different types of funding. What we've needed—and we've been getting bits and pieces of—is funding to do self-evaluation, where we can show some outcome measures. That's a challenge, and none of us has the time. We're working on how we hire or contract someone to do that research so that we can bring the numbers back, because that's what they want to hear. They want to hear the numbers. They want to know that there's impact.

**The Chair (Mr. Kevin Daniel Flynn):** Question, Sylvia?

**Ms. Sylvia Jones:** In your brief, on page 2, you talk about the transition of bridging the youth into the adult services. Can you talk about what you have been doing, either successfully or where the roadblocks are with that?

**Brother Richard MacPhee:** First of all, I think there are some challenges between the Ministry of Children and Youth Services and the Ministry of Health, particularly in terms of that population, and also within the delivery level, in that young people, particularly those between the ages of 16 and 18, fall into two categories, one in the adult system and one in the children's system. In Hamilton just recently, we've opened some new mental health beds that have been in the offing for a long period of time, and we have yet to see what that response is. One of the challenges will be that not only are they mental health beds but they're tertiary care beds, so they're going to look after needs within the whole LHIN. We've had some preliminary discussions of where those kids go afterwards, because some of them will be able to go home but some will not be able to.

We have an agency in Hamilton which is called Contact, where all children go for assessment and then a recommendation in terms of a plan of treatment. There has been funding through the Ministry of Children and Youth Services for mental health clinicians, and our agency runs a youth shelter. We have clinicians on the streets who are working with kids and trying to access service, but really, some of the challenges that we're experiencing are, when we identify that kid, how do we get access to service and make sure that we connect with a psychiatrist? We've been lucky in terms of having a psychiatrist within the shelter coming in and visiting, but it's all about relationships. It's not necessarily always about resources. It's about, you know somebody, they do you a favour, we do you a favour and we get something done.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Brother. Thank you for coming today; unfortunately that's all the time we have, but that was a great presentation. Thanks for all you do.

**Brother Richard MacPhee:** Thank you very much.

**M$^{me}$ France Gélinas:** Can I ask a yes or no question?

**The Chair (Mr. Kevin Daniel Flynn):** I don't know. This is a doctor and a brother; are you likely to get a yes or no?

**Brother Richard MacPhee:** You might get a blessing.

**The Chair (Mr. Kevin Daniel Flynn):** Okay, let's try and see what happens.

**M$^{me}$ France Gélinas:** Just curious to see if any of your agencies offer services in French.

**Dr. Lori Regenstreif:** Within our collaborative—

**The Chair (Mr. Kevin Daniel Flynn):** That could be a "oui" or "non" question.

**Brother Richard MacPhee:** We have nurse practitioners that speak French. Yes, we do have that. I'm just trying to remember.

**Dr. Lori Regenstreif:** Some of us speak French and have had to run a clinic in French. We've had to do that before. There's also the Francophone Community Health Centre, but we haven't aligned with them officially.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you very much.

## CANADIAN ASSOCIATION FOR PASTORAL PRACTICE AND EDUCATION

**The Chair (Mr. Kevin Daniel Flynn):** Our next presenter today is Robert Bond from the Canadian Association for Pastoral Practice and Education. If you'd like to come forward, Robert. Make yourself at home there. Get a clean glass.

You've got 20 minutes. You can use that in any way you see fit. If you can leave some time at the end, that would be great, but it's not necessary.

**Rev. Robert Bond:** I'll try to.

**The Chair (Mr. Kevin Daniel Flynn):** The mikes work better if you're about a foot away from them. It's all yours.

**Rev. Robert Bond:** Mr. Chair and members of the select committee, as you have heard, I'm Bob Bond. I am the coordinator of spiritual and religious care at the Welland site of the Niagara Health System. Within the Canadian Association for Pastoral Practice and Education, which I'll call CAPPE throughout this time, I'm certified as a specialist in pastoral counselling and I am co-chair of an Ontario working group on college formation. Thank you again for this opportunity to address your committee.

I have three goals to meet before you. One is to inform you about the work and role of clinically trained chaplains and pastoral counsellors as mental health professionals in Ontario. A second goal is for you to hear from our group affirmation and hope concerning the College of Psychotherapists and Registered Mental Health Therapists. The third is to explore mental health and addiction caregiving needs in Ontario, and how this college's breadth in general and CAPPE's leadership in the specialization of spiritual care therapy in particular can help address the needs.

First, something about CAPPE: Most people, be they patients or practitioners of some sort, bring with them a caricature of the chaplain or the pastoral person that is, at best, something like Father Mulcahy from that wonderful television series M*A*S*H*, and at worst, something like a fundamentalist preacher or televangelist. Even at the better end of this continuum, the Father Mulcahy end, he was a kind and gentle and generous and humble soul, but he was initially quite unaware of his own depths, pretty much stuck in dogma and ritual, and clearly untrained in what he had to face there.

CAPPE, alongside five fraternal American professional associations and several others globally, has for over 50 years in Canada done the clinical training and certifying of specialists and teaching supervisors and their ongoing peer-review processes and all the standards and professional ethics processes, including complaints with the judicial committee appeal process, which together turn a nice and religiously attuned person like Father Mulcahy into a grounded and fully functioning and fully backed spiritual care therapist. Father Mulcahy, by the way, would have done tremendously well in CAPPE because of his openness to hard reality and his honesty with himself and others.

There are 651 members of CAPPE nationally and 347 in the province of Ontario. Of these, 103 are certified as specialists in pastoral care—working in hospitals, prisons, the military, long-term-care facilities, university campuses, drug and alcohol treatment centres, palliative care teams, community health centres, family health teams and a few in churches or local communities of faith. Then there are 28 more alongside me who are specialists in pastoral counselling, working in community counselling centres, employee assistance programs, private practice or any of the previously mentioned institutional settings.

Some folk may bristle at the naming of chaplains and pastoral counsellors as mental health and addiction care providers. At our first meeting with Joyce Rowlands, registrar of the College of Psychotherapists and Registered Mental Health Therapists, I told her about a case from that morning. A patient—and these details are told so as to mask the patient's identity—had come into our emergency room with an infected foot. He was a professional athlete. He lived with a woman with a severe mental health diagnosis whose own needs and demands had, over the years, pushed our current patient to a place where much of his energy was now spent reacting to and managing her state of being. His care for himself, and in particular his care for his diabetes, had fallen by the wayside, and so came about this foot problem, which straightforward got diagnosed as gangrene.

**1420**

Then came necessary, hard decision-making about amputation. I was called in and was met with his declaration, "My life is over anyway. I'll never compete again—the doctor told me so. I have nothing to live for. Why put myself through the surgery? I'll just let things take their course." He had decided no to the surgery with his surgeon and nurse. It was the nurse who referred me to the patient.

The patient and spiritual care provider talked for an hour or more, with the spiritual care provider carefully reflecting back what the patient described and wrestled with. In this process he came to see that his words, "My life is over," were for him an accurate description ever since choices upon choices he made ages ago, whereupon he stopped paying attention to, let alone nurturing and developing, his own life. He had become, in fact, a casualty to his partner's mental disease, that ongoing downward spiral, and he saw clearly that current decision-making about surgery was, in some ways, less demanding than other decisions to be made if he was to choose for life now. He knew, for instance, he could coach rather than be the athlete; he had other talents and passions that could continue unaffected by the loss of his foot or leg. But more fundamentally, he started to imagine his life readjusted so that care and attention to self and nurture of self were put back in place.

Joyce Rowlands heard the story and responded as to how the intervention so very fully lives out the controlled act of psychotherapy. This from a hospital chaplain's everyday work, which is soul care, and therefore, to the etymology of the word "psyche," this is psychotherapy, or mental health care. Now, I should also make explicit, beyond this example, that chaplains and pastoral counsellors directly address mental health illnesses and addictions in the majority of the settings where we work.

