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Mercredi 2 décembre 2009

**Select Committee on
Mental Health and Addictions**

Mental Health
and Addictions Strategy

**Comité spécial de la santé
mentale et des dépendances**

Stratégie sur la santé mentale et
les dépendances

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LEGISLATIVE ASSEMBLY OF ONTARIO

SELECT COMMITTEE ON MENTAL HEALTH AND ADDICTIONS

Wednesday 2 December 2009

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ SPÉCIAL DE LA SANTÉ MENTALE ET DES DÉPENDANCES

Mercredi 2 décembre 2009

The committee met at 1606 in committee room 1.

MENTAL HEALTH AND ADDICTIONS STRATEGY

The Chair (Mr. Kevin Daniel Flynn): If we can call to order, ladies and gentlemen. Welcome to all our guests. This is a meeting of the Select Committee on Mental Health and Addictions. We have a number of people presenting before us.

Just to outline the rules a little bit, everybody's got 15 minutes. You can use that time any way you see fit. If, at the end of the 15 minutes—or before the end of the 15 minutes—there is any time left over, we'll try to share that amongst the members who are present for a discussion.

ASSOCIATED YOUTH SERVICES OF PEEL

The Chair (Mr. Kevin Daniel Flynn): Having said that, I'm going to call forward Kelly Henderson, executive director of Associated Youth Services of Peel, if you'd like to have a seat and at some point introduce your colleague. The floor is all yours. Make yourself comfortable, and thank you very much for coming.

Ms. Kelly Henderson: Thank you. Good afternoon. My name is Kelly Henderson and, as the Chair indicated, I'm the executive director of Associated Youth Services of Peel. With me today is Lisa Bachmeier, one of the clinical managers at our organization.

We are a multi-service organization, working with young people and their families involved in the child welfare, youth justice and children's mental health sectors. In reference to children's mental health, we have been providing support since the mid-1990s in the homes of our clients and in the community. I appreciate the chance to address this committee today and would like to take this opportunity to offer messages about three key themes relating to children's mental health: service integration, the needs of marginalized youth populations, and sustainable funding.

First, service integration: In our community, and I'm sure in many others across the province, we clearly recognize that in order to share our responsibility of supporting young people and their families, we must ensure the integration of services cross-sectorally. Although many of us as service providers exist within differing

mandates and policy frameworks, we realize that the needs of one youth could span many sectors, and the responsibility of ensuring there is integration lies with us as professionals and not with service users.

To exemplify this, I would like to talk about how proud we are as an organization at AYSP to be the community agency lead for our student support leadership initiative. This is an interministerial project which incorporates services provided through education, children's mental health and youth justice. Our community is experiencing a great deal of success with our initiative, not only in how mental health connects with education and youth justice but also how we have expanded that framework to include a broader range of service partners. This has taken considerable time, varied expertise and a significant commitment to planning, with a shared vision that we will do better for children and youth and our community when we work and problem-solve collectively. We have experienced strong success, but we still have work to do.

An opportunity exists to continue this momentum and the momentum of other such initiatives, through a shared philosophy and vision of success for our youth and by interministerially continuing to place responsibility on policymakers and service providers to work collaboratively as a system of support. This would include assurance to joint problem-solving and decision-making at all levels, and an understanding that these processes and outcomes will be monitored and evaluated for success and accountability.

Second, the unique needs of marginalized youth: This will be discussed by examining the needs of the transitional-aged youth population, the homeless youth population and the lesbian, gay, bisexual and transgendered—who I will refer to as LGBT—youth population. When speaking of transitional-aged youth in this context, I'm referring to youth who are 16 and 17 transitioning to adult mental health services. When working to support transitional-aged youth experiencing significant mental health issues, one of the greatest barriers is the existing age range under the Ministry of Children and Youth Services, which dictates children's mental health support to a young person only until the age of 18. If we could change one thing, we would change that ministry definition of "youth," and we would change it to a more broadly accepted definition: up to the age of 24.

In our work with young people, we realize the transition to adulthood needs to be recognized as a unique time

in a young person's life, not a point in time but rather something related to individualized developmental processes. The chronological age of an individual could be 18, but developmentally and emotionally, they could be functioning at a much younger age. Under the current mandate, we have to end service at 18 years, regardless of level of functioning, which could impede a smooth transition to the adult service system and undermine success.

If there was an opportunity to apply a more flexible framework to who is able to obtain children's mental health services, it would be a more inclusive structure which allows individuals with significant mental health issues the time and opportunity to progress at their own pace into adulthood and the adult service system, resulting in better outcomes. This would not be the case for all youth; if they could successfully transition at age 18, they would. This speaks to those youth who would not be successful in that transition and who require ongoing support and expertise from the children's mental health sector. As service providers, it would still be important for us to continue to build partnerships with the adult service system. However, the flexibility would enable plans to be developed which meet the unique needs of individuals and respect their current capabilities.

Another marginalized group of young people are homeless. When working to support homeless youth with significant mental health needs, one of the greatest barriers is lack of affordable and supportive housing. Although our experience is in the Peel community, we believe this issue exists in other communities as well. In reference to affordable housing, our starting point begins with access to Ontario Works. In helping youth to obtain OW, we are aware of the rule that the young person must have an address to obtain support, and an address cannot be secured until proof of the youth's ability to pay is substantiated. Part of our work with homeless youth is to advocate on their behalf to access these funds; however, in the absence of an advocate, youth become frustrated and give up trying to obtain something which appears to them to be inaccessible, often resulting in no shelter.

Once a young person has been approved to receive support through Ontario Works, they soon discover the housing allowance afforded to them is not consistent with the market. As a result, they end up choosing between rent and other basic needs, including food. They often are only able to obtain substandard living accommodations in conditions which are not safe. This results in increased transience, driven by their need to find a safe and supportive space. If they do stay, they may be exposed to antisocial and criminal activity and harassment, including sexual harassment, a particular concern for young females and LGBT youth. These conditions, along with their limited access to nourishment and safe slumber, further serve as a barrier to school and/or work attendance. Additionally, for those youth with persistent mental health needs, there's a lack of supportive programming to allow them to maintain their housing.

In reference to emergency shelters, many work within a framework of zero tolerance for substance use. For

those youth experiencing concurrent disorders, it is another barrier to access. Often, the youth in Peel must travel to Toronto or other regions to find shelter, which limits their ability to maintain school or employment and isolates them from their existing support system, factors so important to their well-being.

Another specific population of marginalized youth includes those who identify as LGBT. When working to support LGBT youth with significant mental health issues, the greatest concern is disparities in health. For the purpose of this presentation, I will focus on mental health and well-being.

When reviewing statistics, we see that the rate of suicide in LGBT youth is three times greater than in the overall youth population. The rate of depression in LGBT youth is three to five times greater than in their heterosexual counterparts. An estimated 30% of LGBT youth have issues with alcohol abuse; 25% of youth whose parents react negatively are disowned and forced to leave their homes; 28% of LGBT youth drop out of high school at some point in time. LGBT youth are five times more likely to be attacked and three times more likely to need medical attention than heterosexual youths.

LGBT youth often experience the same struggles as the transitional-aged youth population and our homeless youth population. They have, however, an additional layer of marginalization, making them a very vulnerable population. They often experience homophobia and transphobia in the form of bullying and harassment, being victimized in their homes, schools and communities, which serves to further isolate them.

In our community, we receive project, time-limited funding to begin to address the needs of LGBT youth. The success of this initiative has been the result of working together, sharing the responsibility of building a service framework specific to this youth population, and building the capacity of the community to respond.

Overall, the needs of the LGBT youth population must be recognized to a greater degree and be identified specifically and on an ongoing basis in any strategy addressing the mental health needs of our youth.

As a final point on marginalized youth, I would underscore the importance of ensuring that our work with this population—in fact, all youth involved in our many systems—has as its foundation interventions which are evidence-based, and that outcomes are proven for success.

Now I'll move to my third point: sustainable funding.

AYSP was one of the four children's mental health agencies reviewed by the Auditor General of Ontario in 2008. Duly noted in the value-for-money audit is the assertion that core funding for children's mental health services across the province has been eroding for the past decade, resulting in reduced services for children and youth needing mental health support. Without a doubt, funding has not kept pace with clearly identified community need, and the process has damaged the development of infrastructure and administrative capacity as it relates to human resources, finance, evaluation and so on,

despite program growth and increased complexity in service delivery across the system.

Although there are often benefits to one-time and time-limited project funding, when it is used to begin programs, create community capacity and expectation and then is terminated, the ability to create a sustainable system of service and support is severely undermined. Moving forward, it is imperative that funding for children's mental health is based on assessed need and population. The mental health of our young people is fundamental when considering their current and future success. I propose that significant increased investment in children's mental health now will minimize costs both financially and socially in the future.

I thank you for this opportunity.

The Chair (Mr. Kevin Daniel Flynn): Thank you very much. You've left a little bit of time for questions, maybe one for each of the parties. Let's start with Christine or Sylvia.

Mrs. Christine Elliott: I'd just like to thank you very much for coming today. Certainly a lot of the issues that you've highlighted are things that we have heard about, and we understand particularly the need for safe, affordable housing and the fact that children's mental health has not been receiving the attention that it deserves. So certainly those thoughts are foremost in our minds.

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

Ms. Sylvia Jones: You mentioned that you received some one-time funding for an LGBT group.

Ms. Kelly Henderson: Yes.

Ms. Sylvia Jones: Where was that funding from?

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Ms. Kelly Henderson: That was through the child welfare secretariat, through the community capacity building funding. Our local children's aid society had identified it through their needs assessment, that work with LGBT youth in our community needed to be enhanced, so that was part of that funding envelope.

Ms. Sylvia Jones: And it was one-time for—

Ms. Kelly Henderson: It's fiscal, so we have benefited from it for the last two years. We applied to the Trillium Foundation and were successful in that bid as well, but again, that's time-limited project funding.

Ms. Sylvia Jones: Thank you.

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

M^{me} France Gélinas: I too would like to thank you for the work that you do, and thanks for coming here.

You're right: The Auditor General talks about lack of funding and it eroding. For your agency, can you share with us the budget that you have, and if you were able to secure more funds, have you given any thought as to how much that would be and what difference it would make?

Ms. Kelly Henderson: Our agency budget is approximately \$6.5 million. About half of that is dedicated specifically to children's mental health. The rest of our programming is relating to youth justice and some work with child welfare.

We have thought about, not specific to our organization, the top three priorities we would have for funding, although we could certainly generalize that to our organizational setting. That would be funding for community planning and service integration, such as student support leadership—because of the time and the expertise that's required for that, specific dollars that are made available to allow us to do planning would be beneficial; services for marginalized youth, as indicated in my presentation today, are lacking and we would want to see that increased; and funding support for the implementation of evidence-based practice would be something that we would see as being important.

M^{me} France Gélinas: Thank you.

The Chair (Mr. Kevin Daniel Flynn): For the government side, Liz?

Mrs. Liz Sandals: We've mentioned a couple of times funding for LGBT youth. Could you tell us a little bit about the programs you were actually able to do when you had that funding?

Ms. Kelly Henderson: I think I might turn that over to Lisa Bachmeier, who's our clinical manager and manages that program, just around the specifics of that.

Ms. Lisa Bachmeier: What we currently offer is the Youth Beyond Barriers program. We provide support for youth from age 12 up until their 18th birthday. With the Trillium funding we were allowed to extend it to their 19th birthday. But we provide weekly youth support groups, one-to-one support, and also facilitation to appear at monthly support group. There are also some Web-based resources because we know that's how the youth are really accessing the services.

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

COMMUNITY NETWORKS OF SPECIALIZED CARE

The Chair (Mr. Kevin Daniel Flynn): Our next speaker this afternoon is Liz Froese. Liz, if you'd like to come forward and make yourself comfortable. There should be some clean glasses and some water there. Mark, if you'd like to come forward as well.

Ms. Liz Froese: Hi. I'm Liz Froese. I'm the coordinator for the Southern Network of Specialized Care, and we're very thankful to have the invitation today to come and speak to you.

I'd like to just introduce the people who are with me today. Mark Dorsey, at the far end, is a family member, and he will be presenting his perspective as a family member. Marc Hadida is here to answer your questions. He's a consumer who lives in Toronto. We will be sending you a copy of a videotape. He's going to videotape his story for you. He's a little bit anxious, and so we thought it would be easier to do it that way and he's graciously agreed to do that. So we'll send that to you in the future. To my immediate right here is Tony Vipond, who is the executive director of Community Living

Huronia. He's also the co-lead for the Community Networks of Specialized Care, central region.

Mr. Tony Vipond: Thank you, Liz, and thank you to the committee today. The goals for our presentation today are to inform the select committee on the role of the Community Networks of Specialized Care in the province of Ontario, to outline the challenges faced by people who have a dual diagnosis, to present recommendations for change, and, most important, to put a human face on the impact of failing to adequately serve people with a dual diagnosis.

Community Networks of Specialized Care: In 2005, the Ministry of Community and Social Services recognized that people with a dual diagnosis and their families or caregivers were not being well served by the existing uncoordinated service structures. In May 2005, four regional networks were created and funded by the Ministry of Community and Social Services: the northern network, the southern network, the eastern and the central network. The mandate of the networks is to improve accessibility for those with a dual diagnosis; to improve coordination and integration so that services and supports from a number of programs, organizations and sectors are working together with people and their families to make a difference; and to improve accountability.

Dual diagnosis refers to people who have a developmental disability and a co-occurring mental health problem or challenging behaviour. Thirty-eight per cent of people with a developmental disability also have a mental health problem. People who have a dual diagnosis have more severe symptoms, are more likely to have co-occurring medical conditions and have fewer resources available to them. The most common problems are mood disorders and challenging behaviours.

Some other facts:

- children with a developmental disability are five times more likely to be abused;

- 77% of adults with a developmental disability live in poverty;

- 60% of people with a developmental disability are out of the labour force;

- estimated percentages of developmentally disabled people in Canada's criminal justice system range from 2% to 36%.

People with a dual diagnosis experience a double jeopardy effect of stigma which occurs when two disabilities, both developmental and mental health, are present in the same person.

In a 2009 study of Ontario ACT teams, of the 67 teams surveyed, 53 reported that their education needs regarding dual diagnosis were medium or high. There was also no consistency across the province in the number of people with dual diagnosis served by ACT teams.

Today, we'd like to present three issues.

Issue number one, lack of access to clinical care and specialized services: First and foremost, people with a dual diagnosis are often denied access to service. There's

limited training for both health and mental health professionals on dual diagnosis and, finally, no consistency in the availability of services province-wide.

Recommendation number one: Every Door is the Right Door must also be true for people with a dual diagnosis, and the full spectrum of mental health services must be available to them.

Recommendation number two: University curriculum for health and mental health professionals must include modules on developmental disabilities and dual diagnosis. Ongoing professional education must include workshops and seminars on the complex needs of people with dual diagnosis.

Recommendation number three: Build on the innovation of specialized care networks which have developed expertise in connecting services to one another for this population and which have training programs already available for developmental services staff so they can learn about mental health problems, and for health staff so they can learn about developmental disabilities.

Issue number two, the need for ministry-level leadership, follow-through and funding for joint policy guidelines for the provision of community mental health and developmental services for adults: (a) Ensure consistent province-wide uptake of the joint policy guidelines for the provision of community mental health and developmental services for adults with a dual diagnosis; (b) Follow-through with dual diagnosis guidelines would not be expensive, but it's naive to assume needed changes will just occur without at least some investment; (c) Many ministries must commit to working together to support this population. The Ministry of Community and Social Services and the Ministry of Health and Long-Term Care both must invest equally to try to support those with a dual diagnosis.

Recommendation number four: Ensure that the joint policy guidelines for the provision of community mental health and developmental services for adults with a dual diagnosis are implemented consistently across all 14 LHINs, along with the appropriate funding for implementation.

Recommendation number five: Coordination of services on the ground begins with coordination of the ministries that fund and produce policies and standards for them. Relevant ministries must challenge themselves to work together for the sake of the people they serve.

Recommendation number six: The Ministry of Health and Long-Term Care must match the investment in the community networks made by the Ministry of Community and Social Services. This would require an investment of \$4 million.

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Issue number three: People with a dual diagnosis are occupying expensive in-patient beds in general hospitals and in specialty psychiatric hospitals, sometimes for many years. Many of these patients do not require such high-cost services. In addition, many forensic beds are occupied inappropriately by people with a dual diagnosis.

(a) The Ministry of Health and Long-Term Care recognizes the need to move people with a dual diagnosis

to community settings, but has failed to develop an investment strategy to assist the Community Networks.

(b) People with a dual diagnosis would be better and more cost-effectively served in community settings.

Recommendation number seven: The Ministry of Health and Long-Term Care must invest in the Community Networks so that they can focus on assisting in the task of moving people with a dual diagnosis to lower-cost, higher-quality-of-life community settings.

Our final recommendation is the Ministry of Health and Long-Term Care must invest in community mental health housing and clinical supports specifically for the dually diagnosed so that these services have the capacity to accept people with dual diagnosis when they are discharged from in-patient and forensic settings.

I'd like now to ask Mark to talk a little bit about his experience.

Mr. Mark Dorsey: Thank you, Tony. My brother, Steven Dorsey, has tuberous sclerosis. It's a rare genetic disease in which benign tumours grow in the brain and other vital organs. As a result of that, my brother is developmentally delayed and he also has some behavioural problems. He also suffers from kidney disease and has numerous seizures on a daily basis.

In spite of his physical limitations, though, my brother has developed into a funny, entertaining and infectious personality. However, at one point, in his late teens, my brother's behavioural problem started to become a major issue, especially as his size grew. In large part, due to the crazy combination of behavioural drugs that he was being prescribed, Steven started getting very aggressive and would often lash out at family members and others who were close to him. Finally, my family came to the very hard decision that we needed to place Steven in a group home, not only for his own safety, but also for the safety of others.

Over the last five years, I have been a student at Guelph university. I've visited my brother in Barrie every other weekend. I was there on the day Steven was admitted into the Bayview Mental Health Centre in Penetanguishene and it was the saddest day of my life. I remember leaving almost in tears because the facility seemed like a prison. I couldn't imagine how lonely and confused my brother must have felt being there. Personally, I felt helpless.

The care that my brother received at Bayview was not very good at all, truthfully. Steven was not allowed to have any of his favourite toys at the group home. He had nobody to interact with and it seemed like the answer to almost every problem was just to sedate him. From what our family noticed, it seemed as though there were all kinds of staff that were coming out of the woodwork during fire drills and stuff like that, but, really, they didn't do much of anything for Steven other than get him off his medication.

My brother's stay at Bayview completely altered his personality. Along with picking up a lot of quirks from others, he stopped talking entirely and lost a dangerous amount of weight. It seemed like his refusal to speak was

his way of getting back at the rest of the family for abandoning him in a prison-like setting.

Of course, the goal of our family was never to have Steven stay at Bayview for such a long term. He ended up staying for so long because of the numerous hold-ups in getting Steven into Pineview treatment centre. Steven eventually did get in, much to the relief of everybody.

I remember the first time that Steven and my father and I visited Pineview to have a look at it. Aside from being a beautiful old house, Pineview also seemed to have a relaxed and friendly atmosphere. There was a giant playroom full of toys and a big screen television, which was a huge bonus for Steven since he's a big movie buff. There was a large room for Steven to move in all of his personal belongings that he had missed so much at Bayview. He was sickly skinny and completely non-verbal coming out of Bayview, but in only a short time at Pineview, he became the old Steven. Sometimes when I would go to Penetang to pick Steven up at Pineview, he would be playing under supervision and would run up to the car excited to see me. Needless to say, it was great to have Steven back.

When a group home vacancy opened up in my hometown of Barrie, Steven transitioned into a group home on Ferris Lane, where he currently lives. The transition from Pineview to his current group home was excellent, thanks in large part to the help of the director of the treatment centre, Marnie McDermott. Members of staff from Pineview brought him to his new group home a couple of times in order to make sure that he was comfortable and got adjusted properly. They've also continued to work closely with our family in Steven's care and they keep in touch with our family on a regular basis.

If I could offer a suggestion to you from my personal experiences concerning the treatment of people with developmental disabilities, it would be that there needs to be an increase in the number of rooms at Pineview, specifically. Even better would be to open up another treatment facility. The goal, in my opinion, should be to get people out of Bayview and into a proper living situation as quickly as possible. Some people are at Bayview for their entire lives, which is horrible to think about. They have very little freedom.

Having done a bit of research on the history of treatment for people with developmental disabilities, Bayview left me with the feeling that not much has changed since the days when people with a mental handicap were just institutionalized and not nurtured at all. Thankfully, Pineview and Steven's current group home in Barrie have restored my faith that there is care out there that offers people with developmental disabilities the opportunity to enjoy relationships, community excursions and other bits of normalcy that we often take for granted.

To see Steven and some others I have encountered go through Pineview Treatment Centre and end up being very successful in a group home is great. However, there are still a lot of people out there who are not being transitioned quickly enough due to a lack of facilities and funding. It's a serious issue that needs to be addressed.