CAPPE's 347 Ontario members attend to over 100,000 citizens of Ontario in a year, and this is me being pretty conservative with an estimate. Our clients across the institutions and private practice settings previously portrayed are folks in some nature of crisis, and we are there to foster consciousness—or, if you prefer, clarity—and connectedness, which some might describe as being grounded and resourced, as these people make their way into their crisis, through it and beyond.

Within Ontario, as a member of both the Ontario Coalition of Mental Health Professionals and the Alliance of Psychotherapy Training Institutions, CAPPE is glad and grateful for the provincial government's work in creating the college of psychotherapy and in conducting the current comprehensive, critical and creative review of how the mental health of Ontario's population can be resourced and improved.

Concerning the college, CAPPE Ontario would urge the government to be expeditious in moving to bring the

College of Psychotherapists and Registered Mental Health Therapists to life. This next requires the actual naming of members of the transitional council, to which naming we look forward in hopes of broad representation for the multitude of currently unregulated practitioners within the province. Here, CAPPE Ontario thinks of the 5,300 members within our Ontario Coalition of Mental Health Professionals.

Also, CAPPE Ontario recognizes spiritual and religious care practitioners outside our organization, and standards, certification and training, but equally addressed by HPRAC, whose 2006 new directions document noted, "Commentators strongly supported the proposition that faith-based practitioners who provide psychotherapy during the course of spiritual or religious care should meet the same qualifications and standards as other practitioners of psychotherapy. This is a matter that should be reviewed further."

Concerning the review and progress here, and in line with your committee's broad mandate, CAPPE Ontario knows that improving our society's mental health is about more than simply expanding access to the Ministry of Health's currently funded services. Furthermore, in line with the Ministry of Health, CAPPE Ontario knows that not all people want or need to receive care within a narrowly defined medical model.

As a practitioner in Welland, for instance, I can point to a broad band of citizens. We've come to call them the worried or wounded, but walking, poor, who are caught up cycling through systems that seldom, if ever, address their mental health needs. If these people do spiral further into severe mental health diagnosis, they then can access treatment via psychiatrist, an outpatient mental health clinic and a public health nurse. But just as they are hurt by trauma, abuse, complicated losses, addictions or the basic and stark deprivations of poverty, there is no mental health resource they can access. In our society, people with money can purchase fee-for-service psychotherapy of many sorts, people with a strong employee and family assistance program from their workplace can get counselling there—a few sessions, anyway—but we watch the worried or wounded, but walking, poor cycle through doctors' offices, emergency rooms, police stations, courts and prisons without any salve for their wounds. These folk need primary health care that includes, and indeed provides without barrier, psychotherapy.

In some jurisdictions, community health centres and family health teams are recognizing and building upon this fact. I know from the earlier presentation, that there was a reference to the Hamilton family health team; they have, for instance, a chaplain on that staff. In some alternative systems of care, such as the work of wise elders in our native communities and the work of rabbis, imams, priests, ministers and others who do pursue training and credentials for use in their local faith communities, the needful care is provided and the results are pleasant to behold. To open up more channels of the same is the challenge that CAPPE Ontario believes or hopes you committee members are here to address.

One barrier might get removed in the follow-through to the bringing to life of the College of Psychotherapists and Registered Mental Health Therapists. If this college's pool of then-registered resources can become funded and applied more fully and creatively, then there's a lot of resources, and the worried or wounded, but walking, poor and everyone else in the province could get far more ready access to what they really need close to home in their local community's primary health care system, be it a health care centre or a family health team or whatever—and then at the next level, not only at the local hospital but through their CCAC and at the end of life within their palliative care team.

In support of which suggestion, without the addictions counsellor, the art therapist, the child therapist, the marriage and family therapist, the music therapist, the nurse psychotherapist, the occupational therapist, the psychotherapist, the spiritual care therapist, the physician-psychotherapist, the psychologist-psychotherapist, the recreation therapy person and the social worker bearing psychotherapy credentials—without these, watch as the general practitioner tries to address the patient with a generalized anxiety disorder, borderline personality disorder or the patient dually diagnosed, to name but three. Watch that GP try to make referrals within and across the medical model and see just how far the case progresses: We are back to cycling around without resolution. Then make interdisciplinary caregiving real and accessible, put the addictions counsellors—that whole long list of psychotherapists, and I'll underscore that spiritual care is among them—to work within primary health care, and it all goes very differently.

Similarly, if realization of the College of Psychotherapists and Registered Mental Health Therapists opens up routes of care via third party payment, again we end up with a truly interdisciplinary approach in order to address the mental health needs of accident victims and victims of crime.

Answering a likely argument that this means increased costs, well, if such channels are opened, then there's the evidence-based truth that when people's actual needs are met, they stop cycling around the systems—the wrong systems that otherwise and somehow have to address them encounter after encounter, eventually by blaming and marginalizing them encounter after encounter.

**1430**

Similarly, there are people within our province's psychiatric systems, perhaps by and large outside major centres, being repeatedly stabilized and discharged with a focus on pharmacy and little reliance on addressing the meanings—the meanings of the condition and the meanings of its origin and the meanings of life lived in its grip. In other words, with little reliance on the possible psychotherapeutic interventions. There too come evidence-based discoveries that as actual deep needs are met with people with severe and profound psychiatric diagnoses, the cycling slows and, better yet, the quality of life improves.

So public access to fully interdisciplinary care right across the many domains of psychotherapy is a creative, needful, human-resource-effective and cost-effective thing for Ontario to do.

To summarize and to emphasize by way of refrain, CAPPE is a self-regulating professional body of chaplains and pastoral counsellors pleased to await inclusion in the College of Psychotherapists and Registered Mental Health Therapists. The specialization we seek to populate there is spiritual care. As spiritual care therapists, we put ourselves forward in our current institutional and private practices and from there into far more broadly possible primary health care settings which systemic change can make possible. We put ourselves forward as a leading discipline among the providers of the healing of illness, which, alongside medicine's curing of disease, will very much help address the province's mental health and addictions needs.

I again thank you for your attention to CAPPE Ontario within these current hearings, and I'm open to entertain conversation and questions.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Bob. Thanks for your presentation. You've left about four minutes. If we have really short questions and short answers, we can probably get one from each party. Let's start with Sylvia.

**Ms. Sylvia Jones:** You mentioned that you have 347 members across Ontario.

**Rev. Robert Bond:** Yes.

**Ms. Sylvia Jones:** I am familiar with the hospital-based chaplains in my community. Would every hospital have chaplains who are affiliated with CAPPE?

**Rev. Robert Bond:** No, not every hospital does, because currently it's not a requirement. It's something that we certainly urge and try to promote, but there is freedom to hire whoever they believe will fit the bill in their accreditation process. I imagine possibly a third of the folks hired are not connected with CAPPE.

**Ms. Sylvia Jones:** Okay. Thank you.

**The Chair (Mr. Kevin Daniel Flynn):** France?

**M$^{me}$ France Gélinas:** You'll have to forgive my ignorance, but what you're saying is that under the College of Psychotherapists a pastoral care practitioner cannot register?

**Rev. Robert Bond:** No. It's a good question, though. The college has yet to register anyone. It's still in formation, having had the legislation pass a couple of years ago. We're waiting for the transitional council to do its work, which will take another couple of years, and somewhere in there the registration process will begin for all of us who are currently unregistered, not only spiritual care but art therapists, music therapists, marriage and family therapists—the whole raft. So we're all just standing, waiting to enter.

**M$^{me}$ France Gélinas:** In the transitional college board, the people who are there, are some of your members being represented?

**Rev. Robert Bond:** We're not sure yet because it hasn't been named.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Bob.