Thanks for letting me talk to you today, and thanks for allowing me to give voice to people like Steven and Marc here.

The Chair (Mr. Kevin Daniel Flynn): Thank you very much for your presentation. We've probably got time for a few short questions, starting with France.

M^{me} France Gélinas: I wish I knew the facilities that you were talking about better than I do. Pineview is a treatment centre for dual diagnosis?

Mr. Tony Vipond: That's correct.

M^{me} France Gélinas: And from there, he was able to be transitioned to a group home where he now lives. When you talk about Penetang, that's when he got admitted into a hospital?

Mr. Tony Vipond: The mental health centre in Penetang.

M^{me} France Gélinas: Okay. Thank you.

The Chair (Mr. Kevin Daniel Flynn): Anybody on this side?

Mrs. Maria Van Bommel: I'm just wondering: Would you be able to give me a sense of how many people with developmental challenges go undiagnosed when it comes to mental health in dual diagnosis, that they're just simply categorized as developmentally challenged and that's that?

Ms. Liz Froese: That's a very good question. A lot of times when people present with a behavioural issue, it could be an underlying mental health issue, so it's misdiagnosed that way, or it's a diagnosis of mental health when the underlying is behavioural. There's a debate always between health and developmental services about whether it's behavioural or mental health. So that can sometimes skew it.

Sometimes we think that the 38% where we say individuals with a developmental disability have mental health issues—sometimes we think that's underrated, because of our experience. We don't have any research to say how many go undiagnosed, but it is a question that's out in the community.

The Chair (Mr. Kevin Daniel Flynn): Thank you, Liz, Sylvia, Christine?

Ms. Sylvia Jones: Thank you very much for appearing. You can probably answer some questions that other organizations would not be able to. I am interested to know, with dual diagnosis treatments—because you have the four nodes, northern, southern, eastern, central, you must know more than most where the system is really falling down, where there is no treatment, where the treatment has huge waiting lists. Can you enlighten us?

Ms. Liz Froese: One of our provincial priorities as community networks is clinical services. Right now, there's such a discrepancy. The north is really suffering from a lack of clinicians who have an expertise in dual diagnosis or an expertise in working with individuals who have a developmental disability. Even when they have openings for professionals, they can't recruit to the north. So what we've done with the networks is video conferencing, trying to bring clinicians in via video. It's

still not the best—face to face—but it's second best for right now.

We don't have the research dollars, but what we'd like to do is find out what best practice is, what is a good clinical service that needs to be in every community to support someone with a developmental disability and mental health issues. So we're working on that right now.

Ms. Sylvia Jones: When do you expect to have that information?

Ms. Liz Froese: That's a good question. When we have a little more resources. We're trying to partner with CAMH and with other service providers to get that research base done. So, hopefully in a year we'll have—I know it's not good enough, but with the lack of time and resources, we're doing our best with what we have.

Ms. Sylvia Jones: And I'm assuming, based on your presentation, that you are receiving no money currently from the Ministry of Health? It's all coming from community and social services?

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Ms. Liz Froese: That's correct.

The Chair (Mr. Kevin Daniel Flynn): Thank you. I just wondered, Marc Hadida, would you be prepared to answer a question?

Mr. Marc Hadida: What am I going to say?

The Chair (Mr. Kevin Daniel Flynn): I have a question for you: If you were going to live by yourself in the community, what would you need every day to do that?

Mr. Marc Hadida: At the hospitals they—I actually don't do anything. I just roam around the halls almost all day. But one of my support workers got me a workshop over at King and Spadina. I go there three days a week, half days—Mondays, Wednesdays and Fridays. Today, as you see, I am not there. That's about it.

The Chair (Mr. Kevin Daniel Flynn): Okay. Thank you very much for coming today. We really do appreciate it. Mark, Marc, Tony and Liz, thanks for presenting. Great presentation.

YOUTHLINK

The Chair (Mr. Kevin Daniel Flynn): We've had a little bit of a change in the agenda, and that is, our 4:45 is going to change places with our 4:30 appointment, so I'm going to call forward Paul Bessin from YouthLink. Welcome, Paul.

Mr. Paul Bessin: Thank you very much.

The Chair (Mr. Kevin Daniel Flynn): I'm assuming you're Paul.

Mr. Paul Bessin: I am.

The Chair (Mr. Kevin Daniel Flynn): If you'd like to introduce your colleague who's with you today. The same rules as everybody else: 15 minutes. Use it any way you see fit. If there's any time at the end, we'll have a little exchange.

Mr. Paul Bessin: Great; thank you very much. I'd like to thank the select committee members for the opportunity to speak here today. I'm Paul Bessin, the manager of counselling and family support at YouthLink in

Scarborough. Beside me is Sabina Chatterjee. She's the manager of Youth Skills Zone and the Inner City youth programs, located on Vanauley Street in downtown Toronto. I'm going to give you a very brief overview of our agency. We've provided a package for further information. Throughout our presentation, we'd like to give emphasis on the importance of prevention which serves to improve mental health in youth, prevention that gives emphasis to the importance of housing, meaningful activity, social relationships and inclusion, all of which we consider necessary for good mental health.

Our particular niche is to provide services that are responsive, flexible, and client- and community-driven, all to bridge the gap that exists because so many mental health and addiction services are currently dependent on medical and psychiatric diagnoses.

To revisit, there are three points that we want to make today, the first one being that YouthLink provides intervention that is not medical-model, diagnosis-driven; that our community-based forms of intervention produce positive outcomes and are crucial to addressing the needs of youth who have mental health concerns; and third, services and programs lack adequate ongoing core funding and are at significant risk of further erosion.

YouthLink has a long history in the city of Toronto, beginning in 1914 as the Big Sisters Association and evolving to Huntley Youth Services in the 1980s, to the present-day YouthLink. Our agency currently provides a continuum of services for young people aged 12 to 21 or to 24, depending on the service or program. The continuum consists of prevention efforts such as public education, employment and housing supports at one end, to a more intensive residential treatment program at the other end. Our prevention efforts are aimed at connecting youth and their caregivers to promote emotional and physical well-being.

Currently, we are funded by the Ministry of Children and Youth Services, the Ministry of Health and Long-Term Care, United Way, city of Toronto, and corporations such as RBC and the Counselling Foundation as well as through private donations.

In terms of who we serve, many of the youth that we're providing service to have had past involvement with other children's mental health organizations; they've had stays in child or adolescent units at hospitals across the provinces, residential programs and shelters. Some youth have long histories of being in and out of care of child protection agencies. They are typically identified as hard to serve or unmotivated. We also provide service to youth with developmental issues living with caregivers who are struggling to plan for the longer-term care of their teen or young adolescent with special needs. There is also a substantial newcomer youth population we provide service to across the city.

Young people we provide service to can be suspicious of the system of help that is available, discouraged with their past experience with and hostile toward people who want to provide assistance. Still, some are rather skilful and adept at managing to get what they need for the

immediate from the system. We're dependent on our staff to engage with these youth, to develop trusting relationships that endeavour to give youth a voice in the help that might be offered. Our assistance always centres on the youths' and caregivers' views and opinions of what might create change in their lives.

In terms of the complex system of help for children and youth, community-based prevention and intervention models or methods are as valuable and deserving of financial and policy supports as are medically driven forms of intervention. We really want to push this point forward today, the point that there are many options of assistance that our agency provides independent of diagnoses and prescription of treatment. Diagnoses must not be the only determinant for help and assistance for young people with mental health concerns. We urgently need equitable funding across the spectrum of hospital inpatient, outpatient and community-based services. We urgently need more work to remove the silos between the Ministries of Health and Long-Term Care, Children and Youth Services, and Community and Social Services. Efforts must focus on eliminating restrictions in legislation, regulations and program criteria.

Our prevention efforts are aimed at reducing family conflict, supporting youth in housing, pre-employment training, providing a harm reduction approach to substance abuse, all of which can alleviate symptoms typically attributed to mental health and prevent further risk in youth. We believe that there's a broad understanding in, and acceptance of, the value of community programs and supports to promote positive mental health; however, the programs are under considerable financial strain and lack solid public policy to ensure their sustenance.

It's a huge challenge for YouthLink and other like-minded organizations to try to provide supports across a broad range of needs for youth living at home and for the street-involved youth population. Our reliance on project-based, limited-year, patchwork funding makes it particularly difficult for our programs to fulfill their potential. As the mental health needs of youth accessing our programs increase with every year, so too do the needs for training, additional staffing and increased service partnerships.

I am now going to turn to Sabina to talk more specifically about the street youth population supported by Youth Skills Zone at Inner City programs located at Queen and Spadina.

Ms. Sabina Chatterjee: I'm really thankful for the opportunity to address the committee, and to provide some focus on a growing, multiply marginalized youth population that is faced with profound mental health and addictions challenges: the street-involved and/or homeless youth population.

Established in 1980, YouthLink's Inner City Drop-In and Resource Centre provides a broad range of support services for street-involved and/or homeless youth in Toronto's downtown core. We offer access to basic needs-based services such as access to showers and laundry facilities, food and clothing within a welcoming and non-

judgmental environment. We also provide street outreach, HIV and hep C support services, harm reduction services and information about healthy sexuality and sexually transmitted infection prevention. The intentional informality of our service provision within the drop-in program has been proven to be a very effective way to provide support for street-involved youth. In addition to those, we also have housing access and follow-up supports, including an intensive follow-up worker who works primarily with youth with more mental health challenges.

The youth who use our services are often transient, and/or very “system shy.” This means that it is essential that supports provided for them need to be easily available, on-site and flexible in meeting the needs of our youth population.

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Our community partners enhance our services by providing on-site health care, legal support, mental health support, identification acquisition, and employment training and resumé building. Having easy access to these services within a space that is comfortable and inviting for street youth is crucial in helping them move from simply surviving to thriving.

In addition to basic support provision, the staffing team at Inner City is committed to providing opportunities for youth engagement that takes into consideration the wide variety of learning needs, mental health issues, cognitive disabilities and life circumstances that may be present in the lives of the youth who access our services. We have a physical recreation program that takes place twice per week and a Thursday night drop-in that provides the opportunity for arts-based programming. Informal activities and workshops are also provided on an ongoing basis within our drop-in hours of operation.

Core to our programming is our commitment to recognizing and building on the strength and resilience of youth. Our peer education program integrates former street-involved youth into the team to work in the drop-in and conduct street outreach alongside staff. The peer educators are able to share their life experiences with an aim of helping young people better use their local community support systems and deter the more vulnerable among them from becoming street-involved.

According to Youth Homelessness in Canada: The Road to Solutions, a research paper authored by Raising the Roof, there are roughly 65,000 young people homeless or living in homeless shelters throughout Canada at some time during the year. According to a study done in 2000, over 20% of youth in Canada live in poverty, 91% of single mothers under 25 live in poverty, and over 78% of aboriginal youth living off-reserve live in poverty.

Aboriginal youth are overrepresented in the street youth population, as well as being overrepresented within the child welfare system. In addition, the number of youth from different ethnocultural groups and newcomer youth who are homeless and/or street-involved has risen sharply in the past few years. It is essential that mental health and substance use services increase their cultural

competency so that they are able to meet the different needs of these populations.

There are many complex issues faced by homeless and street-involved youth: substance use and related issues; homelessness; income inequality; generational abuse; generational poverty; malnutrition; physical, sexual and emotional abuse; youth violence; disengagement from the education system; and sexual health issues.

Many youth who are street-involved have experienced some form of mental illness and substance use. In our experience, the youth who are currently accessing our support services seem to be living and coping with mental health issues that profoundly affect their ability to participate in traditional programming for youth. Even the scope of support provision that we can provide can be dramatically affected by the needs of these youth. The goal-oriented support provision for some cannot focus on housing or employment or education, but rather on basic survival such as eating, wearing shoes in the winter, re-learning how to use a washing machine or having showers.

At YouthLink, we assist youth in accessing the external supports they need. However, this is not without its own challenges. Youth who live with mental health issues and use substances are still told more often than not by mainstream providers that they need to deal with the substance use or the mental health issue. There is such a strong need for support within a concurrent disorders framework, as well as advocacy for the mental health system to be more open to working with youth who may be in crisis in addition to, or because of, their possible substance use.

Just yesterday, we had a young man who self-identified as being in a manic state, with seriously diminished impulse control and near-hysterical laughter, who was expressing his concern over his own safety. He told a staff person that he was worried that if he went home he would throw himself repeatedly against the wall, because, in that moment, it would feel like the right thing to do. The staff member spent a great deal of time trying to connect him with a mental health support program and needed to advocate for the youth to be taken seriously, as the other service provider reacted to the youth's laughter by saying, “Are you sure he hasn't just been using?” Eventually the other service provider agreed to meet with the young man.

We believe that it is very important to work within a harm reduction framework within both Youth Skills Zone and Inner City. We believe that by providing support within that framework, youth who are living with both mental health concerns and substance use issues are able to feel comfortable within our service provision and are able to begin to get the crucial support they need.

Just to underline that, in the last six months, we've had four youth die of suicide and/or overdoses. So there is such an ongoing challenge for us. It becomes really important. These folks are so dislocated from other systems of support that we need to keep on trying to create more options.

So to conclude, we'd like to reiterate the importance of recognizing and supporting the real value of community-based support services such as YouthLink, which provide services for the most multiply marginalized youth in our communities. The pressures of trying to do this very important work within a funding environment of instability and the reliance on project-based, limited-time funding make long-term strategic planning and service delivery very challenging. Our dedication to utilizing trauma-informed, intentionally informal support services for street-involved youth needs to be supported, because providing these services for youth can save their lives.

The Chair (Mr. Kevin Daniel Flynn): Thank you. You've left about a minute for questions. Can we have one quick one, Helena?

Ms. Helena Jaczek: Yes. Thank you both for coming. It's a question for Paul. You have a statement here on page 2: "Efforts must focus on eliminating restrictions in legislation, regulations and program criteria." Could you just give us a couple of examples?

Mr. Paul Bessin: Well, I'm glad to have fallen on the heels of your other presenter, from Peel, who was talking about the fact that there are some programs that limit the age up until 18 when they're funded through the Ministry of Children and Youth Services. We see a lot of transitionally aged youth.

I want to underscore and reiterate the point that she made, that was well articulated, about the fact that there are more young people who are staying at home, who have complex needs, and for them to navigate, to go from youth- or child-focused services into the adult, there's a huge gap there. That's one of the things that I'm making reference to there.

I hope that answered your question.

The Chair (Mr. Kevin Daniel Flynn): Thank you, and thank you very much for appearing before us today. Great presentation. I think you got your point across very clearly.

Mr. Paul Bessin: Thank you very much.

ONTARIO PUBLIC SERVICE EMPLOYEES UNION

The Chair (Mr. Kevin Daniel Flynn): As a result of the change in our agenda, our next presenters are from the Ontario Public Service Employees Union, Patty Rout and Sheryl Ferguson. Make yourselves at home. There should be some clean glasses and some water there. Like everybody else, you get 15 minutes. Use that any way you see fit. If there's any time left over at the end, we'll just split it amongst the groups. We're all yours.

Ms. Patty Rout: Thank you very much for granting OPSEU this opportunity to address your committee. I'm Patty Rout, first vice-president and treasurer of OPSEU. That's the Ontario Public Service Employees Union.

With me is Sheryl Ferguson, the chair of our OPSEU mental health divisional executive and president of

OPSEU Local 431, which is Providence Continuing Care Centre, Kingston.

You have our submission before you. We represent about 130,000 members within OPSEU. Some of those members are nurses—many of them, actually, are nurses—psychologists, psychometrists, social workers, youth care workers and support staff, all of them having an effect on mental illness and addictions, and we hope that we're strengthening the lives of the people who are there.

Our members also are the support staff and faculty members who teach many of the programs in the community colleges. As well, we have corrections staff, who also deal with mental health issues through the judicial system.

Your consultation paper, *Every Door is the Right Door: Towards a 10-Year Mental Health and Addictions Strategy*, has the potential to affect many of our members, so we're really welcoming this opportunity to be involved with the consultation process.

OPSEU agrees with the proposed approach to integrate people with mental illnesses and/or addictions into their communities. However, the integration of mental health and addiction services with the rest of the health system and other pertinent sectors is worrisome.

I must say that integration, in my world, in my experience, usually is translated as meaning cuts to important programs and services.

Despite the latest effort to reform the mental health and addictions strategy for Ontarians for the next 10 years, the provincial government has again failed to properly address multiple core issues related to the provision of quality mental health care.

OPSEU has reiterated the same issues over the course of decades, yet we always appear to come full circle on these problems. In short, OPSEU strongly disagrees with the methodology used in the Caplan report. Although its goals are attainable, the current funding model must be re-evaluated to ensure the services and programs are properly resourced.

Our formula to get the plan right involves the following: Recognizing the importance of psychiatric hospitals, while providing proper resources for patients with mental illness and/or addictions. This would include the fast and efficient delivery of programs and services such as children's mental health, healthy communities, and the need to ensure a viable, well-resourced workforce.

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Increasing funding: Part of the proposed strategy, which focuses on early intervention, identifies a number of key players to assist in creating public awareness. This involves the affected individuals as well as the people in their communities. Although the concept of early intervention through education is logically sound, there are many practical flaws in the proposed strategy. It is commendable to want all workers in related fields to be fully trained, but much more is required to turn that vision into reality. The main issue is sufficient funding for each public sector caring for those people with mental illness or an addiction.

Given the continual lack of funding seen in Ontario for mental health and addiction over the years, this goal seems destined to remain a dream. For example, Ontario is cited as having one of the lowest public per capita mental health expenditures compared to the rest of Canada. The national average is about \$172 per person, whereas Ontario's is \$152 per person. British Columbia's spending is the highest, at \$230 per person. According to the OECD, Canada has one of the lowest rates of mental health spending relative to health spending of all other OECD countries.

Children's mental health services continue to see an all-time low level in funding. They are most vulnerable to cuts to programs and services since they are a non-mandated service under the Ministry of Children and Youth Services, yet child treatment continues to play an important role in mental health and addictions. They provide early intervention, which Caplan cites as being a core component in providing seamless care.

It is important to note that since 1993, the funding of core budgets has increased by only 8%, yet there has been a 30% increase in the cost of living in that same time. To be clear, there needs to be more funding for specialized services such as mental health and addictions, including guaranteed core funding for children's mental health services. This is critical for the future of mental health and addictions in Ontario for all ages. Implementing such an ambitious strategy will require stable funding from year to year to ensure that the relationships can be built, strengthened and sustained.

It is very important for all Ontarians to have access to the same services, as Caplan stated. But where is the assurance that all Ontarians will have access to the same service when there are continued closures of mental health facilities across Ontario? Most recently, the Brockville Mental Health Centre is scheduled to close in March. Individuals with mental illness and addiction will be forced to travel to the Royal Ottawa Hospital from Brockville. This is particularly disturbing given the importance geography plays for individuals when they're trying to access mental health services.

An even more recent example is the threat of reducing the problem gambling treatment program at Lakeridge Health in Oshawa. Even though the program is well utilized, the Central East LHIN is still threatened with hospital cuts—\$3.4 million. The proposed plan is to reduce the number of beds from 20 to 11 and only allow people within the Oshawa area to access the program. This program is a prime example of a valuable program funded from a hospital global budget which is at high risk for closure despite the need in the community. Unfortunately, HAPS has suggested that hospitals under pressure should just eliminate mental health and addiction services funded in this manner without even looking to see if the service is an asset in the community.

Having viable programs and services is critical, but so, too, is accessibility. As with physical health concerns, programs and services must be available to all individuals with mental illness and/or addictions. Therefore, it is

absurd to be closing facilities and reducing the capacity of well-utilized and needed programs.

Increase the capacity by using resources differently and more efficiently: The Caplan report states that there is a belief that capacity will increase by using resources differently and more efficiently. Does this translate into using the same resources, which we have already established as insufficient, to support even more programs and services? Since 1993, the number of children in Ontario requiring mental health services has doubled to over 200,000 children. It has been reported that five out of every six children who require specialized help are not receiving care, and that those who do face an average wait time of five and a half months. This speaks volumes about the need for core funding as opposed to the need to use resources more efficiently, as stated in the Caplan report. The Deloitte report, 2006, states that there have been delays in the discharge of patients with mental illness and/or addictions from hospitals due to the lack of resources in the community, not the misuse of the resources.

Healthy communities feature education, jobs, income and affordable housing. OPSEU agrees that education, employment opportunity, income and affordable housing are the basic building blocks to ensure the stability and well-being of individuals with mental illness and/or addictions. But this isn't new, and where we continue to get bogged down is the lack of commitment towards these goals. These aims cannot be achieved by simply shuffling existing resources. How are individuals with mental illness and/or addictions going to be able to afford to stay in school and have appropriate housing and food when the levels for ODSP are at an all-time low in relation to inflation? Presently, the ODSP level for a single person is approximately \$1,000 per month. The average bachelor apartment in Toronto is about \$700 and food costs \$200 per month. That leaves \$3 a day for other expenses, such as clothing, transportation, telephone and other needs, and if they want to take a part-time job to be able to manage, they end up having to give up 50 cents on every dollar from their ODSP cheque. How can these individuals thrive or ever get ahead with such crushing limitations?