**M$^{me}$ France Gélinas:** So we're at that point.

**The Chair (Mr. Kevin Daniel Flynn):** We'll move on. Helena?

**Ms. Helena Jaczek:** As you know, we've heard some very moving stories from families of young people particularly who have been diagnosed as schizophrenic. Obviously acknowledging what you've said, that a full interdisciplinary team is very valuable, I'm just wondering if your members have been involved in assisting the individual with mental illness, perhaps at the request of a family member, to in fact seek pharmaceutical treatment. Have you been involved in that kind of assistance to families?

**Rev. Robert Bond:** Are you thinking within institutions or out on the streets? I'm just wondering what the setting of your question is.

**Ms. Helena Jaczek:** Either.

**Rev. Robert Bond:** Okay. Certainly within institutions we're fully part of the interdisciplinary team and would urge full treatment of people's conditions. So if they're being resistant or non-compliant or hesitant around the use of medications which are obviously best practice, our role would be to try to work and understand the blocks and the perceptions and to certainly make good argument and use of the full spectrum of possible responses, including the pharmacological.

The urging I'm doing here is, yes, use the medication, but it's also important to address the meanings, the situation, the roots, the experience of living within this condition, and to do it with eyes wide open. That's what spiritual care providers are grounded in: exploring and helping people to address the meanings.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you very much for coming today, Bob. It's appreciated.

**Rev. Robert Bond:** Thank you.

## MARLENE WESTFALL

**The Chair (Mr. Kevin Daniel Flynn):** Our next presenters for this afternoon are Marlene Westfall and Manon Marquis. I'm not sure—I'm sorry?

**Ms. Manon Marquis:** I'm just here to support her.

**The Chair (Mr. Kevin Daniel Flynn):** Oh, good. We all need support. You should try election time.

**Ms. Marlene Westfall:** No, thank you. This is hard enough.

**The Chair (Mr. Kevin Daniel Flynn):** Anyway, you probably weren't here when I introduced the last delegation. You've got 20 minutes. You can use that any way you see fit. If you want to leave a little bit of time at the end for any questions, perhaps that would be a good idea.

You'll find that the mikes work better if you're about a foot away from them. There's some water there if you want; there's a clean glass over there if you need a glass of water or something like that before you start.

*Interjection.*

**The Chair (Mr. Kevin Daniel Flynn):** That's right; it's a certain amount of centimetres. They're saying that I'm old-fashioned because I'm still using feet and inches.

**Ms. Marlene Westfall:** That's okay; I speak both languages.

**The Chair (Mr. Kevin Daniel Flynn):** Anyway, the floor is all yours. If you'd introduce yourself and your guest as well for Hansard, that would be great.

**Ms. Marlene Westfall:** My name is Marlene Westfall.

**Ms. Manon Marquis:** And I'm Manon Marquis.

**Ms. Marlene Westfall:** Before I commence, I'd like to thank the select committee for allowing me the opportunity to bring my concerns to this forum. It's still with great difficulty that I write this submission because of the trauma experienced at the hands of individuals in positions of trust in what we call the mental health care system. I would prefer to coin it the mental health abuse system, because there was nothing caring about my experiences in Hamilton by those within the circle of care and those individuals who have been fraudulently holding out as social workers.

What are supposed to be protected legal rights saw my confidentiality violated in such a perverse manner that there's no doubt it could be interpreted as deliberately cruel. Individuals who ought to have known what constitutes good medical practice and professional conduct appeared to involve themselves in a strange form of medicine.

The charter, whose ambit has been decided in the courts to include hospitals and government agents with legislated obligations, appears to have forgotten that law, the Canadian Constitution Act, 1982, which guarantees every individual the right to safety and the equal benefit and protection of all laws in this country.

Lack of confidentiality and acceptance of clear consent between St. Joseph's hospital and a number of women's shelters was non-existent. Fraud, slander, contempt for legal rights and an "I know what's better for you than you do" attitude replaced the good medicine that is practised in other parts of Ontario.

Access and disclosing personal health information without consent is so serious, there is an offence clause built into the act.

Stated law through Supreme Court decision indicates that hidden and secret files, including written notes, if used to make an assessment or diagnosis, are within a patient's right to access.

Protecting patient information is a human right and also has been decided in the courts as a protected constitutional right, as misuse through fraud can harm a patient, especially those trying to recover or reduce their symptoms within a mental health context.

Stated human rights law and judgments recognize the vulnerability of this enumerated group. This province's human rights commission has provided commentary, in an accepted format as to include it in evidence, that denying an individual under enumerated grounds from obtaining services or withholding services as a result of policy, such as medical care or accommodation, based on that person's perceived disabilities amounts to discrimination.

Entering into a health care and women's shelter system that already holds perceptions about patients with mental illness is compounded by information generated and passed without the benefit of individuals within the circle of care being registered with the college of social workers, where, according to the college's code of ethics and standards of practice, they would have to ensure that they have an understanding that they are in positions of power and have a responsibility to ensure that their clients are protected from the abuse of such power, and any recommendations or opinions they provide are substantiated by evidence and supported by a credible body of professional knowledge. Included in the information is collateral information, and it must be documented.

**1440**

In August 2004, I was removed from a woman's shelter, referred to as shelter number 2, because it was assumed I had a mental illness of some severe extent. I was labelled with a dot blackballing me from future accommodation and from good medical care, as information from Hamilton's women's shelters was passed on to the hospital without my knowledge or consent. This is where it begins.

I went to hospital on September 7, 2004, on a voluntary basis to seek medical help for extreme anxiety and suicidal ideation. I asked for an assessment. I was very frightened as I had never experienced anything so intense and out of control in my life. On this visit, the admitting physician confirmed with me that I would be asked to sign a hospital consent form. This was never done. I was refused treatment by the assessing physician, who was still in residency. None of her peers were assessing with her. I was refused medication to calm me down. Staff at the shelter could have managed these meds in a locked cabinet in the staff office.

The notes taken by nursing staff were judgmental and did not note that the physician refused to provide support to alleviate elevated anxiety caused by decisions of the shelter staff. The shelter staff had me sign an illegal consent form 14 that was repealed in 1995. The staff signed only her first name on this legal document.

The shelter staff collected personal health information from the hospital. The manager confirmed it by telling me, "I know what's wrong with you," but did not share with me what the hospital told her.

The shelter staff were holding out as social workers. None were registered as social workers or social service workers confirmed by the college of social work. A woman associated with Status of Women Canada confirmed that the staff were qualified to provide one-on-one counselling and take notes, which they did. The staff later admitted that most were trained in criminology, not social work.

The shelter was supposed to provide a personal needs allowance, or PNR, on a weekly basis, but the staff didn't know what it was. I signed a consent form with shelter number 2 so they could contact shelter number 3 regarding PNR only. The Ministry of Community and Social Services confirmed shelter number 3 was receiving money from the government to pay for PNR, but I never got it. Since shelter number 3 was getting money for each resident that resided there, I was barred from applying for welfare so I could get first and last month's rent for a room or apartment so I could get out of the shelter system.

I was looking for another place to stay. When I got a phone call from a friend who was trying to help me out, staff did not let me know the call came in, despite me being in the house and the constant requests to other residents to take their phone calls. I felt I was being centred out.

I was refused by staff to allow me to room with residents I was comfortable with. My roommate moved out, but I was forced to stay with an individual whom I knew from shelter number 2. I knew it would be difficult to get along with her and such would increase my anxiety. It was almost as if they knew and deliberately put us together at an inopportune time.

I requested help from shelter staff to get belongings that were with the woman I had been staying with but who refused to give them back. The staff kept saying their van was being used by another site. I felt like I was in jail and there were no avenues to escape the shelter system in Hamilton. It was like I was being forced to stay against my will. This spurred another anxiety attack.

I made a second visit to hospital as treatment was denied on the first visit but the symptoms were getting worse. I had the same physician I had on the first visit. I confronted her about why she told me she would give me a doctor's note and then left without providing one. This was not documented in the medical record. I told her I had every right to request accommodation at the shelter to alleviate heightened anxiety aggravated by deliberate actions of the staff and it was my right to state it under section 8 of the Ontario Human Rights Code. She documented that as a medical symptom, not a legal right.