OPSEU members know through decades of front-line care that the failure by the province to seriously address poverty is a failure to seriously address mental health and addictions. In our workforce, the Caplan report acknowledges, there are shortages of skilled mental health and addiction workers across Ontario, which, in turn, has contributed to your wait lists, job stress and burnout. To improve the crucial recruitment and retention issue, Caplan suggests addressing stigma associated with work and the lack of opportunity for professional development. While we agree that these are relevant concerns, OPSEU believes that the underlying issue remains the inability for people to get full-time employment and the inability to deal with workload concerns.

Several studies, as detailed in our brief, reveal that many new graduates are leaving the health profession

within two years of graduating. This is not surprising, considering the increased workload created by countless divestments and hospital closures. It is no wonder that workers are feeling overworked and stressed. These individuals are asked to do more with less, so they are leaving the profession early or they're forgoing it altogether. We believe the solution to these problems must be multifaceted. Any solution must include increased and guaranteed funding and effective, regular consultation with our members.

In conclusion, many issues have been brought forth by the Caplan report on how to improve mental health and addictions. OPSEU is convinced that in order for Caplan's suggested strategies to be effective, there must be a dedicated plan that can solve the persistent problems of appropriate and secure core funding, including children's mental health, cutbacks to valuable programs and services, the closure of psychiatric facilities and the unstable workforce. These issues are complex and require extensive further discussion. We believe that the government is in a position to implement the necessary changes to make every door the right door. Thank you.

The Chair (Mr. Kevin Daniel Flynn): That's great, Patty and Sheryl. Thank you. You've probably left time for one very brief question. Christine or Sylvia? We've got less than a minute.

Mrs. Christine Elliott: I don't really have a question, more a comment. Thank you very much for coming. It's great to see you again.

I just wanted to mention to you that you know that we're not the authors of the Every Door is the Right Door paper, and I think the important distinction is that we are looking across the broad spectrum at a variety of ministries. So the comments that you're making regarding ODSP issues and so on are very relevant to this committee, and we certainly are taking those into consideration as we formulate our recommendations. I just wanted to reassure you that we are taking all of that into our recommendations for the future.

The Chair (Mr. Kevin Daniel Flynn): Thank you, Patty and Sheryl, for coming today.

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CHILDREN'S MENTAL HEALTH ONTARIO

The Chair (Mr. Kevin Daniel Flynn): Our next presenter this afternoon is Camille Quenneville from the Children's Mental Health Ontario organization, if you'd like to come forward. Good to see you again. Maybe you can introduce your colleague.

Ms. Camille Quenneville: I think he's going to introduce me.

The Chair (Mr. Kevin Daniel Flynn): Oh, really?

Mr. Gordon Floyd: We've got it turned around a little bit.

The Chair (Mr. Kevin Daniel Flynn): Okay. If you'd introduce yourself, then, so that Hansard knows who you are. Same rules as everybody else: 15 minutes.

Use it any way you see fit; if there is any time at the end, we'll share that among the groups. Thanks for coming.

Mr. Gordon Floyd: Thanks very much, Mr. Chairman and members of the committee.

My name is Gordon Floyd. I'm the president of Children's Mental Health Ontario. I'm joined by Camille Quenneville, who's our director of policy and communications. In her spare time, Camille is a volunteer with St. Jude Community Homes here in downtown Toronto, where she serves as chair of the board. She's going to briefly tell you about St. Jude's when my remarks conclude.

I know you've travelled the province, heard countless presentations and read a pile of briefs, so I plan to speak briefly today to allow ample time for a bit of dialogue with you before our time runs out.

Just by way of background, Children's Mental Health Ontario represents 87 community-based agencies that provide support to families and young people. They collectively account for about two thirds of this government's annual expenditure of approximately \$500 million for child and family intervention. They treat a range of social, emotional and behavioural problems including bullying, violence, ADHD, eating disorders, depression, self-harm, anxiety, addictions and more.

There are three important areas I want to touch on and then I'll answer your questions. They are, first, the urgency of system reform; secondly, the need to maintain services until reform happens; and finally, the opportunity to focus scarce dollars where they will have the greatest impact.

First, it is critically important for our sector to have the policy framework for children's mental health, A Shared Responsibility, implemented quickly and efficiently. We are full participants with the ministry in this exercise. We believe the sector has to change and that much of the change is happening or will happen within the sector. We also believe that stable funding to provide an appropriate level of service to every child and youth needing mental health support will hinge on the implementation of this framework. You may recall, when I addressed you in June, that I pressed hard for progress to be made on implementation. I want to acknowledge that much has happened since then and we're pleased to have the mapping process moving along so that we all can know more about where services and gaps in service exist. We look forward to the next concrete steps from the Ministry of Children and Youth Services. At the same time, we'll be working with the Ministry of Health and Long-Term Care to encourage them to renew work on their paper Every Door is the Right Door.

The second topic I want to touch on is that during times of recession or economic slowdown, you're no doubt aware that the need for mental health supports increases. This is true in both the adult and the child and youth mental health systems. The impact on our sector has been immense. The effectiveness of mental health treatment depends first and foremost on the quality and skill of our front-line staff, yet we are steadily losing

well-trained, dedicated staff to other sectors, such as health and education, where the compensation is considerably better—25% to 40%, depending on the community. We work closely with sectors that receive annual funding increases from this government, yet our sector has had only two increases in the past 12 years, both of them only inflationary. While the policy framework is being implemented, we're simply asking for a level playing field with the other services this government funds so that our vulnerable children and youth can be served by the most qualified, the very best staff.

The third topic I want to touch on: In a time of fiscal restraint, it's more important than ever to be strategic in setting priorities and in focusing available funding. Although I realize your mandate covers the lifespan, I would remind you that 70% of all mental health problems first emerge during childhood. That's also when we have the best opportunity for successful treatment. Placing a higher priority on the mental health needs of children and youth will yield benefits both by ensuring we have a productive workforce in the future and by reducing demand for government services of many kinds, especially lifelong mental health services.

It's also critical, especially when dollars are tight, to ensure that they are focused for optimal outcomes. In the field of child and youth mental health, funding is now scattered across 440 transfer payment agencies. Compare that with only 53 agencies that handle all child protection services across Ontario. Consolidating existing dollars in agencies that have the capacity to deliver evidence-based practices and that meet basic quality standards only makes sense. We suggest that only agencies that can meet objective and independently administered accreditation standards should be eligible to receive child and youth mental health funding. To that end, we are currently transferring our in-house accreditation program to an independent agency so that it will have the necessary credibility to become a funding requirement.

As you might imagine, I could go on at great length about the families, children and youth our agencies support. You've heard some of that from our members today and in your hearings across the province. I'm going to resist the temptation to do more, but I will leave you with a sincere thank you for the time, energy and compassion with which you are tackling the issues of mental health and addictions. We're all looking forward to your final report. Now I'll pass it over to Camille for some brief comments about St. Jude Community Homes.

Ms. Camille Quenneville: Hi, everyone. St. Jude Community Homes, which is located in Regent Park in Toronto, was formed in 1986 by a group of very committed citizens who were increasingly concerned about the homeless problem in this city. Today there are three buildings providing supportive housing to 87 adult residents who live with severe and persistent mental health problems. About 95% of our residents have been diagnosed with schizophrenia. All residents are dependent on ODSP and, in some cases, CPP disability.

Our motto at St. Jude's is "Together in community, we succeed," and it's evident the moment you walk through

the doors. Everything we do at St. Jude's fosters that sense of community and the respect and compassion our residents show for one another.

The food program is significant in that regard. Residents pay a monthly stipend which covers both a healthy breakfast and dinner, which is prepared on site. Residents have kitchen facilities in each of their units where they have lunch. Enjoying meals together is critically important for anyone with a mental health issue, as I'm sure you know, to allow a sense of belonging and fellowship. There are activities for our residents and employment supports if their health allows.

As you might guess, the staff at St. Jude's is extraordinary, and we're fortunate to have a psychiatrist from CAMH on our board. When we asked him why he was interested in serving at St. Jude's, he put it simply: He said that he knows that when he refers clients to St. Jude's, he is sending them to the gold standard for supportive housing.

If any of you are interested in your copious spare time, which I know you all have, I would love to shuttle you over to St. Jude's—it's very nearby—and give you a very quick tour. I think we're a model for compassionate treatment of some of our most vulnerable citizens.

The Chair (Mr. Kevin Daniel Flynn): That's wonderful. Thank you, Gordon; thank you, Camille. You've left ample time for questions, starting with France.

M^{me} France Gélinas: I have many points to my question. The first one I want to ask is, we had other presenters talking about children's mental health who talked about the transition period between child and adult mental health, and some of them asking for funding for their service to be available up to age 24. I would like you to comment on that first.

Mr. Gordon Floyd: There is a well-acknowledged problem: a gap in services. When kids reach the age of 18 they kind of fall off the map and are not usually well served by the adult mental health system; they're no longer eligible for service in the children's system. There is clearly a need for the two systems to meet in a much better way. What's going to be appropriate is going to differ from client to client. I think that there is a need for children's mental health agencies to be able to offer services beyond the age of 18, perhaps all the way to 24, just as there is a need for adult mental health services to reach out in a more effective way to young adults. I think that it would be very helpful and very important for children's mental health agencies to have the option of being able to continue service beyond the age of 18.

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The Chair (Mr. Kevin Daniel Flynn): A short one.

M^{me} France Gélinas: We've heard many times that children's mental health is the poor cousin of mental health, which is the poor cousin of health care. Has your association ever quantified that? And of the 440 transfer payment agencies for children's mental health that presently exist, where would you see a reasonable number fall at?

Mr. Gordon Floyd: In terms of your first question, we haven't quantified it in dollar terms but perhaps one

of the best ways to look at it is when you look at wait times. The wait times in the children's mental health system are significantly longer. Most indications would be that they're about half again as long as wait times in the adult mental health system.

Another benchmark would be that the average wait time to get into a children's mental health centre in Ontario is almost exactly twice what the average wait time is for general pediatric surgery.

So we do have a big gap between the way children with mental health problems are treated as compared to the way children with physical health problems are treated. I think the same is undoubtedly true in terms of the gap between child and adult services.

The Chair (Mr. Kevin Daniel Flynn): Thank you, Gordon. We're going to move on. Jeff?

Mr. Jeff Leal: Thanks so much, and thanks so much for your presentation today. Camille and I are friends, so I'll take you up on your offer to come and visit St. Jude. I'd love to do that at the first available opportunity.

A couple of questions, Mr. Floyd. You talked in your presentation today about identifying these mental health difficulties as early as possible. I take it you would be a very big supporter of full-day kindergarten in the province of Ontario, to identify problems early.

Mr. Gordon Floyd: Yes.

Mr. Jeff Leal: My second question to you is, are there just too many agencies fragmenting service to children in the province of Ontario?

Mr. Gordon Floyd: Yes. The 440 agencies that are receiving child and family intervention funding now are about twice as many agencies as were receiving funding 10 or 12 years ago.

If you talk to people within the regional offices of the ministry, if you get them to talk off the record, they will admit that the child and family intervention budget has become a little bit of a discretionary budget within the regional office—it has been used to fill holes—and that an awful lot of the services that are being funded through that budget are not strictly mental health services. They're certainly not services that are being evaluated in any way. They're not services that are being supported through evidence-based practice in any way.

We're really concerned that a significant part—it could be as much as a third of that budget—is bleeding into services that are not appropriately accountable and are probably not as effective as they need to be.

The Chair (Mr. Kevin Daniel Flynn): Thank you, Gordon. We're going to move on. Sylvia?

Ms. Sylvia Jones: Good to see you again. I wanted to follow up on the St. Jude example that you've highlighted. You have 87 adult residents currently; three buildings. Where did the incubation funding for that come from? How did you begin?

Ms. Camille Quenneville: Back in the day, when this group of citizens became concerned, they just took a flyer and applied for funding from, at the time, Canada Mortgage and Housing Corp., which was doling out grants, and much to their surprise, they got one.

They went looking for a place to spend the money. They found a commercial building at the corner of Dundas and Parliament and retrofitted that building for apartment-sized spaces for the residents. We've subsequently grown and added two buildings.

It's a fantastic mix of partnership between the federal government, in that sense, although they have admittedly a smaller role now, the city of Toronto, and of course the province, through the Ministry of Health.

The Chair (Mr. Kevin Daniel Flynn): Thank you, Camille. Thank you, Gordon. Thank you very much for coming today. It was appreciated.

Your next presentation today was anticipated to come from the Bethany Residence, but I understand that that gentleman may have been held up. Is that right?

Interjection: Yes.

The Chair (Mr. Kevin Daniel Flynn): Okay, then we'll move ahead to the next group and come back to you.

YORK CENTRE FOR CHILDREN, YOUTH AND FAMILIES

The Chair (Mr. Kevin Daniel Flynn): The folks from the York Centre for Children, Youth and Families have kindly agreed to come forward. Make yourselves at home.

Interjection: Nobody's been seated down here yet. This poor chair is lonely.

The Chair (Mr. Kevin Daniel Flynn): That's the one with the ejection seat if we don't like what you say.

Interjection: You want to put me there, then, for sure.

The Chair (Mr. Kevin Daniel Flynn): Like everybody else, you get 15 minutes. You use that any way you see fit. If there's any time at the end, we'll have a little exchange.

Ms. Noreen Lee: Thank you, Mr. Chairman. I'm Noreen Lee. I'm chair of the board of directors for the York Centre for Children, Youth and Families. My copresenter today is Donna Massel, mother of a remarkable young man who has become the junior ambassador for York Centre. We appreciate the opportunity to present the following challenges and solutions to the crisis in children's mental health services. These were collaboratively identified by Blue Hills, Kinark and York Centre, the three accredited children's mental health agencies that are currently providing services in York region.

As you've heard before, the greatest and most daunting challenge is inadequate funding. There have been no increases to our base budgets for 13 of the past 15 years. The problem in York region, which is where we provide services, has been exacerbated by a historical disparity in funding in children's services. Assessing the Gap, a 2008 update report, shows that in York region, the funding for children's services was \$127 per capita, whereas the provincial average was \$221, almost twice as much.

Decades of severe underfunding have caused erosion of services, long wait times, high staff turnover and loss of expertise because salaries are not competitive with

similar positions in health and education. The most devastating effect of lack of resources is the ongoing pain of young people struggling with untreated mental illnesses. Their excruciating experience is beyond description. You have to feel their pain as they tell their stories in order to understand the completely undermining force of mental illness.

Investment in children's mental health services not only addresses the urgent needs of children; it's also cost-effective on the part of the government. Treatment, especially early intervention, is effective, and Donna will attest to this in a couple of minutes. It significantly reduces the need for more expensive and long-term support such as youth detention and ongoing psychiatric care. Lost productivity attributable to mental illness in Ontario ranges in the billions of dollars annually.

The following demographic factors create a higher-than-provincial-average need in York region for children's mental health services:

—22% of York region residents are between the ages of zero and 14 years of age. That's much higher than the provincial average of 13.6%.

—Poverty is one of the social determinants of mental health problems. The 10% of children who live in poverty are at much greater risk.

York region has the third-highest number of recent immigrants in the GTA and is home to 204 ethnic groups. This presents the enormous challenge of providing culturally competent mental health services.

The solution to addressing the current and increasing demand for service in York region is the application of a population needs-based funding formula.

1730

Mental health promotion, early identification and intervention are critical components of a more effective and efficient children's mental health service. The challenge is that additional staff and funding for evidence-based training will be required. In addition, it will be necessary to enhance the competencies of workforces in health, education, justice and social services to enable them to identify the early signs and symptoms of children's mental health issues and to intervene appropriately.

York region is recognized as being a leader in collaborative integrated planning. Our COMPASS initiative is a respected example of the development of partnerships between child-serving agencies and school boards. COMPASS has done excellent work helping schools identify the mental health needs of children. However, because of lack of treatment resources, once they get to our doors, they discover an extremely overcrowded waiting room.

The mental health of children must be the highest priority in the 10-year strategy for mental health and addiction. This position is clearly supported by Michael Kirby's shocking statement that "Children's mental health services are the most neglected piece of the Canadian health care system." It would be unconscionable to allow the urgent needs of children and youth to be

neglected for another 10 years, unconscionable to deny young people with mental illness the right to the treatment which would enable them to experience optimal mental health and to reach their full potential.

As the current economic crisis recedes, so must the crisis in children's mental health.

Thank you for your attention and for the good work you do.

Ms. Donna Massel: Hi. They made me write my speech down, because otherwise I could go on for hours.

When my son Matthew entered school, he was a very sociable, confident—

The Chair (Mr. Kevin Daniel Flynn): Just so you know, you've got about seven minutes, so don't feel compelled to rush through it.

Ms. Donna Massel: Okay, thank you.

When he started school, he was a very sociable, confident little boy. But before he finished grade 1, his self-esteem had plummeted. He considered himself the stupidest kid in the class—his words. We were having trouble finding activities that he could be successful at, and he didn't have a lot of friends. I was having no luck at getting the school to diagnose why he was not succeeding at school. I was told that the waiting lists to see psychologists were too long and that his problems weren't severe enough.

We were on our own, so we searched out doctors to help us. We spent thousands of dollars for educational and psychological assessments. Finally, by the middle of grade 5, we had a good handle on what was causing Matthew's challenges. We had a son who had an alphabet soup of labels but who did not fit into the traditional school system, especially because he was extremely bright. I was constantly advocating on his behalf. "Advocating": Isn't that a nice word? It sure didn't feel nice, because I felt like I was always battling to get my child the accommodations and help he needed and was legally entitled to.

Grade 7 started our two years in hell. Matthew couldn't take it anymore. Depression, anxiety and rage became huge problems. In grade 7 and again in grade 8, Matthew was out of school more than he was in. He suffered breakdowns and went into crisis both years. I had a child who was depressed, anxious and really didn't think life was worth living anymore. At night he used to cry in his room and beg us to kill him because he couldn't take it anymore.

The staff at the elementary school was not able to help him reintegrate into the school system. School officials refused my requests for him to see school psychologists, but they did offer to send out the truant officer. What a huge difference it would have made if the school staff had been able to understand his challenges.

Matthew was shuffled from school to school, going to five schools in four years. We kept hoping we could find someone with the training to help him. Finally, after consultation with a special-ed superintendent, I realized something had to change. The superintendent's team and Matthew's psychiatrist recommended York Centre for Children, Youth and Families.

When Matthew started at York Centre for his grade 9 year—grade 9 we're talking about now, from kindergarten—I felt like a huge weight had been lifted from my shoulders. I wasn't alone anymore. Matthew was in a place where the staff was trained, willing and able to help him. He's flourished at York Centre. His pediatrician and his psychiatrist are both amazed at the difference in Matthew. I don't think they see too many success stories like his.

Some of you have met my son. Some of you heard him speak two weeks ago at the celebration here for the 20th anniversary of the United Nations Convention on the Rights of the Child—that's a mouthful. He made a speech on why the government should spend more money to help children like him. He was the tall, blond boy that Andrea Horwath mentioned on the floor, and he stuck his tongue out at her when she mentioned his name—nothing to do with her; it's just his reaction to hearing his name mentioned. I was very proud of him that day—not for sticking his tongue out, but because of the excellent speech that he did and how well he prepared it. Let me tell you, two years ago, he could not have even been in that room, let alone made a speech.

I would like to remind you of a couple of things that Matthew mentioned: One in five children deal with mental illness; of those, only one in five will get help. Matthew is very grateful that he was one of those who got help and he feels very badly that four out of five children that need help do not get it. Matthew ended his speech that day by saying, "If it weren't for the staff at York Centre, my doctors and my parents, I would not be in front of you today ... I would be on the floor screaming my butt off." Well, I agree with him a bit, except he wouldn't be on the floor. If Matthew hadn't gotten the help he needed, Matthew's only option would have been suicide.

Intervention at York Centre saved Matthew—it saved our family. Earlier intervention in grade school would have prevented the need for him to go away from his friends for day treatment. Matthew had a supportive family—emotionally and financially. We are so grateful for the help we received. For that reason, Matthew and I are willing to speak out about our experiences. I am told that hundreds of thousands of families deal with children's mental illness. What happens to those who can't afford thousands of dollars of private testing? How do you balance the need to work with the need to be on 24-hour call for your child? Supposedly, we don't have a two-tiered health care system, and maybe we don't when it comes to medical disabilities, but we certainly do when it comes to mental health disorders.

Matthew's story is not finished. He's in grade 10. Right now, he goes to his home high school in the morning and York Centre in the afternoon. It's been a great way for him to transition. He's currently being served at the high school in the autism class. It's not ideal for him because he's not with his peer group, academically or socially, but we are very grateful for the wonderful staff support that such a program provides.