In the morning a nurse came in to finish the medical assessment instead of a physician or psychiatrist. A number of hours later, I was refused medical treatment again with the bizarre excuse that my "anxiety was too high." No medication was provided to reduce the anxiety. I was told to go to Catholic Family Services for counselling, or I had the option to apply to their outpatient services. The hospital staff still told me that I had a room at the shelter. Whatever it was that the hospital staff were trying to do, none of it made sense, nor did it appear they were practising medicine. It's almost as if they were working for corrections and couldn't differentiate their role to the greater public outside of this system.

When I returned to the shelter, I was refused all my personal belongings, including my eyeglasses as well as my car. Without just cause, I was forced to look for my glasses on the porch of the shelter, a rather humiliating experience but pleasing to the staff. I recall the staff member had pleasure telling me to go to another shelter with a very bad reputation. The shelter was refusing to give me my car, without just cause, even if there was such a thing. They were trying to keep me from using my car to sleep in as they unlawfully impounded it at their other, government-funded facility. I had to go to the Hamilton police to get their help in getting my car back. I managed to stay at a friend's house for one night and was finally able to apply for emergency welfare.

The next night I slept in my car at a campground because I had no place to stay and I had a mandatory welfare meeting the next day. This was the worst night of my first month in Hamilton. I struggled all night not to take the pills I had in my car. I forced myself to listen to music and not go to the hospital, as I was afraid of missing my appointment. I did make it to the appointment and was signed up. They even gave me a Tim Hortons card. There appeared to be some hope.

Since I was made homeless a second time by a women's shelter and was refused medical treatment twice, I drove to Windsor to get medical treatment and stay at my parents' only because they were away on vacation. When I arrived in Windsor, I checked the voicemail messages to find that the RN doing the assessment had contacted my parents' home without my consent. I contacted shelter number 3 to revoke my consent. I was told by the manager I could not. I was also told that all information about their residents is shared with all their facilities, all without consent. I started having anxiety attacks again and contacted the women's shelter in Windsor, where I was given support. They were honest in telling me that they did not have the qualifications to help me, despite all staff there being either registered social workers or studying social work at university. They knew their limits, and I appreciated that. I was afraid to drive, so they provided me a taxi chit to the hospital.

At Hôtel-Dieu in Windsor, they triage you, then you see a qualified registered social worker. The social worker decides whether or not you should see a psychiatric nurse for further triage and then a psychiatrist. This time I was referred to a psychiatric nurse. I was treated with dignity and respect. The nurse said to me, "What you've been through would make anybody suicidal." I then saw a psychiatric resident who was very kind and non-judgmental, and then a psychiatrist. He asked me if I was depressed and of course I responded, "Yes." He prescribed me medication to alleviate my anxiety and to help me sleep. I was finally able to sleep a full night and start to feel more in control.

I returned to Hamilton and rented a room and set up an appointment with outpatient psychiatry. Two days after I moved into my new room, my car was stolen.

At St. Joe's they continued to give me a hard time. I was told that I would be able to access the program despite where I lived. When I met the first clinician, she called me a liar without checking that I was given the okay to get their services out of the catchment. She didn't like that I was getting services out of the catchment. The same nurse clinician continued to be verbally abusive, calling me a bitch and telling me that I had been abusing the system in Windsor without benefit of medical proof from the medical records. She abused my privacy after we had discussed how a female roommate in my new residence was being threatened by one of the males living there. I was scared. Instead of being supportive, she picked up the phone and gave a police officer fabricated information about me in front of me. She knew I already had issues with the hospital breaching my privacy. When I was asked to take medical tests for diabetes, she told me not to bother with the fasting. She said that she never does. This would have made the outcome very different.

On one visit, I was feeling faint. I had asked a person working at the information booth to help me walk to the outpatient building. She said to let the staff at outpatient know that I was not feeling well. I did, but they did not pass it along to the clinician. After the appointment, I was still feeling faint and sat down in the waiting room, drinking water. When reading the notes of this event months later, the clinician had documented that I was sitting in the waiting room for no reason. I had told her that I was feeling faint, but she didn't document it. The reason for this was that I hadn't been eating from the depression and lost 30 pounds. Later tests showed I was anaemic and had inner ear damage, but it appeared this clinician wanted to document some sort of bizarre behaviour instead of a real medical reason for why I was resting.

I requested to go to another clinician and wrote out my concerns in detail. The next clinician I had was a registered social worker. I was there for a month before I got a call from a researcher at St. Michael's Hospital in Toronto. It turns out that the clinician had forwarded my name for research on a mental illness I hadn't been diagnosed with and she did it without my consent. She knew this was a serious issue for me that shouldn't be manipulated, but forwarded my name anyway because the hospital seems to have total disregard for the legal rights of their patients in this branch of medicine. It turned out that I didn't have symptoms of the mental illness to qualify for this research study.

**1450**

I made an appointment with the research ethics chair, and he told me what they did was illegal. I was given an apology letter and decided that if I didn't leave this hospital with all its abuses, I would eventually become seriously mentally ill and be institutionalized, so I left the program.

In November 2004, I asked my mother to attend with me to shelter number 3 so I could obtain and access the notes the staff had been taking in our counselling sessions and to see what information they had passed on and obtained from the hospital. I was refused by the same manager to see my file, so she read it to me. She confirmed that the hospital had contacted them on the second visit.

I applied to get my medical records from St. Joe's. I was asked what I was looking for, and told the records manager that I wanted to see a consent form giving hospital staff the right to contact my family and the shelter. She provided me a copy of the illegal form 14 that was given to them by shelter number 3, not one from the hospital. About a week later, I learned that my brother had been contacted by the assessing nurse, and she had been asking him questions like, "Does she have a son?" and "Did she go to university?" She did this without my consent.

I again applied, but this time I wanted to go through the file. I went through the full file with the copies I had been given earlier with the ones that were already there. I decided to look in another area of the file, and it was here that the records manager had placed medical records that should have been with the rest of the medical file and not in the communications portion. In these records, it was recorded that the resident psychiatrist and the assessing RN who had contacted my mother and brother had written that they were going to contact them and the shelter for collateral information.

According to Supreme Court decision McInerney v. MacDonald, I have the right to access all of my medical record, including any notes on collateral information or history obtained from anyone that is used in making a medical assessment. These notes, or any information taken obtaining collateral information from my family members and shelter staff, were not in the file, but they should have been. I made at least five requests to the hospital, including the chief information and privacy officer, requesting to see that collateral information.

The hospital had 30 days under the new Personal Health Information Protection Act to provide, in writing, where that information was and whether or not I can have access to it. If not, they had to provide a reason why, and in writing. That was four and half years ago, and I still don't have that information, nor do I have a letter indicating where it is.

Also, under the PHIPA legislation I had a right to correct facts or provide a statement of disagreement on anything that is in my medical record. I'm being barred from making these corrections on the collateral information because they are hidden by the hospital. The IPC, the Information and Privacy Commissioner, has done very little if not relieve their hands of this situation.

I understood from outpatient administration that the notes the doctors take to form their assessment are destroyed, which is also illegal.

I was contacted by the chair of the research ethics committee of the hospital, telling me that the chief privacy commissioner would be calling me regarding my requests. She never called.

When I finally found a family physician, I asked her to refer me to a psychiatrist, but she refused, saying that I would not like her. I found out why she said this, because the clinician who forwarded my name for research without my consent noted on the discharge file that I left because I did not like them, not because the hospital had repeatedly and systemically abused my privacy rights. It was also noted on the discharge file that I had diabetes. I never had diabetes in my life, nor did I then. I asked the family physician to refer me to Toronto to see a psychiatrist if she felt I wouldn't like her friend in Hamilton, but she did not.

In March 2005, I applied to the Information and Privacy Commissioner to file a formal complaint against

St. Joseph's hospital for not complying with the legislation. The IPC did not respond for at least three months. I was told by the registrar that they aren't enforcing the law because the law is new. I was told by the staff member handling the complaint that the Supreme Court decision McInerney v. MacDonald did not apply to them. I was sent a letter by another staff member that the transition clause, section 18(7) of the PHIPA legislation, did not exist.

I forwarded the IPC a copy of an e-mail sent to me by the manager of hostels and shelters at the city of Hamilton, indicating that the shelters were free to use blanket consents, violating the PHIPA. I was sent a letter by the registrar and the deputy commissioner. They said they never received the e-mail, despite a record of it being sent.

I was also sent a letter by the deputy commissioner indicating that the shelter was not within the circle of care, and therefore outside their jurisdiction. The person who provided that information was a new manager and lied to the DC during his investigation.

The registrar—yes?

**The Chair (Mr. Kevin Daniel Flynn):** Marlene, just so you know, you have about a minute.

**Ms. Marlene Westfall:** Okay. I've got just a little bit more.

**The Chair (Mr. Kevin Daniel Flynn):** Yes, that's great. I just wanted you to know that.

**Ms. Marlene Westfall:** Yes, I knew I was kind of getting in on—

**The Chair (Mr. Kevin Daniel Flynn):** You're close to the edge, but you're not over it yet.

**Ms. Marlene Westfall:** The registrar got his only information about the shelter from their website. That e-mail and a complaint about the IPC were forwarded to the Attorney General's office and no letter was sent in response. To this day, the IPC continues to tell me to keep requesting to get the information from the hospital, despite the copies of the requests I had sent them in my original complaint. These ludicrous actions by the IPC are incomprehensible and are tantamount to being complicit in violating the legislation along with the hospital. The registrar also contacted my social worker without my consent, where she instructed him to speak to me directly. She had sent a letter to them letting them know how much more anxiety they are causing by not enforcing the act.

I finally had to audiotape the IPC's refusal to allow me the access to my own file to find out what information they were getting about me from the hospital. I was told that the access-to-information legislation did not apply to them.

Staff at St. Joe's urgent care clinic have confirmed that the shelters are providing "shared care." I spoke to the nurse who contacted my family members and she confirmed that they speak to the shelters on a regular basis and that the hospitals keep secret records.

This legislation has an offence clause. I attempted to bring the concern to the Hamilton police. I sat with the chief and he said that their officers were peace officers and should act on offences, but no officer contacted me after this meeting. I called again and I was told by an officer in the fraud department, "I don't care about your privacy issues." It appears nobody does.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Marlene. That was good time management. You hit the 20-minute mark right on the—

**Ms. Marlene Westfall:** Oh, my God. I can't believe it.

**The Chair (Mr. Kevin Daniel Flynn):** Came pretty close to the edge.

**Ms. Marlene Westfall:** I'm sorry I didn't leave any time for questions.

**The Chair (Mr. Kevin Daniel Flynn):** No, that's fine. We understand that. I think you were very clear in your concerns, and I thank you for coming today.

## LORRAINE McGRATTAN

## PAUL HAMEL

**The Chair (Mr. Kevin Daniel Flynn):** The next speaker today is Lorraine McGrattan. Lorraine, if you'd like to come forward? Make yourself comfortable.

*Interjection.*

**The Chair (Mr. Kevin Daniel Flynn):** You've heard it all before?

**Ms. Lorraine McGrattan:** I know the water and—yes.

**The Chair (Mr. Kevin Daniel Flynn):** I say it in my sleep now.

**Ms. Lorraine McGrattan:** This is my brother Paul. He has escorted me here today, and I'm speaking on behalf of my whole family.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you very much for coming today. It's all yours.

**Ms. Lorraine McGrattan:** It has been quite an experience listening to the physician and then to an actual patient, so this is a family's perspective on the challenges. Hopefully it weaves in through all the discussions as well. Just so you know, my talk is approximately 10 to 12 minutes.

The goal today is to give you insight into a deficiency within the structure of the mental health system and to provide a personal, and likely typical, account of one family's struggle with manic depression, or bipolar. We'll touch on three themes: the health care system and mental health sector; the family; and the patient, who is my brother—not this brother. We'll try and limit the emotions from this presentation and focus on what we perceive as flaws in the structure.

The initial onset of the disease was apparent to the family. It was clear to us that our brother, who was approximately 22 years of age at the time, was bipolar. We had absolutely no experience in dealing with him and the disease, so we managed by not answering phone calls. We avoided contact, isolating him from our lives. This was not easy, as we're typically a close family. Our urges for medical help were ignored, and of course there was offence by our gestures to my brother. The illness projected him into a state of homelessness and a lifestyle that we could no longer ignore. Navigating the resources to help us help our brother was unfamiliar territory, challenging and time-consuming. We learned about COAST, we learned about forms 1 and 2, confidentiality, assessment, patient rights, hospital systems, police services, the justice of the peace and much, much more.

So the flaw here is the lack of early diagnosis. For years he weaved his way through society with his highs and lows. There was police intervention and COAST monitoring his behaviour. In fact, we had a form 2 issued on him. We walked and drove the streets looking for our brother to finally have the police bring him to hospital. To our horror, the hospital did not contain him for the 72-hour observation. We were deflated. Why would the family seek help through the justice of the peace and why would he grant a form 2 if there is no just cause? Again, this cog in the wheel is just another opportunity for the patient to fall through the cracks.

**1500**

Flaw number 2: If a JP issues a form 2, it should be a mandatory three-day observation and should also mandate family consultation. With three forms over the past many years, there was never opportunity for family consultation. It gives the family time to inform and educate the health care professionals of his current state and history. He is very intelligent and can suppress conversation just long enough to fool those around him. The other problem during assessment and treatment is that the medical professionals don't really know what they're aiming for because they don't know the patient, and the family does.

Flaw number 3: Patients who are fully manic do not seek medical help. In fact, they resent it and are usually angered by the family's interference. They are manic and justify their thoughts, their actions and the voices that they hear.

We had 20 years of undiagnosed episodes of mental health problems. What repercussions did these have on our brother? It has been impossible to maintain any consistent lifestyle that he deserves. As a teenager he was handsome, very bright, an honour student, a talented musician and an artist—and as I'm reading this, I'm thinking he was very entertaining and humorous and had much more potential to have a rich and full life, like most of us in this room.

Instead, over the years he has become an expert in living frugally because his mental episodes have not allowed him to sustain a lifestyle of employment and lasting relationships, not to mention a family of his own. I thank God there are no children involved who are affected by his bipolar episodes. Rather, I truly wish he could have reaped the rewards of having a family and children of his own. I wonder as well, what cost is there to our society and health care system when his treatment is mismanaged?

Fast-tracking, after 20 years of drama ending after a heroic escape from an ambulance traveling down a main street en route to hospital, our brother was finally clinically diagnosed and treated. For the last 10 years he has been medically managed and has had an adequate lifestyle, but below the standards of most of us. He gained the confidence to become self-employed as an interior painter and has functioned in society as a neighbour, friend and family member. Thankfully, both my parents and my brother were able to enjoy the benefits of normalcy from the medication before they passed away. More recently, something went horrendously wrong.

It's important for you to understand when I say he was a responsible person who fully understood his mental health issues. He religiously attended medical appointments to monitor his lithium levels and took his prescription religiously. That was for 10 years.

Two years ago, we noticed tremors in his hands and encouraged him to seek medical attention. Finally, after a few attempts with his family physician to explore the problem, the tremors were strong enough that he could barely pour liquids from one container to the next, let alone paint. His physician finally took notice after ignoring his inquiries as the tremors went beyond the hands and were very obvious. He ended up in hospital less than two days later—he had a medical appointment, so two days later—with toxic levels of lithium. Imagine a man over 200 pounds on a stretcher with full-body tremors, confused, forgetful and enduring weak bladder function. He was quite entertaining through that experience as well. It was determined that he had 40% function of his liver, a damaged kidney and thyroid. His once pearly whites are crumbling and to date he has feet and leg ailments due to swelling and other drug-related side effects since his episode.