We worry about the future for Matthew. How will he cope in high school when he tries to go back into the mainstream program? What will happen to him when he turns 18? I have been told by other parents that the transition is very difficult. If my son gets the support that he needs, then he could do great things in this world. He wants to be a doctor. If not, he could be a drain on society. Multiply my child by the hundreds of thousands of other children who, if they can get the help they need, can go on to be productive citizens—teachers, policemen, health care professionals, maybe even politicians—or they can sit on welfare rolls, in jails, on the streets or in the grave. It's your choice.

The Chair (Mr. Kevin Daniel Flynn): That's wonderful. Thank you very much for your presentation.

Ms. Donna Massel: See, that's why they were worried I was going to be too long.

The Chair (Mr. Kevin Daniel Flynn): No, you just about hit the nail right on the head there. Unfortunately, there's no time for any questions, but your story was very compelling, and I'm sure I can speak on behalf of the other members of the committee and extend our best to Matthew as well. It was like he was here today as well.

Ms. Donna Massel: Well, if the rest of you haven't heard his speech and are interested in hearing it, they taped it at the advocate's office. I'm sure we could get a copy of it.

Ms. Noreen Lee: There's a copy in the package.

Ms. Donna Massel: Oh, and also, the copy of his speech is in the package.

The Chair (Mr. Kevin Daniel Flynn): It's attached to the package, yes.

Thank you very much for coming today. It was appreciated.

1740

BETHANY RESIDENCE

The Chair (Mr. Kevin Daniel Flynn): Our next presenters are from the Bethany Residence: Peter Turner, Kevin Abraham and somebody who will be introduced.

Ms. Sheri Levy-Abraham: Sheri Levy-Abraham.

The Chair (Mr. Kevin Daniel Flynn): Thank you. Make yourselves comfortable. You've got 15 minutes, like everybody else, and you can use that any way you see fit. If there's any time at the end, we'll split that amongst the groups. We're all yours.

Dr. Peter Turner: Thank you. My name is Dr. Peter Turner. Just allow me one second here to set up my slides while I talk. Originally this was supposed to be a PowerPoint presentation, but I guess we were not able to set it up as such so I'm going to just give a talk based on the handout. I'm going to read it off the computer because the slides here are a little more readable for me.

The Bethany residential care program is a program that's located in Burlington, Ontario, just up the road from here. It's a large community facility that was originally funded as a domiciliary hostel. It specializes in

the community management of severe psychiatric and chronic psychiatric disorders.

The second slide in the PowerPoint presentation: That's my introduction. I'm Dr. Peter Turner. I'm a psychiatrist. I've worked in Burlington since 1977. I'm also affiliated with McMaster University Medical Centre as assistant professor. I consult to the Joseph Brant Memorial Hospital, which is in Burlington, as a consultant to the first-episode psychosis program. I also consult with the North Halton mental health community clinic, which has a large number of chronic-care psychiatric patients. At Brant hospital, I also consulted on and set up originally a case management program, so-called, which is still in existence today. Since 1984, I've been involved in setting up work rehabilitation programs related to my special interest in schizophrenia. I've been a consultant to the Bethany residential care program, which I'm talking about today particularly, since about 1989, approximately.

The presentation objectives are to understand a little bit about the chronic psychiatric illnesses that we face in the community, and how to handle these, and what impact those disorders have in terms of the types of help we have to provide for these clients; and to demonstrate that the Bethany residential program is an important part of the regional services in the Burlington and Halton area.

The Bethany residential program has saved the province significant amounts of money over time, related to the care of clients with severe psychiatric illness. It needs your continued support and upgraded funding to maintain the quality of its clinical and support services and rehabilitation programs.

There is potential for other programs to improve the quality of care further, and potentially save money within the community and hospital budgets.

The next slide has to do with the challenges in the treatment of schizophrenia. We skip along, just to review the clinical course of schizophrenia, basically just to indicate that schizophrenia is not a one-time condition. It's a condition that persists over time and has significant residual disability associated with it and requires ongoing support. Many clients require residential ongoing support, not just outpatient psychiatry care or case management or PACT programs, which we have as well. Although the condition does get more stable over time, that remains as true today as it was historically. Residences like the Bethany program could be very important in maintaining or providing that kind of care.

The other thing to know about schizophrenic illness is that it's associated with multiple other conditions, both medical and psychiatric. These clients have all kinds of other comorbidities, like anxiety disorders and depression. They have increased cardiovascular and diabetes disorders. Substance abuse is a big issue. These comorbidities increase the risk of relapse. These people require an extensive support system, and they're frequent visitors in the hospital unless you take greater care to look after these people adequately.

The next slide again demonstrates the psychiatric comorbidities, life comorbidities, as high as 50% in various types of disorders, including anxiety, depression, substance abuse and so on for patients with schizophrenia.

The risk of medical illness is somewhere around 1.5 times to two times for obesity, twice for diabetes and five times for lipid disorders. They're also very frequently heavy smokers. Medical factors are a big issue.

Similarly, bipolar disorders are also often more chronic than people realize. The reason for that is that while they are more intermittent, bipolar disorders keep on recurring and often get more severe as time goes by. You end up requiring an extensive support system for those clients as well.

To look at the next slide, time spent in specific bipolar disorder affective symptoms: What people don't often realize is that patients with bipolar disorder are frequently mostly depressed, about 30% or so for bipolar I, which is the patients who have manic symptoms, and 50% or so for bipolar II patients, who follow more of a recurrent depression pattern. That is illustrated in the slide just before.

Again, these people need extensive and prolonged support. They also have again, as with schizophrenia, multiple comorbidities. That is a multi-dimensionality of mood disorder, which is your next slide. Substance abuse is often common, as are multiple medical disorders and psychiatric comorbidities.

The impact of bipolar disorders on patients' lives is that their health is reduced by a decade or so, and employment, of course, and marital and personal problems are much more frequent.

Moving on to the mental illness statistics and the challenges that we face: When we look in the Hamilton area, when I came in 1973 to this area to do postgraduate psychiatry, they had still the Barton building, which is part of that picture of the old Hamilton Psychiatric Hospital, which housed over 1,000 patients. Originally the whole Hamilton psychiatry hospital complex had at least 1,500 patients or better. That's been gradually whittled down in the last 30 or 40 years. Where have these patients gone? A lot of these patients have gone to community treatment centres, including places like Bethany. Homes for Special Care is another. There's a lot of those in Hamilton.

The funding for Bethany in particular has been very low. It used to be at \$47.75 per day, which is less than a motel. I think it's important to point out that it's generally underfunded to provide the quality of service that we would like to see for those clients, especially as they have multiple psychiatric and medical issues and all kinds of rehabilitation needs.

The overall national economic costs of mental illness are huge, compared to other medical conditions. Mental disorders cost about \$14 billion annually, and it's very important that they provide the optimum care and support for those disorders.

Homelessness is a common complication of psychiatric disorders. Again, 25% to 50% of homeless people have schizophrenia or some sort of severe mental illness.

In the Burlington catchment region, which is the next slide, if you look at severe mental disorders, which is our main focus here, at least 1,700 people, or about 0.85% of the population would be classified by a statistical analysis based on the projections on the American national plan for the mentally ill survey as having incidents of severe mental illness overall, which particularly includes schizophrenia and bipolar disorders. That would be the number of people who require help in our region for the most severe disorders. Lifetime prevalence of schizophrenia is about 1% but because it's so persistent, it presents a larger chunk of the population in need. Bipolar disorder, which is more frequent by comparison, lists a proportion of severe or poor outcome cases so it's not quite as highly represented, but getting up there as well. Other disorders, like severe depression, anxiety and alcohol-related disorders, also play a role.

How are we doing for time, by the way?

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The Chair (Mr. Kevin Daniel Flynn): You've still got just over two and a half minutes.

Dr. Peter Turner: I'm going to skip ahead to the Bethany bed status slide, and that slide indicates that Bethany, since about 1982, started with about 17 beds and then they were increased to 97 beds, and then to about 125 beds currently. In the meantime, the hospital beds were significantly reduced from, originally, 28 beds to about 16 beds currently, indicating, I think, that Bethany has probably picked up a lot of the more severely psychiatrically ill patients, because I go in there twice a week and see a lot of those clients on rounds.

Similarly, the PACT program for Halton, just looking at the hospitalization rates—Bethany does a very good job of looking after these clients. The PACT program has a hospitalization rate of somewhere around 10.7 days per year, down to 3.8 most recently, compared to Bethany hospitalization rates, in the next graph, showing that for Bethany—the blue or the smallest bar on the right-hand side of those graphs—psychiatric admissions are as low as one patient per year on average. That's very low compared to even the PACT program. It's about 20% of what the PACT program does, so we actually are five times more efficient than the best that the PACT program can do.

The next slide shows a little bit of the picture of what the program looks like—the building. It's privately owned. Sheri and Kevin Abraham, the owners, are here with me. It has regional funding. It's now at 126 beds. I added some graphs in to give you an idea of what kind of clients are in there. There's about 60% schizophrenia and a smaller proportion of bipolar and other disorders here. I think I'm going to stop on that. Am I almost out of time?

The Chair (Mr. Kevin Daniel Flynn): Actually, we've got about three seconds left. You must have some sort of psychic ability.

Dr. Peter Turner: In summary, I would just say that you can read the other things that are on the slides. Basically the Bethany program looks after 126 severely ill clients with very little funding. It has the potential to do more for the community and requires, also, increased

support and funding in order to continue to provide this quality of care that we've been doing for some time and trying to improve the programming for those unfortunate clients that we have.

The Chair (Mr. Kevin Daniel Flynn): Thank you. So, in summary, you're saying that by spending the same amount of money, we can get far more service and better outcomes for the people who are being served?

Dr. Peter Turner: Absolutely. In 15 minutes it's a bit hard to say everything, but it's a unique program. There's nothing else really like it in the province, or in Canada for that matter, that I've seen. We have fairly intense psychiatric care and supervision with such a large amount of clients with such a low re-admission rate. We're really saving hospital beds, in a sense, in that region, and looking after patients who otherwise would be frequent flyers in emergency rooms, in-patient services and out-patients in the hospital. It's a tremendously cost-efficient program. It's hard to say how much it actually saves but it could be in the millions.

The Chair (Mr. Kevin Daniel Flynn): And you'd be open to a tour by any members of the committee?

Dr. Peter Turner: Absolutely. I'd be very welcoming to any people coming by and happy to show you around and demonstrate exactly what we do. I can give you an actual copy of the PowerPoint presentation for people to look at on their computers, which is more readable than the printout.

The Chair (Mr. Kevin Daniel Flynn): I don't live too far from Bethany, so I'd be happy to arrange something through Kevin one day and take a tour myself.

Dr. Peter Turner: We look forward to that.

Ms. Sheri Levy-Abraham: Could I just add one thing? In terms of Bethany's uniqueness, our age group is all the way from 20 to 100. You can age in Bethany, age in place, because you can move throughout Bethany depending on your needs. Also, depending on where you are with your psychiatric illness, you can move around to be more independent or if you require more care.

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

BOB LESTER

The Chair (Mr. Kevin Daniel Flynn): Our final presentation today is Dr. Lester, if you'd like to come forward. Some of us have heard you before. Thank you for agreeing to give us a more intimate presentation today. Like everybody else, you get 15 minutes. You can use that any way you see fit, and if there is any time at the end, maybe we can have an exchange.

Dr. Bob Lester: Thank you very much. I know you're all tired and probably want to get home. As Mr. Flynn said, my name is Bob Lester. I'm a professor emeritus in medicine at the University of Toronto, and in a past life I was the executive vice-president of medical academic and chief medical executive at Sunnybrook.

However, I'm here today to speak to you as a caregiver. My interest in presenting to you was sort of sparked by the fact that in my early discussions with

ministry officials who were charged with developing the 10-year strategy, there was an almost complete absence of mention of dementia and probably not much recognition that dementia is a mental health issue. My concern was that dementia once again was going to be falling through the cracks.

As those of you who have heard me before know, my real interest in this was triggered by the fact that my wife of almost 49 years—in three weeks—has developed advanced frontotemporal dementia.

I've documented this thing as a catharsis for my own mental stress in something that I've called a Journey into Dementia or the Absence of Presence. I think the juxtaposition of the words, "the absence of presence," really describes what goes on in a person who has dementia. Although it primarily recounts our family and my personal experience as a caregiver, I've had the opportunity to reflect on the inability of our health care system to handle the tsunami of dementia that experts are predicting. I feel that my experience of over 45 years in health care as a physician, a hospital executive and recently as a consultant with the Ontario Hospital Association, together with my experience as a caregiver, equips me to speak on this issue.

Just to clarify, the term Alzheimer's disease is often used as a surrogate or synonym for dementia; however, it is only one type of dementia. It is the most common type of dementia, but there are many other forms including vascular dementia, frontotemporal dementia, Creutzfeldt-Jakob disease and Lewy body dementia. Alzheimer's disease, the most common form of dementia, affects men and women of all races, religions and socio-economic backgrounds. All forms of dementia are diseases of the brain. They are diseases of the brain; they are not a normal part of aging. And no one is immune.

My wife was diagnosed at age 62 and, as I think back, the process likely started in her mid-50s; I just missed it. Dementia erases memory, alters personality, steals the ability to think and makes simple tasks such as eating or getting dressed impossible. It robs independence and eventually takes life.

My wife was an excellent athlete and a psychotherapist. She is presently confined to a wheelchair, is incontinent, is unable to speak, has to be fed and does not recognize me, her children or her grandchildren. I always thought that the worst thing in life would be losing a loved one to cancer or heart disease. I now realize that as painful as that must be, there is an end and to some degree, life can go on. For me, watching Judy deteriorate slowly over several years seems so much worse. Death seems to be occurring in an incremental fashion. The grieving process is frozen; there is no end to the grief.

1800

The scary part is that the prevalence of dementia is increasing at an alarming rate. Today, half a million Canadians, or 1.5% of the Canadian population, live with Alzheimer's disease or related dementia. The number will increase by half in just five years and will more than double in 25 years, representing 2.8% of the population. The majority of people with Alzheimer's disease is over

the age of 65. Huge numbers of baby boomers are now entering the years of highest risk. One in three will develop Alzheimer's disease or related dementia.

New statistics also confirm that younger people are increasingly stricken with dementia: One in six of those with dementia is under the age of 65. Clearly, dementia is not just a geriatric problem.

Presently, there are no cures for dementia, but there are drugs that can delay the onset of symptoms, especially if the diagnosis is made in the early stages. Researchers hope that within five to seven years, treatment attacking the disease process itself, not just the symptoms, will be available.

In addition, as the prevalence of dementia grows, so does the community of families and caregivers who look after loved ones. For every person with dementia, 10 to 12 others are directly affected. With the increasing incidence, it is likely that each of you in this room will be touched by this disease. You will develop dementia yourself or a close family member will—your parent or your spouse.

Caregiving is a critical issue for people living with loved ones suffering from dementia. According to the Canadian Caregiver Coalition, one in five Canadians 45 years and over provides some form of care to seniors who have long-term health problems such as dementia. Almost half are between the ages of 45 and 54, many caring for an increasingly needy parent while caring for their own family at the same time.

A quarter of caregivers are seniors themselves, and a third of them, over 200,000 people, are 75 years old and older. Family caregivers are the invisible and hidden backbone of the health and long-term-care system in Canada, contributing over \$5 billion of unpaid care. Caring for someone with dementia is difficult and distressing. It often leads to financial, mental and physical health problems, further taxing social and health care assistance.

Dementia is more than just an important health concern. It has the potential to overwhelm our health care system if fundamental changes are not made in research, funding and care delivery. Dementia currently costs Ontario's health care system \$5 billion per year. That number will rise to an estimated \$15 billion if we don't find a cure. Experts predict that by 2025 it will carry the heaviest economic burden of any disease in Canada.

Dementia results in more years lived with disability than stroke, heart disease and all forms of cancer. Over 70% of those living in Ontario long-term-care homes have Alzheimer's disease or a related dementia. It has been estimated that 25% of all alternative-level-of-care beds and 33% of all alternative-level-of-care days are related to patients with dementia.

We are all familiar with the long wait times for long-term-care beds not only from hospitals but also in the community. My wife was on a waiting list for almost two years. If we can't manage the problem now, what are we going to do when it is projected that the demand for long-term care will be exponentially increasing over the next

30 years? In five years, as I said, the number of people with dementia will have increased by 50%.

Delaying the onset of symptoms of dementia by just five years could, over time, decrease by 50% the number of people with more advanced disease requiring complex community or institutional care. The saving of health care dollars would be huge.

While recognizing the importance of all the other mental health issues you are grappling with, is there another disease where the investment in research, health promotion, early detection and intervention could have a greater payback to society?

The Alzheimer Society is trying to convince the federal government to adopt a national Alzheimer or dementia strategy. They will be releasing an important report in January called the Rising Tide. The numbers will more than give you pause—they will chill you, they will scare you. They certainly did that to me.

Ontario has the opportunity to lead the way by showing that you have seen what the future will look like if we do nothing about dementia, and you refuse to go there. Addressing the issue of dementia must be an important part of Ontario's mental health strategy.

Thank you very much for listening to my presentation.

The Chair (Mr. Kevin Daniel Flynn): And thank you, Dr. Lester. I think we've got time for one question each, starting with France.

M^{me} France Gélinas: Thank you very much for coming. You are a very powerful speaker. It's the second time I've heard you speak, and both times you got your point across really clearly. It is a little bit scary. Basically, you would like research, health promotion and early detection. You talk about the Alzheimer Society. What is it out there that looks promising, that we should look into, that we should invest in that is off the ground and ready to run?

Dr. Bob Lester: I think there are a number of things. First of all, there are some very simple strategies that this Rising Tide paper will indicate, which are basically the same that are going to promote health in any other disease. There's the whole issue of navigation through the system, which is difficult. I've been in the system my whole life and I still had trouble navigating the system. There's looking after the caregivers; that's a huge problem. And then there's the whole issue, now, of better imaging, earlier ability to diagnose disease. The earlier you can diagnose this, the early you can intervene. Finally is this whole exciting area of new drugs that could actually attack the disease itself and perhaps prevent the onset of dementia. I think it's that whole package that we need to look at. Given the magnitude of the problem, it really becomes important to look at it.

The Chair (Mr. Kevin Daniel Flynn): Thank you, Dr. Lester. This side, Maria?

Mrs. Maria Van Bommel: Dr. Lester, you talked about how you missed the early signs of the dementia onset in your wife. You're right, most of us have something in our families, too. I certainly noticed that in my mother-in-law we missed it in the early years. Actually, my father-in-law spent a lot of time hiding it and protect-

ing her from the family knowing that she had dementia. What are some of the early signs? Because that's part of the problem, I think, that the person who is actually suffering from dementia doesn't recognize it or is maybe in denial. What should we make the public aware of in terms of identifying it early enough to get them the help they need?

Dr. Bob Lester: I think that's a great question. The signs and symptoms will alter from person to person. In my wife's case—and again, I totally missed it—there were issues around her driving. We went down to visit our son who lives in Scottsdale and she went for a walk and got lost. I said, "Well, all the houses in Scottsdale look the same. No wonder she got lost." So I kept excusing her.

I think there's not a lot in primary care that helps people detect dementia early. There isn't a good single, simple test that can be applied to act as a screening test for dementia. I've been after people at Sunnybrook now to help develop an early screening test. The mini mental state examination—you've got to be pretty well gone before you fail that thing—is really not a great screening test. I mean, if you can't remember what province you live in or what year it is, it's pretty late.

I think the message that went out around stroke, when you saw those nice little TV blurbs, is the kind of message that we need to get out so that people recognize that there is a problem and can begin to recognize it as they now know what to look for in an early stroke.

The Chair (Mr. Kevin Daniel Flynn): Thank you, Dr. Lester. Final question for the day: Christine.

Mrs. Christine Elliott: Thank you very much, Dr. Lester. It is a quick question, and you've really alluded to care for the caregivers. One of the things that I've certainly heard in my community is that there is a real lack of respite services for the caregivers. During the two-year period that you were waiting for your wife to get into a long-term-care home, did you experience that as a significant problem for yourself and your family members?

Dr. Bob Lester: I did. I'm going to say yes and no to that question. I did, and when I examined the options, I decided I didn't like any of the options. Fortunately, I was in a financial situation where I could actually hire someone to live with me and my wife to help me look after her. In a previous talk I had indicated that it's costing me close to \$70,000 a year to look after my wife. That's my choice, but I think that's the kind of care that everybody should get.

My wife's in Baycrest. It's a world-class organization. They do not have the staff to look after my wife. If I'm not there or someone's not there to feed her, she doesn't get fed regularly. She doesn't get changed; she doesn't get washed regularly, and this is a world-class organization. I shudder to think what must be happening in some of the other facilities. I think it's a huge problem for caregivers. I've been fortunate because I've been able to generate enough income to look after my wife, but I'm sure—in fact, I know—most people aren't as fortunate as I am.

The Chair (Mr. Kevin Daniel Flynn): Thank you, Dr. Lester, for coming forward once again and telling your story. I think people are starting to listen.

Dr. Bob Lester: I hope so.

The Chair (Mr. Kevin Daniel Flynn): Thank you. It's a pleasure having you here today.

We're adjourned.

The committee adjourned at 1808.

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