We were fearful that he had Parkinson's. However, my sister-in-law, who is an RN, informed us that the tremors are a common side effect of lithium and not likely Parkinson's. I blame the doctor for not listening to the concerns of his patient and for not identifying from the blood results that his levels of lithium were toxic. The question now is, how can someone who is monitored routinely become toxic?

The professionals immediately eliminated lithium and for weeks he suffered the withdrawal, and I know it was disturbing to witness. Sadly, the mania was present almost immediately. He was confused and had severe memory loss. As a family, we were very saddened and shocked by his setback. He was discharged with follow-up appointments to monitor his new medication. In short, the patient didn't like the side effects of the drug or the talks with the health professional. He decided to stop going to the appointments and therefore further slipped into a state of manic depression.

Again, as a family, we noticed almost immediately and tried to notify the health professionals at the hospital. They were not eager to learn of this setback nor would they allow me to speak to his psychiatrist due to issues of confidentiality. In fact, they referred me to the family doctor, the very person who mismanaged his care.

Flaw number 4: When he stopped attending the appointments, that was the first flag that he was likely going to slip into a manic-depressive state. What did anyone do at this point? Absolutely nothing. Who would? The family doctor? He's too busy, and it's out of his hands now. The psychiatrist? No, my brother was set up with bridging. Bridging? No, he's 52 years old, and if he decides he doesn't want to go to an appointment, they can't force him. COAST? They have to wait until he has three strikes against him. I was relieved when he received trespassing and harassment notices because the strikes were working in his favour. Lastly, my brother? Not likely—he feels great. The only positive reinforcement and advocate is the family, whose opinion, understanding of the history and knowledge of the current state are not considered. It was shocking how ignorant the people were of his condition and history. With each admission to hospital, the assessments would start at square one, with no concern for history, no understanding of baseline, minimal involvement with the family physician. Again, when you have a family involved every step of the way and their intentions are clearly constructive, involve them. It's like a childhood saying, when a sibling is complaining to the parent and the parent says, "Are you trying to get him into trouble or out of trouble?" Clearly, most families are trying to get their loved ones out of trouble. The system focuses on the minority who might take advantage of the state of mental illness.

Flaw number 5: So here we are in a dilemma, and I approached the family physician, who talked with my brother on a number of occasions, tried to visit and was well aware from a number of incidents that he needed help now. The physician called COAST, and not just once, to bring him to hospital. COAST did an assessment at his home based on their own criteria, and decided that he was not a threat to himself or others, so they did not bring him into hospital.

Flaw number 6: How is it that they can override the judgment of the patient's family doctor, especially after a brief conversation? Please know that COAST is an asset to our community, but I did not approve of their behaviour in this situation. Because my brother eluded his doctor, the doctor could not issue a form 1 as he hadn't assessed him within seven days. That is absolutely ridiculous. Are you protecting the patient from the one bad doctor who may be taking advantage of the patient and his or her state of health? The doctor's intervention would have expedited the resolve and prevented many personal and stressful hours for our family.

Back to my point about who will help my brother, the system is not prepared to take the lead. It more than likely always falls back to the family to advocate on behalf of the patient, and usually against the patient's wishes during the bout of mania. Luckily for us, we have repeated the cycle a few times and can expedite the process and shorten the length of time that our brother is able to further ruin his life by making inappropriate decisions while ill. This includes blowing away an inheritance that could have set him up with a home and a stable lifestyle; apologies in his wake of mania to those offended by his lewd or crude behaviour; behaviour that would turn his usually pristine apartment into a laboratory of experiments and mass destruction unlivable even for a rat. In fact, during this episode he ended up getting a motel because his apartment was a health hazard—and you have pictures in front of you of his apartment. Really, of all of us in our family, he's the tidiest.

Families: For families trying to help the patient, the experience is unbelievably frustrating. The major roadblock is around confidentiality. I ask the question, why is the mental health sector much more likely to pull the confidentiality card out of their back pocket? On a surgical ward, a maternity ward or a medical ward, family assistance is encouraged. We are to believe that mental health should not have stigmas, yet the health professionals stir up much secrecy and stigma with their insistence around privacy for the patient. As an employee at Hamilton Health Sciences, I understand and fully appreciate the importance of confidentiality, but it appears that the mental health care workers use it to the extreme, that it works against the patient's best interests.

My next question is, how can you isolate and protect a patient with mania—someone who hears voices-—to be their own advocate? They have the mentality of a young child in terms of decision-making. This is an opportune time to welcome the family to assist in their care. Ideally, the messaging or the mindset of the workers should be to encourage a partnership with families. At some point in the patient's treatment, they are very likely to welcome the help of their family. In fact, they're often quite relieved.

An example might be—and this could have been used in our case back in December—"We're letting you go home on a new drug, but we can't really monitor you as closely as we would like. Perhaps someone in your family or a friend can come on board to help you with your care." In our case, that individual could have alerted the health care worker directly, and they could have intervened and had him hospitalized immediately.

**1510**

What would this partnership have avoided over the last few months? Damage to his new vehicle—which he shouldn't have been allowed to drive, but who would alert the MTO?—loss of income; family and friends' stress and alienation; public nuisance; embarrassment for everyone; meeting with the justice of the peace; two to three visits by COAST; four to six meetings with the family doctor; visits to the police station; police intervention on two occasions; patient transfer services; a trespassing notice from Hamilton Health Sciences; multiple episodes of extremely bizarre behaviour; conversations and so on; rebuilding his life; and all the apologies. He's tired and exhausted from trying to pick up the pieces now. I invited him today, but it was too overwhelming. He returned to his home just last week and is back to following up with his appointments on an outpatient capacity.

As his only advocate, what are we to do if this happens again when he's 60 or 70? I'm so worried for him and not always able to help him. Mostly, I'm growing so tired of fighting the system after 30 years. It's a losing battle, but how will he manage without family? Imagine climbing into a warm bed with a stomach full of Thanksgiving dinner, all the while knowing your loved one is, through no fault of his own, asleep somewhere on the street?

Now we have issues of benefits. He has lost six months of income, which is cutting into his savings. He is eager to get back to work but unable to stand or paint due to the side effects of his current drug. Also, his teeth have crumbled, so his first impression, especially when quoting paint jobs, will not be the best one. Who will help pay for the dental work? Do I make inquiries with legal aid to help him in determining if the blood levels were obviously above normal for years? Is the doctor accountable here?

My brother is in no condition to fight. He's tired and raging a battle of his own. Do we help fight this battle with all the bureaucracy? I've already made inquiries only to receive the usual responses of confidentiality and so on. The last six months have set my brother back significantly. If not for family intervention, perseverance and love, I can't imagine what his situation would be right now.

To conclude, I've talked about the challenges for families when trying to support their loved ones. Some of the challenges include: confidentiality; early diagnosis; navigational resources for families; family involvement during care; gaps and challenges within the network of professionals—for example, COAST, the family doctor and the justice of the peace; keeping patients accountable while under observation or treatment; enforcing a form 1 or 2 that would contain the person for a minimum of three days; and perhaps an appointed specialist to help weave through all the challenges, which include the above and beyond, for example, the benefits and legal aid.

Thank you for the opportunity to contribute and share a typical experience for any family managing manic depression.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Lorraine, for coming forward. I have a brief question; maybe I can ask you. Throughout Ontario—we started off in Windsor, and we spent yesterday in St. Thomas; now we're here in Hamilton—we've heard many delegations come forward and say that the families need to be involved more; that you're really not just treating the individual, you're treating the family. We've also had people come forward—I think one of the previous presenters said that the institution went overboard and gave out too much information about her. Can you talk about where you think that balance between the privacy of the individual and the rights of the family should be struck ?

**Ms. Lorraine McGrattan:** I think there have been a number of opportunities—and please jump in, Paul. I think 10 years ago it could have been documented that the patient welcomes family intervention, and those files should have stayed with Larry, my brother. But like I talked about in my speech, the health care workers start off at square one, with the patient on their doorstep with the current issues. There's never consideration for the history. So at a time when my brother is of sane mind and body, he could approve our intervention, and that could ride with him so that we don't have to go through all the roadblocks that we have.

Obviously, I listened to the one woman before me who did not encourage family intervention, and that's fine. But if it's documented, that would just save so much time and trouble for so many people.

**Mr. Paul Hamel:** If I could just add one thing to Lorraine's comment, it wasn't so much that we were looking for information from the medical people, it was hoping that they would listen to us to get some feedback, some background, because there is no ongoing file in the case of our brother.

**Ms. Lorraine McGrattan:** We've typically got him to hospital and then backed off, and let the health professionals look after him, all the while just sort of monitoring—if you're a bridging nurse and he says no, then it's a flag to really keep an eye on him. So I think we've given him his space for treatment.

**The Chair (Mr. Kevin Daniel Flynn):** Any further questions? We've got time for one more.

**Ms. Sylvia Jones:** I have one.

**The Chair (Mr. Kevin Daniel Flynn):** Go ahead, Sylvia.

**Ms. Sylvia Jones:** Your comment about the fact that you work at the—was it Hamilton Health Sciences?—and that you see a difference in how health care practitioners deal with mental health patients and their families, and use the privacy more often—did I get that right, that you perceive a difference?

**Ms. Lorraine McGrattan:** I just work in a health care environment where confidentiality is the utmost with every individual who's associated with the hospital. So I understand the issues around confidentiality, but I don't bring my employment here today.

**Ms. Sylvia Jones:** No, and I don't mean to suggest that. My impression of your comment was that you saw a difference between if I have cancer and how the family is engaged, involved or encouraged and if I have a mental health issue.

**Ms. Lorraine McGrattan:** Absolutely. If I was to walk onto a unit, which I've done many, many times because I've had a fellow volunteer or a staff person in hospital—"What room are they in?" and blah, blah, blah. A nurse at the bedside—I've asked questions. There's absolutely a barrier and a difference in the dialogue with the health professionals in the medical field versus the mental health field. Absolutely.

Larry has a friend, or a girlfriend, and I've asked her for feedback to weave into my presentation. Her big issue was all around the confidentiality, the roadblocks, the secrecy, not notifying us that he was even being moved to a whole other hospital. If I was to call any other unit, they'd be very free with that information. So that whole stigma, I think, is fuelled by the secrecy that goes along with it.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you for coming today, Lorraine.

**Ms. Lorraine McGrattan:** Thank you.

## OFFORD CENTRE FOR CHILD STUDIES

**The Chair (Mr. Kevin Daniel Flynn):** We're down to the last two presenters of the day. The first one we're going to hear from is the Offord Centre for Child Studies. Peter Szatmari, if you'd come forward.

**1520**

**Dr. Peter Szatmari:** I'm Peter Szatmari. I very much appreciate the opportunity to speak with you this afternoon. I'm a practising child psychiatrist. In preparing for this presentation, I realized I'm the oldest practising psychiatrist *[inaudible]*. I'm also the director of the Offord Centre for Child Studies. What I want to try to do today is outline a little bit about what I see the scope of the problem is with respect to children's mental health, talk a little bit about what some of the solutions might be and then how I think the Offord Centre might be of help to the committee in terms of its objectives.

So just to really emphasize the scope of the problem, I think there is a good recognition that about 20% of children in Ontario have serious mental health and learning problems and 10% of Ontario's children have mental health problems that are chronic and lead to long-term impairment. In addition to that, though, there is a significant and important gap between what we know in the science of children's mental health—the interventions—and the practice; that is, what actually happens in the community.

It's very disconcerting to realize that only one in six of Ontario's children who have mental health problems are actually receiving services from community agencies. Even perhaps more disturbing is that many of the services that are provided are not evidence-based; that is, they don't have an empirical justification. In fact, there are a lot of interventions that are out there that are currently not being employed.

We know that in general, when it comes to children and youth mental health problems, parents and teachers and primary care providers, including family doctors, often do not recognize mental health problems in children and youth. They see them in a moral context: These are bad kids instead of kids who have serious health problems.

The World Health Organization has demonstrated clearly that of the top 10 causes of adult disability, five of those are in fact mental health problems like schizophrenia, bipolar disorder, obsessive-compulsive disorder, substance abuse. But we have to realize a terribly important finding that's come to the fore in the last couple of years, and that's the recognition that 50% of all adult mental health problems actually begin prior to the age of 15 years. And not only is it mental health that we're talking about, but educational underachievement and physical problems go along with mental health problems. These do not separate out and segregate independently among our children and youth.

There are really important long-term outcomes associated with mental health problems in children and youth. I've listed on this slide a number of those outcomes that are related to attention deficit hyperactivity disorder and disruptive behaviour disorder. You just have to look in the newspaper on any day of the week and you can see columns about individuals caught in these kinds of predicaments and have to realize that at the source of those predicaments are mental health problems.

Mental health problems also have a significant impact on physical illness in adulthood. There's a very strong relationship between early depression and mood disorder and later cardiovascular disease. There's an increasing recognition that asthma and respiratory problems are linked to early anxiety disorders. And obesity, which of course is an epidemic and is becoming a serious health problem in the community, is in fact related to early anxiety and mood problems as well.

Now, we know that there are public health, community-based population interventions that actually can make a difference. An important one is supporting the development of children prior to school entry. The Pascal report and the possibility of a full-day kindergarten is, I think, a very important step in the right direction. We also know that population-based parenting programs for certain children at risk can make a big difference in terms of later behavioural difficulties. The Ontario government has made a very large investment in early intervention in children with autism spectrum disorder. No other province in Canada has done, I think, as good a job in terms of that implementation, and we know that makes a difference. Finally, we know that mentoring programs, either within schools or in the neighbourhood, like Big Brothers Big Sisters, for example, can have a very positive impact.

But that is not going to answer all the questions. I think if somebody were to ask me what are the four most important needs that Ontario needs to come up with in the next decade or so, I'd list these four.

One is a new estimate of what the prevalence and needs are of mental health children. People talk about one in five children having a mental health problem. You may not realize it, but that figure comes from our group. It comes from the Ontario Child Health Study, which we did in the early 1980s. So those data are now 20 years old, and I think we need an updated set of data on what the prevalence and needs are today.

We need much earlier identification and intervention through collaborative partnerships with schools and community mental health agencies. These are two different ships that are floating in the night, often separately, and they need to be able to work much more closely together.

We need more resources for that 10% of children and youth with chronic and severe mental illness—and you've heard, I think, people talk all day about bipolar disorder, schizophrenia, homelessness etc. That is a significant health problem that we just don't have the resources for, and the interventions I've talked about that work are more population-based and aren't going to address those with the most severe types of problems.

Let me tell you just a little bit about our centre. We're a research institute based at McMaster University and McMaster Children's Hospital. We're the originators of the Ontario Child Health Study, which really was the first and I think still the most important epidemiologic study of mental health problems in children and youth in North America. We're a multidisciplinary centre, and we do not only world-class science but we also have innovative and evidence-based knowledge translation approaches. In other words, we realize that it's not only important to do science but actually to get the results of that science out there into the community, to the people who need to have that information so that they can make a difference in the lives of children and youth.

Along with my colleagues, I've thought about a number of ways we at the Offord Centre might be able to help the work of this committee. I've taken the three objectives from your mandate and tried to list them under those. I think we have expertise in determining the mental health needs of children and youth. I mentioned not only the Ontario Child Health Study, but also the early development instrument comes from the Offord Centre. That EDI is now used all over Ontario to monitor the readiness of children prior to school. It's also used in many provinces across Canada and is now being used internationally.

We're also a leader in the use of preference methods to understand the service preferences of parents, youth and service providers. Not everybody wants the same type of service. Families, service providers and teachers have different preferences. What we tend to do now is give everybody the same intervention, the same set of services, not really tailored to the needs of the consumer. Our group has really been able to devise interesting and important ways of determining consumer preference to guide that intervention.

I think we're also very good at identifying effective, evidence-based programs that might be published around the world but that may not be known to the community in Ontario and being able to identify interventions that are effective for children and youth.

I've talked about the possibility of a new Ontario Child Health Study. I think this is a possibility, and I think it would be quite important. That data, as I mentioned—the previous data—is over 20 years old now, and Ontario is a very different place today than it was in the early 1980s, when we did the Ontario Child Health Study. We need to think about estimating mental health needs from multiple perspectives. We need to understand much better what community resources are, not only the formal community agencies, but also the informal supports and resources that are available, like volunteers and families. We need to be able to monitor change over time so that as we introduce community-wide programs like a full-day kindergarten program, we need to be able to evaluate whether that's making a difference in the long term.

I think we can also help the committee identify effective community-based interventions for children and youth. We have special expertise in parenting programs, all the way from parenting infants to parenting teenagers, which, God knows, is a difficult thing to be able to do. We've done extensive work in preventing family violence. We've done a lot of work in peer mediation techniques to reduce bullying. We've developed a number of anxiety and depression prevention programs that are delivered within schools and out that seem to be effective.

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I think too that we can leverage existing opportunities. So, for example, for a number of years now we've been scanning the research literature around the world to identify the best and most important and clinically relevant interventions that are being talked about and are being evaluated. We write up a very brief summary of those interventions and that research evidence and make it available primarily for parents, but also for teachers and family doctors and front-line clinicians. Those summaries are available in English and French, and we have plans to translate them into other languages including aboriginal languages. We've piloted many of these in family health teams in Ontario. You'll see within your packet some of those small information pamphlets about anxiety disorders and behaviour disorders in children. These information packages are also available for free on our website.

Let me leave you with what I think is a sobering thought. This comes from a report from UNICEF: Of the 29 OECD nations, Canada ranks 21st in child well-being, including mental health. I'm sure you'll all agree with me that that is really an unacceptable statistic as it currently stands. We all know—you know this—that the social and economic future of this province depends on the current mental health of its children and youth. The one thing that we all want is a better future for our kids. We strongly believe that part of that better future lies in science and research and getting that research out to the right people at the right time when they actually need it. We very much look forward to working with you in ensuring a better future for our kids.

**The Chair (Mr. Kevin Daniel Flynn):** That's great. Thank you, Peter. Great presentation. There's probably time for one question from each party if we keep it brief, so let's start with France.

**M$^{me}$ France Gélinas:** Thanks for your presentation. I was just curious to see if your centre had studied or looked at—there was a suggestion that we implement screening tools in our schools—let's say, at grade six and grade seven—where we would screen all the kids for mental illness, with the view that lots of it is not being reported, is not being picked up, so we need to be more proactive. Have you studied it? Do you have an opinion?

**Dr. Peter Szatmari:** We've certainly looked at the possibility of how to deliver mental health programs in a high school setting, because you're right, that is an age, at the end of primary school, where a lot of mental health problems really become difficult and manifest. If you institute a screening program, you need to have an intervention that addresses that targeted population. That intervention could be quite expensive and could require a lot of resources; it could be resource-intensive. The approach that we've taken and that we think has better promise is in fact improving the mental health literacy of teachers. So we're going into a high school in this city, for example, and we're having frequent meetings and contact with high school teachers on a face-to-face basis, talking to them about: What do mental health problems look like when they present in school? What are the interventions that the school can do as a whole to reduce stigma, to reduce bullying, to have more inclusive programs? How can we identify the resources in the community that those kids need? They might need a mental health clinic, they might need a family doctor, they might need counselling of some sort so that the school can serve as a resource pool. We think that that approach might be better than a screening tool that targets and identifies a large population of kids and then we're not really sure what to do with those kids, and it might be stigmatizing.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Peter. Maria?

**Mrs. Maria Van Bommel:** In one of your slides you talk about anxiety and depression prevention programs for children and youth. As we've been doing our hearings in the last few days we've heard a lot about the fact that there seems to be a saw-off at the age of 16, so anybody younger than 16 doesn't seem to get the focus or the attention. You talk about prevention programs. What have we got in the province in terms of programs, not only for prevention, but once depression or anxiety presents itself in children under 16? Is Hamilton the only community that has the opportunity to have some kind of programming for that? What happens across the province? Do you have any research on what is happening across the province on that kind of thing?

**Dr. Peter Szatmari:** I think it is fair to say that for kids who have a diagnosable mood disorder or an anxiety disorder, there are two interventions that we know work. One is what we call cognitive behaviour therapy. It's a set of sessions—between 10 and 15 sessions—involving a child or youth, himself or herself, plus the parent, or it can be delivered in a group setting where they have a structured behavioural approach to address the cognitions that are anxious and the mood-inducing cognitions that make kids depressed.

We know that works. That's not being used in Ontario. The training programs within community mental health agencies don't really have the personnel, I think, to be able to deliver a lot of cognitive behaviour therapy intervention. A lot of places do—I don't want to generalize to "everybody"—but certainly, the training programs that we have available don't train mental health professionals in the latest evidence.

That's why we think it's so important to get the evidence out there that's being produced. The new science that's being produced in the children's mental health field is amazing, and often it takes 10 years to get it out there. We think we need to expedite that process to make it much more rapid so that people can learn.

**Mrs. Maria Van Bommel:** But how would we expedite that?

**Dr. Peter Szatmari:** There's very little money for this kind of knowledge translation process. We do this website; we do these pamphlets. It costs us money. We have to take it out of our budget. There's no place we can apply to get sustainable funding to be able to provide this kind of information to the community. It's one thing we would love to do, but it's difficult.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you, Peter. Sylvia?

**Ms. Sylvia Jones:** I want to go back to the comment from France on improving the mental health literacy of teachers. Tell me the logistics of that. Would that have to happen right at the teachers' college level, or is that an opportunity that can happen with professional development?

**Dr. Peter Szatmari:** Both. My daughter has just graduated from teachers' college. She had a great program. She went to OISE; she was there a year. I'd say to her, "Okay, Claire, sweetheart, what did you learn about children's mental health today?" "Uh...". And she works in an inner-city program. She has taught in the inner-city program. That's point number one.

But I do think the best way to do it is with your feet on the ground running; that is, you get the mental health professional and the experts into the school on a Friday. You have a full day and you just have a dialogue. It's that face-to-face interaction and personal relationship that I think will make the biggest difference, and if we can harness that and begin to systematically apply those kinds of relationships between service providers, teachers, academics and scientists, that could be really an exciting way to lift the mental health literacy of certainly schools, but of the community as well.

**The Chair (Mr. Kevin Daniel Flynn):** Very good. Thank you very much for coming, Peter. I remember Dr. Dan.

**Dr. Peter Szatmari:** You do?

**The Chair (Mr. Kevin Daniel Flynn):** From my days at the children's aid society in Halton. He was quite the guy.

**Dr. Peter Szatmari:** Right. He was.

**The Chair (Mr. Kevin Daniel Flynn):** Thank you very much for coming today.

**Dr. Peter Szatmari:** It has been five years since he passed away, but we keep his memory alive as much as we possibly can. Thank you very much.

**The Chair (Mr. Kevin Daniel Flynn):** And so we should. Thank you very much. For the committee, that is our last delegation of the day, as it turns out.

*The committee adjourned at 1538.*

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